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THE RELATIONSHIP OF PERCEPTIONS OF SERVICE AND SUPPORT ADEQUACY TO FAMILY QUALITY OF LIFE FOR FAMILIES OF CHILDREN WITH DEAFBLINDNESS

BY

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Doctor of Philosophy.

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ABSTRACT

This study investigated the relationship between families' perceptions of supports and services and family quality of life (FQOL) for families of children with deafblindness, and the potential of satisfaction with family-professional partnerships and child age as moderators of this relationship. The study was guided by the Unified Theory of Family Quality of Life. Two-hundred and twenty-seven families of children with deafblindness between the ages of birth and 22 completed the Service Adequacy and Family Quality of Life for Families of Children who are Deafblind Survey. Results indicated that families' perceptions of supports and services were significantly related to FQOL and that this relationship was dependent on the level of satisfaction families had with family-professional partnerships and the age of the person with deafblindness in the family. Important predictors included friend and family support, related services, and information services. In addition, four interaction effects significantly predicted FQOL: (a) education services adequacy x family-professional partnerships, (b) related services adequacy x family-professional partnerships, (c) friend and family support adequacy x age, and (d) child care adequacy x age. A discussion of the findings is provided and implications for practice, policy, and future research are discussed.

ACKNOWLEDGEMENTS

Helen Keller once said, “I long to accomplish a great and noble task, but it is my chief duty to accomplish small tasks as if they were great and noble.” I believe this dissertation study, although small in comparison to the knowledge that is needed regarding family support and deafblindness, was an important endeavor. This work would not have been possible, however, without the help, guidance, and support of my mentors, colleagues, friends, and family.

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Chapter 1: Literature Review

In recent years, there has been a growing awareness across educational policy, theory, and research that it is important to evaluate child and family services and supports in terms of how they benefit families. Services are “a range of educational, social, and health-related activities expected to improve outcomes for the individual or family as a whole” and supports are “less tangible resources provided to the individual or to the whole family which are expected to improve outcomes for the individual or family” (Zuna, Summers, Turnbull, Hu, & Xu, in press, p. 12). Understanding parents’ perceptions of the impact of services and supports on their family life is critical in determining how to improve supports and services in the disability field. Following is a review of research that investigated the impact of *families’ perceptions* of service and support adequacy on outcomes for families of children with disabilities. In this chapter, I will (a) provide an introduction on the importance of families as beneficiaries of services and a rationale for a review of the literature examining the impact of services and support adequacy on family outcomes, (b) describe the method used for the literature review, (c) report results of the review, (d) provide a discussion of those results, and (e) introduce the purpose of the present dissertation study.

Introduction

Family Supports and Services: A Priority in Policy, Theory, and Research

Policy is what drives the provision of services and supports for families. In the disability field, policy has provided for a number of services and supports for children with disabilities and their families within the last several decades that were previously non-existent. The inclusion of families as beneficiaries of education services, however, is a concept that has recently become more valuable and, as a result, provisions that emphasize the importance of families in the education of children are evident within aspects of federal education policy. For instance, the Individuals with Disabilities Education Act (IDEA) (2004) provides assurances that families will participate in their child's education and have access to procedures that could remedy the rights afforded under IDEA. A core principle of the No Child Left Behind Act of 2001 is parent participation and choice (Turnbull, Stowe, & Huerta, 2007). Accountability, fundamental to both statutes, has served to promote families as beneficiaries of services (Turnbull, Huerta, & Stowe, 2006). Because of these policies, programs are increasingly being held accountable for documenting the benefits of services they are providing to families, particularly at the early childhood level (Bailey et al., 2006; Bailey et al., 2008; Mannan, Summers, Turnbull, & Poston, 2006).

Even though there is a growing focus on families in service provision, the primary focus, however, remains on the child (Turnbull et al., 2007). Therefore, links between services, supports, and improved child outcomes strengthen the argument for families to become a priority in multiple service systems. Contemporary educational theories such as the family systems theory emphasize the importance of the family's role in a child's development (Turnbull, Poston, Minnes, & Summers, 2007; Turnbull, Turnbull, Soodak, & Erwin, 2006), and empirical research has supported this relationship. Arnold, Zeljo, Doctoroff and Ortiz (2008) found that parents' involvement in their child's preschool education was predictive of stronger preliteracy skills. Epley (2009) found that parent involvement in preschool education was significantly related to academic and social-behavioral performance in kindergarten for children who have disabilities. Additionally, Epley found parents' ratings of preschool service adequacy also significantly predicted academic and social-behavioral performance in kindergarten. Barnard-Brak and Thompson (2009) found a positive association between families of children with disabilities receiving respite care and child academic achievement across time. As a result of this growing body of evidence, arguments for family services and supports in the disability field are increasingly more important.

Families' Perceptions of Services and Supports

There is an undue emphasis on the effects of internal family characteristics (e.g., problem behavior, marital status) in family outcome research in the disability field (Turnbull, Summers, Lee, & Kyzar, 2007). However, studies have shown that external services and supports can have positive effects on families (Beresford, 1993; Friend, Summers, & Turnbull, 2009; Honig & Winger, 1997; Singer, Irvin, Irvine, Hawkins, & Cooley, 1989; Watkins, 1994). Evaluating the direct effect of services and supports on families is critical in understanding how services and supports meet their needs. Studies have investigated families' perceptions or satisfaction with services across a variety of service systems and with a variety of populations (Applequist & Bailey, 2000; Axtell, Garwick, Patterson, Bennett, & Blum, 1995; Bailey, Nelson, Hebbeler, & Spiker, 2007; Heiman, 2002; Bailey, Skinner, Rodriguez, Gut, & Correa, 1999; Liptak et al., 2006; McGill, Papachristouforou, & Cooper, 2006; O'Sullivan, Mahoney, Robinson, 1992; Wodehouse & McGill, 2009). These studies included satisfaction with services or perceptions of service and support adequacy as the outcome. Satisfaction with services is multidimensional and has the potential to significantly impact families. Understanding how parents' perceptions of particular services impact their family life will provide strong evidence that can be used to improve services and supports.

Theoretical Underpinnings of the Review

This review synthesizes the existing research examining the effects of parents' perceptions of service and support adequacy on family functioning, family satisfaction, family quality of life, and family stress in order to understand how this dissertation study contributes to existing knowledge on this topic. The current dissertation study and this review are guided by the unified theory of family quality of life (FQOL) (Zuna et al., in press):

> Systems, policies, and programs directly impact individual and family-level supports, services, and practices. Individual member concepts (i.e., demographics, characteristics, and beliefs) and family-unit concepts (i.e., dynamics and characteristics) are direct predictors of FQOL and interact with individual and family-level supports, services, and practices to predict FQOL. Singly or combined, the model predictors result in a FQOL outcome that produces new family strengths, needs, and priorities that re-enter the model as new input resulting in a continuous feedback loop throughout the life cycle (p. 14).

This unified theory explains the complex and dynamic phenomenon of family quality of life as an overarching concept and serves to generate multiple testable theories related to family quality of life. In this dissertation study, I tested the effects of the interaction between services and supports (i.e., actions that are taken on behalf of individuals with disabilities and their families) and the family unit or individual member’s perceptions of those services and supports on family quality of life. This literature review synthesizes existing knowledge on this topic. Figure 1 provides a visual depiction of the unified theory of family quality of life (Zuna, Summers, Turnbull, Hu, & Xu, in press).

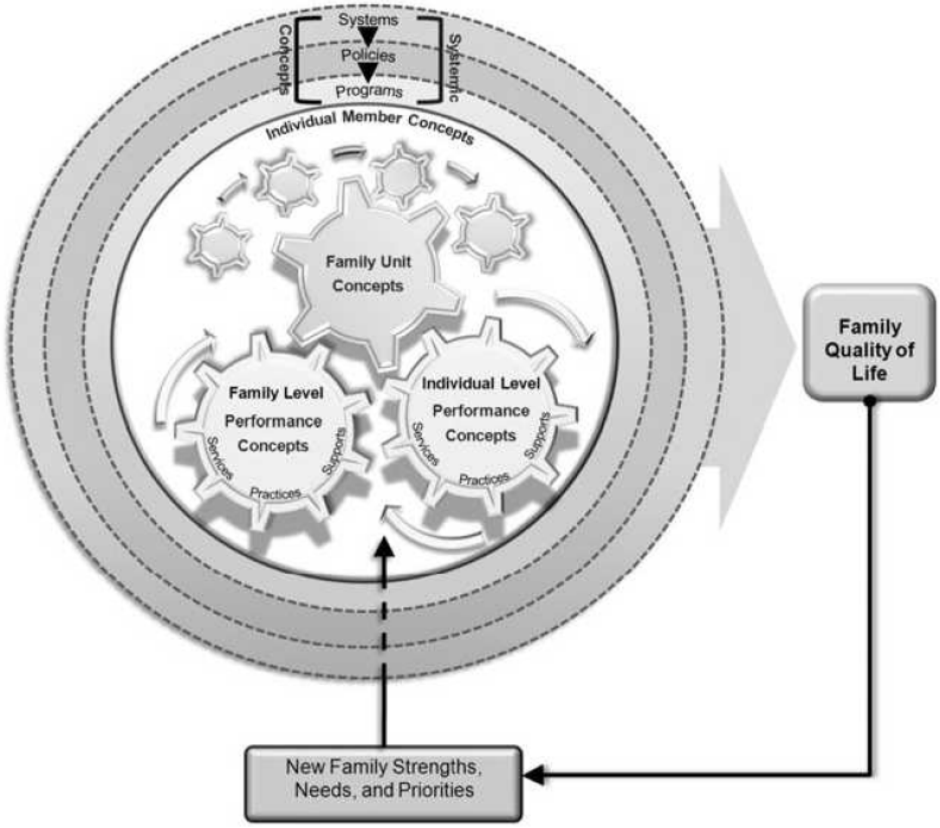

Figure 1. Unified theory of family quality of life (Zuna, Summers, & Turnbull, 2009).

Method

Study Criteria.

Studies included in the review met the following criteria:

- Participants were primary caregivers of individuals with severe, multiple, or developmental disabilities. If the sample included families of children with developmental disabilities, at least one-half of the participants' child's disabilities were moderate to severe and/or multiple in nature; studies that did not describe severity of disability or disability type were excluded.

- The age of the participants’ child with a severe, multiple, or developmental disability was between birth and 22 years. Samples of children older than 22 were eligible for the review if they also included children between the ages of birth and 22.
- Studies included quantitative results related to the impact of families’ perceptions of service and support adequacy on family functioning, family satisfaction, family quality of life, individual quality of life of a particular caregiver, or family stress.
- Studies were published between 1990 and 2010.
- Study findings were reported in English.

To be eligible for the review, studies needed to have described their outcome by using the following terms: family quality of life, quality of life (of parent or caregiver), family satisfaction, family functioning, or stress. I chose to include family satisfaction and family quality of life because they have been reported by service providers, administrators, and families in special education to be valued outcomes of service provision (Dunst & Bruder, 2002). Quality of life articles were also included if they assessed the quality of life of a caregiver. I chose to include family functioning and stress because they are commonly associated with the impact of services on families in the literature. To reduce publication bias, I included published and unpublished studies, including refereed journals, nonrefereed journals, dissertations, government reports, and technical reports. Dissertation abstracts and literature reviews were excluded. Studies conducted outside the U.S. were included; however, I did not include findings related to service provision in the review because service provision in other countries are guided by different policies and practices and cannot be compared to services in the U.S. For these studies, I included only data that related to informal supports, such as friends, extended family, or other parents of children with disabilities.

All families included in this dissertation study had children with deafblindness; additionally, the majority of the sample had children who experienced other severe and multiple disabilities. Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness (20 U.S.C. 1401(3); 1401(30)). The occurrence of severe and multiple disabilities are low. The Institute for Educational Sciences National Center for Education Statistics (2009) reported that in the 2007-2008 school year, there were approximately 138,000 children with multiple disabilities between the ages of 3 and 21 who received special education services and an additional 2,000 students between the ages of 3 and 21 who were deafblind. The percentage of children with multiple disabilities represented 2.1% of the total number of students with disabilities in special education services and 0.3% of the total enrollment of students in public school. The percentages of children with deafblindness compared to the total number of children with disabilities receiving special education services and total enrollment of children in public school were less than one percent (U.S. Department of Education Institute for Education Sciences, 2009). (I was unable to locate numbers on the incidence of severe disabilities from major data reporting sources. It is likely that these data are not reported in traditional incidence assessments because severity of disability represents the degree of the disability and not a disability category.)

Given that the count of children with deafblindness and children with multiple disabilities are low, research on this population is less prevalent. The search did not result in enough articles to justify a review with samples that included only families of children with severe and multiple disabilities; therefore, the inclusion of developmental disabilities was necessary. However, studies that focused solely on autism spectrum disorders were excluded because these studies often include families who have children with less severe disabilities. Studies with samples of families who have children with and without disabilities were included only if they reported results pertaining to the disability group only.

Article Location and Retrieval

In order to retrieve articles, I conducted key word searches in the following social science and medical databases: ERIC, PsychINFO, Google Scholar, ProQuest Dissertations and Theses, ProQuest Research Library, PubMed, Wilson OmniFile, and DB-LINK. In the first seven databases, the truncated keyword term disab* (to cover terms such as disability, disabled, disabilities) was paired with the outcome terms family functioning, family quality of life, and family satisfaction. In order to search for family stress articles, the truncated keyword term disab* and famil* were paired with stress. In addition, separate keyword searches were conducted in each of the first seven databases that included each of the outcome terms paired with the term deafblind. The final database, DB-LINK, includes publications specific to deafblindness, therefore, only the truncated term famil* was used in the search.

Limitations

This review included data regarding the effects of supports (e.g., friends, extended family) on family outcomes that was gathered in countries outside the U.S. It is possible that families are impacted by supports in different ways because of the culture of the area in which they live. The aggregated findings reported in this review may be influenced by this variable. The reader should be aware of this shortcoming when interpreting the results. Another limitation of this review is the inclusion of studies with a portion of samples whose participants have a child with a mild or moderate disability. The sample for this dissertation study includes families of children with deafblindness, the majority of whom have children with severe and multiple disabilities. Indeed, the findings of this review reflect the experiences of families who have children with mostly severe and multiple disabilities, but not solely severe and multiple disabilities.

Results

General Study Characteristics

A total of 16 studies met the inclusion criteria for the review. Refer to Table 1 for a list of the studies categorized by author, publication year, and type of publication. The studies included in the review were all published between 1993 and 2009 and fell within one of two publication types: refereed journal or doctoral dissertation. They are representative of two main service areas: education and health.

Table 1

Studies Included in Review (*N*=16)

Study	Author	Year	Title	Study Type
1.	Beyzavi	1993	Factors contributing to levels of stress perceived by parents of individuals with deaf-blindness (dual-sensory impairments)	Doctoral dissertation
2.	Dyson	1997	Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support	Refereed journal
3.	Fagan &	1993	Mothers of children with spina bifida:	Refereed

Study	Author	Year	Title	Study Type
	Schor		Factors related to maternal psychosocial functioning	journal
4.	Hodapp, Fidler, & Smith	1998	Stress and coping in families of children with Smith-Magenis syndrome	Refereed journal
5.	Huang	1996	Families of children with developmental disabilities: The test of a structural model of family hardiness, social support, stress, coping, and family functioning	Doctoral dissertation
6.	Keller & Honig	2004	Maternal and paternal stress in families with school-aged children with disabilities	Refereed journal
7.	McCarthy et al.	2006	Predictors of stress in mothers and fathers of children with fragile X syndrome	Refereed journal
8.	McIntyre	2000	The role of competency-enhancing helpgiving practices in parental adaptation for families of children with special needs	Doctoral dissertation
9.	Mitchell & Hauser-Cram	2008	The well-being of mothers of adolescents with developmental disabilities in relation to medical care utilization and satisfaction with health care	Refereed journal
10.	Neece, Kraemer, &	2009	Transition satisfaction and family well being among parents of young adults with	Refereed journal

Study	Author	Year	Title	Study Type
	Blacher		severe intellectual disability	
11.	Plant & Sanders	2007	Predictors of care-giver stress in families of preschool-aged children with developmental disabilities	Refereed journal
12.	Skok, Harvey, & Reddinhough	2006	Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy	Refereed journal
13.	Smith, Oliver, & Innocenti	2001	Parenting stress in families of children with disabilities	Refereed journal
14.	Trute	2003	Grandparents of children with developmental disabilities: Intergenerational support and family well-being	Refereed journal
15.	Wheeler, Skinner, & Bailey	2008	Perceived quality of life in mothers of children with fragile X syndrome	Refereed journal
16.	White & Hastings	2004	Social and professional support for parents of adolescents with severe intellectual disabilities	Refereed journal

Only one study focusing on deafblindness (Beyzavi, 1993) met the review criteria. The remaining studies included families of children with multiple disabilities, intellectual disability, physical disability (e.g., cerebral palsy), emotional behavior disabilities, developmental delay, autism, and Down syndrome. Five studies (in addition to the study focusing on deafblindness) included samples whose child had a specific disability: fragile X (n=2), cerebral palsy (n=1), spina bifida, (n=1), and Smith-Magenis syndrome (n=1).

Thirteen of the 16 studies (81%) investigated the impact of supports on family outcomes. For some studies, measures included sources of supports for families to rate (e.g., friends, extended family, social groups in the community, professional support), whereas other studies included measures that asked families to identify sources of supports and rate perceived helpfulness based on those individuals. All measures were quantitative in nature, and all used a rating or Likert scale response format. The remaining three studies (19%) examined the impact of the following formal services on families: (a) early intervention helpgiving practices, (b) health care from primary care provider, and (c) transition services (from high school to adulthood). The majority of studies (88%) included stress (either parent or family) as the outcome. Twenty-five percent of the studies included family functioning as the outcome. One study (6%) included quality of life as an outcome, and one study used family satisfaction as the outcome (6%). The latter study (Skok, Harvey, & Reddihough, 2006) included only mothers in the sample and used the Satisfaction with Life Scale (Diener, Emmons, Larson, & Griffin, 1985). Because a multi-informant approach was not utilized in this study, family satisfaction was, in fact, not the outcome; rather, life satisfaction was the outcome. At the outset, I included studies that assessed individual quality of life and family quality of life. To remain parallel with this standard, I also retained the life satisfaction paper for the review. Hereafter, I use the term life satisfaction in place of family satisfaction to accurately reflect the outcome in this study. No study that utilized family quality of life met the review criteria.

Four studies (25%) utilized two of the four outcome variables included in the review. All four of these studies included family functioning and stress. Tables 2 and 3 include descriptive information about the numbers and percentages of studies included in the review according to independent and outcome variables and outline the studies fall in each category.

Ten out of the 16 studies (63%) were conducted in the United States. One study was conducted in the United States and Canada (6%), one in Canada only (6%), and one in the United Kingdom (6%). Finally, three of the 16 studies were conducted in Australia (19%). The participants for each of these studies resided in the country in which the study was conducted. Two of the studies that were conducted outside of the United States included data regarding the impact of services on families. These data are not reported in this review, however, due to intra-country differences in policy and practices; aggregating the findings across studies would not have been appropriate.

Table 2

Studies Categorized by Independent Variable (*N*=16)

Independent Variable	% (n) Studies	Study[a]
Formal/Informal Supports	81% (13)	1, 2, 3, 4, 5, 6, 7, 11, 12, 13, 14, 15, 16
Services	19% (3)	8, 9, 10

[a] Study number can be located by reviewing Table 1.

Table 3

Studies Categorized by Dependent Variable (*N*=16)

Outcome Measure	% (n) Studies[a]	Study [b]
Stress	87% (14)	1, 2, 3, 4, 5, 6, 7, 8, 9, 10[c], 11, 13, 14, 16
Quality of life	6% (1)	15
Family functioning	19% (4)	3, 5, 8, 14
Life satisfaction	6% (1)	12
2 or more outcome measures[d]	19% (4)	3, 5, 8, 14

[a] Studies do not total 16 or equal 100% because four of the studies are included in three of the outcome measure categories (i.e., stress, family functioning, and 2 or more outcome measures).
[b] Study numbers can be located on Table 1.
[c] Study 10 included wellbeing as the outcome; however, stress was one of the major indicators of wellbeing
[d] All studies included in this category utilized only two measures: stress and family functioning.

Sample Characteristics

One study (6%) used random sampling procedures, and one study characterized the sample as representative (6%). The remaining either utilized a sample recruited through an agency, hospital, clinic, or school system, and the resulting sample consisted of parents who volunteered to participate (69%) or the paper did not include a description or sampling procedures (19%). Six of the 16 studies (38%) focused on the mother as the respondent, and eight (50%) focused on the mother and father. No study included in the review focused on the father as the sole respondent. Four of the studies (25%) included samples that were 85% or more White, and four (25%) included samples that were more than 15% White. The majority of the studies (62%) included samples of which 75% or more of the participants were married. Although half of the studies (*n*=8) did not include a description of participants' employment, 44% of the remaining papers included samples of which 25% or more were not employed. Most sample participants had completed an education through high school (50%). Thirty-eight percent included no education description.

Although a large number of the studies did not include information about participants' income (50%), the remaining studies were split. Twenty-five percent of the studies included samples whose household income was greater than $45,000 and 25% included samples whose household income was less than $45,000. Nineteen percent of the studies (*n*=3) included participants whose child was between the age of birth and 2, 31% (*n*=5) included participants whose child was between the age of 6 and 16, 6% of the studies (*n*=1) included participants whose child was 18 years of age or older, and 38% (*n*=6) included studies that crossed age categories.

Across studies, eight instruments were used to measure social supports. In general, the sources of supports were defined as spouse, friends, extended family, and in some cases, professionals or community social groups. The instruments measured one of the following: degree of helpfulness of supports; total number of supports, support size, and frequency of contact; types of supports (e.g., practical, emotional, informational); and support loss. Three measures were used to assess the impact of services on family outcomes. These instruments were

(a) the Helpgiving Practices Scale (Trivette & Dunst, 1994), a measure of mothers' perceptions of helpgiving practices employed by their child's service coordinator in early intervention (McIntyre, 2000); (b) a measure of parents' perception of how well their child's primary care or specialist physician met the needs of the parent or child (parent rated based on the doctor who provided the most care to the family) (Mitchell & Hauser-Cram, 2008); and (c) the Transition Experiences Survey (Kraemer & Blacer, 2001), which assessed families' perception of transition services (transition from high school to adulthood) through both open- and close-ended questions across key transition components—employment, community living, and socialization.

A total of 12 measures were used to evaluate stress; these ranged from those widely used (e.g., Parenting Stress Index, Questions on Resources and Stress—Friedrich Edition) to measures developed specifically for the study included in the review. Three instruments were used to assess family functioning, and one measure each to assess quality of life and life satisfaction. All measures were reported to have good reliability. Refer to Appendix A for information about each instrument assessing constructs used as independent and outcome variables. This Appendix includes two tables that describe the measures used in the studies, including the variable they assessed (independent or outcome), name of the instrument, the construct measured, and the studies in the review that used the measure.

Table 4 includes frequency demographic data for the studies included in the review. In this table, studies are categorized according to the independent variable (supports or services) or the outcome variable (stress, quality of life, family functioning, or life satisfaction) and each study is reported in each category. All studies included either services or supports as the independent variable; therefore, studies total to 16 in this category. There was overlap, however, in outcomes. Four studies included stress and family functioning as an outcome; therefore, outcomes total to 20, not 16.

Table 4

Sampling and Demographic Characteristics of Studies Included in Review

Study Characteristic	Independent Variable			Outcome Variable				
	Support (13 papers)	Services (3 papers)	Total (16 papers)	Stress (14 papers)	Quality of Life (1 paper)	Family Functioning (4 papers)	Life Satisfaction (1 paper)	Total[a] (20 papers)
Sampling Procedure								
• Random / Rep.	1	1	2	2	0	1	0	3
• Volunteer	9	2	11	10	0	3	1	14
• No description	3	0	3	2	1	0	0	3
Family member focus								
• Mother	4	2	6	4	1	2	1	8
• Father	0	0	0	0	0	0	0	0
• Mother and father	7	1	8	8	0	2	0	10
• Other	0	0	0	0	0	0	0	0
• No description	2	0	2	2	0	0	0	2

	Independent Variable			Outcome Variable				
Study Characteristic	Support (13 papers)	Services (3 papers)	Total (16 papers)	Stress (14 papers)	Quality of Life (1 paper)	Family Functioning (4 papers)	Life Satisfaction (1 paper)	Total[a] (20 papers)
Ethnicity								
• 85% + White	3	1	4	4	0	2	0	6
• 15% + non-White	2	2	4	3	1	2	0	6
• No description	8	0	8	7	0	0	1	8
Marital status								
• 75% + married	10	0	10	8	1	1	1	11
• 25% + not married	3	3	6	6	0	3	0	9
Employment								
• 75% + employed	0	1	1	1	0	0	0	1
• 25% + not emp.	7	0	7	6	0	2	1	9
• No description	6	2	8	7	1	2	0	10
Education								
• 75% + at least 12 yr	6	2	8	7	1	2	0	10
• 15% + less than 12	2	0	2	2	0	1	0	3
• No description	5	1	6	5	0	1	1	7

	Independent Variable			Outcome Variable				
Study Characteristic	Support (13 papers)	Services (3 papers)	Total (16 papers)	Stress (14 papers)	Quality of Life (1 paper)	Family Functioning (4 papers)	Life Satisfaction (1 paper)	Total[a] (20 papers)
Income								
• 50% + Income > $45,000	3	1	4	3	1	0	0	4
• Income < $45,000 (<50%)	3	1	4	4	0	2	0	6
• No description	7	1	8	7	0	2	1	10
Age of Child								
• Birth to 5	2	1	3	3	0	1	0	4
• 6 to 18	4	1	5	4	0	1	1	6
• 18+	0	1	1	1	0	0	0	1
• Cross categories	6	0	6	5	1	1	0	7
• No description	1	0	1	1	0	1	0	2

[a]Sixteen studies were included in the review; however, four studies included both family functioning and stress as outcome variables, so the Total column is representative of the number of times an outcome included in the review was reported.

Key Findings

In the following section, I report relevant findings of the studies organized by independent and outcome measures. I begin with a description of the findings related to the impact of supports on family outcomes, then I report the findings related to the effects of services on family outcomes. The majority of studies included stress as an outcome. Therefore, I report the findings of the studies in two groups: (a) stress (*n*=14) and (b) quality of life (*n*=1), family functioning (*n*=4), and life satisfaction (*n*=1). Some studies in the review included groups of families who had children with and without disabilities for comparison purposes. The findings reported in this section are only those from analyses run solely on the disability sub-group. Appendix B includes a table that describes the purpose(s) and sample of each study, independent and outcome measures included, and key results. Refer to this table for more detailed descriptions of each study included in the review.

Supports. In the following section, I highlight key findings of the studies included in the review. I first report the results from articles examining the impact of supports on stress and then discuss the impacts of supports on family functioning, parents' quality of life, and parents' life satisfaction.

Stress. Most studies found significant relationships between stress and social support, and these findings were particularly true for mothers. For example, Dyson (1997) investigated the relationships between stress and social supports for both mothers and fathers of children with developmental disabilities and found that mothers' stress was negatively related to their ratings of social support and fathers' ratings of social support. Similarly, Huang (1996) found that social support had a negative effect on family stress. Both these findings indicated that the more social support mothers have, the less stress they experience. Keller and Honig (2004) investigated influences on paternal and maternal stress in families of school-aged children with disabilities. They found that mothers' satisfaction with social supports [as measured by the *Family Support Scale* (FSS) (Dunst, Trivette, and Deal, 1988)] was significantly negatively associated with the total parenting stress score [as measured by the *Questions on Resources and Stress—Friedrich Edition* (QRS-F; Friedrich, Greenburg, & Crnic, 1983)] and the pessimism subscale of the QRS-F. Through path analysis, these authors found that socio-economic status was directly related to both social support and stress, suggesting that mothers who experienced higher socio-economic status perceived social supports as more useful. Finally, McCarthy, Cuskelly, van Kraayenoord, and Cohen (2006) found that satisfaction with supports (as measured by the FSS) was significantly negatively related to total parenting stress (as measured by the QRS-F) and the pessimism subscale of the QRS-F. However, none of these studies found that fathers experienced significantly less stress as a result of social supports.

One study, however, did show support to be effective in relieving fathers' stress. Trute (2003) investigated the impact of grandparent support on the stress of parents with developmental disabilities. The findings showed that significantly lower levels of stress were associated with emotional support from all four grandparent sources (i.e., their mothers and fathers and their mothers-in-law and fathers-in-law). Mothers in this study also experienced lower levels of stress when they perceived receiving emotional support; however, their levels of stress were only significantly related to emotional support from their own mother. The results of this study showed that instrumental support, or practical help, was not significantly associated with stress for either mothers or fathers. Researchers have also explored the relationship between social support and stress after accounting for other important variables; however, these findings are mixed. White and Hastings (2004) found that although there was a significant relationship between stress and social support for families (mostly mothers) of adolescents with severe intellectual disabilities, this relationship was no longer significant after child adaptive behavior (i.e., level abilities across the domains of socialization, communication, daily living skills, and motor skills) and problem behavior [i.e., self injurious behaviors (e.g., hitting head with hand or other body part); stereotypic behaviors (e.g., rocking back and forth); and aggressive/destructive behaviors (e.g., biting or hitting others)] variables were controlled. White and Hastings also reported that helpfulness of informal support sources (e.g., spouse, extended family, friends) was significantly negatively correlated with stress; but when covariates were included in the analysis, the relationship was only marginally significant.

Social supports did, however, serve to mediate or moderate relationships between other variables and stress. Plant and Sanders (2007) found that partner/family support (i.e., support from the respondents' spouse or partner or support from nuclear or extended family) moderated the relationship between the level of the child's disability (as measured by the Vineland Adaptive Behaviour Scale—Survey Form (Sparrow, Balla, & Cicchetti, 1984) and parent stress. This study included both mothers and fathers as respondents. These authors also found that friend support moderated the relationship between difficult child behavior during caregiving tasks and parent stress.

Friend support was also found to directly impact stress outcomes. Hodapp, Fidler, and Smith (1998) examined the stress and coping in families of children with Smith-Magenis syndrome and found that the number of friends in families' support systems was negatively correlated with parent-family problems and pessimism, as measured by subscales of the QRS-F and total stress scores, as assessed by the QRS-F. In fact, the number of friends was the most important variable in explaining parent-family problems and total stress, accounting for more than 30% of the variance in stress. The respondents for this study were mostly mothers (i.e., 92%).

Beyzavi (1993) was the only study included in the review that specifically examined the effects of supports on the stress of families who have children with deafblindness. This study focused solely on the perspectives of mothers; summed formal family support, informal family support, and total family support scores were used from the following domains: formal kinship (parents, spouse’s parents, relatives, spouse’s relatives, husband or wife, and children) and informal kinship (friends, spouse’s friends, other parents, co-workers). The findings showed that informal family support was negatively associated with Scale 8 (lack of family integration), Scale 9 (limits of family opportunities), and Scale 14 (social obtrusiveness) of the Questionnaire on Resources and Stress (QRS) (Holroyd, 1974), and formal family support was negatively associated with Scale 1 (poor health/mood). Informal, formal, and total family supports were not significantly correlated, however, with total QRS scores for these mothers.

Family functioning, quality of life, and life satisfaction. The findings on the effects of supports on family functioning are mixed. McIntyre (2000), in examining the effects of competency-enhancing helpgiving practices in parental adaptation for families of children with special needs, found that extended family support was significantly correlated with family functioning, as measured by the Feetham Family Functioning Survey (FFFS) (Feetham & Carroll, 1988). Huang (1996) found that for fathers of children with developmental disabilities, recent social support loss was positively correlated with family functioning. However, Huang found that for these same fathers and for mothers in the sample as well, social support did not have an effect on family functioning suggesting that parents are affected equally by children with special needs. However, the author did not provide further interpretation of this finding. Fagan and Schor (1993), in assessing factors related to maternal psychosocial functioning in mothers of children with spina bifida found that a key variable of interest in their study, adult companionship, did not predict family functioning. Similarly, Trute (2003) examined the effects of grandparent support on families of children with disabilities and found no relationships between emotional or instrumental support and family functioning.

Interestingly, although Skok, Harvey, and Reddinhough (2006) included satisfaction with life as an outcome variable in their study, they did not report results that included this measure. (I have made attempts to contact these authors regarding unpublished results; if I am successful in obtaining these results, future reports of this review will include those data.) For the final outcome, quality of life, Wheeler, Skinner, and Bailey (2008), in examining perceived quality of life in mothers of children with fragile X syndrome, reported that family support was significantly positively associated with mothers' quality of life. However, family support was not a significant predictor of mothers' quality of life after accounting for demographic variables (maternal IQ, income, child age, maternal age, child gender, ethnicity, time since diagnosis, number of children with fragile X, marital status); well-being measures (religiosity, family support, parenting stress, trait hope, current and past depression); and child variables (level of disability). Trait hope (i.e., current feelings of hopefulness and general or typical feelings of hopefulness) and total stress were the only significant predictors of mothers' quality of life in the full model.

Services. In the following section, I will report relevant findings related to the impact of parents' perceptions of service adequacy on stress, family functioning, parents' quality of life, and parents' life satisfaction.

Stress. Although McIntyre (2000) did not find significant relationships between competency-enhancing helpgiving practices and stressors, the other two authors investigating the effects of services on stress did find an association. Mitchell and Hauser-Cram (2008) found that maternal satisfaction with care received from their child's physician predicted maternal stress above and beyond the effects of marital status, income, child health, child cognition, child behavior problems, and health care utilization during the 12 months prior to the study. Neece, Kraemer, and Blacher (2009) found that there were significant differences in well-being (stress was a major indicator of well-being in this measure) between transition satisfaction and transition dissatisfaction groups. Sixty-four percent of the families in the transition satisfaction group had high family well-being and 64% of the families in transition dissatisfaction group had low family well-being.

Family functioning, quality of life, and life satisfaction. The only study that assessed the impact of services and used family functioning, quality of life, and/or life satisfaction as an outcome was McIntyre (2000). This author, in examining the role of competency-enhancing helpgiving practices in parental adaptation for families of children with special needs, found that competency-enhancing helpgiving practices were associated with higher levels of family functioning.

Discussion of Results

After rigorous and systematic search procedures examining the research conducted on the effects of service and support adequacy on families over the past 20 years, a total of 16 studies met the criteria for inclusion in the review. Of the 16 studies, two discipline areas are represented: education and health. One study used random sampling procedures, and one additional study characterized their sample as representative of the population they were studying. One-half of the studies included mothers and fathers; however, for the majority of these, mothers were the primary respondent. A surprisingly large amount of studies did not include descriptions regarding the ethnic distribution or income levels of their samples. The samples across studies could generally be characterized as (a) married, (b) not employed outside the home, (c) having at least a high school diploma, and (d) having a child with a disability between the age of birth and 18.

Most of the studies examined the effects of social support, in particular, family and friend support. It appears that these supports are effective at reducing mothers' stress, but not necessarily fathers' stress. Sarason, Levine, Basham, and Sarason (1983) found that social supports are associated with reducing psychological discomfort in women more so than men. Is it possible that social supports do not impact stress or other outcomes for fathers? Or are fathers generally less stressed than mothers? It is interesting that Trute (2003) found that grandparent emotional support appears to be effective at reducing fathers' stress, even more than mothers. Studies that investigate fathers may need to be more specific in the types of supports they include. This literature review did not seek to answer these questions but future review or studies on this topic are needed to understand the nature of fathers' stress in general. Gaining knowledge in this area would help inform practice in terms of meeting fathers' needs.

Of the few studies that investigated the effectiveness of services on family outcomes, the findings are generally positive. Greater satisfaction with care from a physician and increased satisfaction with transition services are influential factors in alleviating mothers' stress. Additionally, it appears that services that seek to improve the competency of mothers in managing the care of their child with special needs are associated with higher levels of family functioning. These few studies, however, cannot be characterized as an evidence base regarding the impact of parents’ satisfaction with or perception of services on families. In fact, according to the U.S. Department of Education Institute of Education Sciences, only studies that utilize randomization in their sampling procedures and have low attrition rates are considered strong evidence and meet current What Works Clearinghouse evidence standards without reservation (Institute of Education Sciences, 2008). Only one study in this review (Trute, 2003) would meet those criteria.

Only one study included in this review focused specifically on families of children with deafblindness (Beyzavi, 1993). The results showed that informal supports, that is, from friends, other parents, or co-workers, increased families’ sense of integration in the community and opportunities available to them and decreased their feelings of social obtrusiveness. Social obtrusiveness was not defined in the study but was reported as a subscale of the Questionnaire on Resources and Stress that was associated with child-related problems. Support from immediate and extended family was associated with improved health and overall mood. This study provided important evidence in understanding the needs of families who have children with deafblindness. However, it was limited by sample size (25 mothers in deafblind group) and the data are more than 15 years old. Constructs such as social obtrusiveness are not as relevant to measure in the climate of family research today, whereby researchers are calling for investigations to focus more on positive outcomes, such as family quality of life, over negative outcomes, such as stress, depression, and caregiving burden (Hastings & Taunt, 2002; Helff & Glidden, 1998). Although some conclusions can be drawn from the findings of this study regarding the support needs of families who have children with deafblindness, they are only applicable when considering the characteristics of the sample, which were mostly White, married, and educated mothers. More research is needed to see if these results are similar to samples of families of children with deafblindness who have other characteristics and to understand the effects of other sources of supports and services on this population of families.

In this paper, I argue that understanding how perceptions of service and support adequacy *from the perspective of the service recipient* impact family outcomes is a key component in understanding (a) what services and supports are important and (b) the most effective methods of implementing services and supports. It is surprising that so few studies (*N*=16) examined this phenomenon when it applies to families of children with severe and multiple disabilities. It is important to note that several studies were excluded from this review because they evaluated a service that was implemented in a country outside of the U.S. (Davis & Gavidia-Payne, 2009; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Hudson, Cameron, & Matthews, 2008). Additionally, there are studies examining the effects of service and support adequacy that were conducted with samples of families of whom the majority of children have mild disabilities or the authors were not descriptive about the type or severity of disabilities included in the sample (Feldman et al., 2007; Hassal, Rose, & McDonald, 2005; Summers et al., 2007). Future literature reviews could broaden the review conditions to gain a more expansive understanding of the effectiveness of supports and services adequacy on families. However, it is clear that additional research is needed to gain a deeper understanding of how these factors affect low incidence populations, particularly related to the impact of services. In addition, future research agendas should focus on gaining a deeper understanding of the effects of supports on not only mothers, but also fathers, and other caregivers of children with severe and multiple disabilities.

Finally, families of children who have moderate to severe disabilities are often the recipient of services and supports from multiple service systems. Deafblindness, in particular, affects language and communication development as well as orientation and mobility skills

(Arnold, 1998). With the exception of those with Usher syndrome, children with congenital deafblindness can experience intellectual disability, physical disabilities, and behavior challenges in addition to their dual sensory impairments (Dalby et al., 2009; Müller, 2006; Murdoch, 2004; Pollard, Miner, & Cioffi, 2000). It is estimated that more than 90% of children who are deafblind have at least one additional disability or special health concern (Malloy & Killoran, 2007). One mother, who participated in this dissertation study, eloquently shared how exceptional her child is in her family:

> *Our Angel was adopted by us. She is not only deaf and blind but her biological mother was addicted to meth and cocaine, and Becca had a stroke before she was born. She is completely paralyzed, has CP, no gag reflex, has a trach, is fed through a g-tube and has little immune system. When we adopted her, the doctors all stated her life expectancy was less than 1 year. She is now 4 1/2 yrs old and praise God she can smile but little else. We love her very much, and we are very protective of her due to her being so fragile. She requires a 24 hour a day [care]. We try to keep her isolated to keep her with us as long as possible due to her low immune system.*

Given the complexity of deafblindness and the multiple service systems that can be involved in meeting the child's needs, effects, both positive and negative, to the child and family are to be expected. The research in this review was only representative of services in the education or health systems. More research is needed in other areas of service delivery, such as social work or child care, so that policy and practice can be better informed and improvements to services in these areas can be made.

In sum, social supports from sources such as friends, spouses, and extended family appear to be beneficial to mothers who have children with moderate to severe disabilities in reducing their stress. However, studies that were included in this review were lacking in the use of random or representative sampling procedures, and were more informative about the impact of social supports than formal services. Even though the studies highlighted the importance of social supports, these studies, for the most part, did not include the following in their sample: (a) caregivers who are not mothers or fathers, (b) mothers or fathers who are employed outside of the home, (c) and families whose child with a disability is 18 years of age or older. Additionally, conclusions cannot be made across the findings about the needs of families from low, middle, or high socio-economic groups or families of varying ethnic diversity because this information was not provided in half of the studies. Research that focuses on gaining knowledge in this area about participants that experience these demographics is needed.

Parents' Perceptions of Service and Support Adequacy and Family Quality of Life for Families of Children With Deafblindness

The current dissertation study sought to examine the effects of services and support adequacy on family quality life (FQOL) for families of children with deafblindness. Services were assessed across a variety of disciplines (e.g., health, education, service coordination) and supports included friends, extended family, support for siblings, contact with other parents of children with deafblindness or similar etiology, and family events such as trainings, networking social events, or conferences. In addition, this study examined the impact of two variables on the relationship between services and support adequacy and FQOL: family-professional partnerships and the age of the person with deafblindness in the family. In this section, I will discuss the influences family-professional partnerships and child age can have on how parents perceive services, explain the study purpose, and provide the research questions that guided the study.

Family-Professional Partnerships

Family-professional partnerships can be defined as “a relationship in which families (not just parents) and professionals agree to defer to each other’s judgments and expertise, as appropriate for the purpose of securing benefits for students, other family members, and professionals” (Turnbull, Turnbull, Erwin, & Soodak, 2006, p. 141). Family-professional partnerships are based on seven core principles, one of which, that is trust, is the keystone. The other six principles include communication, professional competence, respect, commitment, equality and advocacy (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). Given the collaborative nature of partnerships, it is not surprising that they have been shown to affect family outcomes (Davis & Gavidia-Payne, 2009; Dunst & Dempsey, 2007).

The outcome measure used in this dissertation study is family quality of life (FQOL). Examining the impact of parents’ satisfaction with partnerships on the relationship between parents’ satisfaction with services and FQOL will provide information about how the effects of services, if negative, can be mediated, and if positive, can be enhanced. Summers and colleagues (2007) did, in fact, study this effect on FQOL utilizing a sample of 176 parents (mostly mothers); almost half of the sample (i.e., 45.6%) had children with mild disabilities, and 9.4% of the participants had children with severe disabilities. The findings showed that satisfaction with partnerships partially mediated the effects of parent perceptions of service adequacy on FQOL indicating that “the quality of relationships with professionals is also a critical component of effective service models” (p. 334). Arguably, families of children who are deafblind may experience even greater dissatisfaction than the families in the sample for the Summers et al. research study because of the complex support needs they can experience. Indeed, satisfaction with partnerships is a variable of interest to include in an examination of the effects of perceived service and support adequacy on family quality of life.

Age of Child

Services across the lifespan are qualitatively different in terms of the emphasis of family support. The field of early childhood education has been influenced by a paradigm of family support, including the importance of family-centered service delivery and engaging in partnerships with families. Early intervention services, provided for under Part C of IDEA (2004), have a strong family focus and promote the inclusion of family strengths, needs, and priorities in service delivery. As a child ages, however, the culture of including families as partners in educational decision-making and family support practices begins to decline (Dunst, 2002).

A number of studies have investigated the influence of child age on family outcomes (Datta, Russell, & Cookemane, 2002; Hsieh, Huang, Lin, Wu, & Lee, 2008; Macias, Saylor, Rowe, & Bell, 2003). Two examples from the education field are McWilliam et al. (1995) and Summers, Hoffman, Marquis, Turnbull, and Poston (2005). Both studies found an effect of age, citing that families of older children reported lower satisfaction with services. In Summers et al., parents' satisfaction with partnerships were evaluated in terms of how it differs with the age of the child. Age ranges of children were analyzed in the following groups: birth to 2 years (*n* = 48), 3 to 5 years (*n* = 44), and 6 to 12 years (*n* = 55). In general, parents of older children (i.e., 6 to 12 years) were less satisfied than parents of younger children (i.e., birth to 2 years); parents of children between the ages of 3 and 5 years experienced satisfaction ratings that fell between the other two groups. The results of this study highlighted a trend of increasing dissatisfaction with services as the family's child ages. Likewise, McWilliam and colleagues detected differences at the age ranges of three to five when compared to those families whose child was birth to three years of age.

Investigating the influences of age on the relationship between perceived service and support adequacy and family quality of life would provide additional evidence needed in understanding the role child age, as a proxy for the various service systems, plays in affecting family outcomes. This evidence, if shown to have the same effects as the preceding studies, could be used as a catalyst for promoting the increased use of family support practices in programs for older children.

Conclusions

Parents' perceptions of supports and services, parents' satisfaction with family-professional partnerships, and child age have been shown to affect family outcomes. However, little is known about the effects of these variables on family quality of life for families of children with deafblindness. Understanding how supports and services affect these families' quality of life and whether or not child age and parents' satisfaction with partnerships serve to mitigate or enhance the effects of services and supports is critical in informing policy, practice, and future research.

Study Purpose and Research Questions

The purposes of this dissertation study were to (a) evaluate the relationship of perceived service and support adequacy across a variety of service systems (e.g., health, education, social work) and including friend and family support to FQOL and (b) to evaluate family-professional partnerships and/or child age as moderators of the relationship between service and support adequacy and FQOL for families of children with deafblindness. The research questions for this study are as follows:

1. Controlling for income and marital status, are families' perceptions of service and support adequacy significantly related to their FQOL?
2. Controlling for family income and marital status, do satisfaction with family-professional partnerships moderate the relationship between service and support adequacy and FQOL?
3. Controlling for family income and marital status, does age of the person with deafblindness in the family moderate the relationship between service and support adequacy and FQOL?

CHAPTER 2: METHOD

The purpose this study was to determine how well services and supports meet the needs of families who have children with deafblindness and if these perceptions of service and support adequacy relate to FQOL. Two other factors were explored in terms of how they influence this relationship; these included age of the child and the extent to which families are satisfied with the partnership they have with their child's primary service provider. To this end, I utilized survey research design, which included the distribution of the self-administered Service Adequacy and Family Quality of Life for Families of Children who are Deafblind Survey to primary caregivers of individuals who are deafblind. This survey included the following: (a) Services Adequacy Scale for Families of Children who are Deafblind, (b) Beach Center Family Quality of Life Scale (FQOL), (c) Beach Center Family-Professional Partnership Scale, and (d) a demographics section. I used quantitative methods to clean and analyze the data. Following is a description of the participants and procedures used in the study and the limitations of the study.

Participants

A total of 227 caregivers of individuals with deafblindness elected to participate in the study; 98.2% completed a paper-and-pencil version and 1.8% completed the survey online. These caregivers were from 16 states geographically distributed across the nation: Arkansas, California, Illinois, Kansas, Kentucky, Minnesota, Michigan, New Mexico, North Dakota, Pennsylvania, Tennessee, Texas, Virginia, West Virginia, Wisconsin, and Wyoming. Table 5 includes demographic data for the participants in this study.

Table 5

Participant Characteristics (N=227)

Characteristic	Frequency	Percent
Gender		
Male	18	7.9
Female	205	90.3
Missing	3	1.3
Ethnicity		
American Indian or Alaskan Native	6	2.6
Asian or Pacific Islander	4	1.8
Black or African American	19	8.4
Hispanic or Latino	21	9.3
White	179	78.9
Other	3	1.3
Missing	3	1.3
Relationship to deafblind individual in family		
Parent (biological, step, foster, or adoptive)	213	93.8
Grandparent	7	3.1
Aunt or uncle	1	0.4
Sibling (brother or sister)	1	0.4
Other non-relative	1	0.4
Missing	4	1.8
Marital Status		

Characteristic	Frequency	Percent
Married/living with a partner	168	74.0
Not married (widowed, divorced, separated, never married)	55	24.2
Missing	4	1.8
Education		
Schooling but not high school diploma or GED	7	3.1
High school graduate (diploma or GED)	37	16.3
Some college or post-high school, but no degree	46	20.3
Associate degree (AA, BS, etc.)	36	15.9
Bachelor’s degree (BA, BS, etc.)	47	20.7
Graduate degree	39	17.2
Other	9	4.0
Missing	6	2.6
Employment		
Working full-time for pay or profit (hours not defined)	78	34.4
Working part-time for pay or profit (hours not defined)	57	25.1
Unemployed but looking	11	4.8
Not employed (for example, stay-at-home parent or caregiver)	76	33.5
Missing	5	2.2
Family Income		
Less than $14,999	30	13.2

Characteristic	Frequency	Percent
Between $15,000 and $19,999	16	7.0
Between $20,000 and $24,999	12	5.3
Between $25,000 and $29,999	13	5.7
Between $30,000 and $34,999	6	2.6
Between $35,000 and $39,999	7	3.1
Between $40,000 and $49,999	19	8.4
Between $50,000 and $59,999	20	8.8
Between $60,000 and $74,999	27	11.9
Over $75,000	66	29.1
Missing	11	4.8
Geographic location		
Urban (population > 50,000)	68	30
Suburban (population between 10,000 and 50,000)	89	39.2
Rural (population < 10,000)	64	28.2
Missing	6	2.6
Nature of disability in addition to deafblindness[a]		
Developmental delay	181	79.7
Emotional behavioral disorder	37	16.3
Learning disability	122	53.7
Attention deficit disorder	33	14.5
Intellectual disability	87	38.3
Physical disability	154	67.8

Characteristic	Frequency	Percent
Speech or language impairment	185	81.5
Other health impairment	103	45.4
Mental illness	21	9.3
Autism spectrum disorder	19	8.4
Traumatic brain injury	44	19.4
No additional disability	5	2.2
Missing	3	1.3
Age of child		
Birth to 2 years, 11 months	19	8
3 to 5 years	31	13.6
6 to 22 years	173	76.2
Missing	4	1.8
Public benefits accessed by individual with deafblindness in family		
Supplemental Security Income (SSI)	89	39.2
Temporary Relief for Needy Families (TANF)/Katie Beckett Program	8	3.5
Home and Community Based Services (HCBS) Medicaid Waiver	45	19.8
Medicaid / State Children’s Health Insurance Program	100	44.1
Public Assistance (TANF, food stamps, child care, WIC, Lineap)	45	19.8

Characteristic	Frequency	Percent
None	47	20.7
Missing	12	5.3

[a] Percentage does not equal 100% and frequency count does not equal 227.

The majority of the participants were female (90.3%), White (78.9%), and described themselves as the parent (biological, step, foster, or adoptive) (93.8%). Approximately three quarters of the participants were married or living with a partner (74.0%), and half (53.8%) held a degree post-high school (Associate, Bachelor's, or Graduate). Thirty-four percent of the participants were working full-time, 25.1% of the participants were working part-time, and 33.5% were not employed (for example, stay at home parent or caregiver). Approximately 20 percent of the sample reported earning less than $19,999 in the 12 months prior to completing the survey; 33.9% of the participants' incomes fell within the range of $20,000 and $59,999; and the remaining 41% reported an income greater than $60,000. Thirty percent described themselves as living in an urban area, 39.2% lived in a suburban area, and 28.2% lived in a rural area. (Urban was defined as an area whose population is greater than 50,000; suburban was defined as an area in which the population was between 10,000 and 50,000; and rural was defined as a population less than 10,000.)

Participants were asked to report any disabilities the individual with deafblindness in the family had in addition to his or her dual sensory impairment. The majority of participants noted that their child had a speech or language impairment (81.5%), a developmental delay (79.9%) as well as a physical disability (67.8%). Roughly half noted that, in addition to deafblindness, their child also had a learning disability (53.7%) and an 'other health impairment' (45.5%). Finally, around one-third of the individuals with deafblindness in the family also had an intellectual disability (38.3%). Only five participants (2.2%) noted that their child had no additional disabilities. Eight percent of the individuals with deafblindness were between the ages of birth and two, of age to receive early intervention services under Part C of IDEA; 13.6% were between the ages of three and five, of age to receive Section 619 Preschool services under Part B of IDEA; and 76.2% were between the ages of six and 22, of age to receive special education services under Part B of IDEA. Around half of the individuals with deafblindness received assistance from Medicaid or the State Children's Health Insurance Program (SCHIP) (44.1%); 38.2% received Supplemental Security Income (SSI) benefits; 19.8% received both the Home and Community Based Services (HCBS) Waiver and public assistance from programs such as Temporary Assistance for Needy Families (TANF), Food Stamps, Child Care, Women Infants and Children (WIC), or Lineap; and 20.7% reported that their child received no public benefits. Refer to Appendix C for a full report of the participants in this study.

Procedures

This section includes a discussion of the sampling and data collection procedures, measures, and data analysis used in this study.

Sampling

Participants for this study included families of children who were identified as deafblind based on federal deafblind certification guidelines. These guidelines are as follows:

> Individual who is deaf-blind means an individual—
>
> (1)(i) Who has central visual acuity of 20/200 or less in the better eye with corrective lenses, or a field defect such that the peripheral diameter of visual field subtends and angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both of these conditions;

(ii) Who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition; and

(iii) For whom the combination of impairments described in paragraphs (1)(i) and (ii) of this definition causes extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation;

(2) Who, despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral constraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining vocational objectives; or

(3) Who meets any other requirements that the Secretary may prescribe (34 CFR 396.4 (1)-(3)).

Individuals meeting these criteria are included on a deafblind census in their state. The entity that collects and manages census data are state DeafBlind Technical Assistance Projects. There are a total of 53 federally-funded DeafBlind Projects across the United States and U.S. Territories. The overall purpose of these projects is to provide support, training, networking, and technical assistance to families of children with deafblindness and practitioners serving them. States have the flexibility to vary slightly from the above federal definition of deafblindness in terms of the functional hearing and/or vision requirements, but the core definition of deafblindness is consistent among projects.

State deafblind technical assistance projects also varied in terms of the age of individuals with deafblindness that they serve. To be consistent across projects and with the age parameters of the federal special education law, Individuals with Disabilities Education Act of 2004, I included only individuals in the family that were between the ages of birth and 22. It was necessary to include such a wide range of individuals because one of the purposes of this study is to learn the impact of age on the relationship between service and support adequacy and FQOL. Participating families were the primary caregiver of the child (e.g., biological parent, adoptive parent, grandparent), and only one survey was completed per household.

Sample size estimations that are based on a power analysis aid in determining the probability that the results will be statistically different from zero (Cohen, Cohen, West, & Aiken, 2003). Therefore, I conducted an a priori power analysis using the parameters of this study and included the number of predictors used in the moderator analyses, as these analyses included the largest number of variables: $p < .05$, a moderate effect size ($r = 0.15$), power or error probability ($1 - \beta$ err prob) of .80, and 17 variables [two Covariates (discussed in data analysis section); eight Independent Variables (seven average scores representing Perceived Service and Support Adequacy and one Moderator Variable, i.e., Satisfaction with Family-Professional Partnerships/Age of the Child); and seven Interaction Terms] utilizing the G*Power 3.1.2 program (Faul, Erdfelder, Buchner, & Lang, 2009). The results indicated that the total sample size for this study should be 146 and that the Critical $F_{(17,128)}$ would be approximately equal to 1.70.

I obtained participants for this study through cluster or multi-stage sampling, which entailed the identification of groups or organizations (i.e., clusters) that serves as a catalyst for generating a sample (Creswell, 2009; Kalton, 1983). I chose to access state deafblind technical assistance projects as the cluster to obtain participants for this study because they are the entity that manages up-to-date census data on children identified with deafblindness and staff would have access to the names and addresses of families in their state whose child was identified as deafblind according to federal census guidelines. I utilized a multi-stage sampling procedure as follows. Project Directors and Family Specialists from each state deafblind technical assistance project (i.e., a total of 53 projects) were contacted initially by either myself, the Project Director for the Kansas State DeafBlind Technical Assistance Project, or the Chair of the National Council on Deafblind Projects' Parent Liaison Committee by email with an invitation to participate in the study. Refer to Appendix C for the study invitation letter. Please note that this study was originally conceptualized as a mixed methods study. The title of the project in the study invitation letter is reflective of that earlier conceptualization of the project.

After the initial email contact, I followed up by either phone or email with additional information about the study. To provide incentive for states to participate, I offered projects the opportunity to include with the survey distribution a separate questionnaire developed by their project team. This separate measure would not be included within this study; however, after its completion, I would analyze the data from each state-specific section and forward results to the respective project. Each project that participated would receive results from the overall study.

Project coordinators, project directors, or family liaisons from 17 state projects indicated interest in distributing surveys to families in their state. Four states elected to include a state-specific section. Sixteen out of the 17 states distributed a total of 2,028 paper-and-pencil surveys either face-to-face or via US mail; an additional 188 were delivered electronically through email. A total of 227 were returned with an overall response rate of 11.2%. Complete response rate information is included in Table 6.

Data Collection

I began data collection by submitting an application to conduct research for this project to the University of Kansas' Internal Review Board. The Human Subjects Committee on the Lawrence campus (HSCL) approved this study on September 9, 2009. Please note the approval notice on the welcome and consent letter (Appendix C).

Table 6

Study Response Rate to Service Adequacy and Family Quality of Life for Families of Children who are Deafblind Survey

State	Month Distributed	Distribution Method	Number Distributed	Number Returned	Response Rate (%)
West Virginia	October	Family Event	7	0	0%
Kansas	October	Mail	112	28	25%
Minnesota	October	Family Event	15	7	47%
Texas	October	Family Event and Email	150	14	9%
New Mexico	November	Mail	74	13	18%
Pennsylvania	November	Mail	365	46	13%
Michigan	November	Mail	260	37	14%
Kentucky	November	Mail	26	1	4%
California	November	Mail	33	5	15%
Wyoming	November	Mail	30	5	17%
North Dakota	November	Mail	6	1	17%
Wisconsin	December	Mail	259	12	05%

State	Month Distributed	Distribution Method	Number Distributed	Number Returned	Response Rate (%)
Tennessee	January	Mail	167	20	12%
Arkansas	January	Mail	83	10	12%
Illinois	January	Mail and Email	328	18	5%
Virginia	February	Mail	113	10	8%
Total			2,028	227	11%

As previously described, I accessed state deafblind technical assistance projects as the cluster by which I obtained my sample. After recruitment, project staff from 17 states indicated their interest in distributing survey packets, via either email or U.S. Mail. Of the 17, project staff from one state indicated interest but did not distribute packets to families within the timeline of this dissertation study. Future reports of this study will include those data in the findings; however, this report includes data from only 16 states.

Because of privacy restrictions, I did not have access to the names and addresses of the families of children listed on each state’s census. Therefore, I asked state projects that chose to participate to distribute either pre-prepared survey packets (prepared at the Beach Center) or the link to the web survey to all families of children certified as deafblind in their state. The paper packets included (a) a welcome letter explaining the purpose of the study and the participants’ role, including benefits to them, (b) a consent form containing assurances of confidentiality and the option to complete either a web or paper survey, and (c) the self-administered Service Adequacy and Family Quality of Life for Families of Children who are Deafblind Survey (see

Appendix D). The full survey contained four measures; all documents included in the packet were available in both English and Spanish.

Project Coordinators or Family Liasons sent the web survey distribution via email which included an electronic version of the welcome letter explaining the purpose of the study and the participants' role, benefits and potential risks to them, assurances of confidentiality and informed consent, and a link to the web survey. They included all this information in the body of the email message with the request that if they were unable to read or access any portion of the email, they could contact Kathleen Kyzar at kkyzar@ku.edu or 785-864-7601. I did ask for written consent from families who completed web surveys. The narrative in both the email invitation letter and survey instructions included the following informed consent statement: "By completing the survey, you indicate that you have been informed of the important aspects of the study." I set up the SNAP software to route completed surveys directly to me via email. The data were unrecognizable in the email message; to decode responses, I exported the data to the SNAP software program. I took additional confidentiality measures by moving the email message directly to a personal folder stored on my computer's hard drive. Thus, data for this project were not stored in any online format.

I asked families interested in participating in the study who were completing the paper version to return the consent form, signed and dated, along with either their completed survey (completed to the extent they are comfortable) or their email address (to enable me to distribute the web survey to them if they chose that method) directly to Kathleen Kyzar at the Beach Center on Disability. I helped secure confidentiality by asking the participant to mail surveys and consents directly to the Principal Investigator. This method precluded state deafblind project staff from knowing who had responded to the survey request. In addition to their signature, I asked participants to provide contact information (i.e., email address, mailing address, and phone number) so I could reach them for nonresponse purposes. I included two business reply envelopes in the paper mailing so participants could return their consent form and survey separately and at no monetary cost to them. I pre-coded surveys with numbers representing the state in which the individual lived followed by a unique ID. I also wrote the number on the smaller business reply envelope attached to the consent form so identifying information that I received separately from the survey could be internally linked to the data. Upon receipt of paper surveys, I stored data in a locked file cabinet in a locked office on the university campus. I included my phone number and email address on both the paper and web versions so that families could contact me should they have any questions regarding the study. I delivered all web and paper surveys between the months of October and February. Refer to Appendices C and D to review the documents in the welcome packet.

All but four of the state projects distributed surveys in the manner just described. Three out of the 16 states (i.e., West Virginia, Minnesota, and Texas) were hosting family weekends within a short time after my initial contact and indicated their preference to distribute survey packets directly to families at these events as contrasted to sending survey packets by mail or email. They reasoned that the response rates would increase if they had the opportunity to hand deliver the surveys and provide time during the course of the weekend for families to complete and submit surveys in a confidential manner. (Please note that I submitted an addendum for survey distribution in this manner to the Human Subjects Committee, Lawrence Campus and this addendum was approved. Refer to Appendix E to review the modified invitation letter to the study with the Human Subjects approval stamp.) The numbers of participants at these events varied from seven to 60; therefore, for these states, the number of survey packets distributed was not reflective of all the families in the state but rather only those families attending the family event (refer to Table 6). One state, Texas, engaged in an additional distribution after the family event. The family specialist emailed the survey to families in this state who subscribed to three separate listservs the state deafblind project managed. Finally, project staff from one state, Illinois, chose to mail survey packets to all families for whom they did not have email addresses and email surveys to families on their listserv. Therefore, the families on the electronic listserv did not receive paper packets or the option to complete a paper version.

Nonresponse from a large percentage of individuals selected to be in a sample is a potential source of survey error and bias (Fowler, 2009). Because I did not have access to the identifying information of families who were sent survey packets by each state deafblind project, I did not have the means to follow up personally with individuals who did not initially return consent forms and surveys. I did, however, follow-up with individuals who indicated interest in the study by only submitting a consent form. I either mailed or emailed the survey according to their preference on the consent form with an accompanying appreciation letter for their consent to participate in the study.

Upon receipt of completed surveys, I either downloaded the data into a survey software (SNAP Surveys, Version 9) database and subsequently exported the dataset from SNAP into SPSS (PAWS Statistics, Version 17.0) or entered data into SPSS directly. In addition to the large database for the overall sample, I generated a separate database for each state in order to produce the reports promised to them.

Measures

The measures are as follows: (a) Service Adequacy Scale for Families of Children who are Deafblind (SAS-DB), (b) Beach Center on Disability Family Quality of Life Scale, (c) Beach

Center on Disability Family-Professional Partnership Scale, and (d) a demographics section. Following is a description of each measure including psychometric properties, if applicable, as well as a description of the methods used to develop the instrument.

Service Adequacy Scale for Families of Children who are Deafblind (SAS-DB). The Service Adequacy Scale for Families of Children who are Deafblind, hereafter referred to as the SAS-DB, is a 52-item self-administered questionnaire that assesses families' perceptions of how well services and supports adequately met their child and family needs during the 12 months prior to completion of the survey. These items are grouped according to service and support systems, or domains. The domains included are: (a) Health, (b) Education, (c) Related services, (d) Information, (e) Friend and family support, (f) Child care, and (g) Service coordination. The measure is intended to comprehensively evaluate the services and supports individuals with deafblindness and their families have received from a broad range of agencies and assumes participants need and use services and supports in each of these broad categories to at least some degree. However, a *did not use* option is available. In addition to the available items, there is an option to rate an *other* service or support that respondents define in an open-text box field. Items are specific to disability related services but, in particular, the items reflect the service and support needs of families who have children with deafblindness.

The SAS-DB was developed to assess families' overall perception of service and support adequacy across a range of disciplines. A team of Kansas parents and professionals familiar with the needs of families of children who are deafblind developed an initial version of the scale. Content for the candidate items included services and supports families of children who are deafblind typically receive. Measurement error, or the error that occurs when respondents do not provide accurate answers to questions, is a critical consideration in the development of a survey

(Lorenz & Dillman, 1995). As such, during the initial development of the SAS-DB, survey questions were written bearing in mind the importance of questions that every participant (a) is able to readily answer, (b) is willing to answer, and (c) can answer with accuracy (Dillman, 2000; Fowler, 2009). One sensitive question was included (i.e., income); however, it was important to collect data regarding income as this has been shown to impact FQOL (Wang et al., 2004). It is reassuring to know, however, that research has shown that participants are more willing to provide honest answers to self-administered questionnaires than to interview questionnaires (Fowler, Roman, & Di, 1998). Question instructions and the questions themselves were kept brief and straightforward to increase the participants' motivation to respond (Dillman, 2000) and descriptors were provided with response categories (e.g., services met my needs "not at all," or "a little") to increase consistency of interpretation across participants (Fowler, 2009). Finally, a software program, SNAP Survey Software Version 9, which is dedicated to survey design, was used for the purpose of helping to ensure that the survey was visually appealing to participants, thus easing their ability to complete the survey without distractions.

Dillman (2000) recommended that after a draft survey has been developed, it should be pretested by knowledgeable colleagues to identify problems and to learn if respondents understand the questions. Having generated an item pool and format for measurement, I asked for two experts in the area of deafblindness to review the preliminary scale (DeVellis, 2003). These experts included one state Technical Assistance Deafblind Grant Coordinator and one Family Liaison to these projects. Project coordinators are trained in the area of deafblindness and are strongly connected to the everyday needs of children who are deafblind and their families. The Family Liaisons are family leaders with personal experiences related to service adequacy.

After receiving their feedback, I revised the questions and edited the content to improve readability.

After the expert review, Dillman (2000) further recommended that the survey developer undergo interviews to evaluate cognitive and motivational qualities of the survey. For self-administered surveys, Dillman recommended cognitive interviews. Cognitive interviews can be defined as “the administration of draft survey questions while collecting additional verbal information about the survey responses, which is used to evaluate the quality of the response or to help determine whether the question is generating the information that its author intends” (Beatty & Willis, 2007, p. 288). Cognitive interviewing can utilize a think aloud approach, in which respondents verbalize their thought process as they complete the survey. Or alternatively, a probe approach can be used. Both offer advantages and disadvantages; however, evidence has shown that using a think aloud approach is more taxing on the participant and can interfere with navigation, which can impact the response process (Redline, Smiley, Lee, DeMaio, & Dillman, 1998; Russo, Johnson, & Stephens, 1989; Willis, 1994). Using probes may create less intrusion into the typical thought process of completing a survey while still accessing the reactions stored in the short-term memory (Beatty & Willis, 2007).

In this study, I utilized the cognitive interviewing technique with scripted and unscripted retrospective probes (Nápoles-Springer, Santoyo-Olsson, O’Brien, & Steward, 2006) as an additional pretest evaluation of the SAS-DB. Retrospective probes allow the participant to complete the questionnaire in the same format and setting as the broader sample. In this case, the participant is intended to receive the survey at home and complete it on their own. Due to the geographic diversity of families, I was unable to engage in face-to-face interviews. Therefore, a limitation of this pretest is that the visual observations that can provide additional depth to the examination of the participants’ responses (e.g., hesitations, confused expressions, erasures) (Dillman, 2000) were not accessible in this study.

To gain participants, I contacted the Family Liaison for the Kansas Deafblind Project and asked if she could provide information about the interviews to families she thought might be interested. Out of the ten families she contacted, three indicated interest. I sent a copy of the survey to these three parents at staggered intervals, and they completed the survey in a relatively short time period before our interview. On average, interviews lasted around 30 minutes, and questions were based around three main areas: (a) instructions, (b) content of the candidate items, and (c) response format. I made changes to the survey after each interview and sent subsequent respondents a revised survey. After the third interview was complete, I forwarded the survey to two Family Specialists from different states for a final check (Dillman, 2000). These Family Specialists completed the survey in its entirety and provided feedback regarding the clarity and content. After incorporating final revisions, two graduate students reviewed the survey for spelling or grammatical errors, clarity of instructions, and numbering of items. They also checked the final copy against previous versions to ensure all necessary changes were included.

After completion of the (a) expert review, (b) retrospective interviews, and (c) final check, the development of the SAS-DB was complete. Table 7 includes the seven domains and sample items from each domain. Participants are asked to rate the degree to which each service category has, on average, met their needs during the 12 months prior to completing the survey on a 5-point scale, which ranges from *1- not at all* to *5- completely*. Respondents have the option to add any additional comments in an open text box field within each domain. Please refer to pages 3 through 9 of Appendix D to review the full copy of the SAS-DB.

Table 7

Items and Examples Provided: Services Adequacy Scale for Families of Children who are Deafblind

Item	Sample Items
Health services	• Well-child checks, nursing services, medical evaluations
Education services	• Special Education, early intervention, hearing services, vision services
Related services	• Intervener, augmentative and alternative communication or speech therapy, assistive technology
Information	• State deafblind projects, online social networks, health care providers
Family and friend support	• Extended family and friends, contact with other parents of children with deafblindness or similar etiology, support for siblings
Child care	• Respite programs (for example, church mothers' day out, agency services); regular daily after-school care; full- or part-time center or child care in homes
Service or care coordination	• Case management and/or care coordination, fiscal management services, medical home

Beach Center on Disability Family Quality of Life Scale. The FQOL Scale is a 25-item measure that assesses families' perceived satisfaction with their quality of life across the following five domains: (a) Family Interaction, (b) Parenting, (c) Emotional Well-Being, (d) Physical/Material Well-Being, and (e) Disability-Related Support. Participants report their satisfaction with their quality of life on a 5-point scale, which ranges from 1- very dissatisfied to 5- very satisfied. Sample items for each domain and their measures of internal consistency can be found in Table 8.

Table 8

Sample Items by Domain: Beach Center Family Quality of Life Scale

Domain	Sample Item How satisfied am I that…	Cronbach's α (Hoffman et al., 2006)
Family Interaction	• My family solves problems together.	.90
Parenting	• Adults in my family know other people in the children's lives (friends, teachers, etc.).	.86
Emotional Well-Being	• My family has the support we need to relieve stress.	.84
Physical/Material Well-Being	• My family feels safe at home, work school, and in our neighborhood.	.74
Disability-Related Support	• My family member with special needs has support to make progress at home.	.85

The FQOL Scale is used for family outcome research and for the evaluation of services or policies. It was originally developed through qualitative methods with a demographically diverse sample of families (Poston et al., 2003) and subsequently evaluated through a national survey to explore the empirical structure and preliminary psychometric properties (Park et al., 2003). Confirmatory factor analyses from a second round of data collection resulted in the final

FQOL Scale, inclusive of 25 items across the five domains listed above (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). Refer to Hoffman et al. (2006) for a full description of the psychometric properties. Most recently, Zuna, Summers, Turnbull, Hu, and Xu (in press) offered an initial theoretical model that explained the relationships among the factors that contribute to the construct of FQOL. Prior to this, FQOL has lacked theoretical underpinnings. Out of a growing concern that findings from the body of research utilizing FQOL as an outcome are not translated into practice, Zuna, Turnbull, and Summers (2009) provided illustrations of how the FQOL theory (Zuna et al., in press) might be used in professional practice.

To expand the use of the FQOL Scale, Zuna, Selig, Summers, and Turnbull (2009) evaluated its validity with a sample of families with children who did not have disabilities. In assessing the measurement properties of the FQOL Scale with this population, the authors modified the FQOL Scale by omitting the domain of Disability-Related Support; this resulted in the distribution of a 21-item scale to the participants. Results indicated adequate fit with the sample data to the factor structure. Individual factors were reported to have acceptable Cronbach's α reliability index scores (Family interaction = .85; Parenting = .83; Emotional well-being = .79; and Physical/material well-being = .77) and the overall scale yielded excellent internal consistency (Cronbach's α = .92). Confirmatory factor analysis validated the measure for use with four domains (excluding the disability-related support subscale) with families of children without disabilities. Refer to Zuna and colleagues (2009) for a full description of the factor structure and psychometric properties of the modified FQOL Scale.

The sample in this study included only families who have children with disabilities, specifically deafblindness. However, because most of the items in the Disability-Related Supports domain will be accounted for in the SAS-DB, duplication of these items in the FQOL outcome measure would be redundant with the predictor variable. The sub-scale components of the FQOL have good established internal consistency, and Zuna et al. demonstrated the satisfactory characteristics of the four-factor, 21-item solution. Therefore, I distributed the revised version of the FQOL Scale (i.e., with 21-items) to participants in this study. Refer to pages 10 through 12 of Appendix D for a copy of the FQOL Scale to be used in the proposed dissertation study.

Beach Center on Disability Family-Professional Partnership Scale. The Family-Professional Partnership Scale (hereafter referred to as the Partnership Scale) is an 18-item measure that assesses families' satisfaction with their relationship with a professional serving their child and family across the following two domains: Child-Focused Relationships and Family-Focused Relationships (Summers et al., 2005). Parents are instructed to choose the type of service provider who has worked with their child the most (e.g., physical therapist, social worker, nurse) prior to beginning the survey over the last six months. Participants report their satisfaction with this partnership on a 5-point scale, which ranges from 1- very dissatisfied to 5-very satisfied. Refer to Table 9 to review sample items from each domain.

Similarly to the FQOL Scale, the Partnership Scale was originally developed through qualitative inquiry. Blue-Banning, Summers, Frankland, Nelson, and Beegle (2004) conducted focus groups and in-depth individual interviews with families of children who had limited English proficiency and the professionals who supported them. This work resulted in six themes that, as a whole, represented the construct of collaborative family-professional partnership. In the second phase of development, Summers et al. (2005) undertook two separate studies to further develop and refine the measure and to examine the psychometric properties with a population of families with children of a wide range of ages and severity of disabilities.

Table 9

Sample Items by Domain: Beach Center on Disability Family-Professional Partnership Scale

Domain	Sample Item
Child-Focused Relationships	How satisfied are you that your child's service provider… • Treats your child with dignity. • Builds on your child's strengths. • Has the skills to help your child succeed.
Family-Focused Relationships	How satisfied are you that your child's service provider… • Is available when you need them • Uses words you understand • Is honest, even when there is bad news to give

Through initial exploratory analyses, the original six themes, or domains, (i.e., communication, commitment, equality, skills, trust, and respect) were reduced to two subscales: Child-Focused Relationships and Family-Focused Relationships. Confirmatory factor analysis confirmed the two-factor structure; both the overall measure, inclusive of 18-items and the two 9-item sub-scales were reported to have excellent unidimensional and internal consistency (Cronbach's α overall measure = .96; Cronbach's α Child-Focused Relationships = .94; Cronbach's α Family-Focused Relationships = .92). Refer to Summers et al. for a full description of the psychometric properties. See pages 13-14 of Appendix D for a copy of the Beach Center Family-Professional Partnership Scale.

Demographics. The final portion of the Services Adequacy Survey is the General Individual and Family Information section. This section includes general questions such as participants' gender, the year they were born, their race/ethnicity, marital and employment status, and highest level of education. Respondents are asked to report their total household income for the past year and are given 10 categories from which to choose (Less than $14,999; Between $15,000 and $19,999; Between $20,000 and $24,999; and so on). In addition, they note how many family members are supported on this income. Participants are also asked to mark all public benefits they or their child has received during the 12 months prior to completing the survey from a partially closed-ended question list; respondents are given the option to list 'other' benefits. Finally, this section also includes information about geographic location such as the state in which they live; their zip code; and whether they live in an urban, suburban, or rural area with these terms defined in terms of population counts. Additional close-ended questions related to the effects of deafblindness on the respondent's employment or the employment of their child's other caregiver are also included. Refer to pages 15-16 of Appendix D to review these demographic items.

In addition to the demographic questions included in the General Individual and Family Information section, I have included several other demographic questions in other sections of the survey. Before completing the FQOL, items ask respondents to report their relationship to the child with deafblindness in their family with the following choices: (a) Parent (biological, step, foster, or adoptive); (b) Grandparent; (c) Aunt or Uncle; (d) Sibling (brother or sister); and other non-relative (please specify). Prior to completing the Partnership Scale, items target information about the type of provider with which participants have worked the most over the last six months with the following options: (a) Intervener for your child (home, school, and/or community), (b) Health service provider (for example, primary care doctor, school nurse or nurse that accompanies your child at school, family counselor); (c) Education service provider (for example, early intervention provider, your child’s classroom teacher, special education teacher, vision or hearing specialist); (d) Related services provider (for example, your child’s speech therapist, occupational therapist, physical therapist); (e) Child care provider (for example, respite care provider, child care teacher); (f) Service coordinator (for example, your care coordinator or case manager for medical care, case manager for early intervention services, individual that coordinates your child’s school services; and (g) Other (please specify). Finally, the instructions for the SAS-DB asks that participants report any additional disabilities their child may experience by selecting ALL that apply from the following list: (a) Developmental delay, (b) Emotional behavioral disorder, (c) Learning disability, (d) Attention deficit disorder, (e) Intellectual disability, (f) Physical disability, (g) Speech or language impairment, (h) Other health impairment, (i) Mental illness, (j) Autism spectrum disorder, (k) Traumatic brain injury, or (l) No additional disability. An ‘other’ category, in which participants are asked to write in their child’s additional disability, is also available.

Data Analysis

In this section, I describe the procedures used to clean the data, preliminary data analyses, and analyses pertinent to the research questions in this study.

Initial analytic procedure. Scores on the SAS-DB were on a scale from 1 to 6, with 1 through 5 representing participants’ ratings of how well a particular service or support met their needs in the 12 months prior to completing the measure, and a score of 6 indicated that participants did not use the service. It was necessary to recode these data into different variables to accurately reflect parents’ perceptions of services and supports on a scale from 1 to 5 and not 1 to 6. Therefore, I created a new SAS-DB variable that included the original ratings of 1 through 5 and any existing missing data; ratings of 6 (i.e., indicating the participant did not use the service) became missing data. I then recoded the original data again to create a new "service use" dichotomous variable whereby any rating of 1 through 5 became a score of "0", which indicated that participants used the service, and ratings of 6 became a score of "1", indicating that participants did not use the service; any original missing data was retained in this new "did not use" variable.

To determine accuracy of the data and subsequent results of this study, I cleaned and screened the data before conducting data analyses. Pryjmachuk and Richards (2007) explained that examining raw data ensures the integrity of the data and "introduces a degree of audit into the data-analysis process in that it can help correct some of the errors that arise during the data collection, tabulation and entry phases" (p. 44). As a first measure, I randomly selected 10% of the cases in the SPSS dataset and a graduate student checked accuracy of the data in these cases with the original paper or web survey. The graduate student found two errors when comparing the dataset with the original data. I corrected both errors and then conducted frequency analyses of all independent and outcome variables to assess the variability, identify missing or incorrect data, and test skewness and kurtosis. All distributions were within acceptable ranges, and there did not appear to be any patterns of invalid responses. Those components represented the data cleaning phase of the data exploration.

After ensuring that the data were clean and free of errors, I conducted exploratory data analysis to ensure I would not be violating any assumptions of future statistical tests and to screen for influential observations. Through examination of residual plots, it was evident that linearity and homoscedasticity assumptions were met. Residuals analysis was also used to identify other patterns of error; none were evident. To further examine possible outliers, I ran casewise diagnostis through SPSS, for a report of any scores outside three standard deviations from the mean. This report revealed two outliers of which the standardized residual score was greater than two in absolute value. Pedhazur (1997) explained that standardized residuals greater than two in absolute value should caution the researcher to examine the extreme score but not designate it as an outlier. Examining the item level scores revealed data entry errors for the two cases; these were corrected and were no longer extreme scores. Subsequent analyses were run with the corrected dataset.

Preliminary data analyses. Preliminary data analysis included (a) reliability and exploratory factor analyses of the FQOL and Partnership measures and (b) univariate analyses of variance to determine optimal independent variables for this study.

Reliability and exploratory factor analyses. The FQOL Scale is an established measure in terms of reliability and validity with samples of families who have mild or moderate disabilities. Only one study has evaluated the FQOL with samples of families who have children with more severe disabilities and found the FQOL Scale to be a fairly reliable and valid instrument for measure the quality of life for these families (McFelea, 2007); however, this study was limited in the sample size. No study to date has evaluated the psychometric properties of the FQOL with samples of families with children who have multiple disabilities. Likewise, the Partnership measure has not been administered to families of children with multiple disabilities. Therefore, it was necessary to conduct an exploratory factor analysis to determine the underlying latent constructs inherent in FQOL and satisfaction with partnerships for this population of families.

First, utilizing the principal axis factoring method with promax rotation, I conducted a factor analysis of the FQOL measure. The results of the factor analysis suggested three factors that together account for 58.569% of the variance in FQOL. These factors were defined by the following latent constructs: (a) Family Interaction (12 items, Cronbach's α = .931); (b) Emotional Well-Being (four items, Cronbach's α = .855); and (c) Physical/Material Well-Being (five items, Cronbach's α = .788). These findings suggest a different factor structure than has been previously reported; namely, the Parenting and Family Interaction factors reported in previous studies were collapsed into one factor, Family Interaction, for this sample. The overall scale, with 21 items, had excellent internal consistency (Cronbach's α = .940) and results of the factor analysis showed that all three factors strongly correlated with each other; therefore, a mean score of all 21 items representing overall FQOL was used in future analyses of this data.

A factor analysis utilizing the principal axis factoring extraction method with promax rotation was also conducted on the Partnership Scale. Results were similar to previously reported factor structures (see Summers et al., 2005). The resulting two factors strongly correlated with each other (r=.789), and the overall measure, with 18 items, had excellent internal consistency (Cronbach's α = .973). Therefore, a mean score across all 18-items was used to represent participants' overall satisfaction with partnerships with professionals. For more detail regarding the findings of the two factor analyses, refer to Appendix F.

Measurement error in the independent variable in multiple regression can lead to overestimation of the effect on the dependent variable (Pedhazur, 1997). Therefore, it is important to report that the reliability, or precision of measurement, of the SAS-DB, with all 37-items is excellent (Cronbach's α = .973), and the reliability statistics (Cronbach's alpha) for each sub-domain are as follows: Health (four items, .742); Education (seven items, .849); Related Services (seven items, .874); Information Services (seven items, .924); Friend and Family Support (five items, .862); Child Care (four items; .731), Service Coordination (three items, .813). One item, 'regular after school care,' was removed from the Child Care domain due to its low correlation with the other items in the domain. This item was omitted from future analyses of these data, and the Cronbach's alpha reported for the Child Care domain represented the internal consistency without the 'regular after school care' item. As previously reported, the partnership measure also had excellent reliability with this sample.

Univariate analyses of variance. Previous research has shown severity of disability and income as significantly predicting FQOL (Park, Turnbull, & Turnbull, 2002; Tien, 2003; Wang et al., 2004). To ensure that the effects shown in this research study were, in fact, above and beyond the effects of these two variables, I ran two separate Univariate Analyses of Variance: (a) Severity of Disability [summed composite score across 11 disability types; scores ranged from 0 (no additional disabilities) to 11 (11 additional disabilities)] and FQOL as the outcome variable and (b) Income (9 levels) and FQOL as the outcome variable. In the first analysis, a main effect of Severity of Disability was not found ($F_{(1,11)} = .820$, $p = .620$). In the second analysis, a main effect for income was found ($F_{(1,8)} = 3.264$, $p = .002$). As a result of these findings, I controlled for Income in subsequent analyses to ensure that the results were, indeed, above and beyond the effects of this variable.

Given the findings of the literature review showed that fathers and mothers may differ in how services and supports affect their stress levels, I ran two separate one-way between-subjects Analyses of Variance with two levels (i.e., male and female) to determine the effects of gender on participants' overall average perceptions of services and supports (using a computed mean score across all 38 items of the SAS-DB) and to determine the effects of gender on FQOL. The results showed that the fathers and mothers in this study did not differ on their ratings of service adequacy ($F_{(2,220)} = .417$, $p > .05$) or family quality of life ($F_{(2,221)} = .006$, $p > .05$). Mothers and fathers also did not differ in terms of their perceptions of the adequacy of each service domain:

Health Services ($F_{(2,209)} = 2.213$, p > .05), Education Services ($F_{(2,216)} = .593$, p .05), Related Services ($F_{(2,215)} = .463$, $p > .05$), Information Services ($F_{(2,215)} = .480$, $p > .05$), Friend and Family Support ($F_{(2,215)} = .004$, $p > .05$), Child Care Services ($F_{(2,195)} = .428$, $p > .05$), and Service Coordination Services ($F_{(2,189)} = .670$, $p > .05$).

One way ANOVAs were also run on all other demographic variables, with the exception of the state in which participants resided when completing the survey, to determine if significant differences existed in participants' FQOL based on ethnicity, age, marital status, employment, and education. Among these factors, marital status (two levels: married vs. not married) was the only main effect that was found ($F_{(1,221)} = 7.089$, $p < .01$); participants who were married, on average, had higher FQOL scores (M=3.991) than participants who were not married (M =3.724). Therefore, in future analyses of these data, I controlled for marital status in addition to income to ensure that the findings are above and beyond the effects of whether or not participants were married and their total household family income.

Ten out of the 15 states included fewer than 15 participants; 12 included less than 25 participants. Only three states had greater than 25 participants, a number generally recognized as appropriate for statistical analyses (Shavelson, 1996). Because the numbers in most groups did not provide for a robust analysis against Type I and Type II error, I chose not to analyze the effects of the state in which participants' resided on FQOL. Refer to the limitations section for further discussion of the effects of this variable on the outcome of this study.

Data Analyses. The preliminary data screening and analyses were necessary to ensure accuracy of the data and optimal variables for the proposed data analysis. For this study, I conducted quantitative analyses in order to explore relationships between service and support adequacy and FQOL, and the impact of both the age of the individual with deafblindness in the family and families' satisfaction with partnerships on that relationship. In this section, I discuss the type of analyses and variables that were included organized by research question. Each analysis included two covariate variables: Income and Marital Status. Following is a description of each analysis in the context of the corresponding research question. To review, the research questions for this study were as follows:

1. Controlling for family income and marital status, are families' perceptions of service and support adequacy significantly related to their FQOL?
2. Controlling for family income and marital status, do partnerships with professionals moderate the relationship between overall service and support adequacy and FQOL?
3. Controlling for family income and marital status, does age of the family's child interact with overall service and support adequacy to impact FQOL?

Research question 1. Hierarchical multiple regression allows for the exploration of collective and separate effects of independent variables on an outcome (Pedhazur, 1997). To determine the collective and unique effects of perceived service and support adequacy on FQOL, I conducted a hierarchical multiple regression analysis using listwise deletion. The analysis included the following variables: (a) Income; (b) Marital Status; (c) seven SAS-DB domain average scores utilizing the new SAS-DB variable described as an initial analytic procedure to represent participants' perceptions of service and support adequacy (i.e., Average Health Score, Average Education Score, Average Related Services Score, Average Information Score, Average Friend and Family Score, Average Child Care Score, and Average Service Coordination Score); and (d) a mean item-level FQOL Score representing participants' average satisfaction with their FQOL. All variables included in the analysis, with the exception of marital status, were continuous. I chose to use seven SAS-DB average scores so I would be able to determine the unique effects (by examining the semi-partial correlations) of each domain (health, education, etc) on FQOL. The covariates were entered in Block 1 and the SAS-DB scores in Block 2.

Research question 2. To determine if family-professional partnerships moderated the relationship between perceived service and support adequacy and FQOL, I conducted a hierarchical multiple regression moderator analysis. Jaccard and Turrisi (2003) explained that "…a moderated causal relationship is one in which the relationship between X and Y is moderated by a third variable, Z. In other words the nature of the relationship between X and Y varies, depending on the value of Z" (p. 1). In this moderator analyses, I determined if the effects of perceived service and support adequacy were dependent on the effects of parent-professional partnerships, that is, if an interaction effect existed between perceived service and support adequacy and parent-professional partnerships (Miles & Shevlin, 2006).

As in the analysis for Research Question 1, I included Income and Marital Status as the covariate; Income was continuous and Marital Status was categorical (two levels: married vs. not married). I used the seven average SAS-DB scores to determine which areas of services and supports interacted with partnerships. I utilized a mean item-level score across all 18 questions to represent parents' satisfaction with the partnerships they had with professionals. In addition, I centered the independent variables by subtracting the overall mean score from the observed scores than then computed seven interaction terms by multiplying each of the seven SAS-DB average scores by the Parent-Professional Partnership average score. Centering the scores reduces the effects of multicollinearity and yields more desirable statistical properties (Aiken & West, 1991). I entered the covariate variables in Block 1; the Parent-Professional Partnership mean score in Block 2; the seven SAS-DB average scores were entered in Block 3; and the Interaction Terms (Average_Health x Partnership_Mean; Average_Education x

Partnership_Mean; Average_RelatedService x Partnership_Mean; Average_InformationService x Partnership_Mean; Average_Friend_Family x Partnership_Mean; Average_ChildCare x Partnership_Mean; Average_ServiceCoordination x Partnership_Mean) in Block 4.

Research question 3. To determine if age of the child interacted with perceived service and support adequacy to impact FQOL, I conducted a second hierarchical multiple regression moderator analysis. In this analysis, all variables, with the exception of Marital Status, were continuous. I treated each predictor included in previous analyses (i.e., for research questions 1 and 2) in the same manner in this analysis: Income was continuous, Marital Status was categorical (two levels: married vs. not married). Additionally, I used the seven SAS-DB average domain scores to represent participants' perceptions of service and support adequacy. Age of the Child was continuous and participants had children within the age ranges of 0-22. I computed an interaction term by first centering the independent variables and then multiplying Age of Child by each average SAS-DB domain scores. I entered the variables in the following order: (a) Income and Marital status were entered in Block 1, (b) Age of Child was entered in Block 2; (c), the seven SAS-DB average domain scores were entered in Block 3; and (e) the Interaction Terms (Average_Health x Age, Average_Education x Age, Average_RelatedServices x Age, Average_InformationServices x Age, Average_Friend_Family x Age, Average_ChildCare x Age, and Average_ServiceCoordination x Age) in Block 4.

Limitations

Nonresponse from participants is a source of sampling bias. In this study, I did not follow up with participants who did not respond to the initial study invitation request. Project staff from participating state deafblind projects distributed the initial welcome packets to families of children identified as deafblind according to census guidelines. This information was confidential; therefore, I was not able to engage in nonresponse procedures recommended by survey methodological experts (Dillman, 2000). The overall response rate to this study was 11%; therefore, it is possible that this sample is biased and the resulting responses are characteristic of those who were highly motivated to share their experiences with services, partnerships, and FQOL.

Regression analyses for this dissertation study were conducted utilizing a subset of the overall sample. This subset consisted of only participants who had a data point on each measure included in the respective analysis. To be included in the first analysis (i.e., research question 1), participants must have had an average score on all domains of the SAS-DB and FQOL. Participants in the second analysis (i.e., research question 2) needed to have these data points and an average score for the Partnership Scale. Participants were only included in the third analysis (i.e., research question 3) if they had an average score for all seven domains of the SAS-DB, an FQOL average score, and provided the age of the person with deafblindness in the family. Because of these requirements, the sample was reduced from 227 to (a) 152 in the first analysis, (b) 149 in the second analysis, and (c) 150 in the third analysis. Because these subsamples were composed of only the participants who utilized services under each of the service and support areas, they are samples with the highest intensity service needs. The reader should be aware that the perceptions of families who had children with deafblindness whose service needs were not as intense are not necessarily represented in this study.

The overall purpose of this research study was to investigate the effects of services and supports on families of children with deafblindness. A number of different states (i.e., 15) were included in the study, all with varying policies and procedures regarding service provision. Due to low numbers in most state groups, it was inappropriate to interpret results from analyses that compared differences in FQOL for participants according to the state in which they lived. An effect of this variable on FQOL is possible and the reader should interpret the findings reported in this study bearing in mind that the potential effects of the varying policies, services, and practices these families experienced as a result of the state in which they lived on FQOL were not controlled.

The Beach Center Family Quality of Life Scale is intended to evaluate *Family* Quality of Life and not the Quality of Life of individual family members. Wang and colleagues (2006) found that fathers and mothers view FQOL similarly and thus the Beach Center FQOL Scale holds promise for use with mothers and fathers in assessing FQOL across multiple family members. There tends to be an overreliance in the field, however, in utilizing the mother's perspectives as a proxy for the family (Turnbull et al., 2007) and this study is no exception. The current study did not utilize a multi-informant approach and the majority of the respondents were mothers. The reader should be aware that the findings ought to be interpreted as they relate to mothers' experiences and cannot necessarily be generalized to other family members.

Finally, the Partnership Scale was designed so that families could rate their satisfaction with partnerships according to their child and family's major provider (e.g., education, health, related services). Because of this flexibility, however, it is not possible to connect the findings of this study to service providers in one specific discipline. Although a strength of this study is that it assesses families' needs across a range of services and supports, future studies could limit the scope to one particular area of service or support to gain a deeper understanding of families' experiences in that domain of their life.

CHAPTER 3: RESULTS

This study investigated the impact of parent perceptions of service and support adequacy on FQOL for families of children who are deafblind. I also examined parents' satisfaction with the partnerships they have with professionals and child age as potential moderators of the relationship between service and support adequacy perceptions and FQOL. In this chapter, I report the findings of this dissertation study.

Parent Perceptions of Service and Support Adequacy and FQOL

Parent perceptions of service and support adequacy, represented by seven average SAS-DB scores across the domains of Health, Education, Related Services, Information Services, Friend and Family Support, Child Care Services, and Service Coordination Services, were used as predictors of FQOL in a hierarchical multiple regression model to understand if parents' perceptions of services and supports were significantly related to FQOL above and beyond the effects of income and marital status. Because I chose to use listwise deletion, the statistical software program omitted any participant who did not have an average score on any of the independent or outcome measures from the analysis; this resulted in a total of 152 participants (N=152). The grand FQOL mean was 3.95 (M=3.9457, SD=.66220). The average income for participants was \$52,631 (SD=\$25,619). Overall, participants rated Health services the highest in terms of how well this service met their needs (M=3.9688, SD=.89854), and they rated Service Coordination the lowest (M=2.9485, SD=1.25841).

The results of the hierarchical multiple regression analysis showed that parents' perceptions of service and support adequacy significantly predicted FQOL above and beyond the effects of income and marital status, and these perceptions uniquely explained 22.2% of the variability in FQOL ($R^2\Delta = .222$, $F_{(9,142)} = 6.454$, $p < .001$). The full model, including covariates, accounted for 29.0% of the variance in FQOL ($R^2 = .290$, $F \Delta_{(7, 142)} = 6.344$, $p < .001$). Friend and Family Support was a significant predictor of FQOL and had the most influential effect ($\beta = .328$, $t = 3.396$, $p < .01$) followed by Related Services ($\beta = .206$, $t_{(9,142)} = 2.038$, $p < .05$). None of the other independent variables included in the analysis were significant in predicting FQOL. Holding all other variables constant, Friend and Family Support uniquely accounted for 5.8% of the variance in FQOL. Perceptions of support adequacy from friends and family (i.e., extended family, friends, other parents of children with deafblindness or similar disability, family events, support for siblings) were positively related to FQOL; this suggests that as families perceptions of how well Friend and Family Support meet their needs increase, FQOL also increases. Related services and FQOL were also positively related, suggesting that increased related service adequacy is associated with increased FQOL. To review R^2_Δ and R^2 statistics, the unstandardized (B) and standardized (β) regression coefficients, semi-partial correlations, and their respective significance, of all the independent variables in this analysis, refer to Table 10.

Table 10

Hierarchical Multiple Regression Analysis Predicting FQOL From Parents' Perceptions of Service and Support Adequacy (N=152)

Predictor	R^2_Δ	R^2	B	β	sr^2
Block 1	.068**	.068**			
Income			6.981	.027	0.1
Marital Status			-.327*	-.209*	3.3*
Block 2	.222***	.290***			
Perceptions of health services			.034	.046	0.1
Perceptions of education services			-.031	-.044	0.1
Perceptions of related services			.134*	.206*	2.1*
Perceptions of information services			-.090	-.159	1.4
Perceptions of friend/family support			.187**	.328**	5.8**
Perceptions of child care services			.073	.150	1.4
Perceptions of service coordination			-.005	-.009	0.0

*$p < .05$. **$p < .01$. ***$p < .001$

Perceptions of Service and Support Adequacy, Satisfaction with Partnerships, and FQOL

In this analysis, I sought to determine if the impact of perceptions of service and support adequacy on FQOL were dependent on parents' satisfaction with the partnerships they have with professionals. I used listwise deletion; therefore, the sample for this analysis was reduced from the overall sample of 227 to 149. To be included in this analysis, participants were required to have a mean score for all seven domains of the SAS-DB, a mean score for the FQOL Scale, and a mean score for the Partnership Scale.

The FQOL grand mean was 3.94 (*M* = 3.9387, *SD* = .66130), and the average Income was $52,567 (*SD* = $25,584). The Partnership grand mean was 4.15 (*M*=4.1499, *SD*=.68504). To learn if parents' satisfaction with partnerships moderated the relationship between perceptions of service and support adequacy and FQOL, I examined the F test in Model 4 which included the covariate variables, the mean Partnership Score, the seven average SAS-DB scores, and the seven interaction terms. The results showed a significant interaction effect between perceptions of service and support adequacy and participants' satisfaction with the partnerships they have with professionals to impact FQOL, which uniquely explained 6.5% of the variability in FQOL ($R^2\Delta = .065$, $F\Delta_{(7,131)} = 2.293$, $p < .05$) and the overall model, with all predictors and covariates accounted for 46.8% of the variance in FQOL ($R^2 = .468$, $F_{(17,131)} = 6.777$, $p < .001$).

A significant interaction effect between Related Services and Satisfaction with Partnerships ($\beta = -.288$, $t_{(17,131)} = -2.405$, $p < .05$) was present. The interaction between perceptions of Related Services and satisfaction with Partnerships were negatively related to FQOL suggesting that as perceptions of related services and satisfaction with partnerships increase, FQOL decreases. The interaction between Related Service adequacy and satisfaction with Partnerships uniquely accounted for 2.3% of the variability in FQOL. The interaction effect between satisfaction with Partnerships and perceptions of Education Service Adequacy was also significant ($\beta = .312$, $t_{(17,131)} = 2.654$, $p < .01$). This relationship was positive and suggested that, on average, as families' satisfaction with Partnerships and perceptions of Education Service adequacy increase, FQOL increased. The interaction between Partnerships and Education Service adequacy uniquely contributed 2.9% to the variance in FQOL. Table 11 includes R^2_Δ and R^2 statistics, the unstandardized and standardized regression coefficients, semi-partial correlations, and their respective significance for all independent variables included in this hierarchical multiple regression moderator analysis.

Table 11

Hierarchical Multiple Regression Analysis Predicting FQOL From Parents' Perceptions of Service and Support Adequacy and Satisfaction With Family-Professional Partnerships (*N*=149)

Predictor	R^2_Δ	R^2	B	β	sr^2
Block 1	.075**	.075**			
Income			-9.052	-.035	0.1
Marital Status			-.278*	-.177*	2.4*
Block 2	.185***	.260***			
Partnership mean			.38***	.39***	8.8***
Block 3	.143***	.403***			
Perceptions health services			-.022	-.030	0.1
Perceptions education services			-.098	-.136	0.9
Perceptions related services			.106	.162	1.2
Perceptions information services			-.041	-.073	0.3
Perceptions friend family support			.171**	.302**	4.5**
Perceptions child care services			.073	.148	1.3
Perceptions service coordination			-.016	-.030	0.0
Block 4	.065*	.468*			
Partnership x Health			-.142	-.141	0.7
Partnership x Education			.298**	.312**	2.9**
Partnership x Related			-.241*	-.288*	2.3*

Predictor	R^2_Δ	R^2	B	β	sr^2
Partnership x Information			.058	.089	0.2
Partnership x Friend Family			.058	.081	0.2
Partnership x Child Care			.014	.019	0.0
Partnership x Service Coordination			.052	.077	0.3

$*p < .05$. $**p < .01$. $***p < .001$.

Perceptions of Service and Support Adequacy, Child Age, and FQOL

This moderator analysis was conducted to determine if the relationship between parents' perceptions of service and support adequacy and FQOL differed according to the age of the person in the family with deafblindness. Similarly to the first two analyses, I used listwise deletion and, as a result, the sample size was reduced from 227 to 150. However, this number was sufficient to meet adequate power for the analysis (i.e., .80). The grand mean for FQOL was 3.95, (*SD*=.66551) and the grand mean for income was $52,716 (*SD*=$25,564). The average age of the person with deafblindness in the family was 10.61 years (*SD*=5.925).

The results of the hierarchical multiple regression moderator analysis showed an overall significant interaction effect, which uniquely explained 7.8% of the variability in FQOL ($R^2\Delta$ = .078, $F\Delta_{(7,132)} = 2.330$, $p < .05$). The full model, including all predictors and the covariates, explained 36.9% of the variance in FQOL ($R^2 = .369$, $F_{(17,132)} = 4.547$, $p < .001$). A main effect of perceptions of Information Services was present ($\beta = -.196$, $t_{(17,132)} = -2.084$, $p < .05$); Information Services uniquely accounted for 2.1% of the variance in FQOL and this finding showed that as perceptions of information services adequacy increased, FQOL decreased.

A main effect was found for Friend and Family Support ($\beta = .347$, $t_{(17,132)} = 3.629$, $p < .001$); however, this was not interpretable due to the presence of a significant interaction effect between Child Age and perceptions of Friend and Family Support adequacy (β = .236, $t_{(17,132)}$ = 2.316, $p < .05$), which uniquely explained 2.6% of the variability in FQOL. The relationship was positive, suggesting that, on average, as perceptions of friend and family support adequacy and child age increased, FQOL increased. The interaction between Child Age and perceptions of Child Care service adequacy also significantly predicted FQOL (β = -.287, $t_{(17,132)}$ = -2.846, $p <$ .01) and uniquely accounted for 3.9% of the variability in FQOL. The interaction between Child Care and Age was the strongest predictor of FQOL and the relationship was negative. Table 12 includes R^2_Δ and R^2 statistics, unstandardized and standardized regression coefficients, the semi-partial correlations, and respective significance levels for all independent variables included in this analysis.

Table 12

Hierarchical Multiple Regression Analysis Predicting FQOL From Parents' Perceptions of Service Adequacy and Child Age (*N*=150)

Predictor	R^2_Δ	R^2	B	β	sr^2
Block 1	.071**	.071**			
Income			1.770	.068	0.3
Marital Status			-.328	-.209	2.9
Block 2	.006	.077			
Child Age			-.004	-.035	0.1
Block 3	.215***	.291***			
Perceptions health services			.009	.012	0.0
Perceptions education services			-.046	-.064	0.2
Perceptions related services			.134	.202	1.8

Predictor	R^2_Δ	R^2	B	β	sr^2
Perceptions information services			-.111*	-.196*	2.1*
Perceptions friend family support			.199***	.347***	6.3***
Perceptions child care services			.069	.141	1.2
Perceptions service coordination			.026	.049	0.1
Block 4	.078*	.369*			
Child Age x Health Perceptions			-.008	-.055	0.2
Child Age x Education Perceptions			-.016	-.119	0.7
Child Age x Related Perceptions			.016	.133	0.9
Child Age x Information Perceptions			-.001	-.005	0.0
Child Age x Friend Family Perceptions			.022*	.236*	2.6*
Child Age x Child Care Perceptions			-.023**	-.287**	3.9**
Child Age x Service Coordination			.013	.155	1.2

*$p < .05$. **$p < .01$. ***$p < .001$.

CHAPTER 4: DISCUSSION

This study investigated (a) the impact of parents' perceptions of service and support adequacy on family quality of life, (b) the influence of family-professional partnerships on the relationship between service and support adequacy and family quality of life, and (c) the influence of the age of the person with deafblindness in the family on the relationship between service and support adequacy and family quality of life. In this chapter, I discuss the findings of this study and the fit of those findings to the unified theory of family quality of life. Within the discussion, I highlight implications for policy, practice, and future research.

Parents' Perceptions of Services and Support Adequacy and FQOL

The results of this study showed that for families of children with deafblindness, perceptions of services and supports significantly affected family quality of life. In particular, these findings highlighted the effects of related services and friend and family support. Both of these factors had significant unique effects on FQOL; however, of the two, friend and family support was the most influential.

Overall Model Findings

A major finding of this study is that families' overall perceptions of services and supports are significantly related to family quality of life for families of children with deafblindness. In this study, services included: health services, education services, related services, information services, child care services, and service coordination services. I defined supports as friend and family supports and included the following items: extended family, friends, contact with other parents of children with deafblindness or similar etiology, family events, and support for siblings.

The findings of the literature review presented in Chapter 1 showed that the majority of studies examined the effects of supports on family outcomes (*n*=13) and far fewer evaluated the effects of services on family outcomes (*n*=3). In general, across studies supports were defined narrowly as friends or extended family. Of those studies that examined services, the focus was on specific services (i.e., health services and transition services) (Mitchell & Hauser-Cram, 2008; Neece et al., 2009) or the method of service delivery (McIntyre, 2000). This study provides a unique contribution to the literature, showing that services and supports, when assessed together and comprehensively, have an overall affect on family quality of life for families of children with deafblindness.

Friend and Family Support

The literature review presented in Chapter 1 examined studies investigating the effects of services and supports on families of children with moderate to severe and multiple disabilities. One of the major findings of this review was that across studies, supports, particularly those provided by extended family and friends, reduced mothers' stress. Only one study in the review examined the effects of supports on families of children with deafblindness (Beyzavi, 1993). In this study, Beyzavi concluded that there was a negative relationship between social supports and stress (i.e., lower stress was associated with greater social supports). The findings of the current study showed that supports, in the form of friends, extended family, other parents of children with deafblindness or similar etiology, family events such as conferences or social gatherings for families of children with disabilities, and support for siblings, have a positive effect on family quality of life for families of children with deafblindness. The present study differed from Beyzavi in that it included a larger sample (*N*=227 vs. *n*=25), defined supports more expansively, and included a more positive outcome (i.e., FQOL vs. stress); however, the findings of the current study are consistent with those of Beyzavi. All in all, it appears that social supports are not only a positive asset for families of children with moderate to severe disabilities, they are also helpful in decreasing psychological discomfort/increasing the quality of life of families who have children with deafblindness.

In addition to contributing to the existing knowledge regarding the importance of friend and family support, this study also showed that supports were more important than services, related services in particular, in affecting family quality of life for families of children who are deafblind. Studies have shown that families of children with disabilities have unmet social support needs (Douma, Dekker, & Koot, 2006; Shin & Nhan, 2009; Werner et al., 2009) and that professional help in securing supports can be effective in improving family outcomes (Honig & Winger, 1997). Wang and Brown (2009) emphasized that providers, in particular social workers, should “look for attributes, needs, and processes that have the greatest positive impact on FQoL and then provide resources to families and professionals to make things happen to stabilize and improve FQoL” (p. 159). Examining FQOL can provide practitioners with an assessment of external supports that would benefit families as contrasted with other family outcome measures (e.g., stress, well-being, adaptation). These measures typically assess the impact of internal family characteristics and provide less information about appropriate interventions that would serve to enhance families’ social supports (Turnbull et al., 2007). The Beach Center Family Quality of Life Scale could prove useful to service providers in helping them identify areas of social support that would be helpful to families (Summers et al., 2005; Zuna et al., 2009).

Another way service providers can help families seek and maintain social networks is to extend their services from a sole focus on the child with a disability and his or her immediate family to providing services to individuals within their support networks. Schippers and van

Boheemen (2009) investigated the use of an intermediary, or a professional who provided personal support consistent with the family needs in pursuit of their family quality of life, with families of young adults with intellectual disability. They found that when the intermediary supported all members of the social network including relatives and friends, family quality of life was not only enhanced for families of the young adult with intellectual disability but also those in their support network.

Due to the nature of deafblindness, families may be at a greater risk for social isolation. Educators, related service professionals, health providers, and social services should aim to build upon family resources through expanding social networks and supports. Policy makers at all levels (local, state, and federal) should consider including provisions that encourage providers to engage in activities that expand and promote families' use of external supports.

Related Services

Related services were defined in this study as: occupational therapy, physical therapy, intervener (home, school, and/or community), orientation and mobility, speech therapy, assistive technology, and interpreter (for child in classroom and/or community). Research has shown that parents' satisfaction with service provision may be a function of disability type (Kasari, Freeman, Bauminger, & Alkin, 1999). Deafblindness in particular affects two main areas of development: communication and orientation/mobility (Arnold, 1998). These areas of development are addressed through the provision of related services. Given that most families who have children with deafblindness use related services and depend on these services to help their child develop skills that foster independence (i.e., communicating their needs and physically navigating their environment), it is not surprising that this service area would be critical in the lives of these families.

Specifically, the finding of this study is that the more parents' feel related services meet their child and family needs, the higher their family quality of life becomes. Considering the inverse relationship is also critical: What if families feel related services do not meet their needs? Studies have shown that families of children with severe and multiple disabilities experience unmet need with related services in particular (Axtell et al., 1995; Wodehouse & McGill, 2009). Thus, an implication of this finding is that related service providers should assess the needs of families who have children with deafblindness to determine how best to implement services. These providers should be informed of the importance their services have in the lives of families who have children with deafblindness. Even though the incidence of deafblindness is low, the impact of related services on these families is high. Administrators should consider related services as a priority when taking into account the service needs of families who have children with deafblindness. Sufficient resources should be allocated to related service provision to ensure that children and families receive the appropriate quantity and quality of these services.

Parents' Perception of Service and Support Adequacy, Family-Professional Partnerships, and FQOL

The findings of this moderator analysis suggested that the relationship between service and support adequacy and FQOL is dependent on the level of families' satisfaction with professionals. This was particularly true for two domains of the SAS-DB: Education and Related Services. The interaction between education services and partnerships was positively related to FQOL, whereas the interaction between related services and partnerships was negatively related to FQOL.

The Overall Model

The findings of this study are consistent with research conducted by Summers and colleagues (2007). These authors investigated the relationship of perceived adequacy of services, family-professional partnerships, and FQOL in early childhood programs. Summers et al. defined services broadly and included activities such as therapies, specialized services such as special education, and service coordination. The sample included families of children with mostly mild and moderate disabilities (i.e., 67.8%), and the authors found that partnerships partially mediated the effect service adequacy had on FQOL, suggesting that both factors contribute to FQOL.

It is noteworthy that the full model, which included the covariates (Income and Marital Status); satisfaction with partnerships; the seven SAS-DB average scores (Health, Education, etc.); and the seven interaction terms (Health x Partnership, Education x Partnership, etc.), accounted for approximately 47% of the variability in FQOL. With the addition of partnerships, the variability accounted for in FQOL was increased from 29% (in the first analysis with only the seven average SAS-DB scores as predictors) to 47%. Indeed, family-professional partnerships are important to consider when evaluating the effects of services and supports on families.

Education Services and Family-Professional Partnerships

The results of this study showed that families with higher ratings of education service adequacy and family-professional partnerships had higher FQOL. I defined education services in this study as: early intervention (birth to 2 years, 11 months); Special education (Preschool to 12th grade; ages 3-21); hearing services; vision services; paraprofessional services; transition services (for example, from early intervention to pre-k, from pre-k to kindergarten, from high school to adult); and summer school or extended school year (ESY) services.

Partnerships with professionals have been shown to significantly affect FQOL (Davis & Gavidia-Payne, 2009; Ho, 2005) as well as other psychological family outcomes (Dempsey & Keen, 2008; Dempsey et al., 2009; Dunst & Dempsey, 2007; King, King, Rosenbaum, & Goffin, 1999). Studies have also highlighted the effects of partnerships on satisfaction with education services (Rao, 2000; Servillo, 2008; Stallard & Lenton, 1992). The findings of this study provide a unique contribution to the literature, showing that partnerships and education service adequacy interact to affect FQOL for families of children with deafblindness.

There are several implications of this finding related to service provision in the education field. First, faculty in teacher preparation programs need to provide professional development to teachers to build effective partnerships with families, highlighting the unique needs of families who have children with low incidence disabilities. Additionally, preservice teachers must graduate with the skills to meet the needs of children with deafblindness and other severe and multiple disabilities. Since IDEA includes provisions regarding education in the least restrictive environment, educators (both special education and regular education providers) should be prepared to meet the needs of children with deafblindness and severe/multiple disabilities. Preparing teachers in preservice programs could be a challenge, however, because colleges and universities may not be able to financially support programs dedicated to these low incidence disabilities. Still, including faculty with expertise in low incidence disabilities who can infuse learning about these populations and their families throughout the teacher preparation curricula is important according to the findings of this study. Second, service providers in the education field should be provided with ongoing professional development and support to learn about evidence based interventions to use with learners who have deafblindness and other severe and multiple disabilities and about best practices in family-professional partnerships. Third, policy makers should consider incorporating accountability measures related to the quality of family-professional partnerships in which education service providers engage. Finally, future research agendas should explore this finding further by interviewing families to understand which education services hold more weight in predicting FQOL in their interaction with partnerships. Is it possible that partnerships are not as important for some than others? Future research should explore these topics to further understand the nature of this interaction effect.

Related Services and Family-Professional Partnerships

Families who indicated that their related services needs were being met and that they were satisfied with partnerships had a lower family quality of life. This finding, which shows a relationship between lower FQOL and the partnership and related services variables, suggests that formal services, in the form of related services, may hold more weight for families of children with deafblindness who experience a lower FQOL. It is important to note that in this moderator analysis, I utilized an average partnership score to represent parents' overall satisfaction with the partnerships they had with professionals. Through the use of one average score, it is impossible to determine with which provider the families most partnered (e.g., their child's classroom teacher, the related service provider, their child's service coordinator) or if they defined partnerships as using multiple providers. Therefore, in interpreting this finding, it would be incorrect to assume that families were more satisfied specifically with their related service provider. In this same analysis, the interaction between Education Services and Partnerships was positively related to FQOL. It is possible that families were referring to their child's education service provider when rating their satisfaction with partnerships and that the negative relationship of Related Services x Partnerships and FQOL is an artifact of the referent for the Partnership Scale. Regardless, this finding highlights the need to understand more about families’ partnerships with related service providers. Future research could examine the frequency, duration, and quality of related services and whether these variables mediate or moderate the relationship between families’ partnerships with related service professionals and their FQOL for families of children with deafblindness.

Friend and Family Support

Finally, Friend and Family support continued to be positively related to FQOL after accounting for all other variables in the model. Indeed, this is a critical area to consider when evaluating families’ quality of life. Above and beyond the effects of family-professional partnerships, an area that is well-established in terms of its relationship to FQOL, friend and family support continued to uniquely contribute to the variability in FQOL. Bailey and colleagues (1998) emphasized that helping families build a strong social support system should be an important outcome of early intervention and that providers can help families by connecting them to parent groups or community activities. Future reports of this data could include results related to differences in families’ perceptions of friend and family support according to the age of their child; however, overall, families in this study did not differ in their FQOL according to the age of their child. Therefore, I conclude that the age of the family’s child did not define differences in the families who participated in this study. In fact, age alone was not a factor in the moderator analysis that affected family quality of life ($\beta = -.035$, $t_{(17,132)} = -.458$, $p > .05$); age only became a factor predicting FQOL when it interacted with families’ perceptions of supports and services (see below). Thus, a key finding in this study is that fostering social supports for families should not only be an outcome of service provision for families of young children (e.g., early intervention services) but also for families of children who are in pre-adolescence, adolescence, and adulthood.

Parents’ Perceptions of Service and Support Adequacy, Child Age, and FQOL

The results of this study showed that the age of the person with deafblindness in the family moderated the relationship between service and support adequacy and FQOL. That is, the relationship between service and support adequacy and FQOL was dependent on the age of the family’s child.

The Overall Model

Overall, age of the person with deafblindness is indeed a factor to consider when assessing the relationship between families’ perceptions of services and supports and FQOL. Age of person with deafblindness in the family in this study could serve as a proxy for other factors, such as the service system (IDEA Part B services or IDEA Part C services), length of time in the service system, or the age of the parent. A number of studies have investigated the influence of child age on family outcomes (Datta et al., 2002; Hsieh et al., 2008; Macias et al., 2003). The findings of this study, however, show that the impact of age on family outcomes should be interpreted in light of parents’ perceptions of services, particularly for families of children with deafblindness. Because I utilized seven SAS-DB mean scores to represent parents’ overall perception of services, I am unable to evaluate the direction of the omnibus effect of Age x Service Adequacy on FQOL. Examining the unstandardized and standardized coefficients of the effect of age as a single factor in the model showed that there was a non-significant negative relationship between age and FQOL ($\beta = -.035$, $t\ (17,132) = -.458$, $p > .05$). It is possible that the overall interaction effect of Age x Service Adequacy would have been negatively related to FQOL; however, I am unable to draw those conclusions because an overall mean service adequacy score was not used in this study. Future reports of this data could include those data. This study did, however, show that two interaction terms related to specific SAS-DB domains were significant in predicting FQOL: Age x Friend and Family Support and Age x Child Care Services.

Age of Child, Friend and Family Support, and FQOL

The interaction between Age and Friend and Family Support was positively related to FQOL, suggesting that families of older children who experience adequate friend and family support also experience greater FQOL. This finding highlights the continued importance of friend and family support in predicting FQOL. This variable has been a significant predictor of FQOL in all the models included in this study. This particular finding shows that friend and family support may become increasingly more critical as the person with deafblindness in the family ages.

The age of a family's child has been shown to negatively affect family outcomes. For example, Freeman, Alkin, and Kasari (1999) found that parents of younger children with Down syndrome, that is children in early intervention programs and early general education programs, were more satisfied with their child's current educational program. Macias et al. (2003) found that mothers of children with spina bifida experienced higher stress as their child aged; they attributed the stress to the potential for disability-related differences in their children to become more apparent as their child grew. Datta et al. (2002) found that age was positively correlated with caregiver burden, showing that with increased age of the child, caregivers experienced increased burden. They concluded that this relationship exists because of the greater discrepancy between the child's physical size and developmental capacity and visibility of the disability, particularly in inclusive settings. Additionally, the relationship between age and caregiver burden could be explained by parents' lack of information regarding preadolescence problems and managing the daily life of children as they grow. Parish (2006) found that mothers of adolescents with developmental disabilities found it difficult to balance paid work outside the home and caregiving responsibilities. They attributed this increased stress to the loss of support services during their child's adolescence.

Given the findings of these studies that show the negative impact of age on families (i.e., that as a child ages, families experience more negative outcomes), it is not surprising that the effects of friend and family support, which have been shown to be significant elsewhere in this study, are so critical for families of older children. The implications of this finding are clear: Service providers, policy makers, and researchers should focus efforts on identifying and building social supports for families of older children who have deafblindness.

Age of Child, Child Care Services, and FQOL

The relationship between the Age x Child Care Services interaction and FQOL was negative. This suggests that there is a decrease in FQOL as a family's child ages and they are more satisfied with child care services. This effect had the strongest weight in predicting FQOL. In this study, Child Care was defined by the following services: respite programs (for example, church, mother's day out, agency services); babysitting; full- or part-time child care in a licensed home setting (birth to 5); and family care (e.g., grandparent, sibling, aunt or uncle—can include after school care or birth to 5 care). Research has shown that increased use of some services correlates with negative outcomes of families of children with disabilities (Bailey et al., 1998). This has also been shown to be true for respite services (Grant & McGrath, 1990; Hoare, Harris, Jackson, & Kerley, 1998). Moreover, families of children with disabilities consistently experience unmet respite care needs (Gallagher, 1997; Reilly & Platz, 2004; Wodehouse & McGill, 2009); when they receive respite, families frequently express a need for a (a) greater frequency in respite services, (b) varied types of respite care in different natural environments, and (c) greater flexibility in accessing this service (Burton-Smith, McVilly, Yazbeck, Paramenter, & Tsutsui, 2009). Ceglowski, Logue, Ulrich, and Gilbert (2009) found that although families of children with disabilities in their study reported that their child received adequate child care, they also expressed concern about the extent to which they were informed of community services and programs and costs.

In this study, I found that families of older children who experience greater child care service adequacy had lower FQOL. It is possible that families who need to use some types of child care service (e.g., respite care) may inherently experience a lower FQOL because the use of these services is associated with greater support needs. Additionally, families' satisfaction with child care services may not be strong enough to increase their FQOL because of other factors such as the financial burden it places on families or the fact that the services they have still do not satisfy all their child care needs. The majority of the participants in this study had children with severe and multiple disabilities, and a large number of these children experienced challenges with their health. As children age, care demands can become greater. Although families of older children with deafblindness may be receiving some child care and are satisfied with the care they receive, it is possibly not be enough to sufficiently enhance FQOL.

This finding has strong implications for disability policy. Since child care significantly affects FQOL as children age, programs that provide child care to families of children with deafblindness need to be well-funded to give families access to quality respite care that meets the needs of their family. Further research is needed to “unpack” this finding. What aspects of child care are more critical in affecting FQOL? Is one type of child care (e.g., regular care by extended family or friends vs. respite care provided by an agency) more critical in explaining FQOL than another?

Information Services

Finally, I found that parents' perceptions of Information Services were negatively related to FQOL. That is, as families felt information services increasingly met their needs, their FQOL decreased. This finding suggests that as families experience more awareness about the nature of their child's disability and the vast array of services and supports that are available to them, their FQOL decreases. It is possible that the information is overwhelming or is perceived negatively by the family because, for example, it predicts a negative outlook for the child. This finding, that increased awareness can be associated with negative outcomes is also present in other studies.

For example, Skinner and Schaffer (2006) found that 83% of families in their study used the internet to learn more about their child's genetic condition and although there were positive outcomes of internet use (e.g., networking with other parents, direct contact with experts), parents also experienced negative outcomes. Namely, families became more anxious after gaining more information from the internet about their child's disability due to contradictory advice, information that failed to answer their questions, and/or resources that provided a grim outlook regarding their child's future. In addition, as families obtained more information, they felt they needed to keep searching to find the missing link that would help their child. These authors concluded that service providers will be critical in helping families access and make sense of information that is available.

Bailey and colleagues (1999) found that awareness and use of services were associated with greater dissatisfaction with services for Latino parents of children with disabilities. Fathers tended to be unaware of the nature of services provided to the family, and, as a result, they were happier with services in general. Their role in the family was to work outside the home to provide financial security. Mothers were the managers of services and their increased awareness and use resulted in greater dissatisfaction. Increased satisfaction was associated with the presence of a service provider who helped them navigate the service system.

The findings of both these studies show that increased information and awareness about disability-specific resources or services in and of themselves are not especially helpful to families. Information that is easy to navigate and is more positive in the portrayal of children with disabilities and their families may have more positive effects on family outcomes. The findings of this research study could follow a similar trend, whereby families of children with deafblindness may be happy that they are given more information by service providers but the information they receive is not effective at meeting their needs. Providing information to families is critical; more research is needed in this area to determine (a) the most helpful method of providing information and (b) the most effective format for the information so that FQOL can be increased.

Study Findings and The Unified Theory of Family Quality of Life

Zuna and colleagues (in press) offered a Unified Theory of FQOL to define the overall experiences families have with FQOL; these experiences are dynamic and highly individualized in nature. This grand theory is not testable by any one research study but provides for multiple testable middle-range theories that researchers can examine empirically. Specifically, these authors state that “the family-unit, individual family member factors, and performance factors are the key direct predictors of FQOL, both singly and interactively, as mediators and moderators” (p. 15). Performance factors are defined as services, practices, and supports provided at the individual and family level. These performance concepts interact with the family unit and individual members to affect FQOL.

In this study, data indicated that families' perceptions of services (as interpreted largely by the mother) have a significant effect on FQOL. Additionally, partnership practices interact with services to significantly affect FQOL and one specific individual member concept, i.e., age also interacts with services to significantly affect FQOL. The results of this study fit within the overall conceptualization of the Unified Theory of FQOL Theory, and as has been discussed in this chapter, have significant implications for practice, disability policy, and future research.

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Appendix A

Independent and Outcome Measures Used in Studies Included in the Review

Table A1

Measures Used to Assesses Independent Variable Constructs in Studies Included in the Literature Review

Independent Variable	Instrument	Construct Measured[a]	Used in Studies[b]
Support	Family Support Scale (Dunst, Jenkins, & Trivette, 1984)	Assesses helpfulness of social supports and resources used by families in caring for their children; has a four factor structure defined by the following latent variables: parents and relatives, spouse and friends, outside helpers, and social groups	Beyzavi, 1993; Dyson, 1997; McCarthy et al., 2006; Smith et al., 2001; White and Hastings, 2004
Support	Family Support Scale (Dunst, Trivette, and Deal, 1988)	Assesses perceived helpfulness of social supports and resources used by families in caring for their children	Keller and Honig, 2004; Wheeler et al., 2008

Independent Variable	Instrument	Construct Measured[a]	Used in Studies[b]
Support	The short form of the Social Support Questionnaire (Sarason, Levine, Basham, & Sarason, 1983)	Assesses perceived number of social supports and satisfaction with social supports	Fagan and Schor, 1993
Support	The Family Support Questionnaire (adapted from Kazak, 1987)	Assesses parents' support networks in terms of how helpful individuals in their network are to them and whether they provide emotional, informational, tangible, or service support.	Hodapp et al., 1998
Support	Norbeck's Social Support Questionnaire (Norbeck, Lindsey, & Carrier, 1983)	Assesses social support across multiple dimensions: nine sources (e.g., friends, family, significant others); functional properties—affect, affirmation, and aid; and social network properties—size, duration, frequency of contact, and changes in support system due to loss of relationships.	Huang, 1996
Support	The Social Support and Caregiving Questionnaire (developed for study #11)	Assesses perceived helpfulness of family/partner support, friend support, and external/professional support in carrying out caregiving tasks	Plant and Sanders, 2007

Independent Variable	Instrument	Construct Measured[a]	Used in Studies[b]
Support	The Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)	Assesses social support across three main sources—friends, family, and significant others.	Skok et al., 2006
Support	The Grandparent Support Index (designed for study #15)	Assesses grandparent support regarding acceptance of disability, relationship with the grandchild, practical help, and emotional support for parents.	Trute, 2003
Service	The Helpgiving Practices Scale (Trivette & Dunst, 1994)	Assesses mothers' perception of helpgiving practices employed by their child's service coordinator. The Helpgiving Practices Scale has two factors: participatory involvement (i.e., helpgiver's ability to build on families' existing strengths) and helpgiver/helpseeker attributions (i.e., beliefs about helpgiver and perceptions about beliefs helpgiver holds regarding the helpseeker).	McIntyre, 2000

Independent Variable	Instrument	Construct Measured[a]	Used in Studies[b]
Service	One instruments from the Your Voice Counts parent booklet (Krauss et al., 2001; Warfield & Gulley, 2006)	Assesses parents' perception of how well the physician (primary care physician or specialist) met the needs of the parent or child.	Mitchell and Hauser-Cram, 2008
Service	The Transition Experiences Survey (Kraemer & Blacer, 2001)	Assesses families' perception of transition services (transition from high school to adulthood) through both open- and close-ended questions across key transition components—employment, community living, and socialization	Neece et al., 2009

[a] Descriptions are limited to the information provided in the studies.

[b] To conserve space, studies with more than two authors were cited as only the first author followed by et al.

Table A2

Outcome Measures Used in Studies Included in the Literature Review

Outcome Variable	Instrument	Construct Measured[a]	Used in Studies[b]
Stress	Questionnaire on Resources and Stress (QRS) (Holroyd, 1974)	Assesses the influence of an individual with a disability or chronic illness on family members. The QRS has 285 true/false items included in 15 subscales across three broad domains: personal problems for the respondent, family problems, and problems for the index case (individual in the family). Higher scores indicate higher levels of stress.	Beyzavi, 1993
Stress	Questionnaire on Resources and Stress—Short Form (QRS-F) (Friedrich et al., 1983)	Assesses family perceptions of stress and resources in relation to a family member with a disability. The QRS-F has 54-items and yields a total score; there are four factors: parent and family problems, pessimism, child characteristics, and physical incapacitation. This measure was designed for families of children with a disability. Higher scores indicate higher levels of stress.	Dyson, 1997; Hodapp et al., 1998; McCarthy et al., 2006; White and

Outcome Variable	Instrument	Construct Measured[a]	Used in Studies[b]
Stress	Malaise Inventory (Rutter et al., 1970)	Assesses physical symptoms and emotional distress in mothers and has been widely used with families of children with physical disabilities.	Fagan and Schor, 1993
Stress	Family Inventory of Life Events and Changes (FILE) (McCubbin & Patterson, 1991)	Assesses family stress; has a total of 71 items across 9 subscales: Intrafamily Strains (including conflict and parenting strains); Marital Strains; pregnancy and Childbearing Strains; Finance and Business Strains; Work-Family Transition and Strains; Illness and Family “Care” Strains; Losses; Transitions “in” and “Out”; and Legal. Respondents indicate whether or not specific life changes occurred within the family across all items during the 12 months prior to completing the measure. A “yes” response indicates a stressor. A high score indicates high stress.	Huang, 1996; McIntyre, 2000

Outcome Variable	Instrument	Construct Measured[a]	Used in Studies[b]
Stress	Parenting Stress Index (PSI) (Abidin, 1995)	Assesses the amount of stress in the parent/child system. Includes 101 items across 2 domains: parent characteristics and child characteristics. High scores in the parent domain indicate that stress may be due to parent functioning; high scores in the child domain indicates that child behavior may be the source of stress. The PSI includes a Likert-type response format and higher scores indicate higher levels of stress.	Keller and Honig, 2004; Mitchell & Hauser-Cram; 2008; Smith et al., 2001; Trute, 2003
Stress	Family Well-Being Index (measure created for Study 10)	Assesses family well-being; it was conceptualized as having negative components, e.g., depression, as well as positive components, e.g., positive impact on parenting. The Family Well-Being Index was developed through the coding of detailed descriptions in field notes. Stress is one of the major indicators of well-being in this measure.	Neece et al., 2009

Outcome Variable	Instrument	Construct Measured[a]	Used in Studies[b]
Stress	Care-giving task specific parenting stress scale	Assesses parenting stress associated with care-giving tasks. Respondents indicated how stressful they found completing tasks associated with direct care-giving on a 7-point Likert scale ranging from 1-not stressful at all to 7-extremely stressful. The items were: in-home therapy, attendance at medical appointments, supervisions of the child's activities, involvement in leisure and play activities, education and information about disability, advocating for services, and managing child behavior. Higher scores are associated with higher stress.	Plant and Sanders, 2007
Family Functioning	The Family Assessment Device (Epstein et al., 1983)	Assesses the ability of families to plan activities, availability of support from family members in times of crisis, ease with which family members can discuss fears and concerns, ability of family members to confide in one another, and others. Overall, it measures the quality of family life.	Fagan and Schor, 1993

Outcome Variable	Instrument	Construct Measured[a]	Used in Studies[b]
Family Functioning	Feetham Family Functioning Survey (FFFS) (Feetham, 1988)	Measures three dimensions of family functioning: family and broader social units, family and subsystems, and family and its members. Respondents indicate importance of each items, their perceptions of the items' current availability (i.e., "How much is there now?"), and their perceptions of the potential of the items, essentially how much they desire from each item (i.e., "How much should there be?"). Higher FFFS scores indicate higher greater dissatisfaction with family functioning.	Huang, 1996; McIntyre, 2000
Family Functioning	Brief Family Assessment Measure III (B-FAM) (Skinner, Steinhauer, & Santa-Barbara, 1983)	Assess family organization and family functioning. The B-FAM is a 50-item scale with seven subscales and offers a unidimensional measure of overall family functioning. Higher scores indicate lower levels of family wellbeing.	Trute, 2003

Outcome Variable	Instrument	Construct Measured[a]	Used in Studies[b]
Quality of Life	The Quality of Life Inventory (Frisch, 1994)	Assesses participants' perceived quality of life in 16 areas, encompassing both internal and external influences. Respondents rate the importance of and satisfaction with items to his or her happiness on a three-point scale. Based on responses, participants are categorized as having a high, average, low, or very low quality of life relative to the norming sample.	Wheeler et al., 2008
Life Satisfaction	Satisfaction With Life Scale (SWLS) (Diener et al., 1985)	Assesses a respondent's satisfaction with his or her own life. The SWLS includes five global items and participants rate their level of agreement with the statements. The SWLS allows the respondent to judge their wellbeing based on their own criteria.	Skok et al., 2006

[a] Descriptions are limited to the information provided in the studies.

[b] To conserve space, studies with more than two authors were cited as only the first author followed by et al.

Appendix B

Descriptions of Studies Included in the Literature Review

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
Beyzavi, 1993 • *Study foci:* (a) Compare the stress of mothers who have children with deafblindness with mothers of children who have hearing loss only and mothers of children without disabilities and (b) Examine the impact of child, parent, and family characteristics	• *Demographic measure* • *Social support:* Family Support Scale (FSS) (Dunst et al., 1984)	• *Stress:* Questionnaire on Resources and Stress (QRS) (Holroyd, 1974). This measure includes 15 Scales that include three broad domains: (a) personal problems for the respondent (scales 1-7), (b) family problems (scales 8-10), and problems for the individual in the family	• Informal, formal, and total family supports were not significantly correlated with total QRS scores for the mother of children with deafblindness • Formal support was significantly correlated with Scale 15 of the QRS; this scale deals with difficult personality related to the individual in the family. • Informal support was negatively associated with Scale 8 (lack of

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
and utilization of resources (including social support) on stress for all three groups *Sample:* 89 mothers of children ages 6-16; 25 mothers of children with deafblindness, 32 mothers of children with hearing loss, and 32 mothers of children without disabilities		(11-15)	family integration) (r = -.98), Scale 9 (limits of family opportunities) (r = -.90), and Scale 14 (social obtrusiveness) (r = -.94); and Formal Support was negatively related to Scale 1 (poor health/mood) (r = -.90) for mothers of children with deafblindness who were 12 to 16 years of age.

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
Dyson, 1997 • *Study foci:* (a) Compare fathers and mothers of children with disabilities with each other and with fathers and mothers of children without disabilities and (b) Examine the impact of family functioning and social support on parent stress. • *Sample:* 124 parents, 62 pairs of mothers and	• *Demographic measure* • *Family support:* The Family Support Scale (Dunst et al., 1984)	• *Perception of stress and resources:* Questionnaire on Resources and Stress-Short Form (Friedrich et al., 1983) • *Social environmental characteristics of the family:* The Family Environment Scale-Form R (Moos & Moos, 1981)	• For families of children with disabilities, mothers' stress was negatively related to their ratings of social support and also to fathers' ratings of social support. • In families of children without disabilities, mothers' stress was moderately related to fathers' ratings of social support.

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
fathers divided into group of parents of children with disabilities (*n*=30) that were mostly moderate to severe in degree (*n*=18) and parents of children without disabilities (*n*=32). Children's mean age was 9.3, *SD*=1.8.			
Fagan & Schor, 1993 • *Study focus:* Examine the relationship of adult companionship, family	• *Demographic measure:* developed by authors, asked mother's race, income, age, marital	• *Family functioning:* The Family Assessment Device (Epstein et al., 1983)	• Adult companionship predicted maternal satisfaction above and beyond the effects of marital status (*F*(2,46)=13.66, p<.001).

Key Findings	e(s)	Outc	Inde Focus/Sa Study/R
income, a number of social supports, and family income to measures of psychosocial functioning *Sample:* 50 mothers of individuals with spina bifida, with a mean child age of 8.1 years	status, availability of another adult companion for at least the past year *Social Support:* The short form of the Social Support Questionnaire (SSQ) (Sarason and colleagues, 1983)	• *Maternal psychosocial functioning:* Malaise Inventory (Rutter et al., 1970) measured physical symptoms and emotional distress in mothers; Self-Perceptions of the Parental Role (MacPhee et al., 1986) measured maternal competence and satisfaction	• Neither adult companionship nor marital status predicted wellbeing or maternal competence. Adult companionship and social supports significantly predicted mothers' satisfaction with parenting (r^2=.33, p<.001).
Hodapp, Fidler, & Smith, 1998	• *Demographic measure* • *Family support:* Family	• *Family Stress:* Questionnaire on	• The number of friends in families' support system was negatively

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
• *Study focus:* Examine the impact of child, family, and support characteristics on family stress *Sample:* Thirty-six parents of children 18 years of age and younger with Smith-Magenis syndrome. Smith-Magenis syndrome is characterized by moderate levels of intellectual disability,	Support Questionnaire (adapted from Kazak, 1987) • *Child behavior:* Child Behavior Checklist (Achenbach, 1991); Vineland Adaptive Behavior Scales—Screener Edition (Sparrow et al., 1983) • *Sleep:* Sleep Questionnaire (Smith et al., 1997)	Resources and Stress—Friedrich edition (QRS-F) (Friedrich et al., 1983)	correlated with parent-family problems (r = -.60, p < .0001), pessimish (r = -.40, p < .0001), and QRS-F (r = -.55, p < .001). Number of friends was most important variable in explaining parent-family problems and QRS-F, accounting for more than 30% of the variance in each outcome.

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
hyperactivity, and problem behaviors.			
Huang, 1996 • *Study foci:* (a) Test a structural model of family hardiness, social support, stress, coping, and family functioning and (b) Compare perceptions of fathers and mothers on the above listed variables • *Sample:* 76 fathers and 76 mothers of children	• *Family hardiness:* Family Hardiness Index (FHI) (McCubbin et al., 1991) • *Social support:* Norbeck's Social Support Questionnaire (NSSQ) (Norbeck et al., 1983)	• *Family stress:* Family Inventory of Life Events and Changes (FILE) (McCubbin & Patterson, 1991) • *Family functioning:* Feetham Family Functioning Survey (FFFS) (Feetham, 1988)s • *Family coping:* Coping Health Inventory for	• For fathers: o recent social support loss was positively correlated with family functioning ($r = .25, p < .01$) o Social support had a direct effect on family coping ($\gamma_{22} = .20, p < .05$) but not on family stress or family functioning. • For mothers o nonsignificant positive

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
with developmental disabilities between the ages of 2 and 7 years		Parents (CHIP) (McCubbin, 1991)	correlations were found between functional support and family functioning ($r = -.11$, $p > .05$) o Social support had a significant negative effect on family stress ($\gamma_{12} = .22$, $p < .05$).
Keller & Honig, 2004 • *Study focus:* (a) Examine the stress mothers and fathers of school-age children with disabilities experience and (b)	• *Family harmony:* Family Environment Scale (Moos & Moos, 1994) • *Social support:* Family Support Scale (Dunst et al., 1988)	• *Parent stress:* Parenting Stress Index (PSI) (Abidin, 1995)	• For fathers, social support did not have a direct effect on stress. • For mothers, socio-economic status (SES) was significantly related to social support and stress suggesting that higher SES mothers perceived

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
examine mediating effects of family harmony and the use of social support on stress *Sample:* 30 mother/father pairs (60 participants total) of children with disabilities (73% moderate to severe in nature; 13% multiple disabilities) who were school-age (*M* = 10.47; *SD* = 2.35)			social support as more useful.

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006 • *Study focus:* (a) Examine the impact of predictors of stress experienced by mothers and fathers of a child with fragile X syndrome and (b) Examine differences in stress levels of mothers and fathers. • *Sample:* 67 parents (39 mothers and 28 fathers)	• *Psychological distress:* Brief Symptom Inventory (BSI) (Derogatis, 1993) • *Problem and adaptive behavior:* Behavior Assessment System for Children—Parent Rating Scale (BASC-PRS) (Reynolds & Kamphaus, 1998) • *Satisfaction with marital relationship:* Dyadic Adjustment Scale (DAS) (Spanier, 1989)	• *Perceived stress and coping:* Questionnaire on Resources and Stress—Friedrich edition (QRS-F)	• For mothers, satisfaction with supports and (measured by the FSS) was significantly negatively correlated with (a) total parenting stress scores (QRS-F) and (b) the pessimism subscale of the QRS-F. • For fathers, family support was not significantly related to parenting stress. • When all predictors were entered into the regression model, family support variables (number of supports and satisfaction with supports) did not significantly

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
with at least one child who had fragile X syndrome and was between the ages of 4 and 17 years living in Australia.	• *Family support:* Family Support Scale (FSS) (Dunst, Jenkins, & Trivette, 1984)		predict parenting stress for either mothers or fathers.
McIntyre, 2000 • *Study focus:* Examine the impact of competency-enhancing help on adaptation for mothers of children with disabilities • *Sample:* 77 mothers of	• *Demographic measure* • *Family's social, psychological, community, and financial resources:* The Family Inventory of Resources for Management (FIRM) (McCubbin, Comeau, &	• *Parental adaptation:* Family Member Well-being Index (FMWB) (H. McCubbin & Patterson, 1983)*;* Feetham Family Functioning Survey (FFFS) (Feetham, 1985)	• No significant relationship between the use of competency-enhancing helpgiving practices and stressors • Greater family resources (assessed by the FIRM, which includes a subscale of extended family social support) were related to higher levels of maternal wellbeing ($r = -,74$, $p <$

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
infants or toddlers, ranging from 8 to 42 months with special needs; a total of 66% had developmental (46%) or multiple disabilities (26%)	Harkins, 1981) *Mothers' perception of helpgiving practices of child's service coordinator:* The Helpgiving Practices Scale (Trivette & Dunst, 1994)	• *Family stress:* Family Inventory of Life Events (FILE) (McCubbin et al., 1983) *Coping*: The Family Crisis Oriented Personal Evaluation Scales (F-COPES) (H. McCubbin et al., 1981)	.001); subscale of extended family support was significantly correlated with both the well-being (FMWB) and family functioning (FFFS) outcomes. • Competency-enhancing helpgiving practices was associated with higher levels of maternal wellbeing (r = .32, p = .005) and satisfaction with family functioning (r = -.37, p = .001). Controlling for family background variables, stressors, family resources, and parental coping, helpgiving

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
			practices did not uniquely contribute to maternal wellbeing (F_{Δ} = 2.04, p = .158). Examining the t-tests for beta weights showed that family resources was the only variables that accounted for a significant amount of the variance in maternal wellbeing.
Mitchell & Hauser-Cram, 2008 • *Study focus*: Examine the impact of utilization and satisfaction with health care provided by the child's doctor on	• *Child behavior:* The Child Behavior Checklist (CBCL) (Achenbach, 1991) • *Cognition:* Stanford-Binet Intelligence Scale (Thorndike et al., 1986)	• *Maternal stress*: Parent Domain of the Parenting Stress Index (PSI) (Abidin, 1995) • *Depression*: Center for Epidemiologic Studies Depressive	• Maternal satisfaction with care received from child's physician predicted maternal stress (β=.-23, p=.043) above and beyond the effects of marital status, income, child health, child cognition, child behavior problems, and health care

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
maternal wellbeing *Sample*: 73 mothers of 15 year old children with developmental disabilities	• *Child disability:* three disability categories – Down syndrome, motor impairment, and developmental dealay • *Child health, child and family demographics* • *Medical care utilization and satisfaction:* two measures from the Your Voice Counts parent booklet (Krauss et al., 2001; Warfield & Gulley, 2006); count of doctor	Symptomatology Scale (CES-D) (Radloff, 1977)	utilization in the past 12 months. • Health care utilization did not significantly predict maternal stress (β = .15, p = .168). • Controlling for the above variables, maternal satisfaction with care significantly predicted maternal depressive symptoms (β= -.25, p=.014). Greater utilization of health care was a significant predictor of greater depression (β= .24, p= .019).

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
	visits in previous 12 months *Satisfaction with care:* measure created for present study		
Neece, Kraemer, & Blacher, 2009 • *Study focus:* Examine the impact of parents' transition satisfaction (transition from high school to adulthood) on family wellbeing. • *Sample:* 128 caregivers	• *Young adult variables:* Vineland Adaptive Behavior Scale (Sparrow et al., 1984); Reiss Screen for Maladaptive Behavior (Reiss, 1986); Quality of Life Questionnaire (Schalock & Keith, 1993); Age;	• *Transition satisfaction:* Transition Satisfaction Index (measure created for this study; generation of nominal scale through qualitative analysis of field notes) • *Family Wellbeing:* Family Well-Being	• Parents were categorized into one of three groups according to analysis of key transition satisfaction factors: (a) transition satisfaction (52.3% of sample); (b) transition dissatisfaction (43.0% of sample); and (c) cannot classify due to lack of information (4.7% of sample) and one of the following groups according to

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
(mostly mothers) of 128 young adults between the ages of 19 and 28 years with severe intellectual disability who had all exited the public school system.	Severity of disability • *Family characteristics:* Family Data Sheet; Transition Experiences Survey (Kraemer & Blacher, 2001); Parental Involvement in Transition Planning (Kraemer & Blacher, 2001) *Environmental characteristics:* Data related to school programming and service	Index (measure created for this study; conceptualized as having negative components, e.g., depression, as well as positive components, e.g., positive impact on parenting); *Parental depression:* Center for Epidemiologic Studies—Depression Scale (Radloff, 1977); *Family impact:* Family	analysis of key wellbeing factors: (a) high family well-being group (33% of sample), (b) a low family well-being group (55% of sample), and (c) cannot classify group (12% of sample). Significant differences on the Family Well Being Index between transition satisfaction and transition dissatisfaction groups (χ^2 (1, N = 122) = 6.70, p = .01); 64% of families in transition satisfaction group had high family well being and 64% of families in transition

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
	quality	Impact Questionnaire (Donenberg & Baker, 1993)	dissatisfaction group had low family well-being.
Plant & Sanders, 2007 - *Study focus:* Examine the impact of multiple predictors related to caregiving and severity of disability on parenting stress; Examine the influence of cognitive appraisal of caregiving responsibilities as a mediator and external	- *Demographic measure:* Family Background Checklist (Plant & Sanders, 1999) - *Caregiving tasks measures:* Questionnaires with a Likert-scale response format assessing the following: (a) Stressfulness of caregiving tasks, (b)	- *Caregiving task specific parenting stress:* Respondents indicated how stressful they found completing tasks associated with direct caregiving on a 7-point Likert scale ranging from 1-not stressful at all to 7-extremely stressful. The items	- Partner/family support moderated the relationship between the level of the child's disability and parent stress. This interaction effect uniquely accounted for 6% of the variance in parent stress. - Friend support moderated the relationship between difficult child behavior during caregiving tasks and parent stress. The overall model accounted for 46% of the variance in

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
supports and coping as moderators on the relationship between the predictors and stress. *Sample:* 105 families with a preschool aged child (less than 6 years) with a developmental disability in Australia.	Difficulty of caregiving tasks, (d) Time involved in caregiving tasks, (e) Difficult child behavior during caregiving tasks • *Level of child disability:* Vineland Adaptive Behaviour Scale—Survey Form (Sparrow et al., 1984) • *Cognitive appraisal of caregiving responsibilities:* Ways of Coping Checklist	were: in-home therapy, attendance at medical appointments, supervisions of the child's activities, involvement in leisure and play activities, education and information about disability, advocating for services, and managing child behavior.	parent stress.

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
	(Vitaliano et al., 1985) • *Social support and caregiving:* Questionnaire with 7-point Likert Scale Format assessing (a) Family/partner support, (b) friend support, and (c) external/professional support		
Skok, Harvey, & Reddihough, 2006 • *Study focus*: Examine the impact of stress and	• *Perceived stress:* Perceived Stress Scale (Cohen, Kamarch, & Mermelstein, 1983)	• *Wellbeing*: Authors used combination of the Psychological Wellbeing subscale of	• Severity of disability was not significantly correlated with wellbeing • Significant relationships between

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
social support on parent wellbeing - *Sample*: 43 mothers of children with cerebral palsy aged 5-12 years	- *Perceived social support:* Multidimensional Scale of Perceived Social Support (Zimet and colleagues, 1988); Profile of Adaptation to Life—Clinical Scale (Ellsworth, 1979); Satisfaction With Life Scale (Diener et al., 1985)	the Profile of Adaptation to Life—Clinical Scale (Ellsworth, 1979) and the Satisfaction With Life Scale (Diener et al., 1985)	perceived stress and wellbeing - Stress significantly predicted social support and accounted for 13% of the variance in social support. - Perceived stress significantly predicted wellbeing, accounting for 33% of its variance. Social support mediated the relationship between stress and wellbeing (R^2 = .55, $F(2,40)$=26.9, p,.001). The overall model accounted for 55% of the variance in wellbeing and perceived social support held the strongest weight in predicting

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
			wellbeing (*β* = .52)
Smith, Oliver, & Innocenti, 2001 • *Study focus:* Examine the impact of child and family functioning predictors on parenting stress • *Sample:* 880 parents of a child with a moderate to severe developmental delay. Average age of the child was 2 years 11 months (*SD*=19 months)	• *Child functioning:* BDI: personal/social, adaptive behavior, motor, communication, and cognitive development (Snyder et al., 1993) • *Family functioning:* Family Support Scale (FFS) (Dunst et al., 1984); Family Resources Scale (FRS) (Dunst & Leet, 1985); Family Inventory of Life Events	• *Parenting stress:* Parenting Stress Index/Short Form (PSI/SF) (Abidin, 1990)	• All three measures of family functioning significantly correlated with parenting stress. • With all variables entered into regression model, family resources (β = -.261) was the strongest predictor of parenting stress. Child functioning (β = -.198), family social support (β = -.185), and family stressful life events (β = .185) were the other significant predictors of parenting stress in the model. • Family functioning variables

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
	and Changes (FILE) (McCubbin, et al., 1983)		explained more variance in parenting stress than child functioning variables.
Trute, 2003 - *Study focus:* Examine the impact of grandparent support on the well-being of mothers and fathers who have children with developmental disabilities - *Sample:* 64 families, including 17 single	- *Grandparent support:* The Grandparent Support Index (designed for this study): assessed four key elements of grandparent support: (a) acceptance of disability, (b) relationship with child, (c) practical help, and (d) emotional support for parents.	- *Parent stress:* Parenting Stress Index—Short Form (PSI-SF) (Abidin, 1995) - *Family functioning:* Brief Family Assessment Measure III (B-FAM) (Skinner et al., 1983, 1995) - *Depression:* Beck Depression Inventory—	- For mothers, emotional support from maternal grandmothers was significantly related to higher self-esteem ($r = -.39$, $p < .05$), lower levels of depression ($r = -.41$, $p < .05$), and lower levels of stress ($r = -.32$, $p < .05$). In addition, emotional support from paternal grandmother (i.e., mothers-in-law) was significantly related to lower levels of depression ($r = -.31$, $p < .05$).

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
mothers, 3 single fathers, one blended family, 42 married couples, and 2 separated couples (both partners were interviewed). Children experienced a range of disabilities, from mild to severe, with 49% having multiple disabilities. On average, the children were 12 years old at the time of data collection.		Short Form (BDI-SF) (Beck & Beck, 1972) • *Self-acceptance*: Rosenberg Self-Esteem Inventory (RSE) (Rosenberg, 1965)	• For fathers, lower levels of stress was associated with emotional support from their mothers-in-law (r = -.47, p < .05), fathers-in-law (r = -.51, p < .05), mothers (r = -.49, p < .05), and fathers (r = .46, p < .05). In addition, emotional support from paternal grandmothers (i.e., their mothers) was significantly correlated with higher self-esteem (r = -.48, p < .05) and lower depression levels (r = -.58, p < .001). Instrumental support, or practical help, was not significantly associated

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
			with self-esteem, depression, stress, or family wellbeing.
Wheeler, Skinner, & Bailey, 2008 - *Study focus:* Examine factors, both internal and external to the family, that impact perceived quality of life for mothers of children with fragile X syndrome - *Sample:* 101 biological mothers of children between the ages of 10	- *Child demographic variables:* (a) child developmental status: Mullen Scales of Early Learning (Mullen, 1995) or Leiter International Performance Scales-Revised—Leiter-# (Roid & Miller, 1997); (b) behavioral and emotional characteristics: Child Behavior Checklist—	- *Quality of life:* The Quality of Life Inventory (Frisch, 1994); semistructured interviews	- Family support and mothers' quality of life were significantly positively correlated (r = .33, $p < .001$). - Family support was not a significant predictor of mothers' quality of life in hierarchical regression model that included demographic variables (maternal IQ, income, child age, maternal age, child gender, ethnicity, time since diagnosis, # of children with fragile x, marital status); maternal well-being measures

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
months and 14 years with full-mutation fragile X syndrome (characterized by mild to moderate intellectual disability and challenging behaviors)	• CBCL (Achenbach & Rescorla, 2000); and (c) assess autism characteristics: Childhood Autism Rating Scale (Schopler et al., 1988) • *Maternal hope:* The State Hope Scale and Trait Hope Scale (Snyder et al., 1991) • *Maternal stress:* The Parental Stress Index, short form (Abidin,		(religiosity, family support, parenting stress, trait hope, current and past depression); and child variables (level of delay). Only trait hope and total stress were significant predictors of mothers' quality of life in the full model.

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
	1995) - *Current and past depression:* Nonpatient edition of the Structured Clinical Interview for DSM-IV-NP (First et al., 2002) - *Potential sources of resources and support:* Family Support Scale (Dunst et al., 1988); Personal Assessment of Intimate Relationships Inventory: Emotional		

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
	Intimacy Subscale (Schaefer & Olson, 1981); Fewell Religion Scale-adapted (Fewell, 1986; Skinner et al., 2001) *Cognitive functioning of mothers*: Wechsler Abbreviated Scale of Intelligence-WASI (Wechsler, 1999)		
White & Hastings, 2004 • *Study focus*: Examine the impact of multiple	• *Perceived Social Support*: Family Support Scale (Dunst et al.,	• *Parent well-being*: Hospital Anxiety and Depression scale	• Helpfulness of informal support sources was significantly negatively correlated with parent anxiety,

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
measures of social support on positive and negative caregiving outcomes *Sample*: 33 parents of adolescent children with moderate-profound intellectual disabilities. Child age ranged from 13 to 18 years.	1984); Support Functions Scale (Dunst et al., 1996); Professional Services Support Scale, a checklist that included 16 different types of professional support provided by health, education, and social services (designed for the present study) • *Demographic variables* *Child behavior:* The Behavior Problems	(Zigmond & Snaith, 1983); Questionnaire on Resources and Stress Friedrich short form Friedrich et al., 1983); Carer's Assessment of Satisfactions Index (Nolan et al., 1988)	depression, and stress. • Practical support functions were significantly negatively correlated with depression and stress. • Controlling for child adaptive and behavior problems and autism, stress was marginally significantly related to helpfulness or informal supports and not significantly related to practical support. Accessing more services and supports was indicative of higher levels of stress; no relationship when controlling for correlates (adaptive

Study/Research Focus/Sample	Independent Variable(s)	Outcome Measure(s)	Key Findings
	Inventory (Rojahn et al, 2001); VABS measure of adaptive behavior (Sparrow et al., 1984)		and behavior problems and autism)

Appendix C

Study Invitation Letter

Approved by the Human Subjects Committee University of Kansas, Lawrence Campus (HSCL). Approval expires one year from 9/9/2009. HSCL #18230

Welcome Letter and Consent Form
Study Title: *The Relationship of Perceptions of Service Adequacy to Family Quality of Life: A Mixed Methods Study of Families Who Have Children that are Deafblind*

Beach Center

1-866-783-3378 (toll free) 1-785-864-7605 (fax) 1-785-864-7600
beachcenter@ku.edu

A Special Invitation to You . . .

My name is Kathleen Kyzar and I am a doctoral candidate focusing on Family and Policy Studies in Special Education at the Beach Center on Disability at the University of Kansas. I am working with the <<state>> Deafblind Technical Assistance Project to assist them in better understanding how well service programs meet the needs of families like you. We want to know more about how different education, health, and family support programs meet your needs, and what more you might need to enjoy a better quality of life for your family at the same time you are working so hard to meet the needs of your child. We also want to know more about what your state Technical Assistance Project can do to help your family – either directly through providing more family support services, or indirectly through training to your child's teachers, health care providers, or others.

One thing that makes this study different from other surveys you may have been asked to complete is that we will also be asking you to complete our Family Quality of Life Scale, which will help us learn how and whether the services you receive actually impact your family life. There is no current research to show how services impact families of children with deafblindness, and therefore no way to show policy makers how important it is to provide the right kind of services, professional and paraprofessional training, and other supports to families like yours.

I am writing to invite you to be part of this study. If you choose to participate, your involvement would include completing the consent letter and survey included in this packet. The survey contains three brief sections and asks that you provide some demographic information. Estimated time of completing all components of the study is approximately 20 minutes.

Your participation in this study is completely voluntary; we invite you to participate to the extent you feel comfortable. By returning the attached reply form and survey directly to me, nobody in your state will know the names of the families who are participating in the study from their state. Your name will not be used on any reports resulting from this study and all the information you provide on the survey will be confidential. We will provide a general report to your state with the overall information pulled together from all the families in your state, but they will be discussed in general terms and reports will include a description of study participants in groups, never as individuals.

The benefits to you for participating in this study are:

- Your information will help your state's Deaf-Blind project improve their services and supports to families.
- Our survey will help you reflect on your family's strengths and resources.
- If you wish, we will provide you with a copy of our report that we will be compiling for your state, so that you can see the results and recommendations. Please email Kathleen Kyzar (kkyzar@ku.edu) if you would like a copy of the results.

We do not think there are many risks to your participation, but the following could be a risk for you or your family:

- Your time of course is valuable and we recognize that we are impinging on the many demands you have in caring for your child.

Your help would be greatly appreciated. If you agree to participate in this study, your answers will be used in the following ways:

- The U.S. Department of Education will use this information to establish policies and funding programs to benefit families.
- Your state Deaf Blind Technical Assistance Project will use this information to help improve their services and supports.
- Universities and state inservice training programs will use this information to train future teachers and other professionals to be more responsive to families.

If you are interested in having YOUR voice count . . . .

- ✓ **Please fill out the attached response form** and return it to us using the *smaller* business mail reply envelope included in this packet. This mailing is at no monetary cost to you.

- ✓ If you would like to complete a **paper survey**, please complete the survey provided to you in this packet and return it using the *larger* business reply form provided. The mailing is at no monetary cost to you.

- ✓ If you prefer to complete the **survey online** using a secure website, please mark the appropriate box on the consent form provided in this packet and provide your email address. We will send you a link to the email address you provide that will enable you to access a confidential survey which you can complete at your convenience.

- ✓ Both surveys (online and paper) are identical; they just come in different formats.
- ✓ Your answers will be kept completely confidential. Information about your identity will be kept in a separate, locked place, and your answers on the survey will be combined with answers from other families.

✓ You may choose to withdraw from the study at any time and may choose to refuse to answer any individual questions on the survey, without penalty of any kind.

If you want more information about this study or about the Beach Center on Disability, you can call us toll-free at 1-866-783-3378. Ask for Kathleen Kyzar, Doctoral Research Candidate, or you may contact her by e-mail at kkyzar@ku.edu. If you have any additional questions about your rights as a participant, you may call (785) 864-7429 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email **mdenning@ku.edu**.

Finally, please know that we understand the many demands on your time and that we truly appreciate your help! Please contact myself, Kathleen Kyzar, or Jean Ann Summers (contact information below) if you have any questions.

Sincerely,

Kathleen Kyzar
Doctoral Candidate/
Graduate Research Fellow
Beach Center on Disability
785-864-7601
kkyzar@ku.edu

Jean Ann Summers, Ph.D.
Research Director, Family Research
Programs
Beach Center on Disability
Research Director
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HSCL #18230
Study Title: *The Relationship of Perceptions of Service Adequacy to Family Quality of Life: A Mixed Methods Study of Families Who Have Children that are Deafblind*

Deafblind Family Study Acceptance Form

Yes! I have read your letter (or it has been read to me) and I want to participate in the ***Deafblind Family Study***. I have had a chance to ask questions and have received answers to any questions I had about information that will be used and shared in this study. I know that the information about me and my family will be kept private.

I give permission to be part of this study, knowing that I can drop out of the study if I decide to. I also agree to the use and sharing of the information I provide on the survey as described above. By signing this, I verify that I have received a copy of this consent form to keep.

The exact same survey is available in both online and paper versions. I would prefer to complete the survey by (please check one):

_____ filling out a paper version mailed to the address below (please mail survey using *larger* business reply form provided)

_____ filling out an on-line survey using a protected web site.
Email address (you will receive a link): ________________________________

NAME ____

SIGNATURE ________________________________ **DATE** ________________

HOME ADDRESS ____
Street Address *Apt/Unit/Lot #*

____
City *State* *Zip Code*

PHONE NUMBER ____

<u>Thank you for your participation. Please mail this form using the smaller business reply form provided.</u>

For Beach Center Use Only

____
Receiving Date

Appendix D

Service Adequacy and Family Quality of Life for Families of Children who are Deafblind Survey

ID Number ☐

SERVICE ADEQUACY AND FAMILY QUALITY OF LIFE FOR FAMILIES OF CHILDREN WHO ARE DEAFBLIND

Developed by the Beach Center on Disability at the University of Kansas in partnership with families, service providers, and researchers, 2009

1200 Sunnyside Avenue, 3136 Haworth Hall, Lawrence Kansas 66045

For information, contact:

Kathleen Kyzar: kkyzar@ku.edu, 785-864-7601

or

Jean Ann Summers, PhD: jsummers@ku.edu

Or leave a message at our toll-free number: 1-866-783-3378

Survey Information and Instructions

Thank you for agreeing to complete this survey. In this study, we want to understand how the supports and services that families of children who are deafblind receive impact their family quality of life. You can help by providing information about your family. Here is what we are most interested in learning from you:

- ✓ How well services meet your family's and child's needs;
- ✓ How well professionals work with your child and family; and
- ✓ Your satisfaction with your family's quality of life.

All the information you provide is **confidential** and your name will not be attached to any of the information you give us. Please answer as many questions as you can. However, if you are uncomfortable with a question, please feel free to skip it.

It should take you around 20 minutes to complete the survey.

Answering Questions: **Please use a pencil to mark your answers. Use a check mark (✓) or "X" -- please do NOT shade in the whole box. If you change any answers, please completely erase any previous answers or any extra pencil marks on the page. Please do not make any stray marks, on the form. If you include written comments, please write as neatly as possible. If you find there is not enough room in the comment boxes provided or have additional comments to share, you may email them to: Kathleen Kyzar (kkyzar@ku.edu) or Jean Ann Summers (jsummers@ku.edu).**

Thank you so much for sharing your experiences with us!

By completing this survey, you indicate that you have been informed of the important aspects of this study.

I. Services Adequacy Scale for Families of Children who are Deafblind

In this section of the survey, we want to know how well the services your family and your child receive meet your needs. In completing the survey, consider only those services your family and/or your child have received **in the last 12 months**.

The services itemized in this section of the survey were identified by (a) families who have children who are deafblind and (b) service providers that work with families on a daily basis. We want to know how well these services meet your family's needs. Please check the boxes on the following pages that reflect the degree to which each item has met your needs **over the last 12 months.** If you would like to add additional information, please use the comments section provided.

✓ Checking the **first square, "not at all,"** means that, on average, the services **did not meet** your child or family's needs **at all.**

✓ Checking the **fifth square, "completely,"** means that, on average, the services **completely** met your child or family's needs.

✓ Checking the **last square, "did not use,"** means that your family **did not use** the service in the last year. Before checking this box, please read the examples thoroughly; it is estimated that in general, families will utilize most of the services listed to at least some degree.

Thank you very much for sharing your experiences with us!

I. Services Adequacy Scale for Families of Children who are Deafblind

Q1 **In the last 12 months, to what degree were your child or family's needs met <u>on average</u> by the following HEALTH services:**

	Not at all	*A little*	*Somewhat*	*Adequately*	*Completely*	*Did not use*
Well-child checks	☐	☐	☐	☐	☐	☐
Nursing services (for example, home, school, other)	☐	☐	☐	☐	☐	☐
Nutrition	☐	☐	☐	☐	☐	☐
Mental health services	☐	☐	☐	☐	☐	☐
Other (please specify in box below)	☐	☐	☐	☐	☐	☐
<u>On average</u>, how do HEALTH services meet your child and family's needs?	☐	☐	☐	☐	☐	☐

If you would like to expand on your answer above, please write in here:

Q2 **In the last 12 months, to what degree were your child or family's needs met <u>on average</u> by the following EDUCATION services:**

	Not at all	*A little*	*Somewhat*	*Adequately*	*Completely*	*Did not use*
Early intervention (birth to 2yrs, 11 months)	☐	☐	☐	☐	☐	☐
Special Education (Preschool to 12th grade; ages 3-21)	☐	☐	☐	☐	☐	☐
Hearing services	☐	☐	☐	☐	☐	☐
Vision services	☐	☐	☐	☐	☐	☐
Paraprofessional services	☐	☐	☐	☐	☐	☐
Transition Services (for example, from early intervention to pre-k, from pre-k to kindergarten, from high school to adult)	☐	☐	☐	☐	☐	☐
Summer school or extended school year (ESY) services	☐	☐	☐	☐	☐	☐
Other (please specify in box below)	☐	☐	☐	☐	☐	☐
<u>On average</u>, how do EDUCATION services meet your child and family's needs?	☐	☐	☐	☐	☐	☐

If you would like to expand on your answer above, please write in here:

I. Services Adequacy Scale for Families of Children who are Deafblind

Q3 **In the last 12 months, to what degree were your child or family's needs met <u>on average</u> by the following RELATED services:**

	Not at all	*A little*	*Somewhat*	*Adequatel y*	*Completel y*	*Did not use*
Occupational Therapy (OT)	☐	☐	☐	☐	☐	☐
Physical Therapy (PT)	☐	☐	☐	☐	☐	☐
Intervener (home, school and/or community)	☐	☐	☐	☐	☐	☐
Orientation and Mobility (O&M)	☐	☐	☐	☐	☐	☐
Speech Therapy (ST/SLP) or Augmentative and Alternative Communication (AAC)	☐	☐	☐	☐	☐	☐
Assistive Technology (AT)	☐	☐	☐	☐	☐	☐
Interpreter (for child in classroom and/or community)	☐	☐	☐	☐	☐	☐
Other (please specify in box below)	☐	☐	☐	☐	☐	☐
<u>*On average*</u> how do RELATED SERVICES meet your child and family's needs?	☐	☐	☐	☐	☐	☐

If you would like to expand on your answer above, please write in here:

I. Services Adequacy Scale for Families of Children who are Deafblind

Q4 **In the last 12 months, to what degree were your child or family's needs met <u>on average</u> by the following INFORMATION services:**

	Not at all	*A little*	*Somewhat*	*Adequately*	*Completely*	*Did not use*
State Deafblind Projects (for example, conferences and webinars, workshops, technical assistance, family events)	☐	☐	☐	☐	☐	☐
Online social networks (for example, yahoo groups, email listservs, blogs)	☐	☐	☐	☐	☐	☐
Parent/Family Organization	☐	☐	☐	☐	☐	☐
Outreach or Consulting (for example, from State School for the Deaf or Blind, private consultants)	☐	☐	☐	☐	☐	☐
State Department of Education	☐	☐	☐	☐	☐	☐
Parent Training and Information Center (PTI) and/or Protection and Advocacy (P&A) Disability Law Center (legal rights)	☐	☐	☐	☐	☐	☐
Health care providers (for example, physician, therapist, opthamologist, ear nose and throat [ENT] physician)	☐	☐	☐	☐	☐	☐
Other (please specify in box below)	☐	☐	☐	☐	☐	☐
<u>On average</u>, how do INFORMATION services meet your child and family's needs?	☐	☐	☐	☐	☐	☐

If you would like to expand on your answer above, please write in here:

I. Services Adequacy Scale for Families of Children who are Deafblind

Q5 **In the last 12 months, to what degree were your child or family's needs met <u>on average</u> by the following FRIEND AND FAMILY SUPPORT services:**

	Not at all	*A little*	*Somewhat*	*Adequately*	*Completely*	*Did not use*
Extended family (external to your immediate family)	☐	☐	☐	☐	☐	☐
Friends	☐	☐	☐	☐	☐	☐
Contact with other parents of children with deafblindness or similar etiology/disability	☐	☐	☐	☐	☐	☐
Family events	☐	☐	☐	☐	☐	☐
Support for siblings	☐	☐	☐	☐	☐	☐
Other (please specify in box below)	☐	☐	☐	☐	☐	☐
<u>On average,</u> how do FAMILY AND FRIEND SUPPORT services meet your child and family's needs?	☐	☐	☐	☐	☐	☐

If you would like to expand on your answer above, please write in here:

Q6 **In the last 12 months, to what degree were your child or family's needs met <u>on average</u> by the following CHILD CARE services:**

	Not at all	*A little*	*Somewhat*	*Adequately*	*Completely*	*Did not use*
Respite Programs (for example, church, mothers' day out, agency services)	☐	☐	☐	☐	☐	☐
Babysitting	☐	☐	☐	☐	☐	☐
Regular after-school programs	☐	☐	☐	☐	☐	☐
Full- or part-time center or child care in a licensed home setting (birth to 5)	☐	☐	☐	☐	☐	☐
Family care (for example, grandparent, sibling, aunt or uncle; can include after school care or birth to 5 child care)	☐	☐	☐	☐	☐	☐
Other (please specify in box below)	☐	☐	☐	☐	☐	☐
<u>On average,</u> how do CHILD CARE services meet your child and family's needs?	☐	☐	☐	☐	☐	☐

If you would like to expand on your answer above, please write in here:

I. Services Adequacy Scale for Families of Children who are Deafblind

Q7 **In the last 12 months, to what degree were your child or family's needs met <u>on average</u> by the following SERVICE COORDINATION services:**

	Not at all	*A little*	*Somewhat*	*Adequatel y*	*Completel y*	*Did not use*
Case management and/or care coordination	☐	☐	☐	☐	☐	☐
Financial management services (for example, fiscal intermediary/agency)	☐	☐	☐	☐	☐	☐
Medical home (comprehensive primary care)	☐	☐	☐	☐	☐	☐
Other (please specify in box below)	☐	☐	☐	☐	☐	☐
<u>On average</u>, how to SERVICE COORDINATION services meet your child and family's needs?	☐	☐	☐	☐	☐	☐

If you would like to expand on your answer above, please write in here:

Q8 **If you would like to add any additional comments regarding the items in this section, please write in here:**

I. Services Adequacy Scale for Families of Children who are Deafblind

Q9 **Please tell us the nature of your child's disability (if any) in addition to his/her vision and hearing loss. Please check ALL that apply.**

☐ *Developmental Delay*
☐ *Emotional behavioral disorder*
☐ *Learning disability*
☐ *Attention deficit disorder*
☐ *Intellectual disability*
☐ *Physical disability*
☐ *Speech or language impairment*
☐ *Other health Impairment*
☐ *Mental illness*
☐ *Autism spectrum disorder*
☐ *Traumatic brain injury*
☐ *No additional disability*
Other, please specify: ☐

Q10 **Would you be willing to participate in an interview to share your story and insights regarding how well services meet the needs of children who are deafblind and their families?**

☐ *Yes*
☐ *No*

Q11 **If "yes", please provide your name and phone number so we can contact you in the space below. Your name will be kept confidential and will not be associated with any report of this study.**

Name.. ☐
Phone.. ☐

Thank you for completing this portion of the survey. Please continue to begin Section II: Family Quality of Life Scale

II. Family Quality of Life

In this section of the survey, we want you to tell us how you feel about your life together as a family. We will use what we learn from families to improve policies and services for children and families.

Your "family" may include many people - mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as those people:

✓ Who think of themselves as a part of your family (even though they may not be related by blood or marriage), and

✓ Who support and care for each other on a regular basis.

For this survey, 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 items below are things that hundreds of families have said are important for a good family quality of life. We want to know how satisfied you are with these things in your family. Please check the boxes on the following pages that reflect your level of satisfaction with each item.

✓ Checking the first square means you are very dissatisfied.

✓ Checking the last square means you are very satisfied.

Thank you very much for sharing your experiences with us!

II. Family Quality of Life

Q12a **How satisfied am I that...**

	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
My family enjoys spending time together.	☐	☐	☐	☐	☐
My family members help the children learn to be independent.	☐	☐	☐	☐	☐
My family has the support we need to relieve stress.	☐	☐	☐	☐	☐
My family members have friends or others who provide support.	☐	☐	☐	☐	☐
My family members help the children with schoolwork and activities.	☐	☐	☐	☐	☐
My family members have transportation to get to the places they need to be.	☐	☐	☐	☐	☐
My family members talk openly with each other.	☐	☐	☐	☐	☐
My family members teach the children how to get along with others.	☐	☐	☐	☐	☐
My family members have some time to pursue their own interests.	☐	☐	☐	☐	☐
My family solves problems together.	☐	☐	☐	☐	☐
My family members support each other to accomplish goals.	☐	☐	☐	☐	☐
My family members show they love and care for each other.	☐	☐	☐	☐	☐
My family has outside help available to us to take care of special needs of all family members.	☐	☐	☐	☐	☐

II. Family Quality of Life

Q12 **How <u>satisfied</u> am I that…**

	Very Dissatisfied	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
Adults in my family teach the children to make good decisions.	☐	☐	☐	☐	☐
My family gets medical care when needed.	☐	☐	☐	☐	☐
My family has a way to take care of our expenses.	☐	☐	☐	☐	☐
Adults in my family know other people in the children's lives (friends, teachers, etc.).	☐	☐	☐	☐	☐
My family is able to handle life's ups and downs.	☐	☐	☐	☐	☐
Adults in my family have time to take care of the individual needs of every child.	☐	☐	☐	☐	☐
My family gets dental care when needed.	☐	☐	☐	☐	☐
My family feels safe at home, work, school, and in our neighborhood.	☐	☐	☐	☐	☐

Q13 **Please tell us your relationship to the child who is deafblind in your family:**

☐ *Parent (biological, step, foster, or adoptive)*
☐ *Grandparent*
☐ *Aunt or Uncle*
☐ *Sibling (brother or sister)*
☐ *Other non-relative (please specify below, in the box)*

Thank you for completing this portion of the survey. Please continue to begin Section III: Family-Professional Partnerships

III: Family-Professional Partnership

In this section of the survey, we want to know how you feel about the main person who works with you and your child at home or at school. We will use what we learn from families to inform policy makers and service providers for children and families.

There may be many different service providers who work with your child with special needs, such as teachers, social workers, or speech, occupational, physical, or behavior therapists. Think about the service provider who has worked THE MOST with your child over the last six months according to the categories provided below. If you would like to provide us with additional information about the type of service provider you chose, please do so in the comments section. If you are working closely with someone not listed, please check "other" and write in the type of service provider in the space provided.

Please tell us what type of service provider you are thinking about:

Q14 **Please check only one:**

☐ *Intervener for your child (home, school, and/or community)*

☐ *Health service provider (for example, primary care doctor, school nurse or nurse that cares for your child, family counselor)*

☐ *Education service provider (for example, early intervention provider, your child's classroom teacher, special education teacher, vision or hearing teacher)*

☐ *Related services provider (for example, your child's speech therapist, occupational therapist, physical therapist, audiologist)*

☐ *Child care provider (for example, respite care provider, child care teacher)*

☐ *Service coordinator (for example, your care coordinator or case manager for medical care, case manager for early intervention services, individual that coordinates your child's school services)*

☐ *Other*

If other, please specify in the space provided adjacent and below this text:

Q15 **Please add any additional comments in the section below:**

III: Family-Professional Partnership

Please think of the service provider you listed on the previous page as you complete this section.

Q16 **How satisfied are you that your child's service provider...**

	Very Dissatisfied	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
Helps you gain skills or information to get what your child needs.	☐	☐	☐	☐	☐
Has the skills to help your child succeed.	☐	☐	☐	☐	☐
Provides services that meet the individual needs of your child.	☐	☐	☐	☐	☐
Speaks up for your child's best interests when working with other service providers.	☐	☐	☐	☐	☐
Lets you know about the good things your child does.	☐	☐	☐	☐	☐
Is available when you need them.	☐	☐	☐	☐	☐
Treats your child with dignity.	☐	☐	☐	☐	☐
Builds on your child's strengths.	☐	☐	☐	☐	☐
Values your opinion about your child's needs.	☐	☐	☐	☐	☐
Is honest, even when there is bad news to give.	☐	☐	☐	☐	☐
Keeps your child safe when your child is in his/her care.	☐	☐	☐	☐	☐
Uses words that you understand.	☐	☐	☐	☐	☐
Protects your family's privacy.	☐	☐	☐	☐	☐
Shows respect for your family's values and beliefs.	☐	☐	☐	☐	☐
Listens without judging your child or family.	☐	☐	☐	☐	☐
Is a person you can depend on and trust.	☐	☐	☐	☐	☐
Pays attention to what you have to say.	☐	☐	☐	☐	☐
Is friendly.	☐	☐	☐	☐	☐

Thank you for completing this portion of the survey. Please continue to begin Section IV: General Individual and Family Information

Section IV: General Individual and Family Information

In this final portion of the survey, we will ask you a few questions about you and your family. Our reports of the study will only include descriptions of study participants in groups, never as individuals, and in general terms so your answers will be kept confidential.

Please answer these questions about yourself:

Q17 What is your gender

- ☐ *Male*
- ☐ *Female*

Q18 What is your race/ethnicity? (Check all that apply)

- ☐ *American Indian or Alaskan Native*
- ☐ *Asian or Pacific Islander*
- ☐ *Black or African American*
- ☐ *Hispanic or Latino*
- ☐ *White*
- ☐ *Other*

Q19 How old is your *child*?

Child's date of birth (MM/DD/YYYY) .... ☐

Q20 What is your marital status?

- ☐ *Married/Living with a partner*
- ☐ *Not married (widowed, divorced, separated, never married)*

Q21 What is your employment status?

- ☐ *Working full-time for pay or profit for a company or a family business*
- ☐ *Working part-time for pay or profit for a company or a family business*
- ☐ *Unemployed but looking*
- ☐ *Not employed (for example, stay-at-home parent or care-giver, retired, public assistance pay, disability)*

Q22 To what extent do the needs of your child with deafblindness affect your employment status?

- ☐ *Not at all*
- ☐ *Some*
- ☐ *A lot*
- ☐ *Not applicable*

Q23 To what extent do the needs of your child with deafblindness affect the employment of your child's other parent/guardian?

- ☐ *Not at all*
- ☐ *Some*
- ☐ *A lot*
- ☐ *Not applicable*

Q24 What is the highest level of education that you have completed? (please check ONLY one)

- ☐ *Schooling but not high school diploma or GED*
- ☐ *High school graduate (diploma or GED)*
- ☐ *Some college or post-high school, but no degree*
- ☐ *Associate degree (AA, AS, etc.)*
- ☐ *Bachelor's degree (BA, BS, etc.)*
- ☐ *Graduate degree*
- ☐ *Other*

Please specify: ☐

Section IV: General Individual and Family Information (continued)

Q25 What was your total household income from all sources for the past year? Be sure to include income from all sources (such as family subsidy or child support).*

☐ *Less than $14,999*
☐ *Between $15,000 and $19,999*
☐ *Between $20,000 and $24,999*
☐ *Between $25,000 and $29,999*
☐ *Between $30,000 and $34,999*
☐ *Between $35,000 and $39,999*
☐ *Between $40,000 and $49,999*
☐ *Between $50,000 and $59,999*
☐ *Between $60,000 and $74,999*
☐ *Over $75,000*

Q26 How many people are supported on this income?

☐ *1*
☐ *2*
☐ *3*
☐ *4*
☐ *5*
☐ *6*
☐ *7*
☐ *8 or more*

Q27 What public benefits have you accessed in the last 12 months (Check all that apply)?

☐ *SSI*
☐ *TEFRA / Katie Beckett Program*
☐ *Home and Community Based Services (HCBS) Medicaid Waiver*
☐ *Medicaid / SCHIP (Health assistance programs)*
☐ *Public assistance (TANF, Food Stamps, Child Care, WIC, Lineap)*
☐ *None*
Other, please specify: ☐

Q28 Please choose if you live in an urban, suburban, or rural area below. Please mark only one:

☐ *Urban (population greater than 50,000)*
☐ *Suburban (population between 10,000 and 50,000 people)*
☐ *Rural (population less than 10,000)*

Q29 In what state do you live?

☐

Q30 What is your zip code?

☐

***Your answers to this survey will be kept confidential. Information about your identity will be kept in a separate, locked place, and your answers on the survey will be combined with answers from other families. If you included your name in Section I of this survey, that page will be removed from the remainder of the survey so that your name is not attached to this form.**

Thank you! You have finished completing the survey. Please make sure you erase any extra marks and have answered all the questions. Place your survey in the envelope provided and make sure the envelope is sealed prior to submitting to your family specialist or mailing.

Appendix E

Modified Welcome and Consent Letter

Welcome Letter and Consent Form
Study Title: *The Relationship of Perceptions of Service Adequacy to Family Quality of Life: A Mixed Methods Study of Families Who Have Children that are Deafblind*
Modified version for states distributing the survey at state parent meetings.

Beach Center

1-866-783-3378 (toll free) 1-785-864-7605 (fax) 1-785-864-7600 beachcenter@ku.edu

A Special Invitation to You . . .

My name is Kathleen Kyzar and I am a doctoral candidate focusing on Family and Policy Studies in Special Education at the Beach Center on Disability at the University of Kansas. I am working with the <<state>> Deafblind Technical Assistance Project to assist them in better understanding how well service programs meet the needs of families like you. We want to know more about how different education, health, and family support programs meet your needs, and what more you might need to enjoy a better quality of life for your family at the same time you are working so hard to meet the needs of your child. We also want to know more about what your state Technical Assistance Project can do to help your family – either directly through providing more family support services, or indirectly through training to your child's teachers, health care providers, or others.

One thing that makes this study different from other surveys you may have been asked to complete is that we will also be asking you to complete our Family Quality of Life Scale, which will help us learn how and whether the services you receive actually impact your family life. There is no current research to show how services impact families of children with deafblindness, and therefore no way to show policy makers how important it is to provide the right kind of services, professional and paraprofessional training, and other supports to families like yours.

I am writing to invite you to be part of this study. If you choose to participate, your involvement would include completing a survey that your family specialist will deliver to you. The survey contains three brief sections and asks that you provide some demographic information. Estimated time of completing all components of the study is approximately 30 minutes.

Your participation in this study is completely voluntary; we invite you to participate to the extent you feel comfortable. Your name will not be used on any reports resulting from this study and all the information you provide on the survey will be confidential. We will provide a general report to your state with the overall information pulled together from all the families in your state, but they will be discussed in general terms and reports will include a description of study participants in groups, never as individuals.

I have included a postage paid envelope addressed to me at the Beach Center with the survey to ease you in returning your completed survey and consent letter. Or, if you prefer, you can give your completed survey and consent letter to your family specialist who will return the survey directly to me.

The benefits to you for participating in this study are:

- Your information will help your state's Deaf-Blind project improve their services and supports to families.
- Our survey will help you reflect on your families' strengths and resources.
- If you wish, we will provide you with a copy of our report that we will be compiling for your state, so that you can see the results and recommendations.

We do not think there are many risks to your participation, but there are a few:

- Your time of course is valuable and we recognize that we are impinging on the many demands you have in caring for your child.

Your help would be greatly appreciated. If you agree to participate in this study, your answers will be used in the following ways:

- The U.S. Department of Education will use this information to establish policies and funding programs to benefit families.
- Your state Deaf Blind Technical Assistance Project will use this information to help improve their services and supports.
- Universities and state inservice training programs will use this information to train future teachers and other professionals to be more responsive to families.

If you are interested in having YOUR voice count . . . .

- ✓ Attached to this letter you will find a copy of our survey along with two separate copies of the consent form. Please sign and complete <u>one of the</u> <u>consent forms</u> provided (keep the other for your records) <u>and return it with your completed survey</u> in the self-addressed stamped envelope provided. Or, you can give it to your state family specialist and he/she will return it to me by mail.
- ✓ Regardless of how you choose to return the form (independently mailing or giving it to your family specialist to mail), **<u>PLEASE PLACE YOUR SIGNED CONSENT FORM ALONG WITH YOUR COMPLETED SURVEY IN THE BUSINESS REPLY FORM PROVIDED AND SEAL THE ENVELOPE.</u>**

- ✓ Your answers will be completely confidential. Information about your identity will be kept in a separate, locked place, and your answers on the survey will be combined with answers from other families.
- ✓ You may choose to withdraw from the study at any time and may choose to refuse to answer any individual questions on the survey, without penalty of any kind.

If you want more information about this study or about the Beach Center on Disability, you can call us toll-free at 1-866-783-3378. Ask for Kathleen Kyzar, Doctoral Research Candidate, or you may contact her by e-mail at kkyzar@ku.edu. If you have any additional questions about your rights as a participant, you may call (785) 864-7429 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email **mdenning@ku.edu**.

Finally, please know that we understand the many demands on your time and that we truly appreciate your help! Please contact myself, Kathleen Kyzar, or Jean Ann Summers (contact information below) if you have any questions.

Sincerely,

Kathleen Kyzar
Doctoral Candidate/
Graduate Research Fellow
Beach Center on Disability
785-864-5781
kkyzar@ku.edu

Jean Ann Summers, Ph.D.
Research Director, Family Research Programs
Beach Center on Disability
Research Director
785-864-7600
jsummers@ku.edu

HSCL #18230
Study Title: *The Relationship of Perceptions of Service Adequacy to Family Quality of Life: A Mixed Methods Study of Families Who Have Children that are Deafblind*
Modified version for states distributing the survey at state parent meetings.

I have read the information in this letter (or, it has been read to me), and have had a chance to ask questions. I have received answers to any questions I had about information that will be used and shared in this study. I know that the information about me and my family will be kept private.

I give permission to be part of this study, knowing that I can drop out of the study if I decide to. I also agree to the use and sharing of the information I provide on the survey as described above. By signing this, I verify that I have received a copy of this consent form to keep.

____
Name of Participant (Please print clearly)

_____________________________________ Date signed ___________________
Participant's Signature

Appendix F

Factor Loadings for Exploratory Factor Analyses of the FQOL and Partnership Scales

Table F1

Factor Loadings for Exploratory Factor Analysis with Promax Rotation of the FQOL Scale (N=200)

Item	Family Interaction	Emotional Well-Being	Physical/ Material Well-Being
My family solves problems together.	**.88**	.10	-.18
My family members teach the children how to get along with others.	**.86**	-.07	.04
My family members support each other to accomplish goals.	**.85**	.08	-.10
My family members show they love and care for each other	**.82**	-.11	-.03
My family members talk openly with each other.	**.76**	.04	-.02
Adults in my family teach the children to make good decisions.	**.72**	-.12	.09
My family members help the children learn to be independent.	**.72**	.07	-.08
My family is able to handle life’s ups and downs.	**.64**	.70	.16
Adults in my family know other people in the children’s lives (friends, teachers, etc.)	**.56**	.02	.15

Item	Family Interaction	Emotional Well-Being	Physical/ Material Well-Being
My family enjoys spending time together.	**.44**	.25	-.10
My family members help the children with schoolwork and activities.	**.44**	.25	.07
Adults in my family have time to take care of the individual needs of every child.	**.26**	.34	.28
My family has the support we need to relieve stress.	-.06	**1.0**	-.08
My family members have some time to pursue their own interests.	.04	**.69**	.03
My family members have friends or others who provide support.	.08	**.67**	-.02
My family has outside help available to us to take care of special needs of all family members.	.01	**.67**	.11
My family gets dental care when needed.	-.10	-.06	**.84**
My family gets medical care when needed.	-.06	-.03	**.82**
My family has a way to take care of our expenses.	-.00	.12	**.67**
My family feels safe at home, work, school, and in our neighborhood.	.34	-.04	**.35**
My family members have transportation to get to the places they need to be.	.28	.11	**.33**

Table F2

Factor Loadings for Exploratory Factor Analysis with Promax Rotation of the Partnership Scale (N=204)

Item	Family-focused Relationships	Child-focused Relationships
Shows respect for your family's values and beliefs.	**1.05**	-.18
Uses words that you understand.	**.98**	-.19
Listens without judging your child or family.	**.88**	.04
Protects your family's privacy.	**.84**	.04
Pays attention to what you have to say.	**.74**	.21
Keeps your child safe when your child is in his/her care.	**.65**	.23
Values your opinion about your child's needs.	**.64**	.27
Treats your child with dignity	**.63**	.31
Is friendly.	**.57**	.31
Is a person you can depend on and trust.	**.51**	**.43**
Has the skills to help your child succeed.	-.12	**.89**
Speaks up for your child's best interests when working with other service providers.	-.10	**.88**
Provides services that meet the individual needs of your child.	-.00	**.88**
Helps you gain skills or information to get what your child needs.	-.03	**.84**

Item	Family-focused Relationships	Child-focused Relationships
Is honest, even when there is bad news to give.	.34	**.57**
Lets you know about the good things your child does.	.25	**.57**
Builds on your child’s strengths.	.36	**.55**
Is available when you need them.	.33	**.48**