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Family Satisfaction with Early Intervention Services as it Relates to Family Functioning

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A dissertation

presented to

the faculty of the Department of Educational Leadership and Policy Analysis

East Tennessee State University

Johnson City, Tennessee

In partial fulfillment

of the requirements for the degree

Doctor of Education in Educational Leadership

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by

Donna E. Nelson

May 2012

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Dr. Jasmine Renner, Chair

Dr. Catherine Glascock

Dr. Terry Tollefson

Dr. John Wheeler

Keywords: early intervention, family, young children with disabilities, Appalachia

## ABSTRACT

Family Satisfaction with Early Intervention Services as it Relates to Family Functioning

by

Donna E. Nelson

This study examined the perceived impact and satisfaction levels of early intervention services of families living in the Appalachian region of northeast Tennessee. Families living in Hawkins and Johnson counties in the northeast region of Tennessee whose children with disabilities had recently exited an early intervention program participated in the study. The primary sources of data collection were personal interviews based on the Beach Center Family Quality of Life (FQOL) Scale (Beach Center on Disability, 2003), the Family Functioning Style Scale (FFSS) (Deal, Trivette, & Dunst, 1998), and member checks.

The FQOL contains 5 subscales: Family Interaction, Parenting, Physical or Material Well-Being, Emotional Well-Being, and Disability-Related Supports. Each subscale includes items unique to the subscale that participants examined and ranked (Low, Medium, or High) as to how important, how satisfied, and the priority for support regarding each item. The study focused on and addressed 1 of the 4 categories of family-based practices; strengthening family functioning (Trivette & Dunst, 2000). The findings of this study revealed that families, overall, were highly satisfied with the early intervention services received. The findings suggest that families in Hawkins and Johnson counties valued and found the need for family interaction important. The levels of support regarding individual subscales revealed some variations but maintained consistency within group majority expectations and family requirements. It can be concluded

that the perceived impact of early intervention services met the needs of each individual participant in the area of family interaction and the satisfaction level was ranked high.

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## DEDICATION

This dissertation is dedicated to my mother, the memory of my middle sister, Alison, and my precious Mamow, Alma Bailey. My sister Alison, as her short life was the inspiration for my research. My beautiful mother, who is the most courageous and wisest woman I know who took this doctoral journey with me and taught me to take one day at a time, have faith, be faithful, and to remember common sense and humor are the foundations for any task – Mom, you are my heart. My Mamow, who believed I could do anything in the world if I smiled while doing it, was nice no matter the circumstances, and most importantly always had on *earbobs*.

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## CHAPTER 1

### INTRODUCTION

#### Vignette

*I grew up in a rural Appalachian community in northwestern North Carolina. I have a deep respect for the mountains and the traditional values shared among people of this mountainous region. It was in this setting that I was born along with my younger sister, Alison. Alison, whose birth was not typical, required 24-hour-a-day care with a feeding every 2 hours and other special requirements and attention necessary to meet her medically fragile needs to sustain her life. My young sister endured incapacitating disabilities that not only robbed her quality of life, but also that of our family's and halted her ability to develop naturally as with most children. As a result of her medical fragileness and the symptoms that accompanied her developmental challenges, my sister's young life ended at the innocent age of 3.*

*In discussions with my mother, she shared how the doctors approached her immediately following my sister's birth and encouraged her to place Alison in an institution: even offering their "permission" to forget her second-born child with the freedom to continue life as if Alison had never been born. My strong and courageous mother did not consider sending Alison away or forgetting her infant child as an option. My mother proudly took her new baby home with all the determination of any new mother. She left the hospital with the same hope that usually consumes mothers – to give her younger daughter every opportunity to grow, develop, and experience the world as her older daughter had.*

*My mother recounted the endless days she spent caring for Alison's medical needs and the toll that such a responsibility took on her health, our family, and her marriage. In 1968 there were no early intervention programs or links to formal or informal supports for families of*

*children with disabilities or special needs, as the resources were limited and those that were available were not family- or child-friendly. The lack of support and resources took its toll on our family. While my mother worked diligently to meet Alison's needs, which required all of her time, I worked hard to stay out of her way, but to be available to help as much as any young child could with my limited abilities.*

*My father reacted as most men were expected to act in 1960 when babies were born; he withdrew physically and emotionally. My mother said it was the beginning of the end of their marriage, as my father was at a loss for how to help care for Alison, support my mother, take care of me, and manage the family farm and business. My father, a kind and humble man, was just not prepared for the level of involvement Alison's condition required. In addition, the knowledge and skills required for her care exceeded his level of comfort and understanding.*

*I learned at an early age how to be a help-giver and the effect of these experiences with my younger sister led me to study psychology as an undergraduate and earn a master of science in child and family studies. I currently work in early intervention where I help young children with disabilities and their families. My experiences with Alison and my education have guided me to respect children and families and recognize the importance of offering support and resources that meet their individual needs and family values.*

### Introduction

Families with young children with disabilities now have more options for services than what has been available in past years. For the last 30 years the value of early intervention (EI) for children with disabilities and their families has been documented and sanctioned through federal law (ED.gov, 2010). In the past services have been evaluated from the standpoint of the child and not the family (Seligman & Darling, 2007). Based on the reauthorization of IDEA in 2004,

the Office of Special Education (OSEP) mandated that states develop and report activities used in the support of families and their children with disabilities that leads to enhanced child outcomes (Bailey, Scarborough, Hebbeler, Spiker, & Mallik, 2004). In April 2005 OSEP announced new reporting requirements that judiciously included both child and family outcomes (Kahn, Kasprzak, & Colgan, 2011). The Early Childhood Outcomes Center (ECOC) played a pivotal role as it was the center's stake holder suggestions that lead to the eventual approval and acceptance of three family indicators for early intervention (Part C) programs (ECOC, 2012). Early intervention services must make certain that families know their rights, are effectively communicating their children's needs, and are helping their children develop and learn (Kahn et al., 2011).

This qualitative research study described the perceived impact of early intervention services on six families living in the Appalachian region of northeast Tennessee who recently exited an early intervention program. The research was conducted using the Beach Center Family Quality of Life Scale (FQOL) developed by researchers at the Beach Center on Disability (2003) and the Family Functioning Style Scale (FFSS) (Deal et al., 1998).

The FQOL scale (Beach Center on Disability, 2003) was used in this study to measure the extent to which early intervention services contributed to each family's quality of life as determined by their perceived level of importance. The FQOL defines quality of life as: The extents to which a family's needs are met, family members enjoy their life together, and family members have the chance to do things that are important to them. The FQOL was developed through extensive literature reviews, focus groups, and individual interviews with the family of children with disabilities, individuals with disabilities, service providers, administrators of service agencies, and a pilot study. All data were analyzed and the FQOL Scale was refined to 25

items that were each assigned to one of five subscales. By choosing this framework, it is hoped that the study findings will add to the current understanding of the impact of early intervention services for families and the extent of satisfaction as a benefit of such services as it relates to family quality of life.

The FQOL (Beach Center on Disability, 2003) is divided into five subscales: Family Interaction, Parenting, Emotional Well-Being, Physical or Material Well-being, and Disability-Related Support with a total of 25 items. For each of the subscales there were questions explained by the FQOL scale as items unique to that subscale and the items were ranked by each participating family representative regarding how important the item was for them. Participants responded by stating Low (L), Medium (M), or High (H). Next, I asked how satisfied the participants are by stating Low (L), Medium (M), or High (H). I also asked the participants to rank the item for priority by stating Low (L), Medium (M), or High (H). Then, I asked if there was something the participants would like to have received support on in order to make things easier for their family; those notes were marked under the Information area.

Additionally, I administered the Family Functioning Style Scale Questionnaire (FFSS) (Deal et al., 1998). This questionnaire provided an understanding of what participating family representatives considered their strengths and capabilities. The participants included six families living in the northeast region of Tennessee having a child who recently exited an early intervention program. All the children of the participants interviewed were enrolled in the Tennessee Health Insurance option of CoverKids, a comprehensive healthcare coverage program developed by Governor Bredesen that is offered to pregnant women and uninsured children in Tennessee age 18 and under (ARC, 2012).

### The Setting: Northeast Tennessee

The states that make up the Appalachian Region include all or parts of Mississippi, Alabama, Georgia, South Carolina, Tennessee, North Carolina, Virginia, Kentucky, Ohio, West Virginia, Maryland, Pennsylvania, and New York (Appalachian Regional Commission (ARC), 2012). The Appalachian region of northeast Tennessee was the focus setting; participants in the study lived in the rural counties of Hawkins and Johnson. These counties are considered part of the southern Appalachian region as they are located in the Ridge and Valley Providence (Abramson & Haskell, 2006). According to the Appalachian Regional Commission (ARC, 2012) the Appalachian Region is 205,000 square miles extending from northeast Mississippi to the mountains of southern New York; it includes 420 counties in Mississippi, Alabama, Georgia, South Carolina, Tennessee, North Carolina, Virginia, Kentucky, Ohio, West Virginia, Maryland, Pennsylvania, and New York. Of this area and the people who inhabit it 42% are rural as opposed to 20% nationally. It is home to approximately 24.8 million people. The region has had to adapt to a changing world and economy as initially this region was vested in mining, forestry, agriculture, and heavy industry, whereas now it includes various manufacturing and service industries. In 1965 the number of counties struggling economically was 223 and for the year 2012 the number is 96 (ARC, 2012).

The participating families in this study live in Johnson and Hawkins counties located in rural regions of northeast Tennessee. The 2010 population of Hawkins County is 56,833. The percentage of citizens who graduated with a high school degree for 2006-2010 was 78.1% and those earning a bachelor's degree or higher was 12.4%. The 2006-2010 median household income was \$35,392 (US Census Bureau, 2011a). The 2010 population of Johnson County was 18,244. The percentage of citizens who graduated with a high school degree 2006-2010 was

69.1% and those earning a bachelor's degree or higher was 10.1%. The 2006-2010 median household income was \$29,949 (US Census Bureau, 2011b). The 2010 population of Tennessee was 6,346,105. The percentage of citizens who graduated with a high school degree 2006-2010 was 82.5% and those earning a bachelor's degree or higher was 22.7%. The 2006-2010 median household income was \$43,314 (US Census Bureau, 2011c).

### Statement of Purpose

Early intervention services affect families in different ways in the Appalachian region of northeast Tennessee. The purpose of this study is to examine those perceived affects on the family and the children receiving EI services.

### Significance

This study provided a better understanding of the extent to which families with children with disabilities living in the Appalachian region of northeast Tennessee are satisfied with the intervention services they received and to ascertain their assessment of any resulting improvement in family functioning. It is important for early intervention professionals to be aware of the needs of families of children with developmental delays and disabilities. The information gathered will provide agencies with relevant research-based information on the needs of families living in northeast Tennessee. Information on this unique population living in rural communities will help agencies in northeast Tennessee create and adapt early intervention processes that will be effective and functional in meeting the needs of children with disabilities and their families. According to Hebbeler et al. (2007) the early years are significant in setting the stage for young children's future development and for enabling parents to strengthen their skills related to participating in their child's development, future well-being, and educational opportunities.

### Research Questions

This study used two research questions to examine family satisfaction with early interaction services as it relates to family functioning:

1. *What is the perceived impact of early intervention services of families living in the Appalachian region of northeast Tennessee who recently exited Expanding Horizons: Early Intervention Program?*
2. *What are the perceived satisfaction levels of early intervention services of families living in the Appalachian region of northeast Tennessee who recently exited Expanding Horizons: Early Intervention Program?*

### Scope of Study

The central phenomenon studied was limited to a qualitative research study using an interview process with families living in the Appalachian region of northeast Tennessee whose children had recently exited an early intervention program and were no longer receiving services.

### Limitations and Delimitations

First, this study was completed in two rural Appalachian counties of northeast Tennessee, which is a narrow range. The data may not be as beneficial to other demographically varied regions. Second, efforts to select participants resulted in a fair representation as the participant families were all represented by White Anglo-Saxon females; the sample was a fair representation of the target region based on 2010 Census data.

According to Bailey et al. (2006) it remains that qualitative research and ...family outcomes inherently represent “soft data”. According to this argument, family outcomes are impossible to measure objectively; thus any assessment that ask families to report outcomes attained is hopelessly constrained by high levels of family satisfaction

with services for young children and a tendency to rate outcomes positively due to lack of experience with alternative forms of services, tremendous appreciation that any services have been provided.... (p. 247, para. 4)

Because the counties of Johnson and Hawkins are rural, it is considered an underserved population and is limited in professional resources. Additionally, the research is limited to the perspective of mothers and is lacking the perspectives of fathers.

Ongoing research and the literature continue to document the need for early intervention services and the method of its delivery for children with disabilities and their parents. Findings from this study will contribute to a continuing body of research in early intervention but with a focus on those families living in rural and oftentimes underrepresented populations like the northeast region of Tennessee.

### Theoretical Framework

I have chosen a theoretical framework based on family-based practices provided through family-centered intervention. According to Trivette and Dunst (2000),

Family-based practices provide or mediate the provision of resources and supports necessary for families to have the time, energy, knowledge, and skills to provide their children learning opportunities and experiences that promote child development.

Resources and supports provided as a part of early intervention/early childhood special educations (EI/ECSE) are done in a family-centered manner so family-based practices will have child, parent, and family strengthening and competency-enhancing consequences. (p. 39, para. 2)

This definition is significant to family functioning because it refers to resources or supports (formal or informal) and that a family's accessibility to such opportunities may "...enhance the competency of parents and strengthen the family" (Trivette & Dunst, 2000, p. 39, para. 3).

As specified by Trivette and Dunst (2000) family-based practices consist of four general themes:

1. shared responsibility and collaboration,
2. strengthening family functioning,
3. individualized and flexible, and
4. strengths- and asset-based practices.

Shared responsibility and collaboration represent the partnership that is established between the professional and the family as they work toward common objectives that the family has ascertained. Family functioning is strengthened by facilitating the development of formal and informal family resources and supports that can create proactive opportunities for parents to strengthen their skills and encourage family functioning. Individualized and flexible practices call for a strong and thoughtful understanding of the family, its members, and how each family member views what is best for the child. This could entail values and cultural or faith-based beliefs. Strengths-based and assets-based practices show and value the strengths of the child and his or her family; building on those strengths enhances success of the family's chosen objectives.

The study focused on and addressed one of four categories of family-based practices; strengthening family functioning (Trivette & Dunst, 2000). The manner that services are provided to families can additionally strengthen the quality of life a family experiences – every family should have opportunities to enjoy a quality family life together. The FQOL (Beach Center on Disability, 2003) defines family quality of life as,

- “the family’s needs are met,
- family members enjoy their life together as a family, and
- family members have the chance to do things that are important to them” (p. 1).

To continue strengthening family functioning, early intervention professionals can establish methods of working with families that support the family’s ability to maintain quality of life by understanding how family needs are met, how family members enjoy their life as a family, and how often family members have the chance to do things they enjoy (Beach Center on Disability, 2003) Families with opportunities to participate in the care and education of their children have control over the exchanges that occur with professionals. Positive professional help-giver traits and attributes influence value-added benefits. Families that participate in their children’s care and education have value-added benefits in terms of the family’s ability to function with a sense of empowerment (Dunst & Trivette, 1996). An essential characteristic identified by Ridgley and Hallam (2006) that appears to be unique to the field of early intervention is the acknowledgement of the parents’ involvement as not only viable members of their child’s Individual Family Service Plan (IFSP) but solidifying their role equally with that of professionals. Parents and caregivers bring their own knowledge; parental knowledge of their child is acquired through an established history.

### Definitions of Terms

The following terms are applicable to this study:

Appalachian region – Includes 420 counties in 13 states including Mississippi, Alabama, Georgia, South Carolina, Tennessee, North Carolina, Virginia, Kentucky, Ohio, West Virginia, Maryland, Pennsylvania, and New York (Appalachian Regional Commission (ARC), 2012).

Appalachian region of Northeast Tennessee – Two of the many counties in the Appalachian region are the northeast Tennessee counties of Johnson and Hawkins.

Developmental delay – A child may have a developmental delay when he or she falls behind other children of the same age in one or more of the five domains listed here, or if, after a developmental assessment, the child’s doctor determines the child meets Tennessee standards:

1. motor (crawling, walking, and using their hands to play);
2. communication (babbling, talking, and indicating wants and needs);
3. cognitive (thinking skills, including making choices and solving problems);
4. social (playing near or with other children or adults); or
5. adaptive (taking care of one’s needs).

In Tennessee a diagnosis from the list shown in Appendix A or an evaluation resulting in a 25% delay in two developmental areas or a 40% delay in one area results in eligibility for early intervention services (TNDOE, 2012a).

Early intervention – The process of providing services, education, and support to young children with disabilities from birth through age 2 who have been evaluated or diagnosed as having a physical or mental delay that may affect development or educational abilities (Wright & Wright, 2011).

Family – Persons who are connected by blood relationships or chosen alliances like marriage, adoption, fostering, or commitment (Hanson & Lynch, 2004).

Family-based practices – Practices that facilitate the acquisition of resources and supports to enable families to provide options and learning opportunities while encouraging their child’s development (Trivette & Dunst, 2005).

Family-centered intervention – The manner of offering services that are family driven and oriented, not agency driven (Cook, Tessier, & Klein, 2000).

Family functioning – According to the Family Quality of Life Scale, this indicates the family's needs are met, family members enjoy their lives together, and family members have the chance to do things that are important to them.

Formal supports – Professional resources such as early intervention programs, occupational therapists, speech therapists, physical therapists, or any other medical professional.

Informal supports – Resources such as neighbors, faith based organizations, and extended or immediate family.

Individuals with Disabilities Education Act (IDEA) Part C, 2004 – Federal mandate that provides federal grant money to states for programs with early intervention services for infants and toddlers with disabilities birth through 2 years of age and their families (Wright & Wright, 2008).

Natural environment – Defined by law as, “settings that are natural or normal for the child's age peers who have no disabilities” (Justia, 1998, para. 1).

Poverty – The preliminary estimate of weighed average poverty thresholds from the 2008 US Census Bureau for a family of four is \$22,017 (US Census Bureau, 2010).

Tennessee Early Intervention System (TEIS) – In Tennessee, “TEIS links families with supports and services to help them work with their child who has a disability or developmental delay” birth through age 2 (TNDOE, 2008, para. 2).

Young children – Children from birth through age 2.

## CHAPTER 2

### LITERATURE REVIEW

#### Introduction to Early Intervention

The Individuals with Disabilities Education Act (IDEA) was passed in 1990. At present IDEA and later amendments ensure a Free and Appropriate Education (FAPE) to children with disabilities ages 3-21 throughout the nation. IDEA also governs how states and public agencies provide early intervention services. Early intervention emerged out of Public Law 99-457 (1986) first through Part H and with the latest amendment contained in Part C. It remains an optional service under the act, but presently each state chooses to participate. Under Part C infants and toddlers with disabilities and developmental delays (birth to age 2) and their families receive early intervention services (Sass-Lehrer & Bodner-Johnson, 1989).

Part C provisions under IDEA have five primary purposes:

1. To enhance the development of infants and toddlers with disabilities to minimize the possibility of future delays,
2. To reduce the educational costs by minimizing the need for special education after infants and toddlers reach school age,
3. To minimize the likelihood of institutionalization, and maximize the opportunities for independent living,
4. To enhance the capacity of families to meet their child's needs, and
5. To enhance the capacity of state, local agencies, and service providers to identify, evaluate, and meet the needs of under-represented populations such minorities, low-income and rural populations (SSA, 2011).

The overall purpose of early intervention services for young children who are at risk for or who have developmental disabilities is to lessen the effects of the disability or delay within five developmental domains; physical development, cognitive development, communication, social development, and adaptive development.

The first federal legislation, PL 99-457 (1986), provided initial guidelines for states to develop and offer coordinated, multidisciplinary interagency early intervention services to infants and toddlers with disabilities and developmental delays (birth to age 2) and their families. An infant or toddler from birth to age 2 is eligible if he or she has been diagnosed as having a physical or mental condition that may result in a developmental delay. He or she is also eligible if the child is experiencing developmental delays in one or more developmental domains that have been identified by appropriate diagnostic instruments or procedures (Sass-Lehrer & Bodner-Johnson, 1989).

In order to understand where we are with early intervention services, it is important to examine how and where it began. Cook, Klein, and Tessier (2004) reported documented evidence of early intervention services as far back as the 1800s by the French physician Jean-Marc Itard. It is believed that Itard was the first individual to initiate intervention services for children with disabilities. Itard was no less than remarkable in regard to his understanding of what influenced children relative to environmental and physiological stimulation. About 100 years after Itard, Maria Montessori followed a similar strategy with children using an observational approach. Montessori's observations led her to develop learning strategies to promote child development and open a school for very young children. In doing so, Montessori unknowingly propelled the foundations for early education (ACP, 2012). In 1964 the Economic Opportunities Act was passed to provide children in low income families with a chance to have

the same educational opportunities and social interactions as their middle-class peers (PHSA, 2012). This breakthrough legislation was fittingly named Head Start. The development of Head Start opened the door for a societal understanding of the importance of education and the importance of the parent's participation in their children's education. Head Start was *ahead of its time* regarding the involvement of parents as their involvement was expected not only in the classroom but was also expected and valued on policy committees, no doubt setting a precedence for parent involvement in future legislative decisions and the inclusion of young children with disabilities in the classroom. In 1970 schools across the United States educated only one out of five children with disabilities (ED.gov, 2010). Some states even maintained statutes prohibiting children with disabilities from having access to educational opportunities. As a result of the restrictive and humanly stifling definitions used during that time children who were diagnosed as deaf, blind, emotionally disturbed, or intellectually disabled were among children who were denied the right to education. In 1972, Head Start programs mandated that at least 10% of their enrollment included children with disabilities.

It was this lack of educational opportunity for all children that led to the passage of Section 504 of the Rehabilitation Act of 1973 (USDOE, 1995). This act prohibited discrimination against individuals with disabilities in agencies receiving federal funds. Section 504 policies provided support to infants and toddlers with disabilities and developmental delays (birth-2) and their families at a time when institutionalization was considered a viable and acceptable option by the medical and human services community. This was a ground-breaking beginning for individuals with disabilities as history now shows this legislation set the stage for future policies such as the Education of All Handicapped Children Act of 1975, PL94-142 (1975). The intent of this comprehensive federal statute was to support states in their effort to

provide a free and appropriate education (FAPE) to school-age children. This legislation also included provision for the development of Model Demonstration Centers, which provided initial steps toward meeting the needs of infants, toddlers, and preschool children with disabilities (ED.gov, 2010).

By 1983 PL 98-199 for the first time provided the much needed monetary incentives through grant programs for states to provide services beginning at birth. Public Law 99-457, Education of the Handicapped Act Amendments of 1986, included the funding for states to develop early intervention services for infants and toddlers with disabilities and developmental delays (birth-2) and their families. Gallagher, Rhodes, and Darling (2004) later observed that an important feature of this law is that parents of infants and toddlers with disabilities and developmental delays (birth-2) had come to be viewed as partners with early intervention professionals and valued contributors to their child's overall development. According to Bennett, Lingerfelt, and Nelson (1990) "Since the passage of PL 99-457, the field of early childhood special education has entered a new era. One element of this new era is the recognized role of the family..." (p. 1).

In 1990 Public Law 101-476, Individuals with Disabilities Education Act (IDEA, 1990/1997), initiated *person first* language adding new expectations that a child with disabilities deserved to be viewed first as a child and not recognized, addressed, or acknowledged by his or her disability. For example, one would say "a child with Down Syndrome" rather than "a Down Syndrome child." PL 101-476 is significant in that it shifted the way an individual with a disability would be addressed.

In 1991 Public Law 102-119 reauthorized IDEA (1990/1997) to ensure comprehensive services to young children and their families including provisions that strengthened the

commitment to families. In 1997 Public Law 105-17 authorized services to infants and toddlers under Part C (IDEA, 1990/1997). The most recent amendment was enacted in 2004, when Public Law 108-446 reauthorized IDEA. This resulted in continuing funding authorization for preschool services under Part B and supporting identification and evaluation of infants and toddlers under Part C, with the option for states to continue early intervention services until kindergarten. All states have opted to participate.

IDEA and amendments (1990/1997, 2004) introduced a new philosophy regarding individuals with disabilities and defined how services were to be offered for infants and toddlers with disabilities and developmental delays birth-2 and their families (Bowe, 2007). IDEA offers systematic guidelines for states regarding how infants and toddlers with disabilities and developmental delays (birth-2) and their families are to be identified, evaluated, and considered eligible. It has also detailed the importance of parents and has mandated parent participation in all aspects of decision making and services the family receives.

Since the implementation of IDEA and subsequent reauthorizations, early intervention programs across the United States have expanded to serve more than 350,000 infants and toddlers under Part C. In 2010 the state of Tennessee served 4,054 children from birth to 2 years of age and their families; the first district of Tennessee, comprised of eight counties, served 325 of those children and their families, 12 of the children served were in Johnson County, and 25 of the children served were in Hawkins County (TNDOE, 2010).

Cook et al. (2004) reviewed the history of early childhood intervention and its significant growth. During the 1950s and 1960s new ways of thinking that paralleled the civil rights movement began to emerge based upon the realization that persons with disabilities represented a minority (Bowe, 2007). Under this minority status and a newly defined social status, society is

duty-bound to provide normalcy beyond modifying physical environments for persons with disabilities. This societal epiphany led to Congressional measures in 1973 and 1975 concerning the right to a free and appropriate education regardless of disability. Awareness came to fruition in the 1980s as people gradually recognized the needs of young children with disabilities. During the 1990s attention was drawn to the rights of families with young children with disabilities. The early part of the 21<sup>st</sup> Century will be remembered for serving young children with disabilities and their families in their natural environments.

### Early Intervention Introduction Summary

As with other human rights movements, the realization of the provision evolved slowly. These amendments served as a foundation for future laws that would provide support for families and their children. Society eventually recognized that those with disabilities required support and that the means should be made available for persons with disabilities to have that support (Odom & Wolery, 2003).

### Early Intervention Practices

According to Wagner, Spiker, Inmann Linn, Gerlach-Downie, and Hernandez (2003), "The primary method of early intervention programs for birth to two is to help parents identify strategies for providing stimulating, responsive care that nurtures children's emerging capacities while also acknowledging the challenges of the caregiver's unique environment" (p. 171). NICHCY (2011) said, "Early intervention services are designed to meet the needs of infants and toddlers who have a developmental delay or disability" (para. 3). Seligman and Darling (2007) indicated that those who worked with children and families must take into consideration the culture that is their world. From this sociological perspective, no matter the cultural background, it is each family's right to determine its current path and the path of its

future. This point is further clarified by explaining that the social worlds in which parents live were created long before their children arrived and that world defines the family's reactions to the child and to early intervention professionals. The professional's role is to honor and respect the family's cultural beliefs and social standing.

Currently early interventionists serve children with disabilities birth through age 2 and their families in their homes or other natural environment based on the governances of IDEA (1990/1997) PL 99-457 (Blasco, 2001). Seligman and Darling (2007) credit Carl Dunst and his fellow researchers for devising and introducing family-based practice in the late 1980s.

Early intervention services for each family usually occur at a rate the family determines and as indicated by an Individual Family Service Plan (IFSP). A qualified professional early interventionist offers these services. Appointments are approximately 30 minutes to 1 hour with the child and family members or caregivers present and participating to a level of their choice. Other service providers who may be involved with the child and his or her family can include physical therapists, occupational therapists, speech therapists, pediatricians, neurologists, geneticists, developmental pediatricians, or any other specialists the family may request or the child's needs may require. Guralnick (1991) referred to the value-added benefit of family-based intervention by saying, "Central to this commitment is a belief that the array of early intervention services makes positive and important differences in the lives of children with disabilities and to their families" (p. 174).

Gallagher et al. (2004) also embraced family-based practices with parents in partnership with professionals as an integral part of the family's role including participation in policy development and program planning. The support premise was the recognition of a positive relationship between parents and their children and, in addition, noting the necessary and

primary goal of the development of a proactive relationship between parents of children with disabilities and early intervention specialists (Odom & Wolery, 2003). The family-centered approach provides the means for the early interventionist and families to work together to provide developmentally appropriate and important environments for infants and toddlers with disabilities (Odom & Wolery, 2003). Dunst, Brookfield, and Epstein (1998) reported that the use of family-centered practices results in not only increased positive family outcomes but also the effect that family members value the services and intervention provided to their family.

Trivette and Dunst (2005) described this orientation with families and its value-added effect as a benefit of early intervention. These researchers described the value-added effect as reinforced when the early interventionist used the process of strengthening families by assuming competence, encouraging decision-making, and offering support and resources that matched their needs. Trivette and Dunst (2000) stated, “Professionals must strengthen families’ abilities to support the development of their children in a manner that is likely to increase families’ sense of parenting competence, not families’ sense of dependency on professionals or professional system” (p. 39). McWilliam (2010) distinguished family ecology as opposed to the term social supports as means of explaining a family’s formal and informal support systems. In examining the ecology of a family and its immediate possible support systems, the two interchangeable terms refer to anyone in the lives of the family members who provides one or more of the following: a connection to information, financial support, the means to meet daily needs, consultation, or guidance (Trivette & Dunst, 2000). Those persons making up a social support network may be formal as with early intervention professionals or informal as with family members, neighbors, and friends (Trivette & Dunst, 2005).

### Shift to Family-Based Services: Family-Centered Intervention

The field of early intervention has not always recognized the importance of the family. It was once the standard to focus solely on the child (Seligman & Darling, 2007). The basic assumption for family-centeredness draws on systems theory (Bjorck-Akesson & Granlund, 1995). As early as 1988 Bryant recognized the need for families to be viewed as a unit. In order for the systems approach to be effective, professionals must support the family's ability to access both their formal and informal resources, "From a family systems approach, the interventionist must believe that every family has strengths" (Blasco, 2001, p. 158). To effectively work with families, some professionals reportedly have needed to abandon their long held "...clinical worldview..." (Seligman & Darling, 2007, p. 378). These researchers explained that such a limited viewpoint defined families in terms of their child's disabilities or from a judgmental perspective. Based on a review of practices, Dunst (2000) suggested that effective early intervention programs are shifting from a professionally driven deficit approach to a supportive perspective, emphasizing supporting families with children with disabilities, recognizing their strengths, and respecting each family's natural environment.

In a publication on recommended practices produced by the Council of Early Childhood, Division for Early Childhood, Trivette and Dunst (2000) describe family-centered practices in early intervention as strategies offered in a manner that strengthens the family, enabling them to meet their identified needs by offering information and support (formal and informal) to families so that they can make their own decisions about what is best for them and their child with disabilities. Dunst (2007) presents three guiding principles based on IDEA and with a focus on "...strengthening parents' capacity to promote their children's learning and development" (p. 162, para. 5).

Principle 1. The experiences and opportunities afforded infants and toddlers with disabilities should strengthen children's self-initiated and self-directed learning and development to promote acquisition of functional behavioral competencies and children's recognition of their abilities to produce desired and expected effects and consequence.

Principle 2. Parent-mediated child learning is effective to the extent that it strengthens parents' confidence and competence in providing their children with development-instigating and development-enhancing learning experiences and opportunities.

Principle 3: The role of early-intervention practitioners is parent-mediated child learning is to support and strengthen both parent capacity to provide their children with experience and opportunities of known qualities and characteristics (i.e., evidence based) that are most likely to support and strengthen both parent and child capacity. (p. 163)

It is the responsibility of early intervention programs to provide resources and supports using a strengths-based approach in order for family-based practices to have not only value benefits but value-added effects (Trivette & Dunst, 2000) to increase family functioning. Dunst and Trivette reported in 1996 that empowerment of families through the use of help-giving practices results in value-added benefits to families. Trivette and Dunst (2000) define value-added benefits as outcomes occurring over and above the expected outcomes of early intervention. To promote improved family functioning, it is essential that early childhood professionals be trained to offer competency-based interventions. As indicated by Dunst and Bruder (2002) and their study of valued outcomes in early intervention, "...it would be reasonable to expect that provision or mobilization of supports and resources...would improve family quality of life..." (p. 372, para. 37).

According to Odom and Wolery (2003) the operational belief was that children with disabilities who received interventions in their natural environment and who were actively involved in community activities had more similar opportunities and fewer societal barriers when compared to their siblings and typical-developing peers. Bjorck-Akesson and Granlund (1995) support the parents' claim that they are the most important persons in the lives of their children.

A use of the term "natural environment" appears in PL 105-17 of IDEA (1990/1997) and states, "To the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate" (PL 102-119, 1991). A natural environment is also defined by law as, "a setting that is natural or typical for the child's age peers who have no disabilities" (34 C.F.R. 303.18) (IDEA, 1990/1997). Because most early intervention professionals view parents as knowing their child the best, then it follows that they would make the best teachers when services are presented in the child's natural environment (Childress, 2004). According to Dunst, Hamby, Trivette, Raab, and Bruder (2000) interventions are prompted by following the child's lead and that of the family; these prompts are based on the family's daily routine and the activities occurring during their days. Jung (2003) adds support to offering interventions in the natural environment, as parents can provide significantly more child development opportunities than an early intervention professional who visits in the home no fewer times than monthly and in most cases no more often than weekly.

A study conducted by Dunst and Bruder (2002) examined the most beneficial early intervention practices and services found by professionals and parents of children with disabilities from Part C of IDEA regarding coordination of services, early intervention, and the use of natural environments. They found that professionals and parents agreed on the outcomes

that were most important and beneficial: satisfaction and improved quality of life. The researchers defined family satisfaction as parent and family satisfaction with the services provided. Family quality of life was defined as the physical and psychological betterment of the parent and family. In the Dunst and Bruder (2002) study, 879 early childhood practitioners, early childhood program directors, and parents of young children with disabilities in 48 of the 50 states ranked the benefits of the service coordinator and the early interventionist. The most important benefits of a service coordinator were:

1. system coordinator,
2. information and referral,
3. family support and resources,
4. family-centered practices, and
5. teaming.

For the early interventionist the most important benefits were:

1. child development,
2. child quality of life, and
3. parenting competence and confidence.

Although the field of early intervention is relatively new, professional organizations and researchers in the field have evolved principles that are guiding practice (Odom & Wolery, 2003). According to Haring, Lovett, and Chandler (1999) the underlying assumptions are:

1. Supports are needed by families.
2. Early interventionists know how to meet the individual needs of families.
3. Services are offered in a manner that is respectful of family beliefs and cultural values.

The literature documents a deficit attitude among practitioners regarding families. For example, Dunst (2000) points out that early intervention has transitioned from, "...a service-based professional-driven approach that has focused on deficits and needs to a supportive approach emphasizing child and family strengths and natural routines and parents as the agents of change in their child's development" (p. 97). The current need for change in professional attitudes comes as a result of this transition from a child-focused perspective where the professional knows best to a family-based perspective. In order to uphold the spirit of the law, professionals must alter their personal and professional perspectives. Bjorck-Akesson and Granlund in a 1995 article state that in using this perspective, professionals must recognize that, "Parents are the most important people in the lives of their children, giving love, care, and continuity; and educators and other service providers stress the importance of parents for a successful habilitation of children" (p. 520).

Bradley, Burchinal, and Casey (2001) conducted research that also points to the family as an important variable on the impact of early intervention programs. Ridgley and Hallam (2006) note that, "This focus on families has prompted the field to begin to examine the contextual issues that influence the experiences of children and families engaged in the early intervention system in an effort to improve early intervention services" (para. 1). The areas identified as family concerns were parenting a child with disabilities, health issues of the child, and the family issues or characteristics. Concerns of the last category were related to how the family functions or supports each other. This is particularly important to families in the rural Appalachian region of northeast Tennessee. Early intervention professionals must recognize the population diversity they serve and, according to Bruder (2000), be sensitive to the families' systems of belief, value their goals for their child, and respect the cultural environment that influences their resources.

## Overview of Early Intervention in Tennessee

As specified by the Tennessee Early Intervention Services (TEIS) brochure *Growing Together...Little by Little*, as guided by Part C of IDEA and as determined by the Tennessee Department of Education, TEIS serves as the statewide coordination agency and or point of entry for early intervention services. Depending on the child's needs, his or her early intervention services may include (NICHCY, 2011):

- family training, counseling, and home visits;
- special instruction;
- speech-language pathology services (sometimes referred to as speech therapy);
- audiology services (hearing impairment services);
- occupational therapy;
- physical therapy;
- psychological services; medical services (only for diagnostic or evaluation purposes);
- health services needed to enable your child to benefit from the other services;
- social work services;
- assistive technology devices and services;
- transportation;
- nutrition services; and
- service coordination services. (What's included in early intervention services? para. 2)

An early interventionist conducts the intervention with the child and his or her family in the child's natural environment. Early intervention services are, "developmental services that...

to the maximum extent appropriate are provided in natural environments, including home and community settings in which children without disabilities participate” (§1432) (IDEA, 1990/1997). For some families of children with disabilities, this natural environment may be at home; for others the visit may occur at the child’s day care or caregiver’s home. Other service providers also work with the child and his or her family in a location preferred by the family.

- Step 1: A parent, doctor, or anyone concerned about a child’s development calls TEIS to make a referral.
- Step 2: The family is called by a service coordinator.
- Step 3: There is an intake meeting where the family is introduced to Part C in Tennessee and voluntarily participates in a developmental screening or discussion regarding an eligible diagnosis. During the intake meeting, if the family chooses to continue, these topics are discussed:
  - ✓ Principles of early intervention
  - ✓ Rights of infants and toddlers
  - ✓ TEIS central directory (Pathfinder)
  - ✓ The important role of parents and caregivers
  - ✓ TEIS as payer of last resort
  - ✓ Eligibility and IFSP process
- Step 4: Developmental evaluation, hearing screening and vision screening
  - ✓ Authorization for release or use of information form
  - ✓ Social security number and other information
  - ✓ Plan of action form
  - ✓ Targeted case management, insurance and/or other coverage

- Step 5: Determining eligibility using diagnostic or results of developmental evaluation and required medical information.
- Step 6:
  - ✓ If not eligible, a family may be *re-referred* at a later time.
  - ✓ If eligible, a family assessment/routines based interview will be completed with the family prior to the IFSP (McWilliam, 2010).
- Step7: Initial IFSP meeting
- Step 8: Early interventionist assigned if a family desires one.
- Step 9 – Optional: A family may make a written request for an IFSP review if they have concerns regarding their support services, or outcomes.
- Step 10: The IFSP is reviewed at 6 months.
- Step 11: An annual IFSP is written 1 year after the initial IFSP and a year after that, if applicable. Preparation for an annual IFSP includes a new developmental evaluation and updated medical records.
- Step 12: Transition meeting
- Step 13: A child and family are no longer eligible for Part C (TEIS) on the day the child turns 3 years of age.

Seligman and Darling (2007) described the birth of a child as the gaining of a new family member; that when a child with disabilities is born into a family, there were additional persons who could potentially provide care or assistance in the child’s development. A family oftentimes requires and develops an extensive array of resources with additional persons who assist, provide care, and give support not only to the child but the family as well (Berry & Hardman, 1998).

### Principles of Early Intervention

The guiding principles of the Tennessee Early Intervention System (TEIS) (TNDOE, 2012b) include:

- The primary goal of EI is to support families in promoting their child's optimal development and to facilitate the child's participation in family and community activities.
- The focus of EI is to encourage the active participation of families in their child's intervention by imbedding strategies into family routines. It is the parents who provide the real early intervention by creatively adapting their childcare methods to facilitate the development of their child, while balancing the needs of the rest of the family.
- The family must be present and engaged in interventions at all times. The child should never be served by providers separate or isolated from the family.
- EI requires a collaborative relationship between families and providers with participation by all involved in the process. An on-going parent-professional dialog is needed to develop, implement, monitor, and modify intervention activities.
- Intervention must be linked to specific goals that are family-centered, functional, and measurable. Intervention strategies should focus on facilitating social interaction, exploration, and autonomy.
- Intervention shall be integrated into a comprehensive plan that encourages transdisciplinary activities and avoids unnecessary duplication of services. The

plan shall be built around family routines with written home activity programs to encourage family participation in therapeutic activities on a daily basis.

- Intervention should be monitored periodically to assure that the strategies implemented are successful in achieving outcomes.
- Children and their families in Tennessee's Early Intervention System deserve to have services of the highest quality possible. High standards will be set for the training and credentialing of administrative and intervention staff. Training, supervision, and technology will be focused on achieving excellence. (p. 1)

Parish, Rose, Grinstein-Weiss, Richman, and Andrews (2008) reported that children with disabilities were more likely to be born into financially challenged homes. Emerson (2007) notes that poverty leads to disability and disability leads to poverty. Emerson argued that poverty associated with environmental conditions leads to disability and that disability associated with financial stresses in turn can lead to poverty (2007).

Fujiura and Yamaki (2000) found in their research that 28% of children with disabilities in the United States live below the poverty level as opposed to only 16% of typically-developing children. In Johnson County and Hawkins County, which are the focus for this study, overall poverty rates are greater. According to the 2006-2010 United States Census Bureau, Hawkins County reported that out of 56,833 people the poverty estimations were 18.3% (US Census Bureau, 2011a). In Johnson County it was reported that out of 18,244 people the poverty estimations are 23.8% (US Census Bureau, 2011b). The 2006-2010 estimated Tennessee poverty rate was 16.5% while the national poverty rate was 13.8% (US Census Bureau, 2011c).

## Qualitative Research

Ridgley (2004) used a qualitative case study approach to explore the perceptions of five rural low-income families of young children with disabilities, focusing on the needs stated by the family. Parents reported a need for information about services, accessing toys and materials, child health issues, and family issues such as financial needs, safety concerns, and emotional support. The study found that home visits dealt mostly with parenting a child with disabilities and health concerns. While most Individual Family Support Plans were written to represent parenting a child with disabilities and developmental needs, many families' identified needs were addressed. The exception was in needs relating to family issues as these frequently were not addressed and likewise fewer were documented on the Individual Family Support Plan.

O'Kelley (2004) examined the early intervention experiences and supports of families living in poverty. A qualitative research method was chosen with a semistructured interview process. O'Kelley's (2004) data reflected that families were satisfied with their early intervention experiences. The data revealed a family-centered approach and the use of family empowerment could be beneficial in supporting families if help-giving strategies are practiced.

Neely-Barnes, Marcenko, and Taylor (2004) reported that families with children who had medical needs, therapeutic requirements, and personal care challenges were found to have greater financial commitments, more problems at work, and a lack of sleep. Newacheck and Kim (2005) reported that the costs are higher for raising children with disabilities than for a typically developing child. For the most part families are shouldering the financial expenses of their children with disabilities (Parish et al., 2008).

Fujiura and Yamaki (2000) examined childhood disabilities and the connection with the family's economic condition. Their analysis suggested: a) there is a higher risk in single parent

homes, b) there is not a higher risk regarding racial or ethnic backgrounds, and c) there is documented evidence of a higher risk for children with disabilities in poverty-laden environments.

Haring et al. (1999) used a qualitative method of interviewing families to examine the outcomes of families having children with disabilities who live in rural areas. They discovered that early interventionists' responses must be adapted to meet the individual needs of families. For example, some families may require social and emotional support in addition to formal and informal supports. They concluded that it is imperative for early intervention specialists to recognize and respect religious beliefs, the diversity of families in terms of organizational skills, comprehension of formalized strategies regarding paperwork expectations, and accessing assistance.

### Family Quality of life

The Family Quality of Life Conversation Guide (FQOL) was developed by the Beach Center on Disability, University of Kansas (2003), in partnership with families, service providers, and researchers. Quality of life can be defined as: 1) the family's needs are met, 2) family members enjoy their life together as a family, and 3) family members have the chance to do things that are important to them.

In recognizing that a significant focus of early intervention is working with families, Dunst (2000) noted that the role of early intervention experienced a paradigm shift. Working with families in a family centered capacity and offering social support commanded more than just the child's services regarding his or her development but also in supporting the parents' human development. Dunst (2000) explained that supporting parents includes steps leading to the quality of life including, "information, advice, and guidance that both strengthen existing

parenting knowledge and skills and promote acquisition of new competencies necessary to carry out childrearing responsibilities and provide development-enhancing learning opportunities” (p. 101) for parents of infants and toddlers with disabilities and developmental delays (birth – 2) and their families receiving early intervention services.

Bailey et al. (1998) developed eight questions that may serve as a framework for examining family outcomes through a family-centered approach. The questions center on the family’s perceptions of the early intervention experience with services for both the family and the child. The first set of questions was:

- 1) Does the family see early intervention as appropriate in making a difference in their child’s life?
- 2) Does the family see early intervention as appropriate in making a difference in their family’s life?
- 3) Does the family have a positive view of professionals and the special service system?

The second set of questions centered on the influence early intervention had on the family’s quality of life such as informal support systems, and quality of life:

- 4) Did early intervention enable the family to help their child grow, learn, and develop?
- 5) Did early intervention enhance the family’s perceived ability to work with professionals and advocate for services?
- 6) Did early intervention assist the family in building a strong support system?
- 7) Did early intervention help enhance an optimistic view of the future?
- 8) Did early intervention enhance the family’s perceived quality of life?

The last question is a combination of both sets of questions asking the extent that early intervention influenced the child's and family's quality of life? Bailey et al. (1998) noted that their framework had not been validated and was presented as a means for contemplation, examination, consideration, and reflection among policymakers, university faculty, early intervention professionals, and parents of infants and toddlers with disabilities and developmental delays (birth – 2) receiving early intervention services.

### Effects of Rural Poverty in Appalachia

Rehme (2007) stated, "It is commonly argued that there is a link from education and income inequality and growth" (p. 507). Around this shift in thinking, there was a widespread opinion about the level of involvement a parent should or should not have.

The first nationwide study to address family outcomes was the National Early Intervention Longitudinal Survey (NEILS, as cited in Bailey, Scarborough, & Hebbeler, 2003) where phone interviews and mail surveys captured 3,200 families' experiences with early intervention services (Bailey et al., 2003). The results indicated that families of higher socioeconomic levels had more proactive experiences than lower income families. An analysis of the data revealed that lower income families were:

- less likely to discuss their concerns about their child with a doctor;
- more likely to report that it took a lot of effort to find out about services and get them started;
- less aware of the IFSP;
- less satisfied with their degree of involvement in decision-making;
- less likely to see services as individualized;
- less likely to have good feelings about professionals;

- more likely to feel that professionals ignored their opinions and did not respect their values and cultural background; and
- less likely to believe that professionals made them feel hopeful about their child's future.

### Summary

The Infants and Toddlers with Disabilities Program (Part C) of the Individuals with Disabilities Education Act (IDEA) was created in 1986 to enhance the development of infants and toddlers with disabilities, minimize potential developmental delay, and reduce educational costs to our society by minimizing the need for special education services as children with disabilities reach school age. (Goode, Diefendorf, & Colgan, 2011, para. 1)

The method of delivering early intervention (EI) services is a topic drawing much debate and discussion presently and in past years. The concern is who should be the target of early intervention services, the child or the family? Public Law 99-457 and other related legislation state clearly that the family is to be the unit of intervention (Cook et al., 2000). Even though services increasingly appear to be more family-directed, the focal point often remains on the child (Cook et al., 2000). A family-centered EI approach requires that professionals recognize the child as part of the family while respecting the role of each family member and his or her contribution to the family as a whole. Each family unit creates an environment that is a unique representation of its members. EI services take place in the child's natural environment and during the natural routines of their day. More often than not the services occur in the family's home. However, other examples of children's natural environment may refer to preschool facilities, a daytime caregiver's residence, or a hospital room.

## CHAPTER 3

### RESEARCH METHOD

#### Introduction

The purpose of this study was to describe the perceived impact of early intervention services for families living in the Appalachian region of northeast Tennessee who recently exited an early intervention program. Findings of the study will help local agencies and states develop, create, and adopt early intervention processes that are effective and functional in meeting the needs of children with disabilities and their families living in rural areas. I adhered to a qualitative research methodology (Merriam, 1998). This methodology included an exploratory process to gain a clearer understanding of families' satisfaction with early intervention services and perceived quality of life through the lens of the world as they know it (Merriam, 1998).

The qualitative approach provided me the opportunity to discover and gain an understanding of family satisfaction with early intervention services and perceived quality of life. Data were collected through interviews based on the FQOL (Beach Center on Disability, 2003) and participating family representatives' completion of the FFSS (Deal et al., 1998). The scope of the study included families living in the Appalachian region of northeast Tennessee whose children have recently aged out of early intervention services. A fair representation sample was used in this study. The two criteria for selection of families interviewed were:

1. Each family lived in a rural Appalachian region of northeast Tennessee (Hawkins or Johnson County), and
2. Each family had one or more children with disabilities who had exited an early intervention program within the past year.

Face-to-face interviews were conducted with participating family representatives from six families at a location of their choosing. Three were from each of the targeted counties. According to Patton (2002), the researcher should specify a minimum sample size that is information rich and that is representative of the issues and the study purpose.

### Selection of Participants

Families living in the Appalachian region of northeast Tennessee in Hawkins and Johnson Counties whose children with disabilities had recently exited an early intervention program were recruited. Each eligible family received a phone call stating the purpose of the request, the family's role in the research, and information about the researcher. An interview date was determined for those families who agreed to participate. A letter followed the phone call restating the purpose for the request, the family's role in the research, and a confirmation of the scheduled interview. The letter also contained information identifying the researcher including a phone number, email address, and mailing address. One day before the scheduled interview a preconfirmation call was made with an additional confirmation call on the day of the interview.

### Development of the Interview Guide

The interview guide was developed to provide me with a set of guidelines to direct interviews with participating family representatives regarding their experiences with early intervention services. The guide consisted of an introduction stating the focus of the study, the interview questions, and directions regarding informed consent. Interview questions were based on an existing instrument entitled Beach Center Family Quality of Life Scale (FQOL) (Beach Center on Disability, 2003) developed by researchers at the Beach Center on the campus of Kansas University.

Upon receiving written permission from each family member, the interviews began. During each interview, and due to the use of a semistructured interview process, some answers were coded as received. Upon completion of the interview, all information was transcribed to ensure accuracy of the data and later coded. Member checking was used as the transcribed interviews were sent to each interviewee to validate an accurate interpretation by me and the transcriber. Follow-up sessions were scheduled to clarify and assure an understanding of the data.

In order for interview information to be recorded as accurately as possible, I used a primary and a back-up recording device in case the primary equipment failed. With some interviews taking place in family homes, background noise was expected.

Member checks provided an additional means for collecting data as background noise was a risk worth taking in order to interview families in their home environments. However, the scheduling of a data verification interview to double check their responses with participating family representatives provided the opportunity for clarification and accuracy. Merriam (1998) supports the necessity of observation. As such, observations provide an accurate snapshot of the moment and the feelings or emotions experienced during each interview.

#### Authenticity of Documents

Authenticity of documents is a necessary part of a qualitative research study (Merriam, 1998). Personal interview questions were taken from the Beach Center FQOL Survey (Summers et al., 2005) and the Family Functioning Style Questionnaire (Deal et al., 1998). The interview questions have been determined authentic and relevant to the research questions. I developed a system for coding and cataloging responses (Merriam, 1998). Written documents were copied,

coded, and placed in categories to provide easy accessibility to the written document for easier documentation and interpretation purposes (Merriam, 1998).

Written documentation of interviews, the recorded interviews, and interview transcripts are the baseline from which study findings were developed. The information derived from each interview was transcribed as soon as possible following the interview. Any notes I took during the interview regarding observations, direct quotes, or field notes were categorized by time, place, and purpose of the observation (Merriam, 1998).

### Data Collection

In qualitative research data are conveyed by words rather than numbers; the primary research tool for these words is the researcher (Merriam, 1998). Personal interviews based on the FQOL (Summers et al., 2005), member checks, and the Family Functioning Style Questionnaire (Deal et al., 1998) (see Appendix B) were the primary sources of data collection. The common characteristics of qualitative research are description, interpretation, and understanding. These characteristics are a means of identifying recurrent patterns through common themes and the possibility of determining a process is a possible outcome of this type of research (Merriam, 1998).

In qualitative research one of the most common forms of collecting data is the person-to-person interview or, in more common terms, through conversation (Merriam, 1998). The purpose of an interview is to receive information that is representative of that person's life, world, and circumstance (Merriam, 1998). Based on the kind of information needed for this qualitative study, interviewing was the appropriate primary means for data collection (Merriam, 1998).

Additional documentation included books, educational chronicles, official documents, statistical data, Federal Laws, journal articles, and reputable Internet websites. Artifacts can be

divided into three forms: personal documents, official documents, and objects (McMillian & Schumacher, 2006). Official documents may take various forms but maintain a unified purpose, to describe the internal perspective through functions, values, and statistical data. Official documents for my purpose took the form of working papers and statistical data. Working papers provided insight into the historical perspectives to current understanding of early intervention practices and family functioning. Statistical data also provided demographic information regarding current trends of children in early intervention programs and their families, peaked new questions regarding family functioning, and supported potentially new qualitative data. For the purpose of this study, I used statistical data as a means to understand current thought processes in early intervention.

#### Validity and Reliability

Reliability can be a challenge in qualitative research, as replication of human behavior as it is presented can only be associated with that particular moment and the current variables affecting a person's response (Merriam, 1998). Human life and the act of living one's life is a constant assimilation of feelings, emotions, and experiences, as they occur or are being lived again through reflection. The researcher could be viewed as a facilitator encouraging the recall and memory of participants' past early intervention experiences. Each interview relationship was based on a level of trust established between the researcher and participant. The researcher does not expect to isolate human behavior but to "...describe and explain the world as those in the world experience" (Merriam, 1998, p. 204). Additionally, the reliability of such personal encounters lies in the researcher's ability to analyze such data (Lincoln & Guba, 1985).

There are strategies for supporting validity and reliability in qualitative research (Merriam, 1998). Merriam (1998) said that it is not a question of the ability to replicate findings but whether the results are an accurate reflection of the data collected.

First, I triangulated the data using multiple methods: Data gathered during interviews, analysis of Beach Center Family Quality of Life Scale (Beach Center on Disability, 2003) (Summers et al., 2005) rankings, and the Family Functioning Style Scale (Deal et al., 1998) responses.

Second, member checks were performed by offering families the opportunity to review the data and determining if they are an accurate representation of what was said. Changes were made as suggested by the family to maintain data accuracy and reliability.

#### Ethical Protocol

A qualitative research study can be limiting because the primary means of data collection and analysis lies solely with the researcher (Merriam, 1998). There is no systematic method of training regarding observations or the process of interviewing. Likewise, Merriam (1998) shares that there is no expected arrangement for structuring the final report; the researcher is left to follow his or her sense of right and wrong. Hence, “While an investigator can be informed by guidelines and others’ experiences, ultimately, the researcher’s own conscience informs the decision” (Merriam, 1998, p. 218).

Ethical protocol followed the parameters for the 1979 Belmont Report (Franklin, 2007). Participant safety was ensured, as each interview was in the participating family representative’s home or in another place of the family’s choice. Privacy and confidentiality were protected with anonymous names, no pictures, and all raw data and materials were viewed only by the transcriptionist and the researcher. At all times, I remembered that the participant had autonomy

and choices in all situations. As such, participants were treated with respect in terms of language, interactions, and social standing. Participant distress was minimized, as the verbal and nonverbal environment reflected no judgments from me. The communications were offered in a comfortable interaction style of listening, a calm voice, and the use of nonverbal communication messages that are conducive to the ease and comfort of verbal communication. The interview process was addressed as research with time allotted for debriefing and intervention if the conversation or the content became too intense. I recognized that all participating family representatives were mothers of children with disabilities and by nature are fragile human beings who are especially vulnerable as mothers. All efforts were provided to cause no harm or determinant to the participants. Upon occurrence of care provider abuse, with mandatory reporting laws, such abuse would have been reported to the appropriate authorities. In terms of beneficence, kindness was beyond duty, only good was carried with the data, and referrals were offered for care and support when required or requested (Franklin, 2007).

### Summary

The research was conducted through the use of a qualitative research methodology (Merriam, 1998). Personal interview questions taken from the FQOL (Beach Center on Disability, 2003) and the participating family representatives' completion of the Family Functioning Style Questionnaire were the primary data collection methods with the added support of documentation. I used purposeful sampling including six families living in the Appalachian region of northeast Tennessee whose children had recently aged out of early intervention services. I was the principal instrument for collecting and analyzing data, maintaining responsibility for the authenticity of documents, sustaining validity and reliability, and ensuring ethical accountability for the research as it was conducted.

## CHAPTER 4

### ANALYSIS OF DATA

#### Introduction

The purpose of this qualitative study was to examine families living in the Appalachian region of northeast cc Tennessee and determine their perceived impact of early intervention services including issues regarding how it affected enjoying their time together, having the support needed to relieve stress, and their ability to pursue personal interests. Such perceptions by families regarding the services their family received and their assessment of their family functioning style was examined. As documented in Chapter 2, the review of literature provided unyielding documentation of the importance of family-based practices provided through family-centered interventions.

The choice of a qualitative study was motivated by a first person perspective in answering the questions. As someone engaged in a face-to-face interview, participating family representatives were able to tell their story in their own words, providing a heightened level of validity. The process was meticulous and very comprehensive. Because the sample size was small, it allowed me to make use of triangulation. Data were gathered through interviews by using the analysis of responses to the Beach Center Family Quality of Life Scale (Beach Center on Disability, 2003; Summers et al., 2005) and the Family Functioning Style Scale (FFSS) (Deal et al., 1998). The FQOL provided the interview questions. I transcribed each of the six interviews. It is important to note that, although I transcribed all the interviews initially, my home and research materials were destroyed by fire during this study and it was necessary to have a professional transcribe again one of the interviews from a second set of interview tapes held in a safe deposit box. I then adapted Strauss and Corbin's (1998) Constant Comparison

Analysis (CCA) method to integrate and seek out commonality in the themes. Given that I had used the Family Functioning Style Scale in my semistructured interviews, answers were coded upon completion of each interview question, and the interview was transcribed in its entirety for additional comments or insights that may have been shared. Likewise, based on the structure of the tool, the FFSS identified family strengths and capabilities and was coded upon its completion.

Examination of these data may increase the understanding of the extent to which families with children with disabilities living in the Appalachian region of northeast Tennessee are satisfied with the intervention services they received, and may ascertain their assessment of the resulting improvements in family functioning. The information gathered from this unique population provides agencies with relevant research-based data about the needs of families living in northeast Tennessee to better meet those needs.

### Selection of Participants

Face-to-face interviews and follow-up interviews were conducted with six participating family representatives living in the Appalachian region of northeast Tennessee whose children had recently aged out of early intervention services. The purposeful sample used was unique (Merriam, 1998). After gaining permission to access a local northeast Tennessee early intervention agency, I contacted two early interventionists who had served children in the Appalachian region. The steps used to identify and contact prospective participants were:

1. I contacted two early interventionists (EIs) who served children in the Appalachian region of northeast Tennessee.
2. During two meetings I asked each EI if she could identify children who had exited the early intervention program in the last year and received TennCare while living

in the Tennessee counties of Hawkins, Johnson, and Carter. (Note: While the intent of this study was to examine how early intervention services are viewed through the eyes of the Appalachian population, it is important to remember that the majority of EI service recipients are low income or in poverty.) Each EI said she could provide names.

3. I requested 10 names and addresses from each. One EI was able to provide four names from Hawkins County and the other EI provided four names from Johnson County and two from Carter County; the 10 names met the exit requirements of one child from an early intervention program within 6 months to 1 year.
4. I mailed letters to the 10 prospective participating family representatives requesting their permission to meet, participate in an interview, and complete a survey. Upon receiving the 10 letters back, 9 letters were marked “Yes” and one was marked “No.” I randomly choose three of the four Hawkins County letters and, as I received three letters from Johnson County, the sample size of six was met with a minimal use of random selection techniques required.
5. The prospective participants from Carter County were kept in reserve in case I could not collect or maintain a total of three from each of the target areas of Hawkins and Johnson Counties. Given that the minimum sample was received from each of the target counties, the reserve Carter County prospective participants were not accessed nor did circumstances arise that required their use.
6. As required by the East Tennessee State University Internal Review Board (IRB), I had no direct contact with prospective participating family representatives until all IRB materials had been reviewed and approval was granted.

The counties selected in this study were Johnson and Hawkins County. For the purposes of this study, the three Johnson County participating family representatives are identified as A, B, and C and the three Hawkins County participating family representatives are identified as D, E, and F.

Participating family representative A graduated from high school and holds an undergraduate degree. She has two sons, the younger of which received early intervention services. He entered the program at age 5 months and exited at age 3 to attend a Head-Start preschool program. To date the older son has received no diagnosis nor is one anticipated. Participating family representative A's child received early intervention services as a result of prematurity and developmental delay. He received home-based early intervention services once a week (four times each month), office-based speech services at home twice a week (eight times monthly), office-based occupational services and physical therapy services twice a week (eight times a month), and he participated in community based early intervention social group services once a week (four times) for one month before aging out of the program at age 3.

Participating family representative B is a high school graduate with two sons; the younger child received early intervention services. Participating family representative B's older son has a diagnosis of Asperger's and Autism while her younger son was diagnosed with developmental delays when entering the program at age 2 years and 2 months; he exited the program at age 3 to attend a Head-Start preschool program. Participating family representative B's child received home-based early intervention services once a week (four times a month) and office-based behavioral counseling once a week (four times a month). Two months prior to aging out of the early intervention program on his third birthday, the younger child was diagnosed with Pervasive Developmental Disorder.

Participating family representative C graduated from high school and has three children – two older sons and one younger daughter – her daughter received early intervention services. Participating family representative C’s daughter entered the program at age 2 with speech delays and exited the program at age 3 to attend public school. Participating family representative C’s daughter received home-based early intervention services and early intervention Social Group services simultaneously at a rate of once a week (four times a month) for a short 2-month period. Home-based speech therapy services were offered to the child for 30 days but were stopped as the speech service provider stopped serving Johnson County. Changes were made so that Tennessee Early Intervention Services (TEIS) no longer provided home-based early intervention or early intervention community based social group services. After the change in services, participating family representative C’s daughter received only home-based services once a week (four times a month) until age 3.

Participating family representative D graduated from high school and holds an undergraduate degree. She has three children. The oldest child is a boy, the middle is a girl, and the youngest is a boy. Her daughter entered the early intervention program at age 8.5 months and aged out of services, exiting the program at age 3 to attend public school. Participating family representative D reported that her older son has a diagnosis of 1q21.1 micro-deletion, developmental delays, Attention Deficit Hyperactivity Disorder (ADHD), and mental health challenges, and that her younger son has a diagnosis of 1q21.1 micro-deletion and a sub mucous cleft palate. Participating family representative D’s daughter received early intervention services as a result of developmental delays and being physically small for gestational age. She was later given a diagnosis of 1q21.1 micro-deletion, juvenile idiopathic arthritis, and polyq45idular. Participating family representative D’s daughter received home-based early intervention services

once a week (four times a month), office-based speech therapy services two times a week (eight times a month), and office-based occupational therapy services and physical therapy services two times a week (eight times a month).

Participating family representative E received a GED and has had some college. She fosters two boys and it was the younger child who received early intervention services.

Participating family representative E reported that there are three other siblings living separately in another home but she is not aware of their ages, whereabouts, or any personal information.

Participating family representative E reports that her older child has a diagnosis of Reactive Attachment Disorder (RAD) and bipolar. Her younger child was diagnosed with developmental delays and sensory challenges when entering the program at age 1.5 years; he exited the program at age 3 with no transition to a Part C public school system as no options were available at that time in the city limits. Participating family representative E's child received home-based early intervention services once a week (four times a month), home-based speech therapy services twice a week (eight times a month), and home-based occupational therapy services and physical therapy services one time a week (four times a month).

Participating family representative F is a high school graduate with a technical school degree. She has one son who received early intervention services and entered the program at age 2 with developmental delays and exited the program at age 3 to attend a local preschool.

Participating family representative F's son received home-based early intervention services at a rate of once a week (four times a month).

### Data Collection

Letters were mailed to each of the 10 prospective volunteer participating family representatives (see the sample in Appendix C). The letter included information about the

researcher, the study, and how the data would be used. Study participants were offered a \$25 Wal-Mart gift card as compensation for their time during the study. Upon receiving the 10 responses, nine letters were marked “Yes” and one was marked “No.” I randomly chose three letters from the four returned from Hawkins County to gain the required number for that county and used all three “Yes” letters from Johnson County. Originally, names were also requested from Carter County as a back-up plan in case I could not maintain a total of six from the target counties of Hawkins and Johnson.

Each of the 10 families was contacted for the first interview using the Initial Phone Call Contact Guide found in Appendix D. During the initial interview, participating family representatives were asked to complete a short-answer Participant Selection Guide questionnaire (see Appendix E) and, to facilitate the process and assure consistency, a Preliminary Interview Guide was used to direct the initial interview with each family (see Appendix F).

Once the data and interview transcripts were compiled and verified, the participating family representatives were contacted for a follow-up interview; the Data Verification Phone Call Contact Guide found in Appendix G was used when scheduling the final interview. The Data Verification Interview Guide found in Appendix H was used during each follow-up interview when I used member checking to verify the participants’ responses and transcripts as a way to understand what was expressed and clarify that the data had been accurately transcribed. The Gift Card Signature Form shown in Appendix I was signed during the second interview. A confirmation call was made prior to each meeting.

The face-to-face interviews and follow-up interviews were completed in a place of the participating family representatives’ choosing; for consistency, follow-up interviews were conducted in the same location. Five of the six participating family representatives chose to be

interviewed in their home while the sixth participating family representative chose to be interviewed during her lunch break at her work.

The participating family representatives interviewed were all women. Five of the six participants were the birth mother and one was a foster mother. Participant safety was ensured because those interviewed chose the location for the interview and each interview was either in the participating family representative's home or in an alternate place of her choosing. This assured that participants felt comfortable and at ease during the interview. Prior to the start of each interview, before the recorders were turned on, participating family representatives were presented with a copy of the Informed Consent form found in Appendix J and asked if they preferred to read it or have it read to them; all six participating family representatives chose to read it independently in my presence. I provided two copies of the Informed Consent form and asked the participating family representative to sign both copies. One copy was left with the participant and I kept the other. The short-answer Participant Selection Guide found in Appendix E consisted of demographic information, early intervention experience questions, highest grade of school attended, information regarding the child's diagnosis regarding early intervention services, and any siblings.

Privacy and confidentiality were protected by using pseudonyms. Additionally, no pictures were taken and all raw data and other materials were only viewed by the transcriptionist and me. During the interviews, I was careful to remember that the participant had autonomy and choices in all situations; each was treated with respect in terms of language, interactions, and social standing.

Participant distress was minimized, as the verbal and nonverbal environment was one that reflected no judgments by me. Communications were offered in a comfortable interactive style

of listening, a calm voice, and nonverbal interactions were open and conducive to the ease and comfort of a casual conversation. The interviews were addressed as a conversation with time allotted for debriefing if the conversation or the content became too intense. I recognized that all participants are fragile and all efforts were made to cause no harm or detriment to them. Fortunately, there was no occurrence or reason to suspect any care provider abuse, so there was no cause for action regarding reports to the appropriate authorities regarding the children living in the homes (Franklin, 2007).

Five of the six participating family representatives had children present when the initial interview occurred in their home. I was attentive to the needs of the participating family representatives regarding their children as five of the six participants was the mother and the other participating family representative was the child's foster mother. The tape was paused when requested, required, or at any necessary point for the participant to interact with her child(ren) or other family members. Such occurrences are documented in the interview transcriptions as the occasion occurred.

Equally, because one of the six initial interviews took place in the participating family representative's workplace, I was attentive to the needs of the participant regarding privacy and the presence of others in the office. Each interview lasted from 1 to 2 hours, depending on how talkative the participating family representatives were and how often it was necessary to interrupt the interview for routine family happenings or interactions with family members. Likewise, four of the six participating family representatives had children present in her home when the follow-up, verification interview occurred. One participating family representative completed the follow-up interview in her home, as before, but this time her children were in school; the final

participating family representative again completed her follow-up interview at work during her lunch break.

In order to ensure the confidentiality of each participating family representative and her family, I randomly assigned a letter to each of the six participating family representatives. These letters are not related to the participant's ethnicity, given name, or their child's given name.

Family A, Family B, and Family C were from Johnson County, Tennessee. Family D, Family E, and Family F were from Hawkins County, Tennessee.

### Research Questions

The two research questions to be examined in this study are as follows:

1. *What is the perceived impact of early intervention services of families living in the Appalachian region of northeast Tennessee who recently exited Expanding Horizons; Early Intervention Program?*
2. *What are the perceived satisfaction levels of early intervention services of families living in the Appalachian region of northeast Tennessee who recently exited Expanding Horizons; Early Intervention Program?*

### Family Quality of Life: Family Interaction Subscale

The Family Interaction subscale includes six of the items from the FQOL (Beach Center on Disability, 2003). These items were ranked by the level of importance, level of satisfaction, and the priority as high, medium, or low. Any support the families would like to have had is also marked. The results of those rankings are shown here.

Item 1 – Spending Time Together as a Family

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 1 combined and by county.

Table 1.

*Family Quality of Life: Family Interaction Subscale – Item 1 – Spending time together as a family.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	0	2	1
Hawkins	0	0	3	0	0	3	1	1	1
Joint	0	0	6	0	0	6	1	3	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high; six ranked satisfaction as high; and regarding priority for support, two ranked it as high, three ranked it as medium, and one ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and regarding priority for support, one ranked it as high and two ranked it as medium.

The representative from family A said, “Uh, EI was kinda like a family for us. Uh, we definitely looked forward to seeing the early interventionist. Hum, myself and both the kids actually.”

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and regarding priority for support one ranked it as high, one ranked it as medium, and one ranked support as low.

The representative from family D shared,

I do think that Anna uh really put forth the effort to keep our children working as she worked with them individually but she kept working with us as a family and worked with the kids as siblings so that if they were jealous of each other if they uh and she even included my oldest with Samantha you know she would show him how to show Samantha and then it also uh helped him to learn how to do things and help uh whatever they were working on and Bryan would actually work with Samantha during the week on things that Anna (SC) was working on, so I think she is very supportive with that.

The representative from family F shared, when discussing her self-ranked satisfaction level as high for spending time together, “I mean, with working and everything it’s probably as good as it’s gonna get” and then she laughed.

#### Item 2 – Talking Openly With Each Other

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low

the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 2 combined and by county.

Table 2.

*Family Quality of Life: Family Interaction Subscale – Item 2 – Talking openly with each other.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	1	2	0	0	3	0	2	1
Hawkins	0	0	3	0	0	3	2	1	0
Joint	0	1	5	0	0	6	2	3	1

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Regarding importance, five ranked it as high and one ranked it as medium; six ranked satisfaction as high; and regarding priority for support, one ranked it as high, three ranked it as medium, and two ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Regarding importance, two ranked it as high and one ranked it as medium; three ranked satisfaction as high; and regarding priority for support, one ranked it as high and two ranked it as medium.

During the interview the representative from family A ranked priority of support as high and sighed, saying, “I guess that was another issue of importance that they pushed just talking with each other learning to cope with the different disabilities and things of that nature.”

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and regarding priority for support, one ranked it as medium and two ranked support as low.

Item 3 – Solving Problems Together

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 3 combined and by county.

Table 3.

*Family Quality of Life: Family Interaction Subscale – Item 3 – Solving problems together.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	1	0	2	0	0	3	1	1	1
Hawkins	0	1	2	0	0	3	2	1	0
Joint	1	1	4	0	0	6	3	2	1

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Regarding importance, four ranked it as high, one ranked it as medium, and one ranked it as low; six ranked satisfaction as high; and regarding priority for support, one ranked it as high, two ranked it as medium, and three ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Regarding importance, two ranked it as high and one ranked it as low; three ranked satisfaction as high; and regarding priority for support, one ranked it as high, one ranked it as medium, and one ranked support as low.

The representative from family A added, when discussing priority for support, Uh that would probably be a medium. I think we did pretty good on the problem solving. I think that is just something we decided to do and uh, and learned to cope with Smith's disability and learn just learn how to get through them.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Regarding importance, two ranked it as high and one ranked it as medium; three ranked satisfaction as high; and regarding priority for support, one ranked it as medium and two ranked support as low.

#### Item 4 – Supporting Each Other to Accomplish Goals

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 4 combined and by county.

Table 4.

*Family Quality of Life: Family Interaction Subscale – Item 4 – Supporting each other to accomplish goals.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	0	0	3
Hawkins	0	0	3	0	1	2	1	1	1
Joint	0	0	6	0	1	5	1	1	4

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high; regarding satisfaction, five ranked it as high and one ranked it as medium; and regarding priority for support, four ranked it as high, one ranked it as medium, and one ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and three ranked priority for support as high.

The representative from family A shared,

I don’t know what I would have done without my husband or all my family through Smith’s um birth and all his needs from start to here. Um it’s been a huge, huge thing supporting...especially me. (Laughs) I have required a lot of support (Laughs) and I have gotten it so I have been blessed there.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels

of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as medium; and regarding priority for support, one ranked it as high, one ranked it as medium, and one ranked support as low.

The representative from family D said,

I think one of the things on the supporting each other is that I think the therapists sometimes forget to keep the parents informed. Uh such as speech therapy always kept us very informed you know, work on these things this week and uh OT (occupational therapy)... We have one OT uh she kept us very informed and then we were switched to another one. At one point we would not even hear how Samantha was doing sometimes.

I clarified the representative from family D's statements to find out that this family had been switched to another occupational therapist in the same center and she followed with this statement,

And then I ended up and had to request, and I had actually talked to Anna about it and uh she said that you have the right to switch back to who your child is most comfortable with and who you are most comfortable with. So we did that and that fixed the problem. A um PT (physical therapist) (laughs) has not been very good at communication and uh I think part of supporting each other is to keep the parents informed.

The representative from family E added, "Uh, yeah. It was a high priority because I needed them sometimes to show me things to do with them."

#### Item 5 – Showing That You Love and Care for Each Other

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low

the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 5 combined and by county.

Table 5.

*Family Quality of Life: Family Interaction Subscale – Item 5 – Showing that you love and care for each other.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	1	1	1
Hawkins	0	0	3	0	0	3	1	0	2
Joint	0	0	6	0	0	6	2	1	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high; six ranked satisfaction as high; and regarding priority for support, three ranked it as high, one ranked it as medium, and two ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and regarding priority for support, one ranked it as high, one ranked it as medium, and one ranked support as low.

The representative from family A said,

Uh...I think my oldest son is probably the best example of how he was showing, especially learning to deal with Smith who has special needs and very different. Uh, I think my oldest didn’t know how to answer the questions when the other kids would say

what’s wrong with your brother and uh so that was something he learned to do very quickly and does great with supporting him and loving him through this disability and rough times.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and regarding priority for support, two ranked it as high and one ranked support as low.

Item 6 – Handling Life’s Ups and Downs

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 6 combined and by county.

Table 6.

*Family Quality of Life: Family Interaction Subscale – Item 6 – Handling life’s ups and downs.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	1	0	2
Hawkins	0	0	3	0	0	3	1	0	2
Joint	0	0	6	0	0	6	2	0	4

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high;

six ranked satisfaction as high; and regarding priority for support, four ranked it as high and two ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; Three ranked satisfaction as high; and regarding priority for support, two ranked it as high and one ranked support as low.

I asked the representative from family B if the IFSP helped and if having someone come in once a week to talk about things was helpful. The representative from family B responded, "I guess the IFSP helped... cuz, it at least gave us a plan of what we needed to do." I inquired how it made their week go more smoothly and the representative from family B said, "We knew exactly what was gonna be in place and when."

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; three ranked satisfaction as high; and regarding priority for support, two ranked it as high and one ranked it as low.

The representative from family E explained her ranking by saying, "And we have had to have a lot support in that area from their doctors, EI, (laughs) from everybody with that 'cause it's been like a roller coaster actually with them. We feel like one day we will be doing good and the next day we are (laughs and what is said is unintelligible)."

Family Quality of Life: Parenting Subscale

The Parenting subscale includes six of the items from the FQOL (Beach Center on Disability, 2003). These items were ranked by the level of importance, level of satisfaction, and the priority as high, medium, or low. Any support the families would like to have had is also marked. The results of those rankings are shown here.

Item 1 – Helping Your Children Learn to be Independent

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 7 combined and by county.

Table 7.

*Family Quality of Life: Parenting Subscale – Item 1 – Helping your children learn to be independent.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	1	2	0	0	3
Hawkins	0	0	3	0	1	2	0	1	2
Joint	0	0	6	0	2	4	0	1	5

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high; regarding satisfaction, four ranked it as high and two ranked it as medium; and regarding priority for support, five ranked it as high and one ranked it as medium.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as medium; and three ranked support as high.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as medium; and regarding priority for support, two ranked it as high and one ranked it as medium.

The representative from family D said,

Um, I think that's... I think that is one area where the uh I mean the therapist we used could be lacking such as they would show you things in the center that could help them be independent but then you get home and those same things don't work in the home environment. And which is, that's were Anna came in uh some to with ideas but I think that, that is one reason why home therapy has benefits. Uh because you go from the center to the home and it's hard to get a child to be, do those things independent in your home environment and learn how to make those modifications and to get them to be as independent as possible.

The representative from family E shared this while ranking priority of support that, "Uh, it's high, sometimes I want them to...especially when they have problems it's, you know, you want to keep them your babies."

The representative from family F shared in discussing her level of satisfaction, “I guess that’s satisfaction on my part. What I was doing for him when he first came in was probably more like, a medium, because I didn’t know exactly how to do everything for the independence.” She continued by saying, “Yeah, we got a lot of advice on things to do for him. You know, let him do this instead of just doing it for him, you know.”

Item 2 – Helping Your Children With Schoolwork and Activities

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 8 combined and by county.

Table 8.

*Family Quality of Life: Parenting Subscale – Item 2 – Helping your children with schoolwork and activities.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	1	0	2	0	0	3	2	0	1
Hawkins	0	0	3	0	0	3	2	0	1
Joint	1	0	5	0	0	6	4	0	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Regarding importance, five ranked it as high and one ranked it as low; six ranked satisfaction as high; and regarding priority for support, two ranked it as high and four ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Regarding importance, two ranked it as high and one ranked it as low; three ranked satisfaction as high; and regarding priority for support, one ranked it as high and two ranked support as low.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; three ranked satisfaction as high; and regarding priority for support, one ranked it as high and two ranked support as low.

The representative from family D added,

We are doing that. Uh we feel like we have it covered, uh our, you know Anna has been very helpful with ideas though not only for Samantha but Bryan as well. Uh she has a son that has some of the issues that my son has so uh she's been good sharing stuff like even with Samantha and she would say this worked because uh. So she has helped give us some ideas but as far as school (laughs) goes... Uh I mean with Samantha it's been hard because Samantha has memory problems and attention problems where she can be taught something as far as development or school goes but she might not remember it the next day. So uh, no one has really figured out how to correct that. Lately we have uh her using music but to help with her memory. But her therapist even when we were in EI was just; we're always at a loss for how to help her cognitively and educationally. They are just not sure what to do.

The representative from family F said, “Yeah, we usually had a paper left about every other week of what she did – or at least a little note, you know.” I asked if they were able to participate in what they wanted to work on and the representative from family F responded, “No.” Then I asked if it followed the IFSP and the representative from family F responded,

Yeah, well see, Dad was there. There was some things he got to help her with but I didn’t because I was only there for like the first initial meeting because it, she had to come on a work day for me.

Item 3 – Teaching Your Children How to Get Along With Others

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 9 combined and by county.

Table 9.

*Family Quality of Life: Parenting Subscale – Item 3 – Teaching your children how to get along with others.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	1	2	1	0	2
Hawkins	0	0	3	0	1	2	0	0	3
Joint	0	0	6	0	2	4	1	0	5

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high;

regarding satisfaction, four ranked it as high and two ranked it as medium; and regarding priority for support, five ranked it as high and one ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as medium; and regarding priority for support, two ranked it as high and one ranked support as low.

The representative from family B said,

Uh, they had a play group that Tommy he went to once a week for 3 hours, where they had other children where he could play with other children and he learned how to interact with the other children; whereas he wouldn't interact with the others, his brothers here.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as medium; three ranked support as high.

The representative from family F related, "I, I think that by the time it was over with he did pretty well. He shared... started sharing a lot more. Anna did teach him to share. She would do the 'my turn, your turn.'"

#### Item 4 – Teaching Your Children to Make Good Decisions

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low

the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 10 combined and by county.

Table 10.

*Family Quality of Life: Parenting Subscale – Item 4 – Teaching your children to make good decisions.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	1	0	2	0	0	3	1	0	2
Hawkins	0	0	3	0	0	3	1	0	2
Joint	1	0	5	0	0	6	2	0	4

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Regarding importance, five ranked it as high and one ranked it as low; six ranked satisfaction as high; and regarding priority for support, four ranked it as high and two ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Regarding importance, two ranked it as high and one ranked it as low; three ranked satisfaction as high; and regarding priority for support, two ranked it as high and one ranked support as low.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high;

three ranked satisfaction as high; and regarding priority for support, two ranked it as high and one ranked support as low.

The representative from family D said,

Actually think, uh actually think not only as parents but EI has actually helped uh, you.

There has been times that we have had a situation between siblings and uh we but not only Samantha but Mark as well. You know they would be squabbling and Anna would step in and say, you know uh, kind of talk it out and use words and uh, especially with Samantha where she talked so late and taught her signs and would help her be able to make those good decisions, and express it. Uh that's it.

Item 5 – Knowing Other People in Your Children’s Lives

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 11 combined and by county.

Table 11.

*Family Quality of Life: Parenting Subscale – Item 5 – Knowing other people in your children’s lives.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	0	1	2
Hawkins	0	0	3	1	1	1	0	1	2
Joint	0	0	6	1	1	4	0	2	4

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Six ranked importance as high; regarding satisfaction, four ranked it as high, one ranked it as medium, and one ranked it as low; and regarding priority for support, four ranked it as high and two ranked it as medium.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; three ranked satisfaction as high; and regarding priority for support, two ranked it as high and one ranked it as medium.

The representative from family A related,

Ah, they put me in touch with a lot of different people that had been in my shoes and had been successful on the other end. So that was a real eye opener that things get better and he will be fine (laughs).

I asked the representative from family B if group was good for her as well. She responded, "It was good to get out of the house away from the other children (laughs). It just helped me to know I am not the only one with children like Tommy or ..." When the participating family representative hesitated, I prompted by reducing hesitation and acknowledging that she was not alone; she responded, "Uh huh."

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high;

regarding satisfaction, one ranked it as high, one ranked it as medium, and one ranked it as low; and regarding priority for support, two ranked it as high and one ranked it as medium.

The representative from family D ranked it as a high priority for support,

And I wanna say on that one uh, I think that's one area were not just EI but well EI is uh lacking is that when you have kids that have disabilities you often feel very cut off and there's not a way to get or find other people that have, you know, children with those disabilities, too. Uh I knew at one time that they had, you know, some little play groups and stuff. But uh there's not a lot of that in EI. And while you do get to know some people being in therapy center together there's not that connection that I think parents need to keep their sanity. Uh when they are dealing with a child or multiple children with disabilities and there are young children who can't speak, who are frustrated. And, you know, you are frustrated and you don't have that outlet to talk to someone else.

During the interview I asked the representative from family D if she considered this item as a priority and she responded,

Uh, Anna and I had actually discussed that several times. Uh we had talked about she, we talked about one time about one of the little groups that was meeting and I don't even know if it still meets now but they used to do that. Uh but I think it was limited and she was trying to keep certain kids of the same age in. Uh and there wasn't, there was only one that she was doing at that time and we did discuss that especially uh socialization. So, but it, and it, it wasn't really not really anyone's fault that that's not available, it's just I think this area doesn't have the resources so much and I think TEIS in general doesn't make that a priority. Uh they, you know, they want to provide the kids the services rather than uh provide a way to link families whose children have the disabilities.

I clarified the item for the representative from family F and she responded that she mainly knows the children who are at, “Just pretty much day care.” The family F representative ranked it medium in terms of priority of support and followed with this statement, “...because I think we were just more concerned at the time with maybe trying to get him caught up with where he sorta needed to be at the time.”

Item 6 – Having Time to Take Care of the Individual Needs of Every Child

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 12 combined and by county.

Table 12.

*Family Quality of Life: Parenting Subscale – Item 6 – Having time to take care of the individual needs of every child.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	1	0	2	0	1	2	2	0	1
Hawkins	0	0	3	1	0	2	0	2	1
Joint	1	0	5	1	1	4	2	2	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Regarding importance, five ranked it as high and one ranked it as low; regarding satisfaction, four ranked it as high, one ranked it as medium, and one ranked it as low; and regarding priority for support, two ranked it as high, two ranked it as medium, and two ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Regarding importance, two ranked it as high and one ranked it as low; regarding satisfaction, two ranked it as high and one ranked it as medium; and regarding priority for support, one ranked it as high and two ranked it as low.

The representative from family A shared that this was a low priority, "Uh, no not really because I am a stay-at-home [mom] so I don't have to work and I never, that wasn't a very big issue for me 'cause I was blessed enough to get to stay home all the time."

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as low; and regarding priority for support, one ranked it as high and two ranked support as medium.

The representative from family E shared that her satisfaction was "Low, because I would like to, I would like to be able to do more for them."

The representative from family F said that regarding priority for support, "Guess, it was probably about medium 'cause I think I was taking care of too many needs and not letting him do enough for his self." (Laughs) Yeah, it's kinda like, here, come here, let me do that."

#### Family Quality of Life: Physical or Material Well-Being Subscale

The Physical or Material Well-Being subscale includes five of the items from the FQOL (Beach Center on Disability, 2003). These items were ranked by the level of importance, level of

satisfaction, and the priority as high, medium, or low. Any support the families would like to have had is also marked. The results of those rankings are shown here.

Item 1 – Having Transportation

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings are shown here and in Table 13 combined and by county.

Table 13.

*Family Quality of Life: Physical or Material Well-Being Subscale – Item 1 – Having transportation.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	3	0	0
Hawkins	0	0	3	0	0	3	3	0	0
Joint	0	0	6	0	0	6	6	0	0

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high; six ranked satisfaction as high; and six ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and three ranked support as low.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and three ranked support as low.

Item 2 – Having a Way to Take Care of Your Expenses

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 14 combined and by county.

Table 14.

*Family Quality of Life: Physical or Material Well-Being Subscale – Item 2 – Having a way to take care of your expenses.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	1	0	2	0	0	3	3	0	0
Hawkins	0	0	3	0	2	1	2	1	0
Joint	1	0	5	0	2	4	5	1	0

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Regarding importance, five ranked it as high and one ranked it as low; regarding satisfaction, four ranked it as high and two ranked it as medium; and regarding priority for support, one ranked it as medium and five ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Regarding importance, two ranked it as high and one ranked it as low; three ranked satisfaction as high; and three ranked support as low.

The representative from family A explained,

Uh, no. Smith had the TennCare then as a secondary insurance and anything we needed that pretty much covered it medical expense wise. Uh, and my husband you know covered all the bills so we were. Yea it was low priority for that we were pretty blessed and money wasn't too much of an issue. Not going to say it wasn't an issue at all, but it wasn't too big of a concern then.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, one ranked it as high and two ranked it as medium; and regarding priority for support, one ranked it as medium and two ranked support as low.

The representative from family D said,

I had actually discussed that with Mary (SC) uh at some... because we had come up on some things that was not covered by insurance and uh it was covered under our primary but not completely. There was still a big expense after that. TennCare would not pick up the remainder. TEIS would not pick up anything because we had TennCare. Because TennCare would not cover it, TEIS would not cover it either. So I do think there is a need for... You know, not everybody has TennCare as a, as for primary and not everybody uh

with TennCare does you know. Some things are not covered by TennCare. TennCare will deny things that kids need. And you know going through an appeal with TennCare can last a year and when a child needs something, you know, and its therapy based or something like that developmentally based TEIS doesn't pick it up as well as children's social services doesn't either. So you are just left to deal with it, so (Laughs) I think that definitely needs to change.

The representative from family E stated the priority was “Medium because we do not always have the time, I mean the money to do what we want.”

The representative from family F ranked her satisfaction as high and said, “I think there could be more, but we'll just say we're satisfied with it – it pays the bills.”

Item 3 – Feeling Safe at Home, Work, School, and in the Community

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 15 combined and by county.

Table 15.

*Family Quality of Life: Physical or Material Well-Being Subscale – Item 3 – Feeling safe at home, work, school, and in the community.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	1	0	2	1	1	1
Hawkins	0	0	3	1	0	2	1	1	1
Joint	0	0	6	2	0	4	2	2	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Six ranked importance as high; regarding satisfaction, four ranked it as high and two ranked it as low; and regarding priority for support, two ranked it as high, two ranked it as medium, and two ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as low; and regarding priority for support, one ranked it as high, one ranked it as medium, and one ranked support as low.

The representative from family A ranked high satisfaction and stated,

Uh I would say that would be medium priority for support. And we did, we had to have a lot of locks on cabinets for Smith and a lot more safety issues especially around the house with him, uh, and EI helped with that. I think when he was learning to crawl he was banging his head on everything so we had to quit trying to cover everything in the house and just get him a helmet (laughs). So they helped me with that, getting a particular helmet for him ...as far as safety um.

The representative from family B ranked medium as a priority for support and made this reference to her group experience, "Because once he started getting into interacting with the other kids he was more safe and more controlling. You know, he was more of a loving child."

The representative from family C said, "I don't feel my kids are safe at times. Does that make sense?" I responded by saying, "Yes, it does make sense. [Is it] because of who is around you?" She responded, "Well because the school and stuff." I asked, "So you are talking about

school or out here?” The representative from family C answered, “School. I am always afraid they are going to be kidnapped at school or something.”

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as low; and regarding priority for support, one ranked it as high, one ranked it as medium, and one ranked support as low.

The representative from family D ranked importance as high, satisfaction as low, and priority for support as medium, saying,

Uh, the reason I said low on satisfaction is, and it’s really not as much um as far as Anna goes, because Anna, because Anna has always made us feel very safe and supported and so has our therapist. Uh but as far as medically uh where the doctors, where doctors blamed us for some of Samantha’s problems and she even didn’t really have them even though Anna was seeing them in the home. Uh they said that we were making them up. We were causing them; we were making her delays, that they wasn’t seeing them when they would only seeing her 5-minute visits and where her therapists were seeing her for hours a week. Uh it’s left our family with a feeling of not being safe. Uh at school, uh in, in this particular community because child protective services targeted our family and wouldn’t leave us alone. Uh and they went so far to start rumors in the community that Lillian was in a wheelchair. The day care worker at Happy Hands or Happy Hearts wanted uh to talk to us and say oh we heard that Samantha was in a wheelchair. Completely untrue, she walks (laughs); she talks, that was not the truth. So those types of things have left us feeling very insecure uh in the community and you know medical,

even at the therapy center but even though they were 100% supportive for our family we are always very paranoid about who's getting records. Who's uh like Children's Special Services (Child Protective Services) they went and got records from them without anybody giving them permission.

I clarified the agency the representative from family D was referring to and she said,

The health department, so anytime we deal with, now TIES we felt very secure with just because Mary and Anna had been very supportive of family, they have seen these in our home. They've even brought up things that they had saw but medically you know we are always afraid of people getting records that shouldn't have them that uh. Uh, we are always watching, are very careful what we say because we never want anything to be taken the wrong way uh, and we are very insecure because of that and we have found through going through this that we are not the only family in the area that has been through this sort of thing; who has been falsely accused for medically with medical type stuff. And with it happening to our family with a clear cut diagnosis. Uh, people in our, our family, our friends, our church uh people other families at our therapy center it has left them you know, if this can happen to one family, it can happen to any of us. So I think that's one of the reason we don't feel, we feel very insecure.

The representative from family F said, "We always feel safe at home, if nowhere else."

#### Item 4 – Getting Medical Care When Needed

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 16 combined and by county.

Table 16.

*Family Quality of Life: Physical or Material Well-Being Subscale – Item 4 – Getting medical care when needed.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	1	0	2
Hawkins	0	0	3	1	0	2	0	0	3
Joint	0	0	6	1	0	5	1	0	5

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high; regarding satisfaction, five ranked it as high and one ranked it as low; and regarding priority for support, five ranked it as high and one ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and regarding priority for support, two ranked it as high and one ranked support as low.

The representative from family A related,

Uh, as far as medical care, uh, again with the helmet with he had to have a stander and they helped me get that and I think Susan even brought some books for me to look at the different stander and different equipment that would be possible for him.

The representative from family B said,

Well, they help. They helped get Tommy's disability; they provided the paperwork that he needed. Well whatever paperwork Susan had she sent and we sent everything we had on document, because you know how they are. They are very thorough and any without him seeing a doctor and never been to therapist everything we had on file had to go.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as low; and three ranked support as high.

The representative from family D said,

Uh and one of the things I had discussed as far as getting medical care when needed was I had even discussed with Mary about different pediatricians. When we just had TennCare nobody took TennCare. None of the good pediatricians took TennCare and I discussed with Mary over and over and over again about who to go to for pediatrician who's good with special needs children uh and there was a little gap that we went through that we didn't even have a pediatrician and that's when we made the decision to get a primary uh insurance through my husband's work. My husband and I already had it but we thought the kids didn't need it; we didn't need to pay out \$150 a month to get the kids on his insurance because they had TennCare. Uh then we begin to realize that we did need that and when we did that it opened up uh another uh options and uh but unfortunately medical care in this area and you know as much as Mary tried to help and Anna tried to help it lacks and uh there, there was a lot of times there's specific things they needed and

they couldn't get – could not get pediatric rheumatologist around here. Uh different things that they needed they could not get in this area.

The representative from family E ranked high on importance, high on satisfaction, and regarding priority for support said,

Um, I would say high on that. Dr. Holt has been. I wouldn't prefer anybody to Dr. Holt; she is the best for the kids. Yes, Dr. Holt (pediatrician) has been wonderful with these kids it's just unbelievable. Sometimes we would feel like giving up and she would say no, look how far you have come. She is at Jamison Medical Associates in Kingsport, up at Valley Hill. She is the best. She's been with us from the start. You know sometime you have, you have to let them see, you know 'cause we can't always see the progress and sometimes it's good to hear somebody say that... look how far we have come (Laughs).

Item 5 – Getting Dental Care When Needed

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 17 combined and by county.

Table 17.

*Family Quality of Life: Physical or Material Well-Being Subscale – Item 5 – Getting dental care when needed.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	2	0	1
Hawkins	0	0	3	0	1	2	2	0	1
Joint	0	0	6	0	1	5	4	0	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Six ranked importance as high; regarding satisfaction, five ranked it as high and one ranked it as medium; and regarding priority for support, two ranked it as high and four ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; three ranked satisfaction as high; and regarding priority for support, one ranked it as high and two ranked support as low.

The representative from family A said,

Uh nothing that I didn't get. I knew where he was premature, the enamel wasn't on his teeth and it wasn't going to be on his first baby teeth that did come in and just by looking at him you could see they weren't very healthy teeth. So that was definitely a priority of mine and uh they helped me find a dentist that took TennCare so I wouldn't have to pay any dental cost or anything like that. Uh, It was a drive, it's to Bristol so it's about an hour away and that was never really an issue and they were great and I am very, very happy with the dentist, absolutely.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as medium; and regarding priority for support, one ranked it as high and two ranked support as low.

The representative from family D laughed when she said,

We have always had a pediatric dentist; we used one in Knoxville and then switched to Hampton Pediatric dentistry. So uh with Mark's cleft palate you know Mary initially helped us find some dentists that could, you know possibilities that could possible help care for him but uh once we got hooked up with Knoxville you know we didn't need that support anymore we went every 4-6 months and then we switched from there to Bristol and have been satisfied so we've not really needed support on that.

The representative from family F related her satisfaction score, "Um, it's important but I just don't think he'd let anybody come at his mouth at that point in time. He's just now getting to the point where he'll let me do it. So, um, we'll put medium."

#### Family Quality of Life: Emotional Well-Being Subscale

The Emotional Well-Being subscale includes four of the items from the FQOL (Beach Center on Disability, 2003). These items were ranked by the level of importance, level of satisfaction, and the priority as high, medium, or low. Any support the families would like to have had is also marked. The results of those rankings are shown here.

#### Item 1 – Having the Support Needed to Relieve Stress

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 18 combined and by county.

Table 18.

*Family Quality of Life: Emotional Well-Being Subscale – Item 1 – Having the support needed to relieve stress.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	1	2	2	0	1
Hawkins	0	0	3	0	2	1	1	1	1
Joint	0	0	6	0	3	3	3	1	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high; regarding satisfaction, three ranked it as high and three ranked it as medium; and regarding priority for support, two ranked it as high, one ranked it as medium, and three ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as medium; and regarding priority for support, one ranked it as high and two ranked support as low.

The representative from family A ranked all areas of high importance and when asked if it was a priority for support she replied,

Yes, I think so, defiantly ‘cus I was a nut, I was wreck, I didn’t know what to expect. I didn’t think, I thought everything I was doing was right but I still didn’t know. Wasn’t for sure on myself and yes I was very stressed especially at first.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, one ranked it as high and two ranked it as medium; and regarding priority for support, one ranked it as high, one ranked it as medium, and one ranked support as low.

The representative from family D said,

That's not really been an area that we uh have really discussed all that much. We have discussed with Anna a couple of times about respite uh, but as far as you know support for truly stress uh, my mom lives next door so uh I have that and then at the therapy center I have made friends and uh if I need to de-stress and talk to somebody I mean – that's not a problem, I have help there.

The representative from family F ranked all areas as high and stated, "I don't think it can get high enough."

### Item 2 – Having Friends or Others Who Provide Support

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 19 combined and by county.

Table 19.

*Family Quality of Life: Emotional Well-Being Subscale – Item 2 – Having friends or others who provide support.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	1	2	2	0	1
Hawkins	0	0	3	1	0	2	1	0	2
Joint	0	0	6	1	1	4	3	0	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high; regarding satisfaction, four ranked it as high, one ranked it as medium, and one ranked it as low; and regarding priority for support, three ranked it as high and three ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as medium; and regarding priority for support, one ranked it as high and two ranked support as low.

The representative from family A ranked importance as high, satisfaction as high, and for support, “We will put that as high, too. Because the group that we did I met a lot of other parents uh, other kids and they were good examples for me and a lot of good information to share.”

I asked the representative from family C why she ranked medium in terms of satisfaction and inquired, “What’s not happening that you wish was happening with friends or other people for support?” She responded by saying, “I wish I had friends. All my friends have like got

married. Like I don't have any friends at all that I hang out with." I asked how about when she went to group, did she meet anybody there and she replied, "Yea but..." pause... I attempted to help clarify by asking if there was anyone that she clicked with, and she again replied, "Yea." I asked if she ever let her early interventionist know that was a concern and she replied, "I should have; I did not think about that."

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as low; and regarding priority for support, two ranked it as high and one ranked support as low.

The representative from family D explained,

Family uh, family uh, friends is very hard to maintain when you have children with disabilities. With most of my friends from high school, they're just now getting married or having children a lot of them. But those friends that even are sometimes you almost feel like perfect family, perfect kids, you don't fit in. Uh when you have children with disabilities it's like going to a restaurant is a challenge. And they want to go out to eat, you know go to Applebee's and sit down and have a meal... we can't do that. Uh we can't take our kids in a restaurant without constantly you know thinking about all the things that could go wrong while we're there and how to prevent them and, you know, what to do. We can't guarantee there's not going to be melt downs or we can't guarantee there's not going to be problems and we can't do that because you know we have to sit there you know one bite at a time, you chew, chew, chew, uh and make sure our kids eat and work with them to eat because they don't do it with our sitting right there and being right on

them for them to do it or at least two of them don't. Uh Samantha is the one with the most severe feeding issues so friends it's, it's very hard even the couple of friends I have that has children with disabilities uh her one of the friends I have her daughter disabilities she is now actually developmentally on target even though she has a chromosome disorder so even being with them uh and even though her daughter remains in therapy to stay at that point it's hard because a lot of the things we go through they don't understand. Uh having to be sure that Lillian doesn't use too much energy uh walk on too often on hard surfaces. Things like that uh people don't understand that. So it's very hard to have friends providing support when they don't get it themselves.

I asked the representative from family D if she and her husband ever have time alone and the reply preceded by laughter was, "No." I then asked if there was no one for child care and she stated,

My mom won't keep all three of them uh, just take them and keep all three of them. She won't. She won't do that; she can't handle all three of them together. Uh for our anniversary we took Samantha and Bryan and went out to Riccas' (laughs) and left Mark with my mom. Uh it's usually like that if we have to go anywhere when we uh have spare time or if we have to go anywhere and taking a child with us, or two – usually two. My mom usually keeps one. 'Cause she just cannot handle multiple of them.

I clarified what is meant by multiple, which she described as,

Yea, with multiple challenges. Samantha herself is full, you know, it's a fulltime job to take care of Samantha with all of her medications and making sure, you know, she doesn't over do it because you know at 4 with arthritis she doesn't know her limits or she doesn't know "I can't do anymore" or I am going to be in pain so you have to watch her

and make sure she takes her rest and make sure she does what she's supposed to do and make sure she eats and be right on her. Uh so Samantha and Mark together are definitely uh, my mom definitely has trouble with the two of them. Because they are so developmentally close as well, that they fight a lot, too (laughs).

The representative from family E was asked about importance and replied, "That's high because I think you do need them but we don't have any. Because there is really nobody who wants to take them for even minutes, honestly." The representative from family E ranked satisfaction as low and ranked priority for support low. She added, "Yea and I have been needing support with that, I mean really!"

The representative from family F said,

Um, just with people that I thought that I could, there were family members that I thought that I could depend on. They were the ones that really dropped the ball with me. They were the ones that I thought that wouldn't back out on me 'cus they knew everything going on. Going into it they knew what was going on.

### Item 3 – Having Time to Pursue Personal Interests

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 20 combined and by county.

Table 20.

*Family Quality of Life: Emotional Well-Being Subscale – Item 3 – Having time to pursue personal interests.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	1	0	2	0	1	2	2	0	1
Hawkins	0	0	3	1	0	2	0	2	1
Joint	1	0	5	1	1	4	2	2	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Five ranked importance as high and one ranked it as low; regarding satisfaction, four ranked it as high, one ranked it as medium, and one ranked it as low; and regarding priority for support, two ranked it as high, two ranked it as medium, and two ranked support as low.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Two ranked importance as high and one ranked it as low; regarding satisfaction, two ranked it as high and one ranked it as medium; and regarding priority for support, one ranked it as high and two ranked support as low.

The representative from family A ranked medium for priority support stating, “I just think uh as far as personal interest um myself and my husband; we just sat that on the back burner just a little bit for him especially during that time.” I asked if as her son got older did it become more of a priority and the response was, “Yes, absolutely, absolutely...” Next, I asked if in time the pursuing personal interests changed in rank. She replied, “Yes. Yeah, after the first

year every year got better I think with that and he's, I just finished a 6-week class so he handled that fine. I did great.”

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as low; and regarding priority for support, one ranked it as high and two ranked support as medium.

The representative from family D related,

I did. I did talk to Mary and Anna both about respite. We had been told by other people whose children were in EI in other states that a lot of places provide respite so uh many hours a month per month through EI. But unfortunately Tennessee is not one of those states that does that. Uh I have some friends in west Tennessee, but they do it in west Tennessee some. Uh but they don't. And they don't anywhere else that I know of uh in Tennessee. But there are a lot of other states that do. I know Kentucky does, South Carolina does, uh Georgia, and North Carolina. All those around us provide respite. Some of those... Respite is people coming in your home but some of it is... I know one state they even uh like the EIs they would get together one, one time a month uh so many of them would provide respite for the parents just to go out for two or three hours and just keep the children in a setting you know. Like churches would donate you know, like oh you can use our churches or things like that and they would do respite that way. But nothing has ever been established in Tennessee so that's one of the reasons I feel that uh parents with kids with issues can't pursue their personal interest. They have no time uh and you can't get a babysitter for kids with disabilities. You would have to train someone

then you would cost an unreal amount of money just to get someone in to train someone to deal with medication, aspiration, you know those types of things. Uh, you are not going to find that. Uh so I think that is a big need that uh Tennessee just doesn't have.

The representative from family E responded to importance as, "Well medium, it's not a really big thing for me." (She laughs.) "They are my personal interest? They are my life." (She laughs.)

The representative from family F asked, "And that's for me?" She asked if this question was for her – as if surprised – and then replied, "It's not really, you know, important to me right now. I have a little more things to do with him. He'll be 18 one day and I can worry about me then." (She laughs.)

Item 4 – Having Help From Outside the Family to Take Care of the Individual Needs of Each Family Member

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 21 combined and by county.

Table 21.

*Family Quality of Life: Emotional Well-Being Subscale – Item 4 – Having help from outside the family to take care of the individual needs of each family member.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	0	0	3
Hawkins	0	0	3	1	1	1	0	2	1
Joint	0	0	6	1	1	4	0	2	4

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Six ranked importance as high; regarding satisfaction, four ranked it as high, one ranked it as medium, and one ranked it as low; and regarding priority for support, four ranked it as high and two ranked it as medium.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; three ranked satisfaction as high; and three ranked support as high.

The representative from family A explained the ranking by saying,

It was high at first and then it crept down a lot. Uh but he still needs the therapies and stuff that are outside, outside the home so it may be even their home and outside. Because he still needs the therapies and the social interaction. I think he is very, very social and I think that's pulled him up in other areas that he is lacking behind in.

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; regarding satisfaction, one ranked it as high, one ranked it as medium, and one ranked it as low; and regarding priority for support, one ranked it as high and two ranked it as medium.

The representative from family D said,

Because I think that ties into the question before (laughs) uh that, have enough time." In response, I replied that in their situation, all the siblings have something going on, which makes their situation a little more challenging. She answered by saying, "It does uh and

with the particular chromosomal disorder that they have, our family is the only one known right where every child in the family had ended up with it. We are just special. The representative from family E laughed and said, I don't much leave them with them. Nobody. We never call a babysitter. Never, but it would be good if somebody volunteers to say hey I'll take them for an hour. (Laughs) Just let you go do something for a little while. But you really don't have that, really.

#### Family Quality of Life: Disability-Related Supports Subscale

The Disability-Related Supports subscale includes four of the items from the FQOL (Beach Center on Disability, 2003). These items were ranked by the level of importance, level of satisfaction, and the priority as high, medium, or low. Any support the families would like to have had is also marked. The results of those rankings are shown here.

#### Item 1 – Having Support for Your Child to Make Progress at School or Workplace

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 22 combined and by county.

Table 22.

*Family Quality of Life: Disability-Related Supports Subscale – Item 1 – Having support for your child to make progress at school or workplace.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	0	0	3
Hawkins	0	0	3	0	1	2	0	0	3
Joint	0	0	6	0	1	5	0	0	6

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Six ranked importance as high; regarding satisfaction, five ranked it as high and one ranked it as medium; z ranked satisfaction as v; and six ranked support as high.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and three ranked support as high.

When asked if there was anything they would like to have gotten support in that they did not, the representative from family A replied, “No, not at all, I got more than I dreamed of, actually.”

The representative from family B said, “Knowing that someone was coming in with Tommy and try to teach him what he needed to learn and to sit and play with him for a little while.” I inquired if the family had things to work on, practice on, during the week and she replied, “No.” I asked about language and the response was, “No, we worked on the words that

she would try to get him to.” I further inquired if she thought it helped when she practiced during the week and her response was, “If we could get him to do it (laughs). (Pause) She would always tell me what she was working on and give me the paper and we would try to work on it during the week.”

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; regarding satisfaction, two ranked it as high and one ranked it as medium; and three ranked support as high.

The representative from family D said,

I think that kinda ties into the goals that EI does and the therapy services that they put in place uh that ensures the child makes progress and if the child is not making progress of course Anna gets reports they are not and she is going to be coming to the therapy center or me and saying hey child not making progress, what going on? Uh and so I think that you know they have been very supportive in that and if something is not working then they change or do something else.

The representative from family E explained,

In EI, yeah very, very satisfied. Not having a lot of help for school for getting them ready for school. I had a hard time with that uh. The school didn’t want to take them. I know they are going to Head Start this year because the city school just wouldn’t. Oh, in EI, it was wonderful, it really was uh.

I responded by acknowledging it still continues to be high for the family but asked,

“Since transitioning out of early intervention do you feel as supported?” The representative from

family E replied, “No I don’t.” I further acknowledged that she had to rank it, so now would she rank it low? She answered,

Yea, because I don’t have, you don’t have because they just didn’t want to give nothing they I mean I know could have taken it to Nashville, I could have fought it but Head Start was such a good option right now. I mean they, they accepted them with their disabilities and they are willing to make whatever he needs and so I’ll fight city school when they go into kindergarten (laughs).

Item 2 – Having Support for Your Child to Make Progress at Home

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 23 combined and by county.

Table 23.

*Family Quality of Life: Disability-Related Supports Subscale – Item 2 – Having support for your child to make progress at home.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	0	0	3
Hawkins	0	0	3	0	0	3	0	0	3
Joint	0	0	6	0	0	6	0	0	6

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels

of importance, satisfaction, and the item's priority for support. Six ranked importance as high; six ranked satisfaction as high; and six ranked support as high.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; three ranked satisfaction as high; and three ranked support as high.

The representative from family A explained,

No. Smith he did great with them when they would come to the house, I mean he look forward to seeing them that was for sure! He would do stuff for the early interventionist that I couldn't get him to do. I mean for some reason, I don't know why I guess, I am not gonna to do for that Mommy, I will do that for Susan was his mindset I guess though.

They could get him to do just about anything.

I clarified that after he did it initially with them he continued it with you, didn't he? The representative from family A replied, "Yes, yes."

The representative from family B said,

No, she had what she was trying to get him to say, like what she would get him to say, or try to get him to say, and if he said something then that was the word we would work on that week. Whatever he said, she could get out of him, that's what we worked on.

I reworded the question by asking if EI followed his lead and, laughing, she answered, "The *Thomas the Train* are his interest. That's what started the whole thing. He would not say anything until we got him a choo-choo, he kept saying choo-choo-choo-choo."

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels

of importance, satisfaction, and the item's priority for support. Three ranked importance as high; three ranked satisfaction as high; and three ranked support as high.

The representative from family D said,

I think that's where Anna comes in, uh coming into the home and she sees everything and she saw that uh when Samantha wasn't doing something, when she was Samantha wasn't walking that was our main focus. Let's get Samantha to walking! You know everything, everything she could to get Samantha you know to work on walking. And uh she's been a big support for you know she would say leave and okay this week let's do this all through this week to see if it works, you know see if next week she's doing better or she has more balance or more stability. And all through the week we would work on that thing and Anna would come back that next week and it didn't work. We would try something different so uh I really was a very, uh I mean physical therapy did help but I think Anna uh really played a huge part in Samantha walking. She would have Samantha hold things and then just take it away slowly, and uh watch for her balance. Work on, get down in the floor with her and work on crawling and uh and she was just amazing getting her to make progress. Samantha would do things for Anna she would not do for anybody else. (She laughs.) So we were very, very pleased.

The representative from family E said,

Uh, I was very satisfied with it in EI, and the priority for support was very high, because I mean, I wanted to see them succeed. I mean I wanted to succeed and I felt they had good support. I mean I could ask Anna 'Do you know what I could do for certain things?' and she was always ready for an answer, you know. And if she didn't have an answer she would go to Mary, you know, she gave me the answers I needed.

Item 3 – Having Support for Your Child to Make Friends

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 24 combined and by county.

Table 24.

*Family Quality of Life: Disability-Related Supports Subscale – Item 3 – Having support for your child to make friends.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	0	0	3
Hawkins	0	1	2	1	2	0	0	3	0
Joint	0	1	5	1	2	3	0	3	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Regarding importance, five ranked it as high and one ranked it as medium; regarding satisfaction, three ranked it as high, two ranked it as medium, and one ranked it as low; and regarding priority for support, three ranked it as high and three ranked it as medium.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item’s priority for support. Three ranked importance as high; three ranked satisfaction as high; and three ranked support as high.

I inquired about how the group helped with making friends, and the representative from family B said,

He would not play with other children. He would go in his room and he would play by himself. He wouldn't even do this with his brothers (she points to siblings playing together in the floor). And then he just, after he started making a couple of trips, then he started playing with the other kids and he started coming out of his shell a little bit and started to play with them.

The representative from family C explained her ranking, "High (priority) we would love for her to have friends."

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Regarding importance, two ranked it as high and one ranked it as medium; regarding satisfaction, two ranked it as medium and one ranked it as low; and regarding priority for support, three ranked it as medium.

The representative from family D explained,

And that goes back to what I said before uh not only do the parents not have the opportunity to connect with people with children with disabilities, but the children do not have an opportunity to connect to the other children with disabilities. While you want your children to be with normal developing peers, sometimes it's very intimidating for them. Samantha being the size of, you know, a 12- to 18-month-old uh, and your 1-year-old is wearing 0 to 6 months clothes, to expect her to go up to a normal typically developing 1-year-old and make a friend, at that time was not going to happen. Even now kids her age are much taller than her, much bigger than her. She won't try to make

friends. Uh this past weekend I got to see her make friends with two little girls who also have disabilities. Not to the degree Samantha does, they are more developmentally uh, they are pretty age appropriate. But size wise and medical wise they have a lot of issues too and she felt more comfortable being around them. Not completely but more comfortable just because she knew they had disabilities and they were small like she was. And that's been one of her struggles and she goes around saying "me big" "me big" that's because she is so insecure and she doesn't opportunity I don't think anywhere right gives the opportunity to for kids to make friends like that.

The representative from family F said, "Yeah, um, again, there and our intervention goal was just trying to get him caught up to where he needed to be."

Item 4 – Having a Good Relationship With Service Providers Who Work With Your Child

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County each ranked as high, medium, or low the levels of importance, satisfaction, and priority for the item. Their rankings and comments are shown here and in Table 25 combined and by county.

Table 25.

*Family Quality of Life: Disability-Related Supports Subscale – Item 4 – Having a good relationship with service providers who work with your child.*

	Importance			Satisfaction			Priority For Support		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Johnson	0	0	3	0	0	3	0	0	3
Hawkins	0	1	2	1	2	0	0	3	0
Joint	0	1	5	1	2	3	0	3	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Regarding importance, five ranked it as high and one ranked it as medium; regarding satisfaction, three ranked it as high, two ranked it as medium, and one ranked it as low; and regarding priority for support, three ranked it as high and three ranked it as medium.

Individual County Rankings for Johnson County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Three ranked importance as high; three ranked satisfaction as high; and three ranked support as high.

The representative from family A explained, "It was VERY important and we did, they were like family."

I asked the representative from family B what about her relationship with the service provider did she consider made it good? She answered, "Well they always called when they couldn't come or when they needed something done or and just ask. And I never had a problem with what they needed to get done." I inquired about what she meant by the statement "get done" and she answered, "Like if she needed papers for the school to transition to the school."

Individual County Rankings for Hawkins County. The three participating family representatives read the item and were each directed to rank as high, medium, or low the levels of importance, satisfaction, and the item's priority for support. Regarding importance, two ranked it as high and one ranked it as medium; regarding satisfaction, two ranked it as medium and one ranked it as low; and three ranked support as medium.

The representative from family D explained the ranking she gave saying,

And the reason I said medium on that is Anna and I just clicked for the first time that we met. Uh, she was wonderful with Samantha and our family from the beginning. So we never really had a need to, uh and we have a good relationship and we have not had to work on that and I know that does not always happen. Our therapists, we have been very lucky until recently to be with therapists who we connect with and who Samantha connects with and we have been with them for 3 years all the way through EI just about. Uh, you know, the only difficulty we have had is right at the end of our uh, they have changed PTs around several times. Uh while Samantha was in EI and recently and uh that's caused a problem with our relationship with the PT, one who we need a relationship with because she has arthritis but they seem to not really want to have a relationship with the parent and really are not getting down on the child's level either.

I clarified by asking if the representative from family D was ranking a medium based on the overall experience with therapists and she replied, "Uh-huh." But, she was quick to denote that those rankings did not apply to her EI Anna and stated (laughing), "We had a wonderful experience."

The representative from family E said,

Oh yes! (She laughs.) That was high and very satisfied and I think, I think that was a very big pull because if he didn't like them, you know just like with you, you're not Anna so get out of the way. I think it is a priority that, you know, that they like who the people they are working with.

The representative from family F explained,

If you don't have a good relationship with them you probably won't get a lot accomplished. And there are some of 'em that, they, I don't know, it's just a job for 'em, they don't, you walk in and they say, "Hey, yeah, uh huh," and they write it down and they say, "Well, see you 6 weeks." That's, that's aggravating.

#### Additional Post-Interview Comments

There were no additional post-interview comments from participating families in Johnson County. However, two Hawkins County families had something more to say after the formal interview session was finished. The representative from family E said,

I'd just like to say that I thank early intervention for everything they have done; I mean they have really been there for support and they have really helped us in every way for the boys. I mean, you know, they were just great and, and they have always been there. If I just want to call Anna for something, you know, I, we can and she's always made us feel like we could. Bailey learned a song and called on her cell phone and left it...you can ask her about that. (Laughs) She, she, she lets the kids know that they, you know, that they are a part of her. She don't just treat like she's there's for a minute and then gone. She treats them like they are a part of her. She has been wonderful. (She laughs.) She has, everybody has in early intervention. It's been really good. I hated to see them go out (laughs) of EI because of the way they have been treated.

I asked if there was anything that the representative from family F would have liked to have gotten and didn't. Her answer was,

Nothing but other than, I mean, I, I do think that the program helped him. You could tell a difference... once he got used to her and he started looking forward to her coming. You could tell. I mean, it was almost like he had this internal clock and he knew when

Tuesday was. I mean, he'd be up, jazzing around, and he knew that after I left for work it'd be just a little while and she'd be there. And, I mean, Dad said it only took him, or took her about four times and finally he would just, he would get her by the hand and lead her over to the middle of the room where they sit. And he would sit her down – she didn't have to make him sit down – he wanted to interact. And I really think that it helped him as far as going on into the preschool program. I think she did do a lot of good for him.

I inquired if it was good for the family F mother as well and she said,

Yeah. I mean, she was really good about leaving me reports or calling and telling me what was going on and things like that. And I could tell. You could especially tell the actual day she had been there. He kind of seemed like he was a little bit more, you know, goal oriented. He could kinda (unintelligible) his way on what he was doing. And she'd, I mean, she did a lot of, he was sort of becoming more of his own little individual before she got done.

#### Family Functioning Style Scale

I read the instructions of the Family Functioning Style Scale to each participating family representative as stated on the questionnaire. The questionnaire instructed participating family representatives to indicate how their family is like the 26 statements on the questionnaire by ranking each from one to five: Not At All Like My Family (1), A Little Like My Family (2), Sometimes Like My Family (3), Usually Like My Family (4), and Almost Always Like My Family (5).

Each participating family representative was allowed to read the statements and circle their answer independently. If necessary, the statements could have been read by me to the

participating family representative and then they could circle the ranking that was most true for their family (people living in your home during EI). Each participating family representative was asked to provide an honest opinion and feelings. The participating family representative was reminded that her family would not be like all the statements and to mark the ranking that best described how the statement applied to her family. All of the participating family representatives chose to read and rank the 26 statements of the Family Functioning Style Scale independently.

In explaining the results of the FFSS, I have reported the results by listing the statements not in the order the participating family representatives ranked the statements but in numerical order related to the five subscales: Interactional Patterns; Family Values; Coping Strategies; Family Commitment, and Resource Mobilization. None of the participating family representatives selected the Not At All Like My Family (1) ranking and only three selected the A Little Like My Family (2) ranking.

#### Family Functioning Style Subscale: Interactional Patterns

The Interactional Patterns subscale includes 10 of the FFSQ (Dunst, Trivette, & Deal, 1988) statements (5, 8, 9, 12, 13, 16, 18, 19, 21, and 25). The results of those rankings are shown here. Statements 2 and 15 are not reported because those statements were used only to test the instrument; statement 2 is essentially the same as 13 and statement 15 is essentially the same as 21.

#### Statement 5 – We Share Our Concerns and Feelings in Useful Ways.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 26 combined and by county.

Table 26.

*Family Functioning Style Subscale: Interactional Patterns – Statement 5 – We share our concerns and feelings in useful ways.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	1	1	1
Hawkins	0	0	0	2	1
Joint	0	0	1	3	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 3 (Sometimes Like My Family), three ranked 4 (Usually Like My family), and two ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family), one ranked 4 (Usually Like My Family), and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My family) and one ranked 5 (Almost Always Like My Family)

Statement 8 – We Usually Agree About the Things That are Important to Our Family.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 27 combined and by county.

Table 27.

*Family Functioning Style Subscale: Interactional Patterns – Statement 8 – We usually agree about the things that are important to our family.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	2	1
Hawkins	0	0	0	0	3
Joint	0	0	0	2	4

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Two ranked 4 (Usually Like My family) and four ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My Family) and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. Three (all participants) ranked 5 (Almost Always Like my Family).

Statement 9 – We Are Always Willing to “Pitch In” and Help Each Other.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 28 combined and by county.

Table 28.

*Family Functioning Style Subscale: Interactional Patterns – Statement 9 – We are always willing to “pitch in” and help each other.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	2	1
Hawkins	0	0	0	1	2
Joint	0	0	0	3	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Three ranked 4 (Usually Like My family) and three ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My Family) and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My Family) and two ranked 5 (Almost Always Like my Family).

Statement 12 – We Find the Time to be Together Even With Our Busy Schedules.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 29 combined and by county.

Table 29.

*Family Functioning Style Subscale: Interactional Patterns – Statement 12 – We find the time to be together even with our busy schedules.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	2	1
Hawkins	0	0	1	0	2
Joint	0	0	1	2	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 3 (Sometimes Like My Family), two ranked 4 (Usually Like My family), and three ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My Family) and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions.

One ranked 3 (Sometimes Like My Family), and two ranked 5 (Almost Always Like My Family).

Statement 13 – Everyone in Our Family Understands the “Rules” About Acceptable Ways to Act.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 30 combined and by county. Statement 2 (We usually agree about how family members should behave) is essentially the same as this statement 13.

Table 30.

*Family Functioning Style Subscale: Interactional Patterns – Statement 13 – Everyone in our family understands the “rules” about acceptable ways to act.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	1	1	1
Hawkins	0	1	1	0	1
Joint	0	1	2	1	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 2 (A Little Like My Family), two ranked 3 (Sometimes Like My Family), one ranked 4 (Usually Like My family), and two ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family), one ranked 4 (Usually Like My Family), and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 2 (A Little Like My Family), one ranked 3 (Sometimes Like My Family), and one ranked 5 (Almost Always Like My Family)

Statement 16 – We Enjoy Time Together Even if it is Doing Household Chores.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 31 combined and by county.

Table 31.

*Family Functioning Style Subscale: Interactional Patterns – Statement 16 – We enjoy time together even if it is doing household chores.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	2	1
Hawkins	0	0	0	1	2
Joint	0	0	0	3	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Three ranked 4 (Usually Like My family) and three ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My Family) and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My family) and two ranked 5 (Almost Always Like My Family).

Statement 18 – Family Members Listen to “Both Sides of the Story” During a Disagreement.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 32 combined and by county.

Table 32.

*Family Functioning Style Subscale: Interactional Patterns – Statement 18 – Family members listen to “both sides of the story” during a disagreement.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	1	2	0
Hawkins	0	0	0	3	0
Joint	0	0	1	5	0

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 3 (Sometimes Like My Family) and five ranked 4 (Usually Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family), and two ranked 4 (Usually Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. Three (all participants) ranked 4 (Usually Like My Family).

Statement 19 – We Make Time to Get Things Done That We All Agree are Important.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 33 combined and by county.

Table 33.

*Family Functioning Style Subscale: Interactional Patterns – Statement 19 – We make time to get things done that we all agree are important.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	1	0	1	1
Hawkins	0	0	0	2	1
Joint	0	1	0	3	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 2 (A Little Like My Family), three ranked 4 (Usually Like My family), and two ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 2 (A little Like My Family), one ranked 4 (Usually Like My Family), and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My family) and one ranked 5 (Almost Always Like My Family).

Statement 21 – We Usually Talk About the Different Ways We Deal With Problems and Concerns.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 34 combined and by county. Statement 15 (Our family is able to make decisions about what to do when we have problems or concerns) is essentially the same as this statement 21.

Table 34.

*Family Functioning Style Subscale: Interactional Patterns – Statement 21 – We usually talk about the different ways we deal with problems and concerns.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	1	1	1
Hawkins	0	0	1	1	1
Joint	0	0	2	2	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Two ranked 3 (Sometimes Like My Family), two ranked 4 (Usually Like My family), and two ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family), one ranked 4 (Usually Like My Family), and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family), one ranked 4 (Usually Like My family), and one ranked 5 (Almost Always Like My Family).

Statement 25 – We Try Not to Take Each Other for Granted.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 35 combined and by county.

Table 35.

*Family Functioning Style Subscale: Interactional Patterns – Statement 25 – We try not to take each other for granted.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	2	1
Hawkins	0	0	0	1	2
Joint	0	0	0	3	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Three ranked 4 (Usually Like My family) and three ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My Family) and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My family) and two ranked 5 (Almost Always Like My Family).

Family Functioning Style Subscale: Family Values

The Family Values subscale includes five of the FFSQ (Dunst et al., 1988) statements (1, 4, 6, 20, and 22). The results of those rankings are shown here.

Statement 1 – We Make Personal Sacrifices if They Help Our Family.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 36 combined and by county.

Table 36.

*Family Functioning Style Subscale: Family Values – Statement 1 – We make personal sacrifices if they help our families.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	1	2
Hawkins	0	0	0	0	3
Joint	0	0	0	1	5

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 4 (Usually Like My family) and five ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My Family) and two ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. Three (all participants) ranked 5 (Almost Always Like My Family).

Statement 4 – We Take Pride in Even the Smallest Accomplishments of Family Members.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 37 combined and by county.

Table 37.

*Family Functioning Style Subscale: Family Values – Statement 4 – We take pride in even the smallest accomplishments of family members.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	1	2
Hawkins	0	0	0	0	3
Joint	0	0	0	1	5

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 4 (Usually Like My family) and five ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My Family) and two ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. Three (all participants) ranked 5 (Almost Always Like My Family).

Statement 6 – Our Family Sticks Together No Matter How Difficult Things Get.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 38 combined and by county.

Table 38.

*Family Functioning Style Subscale: Family Values – Statement 6 – Our family sticks together no matter how difficult things get.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	2	1
Hawkins	0	0	0	1	2
Joint	0	0	0	3	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Three ranked 4 (Usually Like My family) and three ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My Family) and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My family) and two ranked 5 (Almost Always Like My Family).

Statement 20 – We Can Depend On the Support of Each Other Whenever Something Goes Wrong.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 39 combined and by county.

Table 39.

*Family Functioning Style Subscale: Family Values – Statement 20 – We can depend on the support of each other whenever something goes wrong.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	1	1	1
Hawkins	0	0	0	1	2
Joint	0	0	1	2	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 3 (Sometimes Like My Family), two ranked 4 (Usually Like My family), and three ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family), one ranked 4 (Usually Like My Family), and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My family) and two ranked 5 (Almost Always Like My Family).

Statement 22 – Our Family’s Relationships Will Outlast Our Material Possessions.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 40 combined and by county.

Table 40.

*Family Functioning Style Subscale: Family Values – Statement 22 – Our family’s relationships will outlast our material possessions.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	2	1
Hawkins	0	0	0	0	3
Joint	0	0	0	2	4

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Two ranked 4 (Usually Like My family) and four ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My Family) and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. Three (all participants) ranked 5 (Almost Always Like My Family).

#### Family Functioning Style Subscale: Coping Strategies

The Coping Strategies subscale includes four of the FFSQ (Dunst et al., 1988) statements (3, 10, 11, and 17). The results of those rankings are shown here.

#### Statement 3 – We Believe That Something Good Always Comes Out of Even The Worst Situations.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 41 combined and by county.

Table 41.

*Family Functioning Style Subscale: Coping Strategies – Statement 3 – We believe that something good always comes out of even the worst situations.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	3	0
Hawkins	0	0	1	1	1
Joint	0	0	1	4	1

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 3 (Sometimes Like My Family), four ranked 4 (Usually Like My family), and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Three (all participants) ranked 4 (Usually Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family), one ranked 4 (Usually Like My family), and one ranked 5 (Almost Always Like My Family).

Statement 10 – We Find Things to do That Keep Our Minds Off Our Worries When Something Upsetting is Beyond Our Control.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 42 combined and by county.

Table 42.

*Family Functioning Style Subscale: Coping Strategies – Statement 10 – We find things to do that keep our minds off our worries when something upsetting is beyond our control.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	1	1	1
Hawkins	0	0	1	1	1
Joint	0	0	2	2	2

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Two ranked 3 (Sometimes Like My Family), two ranked 4 (Usually Like My family), and two ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family), one ranked 4 (Usually Like My Family), and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family), one ranked 4 (Usually Like My family), and one ranked 5 (Almost Always Like My Family).

Statement 11 – We Try to “Look at the Bright Side of Things” No Matter What Happens in Our Family.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 43 combined and by county.

Table 43.

*Family Functioning Style Subscale: Coping Strategies – Statement 11 – We try to “look at the bright side of things” no matter what happens in our family.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	3	0
Hawkins	0	0	1	1	1
Joint	0	0	1	4	1

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 3 (Sometimes Like My Family), four ranked 4 (Usually Like My family), and one ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Three (all participants) ranked 4 (Usually Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family), one ranked 4 (Usually Like My family), and one ranked 5 (Almost Always Like My Family).

Statement 17 – We Try to Forget Our Problems or Concerns for a While When They Seem Overwhelming.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 44 combined and by county.

Table 44.

*Family Functioning Style Subscale: Coping Strategies – Statement 17 – We try to forget our problems or concerns for a while when they seem overwhelming.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	2	1	0
Hawkins	0	0	0	3	0
Joint	0	0	2	4	0

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Two ranked 3 (Sometimes Like My Family) and four ranked 4 (Usually Like My family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Two ranked 3 (Sometimes Like My Family) and one ranked 4 (Usually Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. Three (all participants) ranked 4 (Usually Like My family).

#### Family Functioning Style Subscale: Family Commitment

The Family Commitment subscale includes three of the FFSQ (Dunst et al., 1988) statements (23, 24, and 26). The results of those rankings are shown here.

#### Statement 23 – We Make Decisions Like Moving or Changing Jobs for the Good of All Family Members.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 45 combined and by county.

Table 45.

*Family Functioning Style Subscale: Family Commitment – Statement 23 – We make decisions like moving or changing jobs for the good of all family members.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	0	3
Hawkins	0	0	0	2	1
Joint	0	0	0	2	4

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Two ranked 4 (Usually Like My family) and four ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. Three (all participants) ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My family) and one ranked 5 (Almost Always Like My Family).

Statement 24 – We Can Depend Upon Each Other to Help Out When Something Unexpected Happens.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their

family perceives the statement. Their rankings are shown here and in Table 46 combined and by county.

Table 46.

*Family Functioning Style Subscale: Family Commitment – Statement 24 – We can depend upon each other to help out when something unexpected happens.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	1	2
Hawkins	0	0	0	1	2
Joint	0	0	0	2	4

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Two ranked 4 (Usually Like My family) and four ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My Family) and two ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My family) and two ranked 5 (Almost Always Like My Family).

Statement 26 – We Try to Solve Our Problems First Before Asking Others to Help.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their

family perceives the statement. Their rankings are shown here and in Table 47 combined and by county.

Table 47.

*Family Functioning Style Subscale: Family Commitment – Statement 26 – We try to solve our problems first before asking others to help.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	1	0	2
Hawkins	0	0	0	2	1
Joint	0	0	1	2	3

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 3 (Sometimes Like My Family), two ranked 4 (Usually Like My family), and three ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family) and two ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. Two ranked 4 (Usually Like My family) and one ranked 5 (Almost Always Like My Family).

Family Functioning Style Subscale: Resource Mobilization

The Resource Mobilization subscale includes two of the FFSQ (Dunst et al., 1988) statements (7 and 14). The results of those rankings are shown here.

Statement 7 – We Usually Ask for Help From Persons Outside Our Family if We Cannot Do Things Ourselves.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 48 combined and by county.

Table 48.

*Family Functioning Style Subscale: Resource Mobilization – Statement 7 – We usually ask for help from persons outside our family if we cannot do things ourselves.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	1	1	1	0
Hawkins	0	0	1	2	0
Joint	0	1	2	3	0

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. One ranked 2 (A Little Like My Family), two ranked 3 (Sometimes Like My Family), and three ranked 4 (Usually Like My family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 2 (A little Like My Family), one ranked 3 (Sometimes Like My Family), and one ranked 4 (Usually Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 3 (Sometimes Like My Family) and two ranked 4 (Usually Like My family).

Statement 14 – Friends and Relatives Are Always Willing to Help Whenever We Have a Problem or a Crisis.

The three participating family representatives from Johnson County and three participating family representatives from Hawkins County were each directed to rank how their family perceives the statement. Their rankings are shown here and in Table 49 combined and by county.

Table 49.

*Family Functioning Style Subscale: Resource Mobilization – Statement 14 – Friends and relatives are always willing to help whenever we have a problem or a crisis.*

<i>How is your family like the statement?</i>	1 Not At All Like My Family	2 A Little Like My Family	3 Sometimes Like My Family	4 Usually Like My Family	5 Almost Always Like My Family
Johnson	0	0	0	1	2
Hawkins	0	0	0	1	2
Joint	0	0	0	2	4

Combined County Rankings (Johnson and Hawkins). The six participating family representatives read the statement and were each directed to rank their family perception. Two ranked 4 (Usually Like My family) and four ranked 5 (Almost Always Like My Family).

Individual County Rankings for Johnson County. The three participating family representatives from Johnson County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My Family) and two ranked 5 (Almost Always Like My Family).

Individual County Rankings for Hawkins County. The three participating family representatives from Hawkins County read the statement and ranked their family perceptions. One ranked 4 (Usually Like My Family) and two ranked 5 (Almost Always Like My Family).

## CHAPTER 5

### SUMMARY OF FINDINGS AND RECOMMENDATIONS

This chapter presents answers to each of the primary research questions that directed this study. The research study was conducted using the FQOL (Beach Center on Disability, 2003). The FQOL contains five subscales: Family Interaction, Parenting, Physical or Material Well-Being, Emotional Well-Being, and Disability-Related Supports. Each of the subscales contained items unique to that subscale; participating family representatives examined each item and determined how important, how satisfied, and their priority for support regarding the item with instructions to use a Low, Medium, or High ranking for each. The conclusions are based on the participating family representatives' shared answers.

#### Family Interaction

In terms of family interaction, the participating family representatives in both Johnson and Hawkins County rated the importance and satisfaction as high for time spent together as a family, talking openly with each other, solving problems together, accomplishing goals, showing they love and care for each other, and handling life's ups and downs. Priorities for support varied, with spending time together as a family and talking openly ranked as a medium priority for support while solving problems was ranked low as a priority for support.

The findings are clear that each participating family representative in the combined counties valued and found important the need for family interaction. The levels of support regarding individual subscales revealed some variations but maintained consistency within group majority expectations and family requirements. It can be concluded that the perceived impact of early intervention services met the individual needs of each participating family representative in the area of Family Interaction and the satisfaction level was ranked high.

## Parenting

Parenting, specifically in the context of helping children learn to become independent, teaching children to get along with others, and knowing other people in your child's life, were rated high in importance by families from both Johnson and Hawkins counties. Participating family representatives also rated their perceived satisfaction as high and the priority for support as high. Participating family representatives also rated high in importance and satisfaction teaching your children to make good decisions. Families in both counties also rated this as a high priority need for support.

Participating family representatives in Johnson and Hawkins counties rated helping their children with schoolwork and activities as high in importance and satisfaction but somehow rated the priority for support as low for this area. Additionally, having time to take care of the individual needs of every child was ranked by participating family representatives in both counties as high in importance and satisfaction. There was dissimilarity among the participating family representatives regarding the rankings for priority of support as two representatives ranked support high followed by two ranking medium and two more ranking low.

From the findings, it is clear, and it can be concluded, that each participating family representative and combined counties valued and found important their parenting role. The levels of support regarding individual subscales revealed some variations but maintained consistency regarding group majority expectations and family requirements, with the exception of having time to take care of the individual needs of every child. It can be concluded that the perceived impact of early intervention services met the individual needs of each participating family representative in the area of Parenting and the satisfaction level was ranked high.

### Physical or Material Well-Being

Regarding Physical or Material Well-Being, all participating family representatives in Johnson and Hawkins Counties rated having transportation as high in importance and satisfaction but low as a priority for support. The participating family representatives rated having a way to take care of expenses as high in importance and satisfaction but low as a priority for support. Feeling safe at home, work, school, and in the community was rated high in importance and satisfaction by families in both Hawkins and Johnson Counties, but again a dissimilarity emerged among the participating family representatives regarding the rankings for priority for support, as two participating family representatives ranked support high, followed by two ranking medium, and two ranking low. Such a division was represented by the three participating family representatives from Johnson County and the three participating family representatives from Hawkins County. Getting medical care when needed was rated as high in importance and satisfaction and the need as a priority for support by participating family representatives in both Hawkins and Johnson Counties was also ranked high. However, although getting dental care was rated high in importance and satisfaction by participating family representatives in both counties, it was not rated high as a priority for support but low. A distinction was noted by participating family representatives regarding this subscale as a low priority for support.

From the findings, it is clear and it can be concluded that each participating family representative and combined counties valued and found important their Physical or Material Well-Being. The levels of support regarding individual subscales revealed some variations but maintained consistency regarding group majority expectations and family requirements with the exception of feeling safe at home, work, school, and in the community. It can be concluded that the perceived impact of early intervention services met the individual needs of each participating

family representative in the area of Physical or Material Well-Being, as the satisfaction level was ranked high.

### Emotional Well-Being

The families in both Johnson and Hawkins County rated having the support needed to relieve stress as high in importance and somewhat satisfied but low in need for priority of support. They rated having friends or others who provide support as high in importance and satisfaction but somewhat necessary in terms of priority of support. Interestingly, they rated having help from outside the family to take care of the individual needs of each family member as high in importance, satisfaction, and as a priority need. Equally as interesting were the participating family representative rankings for having time to pursue personal interests. Individual Johnson County participating family representatives ranked it differently as each ranked high, medium, and low for importance. The Hawkins County participants all ranked importance as medium. The satisfaction varied as Johnson County was highly satisfied but Hawkins County only medium while the desire for support was moderate.

From the findings, it is clear and it can be concluded that each participating family representative and combined counties valued and found important their family's Emotional Well-Being. The levels of support regarding individual subscales revealed some variations but maintained consistency regarding group majority expectations and family requirements, with the exception of having time to pursue personal interests. It can be concluded that the perceived impact of early intervention services met the individual needs of each participating family representative in the area of Emotional Well-Being and the satisfaction level was ranked high.

### Disability-Related Supports

Having support for their children to make progress at school or in the workplace and having support for their children to make progress at home was rated as high in importance, satisfaction, and the needed priority for support by families in both Johnson and Hawkins Counties. Having support for their child to make friends was rated high in importance, but moderate in satisfaction and priority for support. Having a good relationship with service providers was equally important for participating family representatives from both counties as each were highly satisfied and each ranked the priority for support as high.

From the findings, it is clear and it can be concluded that each participating family representative in the combined counties valued and found important their family's Disability-Related Supports. The levels of support regarding individual subscales revealed some variations but maintained consistency regarding group majority expectations and family requirements, with the exception of having time to pursue personal interests. It can be concluded that the perceived impact of early intervention services met the individual needs of each participating family representative in the area of Disability-Related Services and the satisfaction level was ranked high.

### Recommendations to Improve Practice

Practitioners should consider these recommendations: To improve family satisfaction with early intervention services as related to family functioning, it is recommended that all professionals working with young children with disabilities and their families come to understand, respect, and value the vital role parents fulfill in their young child's life. Such an understanding requires a reverence for cultural diversity far beyond one's skin color, socioeconomic level, or faith. It requires a truer understanding of self that involves examining

one's own prejudices in order to accept others wholly, and the realization that in order to facilitate others' needs, one must listen with a heart that truly hears what is being shared by parents, and acting on that... not commanding one's own will or judgments.

### Future Research

These are suggested areas of research:

1. Future research is necessary to explore the continued professional barriers that exist regarding respecting parents as resources;
2. Develop a method for training professionals on the importance of family functioning as it relates to early intervention;
3. Expand training to include education and supervision of early intervention service professionals in all fields;
4. Conduct further research to understand how family functioning is influenced by demographics relates to formal and informal support; and
5. Conduct further research on the father's role in early intervention as it relates to family functioning and such effects on child outcomes.
6. Examine and research the data from a social validity standpoint.

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## APPENDICES

### APPENDIX A

#### Diagnosis List

Diagnosis	ICD-9 Code
Agenesis or partial agenesis of the Corpus Callosum	742.2
Alagille Syndrome (aka Arteriohepatic Dysplasia)	759.89
Angelman Syndrome	759.89
Aniridia	743.45
Anterior Horn Cell Disorders – Werdnig-Hoffman Syndrome	335
Aphakia	379.31
Argininemia	270.6
Arthrogryposis	728.3
Autism, Autistic	299
Bardet-Biedl Syndrome	759.89
Beckwith-Wiedemann Syndrome	759.89
Bronchopulmonary Dysplasia	770.7
Cerebral Palsy	343.9
CHARGE Syndrome	759.89
Chromosome Abnormality - Unbalanced Numerical	758.5
Chromosome Abnormality – Numerical Trisomy 1-22	758.5
Cockayne Syndrome	759.89
Coloboma	743.49
Cone Dystrophy	783.9
Congenital Brain Malformation	742.9
Congenital Cataract	743.3
Congenital Cytomegalovirus	771.1
Congenital Glaucoma (Buphthalmos)	743.2
Congenital Myopathy	359.9
Congenital Rubella	771
Comella de Lange Syndrome	759.89
Cranioostenosis	756
Cri-du-chat Syndrome	758.31
Di George Syndrome (22q11.2 deletion)	279.11
Down Syndrome	758
Dravet Syndrome (myoclonic epilepsy)	345.1
Encephalocele	742
Epilepsy (also Seizure Disorder)	345.9
Failure to Thrive - Newborn (Birth – 30 days)	779.34
Failure to Thrive – Child (31 days through 2 years)	783.41
Familial Exudative Vitreoretinopathy (FEVR)	362.12
Fetal Alcohol Syndrome	760.71

Fetal Hydantoin Syndrome	779.89
Fetal Valproate Syndrome	655.5
FG Syndrome	759.89
Fragile X Syndrome	759.83
Galactosemia	271.1
Hearing Loss/Impairment, unspecified	389.9
Hearing Loss/Impairment, specified	389.8
Hemiplegia/Hemiparesis	343.1
Homonymous Hemianopsia	368.46
Hunter Syndrome	277.5
Hurler Syndrome	277.5
Hydrocephalus	331.4
Hypertension, Primary or Persistent Pulmonary of Newborn	747.83
Hypothyroidism untreated (acquired)	244.9
Hypoxic Ischemic Encephalopathy - Mild	768.71
Hypoxic Ischemic Encephalopathy – Moderate	768.72
Hypoxic Ischemic Encephalopathy – Severe	768.73
Infantile Gaucher Disease	272.7
Klinefelter's Syndrome	758.7
Klippel-Trenaunay Syndrome	759.89
Kugelburg-Wehlander Syndrome	335.11
Lead Exposure greater than 10 micrograms of lead per deciliter of blood	V15.86
Leber's Congenital Amaurosis	362.76
Lesch-Nyhan Syndrome	277.2
Lowe (-Terrey-MacLachlan) Syndrome	270.8
Maple Syrup Urine Disease	270.3
Methylmalonic Acidemia	270.3
Microcephalus	742.1
Microphthalmos	743.1
Mitochondrial Disorder	277.87
Mobius Syndrome (Motor Neuron)	759.89
Motor Neuron Diseases	335.2
Mucopolipidoses (I-Cell)	277.5
Muscular Dystrophy - Duchenne Type	359.1
Muscular Dystrophy - Becker Type	359.22
Neonatal Abstinence Syndrome	779.5
Neurofibromatosis Type 1	237.71
Niemann-Pick Disease	272.2

Noonan Syndrome	759.89
Optic Atrophy	377.1
Optic Nerve Hypoplasia	377.43
Paraplegia	344.1
Pervasive Developmental Disorder	315.8
Peters' Anomaly	743.44
Phthisis Bulbi	360.41
Pierre-Robin Deformity or Syndrome	756
Pigment Retinopathy	362.74
PKU untreated	270.1
Phelan McDermid Syndrome (22q13)	758.39
Prader-Willi Syndrome	759.81
Prematurity: Less than 24 completed weeks of gestation	765.21
Prematurity: 24 completed weeks of gestation	765.22
Prematurity: 25-26 completed weeks of gestation	765.23
Prematurity: 27-28 completed weeks of gestation	765.24
Prematurity: 29-30 completed weeks of gestation	765.25
Prematurity: 31-32 completed weeks of gestation *	765.26
Prematurity: 32-33 completed weeks of gestation *	765.27
Prematurity: 34-35 completed weeks of gestation *	765.28
Prune Belly Syndrome	756.71
Retinal Detachment	361.9
Retinoblastoma	190.5
Retinopathy of Prematurity (ROP) Grade 3	362.25
Retinopathy of Prematurity (ROP) Grade 4	362.26
Retinopathy of Prematurity (ROP) Grade 5	362.27
Rett Syndrome	330.8
Reduction Deformities of brain	742.2
Rubenstein-Taybi Syndrome	759.89
Russell-(Silver) Syndrome	759.89
Sanfilippo Syndrome	277.5
Schizencephaly	742.4
Seizure Disorder (also Epilepsy)	345.9
Shaken Baby Syndrome	995.55
Sly Syndrome	277.5
Soto Syndrome	253.1
Spina Bifida	741.9
Spinal Cord Injury with Cord Involvement - lumbar	952.2

Spinal Cord Injury with Cord Involvement - sacral	952.3
Sticklers Syndrome	759.89
Sturge-Weber (-Dimitri) Syndrome	759.6
Tay-Sachs Disease	330.1
TORCH complex - Toxoplasmosis, Congenital	771.2
TORCH complex – Toxoplasmosis, Prenatal	655.4
Traumatic Brain Injury	854
Treacher Collins Syndrome	759.5
Tuberous Sclerosis	759.5
Turner Syndrome	758.6
VATER Syndrome	759.89
Velo-cardio-facial Syndrome (22q11.2 deletion)	758.32
Ventilator Dependent	V46.11
Visual Impairment - Legal Blindness	369.4
Visual Impairment - Totally Blind	369
Visual Impairment – Unspecified Visual Loss	369.9
Vitreous anomalies	743.51
Wardenburg Syndrome, Types I and II	270.2
Werdnig-Hoffmann Syndrome	759.89
Williams Syndrome	759.89
Wolf-Hirschhorn Syndrome	758.39

APPENDIX B  
Family Functioning Style Questionnaire

## Family Functioning Style Questionnaire

Angela G. Deal, Carol M. Trivette and Carl J. Dunst

**INSTRUCTIONS:** Every family has strengths and capabilities, although different families have different ways of using their abilities. This questionnaire asks you to indicate whether or not your family is characterized by 26 different qualities. Please read each statement, then circle the response which is most true for your family (people living in your home). Please give your honest opinions and feelings. Remember that your family will not be like all the statements.

How is your family like the following statements:	Not At All Like My Family	A Little Like My Family	Sometimes Like My Family	Usually Like My Family	Almost Always Like My Family
1. We make personal sacrifices if they help our family.	1	2	3	4	5
2. We usually agree about how family members should behave.	1	2	3	4	5
3. We believe that something good always comes out of even the worst situations.	1	2	3	4	5
4. We take pride in even the smallest accomplishments of family members.	1	2	3	4	5
5. We share our concerns and feelings in useful ways.	1	2	3	4	5
6. Our family sticks together no matter how difficult things get.	1	2	3	4	5
7. We usually ask for help from persons outside our family if we cannot do things ourselves.	1	2	3	4	5
8. We usually agree about the things that are important to our family.	1	2	3	4	5
9. We are always willing to "pitch in" and help each other.	1	2	3	4	5
10. We find things to do that keep our minds off our worries when something upsetting is beyond our control.	1	2	3	4	5
11. We try to "look at the bright side of things" no matter what happens in our family.	1	2	3	4	5
12. We find the time to be together even with our busy schedules.	1	2	3	4	5

<b>How is your family like the following statements:</b>	<b>Not At All Like My Family</b>	<b>A Little Like My Family</b>	<b>Sometimes Like My Family</b>	<b>Usually Like My Family</b>	<b>Almost Always Like My Family</b>
13. Everyone in our family understands the “rules” about acceptable ways to act.	1	2	3	4	5
14. Friends and relatives are always willing to help whenever we have a problem or a crisis.	1	2	3	4	5
15. Our family is able to make decisions about what to do when we have problems or concerns.	1	2	3	4	5
16. We enjoy time together even if it is doing household chores.	1	2	3	4	5
17. We try to forget our problems or concerns for a while when they seem overwhelming.	1	2	3	4	5
18. Family members listen to “both sides of the story” during a disagreement.	1	2	3	4	5
19. We make time to get things done that we all agree are important.	1	2	3	4	5
20. We can depend on the support of each other whenever something goes wrong.	1	2	3	4	5
21. We usually talk about the different ways we deal with problems and concerns.	1	2	3	4	5
22. Our family’s relationships will outlast our material possessions.	1	2	3	4	5
23. We make decisions like moving or changing jobs for the good of all family members.	1	2	3	4	5
24. We can depend upon each other to help out when something unexpected happens.	1	2	3	4	5
25. We try not to take each other for granted.	1	2	3	4	5
26. We try to solve our problems first before asking others to help.	1	2	3	4	5

(This chart may be duplicated without permission with proper acknowledgment and citation)

## APPENDIX C

### Request Letter to Participant

March 30, 2010

John Doe  
123 Any Street  
Hometown, TN 123456

Dear Mrs. Murrell,

My name is Donna Nelson and I am a Doctoral Candidate at East Tennessee State University in Johnson City, TN. This letter is to request your help in gathering information for my research project. I will be seeking information from families who have been in an early intervention program and asking them to share their experience during their time in the program. I hope the information that you and other families share will help improve services provided by those who serve you, and give you a voice in how best to meet the family's needs as well as those of the child.

I will need to meet with you for about an hour. During the hour I will be asking you questions about your experience and will also have a short yes or no questionnaire for you to fill-out. You can choose where you would like to meet, your home or another location. Your name will not be used in connection with anything you say or any question you answer on the questionnaire. A Wal-Mart gift card (\$25) will be given to those selected to participate in this research project within two weeks after completion of the project.

If you would like to be a participant check the **yes line**. If you do not want to be a participant check the **no line**. Please place the letter in the self-addressed stamped envelope and return to me. If you are selected as a participant you will be notified within two weeks. At the time of notification I will answer any questions you might have and let you know what I am expected to do before I can meet with you.

Thank you.  
Sincerely,

Donna E. Nelson,  
Researcher  
nelsonde@etsu.edu

\_\_\_\_\_ **Yes**, I would like to be considered as a participant

\_\_\_\_\_ **No**, I do not want to be considered as a participant

## APPENDIX D

### Initial Phone Call Contact Guide

#### Call Family

**Family Answers:** Hello

**Researcher:** This is Donna Nelson and I am following up on a letter that you received a few weeks ago regarding your help in a research project. With whom am I speaking with?

➤ **Someone wants researcher to Call Back**

**Family Responds:** This is John Doe, my wife is not here right now; can you call back in about an hour?

**Researcher Responds:** Yes, I will call back and thank you.

➤ **You talk to the family member**

**Family Responds:** You are talking to Sue Doe and yes, I am interested in helping.

**Researcher:** Thank you Ms. Doe for your willingness to help. I would like to talk to you about your families past experiences in the early intervention system. Your help in this project will provide you a chance to help other families have a better quality of life while they are in an early intervention program.

**Family responds:** What do I need to do?

**Researcher responds:** I will need to spend about one hour talking with you and if you are comfortable with me coming to your house I can do that or we can meet somewhere, whatever is best for you. For helping in the project your family will receive a \$25.00 gift card to Wal-Mart. What is a good for me to come and talk with you?

**Family Responds:** Wednesdays are good for me.

**Researcher:** How about 1:00?

**Family Responds:** No, Sarah Doe eats then, how about 2:30?

**Researcher Responds:** Okay, 2:30 on Wednesday, December 1<sup>st</sup> is good for me to. Can you give me directions to your house?

**Family Responds:** Family gives directions to their house

**Researcher Responds:** Okay, I think I know where that is and I look forward to seeing you on Wednesday, December 1<sup>st</sup> at 2:30.

**Phone conversation ends.**

➤ **I Would Prefer to Meet You Somewhere Else Response**

**Family Responds:** I think I had rather meet you somewhere else then my house.

**Researcher Responds:** (Respond with some type of central location that is conducive to conversation - like a library.) Do you know where the library is?

**Family Responds:** Yes.

**Researcher Responds:** What days are best for you?

**Family Responds:** Wednesdays are good for me.

**Researcher Responds:** How about 1:00?

**Family Responds:** No, Sarah eats then, how about 2:30?

**Researcher Responds:** Okay, 2:30 on Wednesday, December 1<sup>st</sup> is good for me to. I will call before I come to confirm our meeting.

**Family Responds:** Okay

**Researcher:** I look forward to seeing you on Wednesday, December 1<sup>st</sup> at 2:30 at the library.

**Phone Conversation Ends.**

APPENDIX E

Participant Selection Guide

**I. Demographic Information:**

Name of Person Completing Form: \_\_\_\_\_

Relation to Child: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ County: \_\_\_\_\_

Home Phone: \_\_\_\_\_ Cell Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email Address: \_\_\_\_\_

Alternative Phone and Name of Person: \_\_\_\_\_

**II. Early Intervention Experience**

Age Child Entered Program: \_\_\_\_\_ Exited: \_\_\_\_\_

Reason Exited Program: \_\_\_\_\_

Did your child continue receiving special education services upon exiting EI services? Y/N

If yes what type of service: \_\_\_\_\_

If no describe: \_\_\_\_\_

EI Services were Received: 1x4 weeks 2x4 weeks/Other: \_\_\_\_\_

Service Type	Yes	No	How often	Home Based/Office
Speech				
Occupational Therapy				
Physical Therapy				
Other				

**III. Highest School Attended:**

Some HS: Y/N

Graduated HS: Y/N

GED: Y/N

Some College: Y/N

Graduated College: Y/N

Post Graduate: Y/N

**Additional Information:**

Child's Diagnosis: \_\_\_\_\_

Brothers/Sisters Older than Diagnosed Child: 1 2 3 4 5 6 other: \_\_\_\_\_

Brothers/Sisters Younger than Diagnosed Child: 1 2 3 4 5 6 other: \_\_\_\_\_

Number of Siblings with Disabilities: \_\_\_\_\_

Number of Siblings currently receiving EI: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

## APPENDIX F

### Preliminary Interview Guide

#### Families

#### I. Introduction:

##### A. Statement of Intent:

The intent of this study is to describe the perceived impact of early intervention services on families living in Appalachian region of northeast Tennessee who recently exited an early program.

#### II. Informed Consent:

I assure you that your participation in this study will remain confidential. I may use some quotes in my final research report. However, I will not use your name in association with these quotes, nor will I use any identifiers that link you to your words. This session should take approximately one hour. I am tape-recording this session with two tape recorders just in case one fails, I will have a back-up. I am tape-recording our session to have an accurate record of your thoughts, comments, and experiences. Do you have any questions before we start the tapes recorders?

##### A. Activate Tape Recorder:

Do I have your permission to turn on the recorders and record our conversation? Upon receiving the proper permission, the researcher will proceed to the interview questions?

#### III. Main Interview Questions:

For each of the following items the family member participating in the study will be asked by the researcher how **important** each item is for them. The participant will respond by stating Low (L), Medium (M), or High (H). Next, the researcher will ask how **satisfied** they are by stating Low (L), Medium (M), or High (H). The researcher will then ask the participant to rank the item for **priority** by stating Low (L), Medium (M), or High (H). The researcher will finally ask if there is something they would like to have **received support** on in order to make things easier and those notes will be marked under Info.

- Family Interaction
  - 1) Spending time together as a family
  - 2) Talking openly with each other
  - 3) Solving problems together
  - 4) Supporting each other to accomplish goals
  - 5) Showing that you love and care for each other
  - 6) Handling life's ups and downs
- Parenting
  - 1) Helping your children learn to be independent
  - 2) Helping your children with schoolwork and activities
  - 3) Teaching your children how to get along with others

- 4) Teaching your children to make good decisions
- 5) Knowing other people in your children's lives
- 6) Having time to take care of the individual needs of every child
- Physical/Material Well-Being
  - 1) Having transportation
  - 2) Having a way to take care of your expenses
  - 3) Feeling safe at home, work, school, and in the community
  - 4) Getting medical care when needed
  - 5) Getting dental care when needed
- Emotional Well-Being
  - 1) Having the support needed to relieve stress
  - 2) Having friends or others who provide support
  - 3) Having time to pursue personal interests
  - 4) Having help from outside the family to take care of the individual needs of each family member
- Disability-Related Supports
  - 1) Having support for your child to make progress at school or workplace
  - 2) Having support for your child to make progress at home
  - 3) Having support for your child to make friends
  - 4) Having a good relationship with service providers who work with your child

**IV. Conversation Guide** (Beach Center on Disabilities, University of Kansas, FQOL Conversation Guide, 2003)

The family member participating in the study will be asked by the researcher how **important** each item is for them. The participant will respond by stating Low (L), Medium (M), or High (H) and the researcher will mark accordingly. Next the researcher will ask how **satisfied** they are by stating Low (L), Medium (M), or High (H) and the researcher will mark appropriately. The researcher will then ask the participant to rank the item for **priority** by stating Low (L), Medium (M), or High (H). The researcher will ask if there is something they would like to have **received support** for in order to make things easier and those notes will be marked under the Information area. If the participant appears to be struggling, rephrase the question and repeat any information they shared in determining the item priority (i.e. "You just shared with me..." or these areas might pertain to IFSP goals) additionally, the researcher may ask the participant for examples allowing for clarification. Record the participant's suggestions under item of support.

**V. Next the researcher will administer the Family Functioning Style Questionnaire.**

The researcher will read the instructions: Every family has strengths and capabilities although different families have different ways of using their abilities. This questionnaire asks you to tell the researcher whether or not your family can be described by the following statements. The researcher can read the questions to you and circle your answer or you can read the statements and circle your own answer that is most true for your family (people living in your home during EI). Please give your honest opinions and feelings. Your family will not be like all the statements. You will mark the answer that

best describes how the statement read applies to your family: Not At All Like My Family (1), A Little Like My Family (2), Sometimes Like My Family (3), Usually Like My Family (4), and Almost Always Like My Family (5).

The questions are as follows:

- 1) We make personal sacrifices if they help our families.
- 2) We usually agree about how family members should behave.
- 3) We believe that something good always comes out of even the worst situations.
- 4) We take pride in even the smallest accomplishments of family members.
- 5) We share our concerns and feelings in useful ways.
- 6) Our family sticks together no matter how difficult things get.
- 7) We usually ask for help from persons outside our family if we cannot do things ourselves.
- 8) We usually agree about the things that are important to our family.
- 9) We are always willing to “pitch in” and help each other.
- 10) We find things to do that keep our minds off our worries when something upsetting is beyond our control.
- 11) We try to “look at the bright side of things” no matter what happens in our family.
- 12) We find the time to be together even with our busy schedules.
- 13) Everyone in our family understands the “rules” about acceptable ways to act.
- 14) Friends and relatives are always willing to help whenever we have a problem or a crisis.
- 15) Our family is able to make decisions about what to do when we have problems or concerns.
- 16) We enjoy time together even if it is doing household chores.
- 17) We try to forget our problems or concerns for a while when they seem overwhelming.
- 18) Family members listen to “both sides of the story” during a disagreement.
- 19) We make time to get things done that we all agree are important.
- 20) We can depend on the support of each other whenever something goes wrong.
- 21) We usually talk about the different ways we deal with problems and concerns.
- 22) Our family’s relationships will outlast our material possessions.
- 23) We make decisions like moving or changing jobs for the good of all family members.
- 24) We can depend upon each other to help out when something unexpected happens.
- 25) We try not to take each other for granted.
- 26) We try to solve our problems first before asking others to help.

## **VI. Conclusion:**

- A.** Based on the information that has been shared the researcher must remember to summarize participant explanations in attempting to understand the participant’s world. Other phrases that might be used are: “Is my summary correct?” “Please remember I plan to include your thoughts in my research findings.” “What I hear you saying is...” “Based on your thoughts about spending time with your family and your satisfaction level with time spent with family, what would you want me to include in this research project that we might not have covered?” “Likewise, based on your thoughts about the importance of having support to relieve stress

and your satisfaction regarding these supports, what would you want me to include in this research project that we might not have covered?”

- B.** Our session time is now over. Do you have any additional comments or something you might like to share before I stop the tape-recorders?
- C.** Turn off the tape-recorders. Do you have any comments off the record since we have now turned off the tape-recorders?
- D.** I will be calling you in a couple of weeks to go over our notes and to make sure that I have recorded your perceptions correctly. To show my appreciation, I would like to give you a \$25 Wal-Mart gift card as I promised in the Request Letter at the end of that meeting. I will ask you to sign a verification form stating you received your \$25 Wal-Mart gift card (see Appendix I).
- E.** Again, I wish to thank you for your participation in this project and I will be calling you in a couple of weeks to go over our notes.

This Interview Guide is one that I developed by adapting aspects of the Family Quality of Life Conversation Guide (2003) and the Family Functioning Style Questionnaire (see Appendix B).

## APPENDIX G

### Data Verification Phone Call Contact Guide

#### Call Family

**Family Answers:** Hello

**Researcher:** This is Donna Nelson and I am calling about the research project for families whose children have transitioned out of early intervention. May I speak with Sue?

➤ **Someone Wants Researcher to Call Back**

**Family Responds:** This is John Doe, my wife is not here right now; can you call back in about an hour?

**Researcher Responds:** Yes, I will call back and thank you.

➤ **Family is Interested in Talking**

**Family Responds:** You are talking to Sue Doe.

**Researcher:** Hey Sue, Do you remember me, I came to your house and we talked about the early intervention research project?

**Family Responds:** Yes, I remember, how you are?

**Researcher Responds:** I am fine thank you and you?

**Family Responds:** We have been a little sick but we are better now.

**Researcher Responds:** Thank you Ms. Doe for your willingness to talk to me. This is the part of the project where I come back to talk to you about your answers to my questions, to make sure I have correctly understood what you said to me. I would like to schedule about one hour to come and talk with you.

**Go to the \* that applies.**

➤ **Meet Family at Home:**

**Researcher:** Ask what days are best?

**Family Responds:** Wednesdays are good for me.

**Researcher Responds:** How about 1:00?

**Family Responds:** No, Sarah Doe eats then, how about 2:30?

**Researcher Responds:** Okay, 2:30 on Wednesday, December 1<sup>st</sup> is good for me too. I will call before I come to see if you have additional questions regarding the letter that I will be sending that covers what we just talked about on the phone and to confirm our meeting.

**Family Responds:** Okay

**Researcher:** I look forward to seeing you on Wednesday, December 1<sup>st</sup> at 2:30.

**Phone conversation Ends.**

➤ **Meet Family at Location other Than Home**

**Researcher Responds:** I assume you would like to meet at the library (state the location of previous meeting) like last time?

**Family Responds:** Yes, that will be fine with me.

**Researcher Responds:** What days are best for you?

**Family Responds:** Wednesdays are good for me.

**Researcher Responds:** How about 1:00?

**Family Responds:** No, Sarah Doe eats then, how about 2:30?

**Researcher Responds:** Okay, 2:30 on Wednesday, December 1<sup>st</sup> is good for me too. I will call before I come to confirm the time we have scheduled.

**Family Responds:** Okay

**Researcher:** I look forward to seeing you on Wednesday, December 1<sup>st</sup> at 2:30 at the library.

**Phone Conversation Ends.**

➤ **Meet Family at Alternative Location/Decided to Meet at Home**

**Researcher Responds:** I assume you would like me to meet at the library (state the location of previous meeting) like last time?

**Family Responds:** No, I think this time I would like for you to come to my house.

**Researcher Responds:** Okay, I can do that, can you give me directions?

**Family Responds:** Give directions.

**Researcher Responds:** Repeats directions and ask for landmarks.

**Researcher Responds:** What days are best for you?

**Family Responds:** Wednesdays are good for me.

**Researcher Responds:** How about 1:00?

**Family Responds:** No, Sarah Doe eats then, how about 2:30?

**Researcher Responds:** Okay, 2:30 on Wednesday, December 1<sup>st</sup> is good for me too. I will call before I come to confirm the time we have scheduled.

**Family Responds:** Okay

**Researcher:** I look forward to seeing you on Wednesday, December 1<sup>st</sup> at 2:30 at the library.

**Phone Conversation Ends.**

## APPENDIX H

### Data Verification Interview Guide

#### Families

##### I. Introduction:

###### A. Statement of Intent:

The intent of this study is to describe the perceived impact of early intervention services on families living in Appalachian region of northeast Tennessee who recently exited an early program.

##### II. Informed Consent:

I assure you that your participation in this study will remain confidential. I may use some quotes in my final research report. However, I will not use your name in association with these quotes, nor will I use any identifiers that link you to your words. This session should take approximately one hour. I will not be tape-recording this session as was done in the previous session.

##### III. Main Interview Questions:

- Family Interaction
  1. Spending time together as a family
  2. Talking openly with each other
  3. Solving problems together
  4. Supporting each other to accomplish goals
  5. Showing that you love and care for each other
  6. Handling life's ups and downs
- Parenting
  1. Helping your children learn to be independent
  2. Helping your children with schoolwork and activities
  3. Teaching your children how to get along with others
  4. Teaching your children to make good decisions
  5. Knowing other people in your children's lives
  6. Having time to take care of the individual needs of every child
- Physical/Material Well-Being
  1. Having transportation
  2. Having a way to take care of your expenses
  3. Feeling safe at home, work, school, and in the community
  4. Getting medical care when needed
  5. Getting dental care when needed
- Emotional Well-Being
  1. Having the support needed to relieve stress
  2. Having friends or others who provide support

3. Having time to pursue personal interests
  4. Having help from outside the family to take care of the individual needs of each family member
- Disability-Related Supports
    1. Having support for your child to make progress at school or workplace
    2. Having support for your child to make progress at home
    3. Having support for your child to make friends
    4. Having a good relationship with service providers who work with your child

**IV. Conversation Guide** (Beach Center on Disabilities, University of Kansas, FQOL Conversation Guide, 2003)

The family member participating in the study was asked by the researcher how **important** each item is for them. The participant responded by stating Low (L), Medium (M), or High (H) and the researcher marked accordingly and now verifies their response. Next the researcher asked how **satisfied** they were by stating Low (L), Medium (M), or High (H) and the item was marked appropriately and is now verified. The researcher then asked the participant to rank the item for **priority** by stating Low (L), Medium (M), or High (H). The researcher asked if there is something they would like to have **received support** on in order to make things easier and those notes were marked under the Information area and verifies their response. If the participant appears to be struggling rephrase the question and repeat any information they shared in determining the item priority (i.e. “You just shared with me...” or these areas might pertain to IFSP goals) additionally, the researcher may ask the participant for additional examples allowing for clarification. Additional participant examples or perceptions will be recorded at this meeting.

**V. Next the researcher will verify administration of the Family Functioning Style Questionnaire.**

The researcher will read the instructions: Every family has strengths and capabilities although different families have different ways of using their abilities. This questionnaire asks you to tell the researcher whether or not your family can be described by the following statements. The researcher can read the questions to you and circle your answer or you can read the statements and circle your own answer that is most true for your family (people living in your home during EI). Please remember that you were asked to give your honest opinions and feelings. You are also reminded that your family will not be like all the statements. You should re-read the marked answers that best describe how the statement you read applies to your family: Not At All Like My Family (1), A Little Like My Family (2), Sometimes Like My Family (3), Usually Like My Family (4), and Almost Always Like My Family (5).

The questions are as follows:

- 1) We make personal sacrifices if they help our families.
- 2) We usually agree about how family members should behave.
- 3) We believe that something good always comes out of even the worst situations.
- 4) We take pride in even the smallest accomplishments of family members.

- 5) We share our concerns and feelings in useful ways.
- 6) Our family sticks together no matter how difficult things get.
- 7) We usually ask for help from persons outside our family if we cannot do things ourselves.
- 8) We usually agree about the things that are important to our family.
- 9) We are always willing to “pitch in” and help each other.
- 10) We find things to do that keep our minds off our worries when something upsetting is beyond our control.
- 11) We try to “look at the bright side of things” no matter what happens in our family.
- 12) We find the time to be together even with our busy schedules.
- 13) Everyone in our family understands the “rules” about acceptable ways to act.
- 14) Friends and relatives are always willing to help whenever we have a problem or a crisis.
- 15) Our family is able to make decisions about what to do when we have problems or concerns.
- 16) We enjoy time together even if it is doing household chores.
- 17) We try to forget our problems or concerns for a while when they seem overwhelming.
- 18) Family members listen to “both sides of the story” during a disagreement.
- 19) We make time to get things done that we all agree are important.
- 20) We can depend on the support of each other whenever something goes wrong.
- 21) We usually talk about the different ways we deal with problems and concerns.
- 22) Our family’s relationships will outlast our material possessions.
- 23) We make decisions like moving or changing jobs for the good of all family members.
- 24) We can depend upon each other to help out when something unexpected happens.
- 25) We try not to take each other for granted.
- 26) We try to solve our problems first before asking others to help.

## **VI. Conclusion:**

- A. Based on the information that has been shared the researcher has verified the participants’ explanations as a means of understanding their world. Other phrases that might be used are: “Is my summary correct?” “Please remember I plan to include your thoughts in my research findings.”
- B. Our verification session time is now over.
- C. Do you have any additional comments off the record, since we have now completed our session?
- D. To show my appreciation I will now give you the \$25 Wal-Mart gift card that I promised in the Request Letter. Please sign and date the Verification Form stating you have been given your \$25 Wal-Mart gift card. (see Appendix I)
- E. Again, I wish to thank you for your participation in this project; it would not have been possible without your help. I will be sending you a copy of the finished document if you would like.

APPENDIX I

Gift Card Signature Form

I am signing this form to verify that I (write your name) \_\_\_\_\_  
have received my \$25 Wal-Mart Gift card for participation in a research project that was led by  
Donna E. Nelson of East Tennessee State University.

Signature: \_\_\_\_\_

Please Print Name: \_\_\_\_\_

Date: \_\_\_\_\_

Witnessed by: \_\_\_\_\_

Please Print Name: Donna E. Nelson, Doctoral Candidate

Education and Policy Analysis

East Tennessee State University

Date: \_\_\_\_\_

**Thank You.**

## APPENDIX J

### Informed Consent

#### **EAST TENNESSEE STATE UNIVERSITY INSTITUTIONAL REVIEW BOARD**

This Informed Consent will explain about being a participant in a research study. It is important that you read this material carefully or have this document read to you and then decide if you wish to be a volunteer.

#### PURPOSE:

The Purpose of the research study is to hear from you how early intervention services has impacted your family. It will be through the interview questions that the researcher asks you that you can share and describe your own personal experiences with early intervention and those experiences affected the lives of not only your child but your family as well.

#### DURATION:

You are being asked to voluntarily participate in two interviews with the researcher, at locations that you chose. Each interview will take about an hour.

#### PROCEDURES:

The researcher will interview you at a location of your choosing. During the first interview you will be asked questions about the types of services your child received and how they affected your family's quality of life. You will also be asked questions about what you believe are your family's important strengths and capabilities and how they help your family to function. In addition, with your permission the researcher will review your child's records from the early intervention program for information about your child's diagnosis and early intervention experience.

#### ALTERNATIVE PROCEDURES/TREATMENTS:

Since this research does not involve treatment, there is no alternative procedure/treatment available to you if you elect not to participate in this study.

#### POSSIBLE RISKS/DISCOMFORTS:

The researcher does not expect any possible risks and/or discomforts for participants involved in this research.

#### POSSIBLE BENEFITS:

The possible benefits of you taking part in this study is that the information you share about your early intervention experiences can be very helpful to professionals who work with families who have children with disabilities. Since you are providing information about your own individual personal family experiences and how those experiences with early intervention contributed to your family's quality of life you may be helping professionals to better understand families living in the Appalachian counties of northeast Tennessee. Additionally, you will be providing information about what you believe are your family's strengths and how those strengths help your family to function. Your experiences can help professionals who work in early intervention to better understand what makes families strong.

#### FINANCIAL COSTS:

There will be no out-of-pocket costs to you for voluntarily participation in this research if we are meeting you at your home. If you have decided to meet me at another location for the interviews, then at that point you will have the responsibility of providing your own transportation to the location you have chosen.

COMPENSATION IN THE FORM OF PAYMENTS TO RESEARCH PARTICIPANTS:

Because this is a small research study and the researcher as the principal investigator, Donna E. Nelson is offering to you a gift certificate in the amount of \$25.00 to Wal-mart to be given within two weeks of the completion of the second interview.

VOLUNTARY PARTICIPATION: Participation in this research experiment is voluntary. You may refuse to participate.

You can quit at any time. You may quit by calling the researcher, Donna E. Nelson, and my number is 423-384-5029 or you mail your desire to quit to 1030 Pagel Court, Johnson City, TN 37604. You will be told immediately if any of the results of the study should reasonably be expected to make you change your mind about staying in the study.

CONTACT FOR QUESTIONS:

If you have any questions, problems or research-related medical problems at any time, you may call the researcher, Donna E. Nelson at 423-384-5029, or Dr. Jasmine Renner at 423-439-7629. You may call the Chairman of the Institutional Review Board at 423-439-6054 for any questions you may have about your rights as a research subject. If you have any questions or concerns about the research and want to talk to someone independent of the research team or you can't reach the study staff, you may call an IRB Coordinator at 423-439-6055 or 423-439-6002.

CONFIDENTIALITY:

Every attempt will be made to see that your study results are kept confidential. A copy of the records from this study will be stored in the principal investigator's office, 1030 Pagel Court, Johnson City, TN, 37604 for at least 5 years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a subject. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the ETSU IRB, and personnel particular to this research and the ETSU Department of Educational Leadership and Policy Analysis will have access to the study records. All records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above.

PERMISSION TO QUOTE:

Your words may be used in the final research report to clarify or further explain a component of the narrative. The researcher will not identify the source of the quote and will take precautions to ensure that you are not identified in the final publishing of the quote.

By signing below, you confirm that you have read or had this document read to you. You will be given a signed copy of this informed consent document. You have been given the chance to ask questions and to discuss your participation with the investigator. You freely and voluntarily choose to be in this research project. In addition, you are giving your permission for your child's early intervention information and to be used in this study.

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SIGNATURE OF PARTICIPANT

DATE

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PRINTED NAME OF PARTICIPANT

---

SIGNATURE OF INVESTIGATOR

DATE

---

SIGNATURE OF WITNESS (if applicable)

DATE

VITA

DONNA E. NELSON

Personal Data: Birth Place: Winston-Salem, North Carolina

Education: East Tennessee State University, Johnson City, TN  
Ed.D., Educational Leadership, May 2012  
University of Tennessee, Knoxville, TN, M.S. – Child Family  
Studies – 1988  
Gardner-Webb College, Boiling Springs, NC, B.S. – Psychology –  
1987

Professional Experience: Director, Expanding Horizons: Early Intervention Program, East  
Tennessee State University, Johnson City, Tennessee 2005 –  
Present  
Adjunct Faculty Member, Human Development and  
Learning/Special Education, East Tennessee State University