

Family-Unit Needs of Families That Include an Infant or Toddler with a Diagnosis of Autism Spectrum Disorder (ASD) Enrolled in Part C Early Intervention Programs in Kansas

BY

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Submitted to the graduate degree program in Special Education
and the Graduate Faculty of the University of Kansas
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy.

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Spectrum Disorder (ASD) Enrolled in Part C Early Intervention Programs in Kansas

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ABSTRACT

This study explores the family-unit needs of families that include an infant or toddler with a diagnosis of autism spectrum disorder (ASD) enrolled in Part C early intervention programs in Kansas. For families of children with ASD, unmet need of families early in the process might contribute to reported long-term negative impacts of raising a child who experiences ASD. In considering the needs of all family members, it is critical to consider the varied characteristics of children and families. A first step towards meeting family needs is a systematic assessment of those needs. This study suggests that priority support needs for families at this stage include Getting Services and Teaching. The pattern of findings suggest that higher needs for support across domains are reported by parent of infants and toddlers who also report that the impact of ASD on their child's development is severe or profound. There is also a trend suggesting higher needs for support among parents reporting lower income. Future research is needed to compare the results of this subset of parents to parents in Part C programs across the nation. Additional work to validate the Family Needs Assessment Scale (FNA) used in this study for families with children in the birth to three population and specifically the birth to three population with a child with a diagnosis of ASD is needed. The FNA should also be explored as an interview tool to be used by early intervention staff.

ACKNOWLEDGEMENTS

“In this life we cannot do great things. We can only do small things with great love.”

– Mother Teresa

It is my hope that this dissertation study is one of the small things I can offer in this life. This work would not have been possible, however, without many others offering their “small things done with great love.”

First, I would like to thank my “original advisors” Dr. Ann and Rud Turnbull for their unwavering support from the day that I first met them. You have taught me many things over the last five years. Under your mentorship I have come to understand that I do not know what my best effort is because every day brings new opportunity to push that boundary just a bit further. You challenge all of us to assess everything we say and do in context of the beliefs we profess to hold. Your commitment to the field is truly outstanding. To Dr. Winnie Dunn, my minor advisor. You have helped me to know myself, my beliefs, and the theories I hold as truths. You constantly challenge me to match my words to my actions and ultimately to carry these truths into my research and writing. Your belief in me has helped me believe in myself and often the guiding force I needed to keep moving ever forward. Your support will always be a source of strength. To Dr. David Lindeman, thank you for your support from the first moment I came to you with the crazy idea to go for my Ph.D. to being the last one to leave the room on the day of defense. To Dr. Jean Ann Summers and Dr. Karrie Shogren, thank you for being there at the final stretch. I am grateful for your time and your expertise. To Dr. Gregory Cheatham and Dr. Eva Horn, thank you for agreeing to join my committee and for your guidance. You helped make the final stretch of this journey such a pleasant one with your grace and kindness.

To my friends, Dr. Chun-Yu Chiu, Dr. Kathleen Kyzar, Dr. Grace Francis, Dr. Shana Haines, I thank you for being there anytime I asked and value our time together at the Beach Center. I look forward to our continued friendships and work together. To my friend, Vera Lynne Stroup-Rentier, thank you for helping me to have the courage to start this journey and for being a support along the way. To my dear friend, Dr. Diana Stanfill, I could not have made it without your help. You are always there, always willing, always supportive. To my lifelong friends and family, thank you for your kind words, calls and support at every step.

To my mother, Beverly, who has always believed in me, who has always loved me and who drives my passion to support all families. Thank you Mom. To my son, Andrew who reminds me daily what strength, courage, and love looks like. Being your mother helped me understand the role of parent. For my daughter in law, Holly, you inspire me with your drive to be the best possible parent to my grandchildren. For my grandchildren, Andrew and Elizabeth, you are my light and my joy and have made the long days brighter. To Ty, Tayvia, Tara and Trevor, you came into my life and brought happiness to sustain the journey. To my daughter Maggie, the dissertation is finished baby girl. You have grown up by my side the last five years. You never complained about the time I needed to spend on school. You have grown from a little girl to a young woman that I am so very proud of. I hope that this journey has given you as much as it has taken in terms of who you will one day become. I know that I could not have done it if you were not wise beyond your years. I am so grateful for the person you are. And finally, my husband, Tim, your love, your support your unquestionable devotion during it all is a gift from God. I love you. This degree is a family effort and I thank God for the blessings each of you bring to my life.

TABLE OF CONTENTS

LIST OF TABLES	viii
LIST OF FIGURES	ix
CHAPTER 1: LITERATURE REVIEW	1
Introduction.....	1
Overview of Early Intervention Services.....	4
IDEA Focus on Family as a Unit.....	4
Office of Special Education Programs (OSEP) Accountability	5
Child and Family Characteristics for Families Enrolled in Part C of IDEA	6
Child Characteristics.....	6
Family Characteristics	8
Family-Centered Practices	8
Family Needs in Early Intervention.....	10
Family Needs Associated with Having an Infant or Toddler with ASD	15
Measurement of Family Needs	21
CHAPTER 2: METHOD	
Research Questions.....	23
Research Design.....	24
Sampling Plan.....	25
Measures	30
Family Needs Assessment (FNA) Scale.....	30
Demographic Section.....	31
Procedure	31

Data Analysis Plan	33
Developing a database.	33
Initial analytic procedure	34
Exploration of raw data.....	34
Analysis.....	35
 CHAPTER 3: RESULTS	
Family Rating of Need by FNA Scale Domain	36
Family Rating of Need by FNA Item in Descending Order	37
Rating of Need as Expressed as Items Ranked as High/Very High by Domain.....	41
Family Rating of Need as Expressed across Parent and Child Demographic Differences	43
Family and Child Characteristics for Families Identifying Most Need and Least Need across Domains	49
 CHAPTER 4: DISCUSSION	
Interpretation of Results.....	56
Limitations of the Study.....	56
Implications for Future Research.....	66
Conclusions.....	73
REFERENCES	75
APPENDIX A: Survey Materials	90

LIST OF TABLES

Table 1. <i>Participant Characteristics (N=27)</i>	27
Table 2. <i>Survey Distribution Schedule</i>	32
Table 3. <i>Family Mean Ratings for FNA Need Domain Averages in Descending Order (n=27)</i>	36
Table 4. <i>Family Ratings of Need by FNA Item in Descending Order (N=27)</i>	38
Table 5. <i>Percentage of Families Rating Items as High/Very High Need by Domain (N=27)</i>	41
Table 6. <i>Family Rating of Need as Expressed across Parent and Child Demographic Differences</i>	45
Table 7. <i>Families Ranked by FNA Survey Domain Average Scale Score and Identified by Top (+) and Bottom (-) Quartiles</i>	49
Table 8. <i>Family and Child Characteristics for Top Quartile of Families Identifying Most Need for Support</i>	51
Table 9. <i>Family and Child Characteristics for Bottom Quartile of Families Identifying Least Need for Support</i>	52

LIST OF FIGURES

<i>Figure 1.</i> Top Quartile (Most Need) and Bottom Quartile (Least Need) Families by Level of Severity.....	53
<i>Figure 2.</i> Top Quartile (Most Need) and Bottom Quartile (Least Need) Families by Level of Education.....	54
<i>Figure 3.</i> Top Quartile (Most Need) and Bottom Quartile (Least Need) Families by Level of Income.....	55

Chapter 1: LITERATURE REVIEW

Introduction

Support to families and children in early intervention impacts not only the child's development, but also the family's ability to help the child grow and develop (Bailey et al., 1998; Bailey & Bruder, 2005; Friend, Summers & Turnbull, 2009; Sandall, Hemeter, Smith, & McLean, 2005). This two-facet support recognizes that "families are impacted by their child's disability and are in need of supports in their own right" (Friend, Summers & Turnbull, 2009, p. 453). Family integrity and unity is a core concept of disability policy not only at the early intervention stage but also across the full lifespan (Turnbull, Beegle, & Stowe, 2001).

Family integrity and unity refers to preserving and strengthening the family as the core unit of society. It is reflected in services that maintain the family intact; respond to all family members; and take into account the family's cultural, ethnic, linguistic, or other socioeconomic traits and choices (Turnbull, Beegle, & Stowe, 2001, p.142).

Family integrity and unity addresses the dual goals set forth by Congress in Part C of IDEA. These goals intertwine enhancement of the development of infants and toddlers with special needs with enhancement of their family's abilities to meet those needs. IDEA underscores "an urgent and substantial need... to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities..." (Individuals With Disabilities Education Improvement Act (IDEA) of 2004, PL 108-446, Sec. 631(a)(4)). In addition, there exists over two decades of research findings that support the concept that families need and benefit from support to meet the needs of their infant or toddler with a disability. Yet, despite this guidance, there are few actual interventions designed to support the specific needs of the family as a unit. In an analysis of early intervention literature, definitions of family-centered

services included the family as a unit of attention only 60% of the time (Epley, et al., 2006). Of the 25 articles reviewed, 88% identified how to provide support to families (i.e., through relationships) but only 42% identified the types of support that should be provided to families in early intervention (Epley, et al., 2006).

Two theories are applicable as rationales for providing support to the family unit in early intervention – ecological theory and family systems theory. Knowledge of the ecology of families, as well as knowledge of family systems, provides important theoretical perspectives for understanding the rationale and importance of addressing family support needs.

Bronfenbrenner's developmental model for human behavior suggests that an infant or toddler develops within the context or ecology of the family (Bronfenbrenner, 1979). His approach led to the emphasis on the role of the parent as the first and best teacher (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). Research on early brain development (Shonkoff & Phillips, 2000) has helped to underscore the critical role of early experience, and thus the home environment, on children's development. Ecological theory supports the notion that enhanced parental competence will maximize the quality of the home environment and have positive impacts on outcomes for children (Bronfenbrenner, 1979). The two theories validate the notion that the role of early intervention is to help the family to support the child to participate as fully as possible in the daily activities of life.

As a support to ecological theory, family systems theory provides the conceptual framework to help professionals assume a holistic view of the family. The difference between ecological theory and family systems theory is the idea of reciprocal influence on all members of the system. Family systems theory recognizes that a child's needs create reciprocal needs for the entire family and, conversely, that achieving lasting change in child outcomes requires changes

through the family to support progress for the child (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). Family systems theory also recognizes that children's development depends on the capacity of their family to support their development and that families have a variety of tasks to accomplish in addition to parenting.

These theories serve as guiding forces. They are the foundation for the previously outlined legal and research emphasis on the importance of both child and family outcomes in early intervention. The theories support identification of family needs as a first step in provision of intervention that embraces the concept of the symbiotic relationship of child and family needs. Ecology theory and family systems theory demand that a singular focus on child outcomes is not sufficient evidence of benefit in early intervention (Raspa & Fox, 2012). These same theories lay the groundwork for differentiation between two basic types of support for families. One type of support is direct support families need in the here and now to meet the needs of their child, and the other type of support assists families to develop strengths as a long-term resource for the child and for the family as a unit

The major focus of this literature review is to provide discussion of the importance of identifying needs at the family unit level for families that include an infant or toddler with a diagnosis of autism spectrum disorder (ASD). A particular focus is to identify foundational needs at the time of diagnosis that serve to strengthen the family as they move forward through the family lifespan. The following topics will be addressed: overview of early intervention services, child and family characteristics for families enrolled in Part C of IDEA, family-centered practices, family needs in early intervention, family needs associated with having an infant or toddler with ASD, and measure of family needs.

Overview of Early Intervention Services

In addressing early intervention for families of children with ASD, it is necessary to highlight IDEA's focus on the family as a unit and Office of Special Education Programs (OSEP) accountability requirements.

IDEA Focus on Family as a Unit

Part C of IDEA declares that its purposes include these family-related ones: (a) enhance the development of infants and toddlers with disabilities, (b) maximize individuals' potential to live independently, and (c) enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities (Individuals with Disabilities Education Act Amendments of 2004, Title 1, Part C, Sec. 631 (a) (4)). A critical element to Part C of IDEA is the mandate for provision of services in the natural environment, which is defined, as the place a child would be if he or she did not have a disability. This includes home and community settings. IDEA requires a statement within the Individual Family Service Plan (IFSP) as to how services will occur in partnership with parents in all aspects of the Part C process. This includes engaging families in the process at every point from initial evaluation to exit from the program. Families identify concerns, resources, and priorities for their family. The IFSP is measured according to individual family outcomes.

The requirement for a family-directed assessment leading to an IFSP for all children served and their families is further evidence of the role intended for families in early intervention. The assessment should be conducted and the IFSP should be developed in concert with the family and can contain services to both children and families. The family-directed assessment must...be based on information obtained through an assessment tool and also through an interview with those family members who elect to participate in the assessment (Sec.

303.321(c)(2)(ii), emphasis added). The family-directed assessment is intended to gather information on the concerns, priorities, and resources identified by families, which will be used to inform development of child and family outcomes on the IFSP.

In addition to including families in assessment and IFSP development, Part C of IDEA makes provision for specific services for families. Of the 17 services listed in IDEA, two can be identified as specific to families: (a) family training, counseling, and home visits and (b) social work services. In addition, service coordination and special instruction include a focus on the family (Turnbull et al., 2007).

Office of Special Education Programs (OSEP) Accountability

Further evidence of a federal intent for focus on the needs of the family is found in the accountability measures for family outcomes put forth by OSEP. OSEP originally funded the Early Childhood Outcomes Center (ECO) in 2003. The center is now merged with the Early Childhood Technical Assistance (ECTA). Through an iterative process, which included extensive input from stakeholders, five family outcomes have been identified. These outcomes were chosen under the direction of OSEP by stakeholders working with the ECO Center (Bailey, Raspa & Fox, 2012). These are the expected outcomes for families enrolled in programs serving infants and toddlers with special needs under Part C of IDEA. These outcomes require that programs support families to: (a) understand their child's strengths, abilities, and special needs; (b) know their rights and advocate effectively for their child; (c) help their child develop and learn; (d) have support systems; and (e) access desired services, programs, and activities in their community (Bailey et al., 2006). These five outcomes provide a framework for what outcomes might be expected for early intervention, “but fall short of conceptualizing the *types* of family supports and services from which those outcomes derive” (Turnbull et al., 2007, p. 193).

Of the five outcomes recommended by ECO, OSEP chose a more limited focus for measurement purposes as follows: Percent of families participating in Part C who report that EI services have helped the family: (a) know their rights; (b) effectively communicate their children's needs; (c) help their children develop and learn (Bailey et al., 2006). This more limited focus speaks more to an immediate effort to directly support current family needs as contrasted to more long-term focus on development of the family as a resource for the child.

Child and Family Characteristics for Families Enrolled in Part C of IDEA

In addressing any aspect of early intervention, it is important to understand child characteristics and family characteristics. Families of children with ASD make up a sub-set of the children and families who are eligible for early intervention. In this section, I will describe the overall characteristics of children and families enrolled in Part C of IDEA.

Child Characteristics

Part C served 333,982 children nationally in 2013, which represents 2.77% of the general population of children birth to three (IDEA C1-9, 2012). The most recent national data pertaining to children and families receiving early intervention services documents that the most frequent delays/disabilities of children include speech/communication (41%), prenatal/perinatal problems (19%), motor delays (17%), and overall developmental delay (12%) (Hebbeler et al., 2007). There are no national data for Part C that reports the number of children with ASD in Part C. It is assumed that children with ASD are included in the Hebbeler study but there is no data on the most frequent delays/disabilities of this subset. As compared to the general population, children in early intervention are four times more likely to have had low birth weight and eight times more likely to have fair or poor health. More than half of the children enrolled in early intervention services show two or more risk factors and 20% had four or more (Hebbeler et al.,

2007).

These child characteristics only begin to encompass children who should/could be in early intervention. This list does not include an important population of children who would be eligible but are not being identified during the birth-to-three age period. As many as 13% of birth-to-three year olds have delays that would make them eligible for early intervention according to criteria commonly used by states (Rosenberg, Zhang, & Robinson, 2008). In addition, children are being identified late. At 9 months of age, only 9% of children who have delays that would make them eligible receive services, and at 24 months of age only 12% of children who would be eligible receive services (Feinberg, Silverstein, Donaue & Bliss, 2011). There are also racial disparities in the receipt of EI services by black children who would be eligible at 24 months of age being five times less likely to receive services than white children (Rosenberg, Zhang, & Robinson, 2008; Feinberg, Silverstein, Donaue, Y Bliss, 2011). In addition, other children at high risk associated with equally high potential for family needs are being significantly underrepresented. For example, young children experiencing homelessness are greatly underrepresented (U.S. Department of Education, 2006; National Child Traumatic Stress Network, 2005). An estimated 9% to 14% of all children age birth to five with behavioral or emotional problems could potentially receive services, yet professionals struggle to identify these children (Brauner, & Stephen, 2006; U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, 2010).

In addition, while IDEA requires referral to Part C for any child under the age of three who is identified as affected by illegal substance abuse (IDEA, 2004), an estimated 90-95% of newborns identified with prenatal substance abuse are sent home at birth without being identified

or referred for services (National Center on Substance Abuse and Child Welfare, 2009). IDEA similarly requires referral for children involved in a substantiated case of child abuse and neglect. Yet, of the 702,000 children who experienced substantiated abuse or neglect, 40% were sent home without post-investigation services, with one third under age four and infants under the age of one the most likely victims (U.S. Department of Health and Human Services, Administration for children, Youth and Families, 2010). Data from a nationally representative sample of very young maltreated children suggest that 47% would show a delay using moderate Part C eligibility criteria (Rosenberg & Robinson, 2005).

Family Characteristics

In addition to children in early intervention experiencing a range of developmental and other challenges, families of infants and toddlers with disabilities experience challenges at the family-unit level. Approximately one-fourth of families of children receiving early intervention services experience poverty (Rosenberg, Zhang, & Robinson, 2008). Mothers of children in early intervention are less likely than mothers in the general population to have attended college (Hebbeler et al., 2007). Furthermore, 20% of families with one child in early intervention also have another child with special needs (Hebbeler et al., 2007).

Family-Centered Practices

The original intent of Part C was to build and strengthen family capacity to provide early intervention to their children with support and guidance from practitioners (Barber, Turnbull, Behr, & Kerns, 1988; Dunst, 2012). Family-centered practice with infants and toddlers with disabilities and their families has been both mandated and accepted as recommended practice among professionals (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Epley, Summers & Turnbull, 2010; Sandall, McLean & Smith, 2000; Turnbull, Summers, Lee, &

Kyzar, 2007). Family-centered practices are integrated into personnel development (Epley, Summers, Turnbull, 2010; McWilliam, Tocci, & Harbin, 1998; Nelson, Summers & Turnbull, 2004) and are promoted by the Division of Early Childhood (DEC) (DEC, 2014). Today, Part C programs are responsible for outcomes for children *and* families. This connection reinforces the use of family-centered practice in Part C., Summers, and Turnbull (2010) identified five key elements of family-centered practices. These are: (a) family as the unit of attention, (b) family choice, (c) family strengths, (d) family-professional relationship, and (e) individualized family services. They also found a change in the emphases in the literature related to family-centered practices over time. This team reported that from 1996 to 2010, the element of the family as the unit of attention had decreased; family choice, family strengths, and family relationships had increased, and family services had stayed about the same.

In the studies reviewed by Epley and colleagues, half of the studies mentioned family services with the most common services for families being those led by families, not professionals, such as Parent-to-Parent support (Epley, Summers, & Turnbull, 2010). The common services led by professionals were service coordination, parent training, information, and education. Services led by professionals were almost exclusively child-focused family services. Less frequently noted were family services provided by professionals such as respite care, family counseling, and professionals accompanying families to meetings and appointments. References to other family services were limited or isolated. Financial assistance was only referenced in two articles and transportation in one.

An emphasis on how families are treated (i.e., family choice, family relationship) as contrasted to what services are offered (Turnbull, Summers, Turnbull, et al., 2007) is the current trend. A more balanced emphasis on how families are treated and on what services are offered

would align more closely with the original intent of IDEA to build family capacity. Family-centered practices must support both children and families. To do so would necessitate a need to explicate what families identify as needs.

Family Needs in Early Intervention

The function of family-centered services is to meet the child and families' needs. Theoretical definitions of need focus on the gap between one's actual and desired ability, condition, or situation (Epley, Summers, & Turnbull, 2011). Family need is further defined as any support that is desired or lacking but wanted in performing necessary tasks to function as a family unit, achieve a goal, or attain a particular end (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988). Bailey and Blasco (1990) defined family need as a family's expressed desire for services to be obtained.

Part C requires a comprehensive assessment of the child and family's priorities, resources, and concerns. This assessment should result in identified needs for both child and parents. The identified needs become the basis for the child and family outcomes listed on the Individual Family Service Plan (IFSP). Services are chosen based on these outcomes. The requirement to address family outcomes in early intervention presumes some need for services for families as well as children.

In a comprehensive research synthesis, Kyzar, Turnbull, Summers, & Gomez (2012) found that across studies family support was significantly related to family outcomes (family functioning, family satisfaction, family quality of life, and family stress). Epley, Summers, & Turnbull (2011) linked Part C/EI services and family outcomes. These researchers found a path relationship between parents' perceptions of Part C/EI services, immediate outcomes of those services and longer-term family outcomes (i.e., enhanced family quality of life). This study

reinforced the role of parents in identifying needs and individualizing services to meet those needs as a means to enhance immediate family outcomes and quality of life.

The National Early Intervention Longitudinal Study (NEILS, Hebbeler et al., 2007) addressed early intervention as a program for families. To do so, the research team identified a set of family outcomes (Bailey et al., 1998). These outcomes were precursors to those previously discussed in this review and addressed the following questions: (a) did the family see EI as appropriate in making a difference in their child's life; (b) did the family see EI as appropriate in making a difference in their family's life; (c) did the family have a positive view of professionals and the special service system; (d) did EI enable the family to help their child grow, learn, and develop; (e) did EI enhance the family's perceived ability to work with professionals and advocate for services, (f) did EI assist the family in building a strong support system; (g) did EI help enhance an optimistic view of the future; and (h) did EI enhance the family's perceived quality of life?

Overall, NEILS data showed positive outcomes for families. There were two notable exceptions. Low-income and minority families were less likely to report positive outcomes. Few of these families gave negative ratings; instead, the ratings were just less positive than were those of other families. Additionally, some parents reported not being confident about their ability to deal with their child's behavior, and some were not able to take part in community activities as much as they would like. Researchers identified that there may be a need to assist families with behavioral and early mental health issues, as well as a need to focus on helping families participate in community activities (Hebbeler et al., 2007).

The NEILS study outlined a set of outcomes that were likely achieved by meeting the needs of families at child and family levels and two possible needs that were not being

adequately addressed (i.e., behavior support, participation in community). However, in general, the NEILS study did not specify what needs were addressed or how those needs were addressed to arrive at such positive outcomes. Nor did this study discuss any possible differences between families, beyond poverty and minority status, that may have in what the researchers consider needs related to individual child and family characteristics. Characteristics such as single parenthood, homelessness, severity of child's disability, diagnosis, mental health needs of parent, cognitive level of parent, and age of parent were not analyzed. The NEILS study is not the exception: there is very little information on family-unit needs in early intervention. That said there are a few studies that are targeted at needs of families in early intervention.

In 2004, researchers compared self-reported needs of and sources of support for African American and European American caregivers of young children with disabilities living in urban and rural areas. One hundred twenty caregivers of young children in one state's early intervention system responded. African American and European American caregivers differed significantly on the overall level of support they reported. African American caregivers in urban locations reported experiencing higher levels of need regarding personal and family growth. European American caregivers in rural locations reported experiencing higher levels of spouse/partner support. This study suggested that consideration of family needs must take into account differences such as race and ethnicity because services must be different to produce positive results (Darling & Gallagher, 2004).

In another project, a group of researchers collected information on family needs using the Family Needs Assessment developed first at the Beach Center on Disability at the University of Kansas (Aya, Baques, Cabrera, Chiu & Gine, 2014).

In the information specific to the United States and focused on families of children experiencing disabilities, the team found that needs of families differed according to age of the child. In the category of needs for families with children ages birth to five, the top five needs were: teaching communication, providing daily care, accessing therapeutic services, teaching appropriate behavior, and accessing educational services to enable child progress. This differed from parents of older children where planning for the future when the family is unable to provide care and saving money for the future rose to the top.

This same study analyzed the needs of U.S. parents according to level of severity of disability, as reported by parents. Saving money for the future was the top need for all groups except for families with children experiencing profound disability, for whom attending to daily care activities, having a break from caregiving, and having hope for the future were the top needs expressed. Parents of children with disabilities in the mild and moderate categories reported having educational service where the child is progressing as the second most important need after saving money, and parents with children in the severe category identified managing stress. While this study reports that needs differed according to age of child and severity of child's disability, the study did not report differences based on parent characteristics.

In a study of 90 families of children who were at risk for developing maltreatment, Allen (2007) examined parents' perceptions of assets and barriers to intervention practices that are effective in meeting their needs. Parents expressed a desire for support and encouragement from their service coordinator not only in their parenting, but also for dealing with other relationships in their lives and for establishing themselves as independent, productive adults in the community (Allen, 2007). The mothers reported difficulties with service coordinators meeting their material needs, particularly in times of crisis. Parents recognized that gaps in community services can

affect service coordination interventions, however they voiced particular concerns about the lack of resources on the part of the home visiting program to help meet their material needs and to link them with agencies. The respondents appreciated attempts by service coordinators to help find such items as cribs, diapers, and transportation, but the concern came in being successful in accessing resources to pass onto the families. They reported frustration with service coordinators telling them where to call for material resources but not offering to make contacts, bringing items (e.g. diapers, food, high chairs) to their house versus the parent needing to go to a community resource to get the item, or help make community connections. The mothers also expressed a need for being connected to people at other agencies who would give straight answers. From the parents' perspectives, service coordination with families involved meeting the families' needs for intensive advocacy and instrumental support interventions delivered in the community, not just in the families' homes (e.g., working as a liaison beside and with parents to help secure such things as material needs and resources from social service agencies that are difficult to navigate).

In a qualitative study of adolescent mothers, Lea (2006) reported that these mothers expressed a need for a trusting relationship with providers that focuses on strengths and supporting families' priorities and interests. The need expressed was much more in line with the definition of an early intervention coach versus service provider. This would be the shift from early interventionists "thinking of themselves as persons who provide services to thinking of themselves as a coach who encourages, facilitates and guides another to develop competence in their role as a parent of a child with a disability" (Lea, 2006, p. 277). Having a coach would also enable the mothers in this study to move from a role they understood as passive observer and occasional informant about their child's development to one of partnership and action.

As these brief reviews suggest, meeting family needs in general has been a complex and often times confusing process for early interventionists. For example, some families want direct services; others want more intensive service coordination; and still others want coaching and training to learn how to find those services on their own. Meeting needs in the context of individual child and family characteristics is a concept that has rarely been studied. Even more rare is a focus on needs specific to families of infants and toddler with a diagnosis of ASD.

Family Needs Associated with Having an Infant or Toddler with ASD

In the case of families that include an infant or toddler with a diagnosis of ASD, Wallace and Rogers (2010) report:

Parents of infants and toddlers with autism...are parents of an infant or toddler just diagnosed with a serious chronic developmental disorder. They are experiencing a life-altering event, one with long-term effects on everyone in the family. They need information, support, and services for their child. (p. 1316-17).

Research has indicated, that to some extent, needs of families that include a child experiencing ASD might be significantly different than needs of other families (Boyd, 2011; Wallace & Rogers, 2010).

It is important to know if these differences exist and what they are given that a growing number of families receiving early intervention services have an infant or toddler diagnosed with or with a suspected diagnosis of ASD. The United States Centers for Disease Control and Prevention (CDC) estimates 1 in 68 children in the United States have ASD (CDC 2014). ASD occurs in all racial, ethnic, and socioeconomic groups. The diagnosis of ASD in children under three is becoming increasingly common (Stahmer, Brookman-Frazee, Lee, Searcy, & Reed, 2011), and signs of ASD are being identified as young as 12 to 18 months (Johnson, 2008;

Ozonoff et al., 2010). Increases in numbers and decreases in age of identification underscores the need for family support as early as possible after entry into Part C programs.

Most research on families is primarily focused on the outcomes of depression, stress, and caregiver burden related to families of individuals experiencing disabilities (Turnbull, Summers, Lee, & Kyzar, 2007) or in simpler terms, most research is focused on the problems families face. This research extends to parents, especially mothers, who have an infant or toddler diagnosed with ASD as they experience higher incidences of depression, stress, and caregiver burden than do mothers of children with other developmental delays or disabilities (Boyd, 2002; Sanders & Morgan, 1997). In the majority of studies, the problem of the disability itself has more often been a focus, as contrasted to examining the impact of solutions in order to address needs in a successful manner. However, meeting needs, as a means to achieving solutions, especially solutions early in the journey, may be critical for families. Over time families of children with ASD tend to use more coping strategies associated with distancing and escape from their stressors than do families with children with other disorders that tend to use a greater number of coping strategies associated with social support and problem solving (Sivberg, 2002). One longitudinal study examining coping strategies used by families of children with ASD reported that family use of problem-focused coping mechanisms declines over time with a corresponding increase in emotion-focused coping responses (Gray, 2006). The inability to sustain effective coping mechanisms is thought to be correlated with reductions and disruptions in social support systems as the child ages (Gray, 2006).

Studies specific to families of children with ASD give evidence that this group appears to be more adversely affected than other groups of parents whose children experience delay/diagnosis other than ASD. These greater effects may be related to specific stress-related

factors that result from raising a child with ASD. Families of children with ASD often experience special demands including increased intensity of caregiving, concerns about the impact of the disability on family members other than the child with ASD, challenges in planning social events, and responsibilities as decision makers regarding services for the child with ASD (NRC, 2001). These demands may also include financial demands if one parent increases caregiving time and reduces work time. Higher levels of stress are reported in mothers of children with ASD when compared to mothers of children with other developmental disabilities (e.g., Down syndrome) (Boyd, 2011; Sanders & Morgan, 1997). Other studies report both parents of children with ASD may be at increased risk for depression compared with parents of children with other disabilities (Gold, 1993; Koegel et al., 1999). Studies have documented that the three most stressful factors associated with parenting a child with ASD are (a) concerns over the permanency of the condition; (b) poor acceptance of behaviors associated with ASD by society, and often by other family members; and (c) the very low levels of social support received by parents (Boyd, 2011). Another prevalent issue is lack of sleep by the entire family as children with ASD experience more sleep problems than do children with other developmental disabilities or parents of typically developing children (Schreck & Mulick, 2000). Families of children with ASD report more restricted family activities outside the home as compared to families of children with other disabilities, and support networks for families are fewer (Higgins, Bailey, & Pearce, 2005). It is of note that the majority of these studies have been conducted with parents of children with ASD who are between 7 and 18 years old. Few studies are specific to the experiences of parents with young children with ASD.

Family support is critical in addressing needs leading to the mitigation of many of the potential adverse affects on families when an infant or toddler is diagnosed with ASD. Family

support can be categorized into four types of support: (a) emotional support (e.g. parent to parent; family counseling); (b) physical support (e.g. nutrition, health checks, daily living skills of child to include toileting or eating); (c) material/instrumental support (e.g. transportation to doctor's appointments, child care enabling the parents to work); (d) informational support (e.g. written or print materials about ASD or intervention models for infants and toddlers experiencing ASD) (Kyzar et al., 2012).

Families of infants and toddlers with ASD need a tremendous amount of informational and professional support to learn how to interact with their children and to increase the numbers of interactions to the level that is needed for maximum learning opportunities; however, this need is rarely addressed (Dale, Johoda, & Knott, 2006).

Families are often stressed when their children enter treatment and the stressors grow over time. These stressors may be related to the method of intervention delivery. The reported impact of being involved in a family-coached intervention (focusing on child skills) varies. In one study, parents who received coaching 5 hours per week over a 3-month period to facilitate their child's learning and to address behavior management still reported that their children were significant sources of stress. However, the stress scores of the parents whose children made the least amount of progress were significantly higher than those whose children made the greatest gains (Boyd, 2011). It is important to note that in this study coaching was defined as teaching intervention strategies to fidelity and focused on child skill acquisition.

In other studies focused on parent-delivered interventions facilitated through coaching with parents by professionals, positive benefits for families are reported. In a study that investigated the impact of parent-coaching intervention based on the Early Start Denver Model (P-ESDM), this parent-coaching intervention showed promise in maintaining parental adjustment

immediately following their child being diagnosed with ASD (Estes et al., 2014). In another study focused on coaching mothers of children with ASD, findings indicate that parents perceived the therapist-parent relationship as a core feature leading to increased mindfulness and self-efficacy (Foster, Dunn & Lawson, 2012). In a similar study examining the impact of a contextual intervention on parent competence, parents reported feeling more competent (Dunn, Cox, Foster, Mische-Lawson, Tanquary, 2012). These studies indicate that both understanding what parents need during daily routines and activities and a focus on how to meet those needs through use of coaching in a parent-delivered intervention can lead to positive impact on parents as well as children.

Family support has the potential to reduce family stress, leading to more positive interactions. When family functioning is compromised, the negative effects can be seen within the family system as changes in parenting approaches and the emergence of interactions that are increasingly negative or disengaged (Hauser-Cram et al., 2001). Already compromised due to the effects of ASD, the child is particularly vulnerable to the effects of a less than optimal family environment. Therefore, identifying the needs of parents and other family members and determining how those needs can be met is an important goal for professionals (Head & Leonard, 2007; Seligman & Darling, 1997).

In the course of providing family support, of particular concern is consideration of siblings' needs. In addition to general familial impact, psychological problems (e.g., concern about the future, loneliness, peer problems) have been reported among siblings of children with ASD more frequently as compared to control groups (Fisman, Wolf, Ellison, & Freeman, 2000). Rogers and Dawson (2011) reported that families held a less positive view of the sibling(s) and in fact were somewhat more negative about the siblings when the families were involved in an

intensive family-coached intervention as compared to families involved in other treatment programs. Negative sibling impact was increased when other stressors (e.g., low socio-economic status) were increased. This is attributed to the fact that the more stressors that accumulate (e.g., lower income and less parental education), the greater the impact on the sibling (Macks & Reeve, 2007). In support of the family as a unit, it is critical that professionals assist the family to support siblings as well as the target child. Supportive programming for siblings of children with ASD is necessary and valuable to families of children with ASD (Angell, Meadan, & Stoner, 2012).

Patterson and Smith (2011) reported on family needs associated with having an infant or toddler with ASD. Families expressed a desire for increased family support in the form of more one-on-one coaching and parent-to-parent contact to navigate the overwhelming content of an intensive intervention. Families also reported the need for time to discuss emotions; more information on ASD; and specific support for fathers, single parents, and working parents.

The evidence presented in the review of literature on needs of families of children with ASD suggests unmet needs of families early in the process might contribute to the reported long-term negative impact of raising a child who experiences ASD. The evidence suggests that, in meeting the needs of all family members, it is critical to consider varied characteristics of children and families and to include both parents and siblings. There is evidence to suggest that, in meeting the informational needs of parents in reference to models of intervention, there are ways to intervene that have positive impact for both the child with diagnosis of ASD and for the child's parents. A first step towards meeting family needs is a systematic assessment of what those needs may be.

Measurement of Family Needs

The task of addressing family needs involves embracing the complexity of identifying, prioritizing, and providing necessary supports. It is critical that there be a user-friendly, relevant, reliable, and valid instruments to measure and report family needs. If families and professionals can identify and prioritize needs, they can subsequently identify existing and potential resources to address the prioritized needs. Furthermore, results from measures of family needs can provide guidance to federal, state, and local organizations for resource distribution and policy improvement.

In general family research, professionals often collect information on family needs through observations, self-report questionnaires, and interviews (Grotevant & Carlson, 1989). Parents of children with disabilities generally have considered self-report questionnaires as helpful in improving their communication with professionals (Bailey & Blasco, 1990, Chiu, 2013).

In early intervention, few instruments have been developed for measurement of family needs. Measurement of family needs was most prevalent in the 1980's. Most studies during that time period employed the Family Needs Scale (Dunst, Cooper, et al., 1988) or Family Needs Survey (Bailey & Simeonsson, 1988). A few qualitative studies in early intervention collected data through focus groups and individual interviews during this same time period (Chiu, 2012). The relevance and temporal validity (i.e., can results of studies be generalized across time) of the measures are questionable. To address the need for a reliable and valid family needs assessment instrument, an international group of researchers collaborated to develop a tool to collect data on family needs.

The Family Needs Assessment (FNA) is a tool that has been developed to collect data on family needs. The FNA was developed in collaboration with families who have a member with a disability by researchers in Texas, Illinois, and Kansas, USA; Barcelona, Spain; Beijing, China; and Taipei, Taiwan from 2010 to the present time. The FNA is described in detail in the methods section.

Chapter 2: Method

I first introduce the research question, followed by a section describing the research design. Next, in the data collection section, I present the information on sampling, participants, survey distribution and information on instruments included in the survey. Finally, I describe the data analysis methods to address the research question.

Research Questions

The research question for this study is:

1. What are the needs of families that include an infant or toddler with a diagnosis of autism spectrum disorder (ASD) enrolled in Part C early intervention programs in Kansas?

To address the research question, I targeted a representative sample of families that include an infant or toddler with a diagnosis of ASD in Kansas currently enrolled in Part C to further examine family-unit needs. Prior to this dissertation study, Kansas Infant Toddler Services did not have information on the numbers of families that include an infant or toddler with a diagnosis of ASD nor what the needs of these families might be. One result of this dissertation study is that, by collaborating with programs serving infants and toddlers in Kansas to identify the sample for the dissertation study, I was able to generate a count of the number of families that include an infant or toddler with a diagnosis of ASD being served in Kansas, and Kansas Infant Toddler Services knows that at one point in time, January 2015, there were 64 infants or toddlers in Kansas had a confirmed diagnosis of ASD. It is important to note that many programs in Kansas reported that they were also serving toddlers who were in the process of diagnosis or whom they suspected may have a diagnosis but the team, including the family, had not yet begun the process of diagnosis.

This study was, therefore, a collaborative effort with Kansas Infant Toddler Services to analyze the needs of the 64 families so that programs can understand the needs of families in this population and so that interventions can be designed and implemented to meet those needs within the Part C programs. This is an important task, not just for Kansas, but also for the country as the number of infants and toddlers with a diagnosis of ASD continues to rise.

Research Design

In this study, I used a survey research design. The survey I used was the Family Needs Assessment (Turnbull et al., 2011). The FNA is a self-report questionnaire. The advantages of using a questionnaire include: (a) more convenience for respondents who complete the questionnaire on their own time as contrasted to a scheduled interview, (b) data can be gathered from a large sample in a wide geographical distribution in a relatively short time, (c) written forms are standardized reducing the potential bias that may occur in interviews, (d) respondents can take time to think about their answers and to consult records for specific information, and (e) questionnaires provide confidentiality encouraging honest and candid responses. A questionnaire such as the FNA is particularly useful as a research method for examining phenomena that can be assessed through self-reflection, such as attitudes, values, and perceptions (Dillman et al., 2009, Portney & Watkins, 2000).

The FNA was designed to identify the immediate needs (i.e., within the next six months) of families who have a family member with a disability. The FNA measures unmet needs of all family members instead of only the family member with a disability. The FNA can be self-administered or administered through interview. The scale has valid psychometric characteristics, described subsequently, for use with families of children with intellectual disability (Turnbull et al., 2011).

Prior to this study, I applied for and received IRB approval from the University of Kansas Human Subjects Committee of Lawrence to administer the FNA to participants in Kansas early intervention programs. Per IRB requirements, respondents were not required to sign consent but to read an assurance provided by the researcher, then, if they agreed, complete and return the survey. The survey packet distributed to families included the following assurance: “Your responses to the survey are entirely voluntary and will be used confidentially in any report of this study. All reports of family responses will be provided in-group form. Thus, no individual responses will be reported. Your identities will not be associated in any way with the findings.” Appendix A includes my request to tiny-k programs (i.e., programs that provide early intervention services under IDEA, Part C to all eligible children in a defined geographic area in Kansas) to distribute materials; the welcome letter and assurance form for participants; and reminder flyer. Appendix B includes the FNA survey protocol.

Sampling Plan

The Kansas Department of Health and Environment is the lead agency for the Kansas program responsible for implementation of Part C of IDEA. The program collectively serves approximately 9,000 families each year. The program does not currently keep data that would indicate what proportion of the overall population represents families that include an infant or a toddler with a diagnosis of ASD. To that end, my first procedure was to send an inquiry to each of the 36 tiny-k programs. These programs work under the lead agency, Kansas Infant Toddler Services at the Kansas Department of Health and Environment, to implement services for families and young children with disabilities. Services include the 17 required services under Part C of IDEA. A diagnosis of autism enables a child to automatically qualify for this program. As described previously, each program was asked to report of the number of children with a

confirmed diagnosis of ASD to generate the number of families that should be sampled for this dissertation. All 36 programs responded, and the total number of infants and toddlers in the programs with confirmed ASD diagnoses across programs was 64 as of January 2015. As my target population was all families in Kansas with an infant or a toddler with a diagnosis of ASD currently enrolled in a Part C program, this is the number of surveys that I distributed.

In 2014, the Centers for Disease Control and Prevention estimated the rate of Autism Spectrum Disorder (ASD) in approximately 1 in 68 children. Given this estimate, the number of infants and toddlers identified in Kansas Part C programs rate seems low. However, research reports that clinical diagnosis of ASD occurs, on average between the ages of 3 and 4 years (Jeans, Santos, Laxman, McBride, & Dyer, 2014). The tiny-k programs only serve children ages 36 months or younger as defined per Part C of IDEA. Thus the number of infants or toddlers with a confirmed diagnosis is likely low due to the fact that many of the infants and toddlers have not yet received a clinical diagnosis, or have received a diagnosis so recently that they are not yet being served by tiny-k programs. Therefore, while the actual population of children from birth to three with ASD in Kansas is likely to be higher, I defined the population for purposes of this study to be the number of formally diagnosed children who are also being served in Part C programs in Kansas. After identifying the total population that met these criteria (in January of 2015) as being 64, in collaboration with the 36 tiny-k programs in Kansas that provide services under the lead agency, the Kansas Department of Health and Environment, I distributed the survey to all 64 identified families.

Thus, all respondents met the following criteria: (a) living with a child with a diagnosis of ASD who is eligible and enrolled in a Kansas early intervention program and (b) identifying themselves as parents or legal guardians of the eligible and enrolled child.

Of the 64 identified families, a total of 27 families completed the survey and returned it to the researcher. The survey was offered in a paper version with the option to call the researcher and complete the survey by phone. The survey was offered in both English and Spanish versions. Spanish versions were available upon request. No participants requested a Spanish version nor an interview with an interpreter over the phone. Five participants (19% of sample) elected to participate by completing the survey over the phone with the researcher. Table 1 includes the demographic data for the 27 family members and their children who completed the FNA survey.

Table 1

Participant Characteristics (N=27)

Characteristic	Frequency	Percent
Of the Child		
Age of child		
18-21 months	1	3.70
22-25 months	4	14.80
26-29 months	7	25.90
30-33 months	5	18.50
34-36 months	10	37.10
Level of severity		
Mild	10	37.00
Moderate	9	33.30
Severe	5	18.50
Profound	3	11.10
Of the Parent		
Gender		
Male	1	3.70
Female	26	96.30
Relationship to child		
Mother	26	96.30
Father	1	3.70
Race/Ethnicity		
Hispanic/Latino	4	14.80
Black or African American	2	7.40
White	19	70.40
Two or more races	2	7.40
Primary language		
English	24	88.90

Characteristic	Frequency	Percent
Spanish	2	7.40
Other	1	3.70
Age		
20 to 29 years	7	25.90
30 years or older	20	74.10
Marital status		
Married/living with a partner	24	88.00
Not married (widowed, divorced, separated, never married)	3	11.10
Education		
High school graduate (diploma or GED)	7	25.90
Some college or post-high school, but no degree	9	33.30
College degree (undergraduate)	7	25.90
College degree (graduate)	4	14.80
Family income		
Less than \$10,000	1	3.70
\$10,000 to \$40,000	11	40.70
Over \$40,000	15	55.60
Geographic location		
Urban (population greater than 50,000)	7	25.90
Suburban (population between 10,000 and 50,000)	12	44.40
Rural (population < 10,000)	8	29.60

Note: Level of severity = Level of severity of impact of diagnosis of autism on child's development per caregiver report.

The majority of the family members who completed the survey were female ($n = 26$; 96%), white ($n = 19$; 70%), English speaking ($n = 24$; 88%), and described themselves as the mother of the target infant or toddler ($n = 26$; 96%). The participants tended to be 30 years or older ($n = 20$; 74%) and married ($n = 24$; 88%). All participants had at least a high school diploma with most also having between some college ($n = 9$; 33%) or a college degree ($n = 7$; 26%). Over half of the participants ($n = 15$; 56%) had incomes over \$40,000. Many participants incomes fell between \$10,000 and \$40,000 ($n = 11$; 41%). Most families described themselves as living in a suburban area ($n = 12$; 45%). The majority of the parents reported that their child

was between 26 and 36 months ($n=22$; 82%). The severity of the impact of the ASD on development was reported as mild ($n=10$; 37%), moderate ($n=9$; 33%), severe ($n=5$; 19%) and profound ($n=3$; 11%).

I did not have access to the demographics of the 37 families that elected not to complete the survey to explore the degree to which the 27 family members that completed the FNA survey were representative of the overall population. Kansas Infant and Toddler Services does not collect demographic information on parents, with the exception of information on race/ethnicity. When comparing the 27 participants to all families served by Kansas Infant Toddler Services, there was a similar distribution of race/ethnicity. Approximately 70% of the present sample was Caucasian, and 68% of the families served by Kansas Infant Toddler Services are Caucasian. However, if compared to national data of families served in early intervention (Hebbeler et al., 2007), the present sample demonstrates some differences from the national population of families. Although the categories are not identical in the data collected from the sample and in available national data on families served in early intervention, it appears that the families sampled for this dissertation tended to have higher incomes and education levels and were more likely to be married. For example, in the present sample only 1% of families reported incomes less than \$10,000 and 41% reported incomes between \$10,000 and \$40,000, whereas nationally, 27% of families have incomes of less than \$15,000 and 16% have income of \$15,001- \$25,000. Similarly, in the present sample the majority of the sample had some college education, whereas nationally 48% of families serve have a high school degree or less than high school degree. And, in the present sample 88% of families reported being married/living with a partner, while nationally only 62% of children are living with both parents.

Measures

I collected data for the study via a paper-based version of the FNA survey packet, except in cases where families elected to complete the survey over the phone. However, in these circumstances the order and format of the questions on the paper version was followed. The survey packet included two sections: (a) Identifying Needs, and (B) Demographic Section.

Family Needs Assessment Scale. The Family Needs Assessment Scale (FNA) consists of 77 items, organized into 11 domains, including health, daily care, recreation, social relationships, lifespan changes, teaching, getting services, family interaction, emotional health, spirituality, and economics. These domains were developed by an international team of researchers based on a review of literature focusing on the assessment of family needs and grounded in family systems theory (Chiu, 2013). After reviewing available instruments and collecting qualitative data from parents (20 individual interviews and four cross-site focus groups), this team developed an item pool and determined the measurement format. The items were reviewed by five experts (two researchers and three family members, administered to a pilot sample, and re-evaluated in terms of iterative process of scale development. The pilot sample of parents provided social validity feedback. The first drafts of the FNA were in English, although it has subsequently been translated into different languages.

Each item on the FNA is rated on a 5-point Likert scale format, where 1 = *no need*, 2 = *low need*, 3 = *need*, 4 = *high need*, and 5 = *very high need*). The FNA asks the respondent, in completing each item, to consider the need for support for each item over the next six month period. An initial validation study of a translated version of the scale suggested strong construct validity and reliability for the FNA in Taiwanese families (Chiu, Turnbull & Summers, 2013). Specifically, Chiu et al. (2013) sampled 401 family members of a child with a disability. Most

were parents (289 mothers, 72.1%; 74 fathers, 18.5%) recruited through 8 local early intervention centers, 5 parent support groups, and 11 schools. The family members ranged in age from 19 to 73 years. They were primary caregivers of children (260 boys, 138 girls) aged 1 to 18 ($M = 10.49$, $SD = 6.15$). Approximately 73.1% of the children were diagnosed with intellectual disability whereas the remainder had developmental delay diagnoses (Chiu, Turnbull, Summers, 2013). The reliability of the overall scale was 0.96, and an intercorrelation matrix showed consistency of the seven domains of the scale (Turnbull et al., 2011). The FNA has not yet been validated with families in the U.S. Chiu (2013) suggested, however, that the tool had applicability across cultures for use in the disability-related field in research and practice.

Demographic Section. The final section of the FNA survey includes demographic questions for the respondents and their children with disabilities. Participants were asked to disclose (a) gender; (b) relationship to the child; (c) race/ethnicity; (d) primary language; (e) age; (f) age of child; (g) marital status; (h) education; (i) household income; (j) geography; (i) severity of the impact of the ASD on development. These demographic variables were selected to examine how needs are spread across demographic variables of child and family. There is some research to indicate that experiences in early intervention and outcomes for children with ASD differ by income level (Hebbeler, 2007); marital status (Falk, Norris & Quinn, 2014; Hebbeler, 2007); gender (Davis & Carter, 2008); race/ethnicity (Hebbeler, 2007); level of severity of disability (Beurkens, Hobson, & Hobson, 2012).

Procedure

I submitted a proposal to the directors of the 36 tiny-k agencies requesting that they serve as distribution points for the survey, sharing a paper version of the survey with the families they served who had children that met the study criteria. The steps program staff undertook were: (a)

identify the number of families that include an infant or toddler with a diagnosis of ASD so that a survey could be sent to each family; (b) deliver a sealed packet of information that included a welcome letter/assurance statement, survey, and postage-paid envelope to return the survey; (c) inform parents that the packet includes information about a study of the needs of families that include an infant or toddler with a diagnosis of ASD and they can participate if interested but that it is entirely voluntary; and (d) deliver a participation reminder flyer two weeks after the initial distribution. The staff members were typically a family services coordinator or primary services provider (sometimes referred to as a coach). I provided detailed written instructions to the staff on how to introduce the study. I submitted a proposal to each program director, which included: a cover letter to parents (brief overview of project, responsibilities for the collaborative agency and staff who will serve as data collectors); and introduction of the researcher, study timeline, and survey. Staff members at the collaborative agency were responsible for distributing the sealed survey packet to include letter of invitation/welcome/assurance, survey and postage paid envelope (see Appendix A, B) to eligible parents.

Table 2

Survey Distribution Schedule

Time	Distribution Plan
Weeks 1-3	Contacted local agency directors. Provided information to staff. Asked staff to provide number of families in need of survey packets. Asked staff from local agencies to distribute survey packets to all families that include an infant or toddler with a diagnosis of ASD.
Weeks 3-8	Families completed and returned surveys. Asked agency staff to encourage families to complete survey. This included delivering a follow-up notice two weeks after distribution of the survey packets. Sent thank you emails/letters.

The data collection approach was designed to have strengths in feasibility and lower costs. Nevertheless, there is a limitation in generalizing the findings to the population without

random selection. I recognize this sample does not include families of infants and toddlers with a diagnosis of autism in Kansas who do not participate in a tiny-k program and instead access private services. This does not include the subset of parents who choose not to seek services. It also limits the responses to only those of parents who live in Kansas (Creswell, 2009; Dillman et al., 2009). Further, we were unable to collect data from over half of the families served, and the degree to which these families varied on specific socio-demographic characteristics is not clear. An additional limitation is possible bias introduced by the fact that the agency staff was involved in data collection. However, that risk is minimal as staff was only being asked to distribute the sealed packets.

Programs were contacted at the planned times (see Table 2), but there was a low return rate, initially. Thus, I contacted programs two additional times because of a low response to the initial distribution and reminders. By week 4, only two FNA surveys had been returned. Phone calls and emails were made to program coordinators who in turn contacted service providers and encouraged distribution and collection. At week 6, 8 returns were recorded. Additional phone calls and weekly emails began in week 8 and extended to week 12 and improved the return rate. The phone calls and emails encouraged providers to offer potential participants the opportunity to complete the survey with the researcher over the phone. This outreach resulted in the five phone surveys. These efforts led to a total sample of 27 families (42% return rate).

Data Analysis Plan

Developing a database. Upon receipt of the completed surveys, I checked the completion of the survey to see if any incomplete submissions needed to be eliminated. All the returned questionnaires were 100% complete; therefore, there were zero unusable questionnaires.

I then entered the data in a spreadsheet and exported it into SPSS (version 21.0). Each item on the survey is a data point and was assigned a variable name/item number.

Initial analytic procedure. Prior to data analysis, I descriptively explored the data, checking for errors and assessing distribution of responses. In addition, I ran necessary preliminary data analyses. In this section, I discuss the procedures I used for the initial exploration and analyses.

Exploration of raw data. To determine accuracy of the data entry, I cleaned and screened the data before conducting data analyses. Pryjmachuk and Richards (2007) explained that examining raw data ensures the integrity of the data and “introduces a degree of audit into the data-analysis process in that it can help correct some of the errors that arise during the data collection, tabulation and entry phases” (p. 44). As a first measure, I randomly selected 10% of the cases in the SPSS dataset and checked their accuracy with the raw data. I asked a colleague to run the same accuracy check on 20% of the data. The percentage of disagreements on this sample did not exceed 10%; therefore, I did not re-check the raw data forms for all entries. Additionally, I ran frequency analyses of all independent and outcome variables to assess the variability, and identify missing or incorrect data.

After ensuring that the data were clean and free of errors, I screened the data, thus engaging in exploratory data analysis. Examining the item level standardized scores for all cases whose mean score was greater than three standard deviations from the mean enabled me to determine if the pattern of responses appears to be valid. Keppel and Wickens (2004) explain, “Real data often are a little more scattered than a normal distribution—the technical term is over dispersed. These observations are a valid part of the distribution and should be included in the analysis” (p. 146). Outliers have the most drastic effect on correlation coefficients when there is

a small sample size (i.e., $n < 100$) and the participants deviate strikingly from the general cluster (Shavelson, 1996). No cases had missing data and there were 27 cases for analysis.

Analysis. The analysis addressed the research question: What are the needs of Kansas families that include an infant or toddler with a diagnosis of ASD? Due to the small sample size, I mainly used descriptive statistics to analyze and report findings. Primary descriptive statistics included the mean and standard deviation at the item and domain level. I also included frequency counts to determine the number of subjects who endorsed each response. Additionally, I analyzed (a) family mean ratings for the FNA need domain averages in descending order; (b) family ratings of need by FNA item in descending order; (c) percentage of families rating items as high/very high need by domain; (d) family rating of need as expressed across parent and child demographic differences; (e) families ranked by FNA survey domain average scale score and identified by top and bottom quartiles; f) family and child characteristics for the top quartile of families identifying most need for support; and g) family and child characteristics for the bottom quartile of families identifying least need for support. These analyses were undertaken to (a) to summarize the domains where the highest needs were identified (b) to review information at the item level, in addition to the domain level on the highest area of need; (c) to indicate the items that large proportions of families identified as high or very high need areas; (d) to gather descriptive information on the parent and child characteristics that impact reported need; and (e) to provide descriptive information on the characteristics of the families identifying the highest and lowest needs.

Chapter 3: Results

The results of the study provide data that informs the research question: What are the needs of Kansas families that include an infant or toddler with a diagnosis of autism spectrum disorder (ASD)? In this section I present: (a) family rating of need by FNA scale domain; (b) family rating of need by FNA item in descending order; (c) family perception of need expressed as items ranked as high/very high by domain; (d) family rating of need as expressed across parent and child demographic differences; and (e) family and child characteristics for families identifying most need and least need across domains.

Family Rating of Need by FNA Scale Domain

The domains of the FNA scale include Health, Daily Care, Recreation, Social Relationships, Lifespan Changes, Teaching, Getting Services, Family Interaction, Emotional Health, Spirituality, and Economics. Table 3 reports the means and standard deviations of parental rating of need, averaged across items, by FNA domains. I report the means in descending order with higher FNA domain mean scores at the top of the list; to summarize the domains where the highest needs were identified.

Table 3

Family Mean Ratings for FNA Need Domain Averages in Descending Order (n=27)

Domain	<i>M</i>	Standard Deviation
Getting Services	3.06	1.19
Teaching	2.80	1.26
Emotional Health	2.61	1.09
Lifespan Changes	2.51	1.05
Economics	2.36	0.99
Social Relationships	2.34	0.91
Family Interactions	2.34	1.13
Recreation	2.18	0.88

Domain	<i>M</i>	Standard Deviation
Daily Care	2.09	0.88
Health	1.90	0.63
Spirituality	1.78	1.18

Families ranked Getting Services ($M = 3.06$) and Teaching ($M = 2.80$) as the top domains for which they would need support in the next six months. Emotional Health is the third highest-ranking domain ($M = 2.61$). For Getting Services and Teaching, at first glance, the priorities appear to have more to do with the child’s need rather than the family’s needs. However, in reviewing the items included in these domains on the Family Needs Assessment, the questions are related to family needs (a) “Does the *family* need support to get education, social services and health services?”; and (b) “Does the *family* need support to teach members what they need to know to be successful”. As phrased, these questions are about supports that are linked to direct child interventions but also have links to family needs to implement such. The ranking of Emotional Health is at third and is aligned with the literature that indicates that families of children with autism have higher needs for emotional health supports due to high rates of stress for families of children with a diagnosis of ASD (Rivard, Terroux, Parent-Boursier, & Mercier, 2014).

Family Rating of Need by FNA Item in Descending Order

Table 4 reports descriptive data (i.e., means and standard deviations) of family rating of need by FNA item, again in descending order of the level of need. This analysis provides information at the item level, rather than across domains, about the highest areas of need.

Table 4

Family Ratings of Need by FNA Item in Descending Order (N=27)

Question	<i>M</i>	<i>SD</i>
Teaching communication skills	3.56	1.05
Getting information necessary to make sound decisions about services	3.37	1.31
Having access to necessary services	3.37	1.31
Teaching social and emotional skills	3.30	1.21
Teaching child(ren) to attend to toileting needs	3.26	1.34
Knowing and acting on my child(ren)'s educational rights	3.26	1.34
Feeling informed and helped by teachers about the improvement and the difficulties of my child(ren)	3.22	1.55
Having trusting partnership with professionals	3.22	1.42
Monitoring services to make sure that they are beneficial	3.07	1.41
Developing long-term goals for family members	3.04	1.32
Teaching appropriate behavior	3.00	1.29
Teaching choice-making and problem solving	3.00	1.21
Having educational services where my child(ren) are making progress	3.00	1.32
Making changes in services when necessary, even when professionals disagree	2.96	1.49
Teaching safety in the home and other places	2.96	1.48
Helping my child(ren) reach goals during every day routines	2.96	1.19
Teaching independent living skills (such as eating and dressing)	2.89	1.31
Managing stress	2.89	1.34
Saving money for the future	2.85	1.20
Knowing when my child(ren) is making progress	2.85	1.20
Participating in goal-setting to enhance family members' learning	2.85	1.17
Having support from other families who have a child with disabilities	2.81	1.30
Helping all family members to know how to respond to negative situations and attitudes	2.70	1.44
Getting a full nights sleep	2.67	1.52
Feeling supported by professionals at the time of learning about my child(ren)'s disability	2.67	1.46
Helping all family members know how to respond to questions about disability	2.63	1.28
Planning for my child(ren)'s successful transition from early intervention to preschool or preschool to elementary	2.63	1.40
Planning for the future after I'm no longer able to take care of my family members	2.63	1.55

Question	<i>M</i>	<i>SD</i>
Paying for special therapies or equipment for my child	2.59	1.34
Having a break from caretaking (such as respite care)	2.59	1.34
Starting a new school year	2.56	1.42
Helping my family members make friends	2.48	1.01
Feeling hope about the future for our family members	2.48	1.37
Dealing with challenges related to all family members	2.44	1.12
Providing supports to include all members of my family in family activities	2.44	1.31
Helping my family members in socializing with others	2.44	1.01
Enhancing each family member's self esteem	2.41	1.01
Going to bathroom	2.41	1.53
Solving problems together as a family	2.37	1.31
Being flexible as a family in making changes when they are needed	2.37	1.28
Participating in social occasions with friends, co-workers, or others	2.37	1.19
Helping others in knowing how to socialize with my family members	2.37	1.12
Talking about feelings, opinions, and challenges with all members in my family	2.37	1.15
Participating in preferred indoor community recreational activities	2.33	1.15
Applying for government benefits and addressing government benefit denials	2.33	1.38
Having a clear understanding of each family member's strengths and needs	2.33	1.18
Paying school fees and/or childcare	2.30	1.35
Getting new childcare	2.30	1.38
Attending to daily care activities (e.g., bathing, brushing teeth, dressing, eating)	2.30	1.46
Feeling supported by professionals to manage the difficulties associated with daily living	2.26	1.29
Having healthy life style (such as healthy diet/exercising)	2.22	1.36
Going on family vacations	2.19	1.18
Getting child care	2.19	1.39
Teaching motor skills	2.19	1.40
Participating in preferred outdoor community activities	2.15	1.03
Paying for basic needs	2.15	1.26
Establishing close emotional bonds among members of the family	2.15	1.35
Having appropriate dental care	2.07	1.00
Having appropriate extracurricular/holiday care	2.04	1.30
Doing relaxing things/activities at home	2.04	1.13
Coordinating medical care among two or more physicians	2.00	1.24

Question	<i>M</i>	<i>SD</i>
Getting or keeping a job	1.93	1.33
Getting regular and special resources needed by family members	1.93	1.39
Monitoring health conditions (having regular doctor/health checks)	1.93	0.92
Teaching my child(ren) about sexuality	1.89	1.27
Helping with homework	1.85	1.43
Teaching my child(ren) about spiritual beliefs	1.81	1.21
Having appropriate vision and eye care	1.78	0.80
Having a spiritual community that includes my child(ren)	1.74	1.26
Having appropriate transportation	1.74	1.23
Moving within the same community or to a different community	1.74	1.28
Ensuring that home and community settings are accessible	1.74	1.16
Giving medications	1.67	1.18
Relying on my spiritual belief to understand my child(ren)'s disability	1.63	1.25
Having appropriate care for hearing related needs	1.44	0.70
Using technological communications to connect socially with others	1.41	0.81
Preventing substance abuse and other addictions (e.g., alcohol, drugs)	1.07	0.85

When looking at the FNA items individually, family members are reporting some level of need for almost all items. On the FNA a rating of 1 indicated *no need*; 2 indicated *low need*; 3 indicated *need*; 4 indicated *high need* and 5 indicated *very high need*. In Table 5, 61 of the 77 items were rated at 2 (low need) or above. This list of items from the FNA represented in descending order according to mean, indicates that the majority of families may not be reporting need for support at the high (4) or very high (5) need level, however, some level of need (2-3) is pervasive across FNA items. However, some of the items with lower means had higher standard deviations, indicating variability in family needs for these items. Standard deviations ranged from .70 SD to 1.55 SD.

Family Rating of Need Expressed as Items Ranked as High/Very High by Domain

Table 5 reports the percentages of families who reported *high* (4)/*very high* (5) needs for each FNA item. This provides additional information, to supplement the mean ratings, indicating the items that large proportions of families identified as high or very high need.

Table 5

Percentage of Families Rating Items as High/Very High Need by Domain (N=27)

Survey Question	Percentage of High/Very High
Teaching communication skills	56.50
Having appropriate vision and eye care	55.50
Having access to necessary services	51.80
Helping my family members in socializing with others	51.80
Having a trusting partnership with professionals	48.10
Helping my family members make friends	48.10
Knowing and acting on my child (ren)'s educational rights	48.10
Teaching social and emotional skills	48.10
Feeling informed and helped by teachers about the improvement and the difficulties of my child (ren)	44.40
Having educational services where my child(ren) are making progress	40.70
Teaching child(ren) to attend to toileting needs	44.40
Helping others in knowing how to socialize with my family members	40.70
Teaching safety in the home and other places	40.70
Feeling supported by professionals at the time of learning about my child (ren)'s disability	38.40
Having a healthy lifestyle	37.00
Having appropriate dental care	37.00
Helping all family members know how to respond to negative situations and attitudes	37.00
Making changes in services when necessary, even when professionals disagree	37.00
Monitoring services to make sure they are beneficial	37.00
Teaching choice-making and problem-solving	37.00
Teaching independent living skills	37.00
Having support from other families who have a child with disabilities	33.50
Developing long-term goals for family members	33.30
Having appropriate care for hearing related needs	33.30
Having a clear understanding of each family member's strengths and needs	33.30

Survey Question	Percentage of High/Very High
Helping my child(ren) reach goals during everyday routines	33.30
Managing stress	33.30
Planning for my child (ren)'s successful transition from early intervention to preschool	33.30
Planning for the future after I'm no longer able to take care of my family members	33.30
Saving money for the future	33.30
Teaching appropriate behavior	33.30
Getting a full night sleep	29.60
Participating in goal-setting to enhance family members' learning	29.60
Paying for special therapies or equipment for my child	29.60
Monitoring health conditions	29.60
Applying for government benefits and addressing government benefit denials	25.90
Doing relaxing things/activities at home	25.90
Going to bathroom	25.90
Helping all family members to know how to respond to questions about disability	25.90
Knowing when my child (ren) is making progress	25.90
Starting a new school year	25.90
Teaching my child(ren) about spiritual beliefs	25.90
Attending to daily care activities	22.20
Being flexible as a family in making changes when they are needed	22.20
Feeling hope about the future for our family members	22.20
Feeling supported by professionals to manage difficulties associated with daily living	22.20
Getting child care	22.20
Having a break from caretaking	22.20
Helping with homework	22.20
Paying school fees and/or child care	22.20
Solving problems together as a family	22.20
Getting new childcare	18.50
Getting or keeping a job	18.50
Participating in social occasions with friends, co-workers, or others	18.50
Paying for basic needs	18.50
Talking about feelings, opinions, and challenges with all members in my family	17.10
Participating in preferred indoor community recreational activities	16.10
Dealing with challenges related to all family members	14.80
Establishing close emotional bonds among members of the family	14.80

Survey Question	Percentage of High/Very High
Getting regular and special resources needed by family members	14.80
Going on family vacations	14.80
Having appropriate extracurricular/holiday care	14.80
Teaching motor skills	14.80
Teaching my child(ren) about sexuality	14.80
Coordinating medical care among two or more physicians	11.10
Ensuring that home and community settings are accessible	11.10
Giving medications	11.10
Having appropriate transportation	11.10
Relying on my spiritual belief to understand my child(ren)'s disability	11.10
Using technological communications to connect socially with other	11.10
Enhancing each family member's self esteem	7.40
Participating in preferred outdoor community activities	7.40
Preventing substance abuse and other addictions	0.00

Teaching communication skills was reported as a *high (5)/very high (4)* area of need for support by 56.5 % of families. Other items rated as *high/very high* by half of the participants were in the area of Getting Services and Teaching. When reviewing only items that are rated as high/very high, the domain of social relationships is highlighted as an additional area of high need. Participants reported *high (4)/very high (5)* need for (a) “Helping my family members in socializing with others”; and (b) “Helping my family members make friends”.

Family Rating of Need as Expressed across Parent and Child Demographic Differences

Table 6 reports means and standard deviations of parental perception of need across parent (i.e., gender, relationship to child, race/ethnicity, primary language, age, marital status, education, family income, and geographic location) and child (i.e., age and level of severity of impact of diagnosis on development) demographic characteristics. The first section of the table reports mean ratings by child characteristics and the second section by parent characteristics. The columns are organized by the 11 domains of the FNA Scale. The mean for each FNA domain is presented for each demographic variable and shown across the columns with a total mean score

for each row. The standard deviation is shown for each row. This information provides descriptive information on the parent and child characteristics that impact reported need.

Table 6

Family Rating of Need as Expressed across Parent and Child Demographic Differences

Characteristic	H	DC	R	SR	LC	T	GS	FI	EH	S	E	Total Score <i>M</i>	<i>SD</i>
Of the child													
Age of child													
18-21 months	2.00	2.44	2.00	3.29	1.71	2.08	3.67	2.67	3.40	5.00	2.00	2.75	1.00
22-25 months	1.65	1.36	1.56	2.00	2.10	2.09	2.27	1.91	2.30	1.16	1.50	1.81	0.38
26-29 months	1.71	1.60	2.32	2.28	2.59	3.20	3.41	2.95	2.88	1.85	2.81	2.51	0.61
30-33 months	2.17	1.62	2.00	1.82	2.19	2.14	2.55	1.46	1.88	1.13	1.90	1.90	0.39
34-36 months	1.97	2.38	2.42	2.68	2.84	3.22	3.31	2.48	2.82	1.83	2.65	2.60	0.46
Domain mean	1.90	1.88	2.06	2.41	2.29	2.55	3.04	2.29	2.66	2.19	2.17		
Level of severity													
Mild	1.61	1.50	1.80	1.53	1.87	2.28	2.71	1.81	2.20	1.67	2.05	1.91	0.37
Moderate	2.16	1.85	2.00	2.39	2.35	2.36	2.60	2.05	2.24	2.03	2.27	2.21	0.22
Severe	2.08	2.69	2.60	3.46	3.60	3.95	3.95	3.46	3.60	2.53	3.00	3.17	0.63
Profound	2.19	2.85	3.25	2.38	3.33	3.99	4.07	3.05	3.41	1.66	2.55	2.98	0.74
Domain mean	2.01	2.22	2.41	2.44	2.79	3.15	3.33	2.59	2.86	1.97	2.47		
Of the parent													
Gender													
Male	2.75	2.89	3.25	2.43	3.29	3.92	3.89	3.33	3.60	3.00	1.83	3.11	0.62
Female	1.87	1.96	1.96	2.49	2.50	2.92	3.06	2.42	2.57	1.51	2.38	2.33	0.46
Domain mean	2.31	2.43	2.6	2.46	2.90	3.42	3.48	2.88	3.09	2.26	2.11		
Relationship to child													
Mother	1.87	1.96	1.96	2.49	2.50	2.92	3.06	2.42	2.57	1.51	2.38	2.33	0.47
Father	2.75	2.89	3.25	2.43	3.29	3.92	3.89	3.33	3.60	3.00	1.83	3.11	0.62

Characteristic	H	DC	R	SR	LC	T	GS	FI	EH	S	E	Total Score <i>M</i>	<i>SD</i>
Domain mean	2.31	2.43	2.61	2.46	2.90	3.42	3.48	2.88	3.09	2.26	2.11		
Race/Ethnicity													
Hispanic/Latino	2.44	4.56	1.25	2.82	3.18	3.64	3.98	2.58	2.90	2.25	2.70	2.94	0.90
Black or African American	1.13	2.34	1.62	1.43	2.71	1.77	2.61	1.50	2.10	1.00	2.10	1.85	0.57
White	1.69	2.00	2.16	2.25	2.48	2.78	2.88	1.93	2.47	1.56	2.33	2.23	0.42
Two or more races	1.81	4.00	2.75	3.80	2.71	2.73	3.67	2.25	3.20	3.00	2.59	2.96	0.67
Domain mean	1.77	3.23	1.95	2.58	2.77	2.73	3.29	2.07	2.67	1.95	2.43		
Primary language													
English	1.94	2.08	2.26	2.39	2.51	2.80	3.56	2.40	2.52	1.68	2.39	2.41	0.49
Spanish	2.94	2.78	3.25	2.72	3.21	3.88	3.95	3.33	3.10	2.67	2.67	3.14	0.45
Other	1.00	1.00	1.00	1.00	1.14	1.15	1.22	1.00	1.00	1.00	1.00	1.05	0.08
Domain mean	1.96	1.95	2.17	2.04	2.29	2.61	2.91	2.24	2.21	1.78	2.02		
Age													
20 to 29 years	1.53	2.21	3.10	2.19	2.82	3.02	3.29	2.31	2.94	1.67	2.99	2.55	0.60
30 years or older	1.44	2.05	2.10	2.44	2.27	2.85	2.98	2.42	2.64	1.75	2.23	2.29	0.45
Domain mean	1.49	2.13	2.60	2.32	2.55	2.94	3.14	2.37	2.79	1.71	2.61		
Marital status													
Married/living with a partner	1.94	2.00	2.23	2.44	2.63	2.91	3.14	2.38	2.65	1.77	2.39	2.41	0.41
Not married	1.54	2.03	1.75	1.72	1.76	2.05	2.37	2.00	2.20	1.33	2.05	1.89	0.30

Characteristic	H	DC	R	SR	LC	T	GS	FI	EH	S	E	Total Score <i>M</i>	<i>SD</i>
Domain mean	1.74	2.02	1.99	2.08	2.20	2.48	2.76	2.19	2.43	1.55	2.22		
Education													
High school graduate (diploma or GED)	1.89	1.81	2.00	1.65	1.88	2.87	2.71	2.07	1.82	1.23	1.85	1.98	0.46
Some college or post-high school, but no degree	1.78	2.27	2.11	2.59	2.73	3.07	3.50	2.62	3.04	2.29	2.98	2.63	0.50
College degree (undergraduate)	2.02	1.84	2.25	2.60	2.86	2.49	2.53	2.06	2.71	1.33	2.12	2.26	0.44
College degree (graduate)	2.03	2.61	2.50	2.57	2.57	2.67	3.55	2.62	2.80	2.00	2.25	2.56	0.42
Domain mean	1.93	2.13	2.22	2.35	2.51	2.78	3.07	2.34	2.59	1.71	2.30		
Family Income													
Less than \$10,000	3.13	2.67	3.25	3.00	3.29	3.85	4.00	3.33	2.60	2.33	3.50	3.18	0.51
\$10,000 to 40,000	1.76	2.38	2.70	2.31	2.47	3.07	3.25	2.43	2.83	1.60	2.56	2.49	0.50
Over \$40,000	2.05	1.91	2.02	2.11	2.53	2.64	2.96	2.17	2.54	1.83	2.21	2.27	0.35
Domain mean	2.31	2.32	2.66	2.47	2.76	3.19	3.40	2.64	2.66	1.92	2.76		

Characteristic	H	DC	R	SR	LC	T	GS	FI	EH	S	E	Total Score <i>M</i>	<i>SD</i>
Geographic Location													
Urban	2.15	2.21	2.29	2.53	2.29	2.91	2.71	2.52	2.45	2.38	2.50	2.45	0.22
Suburban	1.66	2.27	2.19	2.42	2.81	2.67	3.22	2.19	2.71	1.47	2.58	2.38	0.51
Rural	1.80	1.74	2.00	2.22	2.32	2.93	2.65	2.39	2.57	1.54	1.89	2.19	0.43
Domain mean	1.87	2.07	2.16	2.39	2.47	2.84	2.86	2.37	2.58	1.80	2.32		

Note: H (Health); DC (Daily Care); SR (Social Relationships); LC (Lifespan Changes); T (Teaching); GS (Getting Services); FI (Family Interactions); EH (Emotional Health); S (Spirituality); E (Economics). Level of severity = Level of severity of impact of diagnosis of autism on child’s development per caregiver report.

Table 6 was descriptively reviewed for the magnitude of differences based on child and family characteristics. This table aligns with the information analyzed previously in that across all demographic differences, the domains of Teaching and Getting Services are rated as highest need. That said, needs in most demographic categories fall between 1(*no need*) and 3 (*need*). For the 18-21 month child category, the mean for Spirituality is a 5, however, there is only one child in the population represented for this age group. This highlights that, given the small sample size, the values across groups must be interrupted cautiously. With regard to race/ethnicity, families that identify as Hispanic/Latino (4 families) and families that identify as two or more races (2 families) rank Daily Care at the as a high need, when descriptively compared to other families. When data are reviewed according to the severity of the impact of the ASD on development, the mean for families whose children have more severe impacts is slightly higher than for the other levels of severity. For the profound category (3 families), Getting Services rises to the level of 4 or *high need*.

Family and Child Characteristics for Families Identifying Most Need and Least Need across Domains

Table 7 displays the average scale score for each of the 11 FNA Survey domains as reported by individual survey participants.

To aid in analysis and discussion, a total average scale score was calculated in order to identify and assign families to quartiles.

Corresponding symbols were then added in order to identify the families in the top quartile (families in most need of support) were marked with a “+” symbol; the bottom quartile (families in least need of support) were marked with the “-” symbol.

Table 7

Families Ranked by FNA Survey Domain Average Scale Score and Identified by Top (+) and Bottom (-) Quartiles

	Average Scale Score by Survey Domain											Total Average Scale Score
	H	DC	R	SR	LC	T	GS	FI	EH	S	E	
Family 11+	3.38	4.78	5.00	4.14	4.43	5.00	5.00	5.00	4.80	1.00	3.17	45.69
Family 21+	3.13	2.67	3.25	3.00	3.50	6.92	4.00	3.33	2.60	2.33	3.50	38.23
Family 19+	2.75	2.11	2.50	4.00	3.14	3.46	4.00	3.00	3.20	3.00	3.50	34.67
Family 6+	2.75	2.89	3.25	2.43	3.29	3.92	3.89	3.33	3.60	3.00	1.83	34.18
Family 2+	1.63	3.11	3.50	3.71	3.71	3.54	3.67	1.83	3.00	1.00	3.17	31.87
Family 14+	1.00	2.67	3.00	1.00	3.00	4.69	4.67	4.00	3.60	1.00	2.67	31.29
Family 9	2.00	2.44	2.00	3.29	1.71	2.08	3.67	2.67	3.40	5.00	2.00	30.25
Family 24	1.38	1.89	2.00	2.29	2.57	2.62	2.33	3.00	3.60	3.00	3.17	27.84
Family 3	1.75	1.56	1.25	3.43	3.14	3.62	3.44	2.33	2.40	2.67	2.00	27.59
Family 5	2.13	2.00	1.25	2.43	2.86	3.15	4.56	1.33	3.00	1.00	3.17	26.87
Family 26	1.38	2.67	2.50	2.14	1.86	3.38	3.33	3.00	2.40	1.00	3.17	26.83
Family 7	2.13	2.44	2.00	2.43	2.71	2.31	2.11	3.00	2.40	2.00	2.00	25.53

Average Scale Score by Survey Domain												Total Average Scale Score
	H	DC	R	SR	LC	T	GS	FI	EH	S	E	
Family 13	2.00	1.44	2.00	2.57	2.00	2.46	2.22	3.33	3.40	1.67	2.17	25.27
Family 27	1.75	2.22	2.00	1.86	3.00	2.46	4.33	1.83	2.00	1.00	2.67	25.12
Family 23	1.25	2.67	2.25	1.86	1.57	1.92	4.00	2.00	3.20	1.00	3.17	24.88
Family 12	2.38	1.89	2.00	3.29	3.86	2.38	2.67	1.33	2.40	1.00	1.67	24.86
Family 10	1.50	1.67	2.25	2.57	2.29	3.38	2.44	2.33	2.60	1.00	1.33	23.37
Family 18	2.50	1.33	2.00	1.71	2.71	1.62	2.33	1.33	2.80	1.67	2.83	22.84
Family 4	2.13	1.67	1.50	1.86	1.50	2.54	2.78	1.33	1.00	1.33	2.50	20.13
Family 15–	2.13	1.00	2.00	2.00	2.43	1.92	2.33	1.33	2.00	1.00	1.67	19.81
Family 25–	2.00	2.56	2.75	1.71	1.71	2.08	1.11	1.33	1.60	1.00	1.17	19.02
Family 16–	1.25	1.11	1.25	1.14	1.43	2.38	3.00	2.00	2.00	1.00	1.17	17.73
Family 8–	2.50	1.00	1.25	1.86	1.14	2.62	2.67	1.50	1.00	1.00	1.00	17.53
Family 17–	1.25	1.33	2.00	1.57	1.29	1.23	1.11	1.00	1.00	1.00	1.83	14.62
Family 22–	1.25	1.00	1.00	1.00	1.00	2.15	1.00	1.00	1.00	1.00	1.00	12.40
Family 20–	1.00	1.00	1.00	1.00	1.14	1.15	1.22	1.00	1.00	1.00	1.00	11.52

Note: H (Health); DC (Daily Care); SR (Social Relationships); LC (Lifespan Changes); T (Teaching); GS (Getting Services); FI (Family Interactions); EH (Emotional Health); S (Spirituality); E (Economics). Level of severity = Level of severity of impact of diagnosis of autism on child’s development per caregiver report.

Table 8 and Table 9 respectively display the demographic characteristics of the seven families identified in the top quartile (most need of support) and the seven families identified in the bottom quartile (least need of support). This information provides descriptive information on the characteristics of the families identifying the highest and lowest needs.

Table 8

Family and Child Characteristics for Top Quartile of Families Identifying Most Need for Support

Characteristics	In Rank Order of Most Need for Support						
	Family 11+	Family 1+	Family 21+	Family 19+	Family 6+	Family 2+	Family 14+
<i>Of the child</i>							
Age of child (months)	34	34	29	36	34	35	29
Level of severity	Severe	Severe	Moderate	Severe	Profound	Profound	Profound
<i>Of the parent</i>							
Race/Ethnicity	White	White	White	White	White	Two or more	White
Primary language	English	English	Spanish	English	Spanish	English	English
Age	20-29	20-29	>30	>30	>30	20-29	20-29
Marital status	Married	Married	Married	Married	Married	Married	Married
Education	CG	SC	HS	SC	SC	CU	HS
Family income	>\$40	>\$40	<\$10	>\$40	\$10-40	\$10-40	\$10-40
Geographic location	Suburban	Suburban	Urban	Urban	Urban	Suburban	Rural

NOTE: ND = Schooling but not high school diploma or GED, HS = High School Graduate or GED, SC = Some College; CU = College (undergraduate); CG = College (graduate). Level of severity = Level of severity of impact of diagnosis of autism on child's development per caregiver report.

Table 9

Family and Child Characteristics for Bottom Quartile of Families Identifying Least Need for Support

Characteristics	In Rank Order of Least Need for Support						
	Family 20-	Family 22-	Family 17-	Family 8-	Family 16-	Family 25-	Family 15-
Of the child							
Age of child (months)	23	36	35	32	23	30	23
Level of severity	Mild	Mild	Mild	Moderate	Mild	Mild	Mild
Of the parent							
Race/Ethnicity	Black	White	White	White	White	White	White
Primary language	Other	English	English	English	English	English	English
Age (years)	20-29	>30	20-29	>30	>30	>30	>30
Marital status	Married	Not Married	Married	Married	Married	Married	Married
Education	CG	HS	SC	HS	HS	HS	CU
Family income	>\$40	>\$40	>\$40	>\$40	>\$40	\$10-40	>\$40
Geographic location	Urban	Suburban	Suburban	Urban	Suburban	Rural	Rural

Note: CG = ND = Schooling but not high school diploma or GED, HS = High School Graduate or GED, SC = Some College; CU = College (undergraduate); CG = College (graduate). Level of severity = Level of severity of impact of diagnosis of autism on child's development per caregiver report.

When examining Tables 8 and 9, the families that reported the highest and lowest needs, had similar demographics and were also similar to the overall sample of 27 families. The only areas where there were notable differences were in the child characteristics of severity of the impact of the ASD on development, and in the family characteristics of Level of Education and Level of Family Income. Figure 1 illustrates that for families reporting most needs, the severity of the impact of ASD on development tended to be highest with most families falling in the severe ($n = 3$), and profound ($n=3$) category, with one child having a moderate impact. This compares to the group reporting the least needs in which six children were identified as having mild impacts of and one child moderate impact. Thus, the majority of families who reported high level of need tended to have children with severe to profound levels of disability, while those with the lowest impacts reported having lower family needs.

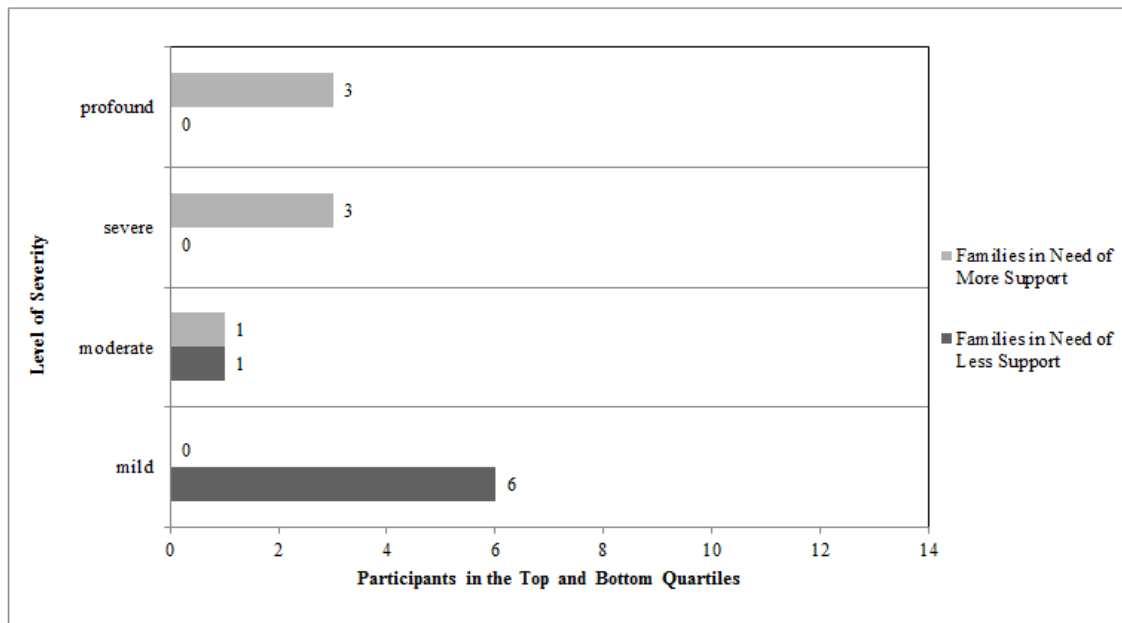


Figure 1. Top Quartile (Most Need) and Bottom Quartile (Least Need) Families by Severity of Impact on Development

Figure 2 shows the breakdown based on the respondent’s education level. Family members who reported the lowest needs tended to have reporting having a high school diploma,

although families at other education levels also fell into low need group. Family members who reported the highest need for family support tended to also report have some college or a high school diploma, although again high and low needs were spread across education levels.

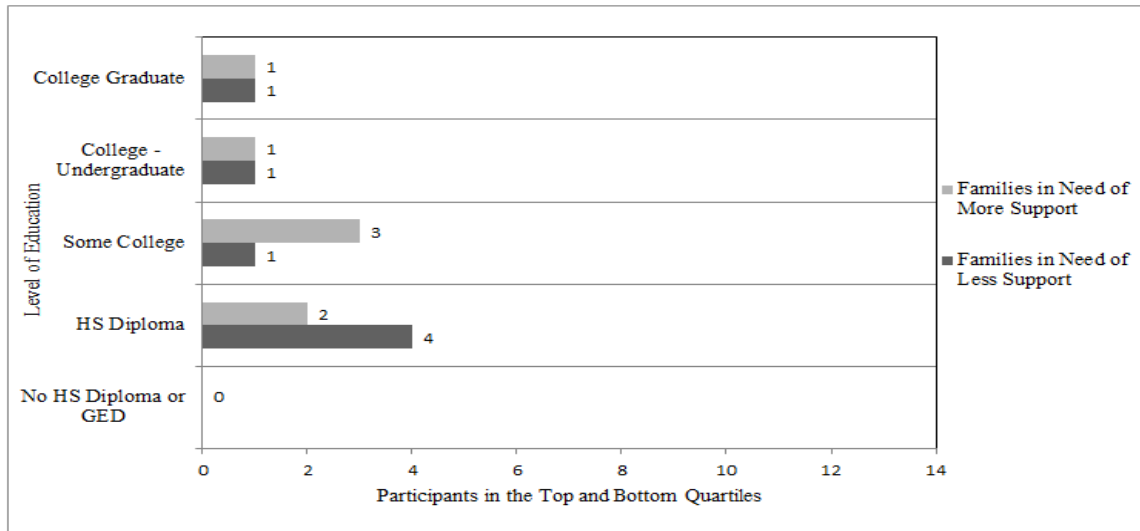


Figure 2. Top Quartile (Most Need) and Bottom Quartile (Least Need) Families by Level of Education.

Figure 3 shows the variation between the Income Levels of the two groups. The group with lowest needs tended to be families with incomes of over \$40,000, with families reporting the lowest needs spread across income levels. Overall the pattern of findings based on family education level and income were not as clear as those based on the severity of the impact of ASD on child development.

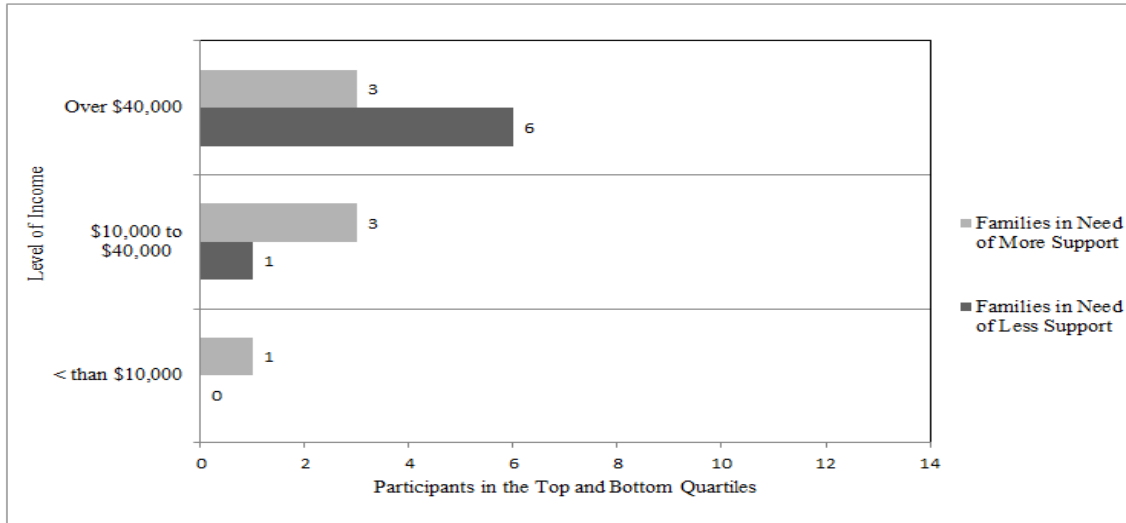


Figure 3. Top Quartile (Most Need) and Bottom Quartile (Least Need) Families by Level of Income

In the analysis of data, a few overall themes emerge which merit discussion in the interpretation of results. Families in the study by and large do not differ significantly in their demographic differences. They do differ slightly from national data reported on the Part C population as a whole (Hebbeler et al., 2007) as the sample had higher income and education levels, and were more likely to be married.

With regards to the findings from the sample, families that have children that are severely and profoundly affected by their ASD tend to report higher levels of need. Across all families, most families do not rate their needs among domains as *high* (4) or *very high* (5). But all families report some level of need for the next six months across all domains albeit the need is primarily rated as *low need* (2) or *need* (3). Even with these generally low or need ratings, there are two domains that are consistently rated higher by families, Getting Services and Teaching, and the specific items that are rated highest are from these domains, as well as the domain of Social Relationships.

Chapter 4: Discussion Interpretation of Results

The aim of this study was to identify and report the needs of Kansas families enrolled in Part C that include an infant or toddler with a diagnosis of autism spectrum disorder (ASD). The literature review suggested that families of children with a diagnosis of ASD had a number of potential needs; however, little research has directly asked families of children with a diagnosis of ASD to specifically identify their short-term needs. Research has suggested, though, that parents of children with ASD consistently report increased parenting-related stress and psychological distress, even when compared to parents of children with other developmental disabilities such as Down syndrome (Estes et al., 2009, Estes et al., 2013). Additionally, the number of negative life events experienced by families of children with a diagnosis of ASD was a significant predictor of parenting stress and sense of parenting competence (Estes et al., 2013). Given research suggesting the additional stress experienced by families with children with ASD, the purpose of this study was to systematically identify families' short-term needs as a first step in providing support to families, especially in light of the fact that parents of infants and toddlers are quickly asked to join in intensive parent-mediated interventions (Estes et al., 2013; Siller et al., 2013). Additionally, a move to identify needs at this early stage might assist in identifying strategies to support families at the foundation of a journey that crosses the lifespan.

I chose the Family Needs Assessment (FNA) as a tool to identify these needs because the FNA is one of a handful of tools related to identifying needs of families. The FNA has been found to be an appropriate tool validated for families with the birth to three population as a subset of a birth to 18 population (Chiu, Turnbull & Summers, 2013). As described previously, numerous studies have documented higher stress and there is a general assumption in the field that families of children with autism have high needs especially related to emotional health.

Parenting stress has been one of the most frequently researched aspects in relation to families that include a child with a diagnosis of autism (Ornstein-Davis & Carter, 2008). Research articles that focus on families of children with ASD often include statements such as “parents of children with autism spectrum disorder are known to experience more stress than parents of children with other conditions” (Rivard, Terroux, Parent-Boursier & Mercier, 2014, p.1610).

However, the parents in this study did not report high needs in Emotional Health as would be predicted by research suggested higher levels of stress in families of children with ASD. The domains that parents rated as highest in terms of need for support were the Getting Services ($M = 3.06$) and Teaching ($M = 2.80$) domains. These are domains are often considered child related and not family related needs. However, in reality, these needs impact quality of life for the family as a unit. Parents report being more stressed if there are issues in Getting Services or Teaching. Studies have linked the availability of resources and experienced professionals in the community, the types of services families have and desire, and parents’ knowledge about the types of service and availability of service to parental stress (Siklos & Kerns, 2006). Parents of children experiencing ASD have significantly greater expectations for the service delivery system than parents of children with other developmental disabilities (Siklos & Kerns, 2006). Researchers hypothesize that families of children with ASD have many stresses that are unique (Siklos & Kerns, 2006). Many times parents are dealing with very difficult behaviors with a child with whom they have no way of functionally communicating or with whom they are unable to interact socially. Communication impairments, uneven cognitive abilities, and problems in social relations are among the autism-related symptoms that were most stressful for mothers and fathers of school-aged children (Ornstein-Davis & Carter, 2008). In addition, researchers have connected a prediction of increased parenting stress with problem behaviors, such as

externalizing behaviors, more so than adaptive behaviors (Ornstein-Davis & Carter, 2008). Elevated parenting stress experienced by parents of newly diagnosed infants and toddlers is correlated with deficits/delays in children's social relatedness for both mothers and fathers (Ornstein-Davis & Carter, 2008). This body of research may explain why Getting Services and Teaching were the domains of highest need for families in this study, particularly given the age of their children.

There is some evidence of this in a study of parent-delivered intervention for parents of very young children with autism. Estes et al. (2013) found that a parent-coaching intervention that provided support for the type of items listed in Getting Services and Teaching, at an intensive level, helped lower parenting-related stress directly after a diagnosis of ASD. On the other hand, the group of parents in this study whose children received services but were not involved in parent-delivered instruction experienced an increase in parenting stress in just a 3-month period. This study supports the hypothesis that, if the parental needs for Getting Services and Teaching go unmet at this early stage, they may well be a contributor to the higher level of stress reported by parents of older children. On the other hand, if met early on as in the Estes study, perhaps they could contribute to subsequent positive psychological functioning and effective coping strategies by parents of children with ASD (Smith et al., 2008; Kuhn and Carter, 2006). Further research is needed to explore the impact of addressing family needs related to Getting Services and Teaching at an early age as a mediator of the emergence of parenting stress.

While the majority of participants in this study did not report *high* (4) to *very high* (5) needs at the level anticipated, it is of note that nearly every item and every domain was rated as in need of some level of support from *low need* (2) to *high need* (5) by the majority of families. Some need of support is typical for all families, and some parenting stress is considered to be

normal for any parent (Ornstein-Davis & Carter, 2008); however, needs for support in every domain at this early stage of parenting a child with ASD may be an early indicator of the increased demands of parenting reported among parents of older children with ASD (Ornstein-Davis & Carter, 2008).

The reported low levels of need (most parents reported need across domains in the low need to need range) could also be indicative that for this relatively small group of parents, the needs for support are low. This finding would be consistent with previous literature showing that families cope with disabilities in a variety of ways (Brown et. al., 2010). The fact is that of the 62 families offered a survey, only 27 completed the survey. Little is known about the needs of the other 35 families in Kansas Part C programs that include an infant or toddler with a diagnosis of autism. Anecdotally, practitioners in the Kansas programs shared that some of the families who did not complete the survey were too busy, stressed, or overwhelmed to complete the survey. While this could be true of any parent of an infant or toddler, it could also be an indicator that higher level of needs might have been reported if recruitment efforts had been successful in reaching the additional 35 families. Further research is needed to determine effective ways to understand the needs of families, particularly those who are experiencing high levels of stress and who do not participate in research studies. Further, as demographic information was not available on the 35 families that did not respond, it is unknown if there are other characteristics that may be impact the needs of these families.

The low level of need reported could also have to do with the level of support the family is currently receiving in the Part C program in Kansas. The Part C program in Kansas has a long history of focusing on partnerships with families. The state agency and technical assistance agency leaders promote both parent and child outcomes on the Individual Family Service Plan

(IFSP). The programs in the state use a family needs assessment, generally the Routines Based Interview developed by McWilliam (2010) to identify outcomes that arise from the family's daily routines and activities. In addition, the programs use the Primary Service Provider Approach to Teaming (Shelden & Rush, 2013), which includes a heavy focus on use of coaching with parents. A recent study suggests that a parent-coaching intervention may help lower parenting-related stress directly after a child is diagnosed with ASD (Estes, et al., 2013). The parents in these programs may report lower levels of need in many areas in the next six months because they perceive their needs as being met already due to the Kansas focus on engagement of parents as partners.

When I reviewed the data at the individual family level, there were as many as 48 - 56% of families rating certain items as *high* (4) to *very high* (5) need. The majority of items reported to be *high/very high* fall into four main domains--Teaching (9 items), Getting Services (8 items), Social Relationships (5 items), and Lifespan Changes (5 items). The top five items include: (a) teaching communication skills; (b) getting information necessary to make sound decisions about services; (c) having access to necessary services; (d) helping my family members in socializing with others; and (e) having a trusting partnership with professionals. These needs align with a study by Siklos and Kerns (2006) who found, using the Family Needs Questionnaire, that there was a difference in the needs expressed by families of children with ASD as compared with families of children diagnosed with Down syndrome. In this study, parents of children with ASD who were on average 8 years of age and at a time between 2-3 years after diagnosis more consistently expressed needs related to professionals working with their child and family as contrasted to parents of children with Down syndrome (Siklos & Kerns, 2006).

When reviewing the items ranked as *high/very high* by domain, a few notable differences emerged. In items ranked *high/very high* by families, a focus on the Social Relationships begins to emerge and the item, teaching social and emotional skills, rises to the top. Among the top ten items ranked as *high/very high* by a large percentage of families are: (a) helping my family members in socializing with others (51.8%); (b) helping my family members make friends (48.1%); and (c) teaching social emotional skills (48.1%). In a study that included families of older children diagnosed with ASD, families report unmet needs for the child/adolescent with ASD to have friends and for siblings' friends to feel comfortable (Hartley & Schultz, 2014).

Still, as stated previously, for the majority of the families Getting Services and Teaching were selected as the domains in need of most support for families. The need for support in these domains aligns with two recent studies. In a presentation on the FNA, Aya and colleagues (2014) reported on initial pilot use of the FNA to assess the support needs of families internationally. For families of children birth to age five in the United States, the top five items included (a) teaching communication, (b) daily care, (c) access to necessary services, such as speech therapy, physio/physical therapy, orientation and mobility, occupation therapy, audiology, and nursing care; (d) teaching appropriate behavior, and (e) having educational services where my child(ren) are making progress. This compares to the top five support needs found for families in this study whose top needs were in the Getting Services and the Teaching domains and the top five items that included teaching communication (1), having access to necessary services, such as speech therapy, physio/physical therapy, orientation and mobility, occupational therapy, audiology and nursing care (2), and teaching social-emotional skills (4). In the second study, Siller et al. (2013), found that the early months after a child's diagnosis are usually a time when parents' knowledge, thoughts, and emotions evolve rapidly. This study, specific to interventions designed for

toddlers, found that one of those needs that is often raised by parents of newly diagnosed children is the broad range of questions about the diagnosis of autism and what it means for their child and their family (Siller et al., 2013).

From a family systems perspective, the fact that the domains of Getting Services and Teaching rises to the top as need areas might be explained in the family support literature around family cohesion. Family cohesion is the “emotional bonding that members of family subsystems have” (Turnbull, Turnbull, Erwin, Soodak & Shogren, 2011, p. 41). Family theorists (Kreppner & Lerner, 1989; Olson, 1999) believe that healthy family functioning occurs when there is a balance between the degree of emotional bonding or sense of “belonging,” and the individual identities of family members. Cohesion at the level that some family theorists call “enmeshment” (Kreppner & Lerner, 1989; Olson, 1999) is especially strong in early childhood, when parents are immersed in caring for their new baby (for example, one might hear a parent say “*we ate our first solid food today*”). This natural tendency at infancy may be exacerbated when a family has received a diagnosis such as ASD. At this point, families may be at a highly cohesive stage when needs and identities of one member are blurred with the needs and identities of another. As a result, these needs that are seemingly child focused, may well be family focused or be connected to the needs of another family member. For example, if a father expresses the need to know how to teach communication skills to his young daughter, it may on the surface be a child-focused skill; however’ if that need is driven by his own need to hear his daughter say “daddy” or to respond when he speaks to her, then it is enmeshed with his own emotional needs and becomes more than just about teaching the child.

While the sample in this study was too small to examine group differences, a trend of results suggests that higher needs for support across domains were reported by parents of infants

and toddlers who also reported that the impact of their child's ASD on development was severe or profound. Several studies link severity of disability to unmet needs (Brown et al., 2010). Correlations between stress levels of mothers and fathers of children experiencing ASD have been found with their child's level of intellectual functioning, severity of symptoms, and adaptive behaviors (Rivard, Terroux, Parent-Boursier & Mercier, 2014). Families reporting that their child's disability was more severe have reported greater unmet needs. (Brown, et al., 2011). Beurkens, Hobson, and Hobson (2013) found that for families of children ages 4 to 14, autism severity adversely affected parent-child interaction which could interfere with teaching and lead to desire for getting services. It is also possible, and there is some evidence to suggest, that parents who rated the impact of the diagnosis of autism on their child's development as more severe, may be parents that are more stressed, which would possibly account for the elevated need for support (Ornstein-Davis & Carter, 2008).

A second trend in this study was higher needs for families with lower incomes. Differences in need by income differed by as much as ten points. The lower the income, the higher the reported need. Studies of older children with autism have linked income level with perceived need. Hartley and Schultz (2014) report a negative correlation between incomes and needs, and reported a higher proportion of important unmet support needs in mothers. Further research is needed, with larger samples, to more meaningfully explore these findings.

Limitations of the Study

In interpreting the results presented here, and in considering implications for future research and implications for policy or practice, certain limitations must be acknowledged. First, is the issue of the sample size. This study represents the experiences of only 27 families of the possible 62 families identified as having children enrolled in a Part C program in Kansas and

being diagnosed with ASD. Although the return rate of 43.5% surpasses many survey studies published in the literature (Erwin & Wheelright, 2002), it is important to recognize that this sample represents a small group of families with children with ASD, especially if the national population of infants and toddlers with a diagnosis of autism were considered. Further research with a larger, national sample is needed.

One of the concerns about this small sample size is that the perspective of the non-responders was not captured. I did not gather data from over half of the families targeted for the survey. The information from the non-responders might very well have represented higher needs as contrasted to the families who responded, particularly given the reports of early intervention providers in Kansas who stated that parents either reported or the providers believed that parents who declined to participate in survey completion were too stressed or overwhelmed to respond to the survey. They also cited lack of available time (estimated 20-60 minutes) given all of their parenting and other responsibilities. Additionally, because demographic information was not available on families that choose not to participate, it is difficult to explore the impact of demographic characteristics on participation. For example, the families that did participate may not be representative of racial/ethnic diversity of the Part C population in Kansas. Even though there was a Spanish version of the survey offered, none were requested, and the overall Part C population in Kansas is 18% Hispanic/Latina (OSEP Federal Data Table 1 –Kansas, 2013).

The target population also only included families who have infants and toddlers in Kansas enrolled in a Part C program. There may be families who have an infant or toddler with a diagnosis of ASD who are not enrolled in a Part C program. Second, because the study was specific to Kansas, the experience of parents who live in other states and are enrolled in other Part C programs is not captured. There is a difference between the sample of this study and the

national sample. The national sample indicates that this sample reported higher incomes and more education. In addition, this sample had higher rate of families reporting being married (Hebbeler et al., 2007). The national sample included children with ASD but did not disaggregate by diagnosis so it is unclear exactly how this sample compares to the national sample.

In addition, because the survey is anonymous in nature, it was impossible to contact parents for a follow-up interview to answer questions about their experiences and thoughts as they completed the FNA. I do not know if they understood that the FNA was asking them to forecast needs for the next six-months, nor do I know that they identified items as future needs, regardless of the fact that those needs might currently be addressed. I have some evidence for this concern with the parents who chose to complete the survey by phone. These parents asked questions for clarification or made comments such as (a) “am I answering for myself or my whole family;” (b) “do I mark it if I already have this in place;” and (c) “I already have that in place so it would not be a need.” Although the directions attempted to make this clear, it is important to realize that the FNA could be confusing to parents concerning whether they have “needs” if those needs have services in place. It might be a particular problem where parents are independently completing the survey rather than completing it in context of an interview. This may be a limitation of the FNA when using it with families of very young children.

Another limitation was the fact that the survey required an estimated 20 – 60 minutes for a parent to complete. The size of the survey and time commitment required may have been a barrier to completion for some parents of very young children.

Implications for Future Research

The value of this study may well be more in the questions it brings to the field than in any answers that it might offer to the field. One thing that is clear from the perspective of participants in this study is that the priority need for support for a family of an infant or toddler with a diagnosis of autism is in getting services and teaching. The participants did not report high levels of need for emotional support. This was an unexpected result as the literature, which for the most part is focused on parents of children 7-18, reports that parents of children with autism have higher levels of stress and depression than parents of typically developing children or parents of children with other disabilities (e.g. Down syndrome) (Boyd, 2011; Estes et al., 2009). The question for research that arises from this group is, why is that so?

The first direction for future research might be to conduct research around the service differences between families in Kansas who expressed lower needs and those who expressed higher needs. What services are already in place for families with lower needs as compared to families with higher needs? Determining ways to sample families who potentially have higher needs, and therefore are less likely to complete the survey, may also contribute to this understanding. Interviewing families in person may be the method that would be more likely to reach these families given reports by their providers of limited time and other life challenges. Another option may be to train the early intervention provider/primary service provider to conduct the FNA as an interview.

A second question would lead to a comparison of needs of families of infants and toddlers experiencing a diagnosis of ASD and enrolled in Part C in Kansas with population of similar families in Part C programs across the nation. Did the Part C culture of Kansas make a difference in this study? Kansas Infant Toddler Services and statewide technical assistance

providers promote evidence-based practices that put the focus on families as a unit. Examples of this include

- Statewide IFSP that promotes both child and family outcomes;
- Contractual obligation for all local programs to provide services according to the Mission and Key Principles For Providing Early Intervention Services in Natural Environments (OSEP TA Community of Practice: Part C Settings, 2008);
- Contractual obligation for all local programs to use the Primary Service Provider Approach (Shelden & Rush, 2013);
- Promotion of statewide adoption of the Routines-Based Interview (McWilliam, 2010).

Another question for study is in the perceptions/definitions families have dependent upon the age of their child(ren) when defining a need and assessing their level of that need. For families of infants and toddlers with ASD, what defines a need? Is the difference in reported needs in this study as compared to studies that involve older children due to age differences?? While there are a few studies that indicate parents are stressed when their children are infants or toddlers (Davis & Carter, 2008; Estes et al., 2014); the majority of studies are focused on parents of older children (Hayes & Watson, 2013; Siklos & Kerns, 2006; Rivard, Terroux, Parent-Boursier & Mercier, 2014). Could it be that at this young age, children are not yet experiencing some of the characteristics of autism that lead to increased parental stress? At the infant toddler stage, a child with a diagnosis of autism has many of the same behaviors as other children his age. Might the lower levels of stress be an indication that parents are not yet significantly concerned or experiencing a significant gap between the development of their child and a same-age peer? All infants and toddlers are still learning to communicate and be social. Many experience behavioral or eating issues. Does the stress level of parents grow as the gap becomes

more apparent with age; and if so, are there interventions that could be put in place for parents to prepare them for the differences in development? These age-related questions are for the most part unanswered in the literature. The literature that puts focus on the needs of parents of children with ASD is primarily that of parent of children of older children (Benson, 2014; Falk, Norris & Quinn, 2014; Hayes & Watson, 2013; Zablotsky, Bradshaw, Stuart, 2012). This issue needs further research, particularly given comments that the parents wrote on the FNA survey in this study, including (a) “ My son’s condition is pretty mild so not too much change is needed as of right now”; (b) “ My son is still young enough that the social part hasn’t affected his life much but I fear [for] him around other children (this parent rated social relationships items as low/no need); (c) “I would really like to do family activities and other things with the family & it is VERY hard with his Autism to do things with him outside of the home. Our other two children suffer b/c they want to do things & we can’t b/c of (child’s name)’s Autism. (This parent rated recreation questions all at 3); (d) “Learning to walk is a high priority (30 month old that family marked a mild impact). Some of these areas I will need help with as boys grow; (e) My child is only 2 ½ so a lot of these particular questions don’t apply to us yet (GS).” In these instances, the comments seem to indicate a higher need than the ratings the parent chose, or serve as an explanation for the lower ratings.

On average, children identified with ASD are not diagnosed until after age four (Frieden et al., 2014), while children in this study were, given they were being served in Part C, diagnosed much earlier than this (between 23 and 36 months of age). Therefore, we can assume they were diagnosed very near to the time the survey was completed. This raises the question of how and whether needs change after the first six months or the first year after diagnosis. Based on the studies of families of older children, needs appear to change as children age (Brown et al., 2011;

Hoefman et al., 2014; Thomas, Morrisey & McLaurin, 2007). An area of study might be to analyze when and how the emotional needs of parents increase in areas of stress and, if this trajectory is known, whether there are parent-focused interventions that can be implemented in these early years to influence the trajectory? What is the impact of interventions to support families early in decreasing or eliminating the later incidence of stress and depression?

Another question that bears potential for research is the evolution of parent need related to getting services and teaching and the factors that influence that evolution. Immediately after a diagnosis, parents often get a barrage of recommendations for high intensity early intervention, most of it to be carried out by the parent if the child is in the 0-3-age range (Estes et al., 2013; Siller et al., 2013). What is the influence of professional recommendations on parents' perception of need related to getting services and teaching? One assumption might be that there was intensification in family cohesion. There is some risk that parents who are encouraged to spend considerable time providing intervention may be unintentionally reinforced for establishing highly cohesive, i.e., enmeshed, relationships with their young children (Turnbull et al., 2000; Turnbull, Turnbull, Erwin, Soodak & Shogren, 2011). Further study is needed to assess if there is a threat to family cohesion at this early age when parents receive strong professional recommendations to teach their child. If this were found true through further study, early interventionists could build in strategies to promote and sustain a balanced level of cohesiveness for families as they work with their child to teach skills.

The characteristics of the non-responders and how to reach the non-responders for study is an area of potential focus for future research. As mentioned previously, early intervention providers reported that families chose not to complete the study due to lack of time or that the family was overwhelmed. Perhaps an interview format of the FNA for these parents might be

more appropriate and helpful in understanding the needs of this group. Is this the group of parents that indeed have or show early indicators for high levels of stress and depression? The answer to this question may point to two subgroups of families--those that do not show early signs of emotional needs (Estes et al., 2013) and those that do (Estes et al., 2009). In studying both groups, it might be possible to identify skills from one subset of families that may help the second subset. A qualitative study would allow for in-depth analysis of the experiences of both subsets of families. This study would need to be in multiple states, given the small number of families that are in this age range at the state level in Kansas.

An area in need of further investigation is the structure of the FNA itself in reference to use with families of infants and toddlers with a diagnosis of ASD. Would the FNA be better received if it were offered as an interview with the family? Would the FNA be better received if the family service coordinator or primary service provider were the interviewer? What can be done to reduce the length of the FNA and thus reduce the time burden on these young and busy families? Previous research conducted with the FNA has included the birth to three population but only as a subset of a 0-18 population (Chiu, 2013). Previous research has also been primarily with families of children with intellectual disability. Validation of the FNA for specific use with families with children birth to three and for families of infants and toddlers with a diagnosis of ASD would strengthen the validity of the FNA for these populations.

Another area of study around the FNA itself might be in clarification of directions. Exploring differing ways of providing direction to promote understanding should be considered. In the FNA, each domain starts with the following instructions: "Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks?" This is the only instruction in the FNA. Did parents

understand how to answer the questions? Did they understand what it meant to be forecasting need for the next six months? Did parents understand that they were to identify needs even if supports to meet the needs were already in place? Should there be an additional column in which parents could report that this need was important but currently met/unmet? Would administration of the FNA by a trained interviewer result in participation of the non-responders as contrasted with completing an anonymous paper version? Survey research outlines a need for clearer and more concise instructions than were included with the FNA (Lavrakas, 2008). This need was first highlighted by participants who chose to complete the survey by phone. These participants expressed lack of clarity with written instructions. They were not sure whose perspective they were to use when answering the question (i.e. their own, the whole family, their spouse). They reported not knowing how to define a need. Was a need present if they were already getting support? Future studies might consider a separate instruction page to assure clarification of instructions (Lavrakas, 2008; Sue & Ritter, 2012). Instructions must be easy to find (Lavrakas, 2008). The FNA instructions are embedded after the question, which may cause confusion and does not follow traditional format where directions would be found (Lavrakas, 2008; Sue & Ritter, 2007). Directions need not be lengthy but must be comprehensive especially if the interview is self administered (Sue & Ritter, 2012). Further research on the FNA must take these points into consideration. Perhaps an interview with a focus group of participants directly after completion of the FNA might give guidance to creation of instructions that will be most support parents in accurate completion of the FNA.

Another question not asked and perhaps missing as a critical component is the question of “why” a family finds each of the items a “need.” For example, if the parents who marked “teaching social and emotional skills” and “teaching communication skills” do so because of a

need to have a hug from their child or have the child say “daddy,” is that cross-related to an emotional health need? This type of information may be addressed more in-depth in an interview format in which interviewers are trained to ask follow-up questions that search for the reason need was marked, which may unveil additional information. Dillman (2000) recommends cognitive interviews, defined as “the administration of draft survey questions while collecting additional verbal information about the survey responses, which is used to evaluate the quality of the response or to help determine whether the question is generating the information that its author intends” (Beatty & Willis, 2007, p. 288).

The difference in identified needs in this study as compared to studies of families who have older children is an area in need of additional research (Estes et al., 2009, Estes et al., 2013). How do needs of parents differ in the infant/toddler years? Is there a difference in family needs for parents who experience diagnosis in the first three years from parents who experience diagnosis in later years? What are the differences between parents of infants and toddlers in family needs in relation to parents of children outside of the early childhood years (e.g. elementary, middle, and high school)? One possible perspective by which to study this issue is time and resources. Parenting any toddler involves a delicate balance between the child’s needs and the family’s needs (Stiller et al., 2014). When concerns about ASD arise, many parents are already managing rather complex family systems. The first months after a child’s ASD diagnosis may be a particularly difficult time. After learning about ASD, parents often spend the available time they have on learning to navigate a new and complex system of services (Stiller et al., 2014). Perhaps other needs of the whole family are delayed until a later time.

A final question for future research is how the needs of parents differ once parents are involved in high intensity, parent-mediated interventions. It is unclear in this study if any of the

parents were already involved at the intensity recommended in the literature. It would be important to study the needs of families involved in these interventions before, during, and after implementation.

Conclusions

As more infants and toddlers diagnosed with ASD and their families are receiving services from the early intervention system, there is a growing need to better understand the experiences of these families. This study was an attempt to identify the needs of families that include an infant or toddler with a diagnosis of ASD who are enrolled in Kansas Part C programs. The intended purpose of an early diagnosis of ASD is to provide children with more opportunities to benefit from intensive and specialized services, usually involving the parent as the primary intervention agent (Dawson et al. 2010; Warren et al., 2011). Given the research that overwhelmingly indicates that as children diagnosed with ASD get older, families report more stress (Boyd, 2011; Estes et al., 2009), a critical function of early diagnosis is identifying current and potential future needs in order to build early supports for families. The early process from diagnosis to intervention to exit from Part C services is complex and typically stressful for families (Bailey, 2008).

The parents in this study rated Getting Services and Teaching as highest in terms of need for support. This group rated nearly every item and every domain as in need of some level of support from *low need* (2) to *high need* (5). Some items were reported by parents as being *high* (4) to *very high* (5) need areas. These items fell into four main domains--Teaching (9 items), Getting Services (8 items), Social Relationships (5 items), and Lifespan Changes (5 items). A trend of results suggests that higher needs for support across domains were reported by parents of infants and toddlers who reported that the impact of their child's ASD on development was

severe or profound. A second data trend in this study was higher needs for families with lower incomes.

Overall, this study produced more questions than answers. A priority area of focus for future research should be on the link between a strong attempt to meet parent's needs for Getting Services and Teaching in the infant toddler stage and decreased levels of stress by parents as children age. Further study should investigate the link between meeting the early needs for support by parents and increased family quality of life.

The emotional needs for this subgroup of parents in Part C, as represented in this study, were somehow mitigated; thus the question as to how and why that happened offers directions for future research. This is important as the research overwhelmingly supports the fact that parents will have significant responsibility to carry out interventions for infants and toddlers with a diagnosis of ASD (Dawson et al, 2010; Warren et al., 2011). It is also important because parent well being is associated with enhanced gains for children with ASD (Ekas, Lickenbrock & Whitman, 2010; Estes, et al., 2014; Osborne et al., 2008). It is noteworthy that the number of negative life events families experience are a significant predictor of parenting stress and sense of competence as parents (Estes et al., 2014). If negative experiences have been somehow lessened for the families in this study, additional research is needed to identify the specific supports and services that have been helpful as the basis for designing interventions that support all families. What continues to be clear is that there is more work to do to understand the needs of families of infants and toddlers who have a diagnosis of autism. A critical period for families is the period of time immediately following the receipt of an ASD diagnosis. A need to support the well-being of parents, in addition to addressing children's direct service, is highly relevant.

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Appendix A Survey Materials

Request to tiny-k programs to distribute materials.

Study Title: *Family-Unit Needs of Families That Include an Infant or Toddler with a Diagnosis of Autism Enrolled in Part C Early Intervention Programs in Kansas*



Beach Center

1-866-783-3378 (toll free)
1-785-864-7600

1-785-864-7605 (fax)
beachcenter@ku.edu

January 01, 2014

Dear tiny-k Coordinators:

Hello. My name is Peggy Kemp. As many of you know, I am a doctoral candidate at the University of Kansas studying at the Beach Center on Disability and Department of Special Education. For my dissertation, I am investigating the needs (for example, health, social relationships, family interaction, emotional health, and financial) of families that include an infant or toddler with a diagnosis of autism. Given the lack of current research on the needs of families that include an infant or a toddler with a diagnosis of autism, this study will provide evidence to share with policy makers at the state and national levels regarding the importance of providing support to address these family-level needs in early intervention.

Toward this end, I will be distributing surveys to families enrolled in tiny-k services across Kansas that include an infant or toddler with a diagnosis of autism. Both English and Spanish versions will be available. I will also offer an option of the parent calling me. The survey will include two sections. The sections will address family needs (Family Needs Assessment) and a demographic section.

I am writing to invite your program to participate in this study. If you choose to participate, your involvement would include sharing the number of packets you will need for your program (this would be one English or Spanish packet for each family that includes an infant or toddler with a diagnosis of autism), distributing a sealed packet to include all study materials to each identified family, and informing them that this is a study in which they might be interested, but their participation is voluntary. You will also be asked to deliver a reminder flyer 2 weeks after the initial packet delivery. There should be no monetary cost to your program in the distribution. Because parents return all survey materials directly to me via a pre-paid envelope, there will be no monetary cost to the families in your program if they choose to participate. This study will close on February 15, 2015.

- 1 -

Appendix A1: Request to tiny-k programs for distribution of materials.

After the results are in, I will forward a report to your project that will include results of the overall dissertation study.

I appreciate you taking the time to read the information I have provided, and I hope you choose to participate in the study. If so, you can contact me, **Peggy Kemp**, directly by phone at **785-383-4188** or through email at pkemp@ku.edu. I would also be happy to answer any questions you may have.

Thank you,

Peggy Kemp
Doctoral Candidate
University of Kansas
Beach Center on Disability
785-383-4188
pkemp@ku.edu

Welcome Letter and Consent Form for Participants

Study Title: *Family-Unit Needs of Families That Include an Infant or Toddler with a Diagnosis of Autism Enrolled in Part C Early Intervention Programs in Kansas*



Beach Center

1-866-783-3378 (toll free)
1-785-864-7600

1-785-864-7605 (fax)
beachcenter@ku.edu

A Special Invitation to You . . .

My name is Peggy Kemp, and I am a doctoral candidate focusing on Family and Policy Studies in Special Education at the Beach Center on Disability and the Department of Special Education at the University of Kansas. I am working with the Kansas Infant Toddler Services to assist them in better understanding how well service programs meet the needs of families like you. We want to know more about the needs of families that include an infant or toddler with a diagnosis of autism. I am supported in this research by Dr. Jean Ann Summers who is the Research Director of Family Research Programs at the Beach Center on Disability.

One thing that makes this study different from other surveys you may have been asked to complete is that we will also be asking you to complete our Family Needs Assessment which will help us learn what your needs are. There is limited current research to show the needs of families of infants and toddlers with disabilities and therefore limited ways to show policy makers how important it is to provide the right kind of services, professional training, and other supports to families like yours.

We are writing to invite you to be part of this study. If you choose to participate, your involvement would include reading the information statement regarding the survey and completing the survey. The survey contains two sections: Family Needs Assessment and a demographic section. Estimated time of completing all components of the study is approximately 30-60 minutes. All of these materials are included in this packet. You will return the survey to me (Peggy Kemp) via the postage-paid envelope included with this packet.

Your participation in this study is completely voluntary; we invite you to participate to the extent you feel comfortable. Because you receive your study participation packet from your tiny-k/Infant Toddler Services staff member/coach, they know there is a possibility you might participate in the study. However, because the survey is completed and returned directly to me via a postage paid envelope, your tiny-k/Infant Toddler Services staff



- 1 -

KU Lawrence IRB # STUDY00001846 | Approval Period 12/5/2014

member/coach will not have access to the completed survey. Your name will not be used on any reports resulting from this study, and all the information you provide on the survey will be confidential. We will provide a general report to Kansas Infant Toddler Services with the overall information pulled together from all Kansas families, but results will be discussed in general terms and reports will include a description of study participants in groups, never as individuals.

The benefits to you for participating in this study are:

- Your information will help your local and state tiny-k/Infant Toddler Services program improve their services and supports to families.
- Our survey will help you reflect on your family's strengths, resources, and needs.

If you wish, we will provide you with a copy of our report so that you can see the results and recommendations.

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

- Your time of course is valuable, and we recognize that we are asking you to take time away from other tasks in order to complete the survey.
- Your tiny-k/Infant Toddler Services staff member/coach will distribute materials and thus they will know there is a chance you may have participated in the study. They will not have access to names of those who actually participated nor to individual results.

We will greatly appreciate your participation in completing this survey. If you agree to participate in this study, your answers will be used in the following ways:

- The U.S. Department of Education will have access to this information and may use the information to establish policies and funding programs to benefit families.
- Your local and state tiny-k/early intervention program may use this information to help improve their services and supports.
- Universities and state inservice training programs in Kansas and hopefully in other states may use this information to train future teachers and other professionals to be more responsive to families.

If you are interested, you will read the information statement at the end of this letter and complete the survey included in the packet. Once you complete the survey, you will send it to me using the self-addressed stamped envelope included in the survey packet.

If you are interested in having YOUR voice count

- ✓ At the end of this letter, there is an information statement regarding your participation. Please read and keep a copy for your records. You will also find a copy of the survey. If



you choose to participate, please complete the survey and send it to me in the postage-paid envelope included in this packet.

- ✓ Your answers will be completely confidential. Information about your identity will be kept in a separate, locked place. Your answers on the survey will be combined with answers from other families.
- ✓ You may choose to withdraw from the study at any time and may choose to refuse to answer any individual questions on the survey, without penalty of any kind.
- ✓ Your choice to participate or not participate in this study will not affect your relationship with your local tiny-k program or Kansas Infant Toddler Services.

If you want more information about this study, results of the study or about the Beach Center on Disability, you can call me toll-free at 1-866-783-3378. Ask for Peggy Kemp, Doctoral Research Candidate, or you may contact her by e-mail at pkemp@ku.edu. If you have any additional questions about your rights as a research participant, you may call (785) 864-7429 or (785) 864-7385, or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7568, or email irb@ku.edu.

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

Sincerely,

Peggy Kemp
Doctoral Candidate
Beach Center on Disability
1-866-783-3378
pkemp@ku.edu

Jean Ann Summers, Ph.D.
Research Director, Family Research
Programs
Beach Center on Disability
Research Director
785-864-7602
jsummers@ku.edu



HSCL #

Study Title: *Family-Unit Needs of Families That Include an Infant or Toddler with a Diagnosis of Autism Enrolled in Part C Early Intervention Programs in Kansas*

The Beach Center on Disability and the Department of Special Education at the University of Kansas at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that even if you agree to participate, you are free to withdraw at any time without penalty.

We are conducting this study to better understand the family needs of families that include an Infant or Toddler with a diagnosis of autism. This will entail your completion of a survey titled the Family Needs Assessment and submission of demographic information. Your participation is expected to take approximately 30-60 minutes to complete. The content of the Family Needs Assessment survey should cause no more discomfort than you would experience in your everyday life.

- ✓ Although participation may not benefit you directly, we believe that the information obtained from this study will help us gain a better understanding of needs of families that include and infant or toddler with a diagnosis of autism. Your participation is solicited, although strictly voluntary.
- ✓ Your name will not be associated in any way with the research findings. Your identifiable information will not be shared unless (a) it is required by law or university policy, or (b) you give written permission. Your answers will be completely confidential. Information about your identity will be kept in a separate, locked place. Your answers on the survey will be combined with answers from other families.
- ✓ It is possible with mailing records, that through intent or accident someone other than the intended recipient may see your response. However, that said there should be no identifiable information that connects your family to this response on the survey or return envelope.

You may withdraw from your participation in this study at any time. A decision to do so will not impact your relationship with your local tiny-k program or Kansas Infant Toddler Services.

If you would like additional information concerning this study before or after it is completed, please feel free to contact us by phone or mail.

Completion and submission of the Family Needs Assessment and demographic information indicates your willingness to take part in this study and that you are at least 18 years old. If you have any additional questions about your rights as a research participant, you may call (785) 864-7429 or write the Human Subjects Committee Lawrence Campus (HSCL),



- 4 -

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University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email irb@ku.edu.

Peggy Kemp
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Jean Ann Summers, Ph.D.
Research Director, Family Research
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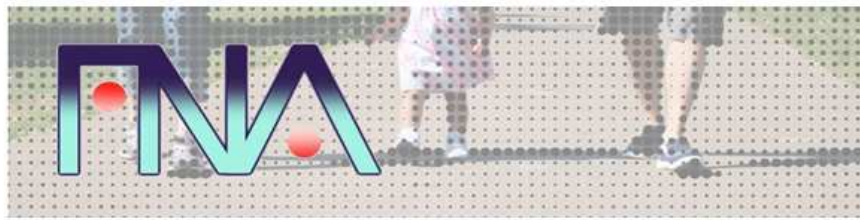
- 5 -

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The Beach Center on Disability, University of Kansas

Family Needs Assessment

(Kansas tiny-k Version)



Identify. Prioritize. Take Action.

Making a Significant & Sustainable Difference in Quality of Life
Beach Center on Disability

Structure of FNA

Domain	General Questions
Health	Does the family need support to make sure that everyone stays healthy and gets care for health problems?
Daily care	Does the family need support to provide caregiving?
Recreation	Does the family need support to play and have fun through leisure activities?
Social relationships	Does the family need support to develop relationships with others for the purpose of companionship and friendship?
Lifespan changes	Does the family need support to transition to next life stage?
Teaching	Does the family need support to teach members what they need to know to be successful?
Getting services	Does the family need support to get education, social services, and health service?
Family interaction	Does the family need support the get along together?
Emotional health	Does the family need support to deal with stress and takes care of emotional well-being?
Spirituality	Does the family need support to engage in religious or spiritual practices
Economics	Does the family needs support to manage finances?

Health

Does the family need support to make sure that everyone stays healthy and gets care for health problems?

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	1-No Need	2-Low Need	3-Need	4-High Need	5-Very High Need	Priority
1. Monitoring health conditions (having a regular doctor/ health checks)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Coordinating medical care among two or more physicians	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Having appropriate vision and eye care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Having appropriate care for hearing related needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Having appropriate dental care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. Getting a full night's sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7. Having healthy life style (such as healthy diet/ exercising)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8. Preventing substance abuse and other addictions (e.g., alcohol, drugs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:

Daily care Does the family need support to provide caregiving?

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	<i>1-No Need</i>	<i>2-Low Need</i>	<i>3-Need</i>	<i>4-High Need</i>	<i>5-Very High Need</i>	<i>Priority</i>
1. Attending to daily care activities (e.g., bathing, brushing teeth, dressing, eating)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Going to bathroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Giving medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Getting regular and special resources (such as technology equipment and materials, adapted switches, special foods) needed by family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Getting child care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. Having a break from caretaking (such as respite care)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7. Having appropriate transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8. Ensuring that home and community settings are accessible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9. Feeling supported by professionals to manage the difficulties associated with daily living.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:

Recreation

Does the family need support to play and have fun through leisure activities?

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	1-No Need	2-Low Need	3-Need	4-High Need	5-Very High Need	Priority
1. Participating in preferred indoor community recreational activities (e.g., movies, concerts, art classes)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Participating in preferred outdoor community recreational activities (e.g., swimming, playing ball, playing in the parks)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Going on family vacations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Doing relaxing things/activities at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:

Social relationships

Does the family need support to develop relationships with others for the purpose of companionship and friendship?

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	1-No Need	2-Low Need	3-Need	4-High Need	5-Very High Need	Priority
1. Helping others (e.g., neighbors, friends) in knowing how to socialize with my family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Helping my family members (e.g., neighbors, friends) in socializing with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Helping my family members make friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Helping all family members to know how to respond to questions about disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Helping all family members know how to responding to negative situations and attitudes (e.g., bullying, teasing, staring)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. Participating in social occasions with friends, co-workers, or others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7. Using technological communications (such as email, Facebook) to connect socially with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:

Lifespan changes

Does the family need support to transition to next life stage?

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	1-No Need	2-Low Need	3-Need	4-High Need	5-Very High Need	Priority
1. Feeling supported by professionals at the time of learning about my child(ren)'s disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Getting new childcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Moving within the same community or to a different community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Planning for my child(ren)'s successful transition from early intervention to preschool or preschool to elementary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Developing long-term goals for family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. Starting a new school year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7. Planning for the future after I'm no longer able to take care of my family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:

Teaching

Does the family need support to teach members what they need to know to be successful?

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	1-No Need	2-Low Need	3-Need	4-High Need	5-Very High Need	Priority
1. Participating in goal-setting to enhance family members' learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Helping my child(ren) reach goals during every day routines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Knowing when my child(ren) is making progress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Teaching choice-making and problem-solving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Teaching safety in the home and other places	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. Teaching independent living skills (such as eating and dressing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7. Teaching child(ren) to attend to toileting needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8. Teaching social and emotional skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9. Teaching appropriate behavior	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10. Teaching communication skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11. Teaching motor skills (e.g., riding a tricycle, walking, climbing stairs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
12. Teaching my child(ren) about sexuality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
13. Helping with homework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:

Getting services

Does the family need support to get education, social services, and health service?

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	1-No Need	2-Low Need	3-Need	4-High Need	5-Very High Need	Priority
1. Having educational services where my child(ren) are making progress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Having appropriate extracurricular / holiday care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Having access to necessary services, such as speech therapy, physio/physical therapy, orientation and mobility, occupational therapy, audiology, and nursing care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Having a trusting partnership with professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Monitoring services to make sure that they are beneficial	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. Making changes in services when necessary, even when professionals disagree	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7. Knowing and acting on my child(ren)'s educational rights	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8. Getting information necessary to make sound decisions about services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9. Feeling informed and helped by teachers about the improvement and the difficulties of my child(ren)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:

Family interaction

Does the family need support to get along together?

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	1-No Need	2-Low Need	3-Need	4-High Need	5-Very High Need	Priority
1. Having a clear understanding of each family member's strengths and needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Talking about feelings, opinions, and challenges with all members in my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Solving problems together as a family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Establishing close emotional bonds among members of the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Being flexible as a family in making changes when they are needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. Providing supports to include all members of my family in family activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:

Emotional health

Does the family need support to deal with stress and takes care of emotional well-being?

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	<i>1-No Need</i>	<i>2-Low Need</i>	<i>3-Need</i>	<i>4-High Need</i>	<i>5-Very High Need</i>	<i>Priority</i>
1. Feeling hope about the future for our family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Managing stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Enhancing each family member's self-esteem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Having support from other families who have a child with disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Dealing with challenges related to all family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:

Spirituality

Does the family need support to engage in religious or spiritual practices

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	1-No Need	2-Low Need	3-Need	4-High Need	5-Very High Need	Priority
1. Having a spiritual community that includes my child(ren)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Teaching my child(ren) about spiritual beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Relying on my spiritual belief to understand my child(ren)'s disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:

Economics

Does the family needs support to manage finances?

Please think about the next six months. Within this timeframe, how much of a need does one or more of your family members have to be able to do the following tasks:

	1-No Need	2-Low Need	3-Need	4-High Need	5-Very High Need	Priority
1. Paying basic needs (such as food, house, clothing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Paying school fees and/or child care (baby-sitter)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Paying for special therapies or equipment for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Saving money for the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Getting or keeping a job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. Applying for government benefits and addressing government benefit denials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please use the space provided below for additional comments about your family's needs:



General Individual and Family Information – Part 2 of Family Needs Assessment Survey tiny-k Version

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

Please answer these questions about yourself:

1. *What is your gender:*

- Male*
- Female*

2. *What is your relationship to child?*

- Mother*
- Father*
- Other _____*

3. *What is your race/ethnicity?*

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

4. *What is your primary language?*

- English*
- Spanish*
- Other _____*

3. *What is your age?*

- Less than 20 years*
- 20 to 29 years*
- 30 years or older*

2. *How old is your child?*

- Months*

3. *What is your marital status?*

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

4. What is the highest level of education that you have completed? (Please check ONLY one)
- Schooling but not high school diploma or GED
 - High school graduate (diploma or GED)
 - Some college or post-high school, but no degree
 - College degree (undergraduate)
 - College degree (graduate)
5. What was your total household income from all sources for the past year?
- Less than \$10,000
 - \$10,000 to \$40,000
 - Over \$40,000
6. Please choose if you live in an urban, suburban, or rural area below. Please mark only one:
- Urban (population greater than 50,000)
 - Suburban (population between 10,000 and 50,000 people)
 - Rural (population less than 10,000)
7. Please indicate the level of severity you believe your child's development is impacted due to diagnosis of autism.
1. Mild
 2. Moderate
 3. Severe
 4. Profound

** Your answers to this survey will be kept confidential. Information about your identity will be kept in a separate, locked place, and your answers on the survey will be combined with answers from other families. Your name will not be attached to this survey in any form.*

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

Appendix A4: Reminder Sent to Survey Participants.

Reminder

Please Complete Your Survey

Study: Family-Unit Needs of Families That Include an Infant or Toddler with a Diagnosis of Autism Enrolled in Part C Early Intervention Programs in Kansas

Benefits/Risks

The benefits to you for participating in this study are:

- Your information will help your local and state tiny-k/early intervention program improve their services and supports to families.
- Our survey will help you reflect on your family's strengths and resources.

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

- Your time of course is valuable and we recognize that we are impinging on the many demands you have in caring for your child.
- Your tiny-k staff member/coach will know there is a chance you may participate in this study.

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

- The U.S. Department of Education will use this information to establish policies and funding programs to benefit families.
- Your local and state tiny-k/early intervention program will use this information to help improve their services and supports.
- Universities and state inservice training programs will use this information to train future teachers and other professionals to be more responsive to families.

Thank You for Your Participation and the Invaluable Gift of Your Time!