Parent Perspectives:

Understanding Support Systems for Kindergarteners with Special Needs and

Their Family Members

by

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ABSTRACT

Having a child with special needs can be overwhelming, emotionally draining and extremely stressful for parents and their family members. Research identifies the support systems families need in order to have quality-of-life. The current study uses mixed methods to evaluate the degree to which parents and other primary caregivers in Arizona view the educational and health related services that their child with special needs and/or other health impairments received when they entered kindergarten. It evaluated the degree to which the caregivers themselves perceived the support/services that they received in order to access quality of life for themselves, their child with special needs and other family members. Finally, the research identified reoccurring themes to better understand the intricacies involved within these support systems/services that promoted or hindered positive family and child outcomes.

DEDICATION

For my boy Cole, I love you very much!

ACKNOWLEDGMENTS

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CHAPTER 1

INTRODUCTION

Context for the Study

Having a child with special needs can be overwhelming, emotionally draining and extremely stressful for parents and their family members. Taking care of and supporting a child with special needs places extra demands on parents increasing their stress levels (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008; Gupta, 2007). Demands range based on each individual child's specific needs but could include; traveling to and from service support providers (speech and language therapies, occupational therapy, and tutoring) and doctor appointments, needed supports for daily living skills (feeding, toileting, medications, and dressing), the caregivers ongoing search for supports and services, along with accessing educational opportunities in order to better understand their child's diagnosis and individual needs. These added demands and the increase in parental stress affect's a family's quality of life (FQOL).

FQOL is attained when the needs of all family members have been met, when the family enjoys their time together, and when they are able to participate in activities that are valuable to them (Park et al., 2003). Research has examined the fact that quality support systems (i.e. professional supports, social supports, family-centered supports, and parental supports) that are made available to children with special needs and their family members can help decrease stress by alleviating some of the demands that are placed on families aiding in their overall quality of life (Davis & Gavidia-Payne, 2009 & Summers et al., 2007).

In this study, mixed methods research design was used to gain access to parent perspectives on the type and quality of services their child with special needs and family members acquired during and prior to their child's entrance into Kindergarten. Qualitative measures were used to obtain a descriptive picture of the parent's point of view and quantitative measures were used to obtain a general understanding of a larger group of parents. Access to both measurements provided a richer, more in-depth understanding of the research questions.

For the purpose of this study, having "special needs" can refer to multiple diagnoses. The term "special needs" has become an all-encompassing umbrella referring to a variety of diagnoses. In this study, the term "special needs" will be used to encompass multiple diagnoses including medical, cognitive and psychological conditions. Furthermore, the terms guardian, parent and primary caregiver will be used interchangeably. The role of a parent/caregiver is defined as the person who cares for the child in the home environment, the individual that makes decisions based on the needs of the child.

Problem Statement

Current literature identifies access to support systems as one of the key components that can help decrease parental stress (Cassidy, 2008; Cavallo, Feldmann, Swaine, & Meshefedijian, 2008; Perry & Henry, 2009; Plant & Sanders, 2007) and can also lead to positive child and family outcomes in turn aiding in their quality of life (Davis, 2009). There are a number of support systems (medical, educational, psychological, social etc.) that families may or may not have access too. Identifying the types of services/supports children with special needs and their family members are

receiving, and how parents feel about these services, will help researchers enhance their understanding of the needs of the entire family structure.

Theoretical Framework

To better understand the varying support systems available to children with special needs and their family members in Arizona, Bronfenbrenner's Ecological Systems Theory (1977) was used to analyze the data pertaining to the research. This theory helped identify support systems across a variety of environments and their effects on child and family outcomes demonstrating how these environments influence one another. Bronfenbrenner has identified 5 systems (Microsystem, Mesosystem, Exosystem, Mascrosystem, and Chronsystem) that are nested within each other that drives a child's development. Within each of these systems the supports that are vital to the development of a child with special needs can be categorized demonstrating how they also influence one another.

The Microsystem is the immediate environment in which the child lives. More specifically the people he/she interacts with such as parents, teachers, and family members. The Mesosystem is the connections between the people the child interacts with. For example, the connections between the child's teacher and his/her parents or the connections between his/her church and neighbors. Within the Exosystem you will find the social system in which the child does not interact with directly, however they impact the child's development because they interact with the structures within the child's microsystem. For example, a child's experience at home may be influenced by a mother's experiences at work. The Macrosystem is the outermost layer of the child's environment which includes cultural values, customs and laws. Finally, the Chronosystem is the

historical change in the previous systems and a child's developmental change over time. These systems were used in this study to better understand how support systems and services influence the development of a child with special needs.

Purpose of Research

In October 2009, in the state of Arizona there were 125,866 school aged (preschool through twelfth grade) children and young adults labeled with special needs, with a total of 9,345 children at the preschool age (AZ Department of Education, 2011). During this time there were budget cuts, in the state of Arizona and across the nation, related specifically to families accessing services for their child with special needs. The purpose of this research was to evaluate the degree to which parents and other primary caregivers in Arizona view the educational and health related services that their child with special needs and/or other health impairments received when they entered kindergarten. It also evaluated the degree to which the caregivers themselves perceived the support/services that they received in order to access quality of life for themselves, their child with special needs and other family members. Finally, the research also identified reoccurring themes to better understand the intricacies involved within these support systems/services that promoted or hindered positive family and child outcomes.

Research Questions

1. How do parents of kindergartners with special needs, in public, private, and charter school settings, view the educational and health-related services available to and utilized by their children?

2. What are the perceptions of such parents regarding the parental/family support systems available to them?

Significance of the Study

Understanding the availability of quality support systems in Arizona based on parent review not only, provides the state with a better understanding of what types of services are needed for families that have children with special needs, but also provides the state feedback as to the quality of current services that are been accessed by families. This knowledge can be used to improve services to better support families leading to positive family outcomes which intern will aid in FQOL.

Organization

In the next chapter, chapter two, is a review of current literature that discusses the stresses that are placed on parents who have a child with special needs, the core principles needed for a family to attain quality of life and the importance family and child support systems and services play on a family's quality of life. In chapter 3, the research design and methodology used to analyze the data collected for this research is described in detail consisting of a mixed methodology utilizing both qualitative and quantitative measures. Specific information about the First Things First External Evaluation (FTFEE) research project in which data was acquired for this research is also described. Chapter four, encompasses the quantitative measures results while chapter five discusses the qualitative results. Finally, chapter six discusses both the quantitative data and the qualitative data, implications for future research and conclusions.

Definitions

Special needs – is a term used in clinical diagnostic and functional development to describe individuals who require assistance for disabilities that may be medical, cognitive, or psychological.

Family Quality of Life (FQOL) – is attained when the needs of all family members have been met, when the family enjoys their time together, and when they are able to participate in activities that are valuable to them (Park, 2003).

Parent/Caregiver – For the purposes of this research parent and caregiver will be used interchangeably. The role of a parent/caregiver is defined as the person who cares for the child in the home environment, and is the individual that makes decisions based on the needs of the child.

Family centered services - As defined by Smith-Bird and Turnbull (2005) family-centered practice addresses the needs of all family members, addresses the importance of families working in partnerships with professionals to address their priority goals and emphasizes the family's strengths.

Optimism – a general disposition to expect the best in all things (worldnetweb)

Disability – as defined by P.L. 101-336, Sec. *"*(a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) a record of such impairment; or (c) being regarded as having such an impairment."

Microsystem – "is a pattern of activities, social roles, and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical, social, and symbolic features that invite, permit, or inhibit engagement in sustained, progressively more complex interactions with, and activity in, the immediate environment" (Bronfrenbrenner, 1977).

Mesosystem – "comprises the linkages and processes taking place between two or more settings containing the developing person (e.g., the relations between home and school,

school and the workplace, etc.) In other words, a mesosystem is a system of Microsystems" (Bronfrenbrenner, 1977).

Exosystem – "comprises the linkages and processes taking place between two or more settings, at least one of which does not contain the developing person, but in which events occur that indirectly influence processes within the immediate setting in which the developing person lives" (Bronfrenbrenner, 1977).

Macrosystems – "consist of the overarching patter of micro-, meso-, and exosystems characteristics of a given culture or subculture, with particular reference to the belief systems, bodies of knowledge, material resources, customs, life-styles, opportunity structures, hazards and life course options that are embedded in each of these broader systems" (Bronfrenbrenner, 1977).

Chronosystem – "encompasses change or consistency over time not only in the characteristics of the person but also of the environment in which that person lives" (Bronfrenbrenner, 1977).

Mixed Methods Research – a research approach that combines and integrates quantitative and qualitative research approaches (Gelo, Braakmann, & Benetka, 2008)

CHAPTER 2

LITERATURE REVIEW

A family's quality of life revolves around eight domains which include; family interactions, parenting, emotional well-being, physical/material well-being and severity/type of disability. Within each domain there are set of indicators and descriptors to identify if the needs of the family within each domain are being met. When a family's needs are not being met within these domains there is an increase in parent/caregiver stress.

Caregiver Stress

The anticipation of becoming a parent in general can be overwhelming but finding out that their child has special needs can be devastating to a parent. Each parents' reaction to this news and how they learn to cope with the added stress varies (Cavallo, 2008; Gupta, 2007). Stress levels can vary based on factors such as parent optimism (Baker, Blacher, & Olsson, 2005), difficulty of care-giving tasks (Plant & Sanders, 2007), marital quality (Gerstein, Crnic, Blancher, & Baker, 2009), parent-well being (Baker et al., 2005; Gerstein et al. 2009; Perry & Henry, 2009), parent-child relationship quality (Gerstein et al., 2009), SES/income (Wang et al., 2004), available support systems (Cassidy, 2008; Cavallo, 2008; Perry & Henry, 2009; Plant & Sanders, 2007) and type/severity of the disability (Davis & Gavidia-Payen, 2009; Gupta, 2007; Hung, Wu, & Yeh, 2004; Mahoney, Sullivan, & Robinson, 1992; Osborne & Reed, 2009).

While each parent deals with the added stress differently and factors vary for each family, Vaaca's (2006) research on parental perspectives of raising a child with severe physical disabilities identifies phases that parents go through in their attempt to develop a

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meaningful relationship with their special needs child. The first phase, *the normative phase,* occurs during the prenatal period. During this phase parents fantasize about their baby and how they would lead a "normal" happy life. Once the child is born and has been identified with special needs parents enter the *self-study phase* where they look at themselves and their previous life events to try to find precursors to the child's disability. During this phase, parents show feelings of blame and grief. They are also constantly second guessing themselves, what can they do better or what should they be doing.

The *acceptance phase* follows the self-study phase. During this phase, parents learn to accept their child's special needs and also learn how to adapt their lifestyles to meet the needs of their child. The fourth phase is the *defining quality of life phase*. During this phase, parents make difficult decision not only regarding the care for their child but also in their own lives so that the family has quality of life.

The final phase is the *planning for future phase.* During this phase, family members re-evaluate their functioning and determine ways that they can improve their functioning together. Vaaca (2006) notes that many times this phase "often lead families back to phase one, where plans for the future serve as inspirations for the family and the child" (p. 70). While families go through certain phase as they learn to adapt to their child's disability, the added stress of caring for a child with special needs is still apparent and varies based on the family's quality of life. Providing supports and services during the fourth phase could potentially help family members adapt to the demands of having a child with special needs.

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Family Quality of Life (FQOL)

Identifying what causes parental stress when caring for a child with special needs is not enough to determine what the family and child needs are and if those needs are being met because stress impacts vary with the characteristics of the child's special needs (Summers et al., 2005). Researchers has come to establish that the focus should be on the family's quality of life. Davis and Gavidia-Payne (2009) state that, "the family as a whole has been largely overlooked" (p. 153) and that a family's quality of life is a useful indicator for program effectiveness and outcome. Summers et al. (2005) also suggests the use of family quality of life as an identifying measure because it can identify short-term outcomes of supports and services which lead to the ultimate long-term outcome of FQOL. Measurements such as The Beach Center Family Quality of Life Scale can be used to better determine the needs of each individual family.

FQOL merged and expanded from research based on family-centered practice and individual quality of life research (Smith-Bird & Turnbull, 2005). As defined by Smith-Bird and Turnbull (2005) family-centered practice addresses the needs of all family members, addresses the importance of families working in partnerships with professionals to address their priority goals and emphasizes the family's strengths. The definition of individual quality of life has emerge and changed throughout the years. The core principals are:

1. It is composed of those same factors and relationships for people with intellectual disabilities that are important to those without disabilities.

2. It is experienced when a person's needs and wants are met and when one has the opportunity to pursue life enrichment in major life settings.

3. It has both subjective and objective components, but it is primarily the perception of the individual that reflects the quality of life he or she experiences.

4. It is based on individual needs, choices and control.

5. It is a multidimensional construct influenced by personal and environmental factors such as intimate relationships, family life, friendship, work neighborhood, city or town residence, housing, education, health, standards of living, and the state of one's nation. (Schalock, et al., 2002, p. 460)

Specific domains that have been found to measure ones FQOL include family interactions (Smith-Bird & Turnbull, 2005), physical/material well-being (Smith-Bird & Turnbull, 2005; Summers, 2007; Wang, 2004), disability-related supports (Davis & Gavidia-Payne, 2009; Smith-Bird & Turnbull, 2005; Summers, 2007), severity/type of disability (Davis & Gavidia-Payne, 2009; Wang, 2004) and supports from extended family members (Davis & Gavidia-Payne, 2009).

While there are a variety of factors that measure a family's quality of life, the support systems that are made available to family members are one of the strongest and most noted predictors in the research that aids in FQOL (Davis & Gavidia-Payne, 2009; Smith-Bird and Turnbull, 2005; Summers, 2005). Supports systems and service vary based on each individual family demonstrating that they should be tailored to each family's unique needs.

Family and Child Support Systems/Services

There are a variety of services and supports that may be available to children with special needs and their family members. Research identifies professional supports both medical (Cheng, Savageau, DeWitt, Bigelow, & Charney, 1996) and educational (Dunst & Dempsey, 2007; Russell, 2003; Spann, Kohler, & Soenksen, 2003), social supports (Judge, 1998; Cheng, 1996), extended family supports (Freedman & Boyer, 2000) and community supports (Dunst & Dempsey, 2007) to be key factors to child and family outcomes. Without these services, obtainment of family quality of life is not possible.

Family-centered services/supports are one of the key defining elements to FQOL (Smith-Bird & Turnbull, 2005) and are considered to be "best practice" in fields concerned with the optimal development of children with special needs (Dempsey & Keen, 2008; King et al. 2003). Family-centered care involves ensuring that parents have ultimate control over decision making, treating parents respectfully and supportively, and providing parents with needed information (King, King, & Rosenbaum, 1996).

Concluding Remarks

When families receive family-centered services, the family is looked at as a whole. This allows families to identify what services are needed to meet their needs, gives them ownership over those decisions decreases parent/caregiver stress. Having access to the supports needed for their child with special needs, along with other pertinent family needs (financial, marital, friendships, transportation) will lead to family quality of life.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

In order to address the research questions, and reflect the larger statewide longitudinal study from which data was drawn, a mixed methods research (MMR) approach was used. A combination of survey research and caregiver interviews provided statistical information along with rich descriptive caregiver/parent accounts pertaining to the research questions. The following sections of this chapter will discuss the purpose of the study, researcher's assumptions, the importance of mixed methods research and how survey research, as well as qualitative analysis of parental interviews provided insight to the research questions. This chapter also describes the two studies in which data was taken from as secondary data and the instrumentations used by these two studies to collect data. Both studies participants, procedures and data analysis are also described. Finally, methods used to ensure validity and limitations and parameters of the study are discussed.

Purpose of the Study

The purpose of this study was to use mixed methods research to evaluate parent perspectives of the support systems available to children in Arizona who have special needs and their family members, more specifically when the child makes the transition to kindergarten. Quantitative data was analyzed to determine what services/supports were being utilized and parent/caregiver views of these services/supports across Arizona. The study then analyzed a more in-depth perspective by reviewing parent/caregiver interviews, focusing specifically on their experiences with these services/supports.

Data from both the Arizona Kindergarten Readiness Study (AKRS) and the Family and Community Case Study (FCCS) were used in combination to answer both research questions, as follow:

(1) How do parents of kindergartners with special needs, in public, private, and charter school settings view the educational and health-related services available to and utilized by their children? and

(2) What are the perceptions of such parents regarding the parental/family support systems available to them?

An assumption of the study is that understanding what available services and how they are utilized for both the child with special needs and his/her family members is important to a family's quality of life.

Assumptions of the Researcher

I have been working with children with special needs and their family members since 1994. During the study's data collection, I lived in Arizona making the study prevalent to my life. I also have a child with special needs who has cognitive, physical and medical needs. Throughout my professional and personal experiences, I have not only come to understand how important support systems/services are for the development of my child and the children I work with, but I have also learned firsthand how these services can affect the entire family structure.

Having personal experiences that relate specifically to the research questions has given me some insight to the research topic, however, this insight could have caused bias issues. In order to evade any bias, I stayed objective when analyzing the data focusing specifically on the results of both research studies, not my own personal experiences.

Mixed Method Research (MMR)

MMR is a class of research that combines both qualitative and quantitative research approaches together to provide more reliable and valid research. The *fundamental principle of mixed methods* (Johnson & Turner, 2003) is to collect multiple data (sources) using different methods in order to better evaluate research questions. Qualitative and quantitative research approaches both have strengths and weaknesses (Johnson & Onwuegbuzie, 2004). Gelo, Braakmann, & Benetka (2008) acknowledge that the strength of one form of research is usually considered the weakness of the other approach and vice versa. When both approaches are used in combination, a researcher could decrease possible limitations by incorporating the strengths of both methodologies (Johnson & Onwuegbuzie, 2004) in turn answering their research questions more thoroughly. There are a variety of ways in which a researcher can combine qualitative and quantitative research in order to complement each other. Both Johnson & Onwuegbuzie (2004) and Gelo, Braakmann, & Benetka (2008) discuss various mixed method designs that can be used however, Johnson & Onwuegbuzie (2004) specifically states that "it is the researcher's task to examine the specific contingencies and make the decision about which research approach, or which combination of approaches, should be used in a specific study" (p. 23).

A concurrent mixed methods design was used to answer the research questions mainly due to the nature of data collection in which both research studies, AKRS and FCCS, were conducted over the same period of time. By

analyzing the data from both research studies at the same time, relationships among the two data sets were identified.

First Things First External Evaluation (FTFEE)

Research data was taken from an ongoing mixed method research project in Arizona, First Things First External Evaluation. It was determined that the combination of a survey and individual interviews complemented each other by providing a variety of data pertaining to the research questions. The survey provided a large quantity of data regarding caregiver beliefs and attitudes concerning the research questions. However, in order to look more deeply into the questions, qualitative interviews were used to capture individual stories.

First Things First (FTF) is a statewide initiative in Arizona that was created by the passage of Proposition 203 in 2006. It "was established to help provide greater opportunities for all children five and under in Arizona to grow up ready to succeed" (FTF 2001). FTF's mission is "to increase the quality of, and access to, the early childhood development and health system that ensures a child entering school comes healthy and ready to succeed" (FTF 2011).

The First Things First External Evaluation (FTFEE) was a large scale longitudinal and cross-sectional evaluation which was conducted by faculty from three universities across Arizona, University of Arizona, Arizona State University, and Northern Arizona University. The purpose of this evaluation was to better understand the impact of FTF on children birth to five and their families. It also evaluated changes in the statewide and regional systems of early care. This evaluation consisted of three specific studies that were conducted over a period of five years; Arizona Kindergarten Readiness Study

(AKRS), the Longitudinal Child Study of Arizona (LCSA) and the Family and Community Case Study (FCCS). In order to answer the research questions for this study, data were obtained from AKRS and FCCS.

Phase I: Arizona Kindergarten Readiness Study (AKRS)

The purpose of AKRS was to provide a snap shot of Arizona children's health and readiness for school. Every other year (2009, 2011, and 2013) of the five-year evaluation process approximately 1,200 children were supposed to be assessed across several interrelated developmental areas that are predictive of kindergarten success; physical well-being and motor development, personal and social development (including approaches to learning), language and literacy, and mathematical thinking. However, data was only collected in 2009. Instrumentation used in this study consists of both direct child measures and a caregiver questionnaire. A proportional, stratified random sampling approach was used for participant recruitment.

For the purpose of this study, part A of the caregiver questionnaire was used to help answer the research questions. The questionnaire was composed of 85-question survey focusing on parent/family demographics, kindergarten transition experiences, rating of family/child support services (Part A), and rating (proficient, in progress, not yet) of children's development in the domains of social, physical, language/literacy, and mathematics (Part B).

Phase II: Family and Community Case Study (FCCS)

The Family and Community Case Study (FCCS) was the qualitative component to the Longitudinal Child Study of Arizona. The purpose of this study was to address issues of access, cultural relevance of programs and other subtle issues in the availability,

accessibility, visibility, quality, and utilization of early childhood care and health services and gain perspectives from service providers as well as children before and after they entered kindergarten (Joanie, Holiday & Widener, 2012). Interviews were initially conducted with 146 families and then conducted with 69 focal families twice per year. Additionally, this study conducted interviews with children (in these families) when they were four years old and when they entered kindergarten. The FCCS project also interviewed community stakeholders in the focal regions, with both individual interviews and focus groups. Seventy-five percent of families were recruited at community events, in public places and other locales that were accessible to families. Local participating FTF families, PPCS and databases were used to identify relevant local child care/early education providers, health providers, and community leaders working with children and families. Stakeholders were contacted by telephone or in person regarding participation. For the purpose of this research, only relevant caregiver interviews were used to help answer the research questions. In other words, only interview transcripts from caregivers who have children with special needs were included in this study. Child or stakeholder interviews were not used.

Instrumentation

Two specific instruments were used for this research; the caregiver questionnaire (Appendix A) from AKRS and the interviews from the FCCS (Appendix B) for interview format/questions. First, the 2009 Readiness Guardian Questionnaire was chosen as an instrument for the study because it provided a large quantity of data regarding caregiver beliefs and attitudes concerning the research questions. Questions on the caregiver questionnaire provided the researcher with descriptive data regarding the primary

caregiver and the child, the child's disability along with caregiver's attitudes regarding the services and supports that were in place for the child and the caregiver.

While the questionnaire provided descriptive information and a composite profile of each family along with specific information pertaining to the research questions it alone was not enough to answer the proposed research questions thoroughly. To better answer these questions, interviews were taken from the FCCS and analyzed. More specifically, interviews from fall 2009, spring 2010 and fall 2010 were reviewed and analyzed in order to provide rich, detailed information in the form of participant narratives of their experiences pertaining to the research questions building on the questionnaire data.

Using both instruments together in the form of MMR provided quantitative information along with rich descriptive accounts. Jointly, comprehensive data was collected and analyzed providing results that can be inferred on the research population. Statistical analysis was completed for the questionnaire and the interviews were coded into themes pertaining to the research questions and then quantified into frequency counts to determine commonalities between the interviews and compared to the questionnaire results. Quotes from the interviews were used to supplement the statistical data.

AKRS Participants

Participants were determined through data review of the FTFEE studies mentioned above. Participants were drawn from the AKRS questionnaire that was completed in fall of 2009, in which participants were randomly selected from lists provided by participating school districts. Questionnaires were distributed to 1,145 parents/guardians of the participating children and 1,025 were returned.

Data analyses from the caregiver questionnaire were reviewed to determine which families had children with special needs, specifically addressing Question 31 of the questionnaire which asks if the child has an Individualized Education Plan (IEP) or Individualized Family Service Plan (IFSP). Families that checked yes on this question were used for this study. Out of the 1,025 questionnaires returned there were 60 participants that had an IEP or an IFSP. Non-IEP parent demographics were then compared to parent demographic of the IEP sample.

AKRS Parent Demographics

Table 1, 2 and 3 provide descriptive statistics for the primary caregiver IEP sample and non-IEP sample. For the purpose of this study, data from the IEP sample will be discussed. The majority of individuals who completed the AKRS questionnaire for the IEP sample listed themselves as the participant's legal guardian (98%) with 100% being the primary caregiver. Of these caregivers, the majority documented that they were married 75% with 15% being single (never married) the second highest variable. Race of the caregivers is closely split between white (54%) and Hispanic (42%) with 72% living in urban residence and 28% in rural areas. Household financial statuses vary with 25% ranging between $50,000 or more annually and 15% ranging between $45,000 and $49,000. Sixty-five percent of the caregivers qualify for free or reduced lunch. Sixty-six percent primary caregivers have a high school degree or higher with 9% having their GED.

Table 1

Descriptive Statistics for Primary Caregiver IEP Sample and Non-IEP Sample

Variables	Non-IEP Sample	IEP Sample
Legal Guardian	99.20%	98.30%
Primary Caregiver	99.50%	100%
Marital Status		
Single never married	16.47%	15.25%
Separated	3.88%	1.69%
Divorced	6.93%	5.08%
Married	71.88%	74.58%
Widowed	0.84%	3.39%
Race		
Hispanic	44.10%	42.10%
American Indian/Alaska Native	1.40%	0.00%
Black/African American	3.10%	0.00%
Asian	4.40%	3.50%
Native Hawaiian/Pacific Islander	0.60%	0.00%
White	46.50%	54.40%

Table 1 compares descriptive statistics of the Non-IEP sample and the IEP sample. Variables identify if the individual who completed the questionnaire is the child's guardian and primary caregiver. There were no differences between the two groups. Marital status and race are also displayed. There are minimal differences between the two samples.

Table 2

House Hold Financial Status: Non-IEP Sample and IEP Sample

Variables	Non - IEP Sample	IEP Sample
House Hold Income		
Less than 5,000	5.93%	7.27%
5,000 - 9,999	3.95%	3.64%
10,000 - 14,999	4.57%	12.73%
15,000 - 19,999	6.67%	1.82%
20,000 - 24,999	4.81%	7.27%
25,000 - 29,999	5.80%	7.27%
30,000 - 34,999	6.17%	9.09%
35,000 - 39,999	6.54%	5.45%
40,000 - 44,999	4.44%	5.45%
45,000 - 49,000	4.81%	14.55%
50,000 or more	46.30%	25.45%
Free or Reduced Lunch	48.26%	65.00%

Table 2 compares house hold income and whether the family receives free or reduced lunch. There was a difference with the 50,000 or more-income variable where 20.85% non-IEP sample recorded that they earned 50,000 or more a year over the IEP sample.

Table 3

Guardian Education Primary Caregiver Non-IEP Sample and IEP Sample

Variables	Non - IEP Sample	IEP Sample
8th or less	4.77%	1.79%
9-12 no diploma	8.70%	1.79%
GED	4.50%	8.93%
HS Graduate	14.63%	26.79%
Vocational, Trade, or Business	7.74%	8.93%
Some College	19.83%	30.36%
Associate Degree	9.01%	0.00%
Bachelor's Degree	19.51%	21.43%
Master's Degree	8.06%	0.00%
Doctorate	3.29%	0.00%

Table 3 shows that there were no difference between the two sample regarding guardian education.

AKRS Child Demographics

Tables 4 and 5 descriptive statistics for the child IEP sample and non-IEP sample. For the purpose of this study, data from the IEP sample will be discussed. The majority of the children were listed as white (83.30%). Participant age was almost evenly split with 47% less than 70 months old and 53% older than 70 months. Finally, the analyses of overall child health list 45.80% as excellent, 27.10% as very good and 22% as good.

Table 4

Descriptive Statistics for Child Non-IEP Sample and Child IEP Sample

Variables	Non - IEP Sample	IEP Sample
Race		
Hispanic	1.40%	2.10%
American Indian/Alaska Native	2.00%	0.00%
Black/African American	3.90%	2.10%
Asian	4.10%	2.10%
Native Hawaiian/Pacific Islander	1.00%	0.00%
White	79.10%	83.30%
Age		
less than 70 months	45%	47%
older than 70 months	52%	53%

Table 4 compares child race and age between the two samples. There are no significant differences.

Table 5

Child's Overall Health: Non-IEP Sample and IEP Sample

Variables	Non - IEP Sample	IEP Sample
Poor	0.10%	1.70%
Fair	2.10%	3.40%
Good	10.90%	22.00%
Very good	27.50%	27.10%
Excellent	59.40%	45.80%

There were no differences between the two samples regarding overall child's health, table 5.

FCCS Participants

Participants were drawn from the FCCS interviews that were conducted in fall 2009, spring 2010 and fall 2010. The FCCS conducted 146 semi-structured family/primary caregiver interviews across Arizona during the fall of 2009. From the 146 participants 69 focal families were selected to be interviewed twice annually for the 3-year duration of the study. Interview transcriptions were reviewed and only participants who had children with special needs were selected. Due to the nature of the interview, semi-structure with open-ended questions, all interviews were read to determine if the family had a child with special needs. There were several questions within each of the three interviews that allowed for the caregiver to share this information. Out of the 69 focal families 15 families were identified as having a child with special needs. Only 10 out of the 15 participants were used for this study. The five participants that were removed, while having a child with special needs their interviews did not provide information relating to the research questions. It is important to note that not all 10

families participated in all three interviews. It is also important to note that there are 11

child participants because one family has two children with special needs.

FCCS Parent Demographics

The FCCS interviews did not discuss if the interviewee was the legal guardian

and/or the primary caregiver. Of the adult participants, 70% were married, 20% had same

sex relationships and 1% was single (never married). However, the single (never married)

participant lived with her boyfriend who is the child's biological father. 80% of the

participant were white. Unfortunately, the other 20% is unknown as this information was

not discussed in the interviews. The analysis of the primary caregiver's education also

had missing data, 40% of the interviews did not reference the caregiver's education. The

interviews that did note caregiver education, 20% had a master's degree, 20% had a

Bachelor's degree, 10% had an Associate degree and 10% had a GED. There was a 50/50

split between geographical locations, five families lived in urban areas and the other five

lived in rural areas. Household income which was identified in the AKRS data was not

available in the FFCS data.

FCCS Child Demographics

The demographics for the children with special needs within the interviewee's

home identified the children's race is 91% White and 9% Hispanic. Regarding their age

range, 91% were less than 70 months old, and data were missing for the other 9%.

Information that could not be derived from the interview that was identified in the AKRS

data included the child's overall health.

Analyzing AKRS Questionnaire

Descriptive statistical analysis was completed for the AKRS questionnaire for those participants who have a child with special needs. Frequency distributions along with percentages was derived to document family demographics (questions 1 – 16), the type of special needs reported (question 34), the types of services the family or child is receiving (question 35), from whom they received these services (question 36) and parental view on the supports/services they are receiving (question 42).

Analyzing FCCS Interviews

Research transcriptions were reviewed, and information about the research questions were copied and placed in a word document for each participant. Each participants document was then highlighted based on the themes relevant to the research questions, for example, all demographic information was highlighted in yellow, orange for support systems, red for negative experiences accessing educational or health services and green for positive experiences accessing educational or health services. Other themes that were identified, such as travel that could potential affect access to support services but does not pertain specifically to the research questions were highlighted in blue. This data was then quantified into frequencies and total percentages in order to compare these results to the questionnaire results. Finally, quotes that specifically answered the research questions were then categorized in another document.

Conclusion

AKRS evaluated approximately 1,200 children Kindergarten and younger. For this study, 60 children with special needs were pulled as participants from the larger study. FCCS interviewed 69 focal family's children also in Kindergarten or younger. For this study, 10 children were identified with special needs. Data based on this specific population, within the larger study, was analyzed to gain knowledge of parent perceptions on the services they and their child was receiving.

Limitations and Parameters of the Study

Secondary data was collected for both research methods (AKRS and FCCS) from a longitudinal research project in Arizona (First Things First External Evaluation). There was very little control over instrumentation development and participation selection because secondary data was used. While the researcher was part of the FTFEE research team during the initial phases and had input into the questionnaire that was used, she did not have input into the interview questions.

Possible limitations may include problems with parent report. For example, with the questionnaire parents are not able to elaborate on their answers. The questions are primarily yes/no questions and a Likert scale rating adequacy of supports. A parent may not understand or misinterpret the question answering the question incorrectly. There is also the possibility that these questions cannot be answered by a caregiver because services or a diagnosis has not been identified yet.

Possible limitations with the interview process include obtaining complete information due to the interview environment and follow up questions. Interviews were conducted in the caregiver's homes where there were frequent distractions.

Limitations of both studies deal with the fact that caregivers may not be aware of what services/supports are available to them and they may report that what they are receiving is adequate when an expert in the field may recommend different services or more services to better serve the family and child with special needs.

CHAPTER 4

ARIZONA KINDERGARTEN READINESS STUDY

QUESTIONNAIRE RESULTS AND ANALYSIS

This chapter presents the quantitative findings based on questionnaire results completed in fall of 2009, as part of a large-scale statewide evaluation project of a state early childhood agency that included a readiness study, the Arizona Kindergarten Readiness Study (AKRS) from which these data were drawn. Participants (focal children and families) were randomly selected from lists provided by participating school districts throughout Arizona.

The AKRS was developed to provide a snapshot of Arizona children's health and readiness for school. For the purpose of this study, 60 participants out of 1,025 were drawn from the AKRS sample. Data analysis of question 31 was used to identify the participants for this component of the study by establishing whether the participants had an Individualized Education Plan (IEP) or an Individualized Family Support Plan (IFSP). To understand parent perspectives regarding educational and health-related services available to and utilized by their children along with parental/family support systems, data derived from the AKRS questionnaire was analyzed and converted into percentages. Questions that were addressed on the AKRS questionnaire that were relevant for this study, summarized by theme, included:

1. Caregiver concerns regarding learning and behavior development and hearing and vision was reported. Further inquiry asked if caregiver concerns were discussed with a medical provider or a school professional. If the child was

limited or prevented in any way in his/her ability to do things most children

the same age could do was also asked.

2. Caregivers were asked to check conditions that their child had, from a

checklist of 14, that was reported by a doctor, professional or previous

primary caregiver.

3. Caregivers were asked to identify services, from a checklist of nine, that their

child received within the last 12 months.

4. Caregivers reported on how adequate seven services were using a Likert scale.

These questions were selected to better understand the child's special needs and

services that were available and utilized for each participant in this study to determine if

there were any connections between caregiver report on adequate services and caregiver

concerns, child conditions, and services utilize. Identifying potential correlations would

provide information that could potentially support future recommendations and research.

Questionnaire Data Results

Caregiver Concerns. Table 6 compares the Non-IEP Sample with the IEP

Sample regarding primary caregivers concerns about their child's learning and behavior

development, and/or hearing and vision. Results on whether the caregivers discussed

these concerns with a medical professional or with a professional at their child's school

are also reported. Finally, caregivers reported on whether their child was limited or

prevented in any way in his/her ability to do the things most children of the same age

could do, results can also be found in Table 6 below. Total population for the Non-IEP

Sample ($n = 1,025$) and IEP Sample ($n = 60$) have been recorded on the table below.

Some caregivers identified more than one concern and some did not report any concerns.

Table 6

Caregiver concerns: Non-IEP Sample and IEP Sample

Variables	Non–IEP Sample	IEP Sample
	$n = 1{,}025$	$n = 60$
Learning/Behavior Development	16.10%	59.30%
Hearing/Vision	10.10%	25.40%
Discussed with Medical Provider	17.40%	66.10%
Discussed with School Professional	16.90%	64.80%
Limited ability	4.90%	31.50%

Caregiver concerns were higher with the IEP Sample than the Non-IEP Sample, as predicted. Parent concerns regarding learning and behavior development had a 43.2% difference between the IEP sample and the non-IEP sample. Concerns about vision and hearing there was a 15.3% difference. Caregivers who discuss these concerns with medical providers, a 48.7% difference. Caregivers who discussed these concerns with the school professional had a 47.9% difference. Finally, caregivers that noted limited ability represented a 26.6% difference.

These results are not surprising. Parents who have children with special needs are more likely to have concerns about current and other potential issues. Unfortunately, the unique needs of a child with special needs can also increase the parent's stress level. A child's condition alone is a factor research has identified associated with parental stress. The condition associated most with parent stress is problem behaviors (Smith-Bird & Turnbull, 2005; Osborne, 2009). Long, Gurka, & Blackman (2008) found higher stress levels with families who have children with behavior problems versus speech and language problems. Oelofsen & Richardson (2006) found high levels of parent stress associated with preschool children who have developmental disabilities. Hung et al.

(2004) found significantly higher levels of parental stress with children who have chronic illnesses versus disabilities.

Further analysis of individualizing conditions will help identify more detailed information on support services caregivers and their children with special needs may need. While identifying a condition will further support the identification of services, general services can support any family such as medical supports, educational supports and family supports.

Reported Conditions. Caregivers (mostly parents) were asked to check the conditions listed in Table 7 based on whether a doctor, other professional or previous caregiver told them that their child had the condition. The IEP sample results were analyzed. Table 7 reports these findings.

Table 7

Conditions Reported for IEP Sample AKRS

Variable	IEP Percentage n=60
ADD/ADHD	7.10
Mental Retardation	3.57
Learning Disability	15.75
ASD	3.57
Developmental Delay	22.81
Behavior/Conduct	10.53
Speech Problems	69.64
Depression	3.50
Anxiety	5.60
Asthma	10.71
Diabetes	0.00
Hearing	17.54
Vision	3.57
Oral Health	17.86

Speech problems was the condition more caregivers reported on, with 69.64% of the IEP Sample. Developmental delays were reported by 22.81% of the caregivers.

Hearing (17.54%) and oral health (17.86%) conditions were also reported by caregivers. Finally, 15.75% caregivers reported learning disabilities was a condition they discussed with a doctor or other professional.

Based on the age demographics for this sample ages five years and younger, it is not surprising to see that speech problems (69.64%), and developmental delay (22.81%) are identified as high incident disabilities for this population. Typically, these categories are more prevalent between the ages of birth to nine years old. This is similar to the lower incidence disabilities identified, which were ADD/ADHD, mental retardation, depression, and anxiety. Again, based on this sample's demographics, these conditions would rarely be identified because the child is too young to determine if they had one of these conditions.

The statistics on autism spectrum disorders, 3.57%, is surprising. National statistics show that the prevalence of autism in 2009 was 1 in 88 children. In the present study, however, out of 991 participants who answered this question, including both the IEP and Non-IEP participants, only four children were identified as having an autism spectrum disorder. This is low based on the national statistics which would predict an incidence rate closer to 11. More interesting is that only two were identified as having an IEP.

There are many factors that affect a young child's development and variables that affect the identified condition they receive. "Reliability of standardized and norm-referenced assessment tools for identification and diagnoses of young children is problematic at these early ages, resulting in inaccurate identification/categorization and potential loss of services" (Hadadian & Koch, INT-JECSE). When a child is older and

the reliability of standardizing and norm-referenced assessments increases due to a change in age, different conditions will be identify, changing the percentages within each conditions population. However, for a child who has been labeled with a condition, it is not the label that is important, it is the services that he or she receives that could potentially increase positive parent and child outcomes.

Services Received. Caregivers were asked to check any services identified in Table 8 if their child or family received them within the last 12 months. Table 8 reports these findings.

Table 8

Services Received for IEP Sample within the last 12 months

Variable	Percentage
Speech/Language Therapy	77.97
Occupational Therapy	15.25
Physical Therapy	5.08
Mental Health Professional	6.78
Special Classes with other Special Needs children	32.76
Private Tutoring or classes for learning Problems	16.95
Vision Services	13.79
Hearing Services	19.30
Social Work Services	5.26

The most received service was speech and language therapy, 77.97%. Speech problems was the condition caregivers identified the most, 69.64%. The percentage of children receiving speech and language services closely matches the percentage of caregivers who identified speech problems as a condition their child has. However, service percentage is higher than the condition is reported. This is surprising because speech and language services can be difficult to access. Cassidy et al. (2008) interviewed 100 parents who had a child with autism, improvement in services was identified as a

needed theme. Most parents wanted improved access to services in which speech and language services was identified the most. There is the possibility that caregivers have access to speech and language services but may not have the recommended amount for them to be adequate. This might account for the high percentage of speech and language services identified in this study.

Caregivers reported special classes that are with other special needs children as the second most frequent service received, at 32.76%. When these services are compared with caregiver reports on possible conditions that would use this service (mental retardation, learning disabilities, autism spectrum disorder, and developmentally delayed), 45.7% would potentially need this service. In this case, services accessed are lower than conditions reported by 12.94%. Cassidy et al. (2008) concluded similar results where parents also identified a need for better access to specialist playgroups and schools.

Hearing services (19.30%) closely matches caregiver reports of children identified having a hearing condition, 17.53%. However, vision services (13.79%) were much higher than the condition was reported, 3.57%. The variability may be due to caregiver perception of these two questions. The vision condition is listed with a group of other conditions that may be perceived as severe (i.e. depression and mental retardation). A caregiver may think that their child does not have vision problems if they just wear glasses. They may perceive this question to refer to individuals with severe vision problems such as blindness. If this is the case then a large increase in vision services, 13.79% is understandable. Caregivers who did not mark vision as a condition due to an inaccurate perception of the question could still report that their child receives vision services if they wear glasses or see an eye doctor.

Finally, occupational therapy services were received by 15.25% of the sample. This percentage is also a bit surprising. Occupational services are also difficult to find. In the Cassidy et al. (2008) study, parents mentioned the need for better access to occupational therapy. Again, it may be that caregivers have access but not an adequate amount.

The results for services received, based on caregiver accounts, were higher than anticipated. While not identified in this research, accessing general services (Knox et al., 2000), specific services (Grindle et al., 2009) or services based on location (Freedman & Boyer, 2000) is frequently identified by parents as a barrier. This barrier can lead to the parent seeking inadequate services. Knox et al. (2000), parents explained that they allowed incompetent service providers provide services to their children due to a lack of service availability. Some of these services, because service providers were not qualified to provide the service and/or had minimal experience implementing the needed services, put children in dangerous situations. Limited access to services and supports can hinder parent and child outcomes; however, the adequacy of those services is just as important. Service providers need to be knowledgeable in their field in order to provide competent services.

Caregiver Reports on Adequate Services. Caregivers were asked to rate the adequacy of the services that they received based on a Likert scale. Table 9 reports these findings.

Table 9

Caregiver Report on Adequate Services

Variable	Don't need Service	Poor	Somewhat Adequate	Good	Excellent
Physical Health	1.80%	1.80%	8.80%	24.60%	63.20%
Oral Health	1.80%	1.80%	8.90%	28.60%	58.90%
Mental Health	37.00%	0.00%	1.90%	22.20%	38.90%
Behavior Services	33.90%	1.80%	5.40%	25.00%	33.90%
Learning Difficulties	16.70%	1.90%	9.30%	29.60%	42.60%
Crisis Services›	42.60%	1.90%	3.70%	22.20%	29.60%
Parental Support	47.20%	1.90%	1.90%	22.60%	26.40%

Caregiver reports on the adequacy of services mostly fall between good and excellent for all services noted in the table, minus those that identified that the service was not needed. The large percentage number recorded as adequate services is surprising. The perception of adequate services could vary from one caregiver the next. There also seems to be some confusion in research about what adequate services entail. Some articles referred to adequacy as the quantity of services (Knox, 2000; Grindle, 2009; Cassidy, 2008) and others referred to it as the quality of services (Freedman, 2000; Howie-Davies, 2007).

Freedman & Boyer (2000) identified lack of qualified staff as a barrier to adequate services. Howie-Davies et al. (2007) identified that inadequate support may be due to the support providers' lack of knowledge of the disability. They also found that while professionals are providing information to families, it may be information that the family does not need. They concluded that, "it is the satisfaction with professional

support rather than the amount of support that is important." Relationships and communication between providers and families remain critically important.

If a caregiver is unaware of what services are available, their perception of adequate services may also be inadequate. Knox et al. (2000) found that a certain percentage of parents were unaware of support systems such as organizations and legislations that were available to them, let alone what questions to ask in order to access adequate services. Not knowing what services are available or what questions to ask can lead to accessing inadequate services.

Just as professional supports are important for parent and child outcomes, parental supports are also needed. Research identifies the most common social supports parents have are extended family members, friends, neighbors, and church members (Cassidy, 2008; Cavallo, 2008; Davis, 2009). Social supports have been found to help boost (mother's) self-esteem, decreasing depression (Weiss, 2002). Family support systems vary from family to family; however, they are needed to help improve a family's quality of life.

Chapter Summary and Discussion

Caregivers in this study identified concerns about the development of their child's learning capabilities or behavior. Medical concerns were also identified regarding their child's hearing and vision. Caregivers noted whether these concerns were discussed with a medical professional and/or a professional within their school system. Child's conditions were compared with services received and these data were compared to related literature and national data. Finally, parent perceptions of the adequacy of the services that they received were discussed.

Parent concerns regarding learning/behavior development, hearing, and vision along with their child's ability to do things that most children of the same age can do varied, their highest concern was learning and behavior development. Over half of the caregivers that identified a concern sought out professional support.

Child conditions and services which they received varied depending on the condition. Speech and language services along with their child attending special classes with other children, some or all who also had special needs, were services caregivers identified most frequently. These services were comparable to the conditions identified by caregivers with the highest frequency.

Parent perceptions regarding the adequacy of the support services they and their children received were relatively high. Services included; physical health, oral health, mental health, child's behavior, child's learning difficulties, crisis intervention, and parenting supports. The majority of caregivers reported the adequacy of these services between the range of good and excellent.

The Microsystem and Macrosystem were the only systems specifically identified based on Bronfenbrenner's Ecological Systems Theory (1977), however, while specific linkages in the Mesosystem were not identified in this research, based on the microsystems that were identified, linkages can be assumed. Supports that were identified in the Microsystem, all of which are professionals, include speech language pathologist, occupational therapy, physical therapy, audiologist, ophthalmologist, mental health professional, teachers, and tutors. While not specifically identified, the caregiver is assumed to be a part of the system because they completed the questionnaire. Race, household income, and guardian education were identified ask potential Macrosystems

that may affect the child. Well not specifically identified how in the studies questionnaire, these three identified systems influence a child's development

Analysis of the support systems identified on the questionnaire provided some insight to parent perspectives of educational and health related services available to and utilized by their children along with parental/family supports. Research identifies adequate parent/family social supports (Cassidy, 2008; Cavallo, 2008; Davis, 2009), professional supports (Dunst, 2007; Cassidy 2008; Gallagher, 1983) and medical supports (Cheng et al., 1996) important to child and parent outcomes. Summers et al. (2007), links service adequacy as a significant predictor of a family's quality of life.

Parameters of the study

The quantitative component of this study provided basic descriptive statistical information on specific questions identified from a questionnaire that was part of a larger study (AKRS), also part of a Longitudinal Child Study in Arizona. Participants were randomly selected from lists provided by participating school districts throughout Arizona. 60 participants out of 1,025 were drawn from the results of the questionnaires, based on IEP identification.

The questions developed for the questionnaire were not specified for this study. If the focus pertained to children with special needs, results might have varied. The questions on the questionnaire were forced choice and Likert response format which could limit caregiver responses.

 Question-wording may have been confusing, hinder caregiver report. Misunderstanding or misinterpreting a question could lead to an incorrect answer. However, the larger sample size provided basic statistical information regarding parent

perceptions regarding the educational and health related services along with parental family support systems available and utilized by them.

This chapter focused on the quantitative component of this mixed methods research. It provided basic statistical insight pertaining to the research questions on a larger scale. Out of 1,025 participants, 60 children with special needs were identified for this study to better understand parent perceptions regarding the services they receive along with the services their child with special needs receives. The following chapter will provide the qualitative component needed to complete this mixed method research. In Chapter 5, interview analysis is described providing detailed accounts further elaborating on perspectives of parents who have children with special needs on the adequacy of educational and health related services available to and utilized by them along with parental/family support systems.

CHAPTER 5

FAMILY AND CHILD CARE STUDY

PARENT INTERVIEW FINDINGS AND ANALYSIS

This chapter presents qualitative findings based on interviews that were conducted in fall 2009, spring 2010 and fall 2010 with primary caregivers, all of whom were parents. All were part of a statewide study that was also part of the larger evaluation of a new early childhood readiness-focused quasi-state agency.

The purpose of the Family and Community Case Study (FCCS) was to address issues of access, cultural relevance of programs and other subtle issues in the availability, accessibility, visibility, quality, and utilization of early childhood care and health services and gain perspectives from service providers as well as children before and after they entered kindergarten (Joanie, Holiday, & Swadener, 2012). For the purpose of the present study, ten participants out of 69 focal families in FCCS were identified as having children with special needs. Transcripts were reviewed and analyzed in order to identify common themes as well as unique responses about the broader research questions:

1. How do parents of kindergartners with special needs, in public, private, and charter school settings, view the educational and health-related services available to and utilized by their children?

2. What are the perceptions of such parents regarding the parental/family support systems available to them?

Each focal family is described and their interview briefly summarized below. Children's ages listed are based on the first interviews conducted in 2009, which were followed by two other interviews over a two-year period. The summaries are intended to

introduce the families and clarify the special needs of their children. Following these summaries, parent perspectives are identified and discussed regarding the educational and health-related services available for their child with special needs, as well as parent/family support systems. All names are pseudonyms.

Focal Families and Interview Summaries

Tammy. Tammy was a stay-at-home mother who lived with her partner Stacy and their two children, Jenny, who was five years old and Tommy, who was three years old. They lived in an urban area in central Phoenix close to public transportation, a community park, fast food restaurants and grocery stores. Both parents were well educated and followed the attachment parenting philosophy. "Attachment parenting focuses on the nurturing connection that parents can develop with their children. That nurturing connection is viewed as the ideal way to raise secure, independent, and empathetic children" (WebMD, 2017)

Jenny, their daughter, had sensory integration issues and pragmatic language disorder. When seeking out services for Jenny's special needs, Tammy had both positive and negative experiences. Positive experiences included access to a social skills class which helped Jenny's pragmatic language disorder and a behavioral child psychologist at Jenny's school who provided supports for her sensory integration issues. A negative experience that Tammy faced was access to a neurologist. They were put on a waiting list and had to wait 6 to 9 months before seeing the neurologist.

Tammy and Stacey's parental/family support system included local friends, Jenny's school, and their church. While they had these support systems, both Tammy and her partner stated that they lack "built in care" because they did not have family living

close to them due to their recent move to Arizona six years ago. This put a strain on their social life, limiting access to further parental/family supports.

Sarah. Sarah was a stay-at-home mom who lived with her husband and three children. They lived in a residential area in central Phoenix that contained older, single-family homes. Within their community, they had access to public transportation, grocery stores, and restaurants.

Callie, who was her three-year-old daughter, had speech and language delays. A speech and language pathologist at Callie's school was viewed as supportive. He gave Sarah a packet of things to work on with Callie over the summer. He also provided her with educational materials about the development of speech and language in which she said gave her peace of mind. Sarah's family had quite a few service constraints.

Accessing healthcare, child care, and speech and language services were difficult due to their financial situation. Sarah was also frustrated with the education system. Specifically, if Callie qualified for speech and language services, in order for her to access those services, she would have needed to attend a Head Start program. Sarah did not want to put Callie in a Head Start program; she felt that she could provide a higher quality of education for both her children at home. If Callie was placed in a Head Start program, speech and language services were minimal, only two-20 minute sessions a week. However, Sarah was concerned if she waited until Callie was in public school, services would begin too late hindering her speech and language development. Sarah was trying to determine which would be more beneficial for Callie's development.

Sarah and her husband lived in Arizona most of their lives, benefiting from a large parental/family support system which included friends, church, and family. They felt like they could lean on those support systems if needed.

Kathy. Kathy lived with her partner and their two children, who were four years old and 10 months old. They lived in a small single-family home in a nice area in central Phoenix. Kathy felt safe in their community and liked the close location of her partner's job and her school. She also liked that there was a park within walking distance for her kids. Kathy was working on her PhD while her partner worked full time.

Cory, their four-year-old boy, had behavior problems that included aggression. Kathy's experience with support services was both positive and negative. She had positive and negative experiences with her son's school and his teachers. Positives included keeping him focused and adjusting to his needs. Negatives included inadequate teachers along with a limited number of teachers in her son's Montessori Pre-kindergarten classroom. Her main concern was the unsafe school environment; Cory was being bullied by other students. Other positive supports included a professor who provided her information on what was developmentally appropriate and a child development specialist that helped them implement strategies that decreased problem behavior. Unfortunately, their family income was another barrier to accessing support services for Cory.

Kathy identified that the only parental/family support system her and her partner had was each other. They had only lived in Arizona for six months. They struggled to find other families with similar life styles. Kathy also stated that once she was done with her degree, they were planning to move back to Carolina. She felt that this may have

hindered access to support systems because they were not trying very hard to form friendships and a supportive network due to their future move.

Cindy. Cindy was a stay-at-home mother who lived with her husband and her two sons, ages four years and 18 months in a small town outside of the Phoenix area. They lived in a two-story house with a large backyard in a new housing development. They were near grocery stores, a Walmart, Home Depot, restaurants and a park just down the street. Cindy's husband traveled to North Carolina frequently, so they attempted to sell their home but due to the market were unable to.

John, who was 18 months old, had a medical condition, an enlarged kidney. Due to John's medical condition, Cindy worked with a variety of medical professionals. She had both positive and negative experiences accessing services in the medical field. She could easily access some doctors and/or specialists but also had difficulty accessing others. Being able to research her son's condition on the internet was helpful aiding in her education so that she could further advocate for her son's needs. Cindy also stressed the importance of feeling respected by the medical professionals she worked with. This too varied between professionals increasing her frustration when encountering professionals who did not respect her opinion and knowledge.

Their parental/family support system included family and friends. However, Cindy stressed that she had trouble making friends in their neighborhood. They went to church on occasion, but she did not feel as though they were a part of that community. With her husband gone frequently, due to work, she at times felt lonely.

Lauren and Tom. Lauren and Tom lived with their two sons, ages four and six along with Lauren's mother. They lived in a rural town 61 miles southeast of Phoenix.

Their house was old and neglected. There was a concern about the safety of their neighborhood due to multiple prisons in their small community. Their son, Daniel attended Head Start which was walking distance from home, the close proximity was reassuring for both parents.

Daniel, who was four, was born with a cleft lip and cleft palette. His lip was surgically repaired, but at the time of the interviews, he still has an open cleft palate. Due to Daniel's medical condition, Lauren and Tom crossed paths with many professionals, educational and medical. These support services were both positive and negative. Health related services included two hospitals; one was a positive experience, and the other was not. They had multiple medical doctors some that were easy to access and some that were not. Daniel's surgeon kept delaying his surgery which became very frustrating for Lauren and Tom. They were worried about his speech and language development and how the surgical delay would impact it. Regarding educational services, Head Start was a positive service for Daniel. He did not receive speech and language services at his public school, however, which was a service his parents felt necessary.

Lauren's mother was their primary parental/family support system. She lived with them and had a consistent job so she could help them financially when needed. She would also watch the boys so that Lauren and Tom could go out and spend time together. Lauren stated that she was a strong support in their family.

Kris. Kris lived with her husband, their three children, ages 18 months, three and four years old, along with her mother. They lived in a very remote rural area on family land surrounded by desert. They lived in a cluttered and "busy" mobile home down the road from family.

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Tony was a three-year-old girl who had developmental challenges and anxiety. The main barrier for this family was accessing services that were needed. This was a challenge because of where they lived. They had to travel to gain access to all services which became a financial constraint. Home-based services were helpful but were not consistent due to the family's location.

Kris and her husband had a strong parental/family support system, as multiple family members lived nearby and were always willing to help. Kris's mother lived with them and would get up with her son.

Abby. Abby was a stay-at-home mom who lived with her husband and two children. They lived in a rural area which made it difficult to access the services they need. However, Abby was happy with their home and their neighbors. Both Becca, three years old, and Fred, four years old, were adopted. Abby and her husband decided to become foster parents when they realized they could not have their own children and could not afford private adoption, and this lead to adopting their two children.

Becca had a speech delay and their son Fred also displayed some speech impairment along with problem behaviors. Abby and her husband crossed paths with many professionals in the field due to having two kids with special needs. While they had both positive and negative experiences, living in a more remote community made it challenging for them to find the services that they needed. Within the medical field, they had positive experiences with their pediatrician, dentist, ear, nose, and throat doctor, and a developmental pediatrician. Easy access and recommendations for further support made for positive experiences with these medical professionals. They also discussed having negative experiences with one specific doctor who did not listen to their concerns

brushing them off as if he knew what was best. They also had a mix of positive and negative experiences with their children's school systems. Fred's teacher and principal were very supportive in the Head Start program he attended. They were patient, encouraging, and listened to Abby's concerns. They also provided her with materials to take home to further support his speech development.

Abby also had negative experiences with potential future school systems for both children. The first negative experience was gaining access to the Head Start program for her daughter Becca due to lack of room; they were put on a long waiting list. When determining which school Fred would attend for kindergarten, she encountered negative experiences with the public-school system and the charter school. She felt that the public-school system would not provide the support that Fred needed. Another barrier with the public-school system included lack of communication regarding her daughters schedule. "I needed to know what they were working on so that with her other therapist we could combine it so that one therapist is doing one thing, and then the other is doing something different, and she's just getting overloaded. We battle so hard to get her to even communicate."

Abby was close to her family; however, they did not live nearby making it difficult for her to rely on them as a support system. A friend of Abby's and the foster parent network were the family's most reliable social support systems.

Trudy. Trudy, who was five months pregnant at the time of the first interview, lived with her boyfriend (her son's father) and her son, Ray, age four, in a rural town outside the Phoenix area. Only one interview was conducted (2009), and it was conducted at the Head Start preschool where Trudy worked. Trudy described her

neighborhood as quiet and safe. She liked that her son's school was across the street from their home.

Ray had a short attention span and problem behaviors. Trudy had positive experiences with a behavior health specialist; she had easy access to this person. However, her experience with the public-school system was negative. She didn't think that they cared. Trudy also identified further service constraints due to living in a rural community.

Trudy's grandfather was the only parental/family support system Trudy talked about. The rest of her family had recently moved to Texas, and her and her boyfriend rarely saw his family.

Vicki. Vicki lived with her husband and their five children, ages ranged from 10 months to 9 years, in a quiet urban area in Arizona. They lived in a medium sized older home on a corner lot. There were three schools and a park within walking distance. However, Vicki had concerns about the safety of the neighborhood and would not allow her children to play in the front yard. Their home was described as quiet chaos, Vicki's demeanor was very calm, but her children created a very busy environment.

Vicki's son Ted, who was two years old, had a speech and language delay. Positive services that Vicky had access to in the town she lived in, which she said had good activities for young children and the speech and language pathologist that worked with her son helped improve his skills. Services that had a negative impact included difficulty accessing child care, accessing initial speech and language services, and the pediatrician's availability. Vicky also stated that the pediatrician would not listen to her concerns regarding Ted's speech and language development.

Parental/family support systems included family and church. Vicki relied heavily on her cousin to care for her kids while she was working and mentioned that if it weren't for her cousin they would be in a bind.

Bobby. Bobby lived with her husband and two sons, ages one and four, in an urban area in Arizona. They lived in a middle to upper-class neighborhood in an older country club area. Bobby explained that the neighborhood did not include many younger families, but she was hopeful that this would change.

George, Bobby's one-year-old son, had asthma. A strong support service for Bobby was George's doctor. She could access him easily, she felt comfortable around him, and he was understanding of their situation. However, their previous doctor's office front staff was "mean and cranky" which is why she switched to the new doctor.

Bobby's parental/family support system was their church. She had a group of moms' in her church that she reached out to for support. However, after Bobby had her second child, she did not feel like she had a lot of support. They did not have any extended family in the area.

Parent Perspectives on Service Providers

All 10 participants identified both positive and negative experiences with the services they encountered. Table 10 identifies service providers with whom the participants interacted and had positive and negative experiences. Table 11 lists ways in which services were supportive. Table 12 list ways in which services were not supportive. Table 13 identifies family support systems, as described in the parent interviews.

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Table 10

Positive and Negative Experiences with Service Providers

Service Provider	# of Positive Experiences	# of Negative Experiences
Physical Health	9	15
Head Start	3	1
Speech and Language	3	3
Insurance	2	2
Parenting websites/Research	2	0
Public Schools	2	5
Mental Health Professional	1	0
Specialty Class/Special Needs	1	0
Home-based Supports	1	1
Child care	0	2
State Coordinator/Social Worker	1	0
Charter School	1	1
Montessori School	1	1
Professor	1	0
Child's Development Specialist	1	0
Assessment	0	1

The top two service providers with whom caregivers identified as having positive experiences included the physical healthcare system with 9 and school systems with 8. The top two service provider's caregivers identified having negative experience was also the physical health care system with 15 and the school system with eight. Caregivers also discussed access to insurance and speech and language services equally, three positive and negative experiences for speech and language and two positive and negative experiences for insurance.

There was a total of 24 experiences linked with physical health services providers, the most frequent variable identified. Research identifies physical health service providers as a key support system for families who have children with special needs. Cavallo (2008) found that parents felt that communicating with healthcare professionals

regarding their child with physical disabilities useful, viewed as a coping strategy to help decrease stress. Over half of the 24 experiences described by parents in this study were negative experiences. This amount is disheartening when this is the one support system that families reached out to the most. Lauren and Tom's experiences with healthcare professionals were daunting and stressful. They moved from doctor to doctor trying to gain access to a surgeon that would fix their sons cleft palate. Luckily their family physician was supportive and easily accessible. Cheng, et al. (1996) identified physicians as a mother's main source of parenting information, based on mother account. Having frequent positive experiences with the family physician could have decreased the amount of stress Lauren and Tom were experiencing trying to access a surgeon.

Perry (2009) concluded that "the role of the healthcare professional during the pregnancy and birth, and thereafter, can be significant in supporting parent's decisions and ability to plan for a child's needs." Having a child with special needs requires constant support from healthcare professionals throughout their life. Physical health services are a support that caregivers access frequently. The adequacy of this support could lead to a decrease in caregiver stress leading to increased child and parent outcomes.

School systems were the second support service identified by caregivers, with a total of 16 positive and negative experiences. Positive and negative experiences were split down the middle, each with eight. In Spann et.al (2003) study, parents reported that schools were not doing enough to address their priorities for their children, parent perceptions varied based on the age of the child, as the child got older parent satisfaction decreases. One possible influence identified for successful relationships between

caregivers and school systems was unrealistic expectations, Russell (2003). Unrealistic expectations can hinder a relationship between caregivers and the school systems. Improving the relationship between school personnel and parents could help improve child outcomes. Abby had both positive and negative experiences with the school system both involving adequate communication. Communication regarding expectations could easily bridge relationships between caregivers in school systems.

Speech and language services were linked to three positive and three negative experiences. Financial services were linked too, two positive and two negative experiences. Both variables affected Sarah in her quest to provide her daughter with the services she needed. Sarah had difficulty accessing speech and language services for her daughter, Callie. Ultimately, it was Callie's pediatrician who told Sarah to hold off and wait until Callie developed more before seeking out services. After 6 to 9 months waiting for further support from Callie's pediatrician, in hopes that he would give her a referral for speech and language assessment, Sarah began to worry how she's going to gain access to speech and language services her daughter needed. With a referral, she was hoping that insurance would pay for the assessment. Without a referral, Sarah would have to seek out assessment services on her own in which she could not financially afford. At the time, she could not afford an EpiPen for her other child.

Placing Callie in a Head Start program was the only other options Sarah had in order to access speech and language services. Callie's specific need was only for speech and language services and attending the Head Start program she would only receive 2-20 minutes sessions a week of speech and language therapy. Sarah felt that she could provide a better education for Callie at home and was having a difficult time justifying

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sending Callie to the head start program when speech and language services would be minimal. However, Sarah was concerned if she waited until Callie was in public school to receive speech and language services, services would begin too late hindering her speech and language development.

Cassidy et al. (2008) found the parents had the most problems accessing speech and language services. Access to support service is just one variable that aids in a family's quality-of-life. The following table provides a breakdown of how support services were identified by the parents as supportive based on positive experiences.

Table 11

How Services Were Supportive/Positive

Variables	Frequency
Direct	7
Training/education	5
Easy access	5
Access to other supports	5
Emotional support	4
Resources/ Materials	3
Financial	1

There were seven factors that determined how a service was supportive. Table 11 lists them from most frequently discussed in participant interviews to least frequently discussed. Direct services were identified seven times as positive and supportive. For Tammy, a specialized social skill class her daughter attended provided the direct services Jenny needed to improve her social skills, "I think the social skills class has really helped her… Just in the past month, she seems to have made a huge jump in terms of her politeness… she's made a marked increase in sharing better with her brother in being more generous and more caring I think. Those are some of the things that we wanted to see in her," Tammy explained. Direct services provide access to professionals that

specialize in services that can increase a child's development is a specific area. In Tammy's case, the specialized direct services her daughter received focused on social skills.

Training/education, easy access, and access to other supports were identified five times each as a determining factor for supportive, positive services. A child development specialist helped educate Kathy identify how they were triggering their son's problem behaviors. "She helped me to see what we were doing to kind of trigger that sometimes... What do I need to be doing differently and how I approach the situation and how I approach him. I think it makes a lot of sense in terms of, like not getting angry in the moment because he responds to the anger and then we just end up in this like cycle kind of thing." Education and training on how to handle her son's problem behaviors helped decrease those behaviors.

For Cindy, whose son has an enlarged kidney, easy access to a doctor was a priority especially after having limited access to previous doctors. Cindy felt that the previous doctors she encountered were incompetent and disrespectful. She limited access to these services until she found a doctor she felt could provide adequate services for her son. When explaining her concerns about her son's medical condition, John's pediatrician developed a plan that addressed Cindy's concerns. "I could just go into her office. Like, I didn't even have to call to make an appointment, just show up there and she will see him," explained Cindy. Due to the medical risks, easy access to the pediatrician was necessary.

After Lauren and Tom had experienced delay after delay for their son's surgery, access to other supports was needed. Luckily, their dentist gave them a referral to a

different doctor. "A dentist that we took him to… gave us a referral to one that has done… he (dentist) has patients that have had surgery done through them. He said, "you know, you might want to talk to them and see if you can get a different opinion" Tom explained. This referral provided them access to an outside support.

Other determining factors included emotional supports, resources/materials, and financial situations. A home-based program provided Kris the support she needed so that she could teach her daughter who had developmental challenges and anxiety. Kris explains, "I'm the teacher. They come out and supervise and they bring me the materials to teach the kids and they just make sure that I'm doing it right." Access to resources and materials can support a child's development and a variety of ways, supplementing direct services, bridging direct services with other environments and provide supports necessary to encourage parent involvement.

To determine if services were adequate seven reoccurring variables were identified by caregivers. Direct services, training/education, easy access, access to other supports, emotional support, resources/materials, and financial support are variables that could easily be implemented by all service providers. Implementation of these variables provided the caregivers in this study with positive, supportive experiences increasing child and family outcomes by allowing them to gain access to services they needed. Each caregiver was given supports needed to move towards obtaining family quality-of-life. Table 12 identifies the issues parents identify in obtaining support services.

Table 12

Issues with Support Services

Variable	Frequency
Difficult to access	14
Lack of emotional support	7
Financial	6
In adequate support/services	6
Lack of communication	4
Qualifying for services	3
Insurance	2

There were seven factors participants identified as issues with support services. Participants discussed gaining access to services as the highest frequency barrier mostly due to location. Many Arizona families living in rural areas where far fewer specialized services and less medical care is available. Abby, who had two kids with special needs had difficulty accessing services for both children due to their location. Abby explained, "I know the area we live in out here. We have trouble getting people out here to come and do services, let alone to find businesses or even speech therapy places have room to take the kids. It's hard to find." Due to their location, the turnover rate is very high. They had five different speech and language therapist for their daughter between the ages of one and three. She further explained, "Turnover, not wanting to come out, can't find anybody to do it. Yeah, it's frustrating to sit here and know that your child has an issue, want the help and nobody gives it to you. I think that's part of the reason why we're two and a half years behind now because the helps not out here unfortunately." Location was not the only variable that hindered access two supports. Service availability was also a barrier, families were put on long waiting lists or they were denied services because there was no room, service providers were not taking new patients.

Lack of emotional support was identified as the second highest issue. Vicki's

child had speech and language delays. When she discussed this with her pediatrician, he

did not listen to her concerns and told her to continue to wait for her son to get older

before she sought out services. "One thing coming up is this two-year-old right here, who

is going to be three soon, he's actually delayed in speech. He's definitely behind. I did

speak to my pediatrician about it, and were kind of in that in between where don't know

if I need to get him into a speech therapist. I don't even know where I would go to look.

I've been told to go through my pediatrician, and he just keeps saying well let's watch

and see, let's watch and see when he's three. Don't really know if I'm missing an

important window of development or if I should just wait and see," expressed Vicky.

Emotional support is an important quality which can aide in a parents well-being. Having

a child with special needs is already stressful enough. Lack of emotional supports can

increase a parent's stress level decreasing the parent's opportunity to have a quality of

life.

Financial constraints and inadequate support services were the third frequently

identified issues. Sarah, whose daughter had a speech and language delays, was dealing

with both issues. Due to financial constraints accessing adequate support services was

limited. Discussing her concerns about her daughter's speech and language delay, Sarah

states, "yeah, and that's been one of those things we checked it out with a pediatrician.

Yeah, we think it's okay, but it's been nine months since then. It's kind of like the big

question what do people like us who are kind of middle income, lower middle income…

how do we negotiate getting what we need in a way that we can afford?" She further

discusses school options in which she felt was inadequate. "I mean it's not speech

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emphasis, it's just Head Start. And she might get some services. But to send her… we don't really send our kids to preschool. And to do that for a 20-minute a week time with the speech therapist to us is just really didn't seem like it was worth the swap." Not being able to financially access the services, a parent feels is necessary for their child's development is stressful. Services that are available but are minimal can be just as frustrating to parents as having no services at all.

Parents identified a variety of issues with support services. Access to services, lack of emotional support, financial barriers, inadequate services, lack of communication, the ability to qualify for services put strains on parents who are trying to access adequate services for themselves and their child with special needs. Without adequate services, a parent stress level increases. The following table identifies the family support systems parents identified that they had and found helpful.

Table 13

Family Support Systems

Variable	Frequency
Family	9
Friends	6
Church	4
School	1
Partner	1
State caseworker	1
Foster parent network	1

While there was limited discussion in the interviews regarding family support systems seven were identified with family being the most frequently identified, friends the second frequently identified and church as the third frequently identified. Trudy's family support system was her grandfather. When asked how he supported her she stated, "Cause he doesn't judge me. If I have problems, he'll give me advice, but he

doesn't, "Oh you shouldn't do that." He doesn't judge me and he doesn't criticize very much so I can go and talk to him." Tammy had several family support systems. "Our support network. It's actually our local friends and the school… and I also think really adding, going to church or to our congregation has really helped to. Because it's really added a connection to another community."

Parent support systems are just as vital as the support systems that influence a child's overall development. Having a strong support system can decrease parental stress simply by having someone to discuss positive and negative experiences, by giving a parent reprieve from the stresses of their daily life, and by providing that extra support needed when everyday life gets in the way. While minimally identified in this research, professional parent support systems could also aid in a decrease in parental stress.

Chapter Summary and Discussion

Each of the participants in the study had positive and negative experiences with similar service providers. The physical healthcare system, the public-school system, and support from speech and language pathologist were the service providers with whom the participants had the most in common. Parent perspectives regarding the adequacy of these services were discussed.

The participants identified direct support, training/education, easy access, and access to other supports as factors which lead to positive experiences accessing the services and supports they needed. However, having difficulty accessing services, lack of emotional support, financial constraints, and inadequate support services were factors that the participants identified as barriers to services and supports they needed which lead to negative experiences.

The participants did not discuss in detail their family support systems; however, seven were identified with family being the most frequently identified, friends the second most frequently identified and church as the third most frequently identified.

Parents identified supports in all five of Bronfenbrenner's nested systems were evident throughout the interviews that were analyzed for this research. Family members, family friends, neighbors, members of their faith community and multiple people within the school environment were identified the most within the Microsystem. Linkages within the Mesosystem included parent and teacher connections, parent and principal connections, home therapist and parent connections, and family member connections. Within the Exosystem experiences with health professionals, insurance companies, work, a professor, and a behavior analyst where mentioned. Religion, sexual preference, finance, AHCCS, guardian education, safe and secure environment, job security, and Arizona Early Intervention Program (AZEP) were just a few Macrosystems identified. Finally, instrumental changes over time (the Chronosystem) included parent education and financial status, children's educational placement, and parents' employment. While not specifically identified how in the studies interviews, these five systems influence a child's development.

Reviewing and analyzing participant interviews, parent perspectives were identified regarding the educational and health-related services available to and utilized by their children. Parent perspectives on the availability of parental/family support systems were also identified. While the participants did not specifically discuss their family's quality of life (FQOL) in their interviews, family and child support systems/services are key factors to child and family outcomes. All participants identified

some level of difficulty with the support systems available or not available to them which could lead to an increase in their stress levels and lower family quality of life. They also identified strengths within the system.

Personal accounts witnessed the vitality of adequate services provided to families in this study. Disability-related supports (Davis et al., 2009; Smith-Bird et al., 2005; Summers, 2007) and extended family member supports (Davis et al., 2009) are domains that have been found to measure FQOL. When adequate services are in place, short term parent and child outcomes are more feasible leading to the ultimate long-term outcome of family quality-of-life.

Parameters of the Study

The qualitative component of this study included a small sample size, that was drawn from a larger study (FCCS) that encompassed 69 focal families. FCCS did not have an explicit focus on children with special needs, thus, only 10 families who had children with special needs were identified for this study. Interviews with these 10 families were analyzed identifying themes pertaining to the research questions.

Interview questions were not developed specifically for this study. If interview questions were developed based on this studies research questions, there may have been more detailed information to analyze, possibly changing the results. However, the detailed accounts that were recorded allowed for commonalities to be identified. These detailed accounts provided an in-depth picture of parent perspectives regarding the adequacy of educational and health-related services available to them. Detailed accounts on the perceptions of the parental/family support systems were lacking.

The following chapter, Chapter 6, pulls analyses from both studies in order to compare and contrast the two providing further information on how support services can impact a family, decreasing stress and aiding a family's quality of life.

CHAPTER 6

DISCUSSION AND IMPLICATIONS

Secondary data were analyzed from the Arizona Kindergarten Readiness Study (AKRS) and the Family and Community Case Study (FCCS) which were a part of a longitudinal study that evaluated kindergarten readiness across Arizona. A mixed methods research (MMR) design was used to analyze data from the Arizona Kindergarten Readiness Study (AKRS) and the Family and Community Case Study (FCCS) to better understand caregivers' (parents and other primary caregivers) views of educational and health related services available to and utilized by their children. This method was also used to reflect on caregivers' perceptions of the parental/family support systems that were available to them. AKRS survey research combined with FCCS caregiver interviews provided basic statistical information along with descriptive caregiver/parent accounts.

In this chapter findings pertaining to the research questions based on analysis of data from AKRS and FCCS studies, are examined using Bronfenbrenner's Ecological Systems Theory (1977). Parent/caregiver reflections on the adequacy of services are reviewed, through comparison and contrast of findings from both studies. Based on the combined analysis, the importance of support systems to help decrease caregiver stress and improve a family's quality of life is discussed. Implications for practice and future research are included. Finally, parameters of the study are identified and I conclude with a brief personal reflection.

Bronfenbrenner's Ecological Systems Theory

The use of Bronfenbrenner's ecological system has been used to help understand how a child's development is influenced based on the environmental systems around

them. There are five systems identified in Bronfenbrenner's ecological systems theory (1977), the Microsystem, Mesosystem, Exosystem, Macrosystem, and Chronosystem. These systems are nested within each other, influencing one another. The use of Bronfenbrenner's theory to understand human development began in 1977 and since has been used to evaluate how an individual's environment influences their behavior. Runyan et al. (1998) used this theory to evaluate child maltreatment and how it affected the child's life course. Russell (2003) evaluated parent expectations of their children with disabilities also using Bronfenbrenner's theory. The mental health impact of a sexually assaulted women (Campbell, Dworkin, Cabral, 2009) was evaluated using this same theory. Bronfenbrenner's theory as evolved passed the analysis of child development based on their environment and has been used across multiple environments based on a variety of conditions. While it has expanded across environments, the use of this theory to understand children and families, including those families that have children special need is still relevant.

For this study, how educational and health related services/supports available to and utilized by children along with parental/family supports can influence a child's development is theorized using Bronfenbrenner's nested system (see figure 1).
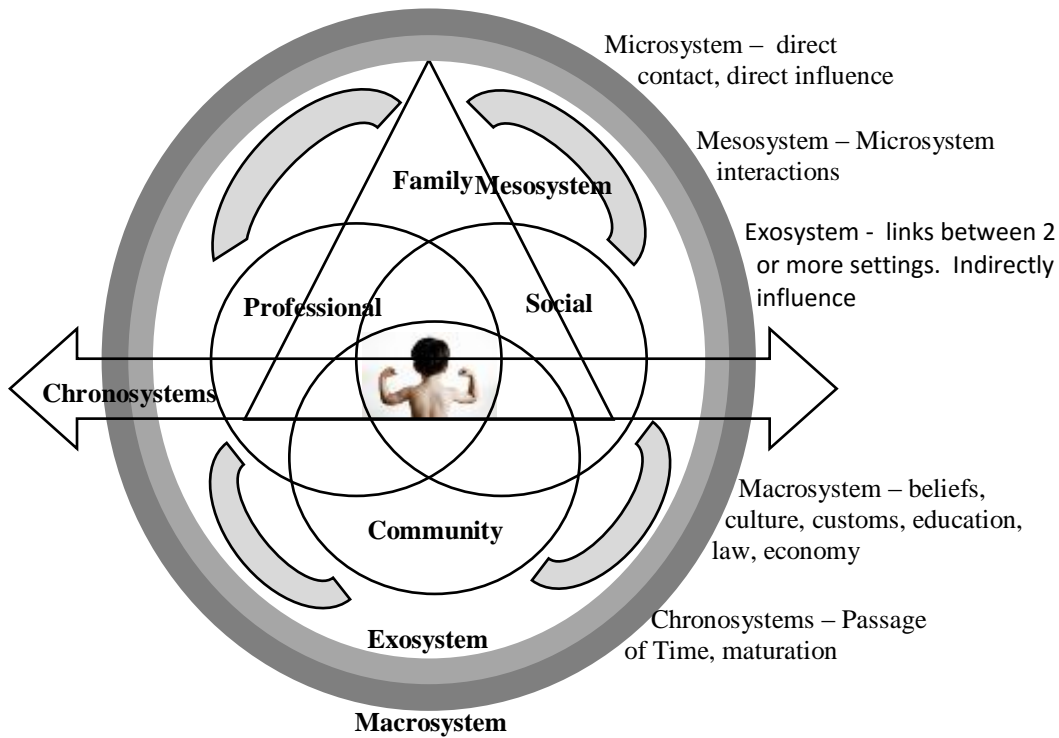
The Microsystem is the immediate environment in which the child lives. More specifically, the people she or he interacts with, including parents, teachers, and family members. Participants in both AKRS and FCCS studies identified multiple supports within the microsystem. Common supports included parents/caregivers/guardians, speech and language therapists, occupational therapists, and teachers. The ARKS Microsystem that was most apparent was speech and language therapy, identified by 77.97% caregivers. Spann et al. (2003) parents identified social interactions and communication skills as a priority service their child should receive at school. Satisfaction was based on personnel and services. Based on the need for communication and social skills services, a speech and language pathologist could easily be a microsystem within a child environment.

Data from the interviews provided a more detailed list of Microsystem identified by parents including multiple people within the school system (peers, principals, assistants), family members (aunts, cousins, grandparents, siblings), family friends, neighbors and members of their faith community. The development of Kathy's child, Cory, could easily have been affected by the lack of support within their Microsystem. Kathy explained that the only support system her family had was her and her partner. They had just moved to Arizona. However, Tammy's identified several family/parent support systems, "Our support network. It's actually our local friends and the school… and I also think really adding, going to church or to our congregation has really helped to. Because it's really added a connection to another community." The connection between Tammy's family and their congregation demonstrates how interactions within the Microsystems that affect the development of a child's Mesosystem.

The Mesosystem is the connections between the individuals with whom the child interacts. For example, the connections between the child's teacher and his or her parents or the connections between his or her church (or other faith community) and neighbors. These connections could also include interactions between service providers. AKRS did not specifically identify linkages between Microsystems; however, 66.10% checked that they discussed their concerns with a medical provider and 64.80% with a professional within the school system. Many families also checked that they received some type of service (Table 8). A possible linkage could be the parent/caregiver, and the teacher of a specialize class. Spann et al. (2003) found that communication between the parent and school personnel was a priority identified by parent/caregivers. Parents who were interviewed reported a 50/50 ratio of positive/negative experiences with professionals in

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the school system. Communication between home and school increases consistency across environments regarding strategies for child improvement across all domains. These connections can improve child outcomes. FCCS identified connections between parents and teachers, parents and principals, home therapist and parents, and family member connections. Trudy explained how her grandfather would give her advice but not criticize her for the choices she made. The connection between Trudy and her grandfather could easily influence her child's development. While varying connections are discussed in the interviews, how they affected the child was not identified.

Within the Exosystem, you find social systems that the child does not interact with directly, however they impact the child's development because they interact with the structures within the child's microsystem. For example, a child's experience at home may be influenced by a mother's experiences at work. Results from the AKRS survey did not specifically ask families to rate/identify interactions within the Exosystem. Interviews with families identified how some of these institutions or policies in the Exosystem influenced the ways in which they cared for and educated their children. Interactions with systems that pushed parents to do something that they were not comfortable with included waiting for services, attending a Head Start program, and access to insurance. These interactions cause parental stress. Vicki's son's pediatrician, specifically his training and or experiences, led him to conclude that she should wait to access speech and language services for her son. Delaying services could have affected her son's speech and language development. In order for Sarah to access speech and language services for her daughter she was told that she needed to send her to Head Start. Sarah did not want to send her daughter to Head Start especially because the speech and language services were

minimal. These systems encourage both parents to do things that they did not feel was in their best interest of their child's development.

The Macrosystem is the outermost layer of the child's environment which includes cultural values, financial status, customs, and laws. ARKS identified race, household income, and guardian education as potential Macrosystems that may affect the child. FCCS 's analysis identified religion, sexual preference, finance, AHCCS, guardian education, safe, secure environment, job security, and Arizona Early Intervention Program (AZEP) as potential Macrosystems. Finance was a Macrosystem identified in both studies. Due to the recession Tom lost clients making it difficult for Lauren and Tom to financially provide their son the services he needed. Kathy was worried about paying medical bills because their Cobra insurance was going to run out. Mahoney (1992) found a family that was more distressed typically to be of lower SES and have children with more severe disabilities. Wang's (2004) results demonstrated that income was significant to a mother's family quality-of-life but not a father's.

Finally, the Chronosystem represents the historical change in the previous systems and a child's developmental change over time. The FCCS interviews conducted were completed over nearly three years, with interviews conducted approximately every 6-8 months with families, in order to document change over time. Some of the specific supports identified that changed over time included parents' education and financial status, children's educational placements, and parents' employment. Due to the recession, Lauren and Tom discussed experiences with access to insurance across all three interviews. At times, they had insurance, and at other times they did not have insurance

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which caused financial hardship when they had to pay out of pocket for needed services, changing their family quality of life.

Bronfenbrenner's Ecological Systems Theory (1977) identifies five nested systems that influence a child's development. These systems were apparent in the analysis of this mixed methods research. Some of these systems were more specifically identified in FCCS providing detailed information regarding the influencing factors within each system. While both studies provided supporting evidence that these ecological systems affect a child's development, they did not specifically identify how. Further studies with this population are needed to document the specific family dynamics and interactions with these systems. Access to services was identified frequently as a barrier which increased family stress. Identifying alternate means for families to access services is needed.

Parent Reflections on Adequacy of Services

There are a variety of services and supports available to families who have children with special needs. A family's support system could include medical services, educational services, mental health/behavioral services, financial supports, social supports, extended family supports, and community supports. Support services vary from family to family and also by location, with many Arizona families living in rural areas where far fewer specialized services and less medical care is available. Research suggests that adequate services deemed by the caregivers can lead to a decrease in stress in turn leading to positive child and family outcomes (citations). Dempsey (2008) found that parent satisfaction with support services was directly related to parent and child outcomes including child development, parent satisfaction with child development, parent stress,

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parenting capabilities, and parent empowerment. King (1999) also found parents with lower stress and better well-being there was a higher satisfaction of the services provided.

Both AKRS and FCCS studies included questions related to whether children were receiving adequate services based on parent perspectives. The AKRS survey specifically asked caregivers to rate the adequacy of the services they were receiving. Caregivers rated their services based on a Likert scale, ranging from poor to excellent or service was not needed. Parent report on adequate services fell mainly between good and excellent for all services noted on the table. Identifying variables on how caregivers determined if the support services were adequate, was not available. Nor were there any other identifying markers.

Services were identified using broad categories which could include multiple services and/or placements. For example, identifying that physical health services were adequate could potentially mean that the parent felt that the family physician provided adequate services. However, their child may have also received services from a nurse, pediatrician, surgeon, endocrinologist, and so on. It is hard to determine if the parent took in to account all the health providers their child received services from or if they were relating the question to one specific provider. Knowing and understanding if services were accurate can be misleading, there are many providers that could fall under the category physical health services.

The FCCS study used semi-structured interviews that were more open-ended so that parents could generate services and other topics that were not specifically on the interview protocol. Parents who were a part of the more in-depth FCCS interviews had varying reflections regarding the adequacy of the support services they were receiving.

All parents discussed positive and negative experiences with service providers. The degree of adequacy was based on access to services, emotional support, communication, and knowledge and delivery of the service. These themes are consistent with both positive and negative experiences however parents do not specifically identify an experience as adequate or inadequate. The number of times caregivers had a negative or positive experience with that individual provider was not recorded. An individual provider was recorded twice if the parent had a positive and a negative experience with him/her. In some instances, parents had both positive and negative experiences with the same provider. If this were the case then the provider was counted twice, once as positive and once as negative.

Easy access to or lack of access altogether was the most important variable identifying service adequacy. One of the main constraints identified as a barrier accessing services was location. 50% of caregivers identified location as a barrier to support services, with 40% living in rural areas. Abby, who lived in a small town southeast of Phoenix, explained, "I know the area we live in out here. We have trouble getting people out here to come and do services, let alone to find businesses or even speech therapy places have room to take the kids. It's hard to find." Many Arizona families living in rural areas where far fewer specialized services and less medical care is available. In AKRS, about 72% of the caregivers lived in urban areas with 28% living in rural areas; however, there were no consistent findings based on this variable. Meaningful comparisons of families by type of location was beyond the scope of the data from AKRS.

Financial conditions were also a barrier, with 60% of the caregivers unable to access supports due to their financial situations. Geographically, 50% lived in urban areas, and 50% lived in rural areas. Lauren and Tom, who lived in a rural area, discussed multiple financial constraints including access to insurance and losing business clients due to economic times most likely causing stress, thus decreasing their family quality of life. Data were collected at the height of the Recession, and there were budget cuts in the state of Arizona and across the nation, related specifically to families accessing services for their child with special needs. These cuts also affected family income.

 Both studies sought to identify the adequacy of physical health services, learning services, mental health/behavior services and parent support services as perceived by parents or other primary caregivers. While there was overlapping data across both studies, there were some unique questions related to services and each study. AKRS also reported on oral health and crisis services however FCCS did not. FCCS identified positive and negative experiences with insurance services, adult education services, state coordinator/social worker services and assessment services. These services were not rated in the quantitative component (AKRS) of this research.

In the AKRS data, caregivers' adequacy rating for physical health services was 63.2% excellent, 24.6% good, 8.8% somewhat adequate, and 1.8% poor. Out of 24 identified experiences with individual physical health service providers in FCCS, 38% were positive experiences, and 62% were negative experiences. These experiences reflect one positive and/or one negative experience per service provider with a total of 24 experiences. Parents in the AKRS study rated their physical health services with higher adequacy (96.6% adequate, ranging from somewhat adequate to excellent) than

caregivers reported in FCCS. Caregivers in FCCS identified more negative experiences (62% were not adequate) with physical health service providers than positive ones (38% were adequate). This is assuming negative experiences infer inadequate services and positive experiences infer adequate services. The results of these two studies seem contradictory, as one identified physical health services as adequate, and the other identified physical health services as inadequate. Possible reasons for contradictions could include the research design, different populations for each study and/or instrument design which are discussed in more detail later in this chapter.

Parents' views on the adequacy of learning services were also reported in both studies. AKRS had one encompassing variable labeled "learning difficulties," in the caregiver questionnaire. In the AKRS findings, 42.6% of caregivers reported adequacy of learning services as excellent, 29.6% as good, and 9.3% as somewhat adequate. Only 1.9% reported learning services as being poor. In order to compare FCCS results with AKRS, identified themes were combined into one category labeled "learning services." The combined variables included Head Start, speech and language, public schools, specialty class/special needs, Charter school, Montessori school, and child development specialist. These service providers were identified based on the nature of their service. Out of 23 identified experiences with learning service providers, 52% were positive experiences, and 48% were negative experiences. These experiences reflect one positive and/or one negative experience per service provider with a total of 23 experiences. Again, these two studies contradict each other assuming that inadequate services are identified with negative experience and adequate services are identified with positive experiences. Parent reports on learning services was 81.5% adequate (ranging from somewhat

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adequate to excellent) in AKRS however in FCCS adequacy of learning services were split, with 52% experiences parents were deemed adequate and 48% were not. As mentioned above, possible reasons for contradictions could include the research design, different populations for each study and/or instrument design which are discussed in more detail later in this chapter.

Mental health/behavior services were also rated as adequate in both studies. There were two variables combined for AKRS, mental health, and behavior services. Combined, adequacy for these services were 36.4% excellent, 23.6% good and 3.65% somewhat adequate. 1.8% was rated as poor. As for FCCS, only one experience was reported under mental health, and it was a positive experience.

Parental Supports was also a variable in which adequacy was reported in both studies. For AKRS, services were rated as 26.4% excellent, 22.6% good and 1.9% somewhat adequate. 1.9% of caregivers rated poor adequacy. FCCS only noted positive experiences with 87% of those experiences linked to a close personal person such as a family member, a friend, and/or individuals within their church. It is not known what parental supports AKRS caregivers received.

The purpose of each study was unique which could easily attribute to the identified contradictions. AKRS and FCCS were different in size and expanded across different regions. AKRS was a preliminary study with the purpose of providing a snapshot of the Arizona children's health and readiness for school. FCCS was nested (69 focal families) within a larger longitudinal study with an N of 7,200 children. FCCS's purpose was to address issues of access, cultural relevance of programs and other subtle issues in early childhood care and health services. While both studies identified parent

perceptions of adequate support services, they were measured very differently, one in interview format and the other using a Likert scale.

The FCCS qualitative interview protocol did not specifically ask parents if they felt the support services they received were adequate. Adequacy of services was derived based on positive and negative experiences. The degree of adequacy was based on access to services, emotional support, communication, and knowledge and delivery of the service. Data derived from the qualitative study could potentially be skewed due to the assumptions of what negative and positive experiences include.

Parent perceptions identified in AKRS was based on a questionnaire that did not define the parameters of adequacy or allow for further explanation for their ratings for the seven items on the survey. Caregivers rated their services based on a Likert scale ranging from poor to excellent or service was not needed. Additionally, definitions for categories of services were not included on the survey. For example, Physical health services could include many different services such as family physician, nurse, pediatrician, surgeon, endocrinologist, and the list could go on and on. A caregiver would have to consider all the services they utilized under physical health services and then decide the adequacy of those services combined.

Both studies, ARKS, and FCCS, provided information regarding the adequacy of support systems caregivers/parents identified as well as identified those systems they felt was pertinent to the development of their child. Both studies identified the adequacy of physical health services, mental/behavioral services, learning services, and parental support services to be important. FCCS also identified variables needed for the services to be adequate; access to services, emotional support, communication, and knowledge

and delivery of the service. Adequate services are just one component that can support a family's quality of life.

Family Quality of Life

"Quality of life is defined by how an individual interprets the environment and how the individuals and groups he/she reference to affect his/her well-being." (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006, pp. 239). The eight quality of life domains that have been identified include emotional well-being, personal development, self-determination, interpersonal relations, social inclusion, rights, material well-being, and physical well-being. These domains, "reflect a person's desired conditions of living" (Schalock, 2000, pp. 121). From the definition of quality of life, family quality-of-life was developed by Hoffman, Marquis, Posten, Summers, and Turnbull, (2006).

Family quality-of-life looks at the family as an entity instead of each person individually. The focus is based on the family's needs in order to live a quality-of-life together. Beach Center Family Quality of Life Scale (Hoffman et al., 2006) identify five domains that support a family's quality-of-life. Those domains include family interactions, parenting, emotional well-being, physical/material well-being and severity/type of disability. Within each domain, there are sets of indicators and descriptors to identify if the needs of a family within each domain are being met. This study focused on parent perspectives of the educational and health related services available for their child with special, as well as parent/family support systems. Indicators and descriptors within each domain were identified in this study determining the adequacy of the supports. Brief summaries of key components of family quality-of- life, as reflected in the findings of this study follow.

Family Interactions. The indicators and descriptors for family interactions include spending time together, talking openly, solving problems together, support each other to accomplish goals, show that they love and care for each other, and are able to handle life's ups and downs. Access to adequate parental supports was identified as a support service needed within this study, specifically extended family member support were identified as the most supportive. Kris has a large extended family that she can reach out to when she needs support. Her son, Toni, has anxiety and developmental delays. Her mother lives with them and will get up Toni in the morning. If she has to run to the bank or the grocery store her sister-in law will take or pick him up from school. "I always have some way to get to him. If I'm not home and the school calls and says he's sick, you need to come back and get him. I have somebody to run and get him if I can't make it. If I'm out of town, if I go to Casa Grande or to Coolidge or something and I can't make it in time to pick him up, I ask somebody there to go get him." Unfortunately, Trudy only has her grandfather to lean on for support, and he doesn't live close. "'Cause he doesn't judge me. If I have problems, he'll give me advice, but he doesn't, "Oh, you shouldn't do that." He doesn't judge me, and he doesn't criticize very much, so I can go and talk to him. I can get it off my chest; whether or not I actually get help, but it gets off my chest."

Parenting. The indicators and descriptors for parenting include helping the child learn to be independent, helping the child complete school work and activities, teaching children how to get along with others, teach the children to make good decisions, know other people in the child's life, and has time to take care of the individual needs of every child. A key theme that parents discussed in the FCCS study was being able to provide

the educational supports their child needs in the home setting. A few parents didn't know how to support them because they needed guidance from outside service providers. Others who were given the supports still needed guidance on how to teach the concept to their children. While on a waiting list to get her child into a Head Start program, services reached out to Kris and provided her with the option to have, what she called, "a home based preschool Head Start thing." She explained further, "I'm the teacher. They come out and supervise, and they bring me the materials to teach the kids, and they just make sure that I'm doing it right." For Kris, this support helped her learn how to teach her child the concepts needed, with the appropriate support, while she waited for a spot to open up at the Head Start program.

Emotional Well-being. The indicators and descriptors for emotional well-being include that families have supports needed to relieve stress, friends or others to provide support, time to pursue their own interest, and have outside help available to take care of special-needs. Access to friends was the second highest positive parental support parents identified in the FCCS study.

Physical/Material Well-being. The indicators and descriptors for physical/material well-being include getting the medical and dental care needed, having transportation, access to financial supports to take care of family expenses, and feeling safe in their home, work, school, and neighborhood environments. This domain seemed to have the most negative experience parents as reported during interviews. The adequacy of physical health and mental health/behavioral health support services was rated by caregivers/parents in both, FCCS and AKRS. Financial security was also a concern with many families in FCCS, 60% of parents, split evenly between rural and urban areas, had

financial constraints making it difficult to access the supports they needed for the well-being of their family. Transportation and location were also discussed as a barrier, identified by 40% of the parents in FCCS. Abby and her family lived in small rural town. Due to their financial constraints and where they lived access to services was minimal. "I know the area we live in out here. We have trouble getting people out here to come and do services, let alone to find businesses or even speech therapy places to have room to take kids. It's hard to find." They had to travel to access speech and language services that both children needed which was expensive.

Severity/Type of Disability. The indicators and descriptors for severity/type of disability include support to make progress at school or workplace, support to make progress at home, support to make friends and good relationships with the service providers. The adequacy of learning services was also rated. AKRS parent/caregivers rated adequacy of learning services high, with 72% ranging between good and excellent. FCCS parents identified 23 experiences with learning service providers, 52% were positive experiences, and 48% were negative experiences. As for the severity or type of the disability, neither study identified this specifically as a barrier to their family's quality of life. Many, however, did discuss their relationships with service providers. Referring the speech and language pathologist working with her son, Vicki stated, "I did. I really have appreciated the help because I have seen him do little things—when he is doing an L sound he will put his finger so he can feel his tongue so he knows he is forming it right. I will see him do little hand things to help him and he is more willing to work with me on pronouncing things correctly whereas before he just had no interest". While Vicki doesn't

speak directly about her relationship with her son's speech and language pathologist, she is appreciative of the progress her son has made.

There were many indicators within each domain that were identified in this study. Adequacy of support services across all domains were identified as being the most prominent family need to obtain quality-of-life. Specific support systems included physical health supports, learning service supports, mental health/behavior supports, and parental support. In Kaczmarek's (2004) family-centered preschool model, parents identified emotional supports, printed information regarding the special education process and other resources beneficial. Supports needed for each family will vary, the one commonality is the adequacy.

Family interactions, parenting, emotional well-being, physical/material well-being and severity/type of disability are domains that have been identified to help families lead a quality of life. Research presented in this study demonstrated the difficulties parents/caregivers face on a daily basis to meet the needs of each domain. It also identified how a family benefits when these domains are being met. Access to adequate services within all domains is just one barrier families face.

Moving Towards Family Quality-of-Life

Adequate services. The perception of adequate services varied from one caregiver to the next. The degree of adequacy identify in FCCS was based on access to services, emotional support, communication, and knowledge and delivery of the service. Access to services or lack of access to services was identified as having the most impact on parents and child outcomes. The quality of services was also acknowledged as important to parent and child outcomes. Quantity and quality of services overlapped each

other when identifying adequacy of the service. Some parents viewed adequacy as the quantity of services they were receiving, including the type of services they were receiving. Others looked at the quality of services. Research also varies when referring to adequacy of services, the quantity of services (Knox, 2000; Grindle, 2009; Cassidy, 2008) and the quality of services (Freedman, 2000; Howie-Davies, 2007). It was not clear what parent perceptions regarding the definition of adequate services (quantity, quality or both) were in the AKRS. However, parent percentages on adequate services where high over a larger number of participants which could possibly mean there is a combination of quantity and quality.

Summer (2007) found that families thought they were receiving adequate amounts of services for their child but felt that they were not receiving adequate amounts of services for their family. Based on a likert scale adequate services for caregivers and their child was identified in AKRS, along with the type of service, but not the quantity or quality. In FCCS parents also identified the type of supports they received but not the quantity or quality, only the need to access them. Howie-Davis (2007) suggested that the quality of the information received by parents was more important than the amount. Further research identifying what parents consider adequate services, quality and or quantity is needed. Identifying and understanding family goals could help determine not only what services are needed but possibly also prioritize them. Understanding what parents perceive as adequate could help prevent some of the barriers families face when attempting to access the services they need.

Barriers Accessing Adequate Services. Barriers accessing adequate support services that were evident in this study included location, availability, financial supports,

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and support provider's knowledge of the disability. These barriers correlate with the indicators and descriptors that Hoffman et al. (2006) identify to help determine if the needs of a family within each domain are being met. These five domains support a family's quality-of-life.

Adequate services, the amount and or the quality, is a component that can help decrease or increase caregiver/parent stress. Parent stress due to adequate or lack of support was not specifically identified in this study. However, based on parent responses during the interview process, parental stress was evident even though not specifically identified. Research has identified other indicators that affect parent/caregiver stress.

Caregiver Stress. Having a child with special needs can add to the parent's stress level ultimately impacting a family's quality of life. Access to adequate services is not the only indicator of family stress. The child's disability and severity of the disability (Cheng et al., 1996; Gupta, 2007; Hung et al., 2004; Long, et al., 2008; Oelofsen & Richardson, 2006; Osborne & Reed, 2009; Parks et al., 2009) social supports (Gallagher et al., 1983, Plant & Sanders, 2007) emotional support (Gerstein et al., 2009) access to information, resources and materials (Kaczmarek et al., 2004, Howie-Davis & McKenzie, 2007) financial status (Heymann & Kidman, 2009; Mahoney et al., 1992; Wang et al., 2004) and communication (Cavallo et al., 2008; Spann, et al., 2003) with the support providers involved with their child can also increase or decrease stress.

A child's disability and the severity of the disability affects stress levels. Parents who have children with problem behaviors and medical conditions have higher levels of stress. Long et al. (2008), parents reported meeting their child's needs with language deficits difficult and hard to cope with. However, their stress levels were higher if the

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child had problem behaviors and those levels increased as a child reached preschool age. Osborne & Reed (2009), had similar results analyzing parent stress with parents who had children with autism spectrum disorders that displayed behavior problems. Hung et al. (2004) found that "parents who had children with cancer had significant higher levels of stress compared with parents of disabled children" (p. 898). There are many variables that can increase a parent/caregiver's stress which affects family quality of life.

Family-Centered Practices. Family-centered practices have been known to decrease parent stress, increasing family quality-of-life and are considered to be "best practice" in fields that support the development of children with special needs (Dempsey & Keen, 2008; King et al. 2003). Family-centered care involves ensuring that parents have ultimate control over decision making, treating parents respectfully and supportively, and providing parents with needed information (King, King, & Rosenbaum, 1996).

There are four, crucial beliefs that drive implementation of family centered services.

1. The family and not the professional is the constant in the child's life.
2. The family is in the best position to determine the needs and well-being of the child.
3. The child is best helped by also helping the family, and this help may extend to an understanding of the family's community and provide information that the family needs.
4. Family choice and decision making in the provision of services, showing respect and affirming family strengths, enhancing family control over the services they receive, and partnerships and collaborations with families are emphasized. (Dempsey & Keen, 2008, p. 42)

These four beliefs, if implemented, lead to the parent having ultimate control over the decision-making of their child with special needs, their family. Knox et al. (2000), expands on these ideas by identifying three considerations that are integral to a parent's sense of control over their family's life. "First, having positive prospects for the family's future, second, genuine sharing of decision-making with service providers, and third, the ready availability of permanent information. In FCCS, many parents stated that they had very little, if no, control at all of the services their child was receiving deterring from locus of control. When a parent has locus of control and self-esteem, there is the potential for better parent and child out comes. Further research is needed to continue to evaluate this practice.

Conclusion

Bronfenbrenner's Ecological Systems Theory and Bush's family quality of life framework was used to analyze qualitative data (FCCS), and quantitative data (AKRS) combined to determine how primary caregivers in Arizona view the educational and health related services that their child with special needs and/or other health impairments received when they entered kindergarten. It also evaluated the degree to which the caregivers themselves perceived the support/services that they received to enhance quality of life for themselves, their child with special needs and other family members. Adequacy was difficult to identify however, quality and quantity of services were factors parents discussed. Services varied, however, those identified most frequently included; physical health, mental health, and educational support. Location, availability, and financial situations were the main factors hindering access to services. Limited Quality and quantity services can increase family stress.

Having a child with special needs can be stressful and emotionally draining. Adequate services can provide that extra support families need to alleviate some of the stress. A decrease in stress can lead to better parent and child outcomes potentially increasing a family's quality-of-life. When the needs of all family members have been met, the family enjoys time together, and when they are able to participate in activities that are valuable to them, family quality of life is attained. (Park et al., 2003). To obtain family quality-of-life support systems need to be put in place so that a family can enjoy their time together and participate in activities together. Family centered practices could help families gain access to the supports that they need by placing the parent in control of the decision-making. Treating parents with respect and providing them with the information they need to make educated decisions for their child with special needs and their family could lead to quality-of-life for the entire family. A parent is a child's first teacher and life-long teacher. Providing parents with necessary means to support their child's special needs or not is important but to teach them how to advocate for their child's needs on a daily basis will ensure continued success as services and service providers change. The parent, typically, is the constant.

Implications for Practice and Future Research

Many Arizona families living in rural areas where accessing specialized services along with medical care is difficult. The recession at this time made it difficult for both rural and urban families to access adequate services. Services need to be more readily available so that all children with special needs and their families receive the services they need to have a quality-of-life. For rural families, remote access to services is one-way services could be evenly available across locations. Some insurance companies

started paying for remote services. Unfortunately, at this time insurance will not pay for the supplies families need to access remote services (computer, video camera, etc.). Financial constraints make it difficult for families in rural areas to travel to the services they need. Finding a way to provide families with the supplies needed for remote access to services would help parent and child short-term and long-term outcomes. For both rural and urban families, understanding what is available and how to jump through the correct hoops in order to access them would help lead towards quality of life.

Future research might evaluate different modes of remote access to services, particularly for families in rural areas, that provide the family with the adequate services they need. Understanding what a parent considers adequate, quality and/or quantity, would also help support services identify a parent/caregivers specific needs. Research regarding how families learn about available services would also be beneficial providing a framework of what steps a family needs to complete to obtain the supports they need to attain family quality of life. Finally, further research might help predict the developmental outcome of a child with special needs based on varying environments using Bronfenbrenner's Ecological systems Theory and then expanding those results using his bio-cological theory.

Parameters of the Study

Mixed methods research (MMR) was used to analyze data from the Arizona Kindergarten Readiness Study (AKRS) and the Family and Community Case Study (FCCS) to better understand caregivers' (parents and other primary caregivers) views of educational and health related services available to and utilized by their children. The quantitative component of this study provided basic descriptive statistical information on

specific questions identified from a questionnaire that was part of a larger study (AKRS),

also part of a Longitudinal Child Study in Arizona. Participants were randomly selected

from lists provided by participating school districts throughout Arizona. 60 participants

out of 1,025 were drawn from the questionnaire results, based on IEP identification.

While the qualitative component of this study included a small sample size, that was

drawn from a larger study (FCCS) that encompassed 69 focal families. FCCS did not

have an explicit focus on children with special needs. Thus, only ten families who had

children with special needs were identified for this study. Interviews with these ten

families were analyzed identifying themes pertaining to research questions.

The questions developed for the questionnaire were not specified for this study

nor were the interview questions. If both instruments pertained only to children with

special needs, results might have varied. The questions on the questionnaire were forced

choice and Likert response format which could possibly limit caregiver responses.

Question-wording may have been confusing, hinder caregiver report. Misunderstanding

or misinterpreting a question could possibly lead to an incorrect answer. The quantitative

component of the study provided a larger sample size which provided basic statistical

information and qualitative component provided detailed accounts giving an in-depth

picture. Both provided data to analyze to understand further parent perceptions of the

educational and health related services along with parental family support systems

available and utilized by them.

Researcher's Reflections

As the freshman in college, I had the dream of becoming a surgical nurse. Those

dreams changed quickly after I took a position in a group home caring for elderly men

with severe mental and physical disabilities. At 19 years old, I witness how inhumane individuals with special needs could be treated. It was at that time I changed my degree to special education hoping that I could gain the knowledge needed make a difference in their lives.

My quest to find adequate services continued with each step I took forward. After completing my bachelor degree, I had the privilege teaching children with autism spectrum disorders in an elementary self-contained, special education classroom. After teaching in the school system and providing in home private services for four years I realized how difficult it was for families to gain access to the services their child needed. At that time, family services was not a thought. As a teacher, I became frustrated with the system and decided to pursue a Master's degree hoping somehow, miraculously, I would be able to access and provide the necessary services my students needed. The purpose was not to help them attain family quality-of-life, but to support them so that they could function in society. Most of the families I worked with had no life outside of their home due to the severity of their child's behaviors.

While pursuing my master's degree I became pregnant with my beautiful son, Cole. During the first ultrasound, his dad and I were informed that he was going to have a severe cleft-lip/palate and partially genesis of the corpus callosum. (How we were treated by the medical staff at that time is another story.) How Cole would be affected was unknown. Being in special education and knowing the complexity of gaining access to needed supports, was the last thing on my mind. Unfortunately, the first thing I thought of was his ability to speak and then would society judge him because he was different. Once he was born, while many more concerns were identified, he became my inspiration in so

many ways. He has made me a strong mother but I think more importantly he has made me a stronger advocate for family and children who are not receiving the services they need.

When people found out that Cole had special needs the first comment they made was, "well he's lucky he has you for a mom". While I know, they meant well, I still cringe at that statement. Unfortunately, in my case, knowing too much was debilitating. As a strove to complete my master's degree I began to see, on a personal level, how difficult it was to gain access to the services, especially because I knew that they were available.

After completing my master's degree, I was fortunate enough to begin my Ph.D. During this experience, I had the pleasure of working on a research project with Dr. Lacey Peters. The acronym of our research project was S.P.E.A.K., supporting parent efficacy and advocacy with knowledge. During this study, I realized that many parents didn't know what services were available to them. Many had no idea that they had control over or even a say in the services that their child was receiving. This changed my quest to help find/provide services for children with special needs, another component was added. My goal changed to include support services for families, but more importantly providing them with educational materials so that they could advocate for themselves and the needs of their child.

When it was time for me to decide what topic I wanted to research for my dissertation, I was clueless. Luckily, Dr. Nancy Perry recommended that I look at the research that was being conducted for first things first to determine if there was a topic of

interest. After reviewing ARKS Questionnaire with her, adequate services became my

project. The idea of the project grew with the addition of FCCS.

With the closing of this chapter in my life and as I reflect back on all that I have

accomplished, I think of that naïve little girl I once was and realize that it takes time for

change to happen. I will continue to strive forward supporting as many families as I can

and advocating for change to increase the quality of life for families with young children.

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APPENDIX A

ARIZONA KINDERGARTEN READINESS STUDY

CAREGIVER QUESTIONNAIRE

FIRST THINGS FIRST EXTERNAL EVALUATION PROJECT
(UNIVERSITY OF ARIZONA, ARIZONA STATE UNIVERSITY, NORTHERN ARIZONA UNIVERSITY)
2009 READINESS GUARDIAN QUESTIONNAIRE

Instructions

- Parents/Guardians: This questionnaire **MUST be submitted by the primary caregiver.** A primary caregiver is a person (not only a legal guardian or a parent) who lives with the child and has primary responsibility for her/his care (i.e., makes decisions about care, including daily routine, health care, and child care) .
- Please fill out **Part A** of this form with regard to yourself, the child, and the child's home.
- Please complete **Part B** of this form with regard to your child.
- Check **one box per question**, unless otherwise instructed.
- All responses are STRICTLY CONFIDENTIAL and will not be viewed by any school staff. If you have any questions, please call us at 1-888-704-8774 (toll free).

Today's date: _____/ _____/ _____

Name of the Person completing this form: _____

Child's Name: _____

PART A:

PRIMARY CAREGIVER DEMOGRAPHIC INFORMATION

1. Are you the legal guardian of this child?
☐ Yes ☐ No

2. Are you the primary caregiver (see instruction box above) for this child? ☐ No   STOP, ONLY THE PRIMARY CAREGIVER SHOULD FILL OUT THIS FORM. PLEASE GIVE IT TO THE PRIMARY CAREGIVER.
☐ Yes

3. How long have you been the primary caregiver for the child?
☐ Since the child was born
☐ Since date: _____ MM/YYYY

4. What is your relationship to the child?
MOTHER/GUARDIAN
☐ BIRTH MOTHER   ☐ STEP
☐ FOSTER   ☐ ADOPTIVE

FATHER/GUARDIAN
☐ BIRTH FATHER   ☐ STEP
☐ FOSTER   ☐ ADOPTIVE

OTHER GUARDIAN
☐ SISTER (STEP/FOSTER/HALF/ADOPTIVE)
☐ BROTHER (STEP/FOSTER/HALF/ADOPTIVE)
☐ IN-LAW OF ANY TYPE
☐ AUNT ☐ UNCLE ☐ COUSIN

☐ GRANDPARENT
☐ OTHER FAMILY MEMBER
☐ OTHER NON-RELATIVE

5. Are you of Hispanic or Latino origin?
☐ Yes ☐ No

6. What is your race? CHECK ALL THAT APPLY.
☐ American Indian or Alaska Native
☐ Asian
☐ Black/African American
☐ Native Hawaiian or Pacific Islander
☐ White

7. What is the highest grade or year of school you completed:
☐ 8th Grade Or Less
☐ 9th-12th Grade No Diploma
☐ GED
☐ High School Graduate
☐ Completed Vocational, Trade Or Business School Program
☐ Some College Credit
☐ Associate Degree (AA, AS)
☐ Bachelor's Degree (BA, BS, AB)
☐ Master's Degree (MA, MS, MSW,MBA)
☐ Doctorate (Phd, EdD) Or Professional Degree (MD, DDS, DVM, JD)

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8. What is the your marital status?
☐ Single, never married ☐ Married
☐ Separated ☐ Divorced ☐ Widowed

9. During the past month, did you work at a job or business for pay?
☐ Yes ____ HOURS PER WEEK counting all jobs
☐ No/**GO TO QUESTION 11**

10. What was the combined total income in 2008 for the HOUSEHOLD where the child lived?
☐ Less than $5,000
☐ $5,000 - $9,999
☐ $10,000 - $14,999
☐ $15,000 - $19,999
☐ $20,000 - $24,999
☐ $25,000 - $29,999
☐ $30,000 - $34,999
☐ $35,000 - $39,999
☐ $40,000 - $44,999
☐ $45,000 - $49,999
☐ $50,000 or more

11. How many adults 18 and older currently live in the same household as the child?
_____ # of adults (18+ yrs)

12. Including the child, how many children under 18 currently live in the same household?
_____ # of children (under 18 yrs)

13. At any time in the last 12 months has any member of the child's household received:
☐ FOOD STAMPS ☐ MEDICAID BENEFITS
☐ TANF OR WELFARE ☐ DON'T KNOW

14. Did the child receive benefits from WIC (i.e., the Special Supplemental Nutrition Program for Women, Infants, and Children) in the last 12 months?
☐ Yes ☐ No ☐ Don't know

15. Does the child receive free or reduced price lunches at school? ☐ Yes ☐ No

16. What is the primary language spoken in the child's home? That is, what language is spoken most often?
☐ English ☐ Spanish
☐ Native American List: _____
☐ Other Language List:_____

17. In a typical week, how often do you or someone in your family do the following things with the child?

	NOT AT ALL	1-2 TIMES/ WEEK	3-6 TIMES/ WEEK	7+ TIMES/ WEEK
a. Read books	☐	☐	☐	☐
b. Tell stories	☐	☐	☐	☐
c. Sing songs	☐	☐	☐	☐
d. Talk about size or weight of things	☐	☐	☐	☐
e. Count	☐	☐	☐	☐
f. Play sorting or matching games	☐	☐	☐	☐
g. Play with toys or blocks to build things	☐	☐	☐	☐

18. Did the child ever attend preschool (a child care center, nursery school, or pre-kindergarten program, including Head Start).
☐ Yes ☐ No/**GO TO QUESTION 21**
☐ Don't know

For the preschool attended for the most time:
a. How many hours each week did child go to that preschool? ENTER NUMBER OF HOURS _____
☐ Don't know

b. How many months did child attend that preschool? ENTER NUMBER OF MONTHS _____ ☐ Don't know

19. What is the name and address of the preschool settings that the child attended?
a. Name (Attended the most time):_____
   City, State, Zip:_____
   Phone:_____

Was this preschool a Quality First center funded by The First Things First Initiative?
☐ Yes ☐ No ☐ Don't know

Did you receive any financial support from The First Things First Initiative for the child to attend this school?
☐ Yes ☐ No ☐ Don't know
b. Name:_____
   City, State, Zip:_____
   Phone:_____

Was this preschool a Quality First center funded by The First Things First Initiative?
☐ Yes ☐ No ☐ Don't know

Did you receive any financial support from The First Things First Initiative for the child to attend this school?
☐ Yes ☐ No ☐ Don't know

c. Name:_____
   City, State, Zip:_____
   Phone:_____

Was this preschool a Quality First center funded by The First Things First Initiative?
☐ Yes ☐ No ☐ Don't know

Did you receive any financial support from The First Things First Initiative for the child to attend this school?
☐ Yes ☐ No ☐ Don't know

20. Rate the top five factors that were most important to you when you chose a child care center. (1= most important, 5 = least important) (Check all that apply)

FACTORS	RATING 1-5
a. Distance	
b. Cost	
c. Accreditation	
d. Reputation	
e. Hours of operation	
f. Teacher/child ratio	
g. Teacher/staff qualification and professional training	
h. Teacher turnover	
i. Age-appropriate curriculum	
j. Variety of learning and play activities	
l. Mix of large and small group activities	
m. Availability of age-appropriate children's literature	
n. Daily outdoor play with access to age appropriate playground equipment	
o. Established rule and policies	
p. A complete schedule of activities	
q. Languages spoken	
r. Safe and clean facility	
s. Handling of medical and other emergencies	

21. Has your child ever been denied entry or expelled by a preschool or child care center for any of the following reasons:

	Denied entry	Expelled
a. Behavioral difficulties	☐ Yes ☐ No	☐ Yes ☐ No
b. Special health needs	☐ Yes ☐ No	☐ Yes ☐ No
c. Learning difficulties	☐ Yes ☐ No	☐ Yes ☐ No

22. Has anyone from a program, health agency, or social service agency visited you at home (or another person's home) since child was born?
☐ Yes ☐ No/**GO TO Question 23**
☐ Don't know

a. From what program or organization did the person(s) who visited the child come from? (Please check all the boxes that apply.)

Organization	Start	Stop	# of visits	Don't Know
Early Head Start/ Head Start				
Healthy Families				
Parents as Teachers				
Nurse Family partnership				
A Promotor or Promatora				
Family Preservation Program or Agency				
Child Protective Services				
Child care home or center				
School				
Health center or program				

b. Did the (person/persons) who visited you and the child:
1. Show you activities that you can do with the child to help him/her grow and learn?
☐ Yes ☐ No

2. Show you how to play with the child?
☐ Yes ☐ No

3. Give you information about injury prevention, child health and nutrition, and development?
☐ Yes ☐ No

4. Check the growth or developmental progress of the child? ☐ Yes ☐ No

5. Provide support and suggest strategies for challenges such as getting child to sleep, toilet training, and handling whining and fussiness?
☐ Yes ☐ No

6. Assist your family during a period of crisis?
☐ Yes ☐ No

23 a. Since the child was born, have you or the primary caregiver attended classes, lectures, group activities, or other events that provided information on parenting or training to help you be a better parent?
☐ Yes/Number of sessions attended _____
☐ No/**GO TO Question 24** ☐ Don't know

b. How helpful were these activities?
☐ VERY HELPFUL   ☐ SOMEWHAT HELPFUL
☐ NOT VERY HELPFUL ☐ NOT AT ALL HELPFUL

c. Did you or the primary caregiver attend any classes, lectures, group activities for parents, or other events that provided information on parenting or training in the last 12 months? ☐ Yes ☐ No

d. List names of the parenting education program(s) in which you participated?
1. Name:_____
   Street Address:_____
   City, State, Zip:_____
   Phone:_____
2. Name:_____
   Street Address:_____
   City, State, Zip:_____
   Phone:_____
3. Name:_____
   Street Address:_____
   City, State, Zip:_____
   Phone:_____

24. Did the child have contact with his/her kindergarten teacher prior to the start of school?
☐ yes ☐ No/**GO TO QUESTION 25**

a. What type of contact did you have with your child's kindergarten teacher prior to the start of school?
(CHECK ALL THAT APPLY)

He/She visited child's home	☐ Yes ☐ No
He/She visited child's preschool classroom	☐ Yes ☐ No
He/She called child's family: Before start of school year	☐ Yes ☐ No
After start of school year	☐ Yes ☐ No
He/She called child: Before start of school year	☐ Yes ☐ No
After start of school year	☐ Yes ☐ No
He/She sent the family a letter: Before start of school year	☐ Yes ☐ No
After start of school year	☐ Yes ☐ No
He/She held open house: Before start of school year	☐ Yes ☐ No
After start of school year	☐ Yes ☐ No
He/She conducted kindergarten readiness assessment: Before start of school year	☐ Yes ☐ No ☐ Don't know
After start of school year	☐ Yes ☐ No ☐ Don't know

The following questions are about the child:

25. Is the child of Hispanic or Latino origin?
☐ Yes ☐ No

26. What is the child's race? (CHECK ALL THAT APPLY)
☐ American Indian or Alaska Native
☐ Asian
☐ Black/African American
☐ Native Hawaiian or Pacific Islander
☐ White

27. How much did the child weigh at birth?
Pounds: _____   Ounces: _____
☐ Don't Know

28. Would you say the child's overall health is:
☐ Excellent   ☐ Fair
☐ Very good   ☐ Poor
☐ Good   ☐ Don't Know

29. In the last 12 months, how many times did your child see a dentist for preventive dental care, such as check-ups and dental cleanings?
_____ # of times _____ Don't know

30. How old was the child when he/she first saw a dentist? _____years _____months
☐ Has not seen a dentist yet

31. Does the child have an Individual Education Plan (IEP) or Individualized Family Services Plan (IFSP)?
☐Yes ☐ No ☐Don't know

32 a. Do you have any concerns about child's learning, development, or behavior?
☐Yes ☐ No

b. Do you have any concerns about child's hearing or vision? ☐Yes ☐ No

c. Have you discussed the concern with child's doctor or another medical professional?
☐Yes ☐ No ☐

d. Have you discussed the concern with child's teacher or school counselor? ☐Yes ☐ No

33 a. Is child limited or prevented in any way in his/her ability to do the things most children of the same age can do?
☐ YES ☐ NO/**GO TO QUESTION 34**

b. Is his/her limitation in abilities because of ANY medical, behavioral, or other health condition?
☐Yes ☐ No

c. Is this a condition that has lasted or is expected to last 12 months or longer?
☐Yes ☐ No

34. For each condition, please check the box (in the table **BELOW**) if a doctor or professional ever told you or previous primary caregiver that the child had the condition. You can check the "yes" box if your child had a condition in the past but not presently. Check the box if the child has received services in the last 12 months for any of these conditions.

	a. CHILD EVER HAD...	b. CHILD RECEIVED SERVICES IN THE LAST 12 MONTHS
a. Attention Deficit Disorder or Attention Deficit Hyperactive Disorder?	☐Yes ☐No	☐Yes ☐No
b. Depression?	☐Yes ☐No	☐Yes ☐No
c. Anxiety problems?	☐Yes ☐No	☐Yes ☐No
d. Behavioral or conduct problems, such as oppositional defiant disorder or conduct disorder?	☐Yes ☐No	☐Yes ☐No
e. Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder?	☐Yes ☐No	☐Yes ☐No
f. Any developmental delay that affects (his/her) ability to learn?	☐Yes ☐No	☐Yes ☐No
g. Stuttering, stammering, or other speech problems	☐Yes ☐No	☐Yes ☐No
h. Asthma?	☐Yes ☐No	☐Yes ☐No
i. Diabetes?	☐Yes ☐No	☐Yes ☐No
j. Hearing problems?	☐Yes ☐No	☐Yes ☐No
k. Vision problems that cannot be corrected with glasses or contact lenses?	☐Yes ☐No	☐Yes ☐No
l. Mental retardation?	☐Yes ☐No	☐Yes ☐No
m. A learning disability?	☐Yes ☐No	☐Yes ☐No
n. Problems with teeth or gums, (e.g. toothache, bleeding gums, broken teeth, tooth decay or cavities?)	☐Yes ☐No	☐Yes ☐No
o. Other?_____	☐Yes ☐No	☐Yes ☐No

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35. In the last 12 months, has the child and your family received any of the following services?

In the last 12 months	Child	Child's Family
a. Speech or language therapy	☐ Yes ☐ No	☐ Yes ☐ No
b. Occupational therapy	☐ Yes ☐ No	☐ Yes ☐ No
c. Physical therapy	☐ Yes ☐ No	☐ Yes ☐ No
d. Vision services	☐ Yes ☐ No	☐ Yes ☐ No
e. Hearing /audiological services	☐ Yes ☐ No	☐ Yes ☐ No
f. Social work services	☐ Yes ☐ No	☐ Yes ☐ No
g. Any treatment or counseling from a mental health professional	☐ Yes ☐ No	☐ Yes ☐ No
h. Special classes with other children, some or all or whom also had special needs	☐ Yes ☐ No	☐ Yes ☐ No
i. Private tutoring or schooling for learning problems	☐ Yes ☐ No	☐ Yes ☐ No

36. Are these services you mentioned in the previous question from:

In the last 12 months	Child	Child's Family
a. Your local school district	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
b. A state or local health or social service agency	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
c. A doctor, clinic, or other health care provider	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
Some other source Specify: _____ _____	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know

37. In the last 12 months, about how many months was the child without HEALTH insurance or health care coverage?

_____ # of months
☐ Not applicable – child has always been covered.
☐ Don't know

38. Is child currently covered by any kind of DENTAL insurance or some other kind of health care plan?
☐ Yes ☐ No

a. Is child currently covered by any kind of HEALTH insurance or some other kind of health care plan?
☐ Yes ☐ No

b. Is child covered by:

	DENTAL	HEALTH
A private insurance plan (from employer, workplace, or purchased directly, or through a state or local government program or community program)?	☐ Yes ☐ No	☐ Yes ☐ No
Medicaid/ AHCCCS?	☐ Yes ☐ No	☐ Yes ☐ No
Kidscare/SCHIP	☐ Yes ☐ No	☐ Yes ☐ No
Military dental care: TRICARE, CHAMPUS, CHAMP-VA?	☐ Yes ☐ No	☐ Yes ☐ No
Indian Health Service?	☐ Yes ☐ No	☐ Yes ☐ No
OTHER? _____	☐ Yes ☐ No	☐ Yes ☐ No

39. Not including HEALTH insurance premiums or costs that are covered by insurance, do you pay any money out –of-pocket for your child's health care?
☐ Yes ☐ No ☐ Don't know

a. How often are these costs affordable?
☐ Never ☐ Always
☐ Sometimes ☐ No out of pocket costs
☐ Usually ☐ Don't know

40. Well-child care visits are visits that are made to a doctor or health care provider who takes care of the child when he/she is not sick, but needs a check-up or a shot. In the last 12 months, how many times as he/she had a well-child visit for a check-up or shot?
_____ # of visits ☐ Don't know

41. When your child needs a shot or a check-up, where do you usually take him/her? (CHECK ONLY ONE)

	Check only one
Doctor or nurse practitioner in a private practice or group practice	☐
Urgent care or walk-in clinic	☐
Community Health Center/Public clinic	☐
Hospital clinic	☐
Emergency room	☐
No one place	☐
School (nurse's office, athletic trainer's office, etc.)	☐
Friend/Relative	☐
Mexico/Other location outside of U.S.	☐

42. How adequate are the services that you have to:

	Excellent	Good	Somewhat adequate	Poor	Don't need services
Address child's physical health	☐	☐	☐	☐	☐
Address child's oral health	☐	☐	☐	☐	☐
Address child's mental health	☐	☐	☐	☐	☐
Address child's behavior	☐	☐	☐	☐	☐
Address child's learning difficulties	☐	☐	☐	☐	☐
Get help when in crisis	☐	☐	☐	☐	☐
Get parenting support	☐	☐	☐	☐	☐

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*Please note that this is **not** a test and should not be administered directly to the child.*
Please think about your child and rate him/her using the scale below.

Proficient: This child demonstrates skill, knowledge or behavior **consistently (i.e. regularly).**
In Progress: This child demonstrates skill, knowledge or behavior **with some regularity.**
Not Yet: This child **cannot perform** the skill, knowledge or behavior.

Social-Emotional Development (Check one box per row)	Proficient	In Progress	Not Yet	Don't Know
1. Sustains positive interactions with other children (e.g. When doing a puzzle, child asks if he can help. The children finish the puzzle together).				
2. Sustains positive interactions with familiar adults				
3. Has friends				
4. Adjusts behavior to correspond to different settings (e.g. child knows when to use a "quiet voice")				
5. Follows household rules				
6. Manages transitions (e.g. When it is time for a story, child puts away the blocks and goes to hear the story)				
7. Shows curiosity as a learner				
8. Makes independent decisions (e.g. , instead of playing with friends, the child decides to read a story)				
9. Attends to tasks (e.g. Child works on building a Lego structure throughout the course of the day)				
10. Seeks help when encountering a problem (e.g. child tells adult, "He took my toy.")				
11. Copes with frustration (e.g. Child says "We have to go inside, it's raining. We can come back out when it stops.")				
12. Takes risks during learning situations				
13. Shows respect for toys				

Physical Development (Check one box per row)	Proficient	In Progress	Not Yet	Don't Know
1. Moves with control (runs, hops, skips, gallops)				
2. Coordinates movements to perform tasks (e.g., kicks a ball, rides a tricycle)				
3. Uses eye-hand coordination to perform tasks (e.g., Child hits a peg with a wooden hammer)				
4. Uses fine-motor skills to manipulate a variety of tools (e.g., uses a fork to eat, child buttons and unbuttons their coat, etc.)				
5. Demonstrates personal safety practices (e.g., Child tells a friend, "Don't go near that stranger's car.")				

Language and Literacy (Check one box per row)	Proficient	In Progress	Not Yet	Don't Know
1. Follows two or three step directions (e.g., tie your shoe, then go outside)				
2. Starts conversations				

Language and Literacy (Check one box per row)	Proficient	In Progress	Not Yet	Don't Know
3. Is understood by others when speaking				
4. Uses multiple word sentences (e.g., I like ice cream)				
5. Makes relevant responses to questions/comments posed by others (e.g. , Child says, "I want to draw" when asked "What would you like to do next?")				
6. Listens to stories read by others				
7. Responds to stories read aloud				
8. Recites familiar stories, poems, or songs (e.g. , the alphabet song)				
9. Holds book upright and looks at pages from front of book or holds a book right side up with the front cover facing the reader and turns the pages one at a time.				
10. Identifies symbols or signs in the environment (e.g., Child points to a McDonald's sign and says, "That says McDonald's!"				
11. Identifies own name in print				
12. Uses letter-like shapes, symbols or letters to convey ideas or tell a story				
13. Recognizes word that rhyme				
14. Recognizes the beginning sound in familiar words				
15. Makes some letter sound matches (e.g. , While writing her name, says, "Taylor makes the "t" sound" as she prints the letter.				

Mathematics (Check one box per row)	Proficient	In Progress	Not Yet	Don't Know
1. Matches and sorts objects (e.g. by color or shape				
2. Counts object using one-to-one correspondence (e.g., Child counts out 4 straws for the 4 children at the table.)				
3. Identifies numerals 1-10				
4. Counts 10 items correctly				
5. Describes changes in two or more sets of objects when they are combined (e.g., Child adds her blocks to her friend's blocks and says, "Now we have more.")				
6. Creates simple patterns (e.g. Child makes a bead necklace using a red-blue-white, red-blue-white pattern.)				
7. Uses positional terms (e.g., under, above, below)				
8. Identifies basic shapes (i.e., circle, square, triangle, rectangle)				
9. Describes attributes of two and three dimensional objects in the environment (e.g., "That tree is tall"; "That cloud looks like a man"; "The pizza is a circle")				
10. Compares objects using measurement terms such as longer, shorter, etc.				

Thank you for your time completing this questionnaire. We appreciate you participation in this important work.
Where should we send your grocery gift card?
Street Address:_____
City, State, and Zip: _____
Telephone: _____ **Email:** _____

APPENDIX B

FAMILY AND COMMUNITY CASE STUDY

PRIMARY CAREGIVER INTERVIEW PROTOCOL

Primary Caregiver Protocol Fall 2010
Family and Community Case Study

Changes

1. Please tell me about any changes that have occurred since we last spoke.
   (This section will be tailored to each individual family)

Pre- and Post-Partum Experiences/Parenting Support
   (these questions will only be asked for parents who have a new child)

Let's talk about the birth of your newest child and his/her first few months.

[Note: If an adoptive family or interviewing non-birth parent, ask more generally about the baby/child's early history.]

2. How did you prepare for your baby's arrival [or: adoption]? Can you tell me about the kinds of help you got during that time (for example... prenatal care; child-birth classes; books; advice from family and friends, social worker visits in preparation for adoption, etc.)? Do you feel that you got the care, advice, and help you needed?

3. Did you prepare differently for the arrival of this child as compared to your other children? If so, how?

4. How do you feel about the childbirth services you received?

5. How did you feel after the baby was born [or: you adopted your child]? How soon did you go back to work? What challenges did you face?

6. Did you receive one or more home visits from an agency or midwife or nurse after the birth of your child? When? Was it helpful? What issues/topics were covered in the visit? If you did not receive a home visit, would you have liked one?

Readiness

(QI explains that we are now going to be talking about new topics and asking new questions to ease this transition.)

7. What do you think are a young child's most pressing needs? (Prompt as needed: for example, academic, social, emotional, developmental, cultural, religious needs?) *(start general and then discuss their own children)*

8. How do you feel Arizona is addressing the needs of children?

9. Before we move on, I would like to ask you to reflect on your own childhood and compare it to your child's. *(Parents should describe differences here)*.

   People think of childhood in very different ways; can you tell me what childhood means to you? *(This will give us an idea of how parents conceptualize childhood and how this compares to the ways policy makers view childhood. Reflecting on difference between their childhood and their child's will speak to the ways in which childhood and kindergarten have changed.)*

Culturally relevant programs

10. Do you feel like the various programs *(e.g. education, healthcare)* that you have access are aware of your family's background, heritage, and culture?

11. Do you feel like the programs available to you are in line with your family's values?

12. Are there ways in which services could be improved to address your family's needs? Do you feel supported as a parent/guardian?

13. Do you feel the programs you use respect your opinion about how to raise your children? Why or why not?

Play, language and literacy events

14. How would you describe your play with your child(ren)? What do they play? How has your child's play changed over the years? What about your partner/spouse? Do they engage in play differently with your child(ren)?

15. What influences your child's play? (TV, friends, videos, books, etc.)

16. Let's talk about language and literacy activities you engage in with your child(ren). *(Interviewer should probe here to elicit information on language and literacy events and those listed below are examples of these probes)*

17. What kinds of books do you read with your child(ren)? Tell me more about how that goes. Can you describe the experience? Who chooses the books?

18. What about songs? Do you sing songs with your child(ren)? Does your child sing songs? Do you use any rhymes or riddles with your children? Where do these songs or rhymes come from? What about sayings (sp: dichos)? Advice (sp: consejos)? Fables (sp: fabulas)? Stories? *(These are not just probes. Each of these categories should be addressed.)*

19. Who else share stories, songs, reads books with your child(ren) – e.g., grandparents, others?

20. What language are they in?

21. Where do these various activities (song singing, reading books, storytelling, etc.) happen? (e.g. At home, church, school, library, on the computer, etc.)

Preschool/Kindergarten:

22. What are your thoughts about kindergarten today? How do you see it? (*This question is not just for parents who have a child entering kindergarten, but to get them to start thinking about what kindergarten means and how they are preparing their children to enter kindergarten. Start general and then narrow the focus*)

23. For you, is there a difference between preschool and child care? (*We need to be sure we know if the child is in childcare or preschool*)

24. What does it mean for you to prepare your child to start school? What kinds of things should children know before they enter school?

25. Why did you choose to put your child in preschool/child care? Why did you choose not to put your child in preschool/child care? (*this and the next question depend on particular circumstances of family*)

26. How do you feel your child is benefiting from being in preschool/child care? **[or]** Do you feel that your child is missing anything by not attending preschool/child care?

27. We have talked before about what happens in your child's preschool. Can you tell me more about what he/she is learning there? What does he/she enjoy most? [or: Is (name of child) happy there?]

28. Are you happy with the curriculum the school provides? How would you improve it? What would you like to see happening there?

29. Are there things other than the curriculum that you would like to change or improve?

30. Do you think there are things that your child is not learning in school but should be learning? Are you doing anything to address this?

Transition to Kindergarten: [adapt for home schooling families]

(These questions are only for parents whose child is in kindergarten at the time of the interview)

31. Can you tell me about the transition to kindergarten for you and your child? How was it?

32. Did you do anything special to prepare for the transition to kindergarten?

33. Did you have communication with anyone at the school prior to the start of kindergarten? [With whom? Who initiated the contact?]

34. How helpful were these activities and communication in the transition?

35. How do you feel about the curriculum in kindergarten?

FAMILY INTERVIEW
First Things First External Evaluation (FTFEE)
Longitudinal Family and Community Case Study

I. Explanation: (pre-interview/IRB)

Ia. "We are doing a study of how families in Arizona with young children are doing. We want to hear about the services families like you are getting for their children and services you need but aren't getting. We'd like to learn about what's helping you and also about any problems you are having getting health and childcare services for your baby/child. This isn't a survey—we have some questions to ask, but it will be a conversation. The answers you give in this interview will be used to improve the services for young children in Arizona.

(If more than one adult is present, say something like, "We want to interview the person who is the primary caregiver (who takes care of the child(ren) most of the time)." We need this person to sign the form and be the one we interview (and mic).

If you agree to participate, your family will be given a $20 grocery gift card. If you are selected to be interviewed again in future years (five years total), your family will receive grocery gift cards in the following amounts: $30, $40, $45 and $50. Your family will also be given a children's book and/or art supplies.

We also want to interview your children, when they are about five years old...

Before we start, if you agree to participate in this study, we will have you review and sign the consent form to indicate that you understand that we will be interviewing and recording the interview, that we will make every effort to protect your identity, and how long the study will be for. If this is OK, would you review this document, ask any questions you have, and then sign it?

Ib. Explain taping

Ic. Each interviewer start your recorder (REC) and state into your mic:
    1. Your name
    2. Whether your recorder is the "lead" or "back-up (which means whether you are the lead or supporting interviewer)
    3. The name (first and last) of the person/people you are interviewing (the one who will be wearing the mics)
    4. The date

Id. Without stopping recording, put the mics on the interviewee's shirt front.

Ie. Use your headphone to make sure the sound level is good.

[When the interviewee has more than one child, ask about each child in questions about pregnancy and birth, child's health, childcare, and education arrangements.
Ask about partner's as well as interviewee's ethnicity, work, extended family, etc.

1. Opening Question

"We'd like to learn about what's helping you with raising your child(ren) and also about any problems you are having getting health and child care services for your baby/child. Let's begin by asking you how is it going raising your child(ren)? What's working well for you? Are you having any problems?"

2. The Family/Household

2a. Please tell me a bit about your family. How many children do you have? How old? Who (helps you) take care of your baby/child?

2b. Extended family: Do you have family who in the area? Where are your parents? Your spouse or partners' parents? How often do you see them? Are they helpful with your baby/child?

2c. Where are you from? How long have you lived in Arizona? What about your partner? How long have you been in the house you are living in now? Where did you live before this?

2d. How would you describe your family in terms of culture/ethnicity? Is this cultural/ethnic identity something that you think about in your child-rearing? Are you trying to pass on a cultural/ethnic identity to your children?

2e. What languages are spoken in your home? What language(s) do you and others who care for your baby/child use with him/her?

2f. Do you belong to a church, temple, or other religious community? Do you get any support with child-rearing and care from your faith community?

2g. What is your neighborhood like? Are there many families with young children in your community? How would you describe your neighborhood (in terms of support, safety, resources)?

2h. Tell me about your work. (Where? Full-time or half-time?) Is it hard to balance work and time with your family? Your partner's work?

2i. Describe a typical day in the life of you and your baby/child(ren). And weekends? (move down)

3. Pre- and Post-Partum Experiences/Parenting Support

Now I'd like to ask you a bit about the birth of your children and his/her first few months.

[Note: If an adoptive family or interviewing non-birth parent, ask more generally about the baby/child's early history.]

3a. How did you prepare for your (first) baby's arrival [or: adoption]? Can you tell me about the kinds of help you got during that time (for example… prenatal care; child-birth classes; books; advice from family and friends, social worker visits in preparation for adoption, etc.)? Do you feel that you got the care, advice, and help you needed?

3b. (If they have more than one child): Did you prepare differently for the arrival of your other child(ren)? If so, how?

3c. How do you feel about the childbirth services you received?

3d. How did you feel after the baby was born [or: you adopted your child]? How soon did you go back to work? What challenges did you face?

3e. Did you receive one or more home visits from an agency or midwife or nurse after the birth of your child? When? Was it helpful? What issues/topics were covered in the visit? If you did not receive a home visit, would you have liked one?

4. Health Care and Other Child Services

4a. Tell me a little about your baby/child's health. What do you do when your baby/child gets sick? Is it hard for you to get care? What obstacles do you face in finding health care (e.g., distance, cost, waiting lines, money)? Do you have health insurance? Do you have a family doctor/pediatrician? Are you satisfied with your baby/child's health care?

4b. Does your baby/child go for regular or "well" child visits? (If a parent/primary caregiver answers "Yes," ask the parent to describe a visit and if they found it helpful.)

4c. Has your child had any dental care? (If not, why not?) Are you satisfied with this care?

4d. Has your child received any other services? Are you satisfied with these services?

5. Being a Parent/Primary Caregiver

5a. Tell us about your experience of being a parent/primary caregiver. What do you like most? What do you find challenging?

5b. What questions or problems do you have (or have you had) in childrearing and concerning your baby/child's development? Who do you go to for help in raising your children? Has this been helpful?

5c. Has your child received any other services (Do not list but these could include speech and other kinds of therapy, YMCA swim and gym, etc.)? Are you satisfied with these services?

6. Early Childhood Care and Education Services

6a. What you are doing about child care and early childhood education? [Note: Adapt if they are not using out of home care to discuss how they are supported in providing care.]

6b. Did you have any problems finding good child care (i.e. language barriers, residency, lack of knowledge on available resources, isolation)? How did you find and choose child care? Where you able to get your first choice?

6c. How do you feel about the childcare services you have? Are they working for you? Do you have concerns about these services? Do you know what goes on each day in your child's child care? How do you know?

6d. Besides childcare, are there other services in your community your child is involved in (e.g. play groups; library programs; sports and arts programs, etc.)?

7. Child Raising Goals and Priorities

7a. What are your hopes and dreams for your child's future?

7b. What are some of your favorite activities to do with your child/ren?

7c. What do you feel are the most important things for your child to learn at home? What are the most important things you (or others in your family) can teach your child?

7d. What do you feel are the most important things for your child to learn at preschool or in child care (e.g. learning, academic, social, emotional, etc.)?

8. Concluding Questions

8a. What kinds of services and support have been the most helpful/beneficial to you?

8b. Do you have any ideas about things Arizona could be doing better for young children and their parents/primary caregivers?

8c. Had you ever heard of *First Things First* before this interview? If so, what did you know about it?

8d. Do you have anything you want to add? Is there something we didn't ask you about that you want to talk about? Do you have questions for us?

SECOND FAMILY INTERVIEW
First Things First External Evaluation (FTFEE)
Longitudinal Family and Community Case Study

I. **Explanation:** (pre-interview/IRB)

Ia. "As you know, we are doing a study of how families in Arizona with young children are doing. We spoke to you before about the services you are getting for your children and services you need but aren't getting. We'd like to continue to learn about what's helping you and any problems you are having getting health and childcare services for your baby/child. Just as before, this isn't a survey—we have some questions to ask, but we'd like for this to be a conversation. The answers you give in this interview will be used to improve the services for young children in Arizona.

"We want to interview the person who is the primary caregiver (who takes care of the child(ren) most of the time). Is that person still you?"

IF YES, THEN PROCEED. IF NO, WE WILL NEED THIS PERSON TO BE INTERVIEWED AND SIGN AN INFORMED CONSENT.
(QIs should explain that the incentive structure has changed from the previous interview. QIs should ask participant to sign Addendum to Informed Consent)

We also want to interview your children when they are five years old. **(QI should identify the child who is five and set up a time when they will be interviewed in the coming weeks.)**

Before we start, we want to make sure that you understand that we will be recording the interview again, we will continue to make every effort to protect your identity, and that the study is projected to continue for the next five years. We have a copy of the consent form here for your review. **(Allow participant to review the informed consent)**

Ib. Explain taping

Ic. Each interviewer present will start the digital recorder (REC) and state into the mic:
    1. Your name
    2. Whether your recorder is the "lead" or "back-up (which means whether you are the lead or supporting interviewer)
    3. State the family code of the person/people you are interviewing (the one who will be wearing the mics)
    4. Indicate the date of the interview

Id. Without stopping recording, put the mics on the interviewee's shirt front.

Ie. Use your headphone to make sure the sound level is good.

[When the interviewee has more than one child, ask about each child in questions about pregnancy and birth, child's health, childcare, and education arrangements.
Ask about partner's as well as interviewee's ethnicity, work, extended family, etc.

This interview protocol will be specific to issues raised in the First Primary Caregiver Protocol. The following section details the systematic approach for selection of follow-up questions.

Protocol for Individualizing Second Primary Caregiver Interview

STAFF
1. Staff member at university reads through the initial primary caregiver interview transcript and listens to accompanying sections of audio file.
2. While reading/listening to the interview/transcript, the staff will highlight areas of the interview that require clarification or that provide additional interesting insights, these include ongoing events, involvement in activities, family crisis, changes in family dynamics, or other areas that would warrant follow-up.
3. Staff member then develops a set of follow-up interview questions to be used in second primary caregiver interview.

QI
4. The qualitative interviewer assigned to the focal family will also listen to and read the same interview transcript to familiarize themselves with the family, their situation and family dynamics.
5. The QI will draft their own set of possible follow-up questions following the outlined guidelines in bullet number 2 (above).

STAFF and QI
1. Staff then meets with the QI to discuss areas they find pertinent for follow-up and determine agreed upon set of follow-up questions for second interview. These questions are drafted in a word document to be inserted into the follow-up interview.
2. Staff and QI will discuss details regarding the focal family, their children, their family dynamics to ensure that the QI is familiar with the family prior to conducting a follow-up interview.

The individualized questions developed from this process will be embedded in the following second primary caregiver interview protocol.

1. Opening Question

Remind participant when the last interview took place
"As you know, we'd like to learn about what's helping you with raising your child(ren) and also about any problems you are having getting health and child care services for your baby/child. In general, have there been any changes in how things are going from the last interview? What's working well for you? Have you encountered any new challenges?"

2. The Family/Household

2a. Please tell me a bit about your family. Have there been any changes from the last interview? (**try to use the time of last interview, i.e. "when we last talked in November"**) Do you have any new additions to your family?

2b. Have there been changes in who is helping you care for your children?

2c. Extended family: Have there been any changes in the help you receive from family members regarding the care of your children?

2d. Have there been any changes in the languages you speak in the home?

2e. Can you tell us whether there has been any change in your involvement with your religious community since the last interview?

2f. How has your neighborhood changed since the last interview (e.g. security, support, resources)? Are there many families with young children in your community?

2g. Tell me about your work. Has your work changed? How about for anyone else in the household (e.g. partner/spouse, changed from full-time to part-time, job loss, promotion)? How is balancing family and work going?

2h. Can you describe to me a typical day in the life of you and your baby/child(ren). A typical weekend day? Has your daily routine changed?

2i. How would you describe your child's nutrition? What does she/he eat?

2j. Do you participate in any programs that help support the nutrition of your children?

3. Pre- and Post-Partum Experiences/Parenting Support

Use these questions ONLY if there is a new child in the family.

Now I'd like to ask you a bit about the birth of your children and his/her first few months.

[Note: If an adoptive family or interviewing non-birth parent, ask more generally about the baby/child's early history.]

3a. How did you prepare for your (new) baby's arrival [or: adoption]? Can you tell me about the kinds of help you got during that time (for example... prenatal care; child-birth classes; books; advice from family and friends, social worker visits in preparation for adoption, etc.)? Do you feel that you got the care, advice, and help you needed?

3b. (If they have more than one child): Did you prepare differently for the arrival of your other child(ren)? If so, how?

3c. How do you feel about the childbirth services you received?

3d. How did you feel after the baby was born [or you adopted your child]? How soon did you go back to work? What challenges did you face?

3e. Did you receive one or more home visits from an agency or midwife or nurse after the birth of your child? When? Was it helpful? What issues/topics were covered in the visit? If you did not receive a home visit, would you have liked one?

4. Health Care and Other Child Services

4a. Tell me a little about your baby/child's health. Have there been any changes in your child's health?

4b. Have there been any changes in your health insurance?

4c. Have there been any changes with your provider?

4d. Has your child received any other health services since we last spoke? Are you satisfied with these services?

5. Being a Parent/Primary Caregiver

5a. Tell us about your experience of being a parent/primary caregiver. Are you facing any new challenges as a parent since we last spoke?

5b. What concerns or problems have you faced in childrearing since the last interview? How about in your baby/child's development since the last interview? Have there been any changes where you find support? (e.g. people, places, programs)

5c. Has your child received any other services since we last spoke (Do not list but these could include speech and other kinds of therapy, YMCA swim and gym, etc.)? Are you satisfied with these services?

6. Early Childhood Care and Education Services

6a. Have there been any changes in your child care arrangements? Have there been any changes in your child's early childhood education experiences? [Note: Adapt if they are not using out of home care to discuss how they are supported in providing care.]

Address questions 6b-6c if parents are newly looking for care or recently found care. If not, skip to question 6d.

6b. Have you had any new problems finding good childcare (e.g. language barriers, residency, lack of knowledge on available resources, isolation)? What are you looking

for in childcare? How did you find and choose childcare? Were you able to get your first choice?

6c. How do you feel about the childcare services you have? Are they working for you? Do you know other parents using that same care provider? Do you have concerns about these services? Are you familiar with the daily routines in that childcare center? How do you know?

6d. Besides childcare, are there other programs in your community that your child now participates in (e.g. play groups; library programs; sports and arts programs, etc.)?

7. Childrearing Goals and Priorities

7a. What are your hopes and dreams for your child's future? (**This question is asked only in the fall**)

7b. Have there been any changes in the favorite activities you do with your child?

7c. Right now, what do you feel are the most important things for your child to learn at home? What are the most important things you (or others in your family) can teach your child? Has this changed from before? How?

7d. Right now, what do you feel are the most important things for your child to learn at preschool or in child care (e.g. learning, academic, social, emotional, etc.)? Has this changed from before? How?

8. Concluding Questions
(**Have there been any changes in any of these?**)

8a. What kinds of services and support have been the most helpful/beneficial to you?

8b. Do you have any ideas about things Arizona could be doing better for young children and their parents/primary caregivers?

8c. Have you learned anything new about FTF since our last interview?

8d. Do you have anything you want to add? Is there something we didn't ask you about that you want to talk about? Do you have questions for us?

APPENDIX C

BEACH CENTER FAMILY QUALITY OF LIFE SCALE

Instrument Title: The Family Quality of Life Scale (FQOL)

Instrument Author: Beach Center on Disability

Cite instrument as: Beach Center on Disability. (2012) . The Family

Quality of Life Scale (FQOL) . Measurement

Instrument Database for the Social Science.

Retrieved from www.midss.ie

FAMILY QUALITY OF LIFE SURVEY

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

For information, contact:
Jean Ann Summers, Ph.D.
Research Director, Beach Center on Disability
jsummers@ku.edu

Suggested reference for reports utilizing this instrument:

Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006).
Assessing family outcomes: Psychometric evaluation of the beach center
family quality of life scale. *Journal of Marriage and Family, 68*(4), 1069-1083.

Beach Center on Disability

Making a Sustainable Difference in Quality of Life

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

FAMILY QUALITY OF LIFE

Thank you for agreeing to complete this survey. The survey is about how you feel about your life together as a family. We will use what we learn from families to inform policy makers and service providers for children and families.

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

For this survey, please consider your family as those people

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

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

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

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

✓ Checking the first square means you are very dissatisfied.

✓ Checking the fifth square means you are very satisfied.

Thank you so much for sharing your opinion with us!

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FAMILY QUALITY OF LIFE (cont.)

How <u>satisfied</u> am I that...	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1. My family enjoys spending time together.	☐	☐	☐	☐	☐
2. My family members help the children learn to be independent.	☐	☐	☐	☐	☐
3. My family has the support we need to relieve stress.	☐	☐	☐	☐	☐
4. My family members have friends or others who provide support.	☐	☐	☐	☐	☐
5. My family members help the children with schoolwork and activities.	☐	☐	☐	☐	☐
6. My family members have transportation to get to the places they need to be.	☐	☐	☐	☐	☐
7. My family members talk openly with each other.	☐	☐	☐	☐	☐
8. My family members teach the children how to get along with others.	☐	☐	☐	☐	☐
9. My family members have some time to pursue our own interests.	☐	☐	☐	☐	☐
10. Our family solves problems together.	☐	☐	☐	☐	☐
11. My family members support each other to accomplish goals.	☐	☐	☐	☐	☐
12. My family members show that they love and care for each other.	☐	☐	☐	☐	☐
13. My family has outside help available to us to take care of special needs of all family members.	☐	☐	☐	☐	☐
14. Adults in our family teach the children to make good decisions.	☐	☐	☐	☐	☐

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FAMILY QUALITY OF LIFE (cont.)

How <u>satisfied</u> am I that...	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
15. My family gets medical care when needed.	☐	☐	☐	☐	☐
16. My family has a way to take care of our expenses.	☐	☐	☐	☐	☐
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	☐	☐	☐	☐	☐
18. My family is able to handle life's ups and downs.	☐	☐	☐	☐	☐
19. Adults in my family have time to take care of the individual needs of every child.	☐	☐	☐	☐	☐
20. My family gets dental care when needed.	☐	☐	☐	☐	☐
21. My family feels safe at home, work, school, and in our neighborhood.	☐	☐	☐	☐	☐
22. My family member with a disability has support to accomplish goals at school or at workplace.	☐	☐	☐	☐	☐
23. My family member with a disability has support to accomplish goals at home.	☐	☐	☐	☐	☐
24. My family member with a disability has support to make friends.	☐	☐	☐	☐	☐
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	☐	☐	☐	☐	☐

Thank you! You have finished completing this survey. Please make sure you erase any extra marks and have answered all the questions.

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