ASSESSING THE RESOURCES UTILIZED AND DESIRED BY FAMILIES OF CHILDREN WITH SPECIAL NEEDS

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ASSESSING THE RESOURCES UTILIZED AND DESIRED BY FAMILIES OF CHILDREN WITH SPECIAL NEEDS

A Project

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Division of Social Work
Abstract

of

ASSESSING THE RESOURCES UTILIZED AND DESIRED BY FAMILIES OF CHILDREN WITH SPECIAL NEEDS

by

Larissa Jang-Mi House

Families of children with special needs experience impacts on their emotional, financial, mental, and physical wellbeing (Green, 2002; Schall, 2000; Dellve et al., 2000). In addition to the complexities of raising a child, parents of children with special needs must navigate through a variety of specialized treatments, which may be costly and time consuming. This study explored the needs, concerns, and desires of parents who had young children with special needs. Thirty-four caregivers participated in 75-minute, mixed-method, face-to-face interviews. Qualitative data were coded and organized into themes. Quantitative data were analyzed by conducting frequency and chi-square analyses. No statistically significant relationship was found between household income and utilization of additional services ($X^2=1.794$, $p>.05$) or between parents’ level of education ($X^2=3.188$, $p>.05$) and household income ($X^2=3.55$, $p>.05$) on their feelings of comfort with navigating the educational system.
Caregivers of children with special needs desired to obtain additional services and information for their children but found cost, lack of knowledge about resources and lack of access to resources to be barriers to accessing desired services.

_______________________, Committee Chair
Teiahsha Bankhead, Ph.D., L.C.S.W.

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Date
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of Tables</td>
<td>ix</td>
</tr>
<tr>
<td>List of Figures</td>
<td>x</td>
</tr>
<tr>
<td>Chapter</td>
<td></td>
</tr>
<tr>
<td>1. THE ISSUE</td>
<td>1</td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Background</td>
<td>2</td>
</tr>
<tr>
<td>Statement of the Research Problem</td>
<td>4</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>5</td>
</tr>
<tr>
<td>Theoretical Framework</td>
<td>5</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>8</td>
</tr>
<tr>
<td>Assumptions</td>
<td>10</td>
</tr>
<tr>
<td>Justification</td>
<td>10</td>
</tr>
<tr>
<td>Limitations</td>
<td>12</td>
</tr>
<tr>
<td>2. REVIEW OF THE LITERATURE</td>
<td>13</td>
</tr>
<tr>
<td>Introduction</td>
<td>13</td>
</tr>
<tr>
<td>Family Impact</td>
<td>13</td>
</tr>
<tr>
<td>Parenting a Child with Special Needs</td>
<td>16</td>
</tr>
<tr>
<td>The Sibling Experience</td>
<td>27</td>
</tr>
<tr>
<td>Financial Impact of Raising a Child with Special Needs</td>
<td>32</td>
</tr>
<tr>
<td>Navigating the Health Care System</td>
<td>38</td>
</tr>
<tr>
<td>Parents’ Interactions with the Education System</td>
<td>40</td>
</tr>
<tr>
<td>Supporting Families of Children with Special Needs</td>
<td>42</td>
</tr>
<tr>
<td>Summary</td>
<td>44</td>
</tr>
<tr>
<td>3. METHODS</td>
<td>46</td>
</tr>
<tr>
<td>Introduction</td>
<td>46</td>
</tr>
<tr>
<td>Design</td>
<td>46</td>
</tr>
<tr>
<td>Population</td>
<td>47</td>
</tr>
</tbody>
</table>
Sample.................................................................................................................. 47
Data Collection ..................................................................................................... 48
Instrument ............................................................................................................ 49
Measurement ........................................................................................................ 51
Data Analysis ........................................................................................................ 51
Human Subjects Protection .................................................................................. 52

4. RESULTS ........................................................................................................... 53
   Introduction ........................................................................................................ 53
   Demographics .................................................................................................... 53
   Research Findings ............................................................................................ 61
   Summary of Findings ....................................................................................... 74

5. CONCLUSION .................................................................................................... 75
   Introduction ........................................................................................................ 75
   Research Content ............................................................................................. 75
   Implications for Future Social Work Practice ................................................ 79
   Limitations and Implications for Future Research ......................................... 82
   Conclusion ......................................................................................................... 84

Appendix A. Consent to Participate in Research.................................................. 86
Appendix B. Questionnaire .................................................................................. 88
References ............................................................................................................ 96
LIST OF TABLES

Page

1. Table 1 Length of Time Receiving Services......................................................... 60
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Figure 1 City of Residence</td>
<td>54</td>
</tr>
<tr>
<td>2.</td>
<td>Figure 2 Age of Primary Caregivers</td>
<td>54</td>
</tr>
<tr>
<td>3.</td>
<td>Figure 3 Estimated Household Income</td>
<td>55</td>
</tr>
<tr>
<td>4.</td>
<td>Figure 4 Level of Education</td>
<td>56</td>
</tr>
<tr>
<td>5.</td>
<td>Figure 5 Ethnic Background</td>
<td>57</td>
</tr>
<tr>
<td>6.</td>
<td>Figure 6 Primary Language Spoken in the Home</td>
<td>57</td>
</tr>
<tr>
<td>7.</td>
<td>Figure 7 Child’s Diagnosis</td>
<td>58</td>
</tr>
</tbody>
</table>
Chapter 1

THE ISSUE

Introduction

What does this mean in real life? It means accommodating Sam’s rigidity and extreme need for routine. It means supporting Sam when he has fear. It means working through his sometimes wildly disproportionate responses to moderate stress. It means teaching Sam to interact appropriately in the social world. It means understanding perseveration, continuous or repetitive focus on a particular subject or activity, as his zone of comfort. It means spending many hours working closely with teachers, therapists, and aids to provide a positive educational experience at school. It means fully celebrating this child as he is and pursuing his potential for growth. It means tolerance and empathy of his individual perceptions and interpretations of the world.

(Louis, 2008, pp. 233-234)

In her article “Walking the Walk: My Autistic Son and the Scholarship of Empathy,” Maureen Louis, mother to a young son with autism and Professor of Communications at Cazenovia College in New York, answers the question of what it means to parent a child with special needs. Although Maureen reflects on how her life has been shaped by the experiences with her own son who has autism, her words highlight the journey that parents of children with special needs face regardless of the needs of the child. The process of adjusting to life’s unforeseen challenges, spending
hours collaborating to create new plans and goals, and learning how to appreciate the uniqueness of their child and his or her development is one that parents continually experience throughout their child’s lifespan beginning when their child is very young.

Being part of a family with a child with special needs impacts both parents and siblings. Added to the challenges shared with families of typically-developing children, they must learn how to understand their child when he or she does not grow in the way the children around them do. They must endure stares or questions from others who do not understand or do not know how to interact with their child. They must adjust their routines and schedules to participate in individual treatments and therapies for their child which may place financial strain on the family. They must shift their ways of thinking to accommodate unexpected and often unpredictable circumstances and support their child even when they feel isolated and unsure. Families with children with special needs face unique challenges in raising their child with special needs.

Background

According to the Centers for Disease Control and Prevention (CDC), approximately 17% of children in the United States under the age of 18 have a developmental disability, which the CDC defines as “a diverse group of severe chronic conditions that are due to mental and/or physical impairments” (Centers for Disease Control and Prevention, 2004, para. 1). These mental and physical impairments may be the result of birth defects, which the CDC defines as “a problem that happens while the baby is developing in the mother’s body [and] may affect how the body looks, works, or both” (Centers for Disease Control and Prevention, 2009, para. 1). The CDC found that
one in every 33 babies is born with a birth defect, which can range from neural tube
defects such as spina bifida to heart defects to orofacial clefts such as cleft lip. Some
developmental conditions, such as Down Syndrome, can be detected before birth, at birth,
or soon after. Others, however, such as Autism Spectrum Disorder, are not detected until
toddlerhood or later. Regardless if it is detected before birth or later in the child’s life,
developmental disabilities impact individuals’ learning, self-help, mental processing,
mobility, language, and communication throughout life. Currently, the CDC estimates
there are 35-43 million people in the United States living with a physical or mental
disability (Centers for Disease Control and Prevention, 2004; Centers for Disease Control
and Prevention, 2009).

Families of children with special needs have a variety of emotional, financial, and
familial stressors. Parents of children with special needs are more likely to score higher
in feelings of stress and negative impact than parents of similarly-aged typically-
developing children (Baker et al., 2003). Parents feel isolated in their unique situations
(Dellve et al., 2006). Siblings struggle with dealing with the demands and
responsibilities of growing up with and taking care of their sibling (Dellve et al., 2000).
Parents must balance their schedules to work, care for their other children, meet their own
needs, and take their child to a variety of therapies and treatments. Families of children
with special needs also struggle financially and are more likely to live in poverty than
families of typically-developing children (Parish & Cloud, 2006).

Research strongly indicates that raising a child with special needs heavily impacts
the entire family system and often presents more initial negative impacts than positive
ones. Given the high prevalence and increasing incidence of children with special needs in families in the United States, families with children with special needs deserve to be continuously studied with the purpose of understanding them as a significant minority population so they may be provided with adequate and competent support as their child develops through the lifespan. Relevant, applicable, and meaningful support cannot be rendered to this population without obtaining a deeper understanding of what they identify as their needs in all aspects of their lives.

**Statement of the Research Problem**

Families with children with special needs access and interact with a variety of resources and services throughout their child’s life. One of the first resources that parents of children with special needs access for their child is early intervention. According to the National Dissemination Center for Children with Disabilities (NICHY), “early intervention services are specialized health, educational, and therapeutic services designed to meet the needs of infants and toddlers, from birth through age two, who have a developmental delay or disability, and their families (National Dissemination Center for Children with Disabilities, n. d.)” This research study focuses specifically on the needs parents identify in raising their child who is currently accessing center-based early intervention services. At this time, local agencies provide early intervention services which also aim to support the social needs of the parents but have not yet formally assessed the current needs of the parents they serve. Formally assessing the needs of parents in Contra Costa County whose children receive center-based early intervention services will provide valuable, concrete and relevant insight into the lives of parents of
young children with special needs.

**Purpose of the Study**

This study’s primary purpose is to identify the needs of parents of young children receiving early intervention services in Contra Costa County through interviews with parents. By interviewing parents and focusing on a variety of aspects in their lives in regards to raising their child, this study aims to discover what parents identify in their own lives as their greatest areas of concern in raising their child.

By discovering the needs parents identify in their own lives, the secondary purpose of this study is to provide service providers such as social workers and counselors with information on what parents themselves identify as important in their lives so that service providers may more competently and relevantly support the needs of the parents and families. With data retrieved directly from parents, this study aims to provide current information on what the local parents identify as relevant topics in their lives as well as the major concerns of families with young children with special needs in Contra Costa County so that services that efficiently meet the needs of parents will be provided.

**Theoretical Framework**

Systems theories provide a framework in which the individual or family is viewed as a member of a larger whole or system. Systems theories focus on relationships between systems instead of simply viewing the individual or family as an isolated unit. By viewing individuals and families through the lens of systems theories, social workers pay key attention to elements both within and outside the system and study the system’s
interactions to better understand the system’s functioning. Because families themselves are a system and interact with a variety of different systems throughout the families’ development, such as schools, employment settings, and medical and treatment teams, systems theories are appropriate frameworks to utilize when interested in the families’ functioning in their environment.

Several key concepts are useful in understanding families as systems and their interactions with their environment, including system, boundaries, role, subsystem, input, output, feedback, homeostasis adaptation, and relationship. A system is a set of units that are interrelated to make a functional whole. Boundaries characterize the relationships of a system and help to give the system a particular identity by serving as indicators as to who is in the system and who is not in the system. They also help create roles based on the behaviors of the families or individuals. Within a system, each individual assumes a role based on his or her patterns of behavior, which impacts the ways the individual interacts with other members of the system. Subsystems are defined as the smaller systems set apart by designated boundaries that are still part of the larger system. Input and output both involve how systems interact with other systems; input is what is received from other systems and output is the resulting processes on other systems after input is received. Feedback is a specific type of input a system receives about its own performance, which can be either positive or negative (Zastrow & Kirst-Ashman, 2004; Hull, Jr. & Mather, 2006).

As systems interact with other systems, a goal is to maintain a sense of homeostasis or balance, readjusting roles and interactions with other systems in an
attempt to maintain a sense of equilibrium as events outside of the system’s control occur. The system’s goal is not simply to maintain a sense of balance, which may or may not involve the healthiest behavior, but to adapt to the stressors as they face inevitable change. This adaptation helps the system become resilient and helps it to not only maintain a balance based on behaviors members are already comfortable with but deal with their situations in the healthiest way. Ultimately, systems theories view individuals in the light of relationships, both among the members of one system and between one system and another. Systems theories value the importance of understanding and recognizing relationships as having an impact on the functioning of the individual or family (Zastrow & Kirst-Ashman, 2004; Hull, Jr. & Mather, 2006).

Families with children with special needs are a system which must interact with a variety of different other systems, including medical teams, social services agencies, educational settings, and supportive services. Viewing their families as impacted by the relationships they have with each other and with other systems allows professionals to obtain a more complete picture of who these families are. Although the child with special needs has the individual condition, because the child is part of the family system, the entire family is impacted by the needs of the child.

Family members take on different roles based on the needs of the family, such as financial provider, responsible sibling, or primary caregiver. These roles impact the relationships they have with each other, creating subsystems which may support some and isolate others. The impact the interactions with outside systems has on families with children with special needs must be understood to determine how the input and feedback
from other systems either support or discourage the families. When families face inevitable change and distressing circumstances, they are forced to adjust to find the homeostasis in their lives, such as adjusting to the demands of raising a child with special needs. The goal, however, is not simply for families to maintain a minimal level of functioning, such as dealing with constant stress, little sleep, and low levels of support because they are adjusted to that way. Instead, families must be given tools to become resilient based on their adaptation to their environments and be supported to obtain the highest levels of functioning.

Systems theories allow for understanding the impact that members within a system have on each other as well as the impact that various systems have on one another. Systems theories are relevant to research of families with children with special needs in two specific ways. Firstly, by understanding that members of a system are impacted by one another, systems theories take into consideration the impact raising a child with special needs has on the other members of the family and the dynamics it creates based on the family’s roles, relationships, homeostasis, and adaptation. Secondly, systems theories help identify the ways the family systems are impacted by their relationships with outside systems and provide a framework for outside systems to understand how they impact the family system and learn how to better meet the needs of the family system based on their interactions with each other.

**Definition of Terms**

A few key terms pertaining to children with special needs are used throughout this report. Their definitions are as follows:
• Developmental Disability: The Centers for Disease Control and Prevention define developmental disabilities as “a diverse group of severe chronic conditions that are due to mental and/or physical impairments” (Centers for Disease Control and Prevention, 2004). Developmental disabilities begin anytime during a person’s development before the age of 22 years and last for the rest of the person’s life. Developmental disabilities result in significant limitations in the areas of language, mobility, learning, self-help, independent living, and/or economic self-sufficiency. Examples of developmental disabilities include but are not limited to autism, behavior disorders, brain injuries, cerebral palsy, Down syndrome, fetal alcohol syndrome, mental retardation, and Spina Bifida (University of Minnesota, 2010).

• Special Needs: Conditions which require early intervention, special education, or other specialized services (First 5 Special Needs Definition, n. d.). These conditions include mental retardation, learning disorders, communication disorders, pervasive developmental disorders, disruptive behavior disorders, feeding and eating disorders, and anxiety disorders (First 5 Special Needs Definition, n. d.). Throughout this report, the term “special needs” is used to describe both birth defects and developmental disabilities as defined above.

• Typically-developing children: Children without developmental disabilities or special needs who are not receiving special education services and who follow a typical pattern of development, such as achieving developmental milestones at an average rate.
Children without special needs: Same definition as typically-developing children and used interchangeably with typically-developing children.

Assumptions

Throughout this report, assumptions are made regarding families with children with special needs. The first assumption is that families of children with special needs are impacted in a unique way that families without children with special needs are not, and a main factor in the unique impact is simply having a child with special needs in the family. Families with children with special needs have unique dynamics that are not shared with families who do not have children with special needs and are impacted by raising their child in a different way than families raising typically developing children. The second assumption is that families with children with special needs are a minority culture, and, like other minority cultures, face clashes with the majority culture in levels of support and access to resources, may feel isolated from the majority culture, and may find support in affiliating with others in their minority culture. This impacts the way they feel and the way they perceive the support of those around them.

Justification

By studying the needs of parents of children with special needs, social workers will be better prepared to provide services to this diverse and vulnerable population. The findings of this research study will benefit the profession of social work by helping social workers uphold three NASW core values when working with families with children with special needs. These core values are competence, importance of human relationships, and service.
It is the goal of social workers to provide competent services to diverse populations. A component of competent services is the relevancy of the services to the clients and their situations. By studying what parents of children with special needs identify as the needs in their lives, social workers will learn what families feel are relevant to them and have the information to create and provide services where the families identify a need. This knowledge will assist social workers in providing competent services and support to families with children with special needs as social workers strive to further understand their dynamics.

Studying the family as a unit whose members mutually impact each other supports the social work value of the importance of human relationships. The outcomes of this research study aim to assist social workers in understanding how parents of children with special needs are impacted by raising their child and the information and knowledge they seek to obtain to support their child. Studying how parents are impacted by their relationship to their children as caregivers to children with special needs is useful to understand the needs of the parents in the family and social environment. Additionally, studying the needs of parents may assist social workers in identifying which outside human relationships need to be strengthened to support these families.

The outcomes of this research study can be used to help social workers better serve parents of children with special needs. There are many elements which impact families in diverse situations, and families with children with special needs are just one example of a diverse family. Through research outcomes based on studying the needs of local families with children with special needs, social workers may be better informed to
provide services that meet those needs. The profession of social work teaches social workers to work with the client and not simply at the client. By including the families in the research process and providing them with an opportunity to identify their needs in their own lives, the outcomes of this research study can assist social workers in providing competent services which the families recognize as relevant to them.

**Limitations**

This exploratory study will identify what families of children with special needs feel are areas they desire to receive more support. This study does not offer predictive data on families of children with special needs, nor does it address causality in the relationships between families and resources. Because of its relatively small sample size and qualitative design, the generalizability of the findings of this study is limited. This study does not primarily address the emotional, social, or financial impact of raising a child with special needs but instead focuses more on the families' access to resources and information and their desires to receive additional support through social services and education.
Chapter 2

REVIEW OF THE LITERATURE

Introduction

This review of the literature is based on an electronic literature search, using terms such as family, impact, special needs, emotional, financial, stress, disability, support, education, health care, and siblings in the Academic Search Premier database. The articles reviewed focus on the impact of a child’s special needs on his or her parents and siblings. Topics such as financial impact and the families’ feelings when interacting with health care, educational, and supportive services are also discussed. These specific articles were chosen because they focused more on the feelings, perspectives, and impacts on the family system around the child with special needs and not necessarily on the direct needs of the child.

Family Impact

Families, including parents and siblings, face many challenges in adjusting to life with a child with special needs. Alongside their concerns for their child’s independence, learning, and social relationships, parents face several concerns of their own, including finances, the child’s behavior problems, the burden of care, and their social needs as caregivers to a child with special needs (Beresford as cited in Jessen, Colver, Mackie, & Jarvis, 2003). Tsibidaki and Tsamparli (2009) identified that parents often struggled with time constraints and tiredness when raising a child with special needs, often having to work long hours watching the children or earning money outside the home to
accommodate the extra expenses of raising a child with special needs. The unpredictable process of waiting for their child to reach each developmental milestone sends families on what one mother of a child with Autism likened to a “roller coaster” ride that “plunged [her] to the deepest despair that their child would not be alright” (Schall, 2000, p 412).

Hughes et al. (2008) surveyed 16 Latino families of children with special needs under the age of 11-years-old who attended urban, predominately Latino public schools in the United States. The researchers used semistructured interviews to learn about Latino families’ perceptions of raising children with special needs, with particular attention to their experiences and involvement in their child’s schooling. Most families maintained the goal of wanting to treat their child as similarly as possible to children without special needs and desired for their children to be independent. The families surveyed identified being much more involved in the life of their child with special needs when compared to their involvement in their typically-developing children’s lives, especially in regards to schooling. They described raising a child with special needs as difficult, intense, and requiring a high level of commitment (Hughes et al., 2008).

Because raising a child with special needs requires a high level of involvement, parents of children with special needs sometimes identify themselves as “overprotective” of their child and worry about what may happen if they are not there to help him or her (Tsibidaki & Tsamparli, 2009).

Raising a child with special needs requires the family’s time, emotions, finances, and support. Parents must learn how to navigate through individualized treatment plans, especially in medical and educational settings (Wood et al., 2009; Janus, Kopeczanski,
Cameron, & Hughes, 2007). They often face the challenges of juggling work schedules with their child’s unique needs (Loprest & Davidoff, 2004). Siblings must adapt to numerous roles as they grow up with their brother or sister, sometimes struggling with the demands placed on them at a young age (Dellve, Cernerud, & Lillemor, 2000). Both parents and siblings feel the emotional impact of caring for a child with special needs (Green, 2002; Schall, 2000; Dellve et al., 2000).

Tsibidaki and Tsamparli (2009) surveyed 30 parents raising a child with a severe disability and 30 parents raising children without disabilities living in the peripheries of Greece. The purpose of this study was to compare the two groups’ family cohesion, adaptability of family functioning, and ideals and desires for their family functioning. Each participant in the study was administered the Family Adaptability and Cohesion Evaluation Scale (FACES-III) and interviewed in a semistructured interview. Tsibidaki and Tsamparli (2009) found that, in spite of the unique challenges of raising a child with special needs, there was no significant difference in the two groups’ family cohesion, adaptability, and aspirations for their families. Although stressors in families with children with special needs can negatively impact the social relationships of parents with each other and their social network (Vacca, 2006; McHatton & Correa, 2005; Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Bilgin & Kucuk, 2010), many families adapt positively (Louis, 2008; Hughes, Valle-Riestra, & Arguelles, 2008; Vacca, 2006) and have the potential to become more connected and supportive of one another through their challenges (Tsibidaki & Tsamparli, 2009; Bilgin & Kucuk, 2010).
Families of children with special needs not only adjust their lifestyles to meet the needs of their child but are also faced with a variety of needs of their own as they navigate through often unfamiliar situations and feelings to provide for their children.

**Parenting a Child with Special Needs**

**Initial Feelings**

Upon the birth of their child with special needs or receiving a diagnosis, many parents often experience a mourning process as they reevaluate the dreams and ideals they had for their child and for themselves as parents (Green, 2002; King et al., 2006). These ideals, which Green (2002) calls “narratives,” are based on cultural and familial expectations that begin upon conception of the child and grow in anticipation of the child’s birth. Receiving a diagnosis, even one parents were prepared for, such as by receiving indications of the child’s disability in utero, is a violation of the expectations that parents hold for their child and presents them with the difficult task of grieving a child that is still with them (Green, 2002; King et al., 2006). Many parents experience feelings of lost control over their lives and their child’s life (King et al., 2006). In a child’s infancy or toddlerhood, parents are forced to alter their dreams of their child’s future, which include his or her academic achievements, relationships with parents, independence, and the child’s future family in which he or she is the parent (King et al., 2006).
According to Barnett, Clements, Kaplan-Estrin, & Fialka (2003), upon receiving a diagnosis or discovering that their child has a disability, parents commonly react in twelve ways:

• Devastation, being overwhelmed, traumatized
• Shock, denial, numbness, and disbelief
• Feelings of crisis and confusion when attempting to cope
• Sense of loss for the child they had been planning and hoping for
• Grief reactions (similar to that experienced at the death of a loved one)
• Future hopes and expectations are challenged or destroyed
• Feelings of guilt, responsibility, and shame
• Strong anger towards the medical staff involved with the child
• Wondering whether things would be better if the child dies
• Lowered self-esteem and parental efficacy as providers and protectors
• Strained marital and family relationships
• Disruption in family routines

Many parents of children with special needs initially engage in self-blame for their child’s condition, such as a parents’ involvement in a war or car accident (Vacca, 2006; Green, 2002). Parents are often conflicted by feelings of being responsible for their child’s condition and struggle with feelings of what they should or could have done differently, examining their own lives and decisions as far back as adolescence (Vacca, 2006).
Although Schuengel et al. (2009) found that most parents resolve their initial feelings towards the diagnosis of their child, the initial perception of raising a child with special needs is predominately negative (Lawson, 2001). Among parents not parenting a child with special needs or parents whose child has recently received a diagnosis, children with special needs are perceived to come with a variety of stressors on parents, ranging from high cost of care to managing complex treatment plans for the child (Lawson, 2001; Vacca 2006).

Stressors on the Parents

Parents of children with special needs commonly face high and unpredictable levels of stress, regardless of the specific diagnosis their son or daughter receives (Narramore, 2008; Dellve et al., 2006; Spratt et al., 2007). Many of the stressors parents of children with special needs face are identical to those faced by parents with typically-developing children; however, added to their lives are their child’s complex medical, developmental, and psychological needs (Dellve et al., 2006). Sometimes, parents feel as though it takes months or years, often well beyond their child’s first birthday, to feel as though they are beginning to adjust to the complex needs and routines of their child (Fowlie & McHaffie, 2004). Parents must balance their lives around their child’s needs while still meeting their own needs and those of the other members of the family. A parent’s success in coping with the stressors differs from individual to individual, largely based on the personal characteristics of the individual, including learned and applied coping mechanisms already in place (Dellve et al, 2006).
Baker et al. (2003) studied 82 families with toddlers with developmental delays and 123 families with toddlers without developmental delays in a 2-year longitudinal study exploring the impact of a child’s intellectual disability on his or her behavior and the emotional stress of the parents. The toddlers were assessed using the Bayley Scales of Infant Development II (BSID-II) and the Child Behavior Checklist for Ages 11/2-5 (CBCL), and parents were administered the Family Impact Questionnaire (FIQ). When compared to parents of similar-aged young children, parents of children with special needs reported significantly more negative views of parenting, social relationships, and family finances, a finding that has been consistent in the literature for over 20 years (Baker et al., 2003).

Parenting stress is highly related to and impacted by a child’s maladaptive behaviors even more than a child’s cognitive delay (Baker et al., 2003; Dellve et al., 2006). Dellve et al. (2006) administered the Swedish Parenthood Stress Questionnaire (SPSQ), the Ladder of Life instrument which measured overall well-being and quality of life, and The Interview Schedule of Social Interactions (ISSI) to 138 families. The purpose of their study was to assess the stress, well-being, and social support of both mothers and fathers of children with special needs. They found that parents, especially mothers, of children with behavior-related disabilities, such as ADHD (Attention Deficit Hyperactivity Disorder) and Fragile X Syndrome, reported the highest levels of stress when compared to parents of children with other types of disabilities (Dellve et al., 2006).
Baker et al. (2003) reported that parent stress and a child’s maladaptive behaviors have “mutually escalating effects” (p. 227) as they found that just as an increase in a child’s maladaptive behaviors is linked to an increase in parent stress over time, the parent’s stress was linked to a child’s maladaptive behaviors as well. Spratt et al. (2007) assessed 226 children ranging from four-years-old to 12-years-old and their families from four different pediatric outpatient clinics to study correlating factors of parenting stress. Although their primary goal was to study the factors contributing to parenting stress, they discussed the mutuality of the parent-child relationship after observing the impact of the child’s behavior on the parent and his or her stress levels and the lack of attention this topic received. Baker et al. (2003) and Spratt et al. (2007) were in agreement that a child’s disability impacts the parenting environment which impacts the parent-child interaction which impacts the child’s behaviors in a cyclical pattern, either harming or supporting the parent-child dyad. Although parents of children with maladaptive behaviors reported the highest levels of stress, parents of children with physical and progressive disabilities also reported very high levels of stress (Dellve et al., 2006).

Lack of control is a common stressor among parents of children with special needs (Fisher, 2001). As they adjust to a diagnosis, parents report an initial struggle with feelings of lack of control (King et al., 2006). Although they often resolve these feelings by exerting control over things in their power such as time management, this resolution is fragile and is easily triggered by situations causing uncertainty (Fisher, 2001).

Higher parenting stress is correlated to parents’ reported feelings of isolation and low support (Spratt et al., 2007; Baker et al., 2003; Dellve et al., 2006). Parents who are
in situations where they feel isolated, such as having a child with a rare disease or being a single-parent, reported higher levels of stress before being connected to resources and support (Dellve et al., 2006). Some parents feel isolated and unsupported in raising their child but have difficulty reaching out for help because they feel their child is their responsibility and they are failing in raising him or her by asking for help (Brett, 2004). However, according to Brett (2004), although parents often initially struggle in asking for help, they eventually report less stress after receiving support.

According to Fowlie and McHaffie (2004), some parents develop mental disorders as a result of the stress of raising a child with special needs. Feldman et al. (2007) used the Beck Depression Inventory (BDI) to assess 178 primary caregivers of two-year-olds with or at risk of a developmental delay and currently receiving early intervention services to investigate predictors of depressive symptoms in caregivers. They found that 20% of caregivers had BDI scores above the clinical cut-off for depression, over 13% higher than the overall prevalence. Although Fowlie and McHaffie (2004) did not find correlation between the severity of a child’s condition and the parents’ levels of stress, Feldman et al. (2007) found that parents who scored above the BDI cut-off for depression shared several tendencies, including decreased social support, increased behavior problems of the child, and the use of escape-avoidance coping techniques. These findings on the characteristics of highly-stressed parents are consistent throughout the literature (Baker et al., 2003; Spratt et al., 2007; Dellve et al., 2006; Feldman et al., 2007).
Although both parents involved in their child's life feel the effect of raising a child with special needs, mothers and fathers are often impacted in different ways, especially with regards to the roles they play in their child's life.

**Mothers**

Mothers of children with special needs are uniquely impacted by the needs of their child. In some cultures, such as the Greek culture, the mothers of children with special needs perform more family-based tasks and are often more in-charge of managing the family’s affairs than the fathers (Tsibidaki & Tsamparli, 2009). Regardless of the mother’s work status outside of the home, mothers face unique challenges and rewards when raising their child with special needs.

Professionals in the field of higher education such as Green (2002), Lawrence (2007), and Louise (2008) have documented their experiences as mothers of children with special needs and included their interactions with others as well as shared experiences of other mothers of children with special needs. Lawrence (2007) described the dread she faced when being questioned about her daughter by a passerby in the park and the uncertainty of which answer she should give in response to a simple question of how old her daughter was when the toddler did not respond to the passerby. Navigating through social situations with a child with special needs is a challenge that may contribute to mothers’ feelings of stress (Green, 2002; Emerson, 2003). Because many disabilities, such as Autism Spectrum Disorder, carried the misconception of being caused by the mother, it is not uncommon for mothers to feel guilty about their child’s condition or uneasy when engaging with parents of typically-developing children (Kuhn
& Carter, 2007; Lawrence, 2007). For many mothers, their first interaction with a child with special needs is with their own child, causing not only a broad range of emotions but also a shift in their perception and understanding of special needs (Green, 2002; Lawson, 2001; Bilgin & Kucuk, 2010).

Mothers often feel the strain of raising their child with special needs and balancing their professional lives. Mothers in the military with children with special needs reported experiencing mixed messages between “family first” and “mission first” (Taylor et al., 2005). While the military mothers interviewed reported varying degrees of support in the workplace, they all expressed tension between working and raising their child (Taylor et al., 2005). Louis (2008), a university professor and mother to a son with autism, described the stress of blending her professional life and parenting responsibilities as “an extra layer of planning and pressure [which] hover over everything that I do” (p. 235). Tunali and Power (2002) found that, when compared to mothers of children without autism, mothers of children with autism placed less emphasis on their careers, placed more emphasis on their roles as mothers, and thought that more mothers of children with autism should stay home with their children although over half of the mothers of children with autism surveyed worked outside of the home.

Mothers often desire to be a part of their child’s intervention services and treatment. Higher levels of maternal self-efficacy, or confidence in their role as mother, were reported in mothers who reported to be more active in promoting their child’s development (Kuhn & Carter, 2007). However, a mother’s active involvement in her child’s interventions can place strains on her life as well.
Schwichtenberg & Poehlmann (2007) interviewed 41 mothers of children diagnosed with an Autism Spectrum Disorder using questionnaires about their child’s behaviors, the emotions and feelings of the mother, the child’s intervention program. The purpose of their research was to assess the impacts of home-based Applied Behavior Analysis (ABA) programs, the intensity of the program, and the involvement of the mother in facilitating the intervention on the mothers’ feelings of stress and well-being. When looking at ABA therapy, a common intervention for Autism Spectrum Disorder, although mothers reported fewer depressive symptoms when their child had more hours in an ABA program each week, mothers who spent more hours of direct involvement in their child’s ABA therapy reported increased feelings of personal strain (Schwichtenberg & Poehlmann, 2007).

Tunali and Power (2002) studied 29 mothers of children with autism and 29 mothers of children who did not have autism to test their 1993 model of the coping mechanisms of mothers of children with autism. To assess coping in the marital relationship, mothers were asked open-ended questions about the strengths of their partner relationship and things they would like to change in their marriage. Social support, especially support from the child’s father, was an important factor for mothers raising children with special needs (Tunali & Power, 2002). When compared to fathers of children with special needs, mothers tend to feel less supported by their partner and more stressed (Dellve et al., 2006). Mothers who lack social support are more vulnerable to the stress of raising a child with special needs, especially when taking care of their child is their primary responsibility (Bilgin & Kucuk, 2010). Mothers who do not feel
supported by the fathers of their children are more susceptible to psychological and emotional issues (Bilgin & Kucuk, 2010).

McHatton and Corea (2005) conducted qualitative interviews with 50 Latina, single mothers of young children with special needs with the purpose of studying stigma and discrimination related to being a single mother of a child with a disability in a culture which already experiences discrimination. They found that although mothers reported that occasionally family members were fearful of interacting with the child or discriminated towards the child due to his or her disability, it was most often the father who became distant. Many mothers studied by McHatton and Correa (2005) reported being single mothers due to the father of their child leaving, which was directly related to the father’s inability to cope with their child’s disability.

**Fathers**

There is considerably less research that focuses specifically on fathers and their needs and interactions with their children with special needs when compared to mothers or parents of children with special needs (Dollahite, 2003; de Falco, Esposito, Venuti, and Bornstein, 2008; Davis et al., 1991). Historically, fathers of children with special needs have tended to have a more indirect approach to raising their child, often putting their efforts into financially supporting their family (Tsibidaki & Tsamparli, 2009; Davis et al., 1991). However, research indicates the importance of direct paternal support and interaction on the development of their children (de Falco et al., 2008; Davis et al., 1991).

De Falco et al. (2008) studied 19 toddlers with Down Syndrome under four-years-old while playing alone and with their fathers. The purpose of their study was to explore
the effects of paternal interaction on the complexity of the child's play when compared to the child's solitary play. De Falco et al (2008) found that, even after controlling for both developmental and chronological ages, the children had more complex and sophisticated play when playing with their fathers compared to when playing alone. Fathers represent an important resource for both the development of their children with special needs and the support of the partners (de Falco et al., 2008; Tunali & Power, 2002). When discussing the importance of paternal involvement, Dellve et al. (2006) projected long-term benefits of fathers' involvement in their families, including increased family harmony and decreased maternal stress.

Dellve et al. (2006) studied 136 mothers and 108 fathers of children with rare disabilities with the purpose of assessing their social support, stress, and well-being. While assessing parenting stress, they found that mothers often felt stressed due to emotional strain while fathers' stress stemmed from feelings of incompetence. When provided intervention and education on how to interact with their child and their child’s abilities, fathers’ perceived knowledge increased and their stress due to incompetence decreased (Dellve et al., 2006). Sources of paternal stress also included concern for their child’s future, the impact of their child’s disability on their marriage, and the stress of their wives (Dellve et al. 2006). Fathers demonstrated improved “active coping” skills after receiving intervention focusing on competency (Dellve et al., 2006).

Davis et al. (1991) created eleven strategies for involving fathers in early intervention, challenging service providers to set expectations that the fathers would actively participate in their child's care and treatment and to understanding that men may
not be involved not because they do not want to be but because they do not know how. These key points are consistent in the literature of the struggles and needs fathers have in raising their child with special needs (Davis et al., 1991; de Falco et al., 2008; Dellve et al., 2006).

Comprehensive understanding of the impact of raising a child with special needs cannot be fully obtained without considering the experiences of the siblings in addition to those of the parents.

**The Sibling Experience**

The relationship between siblings is typically one of the longest-lasting human relationships (Orsmond & Seltzer, 2007; Conway & Meyer, 2008) and often outlasts parent-child and spousal partner relationships. Growing up with a sibling with special needs presents unique challenges for siblings throughout the lifespan.

**Siblings in Childhood**

Children as young as three-to four-years-old demonstrate understanding of a sibling’s special need, even if the sibling does not necessarily appear physically different, such as in the case of learning disabilities (Hames, 2005). Even at a young age, being a sibling to a child with special needs provides a certain insight about the differences and challenges their siblings will face that children without siblings with special needs do not have (Hames, 2005). Young siblings express emotions ranging from enjoyment in playing with them and goals they want to help the siblings with to not feeling it is fair that the sibling hits them but they cannot hit back and frustration about being woken up in the middle of the night (Dodd, 2004). As typically-developing children grow up with
their sibling with special needs, they are both impacted by their sibling as well as impact their sibling’s life.

Siblings may play important roles in the socialization and development of their sibling with special needs, and increasing research is targeting the education and utilization of siblings (Bass & Mullick, 2007; Trent, Kaiser, & Wolery, 2005). In children with autism, siblings as young as preschool-age may play a part in their sibling’s development of social and play skills through strategies taught to young siblings to help facilitate play (Bass & Mullick, 2007). Trent et al. (2005) worked with two dyads, each consisting of a typically-developing sibling in elementary school and her younger sibling with Down Syndrome, twice weekly for 20-60 minutes over the course of three months. Their purpose was to study the effectiveness of interventions targeting typically-developing older siblings to facilitate communication with their younger siblings with Down Syndrome. They found that the older siblings responded positively to the utilization of intervention strategies which taught them techniques in interacting with their siblings (such as pausing at least 5 seconds to give their sibling time to respond to a question) and continued to implement the techniques one the month after receiving the education (Trent et al., 2005).

As siblings grow older, many face a variety of emotions, both positive and negative, pertaining to their siblings with special needs.

**Adolescent Siblings**

Dellve et al. (2000) conducted a qualitative study with 15 adolescent females who had siblings with deficits in attention, motor, and perception or Asperger Syndrome. The
purpose of their study was to explore how adolescent siblings coped with their life experiences of being in a family with a child with special needs. They found that the siblings discussed challenges in dealing with the demands and expectations placed on them, such as having to act like the older sibling when they were not and feeling their needs were not the top priority in the family although they recognized that their parents made an effort to help them feel treated fairly.

Adolescents face unique challenges as they deal with the expectations placed upon them while experiencing typical adolescent developmental milestones. Dellve et al. (2000) found that adolescents expressed a strong desire for independence, sometimes feeling as though they were fighting to obtain it. Some adolescent siblings expressed the desire to distance themselves from their siblings with special needs while others expressed loneliness and sorrow over the sibling relationship they could not have (Dellve et al., 2000), much like the way parents of children with special needs grieve over the lost dreams for their relationships with their children (Green, 2002; King et al., 2005).

Dellve et al. (2000) found that adolescent siblings maintained a strong loyalty to their families and valued their families even though they felt their siblings hindered them from social relationships and achieving their goals. Adolescent siblings face many conflicting emotions and struggle to find the balance in their relationship and roles with their siblings with special needs (Dellve et al., 2000), and support networks including family, spirituality, friends, and health care professionals assist them in coping with their experiences (Bellin, Kovacs, & Sawin, 2008).
As siblings transition to adulthood, although they may no longer live together in the same household, their relationship with their sibling with special needs continues to be a factor in their adult lives.

**Adult Siblings**

Hodapp and Urbano (2007) surveyed 284 adults who had a sibling with Down Syndrome and 176 adults with a sibling with Autism using the Adult Sibling Questionnaire to measure the siblings' lengths of contact, perceived quality of relationship, and perceived health of the adult sibling without special needs. Their purposes were to compare adults with siblings with Down Syndrome to adults with siblings with Autism and to study the changes in sibling relationships as they age. They found that while both sibling sets described their relationships as generally positive, siblings of brothers/sisters with Down syndrome were closer to their siblings, had a more positive relationship with their siblings, had more contact, and experienced better health and less depressive symptoms than siblings with brothers/sisters with autism (Hodapp & Urbano, 2007).

The behavior of the individual with special needs impacts the relationship the individual has with both his or her parents and siblings (Baker et al., 2003; Dellve et al., 2006; Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007b). Research indicates that the relationship between siblings is closer when the sibling with special needs is better at maintaining friendship and more distant when the sibling expresses emotional and behavioral problems (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007a). Orsmond and Seltzer (2007a) found that sibling education levels, coping skills, own family
structure, and perception of the sibling’s disability impacted sibling relationships. As the siblings age, their relationship changes and tends to become less close, which is an important factor to consider as brothers and sisters often become caregivers for their aging siblings (Hodapp & Urbano, 2007; Ormond & Seltzer, 2007a).

**Sibling Support**

Siblings can easily be overlooked when families are caught up in the needs of their child with special needs, but research has shown the value of supporting siblings in their unique needs and relationships with their siblings (Dodd, 2004; Conway & Meyer, 2008). Siblings experience a broad range of emotions as they grow up with their sibling with special needs (Ormond & Seltzer, 2007a; Dellve et al., 2000).

Many siblings benefit from meeting with others who share their experiences (Dodd, 2004; Conway & Meyer, 2008). Dodd (2004) categorized the responses of children ages four to 11 after they attended a two-day sibling group for children with siblings with special needs. Dodd (2004) included the responses of 77 siblings over 8 years who participated in the group and found that a key theme in their responses was the positive view towards the sibling group. When reviewing the specific needs of siblings of children with special needs and current programs in place to meet those needs, Conway and Meyer (2008) discussed the benefits of sibling support groups and stated the importance of preparing and supporting siblings of children with special needs for the experiences they will face.

Up to this point, this literature review has focused primarily on the social and emotional needs and impacts of parents and siblings of children with special needs.
However, raising a child with special needs impacts the economic and financial situations of the family as well. The following section presents information on the financial impact of raising a child with special needs in regards to poverty, childcare, and employment.

**Financial Impact of Raising a Child with Special Needs**

Raising a child with special needs often has a strong financial impact on the family. Caring for a child with special needs commonly includes intensive therapies, adaptation of the physical home environment, medical costs, and special learning tools (Parish & Cloud, 2006), many of which must be paid for out-of-pocket when they are not covered by the child’s insurance. Raising a child with special needs is significantly more expensive than raising a typically-developing child (Parish & Cloud, 2006; Parish, Rose, Grinstein-Weiss, Rich Man, & Andrews, 2008; Emerson, 2003). In addition to the financial needs that parents of typically-developing children face, parents of children with special needs are confronted with additional treatment costs, varied schedules in the treatment of their child, and difficulty in finding childcare for their child, all of which impact the parents’ opportunities to work and earn money (Loprest & Davidoff, 2004).

In a short documentary promoted by Autism Speaks, an organization that focuses on advocacy, research, and education around autism founded by the vice chairperson of General Electric and his wife after their grandson was diagnosed with autism (www.autismspeaks.org), one mother of a young son with Autism Spectrum Disorder compared the extra costs of her son’s therapies and treatments that were not covered by insurance to tuition at an Ivy League College. “I just say we’re sending Daniel (her son) to Harvard over and over again every year for the rest of his life” (Thierry, Watkins, &
Parish and Cloud (2006) attributed the financial stress on the families to be impacted by:

- Elevated costs of raising children with disabilities
- Low levels of public income transfer benefits
- Difficult balancing parental employment and caregiving responsibilities
- Unavailable or high-cost child care
- Inadequate leave time to permit parents to meet their children’s episodic care needs (p. 223)

Because of the high cost of raising a child with special needs, the economic situation of the family plays a strong role in the services the child receives (Loprest & Davidoff, 2004; Parish & Cloud, 2006). Often, the high cost of raising a child with special needs places a financial strain on the family, and many children with special needs belong to families living in poverty (Parish & Cloud, 2006; Fujiura and Yamaki, 2000).

**Impact of Poverty**

Fujiura and Yamaki (2000) found that while 16% of children without disabilities lived in households below the federal poverty level, 28% of children with disabilities lived below the federal poverty level. Having a disability significantly increases a child's likelihood of living in poverty (Parish & Cloud, 2006). According to Leonard, Brust, & Sapienza (2002, as cited in Parish & Cloud, 2006), 12% of the income of low-income families is spent on the expenses of the child. Because low-income families already have limited financial resources, additional expenses of supporting a child with special needs can strongly impact the family. The most common expenses for low income families of
children with special needs were related to medical and special equipment costs (Parish & Cloud, 2006), which often does not include additional recommended interventions not necessarily covered by insurance.

Parish et al. (2008) analyzed secondary data from the 2002 National Survey of America's Families (NSAF). Their study sample included 2,970 households with a child with special needs and 25,171 households with children without special needs. The purpose of their research was to analyze financial hardship in families with children with special needs compared to families without children with special needs by measuring their food insecurity, housing instability, health care access, and telephone disconnection. They compared the two groups' financial hardship and poverty levels and found no significant difference in financial hardship among families of children with special needs living below 100% of the federal poverty level (FPL) and families of children with special needs living between 100% and 199% of the FPL. Additionally, in families with children with special needs, when analyzing financial hardship due to medical costs, families living between 200% and 299% of the FPL showed no significant difference in hardship than those living below the FPL. In contrast, financial hardship sharply declined in families without children with special needs as family income rose above the poverty level, suggesting that families with children with special needs are more severely impacted by financial hardship (Parish et al., 2008).

When impacted by limited incomes, families with children with special needs often face difficulties finding affordable childcare, especially childcare that can
accommodate the special needs of their children (Taylor et al., 2005; Parish & Cloud, 2006; Loprest & Davidoff, 2004).

Childcare

The majority of the available research on childcare for children with special needs focuses on characteristics of a quality childcare program as opposed to the availability or accessibility of programs (Parish & Cloud, 2006). However, finding affordable childcare for a child with special needs is a challenge many parents face (Taylor et al., 2005; Parish & Cloud, 2006; Loprest & Davidoff, 2004). Little research has been conducted regarding childcare services and the specific challenges families face finding childcare as related to children with special needs (Parish & Cloud, 2006), although parents often cite childcare needs and concerns when discussing limitations to working or challenges in raising their child (Taylor et al., 2005; Loprest & Davidoff, 2004).

Parental Employment

The employment of parents with children with special needs is impacted by their child’s special need (Loprest & Davidoff, 2004; Parish & Cloud, 2006; Taylor et al., 2005). Loprest and Davidoff (2004) analyzed secondary data from the 1999 and 2000 National Heath Interview Survey. After limiting the data to only families who lived below 200% FPL, their study sample consisted of 8,591 families with children without special health care needs and 1,253 families with children with special health care needs. The purpose of their research was to compare employment patterns and barriers to employment between the two groups and to study the connection between having a child with special health care needs and the parents’ ability to work. They found that, when
compared to children who did not have a special health care needs, children with special needs were significantly less likely to have at least one parent employed full time (Loprest & Davidoff, 2004). Additionally, they found that while 18% of low-income families without a child with special needs had no working parent, over 25% of low-income families with a child with special needs did not have a parent who worked. They also found, however, a correlation between child health and parental health. Parents of children with special needs were more likely to receive SSI, report limited activity, and report fair or poor health than parents of children without special needs (Loprest & Davidoff, 2004). Loprest and Davidoff (2004) provided several hypotheses to this correlation including genetics, environment, and increased likelihood of receiving medical care when one family member is receiving care and expressed the importance of considering the parents’ health when studying the child’s health in relation to the parents’ work.

Although single parents with low incomes with children with special needs worked less hours per week than parents with low incomes who did not have children with special needs, similar trends were observed in both groups of parents in regards to gender of parent, ethnicity, and education (Loprest & Davidoff, 2004). Single fathers of children both with and without special needs worked more hours than single mothers, single white and not Hispanic parents worked more hours than single black and Hispanic parents, and parents with a high school diploma or GED worked an average of six hours more each week than parents who did not finish high school or obtain their GED (Loprest & Davidoff, 2004).
Research indicates that mothers raising children with special needs are employed less than fathers raising children with special needs and mothers raising children without special needs (Tunali and Power, 2002; Brandon, 2007; Parish, Seltzer, Greenberg, & Floyd, 2004). Mothers of children with special needs face several challenges in maintaining employment and raising a child with special needs.

Parish et al. (2004) analyzed secondary data from the Wisconsin Longitudinal Study collected when participants were, on average, 18, 36, and 53-years-old. The purpose of their study was to compare maternal employment and economic well-being between mothers of children with special needs and mothers of children without special needs. They found that mothers of children with special needs were more likely to work part time or less hours, earn less, and stay at one job for shorter amounts of time than mothers who did not have a child with special needs (Parish et al., 2004). Additionally, at the final comparison when participants averaged 53-years-old, mothers of children without special needs had significantly higher savings and income levels than mothers of children with special needs (Parish et al., 2004). Mothers, who are often viewed by many cultures as the primary caregivers to their children (Tsibidaki & Tsamparli, 2009; McHatton & Correa, 2005), find barriers to childcare as a considerable challenge when being employed (Loprest & Davidoff, 2004; Taylor et al., 2005).

While there are many factors contributing to the employment of parents of children with special needs that may not be directly related to the needs of their child (Loprest & Davidoff, 2004), research and parent testimony indicate that raising a child with special needs poses financial stress and concerns on parents and families (Taylor et
al., 2005; Emerson, 2003; Parish & Cloud, 2006; Parish et al., 2008; Thierry, Watkins, & Solomon, 2006).

As mentioned previously, medical and health care costs often place financial strain on families of children with special needs (Parish & Cloud, 2006). In addition to the financial strain, parents of children with special needs often experience emotional stress around their child's health care needs (Lawson, 2001; Vacca 2006).

**Navigating the Health Care System**

As their child grows and receives medical services, parents of children with special needs become well-acquainted with the health care system. Although parents tend to report satisfaction with the medical services their child receives, caring for a child with special health care needs places significant stress on parents (Wood et al., 2009).

**Accessibility of Services**

The accessibility of the medical services their child receives is a strong concern for parents of children with special needs (Naar-King, Siegel, & Smith, 2002). Children with special needs are often referred to numerous specialists and treatments, and parents experience challenges in accessing medical services that are not in close proximity to their residence (Naar-King et al., 2002). As children were referred to other service providers from their primary pediatrician, Wood et al. (2009) found that over half of the parents surveyed were not satisfied with the support they received from their pediatricians in accessing additional services. Parents often feel that they do not have enough support or information when accessing medical services for their children (Wood
et al., 2009). Wood et al. (2009) found that increased frustration and decreased satisfaction result when parents feel they face barriers to their child’s care.

**Connecting with Professionals**

Fisher (2001) placed the common needs of parents of children with special needs into three categories, one of which is the need for partnership. This need for partnership is especially evident in dealing with the child’s medical needs (Brombley, 2008; Koshti-Richman, 2009). Parents express desire for health care providers to connect with them not only with respect to their child’s treatment plans but also regarding the impact the special needs have on the family at home (Koshti-Richman, 2009; Wood et al., 2009). Medical professionals can help parents feel connected to their child’s treatment plans by identifying and supporting the needs that parents of children with special needs have (Hewitt-Taylor, 2009; Koshti-Richman, 2009; Wood et al., 2009). Parents are impacted by their relationships and interactions with others, including medical professionals (Vacca 2006; Hewitt-Taylor, 2009).

Vacca (2006) conducted two focus group interviews with five parents whose toddlers had a diagnosis of spastic quadriplegic cerebral palsy and were receiving early intervention services. The purpose of this pilot study was to investigate the attachment between parents and children with severe physical disabilities. Although Vacca (2006) was interested in studying attachment, a common theme that emerged from the interviews with the parents was their increased confidence in their abilities due to the support they received from the professionals working with them. As suggested by the parent testimonies in Vacca's (2006) study, parents report feeling positively about medical
professionals when they feel their interactions with them are positive. However, parents often report varying levels of satisfaction with medical care.

**Differing Levels of Satisfaction with Medical Care**

Wood et al. (2009) surveyed 262 families of children with special needs from six different medical practices and conducted focus groups with 28 families using both qualitative and quantitative interviewing. The purpose of their study was to assess their satisfaction with their interactions with medical staff. They found that although parents tend to report satisfaction in the medical services received by their children, certain parent groups express more negative responses than others. Wood et al. (2009) found that parents whose children had more severe medical needs and who felt more heavily impacted by their child’s condition tended to report less satisfaction overall than other parents. Additionally, when compared to fathers of children with cerebral palsy, mothers of children with cerebral palsy felt their child’s treatments were significantly less acceptable (Dahl, Tervo, & Symons, 2007). These findings cause some researchers to speculate that parents who are more heavily impacted by their child’s special need may view their child’s treatments differently and have differing expectations for their child’s care (Dahl et al., 2007; Wood et al., 2009).

In addition to the health care system, another system that families of children with special needs frequently interact with is the educational system.

**Parents’ Interactions with the Education System**

Parents of children with special needs interact with the education system in a different way than parents of typically-developing children do. Beginning from when a
child enters school, parents must learn how to transition between various educational services and navigate through the Individualized Education Plan (IEP) process (Janus et al., 2007; Jung, Gomez, Baird, & Keramidas, 2008). Parents of children with special needs face concerns and struggles as they partner with the schools to educate their children (Jung et al., 2008; Hughes et al., 2008; Kirby et al., 2008).

**Parent Concerns**

Even before their child begins receiving educational services in a structured classroom setting, some parents of children with special needs struggle with knowing whether to place their child in a public or private setting and which services are the best for him or her (Kirby et al., 2008; Janus et al., 2007).

Janus et al. (2007) conducted semi-structured interviews with 20 parents of children with special needs who were in preschool and 20 parents of children with special needs who were in kindergarten. The purpose of their research was to study the process of transitioning from preschool to kindergarten and the impact and concerns of the families. Among parents whose young children had already transitioned to school, much frustration was found around the school’s delay in implementing services designated for their child. Additionally, they found that parents desired to feel supported by educators and administration as they experienced the transition and educational processes (Janus et al., 2007), much like they desire to feel supported by medical professionals when dealing with health concerns (Wood et al., 2009).

The interactions parents have with educators and administration impacts their feelings of frustration and support (Janus et al., 2007; Hughes et al., 2008).
Communication between parents and the school is important for parents so they feel aware of services available to their children as well as their progress (Janus et al., 2007; Hughes et al., 2008; Jung et al., 2008).

In their survey of 16 Latino families with children with special needs in elementary school, Hughes et al. (2008) found that the parents surveyed desired more meetings with teachers and more opportunities to observe their child in the classroom. Even though most parents reported satisfaction with their child’s education, the suggestion of improved and increased communication between teachers and parents was one that was brought up by many parents (Hughes et al., 2008).

Teachers represent only one group of a larger group of individuals and agencies which can become part of the support system for families of children with special needs.

**Supporting Families of Children with Special Needs**

Families with children with special needs face challenges in multiple areas of their lives. Research indicates that parents and siblings experience stress as they balance the services, therapies, emotions, and impact of raising a child with special needs (Spratt et al., 2007; Canary, 2008; Asberg, Vogel, & Bowers, 2007; Narramore, 2008; Dellve et al., 2006; Baker et al., 2003; Dellve et al., 2000), but it also indicates that various factors can mitigate familial stress (Spratt et al., 2007; Parish et al., 2008; Dellve et al., 2006).

One key theme throughout the literature is the importance of support felt by families with children with special needs (Asberg et al., 2007; Canary, 2008; Spratt et al., 2007; Baker et al., 2003; Dellve et al., 2006).
Feeling Supported

Feelings of support are inversely related to familial stress (Spratt et al., 2007; Baker et al., 2003; Dellve et al., 2006; Asberg et al., 2007). Asberg et al. (2007) administered the Parenting Stress Index—Short Form (PSI/SF), Multidimensional Scale of Perceived Social Support (MSPSS), Inventory of Socially Supportive Behaviors (ISSB), and Satisfaction With Life Scale (SWLS) to 35 parents of children with hearing loss ages 31-198 months. The purpose of their study was to explore the relationships among parenting stress, social support, method of communication with the child (such as sign language), and cochlear implant status in the lives of the parents. They found that higher levels of perceived support by parents corresponded to lower levels of feelings of stress. Although the actual receipt of social support was related to life satisfaction in parents, no significant correlation was found between the actual receipt of support and the stress levels in parents (Asberg et al., 2007). This finding supports research that indicates how important it is for professionals to recognize parent’s feelings of being supported through the services received (Narramore, 2008).

Families with children with special needs find support in various arenas, including online support groups and message boards (Koshti-Richman, 2009; Kirby, Edwards, & Hughes, 2008), family intervention and supportive programs (Dellve et al., 2006), and professional settings (Wood et al., 2009; Janus et al., 2007). While stress, although experienced in varying degrees, appears to be an inevitable experience in the lives of families with children with special needs, empowering families by providing them with
support and education positively impacts their feelings and coping skills (Dellve et al., 2006).

**Summary**

Parents and siblings of children with special needs are impacted by their roles in the child’s life. Parents face the challenges of strained social relationships, feelings of incompetence, financial stress, and frustrations with accessing services when navigating through the complicated systems of obtaining and receiving services for their children with special needs. Siblings face various struggles as they grow in their roles and relationship with their siblings with special needs. Research findings suggest the importance of providing families with resources, education, and support as they raise a child with special needs (Dellve et al., 2006; Asberg et al., 2007; Dodd, 2004; Conway & Meyer, 2008). As their child develops through the lifespan, parents of children with special needs often face needs of their own.

After reviewing primary research articles which focused on the needs and experiences of parents of children with special needs that were published between 1985 and 2001, Fisher (2001) summarized the common needs of parents into three categories: The need for normalcy and certainty, the need for partnership, and the need for information. Research indicates that parents face a variety of changes and make adjustments throughout their child's life (Green, 2002; King et al., 2006), and parents learn to cope with these changes by finding normalcy and acceptance in their situations (Hughes et al., 2008; Schuengel et al., 2009). Research also indicates the importance of support on parents of children with special needs, including support from their partner
and family members, social networks, and professionals (Brett, 2004; Dellve et al., 2006). Resch et al. (2010) conducted focus groups of 40 parents of children with special needs. The purpose of their qualitative study was to investigate the challenges experienced by parents of children with special needs which impact their wellbeing. From their focus groups, four major themes emerged: Obtaining access to information and services, financial barriers, interactions with the school and community, and family support. The most common barrier expressed among the participants was their access to information and services. Parents expressed frustration in fighting to access services and feeling like they were running around to access resources after countless referrals. The current literature agrees that parents desire to access information, services, and resources and that barriers to information, services, and resources adversely affect parents' wellbeing (Fisher, 2001, Resch et al., 2010; Hughes et al., 2008). However, what specific services and resources are parents most interested in receiving?
Chapter 3

METHODS

Introduction

To investigate the needs of parents of children with special needs, 34 parents from whose children were receiving early intervention services voluntarily participated in individual, face-to-face interviews and were administered a questionnaire created specifically for this study.

Design

This study design was a needs assessment using a mixed-method, exploratory design to assess the needs of parents of children with special needs (such as Autism Spectrum Disorder or Cerebral Palsy) who are eligible for early intervention services. Because many children below the age of three-years-old do not receive a specific diagnosis, the eligibility criteria to receive early intervention services in the state of California, according to the California Early Intervention Services Act, are a 33% delay in one developmental area between birth and 24 months of age or either a delay of at least 50% in one developmental area or at least a 33% delay in two or more developmental areas for children ages 24 months and older (“California early intervention,” 2009).

Although the majority of the research design was qualitative, four scaling questions were included for participants to self-disclose their levels of comfort, concern, and understanding on a scale of one to five. The qualitative questions were both open and closed-ended in nature.
The needs assessment addressed the needs of a community, namely parents of children with special needs, with interest in the services, information, and resources they accessed, were not accessing, and desired to access. Although the data was collected over a period of two months, this study had a cross-sectional design because data was collected from each participant only once.

**Population**

The population for this study was defined as parents of young children three-years-old and younger with special needs living in the San Francisco East Bay Area whose children received center-based early intervention services through a non-profit agency serving individuals with special needs.

**Sample**

Purposive sampling methods were used to obtain participants for this research study. Criterion sampling was used to target potential participants. The criteria applied to the sample included: 1) Speak either Spanish or English as a primary language, 2) have at least one child between the ages of 0-3 years old who 3) was currently receiving center-based, early intervention services through a non-profit agency serving individuals with special needs in Pittsburg, Concord, or Richmond. The selected agency from which the sample was obtained is a non-profit organization that serves individuals with developmental disabilities and runs both center-based and home-based early intervention programs for young children.

Caregivers who met the criteria were initially contacted through an initial information packet which include an introductory letter and release of contact
information form provided by the researcher and given to agency staff to distribute. Agency staff placed an information packet in each child's cubby and/or personal bag before each child went home from the center. Three waves of permission forms were distributed to parents in their child's personal bag, giving parents a total of approximately 5-7 weeks to respond. Caregivers were first asked to allow the agency to release their contact information to the researcher. Upon receipt of consent, agency staff provided the researcher with the caregivers' contact information. Of the 141 caregivers who received information packets, 38.3% (54 caregivers) returned the consent form to the agency. Ten caregivers declined to release their contact information, and 44 caregivers consented to release their contact information to the researcher. Availability sampling was then used and the researcher contacted the caregivers via telephone calls to recruit participants in her study. Of the 44 who gave permission to be contacted via telephone, 34 agreed to participate in the study.

Data Collection

Before parents were informed of the study and the data collection process was begun, written authorization was obtained from the Director of Children's Services at the agency. After obtaining verbal consent from the caregivers to participate in the study during the initial telephone screening, the researcher then scheduled individual, face-to-face interviews with each participant for a mutually convenient time and location. Interviews were conducted at locations agreed upon by the researcher and participant. Before interviews were begun, written consent was obtained from each client by signing a consent to participate form at the face-to-face interview.
Data were collected for each participant at individual, face-to-face interviews. Interviews were conducted with each participant from a preset questionnaire which included quantitative scaling and open and closed-ended qualitative questions. Interviews were conducted by the researcher in either English or Spanish, according to the preference of the participant. Each participant was asked a variety of demographic questions including age, income, education level, and city of residence. At each interview, the researcher read each question aloud to the participant and recorded his or her answers on the questionnaire. For questions involving more in-depth responses, key phrases were written down when word-for-word transcription was too difficult to record. The interviews lasted approximately 60-75 minutes per participant.

**Instrument**

The questionnaire administered to each participant was created specifically for this study by the researcher. The questionnaire was designed to cover health, psychological, and social aspects of the families' lives with special interest in the services that were accessed. Before the questionnaire was designed, the researcher conducted a literature review of needs assessments of parents with young children and/or children with special needs (Washoe County School District Parent Involvement Council Parent Involvement Needs Assessment, 2008; Matter, 2006; Washington State Department of Early Learning Parent Needs Assessment Phone Survey, 2008) to better understand the instrument’s focus areas and design. The Washington State Department of Early Learning Parent Needs Assessment was used as a foundation for the creation of this needs assessment because of its focus on a variety of aspects of family life, as opposed to
other needs assessments which focused primarily on one aspect, such as academic needs (Washoe County School District Parent Involvement Council Parent Involvement Needs Assessment, 2008; Matter, 2006).

Topics included in the questionnaire were chosen based upon a literature review of parents of children with special needs, casual conversations with parents and service providers of young children with special needs, and themes that emerged from the researcher's work in early intervention. Questions number 32 and 44 of the questionnaire were taken directly from the Washington State Department of Early Learning Parent Needs Assessment (Washington State Department of Early Learning Parent Needs Assessment Phone Survey, 2008) and slightly modified to more specifically target services for families of children with special needs. The questionnaire included 17 demographic questions, 4 questions to obtain additional background information, and 27 questions, both open- and closed-ended, around the participants’ needs in various aspects of their lives. For closed-ended questions, caregivers were prompted to elaborate on their responses by answering “why” or “why not.” Additionally, the questionnaire included five Likert-type scaled questions (on a scale of 1-5) to evaluate caregivers' levels of concern, comfort, or understanding for certain topics.

Upon completion of the study instrument, it was then translated into Spanish by the researcher then edited and back-translated into English by the researcher along with a bilingual service provider who worked with primarily Spanish-speaking families of young children with special needs. Early intervention program administrative staff were provided with a copy of the instrument that would be used for this study and invited to
provide feedback with regard to its relevancy. Although no feedback was received from
the administrative staff members, the bilingual service provider who assisted with the
translation provided feedback to the researcher.

**Measurement**

The closed-ended questions used in the study questionnaire had nominal and
ordinal levels of measurement. Most of the demographic questions had nominal levels of
measurement, and the Likert-type scaling questions were measured using ordinal levels
of measurement. Additionally, nominal levels of measurement were used for questions
which allowed participants to have multiple responses.

**Data Analysis**

Before data analysis was begun, the researcher separated the qualitative from the
quantitative data. Data analysis was conducted on the quantitative data by first coding all
responses, such as the scaling questions and questions which allowed participants to
report more than one answer. A code book was created to record how responses were
coded. Quantitative data were then organized, entered into the computer, and analyzed
using PASW Statistics 18.

Qualitative data were analyzed by conducting a content analysis of participants' responses. The responses were coded and key themes were developed after grouping the
codes into topics. Themes were then organized and compared with special attention to
patterns among the responses. Frequencies were used to present the distribution of
common responses in the data.
Human Subjects Protection

The California State University, Sacramento Division of Social Work Committee for the Protection of Human Subjects approved this research study on September 23, 2010 as a minimal risk study.
Chapter 4

RESULTS

Introduction

This chapter provides the demographic information of the study participants and reviews the results of this study, collected by conducting interviews with caregivers of children with special needs. During the interviews, caregivers spoke of the services and resources they utilized for their children with special needs and the services and resources they would like to utilize in the future. They shared questions and concerns regarding a variety of aspects in their children's lives, including their child's health, nutrition, mental processing, social interactions, and education. They also reflected on their experiences of receiving services for their children.

Demographics

Residence

Thirty-four caregivers participated in this study. All but one of the participants were parents of the child whose information was reported, and all participants lived in the same household as the child. All participants received early intervention services and resided in Contra Costa County (see Figure 1).
Forty-seven percent of primary caregivers were under the age of 44-years-old, and 53% were over the age of 45 (see Figure 2). Almost all study participants were female (92.5%), and 85.3% of participants identified themselves as the child's primary caregiver.
**Income**

More participants reported an estimated annual household income of over $100,000 than any other category (26.5%), and the second-highest category reported was an annual income between $25,000-$34,999 (see Figure 3).

![Figure 3. Estimated Household Income](image)

**Education**

Almost three-quarters (73.5%) of all participants had at least some post-secondary education after graduating from high school or obtaining their GED, and more participants reported they had education beyond a bachelor’s degree than any other category (23.5%) (see Figure 4). Almost one-third (32.3%) of participants had a bachelor’s degree or higher. This figure is slightly lower than the percentage of Contra Costa County Residents with a bachelor’s degree or higher (37.7%) (U.S. Census Bureau,
Participants’ ethnic backgrounds were diverse—27.5% identified themselves as Caucasian, 25% as Latino American, 25% as African American, 5% as Asian American, and 7.5% reported multiple ethnic backgrounds (see Figure 5).
Figure 5. Ethnic Background

The majority of participants identified English as the primary language spoken in the home (76.5%), but 20.6% of families identified Spanish and 2.9% of families identified Chinese as the family's primary language (see Figure 6).

Figure 6. Primary Language Spoken in the Home
**Household Makeup**

Over half (52.5%) of study participants were married, and an additional 15% of caregivers reported to be living with their child's other parent. The average number of children in the home was 2.26, ranging from one child (38.2%) to six children (5.9%). The majority of families surveyed (82.4%) had one child with special needs.

**Diagnosis**

Almost half of the children (47.1%) had not received any official diagnosis and were attending Early Intervention because of significant speech delays. Among children who had received a diagnosis, Autism Spectrum Disorder (14.7%) and Pervasive Developmental Disorder—Not Otherwise Specified (17.6%) were the most common diagnosis in this sample (see Figure 7).

*Figure 7. Child’s Diagnosis*
Length of Time Receiving Services

The average age of the child receiving Early Intervention Services was 30.82 months, ranging from 25 to 38 months. On average, the children had been receiving services through the Regional Center for 10.53 months (SD=8.65), ranging from three months to 34 months (see Table 1).
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Research Findings

The following information was obtained from the caregivers’ responses to the questions outlined in the survey. The questionnaire contained both closed and open-ended questions. All participants responded to all of the questions presented. The themes of health needs, social activities, educational issues, additional services, and reflection on the process of receiving and obtaining services were addressed in the original questionnaire. The responses in each theme will be presented in this section. Within each section and sub-section, results obtained from closed-ended questions will be addressed first (if applicable), followed by results obtained from open-ended question. Additionally, the use of open or closed-ended questions to obtain the reported responses will be indicated before presenting the findings.

Health Needs

Nutrition. The following information was obtained by asking the caregivers to rate their level of concern regarding their child’s nutrition using a scale of 1-5. Caregivers reported varying degrees of concern with their child's nutrition. More caregivers reported they were not concerned about their child's nutrition than any other category (29.4%), although 20.6% reported to be a little concerned, 11.8% reported to be concerned, 17.6% reported to be moderately concerned, and 20.6% reported to be very concerned. When presented with an open-ended question asking parents to identify their sources of nutritional information, most caregivers stated they utilized WIC (44.1%) and their own personal knowledge and research (38.2%) for nutritional information for their
children, often utilizing books and the Internet for answers to their nutritional questions. This will be further discussed in Chapter 5.

When asked an open-ended question about what types of nutritional information they would like to receive, most caregivers reported they would like general information on nutritional recommendations for their children and how to help them eat a variety of foods. Several caregivers voiced the desire to learn more about how a child's symptoms or disorder are affected by what he or she eats. Six parents expressed this topic as their primary nutrition question, but many caregivers mentioned this topic when discussing nutrition, stating they had “heard about different diets,” “thought about trying one,” but were “not really sure what they all mean or how to choose.” One mother, who self-reported spending “a lot of time researching” about the relationship between diet and symptoms said the following:

How do I know what diet intervention works based on an actual, measured perspective? It seems like there are these theories floating around about what [my child] should eat to make him less [symptomatic], but I don't really know which one is valid and which one is hokey, because most of them seem like they could be valid, and at the same time they seem like they could be hokey too. Do I just try them all? Poor guy.

This mother's concern was echoed by many caregivers throughout the interviews.

**Health services.** All families reported their children received speech therapy services and participated in occupational therapy activities integrated as part of the daily Early Intervention program. When provided with a list of services and asked to choose
the ones their child currently received, 32.4% of caregivers reported their child received special health services (speech therapy, occupational therapy, and/or physical therapy) outside of school. While the majority of participants reported wanting additional services for their children (speech therapy—73.5%, occupational therapy—64.7%, and physical therapy—47.1%), both participants who were receiving additional services outside of school and those who were not frequently mentioned the cost of obtaining additional services. When assessing the relationship between household income and additional services obtained outside of school, chi square analysis failed to reject the null hypothesis ($X^2=1.794, p=.180$). No statistically significant relationship was found between participants’ income and their utilization of additional services outside of school.

**Medical insurance and financial burden.** Although this question was not directly asked during the interviews, when asked an open-ended question regarding what additional health or medical information they would like to receive, six parents specifically stated having to terminate or decrease outside therapy services for their children due to out-of-pocket costs. One mother said the following:

> Everyone's cutting back on services. Even though I think I have good insurance, they keep refusing all of [my child's] stuff. Before, it wasn't an issue to pay $110 out of pocket for her extra therapy, but now I can't do that anymore. It's so frustrating knowing [my child] would benefit from the services but I don't have money to pay for them, Regional Center doesn't have money to pay for them anymore, and apparently my insurance doesn't want to pay for them.
Many caregivers shared their frustrations about their insurance companies, and 82.4% desired assistance understanding the process of obtaining services using their insurance. The overall feeling when parents discussed their interactions with insurance was not positive; parents commonly used phrases such as “jumping through hoops,” “left in the dark,” and “getting the run around” to describe their experiences. One mother described the process of obtaining services through insurance as “the frustration of getting denial after denial after denial only to find out I needed to get denied in order for a different funding source to kick in.”

**Psychological health.** Caregivers were asked an open-ended question about information they would like to obtain regarding their children’s psychological health, and the following themes emerged. Over half of the participants was wanting to know how their child processes and understands information. Parents who had older, typically-developing children often commented on the different learning styles they had noticed between their older child and the one attending Early Intervention. One third of caregivers wondered if their child understood them when they were communicating with them and wanted to learn how to communicate in a way the child would understand. Most parents had questions about how to engage their child's attention, and almost 15% of parents expressed this as their primary concern, using phrases like “feeling sometimes disconnected” from their child because he or she is “off in [his] own little world.”

**Social Activities**

Caregivers discussed a variety of topics regarding their family’s social support, including the activities they participated in and the activities and resources they would
like to utilize. Caregivers reported to have participated in a variety of activities for or with their child with special needs, including parent support groups (32.4%), parenting classes or home visits (64.7%), play groups (61.8%), library reading programs (8.8%), and sports, music, or art activities (26.5%).

**Support groups.** When discussing the topic of support groups for parents with children with special needs, parents reported mixed feelings about participating in the groups. Parents were asked a closed-ended question about their interest in support groups, and they seemed to be polarized about participating in them. The participants of this study seemed to either react positively towards the idea of joining a support group and were either in one or strongly desired to be part of one or were adamant they did not want to join a support group. Very rarely were parents ambivalent about participating in support groups, whether or not they had already participated in one before. A follow-up open-ended question about their feelings about support groups resulted in caregivers indicating a variety of reasons for not wanting to join support groups, the most frequent reason being “that's just not the way I deal with things” or “that's just not my style.” One third of participants expressed interest in joining a support group for parents with special needs and were especially interested in joining groups for families with children whose needs were similar to their own.

**Special-needs specific.** The topic of “special-needs specific” came up frequently when answering open-ended questions and discussing their interest in social activities for families and children with special needs. Regardless of the activity parents were interested in, they expressed desire to participate in activities designed especially for
children with special needs. Caregivers frequently reported wanting their child to participate in activities, including sports, music, and play groups, that were designed specifically for children with needs like their own. Caregivers often mentioned difficulty with putting their children in groups with typically-developing children. One mother stated the following:

   It's so hard knowing what age group to put him in. Do I put him with the three-year-olds because he's almost three? Or does he belong with the 18-month-olds because that's where he is cognitively? I don't think the kids will notice too much, but what would that be like with the other people, like the other parents?

**Educational Issues**

Parents were asked an open-ended question about their plans for children's educational future; 73.5% of caregivers planned on sending their children to public school, 14.7% planned on sending their children to private school, and 11.8% were undecided. Open-ended questions allowed parents to provide their feelings about sending their children to preschool and navigating the educational system. Several parents mentioned feeling more comfortable about their child going to preschool because he or she had already experienced a school setting in an Early Intervention Program. One mother stated: “I'm less worried about how he will do because he's doing really well in his program now. It was so hard to send him to school because he was so young, but I really see how good it is for him and I think I don't think I'll be as worried to send him to preschool.”
**Preschool concerns.** The following themes emerged from the open-ended question asking parents what their concerns were regarding sending their children to preschool. The most frequently mentioned concern was how their child would adjust to the new school environment (49.9%), including the teachers and other children. Parents were also concerned their child's new school placement would not have appropriate services or their child's services would be terminated or reduced. Three parents had children who they knew or suspected would not meet criteria for special education services in preschool, and they expressed mixed feelings about this. Although they were happy with the progress their children were making, they were concerned about their children having difficulty integrating into a typical classroom because of the delays that were still present but not significant enough to qualify for services.

**Parents’ comfort in navigating the educational system.** Parents were asked to rate their level of comfort in navigating the educational system on a set scale. The relationship between the participants’ feelings of comfort in navigating the educational system and their socioeconomic status as defined by their income and levels of education was assessed using chi-square analysis. Chi-square analysis failed to reject the null hypothesis for both level of education ($X^2=3.188, p=.203$) and income ($X^2=.355, p=.551$). No statistically significant relationship was found between parents’ socioeconomic status and their feelings of comfort in navigating the educational system.

**Budget concerns.** When asked an open-ended question about their concerns in navigating the educational system, the theme of being concerned because of the state budget for services emerged. Although this topic was not specifically addressed in the
questionnaire, parents frequently expressed concern about California's budget and how the current economic situation would affect their child's services. Twenty-two parents expressed concern about their school district's financial capability to provide resources to their children at least once when talking about their child's educational plans. Caregivers used words like “worried,” “fearful,” and “anxious” to describe their feelings about the state budget and the cuts in services they were afraid their children would experience, especially in regards to special education services. Many parents reported feeling “helpless” when it came to the budget and the negative impact it would have on their children, but two mothers reported becoming more politically involved because of their vested interest in special education. One mother stated: “I've found myself more up-to-date on legislation than I've ever been, and I'm telling my friends and family how these things affect my daughter.” Another reported “I've written letters to everyone. I even wrote a letter to Arnold Schwarzenegger [governor] inviting him to try doing what I do every day for just one day and asking him if he really thinks that cutting services for my baby is a good idea after all that.”

Additional Services

When parents were asked an open-ended question to elaborate on any additional resources they would like to receive, many parents elaborated on the specific services or information they wanted for their children, such as speech therapy or information on the educational system. A few parents, however, used this opportunity to request support in their marital relationship.
Marital support. Four mothers requested support to strengthen their marital relationships, three mothers stated they were in the process of separating from their husband, and two reported they had separated with their partner since their child had been born. The four parents who requested support in strengthening their marital relationships discussed a desire for increased time together with their spouse, identifying lack of time together as a contributing factor to the strain on their marriage. They felt that they had less time with their spouse because of the difficulty with finding someone they trusted to watch their child and because of the overall exhaustion they felt with their child’s services. The mothers, who identified themselves as their child’s primary caregivers, also felt that being the primary caregiver, especially if their husband worked outside the home, contributed to their frustration that their husband was not able to understand their experiences and provide the emotional support they desired. Some mothers shared their desire to receive emotional support from their husbands and felt that their feelings of not being supported were contributing to emotional tension in the marriage.

While some parents felt that having a child with special needs put a strain on the marital relationship, three mothers felt that the strain on the marriage had already been present before their child and that having a child with special needs diverted their attention away from the marriage and onto the child. One mother described her relationship with her husband as “on the back burner,” stating that they were planning on going to marital counseling when their child was diagnosed. As a result, she stated they never went as they have been consumed with understanding and obtaining services for their child and his special need. The parents who discussed the effects of having a child
with special needs on an already strained relationship desired to improve their relationship with their spouse but were unsure how they would find time in their schedules filled with therapies and appointments for their child.

**Reflecting on the Process**

From two open-ended questions, caregivers were asked to reflect on the process of obtaining services for their children and how they felt their own or family's needs had changed over time. The following themes emerged from the parents’ responses to the open-ended question. Most parents felt their child's pediatrician and medical team played important roles in their lives, especially at the beginning. Almost three quarters (73.5%) of families reported being referred to Regional Services by a medical professional, with pediatricians making up the largest referring body in this study (44.1%). Almost one third (32.4%) of caregivers identified a medical professional, usually a pediatrician, as a source of support early on when they were first noticing their child was not following typical developmental patterns. Generally, many parents reported feeling positively about their interactions with their child's pediatrician, although some expressed frustration. Almost one fifth (17.6%) of participants reported they would have liked to have received more support from their child's medical team early on.

When discussing what resources caregivers would have liked to receive early on, three common themes arose. Caregivers reported they would have liked to receive earlier access to services, increased support with the process of obtaining services, and more information on crucial developmental milestones, especially early indicators or “red flags” in their child's development.
Earlier access to services. Caregivers in this sample generally expressed satisfaction with the level of services they were receiving at the time of the interviews, but they frequently mentioned they wished they had received their current services sooner. “I wish I had all the help I'm getting now, but earlier,” one mother said. “It took me a while to get connected to other moms who had gone through this before, and they've given me advice on what I'm about to go through. I wish I had connected with them sooner.” Another mother echoed this desire by stating “I'm so happy with the resources I have now. I just really wish I had what I have now sooner and quicker.”

Increased support around obtaining services. Parents felt it would have been helpful to have someone who could explain to them the process of obtaining and receiving services, especially when initiating the process. Parents reported feeling “frustrated,” “confused,” and “overwhelmed” with the process of obtaining services. “I wish someone told me why I had to go through the process of getting a train of denials from [my son's] insurance before finally getting services,” one mother stated. Another mother stated she would have liked “support around the waiting process [after being referred to services], and support around the process of scheduling a call to schedule a call to wait for someone to call me back so I can get an appointment for my son.” One mother described her experience of obtaining services as “trying to put a puzzle together without knowing what it's supposed to look like. I wish I hadn't had to fight [for my son to get services], but it was worth it.”

Developmental milestones. Parents also wished that they had known what to look for early on in their children's development, often expressing how they wondered if
their child could have received services sooner had they known the warning signs. Some parents felt they had not received any developmental information from their child’s clinic or pediatrician, while others felt that although they had received some developmental information, they were not aware just how important the information was. “When my pediatrician started being concerned about [my son's] pretend play at 18 months,” one mother stated, “I felt like he was going overboard. Now I get it, but information saying 'this is why we assess early' needs to be something that's available to all parents so we can know the importance of why his doctor is saying what he is.” Another mother stated:

If I had seen what qualifies for Autism, I would have had a suspicion much earlier, but the pediatrician never alerted me to it. He didn't give me any indicators. Back then I didn't even know what to look for. More information early on for parents that let them know the possibilities and things to look for without frightening them would be perfect. Looking back, I have this guilt that I did not monitor the milestones closely enough.

**Feeling more positive.** When parents were asked to comment on how their needs had changed from when they first began receiving Regional Services until the present, many parents commented on how their feelings had changed over time. Almost half (44.1%) of parents reported feeling more positive about their child's condition and the process of receiving services. Parents used phrases such as “less guilt,” “less fear and sadness,” “less feeling overwhelmed,” and “less feeling helpless” to describe how their feelings had changed over time. “I look at things differently,” one mother said. “I don't feel special needs is a horrible thing anymore.” “My emotional needs changed once we
started receiving services,” said another mother. “I went from feeling lost in the wilderness to feeling like I could and was doing the best I can. It went from 'help me' to 'okay, I think I can actually do some of this.’” Parents attributed feeling more positively due to their increased comfort in interacting with different systems that provide services to them as well as because of the progress they had seen their children make. “I'm more calm now because he's made so much progress. He's doing more than he did before and is more alert. Instead of focusing on just what's right now, I feel like I can look to the future and encourage him to continue with his progress.” Several parents echoed this mother's sentiment of feeling like their perspectives had shifted from “looking back at what could have went wrong and just trying to get by each day to actually being able to look ahead to the future.”

**Looking towards the future.** As parents were asked to look towards the future and project the services they thought they would need, two common themes arose: 1) Maintaining the services their children were receiving currently and 2) Pursuing additional services, such as speech therapy outside of school. None of the caregivers surveyed desired to decrease the services their children were receiving. Parents who had older children with special needs, were connected to other families who had transitioned from early intervention programs to the school district, or had already begun the transition process themselves expressed concern and unhappiness that their children’s services would be decreased in the school district, such as less hours or days of program at school.
Caregivers expressed a desire to remain informed about their child's condition. Although parents frequently expressed how they had learned how to become more flexible with their expectations, schedules, lifestyles, and desires as parents of children with special needs, they still mentioned that, ideally, they would know what to expect and expressed desire to, as one mother put it, “know what's coming up for my family and my child.” Another mother stated, “I feel like for the past two years, [my child] and I have been growing in this together. I have no idea what to expect. I would at least like to be maybe even one step ahead of him.” Parents also mentioned wanting to see “older versions” of their children. One mother stated “I'm so curious to know what he will be like as a teenager. I just want to see a teenage version of him. What are 15-year-olds with [my child's special need] like?”

**Summary of Findings**

Overall, it was found that caregivers desired increased services and resources for their family and child in addition to the ones they were already obtaining. Caregivers desired increased support throughout the process of obtaining and receiving services as well as information on a variety of topics affecting their child’s development throughout the lifespan, including nutrition, education, and projected needs and growth.

Chapter 5 summarizes the findings of this research and provides recommendations for future social work practice and research.
Chapter 5

CONCLUSION

Introduction

This study aimed to explore the general needs and experiences of parents with children with special needs. Caregivers were asked specific questions from a questionnaire created by the researcher for this needs assessment and were given opportunities to provide additional information through open-ended questions. Themes addressed in the questionnaire were the child's physical and psychological needs, the family's social needs and concerns, and the caregivers' perspectives on the child's educational experiences. While the answers to the set questionnaire allowed the researcher to gain a deeper understanding of the needs of caregivers of children with special needs, much insight was gained from the themes that were brought up by the caregivers themselves that were not originally identified in the questionnaire. These themes were marital support and California state budget concerns. In addition to the aforementioned themes, the themes of participants’ demographic information and feelings about navigating the educational system will be discussed in the following section.

Research Content

Caregivers shared their experiences, concerns, and desires around obtaining and receiving services during their interview with the researcher. The following topics will be further discussed in this section: Participants’ demographic information, marital
support, caregivers’ feelings of comfort with navigating the educational system, and California state budget concerns.

**Participants’ Demographic Information**

The majority of the participants seemed to have relatively high annual household incomes, yet the themes of financial strain and the high percentage of people who utilized WIC for nutritional information were themes that would not typically be expected of people with higher incomes. A factor to consider when analyzing these themes is the geographic location of participants. All participants resided in Contra Costa County, which is part of the San Francisco Bay Area. Higher costs of living in the Bay Area may put additional financial strain on families whose income appear higher.

When considering the large volume of participants who utilized WIC as their primary source of nutritional information and comparing it to the participants’ annual household income, it should be noted that how participants utilized WIC was not asked in the questionnaire. Some families may have utilized WIC in the past when they met the income qualifications and continue to use the information they received although their financial situation no longer allows them to qualify for WIC food packages. It is also possible that some families may have utilized informational brochures from WIC without receiving the food packages from the program. Additionally, families who reported higher household incomes may still qualify for WIC as multiple families may reside in one household.
**Marital Support**

The theme of the effects of their children’s special need on the marital relationship was one that was not specifically identified in the questionnaire, yet many parents volunteered this information during the interview. It was surprising to the researcher how many parents volunteered information about their marital relationships. All of the parents who discussed their marital relationships were mothers, and the information they offered about the effects of their child’s special need on their marital relationship shared several themes, including desire for increased time with their spouse and desire for increased understanding and support from their spouse.

Dellve et al. (2006) found that mothers of children with special needs tended to report lower levels of marital satisfaction than fathers. While none of the fathers in this sample reported marital strain or dissatisfaction, only three fathers participated in the interviews as the primary responder to the questions. Several mothers discussed their desire for increased emotional support from their husband. The mothers’ desires for emotional support from their husband and the importance the mothers placed on that support is consistent with Bilgin and Kucuk’s (2010) findings which place value on social support, including marital support, in mitigating the stress of being a primary caregiver in mothers.

**Caregivers Feelings about Navigating the Educational System**

The chi-square analyses conducted to determine the relationships between the parents’ socioeconomic statuses (as defined by level of education and income) and their levels of comfort in navigating the educational system found no statistically significant
relationship between socioeconomic status (level of education\(= X^2=3.188, p=.203\); income\(= X^2=.355, p=.551\)) and comfort levels. This finding was surprising because it was initially expected that those with higher incomes and levels of education would feel more comfortable navigating the educational system than those with less education and income. In addition to being conducted with a small sample size, these analyses were also conducted with people who were already connected to services. It could be that positive experiences in receiving and obtaining services enable parents to project feeling more positively towards receiving services in the future. Additionally, as part of the early intervention program the children were enrolled in, families receive support with the transition process from early intervention to the public school system. It is possible that parents whose children participated in that particular early intervention program, knowing they will receive support when their child transitions, felt more comfortable about the transition process regardless of their socioeconomic status. This theme will be discussed further when addressing the implications for future research.

**California State Budget Concerns**

Although this topic was not originally addressed in the questionnaire, most parents discussed their concerns and anxiety around the California state budget and economic conditions. Almost two-thirds of all participants expressed concerns about the impact the cuts in the budget would have on their children’s services in public school. Parents who had older children with special needs shared new concerns about how the current economic situation would affect their child’s services, reporting that they had not felt this way previously when their older children were entering public school. The
overall feelings parents had towards the state of California’s economic situation were very negative, and a theme that emerged during the interviews was a sense of helplessness over the services their children would and would not receive due to the state budget.

Although this theme was not initially expected, the parents’ responses provided insight into the impact external factors have on families with children with special needs. The importance of understanding the impact of macro-level factors on micro-level needs will be discussed further when addressing the implications for future social work practice.

**Implications for Future Social Work Practice**

The interviews with caregivers of children with special needs conducted for the purpose of this research project provided caregivers an opportunity to identify the needs in their lives and share their desires to feel supported as they raise their children. From the conversations and suggestions of the caregivers, several recommendations for future social work practice emerged.

**Consolidated Resources**

Parents frequently expressed being confused and frustrated with the amount of information they had to learn as they went along with the process of obtaining and receiving services. When asked to reflect on their experiences receiving services for their children, parents stated they wished there was one place or resource that informed them of the many resources potentially available to their children. Because of this, it is recommended that a short, community resource guide is created and provided to
caregivers of children with special needs at the initial phase of receiving services.

Recommended topics to address in the resource guide include: Low-cost health services (such as speech or occupational therapy with students or interns through university programs), support groups, and assistance with equipment such as wheelchairs. This resource guide should be made available to and distributed by a variety of agencies that provide services to young children with special needs, including pediatrician offices, county clinics, child development programs such as First 5, early intervention programs, and Regional Centers. Additionally, this guide should be available in a variety of languages, as a concern for many monolingual parents who spoke only Spanish was the lack of printed material in Spanish.

**Programs Specifically for Special Needs**

Resources parents highly requested were services specific to children with special needs, especially play groups and community programs. As social workers and social service agencies create and facilitate programs for families with children with special needs, they should create programs specific to children with special needs to support not only the child but also the family. These include playgroups and community programs such as music or art specifically designed for children with special needs.

**Facilitating Peer Support**

Several parents expressed the desire for peer support with other parents with children with special needs, and social workers and social service agencies should provide accessible support groups for parents. Parents who indicated a desire to participate in support groups but were not engaged in one at the time of the interview
identified a variety of barriers, most commonly transportation, time conflict with work schedules, and childcare. Social workers who wish to provide support groups for parents should consider these identified barriers when choosing a location, time, and setting for their groups.

In addition to support groups, parents indicated a desire to connect with other parents who were more experienced than themselves in regards to the process of obtaining and receiving services. Several parents from a variety of backgrounds indicated a desire to have a mentor, which parents identified as another parent who was further along in the process than they were. While some programs connecting parents who have children with special needs currently exist, social workers and their agencies should more thoroughly publicize these programs and facilitate the connection between parents who desire to participate.

**Awareness of Emotional Needs**

Towards the end of the interviews, several caregivers stated that talking with the researcher and sharing their stories was beneficial for them, and many expressed that they felt better after simply talking about their situations. Although the primary role of many social workers working with parents with children with special needs may not be that of a therapist, social workers should be aware of parents’ desires to be heard by an empathetic individual and recognize the therapeutic quality of allowing the parents to share their stories and feelings. This awareness will assist social workers in helping the parents feel supported throughout their interactions. Additionally, most of the participants in this study were mothers, and the mothers tended to be the primary caregiver. Social workers
should be aware of this trend in their interactions with mothers and be attentive to signs indicating mothers’ burnout, exhaustion, and stress. Being aware of the stressors experienced by caregivers of children with special needs also includes acknowledging and understanding the systemic, macro-level issues affecting them.

**Awareness of the Impact of Macro-level Circumstances on Micro Needs**

Currently, the state of California is experiencing several cutbacks in its budget, including cutbacks in services for children and families with special needs. This has been a source of stress and anxiety for many caregivers. When working with families of children with special needs, social workers should be mindful of the external, macro-level factors which could have an impact on the emotional conditions of the families who are affected. At the present time, the external, macro-level factor affecting the caregivers is the budget and the cuts in services their families are experiencing due to the budget. Especially in stressful economic situations, social workers should consider the economy as a factor affecting the well-being of their clients. Because of the impact macro-level decisions have on families with children with special needs, social workers should engage caregivers as policy advocates in advocating for services and assist them in feeling less helpless in processes such as policy matters by empowering and supporting them as advocates.

**Limitations and Implications for Future Research**

**Needs of Families Not yet Connected to Services**

The children of every participant in this research study were enrolled in a center-based early intervention program, and families had been receiving Regional Services for
an average of 10.53 months. All caregivers interviewed in this study were already connected to at least two agencies specializing in supporting individuals and families with children with special needs, and several parents were connected to additional resources. Future research consideration should be given to conducting needs assessments with parents of children with special needs before they are connected with early intervention services or case management through the Regional Center. Because the parents and families who participated in this study were already receiving services for their children, it is speculated that their opinions and feelings reflected in the findings of this research may be different from those of families who have not yet been connected with case management and early intervention services. Further research into the needs of parents of children with special needs before they are connected to services may provide insight into the experience of waiting for and obtaining services.

**Deeper Focus on Specific Topics**

The questionnaire used for this research study covered a variety of topics, including nutrition, the psychological health of the child, social activities, and educational concerns. Future research that focuses specifically on one or two areas during the interviews will allow the researcher to ask more questions related to the topic and provide the participants with opportunities to go further in depth with their responses. Although participants did not seem to be bothered by the length of the interviews, covering several topics during the interviews did not provide parents with the same opportunity to elaborate on the themes as an interview that focused on one or two topics would have.
**Researching the Marital/Partner Relationship**

An additional area of consideration for future research is that of the relationship between parents of children with special needs. Further research on the relationship between parents and the effects of raising a child with special needs on the parental dyad may be valuable in understanding parents’ experiences and supporting them as they raise their children. Several parents reported marital challenges while raising a child with special needs, and this topic was never addressed in the questionnaire used for this project. Asking questions specifically pertaining to the marital relationship of parents with children with special needs will provide an opportunity for more parents to share their opinions and experiences.

**Conclusion**

As found in this research study, families with children with special needs have a variety of needs, and those needs do not seem to end even after they have begun to receive services. Continued research on the needs of families of children with special needs as well as the strengths and resiliency of this population will assist social workers in providing competent and effective services to families with children with special needs, especially in regards to providing services to families who may have children with similar diagnoses but vary drastically in demographic backgrounds.
APPENDICES
APPENDIX A

Consent to Participate in Research

(purpose of the research) You are being asked to participate in research which will be conducted by Larissa House, a graduate student of Social Work at California State University, Sacramento. The study will investigate the various needs that parents of children with special needs identify in their lives.

(research procedures) You will be asked to answer questions in a face-to-face interview with Larissa House about various elements you identify in yourself and your life as a parent of a child with special needs. The interview will be conducted at a time and location convenient to you, such as in your home or a public library. The interview may require up to 60-75 minutes of your time.

(risks) Some of the questions asked during the interview may seem personal, but you do not have to answer any question if you do not want to. This study is considered to be “minimal risk.” While the questions focus primarily on areas in which you would like to be further supported, some parents may find that discussing their lives and their families may elicit emotional responses or feelings. Please see the attached list of local mental health resources that you may utilize if emotional issues or topics arise through exploring the content of the interview.

(benefits) You may feel empowered by identifying the ways you have addressed the needs you have had in your life, or you may not personally benefit from participating in this research. It is hoped that the results of the study will be beneficial and supportive for parents of children with special needs as well as for services providers and agencies to better meet the needs of the families they serve.

(confidentiality) Only first names will be used during the interviews, and you may use something other than your real name if you wish. Notes taken during the interview are for the sole purpose of reporting on the needs parents identify in their lives. Upon completion of the written report, they will be destroyed no later than one year after they were made. Until that time, they will be stored in a secure location. No names will be connected with your responses in the written report.

(compensation) You will not receive any compensation for participating in this study.

(contact information) If you have any questions about this research, you may contact Larissa House at (xxx) xxx-xxxx or email her at larissa_house@yahoo.com. You may also contact Teiahsha Bankhead, PhD, LCSW (thesis adviser) at tcb@saclink.csus.edu or (916) 278-7177.
Your participation in this research is entirely voluntary. You may withdraw from this study at anytime without penalty. Your signature below indicates that you have read this page and agree to participate in the research.

________________________________ ____________________
Signature                                                   Date
APPENDIX B
Questionnaire

Demographic Information
1) Annual Household Income (range)
   - up to $16,999
   - between $17,000-$24,999
   - between $25,000-$34,999
   - between $35,000-$44,999
   - between $45,000-$49,000
   - between $50,000-$74,999
   - between $75,000-99,999
   - above $100,000
   - Declined to state

2) Highest level of education
   - Some high school or less
   - High school diploma/GED
   - Vocational school/Technical school
   - Some college 2-years or less
   - Associates Degree
   - Bachelors Degree
   - Any education beyond Bachelors degree
   - Declined to state

3) What is your racial or ethnic heritage?

4) What is your present marital status?

5) What is your gender?

6) Are you the child’s primary caregiver?

7) What is the gender of the child’s primary caregiver?
8) What is the age of the child’s primary caregiver?
   -under 18
   -18-24
   -25-34
   -35-44
   -45-54
   -55-64
   -65+
   -declined to state

9) What is the age of the partner of the child’s primary caregiver?
   -under 18
   -18-24
   -25-34
   -35-44
   -45-54
   -55-64
   -65+
   -declined to state

10) What city do you live in?

11) Please list how many people live in your home and their relation to you.

12) What are the ages of the children living in the home?

13) How many children with special needs are living in your home?

14) What is the primary language spoken to your child at home?
15) Why is your child attending a center-based early intervention program?

16) How old is your child with special needs?

17) How long has your child been receiving Regional Services?

**Background Information**
18) How old was your child when you realized he/she had a special need?

19) Who referred you to Regional Services?

20) What sources of support were beneficial to you at that time?

21) Looking back, what support/resources/information would you have liked to receive early on?

**Biological**
22) Does your child with special needs follow a special diet? (IE: gluten free/casein free…)

  - If yes, why did you choose to have your child follow this diet?

23) On a scale of 1-5 (1=not at all, 2=a little concerned, 3=concerned, 4=moderately concerned, and 5=very concerned), how concerned are you about the nutrition of your child?
24) What resources do you currently utilize for nutritional information about your child (Internet, WIC, etc)

25) What types, if any, of information or support would you like to receive regarding nutrition and your child?

26) Does your child receive special health services, such as speech therapy, occupational therapy, physical therapy?

-If no, ask “Is this something you would be interested in for your child?”

27) Choose any of the statements that apply to you:

-I would like information regarding speech services for my child

-I would like information regarding physical therapy for my child

-I would like information regarding occupational therapy for my child

-I would like information regarding what Regional Services are available for my child and my family

-I would like information regarding what services my insurance offers for my child and my family

-I would like to learn more about how to obtain additional services for my child.

28) What additional information would you like to obtain about the health needs of your child?
29) What are some issues regarding your child’s health care needs that are most concerning to you at this time?

**Psychological**

30) Choose any of the statements that apply to you:

- I would like information regarding dealing with my child’s energy level
- I would like information regarding effectively disciplining my child with special needs
- I would like information regarding my child’s behaviors
  - If applies, please elaborate on what behaviors your child exhibits that you are interested in learning more about
- I would like more information regarding my child’s level of attention and concentration

31) What are some questions regarding your child’s way of processing information that you have at this time?

**Social Groups**

32) Have you ever…

a. Participated in parent groups that provide support and advice

b. Participated in classes or home visits to help you support your child’s learning and development

c. Participated in play groups for your child (Can be formal or informal)

d. Participated in reading programs for your child (like story times at the library or in other group settings)

e. Had your child participate in activities or classes such as sports, music, or art
*If yes for any, ask “Approximately how many times per month?”

*If no for any, ask “What reasons do you identify for not participating in this activity?”

33) What additional groups or activities would you like to participate in with your child?

**Education**

34) What are your plans for the preschool education of your child (public or private)?

35) What concerns do you have about navigating the educational system?

36) What are some concerns you have about your child going to preschool?

37) On a scale of 1-5 (1=very uncomfortable, 2=a little uncomfortable, 3=somewhat comfortable, 4=comfortable, and 5=very comfortable), rate your current level of comfort in navigating the IEP and transition process.

38) On a scale of 1-5 (1=almost no understanding, 2=little understanding, 3=some understanding, 4=good understanding, 5=very strong understanding), rate your current level of understanding of what services your child is entitled to in the public school setting.

39) On a scale of 1-5 (1=not at all confident, 2=a little confident, 3=somewhat confident, 4=confident, and 5=very confident), rate your current level of confidence in advocating for services for your child at an Individualized Educational Plan (IEP) meeting or with your child’s preschool teachers.
40) What support do you feel would help you feel more confident in advocating for your child in an educational setting?

**Childcare/Daycare**
41) Choose any of the statements that apply to you:

* I have a babysitter that I feel comfortable leaving my child with when I am not present

* I have a daycare for my child that I feel comfortable with

* I have had difficulty finding a babysitter that I feel comfortable leaving my child with when I am not present

* I have had difficulty finding a daycare for my child that I feel comfortable with

**Home Environment**
42) On a scale of 1-5 (1=almost no understanding, 2=little understanding, 3=some understanding, 4=good understanding, 5=very strong understanding), rate your current level of understanding of what things your child should do independently at home.

43) What are some questions you have about making your home environment more supportive of your child’s needs?
**Additional Resources**

44) Please choose all that apply:

I would like more information on:

a. Ways to support my child’s development at different ages  
b. Ways to help my child prepare for preschool  
c. Ways to support my child’s verbal communication  
d. Using signs with my child  
e. Ways to help my child manage his or her own emotions  
f. Ways to help child interact with others  
g. Ways to help my child have a healthy diet and be physically fit  
h. Programs, events, and places to go in my community that are designed for families with children with special needs  
i. How to choose child care for my child  
j. Services and resources for parents concerned about their children’s development or behavior

45) Please elaborate on any additional ways you would like more support for your child and/or your family or any questions you have about raising your child.

46) Looking back, how do you feel your needs have changed since you first began receiving Regional Services up to now?

47) What services do you see yourself interested in for the next few years as your child gets older and attends preschool?
REFERENCES


or at risk for developmental delay. *Journal of Intellectual Disability Research*, 51(8), 606-619. doi: 10.1111/j.1365-2788.2006.00941.x


