

PERCEPTIONS OF SOCIAL SUPPORT AND CHILDHOOD DISABILITY AMONG
FAMILIES OF CHILDREN WITH DISABILITIES

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ABSTRACT

TYWANDA ELLISON: Perceptions of Social Support and Childhood Disability Among Families of Children with Disabilities
(Under the direction of Debra Skinner, Ph.D.)

The present study was an ethnographic study of forty-two families who had children with known or suspected genetic disorders. These families were part of a larger study that investigated culture and family interpretations of genetic disorders. The purpose of the current study was to focus on the social support networks utilized by these families, the families' perceptions of their child with a disability, and whether these constructs vary by ethnicity and income levels. A qualitative approach was employed to investigate these major research questions with interview data analyzed through the use of thematic analysis. The results indicated that social support from both informal and formal networks was significant in the lives of families of children with disabilities. Parents generally viewed their formal and informal networks as supportive and vital to the daily care of their child with disabilities. Ethnicity was not found to be a marked source of variation in families' perceptions of social support. An interpretation of this finding is that families who have a child with a disability come to share common experiences with other parents of children with disabilities. With regard to family perceptions of the child with a disability, the results indicated that medical views of disability, religious beliefs, views of normalcy, labeling, stigma and discrimination were factors influencing how families viewed their child with a disability. These factors influenced parental beliefs regarding the diagnosis, treatment, and prognosis of their child's condition. By using qualitative methodology the results extend what is currently known and

contribute to a better understanding of the context and meanings associated with family perceptions of social support and their child with a disability. This information may facilitate better relationships between families and healthcare providers, and contribute to the development of programs and interventions to better serve them and their children with disabilities.

TABLE OF CONTENTS

LIST OF

TABLES.....	viii
CHAPTER I.....	1
Introduction.....	1
Problem.....	1
Significance.....	3
CHAPTER II.....	5
Review of Related Literature.....	5
Social Support.....	7
Measurement of Social Support.....	16
Perceptions of the Child with a Disability.....	20
Rationale for Study.....	32
CHAPTER III.....	36
Methodology.....	36
Participants and Sample Description.....	36
Procedures.....	37
Instrumentation.....	39
Demographic Questionnaire.....	39
Observation of the Clinical Genetic Session.....	39

Semi-Structured Interview Protocols.....	39
Research Design and Methods.....	40
Analysis.....	41
CHAPTER IV.....	49
Results.....	49
Nature and Meaning of Social Support.....	49
Family and Friends.....	49
Religion/Religious Faith.....	54
Healthcare Professionals.....	56
Schools.....	59
Internet.....	61
Parent Support Groups.....	62
Case 1: Perception of Low Support.....	63
Case 2: Perception of Medium Support.....	67
Case 3: Perception of High Support.....	70
Nature and Meaning of the Perceptions of the Child with a Disability.....	73
Perceptions of the Child with a Disability.....	73
Summary.....	80
CHAPTER V.....	83
Discussion.....	83
Nature and Meaning of Social Support.....	83
Nature and Meaning of the Perceptions of the Child with a Disability.....	89
Limitations.....	96

Conclusions.....	97
Appendix A-Demographic Information.....	99
Appendix B-Interview Protocol.....	101
Appendix C-Social Support Matrix.....	106
Appendix D-Perceptions of the Child with a Disability.....	108
Appendix E-Nudist Search.....	110
References.....	113

LIST OF TABLES

Table

3.1 Demographic Variables.....	45
3.2 Number of Families in Each Income Level by Ethnicity.....	47
3.3 Demographic Variables by Percentages.....	48

CHAPTER I

INTRODUCTION

The present study was an ethnographic investigation of forty-two families who had children with known or suspected genetic disorders. These families were part of a sample that participated in a larger research project (Culture and Family Interpretations of Genetic Disorders, Debra Skinner, PI) funded by the Ethical, Legal, and Social Implications (ELSI) Research Program, a branch of the National Human Genome Research Institute (NHGRI/NIH). The overall aim of the larger study was to examine how parents from different cultural backgrounds who had a child or who were at risk for having a child with a genetic disorder seek out, understand, and use knowledge to interpret genetic disorders and to make decisions about reproduction, health, and services. The purpose of this study was to focus specifically on families' perceptions of their social support networks, their child with a disability, and whether these perceptions varied by ethnicity and income level.

Problem

Families of children with disabilities face unique challenges associated with their child's condition (Noojin & Wallander, 1996; Wallander & Noojin, 1995). The presence of the disability or chronic condition affects the entire family as an interactive unit; that is, if something affects or influences one member in the family, all members of the system can be affected (Fewell, 1986; Seligman & Darling, 1997). Experiences vary, however. A number of studies reported that parental adjustment to caring for a child with a disability varies from

parents who experience psychological distress to those who successfully adapt (Horton & Wallander, 2001; Wallander & Noojin, 1995).

The way in which families understand and adapt to the presence of a child with a disability also varies within and across cultures (Groce & Zola, 1993; Reyes-Blanes, Correa, and Bailey, 1999). Groce and Zola (1993) indicated that there are cultural differences in how disability is defined as well as the interventions adopted by these cultures to address concerns about disability and chronic illness. To date, few studies have examined the role of culture on the conceptualization of disability. Those that do exist (Bailey et al., 1999; Skinner, Correa, Skinner & Bailey, 2001) indicate that it is imperative that culture be considered when addressing the disability needs of persons from ethnic and minority populations since cultural beliefs impact parents' decisions regarding their child's disability (Groce & Zola, 1993; Patterson, 1993 as cited in Turnbull et al., 1993). More empirical knowledge about how families of children with disabilities make sense of and adapt to childhood disability would assist service providers as they face the challenge of meeting the needs of culturally diverse populations. Research studies are also needed that provide insight into how perceptions of social support and of the child with a disability vary among parents across different ethnic cultures and socioeconomic levels.

The present study addresses this gap in the literature by examining the nature and meaning of families' perceptions of (a) social support, (b) their child with a disability, and (c) whether these variables vary across ethnic and economically diverse groups.

Significance

Although numerous studies have examined social support and some have examined parents' perceptions of disability, few studies have examined the nature and meaning of these constructs. Fewer studies have examined the variability of these constructs among culturally and economically diverse populations. Fewer still have examined these constructs in families from a qualitative perspective that would provide a more in-depth and meaning-oriented approach to understanding social support and its relationship to perceptions of disability.

The study of cultural beliefs and practices of families is significant in understanding their perceptions of social support and adaptation to children with disabilities. Members of minority ethnic or cultural groups may have unique sets of beliefs, expectations, and conceptual schemas that help to shape the family's meaning of chronic illness and disability, and perceptions of disability (Patterson 1993, in Turnbull, Patterson, Behr, Murphy, Marquis & Blue-Banning, 1993). The current study contributes to this body of literature in providing a greater understanding of the ways families from diverse cultural and economic backgrounds understand and utilize social support and perceptions in constructing meanings of their child with disabilities.

The use of qualitative measures can yield useful methodological findings that can be applied in the fields of psychology, education, and medicine. Qualitative methods have not been widely used in these fields. These methods have primarily been used in the fields of sociology (Blumer, 1969; Denzin & Lincoln, 1994; Glazer & Strauss, 1967) and anthropology (Bernard, 1995, 1998). Given that few studies have examined social support and perception of disability among culturally and economically diverse populations, many professionals working with minority families of children with disabilities are forced to make

assumptions about the needs of these families based on mainstream American culture. The psychology profession, in particular, can benefit from studies that examine how social support and perceptions of disability are understood, experienced, and acted upon by culturally and economically diverse families. With a greater understanding of families' perceptions of social support and their child with a disability, as well as how ethnicity and income level influence these variables, both researchers and clinicians will likely be better able to meet the therapeutic and community-based needs of these families.

CHAPTER II

REVIEW OF RELATED LITERATURE

Societal changes have impacted families of children with disabilities. Advanced medical care and sophisticated technology have made it possible for more children with special healthcare needs to survive into adulthood, often with chronic illness and disability. Family structure and patterns of family life have changed dramatically in the last two decades. Increasing numbers of children (including those with special healthcare needs) are living in single-parent households. More mothers are in the workforce, and at the same time there has been a decline in the purchasing power of the family income needed to provide resources for the child with disabilities (Pandey, 2004).

The changing demographics in the United States have contributed to changing views and perceptions of children with disabilities. Racial minority children are the fastest growing group in the United States population. It is estimated that by the year 2010, in less than five years, one in every three children will be a child of color (Lunenburg, 2000). These children are also the largest at-risk group for disability associated with poverty. Specifically, lack of access to maternal prenatal care, poor nutrition, and low educational attainment will likely have a negative impact on the child's development (Bailey et al., 1999; Lunenburg, 2000). With this, a growing number of children with disabilities are living in poverty. The caregiving demands imposed by the child's condition coupled with an increase in residential mobility often separate families from their extended families and natural support systems

(Yanicki, 2005). The lack of support created by this situation creates additional stress for these families. Research indicates that primary caregivers of children with disabilities are faced with unique challenges (Noojin & Wallander, 1996; Wallander & Noojin, 1995). Many must deal with the normal hassles associated with daily life but also accommodate to the demands associated with the child's condition (Wallander, Pitt, & Mellins, 1990). Some specific challenges related to raising a child with a disability include difficulty finding competent care providers (Herman, 1994); exclusion from communities (Fewell, 1986; Turnbull & Ruef, 1997); stressed extended family relationships (Turnbull & Ruef, 1997); and lack of a bond or close relationship between the child with a disability and his or her sibling(s) (Meyer, Vadasy, & Fewell, 1985; Turnbull & Ruef, 1997). Some families further report that their experiences with their child's disability isolate them from their friends and family (Fox et al., 2002; Turnbull & Ruef, 1997).

Studies have found that the challenges associated with raising a child with special needs can adversely impact the entire family (Fewell, 1986; Seligman & Darling, 1997; Wallander, Varni, Babani, Banis, DeHaan, & Wilcox, 1989), making normal life difficult (Gray, 1997). This has led to an increased effort by researchers to investigate a child's disability within the context of a family unit. This means that a child's disability does not just affect the primary caregiver in a family, but every person's life in the child's family is altered in some way.

The social construction of normal family life was investigated by Gray (1997) in a study of fifty-three parents of children with high functioning autism or Asperger's Syndrome. Additionally, the study examined how families coped and attempted to construct normal daily routines. Findings indicated that a family's ability to engage in social outings and

activities such as dining at a restaurant or visiting friends influenced their assessment of their family's normality. The child's exhibition of aggressive or disruptive behavior was sensed as a violation of this source of perceived normality. Two themes were common in parents' accounts of their experiences during such activities. One was the potential for disruption that the child with autism produced during family outings and activities. Gray's (1997) findings further indicated that disruptive or aggressive behavior was a threat to the construction of family normality among these families, resulting in extreme emotional distress for family members.

In spite of these challenges, most parents desire to raise their children with special healthcare needs at home even though for some, individual circumstances and societal factors strain the family's ability to provide for their child's special needs. In fact, children with disabilities are more likely to be cared for by their families than any other social organization (Lourie, 1987). Therefore, an adjustment must be made by each family member in order to facilitate the care and development of the child with disabilities. Having to deal with the disability coupled with making the adjustment can create stress in the family unit. There is now overwhelming evidence in the literature that social support can significantly reduce the stress that is experienced by individuals.

Social Support

Social support has been defined as information or social environmental conditions that enable an individual to feel loved and cared for, affirmed, or as belonging to a group of persons with common goals and beliefs (Schaefer, Coyne, & Lazarus, 2002). An individual's perception of support is thought to be a characteristic related not only to the

actual availability of support but also to the criteria that individuals use in interpreting behavior as either supportive or non-supportive.

In the last twenty years, the scientific literature has highlighted the importance of social support as a vital resource for individuals who are dealing and coping with stressful situations (Sarason, Pierce, & Sarason, 1990), such as mothers raising a child with a disability (Dunst, Trivette, & Hamby, 1994; Findler, 2000). Although social support is defined by varying terms in the literature, most researchers agreed that social support refers to the assistance and help that one receives from others (Findler, 2000). House (1981) broadened the definition of social support by defining it as interpersonal interactions between individuals involving one or more of the following: (a) emotional concern (liking, love, empathy), (b) instrumental aid (goods and services), (c) information (about the environment), and/or (d) appraisal (information relevant to self-evaluation) (Findler, 2000; House, 1981).

Dunst et al. (2000) defined social support within the context of a family systems approach in which the family's social network system is instrumental in providing the resources needed for everyday living, in carrying out parenting responsibilities, and in supporting child learning and development. Support is often provided by family members, friends, and community agencies and organizations. These members of the family's social network provided a range of environmental experiences that will ultimately influence the development and behavior of the child and the entire family (Dunst et al., 2000). It has also been reported that these experiences strengthen the family by instilling feelings of competence and promoting new skills that are instrumental in helping families deal with children with disabilities (Dunst et al., 2000).

A review of the relevant literature further highlights a multi-dimensional perspective in the conceptualization and analysis of social support including: formal vs. informal, received vs. perceived, and structural vs. functional (Findler, 2000). This approach to understanding social support as a complex concept with varying definitions was in part driven by the need to understand social support in families of children with disabilities (McCubbin & Patterson, 1983).

The first dimension of social support is formal vs. informal. The distinguishing difference between formal and informal sources of social support is the type of person involved in the network and the families' relationship with that individual. Informal support networks are comprised of individuals such as family members and friends as well as social groups such as church affiliations and social organizations. These individuals and groups typically provide social support for daily life routines (Findler, 2000). Studies indicate that informal networks and the support that they provide act as a buffer and are instrumental to the well-being of the family in the context of a child's disability (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Cohen & Willis, 1985; Wallander & Venters, 1995).

Blankfield and Holahan (1996) investigated family support, coping strategies, and depressive symptoms among fifty-two mothers of children diagnosed with insulin-dependent diabetes mellitus. Mothers were asked to complete a self-report survey during a regularly scheduled visit to their child's healthcare provider. Findings indicated that social support provided by the family was indirectly correlated to maternal depression. When mothers of children with insulin-dependent diabetes had the support of their families they exhibited less depressive symptoms. These findings were mediated by adaptive coping strategies related to family support such as an increase in self-esteem and an ability to cope effectively with the

stressors associated with having a child with this chronic illness (Blankfield & Holahan, 1996).

On the other hand, formal support networks are comprised of professionals (i.e., physicians, social workers, pediatricians, and therapists), and agencies (i.e., hospitals, health departments, mental health centers, and early intervention programs) formally organized to provide assistance and aid to individuals with specific needs (Dunst, Trivette, & Deal, 1988; Findler, 2000). Although families of children with disabilities are typically dependent on medical and other helping professionals, they frequently expressed dissatisfaction with these relationships (Findler, 2000; McDonald, 1996).

According to some researchers, many African Americans with disabilities may utilize psychological defense mechanisms in helping them deal with the anxiety that is associated with a healthcare system that has historically been seen as non-responsive to their basic healthcare needs (Feist-Price & Ford-Harris, 1994). According to Feist-Price and Ford-Harris (1994), these mechanisms result in a mistrust that results in difficulty on the part of African Americans to relax and openly receive the information and services offered by the healthcare industry. Moreover, mistrust may help to explain the low number of African Americans seeking services as well as the high number rejecting the services when offered (Herbert & Cheatham, 1988).

Bailey et al. (1999) investigated the needs and supports in a sample of Latino families in the United States with a child diagnosed with developmental disabilities. In that study, 200 Hispanic parents (50 Mexican and 50 Puerto Rican couples) who resided in the mainland United States were interviewed using both assessment scales and open-ended questions to determine family needs, family supports, beliefs about disability, and perceptions of formal

support services as these variables related to having a child with a disability. Findings indicated that couples rated family and members of their formal network system as more supportive when compared to support from friends and other members of their informal network system. It was hypothesized that Latino parents would most likely rate family members as most supportive and formal support as least supportive. However, several interpretations were provided to explain these findings. One interpretation was that these families with regard to raising a child with a disability may have experienced some difficulty establishing and maintaining informal relationships. Secondly, these Latino families may regard members of the formal sector as more able to meet the needs of their child with disabilities. More importantly, this study suggests that there is a need for additional research and exploration on these variables within the context of minority populations.

It was the work of Bailey et al. (1999) that articulated the need and justification for using a within group methodology for investigating social support and psychosocial factors related to understanding disability in minority groups. These researchers suggested that our current understanding of the needs of minority families of children with disabilities may be compromised because of the paucity of research investigating minority group differences. Thus, they provided the justification for studying within group differences in minority populations.

The second dimension of social support refers to received versus perceived social support. Received social support is defined in terms of behaviors that assist the individual in accomplishing a goal (Findler, 2000; Vaux & Harrison, 1985). On the other hand, perceived social support pertains to the recipients' cognitions regarding the support provided by others. Here the recipient simply interprets the behaviors and intentions of others as being helpful

(Findler, 2000; Vaux & Harrison, 1985). Research further indicates that conceptualizing social support in terms of individuals' perception of social support is the most important aspect of the social support process (Vaux & Harrison, 1985). Sandler and Barrera (1984) found that information regarding an individual's evaluation of their support system is more important than knowledge of the quantity of resources or support available to the individual. Similarly, in a study of parents of children with developmental disabilities, Dunst, Trivette, and Hamby (1994) found that parental views of the nature of support provided by others were related to satisfaction with support rather than the amount of support received. Results further indicated that parental perception of support was directly related to the well-being and functioning of the family.

The third dimension refers to the structural and functional measures of social support networks. Structural measures included characteristics such as the size, range, and interconnectedness of the social support networks (Ferrari & Sussman, 1987). Structural social support measures derived from a socio-epidemiological paradigm are considered to be objective and generally define the existence or lack of fundamental social relationships and ties.

Functional measures of social support refer to the emotional, informational, and instrumental qualities of the social support network (Findler, 2000; Wills, 1985). Emotional support is characterized by behaviors such as an expression of love, care and solidarity, and fulfillment of personal needs. Instrumental support is a tangible action that enables another person to carry out their personal responsibilities (House, 1981). The instrumental qualities of social support include assistance such as goods, services, money, and helping with tasks such as running errands, helping with the child's transportation, or providing respite care.

Informational support is defined by materials providing educational aid and resources that empower individuals and increase their knowledge to improve their current condition (Thoits, 1986). It is not uncommon for parents with a child with disabilities to request additional information from healthcare professionals regarding their child's condition. Until recently, the mechanisms needed to provide this information have been limited. Technological advances now allow the use of the internet to deliver informational support to parents of children with disabilities (Skinner & Schaffer, 2006).

Considerable evidence has shown that social networks and the social support that they provide buffer the adverse psychological impacts of exposure to stress by promoting well-being and enhancing the use of coping processes (Cohen & Wills, 1985; Dunst, Trivette, & Hamby, 1994; Thoits, 1986). Relationships with others, especially spouses, friends, and family members, can help individuals maintain emotional health during stressful life events and ongoing life strains (Blankfeld & Holahan, 1996; Cohen & Wills, 1985). In a study of maternal stress and social support, Crnic, Greenberg, Rogozin, Robinson, and Basham (1983) found that mothers who perceived that they had more social support interacted more positively with their infants. Other research with families of children with disabilities showed that familial support had the most positive effects on maternal interactions with a child (Seligman & Darling, 1997; Turnbull & Turnbull, 1990). This is an important finding given that parents of children with disabilities must often rely on others to help meet the environmental child care demands.

One characteristic of social networks that has come out of the research on childhood disability is that they are typically dense (Kazak, 1987; Kazak & Wilcox, 1984). Further, it seems that those families that function effectively are those that use the support and resources

that result from these close relationships (Folkman, & Moskowitz, 2000; Kazak & Wilcox, 1984). Some of these relationships, particularly for minority group members were established in a religious context. Religious participation and beliefs have been studied as valuable sources of social support and as protective factors against stress (Smith, Fernegel, Gerald, & Marien, 1994).

In its cultural form, religion acts as an interpretive framework, impacting families' reactions and responses to children with disabilities (Koenig, 1995; Seligman & Darling, 1997; Weisner, Beizer, & Stolze, 1991). More specifically, religion provides a way for families to understand disability and why their child and family have been affected, and can help families reframe this event in a more positive context (Koenig, 1995; Skinner, Bailey, Correa, & Rodriguez, 1999; Weisner, Beizer, Stolze, 1991). For example, Skinner et al. (2001) investigated religious support in a sample of Latino families of children with developmental delays. Findings indicated parents used religion to help them understand and accept their child's disability. Religion also helped them deal with the daily experiences and situations associated with the condition.

Additional studies have underscored that religion is a dimension of social support in that it provides a system of understanding. Several studies have shown the importance of religion as a social support system both in its personal dimension as faith and its more formal organizational role. Religion has the potential to offer many different forms of support to families of children with disabilities including faith, an interpretive framework or way of understanding and relating to the disability, social support and activities for the child with problem behavior, social support for parents, and assistance in assessing community-based resources (Fewell, 1986; Skinner et al., 2001; Turnbull & Ruef, 1997; Weisner, Beizer,

Stolze, 1991). For example, in one study of 150 Latino families of young children with developmental delays, Skinner et al. (2001) found that even though most parents regarded church and church programs/activities as supportive in relation to their child, their personal faith was endorsed as more supportive. Personal faith was conceptualized as an individual's intimate relationship with a higher power. Second, seventy percent of the mothers and fifty-four percent of the fathers indicated that their faith increased after learning of their child's condition. Results further indicated that religion provided support in a number of ways, including providing a place where parents could pray and renew their faith, socio-emotional support and practical aid (i.e., transportation) provided by members of the congregation, as well as meeting of needs pertaining to the child's medical and therapeutic treatment.

Religion and spirituality have been studied as psychosocial constructs predictive of many physical and mental health outcomes. Although spirituality is related to religion, the two constructs are distinct. According to the John E. Fetzer Institute (1999), spirituality is concerned with the transcendent or transpersonal, addressing ultimate questions about life's meaning, with the assumption that there is more to life than what we see or fully understand (Okon, 2005). Spirituality is "understood at the level of the individual," and is a fundamental aspect of the person (Miller, 1998, p. 979-980); it does not rely on religious contexts, but focuses on issues of meaning and beliefs and character. Because spirituality deals with the mystical, it is difficult to define (Okon, 2005). While it is beyond the scope of this research to resolve this distinction, it does appear that it is important to investigate religion/spirituality and its relationship with perceptions and disability, particularly among minority populations.

Measurement of Social Support

Over the last 20 years, a number of social support measures have been developed. These measures often share a core set of orientations in the assessment of various types of social support including emotional, instrumental, tangible, financial, and appraisal support. Beyond this core, the measures often differ from one another in what appears to be subtle yet important ways (Heitzmann & Kaplan, 1988). This can be seen in the development of measures for assessing perceived support versus received support. Test items developed to measure perceived support usually are created from some hypothetical condition or state (e.g., if you need help taking care of your child, who could you count on for help). Received social support is usually measured in terms of a behavioral context over a specified period of time (e.g., in the last month, has anyone help you take care of your child). Therefore, an investigator must consider the hypothesis and population being studied, as well as the orientation of social support under examination.

Historically, social support instruments have been studied with regard to their psychometric properties. Given that they typically include multiple items tapping into single domains, they have good internal consistency. They usually include from 15 to 40 items and take between 10 and 20 minutes to administer. Their only weakness from the perspective of external validity is that they were often developed on a very small, often college-aged population. Therefore, the applicability of these measures to populations of heterogeneous middle-age and older adults, and minorities must be ascertained on a case-by-case basis (Heitzmann & Kaplan, 1988).

An analysis of the major social support instruments indicated that those that were developed to measure just the construct (Cohen & Wills, 1985; Procindano & Heller, 1983;

Sarason, Levine, Basham, & Sarason, 1983) are very good measures of social support but do not measure network structure. In fact, the measurement of social support networks has been mostly nonexistent in the psychometric literature. When attempts have been made to measure social networks, it is usually done as a separate construct.

Instruments for measuring social support conceptually define the construct either quantitatively or qualitatively. A qualitative approach reflects the significance and meaningfulness of relationships, reciprocity of social support, and different functions of support (e.g., informational, instrumental, self-esteem, tangible). A quantitative approach focuses on the structural nature of social relationships (e.g., family, friend, neighbor, community organization) which entails measuring the number of an individual's social ties and the diversity of social networks. The majority of the research that has been conducted on social support has used quantitative instruments to assess the construct. In recent years, social support has been used to measure physical and psychological outcomes in chronic pain management, oncology, hematology, and other areas. However, several reviews have reported significant problems with the psychometric properties of these instruments (Heitzmann & Kaplan, 1988). As a result, there has been a movement to include qualitative approaches as a way to better understand social support.

Very few theoretically-based, well-validated, and psychometrically sound measures are available to objectively quantify social support. More specifically, measures that examine children and families with disabilities within the context of factors such as ethnicity, cultural identity (Darling & Gallagher, 2004; Kalyanpur & Harry, 1999), and demographic location (e.g., rural, urban, suburban) are needed (Darling & Gallagher, 2004). This area of research has primarily involved middle-class, European American children and families (Bailey,

Blasco, & Simeonsson, 1992; Darling & Gallagher, 2004; Turnbull & Ruef, 1997). Thus, because most studies have not examined children from diverse backgrounds, the external validity of much of the research in this area is limited to non-minority populations.

Therefore, it is imperative to investigate these issues within minority populations if we are to meet the needs of individuals with disabilities from ethnic and cultural groups in this country. Specifically, what is missing from the literature is knowledge of how moderating and mediating variables such as social support and perceptions of disability operate in samples of diverse groups.

Many social support scales have been developed over the last twenty years. It appears that the problem of measuring social support is not due merely to the lack of available instruments. As indicated above, the psychometric properties for the majority of these instruments have not been “convincingly documented” and in some cases not reported at all (Heitzmann & Kaplan, 1988, p. 103). The foundation of the components (i.e., instrumental, informational) for social support are often times not reported by psychometricians when presenting data regarding the development of these instruments. Although the list of social support scales reviewed here is not exhaustive, it is a representative sample of the kinds of scales and questionnaires that have been used (Heitzmann & Kaplan, 1988).

The lack of a consensus regarding the definition of social support makes it difficult to compare studies that investigate social support and health outcomes. Results from research exploring the nature of social support “must be viewed critically, with careful attention to the quality and type of measurement instrument employed—that is, is the instrument appropriate for the variables being assessed” (Heitzmann & Kaplan, 1988, p. 105). This means that the

appropriateness of the instrument used must be assessed on a case by case basis (Heitzmann & Kaplan, 1988).

The meaning of social support from a culturally based, interpretive framework can be derived through the use of narratives or stories told by families. Narrative accounts can be used as a means of recording personal experiences and as a way of understanding those experiences. Narrative analysis “focuses on the process whereby people draw upon cultural and linguistic resources to formulate stories that make personal sense of the flow of events in their lives” (Skinner, Bailey, Correa, & Rodriguez, 1999, p. 483). Thus, the primary focus of narrative analysis for studying social support in relation to disability is on the ways that individuals describe and link their understandings and perceptions of social support in relation to their child’s disability, their own sense of well-being and adaptations to the disability.

The purpose of the research reported here was to utilize qualitative methods of content analysis and case study to better understand social support and perceptions of the child and the child’s disability. Additionally, this study examined if these constructs would vary across ethnic and economically diverse groups. Groce and Scheer (1990) note that research that analyzes how different cultures view disability is needed to better understand and assist families of children with disabilities. In fact, a review of the literature yielded only one recent article exploring the perceptions of disability in African Americans. This study investigated health seeking behaviors in urban African American males (Plowden & Miller, 2000). There is a need to investigate how individuals and families in minority populations perceive disability in order to better understand how they impact health outcomes related to disability.

In summary, a definitive conceptualization and measurement of social support is lacking and several remaining theoretical and conceptual issues need to be addressed. As mentioned earlier, assessment of the direct effects of life events (i.e., having a child with a disability) and type of social support may be seriously confounded by cultural, racial, and economic variables. Additionally, Cohen and Wills (1985) suggested that the difference between social support as a main effect and social support as a buffer against life stress may warrant further conceptual and methodological considerations. This suggestion is highlighted by Enkenrode and Gore (1981) who framed the causality versus correlational debate regarding the interdependence of support and stress. This review of the literature suggests that sources of support may be the same as sources of stress, perceptions of stress do not necessarily differ from perceptions of the availability of support, and stress may have an impact on support systems and vice versa. It is difficult to separate these two areas; therefore, the purpose of this research was to use a qualitative approach to examine the meaning of social support as well as explore this construct within the context of minority families with children with disabilities. The existing literature suggests that social support may be a key factor in determining how these families both understand and perceive the essence of their child's disability (Green & Rodgers, 2001).

Perceptions of the Child with a Disability

Definitions of health and illness differ among cultures. How a disability is viewed varies by severity, impact on life, beliefs regarding etiology, and preferences for treatment. Additionally, much of how one views an illness or disability is shaped by what is known from a medical and scientific standpoint. Most cultures have been affected by science and technology and thus have incorporated medical information into their health belief systems

(Aranda & Knight, 1997). Traditional folk beliefs, however, are still found to varying degrees in ethnic, racial, and cultural groups in this country and around the world. In order to provide quality treatment to individuals from cultures other than their own, healthcare professionals must understand cultural variations including differences in beliefs about causes and treatments of disabilities. This is especially crucial given that in the next twenty years at least one-third of all clinical caseloads will consist of individuals from minority groups (Sue & Sue, 1990).

An individual's perception of her/his health status is an important health outcome to consider as it measures knowledge of underlying disease, recognition of physical disabilities, and awareness of functional limitations. Individuals typically measure perceived health by utilizing both physical and mental health assessment tools. Defining physical health as such has been shown to predict healthcare utilization and quality of life (Sue & Sue, 1990). Studies have demonstrated that self-rated health is both influenced by, and predictive of, functional limitations. Therefore, it seems important to investigate how perceptions of disability impact families of children with disabilities. Since parents or primary caregivers are often responsible for the overall health of their child with disabilities, it is important to investigate factors that may influence and impact primary care and treatment.

In the last decade, the literature has documented changes in the conceptualization of the meaning of disability. The sources of these concepts are varied including literature and art, media, religious texts, and school books. These "artifacts of culture" impact public attitudes, for individuals with disabilities as well as those who are seeking definitions of what is normal (Gartner, Lipsky, & Turnbull, 1991).

During the twentieth century, the main view of disability has been based on a medical model of disease. Talcott Parsons (1951) noted that this model is comprised of four characteristics: 1) the patient is exempted from normal social obligations; 2) the patient is not held responsible for being sick; 3) the state of being sick is considered legitimate; if 4) the patient cooperates with the legitimate sources of help and works toward recovery. Groce and Scheer (1990) pointed out that by defining disability as a disease state, healthcare professionals view the disabled individual as an anomaly that must be cured or restored to as much of a normal state as possible. Parson's (1951) model, which is a cornerstone of the medical field, has likely impacted decisions made by parents of children with disabilities. For example, parents who incorporate this model in their conceptualization of disability are more likely to consider biomedical interventions as opposed to the consideration of behavioral and psychosocial interventions. Under this model, the problems that are associated with the disability are thought to reside in the person with disabilities. In other words, if the individual is "cured," then these problems will not exist.

Hahn (1987, 1989) characterized disability from an economic viewpoint (Gartner, Lipsky, & Turnbull, 1991). He stated that the impairment associated with disability is translated as a limitation of the amount or type of work individuals with disabilities are able to do, and the extent to which individuals are able to support themselves given that they are unable to work. This view focuses on work as the most important variable in determining how an individual views disability. Thus, if an individual is not able to work and support themselves, she or he considers the disability to be significant (Hahn, 1987).

Gartner, Lipsky, and Turnbull (1991) proposed a sociopolitical view based on the interaction between the individual and the environment. Specifically, this approach

acknowledges the personal misfortune experienced by the individual, highlighting aspects of the environment including architectural, institutional, and attitudinal influences that impact the conceptualization and perception of disability. From this perspective, families of children with disabilities may experience negative reactions including bias, prejudice, segregation, and discrimination from both society and governmental policy. For example, an adolescent girl recently diagnosed with Frederick's Ataxia and her family had to negotiate the architectural issue of wheelchair access with the local school district. Hahn (1987) hypothesized that these negative reactions of society and community to disabilities can be eradicated through policy reform designed to address the rights of persons with disabilities.

Most would agree that disability carries a stigma that individuals with disabilities cope with on a daily basis. Link, Struening, Neese-Todd, Asmussen, & Phelan (2001) described five components of stigma: labeling, stereotyping, separation, status loss, and discrimination. Green, Davis, Karshmer, Marsh, and Straight (2005) investigated the impact of these components of stigma in eight adults with disabilities and seven mothers of children with disabilities. Results indicated that these social factors can negatively impact individuals with disabilities. This research study did not address the influence of culture, ethnicity, and race associated with stigma.

Groce and Scheer (1990) proposed that disability is a product of socialization rather than the obvious physical and mental challenges associated with the disability. While they acknowledge that a disability can impact an individual in many ways (i.e., socially, economically, equality), they contend that the concern for people with disabilities lies within the society and not the individual's physical or mental limitations (Groce & Scheer, 1990). Consequently, researchers need to consider the social context (i.e., family, community,

church, healthcare professionals) shaping the family's meanings and beliefs of their child's disability. Cultural beliefs of various groups, from family to healthcare professionals, may influence the perceptions of the child, which may in turn impact the decisions and actions concerning the child and their disability (Goffman, 1974; Patterson, 1993, as cited in Turnbull, Patterson, Behr, Murphy, Marquis, and Blue-Banning, 1993). For example, some families hold beliefs that inherited disorders are caused by a family curse or "bad blood" that has been passed down from one generation to the next (Groce & Zola, 1993). With such families these views regarding the cause of the disability may impact the family's attitudes toward the child and possibly impact parental choices regarding service utilization and treatment options.

Culture, which affects how others in society define 'disability' and treat individuals with disabilities (Gartner, Lipsky, and Turnbull, 1991), has been well researched and defined in numerous ways (McDermott & Varenne, 1997, as cited in Jessor, Colby, & Shweder, 1997). Some believe that culture encompasses the traditions and beliefs that impact how members of an intergenerational group or community function (Brookins, 1993). For others, culture is defined by the interactions of a group or community based on factors such as class, region, religion, and period of time (Brookins, 1993; Mead, 1955).

Culture which may be influenced by various factors such as race, ethnicity, socioeconomic status or religion, provides an interpretive framework or way of understanding a child with disabilities. These cultural factors are of critical importance and must be considered when examining persons with disabilities. However, few studies have examined issues of culture and disability to provide cross-cultural analyses (Gartner, Lipsky, & Turnbull, 1991; Groce & Scheer, 1990). As a result, we have limited understanding of how

disability is viewed or appreciated cross culturally. Therefore, it is important to investigate disability in minority populations. Since families are typically seen as the major source of support, it is also important to investigate how families view the child with disabilities. Groce and Scheer (1990) acknowledged that cross-cultural comparisons of disability would expand our understanding of disability in various cultural settings as well as provide information about what disability means to those with disabilities and their families.

Seligman and Darling (1997) proposed that a family's response to a child with a disability is influenced by the family's ideological style which is characterized by certain beliefs about disability as well as the family's pattern of interacting with individuals with disabilities. Ideological style is based on a family's beliefs, values, culture, and coping behaviors. It should be noted that the child with disabilities may influence the values of the family. For example, a child with a disability may be born into a family with prejudicial or negative attitudes towards persons with disabilities. The child's disability is certain to have an effect on the family's attitude and will possibly change it considerably. The family is then forced to grapple with redefining the psychological and practical meaning of having a child with a disability (Marshak & Seligman, 1993; Seligman & Darling, 1997). This redefinition may result in a change in perception regarding disability in general.

As a family begins to confront and deal with the presence of a chronic disability, they must also cope with their beliefs surrounding the progress of the illness (Rolland, 1993; Seligman & Darling, 1997). Specifically, the family must assess their beliefs and views about the cause, diagnosis, treatment, and prognosis of the child's disability (Seligman, 1983). However, these views will likely change and new meanings of the child's disability will emerge over time (Patterson, 1993; as cited in Turnbull et al., 1993).

Patterson (1993; as cited in Turnbull et al., 1993) described that through shared experiences families develop a common schema or way of interpreting situations that are characterized by core values, beliefs, as well as perceptions of daily events. Specifically, three levels of meaning were identified. The first level of meaning is described as the situational definition in which the family attempts to search for a cause or reason why it happened. The family's schema will likely influence how they interpret the events related to the disability. The second level assumes that the family relationship schema will be affected by the disability diagnosis. Regular family routines are disrupted by the disability forcing family members to make necessary changes to accommodate the child and the child's disability (i.e., schedules for maintaining the child's illness, familial role changes to ensure that the child's needs are addressed). With this, the old schema will no longer meet the demands associated with having a child with a disability. In the third level, the family members change their worldview, redefining their meaning of disability. The disability becomes the most important factor driving all family activity.

Researchers have also indicated that the perceptions of others may contribute to the family's perceptions and response to a child with a disability. Based on Goffman's (1963) theoretical work on stigma, researchers have found that public perceptions and reactions adversely impact both the stigmatized individual and his/her associates, including family and friends (Seligman, 1983). Green (2003), for example, examined the impact of perceived stigma on emotional (i.e., guilt, shame, anger) and social outcomes (i.e., social isolation) for mothers and children among 81 families of children with chronic disabilities. Using measures of perceived stigma, objective and subjective burden, preference for interactions with people experienced with disability, and frequency of child's peer interactions, results indicated that

the degree of stigma expected by mothers directly impacted emotional and social outcomes for themselves and their children. More specifically, mothers who felt that individuals with disabilities were devalued and discriminated against by individuals in the community tended to feel embarrassed, guilty, ashamed, resentful, worried, trapped, and/or emotionally upset that their child has a disability. However, mothers with more optimistic attitudes did not show these negative feelings. Interview data further suggested that perceived stigma may lead to subjective burden. The interviewees reported that they began the experience of mothering a child with a disability with negative attitudes shared by others. They reported that their attitudes toward individuals with disabilities changed with the birth of their own children.

Despite these changes, findings indicated that these mothers who once had stigmatizing attitudes about the individuals with disabilities may also experience feelings of guilt and shame because they once held the same beliefs. For mothers who still harbored those same negative beliefs, the child's disability may elicit feelings of embarrassment, possible resentment and entrapment. Interviewees also reported that others sometimes blame them for the child's disabilities. These feelings of blame, whether from family or others in the community, can lead to anger, which adds to the emotional burden experienced by mothers of children with disabilities (Green, 2003).

Parents of children with disabilities pick up on the subtle and less-subtle cues from family, friends, and neighbors that they are abnormal or different from the typical family (Laborde & Seligman, 1993). The perceptions of others can impact the degree to which the child with disabilities affects the entire family. These perceptions and reactions contribute to the emotional distress in the form of subjective burden (e.g., embarrassment, guilt, shame,

resentment, worry, and other emotional upset) experienced by mothers of children with disabilities (Green, 2003). In a study of parents of children with cystic fibrosis, (Meyerwitz & Kaplan, 1967) found that many of the parents reported negative community attitudes and reactions to having a child with a chronic illness. Findings further indicated that the parents felt socially isolated from the community.

In one notable investigation that examined the relationship between family perceptions and community involvement, Fox, Vaughn, Wyatte, and Dunlap (2002) interviewed a culturally diverse group of 20 family members who were engaged in a process of family-centered positive behavior support. The aim of the study was to gain an understanding of family perspectives on their child's problem behavior and its impact on the family's lifestyle. All participating children had a developmental disability with challenging behavior and were between the ages of 3-12 years. In a qualitative analysis of semi-structured interviews with the parents, the researchers found that the child's problem behavior impacted the family in pervasive ways. The most dominant theme that formed the landscape for all other reflections was "It's a 24-hour, 7-day involvement." Researchers also found that the stressors associated with the child's problem behavior, including the child's impact on daily life, resulted in the family's social isolation. Most of the families described themselves as having limited activities outside of the home due to the added stress of worrying whether the child would disrupt others (Fox et al., 2002).

Poverty is another factor that should be considered when examining how familial schemas or way of interpreting events affects how they may respond to disability. Research indicates a relationship between poverty and childhood disability (Fujiura & Yamaki, 2000; Brookins, 1993). Prevalence rates of both child and adult disability are higher among

families in poverty. For example, the rate of disability for children aged 3-21 at or above the poverty line in 1996 was nearly 6%, compared to 11% for children below the poverty line (Fujiura & Yamaki, 2000). Poverty and the circumstances associated with poverty such as nutrition, housing conditions, and access to appropriate healthcare may be significant factors contributing to disability. As such, poor minority children are at greater risk for disease and chronic conditions. They are less likely to have access to effective medical care and are less likely to receive preventive care. Also, disability may move some families into poverty because of the increased costs of care and loss of work (Lukemeyer, Meyers, & Smeeding, 2000).

Ethnicity is another factor that may intersect with how families adapt to and understand their child with disabilities. Although ethnicity is not a predictive factor in that individuals within each ethnic group may vary to a great extent based on education, income, place of origin, religion, and age; there still may be some cultural roles, expectations, and conceptual frameworks that impact the understanding of their child's disability. Earlier accounts of Mexican Americans found that they had a number of folk beliefs about the nature and cause of disability. One belief was that *caida de mollera*, sunken fontanel, was caused by a fall or abrupt removal of the nipple from the child's mouth during feeding (Chesney, Thompson, Guevara, Vela, and Schottstaedt, 1980). Wendeborn (1982), in a study of Hispanic families with children with cerebral palsy, found that families had difficulty accepting that their child's condition could not be healed. Many of these families consulted with numerous practitioners at a considerable expense before coming to terms or being able to adjust to the child's disability specifically regarding the prognosis of the disorder.

A factor related to an individual's adjustment to disability is social support. The facilitative role of social support on mental and physical outcomes of African Americans with disabilities has been demonstrated in a number of studies (Belgrave & Gilbert, 1989; Belgrave & Moorman-Lewis, 1986; Miller, 1986). In a study of chronically ill African American patients, Belgrave and Moorman-Lewis (1986) found that social support was significantly related to the perception of disease severity. In a study of 100 African American disabled persons, Miller (1986) found that family support was significantly related to adjustment to disability. In this study, these researchers indicated that social support was a predictor of how families made the adjustment to the disability. Social support was identified as a significant predictor of adjustment to disability in this study.

Perceptions of disability were also a significant predictor of adjustment. The results of a study by Miller (1986) indicated that 50% of the variance in the adjustment to disability in African Americans can be accounted for by three variables: perception of severity of disability, self-esteem, and social support. The findings are consistent with the results of studies which have used samples of Caucasian as well as African American persons with disabilities. In addition to the regression procedure, these researchers also performed a correlation analysis on the variables under consideration in this study. The high and moderate correlations observed between psychosocial adjustment and each of the family competence dimensions suggest that African Americans have the resources needed to flourish during a trauma event such as onset of disability (Miller, 1986).

Several authors have examined the patterns of functioning in African American families (Hill, 1972; Hines & Boyd-Franklin, 1982; McAdoo, 1983; and Ho, 1987). These authors have suggested that the African American family has evolved unique patterns of

competence that serve as buffers to the stressors and crises (e.g., racism, high unemployment, and extreme poverty) commonly faced by its members. Moreover, these buffers are utilized to manage the typical crises that all families may confront (e.g., divorce, death, and disability).

There are several interpretations of the findings of the above study that are noteworthy and consistent with the research questions developed for the current study. First, there was a strong relationship found between adjustment and both family cohesion and expressiveness. The significant association observed in this study supports Alston, McCowan and Turner's (1994) assertion that the strong ties that are often representative of the African American family have enabled them to deal more effectively with issues related to taking care of a person with disabilities. Another possible explanation of these findings is that the emotional support that stems from these close ties to provide a feeling that the individual is not alone because they are connected to a larger network. Also, the strong family cohesion reported by the participants makes it more likely that family members were willing to assist in managing the tasks (e.g., activities of daily living) for the disabled family member. Second, there was a strong relationship found between level of adjustment and perception of general family health and well-being among its members. This seems to suggest that the disability is not be perceived as a disruptive force in African American families. It was Minuchin (1974), the pioneering family therapist, who suggested that families strive for a balance among all their activities which enables them to create an environment devoid of chaos while maintaining trust, enjoyment and growth. Judging from the perceptions of the participants in this study, African American families can accommodate disability while carrying out the normal functions of the family unit without significant disruptions. This

study which only included African American participants has limited generalizability to other minority groups. Therefore, it is necessary to research these variables in other minority groups including Native American and Hispanic populations in order to understand how these factors may impact disability.

There is a need to conduct research studies investigating the perception of disability in African American and other minority families because they now comprise the largest percentage of persons with disabilities (US Census Bureau Disability Status, 2000). Thus, research in this area that focuses on identifying those factors that are unique to minority populations can lead to the development of interventions to assist in helping clients adjust to the disability. The purpose of this study is to explore family's perceptions of their child with a disability. More specifically, this study will investigate how these perceptions vary by ethnicity and socioeconomic status.

Rationale for Study

The review of the literature indicates that families of children with disabilities face challenges associated with their child's disability. Research indicates that many of families of children with disabilities report more psychological distress and social isolation than families of healthy children (Horton & Wallander, 2001; Wallander & Noojin, 1995). Research further indicates that there is considerable variability in the adaptation of parents of children with disabilities. Therefore, the mere presence of a child with a disability does not explain parental adaptation (Horton & Wallander, 2001; Wallander, Pitt, & Mellins, 1990).

Gray (1997) among several other researchers found that the challenges associated with raising a child with a disability can adversely impact the entire family (Fewell, 1986;

Seligman & Darling, 1997; Wallander, Varni, Babani, Banis, DeHaan, & Wilcox, 1989). The literature suggests that many of families are faced with significant stress. Specifically, a stressful life event such as dealing with a child with disabilities requires the family to make major changes in their lives to accommodate the child's needs. However, considerable evidence indicates that social support acts as a buffer against the adverse psychological effects of raising a child with a disability (Cohen & Willis, 1985; Dunst, Trivette, & Hamby, 1994; Fox et al., 2002; Horton & Wallander, 2001).

Social support has been highlighted as a significant resource for families coping with a child with disabilities (Dunst, Trivette, & Hanby, 1994; Kazak & Wilcox, 1984). Although social support has been conceptualized and measured in many ways, most researchers agree that social support refers to the assistance and help that one receives from others (Findler, 2000). Researchers have recently broadened their investigation of social support to include a more multi-dimensional perspective (i.e., informal vs. formal, received vs. perceived, and structural vs. functional). This line of research was in part driven by the need to more accurately understand, define, and measure social support in general and more specifically in families of children with disabilities.

How a child with disabilities is viewed by a family varies by factors such as how disability is perceived among different actors in the individual's social support network system; cultural beliefs regarding diagnosis, etiology, and preferences for treatment; and community and environmental aspects such as stigma. Consequently, both researchers and clinicians should consider the factors that shape a family's meanings and beliefs about their child and their child's disability. Although cultural beliefs alone do not absolutely explain how an individual or his/her family will think about and respond to disability, understanding

the family's belief systems vis-à-vis disability may be instrumental in facilitating the care and treatment of individuals with disabilities.

Although there has been extensive research on social support and some research on perceptions of disability, few studies have examined these constructs among culturally diverse populations. There is little literature from a meaning-oriented approach to these constructs among families from different ethnic and minority populations. By using qualitative methods such as semi-structured interviewing, we can better understand how families construct meanings of social support and familial perceptions of their child and their child's disability. The present study will help to fill in these gaps of information and possibly reveal some unexpected meanings and connections between social support and perceptions of disability constructed by families of children with or suspected of having genetic disorders.

Although scholars of various disciplines have researched the measurement and conceptualization of social support, few studies have examined its actual meaning. In fact, a review of the literature indicates that social support is typically researched using quantitative methods to assess the construct, but that there are significant problems with existing assessment instruments measuring social support. With the use of qualitative methods, the present study obtained narratives of how families define social support and perceptions of disability. Additionally, this study examined these constructs across ethnic and economically diverse populations. This information will provide rich data needed to better define and ultimately measure these constructs. These data can be applied in the development of social support instruments, creating measure of social support applicable to culturally and economically diverse populations.

In the current study, the investigator utilized information drawn from semi-structured interviews with forty-two families from ethnically and economically diverse backgrounds to address three research questions:

1. What is the nature and meaning of social support for families of children with disabilities?
2. What is the nature and meaning of the family's perceptions of their child with a disability?
3. To what extent does social support and perceptions of the child with a disability vary across ethnic and economically diverse groups?

CHAPTER III

METHODOLOGY

Participants and Sample Description

The subjects in the current study were involved in a larger research project, Culture and Family Interpretations of Genetic Disorders (Debra Skinner (PI), funded by the Ethical, Legal and Social Implications (ELSI) Research Program, a branch of the National Human Genome Research Institute). The overall aim of the larger study was to examine how parents from different cultural backgrounds who had a child or who were at risk for having a child with a genetic disorder seek out, understand, and use knowledge to interpret genetic disorders and to make decisions about reproduction, health, and services. The study was ethnographic and longitudinal in design and consisted of two major data collection methods: (1) observation of an initial clinical genetic session (or sessions if a family was scheduled to return for an additional visit) and (2) four in-depth semi-structured interviews with families over a two year period.

The subjects for the current study were a subset of 42 families from the 106 families who participated in the larger study. These families had a child with known or suspected genetic disorders and were referred to a genetic counseling and evaluation clinic. Purposive sampling was used to select these 42 families from the 4 ethnic groups included in the study (12 African American, 12 European American, 10 Latino, and 8 American Indian). Due to the low number of Latino and Native American participants, all subjects who were Latino or

Native American in the larger study were included in the present study. Families from both higher (>\$30,000 annual income a year) and lower (<\$30,000 annual income a year) economic levels were selected for participation (see Tables 3.1 and 3.2). Income level ranges were considered low income if below the median for the entire sample of 106 and high income if above the median regardless of family composition. The median for the entire population of the larger study was \$30,000 annual income a year. Marital status of families varied across ethnic groups with 100% of Latino, 75% of Native American, 50 % of African American, and 75% of Caucasian parents reporting being married (see Tables 3.2 and 3.3). The ages of the children in these 42 families ranged from approximately 3 to 16 years at the time of entry into the study. The functional level of the participants ranged from children who required twenty-four hour supports to children who needed minimal supervision.

Procedures

In the larger study, families were recruited over a two-year period through a university hospital-based pediatric genetics and metabolism clinic. Referrals to this clinic are primarily made through pediatricians, service providers, other medical specialists, and Developmental Evaluation Centers (DEC). This clinic provides medical genetic counseling and evaluation services for North Carolina citizens and their physicians, through evaluation and diagnosis of genetic disorders in children and adults, counseling these clients and their families, and when appropriate, providing long-term medical management and follow-up.

Before the actual counseling session, an ethnographer on the research team met with the parent(s) or primary caregiver(s) to describe the larger study. The ethnographer described the aims and methods of the study, made it clear that the study was independent of the clinic

and their visit, assured confidentiality, and that non-participation in no way affected services received from the clinic. The investigator of the current study was a part of the ethnographic research team that conducted the interviews. Approximately twenty-five of the families in the current study were followed by this investigator.

During the initial visit, the ethnographer closely observed all phases of the initial counseling and evaluation session. Observation of all communication and interactions were recorded in detailed field notes that included information about the nature and content of the dialogues, non-verbal communications, and the overall tenor and context of the sessions.

The first interview typically took place approximately six weeks after families attended the clinic for the first time, soon after they received their test results. For the most part, ethnographers of the same ethnic background as the family conducted a semi-structured interview in either English or Spanish as the family preferred and at the time and place designated by the families, usually their home. These interviews typically lasted between 1-1½ hours and were audio-taped. For some families interviews were conducted with both parents or mother and grandmother simultaneously, if both wanted to participate. Ethnographers posed the same set of questions to all families, but used probes to follow up on their comments and to encourage them to clarify and elaborate their responses. The demographic form was also completed during this initial interview.

Subsequent interviews took place approximately every six months for 1½ years, beginning after the initial interview. When possible, the same ethnographer revisited the families and conducted in-depth semi-structured interviews that were audio taped. These follow-up interviews, which lasted approximately 1½ hours, were designed to elicit the content of and changes in families' beliefs, knowledge, or actions since the initial interview.

As in the initial interview, ethnographers used a common protocol with all families, but individualized it somewhat depending on their particular circumstance and the outcome of the genetic testing.

Instrumentation

The present study utilized the three primary data collection methods employed in the larger study: (1) fieldnotes on the observations of the clinical genetic counseling and evaluation session; (2) transcriptions of semi-structured interview protocols; and (3) demographic questionnaire.

Demographic Questionnaire.

The Demographic Information Questionnaire consisted of 8 items that elicited data on household composition, parents' occupation, marital status, household income, parents' educational level, parents' and child's ethnicity, parents' term for medical condition, and medical diagnosis of focal child (see Appendix A).

Observation of the Clinical Genetic Session(s).

Fieldnotes on the clinic session included the family history taken by the genetics counselor; information exchanged between staff members during the briefing; the verbal and non-verbal interchanges between staff members during the physical examination; and the dialogue and questions asked by both the physician and the family during the actual examination.

Semi- Structured Interview Protocols.

In the larger study, a series of semi-structured interviews were designed to elicit (a) families' understanding of the information disseminated in the clinical genetic visit; (b) the content and tenor of communication in the clinical genetic session; (c) other source of

information and beliefs parent use to make sense of the child and the child's disability and the genetic implications of the condition; (d) the process of how they piece together knowledge and beliefs; (e) their sources of social support; (f) their experiences around the disorder; and (g) how they make decisions about services and other matters related to the child or their own reproductive future or themselves (future) child based on their interpretations and experiences. An initial interview was conducted 6 weeks after the clinical genetic session, and 3 subsequent interviews were scheduled every 6 months over a 1½ year period. As unexpected domains emerged, relevant questions were added to subsequent interview protocols. Also, ethnographers were free to probe and add questions for the purpose of clarification or elaboration. All interviews were taped recorded and transcribed verbatim. Interviews conducted in Spanish were both translated and transcribed. The original ethnographers then reviewed the transcripts for accuracy. An example of a semi-structured interview protocol and questions are included (see Appendix B).

Research Design and Methods

The project was ethnographic and longitudinal in design. This design was selected because of the appropriateness of ethnographic methods in revealing the processes by which families search for information and services, construct knowledge over time, and make decisions in naturalistic contexts. By conducting semi-structured, open-ended interviews, interviewers were able to elicit rich narratives about the ways families perceived their child and the disability and their social supports. In the present study, the interview transcripts, fieldnotes on the clinic observation(s), and a demographic form constituted the set of data that was analyzed. The present study systematically examined these data with a focus on

social network systems, and the family's construction of the meanings of their child with a disability, including their experiences and emotions.

Analysis

Analysis of the data was conducted based on procedures that have been established for qualitative studies. Data were analyzed in two main ways in order to answer the research questions. First, each subject's interviews and clinic observation notes were read as a "case" and the content of these data was interrogated, organized, and reduced (Miles & Huberman, 1994). Specifically, each "case" was read and case summaries were written for each family that distilled information related to the research questions

Second, the data were summarized and displayed in the form of a matrix to provide an organized, condensed compilation of the information. Miles and Huberman (1994) suggest that a display such as a matrix allows the researcher to systematically arrange the data and extract patterns and themes. The dimensions in the display matrix for social support were developed based on the literature and on themes that emerged when doing the case studies. Primarily the dimensions are in line with the formal and informal dimensions of social support outlined by Findler (2000). These dimensions were verified as being an accurate reflection of the data by the principal investigator of the larger study. Specifically, the social support matrix was used to systematically extract information from the data pertaining to sources of social support including spouse, other family, friends, faith/church, schools, healthcare providers, other agencies (e.g., military, social service), support groups, and internet. The matrix was further used to summarize information regarding the families' evaluation of their social support networks including: 1) how the source supported them, 2) negative aspects of social support source, 3) positive aspects of social support source, 4)

barriers to social support, and 5) whether families experienced social isolation as a result of having a child with a disability (see example of matrix in Appendix C).

The display matrix for perceptions of the child with a disability was developed based on the themes in the data as well as the literature addressing the presence of chronic disability and how families cope with their beliefs surrounding the disability (Seligman, 1983) as well as how these beliefs and core values impact familial interpretation of the disability event (Patterson, 1993). The dimensions in the matrix were verified by the principal investigator of the larger study for validity purposes. Specifically, the perceptions of disability matrix was used to systematically extract information from the data pertaining to families' interpretive frameworks that impact how they view their child with a disability including religion, ethnicity/culture, economic constraints, community/social others (stigma), family, formal service sector (e.g., therapists, schools, doctors), parent support groups, and internet. The matrix was further used to summarize information regarding how these interpretive frameworks impact the following: 1) beliefs about the cause, 2) beliefs about factors that impact health and development, 3) beliefs about why it happened or why it happened to their family, 4) beliefs about the condition itself, 5) beliefs about treatment or where to look for help, and 6) beliefs about how disability affects social isolation (see example of matrix in Appendix D). The data from both matrices were used to analyze patterns of responses and narratives concerning social support and perceptions of the child with a disability. These data were further used to systematically compare patterns within and across families of different ethnic and socioeconomic groups.

For validity and reliability purposes, interview transcripts and observation fieldnotes were revisited several times to verify the emerging meanings in line with Miles and

Huberman's statement, "The meanings emerging from the data have to be tested for their plausibility, their sturdiness, their 'confirmability'-that is their validity (1994, p.11). Validity in terms of qualitative analysis means that the conclusions made about the data set are both accurate and defensible. For validity purposes, data summaries captured in the matrices were compared with the entire dataset that had been coded by other researchers using a text management system (NUDIST). Data coded in this system related to social support and perceptions of the child were compiled and compared to the findings of the matrices and case studies. An example of a NUDIST search for social support is included (see Appendix E).

Data obtained from the Demographic Information Questionnaire form was analyzed using descriptive statistics. Descriptive statistics were used to make simple group comparisons (e.g., household composition, household income, parents' and child's ethnicity, and child's diagnosis).

A discussion of the methods used to address each of the research questions follows.

Analyses related to Research Question 1: Research Question 1 addressed the nature and meaning of social support of families of children with disabilities. The source of data for this analysis was the interviews and observations. First, a content analysis of the social support networks (i.e. formal and informal) and the family's perceptions of the quality of these supports were conducted using both case summaries and the matrices to capture the findings and make comparisons between families.

Analyses related to Research Question 2: Research Question 2 addressed the nature and meaning of the perceptions of the child with a disability. The source of data for this analysis was the interviews and observations. Content analyses of the interpretive frameworks (e.g., culture, religion, ethnicity) that influence perceptions of the child with disabilities was

conducted. Results of this analysis were recorded in matrix form so that similarities and differences between families could be systematically analyzed.

Analyses related to Research Question 3: Research Question 3 addressed the variability of the relationships of social support and perceptions of the child with a disability across ethnic and economically diverse groups. Specifically, the variability of these relationships within and among families who vary by ethnicity and income were examined. The matrices used to address research questions 1-2 above were examined systematically for patterns of similarity and difference within and across the sample.

Table 3.1:
Demographic Variables

Family ID	Education	Marital Status	Ethnicity	Annual Family Income	Diagnosis
I01-R05	high school	Married	American Indian	<15,000	Autism
I01-R09	high school	Married	American Indian	<15,000	No Label
I01-R10	9-12 years	Married	American Indian	15,000-29,999	Fredrieich's ataxia
I02-R05	associates	Divorced	American Indian	<15,000	No Label
I02-R10	high school	Married	American Indian	15,000-29,999	No Label
I03-R10	high school	Married	American Indian	15,000-29,999	No Label
I04-R10	some college	Separated	American Indian	<15,000	Trisomy 13, Mosaic
I05-R10	high school	Married	American Indian	15,000-29,999	Trisomy 21
L01-R07	< 9 years	Married	Hispanic	30,000-44,999	Chromosome 18q Syndrome
L01-R12	some college	Married	Hispanic	15,000-29,999	Ehlers-Danlos Syndrome
L01-R13	9-12 years	Married	Hispanic	15,000-29,999	No Label
L02-R07	high school	Married	Hispanic	<15,000	Trisomy 21
L02-R12	high school	Married	Hispanic	30,000-44,999	Muscular Dystrophy
L03-R07	high school	Married	Hispanic	30,000-44,999	Blepharophimosis
L03-R12	associates	Married	Hispanic	<15,000	Neurofibromatosis 1
L04-R12	high school	Married	Hispanic	<15,000	Trisomy 21
L05-R07	bachelors	Married	Hispanic	<15,000	Physical Abnormality
L05-R12	9-12 years	Married	Hispanic	30,000-44,999	Microtia
A01-R01	some college	Married	African American	45,000-59,999	4 q deletion
A01-R02	GED	Married	African American	<15,000	Ectodermal Dysplasia

A02-R10	GED	Never mar	African American	15,000-29,999	No Label
A02-R11	high school	Never mar	African American	15,000-29,999	Developmental Delay
A03-R03	bachelors	Married	African American	>105,000	Developmental Delay
A04-R10	some college	Never mar	African American	<15,000	No Label
A05-R03	masters	Married	African American	>105,000	Autism
A06-R10	bachelors	Divorced	African American	45,000-59,999	No Label
A07-R03	some college	Married	African American	45,000-59,999	No Label
A08-R10	bachelors	Never mar	African American	15,000-29,999	Prader-Willi
A09-R03	GED	Married	African American	<15,000	No Label
A12-R03	associates	Never mar	African American	30,000-44,999	Neurofibromatosis 1
E01-R02	associates	Married	Caucasian	45,000-59,999	Cleft Lip and Palate
E01-R04	high school	Divorced	Caucasian	<15,000	Developmental Delay
E02-R01	high school	Never mar	Caucasian	15,000-29,999	Lung Disease
E03-R02	some college	Married	Caucasian	15,000-29,999	Aniridia
E03-R04	9-12 years	Never mar	Caucasian	<15,000	Prader-Willi
E04-R01	bachelors	Married	Caucasian	>105,000	Hearing Impaired
E05-R06	some college	Married	Caucasian	30,000-44,999	Special Needs
E06-R01	bachelors	Married	Caucasian	90,000-105,000	Trisomy 21
E06-R02	bachelors	Married	Caucasian	90,000-105,000	Cystic Fibrosis
E06-R04	high school	Married	Caucasian	<15,000	No Label
E07-R01	some college	Married	Caucasian	45,000-59,999	Osteoporosis
E09-R08	some college	Married	Caucasian	15,000-29,999	Chromosome Abnormality

Table 3.2:
Number of Families in Each Income Level by Ethnicity

	African American	Native American	Hispanic	Caucasian
LOW INCOME				
<15,000	3	4	4	3
15,000-29,999	3	4	2	3
TOTAL	6	8	6	6
HIGH INCOME				
30,000-44,999	1		4	1
45,000-59,999	3			2
60,000-74,999				
75,000-89,999				
90,000-105,000				2
>105,000	2			1
TOTAL	6	0	4	6

Table 3.3:
Demographic Variables by Percentages

	African American	Native American	Hispanic	Caucasian
Married	50	75	100	75
Not Married	50	25	0	25
Low Income	50	100	60	50
High Income	50	0	40	50

CHAPTER IV

RESULTS

A qualitative approach was employed to investigate the three research questions of this study: (1) What is the nature and meaning of social support for families of children with disabilities? (2) What is the nature and meaning of the family's perception of their child with a disability? and (3) To what extent does social support and perceptions of the child with a disability vary across ethnic and economically diverse groups? The third question is analyzed below within the context of research questions 1 and 2.

The source material for these analyses were fieldnotes from clinic observations and parent and/or caregiver responses to open-ended questions obtained during several semi-structured interviews that provided more detail about the nature and meaning of social support in the lives of these families of children with disabilities, and the perceptions of the child with disabilities constructed by these families. The analyses are based upon a thematic analysis and are presented for each of the three research questions below.

Nature and Meaning of Social Support

Family and Friends

Results from the thematic analysis showed that seventy-five percent of the primary caregivers interviewed regarded their informal social networks including family and friends as supportive. They indicated that family and friends provided emotional, instrumental, and informational support. Emotional support is defined by behaviors such as expression of love,

care and solidarity, and fulfillment of personal needs (Findler, 2000; House, 1981). Families found emotional support from others who talked with them about their child and challenges associated with their child's condition, called them daily to check on the family and child, and attended doctor's appointments with the family. Several parents indicated that the emotional support provided by their family members and friends was important and meaningful. This is illustrated in the case of a Latino family with a child diagnosed with chromosome 18q syndrome. The mother discussed the emotional support she received from her family in Puerto Rico. She commented that even though her extended family is "so far away" in Puerto Rico, "there are a lot of phone calls in support of us." She also highlighted the fact that although her family questioned the etiology of her daughter's condition, believing that the mother might have done something to harm herself while pregnant; they remained supportive throughout the process of getting a diagnosis and treatment.

Similarly, an African American, single mother of a girl diagnosed with prader-willi syndrome talked about the emotional support provided by her daughter's maternal grandmother. The girl and mother resided with the grandmother for many years before moving directly across the street. The emotional support provided by the grandmother decreased the burden of care and the mother's level of distress associated with caring for her daughter. She stated, "My mother was my backbone. I could not have made it without her." She elaborated:

I was a little depressed by it in the beginning (when her daughter was diagnosed). I actually lost a lot of hair. The dermatologist said I was just under a lot of stress. What pulled me through was my mother. I can't put in words how much help she was.

In addition to emotional support, families described the instrumental support provided by family and friends. Instrumental support is characterized as assistance such as goods,

services, money, and helping with tasks such as running errands, providing transportation to and from appointments, and providing respite care (Findler, 2000; House 1981). An example of instrumental support comes from the African American mother of the child diagnosed with prader-willi syndrome. The mother gave very pointed examples of what she needed to assist her in caring for her daughter. She talked about the “hardship” of getting her daughter to her doctor’s appointments, which included needing money for gas, a reliable source of transportation, and someone to assist with driving. As a result of not living in close proximity to a major healthcare facility, this parent had to travel five to six hours in order to receive specialized treatment for her child. As with many families of children with genetic disorders who reside in rural areas, she had to travel outside of her hometown area for intervention and treatment. For this family, instrumental support was provided by the daughter’s biological father and stepmother who traveled two hours to transport them to appointments when needed.

These findings are consistent with research on the experience of minority families of low socioeconomic status. Typically, because of limited resources these parents are dependent on instrumental support to manage their child’s disability. Unfortunately, the family members and friends of these parents are often limited in resources themselves and often are unable to provide all the necessary support.

Informational support is defined as forms of knowledge that empower individuals and enhance their ability to improve their current condition (Thoits, 1986). Families noted that informational support was also provided by family and friends. Several parents talked about the utility of the information that their family members and friends retrieved from the Internet (e.g., information about the child’s disability concerning diagnosis and prognosis),

advice about services and interventions, and information regarding educational and community based resources. A mother of twins, one of whom was developmentally delayed, stated that her sister provided both informational and emotional support during medical appointments. Specifically, she traveled from another city to accompany the family to doctor's appointments to interpret medical jargon. Additionally, this mother reported that she receives informational and emotional support from a friend who also had a child diagnosed with developmental delay. Her friend's experiences with school and community-based programs provided information and support for this mother who was learning to navigate the system.

The availability of informational support was dependent upon access and available resources. Those from lower socioeconomic statuses living in more rural areas were less likely to have received informational support. Some of the information that was received by this group was influenced by cultural beliefs about disability. For example, a Native American mother was told that her child was disabled because he was of "mixed" race. In this family subculture, it was believed that "mixed blood" resulted in mental and emotional problems.

Although most of the interviewees, across ethnicity and socioeconomic status, regarded their family and friends as supportive, approximately sixty percent of the Native American families did not feel as supported by their informal network system. Several mothers reported that many of their family members, both nuclear and extended, blamed them for their children's disabilities. One mother, for example shared her frustrations regarding her family's feelings that she was the reason why her child was disabled. Furthermore, her family refused to keep him when she needed respite or time to herself. She

regarded her family as her “worst enemy.” “They’re the ones that say that there is nothing wrong with him...Or he’s like that because of me.” Another Native American mother noted that some of her family members refer to her developmentally delayed son as “dumb.” As a result, she does not talk to or visit with this part of her family. The lack of support that many of the Native American families reported could be due to a number of factors: their educational backgrounds or different understandings of childhood disabilities as shaped by their cultural beliefs.

Interestingly, all but one Native American family lived in the same township and neighborhood in which they were born. Consequently, these families were surrounded by extended family members including parents, siblings, aunts and uncles, cousins, and friends of the family. Despite their living in close proximity to family members, these family members felt less supported than other interviewees, many of whom did not live near their family members. This homogeneous environment makes it more likely that their understanding of disability would be shaped by factors associated with their cultural heritage. Many of these mothers most likely shared these same cultural beliefs and familial views about disability before reinterpreting the condition once it happened to them and their child.

While the majority of all the mothers said they had support from their informal network of family and friends, most did not talk about their spouses or their child’s father as a source of support. This finding was in spite of the fact that seventy-four percent of the interviewees were married. Of those who did mention spousal support, instrumental support was the most common. Instrumental support typically included financial support and transportation to doctor’s appointments. Latino families, though, did note the emotional support provided by the spouse. Fathers in the Latino sample were reported by the mothers to

be involved and supportive. One mother commented, “I (mother) am for him (father) as he is for me.” Additionally, some mentioned that the child’s disability had brought them closer together (e.g., “[It] has taught [my] husband and I a lot about of things about our marriage and how to communicate”).

Religion/Religious Faith

Analysis further showed that about a third of the families believed that their religion (i.e., organized religion, church community, or faith) was supportive in helping them to cope with the challenges associated with their child and their child’s disability. Some of these families talked at length about how their faith in God helped them deal with their child’s disability, while others discussed the emotional, instrumental, and informational support that they received from their church community. In regard to faith in God, one mother commented, “The man upstairs (God) has been my biggest support.” Even help from professionals was viewed in relation to God. A Latino family of a child diagnosed with chromosome 18q syndrome discussed their perceptions of medical professionals who have been instrumental in helping their daughter who has significant physical, communication, and behavioral difficulties. Specifically, they stated that it is a blessing that God has given these specialists “the ability to understand what is going on in our bodies.”

Most of the families who viewed their faith in God as supportive believed that “God won’t put more on us than we can bear.” Thus, families believed that God had given them the support and strength to be able to cope successfully with their child and their child’s disability. Their religious beliefs were important for their mental well-being.

The church, including the pastor and congregation members, was also highlighted by these families as a source of support. Support provided by the church included members’

praying for the family, and providing emotional support, financial support, and assistance in finding community and school based services for their child. A Native American mother of an autistic child spoke at length about the social support she receives from her local church community. She explained that her son likes to sing along with the congregation during service. He typically sings his ABC song, “getting a couple of letters here and there,” or Twinkle Little Star. She noted that the church members will stop and listen to him “like you could hear a pin drop in there. And they clap for him.” When asked more specifically if they support her disabled child, she elaborated:

Oh yes, yes. And that used to worry me.....People getting upset when he can’t listen to the service, you know. But it don’t any more. The preacher said, “It don’t bother me. I don’t know about the rest of them,” he said, “But it don’t bother me.” He said, “If I can’t preach over a little child, then I need to quit.

Similarly, a Caucasian family of a child with autistic-like behaviors (the child does not have a definite diagnosis), shared information regarding the emotional and informational support provided by their church community. The mother referred to the pastor and members of her church as her “church family.” She reported talking with the pastoral counselor about medical issues before making decisions regarding treatment for her children.

Most families expressed positive perceptions of their church community but a few expressed negative views. Three families reported feeling ostracized and isolated from their church community. A Native American grandmother of a child diagnosed with fredriech’s ataxia, while feeling supported by the church members’ prayers, noted that several of her church associates believe that her grandson was “possessed by devils.” Thus, she infrequently attends church services but does confide in the pastor of the church. Two other parents also anguished over the fact that members of the church community would stare

when their child would not sit still or stop talking during church service. Although these families felt isolated by the church community, they still spoke about their faith in God.

Healthcare Professionals

Families' perceptions of the support provided by healthcare professionals varied. Families expressed both positive and negative perceptions of various healthcare providers. They talked about both their satisfaction and frustration with those responsible for their child's healthcare. Much of the frustration was generated when these families were unable to "get a straight answer" or a definite diagnosis about their child's condition. One mother described the journey to getting a diagnosis in the following way:

It's almost like you have this open book of all these things it could be. And every time you see a doctor, they say, "Well, did you try this?" And we have to say, "Yes." And they mark that off. And they say, "Okay, well try this." And we say, "Okay." And so it's like you are narrowing it down, instead of saying, "This is what he has."

Similarly, a mother of a toddler diagnosed with mosaic-trisomy 13 (a genetic disorder affecting multiple organ systems including kidneys, heart, and vision), talked about her experiences with getting a definite diagnosis from healthcare professionals. She elaborated:

I had no diagnosis. Her former pediatrician did not even refer her for her glasses. I continually questioned her biggest issues as an infant: I questioned her eating, I questioned her eyes and this was for her first check up for 4.5 years. Her eyes, I questioned her constipation. I questioned the stuff that was left for her little finger. I questioned everything and left there just feeling stupid every time. And I knew, you know. When you have total strangers coming up to you in the grocery store asking you or telling you, oh she's so cute, does she have Down's? Or when your family members are like, no, you need to have your doctor check this and that. And I'm like I know something is going on, but what is it?

The search for a diagnosis was a topic in the narratives of several of these families. They talked about their journey through the many evaluations, specialists, and diagnoses of their child's condition. A Caucasian mother of a child diagnosed with cerebral palsy, cleft

palate, and developmental delay declared that she “had to step off the referral trail” because “she had let it (seeking answers from doctors) dominate her life, the family’s life.”

Reportedly, during a trip to see a specialist in Atlanta five hundred miles from their Florida home, this mother had a revelation. Her daughter had come to dread the visits to the doctor and what might happen at each appointment. As the family neared Atlanta, this mother reassured her frightened daughter stating, “They’ll just do the same tests- you know what is going to happen.” This mother realized that the doctors would do the same tests, get the same answers, and they would drive back home. It was at this point that she decided to drive back without seeing the specialist and instead give her daughter the time “to just be a little girl.” This mother’s path toward obtaining a diagnosis is one that several of the families were still traveling when the project ended.

Others talked about the insensitivity and condescending attitudes exhibited by healthcare professionals during scheduled appointments. Joyce, an African American mother of a child diagnosed with 4q deletion and agenesis of the corpus callosum, discussed her experiences with military healthcare professionals. She expressed concern that the quality of her child’s medical care was dictated by how she “dressed and talked” during appointments.

So when I take him to the doctor, when I have the IEP meetings, especially when I’m meeting new people, I try to be sure I wear some of my best clothes, watch how I speak, watch my language ‘cause I can get real country at times. I try to watch my language and use words that I know what they mean. And I have seen a difference in the way I’m treated.....And if people expect to get that, they would need to dress the part, we need to dress, we need to present ourselves, seen as serious, that we mean business; they’re not talking to a dummy. You get better service that way.

Ellicia, another African American mother of a child diagnosed with autism, talked about similar interactions with her child’s healthcare providers. Based on past experiences, she recommended that if parents go to appointments prepared with information and questions

regarding their child's condition and doctors will respect you. Although these mothers were both educated (one had some college and the other a master's degree), they both thought that their choice of words or interactions with the doctor dictated the quality of care their child received.

Although some parents spoke of negative encounters with their healthcare providers, other parents indicated that healthcare professionals were very supportive. One mother evaluated her child's physician in the following way:

But he is, Dr. Smith is great. I don't know if you have ever come across any of his other patients. But I think he's just one of the best doctors. He's very supportive and he's extremely intelligent. So you know he can explain things very well, and I just like him. He's a good doctor. And I've gone through a lot.

In most cases, those who spontaneously talked about healthcare professionals and the social support they provided saw this support as being instrumental (e.g., speech, occupational, and physical therapists providing services to meet the child's needs) and informational (e.g., healthcare professionals providing information about the child's diagnosis, prognosis, and treatment interventions). However, it should be noted that several parents verbalized a need for additional informational support to address their questions and concerns related to the child's condition. In fact, parents of children with disabilities typically requested additional information from healthcare professionals regarding their child's condition. One mother commented:

As I told you before, I think that the doctors and the counselors should have more information or given us phone numbers we can call to ask questions every time we need to do so. Something like a hotline where we can call and receive a quick answer, without having to be calling the doctor and waiting for his answer. They should have an information line available for us; something like a 24 hours a day line, and if we have doubts call them and be able to ask the questions we need to ask. I think they should have more information, a line of information constantly opened.

Healthcare professionals and the informational support that they provided were perceived somewhat more negatively by the Latino families. They indicated that doctors used too much technical information and jargon that they could not understand. Additionally, about fifty percent of the Latino families indicated that pamphlets and other information provided by their healthcare providers were typically in English and not their first language, Spanish. On the other hand, others indicated that their healthcare providers disseminated information in both languages. This variability can most likely be attributed to the differences in individual doctors and healthcare facilities. The percentage of Spanish speaking families in a certain area will dictate the need for available resources for this specific population. Overall, the support received from healthcare professionals are varied consisting of both positive and negative evaluations.

Schools

Families' perceptions of social support provided by the schools included teachers and therapists who provided informational (e.g., information about school and community based services, information about child's diagnosis) and instrumental (e.g., services provided by the exceptional children's program within the schools) support. These sources of social support were viewed positively. In fact, several families highlighted the importance of the instrumental support provided by the early intervention programs services through the schools. A Latino mother commented:

Whenever there is a special needs child, Early Intervention takes over and supplies all forms of support and all kinds of information like phone numbers, people to contact, all the information is given to them to you. Plus the persons who you call give you more contacts and information. It's like a chain. So, with one person you get so much information.

On the other hand, parents noted their concerns about inadequate or unavailable school services (e.g., lapse in therapy services, lack of services for autistic children in the schools) as well as some school staff lacking of knowledge about the child's disability. A mother in a small town evaluated the school this way:

The school system is very political. I don't know if it's just [my] county in general. But I think the school administrators forget that these are actual children that they're talking about. They have to realize that without these special needs children they wouldn't have a job. So they need to go in and get their hands dirty every once in a while and familiarize themselves with what the teacher is dealing with 18 developmentally delayed children. This is why she needs extra funding to have a couple TAs. This is what it's like to have 18 children with runny noses or who can't button their pants or tie their shoes. I think they actually forget that.

Several families talked about how they "educated" the schools and the staff in exceptional children's programs about their child's condition. One mother of a child with a rare genetic disorder reported that she has a binder of information that she gives to new teachers at the start of the academic year including symptoms, diagnosis, treatment, and educational interventions. Findings further indicated that many of the parents who had to educate the schools typically had children diagnosed with rare genetic disorders such as neurofibromatosis (NF-1), trisomy 13, and ehler-danlos syndrome, whereas some of the parents with children with autism, a disorder commonly seen in the schools, noted that they did not have to do as much education.

In general, the school system was seen as providing instrumental support when services were available to parents. Parents from rural areas tended to have more negative views of schools and were more dissatisfied with staff and administration. This particular theme was consistently seen in the interviews conducted with parents from rural and property poor school districts where educational funding is limited.

Internet

In most cases, parents regarded the Internet as a source of informational support. Responses indicated that families tended to use the Internet to get information about their child's diagnosis, treatment, prognosis, as well as preparing for doctor's appointments. Parents stated that the Internet allowed them to "enter one thing and hundreds of things pop up" and that using the Internet was not time consuming. A Native American mother of a child who did not have a definitive diagnosis commented:

The Internet has been a great resource just in general. You can accomplish probably a hundred times more a day online than you could sitting and looking through medical journal, looking through parent's magazines. You enter in one word and hundreds of things pop up.

Several others used the Internet to seek out other families who have children with a similar disorder or chronic illness. As Skinner and Schaffer (2006) found for the total sample of families in this study, these virtual communities provided support for parents searching for information about their child's diagnosis, prognosis and treatment. For example, in an effort to find other children with a similar karyotype as her daughter, Janice used the Internet to find "someone like J." She reported:

There's nobody with the same thing as J. That's the problems I keep running across. I can't find anybody with even a similar carrier type that has the same issues as J. I can find people who have children with different disorders who might have one or 2 similar issues, but not one is like J.

Although most parents evaluated the Internet positively, several parents commented that the amount of information you retrieve when searching for information can be "overwhelming" and "too technical."

These findings indicated that the Internet not only provided informational support but was a gateway to emotional support, providing a virtual community of individuals who

worked together to meet the needs of their children with disabilities. This virtual community gave them a sense that they were not alone in their efforts. The Internet provided a method of seeking out others who were in similar situations (e.g., parents who had a child with a disability, parents seeking school and community based services, parents trying to navigate the healthcare system, parents who had a child with a rare condition).

Parent Support Groups

Thematic analysis indicated that approximately thirty percent of parents regarded support groups as a main source of social support. The families that were involved in parental support groups reported that these groups provided information about school and community-based services, treatment, insurance coverage, and legal advice. A mother of a child with Prader-Willi syndrome commented that all parents should have a support group. She elaborated, “I just think it makes life easier. You don’t feel like you’re the only one out there.” Interestingly, spontaneous responses indicated that parents utilized support groups such as Parents as Partners, Mothers Support Group with TEACCH, and ED National Foundation (ehler-danlos syndrome) to interact with families who had a child with a similar condition. Even mothers who did not use the Internet articulated a need to find other families who had children with similar conditions as a form of support. One mother talked about why she continued to search for a support group:

Right now, I’m just interested in finding people who have what M, see these children, let them play with M, speak with these people, exchange information and ideas. I would really like that. I think I would be more fulfilled, then and it would eliminate a lot of my doubts. There are others with conditions like down syndrome and such, but I would like people with experience specifically with M’s condition. This way we can compare progress.

These findings indicate that parental support groups are instrumental in helping families identify other families of children with a similar condition. These families were

looking for someone to understand their situation in raising a child with a disability. Those who have a child with a similar condition are more apt to understand what these parents are experiencing in many contexts including the school, home, community, and personally. Others were searching for information about the condition including etiology, treatment interventions, and prognosis about their child's disability. One mother of a child diagnosed with mosaic trisomy 13 was very specific in her search for a family of a child with a similar condition. She commented:

There's nobody with the same thing as J. That's the problems I keep running across. I can't find anybody with even a similar carrier type that has the same issues as J. I can find people who have children with different disorders who might have one or 2 similar issues, but no one is like J.

Families varied in terms of how much social support they perceived they had. However, there was much variability across ethnicity and income levels so that it was difficult to associate other factors that determined perceived social support. Three cases studies exploring families' perceptions of low, medium, and high social support are illustrated below.

Case 1: Perception of Low Support

This Native American family includes two grandchildren (Stephen and Seth, twins), their grandmother (Esther), grandfather (Bob), father (John), and stepmother (Susan), all of whom reside in rural North Carolina. The grandmother is a homemaker and is the primary caregiver of her husband, son, and grandsons. John, who lives directly down the street from the grandmother, was diagnosed with Friedrich's ataxia as an adolescent and has been confined to a wheelchair for many years. Susan, the children's stepmother, recently separated from John but visits and calls the children periodically. Stephen, one of the twins, was diagnosed with Friedrich's ataxia within the last several years. Seth, who has behavioral

difficulties, resides in a group home nearby. Bob, Esther's husband, is also very ill and is also cared for by his wife.

During the initial interview, Esther commented that much of the information disseminated during the genetics counseling session "went right over our heads." In fact, the grandmother had no idea why her grandson was being evaluated as well as what tests the geneticists were administering. Interestingly when asked if all of her questions and concerns had been addressed during the session, she reported that they had. Although Esther did not understand the content of the genetics session about genes and chromosomes, she just sat there with a "blank stare" instead of asking for clarification. Anecdotally, the interviewer noted a similar response style during the semi-structured interviews. Esther answered affirmatively to questions when it was clear she did not understand them. She never asked for clarification or felt comfortable acknowledging her lack of understanding of the subject matter. Instead, she would comment in this way, "I would think it would be great," or "Yes ma'am." In regards to healthcare providers, Esther further reported that they were unable to get a diagnosis because none of the doctors in this rural area "knew anything about it." In fact, several of the family's primary healthcare providers had never heard of Friedreich's ataxia. This lack of knowledge about the disability made the family feel less supported by the "experts and doctors" who they felt should know and be able to advocate for them. The family had to travel outside the community to university-based hospitals to get support from specialists that they have never met in a place in which they may or may not feel as comfortable.

This family did not have ready access to medical and scientific technologies. Esther reported that they did not have a computer or the Internet. She requested that the interviewer

search the Internet for her and “see what you can find out about it for the next time (i.e., the next interview).” However, the stepmother at some point had used the Internet at her job or a friend’s house to search for information about the condition. She was able to interpret her findings in a useful way for the family. With that, the informational support that she provided was helpful in assisting the family in understanding the condition, working with healthcare providers, and navigating the system. When the step-mother moved out, this support was no longer available to Esther.

During the second interview, the twin’s stepmother reported that she no longer lived in the home. Apparently, she had abruptly left the home several weeks before and relocated to a town approximately 10 miles away. Susan’s abrupt departure put a burden on the entire family. During the interview (with Esther, John, and Susan), John became very emotional and began to cry as he talked about his current living arrangements. Later in the interview, the grandmother reported that this is yet another loss for the boys that she must help them deal with. John reported:

(We’re) separated now. Stephen is going through some different changes. Seth is going through some different changes. All of them wants their mother back, their stepmother back. And she’s not ready to come back. I have to go to the hospital tomorrow to get some test done. They say we have....attacks. It affects the heart and they think that my heart has been affected and I have to go for some tests for that. Other than that, everything’s going okay.

Esther reported low or no support from her informal network system. Now that the stepmother no longer resided in the home, she had even less support. Here, we see that the grandmother, who is nearly seventy-years-old, is taking care of both the children and her son with no assistance.

See I had to take my husband to the hospital yesterday and he had to go through ICU for a while, about 5 to 6 hours heart and stress test. And then I

had to leave him up there by himself and then to the schoolhouse with Stephen to get him straightened out. And then taking care of John.

At the same time, she reported, that “no one” provides social and emotional support for the family but “God.” Esther reported that God is her only source of support that has helped her “deal with all of this and their conditions” (referring to son and grandson). She commented, “Baby, I’m hanging in there. That’s all I can do. But I’m not doing it all on my own. I have God’s help. I couldn’t make it by myself.”

During the final interview, the grandmother seemed to feel more comfortable sharing some of the difficulties associated with caring for her son, John. She reported that John was very difficult at times being both verbally and physically abusive. In fact, during the previous week he attempted to strike her while sitting in his wheelchair.

He said I was the cause of his being with this disease and I don’t know why, but he blames me first. And he’s evil. He curses me. He does everything and I have to pray to God - he got at me on the ramp one day and was swinging both arms and trying to get to me. And I pleaded the blood of Jesus and you know, he couldn’t come up on that ramp trying to get to me. It’s evil. That’s the reason I was wanting to ask you do this have something – he blames it on this disease.

Esther in an attempt to understand her son’s behavior asked the interviewer about the psychological effects of Friedrich’s ataxia. Most likely, she is also worried that Stephen, her grandson, will eventually begin to exhibit the same behaviors if this is a symptom of the disease.

Overall, Esther seemed overwhelmed by the daily challenges associated with caring for her husband, son, and grandson. She saw God as her only form of support. As it pertains to Stephen, she showed a lack of motivation to actively seek treatment and resources that could ultimately change the situation. For example when asked if she had looked into available resources suggested by the genetics clinic, she commented that she had not. This

primary caregiver is overwhelmed by her situation, which impacts her motivation to advocate for herself and her grandson on many different levels. As with many families who have low support, they may be so “tapped out,” financially, emotionally, physically, and mentally, that they are unable or unmotivated to access available resources.

Case 2: Perception of Medium Support

This family includes mother (Cynthia), father (Juan), and two children (Lisa, aged 17 months and Samantha, aged 2 months). The family is from Puerto Rico but relocated when the armed services moved them to a military base in North Carolina. During the initial interview, Cynthia discussed her initial concerns and search for a diagnosis for Lisa. She reported:

In the hospital, they simply told me that she had to have a genetic test done, from the chromosomes, to find out her condition. But they never gave me the referral, and I have been trying and trying until I finally got it, because since she was born until she was 15th months, when I think she had her first appointment, it was a lot of time that I had to wait until they gave me the first appointment.

Here, we see that this mother was motivated to seek a diagnosis and medical intervention for her daughter. After Lisa’s birth, it seemed as if the doctors “dropped the ball” and failed to follow-up with the family with a genetics referral. Once Lisa’s mother realized that a genetic evaluation was the only way to get a diagnosis and treat Lisa’s condition, she was motivated once again to find out what was going on with her daughter.

During the first interview, Cynthia indicated that she was very comfortable dialoguing with the specialists during the genetic session. Unlike Esther in the case above, Cynthia was not concerned whether the doctors would evaluate her negatively. Instead, she commented that she “was prepared. I wanted to receive all the necessary information and give all the information that she would need regardless what I had to do to get some benefit

for the child.” When she did not understand something, including the medical jargon used by the healthcare provider, Cynthia asked questions.

Well, the words they use and the methods they use are kind of difficult to understand, but if you ask them questions, it’s different. I understood pretty well how the chromosomes are, the numbers of chromosomes each person has, and all the information was easier to understand. So when you ask questions and make them answer them directly, it’s easier. But if they talk about chromosomes too much and they use the words they use, I get lost. But when I asked questions, they resolved my doubts.

Cynthia also endorsed multiple kinds of support including formal, informal, and the Internet. During the first interview, she discussed several sources of informational support including healthcare professionals, Internet, and a friend who has a child with disabilities. The following narrative from Cynthia includes information regarding the quality of the support received from these sources.

Oh Yes! It makes me feel more secure and I feel so much better because I know that what I am talking about is not something I have invented. It is precise information, it is information that comes from professionals. Yes, I feel very well when I express myself, when I explain to others what is the condition of my child because it is something said by professionals. It’s not something that I read in a book or in the computer and I think that may be my child’s condition. No, it’s something done and said by a professional. Yes, I feel stronger now because if someone needs to know I can tell him: look in the computer under chromosome, and you will find a lot of information, and if you have any questions, call me, and I will answer them. So, like I say, I have become an expert in genetics. I have used a lot the computer to look for the 4th chromosome and 18th. I have a friend now that has problems with the 22nd chromosome, so we are sharing information.

However, this mother viewed the Internet as her main source of support. She indicated that the information retrieved from the Internet has been instrumental in helping her to address her husband’s misunderstandings about chromosome 18q syndrome. “He is accepting it more for what it is, but he is still extremely idealistic. He thinks that she will be ‘normal’ but it will just take him longer to get there.” Furthermore, this mother has been empowered by the

Internet and chatting with other parents who have children with similar conditions. More importantly, she is interested in finding more information about the syndrome related to development, “what consequences the future will bring, if she will be independent, if she will always need someone to assist her, what things may get worse and need more surgery later.” This information will allow these parents to plan for the future. Here, we see that this mother is motivated to look beyond the here and now to project the needs of her child later in life.

Although this mother endorsed various sources of support, she did not feel as supported because the family does not qualify for state services such as Medicaid and Social Security. With this additional monies and coverage, Lisa would be covered for most services including therapies and surgeries that she may need. Although the family has insurance coverage with the United States Army, they have their own tailored program through which all services are administered. Based on the information Cynthia has obtained, Lisa would benefit from additional services that the family is unable to pay for without assistance. Specifically, she does not want financial support but “all the access to medical assistance and treatments. That’s what I’m after, not money.” Cynthia reported:

About the help, she had her services since she was born. The army puts them in a special program they have, they give you the appointments. They tell you: your child needs physical therapy, you have to contact this number; the child needs occupational therapy, so call this number, the child needs speech therapy, and so on. They give me all the information and help the child requires. The State helps if your economic condition is bad, but if your economic situation is fine, they don’t help you. This is what I understood, but now I am fighting to get social security, Medicaid... I have a telephonic appointment with them to give them all the information about the child, and they will tell me if she qualify for the services or not. But up to this moment, the army is the one that administrates her therapies, surgeries; everything is covered by the army.

This narrative highlights the struggle for access to services experienced by many families. Many of the families discussed what will be referred to as “caught in the middle” of

the disability system--not poor enough for social services or governmental aids and not affluent enough to personally pay for specialized services. Families are insured but their insurance only covers a certain dollar amount or specific services that typically don't include premium services that go beyond standard care. This Latino family who is insured by the United States Army will not qualify for services such as the Medicaid or Social Security. Cynthia believes that these programs would give Lisa access to "more help, better specialists," thereby possibly giving her daughter a better quality of life.

Case 3: Perception of High Support

This family includes mother (Gale), stepfather (Henry), two children (Lisa, younger sibling; and Sam, who was 10-years-old and diagnosed with autism) and the biological father (Bruce, who lives on the West Coast). Both of the parents are college graduates. The mother works as a manager for a firm and the husband is an engineer.

During the initial interview, Gale said, "Genetics testing is very important to us in helping us to get a diagnosis." After the referral but prior to the appointment, Gale began to search the Internet for relevant information. She reported:

I just went on there searching, you know, for genetic testing. And then I would get hits, so just came up with some stuff I remember seeing. So, I just told my husband, "When we get there, I'll ask, 'What is the purpose,' you know, 'What are we going to accomplish from this session?'" We didn't know if they were going to come back saying, "Well R has another syndrome," you know, or "He has something different." So we didn't really know what to expect. So you know, it met all our needs.

Here, we see that Gale used the Internet as a form of informational support before attending the genetics session. She further stated, "I like to prepare myself before I go to these meetings." This mother indicated that she always uses the Internet to search for information about autism and related issues. She also said she was involved in several parent support

groups associated with TEACCH and the State Autism Society. Along with the Internet, these groups provided emotional and informational support. More importantly, she said, “You don’t feel like you are the only one.” Anecdotally, this mother seemed proud that she was equipped and knowledgeable about her son’s condition. In fact, she encouraged other parents to advocate for their children through information.

Based on the comment above, this mother indicated that her search on the Internet was “too broad” and that she was unable to retrieve any useful information. She indicated, “When we get there (Genetics Clinic), I’ll ask, ‘What is the purpose, ‘you know, ‘What are we going to accomplish from this session?’” This mother felt completely comfortable asking questions of doctors whom she had never met or interacted with in the past. She said: “Because before we go to any doctor’s visits, we write down all our questions. So that we don’t forget when we get there, you know what some of the questions are.” Gale, who is of high income status, reported that the quality of her son’s healthcare is good. She reported that her income status and ability to pay, insurance coverage, and flexible work schedule impacted the quality of healthcare her son receives. Gale, who is in senior management, discussed how the flexibility of her job has allowed her to “go back and forth and do a lot of stuff” for her child with disabilities. She recounts a time when her job was not as flexible:

Well, I'm fortunate because of what I do. I have a very flexible schedule since I'm in senior management; I come and go as I please. If I get up and I need to work from home, I can. And I'm very blessed to have that. Because without that, they would have been no way specifically last year. I would have had to quit. I was at the school literally four days out of a five day week. He would have an accident, I would go home. I sometimes would go back to work. They would call me; he's had another accident. I would go back. At one point, the school just started washing his clothes. That was really hard, because at that time, my territory was East Coast, so there would be times that I'm not in town. And they would call me and I'm in Florida. And my husband would be here but his job is very- you know, he has to stay at work. So he couldn't just

come and go. So that has been really hard. But we've been blessed in my position, I'm able to go back and forth and do a lot of stuff for them.

This is an opposite situation to that of many families who do not have jobs with such flexibility. In fact, many families would likely lose their jobs or be forced to quit in order to have time to address their child's needs. A high income bracket, along with insurance coverage also assisted this family in meeting their child's needs. Throughout the interviews, Gale discussed the many appointments with specialists (e.g., neurologists, behaviorists, nutritionists) in different parts of the country. When the insurance companies did not pay for the needed assessments, Gale said, "We paid out of pocket." Many of the high support groups had access to such resources and services because of adequate insurance coverage or the means to pay "out of pocket." When compared to Cynthia, the mother who endorsed medium support, this was not an option. Her husband who is with the United States Army could not afford to pay "out of pocket" for services not covered by their insurance.

Financial stability, insurance coverage, Internet, family support and parent support groups were among the many supports mentioned by this family. Gale also indicated that Sam's father, who lives in California, provides additional support. He calls almost daily, calls after most doctors' appointments, and provides financial support. In fact, during the last interview, Gale indicated that Sam was going to live with his biological father in California during the next academic school year. The school system in California has specialized services for children with autism. Sam would be able to benefit from empirically based interventions utilized in a public school setting. Based on Gale's research, Sam would not be able to get such services in the state that he currently resides. Sam will benefit from the many supports put in place to address his needs.

In summary, although there was variation in parents' perceptions of their social support networks, overall parents tended to feel supported by others. Generally, parents across ethnic groups and socioeconomic levels identified that the social support received from others assisted them in accomplishing daily goals in caring for their child with disabilities.

Nature and Meaning of the Perceptions of the Child with a Disability

The role of social support systems including formal and informal extend beyond providing social support to families of children with disabilities. These systems also influence, whether directly or indirectly, the families' perceptions of their child with a disability. The perceptions of others, including but not limited to one's family, such as healthcare professionals and society in general, may impact the caregiver's attitudes, thereby influencing factors such as service utilization and treatment options. An analysis of social support indicated that families had support from both formal and informal networks. With that, the current study examined how these parents are forging their views of their child within and against these social support systems. Several themes emerged from the data regarding perceptions of the child with a disability including: biomedical, religion, normalcy, labeling, and stigma and discrimination.

Perceptions of the Child with a Disability

Results from the thematic analysis indicated that approximately seventy percent of the parental responses highlighted a biomedical view of their child's disability. With this view, the problems that are associated with the disability are thought to reside in the person with disabilities and not factors external to the individual (i.e., discrimination and societal

attitudes, labeling and stigma). Parental responses related to this view are represented in the following comments:

“Ok, if my genes that I pass on to K can give, ok, and they’re saying that women are carriers of it, and we can pass it along to sons, then why couldn’t his father have it also?....He’s somebody’s son, too.”

“What has happened, has happened. I have scientific backing (meaning a genetic diagnosis of prader-willi).”

“He can’t do any better because of his genes.”

“Chances (of having another child with the same genetic disorder) are you are remarried and you have a new partner, then chances. I mean the chances would be so, so slim of again finding that autosomal recessive gene again, that you know, the risk would be.”

The biomedical model of disability focuses on the impairment of the individual, and assesses the disability based upon the functional loss caused by the impairment. Research indicates that parents who incorporate this model into their conceptualization of their child’s disability are more likely to consider biomedical interventions. Although the current study did not investigate the interventions used by these families, interview data indicated that these parents were almost exclusively using biomedical interventions to address their child’s needs.

Religion was the second theme that emerged regarding perceptions of the child with disabilities. Results from the thematic analysis indicated that approximately thirty percent of the parents believed that their religion offered an interpretive framework for understanding their child with a disability. These parents’ responses indicated that having a “special” child with a disability was a positive experience. Specifically, these parents believed that having a child with a disability was a blessing or an opportunity to do God’s work. Many reported that this event was an honor or reward in that they were chosen to do what others could not or

would not do. An example of a parent viewing their child's disability from this framework is seen in the following case of a Native American mother who commented on why her son was born with Down syndrome:

My daddy always said that I was good. Like to my nieces and stuff, I was always good with them and stuff, and I've never been hateful to children....An I always...and did things with them. And it was like the Lord was rewarding me for what I had always done. A special child for me to take care of because he knows that I would do it.

Maria, a Latino mother, offered this account of her perception of her daughter (who is diagnosed with chromosome 18q syndrome) and God's divine intervention of why she was chosen:

No, this is a gift from God. It took me 14 years to have my first daughter. That she was born with this problem signifies that the Lord gave her to me because He knows I am up to it. It's a little difficult once in a while, everyone has their limits. But that's just how it is, perfect or imperfect, with problems or without, for me personally and as a mother love is.... The strength He gives me allows me to love my child and I see her as perfect.

The process of achieving an understanding and acceptance of the child's disability was seen in the relationship of the parents' religious beliefs and views of disability in general. Having a child with a disability was seen as adding both value to their life and enhancing their relationship with God. As previously stated, some parents believed that they "have been chosen to do the work of God." It was evident from parental responses that the birth of their disabled child had a profound effect on their perception and appreciation of disability.

Personal experience often has a profound effect on perception. In the context of religion, whether faith or organized religion, the traditional negativity and stigma that is often seen in many communities regarding disability has in this instance been replaced by a much

more positive and empowering view. Joy, a Caucasian mother from a high-income family, viewed her daughter in a very positive way:

You know you see it in these kids and I always say if you ever want to see God's hand in anything, go see a child who had disabilities or is sick. If you're ever going to see it, that's where you'll see it. You'll see it in their family or in them b/c there's just that positive side. They end up giving so much more than they'll ever take. So it's exactly the opposite of that old religious attitude you used to hear about where this was some kind of punishment.

The cliché, “God won't give us more than we can bear,” was used repeatedly by more than half of those parents who talked about the relationship between their religious faith and their perceptions of their child with disabilities. This was consistent across ethnic and socioeconomic levels. As previously mentioned, many of these parents believed that the child with disabilities had been put into their lives for a reason. One mother talked about her belief in God related to her child's disability in this way:

My personal belief is that I have religion in my life. I believe in a higher spirit. I believe there is a higher being than what we've got. I believe in the Lord, I believe in the bible and I believe that old proverb that says He won't put no more on you than you can bear, I believe that.

Normalcy was the third theme that resulted from the analysis of perceptions of the child's disability. Results indicated that about fifteen percent of the interviewees endorsed views of normalcy or viewing their child with a disability as normal. However, many of these same parents were noted to fluctuate back and forth, in one place referring to their child as “normal” and then in another context referring to the child as “special” or having difficulties. A Latino family of a child diagnosed with sturge weber syndrome did this as they discussed their perceptions of their son with a disability:

Father: “No, I still see him the same as I do my daughter and oldest son. I see him the same. I don't try to over protect him or chastise him less or call his attention to things-

Mother: “We treat him the same as the others.”

Father: “Even though he’s special. But he’s not special. He’s the same as his siblings.”

Mother: “I just see him as normal, do you understand?”

This wavering back and forth exhibited by families may be due to their need to see their child with a disability from various frameworks. Many of these families most likely held different views of children with disabilities before reinterpreting them once they had their own child with a condition.

Similarly, another family of a child diagnosed as developmentally delayed, grappled with their perception of normalcy. The mother reported that her family refers to him as “dumb” because he is cognitively delayed when compared to same-aged peers. On the other hand, the mother called him “special.” More importantly, she commented that “he doesn’t give the physical appearance of being sick.” In this case, we see that this family views their child as “normal” because he doesn’t have the physical signs of disability. Anecdotal data indicated that his lack of physical symptoms shaped his mother’s view of her son. Therefore, if he had had obvious physical abnormalities she would have likely seen him differently, not as “normal.”

Labeling was another theme that emerged from the thematic analysis of the perceptions of the child with disabilities. Several parents talked about the labeling and the stigmatizing attitudes of others including the schools and the healthcare system. Selected interviews demonstrated that parents indicated that their child and their entire family had been the victim of labeling. Evidence of these feelings can be seen in an interview by a mother who was concerned about her child being labeled within the public school system:

He’s at Liberty preschool and we’re gonna switch him to JC Turner Head Start. The reason being that JC Turner is a federally funded program with no ties to the public school system. So he immediately won’t be labeled an EC

child. In the worst case he could do 2 years at JC Turner Head Start, hopefully get him caught up to where he needs to be and go into the public school system as just a child that is older, starting kindergarten at 7 instead of 6. But he will be doing age appropriate things, hopefully.

This mother believed that the public school system's process of labeling her son would impact the quality of his educational experience when compared to mainstreamed children. Thus, this mother took measures in her own hands and made a decision to initially place him in a school setting that does not categorize children according to their disability. She commented about her thoughts about labeling:

D is just special. I don't consider him having an illness 'cause he's doesn't give the appearance of being sick. I don't look at him as a disability 'cause if you think of things every person has a disability. So if you think about it, every person has a disability...up here speaking in public. Some may consider that a disability. So it's not right to label them. I'm very against labels. D is just special.

Stigma and discrimination were two somewhat related themes that emerged from parental responses regarding perceptions of their child with a disability. Several parents reported that certain family members would not "visit" or "treated them differently" because they had a child with disabilities. Others reported that they felt they were "not welcome" or were "viewed differently" by customers and staff when the family, including the child with disabilities, patronized an establishment such as a restaurant. As a result of these perceived attitudes of society, these families were less likely to participate in family functions and community outings. They were more likely to isolate themselves from those individuals who did not make them and their child feel accepted. One mother, when asked how her life had changed because of her daughter's condition responded:

Family life or even socializing, I don't do that anymore because I feel like people don't understand Nancy's issues like I do and I can't constantly tell her no, no, no. That's not good for anybody. So, I feel like I stay at home more

and I'm more Nancy proof. I can deal more with her messing up and doing things in my own home that other people wouldn't understand.

Many of the families stated they had experienced stigma during their interactions with several segments of the community (e.g., school, church, family). One mother stated that she felt uncomfortable in social settings because of her child's behavior. She believed that certain individuals had a lack of knowledge concerning genetic disorders. As a result, she felt that they did not understand her and her role in taking care of and managing her child's behavior. She said, "I can't go to restaurants because of the child's behavior--people look at you funny because they think that you can control it--spank him and he will stop." Other parents reported experiencing stigma when their child was rejected by other children in the school and community. One Hispanic parent compared having a child with a disability to racism. She stated:

It's like the racism here when we came to the United States. We had never seen racism in our country and they say here there is racism. It's the same like when you see kids with certain problems and you sympathize because your perspective of life is different, more humane.

This is a poignant example of an immigrant's attempt to help us understand how they felt by using an example of racism. Racism is a powerful social attitude that has impacted the lives of many minorities in the United States. To use racism as a reference, given the historical significance in this country, is quite profound.

Discrimination, a component of stigma (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001), was mentioned by forty percent of all interviewees and fifty-three percent of minorities. Families discussed acts of discrimination related to the child's condition, including issues regarding insurance coverage, access to school based services, financial status, and misdiagnosis. Representative responses include:

“Many providers don’t take Medicaid. They just say “flat out, no.”

“If somebody is sick then they’re (healthcare professionals) gonna investigate it more in a child of a different race than they would, unless it looks suspicious, with the White race or whatever. But if the child is like sick or whatever, they’re gonna investigate more because I guess they may think negatively with a child of a different race.”

“Whether family has insurance or not dictates the kinds of services they can get.”

“You don’t get services in this area unless you know about the University of BU.” (Mom feels that they are unable to get certain services because they live in a rural, impoverished area.)

Faye, a mother of high income status, discussed how financial status, education, and insurance determined the level of care of children with disabilities.

I feel that we accept a lot of things, that people don’t know what’s going on and don’t know that they have the right to keep pushing and they just accept what someone says. And they might not have the resources to follow it up or they might feel intimidated. I’m very lucky that I have good insurance. I’m blessed with that and I think money has a lot to do with it also and time ‘cause this stuff takes a lot of time sometimes. I’m lucky that I can go into the schools and go for all these conferences and take her to these different doctor’s appointments. That takes time and money. I think that has a lot to do with it, too, and also education.

This mother’s access to services offers insight into the discrimination experienced by families who do not have this level of resources and education.

Summary

Overall, findings indicate the importance of social support in assisting these families in their efforts to take care of their child. Specifically, it was found that both informal and formal networks were significant in the lives of these families. Many families reported that their friends and family were instrumental in helping them deal with and manage their child’s disability by providing a variety of supports: emotional (e.g., someone to talk with about the challenges associated with the child’s disability), instrumental (e.g., transportation to doctor’s

appointments), and informational (e.g., information retrieved from the Internet about the child's disability). An interesting and unexpected finding was that grandparents provided an important source of support in assisting the parents with activities of daily living and being a source of strength for these families. The social support provided by one's religion was also seen as important to these families. There was some variability in these findings across ethnic and socioeconomic levels.

Findings regarding formal social support network systems indicated that parents evaluated healthcare providers in both positive and negative ways. On one hand, they thought their doctors provided them with essential information regarding treatment and services. On the other hand, some parents did not like a particular doctor's personality or the nature of the interactions. The interaction was seen as positive when the healthcare provider provided information and was perceived by the parent as having a pleasant personality. There was some variability in these findings across ethnic and socioeconomic levels.

In reference to perceptions of the child with disabilities, several themes emerged from the data analysis. Overall, parental responses indicated that families of children with disabilities incorporate various interpretive frameworks to understand their child with a disability. These views influence their response to the challenges and lived experiences of caring for a child with a disability. These interpretive frameworks offered families an opportunity for a renewed understanding of themselves and their child with a disability. More importantly, these perceptions, whether biomedical, religion, normalcy, labeling, or stigma and discrimination, provided meaning for the experience of having a child with a disability, assistance with coping and other benefits. General findings further suggested that families,

regardless of race, socioeconomic status, or education, exemplified each of the themes analyzed in this study.

CHAPTER V

DISCUSSION

This study examined the perceptions of forty-two families from different cultural backgrounds who had a child or who were at risk for having a child with a genetic disorder. Specifically, the aims of this study were to investigate families' perceptions of social support, their child with a disability, and whether these constructs varied by socioeconomic status or ethnicity.

Nature and Meaning of Social Support

In general, findings indicate that social support from both informal and formal networks was significant in the lives of families of children with disabilities. Findings clearly indicate that family and friends were instrumental in helping families of children with disabilities deal with and manage their child with a disability by providing a variety of supports including: emotional (e.g., someone to talk with about the challenges associated with the child's disability), instrumental (e.g., transportation to doctor's appointments), and informational (e.g., information retrieved from the Internet about the child's disability). These findings were consistent with the scientific literature regarding the importance of social support as a vital resource for individuals who are dealing and coping with a stressful situation, such as parents raising a child with a disability (Dunst, Trivette, & Hamby, 1994; Findler, 2000; Sarason, Pierce, & Sarason, 1990). Findings reported here help to extend previous research such as that of Dunst et al. (2000) who defined social support

within the context of a family systems approach. Within that context, the family's social support network is instrumental in providing the resources needed to adequately care for the child with disabilities including resources for everyday living, carry out parenting responsibilities, and supporting child learning and development. The investigator of this study would expand Dunst's definition of social support to include emotional resources needed to adequately support the primary caregiver or family of a child with a disability. Based on information from the interviews, emotional support was viewed as an important aspect of daily functioning and care of the child with a disability.

While the findings of this study clearly indicates that family and friends were perceived as major sources of support by most families of children with disabilities, some variation in perception was associated with ethnicity of families. Native American families did not feel as supported by their family and friends. They reported that many family members and friends blamed them for their child's condition or had negative evaluations of the child with a disability. These findings could be due in part to characteristics of this Native American sample: their beliefs about disability or, their educational level. The area of North Carolina inhabited by this tribe has been identified as one of the most impoverished areas of North Carolina. This area also has a high illiteracy rate when compared to other areas of North Carolina.

Information from the interviews indicated that most mothers did not talk about their spouses or their child's father as an informal source of support. However, Latino mothers highlighted various kinds of supports provided by their spouses including emotional support. It was undetermined in the current analysis whether mothers of other ethnic backgrounds were actively seeking or felt they needed emotional support from their spouses. Button,

Pianta, and Marvin (2001) in an examination of families raising children with cerebral palsy suggested that future research must attempt to understand how parenting-related and family-system factors are organized into both maladaptive and adaptive patterns. Based on the suggestions of Button, Pianta, and Marvin (2001), future research should examine emotional support in the context of parenting-related and family-system factors to better understand the father's role.

Several families also mentioned grandparents as a main source of support in their daily coping with the child's disability and daily life demands. Vadasy (1987) noted that researchers rarely collect information on the role that grandparents play in the lives of families of children with disabilities. It should be noted that particularly in minority communities, grandparents are often the first people contacted after parents learn about their child's disability and, therefore, may become a key element of the mother's support network (Alston, McCowan, & Turner, 1994). This is certainly consistent with narratives that highlighted the important contributions that grandparents made in the lives of these families (e.g., providing respite care, financial, and emotional support). Ethnographers observed during home interviews that in several families a grandparent, was identified as the secondary, and in some cases the primary caregiver of the child. Although the current study did not investigate social support in regards to the role of grandparents relative to the care of children with disabilities, these observations may warrant more investigation.

Findings further indicate that formal network systems such as healthcare professionals and the schools were also instrumental in helping families of children with disabilities by providing a variety of supports including informational (e.g., information about diagnosis and treatment interventions, information about school and community based

services) and instrumental (e.g., speech, occupational, and physical therapy provided within the schools, referrals to specialists). However, families' perceptions of the support provided by their formal network system varied both within and across participants. For example, some parents evaluated healthcare providers as both helpful and unhelpful. On one hand, they thought their doctors provided them with essential information regarding treatment and services. On the other hand, their narratives suggested that some parents did not like a particular doctor's personality or the nature of the interactions. Interactions were seen as positive when the doctor provided information and was perceived by the parent as having a pleasant personality. This finding was consistent with and extends the findings of Early and Poertner (1993) who examined social support in families of children with disabilities. These researchers found that families of children with disabilities often appeared quite dependent on medical and other helping professionals, although they often expressed dissatisfaction with these formal helping relationships. Specifically, doctors were reported as instrumental in helping the family navigate the healthcare system but most felt that they were not helpful in taking the time to assist them in understanding the child's disability: its cause, diagnosis, and prognosis.

While the findings of this study clearly indicate that the informal network system including healthcare professionals and schools were perceived as supportive of families of children with disabilities, some variation in ethnicity and income level was noted. Latino families were more negative in their views of healthcare professionals and the informational support that they provided. They commented that doctors used "too much technical information and jargon" that they could not understand. Additionally, resources such as pamphlets and information on the Internet were typically in English and not Spanish.

Healthcare providers, school, and other agencies must be mindful of the language barriers. Although families may demonstrate basic interpersonal skills, they may not have the requisite language skills to engage in meaningful dialogue about their child's condition. Information both in English and Spanish should be available for all patients and parents of children. Secondly, an interpreter should be available for appointments with the healthcare provider. The parents would then have an opportunity to ask questions and address concerns with their healthcare provider.

Another finding was that parents from rural, impoverished areas tended to evaluate the public school system negatively. These negative evaluations typically centered on a lack of adequate services available for their child. Future research and legislation should focus on the needs and outcomes of children educated in areas with limited resources. We will most likely find that educational resources available to these families determine outcomes of these children and families (e.g., contribution to society, educational attainment).

Results also indicated that the social support provided by one's beliefs and religion was also important to parents of children with disabilities. Spirituality as conceptualized here involved traditional faith-based activities (e.g., prayer, attending church), personal approaches to meditation, or cultural practices that revived and renewed the families' coping strength and resilience. For a large majority of the families, religious beliefs and practices played a positive role in helping them cope with their child's disability. Many reported that their religious beliefs gave them "strength" and made them feel "special" to be the parent of a child with a disability. Many saw the life event as a blessing that served to increase their faith and enhance their belief in God. Previous researchers have documented similar findings. For example, in Putnam et al. (2003) religion was seen as a variable that significantly impacted

how people were able to cope with a disability. The participants gave credit to their religion and spiritual beliefs for giving them the strength to successfully deal with their disability. In another study, the importance of religious support in relation to coping was documented in a sample of women with disabilities from diverse backgrounds (Noonan et al., 2004). The findings of the current study are consistent with and extend the findings of Elliott et al. (2002) in which parents reported that dealing with their child with disabilities strengthened their belief and relationship with God. Many perceived their child as a “blessing” from God. Others believed that they had been chosen by God to do something (caring for a child with a disability) that others could not or would not do.

Some variation in perceptions of social support was found among families from different ethnic backgrounds but that variation was minimal. One interpretation of this finding is that families who have a child with a disability come to share common experiences with other parents of children with disabilities. Challenges associated with the child and the child’s condition may create a new demographic category-- the “disabled family.” As parents enter the world of disability interventions and services, they may come to learn the language of disability and become advocates for their child (Skinner, 2005). As Skinner (2005) points out, the cultural world of disability is an example of a potential homogenizing culture—one that evens out other differences among families and creates similarities between them from sharing common experiences and concerns.

The finding that parents of children with disabilities perceived both formal and informal network systems as supportive suggests that parents of children with disabilities need support from a variety of systems in order to adequately meet the needs of their child. For example, members of a family’s informal network system may be instrumental in helping

them gain some emotional stability and their formal network system may provide information regarding services in the schools and community; both of which are important to the existence of a family of a child with disabilities.

Nature and Meaning of the Perceptions of the Child with a Disability

In line with previous research studies of families of children with disabilities (Gartner, Lipsky, & Turnbull, 1991; Green et al., 2005; McDermott & Varenne, 1997), the results of this study clearly indicate that societal and medical ideas such as biomedical models of disability, religion, normalcy, labeling, and stigma and discrimination influenced how families viewed their child with a disability. These factors influenced how families thought about and responded to their child. Specifically, these factors served as interpretive frameworks influencing parental beliefs regarding diagnosis, treatment, and prognosis.

The majority of the parents in the study viewed their child with a disability from a biomedical framework which focuses on the impairment of the individual and assesses the disability based upon the functional loss caused by the impairment. Parsons (1951) indicated that parents who incorporate this model in their conceptualization of disability are more likely to consider biomedical interventions. With that, healthcare professionals are vital to the decisions regarding the child's healthcare. Parents of children with disabilities rely on professionals for informational support that shape in part their perceptions of the child with a disability as well as decisions regarding the child's care. However, the healthcare provider must be willing to take the time to address these issues and concerns with the family. Given the recent changes in the healthcare industry, this may be a difficult task but one that will prove to be beneficial over time.

Religion was also an interpretive framework in which families viewed their child with a disability. The event of learning about the child's disability and subsequent questioning led to a redefining of themselves, their understanding of the disability, and how religion fit with these experiences. While redefining spiritual beliefs is common to most people, individuals in this study often recounted stories that suggested that the experience of dealing with their child's disability often challenged them to reach beyond and draw on religious beliefs to develop an understanding of their child with a disability. Many of the families perceived their religion and spirituality as a positive force in their lives. Much of the research in the area of parents' responses to having a child with a disability has focused on the negative outcomes such as depression and psychological distress (Gray 1997; Horton & Wallander, 2001; Wallander & Noojin, 1995), burden of care (Wallander, Pitt, & Mellins, 1990), and isolation from others (Fox et al., 2002; Turnbull & Ruef, 1997). The findings of this study suggest that additional research in the area of positive perceptions and outcomes of families of children with disabilities be conducted. These findings extend the research of Hastings, Allen, McDermott, and Still (2002) and Skinner, Correa, Skinner, and Bailey (2001). In a study of mothers of children with intellectual disabilities, Hastings et al. (2002) found that mother's perceptions of the child as a source of happiness and fulfillment and a source of strength, and personal growth were associated with reframing coping strategies.

Skinner et al's. (2001) study of the role of religion in the lives of parents of Mexican and Puerto Rican origin living in the United States who had children with developmental delays also suggested that more research is needed on religion as a source of support and the ways that religion influences positive experiences and personal transformations around having a child with a disability. This is consistent with the literature that indicates that

disability can be an opportunity for personal growth, spiritual awareness, and self-discovery of inner strength and resilience (Dunn, 1994, 2000; Tedeschi, Park, & Calhoun, 1998). This more positive perspective challenges the traditional, pathology-based views about disability and is a pointed reminder of Trieschmann's (1988) contention that "most persons with disabilities have significant strengths and coping ability, and this fact appears to have been seriously underestimated by many professionals" (p. 85). The ongoing relevance of this contention is implicit in Elliot et al.'s (2002) observation that "participants perspectives have not been consistently taken into account in research and practice" (p. 695) that involves individuals with disabilities.

Perceptions of normalcy were also prevalent in this study. In many cases, parents, regardless of their child's disability, regarded their child as "normal" in some ways and "special" in other contexts. Parents of children with "hidden" disabilities were especially likely to see their children as normal. As one grandmother stated, "she is normal, nothing is wrong with her, she just doesn't learn like other children." As Landsman (2005) found, mothers may work to make their children seem as normal as possible so they will not experience discrimination or stigmatization. Healthcare professionals should also consider that parents view their children as normal in some ways, and work with these perceptions in delivering appropriate treatments and services.

Findings indicate that in many cases, families clearly held the perception that people with disabilities were stigmatized by others in the community. Their perceptions of how and why this stigma existed, however, varied greatly. For example, stigma seemed to be experienced differently based upon whether the disability was "hidden" or visible. Families of children with visible disabilities seemed to experience stigma on many different levels.

They reported “dirty” looks from patrons in restaurants or grocery stores, family members who were critical and rejected the child, as well as the schools that had reduced expectations for the child.

The existence of stigma further makes the situation more difficult and complex for parents as they must deal with the challenges associated with their child’s disability coupled with the prejudices of society. In a qualitative analysis of mothers’ models of disability, Landsman (2005) found that mothers’ perceptions of disability were shaped or influenced by such factors as prejudice, oppression, discrimination and stigma. Therefore, educational programs and workshops are needed to help community residents, healthcare professionals, and educators understand that parents with children with disabilities are likely to bring past experiences of stigma and discrimination to interactions with providers, which may impact the treatment process. This may be manifested as a basic mistrust of healthcare professionals and the school system.

Although parents regarded formal networks as both helpful and unhelpful, mistrust of healthcare professionals and the schools was prevalent. Themes of mistrust were seen in statements such as “I would not trust my pediatrician to give me advice because my doctors didn’t even notice what I noticed about my son.” While there were some positive views regarding healthcare professionals, the negative views seem to have the most profound effect on decisions regarding provider and treatment. For example, even though one parent saw her child’s physician as providing information and being instrumental in assisting them in navigating the system, the physician’s overall personality, approach and “bedside manner” influenced her to search for another provider. This indicated that parental attitudes toward

their physician are an important variable in determining their perceptions of the healthcare system.

Atkins (1988) noted that individuals who seek services for disability come with a specific set of beliefs, attitudes, values, and goals which are determined, to a large extent, by the individual's existing life experiences. These experiences shape an individual's worldview, including attitudes toward healthcare and treatment. Atkins (1988) asserted that African Americans may approach the rehabilitation process with mistrust and guarded optimism, and that this mistrust may translate into low expectancy for success. Also, this mistrust may negatively affect one's perception of available services; thereby reducing the likelihood that the individual will seek these services when needed.

Stigma and discrimination associated with labeling was another perception of the child with disabilities that emerged from the interviews. Several parents talked about the labeling, which led to stigmatizing attitudes of others including schools and healthcare professionals. This perception influenced several parents to reject the labels and diagnoses as assessed by the school and medical professionals. One mother in this study decided to place her child in a school that does not prescribe to labeling in order to avoid her child being labeled as developmentally delayed. She commented that everyone has a disability and that her son should not be labeled. Landsman (2005) found that mothers of recently diagnosed children used the "doctor is wrong" strategies to reject the negative labels such as developmentally delayed "to dissociate themselves from those who 'really are' disabled" (Baynton, 1997, p.85).

The above findings offer a context on which to base developing therapeutic interventions for parents of children with disabilities. All healthcare professionals who work

with families of children with disabilities should consider working to build a trusting relationship with those that they care for. From the initial visit parents want to know that they are being heard; their questions concerning etiology, diagnosis, and prognosis are being addressed; and that their doctor cares about the child and family. Therefore, healthcare providers, including doctors and therapists, should encourage parents to verbalize their feelings, fears, and worries throughout the treatment process. Parents will trust the doctors and other healthcare workers who exhibit a genuine interest and concern for their family and who take measures to help them feel valued and accepted. The use of positive reinforcement for concerns about appropriate care of the child or for the development of skills such as verbalization of feelings is one of the best strategies that the healthcare worker can use to establish trust. For example, parents reported that they were very appreciative when their doctor provided information, allowed them to ask questions, and treated them with concern and compassion. It seems likely that a program designed to increase communication between doctors and parents of children with disabilities would provide an effective intervention to reduce mistrust and increase rapport.

Researchers seem to agree that stigmatized individuals choose a variety of methods to deal with the negative experience of stigma. Perhaps one of the most common reactions is isolation of the child and family from the outside world because of their perceptions of not being tolerated by the mainstream public. While the literature suggests that families of children with disabilities are moving toward integration into society, there is still a lot of work that needs to be done in order for all children to be fully included. There have been efforts resulting in the reduction of labeling, stigmatizing, and discrimination of individuals with disabilities. The findings from this study indicate that the process of inclusion is

underway, but it is not complete. Several parents reported that they felt embarrassed or avoided certain places such as grocery stores and restaurants because of their children's behavior.

In terms of methodology, this study used a qualitative approach to examine social support and perceptions of disability in a sample of parents of children with disabilities. Heitzmann and Kaplan (1988) suggested that there is not a good understanding of social support and what it means; and therefore, operationalizing the construct is difficult. Therefore, this qualitative method was used, in part, to gain a better understanding of the constructs under examination in this investigation. The utilization of a qualitative approach enables us to make a contribution to understanding both the context and meaning associated with family perceptions of social support in families of children with disabilities. The findings from this study will be important to quantitative researchers who are interested in developing new questions related to a more comprehensive conceptualization and psychometrically sound understanding of this important psychological construct. Social support and perceptions of disabilities as it relates to parents of children with disabilities is now seen, as a result of this research, as affecting more aspects of these parent's lives than has previously been documented in the literature. As a result of these findings, these two constructs, at the very least, have been expanded. It has become evident during the course of this investigation that combining qualitative and quantitative methods may represent the best methodology for research purposes with parents of children with disabilities. Mixed method research designs, although increasingly used, have not been fully embraced in the social sciences. This reluctance appears to be related to the fact that most of these designs have lacked specificity and clarity (Tashakkori & Teddlie, 1998). However, Green (2003)

indicated that ethnography is “gaining acceptance as a legitimate and valuable form of scholarship in the social sciences” (p. 1371).

It is the belief of this researcher that quantitative and qualitative methods can be used to complement and extend what we have learned about families of children with disabilities. For example, qualitative assessment has the potential for "infinite flexibility to meet the needs of diverse clients" (Subich, 1996, p. 285). It offers healthcare professionals "methods of helping clients to know and understand themselves better--methods that are flexible, open-ended, holistic, and nonstatistical" (Goldman, 1992, p. 616). Described as "informal forms of assessment" (Okocha, 1998), qualitative assessment has flexibility in terms of its parameters and does not have the rigidity that surrounds quantitative assessment which is guided by a standardized set of questions and closed responses. Therefore, future studies should consider the use of a mixed method design when investigating social supports and perceptions of disability.

Limitations

Demographic and methodological limitations were noted in this study. The participants in the current study were a group of families residing in North Carolina. Additionally, demographic data indicated that a majority of the families were of lower socioeconomic status, and that children had a range of disability types. Thus, these findings on support and perceptions of disability may not generalize to all families of children with disabilities. Additional studies of individuals of African American descent, and well as other minority groups' meanings of social support and perceptions of disability are warranted. Future investigations should consider controls for variables such as family size and composition, income level, and type of disorder. Moreover, factors such as age-of-onset of

disability and severity of disability should be examined for their relation to support and perceptions of disability.

It is important to note that that this study involved a small sample size of families with children with disabilities. The diverse disability composition of the participants in this study may have also influenced the findings. In future studies, researchers should consider utilizing a participant group comprised of a single disability type (e.g., fragile X, autism, neurofibromatosis, attention deficit disorder). This would result in a more homogenous sample by disability. It is quite possible that the type of disability may impact how individuals perceive and deal with the condition. Although some of the children's diagnoses shared common characteristics such as behavioral difficulties, the diagnoses were so varied with confounding characteristics such as severity of disability, that it made it difficult to group the various disorders into categories.

Conclusions

This study analyzed interview data that reflect the lived experiences and the meanings attributed to social support and disability among a small group of parents who had children with disabilities. The culturally diverse composition of this group increased the rigor of this study. The purpose in conducting this study was not to offer results that could be generalized to individuals beyond those who participated in the study but to examine different facets of families' perceptions of social support and their child with a disability.

The findings of this study offer insight into social support as perceived by families of children with disabilities. Families highlighted both informal and formal supports that assist them in meeting the challenges associated with coping and dealing with raising a child with a disability. The findings of this study are consistent with prior research as it relates to

perceptions of disability and the role that social support plays in the lives of parents of children with disabilities. This study extends what is currently known in the existing literature by using qualitative methodology to better understand both the context and meaning associated with family perceptions of social support and the child with a disability. This information will provide a more comprehensive conceptualization and psychometrically sound understanding of these psychological constructs. This study also expanded on the scant literature focusing on how these constructs vary by ethnicity and economic levels.

The finding that informal support networks such as family and friends were important in helping families cope with their child's disability indicates that interventions based on a family systems approach are important. Family intervention uses "systems" theory to evaluate family members in terms of their position or role within the system as a whole.

Based on the findings of this study, the formal network systems including healthcare professionals are encouraged to work with families to determine what would support them. This information could also lead to a better understanding of the cultural beliefs that might impact families' perceptions of disabilities. Additional attention to this information may contribute to the process of developing better relationships between patients and healthcare providers, and the development of programs and interventions to better serve families of children with disabilities.

Appendix A:

DEMOGRAPHIC INFORMATION

Family ID: _____

Adult household members:

Relationship to focal child	DOB	Participant in clinic or interview? (Y/N)	Occupation (Specify)

Children: Focal child: Gender: ___ DOB: _____
 Siblings: Gender: ___ DOB: _____
 Gender: ___ DOB: _____
 Gender: ___ DOB: _____
 Gender: ___ DOB: _____

Marital Status of Primary Interviewee:
 (Circle one)

never married.....1
 married (& living together) 2
 separated 3
 divorced 4
 widowed5

Household income (before taxes): (Circle one)

.....< \$15,000
 15,000-29,999
 30,000-44,999
 45,000-59,999
 60,000-74,999
 75,000-89,999
 90,000-105,000
 > \$105,000

Educational attainment of Primary Interviewee:
 (Circle one)

< 9 years1
 9-12 years2
 High school diploma3
 GED ____ (yrs. completed)4
 Some college, no degree5
 Associate's degree6
 Bachelor's degree7
 Master's degree8
 Advanced professional (J.D., M.D.)...9
 Doctorate (Ph.D.)10

Educational attainment of spouse/
 partner or significant other
 (Circle one)

< 9 years1
 9-12 years2
 High school diploma3
 GED ____ (yrs. completed)4
 Some college, no degree5
 Associate's degree6

	Bachelor's degree7
	Master's degree8
	Advanced professional (J.D., M.D)...9
	Doctorate (Ph.D.)10
Ethnicity of Interviewee: (Circle one)	Black or African-American 1 White or European-American.....2 Latino/a or Hispanic3 American Indian4 Mixed ethnicity5 (Specify:_____)
Ethnicity of spouse/partner or significant other (Circle one)	Black or African-American1 White or European-American.....2 Latino/a or Hispanic.....3 American Indian4 Mixed ethnicity5 (Specify:_____)
Ethnicity of focal child (Circle one)	Black or African-American1 White or European-American.....2 Latino/a or Hispanic3 American Indian4 Mixed ethnicity5 (Specify:_____)
"Family ethnicity" (Circle one)	Black or African-American1 White or European-American.....2 Latino/a or Hispanic3 American Indian4 Mixed ethnicity5 (Specify:_____)
Parents' term for child's condition: _____	
Medical diagnosis (if known): _____	

Appendix B:

SECOND INTERVIEW

[Instructions to the Interviewer: Please adjust this interview to be specific to the family and what you talked about in the first interview. Review the transcript from the last interview and personalize this protocol accordingly, adding and deleting questions as necessary. This pertains especially to families that do not have a diagnosis.]

I. INTRODUCTION

1. How have things been going for you since we last talked? What's been going on with (focal child)?

II. QUESTIONS ABOUT THE CHILD

[Interviewer: You may integrate these questions into the response to question 1 as probes, if the opportunity arises.]

I'd like to ask some general questions about (focal child's name).

1. Tell me about (focal child's name)? What is his/her personality or temperament like?
2. What is his/her favorite activity? His/her least favorite activity?
3. What's his/her daily routine like?
4. Have there been any changes for [child] or in [child's condition] in the last six months?

Probe: what changes, what ramifications in health, development.

III. FIRST AND PRESENT CONCERNS

[You may have learned much of this in the observation and first interview so only ask if you don't know these things.]

I'd like to go back in time a little, to get a sense of the history of your child's problem.

1. When did you first have concerns about your child?
(This may have been answered in the genetic session so you repeat what they said and ask them if this was their first concern)

[If not answered already, ask the following question). If #2 below has been answered previously, verify the answer]:

2. Where was the first place you went for help or advice about your first concerns?
How was that experience?

[If you don't know this already, ask:]

3. You have told me that you were referred to the UNC clinic by _____.

What did they tell you was the reason you were being referred?
Have you had any more contact with them?
Have you talked to them about the results of clinic visit? What was that like?

4. What are your present concerns about [the child's] condition? What are your concerns for your child?
5. Have you had other questions about [child's condition] since we last talked? What are they? Who have you asked about them?

What did you find out?

Were you satisfied with the information/answers?

IV. UNDERSTANDING OF CONDITION

Now, I'd like to ask some questions specifically about the condition that led you to the Genetics clinic.

1. You've told me that you refer to your child's condition as _____. Is this correct?

[Or if you do not know, ask]: What term do you use to refer to your child's condition?

2. Do health professionals refer to the condition by other terms? If so, what is the term or terms?

3. What is your present understanding of [child's condition]?

4. Where would you say that this understanding has come from?

Probe: what sources of information have you relied on most for this understanding?

[If not known already, ask:]

5. What do you now think may have caused (focal child's) condition?

[If they have already given a probable cause above or in the first interview or observation, say "You have told me that you think _____ may be the cause of (focal child's) condition? Has this changed?"]

[Or perhaps they are unsure of the cause. The main thing is to find out their thinking about causality and to see if it's changed.]

6. Have health professionals suggested other causes?

What and which health professional?

Where were they?

What do you think of that (those) explanation(s)?

[If not mentioned in response to 6, then ask]

7. What does the child's primary health physician say about [child's condition]? What is his/her understanding of it? What did (s)he say caused it?

[If not mentioned in response to #6, then ask]

8. Did the genetics staff at UNC suggest another possible cause of [child's condition]?

If yes, what?

What do you think of that explanation?

9. When you describe (focal child's) condition to others, what do you say? Does your explanation vary depending on who you're talking to? How?

10. Have other people, like members of your family, or friends, suggested other causes or explanations for [child's condition]?

If yes, what? Who suggested?

What do you think of that (those) explanations?

I'm going to shift the focus here a little bit.

11. Based on what you've read and heard, what do you think the chances are that you could have another child with the same condition? What is your understanding of that and what do you base it on?

[If the child does not have a specific diagnosis, ask:]

12. Are you searching for a (another) diagnosis? If so, why? What would getting a diagnosis mean for you?

13. What did (or would) getting a **genetic** diagnosis mean as opposed to some other kind of diagnosis?

(Probe here as relevant)

14. Have you had to make any decisions in the last 6 months based on your understanding of [child's condition]? Like what services to look for, what medication to try, treatments, therapies, etc.?

V. QUESTIONS ABOUT SEARCHING FOR INFORMATION/SERVICES

1. Since we last talked six months ago, have you looked other places for information on your child's medical/genetic condition?

Probes: What did you look for—what health, medical or genetic term or condition were you searching for information on?

Where did you search or find information (Internet-name of search engine or sites; library, popular magazines, parent support and advocacy groups)?

[Please record the source and title of the information people have. You can record this on the tape recorder. Record Web sites, names of the groups or authors putting out the information, type of organization they are affiliated with (e.g., university, parent advocacy, parent support group, research center, etc.)

What is your evaluation of the different information? What is useful, what is not, is it easy to understand, suggestions for changes?

2. Have you had any more contact with the UNC Genetics Clinic? Have you had any contact with other genetics professionals?

If so, what was the nature of the contact?

3. Is [the child] currently receiving treatments or services (e.g., medical, educational, therapeutic)?

What treatments or services is _____ now receiving?

How is this different from the last time we talked?

How satisfied are you with current services?

4. What kind of treatment or services do you think your child should receive?
Where did you hear about these?

5. Do other people give you advice about what treatments or services to use? Who, what?

6. What are the most important results you hope to receive from treatment/services?

VI. QUESTIONS ABOUT THE FAMILY

1. How has your life changed because of your / your child's condition?

Probes: family routines (changes in activities--what, who, how extensive changes in physical environment--what, how extensive

- employment / work related changes
 - other changes (leisure, social support, religious)
 - changes in relationship with other children
 - does (the condition) affect your child (or you) physically or emotionally?
2. How do you think [the condition] will affect your child over the years?
How do you think it will affect your family? The child's siblings?
 3. Who provides social and emotional support (family, friends, parent support groups)?
 4. Have you described (the condition) to your friends or family?

What have you told them?
Do you tell different family members different things? What and why?
Do the terms the doctors / genetics professionals used make sense to your friends and family?
 5. Tell me about your family members' reactions to learning of [the child's condition.]

(Probe for different family members and different reactions)
 6. Do you feel like anyone judges or blames you or your child for the condition?
 7. Some people think about an illness or disability in religious terms. Do you think about it this way sometimes?

In what way?

Do others in your family think about [child's condition] in a religious way?
 8. What have you learned from dealing with [your child's condition] that you might not have found out otherwise?

ENDING

Is there anything we haven't talked about that you think is relevant to finding out about where families get information, how satisfied you are with the information, and how you have been affected by the information and your experiences with the health profession?

What questions do you have for me, either about the study or any questions I've asked?

(Inform them that you would like to do another interview in 6 months that will repeat some of the questions from this interview or will cover the sections you did not finish in this one: what changes in the last six months, current services, if any; places they may have looked for information; other experiences with medical or other professionals. Plus we may ask some questions about their opinions on recent advances in genetic knowledge.)

Family ID I01-R09

Child's Diagnosis or Disorder developmentally delayed; dyslexia

Income Level <15,000

Sources of Social Support	Spouse	Other Family	Friends	Faith/ Church	Schools	Healthcare Providers	Other Agencies (military , social service)	Support Groups	Internet	Other
How does the source support them	We provide support for each other 2,32	Sister-in-law attended session w/mom to interpret medical jargon 2,17-18; mom's great aunts call him dumb 3,7	Mom has friend who has child w/ DD that she talks to about services 2,18		school personnel say that it is not their field of expertise and will not call her back3,5	Went to DEC in nearby Co. –no DEC in their County 2,11; pediatrician sends info. To mom 2,25; ARC provides diff. speakers about topics on children 4,5	ARC provides info. And sitting services 2 times a month 2, 25	Family support network of NC-someone to talk to 1,16; utilized Parents as Partners support group 2,25	Get info. From the internet 2,14; you can find so much info. On the internet, “put in one word and hundreds of things pop up” 4,14	Dad's job is very flexible w/ his schedule 2,36; parent magazine that tells of others exp. 3,3
Evaluation of source of SS					Not getting adequate services w/ the schools- hasn't had speech in 6 months 2,11; lapse in services 2,28		Mom uses the ARC services- good bargain for sitting 4 kids 2,25			Mag. Tell their exp. Not how or why dev. Delays happen 3,3
Negative aspects of SS			Other family members do not provide support 2,33		Not enough services 2,11; school says that he will grow out of it and that he does not qualify for services 3,5	Mom thinks that many doctors disassociate themselves from the patient 3,8				Mag. Is too general not enough info. 3,3
Positive aspects of SS										
Barriers to SS					Mom does not want them labeled as EC in schools- will attend Head Start instead 2,11					
Social isolation		Mom does not deal w/aunts 3,7	We don't go to a lot of birthday			Some providers don't take				

			parties b/c of his behavior, they think that he is stupid 3,14			Medicaid and say “flat out no” 4,8				
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Family ID **L01-R07**

Child's Diagnosis or Disorder chromosome 18q-syndrome (chrom ab 18q, t4q)

Income Level 30,000-44,9999

Behavioral, Intellectual, and/or Physical Difficulties hits and bites others; hits head on floor; recently had hip replacement surgery, communication deficit (uses sign language)

Interpretive Framework	Religion	Ethnicity/Culture	Economic Constraints	Community/Social Others (stigma)	Family	Formal service sector (therapists, schools, doctors)	Parent Support Groups	Internet	Other
Beliefs about the cause	Mom believes that this is a test of her faith 2,23; family has gotten closer to God so that he will watch over her 2,24; god gave her to me b/c he knows that I am up to it 3,17			I feel good b/c my info. is from professionals not out of a book and I didn't invent it 1,8	I feel good b/c my info. is from professionals not out of a book and I didn't invent it 1,8; family wanted to know if she had done anything to harm herself while pregnant 2,23	She understands that there is something wrong w/the 18 th chromosome 1,4; it was a great relief to find out the cause 2,14		Mom has found info. about radiation or illness during pregnancy as the cause 2,11	Mom feels up in the air until she finds the cause-she lives day by day until she gets some answers 3,13
Beliefs about factors that impact health and development	With God's help she will be able to walk one day 2,6; I trust in God that she will progress positively 2,22					Genetic testing helped mom to understand that FC will have this the rest of her life-"it is permanent" 1,5; doctor told mom it was mild and that there are severe cases-raised mom's spirits 3,15			
Beliefs about why it happened, or why it happened to us	Those that ask why us have little faith 3,19								Mom wonders if subconsciously she has asked herself why us 3,19
Beliefs about the condition itself				I tell them what she has so they know she doesn't act like	Mon needed to be able to explain why the FC was	Now we can work with her, we know the condition (info.		Mom found that there are many cases of 18q	

				normal children and they will know how to treat her 1,8&12	the way she was 1,5; mom is very unsettled over her condition and what will become of her 2,15	from genetics clinic) 1,12; it is rare but mom says that there are many w/this problem-found info. on internet 2,12 ; sisters in Puerto Rico thought she had down's 2,12		online 2,10; mom does not look into the future she takes day by day based on what she has read 2,22	
Beliefs about treatment or where to look for help	Husband believes that a miracle from God is going to cure her 1,7								
Beliefs about how disability affects social isolation									

Appendix E:

Nudist Searches

(T 8) //Text Searches/SUP

*** Description:

Search for 'SUP', Searching all documents.

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+++ ON-LINE DOCUMENT: A01-R01-10-19-01-I1

+++ Retrieval for this document: 6 units out of 56, = 11%

++ Text units 16-16:

I: Did you connect with them? M: I did. I wrote a letter to the magazine and said, hey, I'm responding to this letter. And they forwarded it to her. And then we connected for a while there, wrote a few letters. We even talked on the phone. And she had an older child, so she was really helpful, real helpful. And that's pretty much where I got the information from. I didn't get hardly anything from doctors, because the just didn't have it. They didn't know. ...in doctors offices where they'd say, now what's that? They don't see it. I: Is it fair to say that you would tell them what it is? M: Oh yeah, oh yeah. Especially the 4Q. Because that's even more rare than the agenesis. They don't see it. Most of their kids are normal. They don't see that. Now when we moved to Alaska- well, first of all, after getting in touch with that parent, I got in touch with a support group for ACC. SEA OTHFAM EVA INF MDP
TER KNO NOR SUP CHG

16

++ Text units 17-17:

I: Of that specific disorder? M: That specific disorder, yes. And I believe I may have found them through the same book. Or that parent put me in touch with them, I can't remember. Anyway, they were closely connected. So but after going with that and getting in touch with them, they sent me a directory and we went Alaska, and there was a family there that had a child. And so when I got there, I got in touch with that parent. I: And how would y'all stay in touch? How did it work, the support group? Phone calls, letters? M: Right there in Alaska, we saw each other on a regular basis. Her son, I, was about ten years older than mine. So it gave me a good idea of what to look for. Except her child is a lot more high functioning. He can talk and all that. But there was another parent there, whom I only got to meet once, who had a little girl. And that's the only little girl- two of the only girls that I've ever know about that have that. Because mostly you find it in boys. I met her once. There was another child in Tacoma when we go down to Madigan to the hospital. I got in touch with her. So I sort of found people who were going through it. That was the best resource. And I got to see both ends of the spectrum. Whereas R was high functioning, L was not. She was very, very low. She could not walk, she was very- in fact, she died a few years ago. So that was the best resource. SUP AMB OTHFAM COMP INF EVA

17

+++ ON-LINE DOCUMENT: A06-R10-08-31-02-I1

+++ Retrieval for this document: 2 units out of 61, = 3.3%

++ Text units 18-18:

I: Okay. We'd also like to get your evaluation of the genetics counseling and evaluation session that took place. I know I was there

for a portion of it since it took place in 2 parts. I'd like to get your impressions about what happened. I want you to summarize for me what happened and how it was for you. Like if you could give me a summary of how that session was for you and then we're going to actually break it down and talk about individual portions of it. M: Okay. I: So generally speaking, how was it for you? M: The session with M? I: Yes. M: Um, it was a little bit frustrating because I didn't really get the information that I felt I was looking for. I didn't feel that I had enough information to really attack the problem, to really ask her the questions that I wanted to ask her. What I'm really looking for is like a forecast, what to expect for M. Is her IQ, if we keep on with this intense intervention does she have a chance for things to get better or is this something she might outgrow? I'm looking for more and I know that it's hard sometimes with genetics to find a cause. It's just unknown and you don't know what happened. One thing that was good with the interview with the interview with C3 was I had a lot of concerns about when I was pregnant 'cause when I first found out I was pregnant I was in Cancun. And I've been carrying that guilt for 6yrs and she relieved my guilt about that. And then M had a bad babysitter the first 6mos and I was really concerned that that might have been a cause. So, that really helped a lot to explain what could happen and the things I had done. I could let go of that. That's really hard living with that trying to figure out what's wrong. And then you start to look at everything you have done to see what could possibly have caused this in my poor child. But, that helped 'cause the doctors did alleviate a lot of my concerns. EVA GCN CHA MOM INF QUE CON PRE GUI BLA SUP COUN MDP 18

++ Text units 58-58:

M: ...a little bit more involved with the children and had resources and knew, if you had a question, where you could go to get help. Just anyplace that people normally congregate that could have more resources because unless you have a problem, people don't know where to go. And sometimes it takes a lot. I've been through a lot of places just to get to this point. I think that would really be helpful. I: I think what you said was very interesting about pediatricians because you know that at some point every child is going to be seen by a pediatrician. So, if that information was available to pediatricians, then you know that information would be available for parents. Actually, that's a very good point and maybe that's a part of what's missing because a lot of parents have talked about 'is there a place I can go to get information?' A lot of parents don't know what's normal and what's abnormal. And like you said, if you're first time parents, you don't have anything to compare it to, you don't have a reference point. There's...good points that you've brought up and these are the kinds of things we want to know so that we can be aware of and pass this information on to healthcare professionals so they can be aware of that. M: Yeah, and I think sometimes the healthcare professionals are so wrapped up in what they're doing that the concerns a parents might have, they don't realize how anxious that might make a parent. And sometimes they kind of smooth things over without really giving you and answer. And unless you really push for that, you accept that and keep going. Sometimes you have to push. I: Why do you think parents don't push? M: I think we are programmed not to make waves. We are programmed to accept what we think is an authority figure. If somebody tells you, don't worry about that, that's normal, then that's what we do. We just accept that and we move on. And sometimes you just have to say, no, I'm not comfortable with that answer. I think that there

is a problem and we need to move forward and find out if there is a
problem. And if you can't help me, I need to know who can help me. SER
SUP PROB PED INF SEA KNO MDP CON MOM VIE NOR QUE

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