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Social Supports Among Parents of Children Recently Diagnosed with Autism: Comparisons between Mothers and Fathers

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SOCIAL SUPPORTS AMONG PARENTS OF CHILDREN RECENTLY DIAGNOSED WITH AUTISM: COMPARISONS BETWEEN MOTHERS AND FATHERS

A Dissertation

Submitted to the Graduate Faculty of the
University of New Orleans
in partial fulfillment of the
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Doctor of Philosophy
in
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by

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DEDICATION

This dissertation is dedicated to all of the families that graciously allowed me into their lives and homes. I could not have accomplished this without their generosity and time.

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First and foremost, I must thank my partner, Tommy. During the time of my writing this dissertation, Tommy has been the most patient and understanding individual, some might say he has been “angelic”. I thank you for your countless hours of listening to me complain and all of your encouragement that helped me to complete this difficult task. Without your support, I don’t know how I could have accomplished this.

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Mom and Rebekah even though I know you both don't fully understand what I went through, your smiling faces and ability to get my mind off of this paper was one of the main reasons that I still have a little bit of sense left in me (I am not saying any common sense is left, but sense nonetheless). You both were there for me when I just needed to sit back and clear my mind.

Mama Pansy you are my biggest fan and greatest supporter. Anytime that I needed to feel good about myself or just needed to have some positive reinforcement, I knew I could count on you. When I felt as though I couldn't go on, or when I felt as if I was not going to make it, I knew I could call you and you would give me words of encouragement and know just what I needed to hear to keep me going!

One final thought: Katrina. Need I say more?

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ABSTRACT

Parents are best able to identify their own support needs, and professionals can assist parents in receiving supports to assist with these needs. There has been an increase of children diagnosed with autism, which has resulted in a major concern for education professionals. Teachers, therapists, and medical personnel are better able to assist families of children with autism in obtaining supports because they are able to view the family and child objectively and are not emotionally tied to the situation.

The focus of this study was to identify the forms of social support that mothers and fathers of children recently diagnosed with autism perceive as being important. Twenty couples (father-mother dyads) of children between the ages of three to five and diagnosed no more than a year and a half with autism participated in this study. Before the study began a social validation process with professionals and parents of children with autism was used to validate the usefulness of the 16 support items. Once the validation was complete, twenty families completed a Q-sort with the items, which allowed for a ranking from "most" to "least" important. Results indicated that both fathers and mothers ranked "information on how I can help my child" as the most important support and "help with transportation" as the least important support. Overall, fathers' preferred instrumental (goods, services, financial assistance, and information) types of supports, such as, "financial help for expenses." Mothers' preferred emotional (someone to talk to about problems, feelings, and attitudes) types of supports, such as, "contact with other parent(s) who experienced the same situation."

T-tests, correlations, and a factor analysis were performed to analyze the data. Significant correlations were from on five support items. "Involvement with a church or strong religious beliefs", "special equipment to help meet my child's needs", "financial help for expenses", “participation in an organized parent support group”, and “information on how I can help my child” were significant at the .05 level. From the findings, implications for professionals who work with families of children with autism and recommendations for future research are discussed.

CHAPTER I

INTRODUCTION

Being a parent is often thought to be one of the most difficult jobs one can have. Having a child with a disability, specifically autism, can add to the difficulty of being a parent (Simpson & Zionts, 2000). This chapter will discuss stress and its role in families of children with disabilities. There will be a discussion of social supports, defining what social supports are, and categories of social supports. Also, the focus of this research study will be discussed, with specific research questions stated, along with a brief description of the methodology to be used.

Statement of the Problem

One of the major goals of early intervention is to provide support and services for both children with special needs and their families (Lerner, Lowenthal, & Egan, 2003). Services and supports may include supportive therapies (speech and language, occupational, and physical therapy), medical services (nutrition, health, audiology, vision, and nursing), counseling (social work and psychology/psychiatry), educational and developmental instruction, transportation, and other services (Individuals with Disabilities Education Improvement Act [IDEA], 2004 Part C, Section 632). Generally, these supports and services are intended to focus on the growth and development of the child, as well as the concerns and priorities of the family.

Autism is one of several disabilities described in both IDEA legislation and in the American Psychiatric Association's (APA) Diagnostic and Statistical Manual (DSM-IV-TR, 2000). Children who have an established condition or are developmentally delayed are mandated to receive services through IDEA, a legislation that addresses children with disabilities and their families. According to the DSM-IV-TR (2000) autism is included in the description of Pervasive Developmental Disorder (PDD) along with Rett's disorder, childhood disintegrative disorder, Asperger's disorder, and pervasive developmental disorder-not otherwise specified. The terms autism and Autism Spectrum Disorders (ASD) are generally used to refer to three of the five pervasive developmental disorders (Autism Society of America, n.d.a). The three disorders are autistic disorder, Asperger's disorder, and pervasive developmental disorder-not otherwise specified. For clarity and consistency, and unless otherwise stated, the term autism will be used throughout this paper to refer to those three disorders.

Kanner first identified autism in 1943 during a time when psychoanalytic theories predominated thinking. These theories suggested that parents were the cause of their child's behavior. Bettelheim (1967) stated that it was the parents' behaviors that caused their child's disability. Therefore, parents were not viewed as people who might require assistance with understanding and raising their child. Ogdon, Bass, Thomas, and Lordi (1968) described the personality of parents of children with autism as having a significant and detrimental effect on their own child's personality. Mandel, Marcus, Roth, and Berenbaum (1971) suggested the lack of interaction by the parents with the child was the cause of autism.

Not all theories of the causes of autism focus on the parents. Recent publicity has raised a question of autism being caused by vaccinations; however empirical evidence, to date, has not substantiated this cause (DeStefano, Bhasin, Thompson, Yeargin-Allsopp, & Boyle, 2004; Hviid, Stellfeld, Wohlfarht, & Melbye, 2003; Madsen, Hviid, Vestergaard, Schendel, Wohlfahrt, Thorsen, Olsen, & Melbye, 2002; Smeeth, Cook, Fombonne, Heavey, Rodrigues, Smith, & Hal, 2004; Taylor, Miller, Lingam, Andrews, Simmons, & Stowe, 2002).

Another alternative theory about the causes of autism is the discovery of genetic factors in autism (Bailey, LeCouteur, Gottesman, Bolton, Simonoff, Yuzda, & Rutter, 1995; Wassink, Piven, & Patil, 2001). Folstein and Rutter (1977) were the first to find that identical twins with autism had a higher rate of occurrence of autism than non-identical twins. Bailey et al. (1995) have replicated these earlier findings. It is generally accepted that autism has a neurobiological origin (Autism Society of America, n.d.b). Bauman (1991) determined by post mortem examination that the brains of individuals with autism were different in shape and structure from those of individuals without autism. Research has also shown differences in the amygdala, one of the areas of the brain dealing with social judgment, of individuals with autism (Baron-Cohen, Ring, Bullmore, Wheelwright, Ashwin, & Williams, 2000; Bauman & Kemper, 1994; Rapin & Katzman, 1998) when compared to people without autism. Present research is on genetic causes of autism, specifically on genetic duplications (Gillberg, Steffenburg, Wahlström, Gillberg, Sjostedt, Martinsson, Liedgren, & Eeg-Olofsson, 1991; Martinsson, Johannesson, Vujic, Sjostedt, Steffenburg, Gillberg, & Wahlström, 1996) and genetic deletions (Wassink et al., 2001).

The incidence rates of children diagnosed with autism are on the rise (Croen, Grether, Hoogstrate, & Selvin, 2002; Gillberg & Wing, 1999). An increase of children with autism in public school (ages 6-21) has increased from 5,094 in 1991 to 140,254 in 2003 (IDEAdata.org, n.d.). This increase is vividly illustrated by the current prevalence rate in California, which climbed from 5.8 children per 10,000 births in 1987 to 14.9 children per 10,000 in 1994 (Croen et al., 2002). According to the Centers for Disease Control and Prevention (2004), the rate of autism has been found to be as high as 6 of every 1,000 children in Europe and Asia. The American Psychiatric Association (2000) reports the prevalence rate of autism to be 5 individuals per 10,000 individuals and states that some findings have shown the prevalence to range anywhere between 2 to 20 individuals per 10,000 individuals.

This increase has been noted in Louisiana as well. The Louisiana Department of Education (2003) reported the number of students with autism enrolled in public schools increased from 621 (school year 1994-1995) to 1,424 (school year 2001-2002). Differences in prevalence rates may be due to several factors including (a) the growing knowledge of autism, (b) the broadening diagnostic terminology that includes more children, (c) new innovations in medicine allowing more medically fragile babies to live, and/or (d) actual increase in the prevalence of autism (Wolf-Schein, 1996).

This increase of children diagnosed with autism has resulted in a major concern for education professionals. A shortage of personnel certified and trained to teach children with autism currently exists (Scheuermann, Webber, Boutot, & Goodwin, 2003). Alongside of this need for certified teachers is a need to provide supports to families. Professionals (i.e., teachers, therapists, and medical personnel) who understand the needs of families of children diagnosed with autism are better able to assist parents with their child’s growth and development (Simpson & Zionts, 2000). Professionals are able to assist these families because they can view the family and child objectively and are not emotionally tied to the situation.

Stress

The birth of a child with special needs, including autism, places stress on the family. Seaward (1997) defined stress as, “the inability to cope with a perceived or real (or imagined) threat to one’s mental, physical, emotional, and spiritual well-being which results in a series of physiological responses to adaptations” (p. 5). Researchers have found that individuals are more able to deal with stress when provided strategies such as social support (Cameron, Armstrong-Stassen, & Orr, 1991; Cohen & Willis, 1985; Houser & Seligman, 1991), finding meaning from life (Holisticonline, 1998-2005; Janoff-Bulman & McPherson-Frantz, 1997), using humor (Abel, 2002; Lefcourt, Davidson, Prkachin, & Mills, 1997; Rotton & Shats, 1996), and exercise (Long & Flood, 1993; Rosenblum, 1985; Stein, 2001).

Stress and Families

According to Anderegg, Vergason, and Smith (1992) families of children with disabilities go through three phases of adjustment to the birth of a child with a disability: "confronting (shock, denial, blame/guilt), adjusting (depression, anger, bargaining), and adapting (life-style change, realistic planning, and expectations)" (p. 20). These stages of adjustment are closely related to Kübler-Ross' (1969) stages of grief associated with the death of a loved one or the approaching death of oneself and may suggest that families perceive the birth of their child with special needs to the "death" of the anticipation of a typically developing child (Cook, Klein, & Tessier, 2004, p. 41). Researchers are beginning to question whether family members are moving through 'stages' (Allen & Affleck, 1985; Turnbull & Turnbull, 2001) but rather 'states' with the final 'state' being one of adjustment or acceptance to the birth of a child with a disability (Flynn, Buzwell, & French, 2000). The theory that families go through states allows for variations in the time and fashion in which families react to raising a child with a disability. The 'state' theory appears the same as the 'stages' theory in that family members are experiencing emotions; however, the difference with the "states" theory is that these emotional experiences are not in a prescribed order.

Several studies have found that families are faced with stress when they have a child with a disability (Beckman, 1991; Embry, 1980; Hadadian, 1994; Peck, 1998; Salisbury, 1990; Tröster, 2001). The stress of having a child with mental retardation has been found to increase divorce and suicide rates for parents (Price-Bonham & Addison, 1978). Other studies have found that children with disabilities are at risk for maltreatment when compared to their typically developing peers (Embry, 1980; Garbarino, Brookhouser, & Authier, 1987).

Families may experience three types of stress related to their child with special needs: emotional, material, and physical (Fewell, 1986a). Emotional stress may include sadness, depression, or grief associated with the birth of a child who is not typical. Material stress may include the high cost of services for this child. Physical stress may be the demands of caring for a child with a disability, which could include lack of sleep or physical demands of transporting the child to therapies (Fewell, 1986a).

Focus of the Study

The focus of this study was to identify the forms of social support that fathers and mothers of young children recently diagnosed with autism perceive as being important. Social support is multidimensional. It includes: physical, emotional, instrumental, and informational functions which can either be a cause of stress or serve to alleviate stress in one's life (Bailey & Simeonsson, 1988; Dunst, Trivette, & Cross, 1986; Flynn, 1990).

Researchers have categorized social supports (Flynn, 1990; Krahn, 1993; Valentine, 1993). These categories consist of explaining social support in terms of sources and types. Sources of social support can be either formal or informal (Schilling & Schinke, 1983; Unger & Powell, 1980; Valentine, 1993). Formal support is thought to be the provision of assistance provided by professionals who have training or expertise in the area of assistance to families (Schilling & Schinke, 1983; Unger & Powell, 1980; Valentine, 1993). Informal support is thought to be the provision of assistance provided by family, friends, or neighbors (i.e., individuals who do not have training or expertise in the area of assistance) (Schilling & Schinke, 1983; Unger & Powell, 1980; Valentine, 1993). Types of social support can be instrumental or emotional (Krahn, 1993). Instrumental support is defined as “tangible support” (Krahn, 1993, p. 240) and includes goods, services, financial assistance, and information provided to families to address a need (Flynn, 1990; Krahn, 1993; Unger & Powell, 1980). Emotional support is defined as having someone to talk to about problems, feelings, and attitudes as well as receiving intimacy and affection (Flynn, 1990; Krahn, 1993; Valentine, 1993).

Several researchers identified the importance of social supports in assisting families to cope with stress (Able-Boone & Sandall, 1990; Colletta, 1981; Jones, Angelo, & Kokoska, 1998; Miner, 1986; Naseef, 1989; Roberts, 1986). Able-Boone and Sandall (1990) interviewed families and found that families benefited if their specific support needs were met. Colletta (1981) found that emotional support to mothers was contingent upon the person who provided the support. The effect of this support was then found to affect their relationships with others and with their child. Jones et al. (1998) found that a variety of social supports were perceived as helpful to mothers and fathers of children who used augmentative and alternative communication. Some of the supports identified were children’s school staff, spouse’s parents, professionals, and own spouse. Miner (1986) examined the role of social support in alleviating stress in 65 parents of children who were hyperactive. The findings indicated that mothers used social supports more than fathers, social support served as a coping mechanism, and social support buffered the impact of perceived family depression.

Numerous studies have examined parent perceptions of support (Ellis, Luiselli, Amirault, Byrne, O’Malley-Cannon, Taras, Wolongeviz, & Sisson, 2002; Jones et al., 1986; McLoyd & Wilson, 1990; Miner, 1986; Valentine, 1993). Ellis et al. (2002) studied families of children with developmental disabilities (ages 3-22) utilizing supports in the form of schooling for their children (either day school or residential care). Families found this support to be helpful in assisting their family, but the family still had other needs to be met. McLoyd and Wilson (1990) found that when mothers of children between the ages of 9 to 17 years of age received financial support, their stress levels were lower than mothers with financial problems. Valentine (1993) interviewed families of children who were between the ages of 28 months to 7 years with developmental disabilities. Families in this study reported receiving support from employment, mother's family, child's school, and church.

A major characteristic in several studies has been the length of time between diagnosis and research. Typically, several years had elapsed between the birth and/or diagnosis of a child with a disability and the actual research study (Donovan, 1988; Factor, Perry, & Freeman, 1990; Gill & Harris, 1991; Koegel, Schreibman, Loos, Dirlich-Whilhelm, Dunlap, Robbins, & Plienis, 1992; Sperry, Whaley, Shaw, & Brame, 1999; Wolf, Noh, Fisman, & Speechley, 1989). This elapse in time could have implications for the findings. For example, parents of older children might have different support needs than parents of younger children. Evaluation of support needs closer to the time of the diagnosis of the child's disability may be necessary in order to determine effective supports for families.

Conceptual Framework

Bronfenbrenner's (1979) social networks model was the conceptual framework for this study. This model of social networks has often been used to describe families of children with disabilities (Berry, 1995; Janko-Summers & Joseph, 1998; Sontag, 1996). Bronfenbrenner's social networks are typically depicted as a group of concentric circles one within another (see Figure 1). The center of the circles is generally the individual and the individual's nuclear family. Moving away from the center, the next outer circle represents the individual's personal acquaintances, friends, and extended family members. The final circle represents the individual's social and work organizations and professional helpers and agencies.

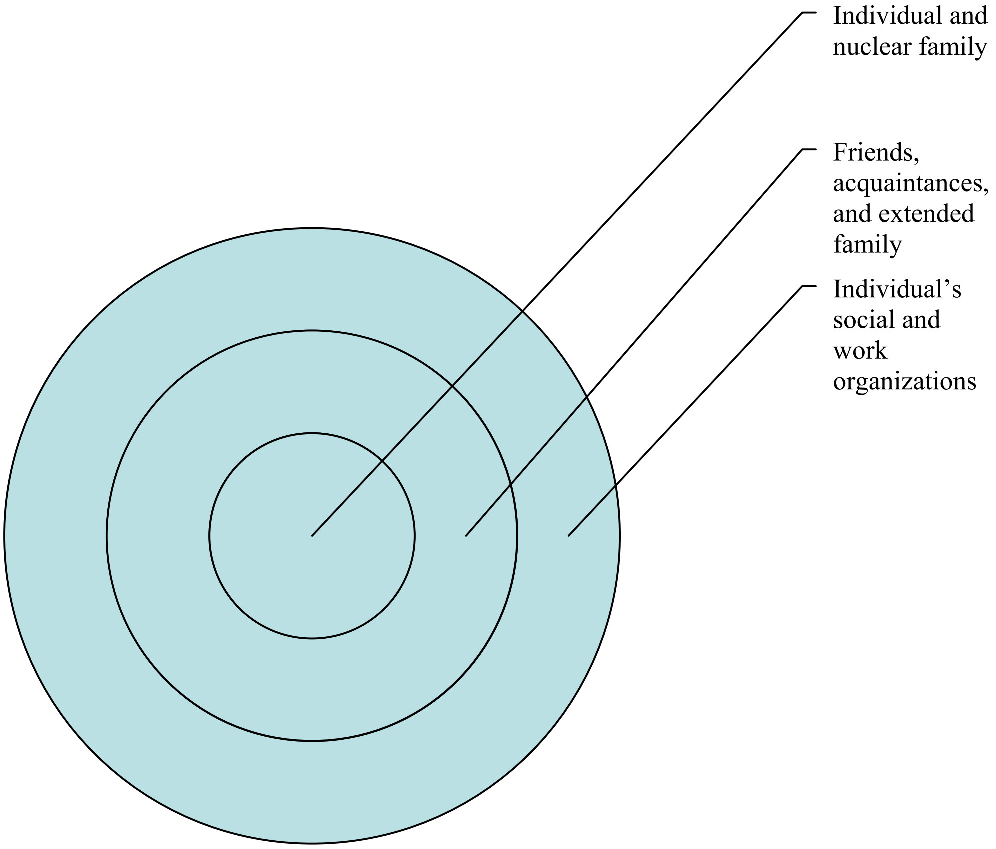

Figure 1: Model of Bronfenbrenner's Social Networks (Adapted from Bronfenbrenner's Ecological Units Model, 1979).

The social networks represented by the circles affect how the individual develops through the interaction between and among the individuals and the systems (Dunst et al., 1986). People are unique in their interactions and the effect these interactions have on them. According to

McMillan (1990), families are not isolated and do not exist in a self-sufficient manner, rather they receive support and provide support to others. This model enhances one's understanding of the uniqueness of each individual and the way an individual operates within his/her family and with others. Consequently, an understanding of the type of support families receive and from whom families receive this support is important.

The premise of this study was that parents are best at identifying the supports that they need. Interventions become more meaningful when parents receive the supports that they, themselves, identify. Thus, professionals can use the information to plan services and supports focused on family-centered needs. In addition, differences between the identified needs of both mothers and fathers may have a significant impact on the child as well as the family unit. Thus, the following research questions guided this study:

(1) What social supports do parents of young children with autism perceive as important?
(2) Are there differences between mothers' and fathers' perceptions of the importance of social supports when a child is diagnosed with autism?
(3) Are there differences between mothers' and fathers' perceptions of the importance of formal as compared to informal support when a child is diagnosed with autism?
(4) Are there differences between mothers' and fathers' perceptions of the importance of instrumental as compared to emotional support when a child is diagnosed with autism?

Q-methodology

The Q-methodology was the technique used to gather data for this study. Stephenson (1953) is primarily associated with developing this methodology as a ranking procedure. This technique is used to identify an individual's subjectivity or personal point of view on a subject using quantitative analysis (McKeown & Thomas, 1988). Specifically, a forced choice Q-sort technique was used to determine the importance of 16 social supports as identified by mothers and fathers of children with autism. Data was collected regarding families' identified and prioritized support needs. The Q-sort technique was used to quantify this information. The hypothesis was that mothers and fathers of children with autism will identify different support needs. These unique needs were identified so that professionals understand and provide needed and optimal supports for the family. Services and supports identified by the family will have the potential to positively impact family members.

Limitations. Q-sort and other ranking techniques have limitations. According to Bolland (1985), it is not possible to measure what a person truly believes or thinks is more important when ranking items. For example, one person may consider item T to be more important than A, D, and P. Yet, all four items may be ranked in the same column with the same value. The Q-sort technique does not differentiate importance within the same column. Because the distances between each category or column appear to be equal, the individual may be forced into ranking an item into a particular category, without distinguishing the differences of opinion between columns. Additionally, individuals are not allowed to identify items that are not listed as an option, but which the individual believes are important. One way to alleviate this situation is to ask the individual if he/she has anything that should be included that was left out or missing from the items on the cards (Flynn, 1990).

Delimitations. One of the delimitations of the current study is that all of the participants for this study were from Louisiana. This limited the ability to generalize the findings of the current study to other families across the United States of America. Another delimitation of the current study is the restriction of only examining mother-father dyads of families. Some families could have consisted of only one parent, same sex parents, or grandparent(s) as the "parent" of the child and they were excluded from this study.

Advantages of the Q-sort. There are several advantages for using the Q-sort technique. First, parents of children with autism have a perception of their support needs and the degree of importance of those needs. Bailey (1994) stated that parents are the best at indicating their own individual needs. The Q-sort allows them to identify their priorities. Therefore, professionals who provide services to parents are in a better position to understand the importance of different supports (Staley-Gane, Flynn, Neitzel, Cronister, & Hagerman, 1996). Since items are ranked from *least* to *most* important, the parent's score on each item reflects the noticeable significance of the support item as an indication of the support priorities. The results of the Q-sort are quantifiable and allow a statistical analysis (McKeown & Thomas, 1988). Forcing items to be sorted into predetermined categories in a fixed distribution reduces duplication of values (VandenBosch, 2001). In other words, all or most of the items cannot be given the same value.

Definitions

The following definitions were used for this study:

(1) Formal support-the provision of assistance provided by professionals who have training or expertise in the area of assistance.

(2) Informal support-the provision of assistance as provided by family, friends, or neighbors (i.e., individuals who do <u>not</u> have training or expertise in the area of assistance).

(3) Instrumental support- goods, services, financial assistance, and information provided to families to address a need.

(4) Emotional support-someone to talk to about problems, feelings, and attitudes as well as receiving intimacy and affection.

Summary

This chapter gave a brief overview of stress and how it relates to families of children with disabilities. Causes of autism, from it first being identified by Kanner (1943) until today were discussed. Research currently states that the cause of autism has to do with genetic factors (Wassink et al., 2001). The incidence rate of children with autism in public schools has more than tripled in the past ten years (IDEAdata.org, n.d.). Alongside this increase of children diagnosed with autism, a shortage exists of personnel certified and trained to teach these children (Scheuermann, et al., 2003).

In this chapter stress related to having a child with a disability was discussed and the use of social supports to alleviate stress. Sources and types of social support were defined and details were given on how these supports are beneficial to parents of children with disabilities. Other information discussed was the conceptual framework, research questions, limitations, and delimitations for the proposed study.

CHAPTER II

LITERATURE REVIEW

The literature review discusses social supports and their relevance to families of children with disabilities. Additionally, a review of social supports and their relevance to families of children with autism is discussed. Definitions of social support found in data based articles, book chapters, and other literature reviews is provided. Social support is discussed in terms of sources (formal and informal) and types (emotional and instrumental). Comparisons between mothers and fathers identified helpfulness of sources and types of support are described. A discussion of the characteristics of children with autism, as well as, support needs of families with children with autism is provided.

Overview of Social Support

Families of children with disabilities have a variety of needs and concerns (Bailey, Skinner, Correa, Arcia, Reyes-Blanes, Rodriguez, Vazquez-Montilla, & Skinner, 1999; Featherstone, 1980; Fewell, 1986a; Koegel et al., 1992). Families may need time away from their responsibilities as a parent (Bailey, 1994; Singer & Irvin, 1991), information about the child's specific disability, and the future outlook for their child (Bailey & Simeonsson, 1988; Flynn, 1990). They may need counseling to deal with depression or discouragement that sometimes accompanies the birth of a child with a disability (Valentine, 1993), or they may need financial assistance for the many expenses that incur with raising their child (Reyes-Blanes, Correa, & Bailey, 1999; Sperry et al., 1999). Each family's priorities are unique to that particular family. No one formula fits all families.

The provision of social support should address the concerns, priorities, and resources of the family. Social support can be either formal or informal (Schilling & Schinke, 1983; Unger &

Powell, 1980; Valentine, 1993). Formal support is thought to be the provision of assistance provided by professionals who have training or expertise in the area of assistance to families (Schilling & Schinke, 1983; Unger & Powell, 1980; Valentine, 1993). Informal support is thought to be the provision of assistance provided by family, friends, or neighbors (i.e., individuals who do not have training or expertise in the area of assistance) (Schilling & Schinke, 1983; Unger & Powell, 1980; Valentine, 1993). Both formal and informal sources of support can be meaningful to families. Researchers have sometimes categorized social supports (Flynn, 1990; Krahn, 1993; Valentine, 1993). Categories vary slightly in the literature; however, for the purpose of this study, social support was clustered into two types of support: instrumental and emotional. Instrumental support is defined as "tangible support" (Krahn, 1993, p. 240) and includes goods, services, financial assistance, and information provided to families to address a need (Flynn, 1990; Krahn, 1993; Unger & Powell, 1980). Emotional support is defined as having someone to talk to about problems, feelings, and attitudes as well as receiving intimacy and affection (Flynn, 1990; Krahn, 1993; Valentine, 1993).

For this study social support was defined as being multidimensional, comprised of both emotional (e.g., affection, sympathy and understanding, acceptance, and esteem from others) and instrumental (e.g., goods, services, and information) functions that aid in mediating stress and dealing with day-to-day interactions (Dunst et al., 1986; Flynn, 1990; Krahn, 1993; Valentine, 1993).

Stress and the Implications for Families. Previous researchers have demonstrated that having a child with special needs increases the amount of stress on the family (Baxter & Kahn, 1999; Embry, 1980; Garbarino et al., 1987; Peck, 1998; Price-Bonham & Addison, 1978; Salisbury, 1990; Suárez & Baker, 1997; Tröster, 2001). Additionally, researchers have found that families of children with autism experience more stress than parents of children with certain other disabilities (Donovan, 1988; Holroyd & McArthur, 1976; Konstantareas, Homatidis, & Plowright, 1992; Wolf et al., 1989). The type and amount of support a parent receives may influence how the parent responds to the stress of having a child with autism. In Krahn's (1993) review of the literature of social supports, a stress-buffering model was proposed by several researchers, which states that social supports aid in reducing stress. This line of research states that social support can ameliorate negative effects of stress on the family. The following two tables (see Tables 1 & 2) highlight studies, literature reviews, and books that address stress in families of children with disabilities.

Table 1. *Data Based Articles on Stress and Implications for Families*

Author(s)/Year	Participants	Findings
Holroyd & McArthur (1976)	• 86 Mothers of children with Downs syndrome, autism, and children undergoing outpatient evaluations at a neuropsychiatric institute • 22 children with autism, 32 children undergoing outpatient evaluations, 22 children with Down syndrome • Ages of children between 3 and 12 years • Instrument: *Questionnaire on Resources and Stress* (child's behaviors, parents stress level, parents depression level)	• Mothers' of children with autism were more stressed than mothers in other two groups

(Table 1 continued)

Wolf et al. (1989)	• Parents (30 mothers, 27 fathers) of 124 children • 31 children with autism (age range 4.5 – 19.5) • Control: 31 children with Down syndrome, 62 developmentally average→ 31 chronological age, 31 mental age • Instruments: *Parenting Stress Index* (stress) & *Revised Kaplan Scale* (social support)	• Parents of children with autism reported more stress than control groups. • Mothers of children with autism were more depressed • Mothers depression was lowered by perception of social support
Salisbury (1990)	• 105 mothers of children with mild/moderate or severe/profound disabilities utilizing respite care • Instruments: *Questionnaire on Resources and Stress* (child's behaviors, parents stress level, parents depression level), *Locke-Wallace Marital Adjustment Scale-Short Form* (marital adjustment), *Beck Depression* (depression), *Family Support Scale* (helpfulness of various resources)	• Child's level of functioning was significantly related to mother's reported stress level • Mothers of children with severe/profound disabilities reported higher stress levels • Mothers with larger number of supports reported lower levels of stress

(Table 1 continued)

Konstantareas et al. (1992)	• 367 parents (89 parents of typically developing children; 155 of children with autism; 63 with learning disabilities; 60 with mental retardation) • Mean ages of the children: 7.2 years typically developing children, 7.7 years children with autism, 9.9 years children with learning disabilities, 8.7 years children with mental retardation • Instrument: *Questionnaire on Resources and Stress* (child's behaviors, parents stress level, parents depression level)	• Parents of children with autism were more stressed than parents of children with learning disabilities • Across all groups, mothers were more stressed than fathers • Mothers and fathers across all groups reported that mothers did more than fathers in taking on responsibilities for child
Suárez & Baker (1997)	• 75 families of children at risk for behavior disorders • 63 1st graders, 11 kindergartners, 1 2nd grader) • Mean age of children 6.7 years • Instruments: *Child Behavior Checklist* & *Teacher's Report* form (behavior), *Dyadic Adjustment Scale* (marital adjustment), *Spousal Agreement and Support Scale* (agreement of parental view of child's behavior*), Global Social Support-Parent Interview* (feelings about being supported by others), *Family Impact Questionnaire* (parent's perceptions of child's impact on the family)	• Marital adjustment and spousal support buffered effects of parenting stress • Mothers were more vulnerable to stress in social relationships because of a lack of these relationships due to care giving responsibilities • Fathers had more social groups from work and this may have buffered child-related stress

(Table 1 continued)

Peck (1998)	• 9 parents of children with autism • Age range was 2 to 6 years • Multicomponent intervention to reduce stress (increase knowledge of autism, knowledge of stress and coping with stress, awareness of social support and advocacy) • Instrument: *Parenting Stress Index* (stress), *Questionnaire on Resources and Stress* (child's behaviors, parents stress level, parents depression level)	• Positive experiences with support group • An increase of family stress was found for these families
Baxter & Kahn (1999)	• 37 families with a child with a diagnosed developmental disability or at risk for developmental delay enrolled at an urban early intervention program • Mean age of children 15.65 months • All low income (earning less than $10,001/year) • Instruments: *Bayley Scales of Infant Development*, *Family Needs Assessment, Family Support Services Interview,* and an adaptation of the *Short Form of the Questionnaire on Resources and Stress* at initial intake and 12-months into the program	• Families reported food, shelter, transportation, medical, informational, and personal time as needs and feeling of stress were felt by all

(Table 1 continued)

Tröster (2001)	• 47 mothers of children with visual impairments • 47 mothers of typically developing children • Age range of children with visual impairments were 8 months to 7 years • Age range of typically developing children was not given, matched for gender and age • Instruments: *Parenting Stress Index* (stress) • Germany	• Higher levels of stress were reported by parents of children with disability • Mothers of children with disabilities perceived less social support available than did other mothers

Table 2. *Literature on Stress and Implications for Families*

Author(s)/Year	Participants	Findings
Price-Bonham & Addison (1978)	• NA	Literature review of families who have children with mental retardation: • Increased suicide and divorce rates among parents of children with mental retardation • Fathers report more stress from financial constraints • Fathers are not generally involved emotionally with their child • Fathers more concerned with future outcomes of their child • Counseling of parents of children with mental retardation is often inadequate

(Table 2 continued)

Embry (1980)	- NA	Literature review: - Stress on a family is increased by the birth and raising of a child with special needs - Children with disabilities are more likely to be maltreated by their parents when compared to their peers
Garbarino et al. (1987)	- NA	Text: - Stress on a family is increased by having a child with special needs - Children with disabilities are more likely to be maltreated when compared to their peers
Krahn (1993)	- NA	Literature review: - Reviewed social support, including definitions, types, categories, sources, and models of support

Tables 1 and 2 provide information on stress and families. This review of the literature on families found that families of children with disabilities experience stress (Baxter & Kahn, 1999) and families of children with autism are more stressed than most families (Konstantareas et al., 1992). Social supports were found in some studies to alleviate stress experienced by families (Krahn, 1993).

From the review of literature on social supports, themes emerged regarding support. One theme was the need for support within the parent's marital relationship (Herman & Thompson, 1995; Naseef, 1989; Reyes-Blanes et al., 1999; Suárez & Baker, 1997). Another finding was the variety of needs that mothers and fathers have (Ellis et al., 2002; Naseef, 1989; Price-Bonham, & Addison, 1978). Other themes found were the need for knowledge about services available for the child immediately and in the future (Bailey, Blasco, & Simeonsson, 1992; Price-Bonham, & Addison, 1978), the need for a supportive network of friends (Featherstone, 1980; Gabel & Kotsch, 1981), the need of support from other parents (Naseef, 1989; Shapiro, 1989), the need for support from other family members (Colletta, 1981; Reyes-Blanes et al., 1999; Roberts, 1986), and the need for support from social agencies such as information regarding services available, training, financial assistance, and laws and rights of the child (Reyes-Blanes et al.; Sperry et al., 1999). These supports fulfill a variety of needs for families. They provide a place to go for emotional support when parents are distressed about their child having a disability. They may serve as a source for financial support, respite/child care, and interaction with someone who has experienced a similar situation.

Emotional Support

Generally, emotional support is provided to a person who is experiencing a range of emotions during a difficult time. Providers of emotional support may offer encouragement and comfort during these times (Prudhoe & Peters, 1995). Emotional support is defined as having someone to talk to about problems, feelings, and attitudes as well as receiving intimacy and affection (Flynn, 1990; Krahn, 1993; Valentine, 1993). Emotional support can be formal or informal and provided by an array of individuals including family members, friends, neighbors, counselors, and a variety of other individuals (Most & Zaidman-Zait, 2001; Prudhoe & Peters, 1995; Valentine, 1993).

Researchers have found that families of children with disabilities typically seek out emotional support from family members, professionals, friends, and/or other parents (Most & Zaidman-Zait, 2001; Prudhoe & Peters, 1995). However, turning to friends and other family members may be a source of stress if they cannot provide the information that the parents need or desire. Additionally, the friends may not be able to relate to the feelings of the distressed parents or understand their position (Valentine, 1993). Families may turn to a social worker, psychologists or other source of counseling for assistance (Valentine, 1993). Other sources of emotional support may come in the form of counseling services or group organizations such as church affiliations, support groups, or other groups with whom the families spend time (Naseef, 1989, 2001; Skinner, Correa, Skinner, & Bailey, 2001).

Counseling Services. Parents of a child with special needs may experience a variety of emotions when confronted with the diagnosis of their child and then the day-to-day raising of their child (Naseef, 2001). They may find comfort in talking to a counselor, a parent of a child with the same disability, or someone affiliated with their church. Valentine (1993) found that one of the most common individuals available for families was a social worker. Valentine stated that a social worker is crucial to assess the needs of a family in order to know what type of supports the family requires. With many families, other types of professionals are available to assess and discuss family priorities.

Group Organizations. Church affiliations or religion can serve as a resource for families. Some may feel that a higher power is looking after their family. Others may find that speaking with a minister provides some comfort for the family. Several researchers found that religion played a significant role in being a support for families (Fewell, 1986b; Skinner et al., 2001; Valentine, 1993). Skinner et al. found that faith or spirituality was more of a support than organized religion itself. The actual church community has been, for some families, a place that their child is accepted and allowed to participate and interact with nonjudgmental individuals (Valentine, 1993).

Families may also find relief in meeting other families who have experienced similar situations (Featherstone, 1980; Most & Zaidman-Zait, 2001, Naseef, 1989). These interactions may be in an organized group setting for families or an informal group of parents who attend a play date, for example. Also, some parents have stated a desire to be part of a support group, and these groups have been reported to be helpful for some families (Most & Zaidman-Zait, 2001; Shapiro, 1989; Valentine, 1993). In one study (Krauss, Upshur, Shonkoff, & Hauser-Cram, 1993), a support group was found to be helpful if the family expressed several needs. On the other hand, the support group had adverse effects on families who expressed very few needs. The following two tables (see Tables 3 & 4) highlight studies, books, and literature reviews that address emotional support for families of children with disabilities.

Table 3. *Data Based Articles on Emotional Support and Implications for Families*

Author(s)/Year	Participants	Findings
Dunst et al. (1986)	• 137 parents (96 mothers, 41 fathers) of preschool children with mental retardation, physical impairments, developmentally at risk for cognitive disabilities • 38 children with mental retardation, 29 with physical impairments, and 29 developmentally at risk • Mean ages of children in months were 38.86 mental retardation, 35.89 physical impairments, 37.38 developmentally at risk • Instrument: *Family Support Scale* (helpfulness of various resources)	• Parental satisfaction with social support networks associated with better personal well-being, more positive attitudes about child, more positive interactions during play, and higher developmental scores for children

(Table 3 continued)

Naseef (1989)	• 31 family members from "functional families" p.6 (13 parents, 13 siblings, 5 children with disabilities) • Families assessed themselves as being successful with their coping with their child's disability • Descriptions of children given in place of ages ("deaf-blind young adult, deaf child, chronically ill child, autistic child, learning disabled college student, child with cerebral palsy, emotionally disturbed teenager with a learning disability" p 5. • Instruments: *CHIP: Coping Health Inventory for Parents* (coping behavior used by parents) • Case study (interviews with families)	Coping behaviors expressed by both mothers and fathers: • Maintaining family stability • Trusting spouse to provide support for self and children • Performing activities as a family • Discussing feelings with spouse • Talking with other families with a child with a disability Coping behaviors expressed by both mothers: • Realization of multiple things to be thankful for • Doing activities with own children
Shapiro (1989)	• 56 mothers of children with disabilities • 36 children with down syndrome the other 20 children had the one of the following disabilities: cerebral palsy, spina bifida, developmental delay, or Williams syndrome) • Ages of children 1 to 5 years • Semi-structured interviews	• Mothers who participated in support groups were less depressed, perceived themselves as less burdened by their child, and tended to engage in more problem-solving coping strategies with their child

(Table 3 continued)

Flynn (1990)	• 17 mothers of infants hospitalized for a minimum of 10 days after birth • Infants were not older than 1 year of age • Instruments: Q-sort consisting of types and sources of support	• No differences between sources of support (formal vs. informal) • Mothers ranked (a) discussions with medical people, (b) financial help, and (c) information about how to help their child consistently higher than other items of support
Krauss et al. (1993)	• 150 mothers of infants with disabilities (Down syndrome, motor impairment, and development delay of unknown origin) • Examined effects of support groups through structured interviews and observations	• Intensity of participation was associated with gains in perceived support from others in the group • Intensity of participation was associated with mothers' elevated reports of personal strain placed by the child on the family
Valentine (1993)	• 25 families of children with developmental disabilities • Age ranges of children were 28 months to 17 years • Ecomap used to assess current family dynamics including support systems	• Identified sources of support: employment, mothers family, child's school, and church • Stated that a social worker is best suited to assist families with finding ways to meet their individual needs
Prudhoe & Peters (1995)	• 12 families of pre-term infants • 40 grandparents of the pre-term infants • Focused interviews with parents and questionnaires for grandparents	• Informal support from family and/or friends was used by all families • Emotional support and physical support (caregiving) was the most common support identified as available by parents of the grandparents • Grandparents reported providing and needing emotional support

(Table 3 continued)

Most & Zaidman-Zait (2001)	• 35 mothers of children either on waiting list or present users of cochlear implants (6 on waiting list, 29 current users) • Mean age of children was 57.9 months • 22 item questionnaire to assess informational and service needs • Israel	• 36.4% reported lack of emotional support • 14.3% reported other parents of children with the implant as desired sources of emotional support • 31.3% reported wanting emotional support in the form of group forum with other parents • 65.6% reported wanting private talk for receiving emotional support
Skinner et al. (2001)	• 250 parents of children with developmental delay or mental retardation • Ages of all children was less than or equal to 6 years • Quantitative data from four questions regarding religion (Narrative answers recorded) • Parents were of Mexican or Puerto Rican origin living in the U.S.	• Viewed church and faith as supportive however faith more than organized religion

Table 4. *Literature on Emotional Support and Implications for Families*

Author(s)/Year	Participants	Findings
Featherstone (1980)	• NA	Text: • Outlines different responses that a family encounters with the birth of a child with a disability
Gabel & Kotsch (1981)	• NA	Literature review: • Discusses research on extended family members offering support and how friends can take the place of family members in offering support

(Table 4 continued)

Fewell (1986b)	• NA	Text: • Outlines different research supporting religion as a support for families of children with disabilities
Naseef (2001)	• NA	Text: • Outlines general experiences of families with a child with a disability and different coping mechanisms

Tables 3 and 4 provide information on emotional support and implications for families of children with disabilities. This review of the literature found that families of children with disabilities have a variety of support needs (Ellis et al., 2002). Emotional support was found to be a type of support helpful for families (Most & Zaidman-Zate, 2001). Emotional support can be received from counseling services (Naseef, 2001), group organizations (Skinner et al., 2001), or from interactions with other families of children with disabilities (Valentine, 1993).

Instrumental Support

Instrumental support is defined as “tangible support” (Krahn, 1993, p. 240) and includes goods, materials, services, financial assistance, transportation, and information provided to families to address a need (Flynn, 1990; Krahn, 1993; Unger & Powell, 1980). Typically, family members and friends are not able to provide instrumental support to families of children with disabilities because they do not have access to or knowledge about the needed resources. Families may seek out these supports from professionals (Valentine, 1993).

Finances. Families of children with disabilities frequently experience financial strains from raising their child/children (Able-Boone & Stevens, 1994; Agosta, 1989; Singer & Irvin, 1991). Maroney (1986) stated that families of children with a disability are generally less financially stable than families with typically developing children. Some of this financial stability could be due to the fact that many mothers give up their careers to stay at home and care for the child (Able-Boone & Stevens, 1994). Bailey et al., (1992) stated that families who have a child with a disability identify financial assistance as a needed support. The cost associated with the birth of a child, hospital stays, therapies, and any other special services that a child with a disability may need places a family's economic resources in jeopardy (Turnbull & Turnbull, 2001).

Services. Families may identify several different types of services as priorities. Families as well as service providers have identified respite care as a need (Bailey, 1994; Singer & Irvin, 1991). Typically, respite is short-term childcare assistance paid for by an agency (Ellis et al., 2002). An example of respite might be a caregiver who watches the child so the parents can go out to dinner and a movie. Families have indicated a preference for another family member or friend to provide respite services rather than a stranger from an agency (Bailey, 1994; Singer & Irvin, 1991). This break might be used for families to become involved in social events with others and, in turn, alleviate some of the stress in having a child with a disability (Kazak & Wilcox, 1984). Turnbull and Turnbull (2001) reported that families may identify transportation to and from doctor's appointments and/or to therapies as helpful services. Families perceive educational and intervention therapies as helpful to them in raising their child with a disability (Turnbull & Turnbull, 2001). Each of these items illustrates an area of need for families in which support would be beneficial.

Information. Families often complain that they do not have access to information about their child's condition (Able-Boone & Sandall, 1990). Parents identify a need to know about future services available for their child and what to expect from their child in the future (Bailey

& Simeonsson, 1988; Bailey et al., 1992). Families want information on services available to their child both in the present and in the future, and they want to know how to handle their child's behavior (Bailey et al., 1999; Ellis et al., 2002). Families may also need assistance in understanding how to use or why their child might require special equipment (Turnbull & Turnbull, 2001). Judge (1998) found that families who received information from service providers were better able to cope with having a child with a disability. The following two tables (see Tables 5 & 6) highlight studies, books, and literature reviews about instrumental support for families of a child with a disability.

Table 5. *Data Based Articles on Instrumental Support and Implications for Families*

Author(s)/Year	Participants	Findings
Bailey & Simeonsson (1988)	• 34 two-parent families with a child in an infant intervention program who had either a cognitive or motor delay • Mean age of children was 14 months • Instrument: *Family Needs Survey* (perceptions of unmet family needs)	• Mothers and fathers: how to teach child, information on services available now and in future, information on child's condition or disability, & reading materials on child's disability • Mothers: more opportunities to talk to other parents with a child with a disability, reading materials about parents with a child like their own, time for self
Able-Boone & Sandall (1990)	• 30 families (30 mothers and 28 fathers) of children with special needs (Down syndrome, cerebral palsy, multiple handicaps, visual, auditory, mild to moderate developmental delays) • Ages of children between birth and 5 years • Structured interviews to find out perceptions of infant and family services as proposed in P.L. 99-457	• Parents reported wanting more information about their child's disability, services available • Parents want professionals to relay information so that they may become better informed to make decisions for their child

(Table 5 continued)

Bailey et al. (1992)	• 422 caregivers (261 mothers, 127 fathers, 24 others: foster parents, grandparents, aunts) of children with special needs • Mean age of children was 26.8 months • Instrument: *The Family Needs Survey* (perceptions of unmet family needs)	Needs expressed by all caregivers: • Family & social system: need want more time for self 37.5% • Informational needs: child's condition or disability 49.8%; handling child's behavior 38.2%; how to teach child 58.5%; future services 72.2%; current services 59.7%; how children grow and develop 39.2% • Financial needs: more assistance with basic expenses 37.3% • Explaining to others: reading materials on how other families shared that their child has a disability 55% • Community Services: want to meet other parents of handicapped children 35.1% Mothers expressed more needs than fathers • Mothers reporting needing more time for self • Mothers reported wanting to meet other families of children with disabilities • Mothers reported wanting help in explaining to others their child's disability

(Table 5 continued)

Able-Boone & Stevens (1994)	• 30 parents (15 mothers and fathers) of children with developmental delays (cerebral palsy, mental retardation, and/or multiple disabilities) and 30 parents (15 mothers and fathers) of children with no developmental delay but with chronic health condition (chronic lung disease and/or feeding difficulties) • Age ranges of children was 1 to 3½ years • Focused interviews on family functioning	• Parents reported limited socialization opportunities, financial struggles, and restriction of career opportunities • Mothers gave up their careers to care for child • Parents of child with disabilities concerned over friends' inability to understand their child • Some fathers reported faith in God as a coping strategy • Both groups reported frustration with locating services
Judge (1998)	• 69 parents (88% mothers) of children with disabilities (mild to profound developmental delay, speech/language delays, physical/sensory impairments, developmentally at risk) • Age ranges of children was birth to five • Instruments: *Ways of Coping Questionnaire* (coping strategies) *Family Hardiness Index* (internal strengths and durability)	• Coping strategies mostly used were seeking informational and emotional support
Bailey et al. (1999)	• 200 parents of children with developmental disabilities (either mental retardation or developmental disability) • Mean age of children "about 3 years" p. 441 • Instrument: *Family Support Scale* (helpfulness of various resources) • Parents were of Latino origin (50 Mexican couples, 50 Puerto Rican couples)	• Parents wanted information (child's condition, how to obtain services for their child, how to cope with child's behavior) • Mothers and fathers reported highest levels of support from family and formal support sources

(Table 5 continued)

Ellis et al. (2002)	• 47 families who received private services for child with developmental disability either in a day school or residential setting • Mean age or children was 8.57 years • Instrument: *Family Needs Survey* (only the needs assessment section)	• Families who utilized day school reported wanting more community services (locating leisure, babysitters) and support (time for self) • Both families utilizing day school and residential setting reported want more information about (future, services currently available, how to teach, laws and regulations • Parents of younger children found to have the most number of needs

Table 6. *Literature on Instrumental Support and Implications for Families*

Author(s)/Year	Participants	Findings
Unger & Powell (1980)	• NA	Literature review: • Family social networks and supports
Maroney (1986)	• NA	Text: • Discussed needs of families with children with a disability
Agosta (1989)	• NA	Text: • Benefits of cash subsidies for families discussed
Singer & Irvin (1991)	• NA	Text: • Discusses different types of supports beneficial for families of children with disabilities

(Table 6 continued)

Bailey (1994)	• NA	• Book chapter concerning working with families of children with special needs and the various items that are important to be cognizant of when working with these families
Turnbull & Turnbull (2001)	• NA	Text: • Discusses strategies for empowering/supporting families of children with disabilities

Tables 5 and 6 provided information on instrumental support for families of children with disabilities. Financial assistance, transportation, information, and services have all been found to be types of instrumental support (Bailey, 1994; Bailey et al., 1992; Ellis et al., 2002).

Comparisons Between Mothers and Fathers

As stated earlier in this literature review, parents of children with disabilities typically experience more stress than parents of children without disabilities (Beckman, 1991; Dyson, 1997; Hadadian, 1994; Krauss, 1993). For mothers, this stress could be due to an increase in caregiving responsibilities and household tasks, plus a lack of support from their husband in fulfilling these obligations (Bristol, Gallagher, & Schopler, 1988; Heller, Hsieh, & Rowitz, 1997; Krauss, 1993; McLinden, 1990). Krauss (1993) found that a father's stress is related to the child's specific behaviors and temperament and their own feelings of attachment to their child.

Researchers found that mothers report wanting and receiving more informal support (Beckman, 1991; Reyes-Blanes et al., 1999) and emotional support (Colletta, 1981; Roberts, 1986) than fathers. When mothers are provided with emotional and informal support their relationship with their child and their own appreciation of themselves as mothers has been shown to improve (Beckman, 1991; Colletta, 1981). Researchers found that fathers reported more interest in receiving instrumental and formal support than mothers (Beckman, 1991; McLinden, 1990; Vadasy, Fewell, Meyer, Schell, & Greenberg, 1984).

Some similarities do exist between supports identified by both mothers and fathers. Mothers and fathers have identified their spouse as being a primary provider of support (Jones et al., 1998; Herman & Thompson, 1995). Mothers and fathers both want information about their child's future (McLinden, 1990). They have also reported receiving support from professionals (Crowley & Taylor, 1994; Jones et al.) and relatives and friends (Hadadian, 1994). Mothers and fathers of children with autism reported having fewer opportunities for and less individuals to be a part of their social network (Kazak & Wilcox, 1984). This finding of having fewer social networks and opportunities for social outings could be an additional source and explanation of why these families experience stress. Table 7 highlights studies, book chapters, and literature reviews that describe supports for mothers and fathers of children with disabilities.

Table 7. *Literature on Supports for Fathers and Mothers*

Author(s)/Year	Participants	Findings
Colletta (1981)	• 50 mothers (age range 15-19 years) • Age ranges of children was 1-3 years • Instruments: *Parental Acceptance-Rejection Questionnaire*: measures maternal role behavior in warmth/affection, aggression/hostility, neglect/indifference, and rejection • Structured interviews examining social support in terms of description of amount and sources of support	Family identified as primary source of emotional support • reported less aggressive, less likely to nag, scold, ridicule, or threaten their children, less rejecting, more likely to understand the developmental needs of their children and to be satisfied with their maternal role Male partner or spouse as primary source of emotional support • interactions with children more positive Friends identified as primary source of emotional support • more satisfied with maternal role performance
Kazak & Wilcox (1984)	• 56 families (34 female, 22 male) with a child with spina bifida • 53 (30 female, 23 female) families of typically developing children • Age ranges of children was 1 year to 17 years • Instruments: *Social Network List* (name up to 10 friends or family members whom contact was made within past 6 weeks) *Social Network Density Grid* (fill in names of individuals in your social network)	• Social networks of mothers and fathers of children with a disability was smaller than typical families • Both mothers and fathers of children with disabilities named less people as providing support

(Table 7 continued)

Vadasy et al. (1984)	• 23 families (mother-father pairs) whose child was enrolled in an early intervention program were assessed during there first year in the program • Age ranges of children was 7 to 48 months (13 with Downs syndrome, 1 each: microcephaly, arthrogyposis, cerebral palsy/severe mental retardation, infant spasm syndrome, trisomy 10Q, Williams syndrome, hemiplegia, and chromosomal disorder/cleft lip and palate, 2 unknown developmental delay • Instruments: *Parent Needs Inventory* (fathers stress level), *Family Environmental Scale* (child's home environment, parents stress level, parents support system), *Beck Depression Inventory* (parents depression level), *Questionnaire on Resources and Stress* (child's behaviors, parents stress level, parents depression level), *Parent Needs Inventory* (fathers knowledge of community resources)	• Fathers had questions about the following: 91% programs for older children, 90% child's future, 87% special education laws, 83% tax information, 74% advocacy groups, 63% public reaction, 44% respite care, 35% religious programs for child • 92% of parents reported spending most weekends and evenings at home • 90% of parents rarely went to lectures, plays, or concerts • 78% of fathers and 65% of mothers were involved in an organized group as a source of support or in organized religion

(Table 7 continued)

Roberts (1986)	• 30 Mothers and fathers of typically developing children • Age ranges of children 3 to 5.8 years • Instruments: *Social Networks Questionnaire* (identify people most important to you), *Horowitz Life Events Inventory* (stressful events) • Q-sorts: *Block's Child Rearing Practices* (for parents), *Preschool Behavior* (for teachers)	• Mothers of older children had more friends (for emotional support and baby-sitting) • Mothers reported receiving emotional support from family members • Fathers reported support from family members as being less positive when compared to results from mothers

(Table 7 continued)

Bristol et al. (1988)	• 56 two parent families (31 with boys who were developmentally delayed, 25 with typically developing boys) • Age ranges of children was 2 to 6 years • 17 children had autism and 14 with severe communication-impairments • Instruments: *Epidemiologic Studies-Depression Scale* (psychological distress of parent), *16-Item Marital Adjustment Test* (perceived marital adjustment), *About Your Child* (structured interviews on how child disrupts normal family routines), *Carolina Family Responsibilities Scale* (spousal instrumental support in responsibility for child care and household tasks), Adapted form of *Personal Assessment of Intimacy in Relationships* (being included loved, understood and valued in interests by spouse), *Home Quality Rating Scale* (ability of parents to adapt to child in the home)	• Both parents of boys with developmental delays and typically developing boys were not at risk for depression • 45% Fathers of boys with developmental disabilities were at risk for significant marital problems compared to 20% of fathers of typically developing boys • Parents of boy with a developmental disability reported more disruptions in daily life • Both mothers and fathers reported that fathers of boys with developmental disabilities assumed less responsibility in child care specific to the child with the disability and household tasks when compared to fathers of children who were typically developing

(Table 7 continued)

McLinden (1990)	• 48 mothers and 35 fathers of children with various disabilities (hearing impaired, motorically impaired, speech/language delays, Downs syndrome, cerebral palsy, and developmental delay) • Age ranges of children 26 to 50 months • Instruments: *Family Support Scale* (helpfulness of various needs), *Family Adaptability and Cohesion Evaluation Scales* (family functioning) *Comprehensive Evaluation of Family Functioning Scale* (time demands, acceptance, coping, social relationships, financial, well-being, and sibling relationships)	Problems indicated by mothers: • 42.6% demands of caring for child takes away from time for self • 42.6% worry about child's future • 38.3% difficulty in completing other household tasks due to caring for child • 40.4% feel fatigued • 38.3% spend more time with child with special needs than other family members • 33.3% demands of child with special needs limits amount of time spent with friends and family Problems indicated by fathers: • 42.9% worry about child's future • 31.4% daily schedule is centered on the needs of the child • 34.3% finding someone to care for child • 31.4% amount of progress child makes

(Table 7 continued)

Beckman (1991)	• 54 families (mothers and fathers) • 27 children were disabled (moderate to severe: cerebral palsy, autism, multiple disabilities, genetic disorders, and general delays) mean age 46 months • 27 children who were typically developing, mean age 48.4 months • Instruments: *Parenting Stress Index* (stress), *Carolina Parent Support Scale* (helpfulness of formal and informal social support), *Caregiving Questionnaire* (caregiving needs of a child)	• Parents of children with a disability were more stressed • Parents of children with disabilities reported more problems with adaptability, demandingness, mood, and overall distractibility/activity level • Fathers of older children with disabilities reported more stress than did fathers of younger children with disabilities • Informal support was seen as a way to reduce stress in mothers in her relationship with her child, and spouse • Formal support was significant in reducing general life stress for fathers
Krauss (1993)	• Married mothers and fathers of 121 children with disabilities • 36 children with Downs syndrome (mean age 3.06 months) • 44 children with motor impairments (mean age 11.2 months) • 38 children with developmental delay (mean age 16.8 months) • Instruments: *Parenting Stress Index* (stress), *Child Improvement Locus of Control* (parental beliefs of who influences improvement in their child), *Family Adaptability and Cohesion Evaluation Scales II* (perceptions of the family environment)	• Fathers reported more stress to child's behaviors and temperament, and their feelings of attachment to their child • Mothers reported more stress with parent health, restrictions in their role, and relations with their spouse

(Table 7 continued)

Crowley & Taylor (1994)	• 922 parents were part of a national longitudinal study of the Early Intervention Research Institute • Instrument: *Family Support Scale* (helpfulness of various needs)	Mothers reported: • Greater levels of support from parents, relatives, friends, parent groups, physician, professional helpers, and early intervention services Fathers reported: • Greater levels of support from wife Mothers and fathers equally reported: • Support from professional agencies, church, social groups, co-workers, and spouse's relatives
Hadadian (1994)	• 30 families (15 with children with special needs, 15 children without special needs) • Ages ranged from 20 to 48 months • Instrument: *Parenting Stress Index* (stress)	• Stress levels were higher for parents of children with special needs • Mothers and fathers who reported receiving support from relatives and friends reported less stress • Mothers who reported receiving support from the community reported less stress
Herman & Thompson (1995)	• 415 families enrolled in cash subsidy program (children with mental retardation, cerebral palsy, autism, and epilepsy) • Mean age of children was 9 years • Instrument: *Family Support Scale* (helpfulness of various needs)	• Mothers and fathers felt their spouse was most helpful in providing support • More than half reported support unavailable from parent groups, social clubs and day care centers

(Table 7 continued)

Dyson (1997)	• 124 parents (62 pairs of mothers and fathers) • 30 parents had a child with a disability of mental retardation, physical and sensory impairments, speech and learning disorder and developmental delay • 32 parents had a child without a disability • Mean age of children with a disability was 8.7 years • Mean age of children without a disability was 9.3 years • Instruments: *Questionnaire on Resources and Stress-Short Form* (child's behaviors, parents stress level, parents depression level), *Family Environmental Scale-Form* (social environmental characteristics of the family), *Family Support Scale* (helpfulness of various needs)	• Stress levels of fathers and mothers of children with disabilities were higher than those of typically developing children

(Table 7 continued)

Heller et al. (1997)	• 226 married parents of children with moderate to profound mental retardation (50% living out of the family home, 50% living in the family home) • Age ranges of the children was 4 months to 49 years • Interviews: examined caregiving burden • Instruments: *Subjective caregiving burden* (effect of the child on the family), *Inventory for Client and Agency Planning* (maladaptive behaviors of the child)	• Mothers spent more hours helping the child and conducting household tasks, provided more types of support to the child, and more involved in organizations, and worked less hours when compared to fathers • More time was spent helping the child who lived at home as opposed to the adult with a disability living at home and this was done by mothers • There was a greater burden of having an adult with a disability living at home than a child with a disability for mothers

(Table 7 continued)

Jones et al. (1998)	• 59 families of children who used augmentative and alternative communication • Age ranges of the children was 4 to 12 years • Instruments: *Parenting Stress Index* (stress), *Family Support Scale* (helpfulness of various needs)	• Most helpful groups identified by mothers were spouse or partner, professional helpers, school/day care center staff • Most helpful groups identified by fathers were spouse or partner, school day/care center staff, own children, professional helpers, and spouse or partner's parents • Least helpful for mothers were relatives of spouse or partner, social groups/clubs, spouse or partner's friends, relatives, professional agencies, church members or minister, spouse or partner's parents, friends, and family or child's physician • Least helpful for fathers were co-workers, social groups/clubs, parents groups, church members or ministers, other parents, relatives, parents, spouse or partners relatives, friends

(Table 7 continued)

Reyes-Blanes et al. (1999)	• 96 mothers of children with mental retardation or developmental delay • Age ranges of children was rang 3 months to 5 years) • Instruments: *Family Needs Survey* (perceptions of unmet family needs), *Family Support Scale* (helpfulness of various needs), and *ABILITIES Index* (measure recognition of child's limitations in functioning) • Mothers were all Puerto Rican (either living in Puerto Rico or moved within last 2 years to Florida)	• Married mothers wanted more informal support from spouse, spouse's parents, and spouse's relatives • Single mothers wanted more external support from social agencies • Mothers who perceived their children as having a significant disability expressed a greater need for support • Mothers in Puerto Rico cohort perceived more support perceived than did mothers from FL cohort

Table 7 provides information comparing the supports identified as a need by mothers and fathers of children with disabilities. Generally, mothers identify a need for informal support (Beckman, 1991) and emotional support (Roberts, 1986), whereas, fathers want formal and instrumental support (Beckman, 1991).

Overview of Autism

According to the Louisiana Department of Education (2003), the number of students with autism enrolled in public schools has increased from 621 (school year 1994-1995) to 1,424 (school year 2001-2002). Wolf-Schein (1996) has contributed the increase of children diagnosed with autism to several factors. These factors include: (a) the growing knowledge of autism, (b) the broadening of diagnostic terminology that encompasses more children, (c) the use of new innovations in medicine keeping fragile babies alive, and (d) actual increase in the prevalence of autism. This increase of children presenting with autism is a concern for individuals providing services to families (Scheuermann et al., 2003).

Service providers are charged with assisting families with their concerns, priorities, and resources. As educators and other service providers understand autism better, a clearer understanding of the priorities of families of children with autism will evolve.

Autism, first identified in 1943 by Kanner, is a neurobiological developmental disability that usually presents by the age of three years old. While the cause of autism is still not definitive, it has been associated with various conditions including tuberous sclerosis, Fragile X, hydrocephalous, and untreated pheylketonuria (Rapin, 1997). Additionally, a genetic etiology for autism has been promulgated (Autism Society of America, n.d.b). Specifically, several studies have looked for a genetic link for autism (Bailey et al., 1995; Wassink et al., 2001). Research has found that autism is more common in identical twins than in nonidentical twins (Bailey et al.; Folstein & Rutter, 1977). Additionally, research has found that individuals with autism have genetic duplications (Gillberg et al., 1991; Martinsson et al., 1996) and genetic deletions (Wassink et al.). There hasn't been much consistency in the theories of the cause of autism. However, over the years since autism was first introduced, the characteristics of someone with autism have been very similar.

Characteristics. Kanner (1943) described individuals with autism as having an extreme withdrawal of contact from other individuals, a compulsive desire for items and situations to remain the same, an interest in non-animate objects over people, and either being nonverbal or using language that isn't usable to communicate with others. Currently, the criteria set forth by the American Psychiatric Association (2000) for an individual to be diagnosed with autism are still very similar to the ones set forth by Kanner. The criteria for diagnosing autism according to the American Psychiatric Association (2000) are the child: (a) has impairments with communication and interactions with others; (b) displays restricted, repetitive, and stereotyped behaviors, interests, and activities; (c) may also have delays in either “social interaction,” “language as used in social communication,” or “symbolic or imaginative play” with onset before the age of 3 (p. 71).

Discussions about Families of Children with Autism and Social Supports

There has not been a clear delineation of specific supports that a family who has recently had a child diagnosed with autism feels are most important. In previous research concerning the identification of needs of families who have a child with autism, the assessment has either been several years after the child was diagnosed or the research does not make a distinction on length of time between diagnosis and time of the assessment of parents’ needs (Gill & Harris, 1991; Sperry et al., 1999; Wolf et al., 1989). Typically, studies have occurred several years after the diagnosis (Donovan, 1988; Factor et al., 1990; Sivberg, 2002). The literature does not indicate that the apparent needs of families may change due to the timing of when the needs are assessed. Families of young children with autism are faced with many of the same needs as families of other children with disabilities. However, little research exists to determine the specific priorities of families of a child diagnosed with autism. The research that has been conducted has not looked at families of children who have been recently diagnosed with autism.

Research has primarily focused on identifying whether or not families are stressed and depressed (Bristol, 1984; Gill & Harris, 1991; Robbins, Dunlap, & Plienis, 1991; Weiss, 2002; Wolf et al., 1989). Generally, research found that mothers experience more stress than fathers (Konstantareas & Homatidis, 1989; Wolf et al.). Additionally, researchers found that the level of the child’s functioning is related to the stress level in the parent, with families of children functioning very low reporting higher levels of stress (Donovan, 1988; Salisbury 1990). Studies have also shown that families of children with autism reported wanting more information about their child, respite, support groups, and assistance from professionals (Koegel et al., 1992; Sperry et al., 1999). Whitaker (2002) found that parents wanted professionals to assist them with understanding their child's condition. Sanders and Morgan (1997) found that families of children with autism have less opportunity for, and participate less in, recreational and sporting activities and have less interest in political, social, intellectual, and cultural activities when compared to families who have children with no known developmental or other disabilities. Sivberg (2002) found that parents of children with autism reported low levels of social support when compared to parents of typically developing children. Dunlap and Fox (1999) stated that little research has been done to assess the support needs of families who have a child with autism. Table 8 highlights studies, and literature reviews that deal with autism and social supports.

Table 8. *Data Based Articles and Literature on Autism and Social Support*

Author(s)/Year	Participants	Findings
Bristol (1984)	• 45 mothers of children from TEACCH in North Carolina • 27 children with autism, 18 children with significant communication and/or behavioral problems • Age ranges from 2 to 10 years • Instruments: *Moos Family Environment Scales* (family home environment, and family resources) • Parental self-assessments, interviews, and direct assessments of the child	• Mothers with the lowest stress "reported greater perceived support on a measure including support from spouse, immediate and extended family, friends, and other parents of handicapped children" p.297 • Important sources of support from spouses, mother's relatives, and other parents of children with disabilities

(Table 8 continued)

Donovan (1988)	• 36 mothers of adolescents with autism (mean age 14.3) • 36 mothers of adolescents who are mentally retarded (mean age of 15.3) • Instruments: *Questionnaire on Resources and Stress-Revised* (child related and marital stress), *Locke-Wallace Marital Adjustment Scale-Short Form* (marital adjustment), *Coping Health Inventory for Parents, Form D* (coping)	• Mothers of an adolescent with autism reported higher levels of stress • Mothers of an adolescent with autism reported more family and parent problems, more difficulty with behavior
Konstantareas & Homatidis (1989)	• 44 parents (mothers and fathers) of children with autism • Age ranges of children was 2 years 4 months to 12 years 7 months • Stress level and severity of children was assessed through an adapted *Childhood Autism Rating Scale* • Semi-structured interviews examining degrees of support	• Mothers generally turn to informal support (usually their husband) • Mothers who rated child as more disabled had higher stress levels than fathers • Mother's stress increased as the degree of support decreased • Father's stress increased as the degree and number of supports decreased

(Table 8 continued)

Factor et al. (1990)	Study 1 • Parents (mothers and fathers) either using or not using respite care services in the form of a “parent relief house” p. 140 • 19 parents were users • 17 parents were non-users • Age ranges of children was 7-17 years • All children had autism • *Family Stress Questionnaire* • Functioning level of children was assessed sing the *Developmental Profile II* Study 2 • 14 parent (mothers and fathers) users and 14 parent non-users • Age ranges of children was 8-19 years • All children had autism • *Interpersonal Support Evaluation List* to measure 4 types of support.	Study 1: • Users of respite have children more significantly involved • Functioning level of children receiving respite was significantly lower on social, communication, and academic areas, and lower but not significant on physical and self-help skills when compared to children who were not receiving respite care Study 2: • Fathers scores on self-esteem scale were significantly lower
Gill & Harris (1991)	• Mothers of 60 children with autism • Ages ranges of children was 2 to 18 years • Examined personalities by measuring the social support and hardiness using *Hardiness Test* (hardiness: control, commitment, and challenge)	• Less stress-related somatic problems and symptoms of depression for mothers who perceived social support as more available than did those with less perceived support

(Table 8 continued)

Robbins et al. (1991)	• 12 mothers of children with autism • Age ranges of children was 29 to 52 months • 3 month period with 5 hours a week of individualized programming for behavior management & learning • Instruments: *Parenting Stress Index* (stress)	• After intervention mothers still reported that their children were a source of stress
Koegel et al. (1992)	• 50 families of children with autism • Mean ages 3.1 to 23.1 years • Instrument: *Questionnaire of Resources and Stress* (child's behaviors, parents stress level, parents depression level)	• Concerned about future of their child, child's ability to function independently, being accepted into the community • Higher stress levels for parents of younger children • Higher stress levels for parents of children who were lower functioning
Sanders & Morgan (1997)	• 54 families parents of children with either autism, Down syndrome, and no disabilities • Age ranges of children was 7 to 11 years • Instrument: *Questionnaire of Resources and Stress* (child's behaviors, parents stress level, parents depression level)	• Families of children with autism reported more parent and family problems, pessimistic of the prospect of child being self-sufficient • Mothers of children with autism and Down syndrome reported less family participation in recreational and sporting activities, less involvement in political, social, intellectual, and cultural activities

(Table 8 continued)

Sperry et al. (1999)	• 28 mothers & 2 fathers of children with autism spectrum disorder • 22 Professionals (educators, administrators, psychologists, project coordinators, consultants, speech language pathologist) • Age ranges of children was 24 months to 30 years of age • Focus groups of parents and providers	• Parents and professionals expressed needs: family support (respite); financial assistance; training; collaboration • Professionals differed from parents by seeing as a need: setting quality programming standards and delineating what constitutes best practice; Transition services as the child ages and moves from one system to another
Sivberg (2002)	• Two groups of 66 parents each of children with autism and of typically developing children • Age ranges of children was 1 to 26 years • Instruments: *Sense of Coherence Test* (comprehensibility, manageability, and meaningfulness), *Purpose in Life Test* (finding a meaning in life), *Family Relations Scale* (level of strain on the family system), *Ways of Coping Questionnaire* (coping behaviors)	• As level of strain on the family increased the level of coping decreased • Parents of children with autism scored higher on behaviors of distancing and escape • Parents of typically developing children scored higher on self-control, social support and problem solving • Parents of children with autism reported low levels of social support

(Table 8 continued)

Weiss (2002)	• 40 mothers of children with mental retardation, 40 mothers of children with autism, and 40 mothers of typically developing children • Age ranges of children was 2 to 7 years • Instruments: *Interpersonal Support Evaluation List* (informal social support), modified *Inventory of Socially Supportive Behavior* (informal social support), *Locke-Wallace Marital Adjustment Test* (informal social support), *Hardiness Test* (hardiness: control, commitment, and challenge), *Beck Depression Inventory* (depression)	• Mothers of children with autism had the least hardy attitudes making them more prone to depression, anxiety, and feelings of depersonalization • Mothers of children with autism were more depressed • Mothers of children with autism perceived emotional support and esteem-boosting friendships to be the least available resources
Whitaker (2002)	• 40 parents of children with autism enrolled in an early intervention • Age ranges of children was birth to 5 years • Structured interviews • England	• Parents reported most helpful when professionals assisted with making sense of their children's development and needs
Dunlap & Fox (1999)	• NA	• Review over 20 articles and book chapters of support for families of children with disabilities including children with autism • Very little research to identify support needs of families of children with autism

Table 8 provided information on autism and social supports. The literature from this table shows that the research on families of children with autism occurred several years after the child was diagnosed (Sivberg, 2002), and/or a widespread of ages of children with autism (Gill & Harris, 1991). Also, the research mainly focused on whether families of children with autism were stressed and depressed. (Robbins et al., 1991; Weiss, 2002).

Summary of the Literature Review

This literature review provided definitions of social support found in data based articles, book chapters, and other literature reviews. Social supports were discussed in terms of sources (formal and informal) and types (emotional and instrumental).

Families of children with disabilities were found to experience stress (Baxter & Kahn, 1999) and families of children with autism were found to be more stressed than most families of children with other disabilities (Konstantareas et al., 1992). Social supports were found in some studies to reduce stress experienced by families (Krahn, 1993). Families of children with disabilities have a variety of support needs (Ellis et al., 2002). Emotional and instrumental support can help in meeting needs of families of children with disabilities (Bailey, 1994; Bailey et al., 1992; Ellis et al., 2002; Naseef, 2001).

This review has shown that extensive research exists on what families of children with various disabilities report as important and what supports they need (Bailey et al., 1999; Reyes-Blanes et al., 1999; Skinner et al, 2001; Sperry et al., 1999; Valentine, 1993). . However, there is a dearth of research on families of children with autism. Due to an increase in the incidence of children diagnosed with autism (Croen et al., 2002), researchers need to assess the priorities of families with a child with autism.

CHAPTER III

METHODOLOGY

Overview

The idea that parents of children with autism are the best source in identifying their own support needs guided this study. Professionals can take the information provided by these parents to plan interventions/services and supports focused on families of children with autism. In addition, the differences in the needs identified by both mothers and fathers may have a significant impact on the child as well as the family unit. The following research questions guided this study:

(1) What social supports do parents of young children with autism perceive as important?

(2) Are there differences between mothers' and fathers' perceptions of the importance of social supports when a child is diagnosed with autism?

(3) Are there differences between mothers' and fathers' perceptions of the importance of formal as compared to informal support when a child is diagnosed with autism?

(4) Are there differences between mothers' and fathers' perceptions of the importance of instrumental as compared to emotional support when a child is diagnosed with autism?

Participants and Setting

Forty parents consisting of mother-father dyads served as participants in the study. When deciding upon the number of participants, Thompson (1981) stated that the number of participants should be at least one-half the number of items contained in the Q-sample. The number of participants for this study exceeded this recommended number of participants (40 parents with 16 cards to sort). Inclusion criteria for parent participation was: (1) child's diagnosis of autism was within the last year and half, and (2) child was between the ages of 36 and 60 months at the time of data collection.

Demographics. Demographic data (see Appendix A) was obtained from parents including age of parent and marital status; child information (age, gender, age at diagnosis, and diagnosis); sibling data (gender, age, and diagnosis, when applicable). Data was used to describe and compare the families.

As shown in Tables 9 and Table 10, the age range of the fathers was 29 to 54 years with a mean age of 37 years. The range for mothers was 24 to 52 years with a mean age of 35 years. All couples were married with the exception of one that was divorced. Additionally, Tables 9 and 10 provides specifics related to the child with autism. Fifteen boys and five girls whose ages ranged from 3 years 1 month to 5 years 4 months with a mean age of 4 years 1 month comprised the children with autism. The specific diagnoses varied with 12 children being diagnosed with autism, one child with Asperger's Syndrome, and seven children with Pervasive Developmental Disorder- Not Otherwise Specified. The length of time for being diagnosed ranged from one month to one and a half years.

Socioeconomic status was determined for each couple by using the *Hollingshead Two Factor of Social Position* (Hollingshead & Redlich, 1958). Social position is assigned by occupation and education in the Hollingshead index. There are four social class categories in the Hollingshead, I being the highest social class and V being the lowest social class. The index is calculated using occupation of the primary wage earner who is the major financial support of the family. From the list of occupations and education level, a scale score is assigned. Higher levels of education and more prestigious occupations are given a lower score. Education is given a factor weight of four and occupation is given a factor weight of seven.

Table 9. *Demographic Data*

	Couple Data						Child Data			
Participant	Age	Role	Marital Status	Educ. Level	Income	Hollings-head	Sex	Age at diag.	Diag.	Months Diag.
101	37	M	M	1	6	I	M	4.6	1	12
201	37	F	M	2	1					
102	34	M	D	4	2	IV	M	4.6	1	6
202	24	F	D	3	1					
103	45	M	M	3	6	II	M	5.0	1	12
203	36	F	M	3	1					
104	48	M	M	3	3					
204	32	F	M	3	1	II	F	3.6	1	12

(Table 9 continued)

	Couple Data						Child Data			
Participant	Age	Role	Marital Status	Educ. Level	Income	Hollings-head	Sex	Age at diag.	Diag.	Months Diag.
105	35	M	M	3	2	III	M	5.4	2	16
205	31	F	M	3	1					
106	41	M	M	2	3					
206	41	F	M	1	4	II	M	4.0	1	18
107	33	M	M	4	1					
207	38	F	M	2	3	II	M	3.7	1	13
108	38	M	M	2	3	III	F	3.2	1	2
208	29	F	M	3	1					
109	54	M	M	2	3	II	M	3.8	3	16
209	52	F	M	3	3					
110	32	M	M	3	4	II	F	4.6	3	16
210	33	F	M	2	3					
111	38	M	M	3	6	II	M	3.7	3	16
211	36	F	M	3	2					

(Table 9 continued)

	Couple Data						Child Data			
Participant	Age	Role	Marital Status	Educ. Level	Income	Hollings-head	Sex	Age at diag.	Diag.	Months Diag.
112	34	M	M	2	4	II	M	3.9	1	9
212	36	F	M	2	1					
113	31	M	M	3	4	II	M	3.2	1	2
213	32	F	M	2	1					
114	32	M	M	2	6	II	M	3.1	1	1
214	30	F	M	2	4					
115	35	M	M	4	2					
215	37	F	M	2	2	II	M	3.5	3	12
116	35	M	M	2	4					
216	31	F	M	2	6	I	M	4.3	1	15
117	37	M	M	3	4	II	M	3.2	1	5
217	29	F	M	2	1					
118	34	M	M	3	2	III	F	5.3	1	7
218	31	F	M	4	1					

(Table 9 continued)

	Couple Data						Child Data			
Participant	Age	Role	Marital Status	Educ. Level	Income	Hollingshead	Sex	Age at diag.	Diag.	Months Diag.
119	40	M	M	1	5	I	M	4.7	3	14
219	37	F	M	2	2					
120	39	M	M	2	4	II	M	5.1	3	13
220	36	F	M	2	2					

Table 10. *Summary of Demographic Data*

Item	Mean	Mode	SD
Mother’s Age	35.0	36.0	5.64
Father’s Age	37.0	34.0	6.25
Child’s Age	4.13	3.20	.737
Months Diagnosed	10.7	12.0	5.23

Note: Key for Tables 9 and 10

Parent’s age: Chronological age listed in years

Role: M = Mother, F = Father

Marital Status: M = Married, D = Divorced

Education Level: 1 = Graduate Degree; 2 = Four-Year University; 3 = Partial College (at least 1 year); 4 = High School Graduate; 5 = Some High School or GED; 6 = Junior High School (up to 9th grade); 7 = 8th grade or below

Income: 1 = 0 – 19,999; 2 = 20,000 – 39,999; 3 = 40,000 – 59,999; 4 = 60,000 – 79,999; 5 = 80,000 – 99,999; 6 = 100,000+

Hollingshead: I = highest social class; II = higher social class; III = middle social class; IV = lower social class

Child’s sex: M = Male, F = Female

Child’s age: Chronological age listed in years . months

Diagnosis: 1 = Autism; 2 = Asperger’s Syndrome; 3 = Pervasive Developmental Disorder- Not Otherwise Specified

For example, the social position for a dentist, the first step would be to determine his education level. Education level for a dentist is a graduate degree, which is a score of 1 and a factor weight of 4 for a score of 4 for education (i.e., 1 x 4 = 4). To determine a score for occupation, a dentist is considered in category 1 of professionals, and would have a factor weight of 7, which would result in a score of 7 (i.e., 1 x 7 = 7). The total social position for a dentist then would be an 11 (i.e., education score of 4 + occupation score of 7 = 11). The possible ranges of scores are 11-77. Higher scores (e.g., 77) indicate lower social status with a total of five social classes.

The *Hollingshead Two Factor of Social Position* has been used in several studies of families of children with disabilities (Beckman, 1991; Bristol et al., 1988; Flynn, 1990; Heller et al., 1997). Additionally, the Hollingshead has been highly correlated with other measures of social position, is easy to compute, and is accepted in social research (Miller, 2002).

Table 9 shows that 15 families had fathers as the primary wage earner and in five of the families, the mother was the primary wage earner. All social classes were represented with this study, with the exception of the lowest social class. There were three families in the first social class, 13 families in the second social class, three families for the third social class, and one family in the fourth social class.

The education levels of both fathers and mothers ranged from high school graduate or GED to completion of graduate school. Many of the fathers (eight) had some college (at least one year) and the majority of mothers (11) had a four-year college degree. The income ranges for both fathers and mothers ranged from $0 – 19,999 to $100,000+. Many of the fathers (six) had an income of between $60,000 – 79,999 and many of the mothers (nine) had an income of between $0 – 19,999.

Measures

Instrumentation. The Q-methodology or Q-sort was used to gather data. Stephenson (1953) is primarily associated with developing this methodology as a ranking procedure. This technique is used to identify an individual's subjectivity or personal point of view on a subject using quantitative analysis (McKeown & Thomas, 1988). The Q-sort is a ranking system that consists of sorting items into categories using a Likert-type scale (see Figure 2). Ranking allows for comparison of items (McKeown & Thomas, 1988). According to Stephen (1985) items placed in the middle of the Q-sort are identified as being less meaningful to the person completing the sort.

A Q-sort is comprised of a set of items for individuals to sort; this set of items is referred to as a Q-set (McKeown & Thomas, 1988). A Q-set, or stimulus items, was compiled and given to the parents to rank. Items in the Q-set were compiled from a review of the literature on social supports, including two validated and reliable family surveys (Bailey & Simeonsson, 1990; Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988) and previous research from Flynn (1990) and Staley-Gane, et al. (1996). The items in the Flynn (1990) study were copyrighted and permission to use these items was obtained (see Appendix B).

The Q-set for this study was composed of 16 items, which parents used to identify their support priorities. The Q-set contained both emotional (having someone to talk to about problems, feelings, and attitudes as well as receiving intimacy and affection) and instrumental (goods, services, financial assistance, and information) support as well as formal (professionals or professional organizations) and informal (family, friends, other parents, church members) sources of support (Flynn, 1990; Krahn, 1993; Unger & Powell, 1980). A forced-choice method is used in Q-sort; individuals are forced to rank choices that may otherwise be seen as very

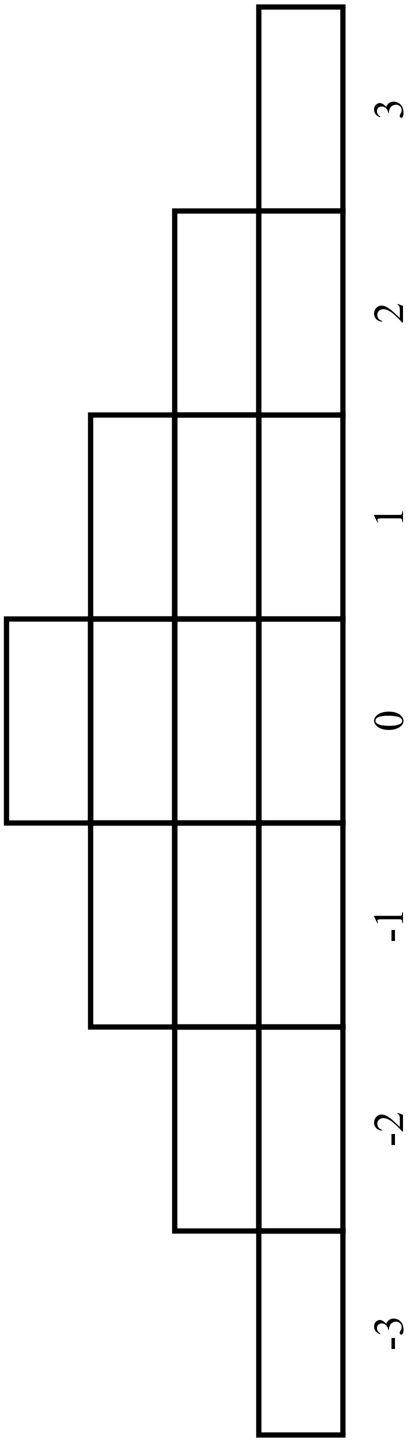

Figure 2. Q-sort Board with Rankings.

similar or ranked equally in importance (Stephenson, 1953). Forced-choice limits the number of slots available for the resulting items in the Q-set (Thompson, 2000). Individuals performing the Q-sort placed items into columns which are assigned a value (-3 through 3). Therefore, each item is compared to all other items. This research methodology has been used in studies with families of children with and without disabilities and with professionals providing services to children both with and without disabilities (Flynn, 1990; Roberts, 1986; Staley-Gane, et al., 1996; Thompson, Hughes, Schalock, Silverman, Tassé, Bryant, Craig, & Campbell, 2002). Sexton, Snyder, Wadsworth, Jardine, & Ernest (1998) reviewed several articles on Q-methodology and verified that this is an appropriate methodology to measure features in early intervention services.

Procedures

Study Procedures. The procedures for this study were the following. The University Committee for the Protection of Human Subjects in Research at the University of New Orleans granted approval (see Appendix C). Upon receiving approval a social validation procedure was used. Participants for the social validation procedure were gathered by word of mouth. These participants were given a consent form (see Appendix D) and once consent was received, they were asked to complete the social validation process using the list of support needs (see Appendix E). (The social validation procedures are discussed in more detail later in this chapter).

Once all of the information from the social validation was compiled, data collection with the parents of children with autism began. Participants were recruited through the following mechanisms: (1) an advertisement/flyer (see Appendix F) was placed in the Louisiana Autism Society newsletter seeking participants; (2) flyers were posted in three clinics that provide services to children with autism including a mental health facility, an occupational therapy program, and a speech pathology facility; (3) flyers were sent to the Greater New Orleans Louisiana Department of Education (LA DOE) Preschool Special Education regional coordinators, the LA DOE coordinator for autism programs, and Family Service Coordinators providing services through Part C throughout the state of Louisiana; and, (4) flyers were passed out at a conference being held in the southern region of the state for parents of children with autism. The advertisement and flyers contained the researcher's contact information (i.e., phone number and email address), a brief description of the research study, and the approximate length of time needed to complete the procedures. The flyers were posted in the waiting rooms of the above listed facilities. The regional coordinators and Family Service Coordinators asked teachers who had children fitting the criteria to give the information to parents, and the coordinator for autism programs emailed the flyer to various professionals and parents throughout the state.

Upon receiving a phone call or email from an interested parent(s), the parent(s) were contacted through a phone call or email by the investigator to discuss the study. A time and date to meet with the parents was arranged during this initial contact, and a consent form (see Appendix G) was mailed to the parents so that informed consent could be gained before data was collected. Data was collected simultaneously from both parents. Parents and the investigator were seated so that only the investigator could see both of the Q-sorts. This arrangement was to ensure that parents could not see each other's Q-sorts responses and, thus, would not be influenced by each other. After data collection was completed, parent's responses were assigned weighted values, and the data was analyzed using SPSS version 13, to answer the following research questions:

(1) What social supports do parents of young children with autism perceive as important?

(2) Are there differences between mothers' and fathers' perceptions of the importance of social supports when a child is diagnosed with autism?

(3) Are there differences between mothers' and fathers' perceptions of the importance of formal as compared to informal support when a child is diagnosed with autism?

(4) Are there differences between mothers' and fathers' perceptions of the importance of instrumental as compared to emotional support when a child is diagnosed with autism?

Social Validation Procedures. Prior to the implementation of the Q-sort with parents, the identified support items (Q-set) underwent a validation procedure. Both professionals who work with children with autism and parents of children with autism reviewed the items. Professionals and parents were asked to evaluate the items for (a) understanding, (b) a genuine support need, and (c) readability or wording. Participants in the social validation included professionals who had at least three years of experience working with children with autism and parents of a child with autism.

Altogether, 11 individuals completed the social validation process: three mothers, three fathers, three teachers, one occupational therapist, and one speech language pathologist participated in the social validation. Specifically, the occupational therapist had four years of experience in working with children with autism, and the speech language pathologist had 32 years of experience of working with children with autism. Two teachers were certified in early childhood special education, with one having four years of experience working with children with autism, and the other having 13 years of experience working with children with autism. The third teacher was certified kindergarten through 12th grade special education and had seven years of experience working with children with autism.

	Formal	Informal
Emotional	7- Information on how I can help my child	1- A close friend or family member to talk to about my concerns 5- Involvement with a church or strong religious beliefs 6- Relaxing and fun activities for my child and family 11- Participation in an organized parent support group 15- Contact with other parent(s) who experienced the same situation
Instrumental	2- Discussions with medical people 3- Involvement with early intervention (infant and toddler), preschool or school program 4- Special equipment to help meet my child's needs 8- Financial help for expenses 9- Information about my child's condition or disability 10- Counseling with a professional person 12- Help with transportation 13- Information about my child's future 14- Help with child care or respite care 16- Help with independent living (housing, job, or personal skills)	

Figure 3. Matrix of Support Items.

Parents and professionals categorized the items as either formal or informal support and instrumental versus emotional support (see Figure 3). The criterion for determining the categories of the support items was 50% or more of the social validators marked an item as either formal, informal, instrumental, or emotional. Also, the same criteria of 50% or more was used for the rewording of an item. The criteria of using 50% as a cut off is the same as was used in a social validation study by McLean, Snyder, Smith, and Sandall (2002).

All of the support items were found to be a genuine support need by meeting the requirement of 50% or more of the participants in agreement except 'involvement with a church or strong religious beliefs'. Even though only 9% of the participants found this to be a genuine support need, it was kept as a one of the support needs for parents to sort. This support item was kept because literature reviewed found that religion may be a critical support need identified by families (Fewell, 1986b; Skinner et al., 2001; Valentine, 1993). Respondents made four different minor suggestions for rewording items, but no items were reworded as the 50% requirement was not met.

Q-sort Procedures. Parents were instructed on the Q-sort procedure by the primary researcher. The home was used as the location for data collection to make this process as convenient and comfortable for the parents as possible. By using the home, the likelihood of gathering data from both parents was increased. Parents were given a Q-sort board with predetermined squares labeled *least* to *most* (see Figure 4). A set of cards with the finalized items (Q-set) on them was also given to the parent. Each card had one item written on it. The mother and father completed the Q-sort at the same time but without the knowledge of each other's ranking of items. The parents were given instructions on how to complete the sorting procedure. The following directions were read from a prepared sheet to ensure consistency in the process:

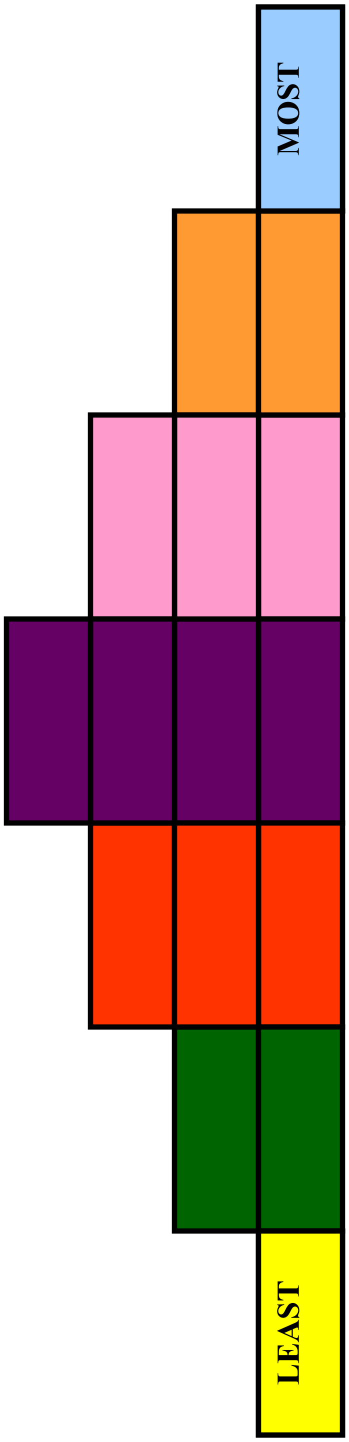

Figure 4. Q-sort Board used with Parents.

Directions: In front of you there is an envelope and a board. There are 16 cards in this envelope. Each card contains a support item that you may feel is important to you and your family. The goal of this activity is to sort these cards into categories that will represent your beliefs about the importance of these supports, regardless of whether you have the support item or not.

Step 1: Take out the 16 cards and read each one. After reading the cards take out the six cards you feel are the *most* important to you and your family. Place the ten remaining cards to the left side of the board.

Step 2: From the six cards you feel are most important, take out the three cards you feel are most important out of these six. Place the three cards you didn’t choose on the right side of the board.

Step 3: Now from the three you chose, take out the one you feel is the *most* important. Place the one card you chose into the *blue* column labeled *most*. Place the two other cards in the two *orange* columns. Now take the cards you placed on your right and place those in the three *pink* columns.

Step 4: Take the remaining cards you placed on the left side of the board and read each one. After reading the cards, take out the six you feel are the *least* important to you and your family. Place the four cards you didn’t choose at the top of the board.

Step 5: From the six cards you feel are least important, take out the three cards you feel are least important out of these six. Place the three cards you didn’t choose on the left side of the board.

Step 6: Now from the three you are holding, take out the one you feel is *least* important. Place the one card you chose into the *yellow* column labeled *least*. Place the two other cards in the two *green* columns. Now take the cards you placed at the left side of the board and place these in the three *red* columns.

Step 7: Take the cards that you placed at the top of the board and place those in the four middle *purple* columns. Look at all of the cards and make sure you have placed them correctly. (all items identified by parents were recorded, see Appendix H)

Step 8: If there was something missing from or not included in the support items that should have been included, please write it on this note card. (additional support items identified by parents were recorded, see Appendix I).

Step 9: Now, turn the items over that you do not have or have not been available to you.

Analysis Design. SPSS was the software used to analyze the data. Demographic data was collected and analyzed. Mean, mode and standard deviation scores for each item was determined. This Q-sort process resulted in a ranking of all support items. Additional analyses included inferential statistics: *t*-tests, analysis of variance (ANOVA) and factor analysis.

Descriptive statistics were determined for all parents including mean scores for each item; then scores were calculated separately for mothers and fathers for each support item. Items identified as not being available to the parents were also analyzed to see if these items were found to be *important* to the parent.

Results were also analyzed using an ANOVA. Factorial analysis of variance is the method of studying mean differences from samples (Mertler & Vannatta, 2002). Based on the results of the social validation, the data could only be analyzed in terms of sources of support (i.e., formal and informal). The study used a one-way factorial analysis of variance to examine differences in total scores of support for husbands and wives. Factor analysis of variance has been used in prior research using Q-methodology (Flynn, 1990; Geoffroy, 1985; Grabinger, 1986; Staley-Gane et al., 1996). Correlations between the dyadic couples were calculated to see the relationships between them to examine similarities in rankings among couples.

Factor analysis is also one of the recommended data analyses for Q-methodology (Dennis, 1986; Stephenson, 1953). Performing the factor analysis involved obtaining correlations among people and across variables (Carr, 1992). For Q-methodology, the rows are the stimulus items (Q-set) and the columns are the participants (Carr, 1992; VandenBosch, 2001). After all of the individuals completed the Q-sort, the results were correlated, and factor analysis identified groups of participants with similar rankings of the Q-sort (Carr, 1992). A factor analysis was computed using the Statistical Package of Social Sciences (SPSS) version 13.

CHAPTER IV

RESULTS

The Q-sorts of fathers and mothers of children recently diagnosed with autism are presented. The first step of the analysis of the data was to calculate descriptive statistics. Descriptive statistics were calculated for each support item 1 through 16 for all participants, and then, specifically, for fathers and mothers as a separate group. Descriptive statistics were calculated for items identified as absent or not available for each group of fathers and mothers separately and, also, overall for all participants. The last descriptive analysis performed was for each of the four support categories of sources (formal and informal) and types (emotional and instrumental) of social support.

Inferential statistics were also calculated from the data set. A t-test was performed to determine if any significant differences existed between fathers and mothers for each of the 16 support items and also for each of the four support categories (formal, informal, emotional, and instrumental). The next inferential statistic calculated was an analysis of variance (ANOVA) to identify differences between the two sources of support (formal and informal). Correlations between couples were also analyzed to determine if mothers and fathers in the same couple identified support items similarly. The final analysis was a factor analysis to identify groups of individuals whose Q-sorts were similar and to describe the factors based on the statements that best define them.

Descriptive Analysis

Support Items for all Participants. Scores for each individual support item ranged from –3 to +3. The mean, mode and standard deviation of each of the support items are listed for all fathers and mothers (see Table 11). Overall, the highest scoring support item or the one

Table 11. *Descriptive Statistics for both Fathers and Mothers for Support Items*

Support Item	Mean	Mode	SD
Information on how I can help my child	1.93	3.00	1.20
Involvement with early intervention (infant and toddler), preschool or school program	1.23	2.00	1.31
Information about my child's future	.70	.00	1.18
Financial help for expenses	.650	.00	1.56
Information about my child's condition or disability	.575	1.00	1.13
Contact with other parent(s) who experienced the same situation	.475	.00	1.24
Relaxing and fun activities for my child and family	.225	.00	1.10
Discussions with medical people	.025	.00	1.18
Counseling with a professional person	-.100	.00	1.47
Participation in an organized parent support group	-.225	.00	1.07
Help with child care or respite care	-.225	-2.00	1.37
A close friend or family member to talk to about my concerns	-.40	-1.00	1.27
Special equipment to help meet my child's needs	-.750	-1.00	1.56
Involvement with a church or strong religious beliefs	-.950	-2.00	1.55
Help with independent living skills	-1.17	-1.00	1.39
Help with transportation	-1.98	-3.00	.947

identified as *most* important was "information on how I can help my child" (*M* = 1.93, *SD* = 1.20) and the lowest scoring support item or the one identified as *least* important was "help with transportation" (*M* = -1.98, *SD* = .947). Other items identified as important for parents were "involvement with early intervention (infant and toddler), preschool or school program" (*M* =1.23, *SD* = 1.31) and "information about my child's future" (*M* = .70, *SD* = 1.18). Additional items identified, as not being important for parents were "help with independent living skills" (*M* = -1.17, *SD* = 1.39) and "involvement with church or strong religious beliefs" (*M* = -.950, *SD* = 1.55).

Support Items for Fathers. The mean, mode and standard deviation of each of the support items for fathers are listed in Table 12. Again, "information on how I can help my child" (*M* = 1.85, *SD* = 1.39) and "help with transportation" (M = -1.80, SD = 1.06) were ranked as the *most* and *least* important support items, respectively, for fathers. Additional items identified by fathers as important were "involvement with early intervention (infant and toddler), preschool or school program" (*M* = 1.30, *SD* =1.22) and "information about my child's future" (*M* = .80, *SD* = 1.32). "Help with independent living skills" (*M* = -1.05, *SD* = 1.43) and "special equipment to help meet my child's needs" (*M* = -.85, *SD* = 1.57) were additional items identified by fathers as being less important.

Support Items for Mothers. The mean, mode and standard deviation of each of the support items for mothers are listed in Table 13. Mothers identified "information on how I can help my child" (*M* = 2.00, *SD* = 1.03) as *most* important and "help with transportation" (*M* = -2.15, *SD* = .813) as *least* important. Mothers also reported "involvement with early intervention (infant and toddler), preschool or school program" (*M* = 1.15, *SD* = 1.42) and "information about

Table 12. *Descriptive Statistics for Each Support Item for Fathers*

Support Item	Mean	Mode	SD
Information on how I can help my child	1.85	3.00	1.39
Involvement with early intervention (infant and toddler), preschool or school program	1.30	2.00	1.22
Information about my child's future	.80	.00	1.32
Financial help for expenses	.750	1.00	1.41
Relaxing and fun activities for my child and family	.350	.00	1.35
Information about my child's condition or disability	.250	.00	.91
Contact with other parent(s) who experienced the same situation	.20	.00	1.40
Counseling with a professional person	.20	.00	1.32
Discussions with medical people	.20	.00	1.24
Help with child care or respite care	-.250	.00	1.37
Participation in an organized parent support group	-.50	-1.00	1.24
Involvement with a church or strong religious beliefs	-.70	-2.00	1.63
A close friend or family member to talk to about my concerns	-.750	1.00	1.29
Special equipment to help meet my child's needs	-.850	-1.00	1.57
Help with independent living skills	-1.05	-1.00	1.43
Help with transportation	-1.80	-2.00	1.06

Table 13. *Descriptive Statistics for Each Support Item for Mothers*

Support Item	Mean	Mode	SD
Information on how I can help my child	2.00	3.00	1.03
Involvement with early intervention (infant and toddler), preschool or school program	1.15	.00	1.42
Information about my child's condition or disability	.90	1.00	1.25
Contact with other parent(s) who experienced the same situation	.75	.00	1.02
Information about my child's future	.60	.00	1.05
Financial help for expenses	.55	-1.00	1.73
Relaxing and fun activities for my child and family	.10	.00	.788
Participation in an organized parent support group	.05	.00	.826
A close friend or family member to talk to about my concerns	-.05	-1.00	1.19
Discussions with medical people	-.15	.00	1.14
Counseling with a professional person	-.40	.00	1.57
Special equipment to help meet my child's needs	-.65	-1.00	1.60
Involvement with a church or strong religious beliefs	-1.20	-2.00	1.47
Help with independent living skills	-1.30	-1.00	1.38
Help with child care or respite care	-2.00	1.00	1.40
Help with transportation	-2.15	-3.00	.813

my child's condition or disability" (*M* = .09, *SD* = 1.25) as additional important items. "Help with independent living skills" (*M* = -1.30, *SD* = 1.38) and "help with child or respite care" (*M* = -2.00, *SD* = 1.40) were additional items identified by mothers as being less important.

Support Items Identified as Absent or not Available for Participants. Percentages of the number of participants who identified each support as absent or not available are listed in Table 14. Sixty-seven percent of participants reported "financial help for my expenses" as being absent or not available, whereas, 5% of participants reported "information about my child's condition or disability" as being absent or not available. All of the participants reported at least one support item as being absent or not available with the range being one to twelve items.

Support Items Identified as Absent or not Available for Fathers. Percentages of the number of fathers who identified each support as absent or not available are listed in Table 15. Seventy percent of the fathers reported "financial help for my expenses" as the support items that was absent or not available to them, whereas, all of the fathers reported that "information about my child's condition or disability" was available or not absent.

Support Items Identified as Absent or not Available for Mothers. Percentages of the number of mothers who identified each support as absent or not available are listed in Table 16. "Help with transportation" and "help with independent living skills" (70% each) were identified as being absent or not available by mothers. Ten percent of mothers reported the following items as being absent or not available: "close friend or family member to talk to about my concerns", "involvement with early intervention (infant and toddler), preschool or school program", "information on how I can help my child", "information about my child's condition or disability", "contact with other parent(s) who experienced the same situation."

Table 14. *Percentage of Participants Identifying Supports as Absent or not Available*

Support Item	% identified as absent or not available
Financial help for expenses	67%
Help with transportation	65%
Help with independent living skills	62%
Help with child care or respite care	55%
Special equipment to help meet my child's needs	50%
Involvement with a church or strong religious beliefs	42%
Information about my child's future	35%
Participation in an organized parent support group	32%
Counseling with a professional person	27%
Relaxing and fun activities for my child and family	20%
Contact with other parent(s) who experienced the same situation	15%
A close friend or family member to talk to about my concerns	10%
Discussions with medical people	10%
Involvement with early intervention (infant and toddler), preschool or school program	10%
Information on how I can help my child	10%
Information about my child's condition or disability	5%

Table 15. *Percentage of Fathers Identifying Supports as Absent or not Available*

Support Item	% identified as absent or not available
Financial help for expenses	70%
Help with transportation	60%
Special equipment to help meet my child's needs	55%
Help with independent living skills	55%
Help with child care or respite care	50%
Involvement with a church or strong religious beliefs	40%
Participation in an organized parent support group	30%
Counseling with a professional person	20%
Information about my child's future	20%
Contact with other parent(s) who experienced the same situation	20%
A close friend or family member to talk to about my concerns	10%
Involvement with early intervention (infant and toddler), preschool or school program	10%
Relaxing and fun activities for my child and family	10%
Information on how I can help my child	10%
Discussions with medical people	5%
Information about my child's condition or disability	0%

Table 16. *Percentage of Mothers Identifying Supports as Absent or not Available*

Support Item	% identified as absent or not available
Help with independent living skills	70%
Help with transportation	70%
Financial help for expenses	65%
Help with child care or respite care	60%
Information about my child's future	50%
Special equipment to help meet my child's needs	45%
Involvement with a church or strong religious beliefs	45%
Counseling with a professional person	35%
Participation in an organized parent support group	35%
Relaxing and fun activities for my child and family	30%
Discussions with medical people	15%
A close friend or family member to talk to about my concerns	10%
Involvement with early intervention (infant and toddler), preschool or school program	10%
Information on how I can help my child	10%
Information about my child's condition or disability	10%
Contact with other parent(s) who experienced the same situation	10%

Descriptive Statistics for Support Categories. Table 17 shows the mean, mode and standard deviations across the four categories of support for all couples and for fathers and mothers, each as a separate group. These scores were calculated by averaging the number of items for each category and some of the same items were represented in more than one category (see Figure 3). Formal sources of supports were found to be *most* important for couples, and separately for fathers and mothers (M = 1.94, SD = 2.58; M = 2.35, SD = 2.67; M = 1.53, SD = 2.48, respectively). Informal sources of supports were found to be the least important for couples, and separately for fathers and mothers (M = -1.26, SD = 2.35; M = -1.56, SD = 2.57; M =-.950, SD = 2.14, respectively). For the couples, emotional types of supports were identified as higher than instrumental supports (M = .654, SD = 2.60; M = .008, SD = 2.82, respectively). Fathers identified instrumental types of supports as higher than emotional supports, whereas, mothers identified emotional types of supports as higher than instrumental support.

Inferential Statistics

For each item a t-test was run to test for gender differences in the ranking of the items. As shown in Table 18, the *t* values for each of the hypotheses that there would be differences found between mothers and fathers for each of the support items do not exceed the critical value at the .05 level of significance. The null hypothesis is not rejected, indicating no statistical difference between the two groups.

A *t* test was performed to determine if there were any significant differences between mothers and fathers for each of the four support categories. Table 19 displays the *t* values for each of the hypotheses that there would be differences found between mothers and fathers for each of the support categories do not exceed the critical value at the .05 level of significance. The null hypothesis is not rejected, indicating no statistical difference between the two groups.

Table 17. *Descriptive Statistics for Support Categories*

	Couples			Fathers			Mothers		
Category	Mean	Mode	SD	Mean	Mode	SD	Mean	Mode	SD
Formal	1.94	2.73	2.58	2.35	2.73	2.67	1.53	2.00	2.48
Informal	-1.26	-2.00	2.35	-1.56	-1.60	2.57	-.950	-2.80	2.14
Emotional	.654	.170	2.60	.283	-.830	2.88	1.03	.00	2.29
Instrumental	.008	-3.10	2.82	.495	-3.10	3.06	-.480	-2.10	2.55

Table 18. *T-Test for Social Support Items Among Fathers and Mothers*

Support Item	*t*	*df*	Sig. (2-tailed)
Information about my child's condition or disability	-1.87	38	.068
A close friend or family member to talk to about my concerns	-1.78	38	.083
Participation in an organized parent support group	-1.66	38	.106
Contact with other parent(s) who experienced the same situation	-1.42	38	.164
Counseling with a professional person	1.31	38	.200
Help with transportation	1.17	38	.248
Involvement with a church or strong religious beliefs	1.02	38	.314
Relaxing and fun activities for my child and family	.716	38	.478
Help with independent living skills	.562	38	.577
Information about my child's future	.531	38	.599
Financial help for expenses	.401	38	.691
Special equipment to help meet my child's needs	-.400	38	.692
Information on how I can help my child	-.389	38	.700
Involvement with early intervention (infant and toddler), preschool or school program	.358	38	.722
Help with child care or respite care	-.114	38	.910
Discussions with medical people	.931	38	3.58

Table 19. *T-Test for Social Support Categories for Fathers and Mothers*

Category	*t*	*df*	Sig. (2-tailed)
Formal	1.01	38	.319
Informal	.816	38	.420
Emotional	-.900	38	.374
Instrumental	1.10	38	.281

An ANOVA was performed to identify father/mother differences in sources of formal and informal support. The effect of source for both formal and informal support was not significant, *F*(1,38) = .427, *p*=.517 and *F*(1,38) = .340, *p*=.563 (respectively).

Correlations between couples were analyzed to determine if mothers and fathers in the same couple identified support items similarly (see Table 20). Correlations ranged from a high of .73 to a low of .06 with five statements being significant. The significantly correlated statements were "special equipment to help meet my child's needs", "involvement with church or strong religious beliefs", "information on how I can help my child", "financial help for expenses", and "participation in an organized parent support group."

A factor analysis was performed using SPSS version 13 FACTOR procedure and a transposed data matrix (i.e., rows comprised of support items and columns comprised of participants). A decision was made to look at all participants as individuals and not in terms of couples because only four items were found to be significantly correlated for the couples (see

Table 20. *Correlations for Couples for Support Items*

Support Item	Correlation	Sig. (2-tailed)
Involvement with a church or strong religious beliefs	.730	.00**
Special equipment to help meet my child's needs	.534	.015*
Financial help for expenses	.491	.028*
Participation in an organized parent support group	.490	.028*
Information on how I can help my child	.440	.05*
Contact with other parent(s) who experienced the same situation	.443	.051
Help with independent living skills	.365	.114
Help with child care or respite care	.356	.123
Involvement with early intervention (infant and toddler), preschool or school program	.344	.138
A close friend or family member to talk to about my concerns	.282	.228
Help with transportation	.282	.228
Information about my child's future	-.251	.285
Information about my child's condition or disability	-.162	.496
Counseling with a professional person	.154	.518
Discussions with medical people	-.127	.594
Relaxing and fun activities for my child and family	.064	.787

** Significant at.01 level

* Significant at.05 level

Table 20). Factors were extracted using the principal component analysis, and results were rotated to the varimax criterion.

There are two generally accepted rules for determining the number of factors for a factor analysis. The first is a graphical method proposed by Cattell (1966). This method involves plotting out the eignevalues in what is known as a scree plot (see Figure 5). The number of factors kept reflects the number prior to a leveling off of the scree line. In this case, the scree plot suggests that three factors would be appropriate. The second rule is the Kaiser criterion (Kaiser, 1960) in which only factors with eigenvalues of 1.0 or greater are maintained. In this case, the criterion would result in a ten-factor solution. For this study, both solutions were examined, but the three-factor solution was selected for parsimony (approximately 60% of the variance was explained by the three-factors), and the amount explained by each of the additional factor gradually diminished (see Table 21). Also, because there were only 40 participants the ten-factor model was able to explain a large portion of the variance, but also left many factors comprised of very few participants.

Brown (1993) recommended using the transposed data matrix obtained from SPSS version 13 FACTOR procedure (i.e., rows comprised of support items and columns comprised of participants) to analyze the factor analysis. The procedure for this analysis involved Q-sorting the factor scores for each one of the items (in this case supports) used in the original Q-sort. Table 22 shows the scores for each factor with the corresponding support item. Scores for each individual factor ranged from 2.01 to -1.73 (factor 1), 2.31 to -1.28 (factor 2), and 1.84 to -2.48 (factor three). The three highest and lowest scores for each support item were used to describe each factor.

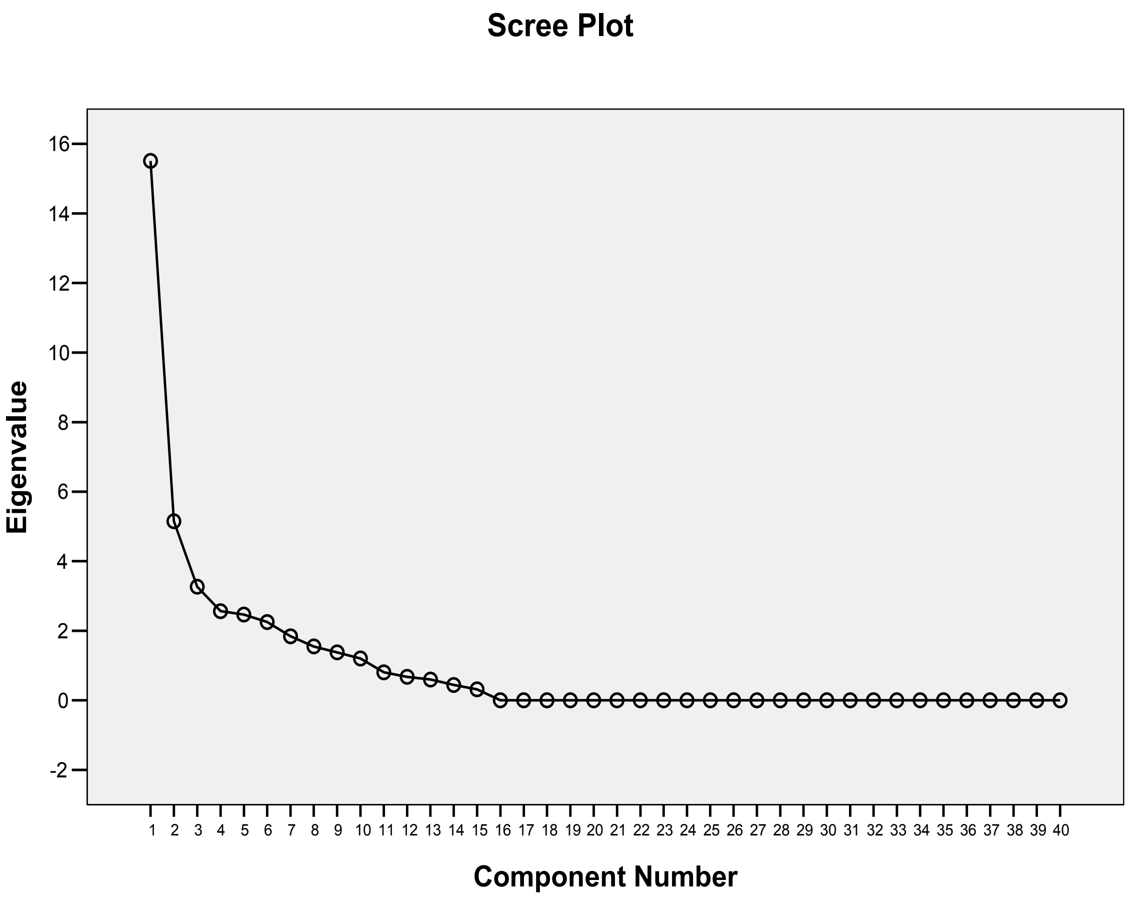

Figure 5. Scree Plot

Table 21. *Total Variance Explained*

Component	Eigenvalue	% of Variance	Cumulative %
1	15.51	38.78	38.78
2	5.15	12.87	51.65
3	3.27	8.16	59.81
4	2.56	6.41	66.22
5	2.46	6.16	72.38
6	2.25	5.62	78.00
7	1.84	4.60	82.60
8	1.55	3.88	86.48
9	1.37	3.44	89.92
10	1.20	3.01	92.93

Table 22. *Factor Scores for Each Support Statement*

Support Statement	Factor 1	Factor 2	Factor 3
A close friend or family member to talk to about my concerns	.405	-1.16	-.319
Discussions with medical people	.377	-.426	-.346
Involvement with early intervention (infant and toddler), preschool or school program	.799	.215	1.83
Special equipment to help meet my child's needs	-1.24	1.08	-.815
Involvement with a church or strong religious beliefs	-.145	.149	.229
Relaxing and fun activities for my child and family	.081	.324	-.018
Information on how I can help my child	2.05	.964	-.377
Financial help for expenses	-.641	2.31	.124
Information about my child's condition or disability	.396	.085	.885
Counseling with a professional person	.306	-1.19	.870
Participation in an organized parent support group	.133	-.964	.713
Help with transportation	-1.73	-1.28	.259
Information about my child's future	.895	.605	-1.33
Help with child care or respite care	-.998	.671	.704
Contact with other parent(s) who experienced the same situation	.842	-.429	.066
Help with independent living skills	-.220	-.951	-2.48

Table 23 shows the individual participants that make up the three-factor model used. Factor one was comprised of 24 participants (13 mothers and 11 fathers) with six of these participants overlapped into one of the two other factors. The support items that were found to be the *most* important in this factor were “information on how I can help my child”, “information about my child’s future” and “contact with other parent(s) who experienced the same situation.” The support items that were found to be *least* important in factor one were “help with transportation”, “special equipment to meet my child’s needs” and “involvement with a church or strong religious beliefs.”

Factor two was comprised of 18 participants (nine mothers and nine fathers) with six of these participants overlapping with one of the other two factors. Participants in factor two found as the most important supports, “financial help for expenses”, “information on how I can help my child” and “special equipment to meet my child’s needs.” The participants in factor two found “help with transportation”, “a close friend or family member to talk to about my concerns” and “counseling with a professional person” as the *least* important support items.

Factor three was comprised of five participants (four fathers and 1 mother) with two overlapping with one of the two other factors. Participants in factor three identified “involvement with early intervention (infant and toddler), preschool or school program”, “information about my child’s condition or disability” and “counseling with a professional person” as the *most* important support items. The items identified as *least* important for participants comprising factor three were “help with independent living skills”, “information about my child’s future” and “special equipment to help meet my child’s needs.”

Table 23. *Rotated Component Matrix to Determine Individuals in Factors*

	Component		
Participant	1	2	3
K_5216	.887		
K_5214	.827		
K_4105	.818		
K_5204	.799		
K_5220	.795		
K_5210	.793		
K_4114	.778		
K_5212	.755		
K_4116	.754		
K_4112	.751		
K_5217	.745	.495	
K_4102	.741		
K_4117	.722	.438	
K_4110	.696		
K_5201	.676	.520	
K_5219	.670		
K_4120	.662		
K_5205	.643		

(Table 22 Continued)

	Component		
Participant	1	2	3
K_4107	.612	.549	
K_5215	.600		
K_4119	.587		
K_5206	.583	.531	
K_4101	.558		.407
K_5213	.454		
K_5207		.795	
K_5203		.752	
K_5218		.692	
K_4108		.670	
K_4103		.669	
K_5208		.653	
K_5211		.594	
K_5202		.585	
K_4118		.522	
K_4111		.491	
K_4106		.478	
K_4113		.439	

(Table 22 Continued)

	Component		
Participant	1	2	3
K_5209			.773
K_4115		.419	.617
K_4109			.540
K_4104			.476

Note: Factors loadings of less than .400 were not reported

CHAPTER V

DISCUSSION

The purpose of this study was to examine the *most* and *least* important social supports of mothers and fathers of children recently diagnosed with autism. An additional purpose was to determine the types (instrumental and emotional) and sources (formal and informal) of support favored by mothers and fathers of children recently diagnosed with autism. Q-sort, the data collection technique, gave a clear indication about the importance of support items as indicated by the ranking decisions made by parents. The research questions that guided this follow:

(1) What social supports do parents of young children with autism perceive as important?

(2) Are there differences between mothers' and fathers' perceptions of the importance of social supports when a child is diagnosed with autism?

(3) Are there differences between mothers' and fathers' perceptions of the importance of formal as compared to informal support when a child is diagnosed with autism?

(4) Are there differences between mothers' and fathers' perceptions of the importance of instrumental as compared to emotional support when a child is diagnosed with autism?

Discussion Regarding the Conceptual Framework

The social networks model (Bronfenbrenner, 1979) guided this study. The social networks are typically depicted in terms of concentric circles, with the circles being comprised of social networks that each have an affect on how the individual develops. Results from this study mirror the theory in the model that each person is an individual and is affected differently by the interactions with the individuals and agencies that comprise each network. Two individuals will each react and develop differently from the same situation. Father-mother dyads in this study only correlated on five of the support items. Even though the couples experienced the same situation (e.g., having and raising a child with autism) they only correlated on the ranking of five items, similar differences were found for parents of children with Fragile X (Staley-Gane et al., 1996). This finding could also support the theory that parents of a child with a disability move through "states" of adjustment (Flynn et al., 2000). Each parent could be experiencing a different state, and therefore the need or importance of a support item is dependent upon the "state" of the individual parent.

Discussion on Descriptive Statistics

Support Items Identified as Most Important. Two out of the three support items ranked high by all participants were those that described information needs. When a child has a disability such as autism, parents may feel that 'information is power.' Information about the diagnosis of autism and how parents can help their child may help parents to support their child to be productive and successful. Information about the child's future outcomes or prognosis may be particularly salient for parents of children with autism because, currently, several treatment plans (e.g., Applied Behavior Analysis, Floor Time, and Treatment and Education of Autistic and related Communication handicapped Children) claim that a child's autistic behaviors may be significantly modified, if a particular treatment is followed (Erba, 2003). In other words, some parents may be looking for a "cure."

The findings of the importance of information replicates past research (Bailey & Simeonsson, 1988; Bailey et al., 1992, 1999; Ellis et al., 2002; McLinden, 1990). Information on ways to help their child with autism has been identified as a support with parents of children with autism (Whitaker, 2002) and also for fathers and mothers of children with various disabilities (Bailey & Simeonsson, 1988). Information about the future of their child has also been identified as a need of parents of children with a disability (Bailey et al., 1992; Bailey & Simeonsson, 1988) and for fathers (Koegel et al., 1992; McLinden, 1990; Vadasy et al., 1984). Mothers have identified receiving information about their child's disability as a needed support (Able-Boone & Sandall, 1990, Bailey & Simeonsson, 1988, Bailey et al., 1992, 1999).

Along with support items about information, both fathers and mothers reported "involvement with early intervention (infant and toddler), preschool or school program" as one of the *most* important supports. All of these families had children that were either in the birth-to-three system or preschool program. Parents may have found that these services for their child were especially useful and, thus, very important (Dunst & Bruder, 2002; Mahoney & Filer, 1996).

Help with finances was also reported by both fathers and mothers as an important support. Even though most of the parents reported an annual income of over $60,000, they still identified help with finances as a need. Raising a child with autism is expensive; in particular, the cost of therapy that is frequently recommended is high (Feinberg & Vacca, 2000; Jacobson, Mulick, & Green, 1998). Regardless of level of income and/or insurance options, raising a child with autism takes a financial toll on families (Jarbrink, Fombonne, & Knapp, 2003).

Support Items Identified as Least Important. The support item identified as *least* important by both fathers and mothers was "help with transportation." Possible explanations of this finding could be that none of the participants were in Hollingshead's lowest social class, which could indicate that they had their own transportation means. The income level of families was relatively high, so families possibly had two cars, one for father and one for mother.

One interesting finding was the low score of "involvement with church or strong religious beliefs" by parents. Some previous researchers (Crowley & Taylor, 1994; Valentine,

1993) reported that religion was a needed support; however, one study by Jones et al. (1998) found that parents reported church members as not helpful in providing support and another study (Flynn, 1990) found that religion or strong religious beliefs were not ranked as important.

Another item identified as *least* important for fathers and mothers was “help with independent living skills.” Even though parents reported being concerned about their child’s future, this support need may have been perceived to be something they would need when their child becomes a young adult. Ellis (2002) found that needs of parents of younger children with a developmental disability were greater than the needs of parents of older children which could indicate that parental needs change as children age. These children were all between the ages of three and five and, perhaps, more age appropriate developmental milestones such as talking and playing with other children were more critical to these families than independent living skills.

“Help with child care or respite care” was ranked low for mothers. A possible explanation of this finding could be that mothers felt that they were the primary caregiver for their child. They may have felt that they were the best person to provide proper care and attention for their young child.

Support Items Identified as Neither Most nor Least Important. Items ranked in the middle of the Q-sort are generally perceived to be items that the individual either has very little experience with or doesn’t have strong feelings about this and, therefore, the items are less meaningful to the individual (Stephen, 1985). Both fathers and mothers ranked “discussions with medical people” in the middle. For the most part, children with autism do not have significant medical complications (Lauritsen, Mors, Mortensen, & Ewald, 2002; Rutter, Bailey, Bolton, & Le Couteur, 1994). Plus, the delivery of the diagnosis may be given to the parents by a psychologist rather than a physician. Therefore, interactions with a medical professional are not ranked high or low.

Fathers reported, “help with child care or respite care” as neither being most nor least important. Possibly, fathers believed that their wife and they themselves were doing an adequate job in raising their children and the need for additional help was not necessary. These fathers may have had adequate resources with child care. Bristol et al. (1988) found that fathers assumed less responsibility in child care, and the fathers in this study possibly also had less responsibility in child care and, thus, found this as lacking importance.

Mothers reported having “a close friend or family member to talk to about my concerns” as neither being most or least important. These mothers may have found that their friends and family members were available to them as a support or they could have found that these individuals were not able to relate to their specific situation and, therefore, could not provide needed support. Valentine (1993) found that friends may not be able to fully understand and relate to the needs of the individual of a child with a disability, and, therefore can not fully meet their support needs.

Categories of Support Items. The items that constitute the particular categories have some overlapping (see Figure 3). Some supports may have served to alleviate some emotional needs of fathers, thereby, causing them to rank emotional supports as lower. This could also be attributed to gender differences. Perhaps, mothers genuinely favor emotional supports, whereas fathers favor instrumental or goods, services, and financial assistance in addressing their needs.

Availability of Support Items

Support Items Identified as Absent or Not Available. The items that parents identified as absent or not available also were reflective of the ranking of items in terms of importance. This finding could mean that parents identify the importance of items in the Q-sort not in terms of whether or not they have the support, but whether or not they are actually important.

The least available support item identified by fathers and mothers was “financial help for my expenses” which was also identified by parents as being one of the *most* important supports. Clearly, personnel need to be aware of the financial burden experienced by parents of a child with a disability, regardless of their income level. Professionals need to know what resources are available to families and how to access those resources.

The other two support items identified as being absent or not available were “help with independent living skills” and “help with transportation” both of which were identified as support items that were *least* important. Perhaps, independent living skill was perceived to be something they would need when their child is older and not between the ages of three to five. Also “help with transportation” may not have been perceived as a need of these families because of the social class of families who participated in this study.

Support Items Identified as Available. Fathers and mothers identified “information about my child’s condition or disability” as the most available support item. In the past few years, information about autism has been more readily available via books, internet, and professionals (Schwartz, Sandall, McBride, & Boulware, 2004). Possibly, fathers in the current study recognized their personal need for information and they sought out this information.

Fathers and mothers identified “involvement with early intervention (infant and toddler), preschool or school program” as one of the most available support items. Jones et al. (1998) found that mothers reported the staff of the child’s school as being one of the most helpful supports. Also, all of these families have just exited the birth-to-three service delivery system and, possibly, they felt that these services were positive and beneficial to their child and family.

T-Test and Correlations

None of the *t*-tests performed in this study were found to be statistically significant. Therefore, fathers and mothers did not statistically differ on the importance of individual support items or on the importance of the categories of supports.

Correlations were found to be statistically significant for five items: “special equipment to help meet my child’s needs”, “involvement with church or strong religious beliefs”, “information on how I can help my child”, “financial help for expenses”, and “participation in an organized parent support group.” Since these items were correlated for fathers and mothers, it shows that these individuals ranked the items similarly. Fathers and mothers generally agreed that *least* important supports were “special equipment to help meet my child’s needs”, “involvement with church or strong religious beliefs”, and “participation in an organized parent support group.” Fathers and mothers agreed with the ranking of “information on how I can help my child” and “financial help for expenses” as being *most* important.

Three-Factors from the Factor Analysis

The first factor in the three-factor analysis corresponded directly with the rankings of *most* and *least* important support items. The support items that were found to be the *most* important in this model were “information on how I can help my child”, “information about my child’s future” and “contact with other parent(s) who experienced the same situation.” The support items that were found to be *least* important in this factor were “help with transportation”, “special equipment to meet my child’s needs” and “involvement with a church or strong religious beliefs.” This first factor was comprised of 24 of the participants which is more than half of the participants, possibly being a result of why these items correspond to the rankings of the support items.

The second factor had some of the same support items identified as important as found in the rankings: “financial help for expenses” and “information on how I can help my child.” Only one of the support items, “help with transportation” were found by the participants who comprised the second factor as not being important. “Special equipment to meet my child’s needs” was identified as an important support for these participants. Generally, special equipment, which might include alternative or augmentative devices, are either needed or not needed at all for a child. The participants who make up factor two may have found that “special equipment” that was utilized by their child was crucial for their child and family. The participants comprising factor two, identified as not being important, the following supports: “a close friend or family member to talk to about my concerns” and “counseling with a professional person.” Perhaps these participants perceived that they had access to these support items or possibly they had negative experiences with these supports and, thereby, ranked them as not being important.

The third factor also had some of the same support items ranked as important and as not being important. The items found to be important for these individuals were “involvement with early intervention (infant and toddler), preschool or school program”, “information about my child’s condition or disability.” The items found to not be important for these individuals were “help with independent living skills” and “special equipment to help meet my child’s needs.” These participants identified “counseling with a professional person” as being important. A possible explanation for this could be that in the birth-to-three service community that these families had experience with, counseling or a counselor is referred to as a psychologist. Frequently, psychologists provide therapeutic techniques and treatments for children with autism. The treatments and therapies that were taught to these families were possibly thought to be beneficial to their child and these participants perceived the psychologist as a counselor. "Information about my child's future" was identified by these participants as not being important. The participants in this factor may have thought this information was readily available by therapists, books, and the internet and not a need for them.

Other Supports Identified by Participants

Appendix I contains the support items that participants identified as lacking or missing from the available supports in the Q-sort. These items were generally very specific needs unique to the particular participant. For example, "information about specialty schools past early intervention" and "information on helping children adjust to a missing parent in the home" were both listed as support items that were missing from the Q-sort. Also, some items identified as missing could be interpreted as items that were contained already in other support items in the Q-sort in broader terms. For example, "financial help that does not tie into my income or disqualify my child because of it" would be a part of the "financial help for my expenses." Another support item that could be thought of as a more specific description of an already existing support item would be "a church where I can go with my autistic son" which would go with "involvement with a church or strong religious beliefs."

Limitations of the Current Study

There are limitations with the current study. The results of this study are from a small number of fathers and mothers of children recently diagnosed with autism. Similar research with more fathers and mothers could assist in the confirmation and the expansion of the current findings.

The categories of support (formal, informal, instrumental and emotional) were not balanced with the same number of items as in past research (Flynn, 1990; Staley-Gane et al., 1996). This imbalance of support items was also a direct result of the social validation performed in this study. The results of the social validation produced 11 formal support items, five informal support items, ten instrumental support items, and six emotional support items.

Additionally, the support items could have been interpreted differently by fathers and mothers. The meaning of the item may have been viewed differently by individuals completing the Q-sort. For example, “involvement with a church or strong religious beliefs” and “participation in an organized parent support group” were both placed in the category of informal supports. Both of these items could have been interpreted to be formal supports if the respondent viewed the support group as being conducted by a clinician and if the involvement with a church included a pastor, who could be viewed as a professional, as well.

Recommendations for Future Research

This study found perceived importance of supports of fathers and mothers of children recently diagnosed with autism. Future research needs to contain longitudinal research to determine how parents’ needs change over time. Past research (Staley-Gane et al., 1996) has found that the length of time a child was diagnosed with Fragile X influenced parents’ needs and needs varied over time. Krahn (1993) cited the need for longitudinal research to determine the changing supports desired by parents of children with disabilities.

More research about social supports of parents of children with autism needs to be conducted. Currently, a very modest amount of research has been conducted.

Researchers have found that stress levels increase in parents as their supports decrease (Gray & Holden, 1992; Konstantareas & Homatidis, 1989). Parents of children with autism have been identified as one of the most stressed parental groups. Future research needs to be conducted to determine what supports may decrease the stress experienced by parents of children with autism.

Additional studies comparing mothers and fathers are needed, especially mothers and fathers in the same family. Previous research was conducted primarily with mothers rather than fathers. Support needs of both parents needs to be conducted to ensure that both perspectives are gathered.

Parents of children with autism have unique needs, as evidenced by this study. Development of graduate programs disability specific (e.g., autism) could help service providers to gain a greater understanding of these needs. Able-Boone, Crais, and Downing (2003) have reported the development of specific graduate programs based on disability, in this case, autism. Research should be conducted to see if these professionals are better able to meet the needs of families when compared to graduates of other programs.

Another recommendation is for service personnel to perform a Q-sort to determine the needs of families. The Q-sort took approximately 20 minutes to complete with both fathers and mothers. The information gained from the Q-sort would allow professionals to better meet the needs of families and enhance the “family-centered” practices of the professional.

Summary

The focus of this study was to identify the forms of social support that fathers and mothers of young children recently diagnosed with autism perceive as being important. Twenty families completed a Q-sort, which allowed for a ranking of support items which indicated the perceptions of support needs of these families. It is crucial to “family-centered” practices that families of the child with the disability are allowed to identify their priorities. By allowing the families to identify their priorities and needs, service providers will be able to better support these families in receiving these supports.

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APPENDICES

Appendix A

Demographic Data Form

Code: ___________ Date: ______________

Demographic Data Form

Participant Information

Age: _____ Sex: Male or Female

Marital Status (circle one): Married Single Separated Divorced

Occupation: _____________________

Circle your highest level of education:

1 = Graduate School
2 = Four-Year University
3 = Some College (at least one year of college)
4 = High School Graduate or GED
5 = Some High School
6 = Junior High School (up to 9th grade)
7 = 8th grade or below

Circle your income level:

1 = 0 – 19,999
2 = 20,000 – 39,999
3 = 40,000 – 59,999
4 = 60,000 – 79,999
5 = 80,000 – 99,999
6 = 100,000 +

Child Information

Birth date: _____________ Sex: _____

Age at diagnosis: __________ Diagnosis: _______________

Sibling Information

List the gender, age and diagnosis if applicable
(for example: male, 15, not applicable; female, 7, attention deficit disorder)

____

____

____

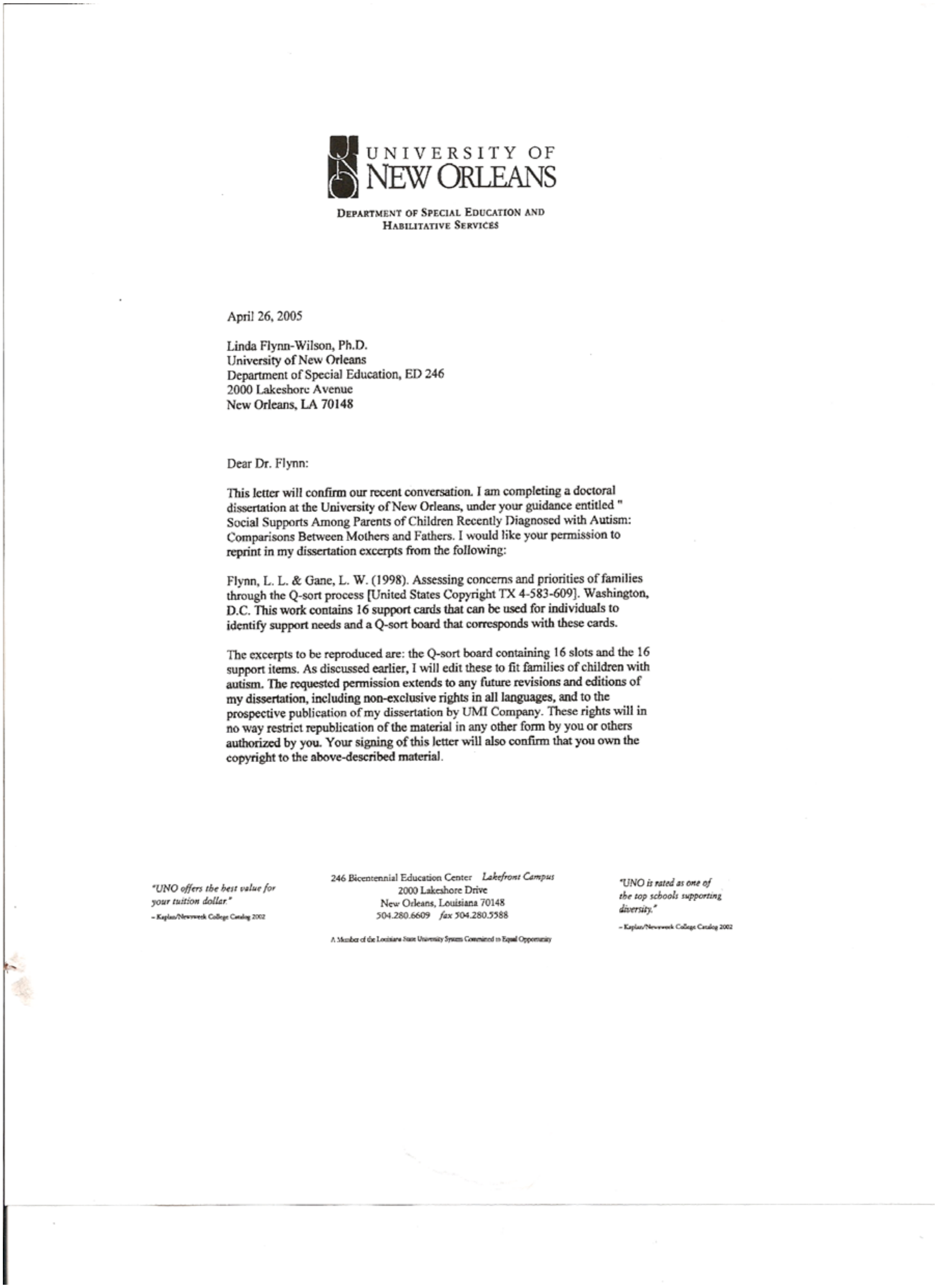
____

____

____

Appendix B

Copyright Permission Granted Letter



UNIVERSITY OF
NEW ORLEANS

DEPARTMENT OF SPECIAL EDUCATION AND
HABILITATIVE SERVICES

April 26, 2005

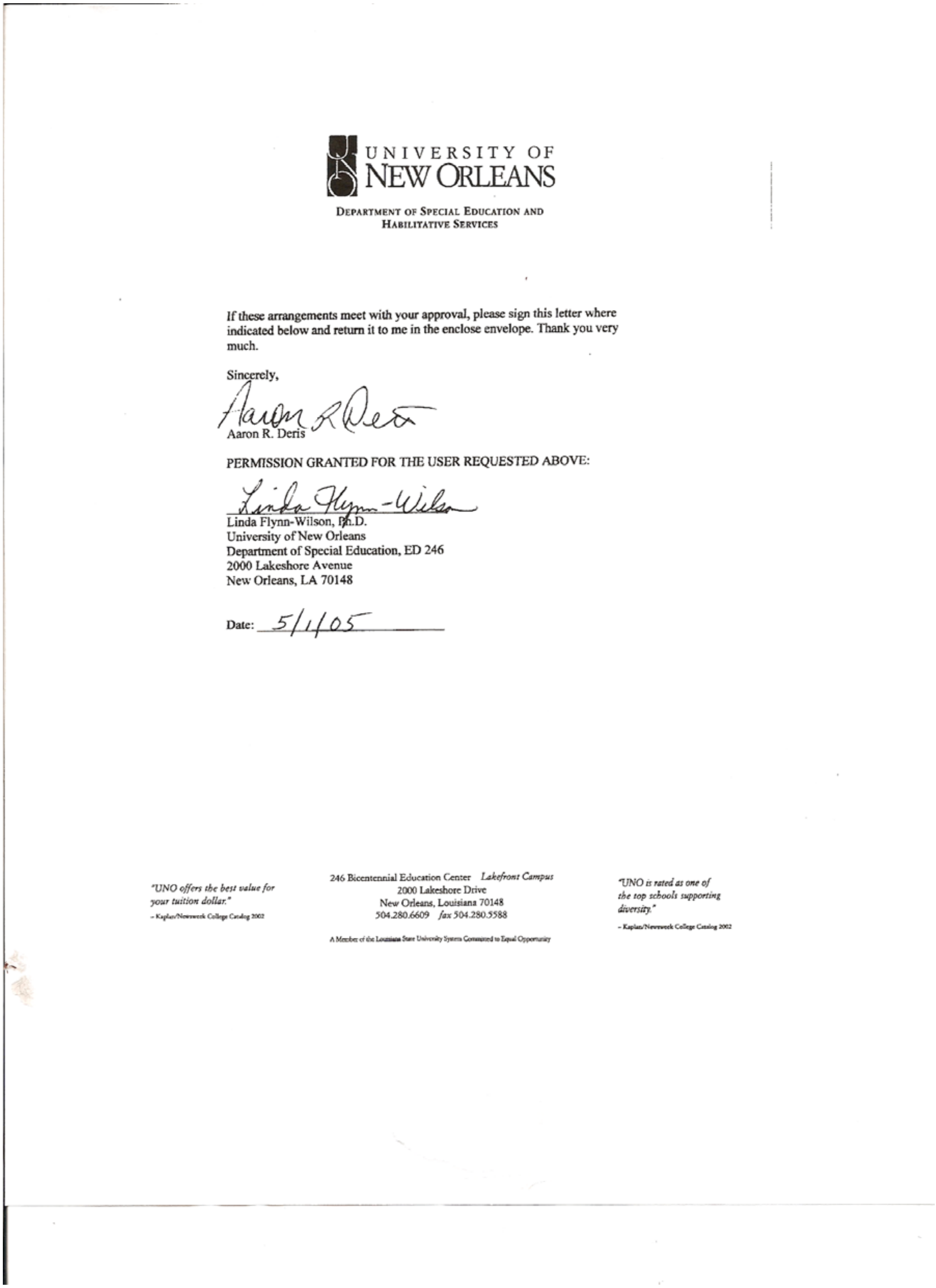
Linda Flynn-Wilson, Ph.D.
University of New Orleans
Department of Special Education, ED 246
2000 Lakeshore Avenue
New Orleans, LA 70148

Dear Dr. Flynn:

This letter will confirm our recent conversation. I am completing a doctoral dissertation at the University of New Orleans, under your guidance entitled " Social Supports Among Parents of Children Recently Diagnosed with Autism: Comparisons Between Mothers and Fathers. I would like your permission to reprint in my dissertation excerpts from the following:

Flynn, L. L. & Gane, L. W. (1998). Assessing concerns and priorities of families through the Q-sort process [United States Copyright TX 4-583-609]. Washington, D.C. This work contains 16 support cards that can be used for individuals to identify support needs and a Q-sort board that corresponds with these cards.

The excerpts to be reproduced are: the Q-sort board containing 16 slots and the 16 support items. As discussed earlier, I will edit these to fit families of children with autism. The requested permission extends to any future revisions and editions of my dissertation, including non-exclusive rights in all languages, and to the prospective publication of my dissertation by UMI Company. These rights will in no way restrict republication of the material in any other form by you or others authorized by you. Your signing of this letter will also confirm that you own the copyright to the above-described material.



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HABILITATIVE SERVICES

If these arrangements meet with your approval, please sign this letter where indicated below and return it to me in the enclose envelope. Thank you very much.

Sincerely,

Aaron R Deris
Aaron R. Deris

PERMISSION GRANTED FOR THE USER REQUESTED ABOVE:

Linda Flynn-Wilson
Linda Flynn-Wilson, Ph.D.
University of New Orleans
Department of Special Education, ED 246
2000 Lakeshore Avenue
New Orleans, LA 70148

Date: 5/1/05

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Appendix C

UNO Committee on Human Subjects Approval Form

University Committee for the Protection of Human Subjects in Research University of New Orleans

Campus Correspondence

Dr. Linda Flynn-Wilson
Aaron Deris

5/3/2005

RE: Social supports among parents of children recently diagnosed with autism: Similarities and differences between mothers and fathers

IRB#: 06may05

The IRB has deemed that the proposed research project is now in compliance with current University of New Orleans and Federal regulations.

Be advised that approval is only valid for one year from the approval date. Any changes to the procedures or protocols must be reviewed and approved by the IRB prior to implementation. Use the IRB# listed on the first page of this letter in all future correspondence regarding this proposal.

If an adverse, unforeseen event occurs (e.g., physical, social, or emotional harm), you are required to inform the IRB as soon as possible after the event.

Best of luck with your project!
Sincerely,

Laura Scaramella, Ph.D.
Chair, University Committee for the Protection of Human Subjects in Research

Appendix D

Consent Form used for Social Validation

UNIVERSITY OF
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DEPARTMENT OF SPECIAL EDUCATION AND
HABILITATIVE SERVICES

IRB #06 May05

CONSENT FORM

1. Title of Research Study

Social Supports Among Parents of Children Recently Diagnosed with Autism: Similarities and Differences Between Mothers and Fathers.

2. Project Director

Principal Investigator -- Linda L. Flynn, Ph.D. Office: 504-280-6541; Education Building Room 246.
Student Investigator-- Aaron R. Deris, M.Ed. Office: 504-280-5594; Education Building Room 220.

3. Purpose of the Research

The purpose of this portion of the research project will be to have both parents and professionals (e.g., psychologists, teachers, speech therapists) to determine if supports found in the literature and used in this research project are either formal or informal and instrumental or emotional sources of support for families of children with autism.

4. Procedures for this Research

You will be asked to identify whether the social supports on the following table are either formal or informal sources of support for families of children with autism. You will be given time to look through the table of supports. You will be asked to determine if the support is either formal or informal source of support. The total time to accomplish this activity will be approximately twenty minutes.

5. Potential Risks of Discomforts

This study is expected to pose no risk or discomfort to its participants. **If you have any questions concerning your rights as a human subject, please contact Dr. Anthony Kontos at the University of New Orleans at 280-6420.**

6. Potential Benefits to You or Others

Your participation will serve as a validation process to a larger study. The larger study will increase awareness of identified needs of families of children with autism. These needs can be shared with professionals and therefore provided to families.

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7. Alternative Procedures

There are no alternative procedures. **Your participation is entirely voluntary, and you may withdraw consent and terminate participation at any time without consequence.**

8. Protection of Confidentiality

All data gathered through this project will be kept confidential. Consent forms, and notes will be kept in a locked office. Names will not be used in the dissemination of any of the findings.

9. Signatures

I have been fully informed of the above-described procedure with its possible benefits and risks and I have given permission of participation in this study.

Signature of Participant	**Name of Participant (Print)**	**Date**
Signature of Person Obtaining Consent	**Name of Person Obtaining Consent (Print)**	**Date**

Appendix E

Social Validation Form

Directions: Please check the columns which **BEST** describe each support item. Determine if the support item is formal **OR** informal and if it is Instrumental **OR** Emotional. Check the box "Genuine Support Need" if you believe this is a need of families of children who recently had a child diagnosed with autism. If you feel there is an alternative wording that would help with readability, please include the suggestions in the section labeled, **"Alternative Wording".**

Use the following definitions:

Formal: the provision of assistance provided by professionals who have training or expertise in the area of assistance

Informal: the provision of assistance is provided by family, friends, or neighbors (i.e., individuals who do not have training or expertise in the area of assistance).

Instrumental: includes goods, services, financial assistance, and information provided to families to address a need

Emotional: someone to talk to about problems, feelings, and attitudes as well as receiving intimacy and affection

	OR		**OR**			
Support item	**Formal**	**Informal**	**Instrumental**	**Emotional**	**Genuine Support Need**	**Alternative Wording?**
A close friend or family member to talk to about my concerns						
Discussions with medical people						
Involvement with early intervention (infant and toddler), preschool or school program						
Special equipment to help meet my child's needs						
Involvement with a church or strong religious beliefs						
Relaxing and fun activities for my child and family						
Information on how I can help my child						
Financial help for expenses						
Information about my child's condition or disability						
Counseling with a professional person						
Participation in an organized parent support group						
Help with transportation						
Information about my child's future						
Help with child care or respite care						
Contact with other parent(s) who experienced the same situation						
Help with independent living (housing, job, or personal skills)						

Please check one of the categories below which best describes you.

Please indicate the age of your child or the # of years of experience you have working with children with Autism Spectrum Disorders (ASD) in parenthesis

_____ I am a parent of a child with an ASD (age of child with ASD _____)

_____ I am a certified teacher in early childhood special education (# of years experience working with children with an ASD_____)

_____ I am a related service provider for children with an ASD (# of years experience working with children with an ASD_____)

Please list below any other supports you feel should be added and whether they are formal or informal:

Flynn, L. L. & Deris, A. R. (2005)

Appendix F

Volunteer Flyer and Advertisement

Volunteers Needed

An exciting project is being conducted with mothers and fathers of children (between the ages of three and five) recently diagnosed (within the past year and a half) with an Autism Spectrum Disorder. Parents will be asked to complete a brief, game-like procedure (Q-sort) in which support for their child and family will be prioritized. The information gathered will be used to guide practices providing services to families of children with an Autism Spectrum Disorder.

The premise for this project is that parents are the most knowledgeable about services their own family wants or needs. For convenience, the individual conducting the Q-sort will come to your house to implement the procedure. The total time needed is approximately ½ hour.

For more information, please contact:
Aaron R. Deris, Doctoral Student
University of New Orleans
Department of Special Education and Habilitative Services
504-280-5594 (office)
504-621-3999 (cell)
Aderis@uno.edu

Linda Flynn, Ph.D., Faculty Supervisor
University of New Orleans
504-280-6541 (office)

Appendix G

Consent Form used with Parents

UNIVERSITY OF
NEW ORLEANS

DEPARTMENT OF SPECIAL EDUCATION AND
HABILITATIVE SERVICES

IRB #06 May05

CONSENT FORM

1. Title of Research Study

Social Supports Among Parents of Children Recently Diagnosed with Autism: Similarities and Differences Between Mothers and Fathers.

2. Project Director

Principal Investigator -- Linda L. Flynn, Ph.D. Office: 504-280-6541; Education Building Room 246.
Student Investigator-- Aaron R. Deris, M.Ed. Office: 504-280-5594; Education Building Room 220.

3. Purpose of the Research

The purpose of this research project will be to determine what parents of children recently diagnosed with autism identify as social supports. Social supports can either be sources (formal or informal) or types (instrumental or emotional). Formal support is the provision of assistance provided by professionals who have training or expertise in the area of assistance to families. Informal support is the provision of assistance provided by family, friends, or neighbors (i.e., individuals who do not have training or expertise in the area of assistance). Instrumental support is *tangible* support and includes goods, services, financial assistance, and information provided to families to address a need. Emotional support is having someone to talk to about problems, feelings, and attitudes as well as receiving intimacy and affection.

4. Procedures for this Research

You will be asked to identify social supports you view are needed for your family. You will be ranking a set of pre-typed cards with identified social supports. You will be given time to look through the set of pre-typed cards, and instructed on how to sort the cards. After sorting the cards there will be time to discuss the social supports and if you have any other supports you think should be added to the list. The total time to accomplish this activity will be approximately thirty minutes.

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– Kaplan/Newsweek College Catalog 2002

246 Bicentennial Education Center *Lakefront Campus*
2000 Lakeshore Drive
New Orleans, Louisiana 70148
504.280.6609 *fax* 504.280.5588

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"UNO is rated as one of the top schools supporting diversity."

– Kaplan/Newsweek College Catalog 2002

IRB #06 May05

5. Potential Risks of Discomforts

This study is expected to pose no risk or discomfort to its participants. However, if you feel that you need to have some supports identified a list of agencies can be provided. The primary investigator takes no responsibility for what information is obtained from the agencies, nor is advocating for these agencies. **If you have any questions concerning your rights as a human subject, please contact Dr. Anthony Kontos at the University of New Orleans at 280-6420.**

6. Potential Benefits to You or Others

Increased awareness of identified needs of families of children with autism. These needs can be shared with professionals and, therefore, provided to families. Your answers will guide professionals in supports that they provide to families and therefore, your participation will assist numerous families of children with autism.

7. Alternative Procedures

There are no alternative procedures. **Your participation is entirely voluntary, and you may withdraw consent and terminate participation at any time without consequence.**

8. Protection of Confidentiality

All data gathered through this project will be kept confidential. Consent forms, and notes will be kept in a locked office. Names will not be used in the dissemination of any of the findings.

9. Signatures

I have been fully informed of the above-described procedure with its possible benefits and risks, and I have given permission of participation in this study.

Signature of Participant	**Name of Participant (Print)**	**Date**
Signature of Person Obtaining Consent	**Name of Person Obtaining Consent (Print)**	**Date**

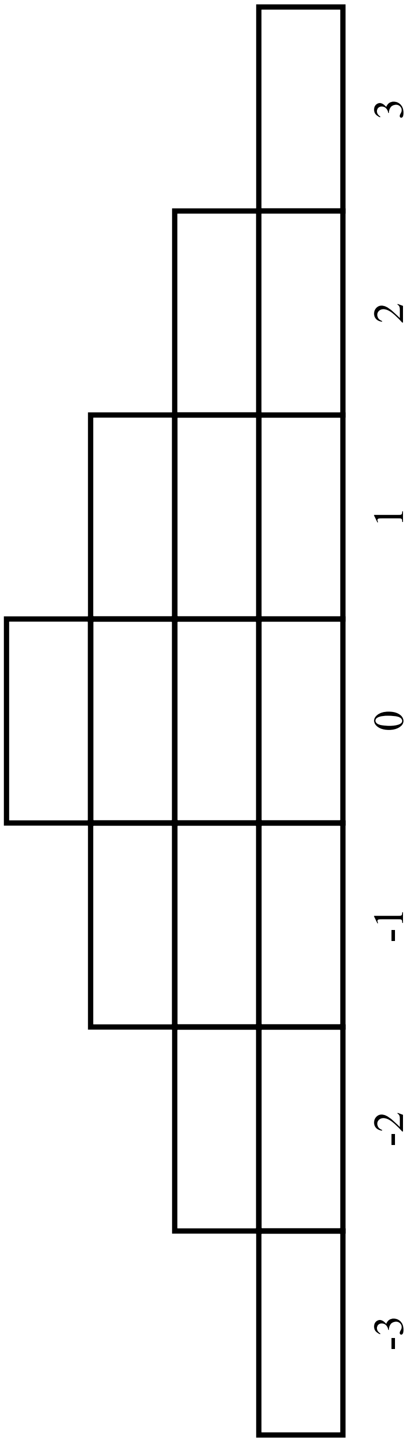
Appendix H

Data Collection Form

Code: _______________ Date: _______________

Child's birth date: _______________

Item #	Items	
	Sort	Absent
1	____	____
2	____	____
3	____	____
4	____	____
5	____	____
6	____	____
7	____	____
8	____	____
9	____	____
10	____	____
11	____	____
12	____	____
13	____	____
14	____	____
15	____	____
16	____	____



Appendix I

Additional Support Items identified by Parents as Missing

Additional Support Items identified by Parents as Missing

5202 Information about specialty schools past early intervention.
Information on helping children adjust to a missing parent in the home.

4103 Financial help that does not tie into my income or disqualify my child because of it.

4104 Physical and alternative therapy.
5204 There is a gap between diagnosis and pediatric reviews
My pediatrician did not and has not signed on the PDD diagnosis despite all other information.

5206 A list of organizations who take kids with special needs (Autism), e.g., karate, dance, swim, etc.
A church where I can go with my autistic son.
4106 Taking part in field trips with children and families with the same condition (autism).

5207 Balance time with child with autism and typically developing child.

4109 Therapy for interventions, such as eye contact.

5211 Alternate speech communication partners for child to give parents a break.
5212 Education professional who could refer a student who could come to our home to offer services.

5214 More available schooling options for my child.
4114 Earlier evaluation by school system to give more time to make a decision moving forward.

5217 A list of providers of Autism services in my community.
Special instruction for pediatricians on the new science of autism.
4117 No pre-school ABA program in the parish.

4118 More information on adults with autism.

5219 A broader explanation of all services available to my child’s diagnosis; not simply what is available in our parish.

VITA

Aaron R. Deris, received a B.A. in Psychology from the University of New Orleans in May 1998, and a M.Ed. in Special Education from the University of New Orleans in 2001. He has worked as a classroom teacher for children with Mild/Moderate disabilities. He has also worked with the birth-to-three population in home-based and center-based settings.

He has done contract work for the Louisiana State Department of Education to evaluate early childhood special education classrooms. He has also presented at local, state, and national conferences. In addition, he has taught graduate level students. His current research interests include autism, program evaluation, applied behavior analysis, program development, and social supports for families of children with disabilities.