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Social Support Domains for Parents of Children with Autism Spectrum Disorder: Assessing Perceived Needs and Stress Levels

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SOCIAL SUPPORT DOMAINS FOR PARENTS OF CHILDREN WITH AUTISM
SPECTRUM DISORDER: ASSESSING PERCEIVED NEEDS AND STRESS LEVELS

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SOCIAL SUPPORT DOMAINS FOR PARENTS OF CHILDREN WITH AUTISM
SPECTRUM DISORDER: ASSESSING PERCEIVED NEEDS AND STRESS LEVELS

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SPECTRUM DISORDER: ASSESSING PERCEIVED NEEDS AND STRESS LEVELS

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The current study investigated types of social support needs through a number of domains reported by parents of children with autism spectrum disorder (ASD) along with the relationship of these needs to reported parental stress. Female participants (N = 35) in the South Central Kentucky region responded to a number of measures regarding perceptions of their current stress levels on the Parenting Stress Index - Short Form (PSI-SF) and their perceptions on social support needs through a modified version of the Family Needs Questionnaire (FNQ). The results indicated that there was a moderately strong correlation between social support needs and parental stress. For exploratory analyses, the results indicated that several social support domains significantly correlated with parental stress. Further research was recommended to explore the seven social support need domains used in the current study with ASD families.

Introduction

Autism Spectrum Disorders (ASD) are considered developmental disorders that encompass a variety of diagnoses including autism, Asperger's syndrome, and Pervasive Developmental Disorders- Not Otherwise Specified (Klin, McPartland, & Volkmar, 2005). These developmental disorders will be discussed in more detail through a description of how ASD is classified as a continuum. For children diagnosed with ASD, a plethora of problems exists, not only for the child, but within the child's family as well (Hutton & Caron, 2005). Numerous research studies have demonstrated that these problems impact families to the degree that stress levels were reported higher within families of a child with ASD versus families of typically developing children (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Hutton & Caron).

Different social supports were found to help with stress levels in ASD families throughout various research studies. The relationship between stress and social support shows that stress is significantly less when parents report social support as being available to them (Gill & Harris, 1991). By incorporating a family systems perspective for the relationship between social support and stress, the perspective can effectively describe how having a child with ASD may impact the family unit as a whole. Several models, which will be discussed later, highlight how families cope with the stressors that typically arise from the child with ASD (Bristol, 1987). Through the use of particular types of social support, whether these supports are formal or informal, parents have identified which supports are most effective for their children and families and whether those supports address the needs they have as a result of having a child with ASD (Hutton & Caron, 2005). The terms *formal* and *informal* social supports will be discussed in more

detail later. Also, the definition of social support will be discussed as well as the various types of social supports commonly reported by parents of children with ASD.

Because there is a lack of research addressing how parents of children with ASD use social supports, the current study will focus on various social support domains that are frequently utilized by parents and their families. Concurrently, little research has addressed parents' perceptions of their needs, as well as parents' need for support (Boyd, 2002; Siklos & Kerns, 2006). Several researchers suggested incorporating multiple dimensions of social support for families of children with ASD (White & Hastings, 2004). The specific types of social support for the current study comprise various key domains that are commonly accessed by families of the ASD population. These domains will be discussed in more detail as each one will be defined and outlined within the study.

As an exploratory study, one objective is to examine which types of social support domains are perceived as most effective and regularly utilized by parents. The relationship between parental stress and social support needs will also be tested. The literature on ASD will be reviewed in the context of social support, a family systems perspective, and the resulting stress levels commonly experienced by parents. The relationship between social support and stress will also be included.

Literature Review

Autism Spectrum Disorder Defined

Autism Spectrum Disorders (ASD) involve an umbrella of developmental disorders, which include Asperger's syndrome, Autistic Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Over the years, empirical data has found that these developmental disorders share considerable overlap in their features. In recent years, there have been advancements in our understanding of the wide range of difficulties in the autism spectrum. The once limited definition of autism has now progressed into a broader definition and contains a variety of diagnoses placed on a continuum.

As a spectrum, these diagnoses are considered to be developmental disorders that range in severity and levels of functioning (Klin et al., 2005). Volkmar and Klin (2005) noted that in recent years, as the definition of autism has become more complex, so has an understanding of the broader phenotype that includes autism. This phenotype, also known as the autism spectrum, considers the genetic influences of *classical autism* and addresses areas of functioning that are affected from autism spectrum characteristics: social development, communication, and behavior. Therefore, with autistic disorder placed along the autism spectrum, other developmental disorders and syndromes also comprise the spectrum because of the behavioral similarities and genetic factors shared by the disorders (Filipek, 2005). Through an evolving conceptualization of the disorders on a spectrum, it makes sense for autism to be characterized on a continuum.

Children who fall on the ASD continuum often endure significant impairment, in which problems are typically manifested in their social interaction, language and

communication, play and imagination, and isolated or limited interests and behaviors (Klin et al., 2005). Noticeable behaviors begin during early infancy and become more apparent over time. Parents may notice and report that their child is acting "differently" than other children, and they may feel that something is just not right with their child [Diagnostic and Statistical Manual—Fourth Edition-Text Revision (DSM-IV-TR); American Psychiatric Association, 2000]. Because of these lifelong impairments and pervasive nature, having autism can contribute to significant problems within the family system. As a result, families are faced with many unique challenges that require them to address the needs of the child with ASD (Hutton & Caron, 2005).

Bryson and Smith (1998) point out that autism is a severe developmental disorder that is more prevalent than prior research has shown. They address that the prevalence of autism, based on Leo Kanner's description, is estimated as occurring in 4-5 per 10,000 individuals. However, it is important to note that this prevalence rate was based on the diagnosis and assessment of autism prior to 1985. More recent findings of the current prevalence rate show even higher rates through a number of studies (Fombonne, 2005). For example, when only looking at autistic disorder and not the full spectrum of disorders, a conservative estimate for the most recent prevalence rate ranges from 10/10,000 to 16/10,000. Therefore, because some studies' range estimates did not take into account Asperger's syndrome or other pervasive developmental disorders, the rate for ASD may even be higher. For example, a compilation of 42 studies that were published between 1966 and 2003 gave prevalence ranges based on different developmental diagnoses; of the studies, 36 studies gave information exclusively on autistic disorder, 3 studies for all types of pervasive developmental disorders (PDDs), and

3 studies just on high-functioning PDDs (Fombonne, 2005). With the seeming increase in prevalence rate, other researchers suggest that more children are being diagnosed at younger ages with ASD (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008). With higher prevalence rates, it is fundamental to understand that this growing population will require the most effective services. This applies not only to the child with the diagnosis of ASD, but to those who are directly and indirectly affected, including the child's family (Bryson & Smith). Overall, there is a growing population of families who will need specific services.

Autism Spectrum Disorder Difficulties

Difficulties for children with ASD encompass multiple areas of functioning. For example, some of these areas may include: sensory, communication, academic, behavioral, and social issues (Chawarska & Volkmar, 2005; Howlin, 2005). Sensory issues can lead a child to experience difficulties, especially at school. For example, sensory issues for a child may include hypersensitivity to light or sound, which leads the child to cry or yell. In turn, this can lead to a misunderstanding if there is lack of awareness about the child's sensory problems (Goodman & Williams, 2007). For children with ASD, the learning process is not easy within academic settings. The learning process also applies to social settings as it may be quite difficult for these individuals to match their behaviors to the context of situational and social demands (Bryson & Smith, 1998). With social problems existing for these individuals, other children may not understand the child's behaviors, and this can lead to teasing and bullying (Attwood, 2007) and then social isolation of the child (APA, 2000). With the issues that can arise in school and social settings, making accommodations for the child

may be necessary to address behavioral management and to create positive changes for the child's situation. The accommodations would not only attend to the educational needs of the child but may help the child make improvements in his or her social network.

Therefore, because there are such significant problems related to ASD, it is essential for social supports to ameliorate the behavioral problems. Goodman and Williams (2007), for example, posit that various strategic interventions have been put in place to address various areas in an academic setting. These interventions are essentially a type of social support for families and their child. For instance, a specific intervention strategy is auditory engagement, in which auditory cues (e.g., using a bell, rhythmic clapping, etc.) may be used when the teacher asks questions to the class. The use of a bell might be used for the child for his or her difficulty in comprehending language. This would support the child's educational needs through a particular social support. Such an intervention may also target a parent's perceived need for his or her child through the school system. Overall, the educational needs of the child would be met along with the perceived need of the parent.

When it comes to medical needs of the child with ASD, Attwood (2007) suggests that neurological and biological aspects of the disorder must be considered to account for some of the problems children face developmentally. Some considerations include: infections during pregnancy and in the child's early infancy, metabolism issues in regards to food intake that produces toxins and affects the brain's development, and other biological factors that contribute to the growth and development of the brain. With these issues, there may be a high need for the child to be provided with adequate medical screenings, neurological testing, and proper pediatrician evaluation, not only in childhood

but throughout adolescence and adulthood. In fact, Bryson and Smith (1998) point out

findings from epidemiological research, which suggest that approximately 25-30% of

those with ASD have associated medical conditions. Of these conditions, the most

common are sensory impairment, tuberous sclerosis, neurofibromatosis, and epilepsy.

Another interesting finding is that co-morbid estimates are possibly more prevalent than

current data suggest (Bryson & Smith). One reason for this is that there may be limited

access to the necessary health or social service resources to properly diagnose medical

conditions. Actually, the symptoms of particular medical conditions have led

professionals to inaccurately diagnose the child. Incorrect diagnoses suggest a greater

need for access to the necessary support services, as well as, better diagnostic services.

Autism Spectrum Disorder and Stress in Families

It has been well-documented that ASD can elicit higher levels of stress on

families who have a child with such a developmental disorder than families who do not

have a child with any developmental issues (Baker-Ericzén et al., 2005; Hutton & Caron,

2005; Tomanik, Harris, & Hawkins, 2004). When taking into account other types of

developmental disorders, there are still higher stress levels for these parents when

comparing ASD to parents of typically developing children (Mancil, Boyd, & Bedesem,

in press). The following quotes exhibit reports by parents when describing their stress of

having a child with ASD: "Continual stress and strain. It stops you from doing things,"

and "A lot of stress on the family. It's been a hard year trying to come to terms with it

and concerns about the future" (Cassidy et al., 2008, p. 121). While these are only a few

qualitative examples of stress, they highlight the impact that the child has had on the

family. Researchers have also suggested that there is a positive relationship between problematic child behavior and parental stress levels (Tomanik et al., 2004).

In a study by Tomanik et al. (2004), stress was the greatest when mothers observed their child as being more irritable, lethargic or socially withdrawn, hyperactive and non-compliant, unable to take care of him- or herself, and unable to communicate or interact with others. The high levels of parental stress were not found to be direct results of the child's behaviors or behaviors but rather from indirect influences of raising a child with ASD. For example, some indirect influences included: increased marital issues, feelings of depression, and isolation (Tomanik et al.). However, it is pertinent to note that overall research has not been consistent in its findings for how parents cope with stressors related to raising a child with ASD. Mancil et al. (in press) noted a variety of coping mechanisms that parents use to handle stress. Therefore, there are other parental perceptions for why high stress levels likely exist (Hutton & Caron, 2005). For example, other parental perceptions have included: continual stress, strain, and lack of sleep (Cassidy et al., 2008). Even with varying perceptions, high stress levels signify a need for "parent-directed" services, which may include individual counseling of the parent (Baker-Erickzén et al., 2005).

Along with establishing the most accurate diagnosis comes the challenge for obtaining the most effective services that will help these families and their child with ASD (Hutton & Caron, 2005). Previous research evidence has supported the idea that parental stress can influence the effectiveness and types of interventions accessed (Baker-Ericzén et al., 2005). One study suggested that two-thirds of the parents in the sample reported that their stress was reduced after their child had received services specific to the

ASD population (Hutton & Caron). This finding suggests that social support intervention is not only crucial, but it also suggests that understanding a parent's stress level may reveal whether and why particular services are accessed. One possibility of accessing services is whether the parents who have a child with ASD value the use of social support within their families (Sharpley & Bitsika, 1997).

The Need for Social Support

Families' coping strategies in dealing with problem behaviors of ASD have been widely documented. Research has presented that there are many difficulties families face from the high demands and challenges of ASD characteristics (e.g., Boyd, 2002; Hutton & Caron, 2005). While the child's unique needs require a variety of therapies and treatments, it is also relevant to understand the unique needs of the family unit and the promotion of its involvement in education and training programs (Becker-Cottrill, McFarland, & Anderson, 2003). For example, one study discussed the need for other models of respite care to be implemented with families requiring unique services. This included in-home or host families as opposed to other types of respite care that could have been instilled (Factor, Perry, & Freedman, 1990). Working with parents who have a child with ASD has changed significantly in the last 30 years. Research and clinical evidence have shown that parents who are empowered to take an active role in their child's treatment can shape positive and lasting effects that may ultimately improve the child's condition (Marcus, Kunce, & Schopler, 2005). This type of parent advocacy has impacted both government and scientific levels in that research funding continues its support of investigations of developmental disorders in children (Rapin, 2005). Because of the range of difficulties and challenges of raising a child with ASD, parents take on an

active role by often turning to certain types of social support in order to meet their

family's needs (Siklos & Kerns, 2006). This also seems to hold true for families across

various cultures that may access more social support than families raising children with

other disabilities besides ASD (Taylor-Dyches, Wilder, Sudweeks, Obiakor, &

Algozzine, 2004).

Overall, the need for parent-professional support in autism intervention has

proven undeniable (Marcus et al., 2005). Supports that specifically address the needs of

parents who have a child with ASD are often the services most frequently used to help

alleviate the difficulties and challenges related to the disorder (Siklos & Kerns, 2006).

Freedman and Capobianco-Boyer (2000) point out that parents commonly reported

needing specific service supports including: case management, types of therapies, such as

behavioral, physical, occupational, or speech, and mental health counseling. These types

of needs fell into categories of: types of services and supports, positive changes for

improved socialization and community involvement for the child, and advances in

education and encouragement (Freedman & Capobianco-Boyer, 2000).

Family Systems Perspective

It has been suggested through research findings that professionals should take on

a holistic rather than individualistic approach when working with families of children

with developmental disabilities (McCubbin & Patterson, 1983). Essentially, both the

unique needs of the child and the needs of the entire family unit need to be addressed.

Therefore, professionals must be flexible and respond to the families' unique needs,

strengths, and cultural values. It has also been conveyed that such professionals should be

trained in a family systems theory so that the most effective services and improvements

can be made within the family unit (Freedman & Capobianco-Boyer, 2000). To

understand how the families cope with challenges of raising a child with a developmental

disability, several researchers have incorporated the Double ABCX Model to explain

stressful situations within the family context (e.g., Bristol, 1987; McCubbin & Patterson,

1983). This model proposed that available support may serve a dual purpose for families:

one, it serves as a safeguard against the challenges and difficulties of raising a child with

an intellectual disability and, two, it aids in the reduction of experienced stress (White &

Hastings, 2004).

The classic ABCX model by Hill (1958) includes how the characteristics of the

stressor event (A), the family's internal crisis-meeting resources (B), and the family's

definition of the stressor (C) influence the prevention or precipitation of a family crisis

(X). The Double ABCX model by McCubbin and Patterson (1983) redefined these

variables, which include other family stressors that make adaptation more difficult (aA),

the social and psychological resources (bB) and coping strategies (BC) that the family

uses in managing potential crisis situations, the meaning the family assigns to the event

(cC), and the range of both positive and negative outcomes possible.

In Bristol's (1987) study, the Double ABCX Model was used as a conceptual

framework for how families of children with ASD cope with stressors. The longitudinal

study consisted of 45 mothers and their children with autism or severe communication

impairments, ages 2 to 10, who were new referrals to the Treatment and Education of

Autistic and Related Communication Handicapped Children (TEACCH) program.

Mothers filled out self-assessments that contained the variables proposed by the Double

ABCX Model. Results of the study showed that elements of the stressor (A, aA), family

resources (B, bB), and family definition of the stressful event (C, cC) significantly predicted all three measures of family adaptation (X). Social support in this study comprised both informal and formal supports. For example, informal social support needs that were perceived being met, along with coping patterns, corresponded to healthier adaptation; informal social support was reported by mothers who perceived having sufficient support from spouses, immediate and extended family, and other parents, and therefore, these mothers were rated as having better family adaptation. In regards to formal support, Bristol points out that while formal support was not a unique predictor of any of the three measures, it is important to keep in mind that parents were evaluated before receiving many of the formal service opportunities, which included the TEACCH program.

Like the Double ABCX model, The Resiliency Model encompasses a family systems perspective for how families deal with stressors (McCubbin, McCubbin, Thompson, & Thompson, 1998, as cited in Taylor-Dyches et al., 2004). In this model, family adjustment is impacted by how the stressor plays into the family's vulnerability, patterns of functioning, resources, appraisal of the stressor, problem-solving, and coping strategies. This, in turn, has an effect on how or whether particular types of social support will be accessed (Taylor-Dyches et al.).

In regards to positive progress within the family system, the goals for the ABCX model are similar to what has been proposed by researchers. For example, Marcus et al. (2005) discussed goals of parent training and other family-based approaches. These goals included aiming to decrease inappropriate behaviors and implement more appropriate child behavior, improving family relationships, increasing family functioning in adaptive

ways, and empowering all family members to make positive changes. Because it is fundamental for the correct techniques to be applied, there is great need to pinpoint the best intervention goals, approaches, and techniques for the child and the family. This may involve a number of various support services in order to meet the needs of child and family.

The Impact of Needs on Parents

Bryson and Smith (1998) proposed that vast improvement has been made over several key areas in recent years. The improvement areas include social services and changes in diagnostic and psychoeducational services. For example, national and international changes have been made within the last ten years that include: a greater fund of knowledge on the underpinnings of autism and other pervasive developmental disorders, such as vaccines and genetic factors; improved classifications in the diagnosis of Asperger's syndrome, reasons for the increasing prevalence rates of autism, Asperger's syndrome, and other pervasive developmental disorders; and the increasing public attention and involvement with ASD (Howlin, 2005).

As previously mentioned, empowerment movements have been made in more recent years for parents and families to take on active roles in their child's treatment (Marcus et al., 2005). First, it is vital to understand how social supports, such as specialized services received from professionals and agencies, relate to the needs of parents. Second, it is imperative for parents receiving these types of services to be assessed on their perceptions of needs (Siklos & Kerns, 2006). Third, it is essential to understand if those needs are being met through programs utilized by families. Fourth, it is crucial to consider how parental needs should be effectively met (Donovan, 1988).

Overall, it is pertinent to understand how the types of needs a family has will ultimately relate to which social supports will be necessary for addressing concerns for the child with ASD.

Relationship of Needs and Social Support

Several studies postulated that families who perceive themselves as having minimal social support systems possess more needs. This suggests the possibility of a relationship between needs and support, given adequate and representative sample sizes (Bailey, Skinner, Correa, et al., 1999; Cassidy et al., 2008; White & Hastings, 2004). However, research on this potential relationship is lacking in regards to characteristics and needs of the ASD population (Cassidy et al.). One reason for this is the complex nature and function of social support, which could be affected by multiple variables such as the severity of the child's disability, the developmental level of the child, or cultural differences within the family structure. Because of such complexities, defining clearer dimensions of social support may be invaluable for families (White & Hastings). In turn, this could lead to families receiving effective services and improving the family unit as a whole. Also, it could help meet the child's unique needs of having ASD, shedding light on the types of social support services that will be used to address those needs (Cassidy et al.).

One study determined whether parental needs were met through a number of questions containing various social supports. Siklos and Kerns (2006) assessed the perceived need for social support of parents of a child with ASD, determining the needs parents felt were most important and if those needs were perceived as being met. The Family Needs Questionnaire (FNQ) was administered to parents of a child with ASD and

Down syndrome, and the items were analyzed based on both child- and parent-centered

needs. Parents of a child with ASD reported that 12 out of 40 *Important* needs were being

met, whereas 14 out of 40 *Important* needs were rated as unmet or partly met. Also from

the results, Siklos and Kerns indicated that parents of children with ASD reported a high

need for consistent therapies for their child, and in addition, they reported wanting

professionals who have an adequate knowledge base of autism. Approximately 93% of

parents of children with ASD reported a lack of adequate financial support for their

child's therapies. The second highest unmet need reported (82%) was the child not

having friends of his or her own (Siklos & Kerns, 2006). The need for a parent's child to

have and make friends alludes to how a specific type of social support might address the

child's social network and social skills. Based on the results, the types of perceived needs

reported were influenced by the types of social supports used by families.

Social Support Defined

Social support has been defined in various ways. One definition of social support

is "information leading the person to believe that he is cared for and loved, valued and

esteemed, and is important in a network of mutual obligation and communication" (Cobb,

1976, p. 300). From a family systems perspective, the network that is referred to in this

definition may include the family structure. In turn, this family structure would serve as

the main type of social support for the child (Cobb). Other researchers, such as Dunst,

Trivette, and Cross (1986) defined social support as "a multidimensional construct that

includes physical and instrumental assistance, attitude transmission, resource and

information sharing, and emotional and psychological support" (p. 403). Some

researchers indicated that social support involved many and various dimensions (White &

Hastings, 2004). It appears that the definition of social support encompasses numerous features. Therefore, research suggests that it is vital to discuss social support in a family context (e.g., Cobb, 1976; Freedman & Capobianco-Boyer, 2000), while keeping in mind that many features comprise the definition of social support (Dunst et al., 1986; White & Hastings, 2004).

Examples of social support might include support from a spouse, the extended family, friends, having free time to engage in recreational activities, outreach from community programs, professional help, and services and programs that are accessible to families who have a child with a disability (Siklos & Kerns, 2006). These examples encompass both formal and informal social supports, as briefly discussed earlier (Bristol, 1987). To further understand the relevancy of formal and informal supports, the following section will elaborate on how researchers define different forms of social support.

Types of Social Support

Several studies differentiate social support into formal and informal supports. Formal social support has been defined as "assistance that is social, psychological, physical, or financial and is provided either for free or in exchange for a fee though an organized group or agency" (Bristol & Schopler, 1983, as cited in Boyd, 2002, p. 212). These types of formal social support include services from professionals such as therapists, psychologists, etc., who work in social service settings. Formal supports might also include structured organizations such as social clubs or churches (Boyd, 2002). Informal support was defined as "a network that may include the immediate and extended family, friends, neighbors, and other parents of children with disabilities" (Bristol &

Schopler, as cited in Boyd, 2002, p. 212). Other examples of informal supports include other individuals close to the family who provide help and assistance (Boyd).

Freedman and Capobianco-Boyer (2000) specifically looked at social support through a "family supports" lens in the context of developmental disabilities. They defined social support as "services, resources, and other types of assistance that enable individuals with developmental disabilities of any age to live with their families and to be welcomed, contributing members of their communities" (p. 59). In their focus group analysis, a number of supports reported by parents emerged. These types of family supports included: respite services, home health care, family education and training, family counseling, support groups and case management. These family supports were found to have directly benefitted parents and children on educational, emotional, and financial levels (Freedman & Capobianco-Boyer).

In another study, Cassidy et al. (2008) asked parents about the social support they received from family and friends. While the majority of parents reported that support most commonly came from their own family and less from friends, neighbors, and church members, 33% of parents reported that no support was given from any of these sources. With professional help, the most common types of professionals that parents had come into contact with and found helpful were speech and language therapists. However, other professionals such as health visitors, pediatricians, educational psychologists, social workers, and home teachers were also reported.

Early intervention in an educational setting often promotes social support through inclusion of mainstream education of children with disabilities alongside same-aged typically developing children. Integration services might also be included to meet the

child's unique needs, which may include speech therapy, occupational therapy, and

applied behavioral analysis techniques. The promotion of parents being educated and

trained in information on ASD is also important in order to address their skills to help

increase their child's development (Baker-Ericzén et al., 2005).

Social Support Needs Commonly Reported by Parents

One need that has arisen from many parents is for health professionals to have

more awareness of developmental problems that occur in children. In their study, Hutton

and Caron (2005) interviewed 21 families with children who were diagnosed with ASD.

The types of services accessed and the outcomes of those services were asked through

interviews to determine what services were utilized by all parents. Based on the

information from the interviews, when parents were asked about the types of intervention

services that were being implemented, the types of services that showed to be most

effective for their child's development were: speech therapy, in-home behavior therapy,

occupational therapy, applied behavior analysis, and physical therapy. These services

were also reported as common types of social supports used by parents, along with:

developmental therapy, respite care, and one-on-one classroom support.

These preceding types of social supports were also similar to social supports

found by Freedman and Capobianco-Boyer (2000) in a study that assessed a number of

unmet needs by parents. The unmet needs reported were: behavioral, physical, medical,

and speech services. Included with the previously mentioned social supports, a variety of

other notable social supports emerged from parent reports in Hutton and Caron's (2005)

study. These commonly reported social supports from parents included: counseling,

music therapy, play therapy, neuro-feedback therapy, social skills training, life-skills

training, and group home placement for the child. Simply from these studies, a wide range of social supports were reported by parents who have a child with ASD. This suggests there are many needs within the family requiring services when a child has been diagnosed with ASD.

As previously revealed, simply raising a child with ASD can lead to negative effects within the family and can impact the types of needs of the family. For example, in Hutton and Caron's (2005) study, when asked about how their child's developmental disorder has affected the family, parents responded with: little or no time for fun and family vacations, a need to plan ahead, stress on the marriage, little free time for self, their child not able to have friends, an impact on the mother's career, and safety concerns. These reports address the personal needs of the parent that should be taken into consideration when assessing the types of social supports that would target these needs.

Even with the positive benefits of therapy for the child, parents' needs may still remain unmet. For example, Freedman and Capobianco-Boyer (2000) revealed that parents often reported having problems when their child's therapies were interrupted due to summer months and school breaks. Other unmet needs parents reported for their children with a developmental disorder are the lack of social and recreational opportunities, which included minimal weekend activities and limited opportunities to make friendships.

When responding to how their other children's needs were being met in regard to the problems faced with the sibling who has autism, parents reported that they took measures to educate their other children about ASD, spent extra time alone with them, involved them in therapy, and separated them when they were fearful. In receiving

support from other family members, 90% of parents responded that their own siblings were supportive in how the diagnosis of their child was handled. However, almost half of the grandparents were reported as not being accepting or understanding of the child's diagnosis (Hutton & Caron, 2005).

Needs that were reported as not being met by parents were: the need to adapt the family's schedules and to have more structure in the home. The lack of support groups in the families' regional area suggested the need for more availability of such groups so that parents can network and obtain the knowledge necessary to make positive steps for their given situations. Approximately half of the parents reported they did not feel respected by professionals, which included doctors and therapists. For parents whose child received a late or inaccurate diagnosis, the consequences may have detrimental impact because information regarding the perceived needs of parents was overlooked (Hutton & Caron, 2005). In Freedman and Capobianco-Boyer's (2000) study, unmet needs included socialization opportunities and community inclusion, coordination of services, and education and advocacy.

In a study by Kohler (1999), various intervention services were incorporated to assess the types of services many families of children with ASD received. Results showed that families use a variety of agencies to obtain the services required to meet their families' needs, similar to other studies' findings (e.g., Freedman & Capobianco-Boyer, 2000). From the study, the majority of families obtained, on average, six different services from four or more agencies. Also, approximately seven or more professionals assisted the families, and the families were spending around 37 hours a week for interventions with the child (Kohler).

How Social Support is Influenced by the Diagnosis

Diagnosing a child with ASD at an early age poses greater benefits compared to a child who is diagnosed later on in life (Chawarska & Volkmar, 2005). This is because early intervention shows to be a vital component for receiving the best and most effective services (Attwood, 2007; Chawarska & Volkmar). A movement toward early intervention has been suggested so that the most naturalistic educational experiences for both child and parent can be established (Baker-Ericzén et al., 2005). Therefore, assessing the perceived needs of parents to be able to guide them to specialists earlier on is vital, not only for the child but for the family as well.

While early diagnosis is vital, parents still may report a number of difficulties with their child's diagnosis of ASD. For example, in a study by Hutton and Caron (2005), parents reported feeling sad, frustrated, and devastated, this may also be playing into their increased levels of stress, along with the behavioral problems their child displays. As a result, parents might turn to counseling services or other services to help them deal with their emotional distress. It was common for most families to be assigned a case manager after the diagnosis had been made so that the best intervention services could be put in place (Hutton & Caron).

For families from various cultures who raise a child with ASD, it is also important for professionals to understand how parents perceive their needs for social support, along with the types of support being accessed. In this way, the best treatments will be available and there will be an increased understanding of multicultural children with ASD (Taylor-Dyches et al., 2004).

Difficulties in Accessing Social Support

Bryson and Smith (1998) point out that it may be difficult for some families to obtain services based on some technicality, such as having an above average IQ, even though a great degree of "autism-related behavioral impairment" remains (p. 100). These individuals might not be viewed as having problems because their functioning does not appear impaired. However, the unnoticed problems have actually caused difficulties in accessing services. Social support services have actually been denied to some children with ASD who have an average to above average IQ. For example, having an above average IQ may not pose as many problems compared to an individual having a very low IQ. A low IQ is typically characterized with the child requiring more dependency and constant supervision from others. Therefore, the above average IQ is restrictive and would not allow eligibility for the higher-functioning child (Bryson & Smith).

With the IQ example, it is crucial to note that not only lower to low-functioning children with ASD encounter difficulties. Another example highlights the idea that there are comorbid features in individuals with ASD. While high-functioning individuals, including those with Asperger's syndrome, often appear to be free of any impairment, anxiety and depression are common comorbid features that arise in adolescence and young adulthood. This may be due to the difficulties of establishing significant relations with others, making friends, and having romantic partners (Klin et al., 2005). Other barriers that have hindered many families from receiving services may be a lack of information and outreach, tedious administrative regulations, and inflexible services (Freedman & Capobianco-Boyer, 2000).

Lack of Social Support Research

Boyd (2002) addressed the notion that there is a lack of research in how parents of children with ASD use social supports. To address this lack of research, it is thought that future studies must look at the types of social support that are most effective for and available to parents. Siklos and Kerns (2006) also proposed that there is a lack of research in this area, indicating that few studies have looked at parents' perceptions of needs, as well as, needs that are met and unmet. Cassidy et al. (2008) point out that children are being diagnosed at younger ages, which is expanding the population of families who will require services for their children with ASD. As mentioned, researchers have noted that there is little known about families' needs for support (Boyd, 2002; Siklos & Kerns, 2006). To understand the need for social support within families of a child with ASD, the specific needs of the particular client group must be established. Therefore, social support services must be tailored to the unique needs of the children and of their families (Cassidy et al., 2008).

Dimensions of Social Support and Parental Perceptions

To adequately assess the needs of parents, it is imperative for researchers to determine the multiple dimensions of support that are serving as effective and positive availabilities for families who have a child with ASD (Shin, 2002). Other findings from research suggested similar propositions. For example, White and Hastings' (2004) findings showed that social support is usually studied in the context of family functioning rather than by itself and that social support is multidimensional. This means that there are various types of social support used by parents and families, including receiving social support from the extended family, friends, religious groups, statutory services, and

voluntary services. The types of dimensions in White and Hastings' study included various social support dimensions, such as availability, helpfulness, and whether the source was a formal or informal support. In regards to formal and informal supports for the study, the number of (a) informal supports and (b) helpfulness of informal supports from the Family Support Scale (FSS), (c) emotional and (d) practical support functions, which were derived by summing the ratings of the Support Function Scale, and (e) the Professional Services Support Scale (PSSS) total score, were included. Specifically, White and Hastings examined dimensions of informal supports, including sources such as a spouse, the extended family, and friends and how these related to social support. While there were no significant relations between the types of social support dimensions, findings showed that the informal supports were reported as being more helpful. The informal supports were associated with more practical support and a higher number of informal support services.

White and Hastings (2004) also suggest that the types of support being used might also differ, meaning that other dimensions might be used for further research studies. For example, one study examined the lack of support by formal agencies (Sanders & Morgan, 1997), whereas another study looked at the lack of support from spouses (Konstantareas & Homatidis, 1989). From other findings, Factor et al., (1990) attest that other factors of social support should also be considered, such as the family perceptions, including parental guilt or feelings about leaving the child with strangers, and how respite care is interpreted. This conveys the need to assess parental perceptions within the family system, which has shown to be an area that is currently lacking in research (e.g., Siklos & Kerns, 2006).

Social Support on Parental Stress

According to Cobb (1976), social support aids in coping with crisis and adaption to change. This idea can be applied to a family systems perspective since it is similar to the Double ABCX Model with family coping to specific stressors (Bristol, 1987). Some research studies demonstrated an inverse relationship between stress and social support for parents of a child with ASD. For example, when mothers' perceived social supports as being more available, they reported significantly less stress than those who did not perceive social support as being as available (e.g., Gill & Harris, 1991). The perceived availability of supports also applies to parents of children with disabilities. For example, one finding illustrated that there is a relationship between both mothers' and fathers' perceived stress levels and the support received from relatives and friends; this relationship yielded a negative correlation (Hadadian, 1994).

Another finding from a study found that lower parental stress was related to parents who had a higher level of understanding about their child's problem behaviors and had also received assistance by family members (Sharpley & Bitsika, 1997). Similar research demonstrated that as the higher number of perceived and experienced needs of mothers increased, a positive family relationship was established. In turn, there was less stress and greater well-being within the family system (Dyson, 1997; White & Hastings, 2004). Therefore, parents who reported using more social supports and more helpful social supports also reported higher levels of well-being than for parents who reported less (White & Hastings).

Many researchers suggest that families experience high levels of stress in raising a child with ASD and that these levels of stress are significantly higher compared to

parents of typically developing children (Mancil et al., in press). In turn, there may be a high need for social support because stress levels are so severe. Therefore, this may be why families who experience high levels of stress in raising a child with ASD may seek out more social support than those who have lower levels of stress (Taylor-Dyches et al., 2004). The idea that social support can help decease parental stress may be due to "perceived expertise" of the family member who offers respite care for the parents (Sharpley & Bitsika, 1997). This type of respite care includes emotional and social support that is made through members of the immediate family, such as grandparents, aunts, uncles, and siblings. Receiving social support from these types of individuals suggests a high degree of family support. Family social support from immediate family members has also been documented. For example, results of the supports used from the parents sampled in a study by Sharpley and Bitsika (1997) showed that 61.5% of parents reported having other family members help in the assistance of child care. However, this finding also suggests that there may be a higher need for family support within a number of families due to 38.5% of parents sampled who did not receive this type of support.

Tunali and Power (2002) found that social support from the extended family can be crucial in meeting the social and affiliative needs of parents. This finding was similar to an implication discussed by Sharpley and Bitsika (1997), which suggests that parents may value social support the most when assistance is provided by immediate family members. Also, the assistance to the family is most effective when it includes an understanding or knowledge of the child's diagnosis of ASD. Other sources of stress that are linked to social support included: the child's educational placement, especially for inclusion in mainstream classrooms; difficulty obtaining babysitters and respite care

providers; and managing daily life of the child with a developmental disability (Dyson, 1997).

To summarize the literature, children with ASD present a variety of behaviors that often become problematic within the family context. These problems can affect both the needs of parents and the types of social supports that address those needs. The following are commonly reported needs and the associated social supports that typically correspond to the needs: language issues that are addressed in speech therapy, medical conditions requiring services such as occupational or neurological testing, reducing inappropriate behaviors through counseling and therapies, improving socialization through social skills training, and addressing educational concerns within the school or academic setting for the child with ASD. While these are only examples of reported needs, they are needs that arise frequently within families of the ASD population.

For families of children with ASD who may have a variety of needs, a number of reasons exist for why the needs are not met. Difficulties in accessing services based on diagnosis (Bryson & Smith, 1998) or lack of information (Freedman & Capobianco-Boyer, 2000) are some of the reasons for why needs remain unmet. From a family systems perspective, involving the entire family as a source of social support has been suggested throughout the literature (Freedman & Capobianco-Boyer). Social support contains a variety of definitions, but the select research on ASD focuses on the definition in relation to the family unit. For example, social support may include any help from a spouse, the extended family, or friends (Siklos & Kerns, 2006).

While some of the commonly reported needs of parents were previously outlined, little research actually exists on families' overall need for support. In other words, the

existing research suggests that there is an indication of reported needs; however, studies have not been able to conclusively determine *all* the needs that exist within the family as they relate to ASD. The idea that each family system is so complex and unique also makes sense for why it has been difficult to establish every social support need (Becker-Cottrill et al., 2003). Because reported needs encompass only a small piece of the puzzle, using multiple dimensions of social support has been suggested (Factor et al., 1990; Shin, 2002; White & Hastings, 2004). By using multiple dimensions, it is hoped that a better idea of perceived parent needs can be established.

The family systems perspective also addresses how families cope with stressors, specifically those stressors that arise as a result of the child having ASD. On that note, stress is a factor that has been widely documented throughout research on ASD, supporting the notion that clinically high levels of stress exist in parents of children with the diagnosis (Mancil et al., in press). In regards to the relationship between stress and social support, several researchers suggest that there is a negative correlation between the variables. In other words, the higher the stress level, the lower social support level should be. If stress is low, social support is usually high. An example of this relationship comes from a study by Gill and Harris (1991), in which mothers reported significantly lower stress levels when supports were available to them compared to those who did not perceive support as available. Essentially, when social support is perceived as available to parents, stress is not as high compared to when social support is viewed as unavailable. Based on a review of the literature, the present study will focus on various domains of social support in assessing both the needs of parents and the stress levels reported by the

parents. The following section describes the present study and discusses in more detail the types of social support domains.

The Present Study

This study was approved by the Western Kentucky University Human Subjects Review Board (Appendix A). In the current study, social support to families will be looked at through a variety of formal and informal supports. The domains used in the current study will not distinguish whether social support needs are specifically formal or informal. The types of supports are separated into seven different social support domains: (1) Family, (2) Medical, (3) Educational Needs of Parent, (4) Educational Needs of Child, (5) Social Services, (6) Personal, and (7) Child's Social Network. Characteristics of these domains are contained in research literature (e.g., Boyd, 2002; Freedman & Boyer, 2000). The domains target several key social support needs areas for families of children with ASD. It is likely there are other important domain areas not addressed in the current study. The idea to use the seven domains for the current study stemmed from similar findings in previous research. For example, a factor analytic study of the original Family Needs Questionnaire was conducted by Serio, Krueutzer, and Witol (1997). The analysis yielded six distinct factors, which included: health information, emotional support, instrumental support, professional support, community support network, and involvement with care. By incorporating the concept of various social support factors into the current study, this led to the creation of seven similar social support domains. These domains were derived from statements found in the modified version of The Family Needs Questionnaire (Siklos & Kerns, 2006). Through a number modifications for this

study and additions of items (Appendix B), the finalized questionnaire contained the seven domains that were listed above.

Because a review of the literature did not address these specific domains with an ASD population in the context of social support as a whole, the current study will attempt to make connections between findings that have been found in previous research. One goal of the study is to determine which of the seven social support domains is reported as most important as well as related to lower levels of stress in parents. A second goal is to understand the general needs that are reported as important but that are not currently being met.

Hypotheses

For the purposes of this study, the hypotheses focus on the perceived social support needs of parents and how these needs relate to their perceived stress levels. Similar to Siklos and Kern's (2006) study, the current study will examine the perceived social support needs of parents that are most important and whether these needs are being met. It is hypothesized that:

Hypothesis 1: As parental stress increases, met social support needs will decrease; a negative relationship between parental stress and met social support needs is predicted.

Hypothesis 2: As parental stress increases, unmet, important social support needs will increase; a positive relationship between parental stress and unmet, important social support needs is predicted.

Method

Participants

Participants consisted of 35 mothers who had a child, ranging from 2 to 12 years

of age, with a diagnosis of ASD. Participants were recruited from the Kelly Autism

Program at Western Kentucky University in Bowling Green, Kentucky. Parents were also

recruited through several other autism social support groups located in the South Central

Kentucky region. The majority of participants were married ($n = 30$), three were

divorced, and two were single. Highest educational level completed in years of

participants ranged from 2 to 23 years, with an average level of 14 ($M = 14.46$, $SD =$

3.94). The gross annual salary of participants ranged from less than $25,000 to over

$100,000; seven participants reported less than $25,000 as their gross annual salary, 17

participants reported between $25,000 to $50,000, four participants reported between

$75,000 to $100,000, two reported over $100,000, and one participant did not respond.

Participants most commonly reported having a husband who served as a support

within the family ($n = 32$). An outside family member who served as a support for the

family was the second most common social support reported ($n = 26$). Of the six social

support members queried, 54.3% of participants used three members of support or less,

and 45.7% of participants used at least four members of support. Household size ranged

from 2 to 6 members, with an average size of three ($M = 3.83$, $SD = .86$). The reported

number of extended family members living within the household was minimal, with a

range from zero to one members and an average number of zero members ($M = .03$, $SD =$

.17). Regarding the number of other children in the family with a diagnosis of ASD or

with special needs, nine participants reported having at least one other child meeting

either of these criteria; from these nine participants, five parents reported having two children with either ASD or special needs, and four parents reported having one child with either ASD or special needs.

The age the child was diagnosed with ASD ranged from 12 months to 10 years of age, with an average age of 3 years ($M = 3.59$, $SD = 2.21$); the most frequent age of diagnosis was two years. Psychologists were most commonly reported as the professional who made the diagnosis of ASD for the child ($n = 19$), while "other professional" was reported second highest ($n = 7$) and medical professional ($n = 5$) was third highest. The current ages of children ranged from 2 to 12 years of age, with an average age of 7 ($M = 7.10$, $SD = 2.73$). The age in which the parent first became concerned about his son or daughter ranged from 3 months to 6 years, with an average age of 1 year ($M = 1.77$, $SD = 1.04$). A summary of these results can be found in Table 1 below.

Table 1

Demographics Descriptive Statistics (N = 35)

Gender of Parent	
Male	0 (0.0%)
Female	35 (100.0%)
Marital Status	
Married	30 (85.7%)
Single	2 (5.7%)
Separated	0 (0.0%)
Divorced	3 (8.6%)

Household Size

    Range   2 - 6 members

    Mean   3.83

    SD   .86

Highest Level of Education (in years)

    Range   2 - 23 years

    Mean   14.46

    S D   3.94

Gross Annual Salary Income

    Below $25,000   7 (20.5%)

    $25-50,000   17 (50.0%)

    $50-75,000   4 (11.8%)

    $75-100,000   4 (11.8%)

    Over $100,000   2 (6.0%)

Child Receiving Free/Reduced Lunch

    Yes   12 (34.3%)

    No   23 (65.7%)

Extended Family Members Currently Living at Home

    Range   0 - 1 members

    0 members   34 (97.1%)

    1 member   1 (.03%)

Other Children in Family with a Diagnosis of autism/Special Needs

Yes	9 (25.7%)
No	26 (74.3%)

Additional Number of Children with a Diagnosis of autism/Special Needs

Range	0 - 2 children
0 children	26 (74.3%)
1 child	4 (11.4%)
2 children	5 (14.3%)

Age that Child was Diagnosed with autism (in years)

Range	1 - 10 years
Mean	3.59
SD	2.20

Professional who Made the Diagnosis

Medical Professional	5 (14.3%)
Psychologist	19 (54.3%)
Psychiatrist	3 (8.6%)
School/Educational Professional	1 (2.9%)
Other	7 (20.0%)

Child's Current Age

Range	2 - 12 years
Mean	7.10
S D	2.73

Age of Child which Parent First Became Concerned (in years)

Range	3 months to 6 years
Mean	1.78
S D	1.04

Instruments

    A packet containing the Parenting Stress Index-Short Form (PSI-SF), the Life Stress (LS) Scale from the Parenting Stress Index (PSI), the Behavior Assessment System for Children, 2nd Edition (BASC-2), the Family Needs Questionnaire (FNQ), and a demographics sheet were handed out to parents who were interested in participating. The following paragraphs describe each instrument in detail.

    Parenting Stress Index-Short Form. The Parenting Stress Index (PSI) was developed by Abidin (1995) to identify parents who were in need of guidance and support, to identity dysfunctional parent-child relationships, and to identify children who were at risk for emotional and behavioral developmental problems. For the purposes of this study, the shorter version of the PSI was used. The Parenting Stress Index—Short Form (PSI-SF) is a multiple choice and Likert item questionnaire that consists of 36 self-report items chosen from the 101 items of the parent and child domains of the regular PSI. The PSI-SF replication produced the same factor structure, similar factor loading weights, the three-factor interpretation, and the total stress index score. The short form's factors consist of maternal esteem, parent-interaction, and child self-regulation. Alpha reliabilities for the three scales are .87, .80, and .85 respectively, and .91 for the 36-item total stress score. The total stress score ranges from 36 to 180, and the overall amount of

parenting stress is experienced in the parenting role as a function of three scales. These three scales correspond to three factors, which include Difficult Child (DC), Parental Distress (PD), and Parent-Child Dysfunctional Interaction (P-CDI).

A high correlation between the PSI-SF and PSI ($r =.94$), as well as between the PD and Parent Domain scores ($r = .92$), and between the DC and Child Domain scores ($r = .87$) was found. For the PSI-SF, scores are considered clinically elevated at or above the 90th percentile (raw score ≥ 90), which suggest significant parenting stress associated with the parent-child relationship. Norms for the PSI-SF are based on 800 mothers of children from a well-child clinic in Virginia (Abidin, 1995).

The Life Stress (LS) Scale is a measure used to serve as a potential controlled variable that might account for elevated stress levels of the PSI-SF. Typically the LS scale is used in addition to the PSI when the PSI score is a raw score of 260 or greater (above 80th percentile). The LS Scale is an optional and normed scale on the original version of the PSI. The scale measures common stressful situation circumstances that are often beyond the control of parents (e.g., the loss of a job, death of a relative). The purpose of the scale is to identify the amount of current stress that is being experienced outside of the parent-child relationship. The PSI-SF raw score determines stress based on the parent-child relationship and not other life stress circumstances that may exist. A high LS score contributes to the total stress being experienced by a parent (Abidin, 1995). Each item on the LS scale is assigned a given weight, suggesting that stressors differ in the amount of contribution they have on overall stress. A clinically elevated score is raw score of 17 or above (Abidin). This score takes into account the weights for each item.

Therefore, a low LS raw score has much less contribution and would not significantly interfere with the total stress score.

  Behavior Assessment System for Children, Second Edition. The Behavior Assessment System for Children, Second Edition (BASC-2, Reynolds & Kamphaus, 2004) was given to also account as a contributor for the high stress levels of the PSI-SF scores. The BASC-2 is considered a multimethod and multidimensional system that evaluates self-perceptions of child behaviors. The age range of the BASC-2 is 2 to 21 years of age. The tool is considered multidimensional because it views traits of the child on a continuum of severity rather than suggesting if the child has the disorder or not. The parent rating scales measure multiple dimensions, or traits. These dimensions include: personality and behavioral problems; emotional disturbances; and positive traits. The tool is considered a multimethod assessment because the BASC-2 includes a Structural Developmental History and Student Observation System (Reynolds & Kamphaus, 2004). For the purposes of the current study, only the parent report scales were used to evaluate child behavior. The scores from the BASC-2 served as a potential controlled variable for the partial correlation analysis between the PSI-SF scores and scores from the FNQ.

  The current study was interested in the Adaptive Skills Composite score because many characteristics within this composite directly relate to children with ASD. The Adaptive Skills Composite scores were used to account for the contribution of child problems possibly related to parental stress reported from the PSI-SF scores. Some characteristics of the composite include: emotional expression and control; daily living skills; communication skills; and other adaptive skills.

For the Parent Rating Scales, the reliabilities for composite scores are very high; the Adaptive Skills reliability is in the low to middle .90s. For test-retest reliability, the composite scales are high, typically in the low .80s to low .90s (Reynolds & Kamphaus, 2004). With scoring, there is an option of using either a General or Clinical norm sample to obtain the T scores. Scores were calculated using the General scale for each age bracket, which included preschool (age 2-5), child (age 6-11), and adolescent (age 12-21) ages. The Clinical scale was unnecessary to use because the children had already been diagnosed with ASD. Additionally, there was an option to score the Adaptive Skills Composite based on gender. However, because the study was not interested in gender differences among the children, the Combined scale was chosen to obtain T scores that served as the potential controlled variable in the partial correlation analysis.

Family Needs Questionnaire. After completing the PSI-SF, parents completed the Family Needs Questionnaire (FNQ). A tailored version of the FNQ for ASD and Down Syndrome (DS) was developed by Siklos and Kerns (2006), which was modeled on the original FNQ by Kreutzer, Complair, and Waaland (1988) and a modified version by Waaland, Burns, and Cockrell (1993). The original FNQ targeted an adult population of Traumatic Brain Injury (TBI), while the modified version pertained to children with TBI. Specifically, the research of Kreutzer et al. focused on assessing family needs of adults with Traumatic Brain Injury (TBI). The questionnaire looked at the family needs reported by parents, and it focused on determining whether the needs were being met for parents and adult family members with TBI. Siklos and Kerns point out that many social support needs are similar between TBI and ASD groups in regards to the impairment in social functioning and pervasive nature observed in these populations.

By incorporating items from Waaland et al.'s (1993) questionnaire, Siklos and Kerns (2006) developed a modified version of the FNQ to assess for commonly reported social support needs by parents of children with ASD or Down syndrome (DS). In order to modify the original questionnaire, Siklos and Kerns tailored statements geared toward families who have a child with ASD or DS. Essentially, the modified FNQ was structured to assess for the perceived social support needs of parents with have a child with ASD or DS instead of the TBI population. This made the statements of the questionnaire much different than from those on the original FNQ.

The statements used in the current study were based on Siklos and Kerns' needs statements, with revisions on a number of those statements, as well as additional statements on the questionnaire. However, the questions were changed to specifically assess for types of social support needs reported by parents of children strictly with ASD. These types of needs are what have been commonly reported by parents within this population, as previous research found.

In order to finalize the statements for the questionnaire used in the study, the revised FNQ was given to a group of ten psychology graduate students at Western Kentucky University who were asked to rate each statement into the domain they perceived it fit best. Included with the statements, an operational definition was given for each of the seven domains so that the graduate students understood the features of the domains (see Appendix C). The definitions were based on existing research, which suggested that social support needs are comprised of numerous variables (Boyd, 2002) and that using multiple dimensions may be beneficial for future research studies (Shin, 2002; White & Hastings, 2004).

After compiling the responses and comparing each to a set domain from the graduate students, a percent agreement analysis was run and each statement was grouped into the appropriate domain. Of the 67 questions on the questionnaire, 6 items were grouped into the Family domain, 12 into the Medical domain, 14 into the Social services domain, 8 into the Educational needs of parent domain, 13 into the Personal domain, 7 into the Educational needs of the child domain, and 7 into the Child's social network domain. The percent agreement for each item was averaged for each domain and yielded these percentages: Family domain agreement = 93.30%, Medical domain agreement = 94.61%, Social services domain agreement = 93.57%, Educational needs of the parent domain agreement = 92.50%, Personal domain agreement = 82.30%, Educational needs of the child domain agreement = 97.14%, and Child's social network domain agreement = 97.14%. A percentage at or above 80% reflects good percentage agreement among raters (R. Brown, personal communication, September 16, 2008). An internal consistency reliability analysis indicated that the 67 questionnaire items had high internal consistency, $\alpha = .95$. Due to listwise deletion based on all variables in the procedure, only 30 participants' responses were used in the reliability analysis.

Demographics questionnaire. The demographics sheet was a 14-item questionnaire that included information about the parent's gender, gross annual income, socioeconomic status, education level in years, and marital status. Additionally, questions were asked including: household size, the types of members who serve as support for the family, and any other children within the family requiring special needs. The demographics sheet also asked for information about the child with ASD, including the age of diagnosis, the individual who made the diagnosis (i.e., psychologist, school faculty

or professional, medical professional), the age of the child in which the parent was first concerned, the child's current age in years, and the number of blood-related siblings to the child.

Research Design

A bivariate correlational design was used to test hypotheses 1 and 2. For exploratory purposes, bivariate correlations were conducted to determine the relationship of each domain to the reported parental stress. The study explored types of social support domains, so it was essential for each domain to be analyzed and compared separately to the total stress score. This was done to determine which social support domains were the related to lower stress levels and the domains that were related to most importance. The total stress index raw scores from the PSI-SF and the derived raw scores from the FNQ were correlated to test Hypotheses 1 and 2.

Procedure

Parents were asked to complete an Informed Consent Form, a demographics sheet, and four instrument measures: the PSI-SF, the LS Scale from the PSI, the BASC-2, and the FNQ (see Appendix D). All pieces of information in the packet were the same for parents who were given the packet in person and for parents who were mailed the packet after telephone contact. Forty-five parents were given packets, and of this number, 35 parents returned the packets. Fourteen parents were given the packet in person, and 31 parents were contacted by phone and, thereafter, were mailed the packets. Prior to completing the demographics sheet and the two measures, instructions were given to the parents, which included an explanation about the study, the benefits of them helping and being incorporated into the study, the informed consent procedure, and any questions

they had about the study were addressed or clarified either in-person or through telephone.

To ensure confidentiality, the only piece of identifying information was the informed consent page. The instructions took approximately 5 minutes for parents to read. Next, they filled out the PSI-SF and LS scale, which took approximately 10 minutes to complete. Next, they completed the BASC-2, which took approximately 10 minutes to complete. Following this, parents completed the FNQ, which took approximately 15 minutes to complete. Last, parents filled out a demographics sheet, which took approximately 5 minutes to complete. The total time to complete all necessary forms was approximately 35 to 45 minutes. This estimation was determined by asking several of the parents after their completion of the packet. Any questions that arose during the procedure were addressed by contacting the researcher. After completion of the measures, parents were given a debriefing sheet that was presented as the last page of the packet materials. After participants finished with the forms in each packet, the packets were mailed back to the researcher.

Results

A bivariate correlational study procedure was conducted to test Hypotheses 1 and 2. Bivariate correlations were run because prior analyses determined there was no need for controlled variables. A partial correlation was originally proposed to test the hypotheses. This was proposed to account for the potential contribution of both the Life Stress (LS) score and Adaptive Skills Composite score (BASC-2) on the PSI-SF score and FNQ score. However, there was little to no correlation between the Adaptive Skills Composite score ($M = 29.91$, $SD = 6.70$) and the FNQ scores for either Hypothesis 1 ($r = .05$) or Hypothesis 2 ($r = -.20$). Therefore, the Adaptive Skills Composite score was not used in the analyses. The LS scores were quite low among participants, with a range from 0 to 5 life stressor items that were met within the last 12 months ($M = 1.57$, $SD = 1.33$). When the scores were assigned their given weights, only one participant had a weighted raw score of 17 or above. A raw score of 17 or higher on the LS scale suggested significant life stress contribution on the overall parenting stress of the PSI-SF. With only one participant meeting the clinically elevated cutoff, this suggested very little contribution of the current life stressors to the PSI-SF, and therefore, the LS score was not used in the analyses.

With regard to Hypothesis 2 and the exploratory analyses, responses rated either as "important" or "very important" were grouped together and classified as "important." The terminology for importance should be considered as such from this point on with the reported results. An alpha level of .05 or less was used to determine significance for all analyses.

Results for Hypothesis 1

A Pearson Correlation Coefficient was calculated for the variables, parental stress ($M = 101.29$, $SD = 23.43$) and met social support needs ($M = 34.00$, $SD = 14.44$). The results are displayed in Table 2. Results showed that there was support for Hypothesis 1, which stated that as parental stress increases, met social support needs will decrease. Due to pairwise deletions of data, only 34 participants were used in the following analysis. Findings in the table indicate that parental stress was statistically and negatively significantly correlated with the sum of social support needs met ($r = -.58$, $p < .001$). This result indicates a moderately strong negative relationship between parental stress and met social support needs.

Results for Hypothesis 2

A Pearson Correlation Coefficient was calculated among the variables, parental stress ($M = 101.29$, $SD = 23.43$) and unmet, important social support needs ($M = 25.24$, $SD = 14.17$). The results are displayed in Table 2. Due to pairwise deletion of data, only 33 participants were used in the following analysis. Results showed that there was support for Hypothesis 2, which stated that as parental stress increases, unmet, important social support needs will increase. The findings indicate that parental stress was positively and statistically significantly correlated with the sum of unmet social support needs that were reported either important or very important ($r = .46$, $p < .01$). This indicates a moderately strong, positive relationship between higher reported parental stress and unmet, important social support needs. Therefore, both hypotheses were supported by this research.

Table 2

Correlations between Parenting Stress Index and Met and Unmet Social Support

Needs

Parenting Stress Index	Correlation	p
Sum of Needs Met (*n* = 34)	-.58**	.000
Sum of Unmet, Important Needs (*n* = 33)	.46*	.007

p < . 01. **p* < .001.

Exploratory Analyses for Social Support Domains

Bivariate correlations were conducted between the parental stress score and each

of the seven domains created from the FNQ. This was done for exploratory purposes to

determine whether there was a relationship between the number of met social support

needs and parental stress. The following domains provide the descriptive statistics for

met social support needs: the Family domain (*M* = 3.50, *SD* = 1.78), the Medical domain

(*M* = 5.90, *SD* = 4.12), the Educational Needs of the Parent domain (*M* = 5.50, *SD* =

3.68), the Educational Needs of the Child domain (*M* = 4.56, *SD* = 2.20), the Social

Services domain (*M* = 6.43, *SD* = 4.37), the Personal domain (*M* = 5.10, *SD* = 1.42), and

the Child's Social Network domain (*M* = 2.77, *SD* = 2.25). Results showed that

correlation coefficient values ranged from minimal to moderate strength, with four

domains each reaching a significant negative relationship with parental stress, at either

the .05, .01, or .001 level. The relationship of parental stress to each of the domains

included: the Family domain (*n* = 34, *r* = -.60, *p* < .001), the Educational Needs of the

Child domain (*n* =32, *r* = -.41, *p* < .05), the Social Services domain (*n* = 28, *r* = -.64, *p* <

.001), and the Personal domain ($n = 29$, $r = -.49$, $p < .01$). Due to missing pairwise data, the number of participants used in the exploratory analyses varied. A table of these results can be found in Appendix E.

Bivariate correlations were also run to determine the relationship between unmet, important social support needs and parental stress. The following domains provide descriptive statistics for importance and if the need was unmet: the Family domain ($M = 2.60$, $SD = 1.50$), the Medical domain ($M = 6.11$, $SD = 3.71$), the Educational Needs of the Parent domain ($M = 5.65$, $SD = 2.98$), the Educational Needs of the Child domain ($M = 3.81$, $SD = 1.86$), the Social Services domain ($M = 5.33$, $SD = 3.26$), the Personal domain ($M = 1.95$, $SD = 1.17$), and the Child's Social Network domain ($M = 3.97$, $SD = 1.97$). Results showed that correlation coefficient values ranged from minimal to moderate strength, with two domains reaching a significant positive relationship with parental stress at the .05 level: The Educational Needs of the Child Domain ($n = 30$, $r = .41$, $p < .05$) and the Personal Domain ($n = 21$, $r = .48$, $p < .05$). A table of these results can be found in Appendix E. For all other correlation values, the number of participants varied for each domain due to pairwise deletion.

Discussion

A base of research has yet to address the various perceptions of social support needs for families of children with ASD. The current study attempted to assess a number of parent perceptions through a variety of social support needs. These social support needs comprised seven distinct domains that are commonly found in families, specifically relating to families of children with ASD. The idea for incorporating domains into the study arose from research findings that indicated a lack of dimensions for social support with the ASD population (Boyd, 2002).

There were four domains that related to parental stress for met social support needs. All seven domains had a negative correlation to parental stress even those were not significant. The Social Services domain was significantly and negatively correlated to parental stress. For the participants of the study, this implies that social services are minimal within the family system, because when social services needs that are met begin to decrease, parental stress increases. Previous research showed that children with ASD require a number of various social supports because of the unique features that the disorder presents (Hutton & Caron, 2005) and often times there is difficulty in accessing services (Freedman & Capobianco-Boyer, 2000). There are likely other reasons for how social services impact each family's needs, which may include factors such as degree of impairment for the child, severity of the child's behaviors, etc.

The Family domain was significantly and negatively correlated to parental stress, which means that parental stress increases when met social support needs relating specifically to the family decrease. The correlation was also quite high between the Family domain and parental stress, giving support to a consideration of the family rather

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than only the child with ASD. This idea touches on considering not only the unique needs of the child but also the needs of the entire family unit (McCubbin & Patterson, 1983). The Personal domain had a moderate negative correlation with parental stress, which suggests that when personal needs of the parent that are being met decrease, parental stress increases. This correlation is supported by the idea that many of these statements in the FNQ targeted parents' personal beliefs, possibly making them more sensitive to statements that directly related to themselves as parents. The Educational Needs of the Child domain was significantly and negatively correlated with parental stress. This supports the idea that the educational process for children with ASD is very demanding and, therefore, makes the learning process quire difficult for these individuals (Bryson & Smith, 1998). It is possible that the educational needs for families are being met to some extent, but this research suggests that it is more likely for social support needs to remain unmet. Overall, this research showed that a lack of specific social support needs is significantly contributing to reported parental stress levels.

When considering unmet, important social support needs, there was a positive relationship with only two of the domains, the Educational Needs of the Child and the Personal Domains, to parental stress. Therefore, it is possible that the social support needs in the other domains either had the needs met, reported the needs not as important, or reported them as important but already met. There are a number of reasons as to why the other domains did not significantly correlate to parental stress. For example, with the Medical domain, there are a number of medical issues that are dependent on the child's issues. This makes sense because not all children have the same medical problems, and the severity of medical problems may also differ from child to child. It is also likely that

the sample may not have included children with many medical problems. Another domain to explain a lack of correlation to parental stress is the Child's Social Network domain. There are a number of social situations that would make it difficult to encompass all into a select number of statements.

Because there were only a few significant correlations to parental stress for the analysis, it is likely that the domains are interconnected and collectively make a significant contribution to parental stress. This makes sense because the relationship between parental stress and met or unmet social support needs in the hypotheses were significantly correlated but not for all domains by themselves. The idea that the domains are interconnected with one another also relates to the notion that there are multiple variables possibly coming into play that would make a clear relationship more difficult to establish. As mentioned earlier in a review of the literature, some variables might include: the severity of the child's disability, the developmental level of the child, or cultural differences within the family structure (White & Hastings, 2004).

Previous research indicated that the relationship between stress and social support is lacking for the ASD population, along with reports on types of social support needs pertinent to the population (Cassidy et al., 2008). The present study attempted to show a relationship between the stress experienced by a parent and the types of social support needs that were met. The negative relationship between parental stress and met social support needs was similar to a research finding that showed a significant negative relationship between perceived stress and social support received from family and friends for the ASD population (Hadadian, 1994). One research study, for example, supported a negative relationship between parental stress and social support needs in that stress was

significantly less when parents reported social support as being available to them (e.g., Gill & Harris, 1991).

For social support needs that were reported as important yet unmet, parental stress was significantly and positively correlated. This positive relationship between social support and stress is similar to what has been found in research. In a study by White and Hastings (2004), the positive relationship showed that parents who reported using higher numbers of social supports and more helpful social supports also reported higher levels of well-being. In the current study, the idea of a positive relationship can be applied to the unmet, important social support needs and parental stress.

Consistent with other research findings, stress was high for parents of children with ASD. With a score of 90 or above being clinically significant on the PSI-SF, the average score for participants was around 101, suggesting that stress was high among the participants. This is similar to other research in that clinically high levels of stress are expected among families of children with ASD in comparison to families of typically developing children (Mancil et al., in press). However, a control group was not used in the present study, so there can be no comparison of parental stress between a group who have typically developing children. For families who had additional children with either ASD or special needs, the stress levels for these parents varied from low to very high, clinically significant levels. This suggests that simply having another child with either ASD or special needs may not always lead to higher parental stress. When considering education levels, stress was still high for participants regardless of number of years completed. This suggests that higher education levels were not a safeguard against stress compared to lower education levels of parents.

Another finding was that the majority of participants had their child diagnosed with ASD at age two, suggesting that early intervention may have proved advantageous to these families; it is possible that social support needs may have been an early intervention that perhaps helped remediate child problem behaviors and parental stress, and it may have offered several outlets of help for parents to incorporate within their families. For example, Kentucky has a First Steps program to help with early intervention services that may have been accessed by a number of the participants. However, it is important to understand that simply because the majority of children were diagnosed at an early age, intervention may not have been set in place immediately for all families. As mentioned, previous research evidence has supported the idea that parental stress can influence the effectiveness and types of interventions accessed (Baker-Ericzén et al., 2005). In turn, there can be a number of reasons, including financial issues, availability of services, awareness, or the value placed on social support needs for high stress levels being reported.

Summary

The results of this study have extended the research on social support needs, along with the relationship of social support needs and parental stress. Both hypotheses were supported by their correlations of social support needs, whether met or unmet, to parental stress. Therefore, the study showed a relationship having practical significance between social support needs and parental stress. However, the implication from these results is that there are likely a variety of factors that play into how stress is affected by social support needs. This also applies to the seven domains used in that there are a number of domains that might be investigated in addition to the seven described in the study. The

results of the study provide support to high levels of stress existing within families of children with ASD (e.g., Mancil, et al., in press).

Nonetheless, it is clear that high levels of stress are apparent in the families that participated in this study. Stress levels were still clinically high even though there were minimal current life stressors being reported by participants from the LS Scale. With only one participant reporting a significant number of life stressors, the majority of participants reported two or three life stressors occurring within the last 12 months. Therefore, it is possible that stress levels would have been higher for participants if higher numbers of life stressors had been reported.

As mentioned, education levels for participants were irrelevant to high stress levels in that education was not a safeguard against stress. For example, one participant had a raw stress score of 155 and 18 years of education, whereas another participant had a raw stress score of 87 and only eight years of education completed. As mentioned, it is likely that there are a number of other explanations for the existing high stress levels among parents.

Limitations

There are a number of limitations to this study. First, the correlational nature of the study does not allow for causal explanations of the results, and instead only showed a relationship between parental stress and social support needs. Second, the study's quantitative versus qualitative design did not allow for determining why or what specifically was creating higher or lower stress levels from one parent to another. There may be assumptions as to why higher stress exists, but these assumptions may not be getting at the core of what is maintaining the stress. For example, one parent who has

higher stress than another parent may not report receiving as many social support needs, or perhaps may report having fewer members who serve as social support within the family. However, these assumptions may be inaccurate or may not completely encompass parental stress as a whole. This goes back to considering the unique characteristics of the family when a child with ASD resides in the home, with an understanding that stress has different effects for families (Factor et al., 1990). The unique features of the family might include coping strategies, or simply how well the parent is able to handle the child's problematic behaviors and resulting stress.

It is equally important to consider the types of services received by families. For example, some families in the study received services from the Kelly Autism Program whereas other families did not. Therefore, the types of services received by families might also affect perceived stress levels for similar or different reasons. These reasons may include quality, quantity, or satisfaction of the services, or there may be an entirely different set of explanations for why stress is so high among parents.

Using interviews or other means of gathering qualitative data may have helped further determine reasons for high levels of parental stress among parents. Interviews also may have helped the study gain insight into reasons for why each parent rated the items with varying degrees of importance as well as why needs were being met or not met.

Another limitation to consider is the fact that some items on the FNQ did not directly apply to all families. Because some of the items did not apply to the family context, responses for these items were often left unanswered, which may not have given the most ideal results. For example, several items on the FNQ query about other children in the home. For families that only have one child residing in the household, this

statement did not apply. This resulted in leaving out a few participants due to a number of unanswered, inapplicable responses.

The types of social support needs were limited in that a variety of other needs might have been asked. Similarly, the selected social support domains covered only a small range of other dimensions that may have been applied. For example, the Social Services domain could have been further broken down into several other domains including: beliefs and satisfaction about services; the types of social services available to the family, either financially or within the region in which they reside; and the actual services provided by professionals. These are only a few examples to emphasize the possibilities of studying multiple dimensions of social support needs.

Another limitation was the small number of participants. The small size prevents generalization of the results to other settings. The low rate of participation in this study may have been partially due to the indirect method of communication: the questionnaire packets were sent out to parents' homes, which may have resulted in being too busy to fill out the paperwork or forgetting that a packet had to be mailed. An ideal situation would have been to have parents fill out the packets during a group meeting at a particular location. Also, the sampling group consisted of residents in the South Central Kentucky region. It is possible that the results of the study may be different for other regions. The sample consisted of all mothers or female guardians for the study. Thus, it is unknown how stress levels and social support needs may be related any differing perceptions from parents. It is also important to keep in mind that the majority of participants were married. It is likely that stress levels and social support needs would be

viewed differently in single parent households, or from parents who are divorced or separated.

Another limitation was the use of a convenience sample as opposed to random sampling. Participants were recruited through the Kelly Autism Program in Bowling Green, Kentucky as well as other local autism social support groups in the South Central Kentucky region. The select age range (2-12) of children with ASD was another limitation to the study because it prevents the generalization of the results to families of children with ASD who are outside this age range. Finally, the data were entirely derived from self-reports, which are susceptible to social desirability biases.

Suggestions for Future Research

Further research is clearly needed to establish the use of the social support domains that were applied to the present study. It is quite possible for other domains to be created in addition to the ones used for this study, and the need for revisions of items and domain characteristics may be necessary for future studies. This also relates to possible revisions for the FNQ. Obviously, a number of additional items might be included that would relate specifically to the ASD population. Gathering data on the perceptions of parents in regards to stress levels and social support needs will ultimately influence the types of services that will be accessed and available to families of children with ASD. This includes not only quantitative but qualitative data; both will be invaluable for research on this topic.

Though there was no intervention in the current study, it would be beneficial for future studies to incorporate an intervention to determine if stress could somehow be reduced among parents. This is consistent with the research study by Hutton and Caron

(2005), which showed that two-thirds of the parents in the sample reported that their stress was reduced after their child had received services specific to the ASD population.

Another consideration may be to include the PSI long form instead of the PSI-SF that was used for the present study. In doing so, the long form may be able to better target high scores on a particular domain than on the short form. For example, high scores on the Child Domain of the PSI may correspond with children who display problematic child behaviors that might make parenting roles difficult to fulfill (Abidin, 1995). This would be especially important to consider for the ASD population since problematic behaviors that affect the family are common among these children (Hutton & Caron, 2005).

It would be important for future studies to look at whether the types of social support needs queried are actually available to families in their residing area. This might also apply to parents perceptions on social supports, including satisfaction and awareness of the social supports that exist. Future research may also want to assess the length of time and types of social supports that have been accessed, the reasons for why services are or are not accessed, and whether the social supports apply to the family or child with ASD.

Another suggestion for future research may be to run a factor analytic study for the domains incorporated in the present study. This would be similar to the principal components analysis done by Serio et al. (1997) that yielded six distinct factors: health information, emotional support, instrumental support, professional support, community support network, and involvement with care. A large sample size would need to be

obtained to ensure an accurate number of factors that would ideally represent each domain used.

One last suggestion would be to incorporate a Likert scale scoring method for importance, specifically for the each item in the FNQ. Even though the current study incorporated a five point scale for importance of the FNQ statements, it would be crucial to understand the overall importance for each statement in a given social support domain. This would entail analyzing each response in a given domain to compare importance levels among participants' responses and to compare the importance of a given item to the overall importance of the social support domain.

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Appendix A

Human Subjects Review Board Approval Letter

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A Leading American University with International Reach
Human Subjects Review Board

In future correspondence, please refer to HS09-132, February 26, 2009

Rachel Wolf
c/o Dr. Wm Pfohl
Psychology
WKU

Dear Rachel:

Your revision to the research project, *Using Social Support Domains for Parents of Children with Austim Spectrum Disorder: Assessing Perceived Needs and Stress Levels*, was reviewed by the HSRB and it has been determined that risks to subjects are: (1) minimized and reasonable; and that (2) research procedures are consistent with a sound research design and do not expose the subjects to unnecessary risk. Reviewers determined that: (1) benefits to subjects are considered along with the importance of the topic and that outcomes are reasonable; (2) selection of subjects is equitable; and (3) the purposes of the research and the research setting is amenable to subjects' welfare and producing desired outcomes; that indications of coercion or prejudice are absent, and that participation is clearly voluntary.

1. In addition, the IRB found that you need to orient participants as follows: (1) signed informed consent is required; (2) Provision is made for collecting, using and storing data in a manner that protects the safety and privacy of the subjects and the confidentiality of the data. (3) Appropriate safeguards are included to protect the rights and welfare of the subjects.

This project is therefore approved at the Expedited Review Level until July 31, 2009.

2. Please note that the institution is not responsible for any actions regarding this protocol before approval. If you expand the project at a later date to use other instruments please re-apply. Copies of your request for human subjects review, your application, and this approval, are maintained in the Office of Sponsored Programs at the above address. Please report any changes to this approved protocol to this office. A Continuing Review protocol will be sent to you in the future to determine the status of the project. Also, please use the stamped form that accompanies this letter.

Sincerely,

Paul J. Mooney, M.S.T.M.
Compliance Manager
Office of Sponsored Programs
Western Kentucky University

cc: HS file number Wolf HS09-132

HSRB APPLICATION # 09-132
APPROVED 2/26/09 to 7/31/09
EXEMPT (EXPEDITED) FULL BOARD
DATE APPROVED 2/26/09

The Spirit Makes the Master

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Appendix B

Family Needs Questionnaire : Modified and New Items

FNQ items from Siklos and Kerns (2006) and new/modified items

All items

(I need to be actively involved in my child's treatments and therapies.)

I need to have different professionals agree on the best way to help my child.***

(I need to be shown that my opinions are used in planning my child's treatment, therapies, or education.)

I need to have a professional to turn to for advice or services when my child needs help.**

I need to have help from other family members in taking care of my child.

I need to be told why my child acts in ways that are different, difficult, or unusual.*

I need to be shown what to do when my child is acting unusually or is displaying difficult behaviors.*

I need to have information regarding my child's therapeutic or educational progress.*

I need to have help in deciding how much to let my child do by himself/herself.*

I need to have help with housework.*

I need to get enough rest or sleep.*

I need to get a break from my responsibilities.*

I need to spend time with my friends.*

I need to be told if I am making good decisions about my child.*

I need to have other family members understand my child's problems.

I need to have my child's after-school friends understand his/her problems.

I need to discuss feelings about my child with a parent who has a child with the same disorder.*

I need to be reassured that it is not uncommon to have negative feelings about my child's unusual behaviors.*

I need help dealing with my fears about my child's future.*

I need help in remaining hopeful about my child's future.*

I need to be encouraged to ask for help.*

(I need to have professionals working with my child to speak to me in terms I can understand.)

I need to be well-educated about my child's disorder in order to be an effective decision-maker regarding the needs of my child. *

I need services continuously rather than only in times of crisis.*

I need to have consistent physical therapy for my child.

(I need for professionals to be discrete when talking about my child while he/she is in the room.)

I need for my child to have friends of his/her own.

I need to have consistent behavioral therapy for my child.

I need weekend and after-school activities for my developmentally delayed child.*

I need to work with professionals who have expertise working with children who have the same developmental disorder as my child.**

I need to have consistent occupational therapy for my child.

I need to have time to spend alone with my other children.*

(I need for my developmentally delayed child to have social activities other than with his/her own parents and siblings.)

(I need to have consistent speech therapy for my child.)

(I need to have counseling for myself and my spouse/partner.)

I need for the professionals working with my child to understand the needs of my child and my family.**

I need for my children's friends to feel comfortable around my child.

I need to have my child's therapies continue throughout the summer months and school breaks.*

(I need to have my questions answered honestly.)

I need to have counseling for my other children.*

I need information about special programs and services available to my child and my family.*

I need to be shown respect by the professionals working with my child.*

(I need financial support (e.g. from government) in order to provide my child with his/her therapies, treatments, and care.)

(I need respite care for my child.)

I need the children in my child's classroom to understand that my child cannot help his/her unusual behaviors and difficulties.*
I need to have time to spend alone with my partner.*
I need my child's school to set up a specialized education plan for my child.*
I need my child to have a teacher's aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child.
I need to have my spouse and me agree on decisions regarding our developmentally delayed child.*
I need my child's doctor and dentist to have experience working with children with the same disorder as my child.**
I need to go out to dinner with my family three times each week.*
I need to take 3-week long family vacations each year. *
I need to take week-long vacations by myself each year.*

I need for my child to engage in social activities with others his/her own age.
I need to have my child's school set up consistent speech therapy for my child as part of his/her education plan.
I need to have medical professionals address my child's medical needs on a consistent basis.
I need to have counselors or therapists address my child's emotional needs on a consistent basis.
I need to have a range of medical services available for my child.
I need to have a range of social services available for my child.
I need hospital services that are readily available for my child.
I need medical screening tests for my child every so often.
I need a pediatrician who is able to help my child meet his/her nutritional and physical needs.
I need my child's school environment to have more structure or routine.
I need my child to have access to visual aid teaching while at school.
I need home-school collaboration for my child.
I need my child to be in group therapy for his/her behavioral issues.
I need my child to have some type of sensory integration therapy.
I need my child to have social skills training by a licenses professional, therapist, or counselor.
I need for my child to interact with others his/her own age.

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* = items that were modified for the final FNQ version
( ) = items that were omitted from the final FNQ version
In bold = items that were added to the final FNQ version

Appendix C

Social Support Domain Definitions

Pretend you are a parent who has a child with autism (autism spectrum disorder). If you don't know much about autism, imagine having a plethora of difficulties and having to manage a variety of different needs for you and your family. In other words, imagine that as a parent, you and your family have specific needs that are influenced by your child having autism.

Please read each of the domain definitions, then begin reading where it says, "I NEED." You will read each statement and circle on the right which domain you believe fits the statement. For example, if you feel a statement fits into the Family Domain, you would circle a "1" for that statement, "2" for Medical, etc. Refer back to this page as often as needed. Thank you for your help.

Domain Definitions:

1) <u>Family</u>: needs relating to all or specific family members, including the extended family, but not only about the child with an autism spectrum disorder for whom the survey is intended.

2) <u>Medical</u>: needs relating to medical services, hospitalizations, screenings, and professionals such as pediatricians, physicians, doctors, and dentists.

3) <u>Social Services</u>: needs relating to professional services such as psychologists, therapist, counseling, and types of therapies and counseling for all or some family members, the parent, and/or the child with an autism spectrum disorder.

4) <u>Educational Needs of Parent</u>: needs for obtaining information, knowledge, or understanding for the parent about his or her child for whom the survey is intended.

5) <u>Personal</u>: needs that apply to the parent's specific personal requests and/or desires that apply to the parent's own psychological well-being, physical needs, and emotional needs.

6) <u>Educational Needs of Child</u>: needs relating to the child's education, including classroom modifications, education plans, and the classroom environment with other students.

7) <u>Child's Social Network</u>: needs for the child that promote social relationships, social activities, and social interactions outside of the school environment.

I NEED….

1. to be well-educated about my child's
    autism (autism spectrum disorder)
 in order to be an effective decision
    maker regarding the needs of my child.   1 2 3 4 5 6 7

2. social services continuously rather than only in   1 2 3 4 5 6 7
times of crisis.

 3. to have consistent physical therapy for
my child.   1 2 3 4 5 6 7

4. for my child to have friends of his/her own.   1 2 3 4 5 6 7

5. different professionals such as psychologists/counselors
    to agree on the best therapy options for my child.   1 2 3 4 5 6 7

 6. different professionals such as physicians and
    medical doctors to agree on the best treatment
    options for my child.   1 2 3 4 5 6 7

7. to have a therapist/counselor to turn to for advice
    or therapy services when my child needs help.   1 2 3 4 5 6 7

8. to have a physician/medical doctor to turn to for advice
    when my child needs help.   1 2 3 4 5 6 7

9. for my child to have consistent behavioral therapy   1 2 3 4 5 6 7

10. support from other family members
in taking care of my child.   1 2 3 4 5 6 7

11. weekend and after-school social activities
    for my child.   1 2 3 4 5 6 7

12. therapists or counselors who have
    expertise working with children who have
    autism (autism spectrum disorder) like my child.   1 2 3 4 5 6 7

13. to have consistent occupational therapy
    for my child.   1 2 3 4 5 6 7

14. to be educated as to why my child
acts in ways that are different, difficult or unusual.   1 2 3 4 5 6 7

**15. for myself to have time to spend alone with my other
children in my family.**   1 2 3 4 5 6 7

**16. to be educated on what to do when my child
is acting unusually or is displaying difficult
behaviors.**   1 2 3 4 5 6 7

**17. to obtain information and knowledge regarding my
child's therapeutic or educational progress.**   1 2 3 4 5 6 7

**18. to be educated on how much to
let my child do by himself/herself.**   1 2 3 4 5 6 7

**19. for my child to engage in social activities
with others his/her own age.**   1 2 3 4 5 6 7

**20. to have my child's school set up consistent
speech therapy for my child as part of
his/her education plan.**   1 2 3 4 5 6 7

21. for myself to have help with housework.   1 2 3 4 5 6 7

22. for myself to get enough rest or sleep.   1 2 3 4 5 6 7

23. for myself to get a break from my responsibilities.   1 2 3 4 5 6 7

24. for myself to spend time with my friends.   1 2 3 4 5 6 7

**25. to understand if I am making good decisions
about my child.**   1 2 3 4 5 6 7

**26. for medical professionals working with my child
to understand the health needs of my child.**   1 2 3 4 5 6 7

**27. for counselors or therapists working with my child
to understand the emotional needs of my child.**   1 2 3 4 5 6 7

**28. for other children to feel comfortable
around my child when in social settings.**   1 2 3 4 5 6 7

**29. to have other family members understand my
child's problems.**   1 2 3 4 5 6 7

**30. to have my child's after-school friends to
understand his/her problems.**   1 2 3 4 5 6 7

31. for myself to express feelings about my child with
    a parent who has a child with
autism (autism spectrum disorder).   1   2   3   4   5   6   7

32. my child's social services to continue
    throughout the summer months and school
    breaks.   1   2   3   4   5   6   7

33. for myself to be reassured that it is not uncommon
    to have negative feelings about my child's
    unusual behaviors.   1   2   3   4   5   6   7

34. for myself to help deal with my fears about my child's
    future.   1   2   3   4   5   6   7

35. for myself to have help in remaining
    hopeful about my child's future.   1   2   3   4   5   6   7

36. for myself to be encouraged to
 ask for help from others.   1   2   3   4   5   6   7

37. my other children to have counseling.   1   2   3   4   5   6   7

38. to obtain information about special programs and
    services available to my child for my own education.   1   2   3   4   5   6   7

39. to be personally shown respect by those
    working with my child.   1   2   3   4   5   6   7

40. to have my child's teacher to be able
    to teach other students in the classroom
    about his/her unusual behaviors in a constructive way.   1   2   3   4   5   6   7

41. for myself to have time to spend
 alone with my partner.   1   2   3   4   5   6   7

42. my child's school to set up an individualized
    education plan for my child.   1   2   3   4   5   6   7

43. my child to have a teacher's aide with
    him/her at school who has knowledge about,
    or experience with, working with children with
    the same disorder as my child.   1   2   3   4   5   6   7

44. to have medical professionals address my child's
    medical needs on a consistent basis.   1   2   3   4   5   6   7

45. to have counselors or therapists address my child's
     emotional needs on a consistent basis.   1 2 3 4 5 6 7

46. for my family to agree on decisions
 regarding our developmentally delayed child.   1 2 3 4 5 6 7

47. my child's physician or medical doctor to have
     experience working with children with
     autism (autism spectrum disorders).   1 2 3 4 5 6 7

48. my child's counselor or therapist to have
     experience working with children with the same
     disorder as my child.   1 2 3 4 5 6 7

49. for my family to go out for dinner together
     a certain number of times each week.   1 2 3 4 5 6 7

50. for my family to take more vacations
     each year.   1 2 3 4 5 6 7

51. to take week-long vacations by myself
     each year.   1 2 3 4 5 6 7

52. to have a range of medical services
     available for my child.   1 2 3 4 5 6 7

53. to have a range of social services
     available for my child.   1 2 3 4 5 6 7

54. hospital services that are readily
     available for my child.   1 2 3 4 5 6 7

55. medical screening tests for my child
     every so often.   1 2 3 4 5 6 7

56. a pediatrician who is able to help my
     child meet his/her nutritional and physical needs. 1 2 3 4 5 6 7

57. medical professionals to agree on the best
     ways to treat my child.   1 2 3 4 5 6 7

58. to be educated regarding my
     child's therapeutic and educational progress.   1 2 3 4 5 6 7

59. my child's school environment to have
   more structure or routine.   **1 2 3 4 5 6 7**

60. my child to have access to
  visual aid teaching while at school.   **1 2 3 4 5 6 7**

61. home-school collaboration for my child.   **1 2 3 4 5 6 7**

62. my child to be in group therapy
 for his/her behavioral issues.   **1 2 3 4 5 6 7**

63. my child to have some type of
  sensory integration therapy.   **1 2 3 4 5 6 7**

64. my child to have social skills training
  by a licensed professional, therapist, or counselor.   **1 2 3 4 5 6 7**

65. for my child to interact with
  others his/her own age.   **1 2 3 4 5 6 7**

66. to have more structure at home
  with my family.   **1 2 3 4 5 6 7**

67. for my child to desire social interactions
with other children.   **1 2 3 4 5 6 7**

Appendix D

Data Collection Protocol for the Study

INFORMED CONSENT

Project Title: Using Social Support Domains for Parents of Children with Autism Spectrum Disorder: Assessing Perceived Needs and Stress Levels

Investigator: Rachel Wolf, Psychology Department, Phone Number: 270-745-2695; Kelly Autism Program Phone Number: 270-745-8903

You are being asked to participate in a project conducted through Western Kentucky University and the Kelly Autism Program. The University requires that you give your signed agreement to participate in this project.

The investigator will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask the researcher any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher any questions you may have.

If you then decide to participate in the project, please sign on the last page of this form in the presence of the person who explained the project to you. You should be given a copy of this form to keep.

Nature and Purpose of the Project: The purpose of this project is to help a graduate student's thesis, which is focusing on families who have a child with autism (autism spectrum disorder). Specifically, the goal is to understand your beliefs, as a parent, on situations that are common in families. We are also interested in determining social support needs that you have. This includes your needs as a parent, needs within your family, and the needs of your child diagnosed with autism (autism spectrum disorder). It is also beneficial to know the importance you place on these social support needs. In order to understand your needs, we are asking you to complete multiple packets of information.

Explanation of Procedures: You will complete a packet and a sheet that contains information on various family situations. Then, you will be asked to complete statements about your child's behaviors. Next, you will complete a questionnaire that focuses on your needs, as a parent, as well as the needs of your child who has autism (autism spectrum disorder). Finally, you will be asked to fill out some basic information about yourself, which includes items, such as your gender and education level. Some questions will also target other members within your family. These procedures will take approximately 55 minutes one hour to complete in total. You may take a break while completing the packets if needed. An information sheet about the study will be given to you after completion of all items.

Discomfort and Risks: There are no anticipated risks for the study, but should you have any questions or concerns, you may ask the researcher at any point of the process and after, if needed.

HSRB APPLICATION # 09-132

APPROVED 2/26/09 to 7/31/09

EXEMPT EXPEDITED FULL BOARD

DATE APPROVED 2/26/09

Benefits: It is anticipated that your help in the study will increase awareness on the types of social support needs available to families in the Western Kentucky region and how these social support needs will be addressed for the future. You may also gain insight into the purposes of the study for your own information within your family.

Confidentiality: This information will not be disclosed with any identifying information, meaning that your name will not be present for any purposes of the study and that your name will be held confidential at all times. Your name and information will not be released to anyone or any other facilities. The Kelly Autism Program will not hold the obtained information, but it will be kept confidential within the Psychology Department at Western Kentucky University.

Refusal/Withdrawal: Refusal to participate in this study will have no effect on any future services you may be entitled to from either Western Kentucky University or the Kelly Autism Program. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

_____   _____
Signature of Participant   Date

_____   _____
Witness/Researcher   Date

THE DATED APPROVAL ON THIS CONSENT FORM INDICATES THAT
THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY
THE WESTERN KENTUCKY UNIVERSITY HUMAN SUBJECTS REVIEW BOARD
Sean Rubino, Compliance Manager
TELEPHONE: (270) 745-4652

HSRB APPLICATION # 09-132

APPROVED 2/26/09 to 7/31/09

EXEMPT EXPEDITED FULL BOARD

DATE APPROVED 2/26/09

Directions for Participants

This study is interested in families of children diagnosed with autism (autism spectrum disorder). Specifically, our goal is to understand your beliefs as a parent on a series of items that deal with you, the parent, your family, and your child diagnosed with autism (autism spectrum disorder). In order to understand your beliefs as a parent, we are asking you to complete three packets of information. All five packets will take approximately 55 minutes to an hour to complete, combined.

First Packet
1) Contains questions about situations within your family that are common in many
families.
2) Answer each question.

Second Packet
1) Contains specific life situations that may apply to you within the last 12 months.
2) Circle *Yes* (Y) or *No* (N) for the situations that apply to you.

Third Packet
1) Contains questions regarding your child's functioning with having autism (autism spectrum disorder.
2) Answer each question.

Fourth Packet
1) Questions about the types of social support needs that are met within your family and the importance that you, as a parent, place on these needs in relation to your child having autism (autism spectrum disorder).
2) Answer each question by circling the *Importance (1 = Unimportant; 2 = Slightly Important; 3 = Moderately Important; 4 = Important; 5 = Very Important)* of the need AND if by circling if the need is currently *Met (Yes = Y; No = N).*

Fifth Packet
1) Contains questions about you, and your child who is diagnosed with autism (autism spectrum disorder).
2) Answer each question.

Life Experiences Checklist

   During the last 12 months, have any of the following events occurred in your immediate family? Please circle *Yes* (Y) or *No* (N) below to any that have happened within the last 12 months.

Y N Divorce

Y N Martial reconciliation

Y N Marriage

Y N Separation

Y N Pregnancy

Y N Other relative moved into household

Y N Income increased substantially (20% or more)

Y N Went deeply into debt

Y N Moved to a new location

Y N Promotion at work

Y N Income decreased substantially

Y N Alcohol or drug problem

Y N Death of close family friend

Y N Began new job

Y N Entered new school

Y N Trouble with superiors at work

Y N Trouble with teachers at school

Y N Legal problems

Y N Death of immediate family member

FAMILY NEEDS QUESTIONNAIRE

DIRECTIONS: The following statements describe needs that parents of children with autism (autism spectrum disorders) sometimes have. Because many of these needs are likely to be important to you, <u>please respond according to how important each need is in relation to your overall needs.</u> Also, these needs normally change over time. We are interested in knowing how important they are to you <u>at the present time</u> and whether they are being met. The information you provide will help us to understand the needs of your family and other families of children with similar problems.

Please show how important you feel these needs are**,** <u>relative to your overall needs</u>, by using the scale below and placing a circle around the number which best describes your answer:

1	2	3	4	5
Unimportant	Slightly Important	Moderately Important	Important	Very Important

Use this scale to tell us whether each need is being met by circling: Y (<u>Yes</u>) or N (<u>No</u>):

Y	N
Yes	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?					NEED MET NOW?	
1. to be well-educated about my child's autism (autism spectrum disorder) in order to be an effective decision maker regarding the needs of my child.	1	2	3	4	5	Y	N
2. social services continuously rather than only in times of crisis.	**1**	**2**	**3**	**4**	**5**	**Y**	**N**
3. to have consistent physical therapy for my child.	**1**	**2**	**3**	**4**	**5**	**Y**	**N**
4. for my child to have friends of his/her own.	**1**	**2**	**3**	**4**	**5**	**Y**	**N**
5. different professionals such as psychologists/counselors to agree on the best therapy options for my child.	**1**	**2**	**3**	**4**	**5**	**Y**	**N**
6. different professionals such as physicians and medical doctors to agree on the best treatment options for my child.	**1**	**2**	**3**	**4**	**5**	**Y**	**N**
7. to have a therapist/counselor to turn to for advice or therapy services when my child needs help.	**1**	**2**	**3**	**4**	**5**	**Y**	**N**

1	2	3	4	5	Y	N
Unimportant	Slightly	Moderately Important	Important	Very Important	Yes	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?					NEED MET NOW?	
8. to have a physician/medical doctor to turn to for advice when my child needs help.	1	2	3	4	5	Y	N
9. for my child to have consistent behavioral therapy.	1	2	3	4	5	Y	N
10. support from other family members in taking care of my child.	1	2	3	4	5	Y	N
11. weekend and after-school social activities for my child.	1	2	3	4	5	Y	N
12. therapists or counselors who have expertise working with children who have autism (autism spectrum disorder) like my child.	1	2	3	4	5	Y	N
13. to have consistent occupational therapy for my child.	1	2	3	4	5	Y	N
14. to be educated as to why my child acts in ways that are different, difficult, or unusual.	1	2	3	4	5	Y	N
15. for myself to have time to spend alone with my other children in my family.	1	2	3	4	5	Y	N
16. to be educated on what to do when my child is acting unusually or is displaying difficult behaviors.	1	2	3	4	5	Y	N
17. to obtain information and knowledge regarding my child's therapeutic or educational progress.	1	2	3	4	5	Y	N

1	2	3	4	5	Y	N
Unimportant	Slightly	Moderately Important	Important	Very Important	Yes	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?					NEED MET NOW?	
18. to be educated on how much to let my child do by himself/herself.	1	2	3	4	5	Y	N
19. for my child to engage in social activities with others his/her own age.	1	2	3	4	5	Y	N
20. to have my child's school set up consistent speech therapy for my child as part of his/her education plan.	1	2	3	4	5	Y	N
21. for myself to have help with housework.	1	2	3	4	5	Y	N
22. for myself to get enough rest or sleep.	1	2	3	4	5	Y	N
23. for myself to get a break from my responsibilities.	1	2	3	4	5	Y	N
24. for myself to spend time with my friends.	1	2	3	4	5	Y	N
25. to understand if I am making good decisions about my child.	1	2	3	4	5	Y	N
26. for medical professionals working with my child to understand the health needs of my child.	1	2	3	4	5	Y	N
27. for counselors or therapists working with my child to understand the emotional needs of my child.	1	2	3	4	5	Y	N
28. for other children to feel comfortable around my child when in social settings.	1	2	3	4	5	Y	N

	1	2	3	4	5	Y	N
	Unimportant	Slightly	Moderately Important	Important	Very Important	Yes	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?					NEED MET NOW?	
29. to have other family members understand my child's problems.	1	2	3	4	5	Y	N
30. to have my child's after-school friends to understand his/her problems.	1	2	3	4	5	Y	N
31. for myself to express feelings about my child with a parent who has a child with autism (autism spectrum disorder).	1	2	3	4	5	Y	N
32. my child's social services to continue throughout the summer months and school breaks.	1	2	3	4	5	Y	N
33. for myself to be reassured that it is not uncommon to have negative feelings about my child's unusual behaviors.	1	2	3	4	5	Y	N
34. for myself to help deal with my fears about my child's future.	1	2	3	4	5	Y	N
35. for myself to have help in remaining hopeful about my child's future.	1	2	3	4	5	Y	N
36. for myself to be encouraged to ask for help from others.	1	2	3	4	5	Y	N
37. my other children to have counseling.	1	2	3	4	5	Y	N
38. to obtain information about special programs and services available to my child for my own education.	1	2	3	4	5	Y	N

	1	2	3	4	5		Y		N
	Unimportant	Slightly	Moderately Important	Important	Very Important		Yes		No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?					NEED MET NOW?	
39. to be personally shown respect by those working with my child.	1	2	3	4	5	Y	N
40. to have my child's teacher to be able to teach other students in the classroom about his/her unusual behaviors in a constructive way.	1	2	3	4	5	Y	N
41. for myself to have time to spend alone with my partner.	1	2	3	4	5	Y	N
42. my child's school to set up an individualized education plan for my child.	1	2	3	4	5	Y	N
43. my child to have a teacher's aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child.	1	2	3	4	5	Y	N
44. to have medical professionals address my child's medical needs on a consistent basis.	1	2	3	4	5	Y	N
45. to have counselors or therapists address my child's emotional needs on a consistent basis.	1	2	3	4	5	Y	N
46. for my family to agree on decisions regarding our child with autism (an autism spectrum disorder).	1	2	3	4	5	Y	N
47. my child's physician or medical doctor to have experience working with children with autism (autism spectrum disorders).	1	2	3	4	5	Y	N

1	2	3	4	5	Y	N
Unimportant	Slightly	Moderately Important	Important	Very Important	Yes	No

I NEED....

	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?					**NEED MET NOW?**	

48. my child's counselor or therapist to have experience working with children with the same disorder of autism as my child.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

49. for my family to go out for dinner together a certain number of times each week.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

50. for my family to take more vacations each year.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

51. to take week-long vacations by myself each year.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

52. to have a range of medical services available for my child.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

53. to have a range of social services available for my child.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

54. hospital services that are readily available for my child.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

55. medical screening tests for my child every so often.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

56. a pediatrician who is able to help my child meet his/her nutritional and physical needs.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

57. medical professionals to agree on the best ways to treat my child.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

58. to be educated regarding my child's therapeutic and educational progress.

| | 1 | 2 | 3 | 4 | 5 | Y | N |

	1	2	3	4	5	Y	N
	Unimportant	Slightly	Moderately Important	Important	Very Important	Yes	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?					NEED MET NOW?	
59. my child's school environment to have more structure or routine.	1	2	3	4	5	Y	N
60. my child to have access to visual aid teaching while at school.	1	2	3	4	5	Y	N
61. home-school collaboration for my child.	1	2	3	4	5	Y	N
62. my child to be in group therapy for his/her behavioral issues.	1	2	3	4	5	Y	N
63. my child to have some type of sensory integration therapy.	1	2	3	4	5	Y	N
64. my child to have social skills training by a licensed professional, therapist, or counselor.	1	2	3	4	5	Y	N
65. for my child to interact with others his/her own age.	1	2	3	4	5	Y	N
66. to have more structure at home with my family.	1	2	3	4	5	Y	N
67. for my child to desire social interactions with other children.	1	2	3	4	5	Y	N

TO ENSURE CONFIDENTIALITY, DO NOT WRITE YOUR NAME

ANYWHERE ON THESE PAGES.

Please read each question carefully and check/write the appropriate response. The first set of questions applies to you, as a parent, and the next set of questions applies to your child who was diagnosed with autism (autism spectrum disorder).

Questions about you (the parent):

1. Please indicate your gender:
   - ☐ Male
   - ☐ Female

2. Please indicate your marital status:
   - ☐ Married
   - ☐ Single
   - ☐ Separated
   - ☐ Divorced

3. What is your household size?

   _____ (number of people)

4. Please indicate the members who serve as a support for your family (check all that apply):
   - ☐ Husband/Wife
   - ☐ Boyfriend/Girlfriend
   - ☐ A family member outside of your immediate family (i.e., your mother/father, your sister/brother, etc.)
   - ☐ Family friend
   - ☐ Neighbor
   - ☐ Other: _____

5. What is the highest educational level you have completed in years?:

    _____ (years)

6. Please indicate your gross annual salary income:
    ☐ Less than $25,000
    ☐ $25,000 to $50,000
    ☐ $50,000 to $75,000
    ☐ $75,000 to $100,000
    ☐ Over $100,000

7. How many extended family members currently live in your home?

    _____

8. Do other children in your family have a diagnosis of autism or have special needs?
    ☐ Yes
        If Yes, How many children? _____
    ☐ No

Questions about your child with autism (or an autism spectrum disorder):

9. Please indicate the age your child was diagnosed with autism:

    _____ (years)

10. Please indicate who made the diagnosis of autism for your child:
    ☐ Medical professional (i.e., pediatrician, physician)
    ☐ Psychologist
    ☐ Psychiatrist
    ☐ School/educational professional
    ☐ Other:_____

11. Please indicate the current age of your child:

_____ (years)

12. Does your child receive free or reduced lunch at school?

☐ Yes
☐ No

13. What age was your child when you first became concerned about him/her?

_____ (months)   or _____ (years)

14a. How many blood-related siblings does your child have?

_____

14b. How many other siblings does your child have?

_____

Debriefing Sheet

Thank you for taking part in this research study. You have just responded to statements that reflect common social support needs of families who have children with autism spectrum disorders. You also reported on statements that discuss common family situations and relationships. The researcher thanks you for expressing your beliefs as a parent. Your responses will greatly benefit the study, especially for the autism spectrum population. Should you have any questions about the procedures of the study, please contact the researcher, Rachel Wolf. She is a graduate student at Western Kentucky University in the Clinical Psychology program, and her contact information is found below.

Rachel Wolf
Tate Page Hall, Room 253
Western Kentucky University
Phone #: 419-305-4702

Appendix E

Pearson Correlation Matrices for Exploratory Social Support Domains and Parental
Stress

Exploratory Correlation Analysis for Domains of Met Social Support Needs

		Parenting Stress Index Short Form raw score	Mean	SD
Parenting Stress Index Short Form raw score	Pearson Correlation	1.00		
	Sig. (2-tailed)			
	N	35		
Family Domain Importance	Pearson Correlation	-.60***	2.60	1.50
	Sig. (2-tailed)	.00		
	N	34		
Medical Domain Importance	Pearson Correlation	-.28	6.11	3.71
	Sig. (2-tailed)	.14		
	N	30		
Educational Needs of Parent Domain Importance	Pearson Correlation	-.14	5.65	2.98
	Sig. (2-tailed)	.51		
	N	26		
Educational Needs of Child Domain Importance	Pearson Correlation	-.41*	3.81	1.86
	Sig. (2-tailed)	.02		
	N	32		
Social Services Domain Importance	Pearson Correlation	-.64***	5.33	3.26
	Sig. (2-tailed)	.00		
	N	28		
Personal Domain Importance	Pearson Correlation	-.49**	1.95	1.17
	Sig. (2-tailed)	.01		
	N	29		
Childs Social Network Domain Importance	Pearson Correlation	-.30	3.97	1.97
	Sig. (2-tailed)	.10		
	N	30		

*$p < .05$. **$p < .01$. ***$p < .001$.

Exploratory Correlation Analysis for Domains of Unmet, Important Social Support

Needs

		Parenting Stress Index Short Form raw score
Parenting Stress Index Short Form raw score	Pearson Correlation	1.00
	Sig. (2-tailed)	
	N	35
Family Domain	Pearson Correlation	.30
	Sig. (2-tailed)	.14
	N	25
Medical Domain	Pearson Correlation	.20
	Sig. (2-tailed)	.33
	N	26
Educational Needs of Parents Domain	Pearson Correlation	.28
	Sig. (2-tailed)	.15
	N	29
Educational Needs of Child Domain	Pearson Correlation	.41[*]
	Sig. (2-tailed)	.04
	N	27
Social Services Domain	Pearson Correlation	.36
	Sig. (2-tailed)	.07
	N	27
Personal Domain	Pearson Correlation	.48[*]
	Sig. (2-tailed)	.03
	N	21
Child's Social Network Domain	Pearson Correlation	.28
	Sig. (2-tailed)	.14
	N	30

*p < .05. ** p < .01.