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**Stress and the Need for Resources
in Families of Children With Autism in Calgary**

by

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ABSTRACT

The present study used Hill's (1949) ABCX model of family stress as a framework for identifying which resources parents of children with autism find essential and which are lacking. Differences between high- and low-stress parents were also investigated. Fifty-five parents ranked among their greatest needs financial assistance, spousal support, support of relatives, a good day program for their children, an early and consistent diagnosis, and support of knowledgeable professionals. Low-stress parents reported that their children had less severe autism and had less of an impact on their families. Low-stress parents did not differ significantly from high-stress parents in terms of their perception of how well their needs were being met. Sixty percent of all parents reported clinically significant levels of stress. Parents who received a diagnosis for their children within the past year reported significantly more stress than parents who received a diagnosis more than a year ago.

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DEDICATION

To my very best friends, Lance and Don.

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CHAPTER ONE

Introduction and Literature Review

Most researchers and clinicians currently agree that autism is a biologically-based disorder, probably of multiple etiologies (Schopler, 1994). However, they are also aware of mediating factors in the long-term prognosis of this disorder. These factors include having an IQ over 70, having verbal language skills before the age of 5, and having a preschooler with autism in an intensive early education environment 25-40 hours per week (Hameury, Roux, Lenoir, Adrien, Sauvage, Barthelemy, & Lelord, 1995; Harris, Handleman, Gordon, Kristoff, & Fuentes, 1991; McEachin, Smith, & Lovaas, 1993). These resiliency factors are associated with more favorable outcomes in behavior, communication, socialization, and learning.

Autism has a tremendous psychological impact on a family. In order to seek out, set up, and coordinate an intensive early education program, for example, parents must be coping adequately with their stresses. While more favorable outcomes are possible for children with autism, they do not happen without great effort. Understanding the impact of this disorder on the family may enable professionals to help the family cope with stress and meet its needs in raising a child with autism. This study attempts to clarify some of the stressors and needs of parents of children with autism in Calgary.

What is Autism?

According to DSM IV, autism is classified as a pervasive developmental disorder that has its onset before the age of 3 (American Psychiatric Association, 1994). It is about

3 times more common in males than females and occurs in about 1 birth per 1,000 (Bryson, Clark, & Smith, 1988). The incidence of autism has doubled in recent years. Most researchers attribute the increase to broadened diagnostic criteria and better recognition of the disorder.

The characteristics of persons with autism have been described consistently by many individuals, including psychologists, psychiatrists, and parents (Dunlap & Robbins, 1991; Lovaas & Smith, 1989; Maurice, 1993). Autism is a spectrum disorder, manifesting in varying degrees of severity. The most severe deficits for all persons with autism occur in the areas of language and social interaction. Typically, children with autism do not show any interest in playing with peers or making eye contact, but prefer to engage in more stereotyped behaviors. Stereotyped behaviors are ritualistic, repetitive, and often restricted. Examples include such things as flapping their hands in front of their eyes, rocking, or vocalizing a certain pattern (Smith, 1993). Children with autism often have unusual interests or restricted interests, such as lining up blocks or playing with decks of cards. Their stereotyped behaviors are self-involved; they rarely require others' participation.

Language skills vary among children with autism. Although some children are mute, those who are verbal have varying expressive capabilities. Many individuals are echolalic, some display unusual or repetitive vocalizations, while there are a minority who can engage in more complex, typical dialogue (Beitchman & Inglis, 1991; Charlop & Haymes, 1994).

Along with language and social skill deficits, accompanying deficiencies are usually found in self-care and self-preservation. Many individuals are not toilet-trained during the preschool years and some individuals are self-injurious or aggressive. Individuals with autism often require lifelong care and do not spontaneously recover. Bryson et al. (1988) found that autism was accompanied by mental retardation 75% of the time. However, children are typically physically attractive, so their behavior belies their appearance. This incongruity can contribute to parents' stress and to misconceptions by the community when the family is in public (Marcus, 1977).

The exact cause(s) of autism have not yet been determined but most researchers now agree that there are multiple etiologies, and that these multiple etiologies may account for the variability in severity (Harris, 1994; Klinger & Dawson, 1996). Research has suggested that persons with autism show neurochemical (i.e., chemical imbalances) or neurophysiological dysfunction (i.e., brain abnormalities) (Tsai & Ghazuiddin, 1992; Courchesne, 1987). Atypical levels of serotonin and dopamine have been found in persons with autism. Further, some studies have reported cerebellar and brainstem abnormalities (Courchesne, 1987; Courchesne, Townsend, Akshoomoff, Yeung-Courchesne, Press, Murakami, Lincoln, James, Saitoh, Egaas, Haas, & Schreibman, 1994; Schmahmann, 1994).

Stress

Stress, according to Webster's Dictionary, is a "mental or physical tension or strain" or "urgency, pressure, etc. causing this" (p.1409). McCubbin & Patterson (1983)

describe stress as a “demand-capability imbalance” (p.11). Just from experience alone, however, most of us have a good understanding of stress. In order to eliminate a stressor, we are required to adjust our priorities, mobilize our resources, and change our patterns of behavior (McCubbin & Patterson, 1983). If not, we are likely to suffer from “burn-out.” Burn-out is described by Sullivan (1979) as the “exhaustion of a person’s psychological and/or physical resources....” (p.112). Burn-out often occurs after a period of intense work or caring.

Stresses can be viewed as positive or negative and will vary depending on whether the causes are predictable, long-lasting, or intense (Wolf et al., 1989). The perception of the stress depends not only on the resources and social supports available to the family, but the characteristics of that family and the personalities of the individuals within it (Bristol & Schopler, 1983). Although family systems may exist as patriarchal, matriarchal, democratic, or something entirely different, each one’s functioning is based on the interdependence of its members. The dynamic system of a family adjusts itself continuously as family members grow and mature. Thus, the stress of a particular situation on a family is mediated by the stress perceived by each individual member of that family (Seligman, 1991).

Hill (1949, 1958) proposed an ABCX model of family stress that has been applied to families in many types of stressful situations, including tornadoes, divorce, and separation due to war. According to Hill, “...A (the event) - interacting with B (the family’s crisis meeting resources) - interacting with C (the definition the family makes of

the event) - produces X (the crisis)" (p.141). The B and C factors affect the degree to which the stressor produces crisis.

In the past two decades, this model has been applied extensively to families of children with autism (Bristol, 1984; Harris, 1994). Stressor events (factor A) may be singular or multifaceted and may include the initial diagnosis, the inability of the child to become toilet trained, or the need to arrange bus transportation to and from school. The family's resources (factor B) include both internal and external sources of support. Internal sources of support include personality traits, individual self-esteem, and family interaction style, while external sources of support include the support of neighbors and educational or vocational opportunities (Harris, 1994; McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980). The definition of the event (factor C) refers to the subjective meaning attached to the stressor. A single event may be perceived as a cross to bear, a surmountable challenge, or fate by any one member of a family. Further, each member of the family may perceive the event differently from other family members.

Hill (1949; 1958) provided a relatively simplistic model for understanding the factors that affect stress and the potential for crisis. More recent theoreticians in the area of stress have developed models that take into account concurrent stressors, active coping strategies, and the chronic nature of stress (Lazarus & Folkman, 1984; McCubbin & Patterson, 1983; Trumbull & Appley, 1986). McCubbin & Patterson (1983) proposed the Double ABCX model of stress that builds upon Hill's model by considering additional family stresses and active coping strategies of the family. Lazarus & Folkman (1984) and

McCubbin & Patterson (1983) both addressed the immediate and long-term effects of stress and post-crisis adjustment over time in their models. Schönflug (1986) provided a dynamic behavior economics model of stress that was based on a cost-benefit analysis of stressful situations. The perceived benefits of coping were weighed by an individual against the resources (costs) invested to determine whether a coping response was carried out or rejected.

Impact on the Family

Studies have consistently shown that parenting a child with autism is more stressful than parenting other special needs children, like those with cystic fibrosis, Down Syndrome, or other forms of mental retardation (Bouma & Schweitzer, 1990; Harris, 1994; Holroyd & McArthur, 1976). Holroyd and McArthur (1976) gave questionnaires on stress to 22 mothers of children with autism, 22 mothers of children with Down Syndrome, and 32 mothers of outpatient psychiatric children. They found that the mothers of children with autism were more disappointed with their children, more concerned about their children's dependency and impact on the family, and more concerned about being unable to keep their children occupied.

Mothers of children with autism typically experience more stress and depression than fathers (Harris, 1994; Wolf, Noh, Fisman, & Speechley, 1989). Wolf et al. (1989) studied stress, dysphoria, and social support in 123 mothers and 115 fathers of typical children, children with autism, and children with Down Syndrome. Consistent with previous research, they found that mothers of children with autism were at more risk than

fathers for dysphoria due to parenting stress. Increased perception of social support was found to moderate the impact of the stress for both mothers and fathers.

Families of children with autism experience many other feelings besides depression. Parents often report feeling isolated, guilt-ridden, disappointed, out of control, and unsure of the future (DeMyer & Goldberg, 1983; Marcus, 1977; 1984). The feeling of isolation may result when friends and family do not know what role to play and become too uncomfortable to stay accessible. Guilt may result when the other children in the family receive disproportionately less time with their parents. DeMyer & Goldberg (1983) quoted one parent as saying "I now realize that we don't have just one handicapped child - all five of the kids have become limited to some degree because of the strains of Jerry. It's impossible for any of us to have a life of our own" (p.232).

Siblings of children with autism experience unique stresses. Siblings have reported that they felt their parents favored the disabled child (McHale, Sloan, & Simeonsson, 1986). They have also reported that they felt they were expected to take on more caretaking responsibilities in the household (Bagenholm & Gillberg, 1991; Mates, 1990). Some children stated that their friendships had been affected, that they felt lonely or that they had trouble coping with the feelings of rejection they experienced for their disabled sibling (Bagenholm & Gillberg; Mates, 1990).

As typical children grow and become more independent, parents' time and energy is usually freed up to do other things. Parents are reassured to know that as they age, their children are becoming more able and willing to take care of themselves. However,

for parents of children with autism, typical levels of independence are rarely reached (Shea, 1984). Parents continue to worry over their children every hour of every day, as long as their children with autism live in the home. The burden of unrelieved care, of being on 24 hour patrol, is one of the greatest stresses these parents face (DeMyer & Goldberg, 1983; Marcus, 1984). Several researchers have found that parental stress is significantly lessened by having adequate resources and supports available so that stresses do not compound one another (Bristol & Schopler, 1983; Wolf, et al., 1989). These supports, including the support of spouses and relatives, training in behavior management, and parent support groups, will be expanded upon below.

Severity of Autism

Little research has been done to examine the extent to which the severity of a child's autism affects parental stress. Bebko et al. (1987) compared the ratings of 20 families on a 14-item adaptation of the Childhood Autism Rating Scale (CARS). They were asked to rate the severity of the symptoms and the degree of stress associated with each symptom on a 4-point scale. Mothers and fathers agreed on both the severity of their children's autism and the degree of stress they were experiencing. Further, parents who reported more severe autism in their children also reported more stress.

Konstantareas & Homatidis (1989) found similar results in their study of 44 families. Using the same scale as Bebko et al. (1987), they found a high degree of agreement between mothers' and fathers' ratings of their children's symptom severity.

Self-abusive behavior was the strongest predictor of fathers' stress, while self-abuse, hyperirritability, and older child age were strong predictors of mothers' stress.

Need for Resources

It has been noted that family resources may include both internal and external supports. Internal supports are of a personal/psychological nature and include such things as self-confidence, good health, and intelligence. External supports may be subdivided into formal and informal supports. Formal supports include training in behavior management and legal counseling (Bristol, 1983; Dunlap & Fox, 1996), while informal supports include having a network of friends and family to socialize with (Bristol, 1984).

Most parents indicate that caring for their disabled child has a huge impact on their social life, physical health, and recreational opportunities (Darling, 1991; Dunlap & Fox, 1996). Researchers have found that one of the most predominant needs of parents of children with autism is for respite or relief care, including baby-sitters (DeMyer & Goldberg, 1983; Sullivan, 1979). DeMyer & Goldberg (1983) surveyed 22 mothers and 21 fathers of children with autism on family impact and needs. Respite was the second highest-ranking need in the parents of children aged 12 and under. This need is both formal (need for a service) and personal/psychological (giving parents a break). Time away from a high-needs child allows parents time to re-energize by caring for themselves for awhile. Other needs commonly voiced by parents include the need for an early and consistent diagnosis, contact with other parents of children with autism, more money to

pay for services, and a good day program which runs all day, all year (Dunlap & Fox, 1996; Marcus, 1984).

If parents of children with autism cannot manage the stresses they face, they will burn-out. Researchers have found that there are a few key factors that help significantly in preventing or ameliorating the effects of stress. McCubbin and his colleagues (1980) found in their review of a decade's research that social support and family problem solving ability were strongly associated with reduced stress. Bristol & Schopler (1983) reported that service availability and severity of the child's disability strongly predicted levels of stress in mothers of children with autism. Harris (1994) noted that social support, family unity, and personality traits influenced the impact of the stress on families of children with autism.

Provision of necessary resources can enable families to cope quite well with their disabled child. Without access to adequate resources, stresses can compound each other, resulting in a less effective family unit. Parents who are unable to meet their child's needs perceive that the burden on the family increases. As the burden increases, parents with few resources will be able to cope less effectively with their child. The child, in turn, without consistent intensive support, will often pose more of a behavioral challenge. The effect appears at least cyclical, if not downward spiraling in some cases. If we can better understand what parents' needs are and provide them with the necessary services, we may help prevent a family crisis. As Bristol (1984) points out, parents of a child with autism are more susceptible to burn-out or crisis due to the "ambiguity of the stressor and its

severity, duration, and lack of congruence with community norms” (p.291).

Understanding the different ways in which a child with autism affects family life may help professionals assist families in coping (Harris & Powers, 1984).

Scope

The participants in this study have been limited to those parents with children 12 years of age or younger. Research has indicated that parents of adolescents are affected by quite different stressors and have different needs compared to parents of young children (Bristol & Schopler, 1983; Upshur, 1991). Parents with younger children most often report needing an accurate diagnosis by understanding professionals and good early schooling opportunities. Once children reach adolescence, however, parents’ needs centre around the child’s size, sexual maturity, vocation, and future residence.

This study focuses on external sources of support rather than individual, psychological coping mechanisms. Since external resources are easier for professionals to effect change on, it seems fitting that they should be the focus of this study. Bristol (1984) suggests that “without adequate services, it is unlikely that any amount of psychosocial support can prevent family stress” (p.307). These services form one part of Hill’s (1958) B factor (the family’s crisis meeting resources) as discussed above.

Summary

Having numerous resources available for families may not be sufficient. We need to know which resources parents find essential and which are lacking so that we can direct our efforts towards bettering those, if necessary. We need to be as effective as possible in

helping families meet their needs. Harris (1994) suggests that this awareness of needs gives us the opportunity “to consider educative, supportive, and therapeutic interventions that might enhance family functioning” (p.168). This study allowed us to identify the needs of parents of children with autism in Calgary. The second purpose of this study was to gather information on whether less-stressed families of children with autism perceived that their needs were being met better than more highly stressed families.

Hypotheses

The following hypotheses were examined:

1. Parents of children with autism who have lower stress scores will perceive that more of their needs are being met than parents whose stress scores are higher.
2. Parents of children with autism who have lower stress scores will report that their children have a lower level of impact on the family than parents whose stress scores are higher.
3. Parents of children with autism who have lower stress scores will have children with less-severe autism compared to parents whose stress scores are higher.
4. Needs related to factors such as financial and social support will be rated more highly by parents than needs in other areas (i.e., legal help, recreational opportunities, residential treatment).

CHAPTER TWO

Method

Participants

Fifty-five parents of children with autism aged 12 or under were recruited from mailing lists at the Society for Treatment of Autism, Autism Calgary Association, Renfrew Educational Services, Janus Academy, and Alberta Children's Hospital between October 1997 and April 1998. The study included 54 parents from the city of Calgary and one parent from the nearby town of Cochrane. Thirty-five of the participants were mothers and 20 were fathers. Parents ranged in age from 26 to 43 years. Mothers' mean age was 35.97 years ($SD = 4.90$) and fathers' mean age was 37.12 years ($SD = 4.00$). Nineteen parents participated together with their partners, 16 mothers participated alone, and 1 father participated alone. All of the participants had a spouse or partner except for one divorced mother, one separated mother, and one separated father. One couple participated twice because they have two sons with autism. Five families had someone other than an immediate family member living with them (e.g., a nanny).

Thirty-six different children were represented in this study. Most families had placed their children in a full-day educational program of some type. Eight children attended the Discovery Centre run by the Society for Treatment of Autism, seven attended public or Catholic schools, five attended Renfrew Educational Services' schools, and four attended Janus Academy. Four children received solely in-home therapy in the form of a Leaf or Lovaas program. At least two other children participated in Leaf or Lovaas

programs concurrent with one of the others listed above. One child did not participate in any formal education or therapy program. There were seven children for whom schooling or therapy information was not provided.

Procedures

Initial mail-outs were done by Society for Treatment of Autism, Autism Calgary Association, Renfrew Educational Services, Janus Academy, and Alberta Children's Hospital on behalf of the researcher in order to maintain confidentiality until parents agreed to participate. The initial package contained a letter outlining the study and a self-addressed stamped envelope for parents to return to the researcher if they were interested in participating (see Appendix A). Consenting parents were then sent a package containing a copy of the Parenting Stress Index (PSI) Third Edition, the Family Impact Questionnaire (FIQ), the Gilliam Autism Rating Scale (GARS), the Resource/Needs Inventory, and the Fulfilled Needs Inventory (see Appendix B for questionnaires). A demographic information report (Appendix C) was also sent to parents, along with a Consent Form (Appendix D). Approximately one week after the package was sent out to a family, the researcher contacted them by phone. Arrangements were made regarding a time and place to meet at the parents' convenience. During the meeting, parents were given an opportunity to clarify any concerns that arose while completing the questionnaires, while the researcher checked the questionnaires for completeness.

Measures

Parenting Stress Index (PSI) Third Edition.

The PSI is a measure of various facets of the parent-child relationship that may be causing stress. It consists of 101 items presented in a 5 point Likert-type scoring system ranging from strongly agree to strongly disagree. It provides three scores: the Child Domain score, the Parent Domain score, and the Total Stress score. An optional fourth score (Life Stress) is based on changing life circumstances in the past year (e.g., losing a job). Six subscales form the Child Domain and seven subscales form the Parent Domain, which add to yield the Total Stress score. The subscales of the Child Domain are (a) Distractibility/Hyperactivity, (b) Adaptability, (c) Reinforces Parent, (d) Demandingness, (e) Mood, and (f) Acceptability. High scores in the Child Domain suggest that the child displays qualities which make parenting difficult. The subscales of the Parent Domain are (a) Competence, (b) Isolation, (c) Attachment, (d) Health, (e) Role Restriction, (f) Depression, and (g) Spouse. High scores in this domain suggest that the source of stress may lie with the parent's own abilities.

The PSI was standardized for use with parents of children ranging from 1 month to 12 years based on the response of 2,633 mothers and 200 fathers. Alpha reliability coefficients ranged from .70 to .83 for the Child Domain subscales and .70 to .84 for the Parent Domain subscales. Reliability coefficients for the two domains were calculated to be .90 and .93 for the Child and Parent Domains, respectively. The reliability coefficient for Total Stress was .95. Test-retest reliability results are available from four sources in

the manual (Abidin, 1983). Across a 1- to 3-month interval, reliability coefficients of .63 for the Child Domain, .91 for the Parent Domain, and .96 for the Total Stress score were obtained. Another study with a 3 month lapse reported coefficients of .77 for the Child Domain, .69 for the Parent Domain, and .88 for the Total Stress score. In a third study, test-retest reliability after 3 weeks was .82 for the Child Domain and .71 for the Parent Domain.

Family Impact Questionnaire (FIQ).

The FIQ measures a child's impact on the family based on information collected from a 50 item questionnaire. The FIQ is presented in a 4 point Likert-type scale from not at all to very much. It consists of six subscales: (a) Impact on Social Life, (b) Negative Feelings Toward Parenting, (c) Positive Feelings Toward Parenting, (d) Financial Impact, (e) Impact on Marriage, and (f) Impact on Siblings. The original sample contained 133 mothers of preschool-aged children with problem behaviors. The FIQ has been used with both sexes across a wide range of socioeconomic status (SES), with parents of children aged 3 to 19. It has also been used with parents of typical children, children with internalizing and externalizing behavior disorders, and children with mental retardation.

Test-retest reliability after 2 years ranged from .43 (Financial Impact) to .72 (Impact on Social Life) for the six subscales. Donenberg & Baker (1993), the developers of the questionnaire, found a high correlation between two of their subscales and the Child Domain of the PSI. Specifically, correlations of .68 were found for both Impact on Social Life and Negative Feelings Toward Parenting.

Gilliam Autism Rating Scale (GARS).

The GARS is a 42 item behavioral checklist that helps identify persons with autism. It has been standardized for use with individuals aged 3 through 22. It includes three subtests: (a) Stereotyped Behaviors, (b) Communication, and (c) Social Interaction. A fourth subtest, Developmental Disturbances, is optional for parents to complete. Total subtest scores yield an Autism Quotient. Items are presented in a Likert-type format from 0 (never observed) to 3 (frequently observed) in the first three subtests and as Yes/No questions in the Developmental Disturbances subtest. The GARS was normed on a sample of 1,092 children and young adults who had been diagnosed with autism in the United States, the District of Columbia, Puerto Rico, and Canada.

Items on the GARS are usually presented as statements describing characteristic behaviors of autism. The GARS can be completed by anyone familiar with the child. Norms are provided for determining the likelihood that a person has autism and the severity of autism. Scores between 90 and 110 indicate an average probability of the person having autism as well as average severity of autism.

Alpha coefficients for the GARS are as follows: Stereotyped Behaviors .90, Communication .89, Social Interaction .93, Developmental Disturbances .88, and Autism Quotient .96. Test-retest reliability after 2 weeks calculated for each subtest ranged from .81 to .88. Interrater reliabilities were calculated between teachers, between parents, and between a teacher and a parent. Reliabilities ranged from .55 for parent-to-parent ratings

of Social Interaction to .99 for teacher-to-parent ratings of Stereotyped Behaviors and the Autism Quotient.

Resource/Needs Inventory.

This author, based on the prior research findings of several researchers (Bristol & Schopler, 1983; Darling, 1991; DeMyer & Goldberg, 1983; Dunlap & Fox, 1996) developed the Resource/Needs Inventory (Appendix B). Previous researchers have consistently found that parents rate some resources as more essential than others. Typically, support of relatives and spouses has ranked highly, while support of church has ranked low. All of the most frequently measured external resources used in previous research were compiled into the Resource/Needs Inventory. The external resources were listed in a random order on the inventory. Resources were ranked by each parent from 1 through 20, with 1 being the most important resource and 20 being the least important.

Fulfilled Needs Inventory.

The Fulfilled Needs Inventory was developed by this author, based on the research used to formulate the Resource/Needs Inventory. Parents were asked to indicate their perceptions of how well their needs were being met on a 5 point Likert-type scale ranging from not at all to very well. A total score was calculated for each parent by adding the rating for each variable (not at all = 0, barely = 1, adequately = 2, mostly = 3, and very well = 4).

Demographic Information Questionnaire.

Demographic information including number, sex and ages of persons in the home, and education and occupation of the parent(s) was collected using a two page questionnaire. Each parent in the household completed his or her own questionnaire.

CHAPTER THREE

Results

The results are presented in six sections. First, demographic characteristics of the sample are described. Second, preliminary analyses of the data including descriptive statistics are presented. The sample is subdivided into four groups: mothers' scores, fathers' scores, mothers' scores for those who participated in the study with a partner, and mothers' scores for those who participated in the study alone. Descriptive statistics are presented for the entire sample as well as each subgroup on the PSI, FIQ, GARS, and Resource/Needs Inventory. Third, correlation coefficients are used to examine the relationships among the PSI, FIQ, GARS, Resource/Needs Inventory, and the demographic variables. Fourth, group differences are examined for mothers versus fathers, mothers versus fathers from the same family, and mothers who participated with a partner versus mothers who participated alone in relation to the PSI, FIQ, and GARS. Group differences are also examined for high-stress versus low-stress parents, parents of a child who received the diagnosis of autism within the past 12 months versus those who received the diagnosis more than 12 months ago, and high life-stress parents versus other parents. Fifth, non-parametric tests are used to examine the mean ranks on the Resource/Needs Inventory. Group differences are examined for mothers versus fathers, mothers versus fathers from the same family, mothers who participated with a partner versus mothers who participated alone, and high-stress versus low-stress parents. Group differences on mean rankings are also examined for parents of children over age 6 versus

parents of children under age 6 and high life-stress versus other parents. Finally, chi-square analyses are used to assess needs met for mothers versus fathers, mothers who participated with a partner versus alone, and high-stress versus low-stress parents. Due to the exploratory nature of this study, a correction for Type I error was not used. An alpha level of .05 was used for all statistical tests.

Demographic Characteristics

Parents were asked to report the highest educational level for themselves and for their partners, if they had one. In this study, overall family educational level was based on the highest educational level within each family. Four percent of parents did not have a high school diploma. More mothers than fathers reported a university degree within their families (51% and 45%, respectively). The majority of families (49%) reported having at least one university degree. Table 1 lists demographic information for the parents.

The Blishen Index is a measure of SES that was developed using 1981 Canadian census data relating to income and education level (Blishen, Carroll, & Moore, 1987). The SES score was based on the highest-level occupation within each family. Occupations fall into six levels of SES on the Blishen Index. Levels 1 and 2 SES scores are considered low and range to 39.99. Levels 3 and 4 SES scores are considered middle and range from 40 to 59.99. Levels 5 and 6 SES scores are considered high and range from 60 up. The mean score for the current sample was 54.41 ($SD = 14.41$) with scores ranging from 22.08 to 79.23. The majority of families (80%) fell into the middle to upper classes.

Table 1**Demographic Characteristics of the Mothers and Fathers**

Demographic variables	Entire sample <u>N</u> = 55	Mothers <u>n</u> = 35	Fathers <u>n</u> = 20
Mean age (years)	36.39	35.97	37.12
<u>SD</u>	(4.59)	(4.90)	(4.00)
Education			
No high school	0 (0%)	0 (0%)	0 (0%)
Some high school, no diploma	2 (4%)	1 (3%)	1 (5%)
High school diploma	0 (0%)	0 (0%)	0 (0%)
Some post-secondary, no diploma or degree	10 (18%)	6 (17%)	4 (20%)
Post-secondary diploma (e.g., technical)	16 (29%)	10 (29%)	6 (30%)
University degree	27 (49%)	18 (51%)	9 (45%)
Blishen SES Index			
Low (<40)	11 (20%)	7 (20%)	4 (20%)
Middle (40-59.99)	25 (45%)	15 (43%)	10 (50%)
High (60+)	19 (35%)	13 (37%)	6 (30%)

In examining the child characteristics (see Table 2) of the sample, the mean age of the children was 5.70 years ($SD = 2.48$) and the mean age at diagnosis as reported by the parents was 36.44 months ($SD = 10.05$). The gender ratio was about 6:1 (31 males and 5 females). Current prevalence rates place the ratio at about 3:1 (Bryson et al., 1988; Volkmar, Szatmari, & Sparrow, 1993). It appears that females with autism were underrepresented in this study. Most of the children in the study had 1 or 2 siblings. Fifteen children had older brothers, 12 had older sisters, 9 had younger brothers, 8 had younger sisters, and 1 had a twin brother. All children with autism in this study lived at home with at least one parent.

Descriptive Statistics

Parenting Stress Index (PSI) Third Edition.

Mean scores were calculated for the entire sample, mothers only, and fathers only for each PSI subscale and domain. Table 3 presents the means and standard deviations on the PSI for this sample and the normative sample. Table 4 presents the means and standard deviations on the PSI for the mothers and fathers in this sample. Group differences between mothers and fathers were examined using t tests, and are discussed in a later section. According to Abidin (1983), the developer of the PSI, Total Stress scores on the PSI of 258 or greater fall at or above the 85th percentile and are considered high-stress scores. This cutoff was used for all subsequent analyses in this study. Thirty-three parents (60%) fell into the high-stress category, while 22 parents (40%) fell into the low-stress category. Abidin (1983) states that parents who obtain a Total Stress score at or

Table 2Demographic Characteristics of the Children

Demographic variables	Total
	<u>N</u> = 36
Mean age of child (years)	5.70
<u>SD</u>	(2.48)
Mean age of child at diagnosis (months)	36.44
<u>SD</u>	(10.05)
Gender of child	
Male	31
Female	5
Number of other children in the family	
No siblings	1
One sibling	21
Two siblings	13
Three siblings	1

Table 3**Means and Standard Deviations for the Current Sample and PSI Normative Sample**

Measure and subscales	Current sample	Normative sample
	<u>N</u> = 55	<u>N</u> = 2,633
	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)
PSI Child domain	141.29 (24.77)	99.70 (18.80)
Distractibility/hyperactivity	31.16 (6.63)	24.70 (4.80)
Adaptability	34.73 (6.24)	24.90 (5.70)
Reinforces parent	14.05 (5.74)	9.40 (2.90)
Demandingness	27.75 (6.34)	18.30 (4.60)
Mood	12.89 (3.14)	9.70 (2.90)
Acceptability	21.25 (4.71)	12.60 (3.50)
PSI Parent domain	131.80 (29.46)	123.10 (24.40)
Competence	30.49 (7.33)	29.10 (6.00)
Isolation	14.42 (4.67)	12.60 (3.70)
Attachment	12.85 (3.78)	12.70 (3.20)
Health	14.22 (4.27)	11.70 (3.40)
Role restriction	21.00 (6.18)	18.90 (5.30)
Depression	20.09 (6.09)	20.30 (5.50)
Spouse	18.91 (5.58)	16.90 (5.10)

(table continues)

	Current sample	Normative sample
	<u>N</u> = 55	<u>N</u> = 2,633
Measure and subscales	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)
PSI Total stress	272.73 (47.50)	222.80 (36.60)
Life stress	9.71 (9.26)	7.80 (6.20)

Table 4**Means and Standard Deviations for Mothers and Fathers on the PSI**

Measure and subscales	Entire sample	Mothers	Fathers
	<u>N</u> = 55	<u>n</u> = 35	<u>n</u> = 20
	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)
PSI Child domain	141.29 (24.77)	141.23 (25.35)	141.40 (24.36)
Distractibility/hyperactivity	31.16 (6.63)	31.63 (6.57)	30.35 (6.82)
Adaptability	34.73 (6.24)	34.63 (6.73)	34.90 (5.45)
Reinforces parent	14.05 (5.74)	13.49 (5.29)	15.05 (6.48)
Demandingness	27.75 (6.34)	28.17 (6.34)	27.00 (6.42)
Mood	12.89 (3.14)	13.03 (3.44)	12.65 (2.60)
Acceptability	21.25 (4.71)	21.14 (4.72)	21.45 (4.81)
PSI Parent domain	131.80 (29.46)	134.11 (29.02)	127.75 (30.53)
Competence	30.49 (7.33)	30.94 (8.11)	29.70 (5.84)
Isolation	14.42 (4.67)	14.26 (4.31)	14.70 (5.34)
Attachment	12.85 (3.78)	12.09 (3.39)**	14.20 (4.12)**
Health	14.22 (4.27)	14.49 (4.38)	13.75 (4.13)
Role restriction	21.00 (6.18)	21.66 (5.76)	19.85 (6.86)
Depression	20.09 (6.09)	20.71 (6.44)	19.00 (5.39)
Spouse	18.91 (5.58)	19.97 (5.43)*	17.05 (5.46)*

(table continues)

	Entire sample	Mothers	Fathers
	<u>N</u> = 55	<u>n</u> = 35	<u>n</u> = 20
Measure and subscales	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)
PSI Total stress	272.73 (47.50)	274.77 (46.37)	269.15 (50.43)
Life stress	9.71 (9.26)	10.34 (10.20)	8.60 (7.44)

* $p < .10$. ** $p < .05$.

above 260 should be offered professional assistance. In this sample, 32 of the parents (58%) scored at or above 260.

The PSI contains a Defensive Responding score designed to identify parents who may be responding defensively to the questionnaire. A score of 24 or less may indicate dysfunction in the parent-child system or alternatively, a parent who is functioning very well and under a low level of stress. Seven parents in this sample received defensive scores. One parent participated alone, two were from the same family, and the other four came from different families, although they all participated with their partners. None of the four spouses of the defensive-scoring parents had PSI Total Stress scores in the high-stress range, which suggested that they might be part of families who are coping quite well at this time.

The Life Stress score measures stressful circumstances that are often out of a parent's control (e.g., death of immediate family member). High Life Stress scores tend to intensify the total stress that a parent is experiencing. A Life Stress score of 14 falls at the 85th percentile. Sixteen parents (29%) had scores at or above the 85th percentile. Abidin (1983) suggested that professional assistance may be necessary when the Total Stress score is above 250 and the Life Stress score is 17 or above. Eight parents from this sample (15%) fell into this grouping. Five parents were female and three were male. Two couples were included in the group, along with one divorced mother, a recently separated father, and two mothers in a two-parent partnership. The children of these eight parents ranged in age at the time of the study from 34 months to 64 months. The time since

diagnosis ranged from 8 months to 37 months. The severity of the children's autism, as reported by the parents, ranged from 88 (below average) to 120 (above average).

Family Impact Questionnaire (FIQ).

Table 5 contains means and standard deviations of mothers and fathers on the six subscales of the FIQ. A higher score indicates more severe impact. Norms for the FIQ have not been published.

Gilliam Autism Rating Scale (GARS).

Means and standard deviations for the GARS can be found in Table 6. Scores on the GARS determine the likelihood that a person has autism and the severity of the disorder. The normative mean is 100 (SD = 15). In this sample, the mean Autism Quotient was 91.36 (SD = 15.16). A score of 90-110 indicates an average probability of the person having autism. Scores in this study ranged from 57 (very low probability of/severity of autism) to 123 (high probability of/severity of autism). All children participating in this study had received a diagnosis of autism previously.

Subtest standard scores for the GARS have a normative mean of 10 and a range of 8 to 12. Mean scores on the Stereotyped Behaviors, Communication, Social Interaction, and Developmental Disturbances subtests for this sample fell in the average probability of autism range of 8-12. Children who do not talk or sign do not receive a score on the Communication subtest. Thirteen children (24%) in this sample were omitted from the Communication subtest.

Table 5**Means and Standard Deviations for Mothers and Fathers on the FIO**

	Entire sample	Mothers	Fathers
	<u>N</u> = 55	<u>n</u> = 35	<u>n</u> = 20
Subscales	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)
Social life	14.76 (8.01)	15.43 (8.01)	13.60 (8.08)
Negative feelings toward parenting	11.55 (5.39)	11.37 (5.05)	11.85 (6.06)
Positive feelings toward parenting	8.93 (5.64)	9.60 (6.01)	7.75 (4.83)
Financial impact	10.02 (5.70)	11.03 (5.37)*	8.25 (5.98)*
Impact on marriage	4.85 (3.95)	4.73 (3.97)	5.05 (4.01)
Impact on siblings	7.81 (4.64)	7.77 (4.83)	7.88 (4.43)

* $p < .10$.

Table 6**Means and Standard Deviations for Mothers and Fathers on the GARS**

Measure and subscales	Entire sample		Mothers		Fathers	
	<u>M (SD)</u>	<u>N</u>	<u>M (SD)</u>	<u>n</u>	<u>M (SD)</u>	<u>n</u>
Stereotyped behavior	8.35 (2.91)	55	8.29 (2.83)	35	8.45 (3.12)	20
Communication	9.67 (3.02)	42	9.71 (2.94)	28	9.57 (3.27)	14
Social interaction	8.18 (2.84)	55	8.11 (2.46)	35	8.30 (3.48)	20
Developmental	9.02 (2.09)	55	8.97 (2.16)	35	9.10 (2.00)	20
Autism quotient	91.36 (15.16)	55	90.80 (14.64)	35	92.35 (16.38)	20

Resource/Needs Inventory.

Means and standard deviations are presented for mothers and fathers on ranking of needs variables from the Resource/Needs Inventory. A summary is provided in Table 7. One couple was excluded from the ranking of the residential treatment variable because they interpreted it as in-home treatment rather than institutional care.

Mothers who participated with a partner or alone.

Mean scores on the PSI, FIQ, and GARS for mothers who participated with their partners ($n = 19$) and mothers who participated alone ($n = 16$) are presented in Tables 8, 9, and 10. Similar comparisons were not done for fathers, because only one father participated alone. Group differences are examined in a later section.

Correlations

SES, educational level and parent sex.

Correlation coefficients were calculated to examine the relationships among the PSI, FIQ, GARS, Resource/Needs Inventory, and demographic variables. Socioeconomic status and educational level for this study were based on the highest-level occupation and level of education in each family, respectively. No significant correlations were found between family SES, educational level, parent sex and the PSI, FIQ and GARS (see Table 11). Some significant correlations were found between SES, educational level, parent sex and the variables on the Resource/Needs Inventory (see Table 12). Socioeconomic status correlated negatively with the need for other parent contact/support groups ($r = -.39, p < .01$) and the need for community acceptance/understanding neighbors ($r = -.36, p < .01$)

Table 7Means and Standard Deviations for Mothers and Fathers on Resource/Needs Inventory

Need	Entire sample	Mothers	Fathers
	<u>N</u> = 55	<u>n</u> = 35	<u>n</u> = 20
	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)
Money	4.42 (3.74)	4.23 (3.85)	4.75 (3.61)
Support of relatives	7.73 (3.97)	7.34 (4.34)	8.40 (3.23)
Respite	10.44 (5.32)	10.31 (5.25)	10.65 (5.56)
Support of spouse	4.81 (5.28) ^a	4.91 (4.90) ^c	4.65 (6.01)
Support of church	16.55 (3.24)	16.37 (3.43)	16.85 (2.92)
Other parent contact	10.16 (3.91)	9.51 (3.34)	11.30 (4.62)
Babysitters	9.45 (4.15)	9.23 (4.13)	9.85 (4.26)
Recreation for self	11.98 (4.21)	11.86 (3.72)	12.20 (5.06)
Recreation for child	10.07 (3.73)	10.60 (3.90)	9.15 (3.28)
Community acceptance	11.42 (3.66)	11.89 (3.38)	10.60 (4.06)
Counseling	13.45 (3.59)	13.14 (4.00)	14.00 (2.73)
Residential treatment	15.92 (3.51) ^b	15.77 (4.20) ^c	15.42 (3.79) ^d
Early diagnosis	6.13 (4.71)	5.54 (4.53)	7.15 (4.98)
Agency information	9.85 (4.47)	10.20 (4.70)	9.25 (4.08)
Transportation for child	11.67 (4.93)	11.83 (4.82)	11.40 (5.23)

(table continues)

	Entire sample	Mothers	Fathers
	<u>N</u> = 55	<u>n</u> = 35	<u>n</u> = 20
Need	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)	<u>M</u> (<u>SD</u>)
Knowledgeable professionals	6.44 (4.01)	6.20 (3.82)	6.85 (4.40)
Legal help	14.87 (4.12)	14.54 (3.90)	15.45 (4.52)
Day program/teachers	5.56 (4.24)	5.17 (3.97)	6.25 (4.70)
In-home training	11.09 (5.44)	12.43 (5.18)	8.75 (5.20)

^an = 54. ^bn = 53. ^cn = 34. ^dn = 19.

Table 8

Mean Scores and Standard Deviations for Mothers Who Participated With a Partner and Mothers Who Participated Alone on the PSI

Measure and subscales	Mothers (partner participation)		Mothers (alone)	
	<u>M (SD)</u>	<u>n</u>	<u>M (SD)</u>	<u>n</u>
PSI Child domain	144.53 (22.00)	19	137.31 (29.08)	16
Distractibility/hyperactivity	31.63 (6.85)	19	31.63 (6.44)	16
Adaptability	35.95 (6.80)	19	33.06 (6.50)	16
Reinforces parent	13.53 (4.46)	19	13.44 (6.28)	16
Demandingness	28.11 (6.30)	19	28.25 (6.60)	16
Mood	13.21 (3.15)	19	12.81 (3.85)	16
Acceptability	22.11 (3.70)	19	20.00 (5.61)	16
PSI Parent domain	131.84 (33.78)	19	136.81 (22.92)	16
Competence	31.74 (9.56)	19	30.00 (6.13)	16
Isolation	14.05 (4.71)	19	14.50 (3.92)	16
Attachment	11.84 (3.06)	19	12.38 (3.83)	16
Health	14.21 (5.08)	19	14.81 (3.51)	16
Role restriction	20.79 (5.44)	19	22.69 (6.13)	16
Depression	20.84 (7.68)	19	20.56 (4.83)	16
Spouse	18.37 (4.88)*	19	21.88 (5.58)*	16

(table continues)

Measure and subscales	Mothers (partner participation)		Mothers (alone)	
	<u>M (SD)</u>	<u>n</u>	<u>M (SD)</u>	<u>n</u>
PSI Total stress	276.37 (48.07)	19	272.88 (45.77)	16
Life stress	11.84 (9.74)	19	8.56 (10.77)	16

* $p < .10$.

Table 9

Mean Scores and Standard Deviations for Mothers Who Participated With a Partner and Mothers Who Participated Alone on the FIO

Subscales	Mothers (partner participation)		Mothers (alone)	
	<u>M</u> (<u>SD</u>)	<u>n</u>	<u>M</u> (<u>SD</u>)	<u>n</u>
	Social life	13.84 (7.32)	19	17.31 (8.62)
Negative feelings toward parenting	11.26 (4.66)	19	11.50 (5.63)	16
Positive feelings toward parenting	8.74 (5.75)	19	10.63 (6.33)	16
Financial impact	8.84 (4.81)***	19	13.63 (4.92)***	16
Impact on marriage	4.95 (4.36)	19	4.43 (3.50)	14
Impact on siblings	7.44 (3.50)	16	8.14 (6.14)	14

*** $p < .01$.

Table 10

Mean Scores and Standard Deviations for Mothers Who Participated With a Partner and Mothers Who Participated Alone on the GARS

Measure and subscales	Mothers (partner participation)		Mothers (alone)	
	<u>M (SD)</u>	<u>n</u>	<u>M (SD)</u>	<u>n</u>
Stereotyped behavior	9.11 (2.60)*	19	7.31 (2.87)*	16
Communication	9.92 (3.40)	13	9.53 (2.59)	15
Social interaction	8.47 (2.46)	19	7.69 (2.47)	16
Developmental	9.32 (2.21)	19	8.56 (2.10)	16
Autism quotient	93.53 (14.42)	19	87.56 (14.68)	16

* $p < .10$.

Table 11Correlations Between SES, Educational Level, Parent Sex and the PSI, FIQ, and GARS

Measures and subscales	SES	Educational level	Parent sex
PSI – Child domain	.12	-.01	.00
PSI – Parent domain	-.08	-.16	.11
PSI – Total stress	.00	-.11	.06
FIQ – Social life	.14	.09	.11
FIQ – Negative feelings toward parenting	.14	.13	-.04
FIQ – Positive feelings toward parenting	-.16	-.25	.16
FIQ – Financial impact	.22	.18	.24
FIQ – Impact on marriage	-.17	-.01	-.04
FIQ – Impact on siblings	-.03	-.07	-.01
GARS – Autism quotient	-.09	-.22	-.05

Table 12Correlations Between SES, Educational Level, Parent Sex and the Resource/NeedsInventory

Need	SES	Educational level	Parent sex
Money	.21	.11	-.07
Support of relatives	-.21	-.35***	-.13
Respite	.07	.10	-.03
Support of spouse	-.04	-.28**	.02
Support of church	-.18	-.19	-.07
Other parent contact	-.39***	-.22	-.22
Babysitters	-.01	.02	-.07
Recreation for self	.04	.16	-.04
Recreation for child	.05	-.12	.19
Community acceptance	-.36***	-.38***	.17
Counseling	.15	.26*	-.12
Residential treatment	.37***	.55***	.11
Early diagnosis	-.01	.01	-.17
Agency information	.04	-.08	.10
Transportation for child	.02	.21	.04
Knowledgeable professionals	.16	-.04	-.08

(table continues)

Need	SES	Educational level	Parent sex
Legal help	.12	.18	-.11
Day program/teachers	-.03	-.08	-.12
In-home training	-.03	-.06	.33**

* $p < .10$. ** $p < .05$. *** $p < .01$.

and positively with the need for good residential treatment ($r = .37, p < .01$). Educational level correlated negatively with the need for support of relatives ($r = -.35, p < .01$), need for support of spouse ($r = -.28, p < .05$), and the need for community acceptance/understanding neighbors ($r = -.38, p < .01$), and correlated positively with the need for good residential treatment ($r = .55, p < .01$). Parents who fell into higher SES levels reported increased needs for other parent contact and community acceptance and a lesser need for residential treatment. Parents who fell into higher educational levels reported increased needs for the support of relatives and spouses, as well as an increased need for community acceptance, and a lesser need for residential treatment. Parent sex correlated significantly with the need for in-home training in managing the child ($r = .33, p < .05$). Mothers indicated a lesser need for in-home training.

Other demographic variables.

The age of the child at diagnosis (see Table 13) correlated negatively with the PSI Child Domain ($r = -.28, p < .05$), FIQ – Negative Feelings Toward Parenting ($r = -.29, p < .05$), and GARS – Autism Quotient ($r = -.28, p < .05$). The earlier the child received the diagnosis, the higher the scores on these three variables. These findings suggest that children who received an earlier diagnosis had more severe autism and were the source of more stress to their parents. Further, parents of children with earlier diagnoses reported more negative feelings toward parenting.

The current age of the child correlated negatively with the PSI Parent Domain ($r = -.32, p < .05$), PSI Total Stress score ($r = -.27, p < .05$), and FIQ – Negative feelings

Table 13Correlations Between Age at Diagnosis, Current Age and the PSI, FIQ, and GARS

Measures and subscales	Age at diagnosis	Current age
PSI – Child domain	-.28**	-.14
PSI – Parent domain	-.13	-.32**
PSI – Total stress	-.23*	-.27**
FIQ – Social life	-.17	-.03
FIQ – Negative feelings toward parenting	-.29**	-.35***
FIQ – Positive feelings toward parenting	.07	.12
FIQ – Financial impact	-.20	-.12
FIQ – Impact on marriage	-.20	-.07
FIQ – Impact on siblings	-.24	.01
GARS – Autism quotient	-.28**	.22

* $p < .10$. ** $p < .05$. *** $p < .01$.

toward parenting ($r = -.35, p < .01$). Parents with younger children reported more stress over their ability to parent, more overall stress, and more negative feelings toward parenting.

The number of siblings in a family (see Table 14) correlated negatively with the PSI Child Domain ($r = -.28, p < .05$), FIQ – Negative Feelings Toward Parenting ($r = -.29, p < .05$), and FIQ – Impact on Marriage ($r = -.34, p < .05$). Interestingly, families with more children reported less stressful child-rearing experiences, fewer negative feelings toward parenting, and that their children with autism were having less of an impact on their marriages. Sex of the child did not correlate significantly with the PSI, FIQ, or GARS.

The age of the child at diagnosis (see Table 15) correlated negatively with the following items on the Resource/Needs Inventory: need for support of spouse ($r = -.36, p < .01$), the need for other parent contact/support groups ($r = -.39, p < .01$), and the need for community acceptance/understanding neighbors ($r = -.36, p < .01$). The older the child at diagnosis, the greater the need for spousal support, other parent contact, and community acceptance.

The child's current age (see Table 15) correlated negatively with the needs for other parent contact, $r = -.30, p < .05$ and community acceptance, $r = -.27, p < .05$. The child's age correlated positively with the needs for an early diagnosis, $r = .38, p < .01$ and in-home training in managing the child, $r = .43, p < .01$. Parents of younger children

Table 14Correlations Between Number of Siblings, Child Sex and the PSI, FIQ, and GARS

Measures and subscales	Number of siblings	Child sex
PSI – Child domain	-.28**	.11
PSI – Parent domain	-.11	-.13
PSI – Total stress	-.22	-.02
FIQ – Social life	.08	-.11
FIQ – Negative feelings toward parenting	-.29**	-.02
FIQ – Positive feelings toward parenting	.19	.15
FIQ – Financial impact	.08	-.06
FIQ – Impact on marriage	-.34**	-.20
FIQ – Impact on siblings	.12	-.14
GARS – Autism quotient	-.09	-.08

**p < .05.

Table 15

Correlations Between Child's Age at Diagnosis, Child's Current Age, Number of Siblings, Child Sex and the Resource/Needs Inventory

Need	Age at diagnosis	Child's current age	Number of siblings	Child sex
Money	-.01	.07	-.19	-.09
Support of relatives	-.15	-.20	-.02	-.22
Respite	.11	.02	-.27*	.28**
Support of spouse	-.36***	-.23*	.00	-.09
Support of church	.02	-.04	.15	.04
Other parent contact	-.39***	-.30**	-.40***	-.21
Babysitters	.16	.11	-.04	.12
Recreation for self	.03	.01	.03	.13
Recreation for child	-.14	-.07	.03	-.21
Community acceptance	-.36***	-.27**	-.03	-.21
Counseling	-.02	-.04	-.03	.06
Residential treatment	-.08	.07	.07	.23*
Early diagnosis	.02	.38***	.34**	.10
Agency information	.27	.26*	-.11	-.21
Transportation for child	.30	.03	-.01	-.04

(table continues)

Need	Age at diagnosis	Child's current age	Number of siblings	Child sex
Knowledgeable professionals	.06	.04	.23*	.19
Legal help	-.12	-.26*	.15	.08
Day program/teachers	.05	-.18	-.02	.00
In-home training	.22	.43***	.19	.02

* $p < .10$. ** $p < .05$. *** $p < .01$.

reported less need for other parent contact and community acceptance and a greater need for an early, consistent diagnosis and in-home training.

Families with more siblings reported greater need for other parent contact, $r = -.40$, $p < .01$ and less need for an early, consistent diagnosis, $r = .34$, $p < .05$. Parents of female children reported less need for respite than parents of male children, $r = .28$, $p < .05$.

Stress in parents.

To examine the relationship between parental stress and the perception of whether parents' needs were being met (Hypothesis 1), the correlation between the PSI Total Stress score and the total score on the Fulfilled Needs Inventory was calculated. Response rates for three of the Fulfilled Needs Inventory variables were quite low, because many parents labeled them "not applicable." Consequently, they were not included in the total score on the Fulfilled Needs Inventory. These three variables were: need for support of church/synagogue ($n = 18$), need for good residential treatment ($n = 32$), and need for legal help ($n = 43$). The remaining 16 variables were used to calculate a total score on the Fulfilled Needs Inventory for each parent. Results indicated that the Fulfilled Needs score did not correlate significantly with the PSI Total Stress score ($r = -.26$, $p = .08$). However, the trend toward significance suggested that parents with lower Total Stress scores perceive more of their needs are being met than parents with higher Total Stress scores.

PSI, FIQ, and GARS.

To examine the relationship between parental stress and the level of impact of the child with autism on their families (Hypothesis 2), the PSI and FIQ were correlated. Results indicated that all six subscales of the FIQ correlated significantly with the PSI Child Domain, PSI Parent Domain, and PSI Total Stress score (see Table 16). This suggests that parents with lower levels of stress feel their children with autism are having less of an impact on their families.

To investigate the relationship between parental stress and severity of autism, scores on the PSI and the GARS were correlated (Hypothesis 3). Results indicated that the GARS Autism Quotient correlated significantly with the PSI Child Domain, $r = .59$, $p < .01$ and the PSI Total Stress score, $r = .41$, $p < .01$ (see Table 17), suggesting that parents with lower levels of stress have children with less severe autism.

Table 18 lists the correlations between the GARS Autism Quotient and the six subscales of the FIQ. Significant correlations were found between the GARS and FIQ – Social Life ($r = .36$, $p < .01$), FIQ – Negative Feelings Toward Parenting ($r = .29$, $p < .05$), and FIQ – Impact on Siblings ($r = .51$, $p < .01$). Parents who reported having children with more severe autism also reported more negative feelings toward parenting and that their children had more of an impact on their social lives and on their siblings.

Table 16Correlations Between the PSI and FIQ

Subscales	PSI – Child domain	PSI – Parent domain	PSI – Total stress
FIQ – Social life	.65***	.51***	.65***
FIQ – Negative feelings toward parenting	.71***	.56***	.72***
FIQ – Positive feelings toward parenting	-.57***	-.46***	-.59***
FIQ – Financial impact	.41***	.29**	.38***
FIQ – Impact on marriage	.34**	.55***	.52***
FIQ – Impact on siblings	.66***	.39***	.59***

p < .05. *p < .01.

Table 17Correlations Between the PSI and GARS

Measure and subscales	GARS – Autism quotient
PSI – Child domain	.59***
PSI – Parent domain	.18
PSI – Total stress	.41***

*** $p < .01$.

Table 18Correlations Between the FIQ and GARS

Subscales	GARS – Autism quotient
FIQ – Social life	.36***
FIQ – Negative feelings toward parenting	.29**
FIQ – Positive feelings toward parenting	-.20
FIQ – Financial impact	.16
FIQ – Impact on marriage	.15
FIQ – Impact on siblings	.51***

p < .05. *p < .01.

Examination of Group Differences

Mothers versus fathers.

Differences between mothers and fathers scores on the PSI, GARS, and FIQ were examined using t tests. Means are presented in Tables 4, 5 and 6. Results of the t tests are shown in Table 19. On the PSI, mothers and fathers differed significantly on the Attachment subscale, $t(53) = 2.06, p < .05$. The higher scores of fathers suggested that they were significantly less emotionally close to their children with autism and felt unable to understand their children's feelings, compared to mothers. Abidin (1983) notes in the PSI manual that many parents who receive high scores on this subscale are less vigilant in monitoring their children's behavior.

One subscale of the FIQ, the Financial Impact subscale, approached significance, $t(53) = -1.77, p = .08$. Mothers' scores were higher than fathers' were, suggesting that they perceived their children with autism as having more of a financial impact on their families than fathers. There were no significant differences between mothers' and fathers' scores on the GARS.

Mothers versus fathers from the same family.

Differences between mothers and fathers from the same family ($n = 19$) were examined using paired samples t tests. Consistent with the finding for the whole sample, mothers and fathers who participated together (i.e., same child) were significantly different in their scores on the PSI Attachment subscale, $t(18) = -2.60, p < .05$. The trend toward

Table 19Independent t Test Results Comparing Mothers and Fathers on the PSI, FIQ, and GARS

Measures and subscales	t value	df	p
PSI Child domain	0.02	53	.98
Distractibility/hyperactivity	-0.69	53	.50
Adaptability	0.15	53	.88
Reinforces parent	0.97	53	.34
Demandingness	-0.66	53	.52
Mood	-0.43	53	.67
Acceptability	0.23	53	.82
PSI Parent domain	-0.77	53	.45
Competence	-0.60	53	.55
Isolation	0.34	53	.74
Attachment	2.06**	53	.05
Health	-0.61	53	.54
Role restriction	-1.04	53	.30
Depression	-1.01	53	.32
Spouse	-1.92*	53	.06
PSI Total stress	-0.42	53	.68
Life stress	-0.67	53	.51

(table continues)

Measures and subscales	t value	df	p
FIQ – Social life	-0.81	53	.42
FIQ – Negative feelings toward parenting	0.31	53	.76
FIQ – Positive feelings toward parenting	-1.18	53	.25
FIQ – Financial impact	-1.77*	53	.08
FIQ – Impact on marriage	0.28	50	.78
FIQ – Impact on siblings	0.08	45	.94
GARS – Stereotyped behavior	0.20	53	.84
GARS – Communication	-0.14	40	.89
GARS – Social interaction	0.23	53	.82
GARS – Developmental	0.22	53	.83
GARS – Autism quotient	0.36	53	.72

*p < .10. **p < .05.

significance on the FIQ – Financial Impact subscale for mothers and fathers in total did not emerge in this sample, $t(18) = .89, p = .39$.

Mothers who participated with a partner versus mothers who participated alone.

Group differences on the PSI, FIQ, and GARS between mothers who participated with a partner in the study and mothers who participated alone were investigated using independent t tests. Group means are reported in Tables 8, 9 and 10. Resulting t test values for all three scales are listed in Table 20. There were no significant differences between the two groups of mothers on the PSI, although there was one trend towards significance. On the Spouse subscale of the PSI, there was a trend for mothers who participated alone to have higher scores, $t(33) = 1.98, p = .06$. Higher scores on this subscale suggest that parents are lacking emotional, and tangible or physical support of their partners in managing their children (Abidin, 1983).

On the six subscales of the FIQ, only Financial Impact reached significance, $t(33) = 2.90, p < .01$. Mothers who participated alone received a higher mean score, suggesting that they felt their children with autism were having a significantly greater financial impact on the family than mothers who participated with a partner. Five of the six subscale mean scores were higher for mothers who participated without a partner.

There was one trend towards significance on the Stereotyped Behaviors subscale of the GARS. Mothers who participated with a partner received higher scores than mothers who participated alone, $t(33) = -1.94, p = .06$. Mothers who participated with a partner received a mean score of 9.11 ($SD = 2.60$), which is quite close to the normative

Table 20

Independent t Test Results Comparing Mothers Who Participated With a Partner and Mothers Who Participated Alone on the PSI, FIQ, and GARS

Measures and subscales	t value	df	p
PSI Child domain	-0.84	33	.41
Distractibility/hyperactivity	0.00	33	1.00
Adaptability	-1.28	33	.21
Reinforces parent	-0.05	33	.96
Demandingness	0.07	33	.95
Mood	-0.34	33	.74
Acceptability	-1.33	33	.19
PSI Parent domain	0.50	33	.62
Competence	-0.63	33	.54
Isolation	0.30	33	.77
Attachment	0.46	33	.65
Health	0.40	33	.69
Role restriction	0.97	33	.34
Depression	-0.13	33	.90
Spouse	1.98*	33	.06
PSI Total stress	-0.22	33	.83

(table continues)

Measures and subscales	t value	df	p
Life stress	-0.95	33	.35
FIQ – Social life	1.29	33	.21
FIQ – Negative feelings toward parenting	0.14	33	.89
FIQ – Positive feelings toward parenting	0.92	33	.36
FIQ – Financial impact	2.90***	33	.01
FIQ – Impact on marriage	-0.37	31	.72
FIQ – Impact on siblings	0.39	28	.70
GARS – Stereotyped behavior	-1.94*	33	.06
GARS – Communication	-0.34	26	.73
GARS – Social interaction	-0.94	33	.35
GARS – Developmental	-1.03	33	.31
GARS – Autism quotient	-1.21	33	.24

*p < .10. **p < .05. ***p < .01.

mean for the GARS, while mothers who participated alone received a mean score of 7.31 ($SD = 2.87$). The mothers who participated alone rated their children's autism as significantly less severe than mothers who participated with a partner. On all subscales of the GARS, mothers who participated alone reported lower mean scores.

High- versus low-stress parents.

To test the hypothesis (Hypothesis 1) that low-stress parents of children with autism perceived that more of their needs were being met than high-stress parents, independent t tests were run to compare the groups. High-stress parents were classified as those who received Total Stress scores at or above 258 (85th percentile) and low-stress parents were classified as those who received Total Stress scores below 258. The three variables on the Fulfilled Needs Inventory which received low response rates (several "not applicable" items) were removed: need for support of church/synagogue, need for good residential treatment, and need for legal help. Results indicated no significant group differences, $t(43) = 1.41$, $p = .17$. Thus, high- and low-stress parents did not differ in terms of their perception of how well needs were being met.

In order to investigate the hypothesis (Hypothesis 2) that low-stress parents perceived that their children with autism had a lower level of impact on the family than high-stress parents, independent t tests were run. Results were significant for all six subscales of the FIQ: Social Life, $t(53) = -3.84$, $p < .01$; Negative Feelings Toward Parenting, $t(53) = -4.05$, $p < .01$; Positive Feelings Toward Parenting, $t(53) = 3.02$, $p < .01$; Financial Impact, $t(53) = -2.78$, $p < .01$; Impact on Marriage, $t(50) = -3.04$, $p < .01$;

and Impact on Siblings, $t(45) = -3.24$, $p < .01$. These results indicate that low-stress parents perceived that their children with autism had a lower impact on their families than high-stress parents.

The hypothesis (Hypothesis 3) that low-stress parents perceived their children as having less-severe autism, was initially supported by correlational data. Independent t test results comparing the GARS Autism Quotient and subscale scores for the high- and low-stress groups (see Table 21) indicated one trend toward significance, $t(53) = -1.74$, $p = .09$. Thus, the results provide some evidence of an association between level of stress and severity of autism.

Parents with a recent diagnosis versus parents with a former diagnosis.

Parents who had received the diagnosis of autism for their child within the past 12 months ($n = 21$) were compared to the remainder of the parents ($n = 34$). These two groups showed several differences in their scores on the PSI, GARS, and FIQ (see Table 22). Significant differences were found on six subscales of the PSI. Demandingness, a subscale score of the Child Domain, relates to the parent's experience of the child placing a lot of demands on him or her. Separation anxiety and lack of compliance are two key features of this subscale (Abidin, 1983). Parents with a more recent diagnosis reported a higher score on the Demandingness subscale, $t(53) = 3.13$, $p < .01$. Acceptability, another dimension of the PSI Child Domain, measures a parent's expectations or hopes for the child. Higher scores on this domain, reported by the parents with a more recent

Table 21

Independent t Test Results Comparing High- to Low-Stress Parents on the GARS

Measure and subscales	t value	df	p
Stereotyped behaviors	-1.10	53	.28
Communication	-1.25	40	.22
Social interaction	-1.67	53	.10
Developmental	-0.18	53	.86
Autism quotient	-1.74*	53	.09

*p < .10.

Table 22

Means and Standard Deviations for Parents of Children Having Received a Diagnosis of Autism Within the Past 12 Months and Parents of Children Having Received a Diagnosis More Than 12 Months Ago

Measures and subscales	Diagnosis within past 12 months <i>n</i> = 21	Diagnosis more than 12 months ago <i>n</i> = 34
	<u>M (SD)</u>	<u>M (SD)</u>
PSI Child domain	149.67 (23.43)**	136.12 (24.47)**
Distractibility/hyperactivity	32.71 (7.50)	30.21 (5.94)
Adaptability	35.14 (4.59)	34.47 (7.13)
Reinforces parent	15.62 (5.77)	13.09 (5.58)
Demandingness	30.90 (5.03)***	25.79 (6.33)***
Mood	13.52 (3.04)	12.50 (3.18)
Acceptability	23.19 (3.53)**	20.06 (4.98)**
PSI Parent domain	145.14 (26.33)***	123.56 (28.57)***
Competence	33.76 (7.83)***	28.47 (6.31)***
Isolation	16.29 (3.39)**	13.26 (5.00)**
Attachment	13.67 (3.35)	12.35 (3.98)
Health	15.76 (4.63)**	13.26 (3.79)**

(table continues)

Measures and subscales	Diagnosis within	Diagnosis more than
	past 12 months	12 months ago
	$n = 21$	$n = 34$
	<u>M (SD)</u>	<u>M (SD)</u>
Role restriction	23.24 (4.95)**	19.62 (6.52)**
Depression	21.95 (7.22)*	18.94 (5.04)*
Spouse	20.48 (5.22)	17.94 (5.64)
PSI Total stress	294.81 (42.82)***	259.09 (45.59)***
Life stress	11.19 (9.80)	8.79 (8.94)
FIQ – Social life	18.19 (7.99)	12.65 (7.36)
FIQ – Negative feelings toward parenting	13.67 (5.07)	10.24 (5.23)
FIQ – Positive feelings toward parenting	6.19 (4.40)	10.62 (5.70)
FIQ – Financial impact	10.48 (4.98)	9.74 (6.17)
FIQ – Impact on marriage	6.15 (3.91) ^c	4.03 (3.81) ^b
FIQ – Impact on siblings	8.15 (5.47) ^d	7.68 (4.37)
GARS – Stereotyped behavior	8.43 (3.06)	8.29 (2.87)
GARS – Communication	9.10 (1.60) ^a	9.84 (3.34) ^b
GARS – Social interaction	8.19 (2.44)	8.18 (3.10)
GARS – Developmental	8.29 (2.51)**	9.47 (1.66)**
GARS – Autism quotient	89.48 (14.05)	92.53 (15.90)

^a $n = 10$. ^b $n = 32$. ^c $n = 20$. ^d $n = 13$

* $p < .10$. ** $p < .05$. *** $p < .01$.

diagnosis, suggest that their children have not met parents' hopes and expectations, $t(53) = 2.51, p < .05$.

Scores on four subscales of the PSI Parent Domain were significantly higher for parents with a more recent diagnosis. Those subscales were Competence, $t(53) = 2.76, p < .01$; Isolation, $t(53) = 2.44, p < .05$; Health, $t(53) = 2.18, p < .05$; and Role Restriction, $t(53) = 2.18, p < .05$. Competence relates to a parent feeling overwhelmed with the parenting role. Abidin (1983) reports that parents of disabled children often have elevated scores. The Isolation subscale is an expression of parents' feeling isolated from their spouses, relatives, or friends. High scores in this area are of considerable significance, as these parents are often neglectful of their children and are at greater risk of abusing them. This risk is elevated even more when the Role Restriction subscale is high (Abidin, 1983). High scores on the Health subscale indicate that parents' health may be deteriorating as a result of some dysfunction in the parent/child system. High scores on the Role Restriction subscale are suggestive of parents' feeling they are controlled by their children and have little freedom. Parents of children with a more recent diagnosis had significantly higher scores on all four subscales compared to parents with a former diagnosis. Parents of children with a more recent diagnosis also displayed a trend towards elevated scores on the Depression subscale of the PSI, $t(53) = 1.82, p = .07$. High scores on this subscale indicate not only depression, but also guilt and dissatisfaction. The PSI Child Domain score, $t(53) = 2.03, p < .05$, PSI Parent Domain score, $t(53) = 2.80, p <$

.01, and PSI Total score, $t(53) = 2.89$, $p < .01$ were all significantly higher in parents with a more recent diagnosis.

Parents of children with a more recent diagnosis were significantly different from the rest of the parents on two of the FIQ subscales: Negative Feelings Toward Parenting, $t(53) = 2.39$, $p < .05$, and Positive Feelings Toward Parenting, $t(53) = -3.04$, $p < .01$. Parents with more recently diagnosed children reportedly felt more negative feelings towards parenting and fewer positive feelings toward parenting. Scores on a third subscale, Impact on Marriage, were also elevated for the recently-diagnosed group, although not significantly, $t(53) = 1.93$, $p = .06$.

Finally, on the GARS, only one significant difference was found between parents of children with a more recent diagnosis and parents of the rest of the children. Specifically, parents of children with a more recent diagnosis reported a lower Developmental Disturbances subscale score, $t(53) = -2.11$, $p < .05$.

High life-stress parents versus other parents.

Eight parents in the sample had PSI Total Stress scores in excess of 250 concurrent with Life Stress scores of at least 17. Abidin (1983) suggested that those parents who fall into this group may be in need of professional assistance. To look for differences between this group of eight parents and the remainder of the sample, t tests were conducted. These high life-stress parents reported significantly higher scores on five components of the PSI: Distractibility/hyperactivity, $t(53) = 2.46$, $p < .05$; Isolation, $t(53) = 2.17$, $p < .05$; Spouse, $t(53) = 2.34$, $p < .05$; Parent Domain, $t(53) = 2.05$, $p < .05$;

and Total Stress, $t(53) = 2.10, p < .05$. This same group of parents also reported a significantly higher score on the Impact on Siblings subscale of the FIQ, $t(45) = 3.62, p < .01$ and significantly higher scores on three components of the GARS: Stereotyped Behaviors, $t(53) = 2.51, p < .05$; Developmental Disturbances, $t(53) = 2.47, p < .05$; and Autism Quotient, $t(53) = 2.37, p < .05$.

Comparisons of Ranked Data

Entire sample.

Freidman tests were conducted to examine the hypothesis that financial and social support-type needs would be ranked higher than legal help, recreational, and residential needs (Hypothesis 4). Three parents were omitted from the tests because one mother rated need for spouse/partner as “not applicable” and one couple interpreted the need for good residential treatment to be in-home therapy rather than institutional care. Results indicated significant differences between variables in terms of their ranks, $\chi^2(18, N = 52) = 395.04, p < .01$. Mean rankings for the sample as a whole are listed in Table 23. Parents ranked the need for money/financial assistance most highly ($M = 4.19$). Need for family social supports also ranked highly (i.e., support of spouse, $M = 4.21$, support of relatives, $M = 7.52$). Community social supports, however, were not ranked as highly (i.e., other parent contact, $M = 10.12$, community acceptance, $M = 11.31$). Very high rankings were also found for professional support needs (i.e., day program/teachers, $M = 5.38$, early diagnosis, $M = 6.11$, knowledgeable professionals, $M = 6.48$). As hypothesized, needs related to legal help and residential treatment ranked low. Need for

Table 23Resource/Needs Inventory Mean Ranks in Descending Order

Need	Mean rank
Money	4.19
Support of spouse	4.21
Day program/teachers	5.38
Early diagnosis	6.11
Knowledgeable professionals	6.48
Support of relatives	7.52
Babysitters	9.32
Recreation for child	9.87
Other parent contact	10.12
Agency information	10.12
Respite	10.48
In-home training	11.17
Community acceptance	11.31
Transportation for child	11.48
Recreation for self	11.92
Counseling	13.35
Legal help	14.81
Residential treatment	15.77
Support of church	16.40

church support also ranked low. Need for recreation opportunities was ranked as less important for self ($M = 11.92$) than for child ($M = 9.87$).

Mothers versus fathers.

Mann-Whitney U tests were used to compare mothers' and fathers' mean rankings for the 19 variables of the Resource/Needs Inventory (see Table 24). A significant difference was found for the need for in-home training in managing the child, $U = 212.50$, $p < .05$. Fathers' mean ranking for this need was 8.84, while mothers' mean ranking was 12.52, suggesting that fathers, compared to mothers, felt a significantly greater need for in-home training. Fathers ranked support of spouse as their greatest need ($M = 3.89$), while mothers ranked it second ($M = 4.39$) to their need for money ($M = 4.03$).

Mothers versus fathers from the same family.

Differences between mothers and fathers from the same family were examined using Wilcoxin Signed Ranks tests. Consistent with the finding for the whole sample, parents who participated together ranked two needs significantly different. Specifically, a significant difference was found in the need for in-home training in managing the child, $z = -2.44$, $p < .05$. Mothers' mean rank was 12.32 and fathers' mean rank was 8.95, suggesting that fathers felt the need for in-home training was more important, compared to mothers. Concerning the need for recreation opportunities for the child, fathers ranked this need as significantly more important than mothers, $z = -2.20$, $p < .05$. Fathers' mean rank was 9.26 and mothers' was 11.63.

Table 24

Resource/Needs Inventory Mean Ranks for Mothers and Fathers

Need	Entire sample N = 52	Mothers n = 33	Fathers n = 19
Money	4.19	4.03	4.47
Support of spouse	4.21	4.39	3.89
Day program/teachers	5.38	5.21	5.68
Early diagnosis	6.11	5.38	7.37
Knowledgeable professionals	6.48	6.24	6.89
Support of relatives	7.52	7.18	8.11
Babysitters	9.32	9.11	9.68
Recreation for child	9.87	10.45	8.84
Other parent contact	10.12	9.39	11.37
Agency information	10.12	10.48	9.47
Respite	10.48	10.42	10.58
In-home training	11.17	12.52**	8.84**
Community acceptance	11.31	11.85	10.37
Transportation for child	11.48	11.67	11.16
Recreation for self	11.92	11.67	12.37
Counseling	13.35	13.18	13.63
Legal help	14.81	14.48	15.37
Residential treatment	15.77	16.03	15.32
Support of church	16.40	16.30	16.58

**p < .05.

Mothers who participated with a partner versus mothers who participated alone.

Table 25 lists the mean ranks for mothers who participated with a partner in the study and mothers who participated alone. Examination of group differences using Mann-Whitney U tests revealed no significant differences between the two groups of mothers on their mean ranks. However, mothers who participated with a partner ranked support of spouse as their greatest need ($M = 3.67$) while mothers who participated alone ranked it ($M = 5.27$) after their need for money ($M = 4.33$) and good day programs/teachers ($M = 5.00$).

High- versus low-stress parents.

Table 26 lists the mean ranks for high- and low-stress parents. Examination of group differences using Mann-Whitney U tests revealed significant differences between groups on the need for support of the church, $U = 232.50$, $p < .05$ and the need for agency information/cooperation, $U = 225.00$, $p < .05$. Low-stress parents ranked the need for agency information more highly than high-stress parents (8.00 versus 11.67). Low-stress parents ranked their need for church lowest (17.64), as did the high-stress parents (15.50), but their mean ranking was over two points lower.

Children over age 6 versus children under age 6.

To examine whether there were differences between parents of older children and parents of younger children in perception of needs, mean rankings of the Resource/Needs Inventory for parents of children age 6 and over and parents of children under age 6 were

Table 25

Resource/Needs Inventory Mean Ranks for Mothers Who Participated With a Partner and Mothers Who Participated Alone

Need	Entire sample	Mothers (partner participation)	Mothers (alone)
	<u>N</u> = 52	<u>n</u> = 18	<u>n</u> = 15
Money	4.19	3.78	4.33
Support of spouse	4.21	3.67	5.27
Day program/teachers	5.38	5.39	5.00
Early diagnosis	6.11	5.72	4.97
Knowledgeable professionals	6.48	6.22	6.27
Support of relatives	7.52	6.83	7.60
Babysitters	9.32	8.78	9.50
Recreation for child	9.87	11.28	9.47
Other parent contact	10.12	9.61	9.13
Agency information	10.12	10.44	10.53
Respite	10.48	9.11	12.00
In-home training	11.17	12.78	12.20
Community acceptance	11.31	11.61	12.13
Transportation for child	11.48	11.89	11.40
Recreation for self	11.92	12.11	11.13
Counseling	13.35	13.00	13.40
Legal help	14.81	15.06	13.80
Residential treatment	15.77	16.61	15.33
Support of church	16.40	16.11	16.53

Table 26

Resource/Needs Inventory Mean Ranks for High- and Low-Stress Parents

Need	Entire sample N = 52	High-stress n = 30	Low-stress n = 22
Money	4.19	4.40	3.91
Support of spouse	4.21	4.63	3.64
Day program/teachers	5.38	5.87	4.73
Early diagnosis	6.11	5.55	6.86
Knowledgeable professionals	6.48	6.23	6.82
Support of relatives	7.52	7.07	8.14
Babysitters	9.32	9.08	9.64
Recreation for child	9.87	9.60	10.23
Other parent contact	10.12	9.93	10.36
Agency information	10.12	11.67**	8.00**
Respite	10.48	10.43	10.55
In-home training	11.17	11.93	10.14
Community acceptance	11.31	10.63	12.23
Transportation for child	11.48	11.83	11.00
Recreation for self	11.92	11.67	12.27
Counseling	13.35	13.43	13.23
Legal help	14.81	15.27	14.18
Residential treatment	15.77	15.27	16.45
Support of church	16.40	15.50**	17.64**

**p < .05.

compared. Means are listed in Table 27. Parents with younger children ranked two needs significantly more highly than parents with older children: need for early/consistent diagnosis, $U = 225.00$, $p < .05$, and need for in-home training in managing the child, $U = 233.00$, $p < .05$. Parents with older children ranked three needs more highly than parents of younger children: need for support of relatives, $U = 225.00$, $p < .05$, need for other parent contact, $U = 174.50$, $p < .01$, and need for community acceptance/understanding neighbors, $U = 229.00$, $p < .05$.

High life-stress parents and other parents.

Scores of parents in this high life-stress subgroup showed significant differences on three of the needs variables from the Resource/Needs Inventory. The high life-stress parents indicated a significantly greater need for respite, $U = 67.00$, $p < .01$ and residential treatment, $U = 32.50$, $p < .01$ and significantly less need for church, $U = 81.50$, $p < .01$.

Chi-Square Analyses

Chi-square analyses (see Table 28) were conducted to examine whether parents differed on the Fulfilled Needs Inventory, the measure of how perceived needs were being met. Each variable was compared for mothers versus fathers, mothers who participated with a partner versus mothers who participated alone, and high-stress versus low-stress parents.

Mothers versus fathers.

Initial chi-square tests for mothers and fathers had more than 20% of cells with an expected cell count less than five. The 5-point Likert-type scale for the Fulfilled Needs

Table 27

Resource/Needs Inventory Mean Ranks for Parents of Children Age 6 and Over and
Children Under Age 6

Need	Entire sample N = 52	Age > 71 mos n = 21	Age ≤ 71 mos n = 31
Money	4.19	4.81	3.77
Support of spouse	4.21	3.71	4.55
Day program/teachers	5.38	4.62	5.90
Early diagnosis	6.11	7.88**	4.90**
Knowledgeable professionals	6.48	7.10	6.06
Support of relatives	7.52	6.00**	8.55**
Babysitters	9.32	9.98	8.87
Recreation for child	9.87	9.33	10.23
Other parent contact	10.12	8.10***	11.48***
Agency information	10.12	10.95	9.55
Respite	10.48	11.48	9.81
In-home training	11.17	13.00**	9.94**
Community acceptance	11.31	10.14**	12.10**
Transportation for child	11.48	10.76	11.97
Recreation for self	11.92	11.43	12.26
Counseling	13.35	13.62	13.16
Legal help	14.81	14.05	15.32
Residential treatment	15.77	16.57	15.23
Support of church	16.40	16.48	16.35

p < .05. *p < .01.

Table 28Chi-Square Analyses of the Fulfilled Needs Inventory

Need	Mothers versus fathers	Low-stress versus high-stress parents	Mothers with partner versus alone
Money	0.13	0.01	2.76
Support of relatives	0.21	8.15***	0.46
Respite	0.62	0.82	1.17
Support of spouse	2.47	2.88	1.56
Support of church	2.92	1.17	1.03
Other parent contact	1.11	0.20	0.34
Babysitters	0.96	1.31	2.51
Recreation for self	3.42*	8.92***	1.17
Recreation for child	0.29	2.27	0.44
Community acceptance	0.93	1.42	2.33
Counseling	0.25	1.17	0.52
Residential treatment	1.25	1.89	0.01
Early diagnosis	0.17	0.05	0.05
Agency information	0.38	0.31	0.02
Transportation for child	1.46	0.01	0.44

(table continues)

Need	Mothers versus fathers	Low-stress versus high-stress parents	Mothers with partner versus alone
Knowledgeable professionals	0.62	0.63	0.14
Legal help	0.49	0.27	5.06**
Day program/teachers	0.30	1.09	0.48
In-home training	3.19*	0.84	1.18

* $p < .10$. ** $p < .05$. *** $p < .01$.

Inventory was then collapsed into two groups, a Low Needs Met group (not at all and barely) and a High Needs Met group (adequately, mostly, and very well). Mothers and fathers were compared again using the 2x2 chi-square matrix. Fisher's exact test, a more conservative test of the null hypothesis, was used because it is not dependent on the χ^2 distribution. Exact probabilities are computed (Shavelson, 1988).

Mothers and fathers did not differ significantly on any of the needs met but there were two trends toward significance. Mothers reported more often that their need for recreation for themselves was either not being met or barely being met, while fathers reported more often that their need for recreation was adequately, mostly, or very well met, $\chi^2 (1, N = 55) = 3.42, p = .09$. The need for in-home training in managing the child, also showed a trend toward significance, with mothers reporting more often that this need was better met than fathers, $\chi^2 (1, N = 49) = 3.19, p = .09$.

Mothers who participated with a partner versus mothers who participated alone.

Fisher's exact test was also used to look for differences between mothers who participated with a partner in the study and mothers who participated alone. Results revealed one significant difference. Mothers who participated with their partners reported more often that their need for legal help was either barely being met or not being met at all, compared to mothers who participated alone, $\chi^2 (1, N = 26) = 5.06, p < .05$.

High- versus low-stress parents.

Finally, Fisher's exact test was used to compare high-stress parents to low-stress parents on their perception of needs being met. High-stress parents reported more often

that their need for support of their relatives was not being met or was barely being met compared to low-stress parents, $\chi^2 (1, N = 55) = 8.15, p < .01$ and that their need for recreational opportunities for themselves was more often either not being met or barely being met, $\chi^2 (1, N = 55) = 8.92, p < .01$.

CHAPTER FOUR

Discussion

Hypothesis 1

The first hypothesis was that parents of children with autism who have lower stress scores would perceive that more of their needs were being met than parents whose stress scores are higher. The correlation between the PSI Total Stress score and the total score on the Fulfilled Needs Inventory showed a trend toward significance. However, t test results comparing the high- and low-stress groups were not significant. Taken together, these results do not provide support for Hypothesis 1. These findings suggest that there are other factors contributing to parents' stress, regardless of needs met, such as the severity of a child's autism or internal traits of the parents. Another possible explanation for this finding is that the sample size is too small to detect group differences. In order to investigate whether high- and low-stress parents differed on their perceived needs, chi-square tests were conducted. The results suggest differences between high- and low-stress parents on two particular needs. Low-stress parents report that their need for support from their relatives is better met than high-stress parents, as is their need for recreational opportunities for themselves.

Hypothesis 2

Hypothesis 2 was that parents of children with autism who report lower levels of stress will also report that their children have a lower level of impact on the family than parents who report higher levels of stress. Correlations between scores on the PSI and the

FIQ and the results of t tests that examined group differences between high- and low-stress parents indicate significant differences between these two groups. This is consistent with previous research which has found that parents who report lower levels of stress also report that their children with autism have a lower level of impact on their families (Donenberg & Baker, 1993).

Hypothesis 3

The third hypothesis that was examined was that parents of children with autism who have lower stress scores will have children with less severe autism than parents whose stress scores are higher. The correlation between the PSI Total Stress score and the GARS Autism Quotient was significant. Consistent with the findings of Bebko et al. (1987) and Konstantareas & Homatidis (1989), parents reporting higher levels of stress also reported more severe symptoms of autism in their children. The results of t tests that examined group differences between high- and low-stress parents on the GARS indicated a trend toward significance. Parents with higher levels of stress reported more severe symptoms of autism in their children, compared to parents with lower levels of stress. Taken together, these tests are suggestive of a link between parental stress and severity of autism. Children with more severe autism likely intensify parents' stress. With a larger sample, significant differences may have been detected between the high- and low-stress groups.

Hypothesis 4

The fourth and final hypothesis was that needs related to financial and social support would be rated more highly by parents than other needs. This hypothesis received some support from the results of the study. Parents rank their need for money/financial assistance most highly. Social support needs also rank highly, but only for needs related to family support (i.e., support of spouse, support of relatives). Social support needs from the community are not among the needs ranked most highly by parents. Parents also rank many of the needs related to the professional community highly (i.e., day program/teachers, early/consistent diagnosis, knowledgeable/concerned professionals). Lowest ranking needs include the need for legal help, residential treatment, and support of a church. These findings are consistent with previous research which has found that parents rank their need for support from spouses and relatives among their most important and that those parents who receive the greatest support from their spouses and relatives report the least amounts of stress (Bristol, 1984; Bristol, 1987). Professional support needs have not been emphasized as much as family support needs in the literature. However, many researchers have noted the importance parents place on good day-programs or training to be their own children's therapists (Bristol & Schopler, 1983; Dunlap & Fox, 1996).

The need for babysitters and respite do not appear to be prominent needs for parents, relative to their other needs. This finding is in contrast with the findings of DeMyer & Goldberg (1983) who reported that the need for respite was the second highest

ranking need for parents of children aged 1 to 5 and parents of children aged 6 to 12. In contrast, parents in this sample with children under age 6 ranked respite 14th and parents with children age 6 to 12 ranked respite 9th. There are several possible explanations for this finding. First, DeMyer & Goldberg's study involved parents of children aged 9-29. Only two children were under the age of 12 at the time the study was done. Thus, the study was partially retrospective in nature, relying on parents' recall of the most important needs at different points in their lives. As a result, parents may have been susceptible to recall bias, recalling the need that seemed least met rather than the need that was most important at that time. Further, DeMyer & Goldberg provided no information on the education or therapy programs participated in by the children with autism. In the current study, at least 78% of the children were involved in full-day school or therapy programs. These programs may be providing sufficient relief for parents that they do not feel a great need for more respite. A third possible explanation of this finding is that parents may not believe respite is feasible. Several parents said during their interviews that either their children were too young to leave overnight in another's care or that they couldn't find such care anyway.

Another interesting finding is that the need for other parent contact/support groups ranked 9th overall. Previous research has found that many parents, especially those with school-age children, find support in networking with other parents of children with autism (DeMyer & Goldberg, 1983; Dunlap & Fox, 1996). Consistent with this research, a significant difference was found between groups of parents with preschoolers and parents

with school-age children on the ranked need for other parent contact. Parents of school-age children report a much greater need. Newer parents, it seems, have more of an interest in an early/consistent diagnosis and in-home training in managing their children.

Other Findings

Mothers versus fathers.

Comparisons of mothers to fathers yielded several interesting results. Scores on the PSI Attachment subscale, a measure of the closeness between parent and child, suggest that fathers are less attached to their children with autism than mothers. This could explain, in part, why fathers rank the need for in-home training in managing their children as much more important than mothers. Fathers may feel that they do not understand their children's needs and consequently may need more support in the home to help them communicate with their children or deal with their behaviors. Fathers from the same family as mothers (i.e., with the same child) also report needing more recreational opportunities for their children compared to mothers. Fathers may feel that increasing recreation opportunities would provide the family with some short-term relief from the burden of caring for their children.

A trend toward significance on the Spouse subscale of the PSI suggests that mothers feel a lack of emotional and physical support from their spouses or partners. This is consistent with previous research (Bristol, Gallagher, & Schopler, 1988; Konstantareas & Homatidis, 1989) which has found that mothers often report feeling that they lack spousal support. Fathers, who report feeling significantly less attached to their children

than mothers in this sample, are likely to be less involved in their children's care, increasing the burden on mothers. Many mothers reported in the interviews that they feel solely responsible for the success or failure of their children's treatment programs. They also reported that being continuously vigilant over teachers, curriculums, and treatment programs is exhausting.

There is also a trend on the FIQ suggesting that mothers feel their children are having more of a financial impact on their families, compared to fathers. One possible explanation of this finding is that many mothers are not working outside the home and as a consequence may feel that they are less able to help with the financial situation of their families.

Consistent with the findings of other researchers (Bebko et al., 1987; Konstantareas & Homatidis, 1989), mothers and fathers in this sample agreed on the severity of their children's symptoms of autism. Mothers' and fathers' scores were all below the normative means on the GARS, suggesting that the children in this sample have less severe autism than is typically observed in persons with autism. One possible explanation of this finding is that the majority of children in the sample were involved in behavioral training programs designed to reduce abnormal behaviors. Thus, they may have presented with less severe symptoms as a result of their participation in intensive intervention programs. Indeed, many parents remarked that their children use to display more of the abnormal behaviors listed on the GARS.

Mothers who participated with a partner versus mothers who participated alone.

Mothers who participated in the study without a partner report significantly more financial impact and lack of support from their partners than the mothers who participated with a partner. Previous research has indicated that single mothers of handicapped children report more stress compared to mothers in a dual-parent home (Holroyd, 1974). However, only 2 of the 16 mothers who participated alone did not have a spouse or partner. These findings suggest that there may be more chronic stress associated with the families in which only one partner participated.

Mothers who participated alone in the study reported lower mean scores for all subscales of the GARS compared to mothers who participated with a partner. One possible explanation for this result is that the mothers, who tend also to lack spousal support, may be coping by viewing their children's functioning as better than it actually is.

Parents with a recent diagnosis and parents with a former diagnosis.

Thirty-eight percent of the parents in this sample have children who were diagnosed with autism within the past year. These parents indicate higher levels of stress in several areas compared to parents with a less recent diagnosis. They report their children to be more demanding of their time and attention and feel that they are more restricted by their children. They also report feeling disappointed with their children, incompetent, isolated, and generally unhealthy. Further, they report more negative feelings associated with parenting and that their children with autism have had greater impact on their marriages. It appears that receiving the diagnosis of autism is an

extremely stressful experience that greatly impacts parents' social life and health and places great pressure on their marriages.

Interestingly, parents who had their children diagnosed more than a year ago report higher scores on the GARS Developmental Disturbances subscale. This finding could be the result of recall bias. On this subscale, parents recall and note what developmental milestones their children displayed before the age of 3 (e.g., playing pat-a-cake, showing stranger anxiety). Parents may have a difficult time remembering their children's behaviors from several years ago and may doubt that their children ever showed such skills, considering their current diagnosis. Another possible explanation for this finding is that parents who received the diagnosis more than a year ago are more realistic about the behaviors and skills of their children, whereas parents with a more recent diagnosis may be down-playing the degree of the disability.

The finding that the parents who received a diagnosis within the past 12 months are more stressed than parents who received a diagnosis over a year ago is consistent with the results of previous research (Darling, 1991; Dunlap & Fox, 1996; Marcus, 1984). Parents whose children have been recently diagnosed with autism are an especially important group to target for professional support. The intense pressures in the first year after diagnosis attest to the need for support to be in place promptly to reduce the stress on the family.

It is possible that there does exist a high-stress group of parents with less-recent diagnoses who, because of disillusionment with professionals or overwhelming levels of

stress, chose not to participate in this study. Further, there may be specific phases during a child's development where parents experience higher levels of stress (e.g., diagnosis, school entrance). Parents with a less-recent diagnosis may have children who are not in a transitional phase in their development at this time. Keeping the above considerations in mind, caution should be exercised when interpreting the differences between parents with recent versus former diagnoses.

High life-stress parents versus other parents.

In this sample, 15% of parents report high levels of overall stress concordant with several stressful life experiences in the past year. These parents are an important subgroup because their stresses are so great that they are at increased risk for abusing or neglecting their children (Abidin, 1983). These high life-stress parents report having children with more severe autism and feel that their children are more hyperactive. They are also feeling isolated and lacking in support from their spouses. They report that their children with autism are having more of an impact on their siblings. Consistent with the suggestions for intervention in the PSI manual, these parents report having more respite and residential treatment needs. There does not appear to be any literature on this subgroup of parents. Future research in this area may help us understand whether these children are truly at risk of abuse and how parents may be helped to lower the levels of stress in their lives.

Siblings.

A significant correlation was found between the number of children in a family and parents' perception of child-rearing stress and the impact of the child with autism on the

family. Bouma & Schweitzer (1990) reported no differences between families with more or less children, although most researchers have suggested that more siblings would be more stressful to families. In this sample, parents who had more children report less stress and impact on the family. Although parents are concerned about the impact of the children with autism on their siblings, it appears that the added help and company of other children in the family alleviate some of the stress parents are feeling. Parents with more children have the opportunity to feel many of the joys of parenting (e.g., a warm hug, hearing the words “I love you”) that children with autism rarely provide. Parents with more children may feel more competent in their role as parents because they have more proof that they can be competent in their role.

Limitations of the Study

The relatively small sample size was one limitation of this study. A small sample size results in inadequate power to detect group differences. The small sample size precluded the use of analyses of covariance (ANCOVAs) to control for demographic variables that correlated with the Resource/Needs Inventory. In addition, due to the small sample size and the large number of analyses performed, it is possible that by chance alone a significant result could have been found (i.e., a false positive).

Two potential limitations were encountered using the GARS. First, the self-report nature of questionnaires like the GARS has been criticized for being subject to recall bias and recall loss. Parents may not accurately recall the skills and behaviors their children displayed from several years ago. A second limitation was that ratings of autism severity

were only provided by parents. It may have been useful to have a clinician or teacher rate the severity of autism for each child. These ratings could have then been compared to parent reports to see if perceptions of severity differed.

One final limitation was that the higher parent's educational level was used as the measure of family education. This resulted in a potential confound because a parent may have received a high educational rating (e.g., if the spouse had a university degree) even though his or her own educational level may have been a high school diploma. Thus, correlations between educational level and scores on the questionnaires may not accurately reflect true relationships.

Conclusion

Parents of children with autism in Calgary identified the need for financial assistance as greatest. Many parents stated that they need money to pay for good day programs and teachers for their children. Intensive early intervention, a mediating factor in the long-term outcome of children with autism, involves high costs. Research has shown that children with autism who do not participate in an intensive early intervention program are likely to cost society much more in the long run (Lovaas & Smith, 1989; Schopler & Hennike, 1990). These children, as adults, will require more support in daily living.

Parents also need support from their spouses, relatives, and the professional community. These needs may be especially crucial in the first year after diagnosis, when parents are learning about the implications of this diagnosis on their families. It is unlikely,

however, that spousal support, in the absence of professional and financial assistance will be adequate in preventing a family crisis (Bristol, 1984). Professionals should take note that parents do not stop needing their services after the initial diagnosis. Many parents report feeling that they got the diagnostic runaround and feel that many practitioners are biased toward particular treatment programs and do not disclose all the treatment options to them.

Sixty percent of parents in this sample are reporting clinically significant levels of stress. Fifteen percent are experiencing high levels of overall stress concordant with several stressful life experiences in the past year. It has been suggested that these parents are at great risk of neglecting or otherwise abusing their children (Abidin, 1983). Parents' stresses were often apparent during interviews. Many parents cried while talking about their experiences. They felt frustrated with Handicapped Children's Services (HCS), the primary funding agency with which parents interact. Most parents in this study came from the middle- and upper-SES levels, but many commented on the humiliation they feel in approaching HCS for funding for their children's daytime intervention programs. Several parents report feeling that they are treated like "welfare cases" when they approach HCS for funding. Many parents feel the system is adversarial.

Parents also note that the first request for educational or therapeutic funding is often rejected, but appeals are almost always successful. In the months that lapse before the appeal is heard, however, parents often enroll their children in daytime therapy programs because they have learned how critical early intervention is for children with

autism. They often use a line of credit to finance these programs. One parent stated during an interview that she and her husband would lose their home if their appeal was rejected.

This study has helped us to better understand what parents' needs are and which needs ameliorate their levels of stress. It has highlighted the high levels of stress that parents experience in the first year after diagnosis and parents' need for caring professionals who will provide an early, consistent diagnosis and who are knowledgeable, open, and honest about treatment options. It may be advantageous for future studies to follow parents longitudinally, beginning at the time of assessment in order to study in more detail the effects of the diagnosis on family functioning.

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Appendix A

Sample Recruitment Letter and Sign-up Form

October 1997

Dear Parent:

The Coordinator at Renfrew Educational Services has been kind enough to send this to you so that I may invite you to participate in a study that I am conducting as part of the requirement towards a M.Sc. degree in the Department of Educational Psychology at the University of Calgary. I am working under the supervision of Dr. Deborah Dewey of the Department of Pediatrics at the University of Calgary. I have not been given your name or address, so your privacy has been ensured.

I am conducting this study to identify the needs of parents of children with autism in Calgary. In addition, I am interested in finding out how well parents feel their needs are being met and how much stress they are coping with as a result. I am looking for mothers and/or fathers to participate.

What would we ask of you? Each parent in a family who responds will be asked to complete two questionnaires about his or her sources of stress and two questionnaires regarding needs. That parent would also be asked to fill out an autism rating scale for his/her child and answer some general demographic questions. A brief meeting will be scheduled afterwards at your convenience to review the questionnaires and discuss any concerns that arose for you while completing them. Participation in this study will involve no greater risks than those ordinarily experienced in daily life.

How much time will it take? The questionnaires should take approximately 90 minutes to complete. The meeting should take no more than 30 minutes.

Are there any requirements? Your child must have a diagnosis of autism (i.e., not PDD-NOS or Asperger's) and be aged 10 or younger.

How is your privacy ensured? Your responses on the questionnaires will be kept in strictest confidence. Once I have received your completed questionnaires and scored them, they will be retained for 3 years in locked file cabinets at the Behavioral Research Unit of Alberta Children's Hospital. They will be accessible only by the graduate student named in this letter and her supervisor. After 3 years has elapsed, all of the original documents will be destroyed. Only group results will be reported in any published studies.

If your family is willing to consider taking part in this study, please complete the enclosed form with your name, address, phone number, and the number of parents who will be completing the questionnaires. Please forward the form to me in the enclosed envelope. I will then send you the questionnaires along with two copies of the consent form. Returning the attached form is entirely voluntary and does not oblige you to

participate. If you would like any further information concerning this study please do not hesitate to contact Bernadette Benson at 210-0886 or Dr. Deborah Dewey at 229-7365.

If you have any questions about your child's or your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, at 220-7990.

Thank you for your time and cooperation.

Bernadette Benson, B.A. (Hons)
Educational Psychology Graduate Student
University of Calgary

Deborah Dewey, Ph.D.
Assistant Professor
University of Calgary

RESEARCH PROJECT: Stress and the Need for Resources in Families of Children With Autism in Calgary

INVESTIGATORS: Bernadette Benson, B.A.(Hons) and
Deborah Dewey, Ph.D.
University of Calgary

Returning this form does not oblige you to participate in my study, it only indicates interest. Upon receipt of this form, I will send you more information about the study including a formal consent form and the required questionnaires. You may then decide whether to participate.

Yes, please send our family the information we require to participate in the above-named research project.

Name _____

Mailing address _____

Phone number _____

How many packages do you need (i.e., are one or both parents interested in participating)?

Please circle: 1 2

Thank you for taking the time to help us with this study. Please mail this form to us in the pre-stamped envelope provided.

Appendix B
Questionnaires

Resource/Needs Inventory

Please rank which resources you need from most (1) to least (19 or 20):

- _____ Money/financial assistance
- _____ Support of your relatives
- _____ Respite (overnight care, weekends, or longer)
- _____ Support of your spouse
- _____ Support of your church/synagogue
- _____ Other parent contact and/or support groups
- _____ Baby-sitters
- _____ Recreation opportunities for yourself
- _____ Recreation opportunities for your child with autism
- _____ Community acceptance/understanding neighbors

- _____ Parent/sibling counseling
- _____ Good residential treatment
- _____ Early/consistent diagnosis
- _____ Better agency information/cooperation
- _____ Transportation for your child
- _____ Knowledgeable/concerned professionals
- _____ Legal help (for example, for advocacy or estate planning)
- _____ Good day program/teachers (all day, all year)
- _____ In-home training in managing your child
- _____ Other (please list) _____

Fulfilled Needs Inventory

How do you find these needs are being met? Please check one per row.

	Not at all	Barely	Adequately	Mostly	Very well
Money/financial assistance					
Support of your relatives					
Respite (overnight or longer)					
Support of your spouse					
Support of your church/synagogue					
Other parent contact and/or support groups					
Baby-sitters					
Recreational opportunities for you					
Recreational opportunities for your child					
Community acceptance/understanding neighbors					
Parent/sibling counseling					
Good residential treatment					
Early/consistent diagnosis					
Better agency information/cooperation					
Transportation for your child					
Knowledgeable/concerned professionals					
Legal help (i.e., for advocacy or estate planning)					
Good day program/teachers					
In-home training in managing your child					
Other (please list) _____					

Family Impact Questionnaire (FIQ-R)

Name: _____

Date: _____

Being a parent can be difficult, and children have different effects on the family. We would like to know what impact your child has had on the family compared to the impact other children his/her age have on their families. The following questions attempt to understand children's impact on different areas of family functioning. Please check the category that best describes your situation in terms of how things have been in general for you with reference to the child who is participating in the program.

Your feelings and attitudes about your child Not at all Somewhat Much Very much

COMPARED TO CHILDREN AND PARENTS WITH CHILDREN THE SAME AGE AS MY CHILD ...				
1. My child is more stressful.				
2. I enjoy the time I spend with my child more.				
3. My child brings out feelings of frustration and anger more.				
4. My child brings out feelings of happiness and pride more.				
5. When I am with my child, I feel less effective and competent as a parent.				
6. It is easier for me to play and have fun with my child.				
7. My child's behavior bothers me more.				
8. My child makes me feel more loved.				
9. I feel like I am working alone in trying to deal with my child's behavior.				

Not at all Somewhat Much Very much

10. My child makes me feel more energetic.				
11. I feel like I could be a better parent with my child.				
12. My child makes me feel more confident as a parent.				
13. I feel like I should have better control over his/her behavior.				
14. My child does what I tell him/her to do most of the time.				
15. I feel like I know how to deal with my child's behavior most of the time.				
<u>The impact of your child on your social life</u> COMPARED TO CHILDREN AND PARENTS WITH CHILDREN THE SAME AGE AS MY CHILD ...				
16. My child's behavior embarrasses me in public more.				
17. My family avoids social outings more (e.g., restaurants, public events) because of his/her behavior.				
18. It is more difficult to find a baby-sitter to stay with him/her.				
19. My family visits relatives and friends less often than I would like to because of my child's behavior.				
20. My child interferes more with my opportunity to spend time with friends.				

Not at all Somewhat Much Very much

21. I feel more tense when my family goes out in public, because I am worried about his/her behavior.				
22. I need to explain my child's behavior to others more.				
23. I participate less in community activities because of my child's behavior.				
24. I have guests over to our house less often than I would like to because of my child's behavior.				
25. I take my child shopping and on errands less.				
<u>The financial impact of your child</u> COMPARED WITH OTHER CHILDREN MY CHILD'S AGE ...				
26. The cost of raising my child is more.				
27. The cost of child care is more.				
28. The cost of food, clothes and/or toys is more.				
29. The cost of home alterations and/or fixing and replacing items in the home is more.				
30. The cost of medication, medical care and/or medical insurance is more.				
31. The cost of educational and psychological services is more.				

Not at all Somewhat Much Very much

32. The cost of recreational activities (e.g., music, swimming, gymnastics) is more.				
IF YOU ARE MARRIED COMPLETE THE FOLLOWING SECTION. OTHERWISE SKIP TO QUESTION NUMBER 40.				
<u>The impact of your child on your marital relationship</u> COMPARED TO PARENTS WITH CHILDREN THE SAME AGE AS MY CHILD ... 33. My spouse and I disagree more about how to raise this child.				
34. My spouse is more supportive of the way I deal with my child's behavior.				
35. This child pits my spouse and me against each other more.				
36. Raising this child has brought my spouse and me closer together.				
37. My child causes more disagreements between my spouse and me.				
38. My spouse is less supportive of the way I deal with my child's behavior.				
39. Raising this child has pushed my spouse and me farther apart.				
IF YOU HAVE OTHER CHILDREN, COMPLETE THIS SECTION. OTHERWISE SKIP TO QUESTION NUMBER 49.				

Not at all Somewhat Much Very much

The impact of your child on his/her siblings COMPARED WITH OTHER CHILDREN MY CHILD'S AGE ...						
40. The other children in the family help take care of him/her more.						
41. My child prevents his/her siblings from participating in activities more.						
42. The other children in the family complain about his/her behavior more.						
43. The other children in the family feel more embarrassed by his/her behavior.						
44. My child is more rejected by his/her siblings.						
45. The other children in the family invite friends over to the house less often because of his/her behavior.						
46. The other children in the family enjoy spending time with him/her more.						
47. My child uses his/her siblings' toys without asking permission more.						
48. My child breaks or loses his/her siblings toys more.						
General Questions						
49. Compared with other children my child's age, the degree of difficulty living with him/her is:						
Much Easier	Easier	Slightly Easier	About the Same	Slightly More Difficult	More Difficult	Much More Difficult

50. Compared with other children my child's age, the impact of my child on our family is:

Much Less Positive	Less Positive	Slightly Less Positive	About the Same	Slightly More Positive	More Positive	Much More Positive

Appendix C

Demographic Information Questionnaire

YOUR CHILD WITH AUTISM:

1. Date of birth of your child: _____
2. Sex of your child (circle one): Male Female
3. How old was your child when you received a diagnosis of autism?
_____ years _____ months
4. Does your child have any other condition(s) along with autism? (Circle all that apply).

Mental retardation Tourette's Syndrome Epilepsy

Please list other conditions _____

5. What types of treatment have you tried with your child? (Circle all that apply, even if you aren't following that treatment anymore).

Medications Restricted diet Megavitamins Behavior Management

Please list other treatments _____

6. Is your child with autism living at home now? yes no (Please circle one)

YOURSELF:

1. Are you the father mother? (Please circle one)
2. What is your date of birth? _____
3. What is your occupation? _____
4. What level of education have you completed? (Please circle one)

- (a) No high school
- (b) Some high school, no diploma
- (c) High school diploma
- (d) Some post-secondary, no diploma or degree
- (e) Post-secondary diploma (e.g., technical)
- (f) University degree

YOUR SPOUSE/PARTNER:

1. His/her date of birth: _____
2. His/her occupation: _____
3. What level of education has he/she completed? (Please circle one)
 - (a) No high school
 - (b) Some high school, no diploma
 - (c) High school diploma
 - (d) Some post-secondary, no diploma or degree
 - (e) Post-secondary diploma (e.g., technical)
 - (f) University degree

SIBLINGS/OTHER FAMILY MEMBERS:

1. Are there others living in the home now besides the parents and children? For example, are there grandparents living with you? If so, please list the others in your home: _____

2. Please list the other children in your home, their ages, and sex:

Name: _____	Age: _____	Sex: _____
Name: _____	Age: _____	Sex: _____
Name: _____	Age: _____	Sex: _____
Name: _____	Age: _____	Sex: _____
2. Do any of these children have a condition such as a chronic illness, developmental delay, or language/learning disorder? Please list each child and all conditions:

Name: _____	Condition(s): _____
Name: _____	Condition(s): _____
Name: _____	Condition(s): _____
Name: _____	Condition(s): _____

Appendix D

Consent Form

RESEARCH PROJECT: Stress and the Need for Resources in Families of Children With Autism in Calgary.

INVESTIGATORS: Bernadette Benson, B.A.(Hons) and
Deborah Dewey, Ph.D.
University of Calgary

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The main purpose of this project is to identify the needs of parents of children with autism in Calgary. In addition, we are interested in finding out how well parents feel their needs are being met and how much stress they are coping with as a result. You will be asked to complete two questionnaires regarding your sources of stress and two questionnaires regarding needs. You will also be asked to fill out an autism rating scale for your child and answer some general demographic questions. A brief meeting will be scheduled afterwards at your convenience to review the questionnaires and discuss any concerns that arose for you while completing them. The questionnaires should take approximately 90 minutes to complete and the meeting should take no more than 30 minutes.

Your child and family may not personally benefit from participating in this study, but by serving as a subject, you may contribute new information which may provide future benefit to children with autism and their families.

All information collected during this study will be completely confidential and will be used for research purposes only by the investigators named above. The results of the research will be reported as group data so that no individual identities will be revealed. Neither your name nor identity will be used for publication or publicity purposes. Within 3 years of completion of the research, the questionnaires will be destroyed.

Your participation in this study may be terminated at any time by your request or at the request of the investigators. Participation in this project and/or withdrawal from this project will not adversely affect you or your child in any way.

If you are interested in obtaining a copy of the study's results, please indicate so during the course of the study and we will mail them to you from the Behavioral Research Unit, Alberta Children's Hospital.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to your family's

participation. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your child's health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact Dr. Deborah Dewey or Bernadette Benson at (403) 229-7365. If you have any questions about your child's or your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, The University of Calgary, at 220-7990.

(Name of Parent/Legal Guardian)

(Signature of Parent/Legal Guardian)

(Name of Witness)

(Signature of Witness)

(Name of Investigator)

(Signature of Investigator)

(Name of Investigator)

(Signature of Investigator)

A copy of this consent form has been given to you. Please keep it for your records and future reference.

Appendix E

Comparison of Needs Met for Mothers and Fathers

	Need	Not at all/ barely	Adequately	Mostly/ very well
Money	Mothers	40%	31%	29%
	Fathers	45%	35%	20%
Support of spouse	Mothers	12%	9%	80%
	Fathers	0%	10%	90%
Day program/teachers	Mothers	14%	23%	62%
	Fathers	20%	10%	70%
Early diagnosis	Mothers	46%	37%	17%
	Fathers	40%	15%	45%
Knowledgeable professionals	Mothers	34%	20%	45%
	Fathers	45%	15%	40%
Support of relatives	Mothers	20%	34%	46%
	Fathers	15%	30%	55%
Babysitters	Mothers	33%	38%	30%
	Fathers	20%	30%	50%
Recreation for child	Mothers	37%	37%	25%
	Fathers	30%	30%	40%

(table continues)

	Need	Not at all/ barely	Adequately	Mostly/ very well
Other parent contact	Mothers	18%	44%	39%
	Fathers	30%	40%	30%
Agency information	Mothers	49%	40%	12%
	Fathers	40%	40%	20%
Respite	Mothers	66%	20%	14%
	Fathers	55%	35%	10%
In-home training	Mothers	17%	45%	39%
	Fathers	39%	33%	28%
Community acceptance	Mothers	20%	46%	34%
	Fathers	10%	15%	75%
Transportation for child	Mothers	10%	58%	32%
	Fathers	23%	33%	44%
Recreation for self	Mothers	65%	9%	26%
	Fathers	40%	25%	35%
Counseling	Mothers	42%	42%	16%
	Fathers	35%	40%	25%

(table continues)

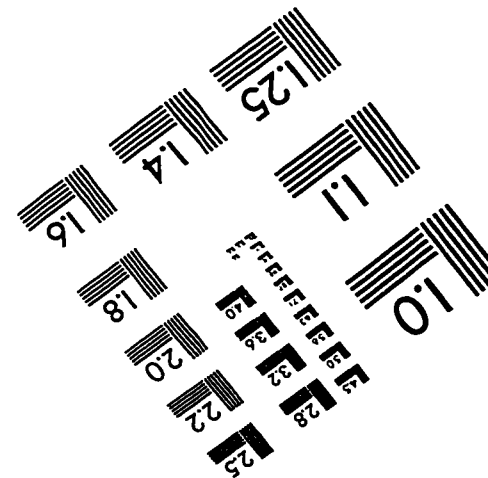
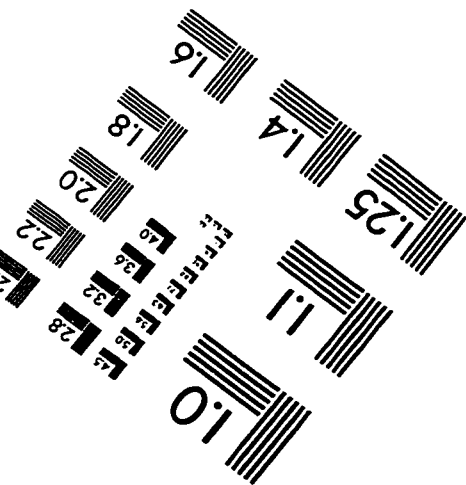
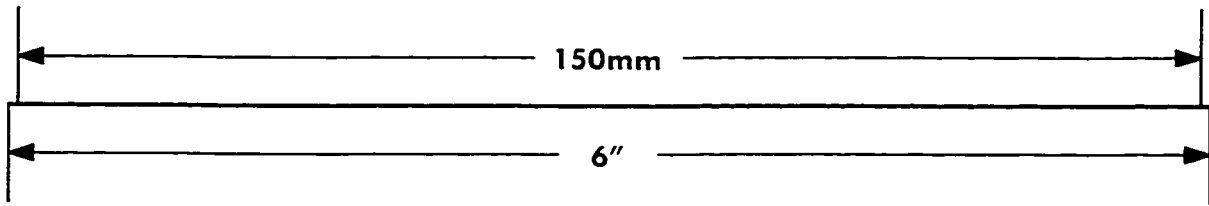
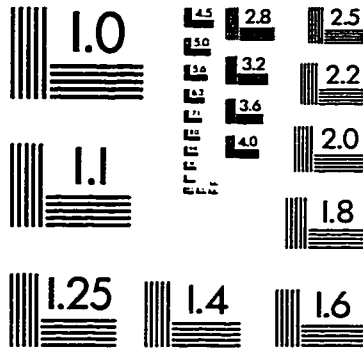
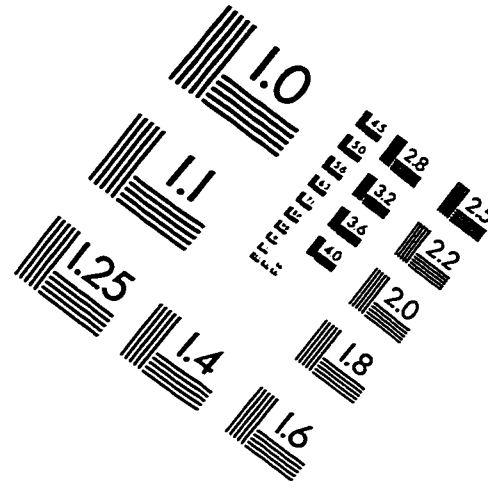
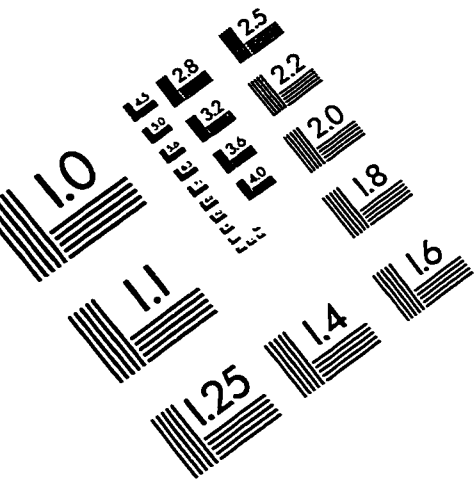
Need		Not at all/ barely	Adequately	Mostly/ very well
Legal help	Mothers	69%	19%	12%
	Fathers	58%	29%	12%
Residential treatment	Mothers	56%	33%	11%
	Fathers	36%	36%	28%
Support of church	Mothers	25%	25%	50%
	Fathers	66%	17%	17%

Note: due to rounding error, numbers across rows may not add to exactly 100%

Appendix F**Resource/Needs Inventory Mean Ranks for SES Levels**

Need	Entire sample	Low-SES	Middle-SES	High-SES
	<u>N</u> = 52	<u>n</u> = 11	<u>n</u> = 22	<u>n</u> = 19
Money	4.19	3.18	3.82	5.21
Support of spouse	4.21	4.45	4.05	4.26
Day program/teachers	5.38	4.45	5.50	5.79
Early diagnosis	6.11	8.05	4.82	6.47
Knowledgeable professionals	6.48	5.91	6.27	7.05
Support of relatives	7.52	8.82	7.59	6.68
Babysitters	9.32	9.23	9.55	9.11
Recreation for child	9.87	8.64	10.82	9.47
Other parent contact	10.12	11.82	11.45	7.58
Agency information	10.12	10.09	9.86	10.42
Respite	10.48	9.45	10.77	10.74
In-home training	11.17	12.45	10.41	11.32
Community acceptance	11.31	13.18	12.09	9.32
Transportation for child	11.48	10.45	11.41	12.16
Recreation for self	11.92	11.64	12.05	11.95
Counseling	13.35	11.91	13.68	13.79
Legal help	14.81	14.45	14.32	15.58
Residential treatment	15.77	14.55	14.64	17.79
Support of church	16.40	17.27	16.91	15.32

IMAGE EVALUATION TEST TARGET (QA-3)



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