THE UNIVERSITY OF CALGARY

Child and Family Characteristics and Adjustment in Families of Young Children with Autism

by

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A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE

DEPARTMENT OF PSYCHOLOGY

CALGARY, ALBERTA AUGUST, 1997

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0-612-24649-3



ABSTRACT

To better understand the specific variables associated with successful adaptation in families of young children with autism, the present study examined the perceptions of parents on several measures pertaining to the experiences of parenting and family functioning using the ABCX model as a general guiding framework. Severity of autism was the predictor variable, and social support and parental locus of control were moderating variables. Contrary to expectations, no support was found for the moderating role of social support and locus of control for 50 mothers of children with autism on the measures of parenting stress, dyadic adjustment, family relationships and family social integration. However, the more severe the autism as reported by the mothers, the higher levels of parenting stress and lower levels of family social integration reported. Also, a more external parental locus of control orientation was predictive of higher levels of parenting stress. Overall, mothers of children with autism were managing satisfactorily in their parenting roles and their families were generally well adjusted. Mothers and fathers had similar perceptions on the parental locus of control scale, dyadic adjustment and the quality of the family environment. Mothers and fathers scores were significantly different on the Parenting Stress Index. Mothers reported higher stress in the areas of role restriction and relationship with spouse. The implications of the findings for practitioners were discussed

ACKNOWLEDGMENTS

I would like to extend my sincerest thanks to my supervisor, Dr. Eric Mash, whose constant support, encouragement, and availability far surpassed my expectations of a supervisor. Dr. Mash provided continual guidance and patience through all phases of the research project, and for that I am very grateful.

I would also like to thank:

-the members of my supervisory committee, Dr. Susan Boon and Dr. Lorne Sulsky, for the invaluable advice and assistance they provided me;

-my external examiner Dr. Beverly Anderson for her insightful comments and helpful recommendations;

-Dr. Tak Fung and Dr. Bruce Dunn for assisting me with my data analysis;

-the staff at the Society for Treatment of Autism, Calgary, AB; Children at Risk, Ottawa, ON and the Health Science Centre (Autism Program), Winnipeg, MB for their assistance during the data collection phase of this project;

-all the parents who took time from their busy schedules to take part in the study;

-Dr. Kim Ward who never stopped believing in me and encouraged me during the more stressful phases of the research, truly a great role model; and

-Phil, for being the most supportive, patient, encouraging and understanding husband any grad student could ask for.

Finally, I would like to acknowledge the financial support provided to me by the University of Calgary.

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CHAPTER ONE

INTRODUCTION AND LITERATURE REVIEW

Autistic disorder is a severe lifelong disability that affects not only the child's ability to learn and function in the 'outside' world but also his/her ability to relate to members of his/her own family (Bristol, 1984). The negative effects of autistic children on their families have been documented by parents as well as by researchers (Holroyd & McArthur, 1976). However, there is clinical evidence that some families adapt quite well to the presence and care of a child with autism, despite the increased demands that are associated with parenting a child with such a severe disorder (Bristol, 1984). Yet, not much is known about the characteristics of autistic children and the resources in their families and communities that allow some families to cope successfully in the face of ongoing stress while others do not (Bristol, 1984).

Successful family adaptation to the demands of raising a child with an autistic disorder is best understood in the context of successful family coping with any kind of stressful event. There is an increasing amount of research that is helpful in explaining how families cope with chronic stress, whether the stress is general life change, physical illness, or the stress of separation (Hill, 1958; Olson & McCubbin, 1982). From the research it is clear that no stressor or stressful event, including the care of an autistic child, invariably causes a family crisis. Researchers have been struggling with the question of why some families are able to cope with ease and even thrive on life's hardships while other families, faced with similar if not identical stressors or family transitions, give up in the face of seemingly minor life changes (McCubbin & Patterson, 1983). In order to examine this

question further, the literature which has examined successful family adaptation to any kind of stress will first be reviewed.

The Hill ABCX Model

Hill (1949, 1958) proposed the ABCX model, which has been widely used as a framework for understanding how families cope with stress: The ABCX model proposes that a stressful event (A), interacts with the family's resources for meeting a crisis (B), and with the definition the family makes of the event (C), to produce the crisis (X) (McCubbin & Patterson, 1982). In this model, the family's resources and definition of the problem influence the family's effectiveness in preventing a stressful event from creating a crisis in the family (Bristol & Schopler, 1983). Although the severity of the stressor is important (Hill, 1958), the resources of the family to deal with the stressor and the subjective definition the family makes of the stressor are of equal importance.

McCubbin and Patterson (1982) have defined a stressor as a life event (e.g., becoming a parent, death of a family member) impacting upon the family which produces changes in the family. In addition, part of the (A) factor in the ABCX model are family hardships, which are defined as demands on the family specifically associated with the stressful event (McCubbin & Patterson, 1983). The (B) factor, the family's resources for meeting the demands of the stressful event and hardships, has been described as the family's effectiveness in preventing an event or transition in the family from creating a crisis or disruption (McCubbin & Patterson, 1983). The (C) factor in the ABCX model refers to the family's subjective definitions of the stressful event, accompanying hardships, and their effects on the family. This subjective meaning reflects the family's values and

previous experience in dealing with change and meeting a crisis (McCubbin & Patterson, 1983).

In the ABCX model, the likelihood that any stressor will precipitate either a family crisis or a successful adaptation is a function of the characteristics of the stressor, moderated by the resources that the family has to deal with that stressor and by subjective family beliefs. In the present study I conceptualized the demands of caring for a child with a severe disability as a stressor. The family's adaptation, specifically, the level of parenting stress, parental marital adjustment, family relationship, and family social integration, was hypothesized to be a function of the severity of the child's disability, moderated by the family's resources for coping and cognitive appraisal of their ability to deal with the stressor. Severity of the stressor was defined by the child's level of functioning based on a measure of the frequency with which common behavioural symptoms of autism occurred. Resources for coping were assessed by examining parents' satisfaction with their social support network. Resources for coping were viewed as representing part of the family's capabilities for resisting crisis.

McCubbin and Patterson (1983) state that a family's outlook can vary from seeing life changes and transitions as challenges to be met, to interpreting a stressor as uncontrollable and as a prelude to the collapse of the family. In this context, parental locus of control was conceptualized as an index of the parents' cognitive appraisals. A number of researchers have reported that the negative effects of stress appear to be reduced if one perceives that he or she has some degree of control over his or her environment (Lefcourt, 1976). One of the key variables affecting the perception of one's

environment is that of their locus of control orientation (degree of internality or externality). Findings suggest that parents with a more external locus of control orientation see their children's behaviour problems as being outside their control.

Conversely, parents with a more internal locus of control orientation see their children's behaviour problems as controllable as a direct function of their own behaviour toward the child (Mouton & Tuma, 1988).

Prior to discussing the study in more detail, relevant background information regarding the syndrome of autism will be presented. This will be followed by a discussion of the research concerning severity of autism and child characteristics, followed by a discussion of social support and parental locus of control as stress moderating variables. Finally, the relevant literature concerning social support, parental locus of control, parenting stress, marital adjustment, family relationship, and family social integration will be reviewed in the context of families of children with autism.

Background Information Regarding Autism

Autism is a severe and relatively rare developmental disorder, occurring in 7 to 13 cases per 10,000 live births (Klinger & Dawson, 1996). Historically, autism was reported to occur in 4 to 5 cases per 10,000 live births. It is believed that the increase in prevalence estimates is due to both a broadening of diagnostic criteria and an improved awareness and recognition of the disorder (Klinger & Dawson, 1996). Epidemiological research has consistently found that autism is three to four times more common in males than in females (Lord, Schopler, & Revicki, 1982).

The precise etiology underlying autism is unknown. However, autism is no longer thought of as a type of psychosis (schizophrenic or otherwise) or as a psychogenically induced condition caused by the parents and the social environment they provide (Bailey, Phillips, & Rutter, 1996). Although a specific biochemical marker or neurophysiological abnormality has yet to be demonstrated, it is now generally accepted that autism is a neurodevelopmental disorder, in which specific cognitive deficits play a key role and for which genetic factors predominate in etiology (Bailey et al., 1996). Although this disorder is biological in origin, it is still important to study the families of children with autism. It is often the case that how a family responds to a child's autism can, in some cases, influence the child's educational gains and behavioral adjustment (Harris, 1994). For example, a chaotic disorganized family may have difficulty creating the kind of consistency to which children with autism best respond. Thus, family problems can influence the development of the child with autism. Conversely, the child's autism can have a major impact on family functioning. These two factors may influence one another reciprocally, with family dysfunction heightening the child's needs, and the child's behaviour problems intensifying family difficulties (Harris, 1994).

Although individuals with autism constitute a heterogeneous population, a number of generalizations regarding symptomatology can be made. Rutter and Schopler (1987) suggested that autism can be regarded as a disorder which typically involves: early onset (i.e., prior to 36 months); impairment in the development of social skills; deficits in communication skills; and stereotyped repetitive patterns of behaviour. Two of the most distinguishing deficits in social skills are a lack of social reciprocity and an impaired ability

to develop loving relationships on the basis of interpersonal interactions (Bailey et al., 1996). Other social abnormalities are deficiencies in social signaling and recognition of other people's social cues, and poor integration of social, communicative, and emotional information. In addition, children with autism show little interest in sharing pride or pleasure with other people (Bailey et al., 1996).

It is not uncommon for children with autism to have significantly delayed language development but it is their deviant communication features that are most striking (Bailey et al., 1996). These include a lack of social chat even when language has developed, pragmatic deficits, pronoun reversal, immediate or delayed echolalia, neologisms and idiosyncratic unusual usages of language (Bailey et al., 1996; Klinger & Dawson, 1996). There appears to be a deficit in the child's capacity to use language for social communication. These children often find it difficult to maintain an ongoing topic of conversation, display a lack of reciprocity in conversational interchange, show a relative lack of creativity and fantasy in thought process, and an inadequate response to other people's verbal and nonverbal overtures (Rutter & Schopler, 1987).

The third main behavioral characteristic in children with autism concerns restricted, repetitive, and stereotyped patterns of behavior. Some of the ways in which the stereotyped patterns may be displayed include (a) an encompassing preoccupation with stereotyped and restricted patterns of interest, (b) attachments to unusual objects, (c) compulsive rituals, (d) stereotyped and repetitive motor mannerisms, (e) preoccupation with part-objects or non-functional elements of play material, and (f) distress over changes in small details of the environment (Rutter & Schopler, 1987).

Parents report that the most common motor stereotypies in their children are rocking, toe-walking, arm, hand or finger flapping, and whirling (Klinger & Dawson, 1996). These repetitive motor movements tend to occur more often in younger and in lower functioning children with autism than in older and higher functioning children (Wing & Gould, 1979). It has been observed that children who are higher functioning with less severe levels of mental retardation display more elaborate routines (Klinger & Dawson, 1996). These routines may include a complex series of motor movements, or repeated rearranging or ordering of toys. It is common for higher functioning individuals with autism to have perseverative interests that usually involve memorization of facts about a special topic (e.g., bus schedules) (Klinger & Dawson, 1996).

The data also indicate that the majority of autistic individuals are mentally retarded. According to Ritvo and Freeman (1978), approximately 60% of autistic children have IQs below 50, 20% between 50 and 70, and 20% 70 or above. Bryson, Clark, and Smith (1988) studied a Canadian sample of individuals with autism and found that 75% of individuals in their sample had IQs below 50. Although, a majority of children with autism are retarded, the fact that at least a quarter of children with autism have normal intellectual ability indicates that autism and mental retardation are distinct disorders (Klinger & Dawson, 1996).

In reviewing the general characteristics and symptoms of autism, it is not difficult to understand why families may experience adjustment difficulties while parenting a child with autism. For example, the give and take social exchanges that are present in most parent-child relationships are disrupted or absent. The child's communication problems

may hinder the parent from understanding the child's wants and needs. The child may have difficulty understanding the parents' demands and expectations. The parent needs to try and maintain order in the family environment, yet the child's retardation may necessitate that parents take more responsibility for child care than other parents, while still trying to satisfy their own personal needs and those of other family members.

Children with autism appear physically normal and do not show any of the visible stigmata that characterize children with mental retardation. However, these children present behavioral difficulties, which often makes it difficult for the parent to take them out into the community. When a child who is visibly handicapped throws a tantrum in the middle of a restaurant, the majority of onlookers are likely to be sympathetic. When a child with autism who appears to be physically normal does the same thing, sympathetic understanding may turn to hostility and to unsolicited advice on child-rearing, which may add to the parent's sense of inadequacy and contribute to a potential family crisis. Other demands on the parent include coping with the child's bizarre and ritualistic behaviors, and constantly monitoring a child who may not recognize dangers.

Families who participated in the present study have a child who was diagnosed with either Autistic Disorder or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). PDD-NOS is a diagnosis used when there is a severe and pervasive impairment in the development of social skills, communication skills, and repetitive stereotyped behaviors as discussed above, but the criteria are not met for any of the other specified Pervasive Developmental Disorders (American Psychiatric Association, 1994). PDD-NOS is sometimes called "atypical autism" since the category is often used

for children who fail to meet criteria for autistic disorder because of their late age of onset, atypical symptoms, subthreshold symptoms or all of these (American Psychological Association, 1994). An important point to consider when studying autism, is that autism is a spectrum disorder, which means that the expression of symptoms and characteristics may range from severe to mild. The manifestation of social and other impairments varies widely in all combinations of subtype and severity (Freeman, 1993). At one end of the spectrum you may find a nonverbal child, sitting alone in a corner of the room rocking back and forth for hours; at the other a young man who holds down a job in the local library putting books back on the shelf, a job which does not require him to socially interact with other people. Although children with autism share many of the same characteristics, two children with a diagnosis of autism can be vastly different from one another.

Acknowledging the complexity of this severe disorder, a synopsis of some of the stress-related problems that many of these families experience will be reviewed.

Review of Research

Stress in Families of Autistic Children

Studies have found that families of developmentally disabled children often experience stress-related problems. For instance, Holroyd and McArthur (1976) and Wolf, Noh, Fisman, and Speechly (1989) found that parents of children with autism reported higher levels of stress than parents of normally developing children and parents of children with other disabilities (i.e., Down syndrome, outpatients in a psychiatric clinic).

Bristol (1984) found that mothers of children with autism reported more stress than mothers of children with Down syndrome in areas such as taking their children to public places, and more embarrassment and disappointment than the parents of the children with Down's syndrome. The children with autism were also reported to have fewer activities that occupied them, fewer services, and poorer prospects for employment and independent living than children with Down syndrome. Bristol (1984) found that family integration as measured by activities such as mealtime, vacations, or outings were more disruptive for families with a child with autism than for families with a child with Down syndrome (Bristol, 1984).

Studies are inconsistent in finding a high level of stress in all areas of family functioning (e.g., Koegel, Schreibman, O'Neill, & Burke, 1983; Wolf et al., 1989), but report that the presence of an autistic child may lead to stress in specific areas of family life (Bouma & Schweitzer, 1990; DeMyer, 1979; Holroyd & McArthur, 1976; Koegel et al., 1983). Koegel et al. (1992) compared the stress profiles of 50 mothers of children with autism who ranged in age from 3.1 years to 23.1 years, and functioned within a range of severely retarded and untestable to near normal on standardized tests (Koegel et al., 1992). The mothers lived in different cultural and geographic environments including California, Appalachia, and Germany. They found a significant difference between mothers of the children with autism and a normative sample in the overall amount of reported stress. Differences were found on scales measuring stress associated with dependency and management, cognitive impairments, limits on family opportunity, and life-span care. No significant differences were found between the families with a child with

autism and the normative families on scales measuring stress related to family disharmony, lack of personal reward, terminal illness, physical limitations, finances, preference for institutionalization, and personal burden.

Other researchers have identified specific characteristics that are associated with higher levels of stress in families with an autistic child. The identified characteristics include: maternal and child age (older parents and parents of older children report higher levels of stress) (Bristol, 1984), child gender (parents of boys report more stress than parents of girls), presence of self abuse by the child, and the child's overall level of functioning (Bristol, 1984; Konstantareas & Homatidis, 1989).

There are a number of factors that may alleviate or precipitate stress in families. Some of these include the characteristics of the child, including the severity of autism, whether or not social support is available and/or if it is perceived to be helpful, and whether or not the parent is guided by beliefs that they can control life events and are motivated to work on their child's behalf. The research concerning certain child characteristics will be discussed first followed by social support and parental locus of control as stress-moderating variables.

Child Characteristics

The raising of a child with autism in a family environment has been documented to contribute additionally to the stresses of family functioning in a variety of ways (Bebko, Konstantareas, & Springer, 1987). Bebko et al. (1987) examined which individual symptoms of autism parents felt were the most stressful, and assessed the accuracy of professionals in estimating parents reported level of stress. Mothers and fathers of 20

children with autism and 20 therapists working with these children independently rated the severity of the common symptoms of autism in their child, and how stressful they found each symptom. The therapists also estimated parental stress.

The two symptoms that were reported as most stressful and severe by mothers and fathers were the autistic child's difficulty and degree of cognitive and verbal impairments. Cognitive impairment in this study represented the inconsistency of the child's abilities; high in some areas and low in others. The term verbal impairment referred to deficits in the child's verbal expressive language skills. Fathers, but not mothers, rated the child's social impairment as a significant stressor. Rated as least stressful was the child's difficulty with environmental change. The overall severity of the child's autism was related to the parents' reports of stress, for both mothers (r = .93) and fathers (r = .63). A lower symptom severity total for older children was accompanied by lower stress levels in mothers; however, this relationship was not found for fathers. Fathers rated their older children's symptoms as less severe, but were as stressed by them as were fathers of younger children. Interestingly, professionals judged the parents as more stressed by the child's symptomatology than did the parents themselves. It should be noted that two possible stress-producing characteristics of a minority of children with autism were absent in the scale used to assess stress in this study: aggression and self-injury. These additional symptoms could contribute to higher overall symptom severity and stress scores for mothers and fathers.

Konstantareas and Homatidis (1989) assessed the relationship between child symptom severity and stress in 44 mothers and fathers of children with autism who ranged

in age from 2 to 12 years. Parents rated their child's symptom severity and their own stress on a 14-item symptom scale. Thirteen child and family characteristics were also examined to assess how they related to ratings of symptom severity and stress. Preschool autistic children were rated as less symptomatic by their parents than by the clinicians. This is contrary to available evidence on the attenuation of at least some symptoms with age (Konstantareas & Homatidis, 1989). Assuming the clinicians' ratings to be more accurate than parent ratings, and that symptoms of autism decrease with age, the results might be at least partly explained by parental defensiveness in accepting the diagnosis of autism with its many adverse implications. Parents of younger children may still be engaged in the "diagnostic run-around" which usually stops later on, when they come to terms with the diagnosis (Mack & Webster, 1980). Children who were lower functioning, nonverbal, odd-looking, self-abusive, suffering from seizures, and hyperirritable were rated as more symptomatic than autistic children who did not display these characteristics. The best predictor of stress for mothers and fathers was the presence of self-abusive behaviour in the child. Parents reported feeling helpless, overwhelmed and frightened by their child's self-abusive behavior. These parents interpreted the self-abusive behavior as a reflection of their child's inability to relate appropriately to them, and to their own poor child management skills and general ineffectiveness in parenting their child. For mothers, but not fathers, in addition to self-abuse, their child's hyperirritability (e.g., pacing or running around the house, destruction of objects, vocalizing in an ongoing manner) and older age were also associated with elevated stress scores.

Social Support and Locus of Control as Moderating Variables Social Support

Most definitions of social support are based on the assumption that people must rely on one another to meet certain basic needs. For some theorists, social support is the fulfillment by others of an individual's basic ongoing requirements for well-being (Cutrona, 1996). For other theorists, social support emphasizes the fulfillment of needs that arise as a consequence of stressful life events or adverse personal or environmental circumstances (Cutrona, 1996). For the present study, social support will focus on the latter definition.

Research has revealed that although some people succumb to negative outcomes in the face of negative life events, many others do not (Rabkin & Streuning, 1976). This has led to a search for factors that might protect or buffer people against the deleterious effects of stress. One such factor that has been identified is high-quality relationships with others (Cutrona, 1996). The primary benefit to the recipient of social support is protection against the deterioration of health and well-being that might otherwise be caused by the pressures of recent or ongoing stressful events (Cutrona, 1996). In this viewpoint a moderating effect of social support on outcomes is predicted (i.e., a statistical interaction between stress and social support in the prediction of adjustment outcomes). At low levels of support those with high levels of support, even those experiencing high stress do not succumb to declining health, or they experience a less severe decline (Cutrona, 1996). Another implication of this interaction between stress and social support in the

prediction of health outcomes is that social support is beneficial only under conditions of high stress. When levels of stress are low, social support is unrelated to well-being (Cutrona, 1996).

Cobb (1976) defined social support as information leading the person to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligation and communication. Cobb noted that the actual exchange of goods and services in such a relationship is less important than having the persons know that they are loved and valued and that they can count on help from others and be expected to provide assistance in return. Social support has been suggested as a moderating factor in determining an individual's response to the external environment. It has been said to protect an individual against distressing life events, extend coping resources, and facilitate adaptation (Schultz & Saklofske, 1983). Caplan (1974) suggests that social support buffers stress by providing the individual with emotional support, guidance, assistance with tasks, or physical supplies. Because social support has been proposed as a key resource for overcoming life crises (Caplan, 1974), it has acquired a prominent place as a moderator variable in epidemiological models of stress and maladjustment. Specifically, the relationship between stress and maladjustment is thought to be greater for those who lack support than for those who are adequately supported (Sandler & Barrera, Jr., 1984).

The concepts of social support and stress have been closely tied in both theoretical and empirical work on the influence of support on health and well-being (Cobb, 1976).

Although theorists differ in the specifics, there is wide agreement that social support is a multidimensional phenomenon (Cobb, 1976). A broad range of interpersonal behaviors by

members of a person's social network may help him or her successfully cope with adverse life events and circumstances (Cutrona & Russell, 1990). A number of different forms of support, for example, direct advice, encouragement, companionship and expressions of affection all have been associated with positive outcomes for persons facing various life strains and dilemmas (Cutrona & Russell, 1990).

Social support systems may assist in coping with undesirable life events by providing the person with behavioral norms or information feedback of a practical nature. In doing so, not only would the harmful effects of stress be lessened, but one's sense of control over these same events would be increased. If self-reliance is encouraged by one's supports, an individual may feel a greater sense of personal control (Schultz & Saklofske, 1983).

Although the model of social support as a moderator or "buffer" of stress (Cobb, 1976) has received empirical validation, overall, findings have been mixed. Stress-moderating effects of social support have been found in many studies (e.g., Wilcox, 1981) and these studies have reported main effects for support as well as interaction effects when adjustment measures served as criterion variables. However, the stress-moderating effect has failed to receive validation in many studies and some studies have found results opposite to those hypothesized (Sandler & Barrera, Jr., 1984). A critical factor that makes it difficult to integrate the findings on the effects of support is the variety of conceptually different instruments used to assess it (Sandler & Barrera, Jr., 1984).

Some measures of perceived support stress availability; some stress satisfaction; some combine both aspects of support into an overall score; and some keep separate

scores for the two. Variables thought to describe the availability and helpfulness of the support system are considered to reflect qualitative characteristics (Schultz & Saklofske, 1983). Quantitative characteristics have been defined as those which provide information about the number and types of social support. Wilcox (1981) found that the quality of a person's supportive network rather than the number of persons providing that support, seems to be the most important factor with respect to the buffering effect of social support on psychological distress. Sandler and Barrera Jr. (1984) supported Wilcox's finding in their own study. They suggest that sheer quantity of help received is not the critical feature of social support. For purposes of the present study, the overall analyses to test the predictions will use satisfaction with social support. Following this analysis, a secondary analysis will examine the number of social supports available.

Locus of Control

Stress has been found to be moderated by beliefs regarding efficacy and control (Lefcourt, 1983). In examining locus of control, persons with an internal locus of control are guided by the belief that they can control their life events and be more motivated to act on their own behalf, whereas persons with an external locus of control often express pessimism about their ability to manage their own lives (Lefcourt, 1983).

The prevalent view of the relationship between locus of control and life stress is that individuals who define events in their lives as outside their control will be less able to cope effectively with stress, and therefore, more likely to experience physical and psychological distress than persons with internal locus of control beliefs (Krause & Stryker, 1984). Numerous studies have examined the reactions of individuals with an

internal versus external locus of control to stressful situations. Researchers have concluded that persons with an internal locus of control display greater resistance to influence and handle success and failure in a more realistic fashion than do persons with an external locus of control (Krause & Stryker, 1984). More specifically, internals display mastery and coping skills while externals are unable to constructively and effectively deal with the stress because of their belief that their actions will not make any difference in the course of events in their lives (Krause & Stryker, 1984).

Researchers have conducted several studies to directly assess the role of locus of control beliefs in moderating the relationship between life stress and well-being. Most of these studies support the hypothesis that internals cope more effectively with stress (Krause & Stryker, 1984).

Social Support and Locus of Control

Although social support and the characteristics of the person receiving support are both involved in the process by which individuals cope with the stress, the empirical literature has treated these two moderating variables separately. However, there is reason to believe that personal characteristics such as locus of control can influence the use and impact of support (Sandler & Lakey, 1982).

Two differing views have been put forward in attempting to explain how persons with an internal or external locus of control utilize social support to reduce the negative effects of stressful events. The first view is that under stressful conditions persons with an external locus of control are more likely to report feeling stress and anxiety (Lefcourt, 1976). Since people tend to affiliate more under conditions of stress, persons with an

external locus of control should utilize more support than persons with an internal locus of control (Sandler & Lakey, 1982). The other view is that internals will make better use of their support than will externals. In a review of the literature on locus of control and health behaviour, Sandler and Lakey (1982) found that persons with an internal locus of control, as contrasted with persons with an external locus of control, tended to know more about and make better use of information about their disease and treatment.

Sandler and Lakey (1982) examined the role of locus of control and social support as stress moderating variables and found that externals had a greater quantity of support than did internals but the stress-buffering effect of support was obtained for internals and not externals. It appears that more support is not necessarily equivalent to better support. The finding that support buffers the effects of stress for internals is consistent with previous evidence about how internals cope in stressful situations. Thus, if social support is viewed as a multifaceted resource (including information, task assistance, social support, etc.) which one can use to utilize to assist in coping with stress, it is reasonable to expect that internals will make better use of this resource than will externals.

Dalgard, Bjork, and Tambs (1995) suggested that one possible explanation of a positive effect of social support might be a common underlying personality factor that affects mental health and social network in a positive direction. Among the possible personality factors with such an effect, they examined locus of control using an abbreviated form of the Rotter scale of locus of control. Their findings clearly favor the view that social support exerts a positive effect on mental health by buffering the risk of developing mental disorder when exposed to negative life events. Social support or

negative life events alone exert little influence upon the course of mental health. There was, however, an interaction between negative life events, social support, and locus of control with respect to the course of mental health, especially for depression. For persons with an internal locus of control orientation there was no buffering effect of social support, unlike the individuals with a more external orientation. This findings suggests that individuals with an internal locus of control orientation (those who see themselves as the most important factor in controlling their own lives) do not need as much support from other people to cope with life stressors. Individuals with an external orientation, on the other hand, who have a feeling of powerlessness, may need the support of others to be able to cope (Dalgard et al., 1995).

In summary, findings from the general literature concerning social support and locus of control indicate that these two variables may serve as important 'buffers' against the effects of stress. The discussion will now turn to the literature on families of children with either a developmental disability or autism and how social support and locus of control relate to family adjustment, particularly to the parent's marital adjustment, family relationships, and the family's social integration.

Research Focusing on Families of Children with Developmental Disabilities

Social Support

Social support is an important resource for parents faced with the demands of raising a child with a chronic disability. As discussed, the power of social support for moderating the effects of significant life stressors has been well documented and there is

some evidence that social support can serve a similar function for parents of children with autism (Bristol, 1984).

In a study of 40 mothers of children with autism ranging in age from 4-19 years, Bristol (1984) found that mothers who reported higher levels of perceived support on a measure that included support from spouse, immediate and extended family, friends, and other parents of handicapped children reported lower levels of stress.

Peterson (1984) studied 105 mothers of children with various developmental disabilities (e.g., profoundly/moderately multihandicapped, Down's syndrome, cerebral palsy, spina bifida and smaller categories such as primary sensory disorders, language communication dysfunction and learning disabilities) who ranged in age from 1-19 years (M = 6.53). Each child was given a symptom severity score based on the number of medical/developmental problems. It was hypothesized that family resources would help buffer the stresses the mothers experienced as a result of bearing and rearing a child with a handicap. Family resources included both emotional support and physical help. Peterson (1984) found that mothers with high stressors and high resources had fewer negative outcomes than those with similar levels of stress and low resources. Negative outcomes were assessed using a composite score of marital adjustment and physical symptoms as reported by the mother. The possible range in this variable was from poor health and marital adjustment to excellent health and marital adjustment. The study supported the presence of social support as a moderator variable influencing the relationship between life stress and dysfunction in families of children with a handicap.

Bristol (1987) studied 45 mothers of children with autism or communication impairments who ranged in age from 2.3 to 9.7 years ($\underline{M} = 5.3$). The Carolina Parent Support Scale (CPSS) was used to assess parental perceptions of adequacy of support regarding their handicapped child. This scale measures the availability and helpfulness of both informal and formal sources of support for parents of handicapped and chronically ill children. Mothers who had more adequate support from their spouses, immediate and extended family, and from other parents reported happier marriages, and were rated by interviewers as having better family adaptation.

Gill and Harris (1991) examined social support as a predictor of psychological discomfort in mothers of children with autism who ranged in ages from 2-18 years (M = 9.9). They used two separate measures of social support. The first, Interpersonal Support Evaluation List (ISEL), is a measure of the perceived availability of social support that consists of several subscales. The two subscales used in their study were the Appraisal Scale and the Self-esteem scale. The Appraisal scale measures the perceived availability of someone with whom to discuss one's problem. The Self-esteem scale measures how one sees oneself and how one believes one is perceived by others. The second measure of social support assessed the receipt of functional support during the preceding month. This scale is a modification of the Inventory of Socially Supportive Behaviors (ISSB). Mothers who perceived social support as more available experienced significantly fewer stress-related somatic problems and depressive symptoms than those with less perceived support. There was no significant relationship between the actual receipt of functional support and measures of stress-related symptoms, suggesting that the

critical variable in social support may be perceived availability (Gill & Harris, 1991). The findings for this study are consistent with the buffering effect of social support that was reported in previous research by Bristol (1984).

Henderson and Vanderburg (1992) studied 49 mothers of children with autism whose mean age was 10.2 years. They assessed the mother's social support with the Inventory of Socially Supportive Behaviors (ISSB), and found that family adjustment was higher for mothers of autistic children who reported higher levels of social support. Gray and Holden (1992) studied psycho-social well-being among an Australian sample of 172 parents of children with autism ranging in age from 3-28 years (M = 7.0). The relationship between sociodemographic characteristics, health and treatment status of the child, parental coping behaviours and parental depression, anxiety and anger was examined. The measure of social support used in the study was the Social Support Index (SSI) developed by McCubbin and associates. The SSI is designed to measure social support from the family and the community. Gray and Holden (1992) found that fathers, and mothers who received more social support, reported lower levels of depression, anxiety and anger than mothers who received less social support.

In summary, a limited number of studies have examined social support in families of children with autism. The findings that are available are suggestive in supporting the role of social support in moderating stress and increasing parental adjustment in families of children with autism. However, studies to date have used different measures of social support, and the children studied have been primarily of school age or older. The studies that have included preschool age children have not investigated these children separately,

but rather have included them with a larger group of older children of varying ages.

Recent advances in early identification and diagnosis of children with autism have left a void in the research concerning the adjustment of families with young children. It is important for both researchers and professionals to gain a better understanding of these families of young children with autism in order to identify the characteristics which may contribute to their successful adaptation. Similar strengths and attributes might then be fostered through early intervention efforts.

Parental Locus Of Control

Henderson and Vanderburg (1992) studied several factors that related to the adjustment of families with a child with autism, including severity of autism, social support, and locus of control. Autism was viewed as an external stressor that placed unusual demands on a family. Mothers of 49 school age children with autism (M=10.2 years) completed four questionnaires designed to assess stressor severity, social support, family perception (locus of control measure), and family adjustment. Symptom severity was used as the measure of the intensity of external stress and demands confronting families of children with autism. Assessment of severity was based on the Adaptive Behavior Scale, School Edition. This scale yields five factors, and a single comparison score derived from three of these discriminates between normal, educable, and trainable mentally retarded students (Henderson & Vandenberg, 1992). The locus of control measured used in the study was the adult form of the Nowicki-Strickland Locus of Control Scale. Family adjustment was assessed using mothers' responses to the Family Relationship Index (FRI) of the Family Environment Scale (FES). The FRI is a composite

measure of scores for the cohesion, conflict, and expressiveness subscales of the FES. It was found that family adjustment was better for mothers when the external stressor of symptom severity was less severe (Henderson & Vandenberg, 1992). Adjustment was higher for families with greater social support, and for those with greater internal locus of control. Persons who have an internal locus of control presumably are more likely to engage in behaviors aimed at reducing the impact of an external stressor than those who believe that their actions are of no consequence (Henderson & Vanderburg, 1992). Those with a higher internal locus of control may feel less helpless and overwhelmed than those with a more external focus in dealing with the burden of raising a developmentally disabled child

McKinney and Peterson (1987) studied the predictors of stress in mothers of a heterogeneous group of non-autistic developmentally disabled children ages 7 to 41 months. Child diagnosis (i.e., Down syndrome or cerebral palsy), type of early intervention program, social support networks, and locus of control were examined as moderators of parenting stress. The measure used to assess locus of control was the Spheres of Control (SOC). This scale correlates with Rotter's (1966) Internal-External Locus of Control Scale (r = .75). It was found that mothers with an internal locus of control reported lower levels of stress than mothers with an external locus of control.

Research has found that locus of control is an important variable to consider when assessing family adjustment. A number of the studies that have examined parental locus of control have used various different measures, none of which are specific to parenting.

Rotter (1975) stated that the Internal-External Locus of Control Scale (I-E) is a measure

of generalized expectancies and is therefore only appropriate for predicting behaviour in situations that are ambiguous and/or novel to the individual. Thus, although the general nature of the I-E make it applicable to numerous situations, it does so at the cost of reduced predictive efficacy (Rotter, 1966). In recognition of the need for more focused assessment of specific expectancies for control, some researchers have developed criterion-specific locus of control measures (Campis, Lyman & Prentice-Dunn, 1986). For example, scales have been developed to measure locus of control beliefs in such domains as weight management, health, and teaching. Validation studies have improved the predictive efficacy of such topical measures when compared with Rotter's more generalized instrument (e.g., Saltzer, 1982).

In order to provide investigators with a focused instrument for the assessment of parental locus of control, Campis et al. (1986) developed a 47-item Parental Locus of Control Scale (PLOC). This measure includes five subscales: Parental Efficacy, Parental Responsibility, Child Control, Fate/Chance, and Parental Control. The PLOC correlates moderately with the Rotter I-E scale (r = .33, p < .01) and allows researchers to measure locus of control in the context of parenting. This is important when studying the parent's cognitive appraisal. Among the factors that affect parents' performance of their parenting responsibilities are the beliefs they hold about children and their transactions with them. Perhaps central among these beliefs are those that focus on the parents' ability to influence their children's behaviour and development (Koeske & Koeske, 1992). On the one hand, parents may believe they have a powerful influence on their children's lives and are critical agents in their children's behavior and development. On the other hand, they may think

they have little ability to control their children's development because of competing outside influences, such as society and peer groups, luck, or the limitations imposed by children's temperament or developmental stage (Koeske & Koeske, 1992). The availability of a measure for assessing parents' beliefs about control may facilitate parent training efforts. Confronting inappropriate expectations or exploring the bases of feeling helpless and ineffectual with one's children may lessen family strain and conflict and thus may decrease the potential for ineffectiveness. If the parent perceives that he or she has some degree of control over his or her child the negative effects of child related stressors such as autism may be reduced.

Marital Adjustment

Marital relationships in the families of developmentally disabled children have been a subject of much clinical concern because of the increased stress that is presumed to be present in these families (Crnic, Friedrich, & Greenberg, 1983). The research to date does not present a clear picture of marital functioning. Friedrich (1979) examined a large number of psychosocial and demographic variables as predictors of the coping behavior of mothers of handicapped children ranging in age from 2-19 years (M = 9.8). Subjects were 98 mothers of children with a wide variety of handicapping conditions. All mothers were mailed a packet of questionnaires that included: Questionnaires on Resources and Stress, the short version of the Marital Adjustment Inventory, the Psychological Well-Being Index, a social support index, and a religiosity index. The most significant predictor of effective coping behaviour was a mother's report of feeling secure in the marital relationship.

Rodrigue, Morgan, and Geffken (1990) compared mothers of 20 children with autism ($\underline{\mathbf{M}} = 10.71$ years), 20 with Down syndrome ($\underline{\mathbf{M}} = 11.93$ years) and 20 developmentally normal children ($\underline{\mathbf{M}} = 3.8$ years) matched on several pertinent demographic variables including sex, race, birth order, family size, and socioeconomic status. It was found that mothers of children with autism reported less marital satisfaction, less parenting competence, more family cohesion, and less family adaptability than mothers in the other two groups.

The findings that mothers of children with autism reported less marital satisfaction than the other two groups contrasts with previous research which found that parents of children with autism reported moderately high levels of marital satisfaction (Koegel et al., 1983). The discrepancies in the findings may be due to sample differences. In the Koegel et al. (1983) study, the children with autism were quite young ($\underline{M} = 5.75$ years), all were accepted for treatment in an autism clinic, and the vast majority of mothers were homemakers. In contrast, in the Rodrigue et al. (1990) study the children were older $(\underline{M} = 10.7 \text{ years})$, functioned at a very low level, and the majority of mothers worked outside the home. It can be argued that the stress of working outside of the home and raising a low-functioning older autistic child may precipitate marital tension (Rodrigue et al., 1990). However, it may also be beneficial for the mother to work outside the home as it would provide the mother with a satisfying role outside of the home and some relief from the burden of caring for a child with autism. The two studies used different measures to assess marital functioning. Rodrigue et al. (1990) used the Marital Adjustment Scale (MAS) developed by Locke and Wallace, while the Koegel et al. (1983)

study used the Dyadic Adjustment Scale (DAS) developed by Spanier (1976). However, this should not make a large difference as these two measures have been found to be highly correlated (r = .93) (Spanier, 1976). The study by Rodrigue et al. (1990) found that mothers of children with autism reported lower marital satisfaction than mothers of children with Down syndrome. Both mothers and fathers of children with autism reported that language and cognitive impairments and children's self-abusive behaviour were very stressful, which could contribute to the lower report of marital satisfaction in parents of children with autism versus those with mental retardation.

The Rodrigue et al. (1990) study was the first systematically controlled study to report low marital adjustment among parents of children with autism. It is not known from the study whether lower levels of marital satisfaction followed the birth of the autistic child or whether marital relations were strained prior to the child's birth, or independent of the autism. Farber (1959), for instance, found that marital satisfaction among parents of severely retarded children was best predicted by parents' marital satisfaction prior to the birth of the child.

Rodrigue, Morgan, and Geffken (1992), in one of the few studies of fathers of children with autism, compared fathers of 20 children with autism, 20 children with Down syndrome, and 20 developmentally normal children on several measures of psychosocial adaptation. Similar to the results reported by Koegel et al. (1983) they did not find any significant between-groups differences for fathers' reported level of marital satisfaction. It is possible that fathers did not report many personal or family adjustment problems because they are removed from day-to-day child management activities relative to their

spouse. Since mothers often assume primary responsibility for the care of the special child (Rodrigue et al., 1990) and are usually quite successful in this role, fathers may harbor the perception that their personal and family lives have not been significantly disrupted.

The variability in the findings on marital satisfaction suggests that marital response in families of children with autism is not uniform and may be dependent upon factors other than the presence of a disabled child, possibly including the age of the child, distribution of burden of care, and the quality of the marital relationship prior to the birth of the child (Crnic et al., 1983). The conflicting results noted may reflect sample differences on these and other characteristics.

In light of the inconsistent findings reported by Koegel et al. (1983) and Rodrigue et al. (1990) regarding marital satisfaction of parents of children with autism, no specific hypotheses will be proposed with regard to symptom severity of autism and marital adjustment, or to the potential buffering effects of social support or parental locus of control and marital adjustment.

Family Relationships

The Family Relationship Index (FRI) is a measure of the quality of the family environment. It is comprised of scores on the cohesion, conflict, and expressiveness subscales of the Family Environment Scale (FES). Bristol (1984) reported that interviewers rated families of children with autism as high in cohesion, as showing more acceptance of and more competence in coping with their child, and the mothers reported fewer depressive symptoms, and better marital adjustment. Henderson and Vandenberg (1992) used the FRI as a measure of family adaptation in their study of 40 mothers of

children with autism. They found that family adjustment was higher when the external stressor was less severe, when there was a higher level of social support, and when mothers had a more internal locus of control orientation.

Family Social Integration

There is not an abundance of literature on families of children with autism and their integration into the community. Bristol (1984) found that families of children with autism were higher on moral-religious emphasis and lower on participation in social and recreational activities than the Family Environment Scale (FES) normative sample. Bristol further reported that families with an active-recreational orientation, that is, those who participated in social and recreational activities outside of the home or with persons outside the immediate family, were rated as better adapted and more accepting of the child and reported having happier marriages. Wolf et al. (1989), in their study of 30 mothers and 27 fathers of children with autism ranging in age from 4.5 -19.5 (M = 9.34), used a compatibility subscale in their marital intimacy measure. This measured the couple's ability to work and play together comfortably. The mothers and fathers of children with autism reported a lower score than parents of developmentally normal children and parents of children with Down syndrome. The authors suggested that this lower score may reflect the lack of recreation time in families with children with autism. Parents of children with autism frequently complain of a lack of time for recreation, for each other, and for family activities because of the heavy burden of parenting, particularly when parent relief and other services are not available (Fisman & Wolf, 1991).

Comparison of Mothers' and Fathers' Perceptions of their Young Children

There are few studies that have compared the profiles for mothers and fathers of children with autism and other developmental disabilities on various family functioning measures. However, there are some general findings comparing mothers and fathers of children with autism or other developmental disabilities on ratings of symptom severity, parenting stress, social support, marital adjustment and family environment. There is no research comparing mothers' and fathers' perceptions of parental locus of control.

Symptom Severity

Three studies have examined the amount of agreement between mothers and fathers of children with autism on their children's behaviour. Bebko et al. (1987) found that the level of agreement between mother and father total symptom ratings for their own children was high. The instrument used in this study was a 14-item adaptation of the Childhood Autism Rating Scale. Families rated their child on the degree of severity for 14-items using a 4-point scale: 1 (normal) to 4 (severely abnormal).

Konstantareas and Homatidis (1989) found similar results in their assessment of agreement between mothers' and fathers' ratings of their childrens' symptom severity. The degree of agreement between parents was very high. Konstantareas and Homatidis used the same scale as Bebko et al. (1987) and found only two symptoms where the mothers and fathers differed, impairment in human relations and inappropriate affect, which the mothers rated as more severe.

Freeman, Perry, and Factor (1991) also examined if mothers and fathers agreed on the severity of child behaviours. Data were collected from 16 mothers and 16 fathers of children with autism who ranged in age from 3.9 years to 20.11 years (M = 10.70). Freeman et al. (1991) employed the same measure as in the two studies just described, and found that mothers and fathers agreed on their ratings of child functioning. In summary, the research to date suggests that mothers and fathers perceive the severity of their children's symptoms in similar ways.

Parenting Stress

Wolf et al. (1989) examined parenting stress with the Parenting Stress Index (PSI) in 30 mothers and 27 fathers of children with autism who ranged in age from 4.5 to 19.5 years ($\underline{M} = 9.34$). They found that mothers and fathers reported similar amounts of stress. Moes, Koegel, Schreibman, and Loos (1992) examined how mothers and fathers differentially experience stress using the measure Questionnaire on Resources and Stress. The study included 18 mothers and 12 fathers of children with autism ranging in age from 3 to 14 years ($\underline{M} = 6.00$). Moes et al. (1992) found that mothers reported significantly higher stress than fathers. The stress was related to family and parent problems, which suggests that mothers perceive greater stress for themselves, other family members, and the family as a whole in caring for the child with autism.

Perry, Sarlo-McGarvey, and Factor (1992) compared 21 mothers and 21 fathers of girls with Rett syndrome ranging in age from 2.11 years to 19.6 years (M = 9.50) on several measures of family functioning. Parenting stress was measured using the PSI, and Perry et al. (1992) found no significant mother-father differences for both the Child and Parent Domains.

Beckman (1991) compared 27 mothers and 27 fathers of children with heterogeneous types of disabilities ranging in age from 18 to 72 months (M = 46 months), on their reported level of parenting stress using the PSI. The range of disabilities included cerebral palsy, autism, multiple disabilities, genetic disorders resulting in developmental delay and general delays of unknown origin. Beckman (1991) found that mothers and fathers reported similar levels of stress on the Child Domain and General Life Stress scales. However, there was a significant difference between mothers and fathers in the Parent Domain. Mothers reported higher levels of stress on the following subscales: sense of competence, isolation, health, role restriction, depression, and relationship with spouse. Fathers reported higher levels of stress in the area of attachment. Beckman (1991) suggests that the mothers and fathers had different perceptions of the effect of their child on their lives.

Using the PSI, Kraus (1993) examined the similarities and differences in parenting stress in 121 mothers and 121 fathers of toddlers with disabilities ranging in age from 3 months to 16 months. The range of disabilities included Down syndrome, motor impairment, and developmental delay of unknown origin. Kraus (1993) found that fathers reported significantly more stress than mothers in the Child Domain, specifically in the areas of child's adaptability, mood, and reinforcement of the parent. In the Parent Domain mothers reported significantly more stress than fathers, specifically in the areas of restrictions in their role, relations with spouse and parent health. Fathers reported significantly more stress associated with attachment.

Social Support

Crowley and Taylor (1994) compared the perceptions of 922 mothers and 922 fathers on the Family Support Scale (FSS) in a sample of parents of children with disabilities. Data for this research comes from the longitudinal studies of the Early Intervention Research Institute. Families were recruited at 17 different sites across the United States. Demographic information concerning the age range of the children or their specific disabilities was not provided. Crowley and Taylor (1994) found that mothers and fathers responses were significantly different on 11 of the 17 items investigated. The item concerning school support was not included in the analyses because the majority of children in the sample were not attending school due to their age. Mothers reported higher satisfaction with support from parents, relatives, friends, parent groups, physicians, professional helpers, and early intervention services. Fathers reported having more spousal support (e.g., spouse, spouse's parents and spouse' friends). Mothers and fathers reported similar levels of support from professional agencies, church, social groups, coworkers, and spouse's relatives. Kraus (1993) compared the mothers' and fathers' responses on the FSS and found no significant differences between the parents on the network size or satisfaction of their social support.

Marital Adjustment

Perry et al.(1992) examined 19 mothers and 19 fathers of girls with Rett syndrome on the Dyadic Adjustment Scale (DAS) and found no significant differences in reported level of marital satisfaction between mothers and fathers.

Family Environment

Perry et al. (1992) compared the scores of 20 mothers and 20 fathers of girls with Rett syndrome on the FES. They found mothers scored significantly higher than the fathers on three of the subscales, Cohesion, Expressiveness, and Independence.

There are inconsistencies in the literature concerning mothers' and fathers' perceptions of both parenting stress and social support and little research examining marital adjustment and family environment. Many of these inconsistencies are due to the different samples used in the various studies. The studies vary across age of child, disability of child, size of sample, and measures used to assess family functioning. At this point there is little information about fathers and how their perceptions are similar to or different from mothers. For the present study, due to the sparse amount of literature and not knowing how many fathers would participate in the study, no specific hypothesis were proposed.

Description of Present Study

In an attempt to better understand the specific variables associated with successful adaptation in families of young children with autism, the present study examined the perceptions of parents on several measures pertaining to the experiences of parenting and family functioning. The study focused on parents of children aged 6 years and younger to try and identify some of the variables that may be related to better adjustment for these families. Most studies demonstrating a relationship between childhood behaviour disorders and family stress or parent adjustment have focused on school-aged children (Donenberg & Baker, 1993). It is important to examine the magnitude and type of reaction that

children with autism have on their families during the preschool years, a time when intervention may be especially effective. In the past, detection of autism tended to occur unacceptably late, usually never before the child was 3 years of age (Baron-Cohen, Allen, & Gillberg, 1992). However, research has shown that the early years (i.e., from birth to three years) are critical for the autistic child, and that early intervention programs represent a promising treatment option (Lovass, 1987; McEachin, Smith & Lovass, 1993). Therefore, early diagnosis is essential. In order for the families to begin treatment after receiving a diagnosis they need to be coping effectively in order to begin the process and make informed decisions. Dunst, Leet, and Trivette (1988) suggest that parents will be more willing and able to positively affect their children's development when the parents' most pressing needs for personal well-being are met. The findings of the current study may help professionals and parents to gain a greater awareness of the factors related to adjustment in families of young children. In the future, this increased awareness may be beneficial both to families and professionals in identifying resources that are most helpful to parents raising a child with autism.

In the field of childhood disability and the family's response to it, mothers have been the most studied family member (Seligman & Darling, 1997). There are only a handful of studies of fathers of children with disabilities (Marsh, 1992). Most of these have focused on fathers of children with mental retardation to the exclusion of children with other developmental disabilities (Seligman & Darling, 1997). Fathers have been largely neglected in previous research of families of children with autism, especially fathers of preschool age children. Fathers were asked to participate in the present study to learn

more about the dynamics of the entire family by investigating the similarities and differences in the adjustment of mothers and fathers to the demands of raising a child with autism

Using the Hill ABCX model as a general guiding framework, the parent's perception of the severity of autism was conceptualized as an ongoing stressor for the family. Social support was viewed as a resource with the potential to buffer the impact of autism severity on family adjustment. Parental locus of control was viewed as an index of the family's cognitive appraisal. Adjustment in the family was measured by investigating parenting stress, marital adjustment, family relationship, and the family's social integration into the community.

Hypotheses

Parenting Stress

Hypothesis 1. Based on the findings of the Konstantareas and Springer (1987) study which found that severity of autism was significantly related to parental stress, it is predicted that the more severe the child's autism, as defined by the frequency of symptomatic behaviors, the higher the level of parent reported stress.

Hypothesis 2. Based on the findings of the Bristol (1984), Wolf et al. (1989), Gill and Harris (1991) and Henderson and Vanderburg (1992) studies that found that stress among mothers of children with autism was less when mothers received social support, it is predicted that the higher the parent's satisfaction with social support the lower the level of parent reported stress

Hypothesis 3. Based on the findings of the Henderson and Vanderburg (1992) study that found that family adjustment was greater for those with a higher internal locus of control orientation, it is predicted that the higher degree of internality, the lower the level of parent reported stress.

Family Relationships

Hypothesis 4. Based on the findings of the Henderson and Vandenberg (1992) study which found that severity of autism was related to family adjustment, it is predicted that the less severe the autism, the higher the scores for family relationship as reported by the parent.

Hypothesis 5. Based on the findings of the Henderson and Vandenberg (1992) study which found that social support was related to family adjustment, it is predicted that the higher the parent's satisfaction with social support, the higher the scores for family relationship as reported by the parent.

Hypothesis 6. Based on the findings of the Henderson and Vandenberg (1992) study which found that locus of control was related to family adjustment, it is predicted that the higher the degree of internality, the higher the scores for family relationship as reported by the parent.

Family Social Integration

Hypothesis 7. Based on the findings of Bristol (1984), it is predicted that the more severe the child's autism as measured by frequency of symptomatic behaviors, the lower the level of family integration as reported by the parent.

Hypothesis 8. Based on the findings of Bristol (1984), which found that social support was an important family resource in successful adaptation to the demands of parenting a child with autism, it is predicted that the higher the satisfaction with social support the higher the level of social integration as reported by the parent.

Hypothesis 9. Based on the literature concerning locus of control, it is predicted that parents who report a higher degree of internality will report higher levels of social integration.

Moderating Effects of Social Support and Parental Locus of Control

Hypothesis 10. Based on the findings of the Peterson (1984) and Wolf et al. (1989) studies that found the positive effects of social support as a moderator variable, it is predicted that social support will moderate the effects of autism severity on the criterion measures reported by the parents. It is predicted that the reports for parenting stress, marital adjustment, family relationships, and family integration for parents with low and high levels of satisfaction with social support will not be different under low symptom severity but will differ under reports of high symptom severity. The buffering effect indicates that support is effective only for subjects under high stress.

Hypothesis 11. Based on the findings of Krause and Stryker (1984) that locus of control has a moderating effect in the relationship between life stress and well-being, it is predicted that the relationship between severity of autism and parenting stress, marital adjustment, family relationships and family integration will be weaker for a parent with an internal as compared to an external locus of control orientation. It is predicted that parents who report higher levels of symptom severity and have a more internal locus of control

orientation will have lower levels of reported stress, higher levels of marital adjustment, and higher family relationship and family integration than parents who report high levels of severity of autism and have a more external locus of control orientation. It is hypothesized that parents with a more internal parental locus of control orientation are less influenced by stressors than are parents with a more external locus of control orientation.

Hypothesis 12. Based on the findings of Sandler and Lakey (1982) concerning social support and locus of control as moderator variables, it is predicted that parents who report high levels of severity of autism, and who have a more internal locus of control orientation will be more satisfied with their social supports than parents who have a more external locus of control orientation.

CHAPTER TWO

METHOD

Participants

Fifty-two families of preschool age children (2-6 years) with an autistic or pervasive developmental disorder were recruited from the Calgary, Winnipeg, and Ottawa regions. Due to the low prevalence rate of autism, multiple sites were contacted in an effort to obtain the largest possible sample. For 22 of the families, both the husband and the wife participated; for 28 families only the mother participated. Of these, 20 mothers were from two parent families in which the father did not participate and 8 were single mothers. For two families, only the father participated, the mothers did not return their package. Thus, a total of 50 mothers and 24 fathers participated in the study. Parents ranged in age from 25 to 56 years. The mean age for the mothers was 35.4 years (SD = 5.76); the mean age for the fathers was 38.4 years (SD = 5.95).

Measures

The following seven self-administered questionnaires were included in the package that was mailed to the parents participating in the study: (a) a demographic information form which was constructed for this study; (b) the Gilliam Autism Rating Scale (GARS; Gilliam, 1995); (c) the Parental Locus of Control Scale (PLOC; Campis et al., 1986); (d) the Family Support Scale (FSS; Dunst, Jenkins, & Trivette, 1984); (e) the Dyadic Adjustment Scale (DAS; Spanier, 1976); (f) the Parenting Stress Index (PSI; Abidin, 1995); and (g) the Family Environment Scale (Moos & Moos, 1994).

With the exception of the demographic measure, all questionnaires had been developed and tested previously in research with families with children with a developmental disability. Descriptions of these measures are presented below.

Demographic Information Form

This instrument (entitled Family Information; see Appendix A) requested information from the parent who completed the questionnaire about themselves and their families. If both parents were participating in the study the form was completed by both the mother and the father. The demographics of primary interest were: age of primary caregiver, marital status, education, occupation, employment status, age of child, diagnosis of child, type of treatment, and number of children in the home.

Gilliam Autism Rating Scale (GARS)

The Gilliam Autism Rating Scale was developed by Gilliam (1995) to identify and diagnose autism in individuals ages 3 through 22, and to estimate the severity of the problem. Items on the GARS are based on the definitions of autism adopted by the Autism Society of America and the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association, 1994). Each item on the GARS is based on behavioral descriptions of examples of autistic characteristics used in these definitions. Because the definitions are behaviorally specific, and replete with examples, the relationship between the definitions and the test items is easy to see (Gilliam, 1995). The GARS is a behavioral checklist that is comprised of subtests of 14 items each. Each subtest is comprised of items describing behaviors that are symptomatic of autism. There are four subtests on the GARS: Stereotyped Behaviours, Communication, Social

Interaction and Developmental Disturbances. A brief description of each of the subtests is contained in Appendix B. A total score is tabulated from the four subtests which gives an Autism Quotient. The GARS is easily completed by parents and others who have knowledge of the subject's behaviour or the greatest opportunity to observe him or her. Norms are provided for determining the likelihood that a subject has autism and the severity of the disorder. The response format of the scale is a rating system. The respondent is asked to rate each item according to its frequency of occurrence. The following guidelines are given: 0= Never Observed; 1 = Seldom Observed; 2 = Sometimes Observed; and 3 = Frequently Observed.

The GARS was standardized on a sample of 1,092 individuals with autism from 46 states in the U.S, the District of Columbia, Puerto Rico, and Canada. Thirty-one percent of the normative sample used in the development of this instrument were children aged 6 years and under. Internal consistency of the GARS revealed Cronbach's alpha coefficients of .90 for Stereotyped Behaviors; .89 for Communication; .93 for Social Interaction; .88 for Developmental Disturbances; and .96 for the Autism Quotient. The validity of the GARS was demonstrated through several research studies. Discriminant validity studies demonstrated that scores from the GARS can be used to identify subjects who belong to different diagnostic groups. Concurrent validity refers to the fact that the scale correlates with other measures in a theoretically meaningful way. Concurrent validity was established by correlating scores on the GARS with scores from the Autistic Behaviour Checklist (ABC) (Gilliam, 1995). Significant positive correlations (ranging from r = .37 to r = .94) were obtained between comparable subtests on these two instruments.

Parental Locus of Control Scale (PLOC)

The Parental Locus of Control Scale (see Appendix C) was developed by Campis et al. (1986) to measure parental expectancies to determine if parents view their child's behaviour as a direct consequence of their parenting efforts (internal locus of control) or as outside the reach of their parenting efforts (external locus of control). The instrument consists of 47 items rated on 5-point Likert scales. The items are grouped into 5 subscales each of which yields a separate score. These are Parental Efficacy, Parental Responsibility, Child Control of Parent's Life, Parental Belief in Fate or Chance, and Parental Control of Child's Behaviour. A brief description of each of the subscales is contained in Appendix D. Low scores on the PLOC suggest an internal orientation, whereas high scores indicate the opposite.

Campis et al. (1986) reported good total scale reliability (alpha = .92). Four of the five PLOC subscales had adequate reliability coefficient values. Alpha coefficients for the individual subscales were .79 (Parental Responsibility), .66 (Child Control), .70 (Fate/Chance), and .71 (Parental Control). The fifth subscale, Parental Efficacy, had a much lower alpha coefficient value (.44). However, the authors found that deleting one item from the scale which was ambiguous improved the coefficient to .62. The authors further recommended that future researchers omit this item, ("My child usually ends up getting his/her way, so why try"). Thus, for the purposes of this study this item was deleted from the questionnaire. The study provided evidence for the construct validity of the overall PLOC and its five subscales as measures of parents' locus of control beliefs. A moderate correlation (r = .33, p < .01) between the PLOC and a more general construct of

locus of control as measured by the Internal-External Locus of Control Scale (I-E) developed by Rotter (1966) indicated that the PLOC taps a related but not identical locus of control construct. The I-E scale is a measure of generalized expectancies and is therefore only appropriate for predicting behaviour in situations that are ambiguous and/or novel for the individual (Campis et al., 1986).

Roberts, Joe and Rowe-Hallbert (1992) examined the internal consistency and test-retest reliability of the PLOC in samples of parents of 2 to 12 year old children. Good total scale reliability was reported (alpha = .81). The test-retest reliability coefficient was .83. A review of item content indicated that all items were developmentally appropriate for parents with 2 to 12 year old children (Roberts et al., 1992). Roberts et al. (1992) tested the discriminant validity of the PLOC on their sample of clinic (n=72) and nonclinic (n=31) parents. Roberts et al. (1992) used all five subscales in their research and found a significant effect indicating that clinic parents ($\underline{M} = 121.7$) tended to have a more external locus of control than nonclinic parents ($\underline{M} = 108.2$).

Family Support Scale (FSS)

The Family Support Scale (see Appendix E) was developed by Dunst et al. (1984) to assess a parent's perception of the helpfulness of various support sources in raising young children. The FSS is designed to measure qualitative aspects of support; namely satisfaction with support as well as degree of perceived helpfulness. The FSS is an 18-item self-report measure designed to assess the degree to which potential sources of support have been helpful to families rearing young children. Ratings are made on a five-point Likert scale ranging from Not At All Helpful to Extremely Helpful. The scale was

originally developed as part of an investigation examining influences of social support on the personal and familial well-being and coping of parents rearing preschool handicapped children (Dunst et al., 1984).

Recent analyses have been done in order to further establish the reliability and validity of the scale (Dunst, Trivette, & Hamby, 1994). To investigate reliability and validity, the authors examined the responses of 224 parents of developmentally handicapped preschool children. Coefficient alpha computed from the average correlations among the 18 scale items was .79.

The authors conclude that the FSS is a highly reliable and valid instrument capable of discriminating among persons differing in levels and degrees of stress, coping and family integrity. In addition to predicting personal and familial well-being, the scale predicts styles of parent-child interactions, personal expectations for children, and parental perceptions of child behavior problems.

Dyadic Adjustment Scale (DAS)

The Dyadic Adjustment Scale was developed by Spanier (1976) to assess different areas of marital functioning. There are four subscales on the DAS: Dyadic Consensus, Dyadic Satisfaction, Affectional Expression and Dyadic Cohesion. A brief description of each of the subscales is contained in Appendix F.

The DAS has been widely used in many studies, and scores on the DAS are positively correlated with scores on other measures of marital adjustment (Spanier, 1976). Also, scores on the DAS have been shown to discriminate between married and divorced respondents (Spanier, 1976). The internal consistency reliability coefficients for the total

scale and the four subscales are quite high; Dyadic Consensus Subscale (.90); Dyadic Satisfaction Subscale (.94); Dyadic Cohesion Subscale (.86); Affectional Expression Subscale (.73); and the overall scale (.96) (Spanier, 1976).

The Dyadic Adjustment Scale has been used in hundreds of clinical and experimental research studies, and its validity has been well established using a number of different techniques. Overall, the significance of the evidence gained from this extensive literature is that the DAS assesses an important construct which has strong explanatory and predictive utility in the characterization of marital and other dyadic relationships (Spanier, 1989).

Parenting Stress Index (PSI)

The Parenting Stress Index was developed by Abidin in 1985 to assess general stress and challenges in parent-child dyads. The PSI is a 101-item self-report questionnaire designed for screening and diagnosis of parental stress in parents of children under age 10. The PSI assesses stressful child, parental, and situational characteristics. In the child domain, the subscales include Child Distractibility/Hyperactivity, Adaptability, Child Reinforces Parent, Child Demandingness, Child Mood, and Acceptability of the Child to the Parent. In the Parent domain, subscales include Parent's Sense of Competence, Social Isolation, Parent Attachment, Physical Health, Restrictions Imposed by the Parental Role, Parent Depression or Unhappiness, and Relationship with Spouse. A brief description of each of the subscales is contained in Appendix G.

The reliability information given in the manual reports that test-retest correlations in the Parent domain were .71, .91, and .69 and in the Child domain, .82, .63, and .77 for

intervals of 3 weeks, 1-3 months, and 3 months, respectively. Alpha reliabilities ranged from .62 to .70 for the subscales of the Child domain and .55 to .80 for the subscales of the Parent domain; alpha for the total Child domain score was .89 and alpha for the Parent domain was .93. Total stress score alpha was .95. The manual outlines many studies that have successfully demonstrated the PSI's content, construct, and criterion-related validity. For example, the PSI successfully discriminated between samples of physically abusive and nonabusive mothers (Mash, Johnston, & Kovitz, 1983). In a study comparing parenting stress for families of children with autism, children with Down syndrome, and normally developing children (Wolf et al., 1989), PSI scores were highest for mothers and fathers of children with autism.

Family Environment Scale (FES)

The Family Environment Scale was developed by Moos and Moos in 1986 to measure the social-environmental characteristics of all types of families. The Real Form (Form R), consists of 90 true/false items that measure people's perceptions of their conjugal or nuclear family environments. The FES is comprised of ten subscales that assess three underlying domains, or sets of dimensions: The Relationship dimensions, the Personal Growth dimensions, and the System Maintenance dimensions.

The Relationship dimensions are measured by the Cohesion, Expressiveness, and Conflict scales. The Personal Growth or Goal Orientation dimensions are measured by the Independence, Achievement Orientation, Intellectual-Cultural Orientation, Active-Recreational Orientation, and Moral-Religious Emphasis subscales. The System

Maintenance dimensions are measured by the Organization and Control Subscales. A brief description of each of these subscales is contained in Appendix H.

The internal consistencies (Cronbach's alpha) are all in an acceptable range:

Cohesion (.78), Expressiveness (.69), Conflict (.75), Independence (.61), Achievement

Orientation (.64), Intellectual-Cultural Orientation (.78), Active-Recreational Orientation

(.67), Moral-Religious Emphasis (.78), Organization (.76), and Control (.67). Test-retest reliabilities after 8 weeks are all in an acceptable range, varying from a low of .68 for Independence to a high of .86 for Cohesion.

The Family Relationship Index (FRI), is a summary index derived from the FES that is a measure of the quality of social relationships in the family environment. The FRI is the sum of the Cohesion, Expressiveness, and Conflict (reversed) subscales. This index has high internal consistency (alpha = .89) and good construct validity (Billings & Moos, 1982; Hoge, Andrews, Faulkner, & Robinson, 1989; Holahan & Moos, 1982).

The Family Social Integration Index (FSII), is a summary index derived from the FES that is a measure of the family's involvement in the community. The FSII is the average of the standard scores for the Intellectual-Cultural Orientation, Active-Recreational Orientation, and Moral-Religious Emphasis subscales. To obtain a high score on each of these scales requires involvement in the community (e.g., going to a concert, joining an athletic team, being involved in church activities). This index is reported to be internally consistent and as having good construct validity (Moos & Moos, 1994). It has been used as summary measure of the extent to which a family is socially integrated into

the community. The alpha for this index is .66 (Corse, Schmid & Trickett, 1990; Trickett, Carlson, Aber, & Cicchetti, 1991).

Procedures

Initial contacts were made with families of preschool age children with an autistic or pervasive developmental disorder through a letter explaining the project (see Appendix I) and an accompanying letter of support from the participating agencies (Society for Treatment of Autism, Calgary, AB; Children at Risk, Ottawa, ON; Health Sciences Centre (Autism Program), Winnipeg, MB) (See Appendix J). Parents of children receiving home based therapy in the Calgary area were contacted via individuals familiar with the families. The initial recruitment letters were distributed in the Calgary region at the beginning of July, 1996, followed by the distribution of letters in Ottawa towards the end of July, 1996. The letters to Winnipeg were not sent out until the end of August, 1996. To preserve the confidentiality of both the agencies' mailing lists and the families, parents who wished to participate were asked to contact the researcher. The parents in Calgary and Ottawa were given a phone number to contact the researcher directly. A toll free number was provided for all families who lived outside of the Calgary region. Due to the initial poor response rate from the Calgary and Ottawa families a modification was implemented for the Winnipeg families. The families who wished to participate in the study had the option of phoning the researcher or sending a form with their name and phone number in a selfaddressed stamped envelope indicating interest, and the researcher would contact them directly.

In an effort to increase participation rates a second letter was sent to the families in Calgary approximately 12 weeks after the initial letter, and in Ottawa approximately 5 months after the initial letter was sent. The second letter (see Appendix K) included the response format modification implemented for the Winnipeg families. The parent had the option of contacting the researcher directly or having the researcher get in touch with them by sending a form indicating their interest for further information regarding the study.

The researcher spoke directly with each parent who inquired about the study. The researcher closely followed a telephone script (see Appendix L) when speaking with the families to ensure that all parents were receiving the same information and were addressed in a similar manner. It was explained that participation would take approximately one hour of their time. If a parent was interested in participating in the study, a package of questionnaires was mailed to their home with a self-addressed stamped envelope for the parent to mail the completed package to the researcher. In accordance with current ethical guidelines for research in which questionnaires are mailed, participants were not required to sign and return an informed consent form. The information required for informed consent was combined with detailed instructions for participation (see Appendix M), and the consent form (see Appendix N) was included with the set of questionnaires in an envelope in which the parent could enclose and return the completed package. A separate form (see Appendix O) was included which participants could complete and return if they wished to receive a summary of the results. To control for potential order effects, the order of questionnaires within sets was completely randomized. Each participating mother and father received their own package which was given a code on the top left corner of the questionnaires which indicated the gender of the participant, the city of residence, and a subject number. All husband and wives who participated jointly were given the same number to ensure the researcher would be able to identify husband-wife dyads.

Arrangements were made in each city for a chartered psychologist to be available to the parents if they felt distressed following the completion of the questionnaires. All three psychologists were contacted at the conclusion of the study, April 1997, and the researcher was informed that none of the families from Calgary, Winnipeg, or Ottawa contacted the psychologists following the completion of the questionnaires.

CHAPTER THREE

RESULTS

Descriptive Statistics

Demographic Characteristics

The study included families from three different cities in Canada; Calgary,
Winnipeg, and Ottawa. A total of 159 families were sent letters inviting them to
participate in the study; 110 parents responded to the letter and agreed to participate in
the study and 76 of these parents completed and returned their questionnaire package.
Two mothers were excluded from the sample because they provided an insufficient
amount of information, leaving 74 parents whose responses were coded for further
analysis. A complete listing of the response and return rates for mothers and fathers who
participated in the study from each of the three cities is presented in Table 1.

Thirteen of the mothers were from Calgary, 25 were from Winnipeg (two mothers were excluded from the study due to an insufficient amount of data on questionnaires), and 14 were from the Ottawa region. Six of the fathers were from Calgary, 11 were from Winnipeg, and 7 were from Ottawa. Forty-one of the 50 mothers were married, 8 were divorced or separated, and 1 was living common-law. All but one of the 24 fathers was married, and one was living common-law (see Table 2). The demographic information presented in Table 2 reveals that 82% of the women in the sample are married which is consistent with the number of two parent families in today's Canadian society. Findings

Table 1

Response and Return Rates for Families Participating in the Study

	Calgary Winnipeg		Ottawa	Total	
Number of letters distributed	35	82	42	159	
Number of families who responded	19 (54%)	30 (37%)	21 (50%)	70 (44%)	
Number of packages sent out					
Mothers	19	30	20	69	
Fathers	9	19	13	41	
Number of packages returned					
Mothers	13 (68%)	25 (83%)	14 (70%)	52 (75%)	
Fathers	6 (67%)	11 (58%)	7 (54%)	24 (59%)	

Note. Two mothers from Winnipeg were excluded from the study due to an insufficient amount of data on questionnaires.

Table 2

Demographic Characteristics of the Parents

Danie Marieklas	Mothers	Fathers	Total	
Demographic Variables	n=50	n=24	N=74	
Mean Age (years)	35.4	38.4	36.9	
SD	(5.76)	(5.95)	(5.85)	
Geographical Location				
Calgary	13 (26%)	6 (25%)	19 (26%)	
Winnipeg	23 (46%)	11 (46%)	34 (46%)	
Ottawa	14 (28%)	7 (29%)	21 (28%)	
Marital Status				
Married	41 (82%)	23 (96%)	64 (86%)	
Separated/Divorced	8 (16%)	0 (0%)	8 (11%)	
Common-law	1 (2%)	1 (4%)	2 (3%)	
Employment Status				
No employment	26 (52%)	1 (4%)	27 (36%)	
Part-time employment	17 (34%)	1 (4%)	18 (24%)	
Full-time employment	7 (14%)	22 (92%)	29 (39%)	
Education				
Below high school	4 (8%)	1 (4%)	5 (7%)	
High school graduate	17 (34%)	6 (25%)	23 (31%)	
Partial college or university	9 (18%)	2 (8%)	11 (15%)	
University/College graduate	19 (38%)	13 (54%)	32 (43%)	
Graduate Training	1 (2%)	2 (4%)	3 (4%)	
Hollingshead SES Index				
Major business/professional	14 (28%)	10 (42%)	24 (32%)	
Medium business/minor professional	16 (32%)	5 (21%)	21 (28%)	
Skilled craftsmen, clerical, sales	14 (28%)	8 (33%)	22 (30%)	
Semiskilled workers	3 (6%)	0 (0%)	3 (4%)	
Unskilled laborers	3 (6%)	1 (4%)	4 (5%)	

from the National Longitudinal Survey of Children and Youth in Canada indicate that ".....84.2% of children in Canada aged 0-11 years live in a two-parent family." (p.28) (Statistics Canada, 1996). Fifty-two percent of the mothers in the sample do not work outside of the home, while 34% work part-time, and 14% work full-time.

The Hollingshead Four Factor Index is a measure of socioeconomic status (SES) that was derived for each family by combining weighted scores for each parents' educational level and occupational type (Hollingshead, 1975). For two-parent families, both parents' education scores (which range from 1 = less than seventh grade education to 7 = graduate degree) are weighted by 3 and averaged. Parents' occupation score (which can range from 1 = menial service workers/chronically unemployed to 9 = major business/professionals) are weighted by 5 and averaged. The two scores are then summed to find the family SES figure. If the mother was a homemaker, just the father's occupational score was used. In the case of single parent homes, only the resident parent's education and occupation scores were used. Scores on the Hollingshead Index can range from 8 (elementary school education, chronically unemployed) to 66 (graduate degree, large business owner or professional). The mean score for the current sample was 44.74 (SD = 13.67) with scores ranging from 12-66. Scores ranging from 40-54 are represented by occupations of medium business, minor professional, and technical workers. The majority of the families fell into the middle to upper classes. Families of low SES are underrepresented in this study.

In examining the child characteristics (see Table 3) of the sample, the gender ratio is between 3-4:1 (39 males and 11 females) which is consistent with what one would

Table 3

Demographic Characteristics of the Children

Demographic Variables	Total N=50
Mean age (months) SD	57.9 8 (12.07)
Mean age of diagnosis SD	34.40 (8.42)
Gender	
Male	39
Female	11
Number of siblings in family	
No siblings	7
One sibling	31
Two siblings	11
Three siblings	1

expect to find in the autistic population (Lord, Schopler, & Revicki, 1982; Volkmar, Szatmari, & Sparrow, 1993). The mean age of children in the sample is 57.98 months (SD = 12.07), and the mean age of initial diagnosis as reported by the parents was 34.40 months (SD = 8.42).

Overall Approach to Statistical Analyses

The results will be presented in five sections. First, preliminary analyses of the data including descriptive statistics for the mother's responses for each of the questionnaires will be presented. This will include the comparison of the mother's scores for children who were diagnosed autistic versus those diagnosed PDD-NOS. For the GARS, PLOC, PSI and the DAS, separate multivariate analyses of variance (MANOVA) were performed as these measures consist of several dependent variables. MANOVA is a generalization of analysis of variance (ANOVA) to a situation in which there are several dependent variables. By considering several dependent variables at once multivariate analyses allow the researcher to hold the probability of making one Type 1 error at alpha. Independent t-tests were carried out for the FSS, FRI, and FSII as there is only one total score for each of these measures.

Secondly, the mother's overall scores on each of the measures will be compared with normative data from previous research. Although the normative groups presented by the authors of the separate measures may not be directly comparable to the current sample in terms of the children's ages and their diagnoses they provide the basis for a general comparison.

Third, an examination of the correlations between certain demographic characteristics of the mothers on the predictor, moderating, and criterion measures will be presented. Fourth, the moderated regression analyses that were used for all hypothesis testing will be presented. The resulting sample size of fathers was insufficient to perform multiple regression analyses. Howell (1992) reports that a sample size which exceeds or equals the number of predictors plus 40 yields acceptable reliability of correlation coefficients in multiple regression analyses. A sample size of 24 fathers is clearly insufficient for 7 predictors. In the present study, a sample size of 50 mothers is adequate. In moderated multiple regression the influence of a presumed moderator variable is tested by means of the inclusion of an interaction term, which is the product of the moderator and main effect variables, in the regression equation. In the present study, in addition to main effect variables of severity of autism, social support, and locus of control, four interaction terms were included in each of the four separate regression equations predicting parenting stress, marital adjustment, family relationship, and family social integration: severity of autism x social support, severity of autism x locus of control, social support x locus of control and finally, severity of autism x social support x locus of control. Harris (1985) reported that one should not test interaction effects with continuous variables by using the raw score cross-products, but instead should use the deviation score (i.e., each score minus its mean) cross-products. Aiken and West (1991) call the variables that have been converted to deviation scores "centered". The centered original variables and the cross-product of the centered variables (the interaction term) are

the predictors. This transformation was done to minimize problems with multicollinearity that often occur with product terms (Jaccard, Wan, & Turrisi, 1990).

The final sections of the results will involve exploratory analyses. In order to determine if certain symptomatic behaviours of autism are more predictive of family adjustment problems, the four subtests of the GARS will be entered into four separate stepwise regressions to examine parental stress, marital adjustment, family relationship, and family social integration. Finally, descriptive information concerning the mothers and fathers will be presented followed by a comparison between the parents across the different measures. These analyses will be done by using repeated measures MANOVA and paired samples t-tests.

Mothers of Children with Autism and PDD-NOS

Fifty mothers of children participated in this study. Thirty of the children had previously been diagnosed as having autistic disorder, and 20 of the children received the diagnosis of PDD-NOS. PDD-NOS is typically thought of as a less severe form of autism and for this reason it was of interest to see if ratings by the mothers of the children with autism differed from those of mothers of children with PDD-NOS. A MANOVA was carried out to compare the two groups on the GARS. Although mothers of children diagnosed with autism rated their children as more severe than the mothers of children diagnosed with PDD-NOS on all of the individual subtests and Total Autism Quotient on the GARS measure (see Table 4), there were no significant differences found between the two groups. In order to determine if these two groups of mothers differed on their ratings on the PLOC, PSI, and DAS, multivariate analyses were carried out. Independent t-tests

Table 4

Comparison of Means and Standard Deviations of Mothers' Standard Scores on the

Gilliam Autism Rating Scale by Diagnosis

	Autism			Develo	Pervasive Developmental Disorder-NOS		Total		
	M	SD	<u>n</u>	<u>M</u>	SD	ū	<u>M</u>	SD	N
Stereotyped Behavior	8.28	2.62	28	8.05	3.41	20	8.19	2.94	48
Communication	9.88	2.67	26	9.00	2.10	20	9.50	2.46	46
Social Interaction	8.07	2.01	29	6.60	2.08	20	7.47	2.15	49
Developmental	8.77	1.99	30	8.40	1.23	20	8.62	1.72	50
Total Autism Quotient	91.46	11.87	30	85.00	10.23	20	89.08	11.52	50

Note. Sample size varies on different subtests as it is not necessary for the parent to complete all subtests in order to receive an Autism Quotient.

were used to compare the two groups on the FSS, FRI and FSII. No multivariate statistical differences were found between the mothers of autistic versus PDD-NOS children for the PLOC, PSI, DAS. There were also no significant differences between the two groups of mothers on the FSS, FRI and FSII using independent t-tests. In light of the lack of statistically significant differences between the mothers of children with autism and the mothers of children with PDD-NOS on the seven measures used in this study, the scores for mothers in the two groups were combined for all subsequent analyses.

Comparison of Current Sample of Mothers to GARS Normative Sample

The GARS' (Gilliam, 1995) normative sample was composed entirely of individuals age 3-22 diagnosed with autism. A subject's score from the GARS can be compared with the scores from the normative sample to determine the likelihood of the person having autism. The best overall estimate of a subject's behaviour is the total test score, in the case of the GARS, the Autism Quotient. This standard score takes into account all the symptomatic behaviors of autism measured on the GARS as shown in (Table 5) and for this reason provides the best prediction of autism (Gilliam, 1995).

According to the information presented in the examiner's manual for the GARS, if the subject's Autism Quotient is 90 or above, the person probably has an autistic disorder. Standard scores on subtests of 8 through 12 or Autism Quotients of 90 through 110 are within the average range for subjects with autism in the normative sample. Approximately 50% of the subjects with autism scored in this range (Gilliam, 1995). Standard scores above 12, on the subtests or Autism Quotients equal to or greater than 111 are highly

<u>Table 5</u>
<u>Guidelines for Interpreting Subtest Standard Scores and Autism Quotients</u>

Subtest Standard Score	Autism Quotient	% ile	% of Normative Sample	% of Current Sample	Probability of Autism
17-19	131+	99+	2	0	Very High
15-16	121-130	92-98	7	0	High
13-14	111-120	76-91	16	0	Above Average
8-12	90-110	25-75	50	42	Average
6-7	80-89	9-24	16	36	Below Average
4-5	70-79	2-8	7	18	Low
1-3	≤69	.1-1	2	4	Very Low

From Gilliam (1995), p. 16.

indicative of autism. The probability of a child without autism receiving scores this high is very unlikely.

Subtest standard scores of 6 or 7 or an Autism quotient of 80 through 89 are below average for subjects with autism and represent borderline scores in terms of the likelihood of autism. The probability that persons who receive quotients in this range have autism is equivocal because in the normative study, only 23% of the autistic subjects scored 89 or lower (Gilliam, 1995). In the normative sample, less than 9% of the subjects with autism had an Autism Quotient below 80. Ninety-eight percent of the sample had an Autism Quotient of 70 or greater (Gilliam, 1995). If the Autism Quotient is below 70, the person is very likely not autistic. In the current sample the mean Autism Quotient was 89.08 (SD = 11.52) with the scores ranging from 62.00 to 110.00. These scores fall within the range of low probability and average probability of having autism. Possible explanations for why scores for this sample are lower than for the normative sample will be addressed in the Discussion.

Comparison of Current Sample of Mothers to PLOC Normative Sample

The norms presented in the PLOC scale are for a sample of 60 parents of elementary school age children. The parents were chosen because they did not report experiencing any difficulties in the parenting role. The PLOC scale only included the means for each subscale and did not include the standard deviations in the published report. The means reported in Table 6 indicate that the mothers of children with autism reported higher scores on the Parental Efficacy, Parental Responsibility, Child Control and Fate/Chance subscales than parents in the normal sample. Overall, the current sample of

parents had a higher locus of control score that norm parents, which suggests that the current mothers have a more external parental locus of control orientation than mothers in the normative group. However, in the absence of adequate information for statistical comparison, these differences, although suggestive, cannot be interpreted.

Comparison of Current Sample of Mothers to FSS Normative Sample

The normative sample for the FSS is taken from a recent analyses designed to further establish the reliability and validity of the FSS developed by Dunst et al. (1984). The subjects were 224 parents (174 mothers and 50 fathers) of children with developmental disabilities or children at-risk for poor developmental outcomes. Eighty-four percent of the sample was married, while the remaining 16% were single, widowed, separated or divorced. The parents and their children were participating in an early intervention program. The mean age of the mothers was 28.81 years (SD = 6.99) and for fathers was 32.07 years (SD = 7.40). The mean age of the children in the early intervention program was not given. Mean scores for each item on the FSS and for the total score are presented in Table 7. Although the two groups are comparable on a number of the items, there are some areas that are different. Overall, the current sample reported a lower total score with satisfaction for available resources than the normative group.

Comparison of Current Sample of Mothers to PSI Normative Sample

As presented in the manual of the PSI (Abidin, 1995), the normative sample consisted of 2,633 mothers who ranged in age from 16 to 61 (mean age = 30.9) years of age. The target children for the sample, ranged in age from 1 month to 12 years of age

Table 7

Comparison of Means and Standard Deviations of Current Sample of Mothers to FSS

Normative Sample

	Current Me	other Sample	Norm Sample	
	N=	= 50	N= 224	
Measure and items	М	<u>SD</u>	<u>M</u>	<u>SD</u>
Family Support Scale				
Own parents	3.00	1.52	3.35	1.43
Spouse or Partner's Parents	2.47	1.23	2.80	1.51
Relatives/Kin	2.42	1.13	2.53	1.22
Spouse or Partner's Relatives/Kin	1.85	1.00	2.30	1.26
Spouse or Partner	3.72	1.33	3.94	1.39
Friends	2.63	1.20	2.62	1.29
Spouse or Partner's Friends	1.97	1.20	2.13	1.20
Own Children	3.05	1.31	2.55	1.52
Other Parents	2.30	1.00	1.99	1.16
Co-workers	1.83	1.04	1.86	1.19
Parent Groups	2.70	1.21	1.75	1.24
Social Groups/Clubs	1.80	0.77	1.41	0.95
Church	2.06	1.62	2.78	1.51
Family/Child Physician	2.53	1.12	3.52	1.17
Early Intervention Programs	3.92	1.23	4.07	1.26
School/Day Care	4.07	1.02	2.48	1.69
Professional Helpers	3.92	1.15	3.8 7	1.13
Professional Agencies	2.98	1.27	2.45	1.51
Total Scale Score	36.98	10.09	48.42	10.73

Note. Total Scale Score for current sample is based on all 50 cases, N varies for current sample on individual items. If the item was "not available" to mothers it was treated as a missing case. The normative sample had no missing cases.

with a mean of 4.9 years (SD = 3.1). Table 8 provides the means and standard deviations for both the current sample of mothers and the normative sample. The mothers of children with autism scored higher than the normative sample on the Child Domain subscale. High scores in the Child Domain may be associated with children who display qualities that make it difficult for parents to fulfill their parenting roles (Abidin, 1995). Mothers of children with autism also scored higher than the normative sample on the Parent Domain. High scores on the Parent Domain suggest that the sources of stress and potential dysfunction of the parent-child system may be related to dimensions of the parent's functioning (Abidin, 1995). The mothers of children with autism also scored higher than the normative sample on the Life Stress scale. Parents who report high Life Stress scores find themselves in stressful circumstances that are often beyond their control (e.g., the loss of a job). The Life Stress scale provides some index of the amount of stress that the parent is currently experiencing outside the parent-child relationship (Abidin, 1995).

Comparison of Current Sample of Mothers to DAS Normative Sample

The normative sample for the DAS consisted of 218 white, married persons whose mean age was 35.1 years. The mean number of years the couple was married was 13.2, and the mean number of children per couple was 2. The mean scores and standard deviations for the subscales and overall adjustment for the DAS are presented in Table 9. Higher scores are indicative of greater marital adjustment. The current sample scored lower on three out of four of the subscales of the DAS and for overall dyadic adjustment.

Table 8

Comparison of Means and Standard Deviations of Current Sample of Mothers to PSI

Normative Sample

	Current	Mother Sample	Norm Sample		
		N=50	N=2,633		
Measure and subscale	<u>M</u>	SD	<u>M</u>	SD	
Parenting Stress Index					
Child Domain	130.32	23.39	99.70	18.80	
Distractibility/Hyperactivity	28.66	5.87	24.70	4.80	
Adaptability	33.38	7.16	24.90	5.70	
Reinforces Parent	11.52	4.51	9.40	2.90	
Demandingness	26.14	6.07	18.30	4.60	
Mood	11.86	3.82	9.70	2.90	
Acceptability	18.76	5.18	12.60	3.50	
Parent Domain	136.24	27.98	123.10	24.40	
Competence	32.08	6.72	29.10	6.00	
Isolation	15.02	4.83	12.60	3.70	
Attachment	11.48	2.91	12.70	3.20	
Health	14.34	4.26	11.70	3.40	
Role Restriction	21.64	6.34	18.90	5.30	
Depression	20.84	5.86	20.30	5.50	
Spouse	20.84	6.25	16.90	5.10	
Total Stress	266.56	43.35	222.8	36.60	
Life Stress	9.74	9.18	7.80	6.20	

Table 9
Comparison of Means and Standard Deviations of Current Sample of Mothers to DAS
Normative Sample

	Current Mot N =	•	Norm Sample $N = 218$		
Measure and subscale	<u>M</u>	<u>SD</u>	<u>M</u>	SD	
Dyadic Adjustment Scale					
Consensus	46.33	8.35	51.90	8.50	
Satisfaction	35.90	8.12	40.50	7.20	
Affectional Expression	7.50	2.86	9.00	2.30	
Cohesion	13.48	4.53	13.40	4.20	
Dyadic Adjustment	103.21	21.35	114.80	17.80	

However, the scores reported by the mothers of the children with autism are within one standard deviation of the normative scores on all of the scales.

Comparison of Current Sample of Mothers to FES Normative Sample

The normative sample for the FES consists of 1,432 families. The normative families included families from all areas of the United States, single-parent and multigenerational families, families drawn from racial minority groups, and families of all age groups, including newly married student families, families with preschool and adolescent children, families whose children have left home, and families of retired adults (Moos & Moos, 1994). The means and standard deviation for each of the ten subscales of the FES are presented in Table 10. Although there is some variability in the scores, the mothers of children with autism are within one standard deviation of the mean of the normative group for all subscales.

In examining the current sample with the normative samples for each of the measures, the mothers of children with autism report higher levels of parenting stress, particularly in the child domain, are less satisfied with their social network, and have a more external locus of control orientation. Despite the findings, these mothers are still within one standard deviation on the scores for marital adjustment, family relationships, and family social integration measures. In summary, even though these mothers are experiencing some stress in their parenting role, they are still reporting satisfactory adjustment in most areas of family functioning. These results must be interpreted with caution as the normative samples are not directly comparable with the current sample in terms of the age of the children and diagnosis of autism.

Table 10

Comparison of Means and Standard Deviations of Current Sample of Mothers to FES

Normative Sample

	Current Mo	ther Sample	Norm Sample	
	N =	50	N =	1,432
Measure and subscale	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Family Environment Scale				
Cohesion	53.58	13.77	50.00	10.00
Expressiveness	51.42	11.78	50.00	10.00
Conflict	47.50	12.08	50.00	10.00
Independence	44.52	11.70	50.00	10.00
Achievement Orientation	44.14	10.71	50.00	10.00
Intellectual-Cultural Orientation	47.56	11.54	50.00	10.00
Active-Recreational Orientation	44.58	10.78	50.00	10.00
Moral-Religious Emphasis	49.84	10.72	50.00	10.00
Organization	50.18	11.76	50.00	10.00
Control	52.80	10.79	50.00	10.00

Moderated Multiple Regression Analyses

Four separate multiple regression analyses were conducted to test the hypotheses, following the convention of conducting moderated multiple regression analyses hierarchically (Aiken & West, 1991). As suggested by Cohen and Wills (1985), adequate tests of main and buffering effects for social support and locus of control require that the predictor variable and the moderating variables are nonoverlapping. Serious confounding of these variables may lead to overestimation of buffering effects. The current results (see Table 11) indicate that both the social support and locus of control variables are not highly or significantly correlated with severity of autism. Another methodological requirement for testing a buffering model is a significant relation between the stressor and the outcome variable. Such an effect indicates that the measurement and range of scores on these variables are adequate (Cohen & Wills, 1985). The intercorrelation matrix in Table 11 shows significant correlations between severity of autism and measures of parenting stress and family social integration. However, there is no such correlation for severity of autism and marital adjustment or severity of autism and family relationship.

Prior to conducting the regression analyses, a correlational analysis was performed between certain demographic characteristics of the mothers and the predictor, moderator, and criterion measures. The demographic characteristics of the mothers that were examined were age of the mother, educational level, socioeconomic status, employment status and number of children in family (see Appendix P). The demographic characteristics were unrelated to the severity of autism. There was only one significant correlation found between demographic characteristics and the moderating variables.

Table 11

Intercorrelations of Predictor, Moderator, and Criterion Variables

Variable	2	3	4	5	6	7
1. Severity of Autism	.13	10	.44**	18	01	39 °°
2. Parental Locus of Control		11	.34°	.11	26	18
3. Satisfaction with Support			31°	.28	.24	.09
4. Parenting Stress				49 **	40 **	42 **
5. Dyadic Adjustment					.67 **	.41 **
6. Family Relationship						.40 **
7. Family Social Integration						

Note. Severity of autism was the predictor variable, parental locus of control and satisfaction with support were moderating variables, and parenting stress, dyadic adjustment, family relationship and family social integration were criterion variables.

[•] p < .05. • • p < .01.

However, level of education was correlated with three out of the four criterion measures. In order to control for possible effects related to education moderated regressions were performed controlling for education. Since none of the other demographic variables were consistently related they were not included. The results of the analyses that included education were comparable to the regression analyses performed without this demographic variable and therefore, the results are presented for analyses that did not include demographics.

Parenting Stress

The criterion variable in the first analysis was parenting stress. Severity of Autism, Social Support, and Parental Locus of Control were entered on the first step, followed by the three two-way interaction terms: Severity of Autism X Social Support, Severity of Autism X Parental Locus of Control, and Parental Locus of Control X Social Support. Finally, the three-way interaction term was entered on the third and final step, Severity of Autism X Locus of Control X Social Support. As shown in Table 12, the first step produced a significant regression analysis, and the R^2 attributable to the addition of the first and second order interaction terms were not significant, contrary to hypotheses 10 through 12. The regression analysis was significant, F(3, 46) = 7.68, F(3, 46) = 7.6

Table 12

Summary of Hierarchical Regression Analysis for Variables Predicting Parenting Stress
(N=50)

Variable	<u>B</u>	SE B	β	R ² Change
Step 1				
Severity of Autism	1.51	.480	.383**	.143
Parental Locus Control	.931	.427	.266*	.069
Satisfaction with Support	-1.07	.547	237	.055
Step 2				
Severity of Autism X Parental Locus of Control	.050	.043	.162	.020
Severity of Autism X Satisfaction with Support	056	.071	108	.009
Parental Locus of Control X Satisfaction with Support	041	.047	117	.011
Step 3				
Autism X Locus of Control X Satisfaction with Support	.000	.005	.000	.000

Note. \underline{R}^2 = .33 for Step 1; \underline{R}^2 Change = .04 for Step 2 (\underline{p} >.05); \underline{R}^2 Change = .00 for Step 3 (\underline{p} >.05).

Finally, although satisfaction with social support was not a statistically significant predictor of parenting stress at the conventional alpha level of .05, it is bordering on significance, $\underline{t}(46) = -1.95$, $\underline{p} = .058$. The more satisfied the mother was with her social support network, the less stress the mothers reported, this was consistent with hypothesis 2.

Dyadic Adjustment

The criterion variable in the second analysis was Dyadic Adjustment. Severity of Autism, Social Support, and Parental Locus of Control were entered on the first step, followed by three two-way interaction terms: Severity of Autism X Social Support, Severity of Autism X Parental Locus of Control, and Parental Locus of Control X Social Support. Finally, the three-way interaction term was entered on the third and final step, Severity of Autism X Locus of Control X Social Support. As shown in Table 13, the first step did not produce a significant result, $\underline{F}(3, 38) = 1.84$, $\underline{p} > .05$ and the change in R^2 attributable to the addition of the interaction terms was also not significant. No specific hypotheses were presented for this outcome variable.

Family Relationship Index

The criterion variable in the third analysis was family relationship. Severity of Autism, Social Support, and Parental Locus of Control were entered on the first step, followed by the three two-way interaction terms: Severity of Autism X Social Support, Severity of Autism X Parental Locus of Control, and Parental Locus of Control X Social Support. Finally, the three-way interaction term was entered on the third and final step, Severity of Autism X Locus of Control X Social Support. As shown in Table 14, the first

Table 13

Summary of Hierarchical Regression Analysis for Variables Predicting Dyadic Adjustment
(N=42)

Variable	<u>B</u>	<u>SE B</u>	β	R ²
				Change
Step 1				
Severity of Autism	- .170	.153	168	.028
Parental Locus Control	.125	.134	.142	.020
Satisfaction with Support	.304	.164	.284	.080
Step 2				
Severity of Autism X Parental Locus of Control	011	.014	135	.013
Severity of Autism X Satisfaction with Support	.026	.021	.209	.030
Parental Locus of Control X Satisfaction with Support	016	.014	175	.025
Step 3				
Autism X Locus of Control X Satisfaction with Support	.003	.002	.316	.065

Note. $\underline{R}^2 = .13$ for Step 1 ($\underline{p} > .05$); \underline{R}^2 Change = .14 for Step 2 ($\underline{p} > .05$); \underline{R}^2 Change = .06 for Step 3 ($\underline{p} > .05$).

Table 14

Summary of Hierarchical Regression Analysis for Variables Predicting Family Relationship

(N=50)

Variable	В	SE B	β	R ² Change
Step 1				
Severity of Autism	.021	.060	.050	.002
Parental Locus Control	092	.054	242	.057
Satisfaction with Support	.104	.069	.213	.044
Step 2				
Severity of Autism X Parental Locus of Control	002	.005	055	.002
Severity of Autism X Satisfaction with Support	.002	.009	.038	.001
Parental Locus of Control X Satisfaction with Support	.000	.006	011	.000
Step 3				
Autism X Locus of Control X Satisfaction with Support	.000	.000	.141	.017

Note. $\underline{R}^2 = .11$ for Step 1 (p >.05); \underline{R}^2 Change =.03 for Step 2 (p >.05); \underline{R}^2 Change = .01 for Step 3 (p >.05).

step did not produce a significant result, $\underline{F}(3,46) = 1.96$, $\underline{p} > .05$ and the change in \mathbb{R}^2 attributable to the addition of the interaction terms was also not significant. This finding was contrary to all the hypotheses put forward for this variable. Severity of autism, parental locus of control or satisfaction with social support were not predictive of quality of family relationships. In addition, there was no support found for the buffering effect of parental locus of control and social support as outlined in hypotheses 10 through 12.

Family Social Integration

The criterion variable in the fourth analysis was family social integration. Severity of Autism, Social Support, and Parental Locus of were entered on the first step, followed by the three two-way interaction terms: Severity of Autism X Social Support, Severity of Autism X Parental Locus of Control, and Parental Locus of Control X Social Support. Finally, the three-way interaction term was entered on the third and final step, Severity of Autism X Locus of Control X Social Support. As shown in Table 15, the first step produced a significant result, $\underline{F}(3, 46) = 3.16$, p < .05, accounting for 17% of the variance, but the change in R^2 attributable to the first and second order interaction terms was not significant contrary to hypotheses 10 through 12. Severity of autism was a significant predictor of family social integration, $\underline{t}(46) = -2.73$, $\underline{p} < .01$ which is consistent with hypothesis 7. The less severe the child's autism, the more the family is socially integrated into the community. No support was found for hypotheses 8 and 9 which stated that parental locus of control and satisfaction with social support would be predictive of a higher level of social integration as reported by the parents.

Table 15
Summary of Hierarchical Regression Analysis for Variables Predicting Family Social
Integration (N=50)

Variable	<u>B</u>	SE B	β	R ² Change
Step 1				
Severity of Autism	159	.058	371**	.134
Parental Locus Control	047	.052	123	.015
Satisfaction with Support	.020	.066	.041	.002
Step 2				
Severity of Autism X Parental Locus of Control	.003	.005	.097	.007
Severity of Autism X Satisfaction with Support	.015	.009	.267	.054
Parental Locus of Control X Satisfaction with Support	.004	.006	.105	.009
Step 3				
Autism X Locus of Control X Satisfaction with Support	.000	.000	021	.000

Note. $\underline{R}^2 = .17$ for Step 1; \underline{R}^2 Change = .06 for Step 2 ($\underline{p} > .05$); \underline{R}^2 Change = .00 for Step 3 ($\underline{p} > .05$).

^{**} p < .01

Number of Social Supports

Four separate hierarchical moderated regressions were performed substituting the moderating variable of satisfaction with social support with the number of available social supports. A summary of these analyses are shown in Tables Q1 to Q4 in Appendix Q. Researchers suggest that the number of supports and satisfaction measures are not highly correlated even when they are measured as scales within the same instrument (Sarason, Sarason & Pierce, 1990). It has been reported that the satisfaction of a person's supportive network rather than the number of persons providing that support seems to be the important factor with respect to the buffering effect of social support on psychological distress (Wilcox, 1981; Sandler & Barrera Jr., 1984). In order to determine if availability was different from satisfaction, moderated regressions were performed on both. The number of available social supports did not produce any significant main effects or interactions on any of the four criterion measures.

Exploratory Data Analyses

Moderated Multiple Regression Analyses

In order to ascertain if the failure to find any significant interaction effects was due to a lack of statistical power an exploratory analysis was carried out. A total of 16 separate regression analyses were performed, 3 two-way and 1 three-way interaction for each of the four criterion variables. The only variable entered was the individual interaction term in one step with the criterion measure. Of the 16 regression analyses performed, only one reached significance level. No follow up analyses were performed. It appears that statistical power may not be the main reason for the lack of findings.

Specific Child Symptoms in Predicting Outcome

The information presented in the GARS manual suggested that the overall Autism Quotient was the most reliable of all the scores generated on the GARS and therefore this score was used in the moderated regression analyses for the present study. However, some research on child characteristics (e.g., Konstantareas & Homatidis, 1989) suggests that certain child behaviours of children with autism are more predictive of problems in the family than others. In order to determine if specific behaviours of autism were more predictive of parenting stress, marital adjustment, family relationship, and family social integration than others, four separate stepwise multiple regression analyses were performed using the four subtests of the GARS (Stereotyped Behaviours, Communication, Social Interaction and Developmental Disturbances) as predictors.

The criterion variable in the first analysis was parenting stress. Using the stepwise regression method, all four of the predictor variables were entered into the equation. In stepwise regression the predictor variable that has the highest correlation with the criterion is selected first. If it passes the criterion, the second variable is selected on the highest partial correlation. The variables are examined for entry, then once in the equation, they are examined for removal. Variables are removed until none remain that meet removal criterion. The overall regression analysis was significant, $\underline{F}(1, 42) = 8.64$, $\underline{p} < .01$, accounting for 17% of the variance in parenting stress (see Table 16). Stereotyped behaviours was the only significant variable in the equation. The higher the score on the subtest Stereotyped Behaviour the higher the stress reported by the mothers. Some examples of the items found on the subtest of Stereotyped Behaviour include: avoids

establishing eye contact, eats specific foods, and refuses to eat what most people will usually eat, rocks back and forth while seated or standing, makes rapid lunging, darting movement when moving from place to place, makes high pitched sounds or other vocalizations for self-stimulation and slaps, hits, or bites self or in other ways attempts to injure self.

The criterion variable in the second analysis was marital adjustment. The four subtests were entered into the first step. The overall regression analysis was significant, <u>F</u> (1, 36) = 5.49, p<.05, accounting for 13% of the variance in marital adjustment (see Table 17). Stereotyped Behaviour was the only significant variable in the equation. In this analysis, marital adjustment is higher for families whose children display less severe Stereotyped Behaviour.

The criterion variable for the third analysis was family relationship. The four subtests were entered into the first step. The overall regression analysis was not significant and no one variable was entered or removed in the block.

The criterion variable in the final analysis was family social integration. The four subtests were entered into the first step. The overall regression analysis was significant, \underline{F} (1, 42) = 8.84, \underline{p} < .01, accounting for 17% of the variance (see Table 18).

Communication was the only significant variable in the equation. Some examples of the items found on the subtest of Communication include: repeats (echoes) words verbally or with signs, repeats words or phrases over and over, looks away or avoids looking at speaker when name is called, avoids asking for things he or she wants, and fails to initiate

Table 16

Summary of Stepwise Regression Analysis for GARS Subscales Predicting Parenting

Stress

Variable	<u>B</u>	<u>SE B</u>	β
Variables Entered On Step 1			
Stereotyped Behaviours	5.93	2.02	0.41 **
Variables Not In The Equation			
Communication	0.23	0.24	0.89
Developmental Disturbances	0.16	0.17	0.95
Social Interaction	0.14	0.14	0.83

Note. $\underline{R}^2 = .17$

^{10. &}gt; g **

Table 17

Summary of Stepwise Regression Analysis for GARS Subscales Predicting Dyadic

Adjustment

Variable	<u>B</u>	SE B	β
Variables Entered on Step 1			
Stereotyped Behaviours	-1.52	0.65	-0.36*
Variables Not In The Equation			
Communication	0.02	0.02	0.89
Developmental Disturbances	0.09	0.09	0.96
Social Interaction	0.16	0.14	0.61

Note. $\underline{R}^2 = .13$

^{*} g < .05

Table 18
Summary of Stepwise Regression Analysis for GARS Subscales Predicting Family Social
Integration

Variable	<u>B</u>	SE B	β
Variables Entered On Step 1			
Communication	-0.85	0.29	-0.42**
Variables Not In The Equation			
Developmental Disturbances	-0.26	-0.26	0.84
Stereotyped Behaviours	-0.01	-0.01	0.89
Social Interaction	-0.17	-0.14	0.57

Note. $\underline{R}^2 = .17$

^{**} p< .01

conversation with peers or adults. In this analyses, family social integration is lower for families whose children have poorer communication skills.

Comparison of Mothers and Fathers

A total of 24 fathers participated in the present study. Of these fathers, 22 also had a spouse who completed the questionnaire packages. In order to examine possible differences between mothers and fathers from the same family, comparisons were carried out for the 22 two-parent families in which both parents participated.

Demographic Characteristics

Six of the mothers and fathers were from Calgary, 10 were from Winnipeg and 6 were from Ottawa. The mean age for the mothers was 36.14 (SD= 5.0); the mean age for the fathers was 38.14 (SD = 6.15). Ninety-five percent of the fathers were employed full-time (see Table 19), only one father was unemployed. Fifty percent of the mothers did not work outside of the home, 31% worked part-time and 18% worked full-time. Fifty-nine percent of the fathers and 45% of the mothers had graduated from university. Ninety-five percent of the families were considered middle to upper class using the Hollingshead Four-Factor Index (see Table 20). The mean age of the child was 56.86 months (SD = 12.65) and the mean age of the child receiving the diagnosis of autism was 33.91 (SD = 7.50). Nineteen of the children were male and 3 were female which is not representative of the 3-4:1 ratio. Eighty-six percent of the families had other children in the home besides their child with autism. Fifty-nine percent had one other child, and 27% had two other children. Ninety-five percent of the families had their child involved in some type of formal treatment; 32% were involved in an agency based program, 14% were involved in home

Table 19

Demographic Characteristics of the Mothers' and Fathers'

	Mothers N=22	Fathers N=22
Mean Age (years)	36.14	38.14
SD SD	(5.0)	(6.15)
Employment Status		
No employment	11(50%)	1(5%
Part-time employment	7 (32%)	0 (0%)
Full-time employment	4 (18%)	21 (95%)
Education		
Below high school	3 (14%)	1 (5%)
High school graduate	6 (27%)	6 (27%)
Partial college or university	3 (14%)	2 (9%)
University/College graduate	9 (41%)	11 (50%)
Graduate Training	1 (5%)	2 (9%)
Hollingshead SES Index		
Major business/professional	9 (41%)	9 (41%)
Medium business/minor professional	5 (23%)	5 (23%)
Skilled craftsmen, clerical, sales	7 (32%)	7 (32%)
Semiskilled workers	0 (0%)	0 (0%)
Unskilled laborers	1 (5%)	1 (5%)

Table 20
Family Characteristics of the Mothers' and Fathers'

Child	Mothers and Fathers N=22
Mean age of child (months)	56.86
SD	(12.65)
Mean age of child at diagnosis (months)	33.91
SD	(7.50)
Gender of Child	
Male	19
Female	3
Number of other children in family	
0	3
1	13
2	6
Primary Treatment	
Agency based	7
Home based	3
Special Needs Worker	1
Regular Nursery School	5
Regular Kindergarten	2
Special School	2
Speech Therapy	0
Occupational Therapy	i
No Formal Treatment	1
Number of hours per day in program	4.92
SD	(2.01)
Number of days per week attending program	4.62
SD	(1.08)
Length of time in program (months)	16.24
SD SD	(9.50)

Table 21

Intercorrelations of Mothers and Fathers Scores on Measures

Variable	1	2	3	4	5	6	7
1. Severity of Autism	.24						
2. Parental Locus of Control		.51 *					
3. Satisfaction with Support			.16				
4. PSI Total Stress Score				.59 *			
5. Dyadic Adjustment					.66 ***		
6. Family Relationship						.63 ***	
7. Family Social Integration							.64 ***

^{*} p < .05 *** p < .001

The multivariate analysis for the Parenting Stress index was divided into two subsets, the Child Domain and the Parent Domain, due to the large number of dependent variables. The repeated measures MANOVA found no significant multivariate F for the Child Domain. Results of the repeated measures MANOVA found a significant multivariate \underline{F} for the Parent Domain, $\underline{F}(8,13) = 5.72$, $\underline{p} < .01$ (see Table 22). Two of the subscales of the parenting domain were significant. The mothers scored significantly higher than the fathers on the subscale Role Restriction, $\underline{F}(1,20) = 5.72$, $\underline{p} < .05$, and the subscale Spouse, $\underline{F}(1,20) = 6.86$, $\underline{p} < .05$. In order to be able to generalize the findings from the analysis of the mothers and fathers, comparisons were also made between the 22 mothers whose spouse participated and the 28 mothers whose spouse did not participate. There were no significant differences found between the mothers on age, employment status, education, or socioeconomic status. There were also no significant differences between the children of these mothers in terms of diagnosis, age, age of diagnosis, number of days in treatment, number of hours in treatment, or length of time in treatment.

In order to determine if there were any significant differences between the two groups of mothers, MANOVA's were conducted on the mother's scores for the GARS, PLOC, PSI, and DAS. In order to test for differences in the FSS, FRI, and FSII independent t-tests were conducted. Results of the MANOVA reported a significant difference between the two groups of mothers on the GARS, \underline{F} (5,38) = 2.46, $\underline{p} \le .05$ (see Table 23). Two of the subscales and the overall autism quotient were significant. The mothers whose spouse participated in the study reported more communication problems

Table 22
Comparison of Means and Standard Deviations of Mothers and Fathers on the PSI

	Mothers N=21		Fathers N=21	
	M	SD	M	<u>SD</u>
Child Domain	136.00	20.73	130.05	19.76
Distractibility/Hyperactivity	29.67	5.80	29.05	5.50
Adaptability	35.05	6.75	32.81	4.46
Reinforces Parent	12.38	4.80	13.24	3.87
Demandingness	26.62	5.87	23.47	6.00
Mood	11.86	4.03	12.10	3.43
Acceptability	20.43	3.44	19.38	4.25
Parent Domain	137.33 _a	24.38	129.90ь	23.68
Competence	32.33	5.12	31.71	5.79
Isolation	14.86	4.67	15.90	4.40
Attachment	12.43	3.14	13.86	3.77
Health	13.29	3.89	11.86	2.80
Role Restriction	21.38 a	4.92	18.81 ь	4.27
Depression	22.09	4.95	20.05	5.00
Spouse .	20.95 a	5.02	17.71 ₆	4.27
Total Stress Score	273.43	38.54	259.95	40.09
Life Stress	10.28	11.03	6.86	5.87

Parent Domain Multivariate $\underline{F}(8,13) = 5.59$, $\underline{p} < .01$

Note. Means with different subscripts in the same row differ significantly at p<.05.

Table 23

Comparison of Mean Scores and Standard Deviations of the Mothers Whose Spouse

Participated with Mothers Whose Spouse did not Participate on the GARS

	Mothers (Partner Participation)			Mothers (No participa		
	<u>M</u>	<u>SD</u>	<u>n</u>	<u>M</u>	SD	ū
Stereotyped Behavior	8.09	2.72	21	8.26	3.16	27
Communication	10.35 a	2.08	20	8.85 _b	2.57	26
Social Interaction	7.82	1.89	22	7.19	2.34	27
Developmental	9.23 a	1.54	22	8.14 _b	1.74	28
Total Autism Quotient	93.14 a	8.82	22	85.89 ե	12.50	28

Note. Means with different subscripts in the same row differ significantly at p<.05

for their children, $\mathbf{F}(1,42) = 4.48$, $\mathbf{p} < .05$. The mothers whose spouse participated also reported more developmental disturbances, $\mathbf{F}(1,42) = 4.09$, $\mathbf{p} < .05$. Finally, the mothers whose spouse participated reported a higher overall Autism Quotient score than the mothers whose spouse did not participate, $\mathbf{F}(1,42) = 4.41$, $\mathbf{p} < .05$. There were no significant multivariate F's reported for the PLOC, PSI, and DAS measures. The results of the independent t-tests found no significant differences between the mothers on the measures of FSS, FRI, and FSII.

Overall, the only difference found between the mothers whose spouse participated in the study versus those whose spouse did not participate was found on the GARS, with these mothers having children with a higher severity of autism. Although these mothers have children with more reported symptoms there was no significant difference on any of the other measures. In summary, the findings reported from the mothers and fathers who both participated in the study can be generalized to the entire sample. The mothers' and fathers' reports on the family functioning measures were comparable, which suggests that the mothers and fathers have similar perceptions of the functioning of the family environment.

CHAPTER FOUR

DISCUSSION

The purpose of this study was to gain a better understanding of the
variables associated with successful adaptation in families of young childr
aged 6 years and younger. Most previous studies demonstrating a relation
autism and family stress or parent adjustment have focused on school-age
the ABCX model as a general guiding framework, the parent's perception
of autism was conceptualized as an ongoing stressor. Social support was
family's resource for coping and parental locus of control was conceptua
of the parents' cognitive appraisals. Family adjustment was assessed usin
parenting stress, marital adjustment, family relationships, and the family's
integration into the community. Prior to discussing the specific hypothese
addressed, it is important to examine other critical findings which emerge
specifically, it was found that mothers with children diagnosed with autis
significantly different from mothers whose children were diagnosed with
was also found that, as a group, mothers of children with autism were m
satisfactorily in their parenting roles and that their families were generally
discussion of some of the possible reasons for these findings and their im
practitioners will follow.

The mothers who participated in the present study had children versions.

diagnosed with either autism or PDD-NOS. Analyses indicated that wer-

Autism versus Pervasive Developmental Disorder

differences between mothers responses of the two groups of children and that they were comparable on all of the measures. The finding that the two groups of mothers reported similar levels of symptom severity for their children is unexpected. Even though it can be difficult to reliably differentiate between autism and PDD-NOS, it would be expected that children diagnosed with autism would have greater symptom severity than children diagnosed with PDD-NOS. This is because PDD-NOS implies the presence of fewer and, at times less severe signs of autism. As such, the prognosis for children with PDD-NOS diagnosis tends to be more favorable than those with autism. Also, as a group, children receiving the PDD-NOS diagnosis tend to manifest less cognitive impairment than the typical child with autism (Siegel, 1996). Many people who conduct research with and/or treat children with autism have pointed out that the distinction or differential diagnosis between autism and PDD-NOS is not reliable. That is, different clinics and/or professionals tend to display different biases. As Siegel (1996) pointed out the distinction between autism and PDD-NOS is often not worth debating.

It is also thought that some diagnosticians will use the PDD-NOS diagnosis provisionally when they see relatively young children, such as those in the current sample, as many of the diagnostic criteria are difficult to apply to the younger population (Wagner & Lockwood, 1994). One reason for this is that the criteria for autism emphasizes abnormality in social and communicative development, both of which are difficult to assess in infancy or the early preschool period (Baron-Cohen et al., 1992).

When a child is diagnosed with either autism or PDD-NOS he or she is given a label. A label is important for two reasons, one it offers a direction for treatment and two,

it is an avenue for access to services. Treatment funding in certain geographical regions may be dependent on the child receiving a specific diagnosis. Sometimes a clinician may feel that 'PDD' more accurately describes the profile and severity of a particular child's autistic symptoms, but will go ahead and label the problem 'autism' so as to ensure that the child gets as much help as possible (Siegel, 1996).

In summary, there are some plausible explanations to explain why no significant differences were detected between mothers of children who were diagnosed with autism versus those diagnosed with PDD-NOS. The two disorders have overlapping symptomatology which share three common themes: behavioural difficulties, social interaction deficits and communication delays. The overall presentation of the two disorders is also very similar and thus, there is only a fine line between the two groups. For the present study, this finding implies that the child's specific diagnosis (autism versus PDD-NOS) does not differentially influence the parental adjustment process. One possible implication of this finding is that clinicians do not need to be so cautious about giving children the diagnosis of autism if they feel it is warranted. Putting off a diagnosis to try to help the parents cope may not be beneficial to any of the family members. Konstantareas (1989) has encouraged clinicians not to shield parents from a diagnosis of autism in an attempt to shield major stress. The results of this study suggest that the diagnosis of autism does not relate to family functioning any differently than a diagnosis of PDD-NOS.

Comparison of Present Findings to Normative Samples and Previous Research

Severity of Autism

As a group, the mothers' reports of the severity of their child's disorder was lower than the average scores of the normative sample provided by the GARS. In fact, the overall Autism Quotient was considered below average for the cut off point provided for assessing the probability of autism. This was an unexpected finding as all children in the present study had previously been diagnosed with autism or PDD-NOS by trained clinicians. It is not surprising that the mothers of the children diagnosed with PDD-NOS reported a lower score, but the mothers of children diagnosed with autism reported lower scores than expected when examined separately. In addition, research suggests that younger children present with more autistic symptomatology than older children as there tends to be fewer and less severe symptoms with growth and development (Piven, Harper, Palmer, & Arndt, 1996). It would be expected that the younger age children would receive higher scores than those obtained.

There are a number of possible explanations why mothers in the present study reported lower scores than the normative sample. First, the GARS provides an index of the maladaptive or deviant behaviour commonly observed in autism. However, the majority of the autistic children in this study were involved in a behavioral training program designed to eliminate deviant behaviours. Thus, the autistic children in this study may have received lower scores on the GARS because they have been receiving treatment which specifically addresses autistic symptomatology. A number of the mothers made

comments on their questionnaires stating that their child had once displayed a number of the specific behaviours but no longer do since the onset of treatment.

Second, the GARS normative sample was comprised of children and adults aged 3 to 22 years. Only 31% of the children in the normative sample were under six years of age, in contrast to the current study where all subjects were six years and under. Perhaps the items on each of the subtests are not as sensitive to the behaviours displayed by autistic children six years of age and under. Items of the GARS are based on the definitions by the Autism Society of America and by the American Psychiatric Association, as presented in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. As previously mentioned, many of the criteria of autism, particularly in social and communication domains, are difficult to detect in preschool children. It is possible that the parents have seldom observed certain behaviours thus lowering their overall score.

Third, the GARS normative study included ratings by 720 teachers and 372 parents. It is possible that teachers tend to rate children and adults with autism as having more symptoms than the parents, thus elevating the cutoff scores relative to the current sample where ratings were made by parents. Although, there is no research to date in the autistic population to support the notion that teachers rate children with autism as more severe than the parents, there is evidence that, as a group, when compared to professionals parents tend to report fewer symptoms of autism in their children (Konstantareas & Homatidis, 1989). This might be at least partly a result of parental defensiveness in accepting the diagnosis of autism with its many adverse implications. With younger

children parents may still be engaged in the "diagnostic run-around" (Mack & Webster, 1980), which usually ceases later on, when they come to terms with the diagnosis.

One of the implications of the finding that the mothers' reports of their children's autistic symptomatology in the present study is lower than expected may be that the mothers underestimate their child's disorder as a means of coping. Minimizing the severity of autism may actually serve an adaptive function by making it easier for the mothers to meet the day to day demands and challenges of raising a child with autism.

Comparison of Current Sample to Normative Samples

The mothers in the present study reported scores which are comparable to the normative sample scores provided for the measures of parental locus of control (PLOC), family support (FSS), parenting stress (PSI), dyadic adjustment (DAS), and family environment (FES). Relative to the normative samples, mothers of children with autism had a more external locus of control orientation, lower satisfaction with social support, and higher parenting stress. However, they reported similar levels of marital adjustment and family social integration and higher levels of cohesion, expressiveness and lower levels of conflict.

The findings for mothers of young children with autism are comparable to those reported in previous research examining parenting stress and marital satisfaction in mothers of preschool age children with autism. Donnenberg and Baker (1993) compared the differences in family functioning of young children with externalizing behaviours (e.g., hyperactive, aggressive (n=22), autism (n=20), or no significant problem behaviours (n=22). The mean age for the Donnenberg and Baker autistic sample was 58.9 months

(SD = 12.90); the mean age for the current sample is 57.98 (SD=12.07). Two of the measures examined in the Donnenberg and Baker study were the PSI and the DAS. The current sample had a lower Child Domain score but a comparable Parent Domain score to the Donnenberg and Baker autistic sample; Child Domain (current sample, \underline{M} =136.24, Donnenberg sample, \underline{M} =143.2); Parent Domain (current sample, \underline{M} = 136.24, Donnenberg sample, \underline{M} =136.4). The Dyadic Adjustment Scale was also very similar, the current sample had an overall mean of 103.4, while the Donnenberg and Baker autistic sample had an overall mean of 104.2

Koegel et al. (1983) assessed the personality and family-interaction characteristics of parents of children with autism. The parents in the Koegel sample were comparable in terms of education, mothers' employment status and socioeconomic status. No information concerning the age of the parents was provided. One of the measures they examined was the DAS. The mean age for their sample was 69 months. The total DAS score for the current sample was lower than the Koegel sample (current sample, $\underline{\mathbf{M}} = 103.4$, Koegel sample, $\underline{\mathbf{M}} = 119.7$). It is possible that this difference is a result of the fact that the children were somewhat older and therefore the parents had experienced a longer period of adjustment to the demands of raising a child with autism.

Hypotheses Testing

Parenting Stress

Consistent with previous research, severity of autism was related to parenting stress. The more severe the child's autism, as defined by the mothers' reports of frequency of symptomatic behaviour, the higher the level of reported stress. The severity

of the child's autism may interfere with family life in a variety of ways. For instance, a family whose child has very rigid and repetitive behaviours may have to adapt their environment and lifestyle to 'fit' the child. For example, the child may become very upset whenever company comes to the house, thus the parents may avoid having visitors in order to avoid the child's upset. Or the child may become very upset when the parents leave the home and so they may avoid going out very often to try and avoid the conflict. There is also the concern over the visibility of certain behaviours that may cause embarrassment and a feeling of incompetence for the parent. For example, if the parent has the child out in the community and he or she begins to display maladaptive behaviours such as smelling a person's hair or flicking their fingers in front of their eyes, the parent may avoid taking the child out as often in the future.

The finding that the subtest of Stereotyped Behaviours was a significant predictor of parenting stress was not surprising. These behaviours are often outside of the realm of typical parenting and require the parent to adopt unfamiliar behaviour management practices. Society has basic guidelines for how to best address social and communication problems. For instance, parents with very young children often need assistance and are often faced with the task of assisting their child to talk or further develop their social or play skills. However, there are no general parenting guidelines on how to deal with a child repetitively flapping their hands or banging their head. These behaviours may undermine the parent's self-esteem and make them feel inadequate in their parenting role.

For the present study, it was found that the more severe the autism the higher the level of parenting stress. One of the implications of this finding is that practitioners should

be cognizant of families with severely autistic children to provide extra support.

Moreover, an effort should be made to teach parents necessary skills to effectively help with their children's stereotypic behaviour which is often very stressful for these families.

Findings were consistent with previous research on the influence of social support on stress. The more satisfied the mothers were with their social support network, the less stress they reported. One of the implications of this finding is for practitioners to provide support in a manner which suits parental preference. Practitioners may need to present the families with several different options which suits the family's needs best. For instance, parent groups, parent training, social worker, or a relief worker.

Consistent with previous research, locus of control was also related to parenting stress. The higher the degree of internality, the lower the level of parent reported stress. Parental locus of control may reduce parenting stress for mothers who feel that they have some degree of control over their child's behaviour. This may have important practical implications. One element which may help parents feel they have control over their child would be by providing them with enough information at the time of their child's diagnosis concerning the specifics of the disorder and the best treatment approach. Adequate knowledge regarding the disorder and active involvement in treatment planning may help the parent to feel in control and thus, reduce parenting stress.

Marital Adjustment

There was no support for severity of autism, social support or parental locus of control in predicting marital adjustment. The fact that severity of autism was not significantly correlated with marital adjustment may have contributed to the lack of

findings for the social support and locus of control variables. Although there was no main effect found for severity of autism on marital adjustment, these mothers still reported marital adjustment lower than both the normative sample provided by Spanier (1976) and the Koegel et al. (1983) sample.

These findings suggest that factors beyond the severity of a child's disability may be related to marital adjustment. It may be that certain behaviour problems manifested by the child, rather than the severity of autism per se, that causes strain and potentially reduces marital satisfaction. For example, it may be the distribution of burden of care or the quality of the marital relationship prior to the birth of the child.

The finding that Stereotyped Behaviour was a significant predictor of marital adjustment suggests that these behaviours have potential to reduce marital satisfaction. The less severe the stereotyped behaviours the higher the overall marital adjustment reported. This may be related to the idea that parents whose child rates high on the subtest of Stereotyped Behaviours experience conflict on how to best deal with the behaviours of the child that are out of the realm of typical parenting. For example, the child may lick books and the parents are not in agreement on how to best deal with the behaviours. The mother may feel it is acceptable at certain times and the father may feel it is inappropriate all the time. The parents are grasping at straws as to how to approach behaviours that are not typical of normally developing children and outside of their parenting knowledge base.

Family Relationships

Contrary to the findings reported by Henderson and Vandenberg (1992), there was no support for the predictions concerning the index of the quality of the family relationship. Family relationship was a compilation of three of the family environment subscales, cohesion, expressiveness and conflict. High scores reflect high levels of cohesion and expression and low levels of conflict. Severity of autism, satisfaction with social support, and the degree of internality did not predict higher or lower reports of family relationships. It is possible that the inconsistent findings between the Henderson and Vandenberg study and the current study are due to differences in the measures utilized. Symptom severity, social support, and parental locus of control were assessed using different measures than those used in the Henderson and Vandenberg study. The fact that severity of autism is not significantly correlated with family relationship may have hindered contributions by social support and locus of control variables. None of the four subtests of the GARS were significant predictors of the family relationship index.

It is possible that the indices that make up the family relationship index, cohesion, expressiveness and conflict are established within the family prior to the birth or diagnosis of their children. Mothers did report higher levels of cohesion and expressiveness and lower levels of conflict than the norms provided in the FES manual. The onset of autism in the family may actually bring the family closer together as they have to make an extra effort to help one another to meet the demands of the child with autism.

Family Social Integration

The finding that the more severe the child's autism, the lower the level of family integration as reported by the mothers is consistent with previous research. Bristol (1984) found that families of children with autism that were higher on recreational orientation were rated as better adapted and more accepting of the child. If the parent is experiencing more stress due to the severity of the symptomatic behaviour it is not surprising that they do not participate in many active-recreational activities. It is quite possible that a child who is rated as more severe by his or her parents display many maladaptive behaviours that make it difficult for the parents to bring the child outside in the community without having to deal with severe problems (e.g., self-abusive behaviours, or tantrums). In addition, the higher the severity of autism, the more likely that there are more caretaking demands that do not allow the family as much free time to be involved in recreational or cultural activities.

In examining the subtests of the GARS in predicting family social integration,

Communication was the only significant predictor. Family social integration was lower for

families whose children have poorer communication skills. A possible reason for this

finding may be that the recreational/cultural opportunities are more limited for children

who have lower communication skills. For example, children with higher communication

skills may go to library programs, movies or church services and have a better

appreciation and understanding of their surroundings than children who do not

communicate.

Moderating Effects of Social Support and Parental Locus of Control

Contrary to the findings of Peterson (1984) and Wolf et al. (1989) there was no support for the positive effects of social support as a moderator variable on any of the outcome measures. Contrary to the findings of Krause and Stryker (1984) there was no support that locus of control has a moderating effect in the relationship between stress and outcome measures. Contrary to Sandler and Lakey (1982) there was no support for the three way interaction examining severity of autism, social support, and locus of control. It was predicted that the interaction between severity and the moderating variables would be beneficial under conditions of higher stress. Perhaps, the severity of autism as reported by the mothers was not severe enough for a buffering effect to take place.

It is not uncommon for interaction effects not to manifest themselves, even when they are predicted on the basis of common sense or a strong theory. One of the problems in the interaction analysis is a failure to detect interaction effects that do exist (Jaccard et al., 1990). There are a number of possible reasons why true interaction effects may go undetected, some of which include; multicollinearity, measurement error, and small sample sizes (Jaccard et al., 1990). In the present study, in order to reduce potential problems with multicollinearity, the severity of autism, social support and parental locus of control variables were centered prior to the formation of product terms. However, measurement error and sample size were problematic. All the measures used in this study have less than perfect reliability, and unreliable measures can yield biased estimates of regression coefficients in multiple regression. Measurement error is thus a potential problem for the analysis of interaction effects involving continuous variables. It has been shown that

measurement error has the effect of attenuating hierarchical evaluations of product terms (Jaccard et al., 1990). The degree of attenuation is a direct function of the reliability of the product term. If one measure is reliable and the second measure is relatively unreliable, then the reliability of the product term will be lower than the reliability of the least reliable measure. For the mother sample, the reliability of the GARS was .90. However, the reliability for the FSS and the PLOC were relatively low, .63 and .54 respectively. This is one of the difficulties that measurement error can create for hierarchical tests of interaction, especially with low statistical power. Using large sample sizes can often offset the loss of power induced by measurement error for purposes of hypothesis testing. The power of this study to find significant results was less than optimal because the sample size was small relative to the number of predictors. In addition, the greater the number of interaction terms, the lower the power (Jaccard et al., 1990). Having a sample size of 50 and four interaction terms per equation quite likely contributes to possible interaction effects not being detected. However, the regression analyses that were performed in the exploratory analyses with only one interaction term per equation was still not able to detect significant interaction effects.

Mother and Father Comparisons

In examining the data of the husband and wife comparisons some very interesting findings emerged. There are some data that suggest that mothers and fathers of young children with handicaps do not differ in their perception of stress in general but that mothers may experience higher levels of some types of stress than do fathers (McLinden, 1990). These differences may be due in part to the fact that mothers are more

knowledgeable about the severity of their child's handicap and they have more demands placed on their time as a result of role division in the family (McLinden, 1990). This finding was supported in the present study. The mothers reported significantly more stress than the fathers on the Parent Domain, specifically on the Role Restriction and Spouse subscales. High scores on the subscale Role Restriction suggest that the mothers experience the parental role as restricting their freedom and the mothers often see themselves as being dominated and controlled by their child's demands and needs (Abidin, 1995). The mothers who report high scores on the spouse subscale are those who are lacking the emotional and active support of the other parent in the area of child management. Eighty-one percent of the mothers whose husband participated in the study were either home full-time or worked part-time which may explain why more demands are placed on them. The mothers and fathers scores were not significantly different on the other measures, GARS, PLOC, FSS, and FES. The finding that mothers and fathers did not agree on the severity of their children's autism is contrary to what previous researchers have found (e.g., Bebko et al., 1987; Konstantareas & Homatidis, 1989; Freeman et al., 1991). Although there were no significant differences between mothers and fathers on the subtests and Autism Quotient, the correlation between the mothers and fathers was not significant (r = .24).

One interesting finding that emerged was that the mothers whose spouses participated in this study had children whose autism was rated as more symptomatic.

These mothers reported significantly higher scores on the Communication, Developmental subtests and the overall Autism Quotient than the mothers whose spouse did not

participate in the study. It is possible that the greater severity of the child's disorder requires that fathers become more involved, as the mother is unable to cope without assistance from her spouse. Thus, fathers may be more involved in the day to day demands of raising the child. Another possible explanation for this finding is that the 19 of the 22 fathers who participated in the study were the fathers of sons. Rodrigue et al. (1992) found that fathers of sons with autism perceive parenthood to be more satisfying than fathers of daughters. Rodrigue et al. (1992) suggest that fathers may experience more difficulty adjusting their expectations for their daughters, which may precipitate heightened anxiety, frustration, and uncertainty concerning their interactions with them. They found that fathers of girls with autism reported less family cohesion than did fathers of boys. In summary, it may not be that fathers are more involved with children who present with more severe symptomatology but rather are more comfortable in their role as fathers and participating in the day to day demands of parenting their sons more than their daughters.

Limitations of the Study

The limitations of the present study fall into two broad categories, those pertaining to the sample, and those relating to the procedure. One of the major limitations of the present study is that the sample size was relatively small. This is potentially problematic as it limits the generalizability of the obtained results, and reduces the statistical power of the analyses. Although the drawbacks of having a small sample size were recognized, the sample size was dictated by the fact that autism is a relatively rare disorder and that the current study focused on families of preschool age children.

Another potential limitation of the subject sample is the representativeness of the parents who agreed to participate in the study. The response rate was approximately 50% or less depending on the city. It is quite possible that the families who did not respond present much differently. These families may be experiencing many more difficulties due to excessive parenting demands and did not have the time or energy to respond to the study. Another limitation of the representativeness of the sample is that all the families who participated in the study had children who were involved in behavioural treatment programs. The adjustment process in families whose children are not already involved in active treatment may be very different. In addition, the present sample consisted of parents from middle to upper class families. It is possible that the resources associated with higher SES provides the families with support and allows for better overall adjustment.

One of the procedural limitations of this study was not having an independent measure of symptom severity. Having an independent measure of symptom severity would have given a more reliable assessment of the severity of the children's autism and may have elevated the scores on the severity of autism measure. Although the parents perceptions would remain the same, it would have been interesting to compare clinician versus parent reports to see if they perceive their children's disorder differently.

Another drawback in the procedure was the lack of control groups. Due to the paucity of research with parents of preschool-age children, utilizing control groups would have provided more accurate comparisons for the current sample. A handicapped, but nonautistic comparison sample, would have controlled for stress experienced by all

families of handicapped children and would have provided an index for the stressors which are characteristic of parenting an autistic child. A comparison group of families of nonhandicapped children matched on the autistic children's mental age would have been interesting so that the normal stresses of child rearing of mothers and fathers could be compared with the normative sample.

Suggestions for Future Research

The ABCX model outlined in the present study is one of many coping models posited in the stress and coping literature. Future research should examine other models within the context of preschool age children. Of particular interest in this age group would be examining the sequential stages of parental adjustment to the birth of a child with autism. In the literature there is considerable variation in the number, description, and causes of the various stages identified. The most common stages consist of some form of initial crisis response: shock, denial, feelings of detachment, bereavement and bewilderment (Blacher, 1984). Emotional disorganization is frequently used to describe the second stage whereby parents experience such feelings as guilt, disappointment, anger or lowered self-esteem (Blacher, 1984). The final stage is one of emotional adjustment, which includes acceptance and adaptation. Acceptance refers to parents accepting the child as well as others and themselves. Adaptation is when parents become less anxious and enjoy increased comfort with their situation (Blacher, 1984). It would be interesting to assess whether the parents did or are undergoing some stage-related process of adjustment and how it relates to the time frame following diagnosis.

Another suggestion for future research would be to evaluate parent training and support groups for parents of children recently diagnosed with autism using pre and post training measures. Assessing the parenting stress, social support and parental locus of control prior to the training and then providing the parents with information and practical suggestions may make a significant contribution to reducing the stress in the families of children with autism.

Summary and Conclusions

Some of the findings in this study support previous research in examining specific variables associated with successful adaptation in families of children with autism. Overall, the families of young children with autism are managing satisfactorily. The diagnosis the children receives does not seem to relate to family functioning as reflected in parenting stress, dyadic adjustment, or the quality of the family environment. The severity of autism was associated with increased levels of parenting stress, a more external parental locus of control, and less satisfaction with social support. There was no support for the moderating role of social support or parental locus of locus of control on parenting stress, dyadic adjustment, family relationships or family social integration. More research is needed in examining the comparisons between mothers and fathers, especially within the preschool years. The mothers and fathers were in high agreement on levels of marital adjustment, family relationships and family social integration. There were some differences reported in the parenting domain of the parenting stress index. A small sample size may have contributed to lack of statistical findings between these two groups. Increased understanding of the family functioning especially during the preschool years

will assist practitioners in helping families begin the treatment for the child and training and support for the parents.

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Appendix A

Demographic Information Form

Family Information

1.	Person Completing Questionnaire (check one)					
	Mother	Father		Other _		
2.	Age	(year	s)		(months)	
3.	Marital Status: (check one)			S	ommon-law eparated/Divorced	
4.	Are you currently employed outside of the home? no part-time full-time					
	Occupation					
5.	Education: (circle the labelow high school (grade) High school (grade) College (years) University (years) Graduate school (years)	le) 4 5 9 10 1 2 1 2	6 7 11 1: 3 4 3 4	8		
6.	Partner's Occupation					
7.	Partner's Education (c Below high school (grade) High school (grade) College (years) University (years) Graduate school (years)	le) 4 5 9 10 1 2 1 2	6 7 11 12 3 4 3 4	8 2 13 5 5		
3.	Child					
	(a) Age of child (years)	monti	ns	-		
	(b) Gender (check one):	: M F				

	d has received a diagnosis, what was he/she diagnosed with? If your chied more than one diagnosis, please list the three primary ones.
1)	
2)	
3)	
8XâX (d) Âge of chil	d at first diagnosis?
(e) Briefly out	ine the type of treatment program your child is currently enrolled in.
-	
	as your child been attending this program?
	days a week does you child attend the program?
(h) How many	hours a day does your child attend the program?
(i) Do you curr	ently have any other children living in your home?no (please indicate the age and gender of each child)
Age	Gender
	

Appendix B

Gilliam Autism Rating Subtests

Gilliam Autism Rating Scale

Subscale	Description	Examples
Stereotyped Behaviours	Describes stereotyped behaviours, motility disorders, and other unique and strange behaviours.	Avoids establishing eye contact. Makes high-pitched sounds or other vocalizations. Slaps, hits, or bites self or in other ways attempts to injure self.
Communication	Includes items that describe verbal and nonverbal behaviours that are symptomatic of autism.	Repeats (echoes) words verbally or with sign. Avoids asking for things he or she wants. Fails to initiate conversation with peers or adults.
Social Interaction	Includes items that refer to the subject's ability to relate appropriately to people, events, and objects.	Resists physical contact from others. Laughs, giggles or cries inappropriately. Does certain things repetitively, ritualistically.
Developmental Disturbances	Includes key questions about the subject's development during early childhood.	Did the child imitate another person before age 3 (e.g., peek-a-boo)? Did the child appear deaf to some sounds but hear others?

Gilliam (1995).

Appendix C

Parental Locus of Control Scale (PLOC)

Parental Locus of Control Scale

Please read the following statements carefully and indicate how much you agree or disagree using the scale below. Please answer according to how you actually feel not how you think you should feel or would like to feel. While filling out this form please try and keep in mind your child with autism. Thank you.

	Strongly Disagree 1	Somewhat Disagree 2	Neither Agree Nor Disagree 3	Somew Agree 4				rong gree 5	
Pa	rental Efficacy								
1.	1. When I set expectations for my child, I am almost certain that I can help him/her meet them. (R)					2	3	4	5
2.	I am often able to	predict my child	's behaviour in situation	s. (R)	1	2	3	4	5
3.	When my child ge him/her if I stay ca	• •	ally deal with		1	2	3	4	5
4.	What I do has littl	e effect of my chi	ld's behaviour.		1	2	3	4	5
5.	5. No matter how hard a parent tries, some children will never learn to mind.				1	2	3	4	5
6.	When something g there is little I can		en me and my child,		1	2	3	4	5
7.	Parents should add because ignoring	•	th their children them go away. (R)		1	2	3	4	5
8.			nuch from my child a matter of good or		1	2	3	4	5
9.	If your child tantr you might as well		nat you try,		1	2	3	4	5
Pa	rental Responsibil	ity							
10	. I am responsible	for my child's bel	haviour. (R)		1	2	3	4	5
11		who fail to become ough on their opp	e good parents have ortunities. (R)		i	2	3	4	5
12	. My child's behav	iour problems are	e no one's fault but my	own.(R)	1	2	3	4	5

	Strongly Disagree 1	Somewhat Disagree 2	Neither Agree Nor Disagree 3	Somewha Agree 4	t		Agre	•
13.	Parents whose charen't using the b			1	2	3	4	5
14.	There is no such t just good or bad	•	bad children -	1	2	3	4	5
15.	Parents who can't don't understand		en to listen to them with their children. (R)	1	2	3	4	5
16.	Most childrens' be if their parents ha	-	ns would not have develorating skills. (R)	oped 1	2	3	4	5
17.	Children's behavi to mistakes their	•		1	2	3	4	5
18.	When my child is he/she is respondi	-		1	2	3	4	5
19.	The misfortunes a a direct result of		re had as a parent are ur. (R)	1	2	3	4	5
Chi	ld Control							
20.	I feel like what ha mostly determined		îs	1	2	3	4	5
21.	My child does not	control my life.	(R)	1	2	3	4	5
22.	Even if your chil a parent should n		rums,	1	2	3	4	5
23.	My child influence	es the number of	friends I have.	1	2	3	4	5
24.	When I make a mi usually able to con	•	hild I am	1	2	3	4	5
25.	It is easy for me to of my child's atter			1	2	3	4	5
26.	My life is chiefly	controlled by my	child. (R)	1	2	3	4	5

	Strongly Somewhat Neither Agree Disagree Disagree Nor Disagree 1 2 3		Somewhat Agree 4			rong Agre	е		
Par	ental Belief in Fate	/Chance							
27.	Without the right b	reaks one cann	ot be an effective parent.	1	2	3	4	5	
28.	Heredity plays the major role in determining a child's personality.			1	2	3	4	5	
29.	Neither my child nor myself is responsible for his/her behaviour.			1	2	3	4	5	
30.	Success in dealing a matter of the chil rather than one's o	1	2	3	4	5			
31.	In order to have m fit in with the desir	1	2	3	4	5			
32.	I am just one of the to have a good chi	_	ts who happened	ì	2	3	4	5	
33.	Most parents don't how their children accidental happeni	turn out is influ		1	2	3	4	5	
34.	Being a good parer lucky enough to ha			1	2	3	4	5	
35.	I have often found what is going to ha		mes to my children, en.	I	2	3	4	5	
36.	Fate was kind to n know what I would		a bad child I don't	1	2	3	4	5	
Par	Parental Control of Child's Behaviour								
37.	It is not too difficu child's mind about			1	2	3	4	5	
38.	My child's behavior more than I can ha		s	1	2	3	4	5	
39.	Sometimes I feel to control over the ditaking.		_	1	2	3	4	5	

	Strongly Disagree 1	Somewhat Neither Agree Disagree Nor Disagree 2 3		Somewhat Agree 4		Stroi Agi		
40.	I always feel in co	ontrol when it co	omes to my child. (R)	1	2	3	4	5
41.	1. Sometimes I feel that my child's behaviour is hopeless.			1	2	3	4	5
42.	42. It is often easier to let my child have his/her way than to put up with a tantrum.			1	2	3	4	5
43.	3. I allow my child to get away with things.			1	2	3	4	5
44.	44. I find that sometimes my child can get me to do things I really did not want to do.			1	2	3	4	5
45.	5. My child often behaves in a manner very different from the way I would want him/her to behave.			1	2	3	4	5
46.	Sometimes when I do things I normal		ny children	1	2	3	4	5

Note. Subscales and R were not identified on the form given to the parents. R indicates reverse scoring.

Appendix D

Parental Locus of Control Subscales

Parental Locus of Control Scale

Subscale	Description	Examples
Parental Efficacy	High scores indicate a parent who does not feel effective in the parenting role.	What I do has little effect on my child's behaviour.
Parental Responsibility	High scores indicate a parent who does not feel responsible for their child's behaviour.	Children's behaviour problems are often due to mistakes their parents made.
Child Control	High scores indicate a parent who feels that their child's needs and demands dominate their life.	My child influences the number of friends I have.
Parental Belief in Fate/Chance	High scores indicate a parent that believes that parenting and child behaviour are influenced by external factors such as fate and chance.	Without the right breaks one cannot be an effective parent.
Parental Control of Child's Behaviour	High scores indicate a parent who feels unable to control their child's behaviour.	It is often easier to let my child have his/her own way than to put up with a tantrum.

Campis, Lyman and Prentice-Dunn (1986)

Appendix E

Family Support Scale (FSS)

Family Support Scale

Listed below are people and groups that often times are helpful to members of a family raising a young child with autism. This questionnaire asks you to indicate how helpful each source is to your family.

Please circle the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response. The last two columns are for you to enter any sources of support that are not mentioned in the table.

How helpful has each of the following been to you in terms of raising your child	Not Available	Not At All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
My parents	NA	ī	2	3	4	5
My spouse or partner's parents	NA	1	2	3	4	5
My relatives/kin	NA	1	2	3	4	5
My spouse or partner's relatives/kin	NA	1	2	3	4	5
Spouse or partner	NA	1	2	3	4	5
My friends	NA	1	2	3	4	5
My spouse or partner's friends	NA	1	2	3	4	5
My own children	NA	1	2	3	4	5
Other parents	NA	1	2	3	4	5
Co-workers	NA	1	2	3	4	5
Parent groups	NA	1	2	3	4	5
Social groups/clubs	NA	1	2	3	4	5
Church members/ minister	NA	1	2	3	4	5
My family or child's physician	NA	1	2	3	4	5
Early childhood intervention program	NA	1	2	3	4	5
School/day-care center	NA	1	2	3	4	5
Professional helpers (social workers, therapists, teachers etc.)	NA	1	2	3	4	5
Professional agencies (public health, social services, etc.)	NA	1	2	3	4	5
SELVICES, Etc.)	NA	1	2	3	4	5
	NA	1	2	3	4	5

(FSS:Dunst, Jenkins & Trivette, 1984)

Appendix F Dyadic Adjustment Subscales

Dyadic Adjustment Scale

Subscale	Description	Examples
Dyadic Consensus	Assesses the extent of agreement between partners on matters important to the relationship.	Handling family finances. Religious matters. Household tasks.
Dyadic Satisfaction	Measures the amount of tension in the relationship, as well as the extent to which the individual has considered ending the relationship.	Do you confide in your mate? Do you ever regret that you married? How often do you and your partner quarrel?
Affectional Expression	Measures the individual's satisfaction with the expression of affection and sex in the relationship.	Demonstration of expression. Being too tired for sex. Not showing love.
Dyadic Cohesion	Assesses the common interests and activities shared by the couple.	Have a stimulating exchange of ideas. Laugh together. Calmly discuss something.

Spanier (1989).

Appendix G

Parenting Stress Index Subscales

Parenting Stress Index

Child Domain

Subscale	Description	Examples
Distractibility/ Hyperactivity	High scores are associated with children who display many of the behaviours associated with ADHD.	Compared to most, my child has more difficulty concentrating and paying attention.
Adaptability	High scores are associated with characteristics that make the parenting task more difficult by virtue of the child's inability to adjust to changes in his or her physical environment.	My child reacts very strongly when something happens that my child doesn't like.
Reinforces Parent	High scores are associated with parents who do not experience their child as a source of positive reinforcement.	My child rarely does things for me that make me feel good.
Demandingness	High scores are associated with parents who experience their child as placing too many demands upon him or her.	My child turned out to be more of a problem than I had expected.
Mood	High scores are associated with children whose affective functioning shows evidence of dysfunction.	When playing, my child doesn't often giggle or laugh.
Acceptability	High scores are associated with parents who feel that their child's physical, intellectual and emotional characteristics do not match their expectations.	In some areas, my child seems to have forgotten past learning and has gone back to doing things characteristic of younger children.

Abidin (1995).

Parenting Stress Index

Parent Domain

Subscale	Description	Examples
Competence	High scores may be produced by a number of factors: parents of an only child, or parents lacking practical child knowledge skills.	I often have the feeling that I cannot handle things very well.
Isolation	High scores are often indicative of parents who are socially isolated from peers, relatives, and other emotional support systems.	Since having children, I have a lot fewer chances to see my friends and to make new friends.
Attachment	High score may be a result of the parent not feeling a sense of emotional closeness to the child or the parents real or perceived inability to observe and understand the child's feelings and/or needs accurately.	It takes a long time for parents to develop close, warm feelings for their children.
Health	High scores are suggestive of deterioration in parental health that may be the result of parenting stress or an additional independent stress in the parent-child system.	During the past six months, I have been sicker than usual or have had more aches and pains than I normally do.
Role Restriction	High scores suggest that the parents experience the parental role as restricting their freedom and frustrating them in their attempts to maintain their own identity.	Since having a child, I feel that I am almost never able to do things that I like to do.
Depression	High scores are suggestive of the presence of significant depression in the parent.	I feel every time my child does something wrong, it is really my fault.
Spouse	High scores indicate that the parent is lacking the emotional and active support of the other parent in the area of child management.	Since having a child, my spouse and I don't spend as much time together as a family as I had expected.

Abidin (1995).

Appendix H

Family Environment Subscales

Family Environment Scale

Subscale	Description	Examples
Cohesion	The degree of commitment, help and support family members provide for one another.	There is a feeling of togetherness in our family.
Expressiveness	The extent to which family members are encouraged to express their feelings directly.	There are a lot of spontaneous discussions in our family.
Conflict	The amount of openly expressed anger and conflict among family members.	Family members sometimes get so angry they throw things.
Independence	The extent to which family members are assertive, are self-sufficient, and make their own decisions.	Family members strongly encourage each other to stand up for their rights.
Achievement- Orientation	How much activities are cast into an achievement-oriented or competitive framework.	We feel it is important to be the best at whatever we do.
Intellectual-Cultural Orientation	The level of interest in political, intellectual, and cultural activities.	We often talk about politics and social problems.
Active-Recreational Orientation	The amount of participation in social and recreational activities.	Friends often come over for dinner or a visit.
Moral-Religious Emphasis	The emphasis on ethical and religious issues and values.	Family members have strict ideas about what is right and wrong.
Organization	The degree of importance of clear organization and structure in planning family activities and responsibilities.	Activities in our family are pretty carefully planned.
Control	How much set rules and procedures are used to run family life.	Rules are pretty inflexible in our household.

Moos and Moos (1994).

Appendix I

Initial Recruitment Letter for Families in Calgary, Ottawa, and Winnipeg

July 3, 1996

Dear Parent(s):

We are studying the experiences, perceptions, and adjustments of parents of young children with autism. This research may provide a better understanding of how different families adapt and adjust to raising a child with an autistic disorder. The findings will be helpful to both professionals and parents in increasing the awareness of the factors related to adjustment in families of young children. In the future, this increased awareness may be beneficial to families in identifying resources that are most helpful to parents raising a child with autism.

We are looking for mothers and fathers of children with autism who are six years old and younger. If you agree to participate in this study you will be asked to complete a packet of questionnaires that will take approximately 75 minutes of your time. The packet contains a form concerning family information, followed by six questionnaires. These questionnaires will ask for your views about your child, your relationship with your partner (if in a current relationship), the amount of social support you receive, views about daily family living, and your views about parenting. There are no right or wrong answers to any of these questions. Your answers describe how you feel. If you have any questions while filling out the questionnaires you will have a number to call for further clarification.

Your participation is completely voluntary and you are free to withdraw at any time. To protect your privacy, no names will be used on any of the questionnaires. We will be glad to share the general findings with you at the end of the study as well as answer any questions you may have now or later.

If you decide not to participate in this study, this will in no way affect the quality of service your child receives from Society for Treatment of Autism (Calgary).

If you think you and/or your partner may be interested in participating in the study please call Deborah Brown-Godsave at 251-6158 for more information and answers to any questions you might have. If you do not reach me directly, please leave a message on my personal answering machine and I will return your call. Thank you.

Deborah Brown-Godsave (Researcher)
Graduate Student
Department of Psychology
University of Calgary
Calgary, AB T2N 1N4
Phone: (403) 251-6158

Dr. E. J. Mash (Research Supervisor)
Professor
Department of Psychology
University of Calgary
Calgary, AB T2N 1N4
Phone: (403) 220-4959

Appendix J

Agency Letters for Calgary Families

104 94TH AVENU

June 10, 1996

Dear Parent(s) or Guardian(s):

,

TEL (403) 253 2

In the Society's continuing effort to support research on autism, enclosed please find information on a research project being conducted by Ms. Debby Brown-Godsave, a graduate student from the University of Calgary. Ms. Brown-Godsave is seeking families with an autistic child six years of age and younger to participate in her study.

I thank you for taking the time to read through her proposal.

FAX (403) 253 6

Sincerely,

Sylina Leong, B.S.W., R.S.W.

Social Work Supervisor



Appendix K

Sample of Second Recruitment Letter for Calgary and Ottawa

September 16, 1996

Dear Parent(s):

My name is Debby Brown-Godsave and I am presently completing my Master's degree in Psychology at the University of Calgary. Prior to attending graduate school I worked with persons with autism for four years in Ontario. I have been associated with the Society for Treatment of Autism (Calgary) for one year.

A letter should have been sent to you in July which you may or may not have received. The reason that I am sending out a second letter is that the response from families has been low. In order to complete this study, I am in need of the support of many families. In the letter I explained that I am conducting a research project which I hope will provide a better understanding of how different families adapt and adjust to raising a child with an autistic disorder. The findings will be helpful to both professionals and parents in increasing the awareness of the factors related to adjustment in families of young children. In the future, this increased awareness may be beneficial to families in identifying resources that are most helpful to parents raising a child with autism.

We recognize that as parents you are very busy, but we hope you will be able to help us. We are looking for mothers and fathers of children with autism who are six years old and younger. If you agree to participate in this study you will be asked to complete a packet of questionnaires that will take approximately one hour of your time.

If you decide not to participate in this study, this will in no way affect the quality of service your child receives from the Society for Treatment of Autism (Calgary).

If you think you and/or your partner may be interested in participating and learning more about this study please sign the attached form and return it to Margaret House. Please send the signed form in your child's backpack and it will be forwarded to myself. Please do not hesitate to contact me or my research supervisor if you have any questions. Thank you for your time.

Debby Brown-Godsave (Researcher)
Graduate Student
Department of Psychology
University of Calgary
Calgary, AB T2N 1N4
Phone (403) 251-6158

Dr. Eric Mash (Research Supervisor)
Professor
Department of Psychology
University of Calgary
Calgary, AB T2N 1N4
Phone: (403) 220-4959

I am interested in learning more about the research project entitled "Child and Family
Characteristics and the Adjustment of Families of Young Children with Autism"
conducted by Debby Brown-Godsave.

Name	
Phone Number	
The best time of day to call is	

Appendix L

Outline for Telephone Script

Draft - Introductory Telephone Script

Thank you for your interest in our study. As outlined in the letter you received we are interested in examining the experiences, perceptions and adjustments of parents of young children with autism.

If you should choose to participate in the study a packet of questionnaires will be sent out to your home. If your partner is also interested in participating, a separate packet for him/her will be delivered to your home. We ask that you do not discuss the questionnaires with your partner and fill them out independently of one another. The questionnaires will take approximately one and a quarter hours of your time. The packet contains a form concerning family information, followed by six questionnaires. These questionnaires will ask for your views about your child with autism, your relationship with your partner, the amount of social support you receive, views about daily family living and your views about parenting. Should you have any questions while filling out the questionnaires you will be able to call me for clarification. A self addressed stamped envelope will be enclosed for you to return the packet. You will find a letter followed by a number on the top right hand of the package, this information is for identifying which city you live in and the number of packages sent out -

Your participation is completely voluntary and you are free to withdraw at any time. In order to ensure your privacy, no names will be used on the questionnaires. If you should decide to participate in the study, I will need your name and address and telephone number. I will call you back in approximately three weeks to inquire if you have completed the questionnaires and returned them. You will receive this call even if you have already returned the questionnaires as I will not know who has returned them as I will have no identifying information on the forms.

Upon completion of the study we will send you out a summary of the results if you are interested.

Do you have any questions concerning the study that I may help clarify?

Appendix M

Instructions for Completing Questionnaire Package

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRES

Thank you for your participation in this study. The purpose of this project is to examine parental experiences, perceptions and adjustments to having a child with an autistic disorder. Before you begin, we ask that you please read the letter entitled "INFORMATION ABOUT THIS PROJECT" to ensure you understand and are comfortable with the procedures outlined. This package includes seven questionnaires plus a form requesting a summary of the results following the study. We ask that you please try and keep in mind your child with autism when you are answering the questions. The specific instructions for each questionnaire are presented at the top of the individual forms. We want you to read and consider each question thoughtfully, but don't dwell too long on any one question. We recommend that you answer each question with your first response. Remember, that participation is completely voluntary and you are free to stop at any time or leave any question blank if you choose.

We ask that you complete these forms in private when time permits. Please do not consult family members while filling out the questionnaires, we are interested in your perceptions and impressions of the family unit. If your partner is also completing these forms, please complete them separately and do not discuss your responses until after you have returned your questionnaires. It is not necessary that you complete these forms all in one sitting, However, we do ask that you please complete the forms in the order in which they were received. We would appreciate it if you can please return the completed packet two weeks from the time you receive it.

All the information you provide us with will be completely confidential (please do not put your name on any of the questionnaires). It is important that you understand that there are no <u>right or wrong answers</u> to any of the questions. The study is not designed to evaluate individual family functioning but rather to look for trends across families. If you would like to receive a summary of the results upon completion of the study, please fill out the request form and place it in the separate envelope provided and include it with your packet of questionnaires. When you have finished the questionnaires, please seal the questionnaire package in its self-addressed stamped envelope and deposit it in a mailbox. Once again, thank you for participating in this study. Your time and assistance is extremely helpful to us. If you have any questions at all concerning the instructions, please do not hesitate to contact Deborah Brown-Godsave at 251-6158.

Researcher
Deborah Brown-Godsave
Graduate Student
Department of Psychology
University of Calgary
Calgary, AB
T2N 1N4

Phone: (403) 251-6158

Research Supervisor
Dr. Eric Mash, Ph. D.
Professor
Department of Psychology
University of Calgary
Calgary, AB
T2N 1N4
Phone: (403) 220-4959

Appendix N

Informed Consent Forms

University of Calgary

Information About This Research Project

Research Project Title: Child and Family Characteristics and the Adjustment of

Families of Young Children with Autism

Researchers: Ms. Deborah Brown-Godsave, B.A. (Researcher)

Department of Psychology, University of Calgary

Telephone: (403) 251-6158

Eric J. Mash Ph.D., C. Psych (Research Supervisor)
Department of Psychology, University of Calgary

Telephone: (403) 220-4959

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 is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Please take the time to read this form carefully and to understand any accompanying information.

We are conducting a study to examine the experiences, perceptions and adjustments of parents of young children with autism. The findings of this study will help professionals and parents to gain a greater awareness of the factors related to adjustment in families of young children. In the future, this increased awareness may be beneficial to families in identifying resources that are most helpful to parents raising a child with autism.

Your participation in this study will involve completing a packet of questionnaires, which should take no more than 75 minutes to complete. The packet contains a form concerning family information, followed by six questionnaires. These questions will ask for your views about your child, your relationship with your partner (if in a current relationship), the amount of social support you receive, views about daily family living, and your views about parenting. There are no right or wrong answers to any of these questions, your answers describe how you feel. Please complete the questionnaires in the order in which they appear in your packet. When you have finished, please seal the completed set of questionnaires in the envelope provided, and deposit in a postal box within two weeks of receiving the packet.

Some of the items in the attached questionnaires deal with relationship and family issues, there is a slight possibility that some items may make you feel uncomfortable. You are free to not answer any questions or to discontinue filling out the questionnaires at any time if you wish, and you are free not to return them if you change your mind about participating. If you have any questions concerning the questionnaires while you are completing them you may contact the researcher at the above number. Should any concerns arise as a result of completing the questionnaires, you are invited to contact a psychologist, Wayne Sklarski, M.A. C. Psych, for assistance. Wayne can be reached at 253-2291

Your response will be <u>completely anonymous</u>. You will not be asked to provide any identifying information on any of the forms you return. All results will be reported on a group basis. No individual information will be included. If you wish to request a summary of the results of the study, you may supply your name and mailing address on a form provided and enclose in a separate envelope with your packet.

All of the completed questionnaires will be stored in a locked filing cabinet in the Researchers office at the University of Calgary and will only be accessible to the Researcher and the Research Supervisor. The raw data will be destroyed two years after the Researcher successfully defends her Master's Thesis for which this study is being conducted.

Your decision to complete and return this questionnaire packet will be interpreted as an indication of your consent to participate. If you have additional questions concerning this research, you should feel free to ask by contacting Deborah Brown-Godsave at the telephone number given above.

If you have any questions concerning your participation in this project, you may also contact the Office of the Vice-President (Research), University of Calgary, and ask for Karen McDermid, 220-3381.

PLEASE KEEP THIS INFORMATION FORM FOR YOUR RECORDS AND REFERENCE.

THANK YOU. YOUR PARTICIPATION IS VERY MUCH APPRECIATED.

Appendix O

Request for Summary of Results

Request for Summary of Results

To: Ms. Deborah Brown-Godsave and Dr. Eric Mash, Researchers

I was a participant in your study which examined the experiences, perceptions and adjustments of parents of young children with an autistic disorder. I would be interested in receiving a summary of the results once they come available.

Name:		
Address:	•	

NOTE: Please enclose this form in the envelope provided and seal it. Once the envelope is sealed you may enclose it with the questionnaire packet to be returned. Upon receipt of the packet, the envelope with the request form will be removed immediately from the envelope and placed in a separate location. The envelopes with the request form will not be opened until such time as the results are ready to be distributed.

Appendix P

Correlations of Mothers Demographic Characteristics and Predictor, Moderator and Criterion Measures

<u>Table P1</u>

<u>Correlations between Demographic Characteristics and Predictor, Moderators and Criterion Measures</u>

	Age	Educational Level	Hollingshead SES	Employment Status	Number of Children
GARS	.00	04	.24	.02	03
FSS	.19	.16	09	.29 *	.07
PLOC	05	07	12	.04	17
PSI	.15	20	.08	.03	.09
DAS	.05	.37 *	19	04	.12
FRI	.10	.35 *	01	05	.15
FSII	.30 *	,33 *	28 *	00	08

^{* &}lt;u>p</u>< .05

Appendix Q

Summary of Hierarchical Regression Analyses using Number of Supports as a Moderator Variable

Table O1

Summary of Hierarchical Regression Analysis for Variables Predicting Parenting Stress

(N=50)

Variable	B	SE B	β	R ² Change
Step I		-		
Severity of Autism	1.62	.488	411**	.167
Parental Locus Control	1.06	.434	.303*	.090
Number of Support	-2.66	1.89	174	.028
Step 2				
Severity of Autism X Parental Locus of Control	.065	.043	.211	.035
Severity of Autism X Number of Support	080	.173	058	.003
Parental Locus of Control X Number of Support	.000	.180	.000	.000
Step 3				
Autism X Locus of Control X Number of Support	.010	.019	.880.	.004

Note. $\underline{R}^2 = .31$ for Step 1; \underline{R}^2 Change = .04 for Step 2 ($\underline{p} > .05$); \underline{R}^2 Change = .00 for Step 3 ($\underline{p} > .05$).

^{*} p < .05 ** p < .01

Table O2

Summary of Hierarchical Regression Analysis for Variables Predicting Marital Adjustment
(N=42)

Variable	<u>B</u>	SE B	β	R ² Change
Step1				
Severity of Autism	210	.163	208	.041
Parental Locus Control	.087	.140	.099	.010
Number of Support	.391	.650	.098	.009
Step 2				
Severity of Autism X Parental Locus of Control	017	.015	203	.028
Severity of Autism X Number of Support	.021	.060	.057	.002
Parental Locus of Control X Number of Support	089	.058	295	.053
Step 3				
Autism X Locus of Control X Number of Support	003	.009	120	.004

Note. $\underline{R}^2 = .05$ for Step 1; \underline{R}^2 Change = .16 for Step 2 ($\underline{p} > .05$); \underline{R}^2 Change = .00 for Step 3 ($\underline{p} > .05$).

Table Q3

Summary of Hierarchical Regression Analysis for Variables Predicting Family Relationship

(N=50)

Variable	<u>B</u>	SE B	β	R ² Change
Step 1				
Severity of Autism	.016	.061	.037	.001
Parental Locus Control	096	.054	252	.062
Number of Support	262	.235	157	.024
Step 2				
Severity of Autism X Parental Locus of Control	004	.005	115	.011
Severity of Autism X Number of Supports	016	.022	103	.010
Parental Locus of Control X Number of Supports	001	.023	011	.000
Step 3				
Autism X Locus of Control X Number of Support	001	.002	103	.006

Note. $\underline{R}^2 = .09$ for Step 1; \underline{R}^2 Change = .03 for Step 2 ($\underline{p} > .05$); \underline{R}^2 Change = .01 for Step 3 ($\underline{p} > .05$).

<u>Table Q4</u>

<u>Summary of Hierarchical Regression Analysis for Variables Predicting Family Social</u>

<u>Integration (N=50)</u>

Variable	<u>B</u>	SE B	β	R ² Change
Step1		-		
Severity of Autism	160	.058	375*	.138
Parental Locus Control	049	.052	127	.016
Number of Support	003	.225	002	.000
Step 2				
Severity of Autism X Parental Locus of Control	.000	.005	.019	.000
Severity of Autism X Number of Supports	007	.021	046	.002
Parental Locus of Control X Number of Supports	.010	.022	.080	.004
Step 3				
Autism X Locus of Control X Number of Support	002	.002	175	.017

Note. $\underline{R}^2 = .17$ for Step 1; \underline{R}^2 Change = .01 for Step 2 ($\underline{p} > .05$); \underline{R}^2 Change = .02 for Step 3 ($\underline{p} > .05$).

^{* &}lt;u>p</u> < .05

Appendix R

Mother and Father Comparisons

Table R1

Comparisons of Means and Standard Deviations of Mothers and Fathers on the GARS

	Mothers	;		Fathers		
	M	SD	Ū	M	SD	n
Stereotyped Behaviour	8.09	2.72	21	9.24	2.77	21
Communication	10.37	2.14	19	9.58	2.12	19
Social Interaction	7.82	1.90	22	7.73	2.39	22
Developmental	9.19	1.57	21	8.76	1.67	21
Total Autism Quotient	93.14	8.82	22	92.23	10.83	22

Table R2

Comparison of Means and Standard Deviations of Mothers and Fathers on the PLOC

	Mothers N=22			hers =22	
Measure and subscale	M	SD	M	SD	
Parental Locus of Control					
Parental Efficacy	27.05	2.92	25.32	3.24	
Parental Responsibility	33.68	7.51	33.41	6.22	
Child Control	20.23	2.71	21.14	2.36	
Fate/Chance	27.41	4.76	28.05	4.55	
Parental Control	27.23	4.63	27.82	9.70	
Parental Locus of Control Total	135.59	12.45	135.73	16.82	

Table R3

Comparison of Means and Standard Deviations of Mothers and Fathers on the DAS

	Mot N=		Fathers N=21		
Measure and subscale	<u>M</u>	SD	<u>M</u>	SD	
Dyadic Adjustment Scale					
Consensus	45.29	8.41	46.45	6.50	
Satisfaction	36.71	7.15	36.91	6.01	
Affectional Expression	7.57	2.84	7.55	2.42	
Cohesion	13.33	4.54	13.55	2.74	
Dyadic Adjustment	102.90	20.97	104.46	13.42	

Table R4

Comparison of Means and Standard Deviations of Mothers and Fathers on the FSS

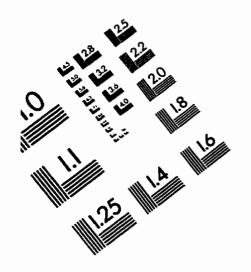
	Mothers N=22		Fathers N=22	
Measure and items	M	<u>SD</u>	M	SD
Family Support Scale				
Own parents	2.93	1.44	2.63	1.36
Spouse or Partner's Parents	2.45	1.10	2.80	1.42
Relatives/Kin	2.34	0.85	1.93	1.03
Spouse or Partner's Relatives/Kin	2.06	1.00	2.35	1.00
Spouse or Partner	4.04	1.13	4.68	0.57
Friends	2.61	1.24	2.48	1.37
Spouse or Partner's Friends	2.00	1.03	2.33	1.20
Own Children	2.84	1.26	2.80	1.40
Other Parents	2.30	1.16	1.90	0.76
Co-workers	1.82	1.17	1.60	0.99
Parent Groups	2.34	1.02	2.27	1.03
Social Groups/Clubs	1.71	0.76	1.56	1.01
Church	2.00	1.05	1.90	1.17
Family/Child Physician	2.48	0.93	3.10	1.22
Early Intervention Programs	4.12	1.23	4.25	0.85
School/Day Care	4.00	1.12	4.00	0.97
Professional Helpers	3.62	1.20	4.19	0.93
Professional Agencies	2.90	1.37	3.14	1.15
Number of Support Available	14.27	2.68	14.54	2.70
Total Scale Score	38.60	10.73	41.82	8.13

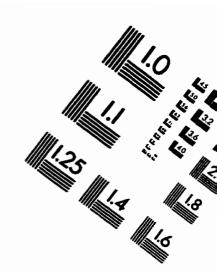
Table R5

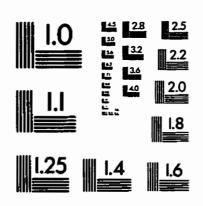
Comparison of Means and Standard Deviations of Mothers and Fathers on the FES

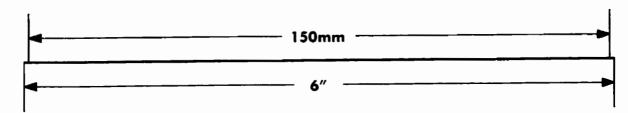
		hers =22	Fathers N=22	
Measure and subscale	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Family Environment Scale				
Cohesion	51.50	15.89	54.59	9.98
Expressiveness	50.05	12.01	47.18	15.02
Conflict	44.96	12.34	47.00	12.77
Independence	43.18	10.45	44.64	11.17
Achievement Orientation	42.91	12.08	46.09	12.04
Intellectual-Cultural Orientation	46.59	10.68	46.73	11.51
Active-Recreational Orientation	43.86	11.34	41.27	11.05
Moral-Religious Emphasis	49.23	10.98	47.27	11.65
Organization	47.55	9.90	47.59	11.97
Control	53.28	12.19	47.00	12.77
Family Relationship Index	19.05	5.64	18.91	5.19
Family Social Integration Index	13.73	4.94	12.86	4.45

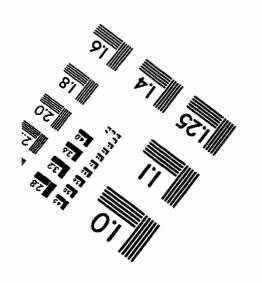
IMAGE EVALUATION TEST TARGET (QA-3)













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