ELEMENTS OF EMOTIONAL STRESS IN PARENTS OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDERS: IMPLICATIONS FOR CLINICAL PRACTICE

by

JUDITH MCKAY PERRY

(Under the Direction of Mick Coleman)

ABSTRACT

This study investigates the extent to which parenting a child diagnosed with an Autism Spectrum Disorder generates emotional stress in parents. Rates of diagnosis of children with autism have increased markedly in recent years and parents raising them incur multiple social, emotional, and economic stressors. Parents experience uncertainty, fear, and feeling overwhelmed with the responsibility of coordinating and accessing resources, treatments, and interventions. The quality of personal, marriage, and family life can be impacted as well.

The purpose of this study was to gain insight into the perceptions and potential stress of parents of children with autism spectrum disorders. Discussion of results highlight implications for clinical and service providers. An intervention model is also proposed to assist clinical and service providers in helping parents of children with autism reduce emotional stress.

INDEX WORDS: Affective anomalies, Asperger’s disorder, Autistic disorder, Childhood disintegrative disorder, Children with autism, Cognitive delay, Co-Morbid diagnoses, Early intervention providers, Fragile X syndrome, Neurodevelopmental disorder, Parental perception of child, Parental roles, Parental stress, Pervasive developmental disorders, Pervasive developmental disorders not otherwise specified, Rett’s disorder, Service providers, Therapy
ELEMENTS OF EMOTIONAL STRESS IN PARENTS OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDERS: IMPLICATIONS FOR CLINICAL PRACTICE

by

JUDITH MCKAY PERRY

B.A., Stratford College, 1969

B.M.M.T., Loyola University, New Orleans, 1973

M.Ed., The University of West Georgia, 1993

Ed.S., Georgia State University, 1996

A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2006
ELEMENTS OF EMOTIONAL STRESS IN PARENTS OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDERS: IMPLICATIONS FOR CLINICAL PRACTICE

by

JUDITH MCKAY PERRY

Major Professor: Mick Coleman
Committee: William Quinn
Charlotte Wallinga

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
May 2006
DEDICATION

This project was conducted in honor of my husband, Thomas, our children: Drew, Neil, and Josh, and our “team:” Nonnie, Grandmother and Granddad, Aunt Marcy and Uncle Fred, Kathryn, Page and Ernest, Joannie and Joel, Toby, David, and “Dr. N.”

The study is dedicated to parents, siblings, and families who are sharing the journey of a child with autism or an autism related disorder.
ACKNOWLEDGEMENTS

I wish to thank my committee chair, Dr. Mick Coleman, for his patience, editing, proofing and design assistance and my committee members, Dr. Charlotte Wallinga and Dr. William Quinn for their time and assistance as well.

I wish to thank Dr. Joseph Wisenbaker for his calm, respectful, style and skill in teaching statistics and Dr. Marty Thomas at Brenau University for his assistance with data management.

I wish to thank the following for assistance with research design, power point, and general cheerleading and encouragement: Carisa Perry-Parrish, Josh Perry-Parrish, Drew Perry, Tita Ramirez, Kate Worley, Neil Perry, Jane McKay, Sally and Jack Perry, Marcy and Fred Fairhead, Nancy Granger, Sally and Bruce Alterman, Janet and Bob Benjamin, and countless other friends and extended family.

I wish to thank my husband, Thomas, for the years of formatting, proofing, patience, love, understanding, and more patience, love, and understanding.
## TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>ACKNOWLEDGEMENTS</strong></td>
<td>v</td>
</tr>
<tr>
<td></td>
<td><strong>LIST OF TABLES</strong></td>
<td>ix</td>
</tr>
<tr>
<td>1</td>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Purpose of the Study</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Research Questions</td>
<td>8</td>
</tr>
<tr>
<td>2</td>
<td>REVIEW OF THE LITERATURE</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Introduction</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Family and Parental Stress</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Sibling Perspective</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Parental Stress and Coping in Parenting a Child with Autism/Special Needs</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td>Autistic Spectrum Disorders</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>Theoretical Perspective</td>
<td>51</td>
</tr>
<tr>
<td></td>
<td>Research Hypothesis</td>
<td>65</td>
</tr>
<tr>
<td>3</td>
<td>METHODOLOGY</td>
<td>70</td>
</tr>
<tr>
<td></td>
<td>Data Analysis Plan</td>
<td>84</td>
</tr>
<tr>
<td>4</td>
<td>RESULTS</td>
<td>89</td>
</tr>
<tr>
<td></td>
<td>Demographic Data</td>
<td>89</td>
</tr>
</tbody>
</table>
5 DISCUSSION .......................................................................................................................106

Limitations and Recommendations for Future Research ...........................................118

Implications for Practice ..............................................................................................123

Psychoeducational Problem Solving Model for Special Needs Families ............127

Conclusion ..............................................................................................................131

REFERENCES .............................................................................................................136

APPENDICES

A DEFINITIONS .........................................................................................................171

B DIAGNOSIS CRITERIA FOR PERVERSIVE DEVELOPMENTAL /
AUTISM SPECTRUM DISORDERS* AND FRAGILE X SYNDROME** ..........178

C COVER LETTER AND CONSENT FORM ......................................................188

D PARENT SURVEY ..............................................................................................193

E TEXT FOR RECRUITING PARTICIPANT(S) IN PERSON ......................................199

F TEXT FOR RECRUITING FORMER CLIENTS BY TELEPHONE AND
TEXT FOR FOLLOW-UP CALL ..............................................................................201

G TEXTS FOR CONTACT CALL TO GROUP CHAIRPERSONS, FOR
INTRODUCTING STUDY TO PARENTS PARTICIPATING IN AUTISM
SPECTRUM PARENT SUPPORT GROUPS, AND NOTE OF THANKS ..........205

H FLIER FOR RECRUITING PARTICIPANTS IN PEDIATRIC MEDICAL
FACILITY ..............................................................................................................209

I SUMMARIZED PERCENTAGE RESPONSE DATA – MODIFIED
INTERNATIONAL CLASSIFICATION OF FUNCTIONING DISABILITY
AND HEALTH CLASSIFICATION SYSTEM ..................................................212
J  SUMMARIZED PERCENTAGE RESPONSE DATA – PARENTAL
  STRESS SCALE........................................................................................................216
K  SUMMARIZED PERCENTAGE RESPONSE DATA – COUPLES
  ASSESSMENT OF RELATIONSHIP ELEMENTS (CARE)........................................220
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1</td>
<td>Demographic Data for Mothers, Fathers, Target Child and Siblings</td>
<td>90</td>
</tr>
<tr>
<td>Table 2</td>
<td>Descriptive Data for Modified International Classification of Functioning</td>
<td>92</td>
</tr>
<tr>
<td></td>
<td>Disability and Health Classification System</td>
<td></td>
</tr>
<tr>
<td>Table 3</td>
<td>Descriptive Data for Parental Stress Scale</td>
<td>93</td>
</tr>
<tr>
<td>Table 4</td>
<td>Descriptive Data for Couples Assessment of Relationship Elements</td>
<td>95</td>
</tr>
<tr>
<td>Table 5</td>
<td>Hypothesis 1: Parents Gender and Parenting Stress</td>
<td>96</td>
</tr>
<tr>
<td>Table 6</td>
<td>Hypothesis 2: Age of Child with Autism Spectrum Disorder and Parenting Stress</td>
<td>98</td>
</tr>
<tr>
<td>Table 7</td>
<td>Hypothesis 3: Perceived Severity of Childhood Problems and Parenting Stress</td>
<td>99</td>
</tr>
<tr>
<td>Table 8</td>
<td>Hypothesis 4: Number of Siblings in Home and Parenting Stress</td>
<td>101</td>
</tr>
<tr>
<td>Table 9</td>
<td>Hypothesis 5: Parent’s Gender and Marital Satisfaction</td>
<td>103</td>
</tr>
<tr>
<td>Table 10</td>
<td>Hypothesis 6: Parental Stress and Marital Satisfaction</td>
<td>104</td>
</tr>
<tr>
<td>Table 11</td>
<td>Comparison of Social Systems Model of Family Functioning (Dunst &amp; Trivette,</td>
<td>126</td>
</tr>
<tr>
<td></td>
<td>1987), Psychoeducational Problem Solving Model for Special Needs Families</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Perry, 1997), A Wellness Model with Family Caregivers (Myers, 2003), and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A Resilience-Oriented Model for Practice (Simon, Murphy, &amp; Smith, 2005)</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER 1
INTRODUCTION

Parents of children with autism will long remember the day their child was diagnosed with an Autism Spectrum Disorder (Russo-Sprouls & Porteus, 1998). They will remember the sense of uncertainty and fear and their multitude of questions (Livneh & Antonak, 2005; Mishel, 1981). They will remember their lack of any sense of appropriate direction, a difficult starting point for the most daunting assignment many of them will ever face (Russo-Sprouls & Porteus, 1998).

Rates of diagnosis of children with autism have increased in recent years due to improvements in screening and the inclusion of not only children with cognitive delay, but also those with no cognitive delay and average to above average intelligence (Carlson, 2002; Pennington, 2002). Autism, a pervasive developmental disorder, can appear with or without co-morbid diagnoses such as Down syndrome or cerebral palsy (Ho & Keiley, 2003; Remig, 2004; Tierney, 2004), with or without significant behavioral issues (Landa, 2003; Russo-Sprouls & Porteus, 1998), and often presents with other bio-neurological and/or genetic disorders such as tic and Tourette’s disorders, Fragile X syndrome, obsessive compulsive and seizure disorders, nonverbal learning disorders, or fetal alcohol disorder (Comings, 1997; Lee, 2005; Mamen, 2002; Remig, 2004; Sturm, Fernell, & Gillberg, 2004; Tierney, 2004). Developmental disorders emerge due to genes, neural tube migration disorders, metabolic insufficiency, immune system errors, neurotransmitter imbalance, toxins, or environmental trauma (Bauman & Kemper, 1994; Pennington, 2002; Remig, 2004). Other possible culprits include family genetics, teenage pregnancy, older mothers giving birth, and premature neonate survival (Remig, 2004).
At present, autism is believed to be a neurodevelopmental disorder (Baron-Cohen, 1995, 2004; Comings, 1997; Crain, 2000; Landa, 2003; Lee, 2005; Pennington, 2002; Remig, 2004; Thomas, 1999; Wilens, 1999; Williams, 1992) with strong genetic influences (Baron-Cohen, 1991, 1995, 2004; Comings, 1997; Folstein & Rutter, 1977; Lee, 2005; Nydén, Carlsson, Carlsson, & Gillberg, 2004; Pennington, 2002; Phipippe et al., 1999; Remig, 2004; Russo-Sprouls & Porteus, 1998; Steffenberg et al., 1989; Sturm et al., 2004; Thomas, 1999). In general terms, autistic individuals proceed through life by rote, learning rules for living, often with very little or limited understanding of the significance or meaning of those rules, limited or no expressive language, and often extreme difficulty with processing information about people and their relationships (Pennington, 2002; Russo-Sprouls & Porteus, 1998; Williams, 1992). For example, the individual may manifest an inability to recognize facial expressions or even comprehend which parts of the face indicate specific feelings (Borod & Caron, 1980; Borod, St. Clair, Koff, & Alpert, 1990; Bowers, Bauer, Coslett, & Heilman, 1985; Campbell, 1978; Chaurasia & Goswami, 1975; Levy, Heller, Banich, & Burton, 1983). In addition, the child or adult with autism may experience difficulty with understanding common social situations and recognizing another person’s feelings from tone of voice, word choice, or other typical conversational cues (Moyes, 2003; Pennington, 2002; Remig, 2004; Willey, 2002; Williams, 1992).

However, some children are diagnosed with Asperger’s syndrome which is a form of autism that does not include language or cognitive delays (Asperger, 1944; Comings, 1997; American Psychiatric Association, 2000; Frith, 1991; Gillberg, 2000; Klin, 2002; Remig, 2004). Others are diagnosed with Fragile X syndrome which includes many if not all of the characteristics of classic autism in addition to some physiological characteristics such as
abnormal positioning or size of the ears (Remig, 2004). Fragile X has one of the two strongest genetic associations with autism thus far identified (Foster & King, 2003; Remig, 2004).

For this study, autism will be characterized as a multifaceted disorder of the brain that has the potential to affect countless aspects of a child’s, parents’ or a family’s life (Tierney, 2004). Autism Spectrum disorders will be discussed in detail in Chapter 3. In order to facilitate the reader’s understanding of the multiple medical/clinical terms that appear in this writing, a list of definitions appears as Appendix A.

The purpose of this project was to conduct a survey study, using The Parental Stress Scale (Berry & Jones, 1995) which explores possible elements of emotional stress in parents who are providing care for a child with an Autism Spectrum Disorder. The scale uses positive themes of parenthood including emotional benefits, self-enrichment, and personal development and negative components including demands on resources, and opportunity costs, and restrictions. In addition, possible differences in gender related parental perspectives were explored.

For this study, the term *family* was understood to mean single-parent families, a married couple living together who are both biological parents of all the children in the home, a blended family in which both parents are not necessarily the biological parents of all the children in the home, foster/adoptive parents, or grandparents serving in a primary caregiver role, all containing a child diagnosed with an autism spectrum disorder. The project was conducted from a family counseling perspective. In addition, demographic information of parental age, gender, and family structure (i.e., married biological parents, blended family, foster/adoptive parents, or grandparents serving in a primary caregiver role), age of the child with autism, and number and ages of all additional children in the household was reported.

Parents who have more than one child in the autism spectrum were asked to target the one child who is the most involved on the spectrum or who presents with the most challenging
behaviors. To strengthen the study, descriptive information regarding parents’ perceptions of their target child with autism was collected, coded, and analyzed. In addition, a brief instrument designed to assess parents’ perceptions of their marriage relationships (where relevant) was included. Finally, implications for practice with parents of children with autism were discussed.

Purpose of Study

A growing number of families in the United States and abroad are providing care to a child with a chronic illness or disability (Ho & Keiley, 2003; Livneh & Antonak, 2005; Seltzer & Heller, 1997). Each family handles such a situation differently. Some manage with acceptable success (Singer & Farkas, 1989; Turnbull et al., 1993), while others experience permanent changes in family dynamics and attitudes of perceived stress (Blacher, 2002; Ho & Keiley, 2003; Lessenberry & Rehfelot, 2004; Lynch & Morley, 1995; Perry, 1997a). Howard (2004), for instance, characterizes caregiving for an individual with a disability as one of the most stressful jobs in the United States today. He observes that even in the (extreme) event of eventual death of the disabled person, stress for the caregiver persists because stress based behaviors are so firmly entrenched that the caregiver may find giving them up to be very difficult. Further, economic costs of specialized childcare can result in loss of job, career change, dependence on public assistance programs, and confusion regarding family roles and personal boundaries (Bouma & Schweitzer, 1990; Floyd & Zmich, 1991).

Even typically developing siblings (especially sisters) are thrust into roles of surrogate parenting (McHale & Harris, 1992; Seligman & Darling, 1997; Stoneman, Brody, Davis, & Crapps, 1987) and experience atypical sibling relationships which are less egalitarian than typical sibling relationships and in which parental expectations for sibling caregiving may have been in place for most of the typical child’s life (Begun, 1989).
When a child is diagnosed with autism and thus, special needs, the impact of such a diagnosis can severely impact parental emotional states (Ehly, Conoley, & Rosenthal, 1985; Falvo, 1999; Floyd & Gallagher, 1997; Modrcin & Robison, 1991) because parents have so many daily challenges to face (Tierney, 2004). For example, in addition to the characteristic delays in the development of social, communicative, and cognitive skills that may be present with autism, the disorder carries a disparate range of symptoms that present themselves in widely varying degrees. For instance, the child must manifest at least six (or more) behaviors from three different lists as outlined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000). The lists include (a) impairments in social interaction such as eye contact and facial expression, (b) impairments in communication such as expressive language or play skills, (c) repetitive or stereotyped patterns of behavior such as hand flapping or complex whole body movements. A given child must manifest two behaviors from the first list of four criteria, and one each from the second two lists of four which can be daunting in their variability, overwhelming, and confusing for parents (Landa, 2003; Pennington, 2002; Russo-Sprouls & Porteus, 1998; Tierney, 2004). The complete diagnostic criteria lists for Autism Spectrum Disorders and Fragile X Syndrome appears in Appendix B.

The vast diversity in symptom expression spurs the need for highly individualized treatment plans that often involve care from multiple providers (Tierney, 2004). Within recent years (particularly the last two decades) a strong trend has appeared toward inclusion of individuals with disabilities rather than segregation in both educational and employment settings. This interface has yielded an expanded set of responsibilities for the family. The net effect is that the family, often especially parents, now plays a more pivotal role than in the past in the care of individuals with disabilities across the life course (Seltzer & Heller, 1997). To further complicate
matters, while parents of children with autism often suspect that something is amiss with their child just a few months after birth, a definitive diagnosis typically takes several years. Months or even years that critical early intervention could be taking place are lost while the parents’ anxiety continues to rise with the growing knowledge that something is seriously wrong (Lynch & Morley, 1995; Tierney, 2004).

Although the literature on the experiences of parents providing lifelong care to a (child) with a disability is growing (Cook & Pickett, 1987; Fisher, Benson, & Tessler, 1990; Heller & Factor, 1993; Landa, 2003; Lee, 2005; Lessenberry & Rehfelot, 2004; Remig, 2004; Tierney, 2004), parental, sibling, and family experiences vary across the life course and are shaped by the milieu of the individual family (Stoneman & Berman, 1993). Also, there is evidence that the quality of (family) relationships is influenced by meanings attributed by the family to the child’s disability, parental reactions to the child’s care, and overall family coping and adaptation (Begun, 1989; Swados, 1991).

Family clinicians can benefit from better understanding the emotional adjustment of parents who have children with autism since the challenges associated with this issue involve all family members (Falvo, 1999; Harris & Glasberg, 2003; Powell & Gallagher, 1993; Singer & Farkas, 1987). Modrcin and Robison (1991) observe that parents should be encouraged to discuss the meaning of their child’s illness or disability to their lives. To this end, they encourage openness in the parent-professional relationship based on trust and empathy.

Further investigation of the emotional experience of adults parenting a child or children diagnosed with an Autism Spectrum Disorder may add meaningfully to the literature and knowledge regarding parent functioning and overall mental health in both home and community settings. Survey instruments such as The Parental Stress Scale (Berry & Jones, 1995) represent
one potential means by which family clinicians might better understand the emotional adjustment of parents who have a child diagnosed with an Autism Spectrum Disorder.

The purpose of this study was to attempt to determine levels of parental stress by exploring positive aspects of parenthood including emotional benefits, self-enrichment, and personal development and negative components including demands on resources, and opportunity costs, and restrictions (Berry & Jones, 1995) and to explore possible gender related differences in parental perspectives in those areas. As previously mentioned, demographic information regarding parental age, gender, and family structure (i.e., single-parent families, married biological parents, blended family, foster/adoptive parents, or grandparents serving in a primary care role), age of the child with autism and number and ages of all other children in the household is reported.

Parents also provided descriptive assessments of their target autistic child using a modified International Classification of Functioning, Disability, and Health classification system (World Health Organization, 2001) in 12 areas: gross and fine motor function, attention, activity level, impulse control, intellectual level, learning, speech development, tics (repetitive behaviors), obsessive-compulsive behaviors, affective anomalies, social interaction, and restricted interests responding “no,” “minor/mild,” or “definite/severe” (Sturm, Fernell, & Gillberg, 2004). In addition, married parents completed the Couples Assessment of Relationship Elements (CARE) (Worthington et al., 1997) to assess marital satisfaction. Results of the study and limitations of the study are discussed, and implications for clinical practice with parents of children with autism are suggested using the Psychoeducational Problem Solving Model for Special Needs Families (Perry, 1997b).
Research Questions

The following research questions guided the current project.

Question 1. Do mothers and fathers who have a child diagnosed with an autism spectrum disorder report different levels of emotional stress across different parenting contexts?

Question 2. For mothers and fathers, is there a correlation between age of child with an autism spectrum disorder and parents’ level of stress across different parenting contexts?

Question 3. For mothers and fathers, is there a correlation between parents’ perceptions of the severity of developmental problems associated with their child with an autism spectrum disorder and their level of stress across different parenting contexts?

Question 4. For mothers and fathers, is there a correlation between the number of siblings in a home with a child with an autism spectrum disorder and parents’ level of stress across different parenting contexts?

Question 5. Will mothers score lower than fathers on a measure of marital satisfaction?

Question 6. For mothers and fathers, are there significant inverse correlations between parents’ marital satisfaction and their level of stress across different parenting contexts?
CHAPTER 2
REVIEW OF THE LITERATURE

Introduction

Stress in families emerges as a matter of perception (Blacher, 2002; Christensen, Skaggs, & Kleist, 1997; Falvo, 1999; McCubbin, 1989; Patterson, 1985; Perry, 1997a; Rivera et al., 1996; Turnbull et al., 1993). Stress is a fact of life in most families with children, and families who have children with disabilities report experiencing a disproportionate amount of stress (Blacher, 2002; Lessenberry & Rehfelot, 2004). However, there are also those parents and families who are able to use cognitive coping strategies as a positive adaptation to stress (Turnbull et al., 1993). For example, some parents report that having a child with disabilities strengthened their own adaptive capacity (Blacher, 2002; Singer & Farkas, 1989).

Many family life events that generate parental and family stress involve some element of transition and can be distilled, at essence, to an issue of loss. For instance, some stressors such as moving from one city or state to another and certainly the death of a family member can be characterized as loss, but even these have a more or less finite beginning and end followed by a period of adjustment. Others such as chronic illness or disability create permanent changes in family functioning that can deeply influence attitudes of perceived stress (Lynch & Morley, 1995; Servaty-Seib, 2004). Responses of parents and other family members such as siblings are often dictated by degrees of internal strength and weakness already present in the interpersonal dynamics of the family (Floyd & Zmich, 1991; Grych, Seid, & Fincham, 1992; Perry, 1997a; Whittaker & Bry, 1991).
In this chapter, literature applicable to the context of parenting a child with special needs will be reviewed. First, a general discussion of family stress will be considered, including links to early scholarship and historical events and the impact of economic stress in families. Second, the perspective of typically developing siblings will be addressed in two parts (a) a brief report of a recent pilot study by this researcher that investigated elements of emotional stress and strength in siblings of children with special needs and (b) the perspective of siblings of children with autism. Third, a review of parental stress and coping issues associated with parenting a child with autism/special needs will be presented. In the fourth section, the various dimensions of autistic spectrum disorder will be examined. In the fifth section, the theoretical underpinnings of the current study will be explained. Finally, the research hypotheses for this study will be presented.

Family and Parental Stress

Links to Early Scholarship and Historical Events

Early scholarly work in the context of family stress from more than one perspective can be applied to parenting a child with special needs. Glasser (1976) observes that many factors influence one’s feelings of strength or weakness on a given day. For example, on a particular day, parents might feel stronger than on another depending on events and situations such as personal health, events in the workplace, or personal trauma such as the child with autism acting out in a public place. All of these can contribute to the state of parental mental and emotional health. Glasser believes that neither individuals nor families are born essentially strong or weak, but, endowed with varying degrees of intelligence and circumstance, can still function from an attitude of strength. May (1969) believes that human will power alone facilitates the manipulation of surroundings, self, and one’s own life. Indeed, Glasser (1976) believes that one chooses attitudes of strength or weakness.
Bowen’s (1978) early work in family therapy that yielded his concept of Differentiation of Self can be applied to the special needs parenting context. Bowen believes that differentiation in individual family members leads to varying degrees of togetherness or individuality. Successful establishment of a healthy sense of individuality enables a person to distinguish between the intellectual process and the feeling process he or she is experiencing. Individuals and families with high degrees of fusion between feelings and thoughts function poorly and are likely to be susceptible to involuntary emotional reactions and tend to become dysfunctional even under low levels of stress. Such persons seem to fuse with whatever emotions are prevalent in the family.

Bowen’s theoretical differentiation of self scale illustrates individual (or family) strengths and weakness in sense of self. Individuals (and families) at the low extreme may have their emotions and intellect so fused that their lives are dominated by the feelings (or circumstances such as constant caregiving of a child with a disability) of those around them. They can be easily stressed into dysfunction and become stuck in a place of crisis. For example, parents can sometimes feel overwhelmed by the ongoing care of the child and suffer a loss of perspective.

A disturbing contemporary social statistic is an increasingly high incidence of physical violence in the home against children with disabilities (White, 2003; White & Allers, 1994). Sabourin, Laporte, and Wright (1990) produced a study that differentiated 75 distressed couples from an identical number of non-distressed couples. The distressed group was found to display less problem solving confidence, poor behavior control strategies, and a tendency to avoid different problem solving activities. In addition, distressed couples displayed significantly more difficulty with such coping efforts as optimistic comparisons, negotiation, and resignation.

Crisis, like stress, is a matter of perception (Blacher, 2002; Cristensen, Skaggs, & Kleist, 1997; Livneh & Antonak, 1990, 2005; McCubbin, 1989; Patterson, 1985; Rivera, Jaffe, Polissar,
Fay, Liao, & Martin, 1996; Turnbull et al., 1993), but some major historical events have been perceived as such by most whose lives they touched and emphatically by observers in other geographical areas or parts of the world. In his classic early work, Elder (1974) sought to determine the impact of catastrophic economic change resulting from the Great Depression in America on the “social roles, self attitude, and life prospects of children” (p. 43). Unemployment and economic losses resulted in instability in families, changing family status, increased reliance on public income sources and multiple perceptions of strain indiscriminately across classes (Elder, 1974).

The concept of crisis can be aptly applied to families containing a child with special needs. Sometimes one or both parents may lose or must give up a job or career in order to move closer to appropriate resources or to provide care for the child. Economic costs of specialized care and adaptive or therapeutic equipment and/or educational supplies usually result in dependence on public assistance programs such as Medicaid even when there is private insurance in place (Fialka, 1997; Klein, 1990). Certainly, instability in the family is generated. Family roles, personal boundaries and perceptions of leadership can become clouded by physical and emotional exhaustion (Perry, 1997a). Likewise, however, in parallel to Elder (1974), families structured on love, understanding, and mutual respect prior to the onset of the ongoing crisis seem somewhat less stressed (Blacher, 2002).

Economic, Social, and Emotional Strain

Cavan (1959) also deals with the emotional and physical impact of unemployment in families across social classes. Once again, strong parallels to the context of parenting a child with special needs can be drawn. Disability knows no class or boundary (Ehly et al., 1985; Fialka, 1997; Floyd & Zmich, 1991; Klein, 1990; Modrcin & Robison, 1991; Remig, 2004; Tierney, 2003). All but perhaps the very wealthy are affected by extreme demands of specialized
therapies and interventions on family income. Getting ahead may seem impossible or even inconsequential (Fialka, 1997).

Cavan (1959) highlights emotional responses to unemployment that are often repeated by families of children with special needs at the point of diagnosis. Parents are often reluctant to leave the relative safety of denial to acknowledge reality by adjusting budgets and cutting expenses (Ho & Keiley, 2003). The specter of seeking and accepting public financial assistance can be perceived as a defeat and a failure to care and provide for one's family. Cavan's concepts are reflected in the emotional responses of parents and families who can slip into elements of depression characterized by periods of crying, sleeping and eating disturbances, difficulties in focusing and concentrating, and inappropriate affect. Again, roles become confused as the family's dependence on specific health care professionals, specialists, and financial assistance agencies grows. Parents can experience perceived loss of social class or status with the social isolation that often partners with parenting a child with special needs (Fialka, 1997; Floyd & Gallagher, 1997; Ho & Keiley, 2003; Klein, 1990).

Voydanoff (1991) also addresses the impact of multiple manifestations of economic distress on family relations such as family size and structure, and employment instability and uncertainty. She observes that the effects of such distress are “extensive and wide ranging” (p. 435) and that the nature and quality of family life is dependent on the worker-earner role, employment, and income. She adds that a minimum level of income and employment stability is essential for family stability and cohesiveness. For instance, earlier scholars found that all of these aspects of family life might be influenced by relationships between chronic strain, mental and physical health, and coping resources, behaviors, and social support (Kessler, 1982; McLoyd, 1989; Menaghan, 1983; Pearlin, 1989). They can certainly be applied to parents raising a special needs child.
Additional earlier studies use family stress theory to link perceived stress in families with life events such as unemployment and serious illness or disability (McCubbin & McCubbin, 1987; McCubbin & Patterson, 1983; Menaghan, 1983; Walker, 1985). These scholars characterize coping as a major player in relationships between stressors and individual health and family functioning. Coping resources include psychological and family system characteristics and available social networks already in place. Coping behaviors include direct action for problem solving and the “regulation of emotions and meanings associated with…distress” (Voydanoff, 1991, p. 437).

Goode’s (1960) theory of strain lends itself well to the context of special needs families. Goode maintains that social roles are set forth and sustained to facilitate the continuation of society and that, for the most part, people wish to comply. Role strain occurs when one player does not wish to comply or when one is struggling with availability/demands of roles that carry different obligations. Inconsistencies between activities and responses demanded by role relationships create additional sources of strain.

An example of this sort of role strain and confusion for parents of a special needs child is the emotional stress created for the parent when the child has after-school therapies, but the sibling(s) have activities also which require some sort of transportation coordination. Parents can be thrust into the role of constant caregiver and feel robbed of their roles of companion, spouse, and friend (Floyd & Gallagher, 1997; Harris & Glasberg, 2003).

Additional early work by Boss and Greenberg (1984) suggests that family stress levels result more from the resulting ambiguity of loss (of expectations) than from the actual event of loss. Family members can be unsure of whether certain members are inside or outside of the family, and designation of roles and tasks can become unclear. When psychological and physical presence do not coincide, ambiguity occurs. For example, an early intervention (three years of
age and under) child diagnosed with autism may have as many as six different therapy events from four different disciplines (physical, occupational, speech and language therapies and special instruction) per week. Most if not all of these take place in the home (Klein, 1990; Landa, 2003; McWilliam, 1996). Certainly, with a constant parade of non-family members in and out of the system on a daily basis, whose specific duty is caring for the child in some way, parenting roles can become confused.

Ambiguity also can arise with the contrasting juxtaposition of where the child is developmentally and where he/she ought to be. While initially denial for brief periods may allow a family to function effectively, long term denial may impede the process of adaptation and reorganization of roles and boundaries in the family system (Boss & Greenberg, 1984; Ho & Keiley, 2003). The family’s transition from one developmental stage to another may be compromised or the family may even become pathologically stuck such that parents and typical developing siblings experience difficulty accomplishing daily tasks and meeting life demands (Perry, 1997a).

Sibling Perspective

_Siblings of Children with Special Needs_

The siblings of children with special needs present a unique population as every facet of their lives is affected on a daily basis. Often this effect is in response to the emotional, economic, and pragmatic impact on parents of the necessary and time/attention consuming care required of them for the child with special needs (Harris & Glasberg, 2003; Powell & Gallagher, 1993). This researcher recently conducted a small pilot study exploring elements of emotional stress and strength in typically developing siblings of children with special needs. The researcher believed that investigating the emotional experience of young children who are typically developing siblings living with a disabled brother or sister might add meaningfully to the literature and
knowledge regarding child behavior and performance in both home and academic settings. The pilot study was also intended to serve as a springboard to the current project and may increase understanding of circumstances that contribute to parental emotional status. The results of that pilot study are summarized as follows.

The participants for this pilot study were 20 typically developing children who were all siblings of a child (or children) with significant special needs. The researcher used an existing data set of House-Tree-Person drawings collected over a 24 month period. All of the children were in treatment (play therapy) with the researcher at the time their drawings were collected. The purpose of the study was to look for any patterns or common themes among a selected group of variables within the set of drawings that might suggest elements of emotional stress or strength. A modified form of the Kinetic–House-Tree-Person drawing (Burns, 1987) was used to analyze the data. There were 12 females and 8 males ranging in age from 5 to 12 years. Though the exceptionalities of the special needs siblings were mixed, 9 of the 20 participating children had a sibling with an autism spectrum disorder.

The study appears to shed additional light on the emotional journey of siblings of children with significant special needs. As they interact and are impacted as members of the family system, the shape and stages of their life course are influenced, and they learn to live in and around family choices that must be made. It seems clear that though the children in the observed sample were apparently experiencing some expected and unexpected elements of negative emotional stress, just as clearly they appeared to be equipped with significant emotional strengths. The study seems to echo earlier and current research that suggests there can be both positive and negative effects on the typically developing sibling of his/her relationship with the child with a disability (Cerreto & Miller, 1981; Harris & Glasberg, 2003; Lobato, 1983; McHale,
The results of the pilot study suggest that though the participating children may have been experiencing mild to moderate levels of depression, they nevertheless displayed adequate levels of emotional adjustment and felt a sense of belonging. They may have experienced a sense of instability and felt discouraged at times but were psychologically accessible and not shy. There was strong evidence that they did not feel traumatized, trapped, or powerless. However, they emerged as feeling somewhat passive, non-assertive, and unable to access opportunities in their environment, they did not display a sense of hostility or aggression.

Scores for the observed sample suggested that in spite of an evident lack of a sense of growth, the children continued to reach out to their environment for nurturing, growth, and feeling connected. In addition, there was evidence that they were not feeling rejected, guilty, or experiencing feelings of low self-esteem.

The children scored as somewhat closed with respect to communication. This apparent discouraged perspective may have influenced an extreme score that suggested a sense of not being heard. It is not difficult to imagine that in the busyness of caring for the child with special needs and the rest of the family as well, that one or more siblings may feel that their thoughts and opinions go unheard. Nevertheless, the study suggests that the children were not feeling weak, fearful, or so discouraged as to feel defeated. Parents often express concern in the clinical setting for the typical sibling’s emotional state or experience even when there is no behavioral evidence to support a sense of compromise. It is heartening to note that though the participants in this study were manifesting some understandable elements of stress, they were apparently equipped with considerable emotional strength as well (Perry, 2004).
Parents of children with autism are confronted by the intense time demands of caring for the child with special needs and struggling to meet other family and life obligations as well. Time required for multiple therapies may seem endless and the challenge of caring for their other children may seem daunting (Remig, 2004; Russo-Spruills & Porteus, 1998). Parents often express concern for how their typically developing children are coping and what they may be thinking or feeling about their sibling with autism (Harris & Glasberg, 2003; Lee, 2005; Powell & Gallagher, 1993). Consequently, because that concern is likely to impact the parents’ emotional state (the focus of this project), it deserves considerable attention.

Powell and Gallagher (1993) point out that no matter what the exceptionality or disability of the special needs child may be, their typical siblings have similar experiences and needs. Siblings tend to discuss similar feelings and emotions, often sharing their joys, fears, and problems. In addition, the sibling bond can be warm and loving, but it can also be negative and tension filled (Bank & Khan, 1982). Blacher and Hastings (2005) observe that siblings of nonverbal children with autism tend to have lower socialization skills as their opportunity for sibling interaction is more limited. In addition, siblings may exhibit deficits in pro-social behaviors such as kindness toward and consideration of other’s feelings, or sharing and empathic behaviors. These authors add that the limited verbal ability of the child with autism may present more every day challenges to the family unit that can have a negative impact on sibling adjustment. They state that “the greater the family stress, as reported by parents, the greater the delays in sibling social skills” (Blacher & Hastings, 2005, p. 81).

Although siblings of children with autism have like concerns, needs, and experiences, each child is unique and experiences life differently; the intensity and chronicity of feelings will vary from child to child. Younger children will sometimes express confusion about what is
wrong with their brother/sister with autism and complain that disciplinary measures used by their parents differ from their sibling to them and they are somehow held to a higher standard. Adolescent siblings of children with autism often wonder if they will be required to provide care for their sibling in adulthood or if autism is a hereditary genetic disorder that might someday impact their own future children (Harris & Glasberg, 2003). In that context, one important and sometimes overlooked factor is that there is an increased incidence of developmental disorders in siblings of children with autism. They are at greater risk of reading difficulties and speech delays. Sometimes, similar problems are even found in parents of children with autism highlighting the very probable genetic link in some families (Folstein & Rosen-Sheidley, 2001). For example, one family might have a child with autism, one with a learning disability, and one who is typically developing. Another might have all three children in the spectrum with one significantly affected and the other two with milder manifestations. Fortunately, most siblings of children with autism do not have language or learning problems, and when they do, they tend to be less challenged than the child with autism (Harris & Glasberg, 2003).

Interaction between siblings changes as children grow. Often there can be temporary behavioral responses such as withdrawal, aggressiveness, dependency, or anxiety from one child as parents’ attention is drawn to the needs of another (Cicirelli, 1995), but with support and reassurance, most children adjust successfully to events such as the birth of a new baby (Harris & Glasberg, 2003). Older siblings act as models of behavior, are leaders in play, and can be a source a source of security for younger children (Cicirelli, 1995). During adolescence, interactions between children become more equal and balanced with shifts in dominance and caretaking and an increase in equality (Dunn, 1992), and though many siblings report considerable levels of conflict in preadolescence and early adolescence, by middle to late adolescence, there is a marked decline in this tension (Buhrmester, 1992).
However, when a brother or sister has autism, the normal course of sibling relationships can be interrupted. Children with autism often do not meet their siblings’ expectations as playmates, may produce multiple troubling autistic behaviors, and be a difficult if not impossible playmate. They may destroy toys, be aggressive, or have severe tantrums (Harris & Glasberg, 2003). In addition, the child with autism may be unable to respond in a typical fashion to the joy and play of childhood. For instance, a little girl may feel frustration and disappointment when her sister shows no interest in playing childhood games and ultimately abandon trying to relate to her. A school-aged boy may be understandably angry if his sibling with autism destroys a model or school project over which he had labored.

There is also the possibility of the sibling relationship evolving into one of sadness or indifference, and children of any age may struggle emotionally when parents seem preoccupied with their sibling with autism and appear to have no time for them (Harris & Glasberg, 2003; Powell & Gallagher, 1993). Young children in particular may feel confused about their sibling’s disability and may, for example, be afraid that they caused the autism by some misbehavior or that it is something they can catch as they would a cold. In addition, they may be reticent to raise questions because they feel ashamed of their own feelings or do not wish to upset their parents. They may learn to conceal feelings, deny their own emotions, and develop inconsistency between feelings and actions. For instance, a child might feel quite frightened but act very boldly or even dangerously as though he wants no support or affection when he really wishes his parents would recognize his sadness. Alternatively, the child might overly identify with the sibling and, for example, be reluctant to go away to summer camp because the sibling with autism is unable to go also (Seligman & Darling, 1997).

Long term caretaking responsibilities such as helping the sibling dress before school or supervising play may truncate an older adolescent from achieving her adolescent independence
Younger children may experience perplexing role reversal such as a nine year old sister supervising a thirteen year old brother and may resent having to care for someone older and larger, may feel embarrassed for her friends to see her responsibility, and may feel guilty about being younger than her sibling who needs her help. The typically developing child can feel angry, ashamed, embarrassed, sad, or defiant (Harris & Glasberg, 2003; Lee, 2005).

Additional research on siblings’ experiences that looked mainly at birth order (first born, middle, or last), age and gender of the child with a developmental disability and the typically developing sibling found that older sisters and younger brothers of children with developmental disabilities were sometimes at greater risk for emotional problems than other children (Seligman & Darling, 1997). However, Harris and Glasberg (2003) point out that relationships between age and gender are complicated, not well understood, and do not always occur. For example, other researchers found that some children between the ages of six and fifteen had mostly positive things to say about their brother or sister with autism and some quite negative. The children in the negative group worried about the future of the child with autism and felt that their parents favored that child, while on the positive side, children who viewed parents and peers as responding positively to the sibling with autism and had a good understanding of the disability tended to have a more positive relationship with their brother or sister (McHale, Sloan, & Simeonson, 1986).

Another team of researchers (Rodrique, Gefken, & Morgan, 1993) compared siblings of children with autism to siblings of children with Down syndrome. They found that parents of children with autism reported more concerns for their typical children about internal feelings such as depression and anxiety and external behaviors such as aggression or defiance than did parents of children with Down syndrome. Even though the children still fell into the typical
range of behavior and their self esteem did not seem to be negatively influenced, the findings of this group suggest a notion that it may be harder to be a sibling of a child with autism than of a child with another disability.

A more recent study by Kaminsky and Dewey (2001) compared similar groups of siblings and added a group of siblings of children with no known disability. Their findings suggest that siblings of children with autism ranging from eight to eighteen years of age experienced less sibling intimacy, positive social interaction, and nurturance than the other groups of children. This finding is consistent with the knowledge that children with autism usually have difficulty showing empathy, helpfulness, and warmth toward their brother or sister (Harris & Glasberg, 2003). Interestingly, Kaminsky and Dewey (2001) also found that siblings of children with autism and Down syndrome described a greater admiration for their brother or sister and fewer feelings of competition than did siblings of typically developing children. This can be viewed as a reflection of the positive feelings children have toward their sibling with autism and the compassion they may feel for the child’s significant challenges (Savarese, 2003).

The above mentioned studies are consistent with a notion that autism may generate relationships between siblings that do differ from those between typically developing children (Harris & Glasberg, 2003). Parenting in a family that includes a child with autism creates differing, complex, and challenging relationships and situations as well (Lee, 2005; Remig, 2004; Russo-Sprouls & Porteus, 1998).

Parental Stress and Coping in Parenting a Child with Autism/Special Needs

Life in a family that includes a child with autism can be much like life in any other family with the added challenge of helping the child (with autism) flourish in an often very confusing world (Harris & Glasberg 2003; Russo-Sprouls & Porteus, 1998). However, medical
emergencies and ongoing therapeutic care can put families in crisis and place extraordinary stress on every family member (Johnson, Crane, & Tatekawa, 2004; Lessenberry & Rehfelot, 2004; Livneh & Antonak, 2005; Singer & Farkas, 1989). Although crisis can bring families closer together, it is more likely to tear them apart (Altmaier & Johnson, 1992). Some of the negative consequences of such crisis may include (a) family members becoming isolated, (b) creating fragmentation and communication blocks, and (c) the revealing of long-standing conflicts (Johnson, 1998).

In an earlier study, Roback (1984) identified five types of stressors for dealing with (medical) crisis which can be applied directly to parents of children with autism: (a) intellectual stressors related to the vast amount of information parents must learn about the condition (autism) they face, (b) instrumental stressors related to the day to day activities for themselves and the rest of the family that must continue, (c) interpersonal stressors related to the consequential disruptions of social relationships, (d) emotional stressors related to the parents’ psychological and physical responses to the crisis, and (e) existential stressors related to parents’ questioning of their own meaning in life, morals, and religious faith. Unfortunately, when coping with this type of ongoing crisis and because of the length of time that often transpires before getting a definitive diagnosis for their child (Tierney, 2004), outside help is often pursued only after a family’s coping resources have been exhausted (Livneh & Antonak, 2005; van der Kolk, McFarlain, & Weisaeth, 1996).

Demands on the parents’ time and energy in providing care and treatment for the child with autism are enormous but critical to the child’s progressing. For instance, Altmaier and Johnson (1992) reported that children’s coping and compliance with medical treatment are related to how well their families are coping with their conditions. James (1989) suggested that if interventions are to be effective, primary caregivers must be involved in the treatment. The
degree to which caregivers are incorporated into treatment usually is assessed according to the needs of the children and the parents’ abilities (Johnson et al., 2004). Sometimes, however, parental stress and reactions to the child’s diagnosis and condition can exacerbate family conflict, promote isolation, and undermine the individual therapy process (Harris & Glasberg, 2003; Johnson et al., 2004). Indeed, Pisula (2003) found in her recent review that parents of children with autism experience profound stress regarding particularly atypical child behaviors and the lack of knowledge about real development limitations and child problems. Mothers of children with autism have reported significantly higher stress levels and lower levels of parenting competency than mothers of children without disabilities, and parents of children with autism report higher levels of stress than parents of children with other disabilities such as Down syndrome and higher frequencies of depression and struggles with challenging behavior (Lessenberry & Rehfelot, 2004).

Earlier research also underscores much of the current investigation into the impact of the child with autism on the family system. Bouma and Schweitzer (1990), for example, found that the presence of autism in a family causes greater parental stress than a chronic or even a terminal illness. While cautioning against generalizing to all illnesses due to the great variability in associated hardships, results of their Questionnaire on Resources and Stress showed a statistically significant difference in amount of overall stress in 24 mothers of children with autism as compared to 24 mothers of children with cystic fibrosis and a numerically matched control group. The mothers of children with autism scored significantly higher than the control group on 6 of the 11 scales regarding emotional stress in parenting. The authors observed that the extent and severity of stress revealed by the autism group seemed to correspond with the symptomatology of the disorder.
Marital and Parental Functioning

In the context of a family where there is a married couple, either biological parents of the children in the home or a blended family, child rearing emerges as a major influence on marital adjustment. This may be particularly true in a context of parenting a child with special needs (Lee, 2005; Modrcin & Robison, 1991; Remig, 2004). Several earlier studies highlight relationships between child behavior problems (such as aggression, defiance, or self injurious behavior one might find in a child with autism) and marital adjustment and conflict. One such study seeks to identify relationships between marital adjustment and child behavior problems in a wide range of children. Jouriles et al. (1991) found correlations in families with clinic referred children ranging from 0.25 to 0.45 as compared to a weaker correlation of 0.10 to 0.25 in non-clinic referred families. The same study suggests that assessing specific aspects of marital functioning such as communication style in the marital dyad might be useful in observing how parental relationships affect child development as well.

Another study suggests that problem behavior in children, which places stress on the marriage, appears to be exacerbated by resulting conflict in the marriage relationship (Grych et al., 1992). These authors found that marital conflict that concerns the child and is hostile, aggressive, or not completely resolved can be destructive for children. Their study, designed to assess their Children’s Perception of Interparental Conflict Scale, involved 222 nine to twelve year old children and a second cross validation study with 144 similarly aged children suggests that unresolved marital conflict is likely to be highly associated with child problems. Thus, a circular pattern emerges in which children who exhibit a variety of impairments exact a negative toll on the marriage relationship of their parents or other relationships in the family, and the overt expressions of stress and conflict in the marriage then impact and exacerbate the child’s unacceptable behaviors.
Whittaker and Bry (1991) conducted a smaller study that also supports this concept. They used parent questionnaires with sixteen families to search for clear correlations between marital acrimony and younger children’s behavior problems. They observed that other types of marital discord such as overt conflict and covert hostility may be related to adolescent behavior problems as well. Results of their study suggest that parents of adolescents with significant behavior problems such as severe acting out or aggression exhibited significantly more frequent overt conflict than did control group parents of children without behavior problems.

Additionally, Suarez and Baker (1997) observed that parenting a child with behavior problems (such as those found in a child with autism) can affect parental functioning. Early studies using parent questionnaires found clear correlations between self-reported marital acrimony and younger children’s behavior problems, even when other possible explanatory variables such as poverty were controlled (Shaw & Emery, 1987). Aggressive or defiant child behaviors are often associated (unfairly) with ineffective parenting strategies and a pile up of these factors can increase parental stress (Harris & Glasberg, 2003; Landa, 2003; Lee, 2005; Powell & Gallagher, 1993; Russo-Sprouls & Porteus, 1998).

Finally, Wilens (1999), comments that it is difficult to determine whether the family situation is causing, or caused by, an acting-out child especially in the case of autism. He observes that many parents develop specific styles of parenting based on the “hard wired” (p. 31) temperament of their child that could, in turn, affect that child’s development. It remains difficult to disentangle if the child is behaving in a particular way based on parenting style or if the parent is reacting to the child’s biologically based problem. For example, if a child with autism does not make eye contact and react to his/her parents’ smiles, eventually the parents may smile less often.
Additional observations highlight the impact of parenting a severely emotionally disturbed or otherwise chronically impaired child in the family unit. Parents of children with autism and other disabilities sustain a significant emotional burden. They suffer a sense of shock, disappointment, and loss (Burke, Hainsworth, Eakes, & Lindgren, 1992). During the months of a normal pregnancy, parents develop a mental image of the hoped-for baby that is a composite of expectations, wishes, and desires that result from the parents’ own experiences and their hopes for the future (Lynch & Morley, 1995). One of the early tasks of parenting is to resolve the hoped-for image with the reality of the real infant. If the child is born with significant, chronic, developmental delays and differences, the discrepancy is larger and parents must grieve the loss in order to engage in the process of attachment (Bristor, 1991). Parents do not anticipate raising a child with a disability and the ensuing crisis can disrupt communication, living patterns, and family roles (Bouma & Schweitzer, 1990; Fialka, 1997; Floyd & Zmich, 1997; Jouriles et al., 1991; Lee, 2005; Modricin & Robison, 1981; Remig, 2004) that persist throughout the family’s life cycle and require continuous adaptation (Floyd & Gallagher, 1997; Livneh & Antonak, 2005; Mishel, 1981). For example, family rituals can be interrupted or even truncated altogether.

*Family Rituals*

Rituals are powerful organizers of behavior within the family system that provide the family with a sense of stability, a unique identity, feelings of belonging, and a means for socializing all family members within their cultural context (Viere, 2001). That stability can be compromised as time and energy for family rituals may be absorbed by the child with autism’s multiple therapies each week, such as speech and language therapy or occupational therapy, and by the communication and cognitive deficits which may prevent the child’s successful socialization into his/her cultural context.
Successful participation in family rituals can influence levels of parental stress. Gruszka (1988) found that mothers of children with cognitive delays perceived that their families engaged in fewer family celebrations than mothers of children without disabilities. In addition, Bucy (1995) investigated rituals and parenting stress and their relationship to the disability characteristics of preschool children. She found that mothers of children with only motor and social skill deficits felt more able to practice family rituals than mothers of children with cognitive delays. Further, mothers of preschool children with disabilities who were able to maintain meaningful participation in family rituals were better able to cope with parenting stress than mothers with less ritual participation.

Psychosocial Coping

Floyd and Gallagher (1997) and others observe that the psychosocial atmosphere in the home impacts the social development of children with disabilities and that successful family coping skills can facilitate maximum social and cognitive development of the (autistic) child while helping to lower distress levels and perceptions of disruption for other family members (Blacher, 2002; Christensen et al., 1997; Landa, 2003; Remig, 2004; Russo-Sprouls & Porteus, 1998). Witol, Sander, and Kreutzer (1996) examined met and unmet, important and unimportant family needs in an attempt to help professionals recognize areas of unmet needs and prepare families to become more active and resourceful. Results revealed that the majority of participants identified emotional support needs as the most commonly unmet needs placing strain on family coping skills and increasing psychological distress.

Coping has been identified as the behavioral (or functional) enactment of the attitudinal and philosophical changes that grow out of the grieving process that is in response to acknowledging the loss of parental expectations of a typically developing child (Lynch & Morley, 1995). Moses (1991) suggests four facets of coping which can be applied to parenting a
child with autism: (a) containing the impact of the loss which would include evaluating severity, accessing resources, and parent advocacy, (b) devaluing “normal” standards or attempting to see the child for who he/she actually is as opposed to comparing to what might have been, (c) enlarging the scope of values or learning to identify all that the child is able to do, and (d) shifting from comparative to asset values as in using a demonstrated strength or interest such as an ability in music to teach math concepts or social skills.

Parents of children with special needs such as autism and specifically parents of children with autism often experience grief, depression, a sense of loss, and mourning (Burke et al., 1992; Dumas, Wolf, Fisman, & Culligan, 1991; Harris & Glasberg, 2003; Powell & Gallagher, 1993; Remig, 2004; Russo-Sprouls & Porteus, 1998). Such non-death related losses are pervasive experiences that can lead to considerable stress and may serve as catalysts for significant emotional disturbance (Bloom-Feshbach & Bloom-Feshbach, 1987; Harvey & Weber, 1998; Hoppes & Harris, 1990; Kasari & Sigman, 1997; Servaty-Seib, 2004). Parents may suffer social embarrassment (Corrigan, 2000; Falvo, 1999), financial and career difficulties (Lee, 2005; Remig, 2004), and experience concerns for and often additional compromise with the affected child’s siblings (Ehly, Conoley, & Rosenthal (1985).

Chronic disability in childhood often engenders permanent change in family dynamics such as attitudes of perceived stress that never ease (Floyd & Gallagher, 1997; Modrcin & Robison, 1991; Robbins, Dunlap, & Plienis, 1991; Singer & Farkas, 1989). However, positive aspects such as families feeling closer because of what they have shared and increased self confidence with a strong sense of mastery in caring for a child with a disability may emerge as well (Singer & Farkas, 1989).

Considerable attention has been and is currently being devoted to the relationship between successful adaptation and the availability of and the family’s ability to access
appropriate and adequate support services and resources (Christensen et al., 1997; Floyd & Gallagher, 1997; McCubbin, 1989; McLaughlin-Beltz, 2005; Patterson, 1985; Rivera et al., 1996; Strickland, 2005). Some services for children with autism such as occupational and speech therapies and special classrooms are available (to a sometimes limited extent) through school systems (Russo-Sprouls & Porteus, 1998). However, typically parents find they must learn about, actively seek and arrange for highly specialized and necessary care on their own (Floyd & Gallagher, 1997). In addition, parents often find they must make special safety precautions and adjustments in the home such as wire mesh around the fireplace, digital locks and codes for the microwave and stove, central air instead of ceiling fans, special locks for refrigerator, cabinets, interior and exterior doors, and alarm systems to keep their climbing, receptive language challenged child with autism safe (Srikanth, 2005).

How the family organizes around the crisis situation can determine the future course of family adaptability and development (Modrcin & Robison, 1991). For example, if the child with autism’s development does not follow predictable stages, persistent tension between reality and parental expectations can be created and family homeostasis disrupted. Attempts to identify and attain appropriate resources can create additional stress, tax coping strategies, and compromise parents’ abilities to meet the everyday needs of other members (Floyd & Gallagher, 1997; Harris & Glasberg, 2003; Lee, 2005; Powell & Gallagher, 1993). The overall family life cycle can be disrupted. Predictable movement through stages of parental roles can often be unalterably stalled and family roles must be adjusted to accommodate the child with autism’s disability. Consequently, the family’s movement through expected developmental stages in larger societal groups such as school and community is also significantly influenced. Expectations and developmental tasks for extended family members can be impacted as well (Modrcin & Robison, 1991).
Families will respond to crisis with attempts to preserve the integrity of the family structure based on the organizational structure in place prior to the onset of the crisis event (diagnosis) or scenario (Modrcin & Robison, 1991). The latter authors observe that in cases of severe and/or chronic stress, the initial family coping response may be taxed beyond the capabilities that exist in the current structure. Thus, even well functioning flexible families can become disordered and chaotic.

Modrcin and Robison (1991) and other scholars (Christensen et al., 1997; McCubbin, 1989; Patterson, 1985; Rivera et al., 1996) caution against focusing too quickly on family pathology or dysfunction at the risk of creating an assumption of powerlessness. McCubbin (1989) and Patterson (1985) use their model of Family Adjustment and Adaptation Response to stress the importance for a family to find a balance between stressors and resources and a range of coping responses and strategies. They found such a range of responses to be more effective than any single response in reducing levels of experienced stress.

Modrcin and Robison (1991) observe that in the context of marriage and parenting, self-reliance has been found to be more effective than seeking dependent help. For instance, a parent learning to advocate for his/her child and how to access community resources can produce lower levels of stress and increase the parents’ sense of self worth more than depending entirely on the school system for information and interventions (Lee, 2005; Remig, 2004; Russo-Sprouls & Porteus, 1998).

Rivera et al. (1996) identified several variables that may indicate positive family outcome: (a) low levels of control or rigidity, (b) high levels of expressiveness so that family members are staying in close emotional touch with each other, (c) good overall pre-(diagnosis) functioning, (d) strong support systems, (e) involvement in outside activities such as church,
neighborhood, school, or community organizations, (f) good communication and problem solving skills, (g) low levels of family conflict and stress, (h) a positive belief system, and (i) strong capabilities.

Children with autism have many skills, but parents and caregivers may have to work considerably harder to help the children demonstrate these skills than they would if the child did not have autism (Harris & Glasberg, 2003; Landa, 2003; Lee, 2005). Clinicians, Early Intervention and other service providers such as family therapists are in a position to help parents learn to manage stress and incorporate parenting the child with autism into successful family functioning (Harris & Glasberg, 2003; Landa, 2003; Lee, 2005; Remig, 2004).

Gender Differences between Parents

Differences in gender related parental responses to child disability can also be applied to families with a child with autism. Although mothers have received considerable research attention (Lynch & Morley, 1995). Sabbeth (1984) found that most fathers were, in general, very psychologically involved with their child with special needs regardless of their day to day participation in the child’s care. Sabbeth observed that fathers were at special risk for developing feelings of helplessness in relation to their child with a disability because of (a) a lack of participation in the child’s care, (b) facing the (perceived) limitations of what can be done medically, (c) lack of control over the child’s disability as fathers are often more comfortable with active achievement of goals, and (d) societal pressure discouraging men from expressing their feelings and a desire to be invulnerable which can lead to emotional isolation.

Fathers and mothers also differ in their emotional and behavioral responses to the diagnosis of their child’s disability. Mothers tend to respond more emotionally and express concern about their ability to manage added responsibilities such as balancing the child’s many therapy appointments with the needs of other family members, while fathers express concern
about long term consequences such as financial impact of care across the life span or expectations for the child’s future (Seligman & Darling, 1997). Interestingly, these early findings are echoed in current gender related sibling work that finds girls to be more likely involved with hands on caretaking and helping (with the sibling with autism) than boys (Blacher & Hastings, 2005). In another earlier study, Damrosch and Perry (1989) found that fathers described their adjustment as a steady, gradual return to their level of adjustment prior to the child’s diagnosis, whereas mothers reported a pattern of emotional peaks and valleys or periods of crisis. In addition, mothers express feeling burdened, overwhelmed, embarrassed and self-conscious in public, and perceptions of being very old (Lynch & Morley, 1995). The latter authors observe that both fathers and mothers experience chronic sorrow with mothers manifesting significantly higher frequencies than those for fathers. Thus, even in the same family, fathers and mothers report unique patterns of adjustment and coping that need to be treated and understood as individual perceptions and interpretations of the child’s disability (Damrosch & Perry, 1989; Lekotek of Georgia, 2005-2006; Lynch & Morley, 1995).

The research reviewed in this section makes clear the need for a better understanding of the different ways by which mothers and fathers of children with autism may experience stress. The purpose of this study will be to undertake an exploration of this relationship.

**Autistic Spectrum Disorders**

Currently, an alarming and unexplained increase in the prevalence of autism is being reported and causing growing concern (McLaughlin-Beltz, 2005; Rimland, 2001; Yeargin-Alsopp & Rice, 2003). For example, in the state of California, which maintains a comprehensive database on autism and other developmental disabilities, the reported increase in the prevalence of autism over the last 20 years is more than one thousand percent. Similar increases are evident elsewhere in the United States and other countries such as the United Kingdom, the Middle East,
and in Asia (Rimland, 2001). Several possible reasons why the number of people counted as having a certain condition changes are (a) a change in the way the condition is identified or classified such as alterations in diagnostic criteria in the DSM-IV, TR (2000), (b) real increases or decreases in actual occurrence or changes in the incidence or prevalence of a condition, and (c) an increase of people who are actually at risk for a certain condition (Yeargin-Alsopp & Rice, 2003). Thomas (1999) observes that true similarities and differences across cultures in the prevalence of autism may be unclear due to three factors: (a) autism has only been labeled a disorder for a little more than 50 years such that information has not been communicated equally across cultures, (b) the manifestation of the disorder can vary significantly from one individual to another, and (c) the methods and thoroughness of gathering data about autism have not been the same from one society to another.

**Medical Etiology of Autism Spectrum Disorders**

Current research classifies autism as a neurological disorder (Comings, 1997; Landa, 2003; Lee, 2005; McLaughlin-Beltz, 2005; Nydén et al., 2004; Pennington, 2002; Remig, 2004; Wilens, 1999; Williams, 1992) with a strong genetic footprint (Comings, 1997; Folstein & Rutter, 1977; Lee, 2005; Nydén et al., 2004; Pennington, 2002; Phippie et al., 1999; Remig, 2004; Russo-Sprouls & Porteus, 1998; Steffenberg et al., 1989; Sturm et al., 2004). In addition, there are often characteristic gastro-intestinal features such as chronic constipation and/or stomach upset (Comings, 1997; Laidler, 2001; Rimland 2001; Williams, 2003) which may or may not be in response to environmental factors such as childhood immunizations or toxic levels of mercury and other elements in the blood (Laidler, 2001; Lee, 2005; Rimland, 2001). The core symptom of autism is a significant and severe withdrawal into one’s own world (Comings, 1997).
Autism often strikes a typically developing child at between 18 to 24 months with a sudden dramatic loss of speech and contact with the environment, as well as self stimulatory behaviors such as hand flapping or spinning objects (Shore, 2003a; Shore, 2003b). In addition, there can be multiple other bizarre or unusual behaviors present such as aggression, self injurious behaviors, learning differences, and behaviors associated with sensory integration dysfunction (Bowe, 2000; Comings, 1997; DSM-IV TR, 2000; Frith, 1991; Harris & Glasberg, 2003; Lee, 2005; Remig, 2004).

There are various forms of autism and conditions on and/or closely related to the autistic spectrum such as Asperger’s or Fragile X syndromes (Coming, 1997; Moyes, 2003; Willey, 2002; Yeargin-Alsopp & Rice, 1993), and co-occurring or co-morbid disorders such as Tourette’s syndrome or Down’s with autism as well (Coming, 1997; Tierney, 2004). Early identification of autism and intervention are critical (Landa, 2003; Lee, 2005; Remig, 2004; Yeargin-Alsopp & Rice, 2003) in order to address children’s educational, social, and functional delays as aggressively as possible (Lee, 2005; Mooney, 2003; Remig, 2004; Russo-Sprouls & Porteus, 1998). In short, autism can be seen at different levels: (a) biological factors cause malfunction in the development of the brain that affects (b) cognitive functions, which then cause (c) behavioral symptoms (Morton & Frith, 1995).

Autism spectrum disorders are referred to as Pervasive Developmental Disorders (PDD) in the DSM-IV, TR (2000). The concept of PDD embraces autistic disorder, Rett’s syndrome, Childhood Disintegrative Disorder, Asperger syndrome, and PDD not otherwise specified (PDDNOS) or Atypical Autism (Comings, 1997; DSM-IV TR, 2000; Sturm et al., 2004; Wilens, 1999). Rett syndrome is a rare disorder with autistic-like features affecting only females and always including severe mental retardation. The girls appear to be essentially typical for the first six months to two years of life and then stop developing mentally. They lose or never develop
purposeful speech, develop stereotypical movements such as hand wringing, suffer from microcephaly (small head size) as the brain stops growing, are clumsy walkers, and often present with seizures. Rett syndrome is a devastating X linked disorder in which males die in utero and females are too compromised to procreate. Since the gene is never passed on, all cases represent new mutations (Comings, 1986, 1997; Perry, Sarlo-McGarvey, & Factor, 1992).

Childhood Disintegrative Disorder also is a rare condition in which the child develops typically for the first several years of life, then slides backwards into mental retardation and pronounced autism spectrum behaviors (DSM-IV TR, 2000). Finally, PDDNOS, or Atypical Autism, is a separate diagnosis as it is not clearly operationally defined and its boundaries are unclear. Often it is utilized to describe individuals who present with autistic-like behaviors or less severe or atypical symptoms, i.e. not fulfilling all criteria for a diagnosis of autism (Sturm et al., 2004).

*Historical Perspective*

The eventual comprehension of autism as a neurological dysfunction has required a process of more than half a century much of which has been spent blaming parents, particularly mothers (Bettelheim, 1967; Comings, 1997; Kanner, 1943, 1949; Lewis et al., 1984; Stott, 1973; Stott & Latchford, 1976; Ward, 1974, 1976, 1990, 1991; Wilens, 1999). Autism was first described by Kanner (1943, 1949) who believed that it was a psychological disorder caused by having cold, unfeeling parents who were guilty of “emotional refrigeration” (Comings, 1997, p. 215). The child with autism’s behavior was supposedly a rage reaction against the mother’s unconscious wish that the child not exist. Kanner (1943, 1949) considered the children’s parents to be obsessive perfectionists (Batshaw & Perret, 1992; Comings, 1997) and for many years this was the prevailing view (Batshaw & Perret, 1992; Rutter, 1972; Thomas, 1999).
By the mid 1970’s opinions emerged that this was a biased view and that the environment of children with autism was the same as or similar to that of children without autism (Cox, Rutter, Newman, & Bartak, 1975; DeMeyer et al., 1973; Rutter, 1972). Nevertheless, even with this new thinking, research in the medical community persisted even into the early 1990’s that continued to hold parents, particularly mothers in a social context both prenatally and postnatally, directly responsible for the mental, emotional, and behavioral conditions of children (Stott, 1973; Stott & Latchford, 1976; Ward, 1976).

For example, in earlier work, Ward (1976) explored the question of a relationship between prenatal maternal anxiety and the development of higher levels of anxiety, higher rates of emotional disturbance, and slower rates of overall development in offspring. He looked retrospectively at pregnancy histories of hospitalized children who had a diagnosis of autism. Review of those histories revealed significant occurrences of psychological stress in 73% (43/70) of the cases plus the largest group of mothers describing themselves as emotionally upset about their pregnancies with emotional attitudes of nervousness, depression, and ambivalence. The range of family discord described in the study included such items as diagnosed mental illness in one of the parents, separation during pregnancy, and frequent arguments. Ward (1991) observed that there was no control group for this study and that a recommendation was made at the time for further prospective or epidemiological study.

Stott (1973) found that children whose mothers experienced ongoing personal tensions during pregnancy such as marital discord or stressful social relationships suffered 82% more behavior disturbance and 58% more developmental delays than a control group of children whose mothers did not report such tensions. Stott and Latchford (1976) followed that work with an epidemiological study of pregnancy and postnatal data on 1,300 children born in a selected year from a non-psychiatric population. These authors reported that marital discord was
significantly associated with such stressors as tension, shock, financial difficulty, and extramarital conception, and it was found to be associated with a negative outcome in the child. In addition, ongoing personal tension was found to be associated with both physical and behavioral disorders, and the authors concluded that in a social group where such tensions are severe, “a wide variety of casualty and handicap” (p. 187) might ensue and that fetuses whose mothers are exposed to severe persistent interpersonal tensions may emerge as “defective, inadequate, and deviant offspring” (p. 189).

As recently as 1990 and 1991, Ward (1990, 1991) continued to look at associations of parental stress and childhood psychopathology in the records of hospitalized children diagnosed with autism, childhood schizophrenia, and severe ego defect. Ward’s hypothesis in the latter study (1991) was that the population would reveal a significant occurrence of prenatal stress. He observed that 36% of the 58 children whose records he investigated were born to unmarried, divorced, or separated mothers and that the postnatal behavior of the children included “neurological and health disorders as well as behavior and habit disorders” (Ward, 1991, p. 103). Ward (1991) linked this study, in which he found a 72% incidence of family problems associated with marital discord and the onset of childhood psychopathology, to his own much earlier work (Ward, 1976).

In that earlier work, Ward found that in a study of cases of childhood autism, 73% of the cases reported a prenatal occurrence of “family discord” (Ward, 1991, p. 104) and the onset of early childhood autism (Ward, 1976). He characterized his entire study as supporting Stott and Latchford’s (1976) earlier findings regarding associations of prenatal marital discord to negative developmental and behavioral outcomes in children. He also included a discussion of changes in maternal affective state (Easterbrooks, 1989) and behavior (Barden et al., 1989) in response to the birth of a child who is seen as being different (Barden et al., 1989). Ward observed that
“depressed mothers continue to view their children in a negative light and as presenting
behavioral problems, long after their behavior has improved (Ward, 1991, p. 107). The entire
body of work mentioned above takes a societal perspective and suggests that children’s
emotional and behavioral problems are rooted in disturbed parenting (Wilens, 1999) “but now
autism is known to be caused by biologically based abnormalities in the brain” (p. 21).

Neuropsychological Perspective

Parents were once categorically blamed for the lack of interaction with the environment
that characterized children with autism, but the middle to late 1990’s have seen a near revolution
in thinking about children’s psychiatric disorders. As experience with autistic children grew, the
psychodynamic explanation of their behavior gave way to the realization that this was a
neurological disorder (Comings, 1997; Thomas, 1999). The findings of genetics, neurobiology,
and brain imaging studies began to encourage mental health and other medical practitioners to
consider an interactional model in which individuals are viewed as biological beings interacting
with the environment with each factor influencing the others (Comings, 1997; Wilens, 1999) and
with, in the context of the onset of autism, something going awry with neurotransmissions in the
brain in response to its development and chemistry (Baron-Cohen, 1995; Crain, 2000;
McLaughlin-Beltz, 2005; Thomas, 1999). The neurological model suggests that behaviors
consistent with autism are consequent to an organized collection of primary disturbances of
attention, compulsive behaviors, and disturbances of communication (Damasio & Maurer, 1978).
Comings (1997), in fact, believes that autism is best described as a genetic, neurochemical
disorder.

Autism is important because it is the earliest of the severe personality disturbances,
usually appearing by the second year of life (Crain, 2000). Primary characteristics of autism
include (a) poor social interactions, (b) poor communication, (c) restricted activities and
interests, and (d) an onset in infancy or early childhood (Comings, 1997; Nydén et al., 2004; Russo-Sprouls & Porteus, 1998; Schreibman & Winter, 2003). Children with autism tend to be physically healthy, but have poor social interactions in that they can be isolated and aloof, often rebuffing or rejecting human interaction altogether (Crain, 2000; Lee, 2005; Remig, 2004; Russo-Sprouls & Porteus, 1998; Thomas, 1999; Wilens, 1999; Williams, 2003). They seem to look through people. They may be and often are cognitively delayed (Thomas, 1999). In addition, they may be unaware of other’s feelings, not seek comfort when upset, show mechanical imitation of actions, fail to develop social play skills, and not be able to seek out and develop friendships (Comings, 1997; Reming, 2004; Thomas, 1999; Williams, 2003). Baron-Cohen (1991) characterizes children with autism as having impaired understanding of situations and desires as causes of simple emotions.

In the context of poor communication, children with autism often do not have expressive language or if they do speak, they are engaging in echolalia, or simply echoing what they hear others say (Comings, 1997; Crain, 2000; Thomas, 1999). Other communication problems can include a lack of gesturing or body language, poor eye contact, an absence of imaginative play, atypical (monotonous or high pitched) speech, or an inability to carry on a conversation all together (Baron-Cohen, 1995; Comings, 1997; Russo-Sprouls & Porteus, 1998; Wilens, 1999).

In the context of restricted activities and interests, individuals with autism also manifest other disturbances such as self stimulation (spinning objects or self) or self destructive behavior (head banging or hand biting when asked to do something involuntarily) (Lovas, 1977; Wenar & Kerig, 2000; Williams, 2003), and stereotyped body movements such as hand flapping (Comings, 1997). Also, children with autism can become upset over trivial changes in schedule, maintain compulsive routines such as demanding that the parent always drive home from school
by the same route (Lee, 2005), and maintain a narrow range of interests such as only focusing on one idea or strong interest such as music (Comings, 1997) or sports trivia (Lee, 2005).

About the same time that Kanner (1943) was identifying and describing autism, Asperger (1944) in Europe was describing a group of children with very similar but also distinctly different developmental delays (Comings, 1997; Lozzi-Toscano, 2004). The children were described as developmentally delayed with bizarre, flat, emotionless speech with a dull, monotonous quality. Nonverbal communication (gesturing) was present but poorly executed and often inappropriate to what was being said. Like autism, social interactions were absent or poor, withdrawn and clumsy, and with no apparent empathy for others. Also like autism, the children often displayed a monotonous fixation on one subject and were resistant to change. In addition, that resistance tended to appear along with stereotyped body movements. Unlike autism, the onset of Asperger’s appeared to be at about four years (Asperger, 1944; Comings, 1997; Moyes, 2003). In addition, oddly, rote memory was often focused with obsessive fixation on a single specialized subject in which the individual actually showed great mastery (Comings, 1997; Willey, 2002; Wing, 1981; Wing & Gould, 1979).

Some children in the autism spectrum, including children with Asperger’s, have remarkable talent in the areas of art, music, math or memory skills (Comings, 1997). An example of such mastery is a bizarre ability in music such as a young child composing music for instruments he does not know how to play, or an ability to calculate large sums mentally without assistance (Rimland & Fine, 1988). An earlier view of such skills was that of the idiot savant because the high level of these skills was considered so disproportionate to the individual’s apparent general intelligence (Hermelin & O’Connor, 1986). Today’s view is that these skills may be in response to a combination of an obsessive compulsively narrow focus along with a
withdrawal from typical social activity (Comings, 1997). Wing (1981) and Wing and Gould (1979) subdivided the children with autism with whom they were working into three groups: (a) aloof or reacting only to satisfy their needs, (b) passive or interacting only on the approach of others, and (c) active but odd. Wing’s (1981) active group displayed behaviors virtually undistinguishable from Asperger’s.

Currently, Asperger’s is considered a form of higher functioning autism without language or cognitive delays and is included diagnostically under the autism spectrum umbrella (Attwood, 1998; Comings, 1997; DSM-IV TR, 2000; Frith, 1991; Gillberg, 2000; Lee, 2005; Lozzi-Toscano, 2004; Mooney, 2003; Moyes, 2003; Powers & Poland, 2002; Remig, 2004; Russo-Sprouls & Porteus, 1998; Schopler & Mesibov, 1986; Sturm et al., 2004; Willey, 2002). Children diagnosed with Asperger’s often present with a verbal intellectual capacity that is quite high and tested IQ levels that are at least average or even above average. However, some individuals do not conform to the accepted diagnostic criteria and this may be particularly evident in female children (Kopp & Gillberg, 1999; Mamen, 2002; Sturm et al., 2004).

Medical Aspects of Autism

As long as autism has been recognized, one of the primary recognized components has been that people with autism seem to have an inability to enter into emotional relationships (Baron-Cohen, 1989a, 1991). The latter author found in a study which included autistic, mentally impaired, and typically developing children that in response to questions testing understanding of beliefs as a cause of emotion, performance of children with autism was significantly worse than either of the other two groups. His findings confirmed earlier work showing that people with autism have difficulty that is more severe than would be expected for their mental age in attributing different beliefs to other people (Baron-Cohen, 1989a, 1989b; Baron-Cohen, Leslie, & Frith, 1985, 1986; Charman & Baron-Cohen, 1990). However, Baron-Cohen’s (1991) study
also revealed that some of the knowledge that people with autism possess in the domain of emotion is appropriate for their mental age. For example, they are aware of the existence of emotion and of situations and desires as simple causes of this, and they demonstrate a close similarity in their understanding of this to people without autism. For instance, when presented with a hypothetical situation of a child being lost from his/her mother, all of the subjects with autism correctly judged that the child would feel sad and further justified their emotion judgment in such terms as “she doesn’t like being alone” (Baron-Cohen, 1991, p. 392).

Studies with both brain-injured patients and neurologically typical individuals suggest that the right hemisphere of the brain is dominant for the perception of emotion (Borod et al., 1990; Bowers et al., 1985; Bryden, 1982; Hellige, 1993; Levy et al., 1983), for identifying emotional tone of spoken material (Ley & Bryden, 1982; Bryden & MacRae, 1989), and for recognizing and producing affective components or language (Ross, 1981; Ross & Meuslam, 1979). Additional research suggests that the right hemisphere is dominant to the left in producing expressions of emotion (Borod & Caron, 1980; Campbell, 1978; Chaurasia & Goswami, 1975; Heller & Levy, 1981; Kolb & Taylor, 1981; Tucker, Watson, & Heilman, 1977), and in the forming of such unconscious mental processes as unaccountable emotions (Kostandov & Arzumanov, 1986).

The body of work cited above suggests that there are emotion-related processes that occur asymmetrically in the brain (Kopp, 1995; Silberman & Weingartner, 1986). Baron-Cohen (1995) now uses his model of “mindblindness” (Thomas, 1999) to explain what has gone wrong in the child with autism’s brain circuitry and thus in the child’s mindreading ability. From his extensive series of experiments with typically developing, cognitively impaired, and children with autism (Baron-Cohen, 1989a, 1989b, 1991, 1995; Baron-Cohen et al., 1985) he concludes that the development of the autistic brain has proceeded adequately in the areas of attention and
eye-direction detection mechanisms, but has gone amiss for shared attention and theory of mind mechanisms. As a result, the autistic child is mindblinded, or unable to estimate what other people are thinking, with disastrous consequences for the child’s social behavior and functioning (Thomas, 1999).

In Baron-Cohen’s most recent work (2004), his ideas have evolved even more. He now defines autism as an imbalance between two kinds of intelligence: (a) the kind used to understand people, or empathizing, and (b) the kind used to understand things, or systemizing. Although flawed brain circuitry seems to be the chief factor in autism, environmental influences can also affect how the malady manifests itself; consequently, a variety of treatments such as pharmacological, childcare, educational, and behavioral can be effective (Erk, 2000; Klein, 1990; Kopp, 1995; Laidler, 2001; Landa, 2003; Lee, 2005; Mooney, 2003; Remig, 2004; Rimland, 2001; Russo-Sprous & Porteus, 1998; Wilens, 1999). In addition, symptoms of autism can diminish as the child matures toward adulthood. So possibly the necessary circuitry for assembling a normal theory-of–mind mechanism is slow to develop in some individuals as opposed to incapable of developing (Thomas, 1999).

Additional research suggests that autism may be associated with aberrant interhemispheric information transfer of information in the brain (Nydén et al., 2004). The latter authors chose neuropsychological testing to measure auditory, visual, and motor functioning as well as information transfer across modalities in thirty children with an autism spectrum disorder. The children with autism performed significantly worse than the control group on most of the tests (p = 0.02) for auditory perception and attention, (p = 0.005) for visual perception, (p = 0.0001) for motor control, and (p = 0.04) for tactile perception. These findings support the notion that aberrant interhemispheric transfer may be involved in the pathogenesis or clinical
course of autism. Importantly, the findings were not accounted for by lower IQ in the group with autism (Nydén et al., 2004).

There is additional evidence for a functional disconnection between the two hemispheres in people with autism (Nydén et al., 2004). For example, in earlier research several authors have reported a high rate of non-right-handedness or mixed hand dominance in individuals with autism (Boucher, 1977; Colby & Parkinson, 1977, Gillberg, 1983). Chiron et al. (1995) showed single-photon emission computerized tomography findings compatible with interhemispheric transfer problems in autism. In that study, children with autism showed an anomalous hemispheric specialization, with left hemispheric hypofunction (or low function) in cortical areas devoted to language and handedness. Egaas, Courchesne, and Saitoh (1995) found a reduced size of the posterior regions of the corpus callosum in patients with autism, and Piven et al. (1997) found a smaller size of the body (of the brain) and posterior subregions. People with autism can integrate information and use cognitive strategies, but only if these functions are developed within the same restricted domain-specific area (Hermelin & O’Conner, 1986; Jolliffe & Baron-Cohen, 1999; Mooney, 2003). Resources of interhemispheric processing, callosal transfer speed and efficiency, and informational complexity of the task are all relevant for or related to the capacity of interhemispheric connection (Banich & Brown, 2000; Nydén et al., 2004).

Additional medical aspects of autism include the possibility that children with the disorder are manifesting a type of mercury poisoning as many of the features of autism bear a striking resemblance to certain features especially (a) immune dysfunctions (Queiroz & Dantas, 1997; Williams, 2003), (b) visual disturbances (Cavalleri & Gobba, 1998; Korogi, 1997), and (c) motor coordination deficits (Eto, 1997). One widely investigated and controversial catalyst for this is the marked increase in the number of childhood vaccines given to children from birth
to age two which rose, for instance, from 8 in 1980 to 22 in the year 2001. In addition, quite a few children with autism show laboratory evidence of anti-oxidant deficiency (Rimland, 2001).

Finally, a large group of metabolic problems can be associated with autism: (a) undigested dairy and/or gluten proteins in urine samples, (b) low levels of sulfur transferase causing salicylate and phenol intolerance and immune deficiencies, (c) untreated subclinical Phenylketonuria which may cause a dopamine excess in the brain that can be associated with chronic anxiety and impulse control problems, (d) leaky gut syndrome, a digestive problem with links to toxicity, immune and auto-immune system problems that can influence brain chemistry and ultimately behavior (Comings, 1997; Mooney, 2003; Remig, 2004; Strickland, 2005; Wilens, 1999; Williams, 2003).

It is important to remember that autism is characterized as a syndrome, not a disease. The diagnosis of autism covers a broad spectrum of children (Yeargin-Alsopp & Rice, 2003), many as different from each other as they are from typically developing children. No one cause has been identified and the possibility exists that autism is not a single disorder but several individual disorders that share a similar presentation. With that in mind, it is not surprising that no single treatment has been found that works for all children with autism (Comings, 1997; Laidler, 2001; Lee, 2005; Mooney, 2003; Remig, 2004; Wilens, 1999).

**Co-morbid Disorders in Autism**

Autism, characterized by delays in development of social, communicative, and cognitive skills, carries a disparate range of symptoms that present themselves in widely varying degrees (Comings, 1997; Tierney, 2004; Wilens, 1999; Yeargin-Alsopp & Rice, 2003). For example, while individuals with autism are often believed to have mental retardation, many are of typical or sometimes even extraordinary intelligence. This can be very difficult to assess due to a scatter in scores on measures of intelligence (scoring high on some parts and low on others) (Sturm et
al., 2004; Tierney, 2004). Early identification is extremely important for getting treatment started as soon as possible (Landa, 2003) but also because individuals with autism frequently have other disorders, or co-morbid disorders, as well (Tierney, 2004).

Many of these disorders have medical and treatment implications that are separate from those expected from a diagnosis of autism alone (Tierney, 2004). For instance, approximately one-third of children with autism experience some kind of seizure activity in the brain (Batshaw & Perret, 1992; Comings, 1997; Sturm et al., 2004; Tierney, 2004; Wilens, 1999; Williams, 2003) which clearly must be treated and any medication titrated by a qualified neurologist or developmental pediatrician (Comings, 1997; Remig, 2004; Wilens, 1999; Williams, 2003). The seizures often occur in conjunction with other brain disorders such as tuberous sclerosis, neurofibromatosis, or phenylketonuria (Comings, 1997; Tierney, 2004) (see Appendix A for definitions). While the seizures are often not serious, they can increase anxiety and further complicate communication. Fortunately, they can usually be controlled by anticonvulsant medications (Tierney, 2004).

Knowing which additional complications to expect or be prepared for helps equip both parents and treating clinicians if an additional disorder becomes apparent. In addition, it is just as important to understand which disorders are not commonly associated with autism. For instance, in the past, children and adults exhibiting symptoms of autism were frequently misdiagnosed as having schizophrenia or other forms of psychosis (Comings, 1997; Tierney, 2004, Wilens, 1999). While some individuals with autism do occasionally present with psychotic disorders, there is no evidence that these disorders occur any more frequently with autism than in the general population (Klin, 2005; Tierney, 2004).

As many as three-quarters of individuals with autism both children and adults alike, experience some form of sleep disorder or consistent sleep disturbance (Tierney, 2004; Wiggs &
Stores, 2004). Severe sleep problems are reported in most children with autism spectrum disorders including extreme difficulty getting to sleep, long periods of night waking, short duration of sleep at night, early morning waking, and daytime sleepiness (Klin, 2005; Richdale, 1999, 2001; Stores & Wiggs, 1998). Other types of disturbed sleep such as certain parasomnias (episodes of disturbed behavior during sleep) have been reported to occur more frequently on children with autism than in other groups of children without autism (DeMeyer, 1979; Schreck & Mulick, 2000) although there are differences in opinion regarding this issue (Patazold, Richdale, & Tonge, 1998; Richdale & Prior, 1995) and multiple diagnostic difficulties such as limited literature on sleep problems, shortcomings in reports that prevent firm conclusions, and changes in diagnostic criteria for autism over time (Stores & Wiggs, 1998). Nevertheless, lack of sleep and the resulting fatigue and inability to focus can exacerbate the symptoms of autism (Tierney, 2004). Effective treatment is important because not only are sleep disorders distressing to the child and family at the time that they actually occur, they can have harmful effects on the child’s learning and behavior in other ways (of particular concern for children already compromised in these areas) (Wiggs & Stores, 2001).

Some of the above mentioned concerns are particularly relevant to the current study. For example, children’s sleep disorders are associated with increased rates of family difficulties such as maternal ill health, marital discord, and impaired parent-child relationships including the use of physical punishment and, possibly, abuse in extreme circumstances (Chavin & Tinson, 1980; Quine, 1991, 1992; Richman, 1981). Fortunately, research shows that successful treatment of child sleep problems reduces or resolves some of these associated negative factors (Quine, 1992; Wiggs & Stores, 2001). Thus it is of critical importance, given the negative associations between childhood sleep problems and child and family function, to investigate ways of treating sleep disorders in children with autism spectrum disorders. Improving understanding on the part of
parents and professionals is an important step towards increasing the number of children and families who receive appropriate help (Wiggs & Stores, 2004).

Nearly half of children and adults with autism also present with clinical depression at some point. Individuals with Asperger’s, considered to be at the least severe end of the spectrum, have the highest incidence of depression. This may be because they are typically of average or above average intelligence. Their problems stem almost entirely from difficulty with interacting socially with others, and therefore, as they age, they become more aware of their differences and thus are more at risk for developing clinical depression (Comings, 1997; Lee, 2005; Remig, 2004; Tierney, 2004). In addition and sometimes in combination, four to six percent of children with autism demonstrate symptoms of Tourette’s syndrome, an inherited disorder characterized by repeated involuntary body movements (tics) and uncontrollable vocalizations (Comings, 1997, Tierney, 2004). In addition, children with autism have an unusually high rate of pica which is a tendency to eat substances that are not food such as soil, paper, and paint chips which can cause bowel obstruction, perforation, and/or high blood lead levels (Tierney, 2004).

Finally, approximately 10 to 16 percent of children with autism also have Fragile X syndrome, the second most common cause of mental retardation after Down syndrome (Batshaw & Perret, 1992; Blomquist et al., 1985; Brown et al., 1982; Comings, 1997; Gillberg & Wahlstrom, 1985; Hagerman et al., 1986). With Fragile X, the long arm of the X chromosome contains a constriction (Lubs, 1969). It is known to be associated with mental retardation in some males. Because Fragile X is a genetic disorder, and therefore diagnosable by blood work, its presence is easy to ascertain (Comings, 1997; Tierney, 2004). Individuals with Fragile X are more prone to attention deficit and hyperactivity disorders than the overall population (Tierney, 2004) and the other behaviors associated with Fragile X such as avoiding eye contact, hand flapping, language delay, and echolalia closely mimic those of autism (Comings, 1997; Hagberg,
Aicardi, Dias, & Ramos, 1983). Indeed, today Fragile X is being considered in the same context as, though not yet formally recognized as a form of autism (Comings, 1997; Lee, 2005; Remig, 2004).

Painting a comprehensive picture of the causes and implications of a disorder as complicated as autism will never be easy, but every day more is learned about correlations between autism and other physical and psychological disorders (Klin, 2005; Tierney, 2004). Treatment strategies vary widely, can be daunting and overwhelming, severely stressful, and can occupy almost all of the parents’ time (Harris & Glasberg, 2003; Landa, 2003; Lee, 2005; Powell & Gallagher, 1993; Remig; 2004; Russo-Sprouls & Porteus, 1998; Schreibman & Winter, 2003). However, ongoing discoveries allow clinicians and parents to break autism into smaller, more discrete and possibly more treatable elements, with the hope of improving focus on communication deficits that prevent children with autism from experiencing their lives and potential to the fullest degree (Tierney, 2004).

There is a need for epidemiological studies focusing on neuropsychiatric and neuropsychological development profiles of children in the autism spectrum (Sturm et al., 2004) and a critical need for parents to respond to treatment findings (Landa, 2003). Hopefully, in the future, it will be possible substantially to link clinical knowledge (and treatment response) to the underlying neurobiological correlates (Sturm et al., 2004). The correct identification or assessment of co-occurring or co-morbid conditions are essential to appropriate interventions and/or treatment planning (Erk, 2000; Zemetkin, 1995) for which parents must be major partners (McWilliam, 1996). The presence, patterns, and influence of comorbidities have provided counseling practitioners and other clinicians working with children with developmental challenges with a foundation for a better understanding for the scope of behavioral neurology that can occur. The impact or effects of behavioral neurology (autism) on academic, personal-
social relationships, self-esteem, and occupational functioning must not be underestimated. Most especially, this concept suggests that these effects can accumulate over the life span of children with autism and their families (Erk, 2000; Harris & Glasberg, 2003; Klin, 2005; Lee, 2005; Powell & Gallahger, 1993; Remig, 2004).

Theoretical Perspective

A responsible clinician cannot conduct reliable and valid assessments of clients with behavioral, social, and/or communication-based problems without being firmly grounded in an orientation as to how these problems might have originated, evolved, or progressed. Developing a solid theoretical understanding of possible origins of the child’s problematic behavior can have important implications when linking autism, its subtypes or co-morbid disorders to emotional stress that parents encounter and workable strategies for them to try at home and in the community (Erk, 2000; Ho & Keiley, 2003). For example, Erk (2000) created the term “neurocounseling” (p. 395) as an appropriate or congruent designation for cases or clients for whom the diagnosis or the majority of the problematic behaviors emanate from or can be attributed to the neurobiology or neurochemistry of the client and which generate dramatic behavioral change. Coontz (2000) observed that historical changes (within a family) that have the most significant impact on family organization and values “often emerge when incremental and quantitative changes suddenly produce something qualitatively new” (p. 292). A diagnosis of autism certainly falls into this category and generates significant and permanent changes for the child in question and for his/her parents and other family members (Fialka, 1997; Floyd & Gallagher, 1997; Harris & Glasberg, 2003; Ho & Keiley, 2003; Klein, 1990; Lynch & Morley, 1995; Lozzi-Toscano, 2004; McHale, Simeonson, & Sloan, 1984; Powell & Gallagher, 1993; Russo-Sprouls & Porteus, 1998).
Family professionals are likely to encounter parents who have been labeled by other professionals as in denial of their children’s intellectual disability. Ho and Keiley (2003) observe that when working with these parents, it is neither helpful nor respectful to use the term denial. They agree with Seligman and Darling (1997) that when parents appear to deny disability, family professionals might accept parents’ views initially while respectfully assisting them to deal with stress and devise problem solving strategies for the child, for themselves, and for the family. For instance, in a study of 55 mother’s reactions to their children’s intellectual disabilities, the mothers reported using coping strategies of denial, finding a purpose, rehearsal of alternative outcomes, and seeking emotional support to deal with the stress of managing the multiple needs of their children (Sequeira, Rao, & Subbakrishna, 1990).

Beckman (1996) expressed concern that labeling parents as being in denial may create a verbal barrier to effective communication and interfere with the creation of bonds between clinicians and parents. Furthermore, labeling tends to stereotype parents and may cause other clinicians to limit their assessment of the family system and dynamics (Ho & Keiley, 2003). Parents’ abilities to receive and respond to information regarding their children’s diagnosis will be affected by their emotional states and how and in what context information is presented (Beckman, 1996; Satir & Bitter, 2000). Thus, there is a critical need to establish a collaborative resource based approach to helping, grounded in theory or theories that facilitate effective structure of assistive techniques and promote understanding of parent concerns (Ho & Keiley, 2003).

Many clinicians find that an eclectic theoretical approach to clinical practice is more effective and appropriate than focusing on one theoretical field and attempting to adjust the single theory to fit all clients (Gaw & Beutler, 1996; McWilliam, 1996; Perry, 1997b; Petrocelli, 2002). There are risks in both directions. If clinical work is not thoroughly grounded in theory,
there is a risk that service delivery will be amoebic and unfocused. If, however, therapeutic work emerges only from a single theory, the therapist risks limiting himself/herself clinically, potentially missing elements significant to the client’s care, and ultimately failing to encourage a maximum of client potential and growth (Perry, 2004). This study is an outgrowth of the researcher’s integrated theoretical approach to clinical practice with families of children with special needs that employs the Family Systems Framework of Process and Development, the Ecological Framework of Human Development, and, to a lesser extent, Social Exchange theory to “custom design” client care.

The Systems Framework of Family Process and Development

The systems perspective on family development has become a major conceptual framework for evaluations of individual interaction and family communications (Olsen, 1995). This perspective includes general systems theory and cybernetics (an analysis of the flow of information in closed systems (Hall, 2003). Some scholars believe that a growing percentage of educators and clinical practitioners identify a systems orientation as their preferred theoretical guide perceiving it as a practical mode of comprehending and addressing the contextual factors imbedded in the individual’s or family’s presenting issues (Montgomery, Hendricks, & Bradley, 2001).

Watts (2001) observes that a systems perspective on family functioning requires that the family must be considered as an entity composed of interacting parts. Hall (2003) adds that the family system is a group of people who interact as a family and create, in the process, a whole entity. Historical events and individual experience are connected through the linked fates of family members and whatever happens to one family member impacts all family relationships (Elder, 1998). A systemic perspective also evaluates interactions and interaction patterns within and among systems (Hall, 2003; Sontag, 1996).
A family systems context allows for expanded definitions of intervention, moving away from the modern nuclear family view of the individual as the sole focus of treatment, the practitioner as an expert, and toward a more postmodern, constructivist approach that promotes growth-producing behavior in individuals, families, and institutions. The focus is then on the unique phenomenological world of the client while engaging the client as an equal partner in the process (Elkind, 1995; Gerber & Basham, 1999; Johnston & Zemitzsch, 1997). An example of such an approach is the use of a systems theory foundation for family therapy to address parent concerns in the context of parenting a child with autism and/or mental retardation and multiple disabilities (Erk, 2000; Ho & Keiley, 2003; Kern & Peluso, 1999; Lynch & Morley; 1995). The parent (in the context of this study) is the leader who is ultimately responsible for the well-being of all the members within the family. The parent sets the tone by providing direction, meaning, and purpose. If the parent or parents are under significant stress, so will the family be (Harris & Glasberg, 2003; Kern & Peluso, 1999; Lee, 2005; Levinson, 1994; Powell & Gallagher, 1993; Remig, 2004). Thus, in order to comprehend behavior in an individual or family relationship, one must look not only at relationship qualities, but at the interactions among members and characteristics of the family unit as well (Watts, 2001).

Historically, the application of systems theory in the context of family preceded applications to more established sciences with the classic work of Bateson, Jackson, Haley, and Weakland (1956) who in their studies of schizophrenia introduced the notion that the family represents a communication system and that the presence of the schizophrenic individual in the family functioned as a symptom of family system pathology in the context of a double bind (Miklowitz, 1995; Olsen, 1995; Rose, 1997). The double bind was believed to be a communication pattern in which verbal and non-verbal messages conflict with and contradict each other such as a parent to child verbal invitation for a hug accompanied by body language...
that is clearly unreceptive to a hug (Rose, 1997). Thus, it is not difficult to imagine how early work with parents of children with autism might have been influenced by systems theory as infantile autism and childhood schizophrenia were considered to be related and autism was thought to be an outgrowth of aberrant parenting (Comings, 1997; Kanner, 1943, 1949; Rutter, 1972; Thomas, 1999; Ward, 1974, 1976, 1990).

Bateson and his colleagues were followed by the work of scholars in other sciences such as sociologist Buckley in 1967 (Miklowitz, 1995), and biologist von Bertalanffy in 1968 (Miklowitz, 1995; Rose 1997; Watts, 2001). von Bertalanffy, with his General Systems Theory argued that contradictions within the biological sciences can be explained by referring to sets of elements or parts (such as subsystems within the human body) which are in interrelation with each other and with their environment and the holistic assumption that a whole entity is greater than the sum of its parts (Mikesell, Lusterman, & McDaniel, 1995; Rose, 1997).

Other classic scholars contributing to the integration of systems thinking into family systems theory include Satir (1967, 1972) who combined historical and here and now interventions in her model of conjoin family therapy (Seaburn, Landau-Stanton, & Horwitz, 1995), and Bowen (1978) who offered his natural systems theory in which the human family is perceived as a result of an evolutionary process in nature (Seaburn et al., 1995; Watts, 2001). Indeed, Scarr (1997) recently observed that “all animal (human and other) behavior is the product of evolution” (p. 4). Bowen contended that the networks of interlocking relationships that comprise families profoundly influence individual members’ thoughts, feelings, and behaviors. Such influences extend across generations and evolve into behavioral patterns that often reflect unresolved family issues contributing to a decrease in differentiation (emotional boundaries) and an increase in emotional enmeshment (Magnuson, 2004).
An example of an influence extending across generations is hereditary compromise to neurological function that is related but differently manifested from one generation to the next. For instance, there might be a history of speech or attentional and/or organizational problems in an child with autism’s grandparent, specific learning difference or disability in the parent, and a presentation of autism in that parent’s child (Comings, 1997; Lee, 2005; Remig, 2004). Such influences can exert long term influences on relational patterns, or responses to loss, change, or developmental transition (Magnuson & Shaw, 2003; McGoldrick, Gerson, & Shellenberger, 1999). Conversely, behavioral patterns that contribute to resilience and strength can also emerge as a legacy. An example of such resilience is a family’s response to chronic illness, disability or crisis (Ho & Keiley, 2003; McGoldrick et al., 1999). Some families and children appear to be resilient to functional changes in a family member where the experience and atmosphere of the ongoing crisis are not necessarily directly related to the degree or nature of changes in functioning and family atmosphere (Lynch & Morley, 1995).

By the 1970s, family systems theory influenced historians to begin investigating the processes that link family members together and to external social institutions (Coontz, 2000). Elder (1974, 1998) began and continues his profound work on the life course examining the intersections between life histories, family needs, and historical forces. Discussion of family strategies has gradually replaced earlier concepts of families as passive receptors of historical change (Coontz, 2000; Erk, 2000; Ho & Keiley, 2003; Lynch & Morley, 1995; Patterson & Garwick, 1994; Satir & Bitter, 2000; Vincent, 1990).

*The Ecological Framework of Human Development*

An ecosystemic view of human development emphasizes the interaction of multiple factors both within the family and beyond the relationship boundaries and bonds of the family with a central focus of adaptation (Seaburn et al., 1995). Patterson (2002), in her recent work on
resilience and family stress, states that adaptation should be a product of family relationships that emerges following a crisis or a period of serious disruptiveness implying significant risk exposure. She further defines adaptation as a process of restoring balance between capabilities and demands between family members and the family unit, and between a family unit and the community. For instance, to treat individuals with chronic developmental delay or disabilities, family professionals may consider the ecological context of the family members (Hanna & Brown, 1995; Satir, 1983). This context is comprised of the total of the subsystems operating between family members: (a) the parent-child subsystem, (b) sibling subsystem, (c) marital subsystem (if relevant), and (d) the broader subsystems of friends, majority culture of society, spiritual affiliation, and social and governmental institutions such as dealing with Medicaid (Ho & Keiley, 2003; McWilliam, 1996).

Even more complex are the interdisciplinary challenges among therapists (physical, occupational, speech/language) and educators (regular and special), and other specialists such as psychologists and family therapists. Thus, collaboration between levels of the ecosystem, the responsibility for which falls largely on the parent, emerges as both complex and necessary (McWilliam, 1996). Family professionals can guide parents to possible resources within their larger ecosystem. Additional resources such as support groups and organizations for parents of children with disabilities or respite care services can help parents to cope better with the stressors involved in raising a child with a disability such as autism (Ho & Keiley, 2003; Lynch & Morley, 1995) and help the child to function better and be healthier because the parents have access to adequate resources to assist them with meeting the demands of daily living (Ho & Keiley, 2003; Patterson & Garwick, 1994; Satir, 1983; Satir & Baldwin, 1983).

Historically, ecological theory has its roots in Gestalt psychology and the classic, early works of Koffka (1935), Lewin (1936, 1942), Werner (1961), and Heider (1958). Applied to
child development, Gestalt theory conceives of the child as a whole organism whose every new experience influences relationships of existing elements in the child’s life thus influencing the patterning of the child’s individuality (Seaburn et al., 1995). The work of the above mentioned authors was followed by the classic work of Barker (1968) who observed that though traditional psychology identified ways in which people differed from one another, it failed to capture the variations in thought, feeling, and action experienced by a child in a given day. Barker contended that a large part of that variation can be accounted for by the child’s environment or behavior settings. In response, even before the passage of the first early intervention law (PL 99-457) researchers were beginning to pay attention to the importance of an inclusion model for children with disabilities (Stoneman, Cantrell, & Hoover-Dempsey, 1983; McWilliam, 1996).

Ecological systems theory is most often associated with the early seminal and current work of Urie Bronfenbrenner (1977, 1979, 1987, 1992, 1995) and Bronfenbrenner and Evans (2000) in his model of human development within a series of human contexts (Rose, 1997). Bronfenbrenner (1979, 1987) clearly envisions the individual’s developing within the ecosystem. He sees the environment as structures each nested inside the next. He builds on Lewin’s (1936) field theory to form his own ideas of contexts in which development occurs. Lewin proposed that behavior is a function of the individual (person) and the environment \( (D = f[PE]) \) (Rose, 1997). Bronfenbrenner (1979) perceives individual human behavior as a response to the interaction between the environment and the person, and in his variation of human developmental ecology states that the child always develops in the context of family type relationships in response to the interaction of genetic endowment with other environmental components. Eventually, Bronfenbrenner added the notion of ecological theory applying throughout the life course and the chronosystem or time as the developmental history of events and experience and its impact on human development (Bronfenbrenner, 1987, 1992, 1995) and Elder (1996) has taken that idea a
step beyond asserting that time assumes the form of a life stage principle which states that “the influence of a historical event on the life course depends on the stage at which the individuals experience the event” (p. 52).

Rose (1997) summarizes Bronfenbrenner’s (1979) original four levels of context in which development occurs. The microsystem implies the interior setting containing the individual and factors such as time, place, and other family members and therapists who might be found in or move in and out of the child with autism’s setting (Lynch & Morley, 1995; Thomas, 2000). The mesosystem refers to interactions between two or more microsystems such as the child’s home and special needs classroom (Erk, 2000; Ho & Keiley, 2003; Lynch & Morley, 1995; McWilliam, 1996). The exosystem describes links between two or more microsystems one of which contains the individual (such as the child with autism) in question and the other does not but nevertheless has relevant implications for that individual (Rose, 1997). An example of exosystem settings might be the child’s daycare facility and another setting such as a hospital based multiple therapy center, aqua or hippotherapy (therapeutic horseback riding) settings, or a monthly respite care event provided by a private not-for-profit organization (Ho & Keiley, 2003; Lynch & Morley, 1995; McWilliam, 1996). These services and settings can help to address the stresses identified by mothers that are directly related to social relationships (which can be so problematical in autism) such as being teased, rejected by others, and giving/receiving help (Lynch & Morley, 1995; Tackett, Kerr, & Helmstadter, 1990).

Finally, the macrosystem refers to the social, cultural, and/or economic subcultures in which all the other systems are nested. Interdependencies between niches occupied by individuals can be linked to patterned sets of activities (Rose, 1997) such as those associated with weekly therapies provided by early intervention services or school systems (Landa, 2003; McWilliam, 1996; Remig, 2004; Russo-Sprouls & Porteus, 1998). An example of a macrosystem
influence on the child’s development might be economic decisions made by state legislators that affect early intervention or special education funding.

Recent studies of younger school children and their ecosystems suggest that strategies to help children adjust and transition from one microsystem to another can facilitate communication and improve effective functioning between systems (Bredehoft, 2001; Caffrey, Erdman, & Cook, 2000; Lusky & Hayes, 2001; Mooney, 1995; Rotter & Boveja, 1999). The latter authors offer a case study of a 9-year-old fourth grade boy referred to a private practitioner for out of control misbehavior in school, academic, and social problems. Rather than treating the individual child, the clinician chose to treat the whole family and focus her intervention efforts on the family-school subsystem and offer problem solving oriented family counseling to the whole group. She created a family-school coalition including the family, the clinician, the school counselor, and the child’s teachers who communicated with each other, shared information, and agreed upon goals for desired change. The coalition helped the child learn to express his emotions appropriately thus facilitating his being more available for learning and generating improvement in the family’s quality of life at home. Consequently, effective functioning and transitioning between systems was improved.

Thus, in the context of adjustment to a child with autism, relationships of child to parent and school, school to school system, and school system to community emerge as fertile ground and corroborate the need for developing efforts to help students, parents, clinicians, and educators learn to collaborate for the benefit of the child, his parents and family, and ultimately, the community (Ho & Keiley, 2003; Lynch & Morley, 1995; Russo-Sprouls & Porteus, 1998). For instance, because the family system is interactive, interdependent, and reactive to change (Hornby, 1994; Marshak & Seligman, 1993; Satir, 1983), as each member changes over time the system (and its relationships with other layers of the ecosystem) are altered and transformed.
Because the family is interdependent, treating the entire system emerges as more effective (Berger, 1984; Coppersmith, 1984). Two examples of this are sharing resources for respite care with parents of children with autism and resource activities for the child with autism that include siblings so that they all can take a break from the constant care and supervision that their child with autism requires. If parents are informed about and access such resources, they may be able to function more effectively with each other, with other family members such as siblings, and in the workplace as well. When the entire family of a child with disabilities is seen in treatment, all of the family members become agents of change (Ho & Keiley, 2003).

Recently, Bronfenbrenner (1995) has added the notion of proximal processes to his theory. It is not only the child’s personal characteristics that foster development, but transactions with the environment that either promote or thwart development as well. Bronfenbrenner states “To be effective, the interaction must occur on a fairly regular basis over extended periods of time. Such enduring forms of interaction in the immediate environment are referred to as proximal processes” (p. 195). Examples of enduring patterns of proximal processes with a child with autism are the ongoing weekly therapies such as speech or occupational therapy which take place in natural environments of home, school, or day care, or other community based activities such as aqua or hippotherapy. All of these activities help the child to learn new skills and may help parents to see their children in a more typical and less pathologized light (Ho & Keiley, 2003; Lynch & Morley, 1995; McWilliam, 1996; Russo-Sprouls & Porteus, 1998).

As Bronfenbrenner (1992, 1995) over the years has continued to elaborate and expand his model, he has substituted the label bioecological theory for ecological theory in order to accommodate such additions as “…symbolic features that invite, permit, or inhibit engagement in sustained, progressively more complex interaction with, and activity in, the immediate environment” (1993, p. 15) to the microsystem. With the realization of a need to study
individuals over a sufficient period of time to reveal ongoing processes at a particular point in time, Bronfenbrenner (1995) has most recently characterized his theory as a person-context-process-time model. He states further that “we are living in a … period of growing chaos in the lives not only of families but in all the day-to-day environments of people of all ages” (Bronfenbrenner & Evans, 2000, p. 123). Family clinicians who work with parents of children with disabilities can provide an invaluable service by identifying and explaining relevant community resources, program policies, and service delivery systems such as medical and financial assistance programs and parent support organizations.

Social Exchange Theory and Symbolic Interactionism

From the Exchange theory perspective, there is, (among many) an assumption that an individual’s motivation explains behavior, that motivation is multidimensional, and that in a micro-utilitarian context that same individual is motivated by self interest (Klein & White, 1996; Thomas, 1999). In the context of this project the concept of profit and cost is enhanced by a consideration of comparison levels which can be utilized to better comprehend degrees of satisfaction associated with outcome (Sabatelli & Sheehan, 1993). For instance, McWilliam (1996) observes that interdisciplinary services should be functional, practical for regular caregivers, and should be the simplest possible to implement (Bricker, Petti-Frontczak, & McComas, 1998). This is based on the belief that young children learn better through ongoing interactions with their natural environment than in isolated lessons or sessions. Consequently it is the child’s natural caregivers (parents, teachers, child care providers) who have the greatest impact on outcome, not the specialist (McWilliam, 1996).

From a macroexchange perspective one must consider generalized exchanges which occur over an extended period of time and require a more pronounced element of trust than microexchanges (Klein & White, 1996). For example, the majority of families of children with
autism and other disabilities are challenged to develop trust that an overwhelming array of physicians, therapists, school systems, and other service providers will actualize their statements of intent. These are mental and emotional gymnastics rarely required of families with all typically developing children. Thus, individual (or parental and family) choices and often quality of life are viewed as determined by macroexchanges between the (family) group and organizations.

Goode’s early (1960) theory of strain in the context of Symbolic Interaction lends itself well to addressing the needs of parents of a child diagnosed with autism and can be appropriately acknowledged here with Social Exchange theory. Goode maintains that social roles are set forth and sustained to facilitate the continuation of society and that for the most part, people wish to comply. Role strain occurs when one does not wish to comply or when one is struggling with availability of roles which carry different obligations. Inconsistencies between activities and responses demanded by role relationships create another source of strain (Goode, 1960). Certainly, parents of children with autism are confronted with all of these factors (Floyd & Gallagher, 1997; Harris & Glasberg, 2003; Klein, 1990; Klin, 2005; Lee, 2005; Remig, 2004; Russo-Sprouls & Porteus, 1998). They are summarily thrust into roles of nurse and constant care giver and can be robbed of time for roles of companion and friend. Parents juggle additional roles of medical crisis interventionist and care coordinator along with roles of taxi and ambulance driver to multiple therapy and hospital appointments, while trying to maintain some sense of normalcy with any additional children who may have scouts, soccer practice, or school activities (Floyd & Gallagher, 1997; Harris & Glasberg, 2003).

This juggling of roles requires parents to engage in a constant deliberation as to the relative costs and rewards associated with their various roles. Unfortunately, inconsistencies in roles are difficult to ignore and delegation and elimination of some roles almost impossible.
Extension becomes involuntary. Thus, a Social Exchange perspective emerges as a better foundation upon which to base solution focused strategies for parents. Pragmatic intervention for effective time management strategies, for instance, can produce substantial improvement by coaching parents to make facilitative choices (exchanges) that can improve the overall quality of life (Lee, 2005; Perry, 2004; Remig, 2004). Resilience can be fostered by teaching parents to reframe their appraisal of and behaviors in response to (choices) and coping in an effort to meet the needs of a given situation and manage any conflicts arising from it (Lynch & Morley, 1995; Patterson, 2002). The role relationship is perceived as a bargain or agreement evaluated in light of rewards and benefits which yield minimal strain.

Indeed, parents and other family members of children with autism must fulfill many roles which may be more costly than beneficial. For instance, as previously mentioned, older siblings (especially girls) are sometimes cast into the role of caregiver (Harris & Glasberg, 2003; Powell & Gallagher, 1993; Stoneman & Berman, 1993; Stoneman et al., 1987). Boss and Greenberg (1984) proposed that family stress levels result more from the ambiguity of loss (the uncertainty and unknown) than from the actual loss (of the expected typically developing child). Family members can be unsure of whether certain members are inside or outside of the family and designation of roles and tasks can become unclear. When psychological and physical presence do not coincide, ambiguity occurs. For instance, with a constant parade of non-family members (such as early intervention providers) in and out of the system on a daily basis, whose specific duty is caring for the child, parenting roles can become confused (Harris & Glasberg, 2003; Landa, 2003). Furthermore, specific ambiguity arises with the contrasting juxtaposition of where the child is developmentally, and where he/she ought to be. While brief periods of denial may allow a family at the initial point of loss (diagnosis) to function effectively, long term denial may impede the process of adaptation and reorganization of roles and boundaries in the family system
(Boss & Greenberg, 1984; Ho & Keiley, 2003; Lynch & Morley, 1995; Perry, 2004). Thus, the family’s transitions from one developmental stage to another can be compromised causing the family to become pathologically stuck (Perry, 2004).

In clinical practice, professionals who work with parents of children with autism can, as Goode suggests, teach role partners to work together and learn to depend on mutual role performance which can increase rewards and reduce strain (Ho & Keiley, 2003; Hornby, 1994; Patterson, 2002). Goode (1960) regards the family as the center for role allocation and responsible for developing problem solving solutions for role strain. Sometimes parents learn to seek, depend on, and expect solutions from outside sources. Significantly, Goode (1960) observes that a family’s perceived inability to meet the needs and demands of roles can change social structure and cause collapse. Family practitioners can empower and teach parents of children with autism spectrum disorders to identify, believe in, and draw upon their own internal strengths (Ho & Keiley, 2003; Lee, 2005; Lynch & Morley, 1995; McWilliam, 1996; Patterson, 2002; Perry, 2004; Remig, 2004).

Research Hypothesis

The goal of this study was to better understand the stress of parents who have children diagnosed with autism spectrum disorders. The researcher hoped that the results of the study would help inform appropriate strategies for clinical practice for this population in the context of marriage and family therapy. The following hypotheses were investigated. A summary rationale is presented for each hypothesis.

**Hypothesis 1: Parent’s Gender and Parenting Stress**

It is expected that mothers of children with autism will score significantly higher than fathers of children with autism on each of the following parental stress subscales: (a) emotional
benefits of parenting, (b) self enrichment, (c) personal development, (d) resources, and (e) opportunity costs and restrictions.

Rationale. As noted, in the literature review, no significant differences in scores on the Parental Stress Scale between mothers and fathers have been found (Berry & Jones, 1995; Lessenberry & Rehfelot, 2004). However, these results were in the context of the overall scale score. To the researchers’ knowledge, the five subscales of interest in this study have not been investigated individually or specifically in regard to parents of children with autism. As previously reported, differences in gender-related parental responses to child disability such as psychological involvement and perspective of fathers (Lynch & Morley, 1995; Sabbeth, 1984), and parental emotional and behavioral responses to diagnosis (Damroch & Perry, 1989; Seligman & Darling, 1997), have been tentatively identified in earlier and more recent inquiries. The researcher believes that separating the subscales to look for differences in scores between mothers and fathers may increase our understanding of parenting a child with an Autism Spectrum disorder. Because of the traditional primary caregiver role assumed by mothers, the researcher further believes that mothers of children will autism will experience significantly more stress than fathers.

Hypothesis 2: Age of Child with Autism Spectrum Disorder and Parenting Stress

For both mothers and fathers of children with autism, it is expected that significant inverse correlations will be found between the age of the target child and parents’ scores on each of the following parental stress subscales: (a) emotional benefits of parenting, (b) self enrichment, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions.

Rationale. Although autism is associated with a number of challenges for families and children, and although there is no one effective treatment, the above literature review suggests
that the variety of pharmacological, child care, educational and behavioral treatments available today can be effective in reducing the symptoms of autism as the child matures. Research is needed to clarify if such anticipated improvements may be associated with the stress of mothers and fathers and, if so, the nature of this association. The results could help guide the development of supportive interventions for the parents of children with autism of different ages. In keeping with the literature, the researcher believes that the level of stress for both mothers and fathers should decrease across all five subscales of interest in this study as the age of their child increases.

Hypothesis 3: Perceived Severity of Childhood Problems and Parenting Stress

For both mothers and fathers of children with autism, it is expected that significant positive correlations will be found between parents’ perceptions of the severity of their child’s developmental problems and their scores on each of the following parental stress subscales: (a) emotional benefits of parenting, (b) self enrichment, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions.

Rationale. As noted in the literature review, parents of children with autism are heavily involved with a number of community professionals in learning about and addressing various developmental problems. To the researcher’s knowledge, no one has investigated the relationship between parents’ perceptions of their child’s developmental problems and their level of stress. Understanding this relationship has implications for clinicians who must help families make sense of the developmental changes they observe during their child’s development and are told about by community professionals. For both mothers and families, the researcher believes that parents who perceive their child to have more severe developmental problems should also report higher levels of stress across all five subscales of interest in this study.
Hypothesis 4: Number of Siblings in Home and Parenting Stress

For both mothers and fathers of children with autism, it is expected that significant positive correlations will be found between the number of siblings in the home and parents’ scores on each of the following parental stress subscales: (a) emotional benefits of parenting, (b) self enrichment, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions.

Rationale. As noted in the literature review, parents of children with autism express concern about the well-being of their typically developing children. This concern can extend to such areas as sibling relationships, family responsibilities, and the development of the typical sibling. Because such concerns can impact the parents’ emotional state, the relationship between the presence of siblings and parental stress deserves attention. The researcher believes that a positive correlation should exist between the number of siblings in the home and parents’ level of stress across all five subscales of interest in this study.

Hypothesis 5: Parent’s Gender and Marital Satisfaction

It is expected that mothers of children with autism will score significantly lower than fathers of children with autism on marital satisfaction.

Rationale. The researcher believes that parenting stress has the potential to impact marital satisfaction. The researcher further believes that this relationship is especially true in families with children with autism where parents face daily challenges that focus their attention on the difficulties associated with their child. Such focus and concern has the potential to interfere with the marital relationship. Since mothers of children with autism are expected to experience more stress than fathers (see Hypothesis 1) it is expected that mothers also will report lower levels of marital satisfaction than fathers.
Hypothesis 6: Parental Stress and Marital Satisfaction

For both mothers and fathers of children with autism, it is expected that significant inverse correlations will be found between parents’ marital satisfaction and their scores on the following parental stress subscales: (a) emotional benefits of parenting, (b) self enrichment, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions.

Rationale. The literature clearly documents the multiple challenges that face parents of children with autism. The researcher believes that these challenges not only impact parents’ level of stress but also their marital satisfaction. And, while the researcher believes that mothers may experience more stress than fathers (see Hypothesis 1) and, perhaps as a result, that mothers’ may experience less marital satisfaction than fathers (see Hypothesis 5), she also believes that the level of marital satisfaction for both mothers and fathers of children with autism is negatively associated with their levels of parental stress.
CHAPTER 3

METHODOLOGY

Participants

The participants for this study were 70 mothers and 51 fathers between the ages of 20 and 53 years (for mothers) and 21 and 58 years (for fathers) from a large southern metropolitan area who are parenting a child diagnosed with an Autism Spectrum Disorder. Mothers and fathers came from single-parent families, families with married couples who were both the biological parents of all the children in the home, blended families in which both parents in the home were not necessarily the biological parents of all the children in the home, foster or adoptive parents serving in the role of primary caregiver, and grandparents serving in the role of primary caregiver. Because of the limited population size from which the sample could be drawn, both mothers and fathers did not necessarily come from the same families.

In families where more than one child carried a diagnosis of autism, parents were asked to focus on their one child who seemed the most involved on the autism spectrum (i.e., the most severe) as the target child for their responses. The researcher chose this rationale as some presentations of PDD can be quite mild and a more involved child is likely to present with a more challenging and distinct array of symptoms.

The 121 parents first read and signed the cover letter and consent form which appear as Appendix C. Parents then completed demographic information, provided descriptive assessments of their children with autism using a modified (Sturm et al., 2004) International Classification of Functioning, Disability, and Health classification system (WHO, 2001), completed the Parental Stress Scale (Berry & Jones, 1995), and, where relevant, the Couples Assessment of Relationship
Elements (CARE; Worthington et al., 1997). A copy of the demographic data form appears as part one of the Parent Survey, Appendix D. A copy of the modified (Sturm et al., 2004) International Classification of Functioning, Disability, and Health classification system (WHO, 2001) appears as part two of Appendix D. A copy of the Parental Stress Scale (Berry & Jones, 1995) appears as part three of Appendix D. A copy of the CARE instrument (Worthington et al., 1997) appears as part four of Appendix D.

Demographic information including age, gender, family structure (single-parent, married, blended family, foster/adoptive parents, or grandparents serving in a primary caregiver role), age of target child with autism, ordinal position of the target child with autism, and number of all additional children in the home and their ages was collected. Information regarding ethnicity and income, however, was not collected. The rationale for the omission of ethnicity and income data collection follows.

Even though participation in the study was confidential in that packets containing the instruments and information to be completed by the participant were identified only by an assigned number, the researcher already knew many of the participants as they were current or former clients and/or they had come in contact with the researcher through public speaking engagements and might engage in a client relationship at some point in the future. The researcher felt responsible for creating and maintaining an atmosphere and a relationship of unconditional positive regard with the participant in which ethnicity was not a mitigating factor. In addition, enough potential participants were themselves of mixed ethnicity, or the couple was of mixed ethnicity, that attempting to tease out relevant information regarding any actual influence of ethnicity on participant responses to the instrument seemed unnecessary. In addition, disability in children crosses ethnic and economic boundaries (Harris & Glasberg, 2003; Lee, 2005; Powell & Gallagher, 1993; Remig, 2004; Russo-Sprouls & Porteus, 1998).
Likewise, the researcher did not collect information from the participants regarding income. Even though previous inquiry indicates that low socioeconomic status can serve as an influence on parental perceptions and levels of stress (Barnett, Hall, & Bramlett, 1990; Coleman & Karraker, 1998; Gorzka, 1999; Patterson, 2002), the researcher believed that requiring participants to acknowledge income levels in the demographic data portion might risk causing participants undue emotional discomfort and might serve as a compromise to presenting an attitude of unconditional positive regard. In addition, the researcher was aware that potential participants represented a wide socioeconomic range from lower to upper middle income levels.

Parents participated in several different settings. Twenty-nine participants were currently engaged as clients in the researcher’s marriage and family counseling practice and completed the survey and accompanying demographic and descriptive information in one of the researcher’s three office locations. Forty-one were former clients who received packets by mail or were given the option to come to one of the office locations to complete their packets. Two participants were recruited by a flier posted in the office of a local well known developmental pediatrician who specializes in children with autism. Parents completed packets in her office. Finally, forty-nine participants were parents belonging to two large autism spectrum parent support groups in the surrounding metropolitan area counties and participated in the study at one of their monthly meetings. The data was collected over a period of approximately two months.

Each family actively or formerly associated with the researcher’s private marriage and family counseling practice was so referred because the practice is specifically designed for families of children with special needs. In the context of this study, parents who are or have been associated with this practice because they have a child or children with an autism spectrum disorder either through active participation as a client or as a member of an autism parent support group for which the researcher has functioned as a guest speaker, were invited to participate in
the study. Each participant is therefore the parent of a child or children with an autism spectrum disorder. Families are referred to this practice through the statewide Early Intervention program and from specialist pediatric physicians, pediatric therapy clinics, and school systems throughout the greater metropolitan area.

Materials

Packets for the participants in this study contained three items. First, a cover letter/consent form (two copies) was used to explain the research project. The letter included a complete description of the project, a statement that the project was in partial fulfillment of requirements for the researcher’s doctoral degree, a declaration of IRB approval, the IRB verbatim oversight paragraph, an assurance of anonymity for the participant, an assurance that their participation was voluntary, a statement of the researcher’s gratitude for their participation, and resource information to be used in the event the participant experienced any stress as a result of participating in the project and felt the need for assistance. A copy of the cover letter/consent form appears as Appendix C.

Second, the Parent Survey (see Appendix D) included the instruments of interest in this study. In particular, the survey included items related to the family demographics, the brief modified (Sturm et al., 2004) International Classification of Functioning, Disability, and Health classification system (WHO, 2001), the Parental Stress Scale (Berry & Jones, 1995), and the Couples Assessment of Relationship Elements (CARE) (Worthington et al., 1997). As mentioned above, many of the parents have been, currently are, or were otherwise familiar with the researcher and therefore are cognizant that the researcher was aware of their life dynamics. Therefore, even though the purpose of the study was revealed in the cover letter, in an attempt to avoid unduly influencing the participants’ responses, their copy of the Parent Survey will not
contain the titles of the above instruments (see Appendix D). The cover letter/consent form and
the Parent Survey were stapled together in the upper left hand corner.

Finally, the packets contained incentives for the participants in the form of coupons
donated from several area restaurants. In addition, decorative number two pencils were provided
for each participant to use while completing the packets and to keep. The researcher used 6x9
catalog envelopes and standard U. S. mail first class stamps to mail packets to participants who
wished to participate by mail. The pencils, coupons, and a self-addressed stamped number ten
envelope to be used for returning completed data sheets by mail were included.

_Demographic Information and International Classification form._ Parents filled out the
demographic information form (described above) and were asked to respond to a modified
(Sturm et al., 2004) International Classification of Functioning, Disability, and Health
classification system (WHO, 2001) to describe their target child with autism in 12 areas: gross
and fine motor function, attention, activity level, impulse control, intellectual level, learning,
speech development, tics (repetitive behaviors, obsessive compulsive behaviors, affective
anomalies (facial expression), social interaction, and restricted interests. Parents responded using
a Likert type scale using “no” (score = 1), “minor/mild” (score = 2), or “definite/severe” (score =
3) to a question of problem or deviation in their child with autism. The possible score range was
12 to 36.

The researcher extracted this instrument from a support study (Sturm et al., 2004), which
involved an investigation of autism spectrum disorders in medical records of children with
normal intellectual levels. Because the original inquiry came from a descriptive classification
system, psychometric information (validity and reliability) has not been established. The
researcher expected the entire packet response to require approximately 12 to 20 minutes of the
participants’ time.
Parental Stress Scale. The Parental Stress Scale (PSS) (Berry & Jones, 1995) (Appendix D) is a self-report survey type measure that contains 18 items representing three pleasure or positive subscales of parenthood (emotional benefits, self-enrichment, personal development) and two negative subscales (demands on resources, opportunity costs and restrictions). Items specifically associated with emotional benefits of parenting are (1) I am happy in my role as a parent, (5) I feel close to my child(ren), (7) My child(ren) are an important source of affection for me, (9) The major source of stress in my life is my child(ren), and (13) The behavior of my child(ren) is often embarrassing and stressful to me. Items associated with self enrichment include (6) I enjoy spending time with my child(ren), (17) I am satisfied as a parent, and (18) I find my child(ren) enjoyable. Items associated with personal development include (8) Having child(ren) gives me a more certain and optimistic view for the future, (10) Having child(ren) leaves little time and flexibility in my life, and (16) Having child(ren) has meant having too few choices and too little control over my life. Items associated with demands on resources are (2) There is little or nothing I wouldn’t do for my child(ren) if it was necessary, (4) I sometimes worry whether I am doing enough for my child(ren), (11) Having child(ren) has been a financial burden, and (15) I feel overwhelmed by the responsibility of being a parent. Items associated with opportunity costs and restrictions are (3) Caring for my child(ren) sometimes takes more time and energy than I have to give, (12) It is difficult to balance different responsibilities because of my children, and (14) If I had it to do over again, I might decide not to have child(ren).

Respondents are asked to agree or disagree with items in terms of their typical relationship with their child (in this case, their target child with autism) and to rate each item on a five-point Likert type scale: (a) strongly disagree = 1, (b) disagree = 2, (c) undecided = 3, (d) agree, = 4 and (e) strongly agree = 5. The eight positive items (1) I am happy in my role as a
parent, (2) There is little or nothing I wouldn’t do for my child(ren) if it was necessary, (5) I feel close to my child(ren), (6) I enjoy spending time with my child(ren), (7) My child(ren) are an important source of affection for me, (8) Having child(ren) gives me a more certain and optimistic view for the future, (17) I am satisfied as a parent, and (18) I find my child(ren) enjoyable are reverse scored so that possible scores on the scale can range between 18 and 90. The possible score range is 18 to 90. Item scores are summed and higher scores on the scale indicate greater stress.

The scale is intended to be used for the assessment of parental stress for both mothers and fathers and for parents of children with and without clinical problems. Berry and Jones (1995) observe that vulnerability to stress has important implications for adjustment and well being and suggest that there is a unique association between individual stress responses and specific stressors. They state further that while a few scales examine family stress (e.g., McCubbin, Comeau, & Harkins, 1987) they either “confound marital stress with parental stress or fail to assess the perceived stress of an individual parent” (Berry & Jones, 1995, p. 464). The PSS (Berry & Jones, 1995) was designed as an outgrowth of and to improve upon the lengthy and more invasive Parental Stress Index (PSI) (Abidin, 1986) which has been criticized for not actually measuring the construct of stress (Conoley & Kramer, 1989).

The PSS (Berry & Jones, 1995) demonstrates satisfactory levels of internal reliability (0.83), and test-retest correlation of 0.81 over a period of six weeks. There were no significant differences in scores between mothers and fathers (Berry & Jones, 1995; Lessenberry & Rehfelot, 2004). The scale demonstrated satisfactory convergent validity (p < .01) with various measures of stress, emotion, and role satisfaction, including perceived stress, work/family stress (Sarason et al., 1983), loneliness (Russell, Peplau, & Cutrona, 1980), anxiety (Spielberger, Gorsych, & Lushene, 1970), guilt (Kugler & Jones, 1992), marital satisfaction, marital
commitment (Monroe & Jones, 1990), job satisfaction, and social support (Hackman & Oldham, 1975). Discriminant analysis demonstrated the ability of the scale to discriminate between parents of typically developing children and parents of children with both developmental and behavioral problems (Berry & Jones, 1995). Reliability for the scale has been supported in a Chinese version with an even higher alpha value of 0.89 (Cheung, 2000), used successfully for other recent studies (Baker, Perilla, & Norris, 2001; Berry & Meyer-Rao, 1997; Caldwell, 2005; Lessenberry & Rehfelot, 2004), and recommended specifically for use with parents of children with autism (California Departments of Education and Developmental Services, 1997). Caldwell (2005) compared initial pre-intervention parent stress scores with non-clinical samples in his study of parents of first time juvenile offenders. These parents showed significantly higher levels of stress (M = 41.37, SD = 10.14) than 115 “non-clinical” parents used to norm the PSS (M =37.1, SD = 8.1), t(282) =3.92, p < .001. Because the instrument typically yields one overall score, reliability and validity correlations for the five subscales were not available. The researcher is not aware of any other studies that consider the subscales of the PSS individually.

Couples Assessment of Relationship Elements (CARE). CARE is a seven-item measure of marital satisfaction. A seven point Likert type scale from 1 (couldn’t be worse) to 7 (couldn’t be better) is used to measure communication and forgiveness. Scores range from 7 to 49 with low total scores indicating low marital satisfaction and high total scores indicating high marital satisfaction.

Worthington et al. (1997) found estimates of internal consistency (Cronbach's alphas were 0.87, 0.94, and 0.93) on three occasions. Previous uses of CARE separated the instrument into two subscales (Global Marital Satisfaction and Marital Skills), but the authors reported better validity and reliability for the entire scale than for the two subscales. Consequently, for this study, the total CARE score will be used.
Worthington et al. (1997) reported that the two CARE subscales correlated with the Dyadic Adjustment Scale (Spanier, 1976) \((r = 0.67 \text{ and } 0.61)\) and the Dedication Scale of the Commitment Inventory (Stanley & Markman, 1992) \((r = 0.38 \text{ and } 0.58)\), suggesting construct validity. Moderate correlations were found with the Constraint Scale of the Commitment Inventory \((r = 0.20 \text{ and } 0.41)\), suggesting discriminant validity (Worthington et al., 1997).

**Procedure**

Prior to any contact with potential participants, the researcher constructed the demographic data form which included the brief modified (Sturm et al., 2004) International Classification of Functioning, Disability, and Health Classification System (WHO, 2001). The researcher then contacted the authors of the Parental Stress Scale (Berry & Jones, 1995) and the Couples Assessment of Relationship Elements (Worthington et al., 1997) to obtain necessary information about obtaining copies of the instruments, any costs the researcher might incur, and the authors’ permission to use their instruments. In addition, the researcher completed the application process for the university’s Institutional Review Board, including all the required supporting documents (see Appendices C through K). The study began once approval from the board was given.

Each parent was invited to participate in this project in one of four ways. First, current clients who have a child with an autism spectrum disorder and who are actively engaged in the researcher’s practice were invited to participate by the researcher in person. Second, former clients who have a child with autism and who have transitioned out of therapy were contacted by the researcher by telephone. Third, potential participants also included parents who are taking part in autism spectrum support groups in the metropolitan area and surrounding counties and were contacted in person by the researcher at one of their monthly meetings. Finally, parents who have a child with autism who are patients of a well known developmental pediatrician in
this metropolitan area who specializes in children with autism spectrum disorders were invited to participate by a flier posted in the doctor’s office.

*Current clients’ participation.* Current clients who are parents who have a child with an autism spectrum disorder and who were actively engaged in the researcher’s private practice at the time of the data collection for this study were invited by the researcher in person to participate in the study, using the Text for Recruiting Participants in Person which appears as Appendix F. The text mirrors the essential elements outlined above for the cover letter. After the delivery of that text, parents were invited to ask any questions or express any concerns they might have and the researcher responded appropriately. If the parent or parents agreed to participate, they were given a packet including the restaurant coupons and decorative number two pencil(s) which they could keep. They were offered the option of signing their consent forms and completing their two sheets of data (demographic/descriptive and survey) either seated in the researcher’s workroom in one of two comfortable chairs where they can work at a table, or they could choose to sit in the researcher’s waiting room. The researcher was not present in the room with them while they were completing their two sheets. However, if they experienced stress or required assistance while they were working, the researcher was available to them. Parents were instructed to retain one copy of the cover letter/consent form, then fold and put their remaining completed sheets into a sealed box which was fitted with a slot in the top through which the folded packet would fit and which was located on the right front corner of the workroom table. Parents who chose to complete their packets in the waiting room were instructed tap on the door when finished to put their completed packets in the box. They retained their copy of the cover letter, coupons, and pencil(s). The researcher thanked parents again for their willingness to participate as they were leaving.
Former clients’ participation. Former clients of the researcher who are parents of a child with autism were contacted by telephone by the researcher from archived files of families who have transitioned out of therapy. The researcher used the Text for Recruiting Former Clients by Telephone (and Text for Follow Up Call) which appears as Appendix G to invite parents to participate. The text included all of the above mentioned elements in the cover letter. After delivery of the text, parents were given an opportunity to ask any questions or express any concerns they may have had and the researcher responded appropriately. If parents agreed to participate, they were given the option to receive their packets through the U. S. mail or to come to the researcher’s office. If they chose to come to the researcher’s office, an appointment time was established and the same protocol described above for current clients was followed. Parents were reminded of driving directions to the researcher’s office if necessary.

If parents chose to receive their packets by mail, the researcher confirmed the preferred mailing address with the parent and informed them in the telephone conversation that the packet(s) would be posted no later than within 12 hours of the conversation. Packets were inserted into a 6x9 catalog envelope, fitted with the incentive coupons and pencils, a self addressed stamped number 10 business envelope for parents to use for returning their packets by mail, marked “please hand cancel,” stamped with the researcher’s business return address, and posted at the U. S. Post Office directly across the street from the researcher’s main office. If parents chose to receive their packets by mail and thus to complete them at home, the researcher instructed them that she would be available by phone if they felt the need for assistance. They were reminded that the contact telephone number appears in the letterhead of the cover letter and in the resource information as well, and reminded of how to reach the live answering service if necessary. In addition, the researcher inquired if parents would like to have a follow up call from the researcher and if so, a time for that call was established. The text for the follow up call also
appears in Appendix G. Parents inserted the two data collection sheets and the signed consent form in the self addressed number ten business envelope provided by the researcher and posted in whatever way was most convenient for them. Parents retained the other copy of the consent form for their records.

If parents declined to participate in the study, the researcher thanked them for their time. If they did agree to participate, the procedure(s) for the above protocol(s) were confirmed with the parents. The researcher thanked the parent(s) on the telephone for their time and ended the call.

_Members of autism spectrum parent support group participation._ The researcher is frequently engaged as a guest speaker for area autism spectrum parent support groups. The researcher contacted the chairpersons of two of these groups to request permission to collect data from the parents attending one of the monthly group meetings. The researcher is acquainted with the chairpersons and most if not all of the parents who attend the meetings are familiar to some extent with the researcher. The researcher determined with the chairperson(s) when the least obtrusive time to come to collect data would be. The researcher requested that the chairperson ask the membership at the next meeting if the membership would be agreeable to the researcher’s coming to their meeting for the purpose of collecting data for her study. The researcher requested that the chairperson(s) call or e-mail the researcher to confirm a date for the data collection if the group membership agreed to allow her to come. The researcher thanked the two chairpersons for their time on the telephone. Text for the contact telephone call appears as the first part of Appendix H, Texts for Contact Call to Group Chairperson(s), for Introducing Study to Parents Participating in Autism Spectrum Parent Support Groups, and Note of Thanks appear as the second, third, and fourth parts.
The support groups meet once a month for about one hour. As the group members agreed that the researcher could attend their meeting for the purpose of collecting data, the researcher arrived on the appointed date at 6:45 for the 7:00 pm meeting. The researcher greeted the chairperson as group members were signing in and getting their children settled in the childcare room provided by the support group. The researcher had approximately the first 20 minutes of the group’s meeting time.

The researcher explained the project briefly using the text that appears as the second part of Appendix H which includes all of the elements included in the cover letter. As many of the participants were somewhat familiar with the researcher, only about two or three minutes was necessary for the explanation. Parents were then invited to ask any questions or express any concerns they may have had and the researcher responded appropriately. The researcher anticipated that questions and concerns might require from zero to one minute, but more time could be devoted to these issues if required. The researcher then used one minute to distribute packets to parents who chose to participate. The incentive restaurant coupons and decorative pencils were given to all parents attending the meeting whether or not they chose to participate in the study.

The researcher left the room while participants were completing their consent forms and two data sheets but was available for anyone who needed assistance. The researcher returned to the room after 10 minutes to collect the three completed sheets (consent form, demographic data form/parent assessment and survey) and gave any parents who needed it five extra minutes. Parents retained the coupons, and pencil(s), and one copy of the consent form for their records. After collecting all completed data, the researcher thanked the group again for their time and departed. Finally, the researcher will sent a note of thanks to the group’s chairman for allowing
the researcher to attend their meeting for the purpose of collecting data for the study. Text for the note of thanks also appears as the last part of Appendix H.

*Participants recruited by flier posted in pediatric medical facility.* The researcher co-treats numerous families with and serves in a consultative role with a well known developmental pediatrician in the metropolitan area who specializes in children who are diagnosed with an autism spectrum disorder. This pediatrician frequently expressed her willingness to assist in any way might be deemed appropriate. The researcher posted several fliers (on the bulletin board and by the patient check-in window in the waiting room of the doctor’s office) and delivered packets to the doctor’s office. Interested parents could request a packet from the doctor’s secretary. They could choose to complete the consent forms and two data collection sheets either in the doctor’s waiting room which is equipped with comfortable chairs and sofas, or in a private room. They were instructed by the secretary to retain one consent form, then fold and put their remaining completed sheets into a sealed box fitted with a slot through which the folded sheets would fit.

Parents retained the coupons and pencil(s) and the remaining consent form for their records. Parents could contact the researcher at any time through her live answering service if they had questions or concerns or felt the need for assistance. They could also indicate a desire for a follow-up call from the researcher by confirming their contact information with the secretary was to forward the request to the researcher. At the end of the data collection period of approximately two months, the researcher retrieved the sealed box from the doctor’s office. The researcher sent a note of thanks to the doctor’s two secretaries for their assistance and invited the doctor (who is a colleague of more than 20 years) to lunch to thank her for her willingness to assist. A copy of the recruitment flier and note of thanks appears as Appendix I, Flier for Recruiting Participants in Pediatric Medical Facility and Note of Thanks.
In order to ensure the participants’ privacy, each set of data collection sheets (Parental Stress Scale (Berry & Jones, 1995) and demographic data form/parent assessment were assigned an identification number rather than using the participants’ names. The cover letter/consent forms were removed from each set. All materials are securely stored in the researcher’s locked office with other confidential records and will be kept for a period of not less than 3 years.

Limitations associated with this study will be explored in more depth in the discussion section of the dissertation. Three key limitations will be discussed here. The first key limitation is selection bias. Because only volunteer parents will participate in the study, this will limit the degree to which results of the study can be generalized to the wider population of families who have a child with autism. The second key limitation is the researcher’s familiarity with some of the parents in her role as clinician. Even though the researcher has taken steps to mitigate this limitation, as described above, it is still possible that researcher-participant familiarity could result in parents trying to present a more positive picture than exists in reality. The third key limitation of the study involves participants completing the study instruments in four different settings. Each setting has the potential to set up different environments and dynamics that could influence parents’ responses. As noted above, all of these limitations, as well as others identified by the researcher during the course of the study, will be discussed in more detail in the discussion section of the dissertation.

Data Analysis Plan

Demographic Data

The demographic data for this study is reported in the text and in a table. The data includes the participants’ age, gender, family structure (single-parents, married/biological parents of all children in the home, married/blended family, foster/adoptive parents or grandparents serving in a primary caregiver role), age of target child with autism, and number of all additional
children in the home and their ages. Measures of central tendency (Huck, 2000) including age ranges, means, and standard deviations for the participants, the target child with autism, and additional children in the household and the mean number of additional children in the households and their age ranges were summarized. Gender of participants and family structure was presented categorically as in number of male participants and number of females.

*Modified (Sturm et al., 2004) International Classification of Functioning, Disability, and Health Classification System (WHO, 2001)*

To compute the brief modified (Sturm et al., 2004) International Classification of Functioning, Disability, and Health classification system (WHO, 2001) score, parents rated each of the 12 items on a three-point Likert type scale: (a) “no” (score = 1), (b) “minor/mild” (score = 2), or (c) “definite/severe” (score = 3) to a question of problem or deviation in their child with autism. Possible scale scores ranged between 12 and 36 with higher scores indicating higher levels of perceived childhood problems. Descriptive results of the survey were reported in the text and summarized in a table.

*Parental Stress Scale*

To compute PSS Scores, the 120 parents rated each item on a five-point Likert type scale: (a) strongly disagree = 1, (b) disagree = 2, (c) undecided = 3, (d) agree, = 4 and (e) strongly agree = 5. The eight positive items (1) I am happy in my role as a parent, (2) There is little or nothing I wouldn’t do for my child(ren) if it was necessary, (5) I feel close to my child(ren), (6) I enjoy spending time with my child(ren), (7) My child(ren) are an important source of affection for me, (8) Having child(ren) gives me a more certain and optimistic view for the future, (17) I am satisfied as a parent, and (18) I find my child(ren) enjoyable will be reverse scored. Item scores from each subscale were summed with higher scores indicating greater levels of stress. Descriptive results of the survey were reported in the text and summarized in a table.
**Couples Assessment of Relationship Elements**

To compute the CARE scores, the approximately 112 married parents rated each of the seven items on a seven-point Likert type scale from 1 *(Couldn’t Be Worse)* to 7 *(Couldn’t Be Better)*. Item scores were summed with higher scores indicating greater levels of marital satisfaction. Descriptive results of the survey were reported in the text and summarized in a table.

**Tests of Hypotheses**

**Hypothesis 1: Parent’s Gender and Parenting Stress.** It was expected that mothers of children with autism would score significantly higher than fathers of children with autism on each of the following parental stress subscales: (a) emotional benefits of parenting, (b) self enrichment, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions.

One-tailed *t* tests for independent samples were calculated to determine if there were significant differences between the mean scores of mothers and fathers on each of the five subscales. Alpha was set at ≤ .05. Results for each of the five subscales are reported in the text and summarized in a table.

The *t* test is a special case of the *F* test in that exactly the same information is derived from either test (*F = t^2* and *t = √F*) (Huck, 2000; Keppel, 1991, p. 121). Also, the *F* test is considered to be unbiased (Huck, 2000; Keppel, 1991) and the *t* test is used most often when the researcher is concerned with one or two means (Huck, 2000).

**Hypothesis 2: Age of Child with Autism Spectrum Disorder and Parenting Stress.** For both mothers and fathers of children with autism, it was expected that significant inverse correlations will be found between the age of the target child and parents’ scores on the
following parental stress subscales: a) emotional benefits of parenting, b) self enrichment, c) personal development, d) demands on resources, and e) opportunity costs and restrictions.

Pearson correlations were calculated to determine if there are significant associations between age of child and parents’ scores on each of the five subscales. Separate sets of correlations were calculated for mothers and for fathers. Alpha was set at ≤ .05. Results for each of the five subscales are reported in the text and summarized in a table.

Hypothesis 3: Perceived Severity of Childhood Problems and Parenting Stress. For both mothers and fathers of children with autism, it was expected that significant positive correlations would be found between parents’ perceptions of the severity of their child’s developmental problems and their scores on the following parental stress subscales: a) emotional benefits of parenting, b) self enrichment, c) personal development, d) demands on resources, and e) opportunity costs and restrictions.

Pearson correlations were calculated to determine if there are significant associations between parents’ perceived severity of childhood problems and parents’ scores on each of the five subscales. Separate sets of correlations were calculated for mothers and for fathers. Alpha was set at ≤ .05. Results for each of the five subscales are reported in the text and summarized in a table.

Hypothesis 4: Number of Siblings in Home and Parenting Stress. For both mothers and fathers of children with autism, it was expected that significant positive correlations would be found between the number of siblings in the home and parents’ scores on the following parental stress subscales: a) emotional benefits of parenting, b) self enrichment, c) personal development, d) demands on resources, and e) opportunity costs and restrictions.

Pearson correlations were calculated to determine if there were significant associations between the number of siblings in the home and parents’ scores on each of the five subscales.
Separate sets of correlations were calculated for mothers and for fathers. Alpha was set at ≤ .05. Results for each of the five subscales are reported in the text and summarized in a table.

_Hypothesis 5: Parent’s Gender and Marital Satisfaction._ It was expected that mothers of children with autism would score significantly lower than fathers of children with autism on marital satisfaction.

One-tailed \( t \) tests for independent samples were calculated to determine if there were significant differences between the mean scores of mothers and fathers on CARE. Alpha was set at ≤ .05. Results are reported in the text and summarized in a table.

_Hypothesis 6: Parental Stress and Marital Satisfaction._ For both mothers and fathers of children with autism, was expected that significant inverse correlations would be found between parents’ marital satisfaction and their scores on the following parental stress subscales: a) emotional benefits of parenting, b) self enrichment, c) personal development, d) demands on resources, and e) opportunity costs and restrictions.

Pearson correlations were calculated to determine if there were significant associations between mothers’ CARE and PSS scores, as well as between fathers’ CARE and PSS scores. Alpha was set at ≤ .05. Results are reported in the text and summarized in a table.

It is hoped that results from this study will shed additional light on the emotional journey of parents who have children diagnosed with an autism spectrum disorder. In addition, it is hoped that results of this study can serve as a springboard to identifying appropriate strategies for clinical practice for this population in the context of marriage and family therapy.
CHAPTER 4

RESULTS

Demographic Data

Descriptive data and results from statistical analyses will be presented in this chapter. First, demographic data will be shared. Descriptive data for each instrument used in the study will follow. Finally, results for each hypothesis will be presented.

Participants for this study were 70 mothers and 51 fathers between the ages of 20 and 58 years who were all parents of a child diagnosed with an autism spectrum disorder (see Table 1). Mothers ranged in age from 20 to 53 years (M = 39.17, SD = 7.65). Fathers ranged in age from 21 to 58 years (M = 39.36, SD = 8.16).

Eight of the participating mothers were single parents and 53 were married to the biological father of all the children in their respective homes. Six mothers were married in a blended family, and three were foster/adoptive parents or grandparents serving in a primary caregiver role.

None of the participating fathers were single parents and 44 were married to the biological mother of all the children in their respective homes. Five fathers were married in a blended family, and two were foster/adoptive parents or grandparents serving in a primary caregiver role.

The target children with autism ranged in age from 1.5 years to 21 years of age (M = 6.44, SD = 4.97). The one 21 year old young man represents an outlier “target child” still living at home because his degree of developmental delay precludes his being able to live
Table 1

*Demographic Data for Mothers, Fathers, Target Child and Siblings*

<table>
<thead>
<tr>
<th></th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>70</td>
<td>51</td>
</tr>
<tr>
<td>Married to target child’s father / mother</td>
<td>53</td>
<td>44</td>
</tr>
<tr>
<td>Married / blended</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Foster / adoptive / grandparent</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Single parents</td>
<td>8</td>
<td>0</td>
</tr>
</tbody>
</table>

**Parents:**

- **Age range**
  - Mothers: 20 – 53 years
  - Fathers: 21 – 58 years

- **Mean age**
  - Mothers: 39.17 years
  - Fathers: 39.36 years

- **SD**
  - Mothers: 7.65 years
  - Fathers: 8.16 years

**Target child:**

- **Age range**
  - Mothers: 1.5 – 21 years
  - Fathers: 1.5 – 21 years

- **Mean age**
  - Mothers: 6.44 years
  - Fathers: 4.97 years

- **SD**
  - Mothers: 4.97 years
  - Fathers: 4.85 years

**Reported siblings:**

- **Age range**
  - Mothers: 0.1 – 22 years
  - Fathers: 0.1 – 22 years

- **Mean age**
  - Mothers: 8.41 years
  - Fathers: 7.76 years

- **SD**
  - Mothers: 5.68 years
  - Fathers: 5.38 years
independently. Mothers reported a total of 72 additional siblings with an age range of 0.1 to 22 years (M = 8.41, SD = 5.68). Fathers reported a total of 54 additional siblings with an age range of 0.1 to 22 years (M = 7.76, SD = 5.38). A total of 78 families were represented in the study with 43 families being represented by both parents. Eight families were represented by only the father, 19 families were represented by the married mother only, and eight families were represented by a single mother.

**Descriptive Results**

The scale and subscale scores of mothers and fathers from the different family structures were compared using descriptive statistics. Similar scores were found across the family structures for each group of mothers and fathers. Subsequently, the scores of mothers and of fathers from the different family structures were grouped together for this section on descriptive results. The same grouping was used for carrying out data analyses which are reported in the next section.

**Modified International Classification of Functioning, Disability, and Health Classification System**

Descriptive results for this instrument are summarized in Table 2. Parents rated each of 12 items on a three-point Likert type scale: (a) “no” (score = 1), (b) “minor/mild” (score = 2), or (c) “definite/severe” (score = 3) to a question of problem or deviation in their child with autism. The 12 items include: (a) gross/fine motor skills, (b) attention, (c) activity level, (d) impulse control, (e) intellectual ability, (f) impaired learning, (g) onset of speech, (h) tics (repetitive behaviors), (i) obsessive/compulsive behaviors, (j) affective (eye contact, gesturing etc.), (k) social interaction, and (l) restricted interests. Possible scale scores ranged between 12 and 36 with higher scores indicating higher levels of perceived childhood problems.
Table 2

*Descriptive Data for Modified International Classification of Functioning Disability and Health Classification System*

<table>
<thead>
<tr>
<th></th>
<th>Combined</th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>n</strong></td>
<td>121</td>
<td>70</td>
<td>51</td>
</tr>
<tr>
<td><strong>Range</strong></td>
<td>16 – 36</td>
<td>16 – 36</td>
<td>16 – 35</td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>27.40</td>
<td>28.01</td>
<td>26.55</td>
</tr>
<tr>
<td><strong>SD</strong></td>
<td>4.21</td>
<td>4.03</td>
<td>4.33</td>
</tr>
<tr>
<td><strong>Average response per item</strong></td>
<td>2.28</td>
<td>2.33</td>
<td>2.21</td>
</tr>
</tbody>
</table>

Combined overall ratings for the sample ranged from 16 to 36 (M = 27.40, SD = 4.21). Ratings for mothers ranged from 16 to 36 (M = 28.01, SD = 4.03). With a possible range of 12 to 36, this result indicates that mothers scored slightly above the midpoint of the scale. A breakdown of percentages for each item across the three-point Likert scale can be found in Appendix I.

Ratings for fathers on this instrument ranged from 16 to 35 (M = 26.55, SD = 4.33). With a possible range of 12 to 36, this result indicates that fathers also scored slightly above the midpoint of the scale. A breakdown of percentages for each item across the three-point Likert scale can be found in Appendix I.

*Parental Stress Scale*

Descriptive results for this survey are summarized in Table 3. Parents rated each of 18 items on a five-point Likert type scale: (a) strongly disagree = 1, (b) disagree = 2, (c) undecided = 3, (d) agree, = 4 and (e) strongly agree = 5. The eight positive items (1) I am happy in my role
Table 3

Descriptive Data for Parental Stress Scale

<table>
<thead>
<tr>
<th></th>
<th>Combined</th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>121</td>
<td>70</td>
<td>51</td>
</tr>
<tr>
<td>Range</td>
<td>23 – 77</td>
<td>26 – 77</td>
<td>23 - 74</td>
</tr>
<tr>
<td>Mean</td>
<td>50.26</td>
<td>55.23</td>
<td>43.45</td>
</tr>
<tr>
<td>SD</td>
<td>12.06</td>
<td>10.95</td>
<td>10.09</td>
</tr>
<tr>
<td>Median</td>
<td>50</td>
<td>57.5</td>
<td>42</td>
</tr>
<tr>
<td>Mode</td>
<td>62</td>
<td>61</td>
<td>49</td>
</tr>
<tr>
<td>Average response per item</td>
<td>2.79</td>
<td>3.06</td>
<td>2.41</td>
</tr>
</tbody>
</table>

as a parent, (2) There is little or nothing I wouldn’t do for my child if it was necessary, (5) I feel close to my child(ren), (6) I enjoy spending time with my child(ren), (7) My child(ren) are an important source of affection for me, (8) Having child(ren) gives me a more certain and optimistic view for the future, (17) I am satisfied as a parent, and (18) I find my child(ren) enjoyable were reverse scored. Item scores from each of the five subscales were summed with higher scores indicating greater levels of stress. The possible score range was 18 to 90.

Combined overall PSS ratings for the sample ranged from 23 to 77 (M = 50.26, SD = 12.06). Ratings for mothers ranged from 26 to 77 (M = 55.23, SD = 10.95). Ratings for fathers ranged from 23 to 74 (M = 43.45, SD = 10.09). In a previous report on a non-clinical sample, the average rating for the 115 parents upon whom the PSS was normed was M =37.1, SD = 8.1 (Berry & Jones, 1995). A clinical sample of parents of first time juvenile offenders yielded scores of M = 41.37, SD = 10.14. Interestingly, in that same study, scores for pre-intervention fathers (M =41.00, SD = 8.35) and mothers (M = 41.46, SD = 10.56) were very closely aligned.
(Caldwell, 2005). In addition, the PSS is designed to discriminate between parents of typically and non-typically developing children (Berry & Jones, 1995) and recommended specifically for parents of children with autism (California Departments of Education and Developmental Services, 1997). Based on these references, the above results suggest high levels of stress for mothers and fathers in this study. Also, these results suggest higher levels of stress for mothers than fathers. As noted in chapter 3, because the PSS typically yields one overall score and no other studies using the subscales were found, psychometric information for the five subscales was not available.

A breakdown of percentages for mothers and fathers for each item across the five-point Likert scale can be found in Appendix J. This breakdown of percentages will be further discussed in the discussion section of the dissertation.

**Couples Assessment of Relationship Elements**

Descriptive results for this survey are summarized in Table 4. The 113 married parents rated each of the seven items on a seven-point Likert type scale from 1 (*Couldn’t Be Worse*) to 7 (*Couldn’t Be Better*). Possible scores ranged from 7 to 49. Item scores were summed with higher scores indicating greater levels of marital satisfaction.

Overall CARE scores for the sample ranged from 12 to 49 (M = 32.40, SD = 9.60). Ratings for mothers ranged from 12 to 48 (M = 32.16, SD = 8.87) with an average response per item of 4.59. Ratings for fathers ranged from 12 to 49 (M = 32.63, SD = 9.77) with an average response per item of 4.66. These results indicate that mothers and fathers scored slightly above the midpoint of the scale. A breakdown of percentages for mothers and fathers for each item across the seven-point Likert scale can be found in Appendix K.
Table 4

Descriptive Data for Couples Assessment of Relationship Elements

<table>
<thead>
<tr>
<th></th>
<th>Combined</th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>113</td>
<td>62</td>
<td>51</td>
</tr>
<tr>
<td>Range</td>
<td>12 – 49</td>
<td>12 – 48</td>
<td>12 - 49</td>
</tr>
<tr>
<td>Mean</td>
<td>32.40</td>
<td>32.16</td>
<td>32.63</td>
</tr>
<tr>
<td>SD</td>
<td>9.60</td>
<td>8.87</td>
<td>9.77</td>
</tr>
<tr>
<td>Median</td>
<td>33.5</td>
<td>34</td>
<td>33</td>
</tr>
<tr>
<td>Mode</td>
<td>43</td>
<td>36</td>
<td>43</td>
</tr>
<tr>
<td>Average response per item</td>
<td>4.62</td>
<td>4.59</td>
<td>4.66</td>
</tr>
</tbody>
</table>

Tests of Hypotheses

Hypothesis 1: Parent’s Gender and Parenting Stress. It is expected that mothers of children with autism will score significantly higher than fathers of children with autism on each of the following parental stress subscales: (a) emotional benefits of parenting, (b) self enrichment, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions. Results for Hypothesis 1 are summarized in Table 5.

Results for this hypothesis suggest that mothers did score significantly higher than fathers on all but one subscale. For subscale (a) emotional benefits of parenting, the hypothesis was supported ($t(119) = 4.59, p (1-tailed) < 0.0001$). For subscale (b) self enrichment, the hypothesis was not supported ($t(119) = 1.40, p (1-tailed) = 0.082$). For subscale (c) personal development, the hypothesis was supported ($t(119) = 5.79, p (1-tailed) < 0.0001$). For subscale (d) demands on resources, the hypothesis was supported ($t(119) = 5.76, p (1-tailed) < 0.0001$) For subscale (e) opportunity costs and restrictions, the hypothesis was supported ($t(119) = 7.34, p (1-tailed) <
Table 5

Hypothesis 1: Parents Gender and Parenting Stress

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Emotional Benefits of Parenting</td>
<td>14.17</td>
<td>11.20</td>
</tr>
<tr>
<td>(b) Self Enrichment</td>
<td>6.54</td>
<td>6.02</td>
</tr>
<tr>
<td>(c) Personal Development</td>
<td>10.60</td>
<td>8.08</td>
</tr>
<tr>
<td>(d) Demands on Resources</td>
<td>13.19</td>
<td>10.78</td>
</tr>
<tr>
<td>(e) Opportunity Costs and Restrictions</td>
<td>10.73</td>
<td>7.37</td>
</tr>
</tbody>
</table>

$t$ Test For Comparing Two Sample means, $df = 119$, $* \alpha \leq 0.05$

<table>
<thead>
<tr>
<th>Subscale</th>
<th>$t_{cv}$</th>
<th>$t_{obs}$</th>
<th>S/NS*</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Emotional Benefits of Parenting</td>
<td>1.66</td>
<td>4.59</td>
<td>S</td>
</tr>
<tr>
<td>(b) Self Enrichment</td>
<td>1.66</td>
<td>1.40</td>
<td>NS</td>
</tr>
<tr>
<td>(c) Personal Development</td>
<td>1.66</td>
<td>5.79</td>
<td>S</td>
</tr>
<tr>
<td>(d) Demands on Resources</td>
<td>1.66</td>
<td>5.76</td>
<td>S</td>
</tr>
<tr>
<td>(e) Opportunity Costs and Restrictions</td>
<td>1.66</td>
<td>7.34</td>
<td>S</td>
</tr>
</tbody>
</table>

Results for Hypothesis 1 suggest that mothers in the sample were experiencing higher levels of stress than fathers on all of the subscales except Self Enrichment. Possible explanations for these higher levels of stress will be discussed in Chapter 5.

Hypothesis 2: Age of Child with Autism Spectrum Disorder and Parenting Stress. For both mothers and fathers of children with autism, it is expected that significant inverse correlations will be found between the age of the target child and parents’ scores on each of the
following parental stress subscales: (a) emotional benefits of parenting, (b) self enrichment, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions. Results for Hypothesis 2 are summarized in Table 6.

For mothers, only one significant inverse correlation was found between the age of the target child and mothers’ scores on the parental stress subscale (d) demands on resources. For fathers, no significant inverse correlations were found. Instead, significant positive correlations were found between the age of the target child and fathers’ scores on the parental stress subscales (c) personal development, and (e) opportunity costs and restrictions.

For mothers’ subscale (a) emotional benefits of parenting, the hypothesis was not supported (r_{cv α=.05, df=68, one tailed} = 0.2319, r_{obs} = -0.0494). For mothers’ subscale (b) self enrichment, the hypothesis was not supported (r_{cv α=.05, df=68, one tailed} = 0.2319, r_{obs} = 0.1221). For mothers’ subscale (c) personal development, the hypothesis was not supported (r_{cv α=.05, df=68, one tailed} = 0.2319, r_{obs} = -0.1466). For mothers’ subscale (d) demands on resources, the hypothesis was supported (r_{cv α=.05, df=68, one tailed} = 0.2319, r_{obs} = -0.2362). For mothers’ subscale (e) opportunity costs and restrictions, the hypothesis was not supported (r_{cv α=.05, df=68, one tailed} = 0.2319, r_{obs} = 0.0334).

For fathers’ subscale (a) emotional benefits of parenting, the hypothesis was not supported (r_{cv α=.05, df=49, one tailed} = 0.2732, r_{obs} = 0.0321). For fathers’ subscale (b) self enrichment, the hypothesis was not supported (r_{cv α=.05, df=49, one tailed} = 0.2732, r_{obs} = 0.1229). For fathers’ subscale (c) personal development, the hypothesis was not supported as a significant positive correlation was obtained (r_{cv α=.05, df=49, one tailed} = 0.2732, r_{obs} = 0.2915). For fathers’ subscale (d) demands on resources, the hypothesis was not supported (r_{cv α=.05, df=49, one tailed} = 0.2732, r_{obs} = -0.0539). For fathers’ subscale (e) opportunity costs and restrictions, the hypothesis was not supported.
Table 6

Hypothesis 2: Age of Child with Autism Spectrum Disorder and Parenting Stress

Pearson Correlation Coefficients *

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Mothers / Age of Child **</th>
<th>Fathers / Age of Child **</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Emotional Benefits of Parenting</td>
<td>-0.0494</td>
<td>0.0321</td>
</tr>
<tr>
<td>(b) Self Enrichment</td>
<td>0.1221</td>
<td>0.1229</td>
</tr>
<tr>
<td>(c) Personal Development</td>
<td>-0.1466</td>
<td>0.2915 ***</td>
</tr>
<tr>
<td>(d) Demands on Resources</td>
<td>-0.2362 ***</td>
<td>-0.0539</td>
</tr>
<tr>
<td>(e) Opportunity Costs and Restrictions</td>
<td>0.0334</td>
<td>0.5111 ***</td>
</tr>
</tbody>
</table>

* $\alpha \leq 0.05$

** df Mothers = 68, df fathers = 49

*** Significant

supported as a significant positive correlation was obtained ($r_{cv \alpha=0.05, df=49, one\ tailed} = 0.2732$, $r_{obs} = -0.5111$). Results for Hypothesis 2 suggest that stress for mothers and fathers in this sample does not reduce as the child with autism ages with the exception of a barely significant inverse correlation for mothers for the Demands on Resources subscale. Possible explanations for this lack of reduction in stress will be discussed in Chapter 5.

Hypothesis 3: Perceived Severity of Childhood Problems and Parenting Stress. For both mothers and fathers of children with autism, it is expected that significant positive correlations will be found between parents’ perceptions of the severity of their child’s developmental problems and their scores on each of the following parental stress subscales: (a) emotional benefits of parenting, (b) self enrichment, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions. Results for Hypothesis 3 are summarized in Table 7.
Table 7

Hypothesis 3: Perceived Severity of Childhood Problems and Parenting Stress

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Pearson Correlation Coefficients *</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers /</td>
<td>Fathers /</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Perceived Problems **</td>
<td>Perceived problems **</td>
<td></td>
</tr>
<tr>
<td>(a) Emotional Benefits of Parenting</td>
<td>0.3794 ***</td>
<td>0.5128 ***</td>
<td></td>
</tr>
<tr>
<td>(b) Self Enrichment</td>
<td>0.4094 ***</td>
<td>0.3917 ***</td>
<td></td>
</tr>
<tr>
<td>(c) Personal Development</td>
<td>0.4795 ***</td>
<td>0.3543 ***</td>
<td></td>
</tr>
<tr>
<td>(d) Demands on Resources</td>
<td>0.3296 ***</td>
<td>0.3112 ***</td>
<td></td>
</tr>
<tr>
<td>(e) Opportunity Costs and Restrictions</td>
<td>0.4474 ***</td>
<td>0.3826 ***</td>
<td></td>
</tr>
</tbody>
</table>

* $\alpha \leq 0.05$

** $df$ Mothers = 68, $df$ fathers = 49

*** Significant

For both mothers and fathers of children with autism, significant positive correlations were found between parents’ perceptions of the severity of their child’s developmental problems and all of their scores on the parental stress subscales. For mothers’ subscale (a) emotional benefits of parenting, the hypothesis was supported ($r_{cv \alpha=.05, df=68, one tailed} = 0.2319, r_{obs} = 0.3794$). For mothers’ subscale (b) self enrichment, the hypothesis was supported ($r_{cv \alpha=.05, df=68, one tailed} = 0.2319, r_{obs} = 0.4094$). For mothers’ subscale (c) personal development, the hypothesis was supported ($r_{cv \alpha=.05, df=68, one tailed} = 0.2319, r_{obs} = 0.4795$). For mothers’ subscale (d) demands on resources, the hypothesis was supported ($r_{cv \alpha=.05, df=68, one tailed} = 0.2319, r_{obs} = 0.3296$). For mothers’ subscale (e) opportunity costs and restrictions, the hypothesis was supported ($r_{cv \alpha=.05, df=68, one tailed} = 0.2319, r_{obs} = 0.4474$).

For fathers’ subscale (a) emotional benefits of parenting, the hypothesis was supported ($r_{cv \alpha=.05, df=49, one tailed} = 0.2732, r_{obs} = 0.5128$). For fathers’ subscale (b) self enrichment, the
hypothesis was supported ($r_{cv \alpha=.05, df=49, one\ tailed} = 0.2732, r_{obs} = 0.3917$). For fathers’ subscale (c) personal development, the hypothesis was supported ($r_{cv \alpha=.05, df=49, one\ tailed} = 0.2732, r_{obs} = 0.3543$). For fathers’ subscale (d) demands on resources, the hypothesis was supported ($r_{cv \alpha=.05, df=49, one\ tailed} = 0.2732, r_{obs} = 0.3112$). For fathers’ subscale (e) opportunity costs and restrictions, the hypothesis was supported ($r_{cv \alpha=.05, df=49, one\ tailed} = 0.2732, r_{obs} = 0.3826$). Overall results for Hypothesis 3 for this sample suggest a strong association between parents perceptions of the severity of their child with autism’s developmental problems and parental stress. Possible explanations for these results will be discussed in Chapter 5.

**Hypothesis 4: Number of Siblings in Home and Parenting Stress.** For both mothers and fathers of children with autism, it is expected that significant positive correlations will be found between the number of siblings in the home and parents’ scores on each of the following parental stress subscales: (a) emotional benefits of parenting, (b) self enrichment, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions. Results for Hypothesis 4 are summarized in Table 8.

For both mothers and fathers of children with autism, significant positive correlations were not found between the number of siblings in the home and scores on the parental stress subscales, with the exception of subscales (a) emotional benefits of parenting, and (b) self-enrichment for mothers. For mothers’ subscale (a) emotional benefits of parenting, the hypothesis was supported ($r_{cv \alpha=.05, df=68, one\ tailed} = 0.2319, r_{obs} = 0.3590$). For mothers’ subscale (b) self enrichment, the hypothesis was supported ($r_{cv \alpha=.05, df=68, one\ tailed} = 0.2319, r_{obs} = 0.3259$). For mothers’ subscale (c) personal development, the hypothesis was not supported ($r_{cv \alpha=.05, df=68, one\ tailed} = 0.2319, r_{obs} = 0.2143$). For mothers’ subscale (d) demands on resources, the hypothesis
### Table 8

**Hypothesis 4: Number of Siblings in Home and Parenting Stress**

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Pearson Correlation Coefficients *</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers / Number of Siblings **</td>
</tr>
<tr>
<td>(a) Emotional Benefits of Parenting</td>
<td>0.3590 ***</td>
</tr>
<tr>
<td>(b) Self Enrichment</td>
<td>0.3259 ***</td>
</tr>
<tr>
<td>(c) Personal Development</td>
<td>0.2143</td>
</tr>
<tr>
<td>(d) Demands on Resources</td>
<td>0.0345</td>
</tr>
<tr>
<td>(e) Opportunity Costs and Restrictions</td>
<td>0.1540</td>
</tr>
</tbody>
</table>

* \( \alpha \leq 0.05 \), one tailed

** df Mothers = 68, df fathers = 49

*** Significant

was not supported \( r_{cv} = 0.2319, r_{obs} = 0.0345 \). For mothers’ subscale (e) opportunity costs and restrictions, the hypothesis was not supported \( r_{cv} = 0.2319, r_{obs} = 0.1540 \).

For fathers’ subscale (a) emotional benefits of parenting, the hypothesis was not supported \( r_{cv} = 0.2732, r_{obs} = 0.1219 \). For fathers’ subscale (b) self enrichment, the hypothesis was not supported \( r_{cv} = 0.2732, r_{obs} = 0.2446 \). For fathers’ subscale (c) personal development, the hypothesis was not supported \( r_{cv} = 0.2732, r_{obs} = -0.0139 \). For fathers’ subscale (d) demands on resources, the hypothesis was not supported \( r_{cv} = 0.2732, r_{obs} = 0.1739 \). For fathers’ subscale (e) opportunity costs and restrictions, the hypothesis was not supported \( r_{cv} = 0.2732, r_{obs} = -0.0839 \).

Results for Hypothesis 4 suggest that, for this sample, there is no positive association between the number of siblings in the home and parent stress with the exception of the
Emotional Benefits and Self Enrichment subscales for mothers. Possible reasons why the number of children in the home does not appear to increase stress will be discussed in Chapter 5.

**Hypothesis 5: Parent’s Gender and Marital Satisfaction.** It is expected that mothers of children with autism will score significantly lower than fathers of children with autism on marital satisfaction. Results for Hypothesis 5 are summarized in Table 9.

Results for this hypothesis suggest that mothers of children with autism did not score significantly lower than fathers of children with autism on 7 elements of marital satisfaction. For item (a) intimacy, the hypothesis was not supported ($t(110) = -0.0184$, $p$ (1-tailed) = 0.4927). For item (b) communications, the hypothesis was not supported ($t(110) = 0.2204$, $p$ (1-tailed) = 0.4130). For item (c) resolution of differences, the hypothesis was not supported ($t(110) = -0.5463$, $p$ (1-tailed) = 0.293). For item (d) freedom of blaming my partner, the hypothesis was not supported ($t(110) = -1.2924$, $p$ (1-tailed) = 0.0995) For item (e) asking for forgiveness from my partner, the hypothesis was not supported ($t(110) = 0.0083$, $p$ (1-tailed) = 0.4967). For item (f) forgiving my partner, the hypothesis was not supported ($t(110) = -0.8050$, $p$ (1-tailed) = 0.2113). For item (g) commitment for the long term, the hypothesis was not supported ($t(110) = 0.8179$, $p$ (1-tailed) = 0.2076). Results for Hypothesis 5 suggest that mothers in this sample did not score significantly lower than fathers on a measure of marital satisfaction. Possible explanations for this lack of significant difference are discussed in Chapter 5.

**Hypothesis 6: Parental Stress and Marital Satisfaction.** For both mothers and fathers of children with autism, it is expected that significant inverse correlations will be found between parents’ marital satisfaction and their scores on the following parental stress subscales: (a) emotional benefits of parenting, (b) self enrichment, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions. Results for Hypothesis 6 are summarized in Table 10.
Table 9

_Hypothesis 5: Parent’s Gender and Marital Satisfaction_

_Mean Scores for Mothers and Fathers by Subscale (nMothers = 62, nFathers = 51)_

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Intimacy</td>
<td>4.11</td>
<td>4.12</td>
</tr>
<tr>
<td>(b) Communications</td>
<td>4.18</td>
<td>4.10</td>
</tr>
<tr>
<td>(c) Resolution of differences</td>
<td>4.08</td>
<td>4.26</td>
</tr>
<tr>
<td>(d) Freedom of blaming my partner</td>
<td>4.29</td>
<td>4.58</td>
</tr>
<tr>
<td>(e) Asking for forgiveness</td>
<td>4.74</td>
<td>4.74</td>
</tr>
<tr>
<td>(f) Forgiving my partner</td>
<td>4.90</td>
<td>5.10</td>
</tr>
<tr>
<td>(g) Commitment for the long term</td>
<td>5.85</td>
<td>5.59</td>
</tr>
</tbody>
</table>

_t Test For Comparing Two Sample Means, df = 111, α ≤ 0.05_

<table>
<thead>
<tr>
<th>Element</th>
<th>$t_{cv}$</th>
<th>$t_{obs}$</th>
<th>S/NS*</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Intimacy</td>
<td>1.66</td>
<td>–0.0184</td>
<td>NS</td>
</tr>
<tr>
<td>(b) Communications</td>
<td>1.66</td>
<td>0.2204</td>
<td>NS</td>
</tr>
<tr>
<td>(c) Resolution of differences</td>
<td>1.66</td>
<td>–0.5463</td>
<td>NS</td>
</tr>
<tr>
<td>(d) Freedom of blaming my partner</td>
<td>1.66</td>
<td>–1.2924</td>
<td>NS</td>
</tr>
<tr>
<td>(e) Asking for forgiveness</td>
<td>1.66</td>
<td>0.0083</td>
<td>NS</td>
</tr>
<tr>
<td>(f) Forgiving my partner</td>
<td>1.66</td>
<td>–0.8050</td>
<td>NS</td>
</tr>
<tr>
<td>(g) Commitment for the long term</td>
<td>1.66</td>
<td>0.8179</td>
<td>NS</td>
</tr>
</tbody>
</table>

* S/NS = Significant / Not Significant
Table 10

**Hypothesis 6: Parental Stress and Marital Satisfaction**

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Pearson Correlation Coefficients *</th>
<th>Pearson Correlation Coefficients *</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers / Marital Satisfaction **</td>
<td>Fathers / Marital Satisfaction **</td>
</tr>
<tr>
<td>(a) Emotional Benefits of Parenting</td>
<td>–0.4553 ***</td>
<td>–0.3878 ***</td>
</tr>
<tr>
<td>(b) Self Enrichment</td>
<td>–0.4283 ***</td>
<td>–0.4369 ***</td>
</tr>
<tr>
<td>(c) Personal Development</td>
<td>–0.4048 ***</td>
<td>–0.3257 ***</td>
</tr>
<tr>
<td>(d) Demands on Resources</td>
<td>–0.4070 ***</td>
<td>–0.3840 ***</td>
</tr>
<tr>
<td>(e) Opportunity Costs and Restrictions</td>
<td>–0.3413 ***</td>
<td>–0.2883 ***</td>
</tr>
</tbody>
</table>

* \( \alpha \leq 0.05 \), one tailed

** df Mothers = 68, df fathers = 49

*** Significant

For both mothers and fathers of children with autism, significant inverse correlations were found between marital satisfaction and their scores on all of the parenting stress subscales. For mothers’ subscale (a) emotional benefits of parenting, the hypothesis was supported (\( r_{cv} \alpha=0.05, df=68, one\ tailed = 0.2319, r_{obs} = -0.4553 \)). For mothers’ subscale (b) self enrichment, the hypothesis was supported (\( r_{cv} \alpha=0.05, df=68, one\ tailed = 0.2319, r_{obs} = -0.4283 \)). For mothers’ subscale (c) personal development, the hypothesis was supported (\( r_{cv} \alpha=0.05, df=68, one\ tailed = 0.2319, r_{obs} = -0.4048 \)). For mothers’ subscale (d) demands on resources, the hypothesis was supported (\( r_{cv} \alpha=0.05, df=68, one\ tailed = 0.2319, r_{obs} = -0.4070 \)). For mothers’ subscale (e) opportunity costs and restrictions, the hypothesis was supported (\( r_{cv} \alpha=0.05, df=68, one\ tailed = 0.2319, r_{obs} = -0.3413 \)).

For fathers’ subscale (a) emotional benefits of parenting, the hypothesis was supported (\( r_{cv} \alpha=0.05, df=49, one\ tailed = 0.2732, r_{obs} = -0.3878 \)). For fathers’ subscale (b) self enrichment, the hypothesis was supported (\( r_{cv} \alpha=0.05, df=49, one\ tailed = 0.2732, r_{obs} = -0.4369 \)). For fathers’ subscale (c)
personal development, the hypothesis was supported ($r_{cv \alpha=.05, df=49, one tailed} = 0.2732, r_{obs} = -0.3257$). For fathers’ subscale (d) demands on resources, the hypothesis was supported ($r_{cv \alpha=.05, df=49, one tailed} = 0.2732, r_{obs} = -0.3840$). For fathers’ subscale (e) opportunity costs and restrictions, the hypothesis was supported ($r_{cv \alpha=.05, df=49, one tailed} = 0.2732, r_{obs} = -0.2883$). Results for Hypothesis 6 suggest that there are significant negative associations for the parents in this sample between marital satisfaction and their scores on the five parental stress subscales. Possible explanations for these strong associations will be discussed in Chapter 5.
CHAPTER 5
DISCUSSION

The results presented in Chapter 4 provide some possible insight into the adjustment of parents who have a child diagnosed with an autism spectrum disorder. In this chapter, each of the six hypotheses will be considered followed by a discussion of possible limitations of the study. Finally, results from this study will be used to describe a model for intervention to assist parents and families of children with autism.

Hypothesis 1

Hypothesis 1 suggested that mothers of children with autism would score significantly higher on each of the five Parental Stress subscales than fathers. Subscale means were compared with the use of \( t \) tests. This hypothesis was supported with statistically significant higher scores for mothers for four of the five subscales. Subscales (a) emotional benefits, (c) personal development, (d) demands on resources, and (e) opportunity costs and restrictions yielded statistically significant differences. The hypothesis was not supported for (b) self enrichment.

These results may be more a function of gender related differences in emotional and behavioral responses to the diagnosis of the child’s disability than to a lack of emotional connection or participation on the part of fathers. High scores on the parent stress scale for fathers were higher than non-clinical samples as well, suggesting that fathers also experience the challenges of a child with autism.

The “emotional benefits” subscale deals with parental happiness, emotional closeness, and overt statements of stress. The \( t \) test yielded a significant higher score for mothers than fathers. This finding may be supported by the notion that mothers tend to respond more
emotionally to daily and ongoing life events. Further study is needed to explore this possibility. In addition, as noted earlier, mothers must manage multiple other responsibilities such as coordinating the child’s many therapy appointments with the needs of other family members. The fathers in the sample may also echo previous research and be more likely to express pragmatic concerns about long term consequences such as the financial impact of care across the life span or expectations for the child’s future (Seligman & Darling, 1997).

As noted in Chapter 4, a breakdown of percentages across parental stress items is provided in Appendix J. A closer examination of this appendix provides further insight into the above findings. Both mothers and fathers indicated financial concerns, but larger differences were observed regarding more emotionally laden issues such as 71.43% of mothers rating their child’s behavior as “embarrassing or stressful” as opposed to only 27.45% of fathers. There are a number of day-to-day situations that may heighten mothers’ emotional responses to situations involving children with autism. Mothers may be more likely to be out in public with their children than fathers as they typically provide the transportation for school and sport related activities for siblings, grocery shopping, and therapy appointments for the child with autism. In addition, it seems reasonable to conclude that mothers in the sample may have been experiencing ongoing stress with continued efforts to communicate effectively with their child with autism (Floyd & Gallagher, 1993; Harris & Glasberg, 2003).

The “self enrichment” subscale deals with parental enjoyment and satisfaction. Mothers’ and fathers’ scores were not statistically significant. This may be a product of consistent low enjoyment scores across the two groups. Just 7.14% of mothers responded “agree” or “strongly agree” to “I find my child enjoyable” while only 1.96% of fathers were able to do so. Likewise, 5.71% of the mothers and 3.92% of fathers expressed enjoyment in spending time with their child. The item “I am satisfied as a parent” yielded similar low scores with 11.43% of
mothers responding with “agree” or “strongly agree” and 7.84% of fathers. This result may be linked to the concept of chronic sorrow experienced by both genders even though mothers are reported to produce somewhat higher frequencies in measures of chronic sorrow (Lynch & Morley, 1995). Once again, these findings suggest that the low scores on this subscale across both groups and the resulting absence of significant difference are not about love, but rather stress related parental sadness and frustration. Further research is needed to explore this possible link.

The “personal development” subscale deals with the impact of the child with autism on the personal outlook and lifestyle of parents. The t tests yielded a statistically significant higher score for mothers than fathers. The mothers in the sample may feel responsible for establishing the psychosocial atmosphere in the family. The perceived responsibility for orchestrating the social and cognitive development of the child with autism, while at the same time attempting to meet the needs of other family members and lowering family stress levels, requires complex coping strategies (Blacher, 2002; Christensen et al., 1997; Landa, 2003; Remig, 2004; Russo-Sprouls & Porteus, 1998). The development and implementation of such strategies leaves little time for pursuing outside interests or even simple exercise. This dilemma may be reflected in this subscale. In addition, because the psychosocial atmosphere in the home impacts the development of children with disabilities (Floyd & Gallagher, 1997), a heightened concern with achieving or maintaining family well being can serve as an impetus for working toward pragmatic interventions that focus on solutions for unmet social and emotional needs.

The “demands on resources” subscale deals with concerns about providing for the child, financial issues, and parental responsibility. The t test yielded a statistically significant higher score for mothers than fathers. Though the results for item 11 “having a child has been a financial burden” suggest that both mothers and fathers in the sample were concerned about
financial issues, other resources such as time and energy (physical and emotional) may have been more relevant to mothers as the daily care giver. This imbalance in time spent with the child may be reflected in the significant results obtained for this subscale. In many cases, mothers must forgo or give up a career to care for the child (Lee, 2005; Remig, 2004) and some mothers’ responses may have been influenced by concern for siblings as well (Ehly, Conoley, & Rosenthal, 1985).

The “opportunity costs and restrictions” subscale deals with time and energy, balancing responsibilities, and considering, if offered the opportunity, whether or not parents would decide to have the child again. The \( t \) test yielded a statistically significant higher score for mothers than fathers and perhaps can be linked to “demands on resources.” In particular, it is possible that worry about whether or not everything possible is being done for the child, worry about meeting needs of other family members, worry about financial issues, the depletion of time and energy, as well as the struggle with balancing responsibilities can lead mothers to feel overwhelmed.

In summary, results for Hypothesis 1 suggest pronounced attitudes of stress (Floyd & Gallagher, 1997; Modrein & Robison, 1991; Robbins, Dunlap, & Plenis, 1991; Singer & Farkas, 1989) among mothers who participated in this study when compared to fathers. The results, however do not discount the presence or possibility of positive aspects of their family lives and levels of emotional connection (Singer & Farkas, 1989).

Hypothesis 2

Hypothesis 2 suggested that for both mothers and fathers, significant inverse correlations would be found between the age of the target child with autism and parents’ scores on each of the five Parental Stress subscales. This hypothesis was supported by only one significant inverse correlation between the age of the target child and mothers’ scores on the parental stress subscale.
(d) demands on resources. Interestingly, fathers’ subscales (c) personal development, and (e) opportunity costs and restrictions yielded significant positive correlations.

These results suggest something different from what was hypothesized. Further research is needed to explore the various factors that may influence the relationship between the age of a child with autism and parental stress. For example, the significant inverse correlation found among mothers for “demands on resources” may be related to their ability to make life adjustments over time to accommodate the various challenges associated with raising a child with autism. If true, identifying the types of adjustments made and the manner in which they are made would make a valuable contribution to our understanding of the impact of autism on mothers’ well-being.

The two significant positive correlations for fathers for “personal development” (which contains the financial piece and feeling overwhelmed) and “opportunity costs and restrictions” (which includes time, energy, and balancing responsibilities) may suggest a sense of discouragement and emotional exhaustion. Further study is needed to explore this unanticipated finding. Perhaps fathers are more easily discouraged by the various challenges associated with raising a child with autism over time, or lack the emotional support or coping mechanisms needed to make life adjustments. It is also possible that certain personality variables or other factors unique to this sample influenced the results obtained.

Finally, it is possible that the nonsignificant findings may simply highlight the ongoing stress that mothers and fathers with an autistic child experience, regardless of the child’s age. It is also possible that while the particular sources of stress may change as the child ages, they are equally stressful for mothers and fathers.

It is also possible that the scores of stress may differ over the time of childhood, but the intensity does not change. For instance, the demands of caregiving to meet physical needs may
be high in early childhood: yet the demands of adolescence and the forces of autonomy and independence as well as cognitive development processes may require high demands of parents as well.

Hypothesis 3

Hypothesis 3 suggested that for both mothers and fathers, significant positive correlations would be found between parents’ perception of the severity of the target child’s developmental problems and the parents’ scores on each of the five Parental Stress subscales. This hypothesis was supported with significant positive corrections found for mothers and fathers across all five subscales.

Parenting a child with autism entails significant extra challenges that tax every aspect of family life and every family member (Harris & Glasberg, 2003; Russo-Sprouls & Porteus, 1998. The results of this study suggest that the parents’ ongoing struggle against existing problematic dynamics may have become more prominent after the child’s formal diagnosis (Altmaier & Johnson, 1992). In addition, the results may be associated with social isolation and problems with communication within the family (Johnson, 1998). These possible associations are worthy of further study.

An excellent link for the results obtained for Hypothesis 3 is Roback’s (1984) five types of stressors for dealing with (medical) crisis, which can be applied directly to parents of children with autism. (a) *Intellectual stressors* related to the vast amount of information that parents must learn about autism can be linked to the “emotional benefits” subscale. Certainly, as parents in the study digested information about the initial diagnosis and subsequent therapy demands, such emotional issues as how they experienced their role as a parent or the stress incurred as a result of that role may have been closely associated with the severity of the child’s developmental problems (Harris & Glasberg, 2003; Johnson et al., 2004). (b) *Instrumental stressors* related to
the day-to-day activities for themselves and the rest of the family can be linked to the “personal
development” subscale. It seems reasonable to conclude that as parents in the study struggled to
effect some kind of continuity in daily life, dealing with their child’s autism and attendant
behaviors may have impacted their time, flexibility and world view, all of which is tied to their
child’s degree of disability (Pisula, 2003).

It is possible that (c) interpersonal stressors that are related to the consequential
disruptions of social relationships can be appropriately linked to the “self enrichment” subscale.
For example, if the child with autism has some language and is able to function in a mainstream
classroom for at least part of the day or with a facilitator, the parents may be likely to have a
reasonably enjoyable relationship with him/her. If, however, the level of impairment is such that
the child must be in a self contained classroom and the parent knows that when called to come
retrieve the child from school due to behavior, that he/she may face an afternoon of screaming
and biting, stress is likely to increase.

Roback’s (1984) (d) emotional stressors that are related to the parents’ psychological and
physical responses to the crisis can be linked to results for the “opportunity costs and
restrictions” subscale. It is possible that the parents in the study may have incurred increasing
amounts of stress that taxed their time and energy in balancing multiple responsibilities as the
degree of the child’s involvement rose (Lessenberry & Rehfelot, 2004). For instance, the more
difficult the child’s behavior, the more difficult finding willing or qualified childcare becomes.
Consequently, the number of responsibilities could increase with little respite.

Finally, (e) existential stressors related to parents’ questioning of their own meaning in
life, morals, and religious faith is aptly related to the “demands on resources” subscale. This
subscale includes considerable worry about meeting the child’s needs adequately, the possibility
of feeling overwhelmed by responsibility, and worry about financial issues. It can be argued that
such worries may be tied to existential issues concerning life and morality. Further, such worries may increase as the level of the child’s involvement on the autism continuum increases (Bouma & Schweitzer, 1990).

The values for Hypothesis 3 do not appear to be artificially large. A Bonferroni adjustment on the obtained values at a level of significance of 0.005 yielded all the values remaining statistically significant except “demands on resources” for fathers. However, consumers of correlational research such as social and medical scientists are well served to keep practical application in mind and to use additional techniques such as $r^2$ or tests for effect size to learn more about the strength of such relationships (Huck, 2000).

Hypothesis 4

Hypothesis 4 suggested that for both mothers and fathers, significant positive correlations would be found between the number of siblings in the home and the parents’ scores on each of the five Parental Stress subscales. This hypothesis was only supported on two subscales for mothers: (a) emotional benefits and (b) self enrichment. There were no significant correlations on number of siblings and stress for fathers.

With the two exceptions mentioned above, the results suggest that the parents in this study may not be experiencing significant stress that can be attributed to the number of children in the home. In the context of the significant scores on the “emotional benefits” and “self enrichment” subscales for mothers, one might imagine them to be a reflection of and linked to stress that is already in place in dealing with the child with autism. The former subscale includes statements of emotional connection such as “I am happy in my role as a parent,” and outright stress such as “the major source of stress in my life is my child.” The latter subscale contains two statements regarding enjoying one’s child and one of satisfaction in parenting.
Siblings can be caught up in a family’s chaos and experience difficulty accomplishing their own life tasks (Perry, 1997a). For instance, if the child with autism is having a difficult day behaviorally, and his/her older sibling has soccer practice or some other activity, the mother may be too exhausted or stressed to make one more drive. Or perhaps the child with autism has a therapy appointment and the sibling must miss the activity. Such situations can serve to upset both siblings and parents generating feelings of anger and frustration for siblings and guilt and depression for parents (Harris & Glasberg, 2003; Powell & Gallagher, 1993).

The other three subscales for mothers and all of the subscales for fathers yielded non-significant scores. This finding has important possible implications. Certainly, one can make a case for fathers not feeling the impact of siblings in the home as much because they may be home less and thus less likely to be dealing with day to day activity and/or crisis. But these values may also be linked to research that suggests that there are positive as well as negative effects to living as a sibling of a child with special needs, and that many children learn to live in, with, and around the various ups and downs of their sibling with autism. Further, the emotional adjustment of siblings with an autistic brother or sister is very much facilitated by parents who work very hard and are doing, for the most part, an excellent job of parenting (Cerreto & Miller, 1981; Harris & Glasberg, 2003; Lobato, 1990; McHale, Simeonson, & Sloan, 1984; Powell & Gallagher, 1993; Seligman, 1983; Senapti & Hayes, 1988; Simeonson & McHale, 1981).

The researcher’s own pilot study that served as a springboard for the current study echoed the above authors and suggested that siblings in that sample felt adequate levels of emotional adjustment and a sense of belonging (Perry, 2004). It seems safe to conclude, therefore, that the responses of parents on this subscale reflect a relative lack of stress associated with the number of children in the home and that in spite of encountered stressors associated with parenting the child with autism, they are maintaining some sense of stability in the home.
**Hypothesis 5**

Hypothesis 5 suggested that mothers of children with autism would score significantly lower than fathers of children with autism on marital satisfaction. Results for this hypothesis were very interesting and perhaps related to Hypothesis 4. This hypothesis was not supported on any one of the seven elements of the marriage satisfaction scale, as none of the scores approached significance. This suggests that marital satisfaction for mothers in this sample was not lower than fathers.

Even a well adjusted family can struggle with crisis, and when the crisis is ongoing developmental stages can be interrupted or truncated. How the family organizes around that crisis can determine the quality of the family atmosphere (Modrcin & Robison, 1991). Although mothers of children with autism often are primarily responsible for much of the logistic scheduling and behavior management (Floyd & Gallagher, 1997; Harris & Glasberg, 2003; Lee, 2005; Powell & Gallagher, 1993), the married mothers in this study may have felt that they were working together as a team with the child’s father to the extent that there was no resulting significant observable difference in their perceptions of the quality of or their commitment to the marriage. It is possible that fathers were participating as competent partners in the marriage in the midst of the challenges of parenting a child with autism. It is also possible that the parents in the study were aware of each others’ efforts to preserve the integrity of the family structure based on the organizational structure in place prior to the onset of the crisis event (Modrcin & Robison, 1991) and that this awareness influenced the mothers’ and fathers’ overall perception of the marriage relationship.

Though problems associated with parenting a child with significant behavior problems (such as a child with autism) are seen as a significant influence on marital adjustment (Lee, 2005; Modrcin & Robison, 1991; Remig, 2004), it is important not to seek out family pathology
or dysfunction (Christensen et al., 1997; McCubbin, 1989; Modrcin & Robison, 1991; Patterson, 1985; Rivera et al., 1996). Just as the results from Hypothesis 4 suggest that parental stress is not necessarily influenced by the number children in the home, and the descriptive results from the CARE instrument suggest similar levels of satisfaction for both mothers and fathers, the results for Hypothesis 5 suggest that although mothers may be experiencing stress in parenting their child with autism, they are maintaining and benefiting from their marriage while continuing to seek a balance between stressors and the marriage.

Hypothesis 6

Hypothesis 6 suggested that for both mothers and fathers significant inverse correlations would be found between marital satisfaction and the parents’ scores on each of the five Parental Stress subscales. This hypothesis was supported with significant values on each subscale for both mothers and fathers.

Even though the parents in this sample seem to be fundamentally satisfied in their marriages in an overall sense, the values reported here may be a reflection of daily stressors that can impact a parent’s sense of marital satisfaction. These values may also be related to all ten significant scores from Hypothesis 3 that expressed a relationship between parental stress and the severity of the child’s developmental problems. As parents are dealing with those problems on a daily basis, the ongoing tasks of marriage may well be impacted, negatively influenced, or interrupted altogether (Grych et al., 1992). For example, if the family is attempting to visit grandparents or extended family and the child with autism’s behavior is disruptive, the parent whose family it is may feel embarrassed and accuse his/her spouse of not trying hard enough to control the child. In such a scenario as this, if a conflict between the two parents ensues, the negative behavior of the child can be exacerbated in response to overt stress between the parents (Whittaker & Bry, 1991). In addition, if the extended family hold the parents responsible for the
child’s behavior or intimate that it may be due to aberrant parenting, stress in the marriage can be increased (Harris & Glasberg, 2003; Landa, 2003; Lee, 2005; Powell & Gallagher, 2003; Russo-Sprouls & Porteus, 1998).

For “emotional benefits,” and marital satisfaction the association for mothers was slightly higher than for fathers. This may be a reflection of mothers in the sample spending more time with the child in general than the father and therefore having more exposure to the child’s behavioral and communication challenges. The “self enrichment” subscale was negligibly higher for fathers and “personal development,” “demands on resources,” and opportunity costs and restrictions” were all slightly higher for mothers. This follows the pattern from Hypothesis 1 where all the $t$ scores were significantly higher for mothers except for “self enrichment.” These two findings may be related. Mothers in the sample may be experiencing their stress in parenting the child with autism as somewhat more highly associated with temporary drops in marital satisfaction than fathers, but the results for this hypothesis seem to suggest that both genders experience such drops at one time or another.

Another possible influence on the sample for this hypothesis is that all of the parents who participated in this study either had been or currently were seeking clinical help or attending a support group to learn better strategies to deal with marriage and parenting issues. Once again, these results may be significant to the parents who participated in this study and not artificially large. A Bonferroni adjustment on these values at a level of significance of 0.005 yielded all the values remaining statistically significant for mothers, and for fathers, a near miss for “personal development” and a weaker inverse correlation for “opportunity costs and restrictions.”
Limitations and Recommendations for Future Research

Several possible limitations emerge as relevant to this study. Possible selection bias, the researcher’s familiarity with some participants, and different settings for parents to complete their surveys were mentioned earlier. Those three and others will be discussed in this section.

Because only volunteer parents participated in this study, selection bias could be considered a factor that might limit the degree to which results of the study might be generalized to the wider population of families who have a child with autism. Pedhazur and Schmelkin (1991) observe that group membership in a quasi-experimental design (such as this study) is almost always a function of self selection (subjects choose to participate) and/or the researcher’s decisions dictated by pragmatic considerations such as participant availability, convenience, economic constraints or considerations, and/or administrative constraints. No matter what non-random selection process is used, there will “almost always” (p. 295) be a correlation between group membership and omitted relevant variables leading to possible bias in the analysis of results. The latter authors acknowledge the futility of attempting to resolve this conundrum noting that no (existing) analytic techniques can be counted on to make proper allowances for uncontrolled preexisting conditions. For instance, Lieberson (1985) pointed out that in an educational context, a statistical adjustment for initial differences in socioeconomic background of students in two types of schools is based on the unsupportable assumption that school selection is determined randomly within different socioeconomic strata without regard to other possible variables such as parental aspirations, racial attitudes, and perceptions of the child’s ability and motivation.

For this study, such an attempt might have omitted less obvious but still relevant variables such as differences in available resources, parental perceptions of the need for resources or research, and logistic factors that contribute to the complexity of a given family’s
daily life. Even a controlled environment such as a clinic population would not improve the situation as only a few families might be able to access (economically) a certain clinic or be relegated for the same reason to another. In addition, as a disability such as autism can strike any family in any circumstance (Ehly et al., 1985; Fialka, 1997; Floyd & Zmich, 1991; Klein, 1990; Modrcin & Robison, 1991; Remig, 2004; Tierney, 2004), the autism becomes the important common factor. Indeed, Lieberson (1985) observes that “under some conditions, the application of controls generates results that are actually further removed from the truth than would occur if no controls were applied whatsoever” (p. 22).

In the context of the current study, all of the above mentioned pragmatic considerations such as participant availability, convenience, economic constraints or considerations, and/or administrative constraints contributed to the researcher’s decision to use a non-randomized design as well. Even with the researcher’s clinical specialization in families of children with special needs, only a partial percentage of the entire caseload is represented by children with autism at any given time. Parents of children with autism are certainly not necessarily readily available in other venues. Administrative constraints/requirements in a school system or regional conference environment, for example, are fraught with multi-level, complex, permission and economic road blocks that can potentially add weeks or even months of time. Economic constraints include but are not necessarily limited to cost of travel. Thus, the parent groups for this study were gathered from reasonable multiple resources (groups) that were both available to and accessible by the researcher. Some target children and family environments were represented by two parents and others by only one. However, the study focuses on the individual parent’s perception of and relationship with his/her child with autism and any apparent differences between and relationships to stress for the two groups. In addition, parents worked independently and did not communicate with each other in any way while completing their surveys.
The second limitation is the researcher’s familiarity with some of the parents who participated in the study, with the concern being that parents might be invested in the relationship to an extent that could influence their responses to the surveys. Parents who are currently in therapy with the researcher come for purposes that may include learning strategies to improve the family’s ability to cope with the child with autism’s behavior, strategies to teach the child how to improve his or her behavior, resource coordination, consultation with school and classroom teachers, and any personal and family issues that may be impacting individuals, marriage, or family quality of life.

The researcher employs a solution focused, problem solving oriented, cognitive approach to therapy that is grounded in developmental and family systems theories and an educational model. When parents arrive for the initial intake session, they are given a document (which they must sign) that clearly states the parameters of the counselor/client relationship. This is used to help set clear boundaries and expectations for what the relationship will and will not be. Clients understand from the beginning that though they certainly will work hard and the relationship will be emotionally intimate, it will also be entirely confined to the office setting. The researcher believes that such clearly stated boundaries helped to avoid an undue desire to please on the parents’ part. In addition, as stated earlier, in order to minimize the risk of influencing responses the researcher was not in the room with current clients or any other participants while they were filling out their surveys. Former clients who had transitioned out of therapy completed their surveys at home away from the researcher altogether. Also, the study was focused in large part on the child with autism and the parent’s perception of that child. The researcher believes that parents are interested in having their voices heard and the reality of their situations understood. In a future replicated study, it might be possible to train volunteer data collectors who would be
unknown to participants if all of the attendant financial, legal, and logistic details could be resolved.

A third possible limitation was the different settings in which participants completed their surveys. This is a question of a possible environmental threat to validity. Huck (2000) observes that the concept of validity is well captured by the word accuracy and is a characteristic of the data produced by an instrument or instruments, not of the instrument itself. In a general sense, a researcher’s data may be considered valid and useful to the extent that the results of the measurement process are accurate. Huck (2000) suggests that participants used (by a researcher) and conditions under which measurements are collected should either be similar to or replicated in other studies. Hopefully this study can/will be replicated perhaps with two of the four types of settings to further control for environmental differences.

For the present study, the researcher attempted to control for environmental threats by establishing quiet, calm, and solitude as constants in each environment. Parents were encouraged to work alone in each setting, and in all but the home environment (former clients), the researcher was able to ensure the condition of the work environment. Former clients were encouraged to complete their surveys at home independently at a quiet, calm time. The pediatrician’s office has subdued lighting much like the researcher’s office, and fortunately one of the support group settings had such lighting as well. The other support group setting was marginally though not significantly brighter. Participant distribution across the potential groups was less varied than expected as only two parents utilized the pediatrician’s office. There were 29 current clients, and the rest of the sample was fairly evenly distributed between former clients and support group members. One additional limitation that emerged as specific to the current study was that the price of gasoline during the time data was being collected literally precluded
former clients at long distances from opting to visit the researcher’s office to participate as opposed to using the mail.

An additional possible limitation might include a relatively small sample size although the researcher was able to gain participation from 20 more mothers than the expected 50 and one more father to total 121 participants. The authors of the Parental Stress Scale, Berry and Jones (1995) had 75 mothers and 50 fathers for their initial scale development. The limitation of sample size could be addressed by using additional parent support groups, gaining permission to conduct research in a large conference setting, or through replication of the study.

Another possible limitation is the variability in presentations of autism that may or may not produce or influence different levels of stress in parents. This issue could be addressed by designing more narrowly focused studies that would, for instance, only include parents of children with Asperger’s or one of the other specifically identified types of autism. Such a model carries its own limitations, however, of expense and logistical challenges of time and identifying potential participants.

One final possible limitation that comes to mind is any personal health difficulties of parents that might influence levels of stress. For instance, the researcher is aware of one mother who has Parkinson’s disease, one with multiple sclerosis, and one father recently diagnosed with lupus. Obviously, such a situation might further complicate family dynamics and the individual’s world view. Perhaps, in a future study, some sort of brief, qualitative, narrative component could be added to the parent survey to assist the researcher in better understanding the individual contexts of participants.

As mentioned in both Chapters 3 and 4, the researcher is not aware of any other studies that employ a breakdown of the PSS into the five subscales. Thus, validity and reliability correlations for the subscales were not available. Consequently, results from this study should be
interpreted with some caution and perhaps an attempt to gain psychometric information for the subscales could be part of a future study. Also, future studies might be well served to use regression or factor analysis to search for specific predictors of stress or degree of importance of specific elements of stress.

Implications for Practice

A paradigm shift in physical and mental health care away from disease and illness and toward an emphasis on wellness, health, coping, and resilience is evident in contexts such as models for early intervention in natural environments and family based intervention strategies that focus on proactive problem solving (Allen & Perr, 1996; Dunst, Bruder, Trivette, & McLean, 2000; Eeltink & Duffy, 2004; Hepting & Goldstein, 1996; McWilliam, 1996; Myers, Sweeney, & Witmer, 2000; Simon, Murphy, & Smith, 2005). In fact, a pioneering thread can be drawn from the early work of Dunst and Trivette (1987) and Modrcin and Robison (1991) who sought to promote self reliance and positive self belief and to empower family members with skills and resources necessary to meet their own needs.

Program development for effective parent support initiatives related to autism is needed based on the results found in this study. Such efforts might be considered a critical need. For example, family social support has been found to protect siblings of children with mild to moderate presentations of autism from developing behavioral problems (Blacher & Hastings, 2005). Social support can be derived from external sources such as proactive, solution focused family intervention programs (Myers, 2003). For instance, fathers, whose reactions are significant in helping families cope with parenting a child with disabilities, may feel isolated if career demands prevent them from fully participating in the care of their child. This concept is reflected in the results for the overall stress scale scores and for Hypotheses 1 where fathers are showing stress but at a somewhat lower level than mothers. Fathers may benefit from an
opportunity to share their feelings, concerns, and ideas in a supportive environment. Likewise, mothers may benefit from programs that promote the development of strategies that may help to lower family stress and an opportunity for an exchange of behavioral strategies and resource information (Lekotek of Georgia, 2005-2006).

Resilient families seem to use a combination of individual, family, and community strengths and resources in adapting to stressful events. In addition to local and neighborhood resources such as schools and other community organizations, an effective development and use of health care and mental health care services appears to strengthen family resilience (McCubbin, Bailing et al., 2002; Simon, Murphy, & Smith, 2005). The parents in this study appear to be somewhat resilient as is reflected in the results for Hypotheses 4 and 5 and in the overall results for the marriage assessment. They are apparently able to handle multiple children and family life with relative success and are benefiting from their marriages. It seems appropriate to offer as a component of the current study a model for family intervention for children with autism and their families that is designed to build on that positive foundation. The model is based on the researcher’s belief and clinical experience that it is the point at which cognition changes that hope is engendered and forward movement for families begins to occur.

Traditional mental health intervention models for families have included (a) a focus on diagnosis as a prerequisite for effective treatment, (b) a focus on the past, (c) assumptions of underlying family pathology, (d) an assumption of family deficiency and need for outside expertise, (e) the role of practitioner as expert, (f) the clinician’s language is deficit oriented (i.e., focused on what is wrong) and interventions originate with the practitioner, (g) a focus on the nature of treatment as problem-focused and pathology driven with minimal use of external supports and resources, (h) a focus on desired outcome that will decrease family dysfunction (Simon, Murphy, & Smith, 2005). Dunst and Trivette (1987), with their Social Systems Model of
Family Functioning, began to attempt to shift the traditional model in a more proactive strength and resource-based direction in which the clinician serves as a collaborator and clients are encouraged toward self reliance and positive self belief.

The researcher’s Psychoeducational Problem Solving Model for special needs families (Perry, 1997b) evolved out of working with siblings of children with special needs and is based on the early work of Dunst and Trivette (1987). The researcher’s model is comprised of four phases: (a) Intake Phase: acknowledge the problem, articulate specific problem areas and issues, determine how specific problems are impacting current family functioning, (b) Problem Solving Phase: generate ideas for problem solving, (c) Practice Phase: try new techniques in safe places such as home, school, and with extended family, (d) Integration Phase: evaluate and make adjustments, generalize to other life experiences. The researcher finds this model to be effective with families of a child or children diagnosed with autism (adaptable also to group work) as it can facilitate not only dealing with child and respondent family behaviors, but encourage the development of more effective, proactive behaviors as well.

Since the early work of Dunst and Trivette (1987), additional models that echo their ideas (including their own recent work with early intervention in natural environments) have continued to emerge drawing the thread of this paradigm shift through to the present (Dunst et al., 2000; Eeltink & Duffy, 2004; Johnston & Zemitzsch, 1997; McCubbin & McCubbin, 1988; McCubbin, McCubbin, Thompson, & Thompson, 1995; Myers, 2003; Myers, Sweeney, & Whitmer, 2000; Simon, Murphy, & Smith, 2005). In the next section, the researcher’s model will be detailed and then summarized in Table 11 with the model from Dunst and Trivette (1987), Myers’ (2003) Wellness Model with Family Caregivers, and Simon, Murphy, and Smith’s (2005) Resilience-Oriented Model to demonstrate the continuation of this paradigm shift to current practice.
Table 11

Comparison of Social Systems Model of Family Functioning (Dunst & Trivette, 1987), Psychoeducational Problem Solving Model for Special Needs Families (Perry, 1997), A Wellness Model with Family Caregivers (Myers, 2003), and A Resilience-Oriented Model for Practice (Simon, Murphy, & Smith, 2005)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intake Phase</strong></td>
<td><strong>Intake Phase</strong></td>
<td><strong>Phase 1 - Introduction of the model</strong></td>
<td><strong>Identify and utilize family resources</strong></td>
</tr>
<tr>
<td>• Acknowledge the problem</td>
<td>• Articulate specific problem areas and issues</td>
<td>• Each component of the model is explained. Client asks questions to determine personal understanding of wellness concepts</td>
<td></td>
</tr>
<tr>
<td>• Determine how specific problems are impacting current family functioning</td>
<td>• Use evaluation instruments such as Kern Lifestyle Scale (Kern, 1995) and genogram</td>
<td><strong>Phase 2 - Assessment of wellness</strong></td>
<td><strong>Identify current and potential family strengths and resources</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Client asks specific questions to determine client's overall perceptions of his/her wellness. Use scaled instruments such as the Wellness Evaluation of Lifestyle (Myers, Sweeney, &amp; Whitmer, 1998) to evaluate specific areas of behavior and function</td>
<td>• Determine that problems indicate unsuccessful solution attempts (i.e., the family is stuck)</td>
</tr>
<tr>
<td><strong>Problem Solving Phase</strong></td>
<td><strong>Problem Solving Phase</strong></td>
<td><strong>Phase 3 - Designing and Implementing Wellness Intervention</strong></td>
<td><strong>Family is resourceful and capable of identifying and pulling together their own resources</strong></td>
</tr>
<tr>
<td>• Generate ideas for problem solving</td>
<td>• Include parent education</td>
<td>• Begin to make use of strengths and resources</td>
<td>• Collaborate with client. Language is strength oriented</td>
</tr>
<tr>
<td>• Include parent education</td>
<td>• Teach stress / time management skills</td>
<td>• Design and implement interventions for specific goals one or two at a time so as not to overwhelm the client</td>
<td></td>
</tr>
<tr>
<td>• Connect family to community resources</td>
<td>• Connect family to community resources</td>
<td>• Engage extended family and community resources</td>
<td>• Interventions emerge from the family's strength, resilience, and resources</td>
</tr>
<tr>
<td><strong>Practice Phase</strong></td>
<td><strong>Practice Phase</strong></td>
<td><strong>Practice Phase</strong></td>
<td><strong>Family displays solution-focused, strength-driven empowerment</strong></td>
</tr>
<tr>
<td>• Try new techniques in safe places such as home, school and with extended family</td>
<td>• Try new techniques in safe places such as home, school and with extended family</td>
<td>• Engage in time management so that time for tasks and leisure can be determined</td>
<td>• Family makes liberal use of external supports and resources</td>
</tr>
</tbody>
</table>
Psychoeducational Problem Solving Model for Special Needs Families

**Intake Phase**

*Families must first acknowledge the problem and admit that they are experiencing difficulty.* Families of children, teens, or adults with special needs are often unaware of their degree of stress or feel so overwhelmed that they enter the therapy setting with a sense of hopelessness and feeling powerless to help themselves (Myers, 2003; Schulz & Salthouse, 1999). They are often stuck in one stage or another of the grief process and require gentle assistance with facing reality (i.e., leaving denial) and fully experiencing their feelings of anger, frustration, and sadness regarding their child’s disability. A mobile serves as an excellent metaphor for illustrating the impact of crisis on the family system and the Bowen (Goldenberg & Goldenberg, 1991) continuum an excellent teaching tool for acknowledging family strengths and assets as well as helping family members discover independently that they are emotionally and behaviorally stuck. In this first part of the intake phase, strengths such as the relatively stable marriage and family life suggested by the results for Hypotheses 4 and 5 can be identified. Also, the significant stressors associated with parenting and the degree of impairment of the child with autism suggested by the results for Hypotheses 1, 2, 3, and 6 can be explored. For instance, the parents with the 21 year old son still at home might be able to identify and express their concern for his future and their own grief and frustration at the loss of their next developmental stage as a couple.

*Family members must identify and articulate specific problem areas.* For young children the play therapy setting is a powerful and appropriate venue for accomplishing this task and, especially for young children with autism, developing age appropriate play skills with which they can learn to communicate (Kottman, 1995; Landrith, 1991, 2001). Parents in this study
clearly indicated their concern with the development of functional communication with a
combined 73.55% of them listing “onset of speech” as a severe problem. During this part of the
intake, parents can begin to develop their wish list for what they hope to accomplish and to set
preliminary goals for achievement. In addition, the researcher uses the Kern Lifestyle Scale
(Kern, 1995) to assist parents in identifying and discovering behavioral and communication
patterns that may or may not be problematical in parenting or in the marriage or other family
relationships. The latter is an excellent tool for highlighting such things as the marriage and
sibling relationship strengths suggested by the mothers and fathers for this study or for beginning
to learn effective communication tools for expressing to each other their considerable concerns
suggested by, for example, the strong associations between level of impairment of the child with
autism and parental stress in Hypothesis 3.

_Families need to explore how crisis situations impact current functioning._ The use of a
genogram at this point in therapy allows parents to acknowledge their personal history and
possible origins of positive and negative behavioral patterns and generational trends (Dunn &
Levitt, 2000). An example of the efficacy of using a genogram with parents of children with
autism is that parents may feel reassured or gain a better understanding of their child’s autism by
seeing other related bioneurological conditions or other presentations of autism spectrum
disorders in other family members in different generations. This seems particularly relevant in
light of the stress reflected in the results for Hypothesis 3 and the impact of parenting the child
with autism on the marriage relationship suggested by the results for Hypothesis 6. Parents can
use information gained from the genogram to better comprehend family patterns which may help
to lower anxiety and stress and provide impetus for them to make a relatively stable family even
stronger. While not dwelling on the past, the genogram serves as an effective catalyst for and bridge to the Problem Solving Phase.

**Problem Solving Phase**

*Together, the family and the clinician will generate ideas for problem solving.* This is the workhorse section of the model. The Kern Lifestyle Scale (1995) and the genogram can be utilized for observations about communication skills which may or may not be working well for individual family members; discussion about necessary adjustments begin here.

Parent education is appropriately begun at this point if both the family dynamics and the corporate decision between the family and the clinician deem it to be potentially beneficial. The researcher uses STEP, Systematic Training for Effective Parenting (Dinkmeyer, McKay, Dinkmeyer, & McKay, 1997) either as a part of the counseling process or as a component of the regular parent consultation with play therapy. An example of the use of such techniques adapted for children with autism is encouraging and teaching non-verbal children to express choices by pointing and vocalizing in response to a visual cue as opposed to grunting, biting, or producing a tantrum. Parents in this study expressed great difficulty with enjoying their child with autism and mothers particularly experienced embarrassment with the child’s behavior in public. Parent education in this model is custom designed to teach parents that they *can* and must develop behavioral expectations for their child with autism. Parents learn how to equalize expectations across all of their children and to reframe their concept of the child with autism to focus on his/her strengths instead of deficits. For instance, parents can use a child’s singular interest in a particular animal to strengthen math or language skills and share their new techniques with the child’s classroom teacher.
Stress and time management skills are offered during this phase; prioritizing, financial issues, personal health and division of labor in the home are all addressed. Specific plans are generated for each of these issues. Such skills are particularly relevant to items associated with subscale (c) “personal development,” (d) “demands on resources,” and (e) “opportunity costs and restrictions.” Time for exercise can be carved out, a budget can be developed, and prioritizing can be taught, all designed to help families learn to lower their own stress level. Families are connected with or direct referrals made to additional appropriate resources in the community such as developmental pediatricians, special needs preschools, and auxiliary therapy programs.

**Practice Phase**

*Family members try new techniques in safe settings such as home or school and with extended family.* Parents and other family members implement new parenting techniques and communication skills with children and each other. They can train extended family members and other helpers and communicate more productively and effectively as equal team members with school and community resource personnel, and health professionals (Myers, 2003; Simon, Murphy, & Smith, 2005). For instance, siblings and extended family such as grandparents can be taught new communication techniques that are working with the child with autism, and invited to be team members by including them in such activities as speech therapy, IEP meetings, and parent and family autism support activities. Results for Hypothesis 1 suggest a possible sense of isolation for both mothers and fathers in that mothers may feel alone in their stress and fathers may have fewer opportunities or feel less comfortable expressing theirs. New parenting, communication, and behavioral techniques can help the whole family, including the child with autism, to feel and be more connected.
Integration Phase

Families evaluate progress and make adjustments. The researcher’s model calls for a constant ongoing evaluation of new techniques with the knowledge that any one approach will not necessarily be effective with or appropriate for a given family. Families learn flexibility and willingness to make changes and adjust priorities. Relationships in the immediate family can improve and stabilize. The researcher suggests weekly family meetings for the purpose of processing and evaluating progress (Dinkmeyer et al., 1997). The meetings can include fun activities designed to address some of the specific concerns expressed by the parents in subscale (b) “self enrichment” such as child enjoyment and parent satisfaction.

Families generalize their new skills to other life experiences. Individual family members expand the use of new techniques to personal and community resources. The parents who participated in this study apparently love all of their children and each other as is suggested by the results for Hypotheses 4 and 5. Successful progress to this point yields family members who feel strong enough to stabilize and encourage relationships with extended family and with social and professional contacts in the larger community (Myers, 2003). An example of this component in the context of the family of a child with autism is inviting a peer from school to play with the child in a safe community setting such as a restaurant with a play facility or community swimming pool, and eventually progress to inviting the new playmate to come play in the child’s home for gradually increased successful periods of time. Future studies can include empirical testing of such models.

Conclusion

This study sheds additional light on the emotional journey of mothers and fathers who are parenting a child diagnosed with an autism spectrum disorder. As they interact with and are
influenced by the family system, as well as advocate for their child, the shape and stages of their life course are influenced, and they learn to live in and around family choices which must be made. The three instruments that were used to gain insight for this study facilitated linking and connecting information from one to the other. It seems clear that though the parents were apparently experiencing some expected elements of emotional stress, just as clearly they appeared to be equipped with elements of emotional strength.

Results of the study suggest that levels of stress for mothers in areas of emotional benefits, personal development, demands on resources, and opportunity costs and restrictions were significantly higher than for fathers, but not in the area of self enrichment. However, scores of fathers suggest higher stress than for non-clinical samples using the PSS. Differences between mothers and fathers may be associated with emotional and behavioral responses to the child’s ongoing disability rather than a lack of interest on the part of the fathers in the study. However, both mothers and fathers expressed difficulty with enjoying their child with autism. This suggests that for mothers and fathers the stress of caring for a child with autism is so great that positive experiences with the child are difficult to access. It is possible that mothers in the sample felt responsible for maintaining a positive atmosphere in the home and that stress was reflected in the difference between their scores and the fathers’. In addition, there may have been an imbalance in mothers’ physical and emotional energy, as they tend to spend more time on daily care with the child than fathers. Significant levels of stress for mothers were suggested, but the possibility of positive aspects of family life and emotional connection were not discounted.

There was no support for the hypothesis that the level of stress reported by parents would decrease as their children with autism became older. Possible gender, personality, or other situational factors not addressed in this study may have influenced this outcome. It is also
possible that the lack of significant findings simply reflects a constant level of stress for mothers and fathers of a child with autism, regardless of the child’s age.

Parental stress appeared to be highly associated with the parents' perception of the level of severity of their child’s developmental problems. It is not difficult to imagine that every facet of personal and family life such as creating continuity, balancing responsibilities, or even finding respite or appropriate childcare is impacted by the daily challenges of caring for a child with autism. The level of stress for the parents in this study certainly appears to be significantly associated with their perceived degree of the child’s impairment. However, parental stress did not appear to be highly associated with the number of siblings in the home. Two exceptions for mothers in the study included the “emotional benefits” and “self enrichment” subscales of the parental stress instrument which include items associated with enjoying the child and parental satisfaction. The other three subscales (personal development, demands on resources, and opportunity costs and restrictions) did not show associations between number of siblings and stress for mothers and none of the values showed such associations for fathers. It seems reasonable to conclude that parents in the study were trying hard to create a positive home environment and to maintain some sense of stability apart from the autism related stress.

An important finding for this study is that not only did mothers in the study not express lower levels of marital satisfaction than fathers, but in fact, both groups expressed similar levels of satisfaction. It was concluded that mothers and fathers in the sample may have perceived themselves as working together as a team with both benefiting from the marital relationship. However, the daily stressors that can impact marital satisfaction in a given moment appear to be reflected in significant associations of high parenting stress and lowered marital satisfaction. It seems reasonable to connect these associations with the already established relationships
between parental stress and the severity of the child’s problems. It is not difficult to imagine that as day-to-day events occur that are impacted by dealing with the child’s autism, satisfaction with specific elements of marriage such as communication, intimacy, and forgiveness might fluctuate as well. Nevertheless, the parents in this study seem committed to staying the course together for the long term.

Despite having to control for some challenges such as possible selection bias, the results of this study provide useful insight into the life of the parents who participated in the study. Future studies may be well served to employ more rigorous statistical analysis for the purpose of identifying predictors or specific areas to be targeted for appropriate intervention. Nevertheless, the results of this study stand well together as a whole and support a need for appropriate models for assistance and intervention. In that context, a proactive, interactive, problem-solving model designed especially for parents and families of children with special needs was offered by the researcher to illustrate the efficacy of focusing on and making use of family strengths and community resources to improve family functioning and quality of life.

The conceptualization of disability as an attribute located solely within an individual is changing to a concept of interaction among the individual, the disability, and the environment, both social and physical (Smart & Smart, 2006). “The brain is made up of many different parts, containing many different abilities. Just because one area is affected doesn’t mean others are too” (Williams, 1992, p. 21). Parenting a child who has autism is challenging, difficult, and sometimes heartbreaking, but not impossible. It is a long and sometimes arduous road, but not necessarily endless. It is not without joy or hope. “It is about brains that work, nearly work, work differently, work slowly, work partly, and sometimes, work poetically” (Rader, 2004, p. 8).
Hopefully, this study contributes to the body of understanding about how those works impact parents and families and what effective strategies can be implemented to assist them.
REFERENCES


APPENDIX A

DEFINITIONS
Definitions

**Affective Anomalies:** A marked qualitative impairment in the use of multiple nonverbal behaviors such as eye contact, facial expressions, body positions, and gesturing to communicate meaningfully with others (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, 1994).

**Asperger’s disorder:** includes severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interests, and activities. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning but not the language and cognitive delays often associated with autism (DSM-IV, 1994).

**Autistic disorder:** The essential features of autistic disorder are the presence of markedly abnormal or impaired development in social interaction and communication and a significantly restricted repertoire of activities and interests. Presentations may vary greatly depending on the developmental level and chronological age of the individual (DSM IV, 1994).

**Childhood disintegrative disorder:** is characterized by a marked regression in multiple areas of functioning following a period of at least two years of apparently typical verbal and nonverbal, social, play, and adaptive development. After age 2 but before age 10, the child exhibits clinically significant losses in at least two of the above areas of developmental skills and/or bowel and bladder control and motor skills. The children exhibit the social and communicative deficits and behavioral features associated with autism. This disorder is associated with severe mental retardation (DSM IV, 1994).
Cognitive Delay: refers to significant delays in overall intellectual functioning and adaptive, and social/emotional skills that yield behaviors, responses, and levels of functioning that are not age appropriate or commensurate with the individual’s age peers (Batshaw & Perret, 1992).

Co-Morbid Diagnoses: are disorders (such as seizures) that have medical and treatment implications that are separate from those expected from a diagnosis of autism alone (Tierney, 2004).

Early Intervention Providers: provide and implement the various therapies (state or privately funded) that a child with one of the Pervasive Developmental Disorders might receive such as physical, occupational, speech and language therapies or special instruction. The parents and/or siblings may also receive mental health care in the form of marriage and family therapy, personal counseling, or play therapy. In addition, there is usually a service coordinator who provides resource information and support. Early intervention services usually apply from the birth of the referred child to the third birthday (Russo-Sprouls & Porteus, 1998).

Fetal Alcohol Syndrome (Fetal Alcohol Effects): is caused by maternal ingestion of alcohol during pregnancy especially in the first trimester. It is characterized by pre-and postnatal growth retardation, microcephaly (small head size), small eyes with droopy eyelids, joint abnormalities, congenital heart disease, and mild to moderate mental retardation (Batshaw & Perret, 1992).

Fragile X Syndrome: is a hereditary form of mental retardation most apparent in males that has been associated with an unusual fragile site on the X chromosome. Considered the most common form of mental retardation in males, it often includes physical features such as prominent jaw, large ears and testes, and mild connective tissue anomalies, macrocephaly, poor coordination, and mitral valve prolapse. Associated behaviors closely mimic those of autism (Batshaw & Perret, 1992).
**Metabolic Insufficiency:** occurs when at birth, infants are faced with the need to supply their own energy requirements for such things as body temperature, muscle activity, and other such metabolic needs. An example is hypoglycemia or low blood sugar (Batshaw & Perret, 1992).

**Neural Tube Defects:** or migrations refer to a group of congenital malformations of the vertebrae and spinal cord such as the most common form of spina bifida in which the malformed part of the spinal cord protrudes from the defective spine in a fluid filled sac (Batshaw & Perret, 1992).

**Neurodevelopmental Disorder:** Any compromise in brain related functioning whether acquired or congenital that results in delays in gross or fine motor skills, cognitive, social/ emotional, or adaptive skills that are not commensurate with an individual’s chronological peer group (Batshaw & Perret, 1992).

**Neurofibromatosis:** is an inborn error of metabolism causing multiple “nerve tumors” (Batshaw & Perret, 1992, p. 600) in the body and on the skin. If the tumors form in critical areas, they can cause serious disability or death. It can present with or without learning disability or mild mental retardation (Batshaw & Perret, 1992).

**Neurotransmitter Imbalance:** is a lack of or imbalance of a specific chemical (the neurotransmitter) that serves as a bridge for impulses in the brain to jump from one neuron to another across a junction thereby interrupting the delivery of brain messages to their intended destination (Batshaw & Perret, 1992).

**Obsessive Compulsive Disorder:** is a personality disorder characterized by recurrent, persistent ideas, thoughts, impulse or images that are experienced as intrusive and senseless. There can be repetitive, purposeful, and intentional behaviors performed in response to obsessions, according to certain rules, or in a stereotyped fashion. The obsessions cause marked distress, are time
consuming, and can significantly interfere with the individual’s normal routine or social
activities (Batshaw & Perret, 1992).

**Pervasive Developmental Disorders:** are characterized by significant and global impairments
or delays in more than one area of development such as reciprocal social interaction,
communication skills, and the presence of stereotypical behavior, interests, or activities
(behaviors). These impairments are deviant relative the individual’s developmental or mental
age. Pervasive Developmental Disorders include Autistic disorder, Rett’s disorder, Childhood
Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not
Otherwise Specified (PDDNOS). These disorders are sometimes observed with other medical
conditions such as chromosomal abnormalities or structural abnormalities of the central nervous
system (DSM IV, 1994).

**Pervasive Developmental Disorders Not Otherwise Specified:** is considered present when the
criteria are not met for Pervasive Developmental Disorder such as atypical autism because of late
onset or other atypical symptomology (DSM IV, 1994).

**Phenylketonuria:** is a single gene defect, a mistake in decoding the DNA message leading to
the production of a malfunctioning or defective enzyme and resultant inborn error of metabolism
in which the enzyme necessary for the breakdown of the amino acid, phenylalanine is not
produced. This condition can lead to mental retardation (Batshaw & Perret, 1992).

**Rett’s disorder:** is the development of multiple deficits after a period of typical functioning and
development after birth through the first five months. Between 5 and 48 months, head growth
decelerates and there is a loss of purposeful hand skills with the development of stereotyped
hand movements such as hand wringing or hand-washing. Other features include diminished
interest in the social environment, problems with coordination and gait, severe impairment in
expressive and receptive language skills, and severe psychomotor retardation. Rett’s disorder appears only in female children and is associated with severe or profound mental retardation (DSM IV, 1994).

**Seizure Disorder:** A seizure is a self-limited, repetitive, simultaneous electrical discharge from the neurons in the cortex of the brain (Clancy, 1990). Seizure disorders are often caused by developmental brain abnormalities, anoxia (lack of oxygen), hypoglycemia (low blood sugar), inborn errors of metabolism, trauma and infections (Batshaw & Perret, 1992).

**Sensory Integration Dysfunction:** is an inability of the brain to process sensory input from the individual’s environment quickly or efficiently enough to keep the individual comfortable. A range of disturbances are reported in children with autism: under-and oversensitivity to certain sounds, indifference to pain or illness, a preference for certain sensations such as taste and smell rather than touch or sound (Batshaw & Perret, 1992).

**Service Providers:** are professionally trained individuals such as physical, occupational, and speech therapists, special instructors, pediatric specialists such as developmental pediatricians, feeding and other behavioral specialists, and mental health professionals all of whom may at one time or another provide therapy or assistance to the child with autism or his/her family (Russo-Sprouls & Porteus, 1998).

**Tourette’s Disorder:** is characterized by multiple motor tics and one or more vocal tics. The tics occur many times a day for more than one year. There is never a tic free period of more than three consecutive months which can cause marked distress, or significant impairment in social, occupational, or other important areas of functioning. The onset is usually before 18 years of age.
**Tuberous Sclerosis:** Hypopigmented areas of skin, acne-like facial lesions in young children, infantile spasms, calcium deposits in brain with mild to moderate mental retardation ((Batshaw & Perret, 1992).
APPENDIX B

DIAGNOSTIC CRITERIA FOR PERVERSIVE DEVELOPMENTAL / AUTISM SPECTRUM

DISORDERS* AND FRAGILE X SYNDROME**
Diagnostic Criteria for Pervasive Developmental / Autism Spectrum Disorders*

and Fragile X Syndrome**

Diagnostic Criteria for Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3).

1. Qualitative impairment in social interaction, as manifested by at least two of the following:
   a. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   b. Failure to develop peer relationships appropriate to developmental level
   c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
   d. A lack of social or emotional reciprocity

2. Qualitative impairments in communication as manifested by at least one of the following:
   a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
   b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   c. Stereotyped and repetitive use of language or idiosyncratic language
d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
   a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   b. Apparently inflexible adherence to specific, nonfunctional routines or rituals
   c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)
   d. Persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder.

Diagnostic Criteria for Rett's Disorder

A. All of the following:
   1. Apparently normal prenatal and perinatal development
   2. Apparently normal psychomotor development through the first 5 months after birth
   3. Normal head circumference at birth

B. Onset of all of the following after period of normal development:
   1. Deceleration of head growth between ages of 5 and 48 months
   2. Loss of previously acquired purposeful hand skills between ages 5 and 30 months
      with the subsequent development of stereotyped hand movements (e.g., hand wringing or hand washing)
   3. Loss of social engagement early in the course (although often social interaction develops later)
   4. Appearance of poorly coordinated gait or trunk movements
   5. Severely impaired expressive and receptive language development with severe psychomotor retardation

Diagnostic Criteria for Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
   1. Expressive or receptive language
   2. Social skills or adaptive behavior
   3. Bowel or bladder control
   4. Play
   5. Motor skills

C. Abnormalities of functioning in at least two of the following areas:
   1. Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
   2. Qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped or repetitive use of language, lack of varied make-believe play)
   3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms

D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

Diagnostic Criteria for Asperger’s Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:
   1. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   2. Failure to develop peer relationships appropriate to developmental level
   3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest to other people)
   4. Lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
   1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   2. Apparently inflexible adherence to specific, nonfunctional routines or rituals
   3. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
   4. Persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Diagnostic Criteria for Pervasive Developmental Disorder Not Otherwise Specified

(Including Atypical Autism)

This category is used when there is severe and pervasive impairment in an individual’s development of reciprocal social interaction, verbal or nonverbal communication skills, or when the development of stereotyped behaviors, interests, and activities are present, but the criteria for another specific pervasive Developmental Disorder, Schizophrenia, or Schizotypal Personality Disorder, or Avoidant personality are not met. This category includes “atypical autism” (DSM-IV, 1994, p. 78) or presentations that do not meet the criteria for Autistic Disorder due to such features as late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

## Diagnostic Criteria for Fragile X Syndrome

### Physical findings in males with Fragile X Syndrome

<table>
<thead>
<tr>
<th>Finding</th>
<th>% of males affected</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prepubescent</strong></td>
<td></td>
</tr>
<tr>
<td>Protruding ears</td>
<td>70</td>
</tr>
<tr>
<td>High arched palate, flattened nasal bridge</td>
<td>50</td>
</tr>
<tr>
<td>Macrocephaly</td>
<td>40</td>
</tr>
<tr>
<td>Epicanthal folds / Simian creases</td>
<td>40</td>
</tr>
<tr>
<td>Poor coordination</td>
<td>50</td>
</tr>
<tr>
<td>Hyperextensible joints / hypotonia</td>
<td>20</td>
</tr>
<tr>
<td><strong>Postpubescent</strong></td>
<td></td>
</tr>
<tr>
<td>Elongated face/prominent jaw</td>
<td>48</td>
</tr>
<tr>
<td>Long ears</td>
<td>80</td>
</tr>
<tr>
<td>Macroorchidism</td>
<td>92</td>
</tr>
<tr>
<td>Mitral valve prolapse</td>
<td>80</td>
</tr>
</tbody>
</table>

### Cognitive and Behavioral Characteristics of Fragile X Syndrome in Young Children

<table>
<thead>
<tr>
<th>Parental concern</th>
<th>% of children affected</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Boys</strong></td>
<td></td>
</tr>
<tr>
<td>Mental retardation</td>
<td>80</td>
</tr>
<tr>
<td>Communication disorder</td>
<td>95</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>65</td>
</tr>
<tr>
<td>Poor eye contact</td>
<td>80</td>
</tr>
<tr>
<td>Self-stimulatory / autistic-like behavior</td>
<td>60</td>
</tr>
<tr>
<td>Condition</td>
<td>Percentage</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Discipline problems</td>
<td>60</td>
</tr>
<tr>
<td>Seizures</td>
<td>20</td>
</tr>
</tbody>
</table>

**Girls**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive deficits</td>
<td>10</td>
</tr>
<tr>
<td>Learning disability</td>
<td>20</td>
</tr>
<tr>
<td>Mild mental retardation</td>
<td>10</td>
</tr>
<tr>
<td>Abnormal speech patterns</td>
<td>30</td>
</tr>
<tr>
<td>Emotional disturbance</td>
<td>30</td>
</tr>
</tbody>
</table>

**Source: Batshaw & Perret (1992).**
APPENDIX C

COVER LETTER AND CONSENT FORM
Informed Consent

ELEMENTS OF EMOTIONAL STRESS IN PARENTS OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDERS: IMPLICATIONS FOR CLINICAL PRACTICE

Dear Participant:

Thank you for agreeing to participate in this study and complete the following questionnaires. Participation in this study will contribute to the growing body of research data designed to assist health care professionals and educators in understanding the complexity of parenting a child diagnosed with an autism spectrum disorder.

The purpose of this study is to attempt to determine levels of parental stress by exploring positive aspects of parenthood including emotional benefits, self-enrichment, and personal development and negative components including demands on resources, and opportunity costs, and restrictions) and to explore possible gender related differences in parental perspectives in those areas. It is hoped that results from this study will shed additional light on the emotional journey of parents who have children diagnosed with an autism spectrum disorder, provide a vehicle through which they may express how parenting that child/children impacts them emotionally, and provide an opportunity for them to assess their child descriptively.

This research project is being sponsored by the department of Child and Family Development at the University of Georgia. The project is being conducted by Judith M. Perry in partial fulfillment of a doctoral dissertation requirement. It is under the direction of Mrs. Perry’s advisor, Dr. Mick Coleman. The UGA Institutional Review Board has approved this project.
You will be given a packet containing two copies of this letter, four additional sheets, a restaurant coupon, and a pencil. On the first of the additional sheets, you will complete confidential information about yourself. On the second, you will complete a small 18 item survey and provide a brief multiple choice description of your “target” child with autism. If you are parenting more than one child with autism, please identify the one child who is most involved on the spectrum (with the most challenging behaviors) as your “target” child. If married, there is an additional 7 item survey. Total time should be 12 to 20 minutes. If you are completing your packet in person, you may put your sheets into the box provided upon completing them. If you are completing them in a pediatric medical office, you may put completed packets into the provided box. If you are completing them at home, you may return them to me along with your consent form in the self-addressed stamped envelope included in your packet. In all cases, you will retain one of the two copies of this consent form for your records.

Your participation in this project is entirely voluntary. Because some of the questions will ask you about your feelings, you may become uncomfortable when answering them. That is understandable. You may skip any questions that you do not feel comfortable answering, and you may stop at any time. If you are completing your surveys in person, I will be available should you feel that you need assistance. If you are completing them at home or in a pediatric medical office, I will be available through my answering service at the number listed below. In addition, I am providing a referral list for your general information. The findings from this study will be analyzed together as a group.

Information obtained from this study is confidential and will be used only for research purposes. You will not use your name anywhere on the instrument sheets. In order to ensure privacy, all materials other than this letter/consent form will be coded with identification
numbers rather than names and will be stored in a locked office. The deidentified data will be kept for not less than three years there will be no master lists that link names to the data.

If you have any questions or concerns about this research, please contact Judy Perry at 770-395-0990 or Dr. Mick Coleman at 706-542-4899.

Thank you for agreeing to participate. Enjoy your dinner out and your new pencil!

I have read the above statement and I understand that I can stop answering the questionnaires at any time. My signature below indicates that the researchers have answered all of my questions to my satisfaction and that I consent to volunteer for this study. I have been given a copy of this form.

_______________________  ____________________  ____________
Print Name                Signature               Date

_______________________  ____________________  ______________
Principal Investigator    Signature               Date

770-395-0990
jmperry1@mindspring.com

Judith M. Perry, LPC: 770-395-0990, ext. 1
Dr. Kelly Ritter, LPC: 770-395-0990, ext. 2
Warren D. Jacobs, MD: 404-237-3371, ext. 3
Mary Griffin-Carlson, MFT, 404-843-9072

UGA IRB Approved
Date: 10/27/05
Expires
Date: 10/26/06
Additional questions regarding your rights as a research participant should be addressed to The Chairperson, Institutional Review Board, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia, 30602-7411; Telephone (706) 542-3199; e-mail address IRB@uga.edu.
APPENDIX D

PARENT SURVEY
Thank you again for your willingness to participate in this study. Please complete the following information. Please **DO NOT** include any names on this sheet.

1. **Background Information**
   a) Your gender: Male ____ Female _____
   b) Your age: ____
   c) Your family structure (Please check one):
   - ____ Single-parent
   - ____ Married, both parents are the biological parents of all children residing in the home
   - ____ Stepfamily / blended family, both parents are not necessarily the biological parents of all children residing in the home
   - ____ Foster or adoptive parents
   - ____ Grandparents serving in primary caregiver role
   d) Age of target child with autism (the one with the most severe diagnosis): ____
   e) Number/ages of all additional children in the home: Number ____
   Ages ____ ____ ____

(PLEASE CONTINUE ON NEXT PAGE)
2. **Your Assessment of the Behavior of Your Child with Autism** *

Does your target child with autism experience problems in the behavior areas listed below? Please check the problem level in each area that best applies to your child.

<table>
<thead>
<tr>
<th>Behavior area</th>
<th>No</th>
<th>Minor/mild</th>
<th>Definite/severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gross and fine motor skills</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Attention</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Activity level</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Impulse control</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Intellectual ability</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Impaired learning</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Onset of speech</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Tics (repetitive behaviors)</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Obsessive/compulsive behaviors</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Affective (eye contact, gesturing etc)</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Social interaction</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
<tr>
<td>Restricted interests</td>
<td>()</td>
<td>()</td>
<td>()</td>
</tr>
</tbody>
</table>

3. **Your relationship with Your Child with Autism** **

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of your relationship with your child with autism who has the most severe diagnosis. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.
1 = Strongly Disagree  2 = Disagree  3 = Undecided  4 = Agree  5 = Strongly Agree

____ 1. I am happy in my role as a parent.
____ 2. There is little or nothing I wouldn’t do for my child if it was necessary.

(PLEASE CONTINUE ON NEXT PAGE)

1 = Strongly Disagree  2 = Disagree  3 = Undecided  4 = Agree  5 = Strongly Agree

____ 3. Caring for my child sometimes takes more time and energy than I have to give.
____ 4. I sometimes worry whether I am doing enough for my child.
____ 5. I feel close to my child.
____ 6. I enjoy spending time with my child.
____ 7. My child is an important source of affection for me.
____ 8. Having child gives me a more certain and optimistic view for the future.
____ 9. The major source of stress in my life is my child.
____ 10. Having child leaves little time and flexibility in my life.
____ 11. Having child has been a financial burden.
____ 12. It is difficult to balance different responsibilities because of my child.
____ 13. The behavior of my child is often embarrassing or stressful to me.
____ 14. If I had it to do over again, I might decide not to have child.
____ 15. I feel overwhelmed by the responsibility of being a parent.
____ 16. Having child has meant having too few choices and too little control over my life.
____ 17. I am satisfied as a parent.
____ 18. I find my child enjoyable.

(ONLY ONE MORE PAGE. PLEASE CONTINUE TO LAST PAGE)
4. Your Relationship with your Spouse ***

This final survey is for married parents and guardians who live with their spouse. Below, you are asked to assess your relationship with your spouse, using the 7-point scale provided at the top of the survey. Please circle one response for each item.

<table>
<thead>
<tr>
<th>Couldn’t Be</th>
<th>Not Bad, Not Good</th>
<th>Couldn’t Be</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worse</td>
<td>Better</td>
<td></td>
</tr>
</tbody>
</table>

1. Intimacy 1 2 3 4 5 6 7

2. Communications 1 2 3 4 5 6 7

3. Resolution of differences 1 2 3 4 5 6 7

4. Freedom of blaming my partner when things go wrong 1 2 3 4 5 6 7
5. Willingness to admit to my
   partner when having hurt 1 2 3 4 5 6 7
   my partner and to ask for
   forgiveness

6. Ability to forgive my
   partner after a hurt 1 2 3 4 5 6 7

7. Commitment to my
   partner for the long term 1 2 3 4 5 6 7

Again, thank you participating in this study!


** Berry & Jones (1995)

*** Worthington et al (1997)
APPENDIX E

TEXT FOR RECRUITING PARTICIPANT(S) IN PERSON
Text for Recruiting Participant(s) In Person

You are aware that we are working together, in part, because you are parenting a child diagnosed with an autism spectrum disorder. I am also focusing my doctoral research on the experience of parenting a child with autism. I want to invite you to participate. I wonder if you might be willing to fill out two short survey sheets. They will require about 10 minutes of your time. There is an informed consent letter (two copies) for you to read and sign which will take about two additional minutes for a total of approximately 12 minutes. After you read the letter, if you have any questions, I will be happy to answer them. You will retain one copy of the consent form for your records. Your decision to participate or not will in no way affect our ongoing work together. Would you like to participate?

If the client agrees:

You may choose to work in the workroom on the table or out in the waiting room. When you are finished, you can put your completed sheets in the box on the corner of the workroom table. I will be available if you need assistance. Thank you so much for your participation.

If the client does not agree:

Thanks for allowing me to tell you about my study and ask for your participation. Please take a restaurant coupon and (one) of the new pencils home with you. I’ll see you at our next appointment.
APPENDIX F

TEXT FOR RECRUITING FORMER CLIENTS BY TELEPHONE AND TEXT FOR FOLLOW-UP CALL
Text for Recruiting Former Clients by Telephone and Text for Follow-Up Call

Hello. This is Judy Perry. I hope I’ve caught up with you at a good time. If not, we can arrange a better time for me to call you back.

It’s nice to reconnect with you. If you remember, several months (years) ago we were working together to assist you with parenting your child with autism. Currently, I am focusing my doctoral research on the experience of parenting a child with autism. I want to invite you to participate. I wonder if you might be willing to fill out two short survey sheets. They will require about 10 minutes of your time. There is an informed consent letter for you to read and sign which will take about two additional minutes for a total of approximately 12 minutes. After you read the letter, if you have any questions, I will be available by phone or in person (depending on how you choose to participate) to answer them. Many potential questions are addressed in the letter. You will retain one copy of the letter for your records. Your decision to participate or not will in no way affect any potential work we might do together. Would you like to participate?

If the former client agrees:

Thank you for agreeing to participate. There are two options for how to go about completing your surveys. You may come by the office to complete them or choose for me to mail them to you.
If the former client chooses the office option:

Let’s arrange a time for you to come. When would be convenient? When you come, you may choose to work in the workroom on the table or out in the waiting room. When you are finished, you can put your completed sheets in the box on the corner of the workroom table. I will be available if you need assistance. Remember to keep one copy of the consent form for your records. Thank you so much for your participation.

If the former client chooses the mail option:

I need to confirm your mailing address. I will put your packet(s) in the mail to you this afternoon. When you receive them, if you need assistance, I will be available by phone. My contact number will appear in the resource information at the end of the letter. If you need immediate attention, dial that number and follow the directions for “an emergency” which are to “press zero.” My answering service will take your call and page me. After signing the forms and completing the surveys, please put them into the stamped addressed envelope included and post them in whatever way is most convenient for you within one week. Please remember to retain one copy of the consent form for your records. You may choose to receive a follow-up call from me within one week of completing your surveys. If so, let’s arrange a time for that now. Thank you again for agreeing to participate.

If the former client chooses not to participate:

It sounds like you would rather not participate. I would like to send you a restaurant coupon and one of the pencils we are using anyway. Thank you very much for taking my call.
Text for Follow-Up Call

Hello. This is Judy Perry. A couple of weeks ago you agreed to participate in my study and I sent you two surveys regarding your experience in parenting a child with autism in the mail. You requested a follow-up call and this is that scheduled call. I wonder if you have any questions or concerns following the completion of your surveys. Are there any additional resources that you need? (Upon the participant’s answer) I would like to thank you again very much for your participation.
APPENDIX G

TEXTS FOR CONTACT CALL TO GROUP CHAIRPERSONS, FOR INTRODUCING STUDY TO PARENTS PARTICIPATING IN AUTISM SPECTRUM PARENT SUPPORT GROUPS, AND NOTE OF THANKS
Texts for Contact Call to Group Chairpersons, for Introducing Study to Parents Participating in Autism Spectrum Parent Support Groups, and Note of Thanks

**Contact call to chairperson:**

Hello. This is Judy Perry. Several weeks (months) ago when I spoke at the Early Intervention conference, you offered your assistance and that of your parent group for my potential study about the experience of parenting a child with an autism spectrum disorder. I am ready to collect my data and wonder if we can pre-determine the best month (and the next best) for me to come that will cause the least interruption in your planned schedule of activities. First, please re-check with your membership to be sure that they are in agreement that I may come. I will assure them that they can choose not to participate but you may want to do that as well. Once you have their permission, please call and leave me a message to confirm the date, time, and directions. I will need a maximum of 15 minutes of your meeting time. Thank you very much for your time and for offering your assistance to me.

**Introduction to parents participating in autism spectrum support groups**

Good evening. I’m Judy Perry. I know your chairperson has told you that I would be here tonight, but I want to tell you a little about my study before we start and give you a chance to ask any questions you may have before we begin. I am focusing my research on the experience of parenting a child diagnosed with an autism spectrum disorder which includes all of us here. I hope that this project will add to research literature designed to assist clinicians and educators with understanding the complexity of parenting a child with autism. The project is in partial fulfillment of a doctoral dissertation requirement. Certainly, you may choose not to participate. You may choose just to receive the pencil and restaurant coupons that are included in the
packets. If you do choose to participate, there are two copies of a cover letter/consent form included that should answer most of your questions. If you have additional questions or concerns, I will be available while you are working. Completion of the cover letter/consent forms and the two surveys should take you about 10 to 12 minutes. Please remember to retain one copy of the consent form for your records. Thank you so much for allowing me to come. Packets are in this box which I will pass around. Please take one. I will put the box on the table by the door.

If you choose to participate, put your completed sheets back in the envelope and into the box when you finish. If you choose not to participate, please remove the restaurant coupon and pencil, then return the packet to the box.

Thanks again.
Note of thanks:

Atlanta Relationship Center

1530 Dunwoody Village Parkway, Suite 207

Atlanta, Georgia, 30338

770-395-0990, FAX, 770-395-6511

Date

Dear (Name of Chairperson)

Thank you so very much for allowing me to come to your meeting to collect data for my study about the experience of parenting a child with autism. I am grateful for your effort in helping to coordinate it and for your members’ willingness to have me. Please convey my appreciation to all of them.

I always enjoy visiting with your group and will welcome another opportunity to serve as a guest speaker should you have such a need. Thanks again for your help.

Sincerely,

Judith M. Perry, LPC
APPENDIX H

FLIER FOR RECRUITING PARTICIPANTS IN PEDIATRIC MEDICAL FACILITY
Flier for Recruiting Participants in Pediatric Medical Facility

Parents of Children with
Autism Spectrum Disorders
Are Invited to Participate
In a Study
Investigating the Experience of
Parenting a Child with Autism.
A Research Project of
Judith M. Perry, LPC
Doctoral Candidate
Department of Child and Family Development
The University of Georgia
Under the Direction of
Dr. Mick Coleman

Total time required: 10-12 minutes
If interested, please see Becky or Sue.
Thank you, thank you, thank you!
Dear Becky and Sue,

Thanks so very much for your ongoing assistance with my project. I know how busy you both are and I really appreciate your willingness to house my survey packets, give them to interested parents, and oversee them getting safely into the box, and gather names of parents who wish to have a follow-up call. I hope that I did not cause you any undue inconvenience.

Thanks for all you do on behalf of the children Dr. N and I both see. I appreciate you both and I know the children’s parents do as well.

Sincerely,

Judith M. Perry, LPC
APPENDIX I

SUMMARIZED PERCENTAGE RESPONSE DATA – MODIFIED INTERNATIONAL CLASSIFICATION OF FUNCTIONING DISABILITY AND HEALTH CLASSIFICATION SYSTEM
Modified International Classification of Functioning Disability and Health Classification System

Percentage Results for Mothers ($n = 70$)

<table>
<thead>
<tr>
<th></th>
<th>Percentage of Mothers Scoring a “1” (No)</th>
<th>Percentage of Mothers Scoring a “2” (Minor / Mild)</th>
<th>Percentage of Mothers Scoring a “3” (Definite / Severe)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gross and fine motor skills</td>
<td>27.14%</td>
<td>57.14%</td>
<td>15.71%</td>
</tr>
<tr>
<td>Attention</td>
<td>1.43%</td>
<td>24.29%</td>
<td>74.29%</td>
</tr>
<tr>
<td>Activity level</td>
<td>17.14%</td>
<td>47.14%</td>
<td>35.71%</td>
</tr>
<tr>
<td>Impulse control</td>
<td>12.86%</td>
<td>24.29%</td>
<td>62.86%</td>
</tr>
<tr>
<td>Intellectual ability</td>
<td>34.29%</td>
<td>47.14%</td>
<td>18.57%</td>
</tr>
<tr>
<td>Impaired learning</td>
<td>12.86%</td>
<td>50.00%</td>
<td>37.14%</td>
</tr>
<tr>
<td>Onset of speech</td>
<td>10.00%</td>
<td>17.14%</td>
<td>72.86%</td>
</tr>
<tr>
<td>Tics / repetitive behaviors</td>
<td>35.71%</td>
<td>45.71%</td>
<td>18.57%</td>
</tr>
<tr>
<td>Obsessive / compulsive behaviors</td>
<td>15.71%</td>
<td>45.71%</td>
<td>38.57%</td>
</tr>
<tr>
<td>Affective (eye contact, gesturing, etc.)</td>
<td>2.86%</td>
<td>42.86%</td>
<td>54.29%</td>
</tr>
<tr>
<td>Social interaction</td>
<td>0.00%</td>
<td>28.57%</td>
<td>71.43%</td>
</tr>
<tr>
<td>Restricted interests</td>
<td>2.86%</td>
<td>22.86%</td>
<td>74.29%</td>
</tr>
</tbody>
</table>
Modified International Classification of Functioning Disability and Health Classification System

Percentage Results for Fathers ($n = 51$)

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage of Fathers Scoring a “1” (No)</th>
<th>Percentage of Fathers Scoring a “2” (Minor / Mild)</th>
<th>Percentage of Fathers Scoring a “3” (Definite / Severe)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gross and fine motor skills</td>
<td>41.18%</td>
<td>50.98%</td>
<td>7.84%</td>
</tr>
<tr>
<td>Attention</td>
<td>9.80%</td>
<td>35.29%</td>
<td>54.90%</td>
</tr>
<tr>
<td>Activity level</td>
<td>19.61%</td>
<td>37.25%</td>
<td>43.14%</td>
</tr>
<tr>
<td>Impulse control</td>
<td>15.69%</td>
<td>29.41%</td>
<td>54.90%</td>
</tr>
<tr>
<td>Intellectual ability</td>
<td>39.22%</td>
<td>41.18%</td>
<td>19.61%</td>
</tr>
<tr>
<td>Impaired learning</td>
<td>19.61%</td>
<td>54.90%</td>
<td>25.49%</td>
</tr>
<tr>
<td>Onset of speech</td>
<td>3.92%</td>
<td>21.57%</td>
<td>74.51%</td>
</tr>
<tr>
<td>Tics / repetitive behaviors</td>
<td>47.06%</td>
<td>37.25%</td>
<td>15.69%</td>
</tr>
<tr>
<td>Obsessive / compulsive behaviors</td>
<td>33.33%</td>
<td>41.18%</td>
<td>25.49%</td>
</tr>
<tr>
<td>Affective (eye contact, gesturing, etc.)</td>
<td>3.92%</td>
<td>52.94%</td>
<td>43.14%</td>
</tr>
<tr>
<td>Social interaction</td>
<td>5.88%</td>
<td>23.53%</td>
<td>70.59%</td>
</tr>
<tr>
<td>Restricted interests</td>
<td>3.92%</td>
<td>33.33%</td>
<td>62.75%</td>
</tr>
</tbody>
</table>
Modified International Classification of Functioning Disability and Health Classification System

Percentage Results for All Parents ($n = 121$)

<table>
<thead>
<tr>
<th></th>
<th>Percentage of Parents Scoring a “1” (No)</th>
<th>Percentage of Parents Scoring a “2” (Minor / Mild)</th>
<th>Percentage of Parents Scoring a “3” (Definite / Severe)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gross and fine motor skills</td>
<td>33.06%</td>
<td>54.55%</td>
<td>12.40%</td>
</tr>
<tr>
<td>Attention</td>
<td>4.96%</td>
<td>28.93%</td>
<td>66.12%</td>
</tr>
<tr>
<td>Activity level</td>
<td>18.18%</td>
<td>42.98%</td>
<td>38.84%</td>
</tr>
<tr>
<td>Impulse control</td>
<td>14.05%</td>
<td>26.45%</td>
<td>59.50%</td>
</tr>
<tr>
<td>Intellectual ability</td>
<td>36.36%</td>
<td>44.63%</td>
<td>19.01%</td>
</tr>
<tr>
<td>Impaired learning</td>
<td>15.70%</td>
<td>52.07%</td>
<td>32.23%</td>
</tr>
<tr>
<td>Onset of speech</td>
<td>7.44%</td>
<td>19.01%</td>
<td>73.55%</td>
</tr>
<tr>
<td>Tics / repetitive behaviors</td>
<td>40.50%</td>
<td>42.15%</td>
<td>17.36%</td>
</tr>
<tr>
<td>Obsessive / compulsive behaviors</td>
<td>23.14%</td>
<td>43.80%</td>
<td>33.06%</td>
</tr>
<tr>
<td>Affective (eye contact, gesturing, etc.)</td>
<td>3.31%</td>
<td>47.11%</td>
<td>49.59%</td>
</tr>
<tr>
<td>Social interaction</td>
<td>2.48%</td>
<td>26.45%</td>
<td>71.07%</td>
</tr>
<tr>
<td>Restricted interests</td>
<td>3.31%</td>
<td>27.27%</td>
<td>69.42%</td>
</tr>
</tbody>
</table>
APPENDIX J

SUMMARIZED PERCENTAGE RESPONSE DATA – PARENTAL STRESS SCALE
## Parental Stress Scale

### Percentage Results for Mothers (n = 70)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Percentage of Mothers Scoring a &quot;1&quot; (Strongly Disagree)</th>
<th>Percentage of Mothers Scoring a &quot;2&quot; (Disagree)</th>
<th>Percentage of Mothers Scoring a &quot;3&quot; (Undecided)</th>
<th>Percentage of Mothers Scoring a &quot;4&quot; (Agree)</th>
<th>Percentage of Mothers Scoring a &quot;5&quot; (Strongly Agree)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am happy in my role as a parent</td>
<td>15.71%</td>
<td>52.86%</td>
<td>10.00%</td>
<td>20.00%</td>
<td>1.43%</td>
</tr>
<tr>
<td>There is little or nothing I wouldn't do for child if it was necessary</td>
<td>57.14%</td>
<td>37.14%</td>
<td>5.71%</td>
<td>0.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Caring for my child sometimes takes more time and energy than I have to give</td>
<td>0.00%</td>
<td>4.29%</td>
<td>0.00%</td>
<td>34.29%</td>
<td>61.43%</td>
</tr>
<tr>
<td>I sometimes worry whether I am doing enough for my child</td>
<td>2.86%</td>
<td>1.43%</td>
<td>4.29%</td>
<td>48.57%</td>
<td>42.86%</td>
</tr>
<tr>
<td>I feel close to my child</td>
<td>40.00%</td>
<td>45.71%</td>
<td>11.43%</td>
<td>2.86%</td>
<td>0.00%</td>
</tr>
<tr>
<td>I enjoy spending time with my child</td>
<td>24.29%</td>
<td>52.86%</td>
<td>17.14%</td>
<td>5.71%</td>
<td>0.00%</td>
</tr>
<tr>
<td>My child is an important source of affection for me</td>
<td>30.00%</td>
<td>34.29%</td>
<td>20.00%</td>
<td>15.71%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Having child gives me a more certain and optimistic view for the future</td>
<td>4.29%</td>
<td>24.29%</td>
<td>24.29%</td>
<td>34.29%</td>
<td>12.86%</td>
</tr>
<tr>
<td>The major source of stress in my life is my child</td>
<td>5.71%</td>
<td>10.00%</td>
<td>5.71%</td>
<td>37.14%</td>
<td>41.43%</td>
</tr>
<tr>
<td>Having child leaves little time and flexibility in my life</td>
<td>0.00%</td>
<td>12.86%</td>
<td>5.71%</td>
<td>48.57%</td>
<td>32.86%</td>
</tr>
<tr>
<td>Having my child has been a financial burden</td>
<td>1.43%</td>
<td>14.29%</td>
<td>10.00%</td>
<td>52.86%</td>
<td>21.43%</td>
</tr>
<tr>
<td>It is difficult to balance different responsibilities because of my child</td>
<td>1.43%</td>
<td>12.86%</td>
<td>2.86%</td>
<td>44.29%</td>
<td>38.57%</td>
</tr>
<tr>
<td>The behavior of my child is often stressful or embarrassing to me</td>
<td>4.29%</td>
<td>12.86%</td>
<td>11.43%</td>
<td>40.00%</td>
<td>31.43%</td>
</tr>
<tr>
<td>If I had it to do over again, I might decide not to have child</td>
<td>35.71%</td>
<td>37.14%</td>
<td>11.43%</td>
<td>8.57%</td>
<td>7.14%</td>
</tr>
<tr>
<td>I feel overwhelmed by the responsibility of being a parent</td>
<td>4.29%</td>
<td>17.14%</td>
<td>11.43%</td>
<td>44.29%</td>
<td>22.86%</td>
</tr>
<tr>
<td>Having child has meant having too few choices and too little control over my life</td>
<td>2.86%</td>
<td>22.86%</td>
<td>21.43%</td>
<td>45.71%</td>
<td>7.14%</td>
</tr>
<tr>
<td>I am satisfied as a parent</td>
<td>8.57%</td>
<td>47.14%</td>
<td>32.86%</td>
<td>8.57%</td>
<td>2.86%</td>
</tr>
<tr>
<td>I find my child enjoyable</td>
<td>27.14%</td>
<td>52.86%</td>
<td>12.86%</td>
<td>7.14%</td>
<td>0.00%</td>
</tr>
</tbody>
</table>
## Parental Stress Scale

**Percentage Results for Fathers (n = 51)**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Percentage of Fathers Scoring a &quot;1&quot; (Strongly Disagree)</th>
<th>Percentage of Fathers Scoring a &quot;2&quot; (Disagree)</th>
<th>Percentage of Fathers Scoring a &quot;3&quot; (Undecided)</th>
<th>Percentage of Fathers Scoring a &quot;4&quot; (Agree)</th>
<th>Percentage of Fathers Scoring a &quot;5&quot; (Strongly Agree)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am happy in my role as a parent</td>
<td>23.53%</td>
<td>50.98%</td>
<td>17.65%</td>
<td>5.88%</td>
<td>1.96%</td>
</tr>
<tr>
<td>There is little or nothing I wouldn't do for child if it was necessary</td>
<td>47.06%</td>
<td>47.06%</td>
<td>5.88%</td>
<td>0.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Caring for my child sometimes takes more time and energy than I have to give</td>
<td>5.88%</td>
<td>52.94%</td>
<td>15.69%</td>
<td>15.69%</td>
<td>9.80%</td>
</tr>
<tr>
<td>I sometimes worry whether I am doing enough for my child</td>
<td>5.88%</td>
<td>21.57%</td>
<td>21.57%</td>
<td>41.18%</td>
<td>9.80%</td>
</tr>
<tr>
<td>I feel close to my child</td>
<td>33.33%</td>
<td>47.06%</td>
<td>13.73%</td>
<td>5.88%</td>
<td>0.00%</td>
</tr>
<tr>
<td>I enjoy spending time with my child</td>
<td>23.53%</td>
<td>66.67%</td>
<td>5.88%</td>
<td>3.92%</td>
<td>0.00%</td>
</tr>
<tr>
<td>My child is an important source of affection for me</td>
<td>29.41%</td>
<td>49.02%</td>
<td>17.65%</td>
<td>1.96%</td>
<td>1.96%</td>
</tr>
<tr>
<td>Having child gives me a more certain and optimistic view for the future</td>
<td>3.92%</td>
<td>27.45%</td>
<td>35.29%</td>
<td>27.45%</td>
<td>5.88%</td>
</tr>
<tr>
<td>The major source of stress in my life is my child</td>
<td>15.69%</td>
<td>50.98%</td>
<td>25.49%</td>
<td>5.88%</td>
<td>1.96%</td>
</tr>
<tr>
<td>Having child leaves little time and flexibility in my life</td>
<td>1.96%</td>
<td>66.67%</td>
<td>11.76%</td>
<td>15.69%</td>
<td>3.92%</td>
</tr>
<tr>
<td>Having my child has been a financial burden</td>
<td>5.88%</td>
<td>17.65%</td>
<td>5.88%</td>
<td>52.94%</td>
<td>17.65%</td>
</tr>
<tr>
<td>It is difficult to balance different responsibilities because of my child</td>
<td>5.88%</td>
<td>62.75%</td>
<td>7.84%</td>
<td>21.57%</td>
<td>1.96%</td>
</tr>
<tr>
<td>The behavior of my child is often stressful or embarrassing to me</td>
<td>7.84%</td>
<td>31.37%</td>
<td>33.33%</td>
<td>17.65%</td>
<td>9.80%</td>
</tr>
<tr>
<td>If I had it to do over again, I might decide not to have child</td>
<td>33.33%</td>
<td>37.25%</td>
<td>15.69%</td>
<td>7.84%</td>
<td>5.88%</td>
</tr>
<tr>
<td>I feel overwhelmed by the responsibility of being a parent</td>
<td>7.84%</td>
<td>68.63%</td>
<td>11.76%</td>
<td>5.88%</td>
<td>5.88%</td>
</tr>
<tr>
<td>Having child has meant having too few choices and too little control over my life</td>
<td>7.84%</td>
<td>52.94%</td>
<td>23.53%</td>
<td>11.76%</td>
<td>3.92%</td>
</tr>
<tr>
<td>I am satisfied as a parent</td>
<td>13.73%</td>
<td>58.82%</td>
<td>19.61%</td>
<td>5.88%</td>
<td>1.96%</td>
</tr>
<tr>
<td>I find my child enjoyable</td>
<td>29.41%</td>
<td>54.90%</td>
<td>13.73%</td>
<td>1.96%</td>
<td>0.00%</td>
</tr>
</tbody>
</table>
Parent Stress Scale

Percentage Results for All Parents ($n = 121$)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Percentage of All Parents Scoring a &quot;1&quot; (Strongly Disagree)</th>
<th>Percentage of All Parents Scoring a &quot;2&quot; (Disagree)</th>
<th>Percentage of All Parents Scoring a &quot;3&quot; (Undecided)</th>
<th>Percentage of All Parents Scoring a &quot;4&quot; (Agree)</th>
<th>Percentage of All Parents Scoring a &quot;5&quot; (Strongly Agree)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am happy in my role as a parent</td>
<td>19.01%</td>
<td>52.07%</td>
<td>13.22%</td>
<td>14.05%</td>
<td>1.65%</td>
</tr>
<tr>
<td>There is little or nothing I wouldn't do for child if it was necessary</td>
<td>52.89%</td>
<td>41.32%</td>
<td>5.79%</td>
<td>0.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Caring for my child sometimes takes more time and energy than I have to give</td>
<td>2.48%</td>
<td>24.79%</td>
<td>6.61%</td>
<td>26.45%</td>
<td>39.67%</td>
</tr>
<tr>
<td>I sometimes worry whether I am doing enough for my child</td>
<td>4.13%</td>
<td>9.92%</td>
<td>11.57%</td>
<td>45.45%</td>
<td>28.93%</td>
</tr>
<tr>
<td>I feel close to my child</td>
<td>37.19%</td>
<td>46.28%</td>
<td>12.40%</td>
<td>4.13%</td>
<td>0.00%</td>
</tr>
<tr>
<td>I enjoy spending time with my child</td>
<td>23.97%</td>
<td>58.68%</td>
<td>12.40%</td>
<td>4.96%</td>
<td>0.00%</td>
</tr>
<tr>
<td>My child is an important source of affection for me</td>
<td>29.75%</td>
<td>40.50%</td>
<td>19.01%</td>
<td>9.92%</td>
<td>0.83%</td>
</tr>
<tr>
<td>Having child gives me a more certain and optimistic view for the future</td>
<td>4.13%</td>
<td>25.62%</td>
<td>28.93%</td>
<td>31.40%</td>
<td>9.92%</td>
</tr>
<tr>
<td>The major source of stress in my life is my child</td>
<td>9.92%</td>
<td>27.27%</td>
<td>14.05%</td>
<td>23.97%</td>
<td>24.79%</td>
</tr>
<tr>
<td>Having child leaves little time and flexibility in my life</td>
<td>0.83%</td>
<td>35.54%</td>
<td>8.26%</td>
<td>34.71%</td>
<td>20.66%</td>
</tr>
<tr>
<td>Having my child has been a financial burden</td>
<td>3.31%</td>
<td>15.70%</td>
<td>8.26%</td>
<td>52.89%</td>
<td>19.83%</td>
</tr>
<tr>
<td>It is difficult to balance different responsibilities because of my child</td>
<td>3.31%</td>
<td>33.88%</td>
<td>4.96%</td>
<td>34.71%</td>
<td>23.14%</td>
</tr>
<tr>
<td>The behavior of my child is often stressful or embarrassing to me</td>
<td>5.79%</td>
<td>20.66%</td>
<td>20.66%</td>
<td>30.58%</td>
<td>22.31%</td>
</tr>
<tr>
<td>If I had it to do over again, I might decide not to have child</td>
<td>34.71%</td>
<td>37.19%</td>
<td>13.22%</td>
<td>8.26%</td>
<td>6.61%</td>
</tr>
<tr>
<td>I feel overwhelmed by the responsibility of being a parent</td>
<td>5.79%</td>
<td>38.84%</td>
<td>11.57%</td>
<td>28.10%</td>
<td>15.70%</td>
</tr>
<tr>
<td>Having child has meant having too few choices and too little control over my life</td>
<td>4.96%</td>
<td>35.54%</td>
<td>22.31%</td>
<td>31.40%</td>
<td>5.79%</td>
</tr>
<tr>
<td>I am satisfied as a parent</td>
<td>10.74%</td>
<td>52.07%</td>
<td>27.27%</td>
<td>7.44%</td>
<td>2.48%</td>
</tr>
<tr>
<td>I find my child enjoyable</td>
<td>28.10%</td>
<td>53.72%</td>
<td>13.22%</td>
<td>4.96%</td>
<td>0.00%</td>
</tr>
</tbody>
</table>
APPENDIX K

SUMMARIZED PERCENTAGE RESPONSE DATA – COUPLES ASSESSMENT OF RELATIONSHIP ELEMENTS
### Couples Assessment of Relationship Elements

#### Percentage Results for Mothers \((n = 62)\)

<table>
<thead>
<tr>
<th></th>
<th>Percentage of Mothers Scoring a “1” (Couldn’t be Worse)</th>
<th>Percentage of Mothers Scoring a “2”</th>
<th>Percentage of Mothers Scoring a “3”</th>
<th>Percentage of Mothers Scoring a “4” (Not Bad)</th>
<th>Percentage of Mothers Scoring a “5”</th>
<th>Percentage of Mothers Scoring a “6”</th>
<th>Percentage of Mothers Scoring a “7” (couldn’t be better)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intimacy</td>
<td>12.90%</td>
<td>12.90%</td>
<td>12.90%</td>
<td>16.13%</td>
<td>12.90%</td>
<td>20.97%</td>
<td>11.29%</td>
</tr>
<tr>
<td>Communications</td>
<td>8.06%</td>
<td>17.74%</td>
<td>11.29%</td>
<td>11.29%</td>
<td>22.58%</td>
<td>20.97%</td>
<td>8.06%</td>
</tr>
<tr>
<td>Resolution of differences</td>
<td>11.29%</td>
<td>8.06%</td>
<td>16.13%</td>
<td>17.74%</td>
<td>22.58%</td>
<td>20.97%</td>
<td>3.23%</td>
</tr>
<tr>
<td>Freedom of blaming my partner when things go wrong</td>
<td>0.00%</td>
<td>4.84%</td>
<td>20.97%</td>
<td>33.87%</td>
<td>22.58%</td>
<td>16.13%</td>
<td>1.61%</td>
</tr>
<tr>
<td>Willingness to admit to my partner when having hurt my partner and to ask for forgiveness</td>
<td>1.61%</td>
<td>3.23%</td>
<td>6.45%</td>
<td>29.03%</td>
<td>32.26%</td>
<td>22.58%</td>
<td>4.84</td>
</tr>
<tr>
<td>Ability to forgive partner after a hurt</td>
<td>1.61%</td>
<td>3.23%</td>
<td>6.45%</td>
<td>20.97%</td>
<td>32.26%</td>
<td>30.65%</td>
<td>4.84%</td>
</tr>
<tr>
<td>Commitment to my partner for the long term</td>
<td>3.23%</td>
<td>4.84%</td>
<td>0.00%</td>
<td>4.84%</td>
<td>16.13%</td>
<td>24.19%</td>
<td>46.77%</td>
</tr>
</tbody>
</table>
## Couples Assessment of Relationship Elements

### Percentage Results for Fathers (n = 51)

<table>
<thead>
<tr>
<th></th>
<th>Percentage of Fathers Scoring a “1” (Couldn’t be Worse)</th>
<th>Percentage of Fathers Scoring a “2”</th>
<th>Percentage of Fathers Scoring a “3”</th>
<th>Percentage of Fathers Scoring a “4” (Not Bad)</th>
<th>Percentage of Fathers Scoring a “5”</th>
<th>Percentage of Fathers Scoring a “6”</th>
<th>Percentage of Fathers Scoring a “7” (Couldn’t Be Better)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intimacy</strong></td>
<td>11.76%</td>
<td>23.53%</td>
<td>3.92%</td>
<td>9.80%</td>
<td>15.69%</td>
<td>21.57%</td>
<td>13.73%</td>
</tr>
<tr>
<td><strong>Communications</strong></td>
<td>9.80%</td>
<td>11.76%</td>
<td>19.61%</td>
<td>13.73%</td>
<td>13.73%</td>
<td>21.57%</td>
<td>9.80%</td>
</tr>
<tr>
<td><strong>Resolution of differences</strong></td>
<td>7.84%</td>
<td>9.80%</td>
<td>15.69%</td>
<td>19.61%</td>
<td>13.73%</td>
<td>25.49%</td>
<td>7.84%</td>
</tr>
<tr>
<td><strong>Freedom of blaming my partner when things go wrong</strong></td>
<td>0.00%</td>
<td>5.88%</td>
<td>11.76%</td>
<td>23.53%</td>
<td>37.25%</td>
<td>17.65%</td>
<td>3.92%</td>
</tr>
<tr>
<td><strong>Willingness to admit to my partner when having hurt my partner and to ask for forgiveness</strong></td>
<td>1.96%</td>
<td>3.92%</td>
<td>5.88%</td>
<td>25.49%</td>
<td>33.33%</td>
<td>25.49%</td>
<td>3.92%</td>
</tr>
<tr>
<td><strong>Ability to forgive partner after a hurt</strong></td>
<td>0.00%</td>
<td>5.88%</td>
<td>7.84%</td>
<td>13.73%</td>
<td>25.49%</td>
<td>37.25%</td>
<td>9.80%</td>
</tr>
<tr>
<td><strong>Commitment to my partner for the long term</strong></td>
<td>3.92%</td>
<td>9.80%</td>
<td>5.88%</td>
<td>1.96%</td>
<td>9.80%</td>
<td>19.61%</td>
<td>49.02%</td>
</tr>
</tbody>
</table>
## Couples Assessment of Relationship Elements

**Percentage Results for All Parents (n = 113)**

<table>
<thead>
<tr>
<th>Element</th>
<th>Percentage of Parents Scoring a “1” (Couldn’t be Worse)</th>
<th>Percentage of Parents Scoring a “2”</th>
<th>Percentage of Parents Scoring a “3”</th>
<th>Percentage of Parents Scoring a “4” (Not Bad)</th>
<th>Percentage of Parents Scoring a “5”</th>
<th>Percentage of Parents Scoring a “6”</th>
<th>Percentage of Parents Scoring a “7” (Couldn’t Be Better)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intimacy</td>
<td>12.39%</td>
<td>17.70%</td>
<td>8.85%</td>
<td>13.27%</td>
<td>14.16%</td>
<td>21.24%</td>
<td>12.39%</td>
</tr>
<tr>
<td>Communications</td>
<td>8.85%</td>
<td>15.04%</td>
<td>15.04%</td>
<td>12.39%</td>
<td>18.58%</td>
<td>21.24%</td>
<td>8.85%</td>
</tr>
<tr>
<td>Resolution of differences</td>
<td>9.73%</td>
<td>8.85%</td>
<td>15.93%</td>
<td>18.58%</td>
<td>18.58%</td>
<td>23.01%</td>
<td>5.31%</td>
</tr>
<tr>
<td>Freedom of blaming my partner when things go wrong</td>
<td>0.00%</td>
<td>5.31%</td>
<td>16.81%</td>
<td>29.20%</td>
<td>29.20%</td>
<td>16.81%</td>
<td>2.65%</td>
</tr>
<tr>
<td>Willingness to admit to my partner when having hurt my partner and to ask for forgiveness</td>
<td>1.77%</td>
<td>3.54%</td>
<td>6.19%</td>
<td>27.43%</td>
<td>32.74%</td>
<td>23.89%</td>
<td>4.42%</td>
</tr>
<tr>
<td>Ability to forgive partner after a hurt</td>
<td>0.88%</td>
<td>4.42%</td>
<td>7.08%</td>
<td>17.70%</td>
<td>29.20%</td>
<td>33.63%</td>
<td>7.08%</td>
</tr>
<tr>
<td>Commitment to my partner for the long term</td>
<td>3.54%</td>
<td>7.08%</td>
<td>2.65%</td>
<td>3.54%</td>
<td>13.27%</td>
<td>22.12%</td>
<td>47.79%</td>
</tr>
</tbody>
</table>