Parental Stress, Family-Professional Partnerships, and Family Quality of Life: Families of Children with Autism Spectrum Disorder

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PARENTAL STRESS, FAMILY-PROFESSIONAL PARTNERSHIPS, AND FAMILY QUALITY OF LIFE: FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER

By

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May 2013
THE GRADUATE COLLEGE

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entitled

Parental Stress, Family-Professional Partnerships, and Family Quality of Life: Families of Children with Autism Spectrum Disorder

be accepted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy in Special Education
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ABSTRACT

Parental Stress, Family-Professional Partnerships, and Family Quality of Life:
Families of Children with Autism Spectrum Disorder

by

Yun-Ju Hsiao

Dr. Kyle Higgins, Doctoral Committee Chair
Professor of Special Education
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The purpose of this study was to investigate the relationship among the quality of life of families that have at least one child with autism spectrum disorder, parental stress level, and partnerships between the family and professionals. Also, parent perceptions of parental stress, family quality of life, and family-professional partnerships were assessed to ascertain if they could be predicted from different variables (e.g., ethnicity, educational levels, income levels, and parental relationship status, etc.). The study examined the relationship among the three variables (e.g., family quality of life, parental stress, and family-professional partnership). Participants were recruited from an autism center located at a state university, a state autism organization, a regional autism organization, and a local autism service provider. A total of 236 parents of children with autism spectrum disorder completed the online questionnaire.

The results of the stepwise multiple regression analysis indicated that the two variables that contributed significantly to family-professional partnership were age of the first child with autism and type of school services received. The only variable that contributed significantly to parental stress was the relationship status of parent(s). The two variables that contributed significantly to family quality of life were total household
income and the age of the first child with autism. However, these variables explained only a small portion of variance for the outcome variables. The results of the structural equation modeling showed that in one model the perceived parental stress level had a direct effect on the parental satisfaction concerning family quality of life. However, the family-professional partnership did not affect the direction and/or strength of the relation between parental stress and family quality of life. In the second model, family quality of life had a direct effect on parental stress. However, family professional partnership(s) did not moderate the effect of parental satisfaction concerning family quality of life on the perceived parental stress level.

These findings have implications for teacher education and collaboration between parents and educators. Coursework to enhance the understanding of the inner workings of families that include a child/youth with autism should be included in teacher education. The training should include components to form successful relationships between parents and educators as well as parent/educator collaborative teams. It is through the formation of strong family-professional partnerships that outcomes for children with autism will be improved.
ACKNOWLEDGEMENTS

First and foremost, I would like to deeply express my gratitude to my committee. I want to express my greatest appreciation to my advisor, Dr. Kyle Higgins. Thank you very much for accepting me into your “family.” I am very grateful for your instruction, guidance, support, advice, encouragement, patience, and kind pushes and nags (I need them) during my dissertation process and throughout my entire doctoral program of study. It is very difficult for me to express how grateful I am using words. I am very thankful to Dr. Tom Pierce for his instruction, mentorship, support, guidance, advice, and leadership. Thank you very much for being there throughout my entire program. Also, I thank Dr. Peggy Whitby for assisting me in finding organizations to participate in my study. I thank Dr. Richard Tandy for sharing his time and wisdom in guiding me with analytical methods. I would not be able to make it this far without all of you. In addition, I want to thank the entire faculty and staff in the special education program for their consistently warm support.

Second, I would like to express my thankfulness to the organizations and service provider for sending out the message regarding my study to parents of children with autism spectrum disorder. Specifically, thank you to Dr. Shannon Crozier and Ms. Jessica Love from the UNLV Center for Autism Spectrum Disorders, Ms. Michelle Scott-Lewing and Ms. Kathryn Quigley from the Autism Coalition of Nevada, Ms. Jennifer Strobel from Families for Effective Autism Treatment of Southern Nevada, and Mr. Chris Holcomb from Tandem Therapy Services. I am also very thankful to parents who participated in my study. Your input to the study is very valuable.
Last, but not least, I would like to thank my family for supporting me. Dad and Mom, without your support, there is no way I could even have finished my Master’s program or start my doctoral program at UNLV. Thank you to my colleagues and friends, Dr. Joseph Morgan (my unofficial mentor), Dr. Neal Nguyen (my Asian brother), Teri Marx, Nancy Brown, Dr. Catherine Howarter, Dr. Wendie Castillo, Dr. Lidia Sedano, Dr. Debra Cote, Dr. Vita Jones, Jessica Love, Chris Holcomb, Pam Juniel, Shannon Sparks, Dolores Williamson, and …… (this list could not ever be comprehensive) for your friendship, support, and the good times and bad times together. I cannot image my doctoral studies without you. Finally, thank you to my Taiwanese friends, Ihsuan Shih, Yuan Ching Lee, Pei Chih Wang, Ya Mei Pan, and Tzu-Liang Chen for your support and encouragement. It is very hard for me to come up with a comprehensive list to say thank you to everybody that has supported me throughout my doctoral program, but I thank all of you that have been there for me. Thank you!
Dedicated to my family,

my father, His-Chi Hsiao (蕭錫錡)

my mother, Yun Hsiao-Chang (張允), and

my brother, Chung-Che Hsiao (蕭崇哲).
This research is supported by the Doug Sperber Grant, from the UNLV Center for Autism Spectrum Disorders.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>iii</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>v</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>ix</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>xii</td>
</tr>
<tr>
<td>CHAPTER ONE INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>The Role of the Family System in Child/Youth Development</td>
<td>2</td>
</tr>
<tr>
<td>The Family System and Typical Children/Youth</td>
<td>3</td>
</tr>
<tr>
<td>The Family System and Children/Youth with Disabilities</td>
<td>4</td>
</tr>
<tr>
<td>Family Quality of Life</td>
<td>5</td>
</tr>
<tr>
<td>Family Quality of Life Defined</td>
<td>6</td>
</tr>
<tr>
<td>Family Quality of Life Domains</td>
<td>7</td>
</tr>
<tr>
<td>Family Quality of Life with Typical Children/Youth</td>
<td>8</td>
</tr>
<tr>
<td>Family Quality of Life with Children/Youth with Disabilities</td>
<td>9</td>
</tr>
<tr>
<td>Parental Stress within the Family System</td>
<td>10</td>
</tr>
<tr>
<td>Parental Stress Defined</td>
<td>10</td>
</tr>
<tr>
<td>Parental Stress with Typical Children</td>
<td>10</td>
</tr>
<tr>
<td>Parental Stress with Children/Youth with Disabilities</td>
<td>11</td>
</tr>
<tr>
<td>The Role of Family and Professional Partnerships in Child/Youth Development</td>
<td>12</td>
</tr>
<tr>
<td>Family and Professional Partnerships Defined</td>
<td>13</td>
</tr>
<tr>
<td>Family and Professional Partnerships for Typical Children/Youth</td>
<td>13</td>
</tr>
<tr>
<td>Family and Professional Partnerships for Children/Youth with Disabilities</td>
<td>14</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>15</td>
</tr>
<tr>
<td>Significance of the Study</td>
<td>18</td>
</tr>
<tr>
<td>Limitations of the Study</td>
<td>18</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>Chapter Two</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>The Family System in Child/Youth Development</td>
<td>22</td>
</tr>
<tr>
<td>The Family System and Typical Children/Youth</td>
<td>23</td>
</tr>
<tr>
<td>The Family System and Children/Youth with Disabilities</td>
<td>33</td>
</tr>
<tr>
<td>Family Quality of Life</td>
<td>47</td>
</tr>
<tr>
<td>Family Quality of Life with Typical Children/Youth</td>
<td>48</td>
</tr>
<tr>
<td>Family Quality of Life with Children/Youth with Disabilities</td>
<td>54</td>
</tr>
<tr>
<td>Parental Stress within the Family System</td>
<td>69</td>
</tr>
<tr>
<td>Parental Stress with Typical Children</td>
<td>70</td>
</tr>
<tr>
<td>Parental Stress with Children/Youth with Disabilities</td>
<td>79</td>
</tr>
<tr>
<td>The Role of Family and Professional Partnerships in Child/Youth Development</td>
<td>92</td>
</tr>
<tr>
<td>Family and Professional Partnerships for Typical Children/Youth</td>
<td>92</td>
</tr>
<tr>
<td>Family and Professional Partnerships for Children/Youth with Disabilities</td>
<td>98</td>
</tr>
<tr>
<td>Chapter Three</td>
<td>Method</td>
</tr>
<tr>
<td>Overview</td>
<td>111</td>
</tr>
<tr>
<td>Research Questions</td>
<td>112</td>
</tr>
<tr>
<td>Participants</td>
<td>114</td>
</tr>
<tr>
<td>Setting</td>
<td>115</td>
</tr>
<tr>
<td>Instrumentation</td>
<td>120</td>
</tr>
<tr>
<td>Materials</td>
<td>123</td>
</tr>
<tr>
<td>Design and Procedures</td>
<td>125</td>
</tr>
<tr>
<td>Data Collection</td>
<td>127</td>
</tr>
<tr>
<td>Treatment of the Data</td>
<td>128</td>
</tr>
</tbody>
</table>
LIST OF TABLES

Table 1 Parent Demographic Information………………………………………………116

Table 2 Significant Predictors for Perceived Satisfaction of Family-professional
Partnerships………………………………………………………………………………136

Table 3 Significant Predictors for Perceived Parental Stress………………………..136

Table 4 Significant Predictors for Perceived Satisfaction of Family Quality of Life…..137
CHAPTER ONE

INTRODUCTION

The family is the primary force contributing to the development of children and youth (Zarrett & Lerner, 2008). This contribution may be positive, neutral, or negative in nature (Family Strengthening Policy Center [FSPC], 2007). Early interaction and secure attachment between a mother and baby result in the wellbeing and development of the child (Saisto, Salmela-Aro, Nurmi, & Halmesmäki, 2008). These early parent-child interactions are associated with social and cognitive development, academic performance, school attendance, behavior, and social skills (Brandon & Brown, 2009; Guajardo, Snyder, & Petersen, 2009; Jakes & DeBord, 2010). This relationship is particularly important for children/youth with disabilities (Brown & Brandon, 2009).

Individual characteristics of every member of the family can either strengthen or limit the entire family unit (Christian, 2006). When a child has a disability, members of the family may respond differently, depending on the characteristics of the child (e.g., the type and the severity of the disability, the onset age of the disability) as well as the characteristics of the family (e.g., family size, number of parents present in the home, birth order) (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). Other characteristics that impact a family are the ability of the individual to problem solve, physical and mental health, communication, and motivation level (Turnbull et al., 2011).

Autism Spectrum Disorders (ASD) is a developmental disability (American Psychological Association [APA], 2000; Individuals with Disabilities Education Act [IDEA], 2004). Children with ASD are characterized by their social interactions, verbal and nonverbal communication skills, and restricted repetitive behavior (APA, 2000).
These children usually are diagnosed before the age of three (APA, 2000; Meadan, Halle, & Ebata, 2010). When a member of a family has autism, the disability impacts the entire family, parents and siblings. For parents, this may include emotional effects (e.g., grief cycle), marital stress, and social pressure (Fein & Dunn, 2007). For siblings, the influence may include negative feelings (e.g., resentment toward their sibling, responsibility, or a sense of being ignored by their parents) (Fein & Dunn, 2007). However, a disability is not always a burden; the presence of a child with a disability may have a positive or neutral impact on the family unit (Fein & Dunn, 2007; Turnbull et al., 2011). Parents report that family relationships can be strengthened and enriched by the child with a disability (Brobst, Clopton, & Hendrick, 2009).

Unfortunately, many parents and families do not have enough supports (FSPC, 2007). This is particularly true for families with a child with autism. Because this disability has very unique characteristics, care of children with autism often is stressful for parents (Meadan et al., 2010). Therefore, it is important to address the needs, professional relationships, and stresses of these families.

**The Role of the Family System in Child/Youth Development**

Family systems theory maintains that a family is a social system that is more than the simple relationship between the parent(s) and child(ren) (Christian, 2006; Parke, 2004). The family is viewed as a complete organization that is influenced by multiple and competing internal factors (e.g., relationships between the two parents, parent and child, or between child and a sibling) and external factors (e.g., school, work, or religion) (Pinkus, 2006). Thus, factors that impact a family are multi-dimensional and may directly or indirectly influence each other (Parke, 2004).
There are several components of the family systems theory. First, a family is viewed as a whole entity; it cannot be understood by looking at its various parts and then combining them together. Second, a family contains several subsystems: (a) the partnership subsystem (e.g., interactions between husband and wife, same-gender partners, or domestic partners), (b) the parent-child subsystem (e.g., interactions between parents and children), (c) the sibling subsystem (e.g., sibling interactions), and (d) the extended family subsystem (e.g., interaction between the nuclear family members and other relatives) (Meadan et al., 2010; Turnbull et al., 2011). Finally, a family is an adaptive organization that reconfigures itself to meet changes or challenges (Pinkus, 2006). Family system research maintains that a family is more robust than the parent-child relationship exclusively and that it is important to examine the larger external systems and the mutual interdependence of subsystems in which a family unit functions (Cox & Paley, 2003).

**The Family System and Typical Children/Youth**

According to family systems theory, the major factor that contributes to child/youth development is the functioning of the family unit, while the parent-child subsystem is associated with the social adaptation of the child (Guajardo et al., 2009; Parke, 2004). In addition to caring for their children, parents also play different roles: (a) as instructors concerning appropriate cultural norms and rules; (b) as supervisors providing guidance on social situations challenges; and (c) as managers regulating their child’s life outside of the family unit (cognitively and socially) (Parke, 2004).

Typically, when there are problems with the child-parent relationship, there often are related problems within the parental relationship. Thus, if problems in the adult
relationship are not addressed, problems in the parent-child relationship will be difficult to solve (Cox & Paley, 2003). Therefore, in order to better understand the development or adjustment of a child, the relationship of the parents and the overall quality of the adult relationship must be explored (Cox & Paley, 2003).

Through interactions with siblings, a child develops a particular pattern of interaction and social understandings. Through this interaction, children practice skills that can be generalized to interactions outside of the family unit (Parke, 2004). Family systems theory focuses on the interactions among parents and children in order to define the context in which individual children learn to address differential treatment and complex social emotions within and outside of the family (Parke, 2004).

The Family System and Children/Youth with Disabilities

When a child/youth with a disability is present in a family, the impact on the marital, parental, and sibling systems varies (Turnbull et al., 2011). Early research indicated that parents of children with disabilities had a higher divorce rate (Hodapp & Krasner, 1995), but current studies show that this is not always the case (Urbano & Hodapp, 2007). Baker, Blacher, and Olsson (2005) found that parents of preschoolers with and without developmental delays did not differ on measures of depression or marital adjustment when compared to each other. Moreover, family experiences (e.g., divorce, mother’s unemployment, and receipt of social welfare) are different depending on the type of disability and health of the child (Wei & Yu, 2012). Family systems theory maintains that the impact of a child with a disability on a family depends on the characteristics of the family (e.g., various parental subsystems) and that further research
is necessary to explore this impact as the definition of family changes overtime (Turnbull et al., 2011).

Sibling interaction in the family (e.g., sibling subsystem) is related to socialization and peer relationships and this may be positive and negative. Thus, the presence of a child with a disability also may have positive, negative, or neutral effects on the sibling subsystem (Fein & Dunn, 2007; Turnbull et al., 2011).

The family system and children/youth with autism. The behavioral repertoires of children/youth with ASD (e.g., difficulty with verbal and nonverbal communication, social behavior) may impact the family system (both immediate and extended family) (Meadan et al., 2010). Meadan et al. (2010) reviewed 57 studies concerning the impact of children/youth with autism on their families. They found either a negative influence or no difference on the marital subsystem (Meadan et al., 2010). However, when couples have a good relationship, dealing with a child’s disability may strengthen and enrich the relationship (Brobst et al., 2009).

Parents of children with autism generally report a higher level of stress than parents of typical children (Meadan et al., 2010). In regards to the sibling subsystem, the results are inconclusive. Some siblings of children with autism experience warm and supportive relationships, while others report isolation and may encounter conflict (Meadan et al., 2010).

Family Quality of Life

The concept of quality of life refers to the appropriate outcomes resulting from services provided to individuals with disabilities (Summer et al., 2007). Because families are the main resource for this population, it is important that appropriate care and support
are provided over time (Brown & Brown, 2004). Therefore, the concept of family quality of life often is used to measure positive outcomes for family support (Summer et al., 2007).

**Family Quality of Life Defined**

Quality of life (QOL) is not an easily interpretable concept; it is a subjective and multidimensional concept (Cella, 1994; Felce & Perry, 1995; Claes, Hove, Loon, Vandevelde, & Schalock, 2010). It is a human service construct that has been influenced by a variety of fields (e.g., health, education, habilitation, mental health) (Schalock, 1994). Quality of life is defined as a reflection of an individual’s satisfaction with home and community living, employment, and health functioning (Schalock, 1994). While it is a subjective construct, it is based on the perception held by an individual concerning various aspects of life experiences, including personal characteristics, objective life conditions, and perceptions of significant others (Cella, 1994; Felce & Perry, 1995; Schalock, 1994). An individual’s perception of QOL impacts their interaction with both the internal and external factors within the family system and, overtime, influences the functions of the family unit (Schalock, 1994).

Quality of life reflects an individual’s personal interpretation of the environment and its impact on their well-being (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006). The QOL construct for individuals with disabilities, especially for persons with intellectual disabilities, has been well-established. It is often used to measure well-being in various domains of functioning (e.g., physical, functional, emotional, and social) (Brown et al., 2006; Cella, 1994; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Lee, Harrington, Louie, & Newschaffer, 2008).
Zuna, Summers, Turnbull, Hu, and Xu (2010) reviewed 24 articles to identify the definitions, concepts, variables, and relationships among the domains of family quality of life. Zuna et al. (2010) concluded that family quality of life is how family members define and inform the dynamic sense of well-being of the unit, collectively and subjectively. While most authors do not provide a definition of family quality of life, Gupta and Sharma (1998) defined it as an enrichment of life, including social production, distribution, and perception of values. Bayat (2005) maintained that family quality of life was the overall well-being and ability of a family to meet its needs and enjoy life. For the purpose of this dissertation, family quality of life was defined as the dynamic sense of well-being of the family (Zuna et al., 2010).

Family quality of life extends beyond a focus on the member with a disability. For the family unit, QOL cannot be attained until the needs of every member are met (Davis & Gavidia-Payne, 2009). Because of the multidimensionality of QOL, researchers have identified the domains encompassing the concept in order to better measure it and identify the manner in which the subsystems interact (Turnbull, Summers, Lee, & Kyzar, 2007).

**Family Quality of Life Domains**

The domains of family quality of life vary in the literature (Poston et al., 2003; Turnbull et al., 2007). Poston et al. (2003) provided the conceptualization of family quality of life using focus groups and individual interviews. Ten domains of family quality of life were identified with six domains focusing on the individual (e.g., advocacy, emotional well-being, health, physical environment, productivity, and social well-being)
and four domains concerned with the family unit (e.g., daily family life, family interaction, financial well-being, and parenting).

International researchers (Brown, Davey, Shearer, & Kyrkou, 2004; Brown, Isaacs, McCormack, Baum, & Renwick, 2004; Neikrug, Judes, Roth, & Krauss, 2004) identified nine domains of family quality of life. These domains include health, financial well-being, family relationships, support from others, support from disability-related services, spiritual and cultural beliefs, careers and preparing for careers, leisure and enjoyment of life, and community/civic involvement.

In order to codify the family quality of life domains, Summers et al. (2005) created the Beach Center Family Quality of Life Scale. They reviewed the existing research and identified five domains to use in the measurement of the construct of family quality of life. These include: family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support. The Beach Center Family Quality of Life Scale was developed to use with families of children with disabilities (Summers et al., 2005). Hoffman et al. (2006) maintained that the convergent validity measure indicated that the hypothesized subscales of the scale were highly correlated with the overall scale structure and test-retest reliability correlations were significant across subscales as well.

Family Quality of Life with Typical Children/Youth

Quality of family functioning and satisfaction with family life are correlated with how families perceive their beliefs on different aspects of efficacy (e.g., self-efficacy, parental efficacy, and spousal efficacy), especially the consensus of the overall ability to manage family affairs (Bandura, Caprara, Barbaranelli, Regalia, & Scabini, 2011).
Moreover, when families have a higher level of familial cohesion and satisfaction with their bonds, they rate their emotional well-being higher (Vandeleur, Jeanpretre, Perrez, & Schoebi, 2009). Typically, families in which the children do not have disabilities experience a higher QOL (Bowman, 2001; Brown et al., 2006).

**Family Quality of Life with Children/Youth with Disabilities**

The majority of the research conducted concerning QOL issues in special education has been conducted with families in which there is a child with an intellectual disability (Bertelli, Bianco, Rossi, Scuticchio, & Brown, 2011; Brown et al., 2006; Poston et al., 2003; Steel, Poppe, Vandevelde, Van Hove, & Claes, 2011; Werner et al., 2009). However, research concerning the conceptualization and measurement of the family quality of life domains is beginning to emerge for other disability groups (Poston et al., 2003). The focus of this research is on the ways in which family life is impacted differentially (e.g., by disability) and the impact of disability on the perceptions of family members concerning the family functioning (internally and externally). This research has examined the influence of services and the community on the family (Brown et al., 2006).

**Family quality of life with children/youth with autism.** Previous research on quality of life has been focused on specific family members (e.g., mothers) (Hoffman et al., 2006). However, little research exists concerning the quality of life domains for families with children with autism (Bayat, 2005; Plimley, 2007). Studies on quality of life in the field of autism have focused on the parents, not the whole family system (Lee et al., 2008; Lee et al., 2009). Thus, research specific to families in which there is a child with autism is needed.
Parental Stress within the Family System

Over the past several decades, family characteristics have changed. There has been an increase in households with a single parent, children living in poverty, and mothers working outside the home (Raphael, Zhang, Liu, & Giardino, 2010; Turnbull et al., 2011). Raphael et al. (2010) indicated that these changes may cause parental stress if not addressed. Research continues to show that stress is related to parenting practices and parent effectiveness (Guajardo et al., 2009). Within the family system, the parent, the child, and their interaction are three possible sources of parental stress (Putnick et al., 2010).

Parental Stress Defined

The conflict between personal life requirements and the reality of everyday functioning may result in parental stress (Saisto et al., 2008). Parental stress is defined as the imbalance between the perceptions of parenting demands and the resources available to the parents (Raphael et al., 2010). Sepa, Frodi, and Ludvigsson (2004) defined parental stress as a condition in which a discrepancy occurs when the perceived parenthood is inconsistent with situational demands and personal resources. It is also a reflection of a parent’s self-adjustment within the family unit (Saisto et al., 2008). This stress may be reflected in poor management of parenting tasks, misbehavior of children, or dysfunctional parent-child interactions (Putnick et al., 2010).

Parental Stress with Typical Children

Factors contributing to parental stress include the relationship between the child and parent(s), insecure and ambivalent attachment, and poor satisfaction with the adult relationship within the family unit (Saisto et al., 2008). Increased financial burden, social
isolation, single parenthood, and lack of social support are factors that also may contribute to this stress (Belcher, Watkins, Johnson, & Ialongo, 2007). When children exhibit a poor temperament (e.g., irregular biological functioning, low adaptability, high-intensity affect, and negative mood), mothers report higher levels of parental stress as well as a decreased level of their confidence in their parenting skills (McBride, Schoppe, & Rane, 2002). Unfortunately, when parents experience stress, they may be less responsive to their child’s needs and exhibit punitive or negligent parenting (Belcher, et al. 2007).

Researchers have focused on maternal stress in various situations. However, studies concerning the stress experienced by fathers is less common (McBride et al., 2002; Saisto et al., 2008). High parental stress for mothers is related to poor social support, low income, and conflicts in the dyadic relationship (Saisto et al., 2008). Also, individual personality characteristics (e.g., neuroticism, vulnerability, and anxiety proneness) may influence parental reactions to stressful situations (Saisto et al., 2008).

**Parental Stress with Children/Youth with Disabilities**

Research indicates that parents of children with disabilities experience a higher level of stress than parents of typically developing children (Eisenhower, Baker, & Blacher, 2005; Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008). This stress is strongly related to the severity of behavior problems of the child with disabilities, rather than to the cognitive function of the child (Baker, Blacher, Crnic, & Edelbrock, 2002; Baker et al., 2003; Baker et al., 2005; Hastings, 2002; Lopez et al., 2008). Also, parental personality variables (e.g. parenting self-esteem, sense of competence, locus of control)
play an important role in the impact of parental stress (Hassall, Rose, & McDonald, 2005; Hill & Rose, 2009).

**Parental stress with children/youth with autism.** Because children with autism have very unique characteristics, the overall care of these children tends to be more stressful for their caregivers/parents (Johnson, Frenn, Feetham, & Simpson, 2011; Mancil, Boyd, & Bedesem, 2009; Phetrasuwan & Miles, 2009; Robbins, Dunlap, & Plienis, 1991; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Parents of children with autism report higher stress levels than parents of children with typical development (Brobst et al., 2009; Mancil et al., 2009; Rao & Beidel, 2009), or parents of children with intellectual disabilities (Dabrowska & Pisula, 2010; Eisenhower et al., 2005; Pisula, 2006), developmental disabilities, or psychiatric difficulties (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009). Moreover, parenting a child with ASD often influences a couple’s relationship (Brobst et al., 2009). If the child’s ASD is perceived as more severe and if the behavior problems are considered intensive, the level of parental stress rises (Brobst et al., 2009; Eisenhower et al., 2005). Although studies have shown that parents of children with autism reported higher level of parental stress, the relation between parental stress and family quality of life has not been examined. This relationship was examined in this study.

**The Role of Family and Professional Partnerships in Child/Youth Development**

The establishment of positive partnerships among families and professionals is important in education (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Dunlap & Fox, 2007; Summers et al., 2005). These partnerships are considered essential
in order to increase the opportunities and supports for all students, but particularly for students with disabilities. In the end, positive interactions among professionals and parents lead to appropriate child development (e.g., academically, behaviorally, socially, and emotionally) (Christenson, 2003; Dunlap & Fox, 2007).

**Family and Professional Partnerships Defined**

Turnbull et al. (2011) maintained that partnerships built among families and professionals benefit children/youth. These partnerships support the child in achieving equal opportunity, independent living, full participation, and economic self-sufficiency in life. The partnerships also indirectly benefit the families and professionals. These relationships involve the expertise and resources of the family as well as the professionals in making joint decisions which benefit students, families, and professionals as they work together over time (Turnbull et al., 2011). Summers et al. (2005) defined this partnership as collaboration, service, integration, multidisciplinary, and family/parent involvement. Dunst, Trivette, and Snyder (2000) also defined family-professional partnerships as professionals and family members working together toward a common goal in a relationship based on mutual trust, respect, and shared decision making. These mutually supportive interactions are imperative so that the needs of all participants are met (Blue-Banning et al., 2004; Summers, Hoffman, Marquis, Turnbull, & Poston, 2005; Summers et al., 2005).

**Family and Professional Partnerships for Typical Children/Youth**

The Parent Teacher Association (PTA) has supported family involvement in schools for over 100 years (Padak & Rasinski, 2010). Christenson (2003) indicated that the barriers to partnerships (e.g., communication, meaningful dialogue, cultural
differences, incorrect assumptions, poor training of educators, etc.) contributed to a lack of parent engagement in their child’s education and often were based on the structural and psychological aspects of the family, educator, and the family-school relationship. These barriers are dynamic in nature, changing overtime; often families from diverse cultural and linguistic backgrounds struggle to be involved in their children’s education due to these barriers (Dotson-Blake, 2010; Pinkus, 2006).

**Family and Professional Partnerships for Children/Youth with Disabilities**

The importance of positive partnerships between families who have a child with a disability and the educational system is reinforced by IDEA (2004). Parental involvement in educational decision making is mandated in this legislation. Unfortunately, even though parent-professional partnerships have been addressed in the policy, research indicates that parents still believe they do not have equal power in their relationship with educators (Hodge & Runswick-Cole, 2008). However, in some studies, parents indicated they have satisfactory relationships with professionals (Fox, Vaughn, Dunlap, & Bucy, 1997; Summers et al., 2007). Families of young children with disabilities report that they are satisfied with the partnerships with their primary service providers, but they also indicate a lower level of satisfaction with the ability of the service providers to provide information concerning services tailored to their child’s individual needs (Summers et al., 2007).

**Family and professional partnerships for children/youth with autism.** It is important for professionals to work with parents of children/youth with autism to build partnerships with families (Gray, Msall, & Msall, 2008; Murray, Ackerman-Spain, William, & Ryley, 2011). Gray et al. (2008) proposed that through efficient parent-
professional partnerships there is a reduction in parental fears and stresses. However, parents of children/youth with autism have indicated that they did not feel valued by educational professionals as an equal partner (Murray et al., 2011). While parents maintained that they had experienced difficulties in support and education provided in inclusive settings as well as in accessing provisions of autism-specific services, they also indicated a level of satisfaction with the quality of autism-specific support and education (Renty & Roeyers, 2006). However, the study of Renty and Roeyers (2006) was conducted in Flanders, not in the United States. More research concerning the perceptions of parents of children/youth with autism that focuses on their partnerships with professionals is needed.

**Statement of the Problem**

The concept of quality of life, as established in the field of intellectual disabilities, has received much attention in special education (Brown et al., 2006). With the increased identification of children as having autism, it is time to define family quality of life in relation to this population. Establishing positive professional partnerships among service providers and parents of children with autism is a key component in the quality of life experienced by the family and eventually by the child. However, there is little literature concerning the partnerships between families with children with autism and the professionals who provide services. The research concerning the parental stress experienced by parents who have children with autism consistently shows that the parents experience a higher level of stress than parents of children without disabilities and parents of children with other disabilities (Johnson et al., 2011; Mancil et al., 2009; Phetrasuwan & Miles, 2009; Schieve et al., 2007).
While there are many studies that focus on parental stress as experienced by parents who have children with disabilities (Brobst et al., 2009; Dabrowska & Pisula, 2010; Eisenhower et al., 2005; Johnson et al., 2011; Lee et al., 2009; Mancil et al., 2009; Phetrasuwan & Miles, 2009; Pisula, 2006; Rao & Beidel, 2009; Schieve et al., 2007), there is little research dealing with family quality of life. In a recent search conducted using several databases (e.g., Academic Search Premier, Child Development & Adolescent Studies, ERIC, PsyINFO, etc.), no research was found that examined the relationship between parental stress and family quality of life in families with children with ASD. Moreover, the studies regarding family-professional partnerships have focused on young children with disabilities, since the family-centered approach is applied more often in early childhood special education (Summers et al., 2007). While family-professional partnerships, specific to parents with disabilities, have been studied to some extent these studies are not specific to children with autism (Hodge & Runswick-Cole, 2008; Kasahara & Turnbull, 2005; Rogers, 2011). Therefore, it is imperative to explore how parents of children with autism perceive their partnerships with professionals and if this variable is a moderator of family quality of life and parental stress.

The purpose of this study was to determine the relationship among family-professionals partnership, parental stress, and family quality of life for families in which at least one child had autism. The two hypothesized models (see Appendix A) depict the relationship that the family-professional partnership plays as a moderator between the level of stress experienced by parents and the overall family quality of life. That is, how the family-professional partnership affects the direction and/or strength of the relation
between parental stress and family quality of life. Following are the specific research questions that were addressed in this study:

**Research Question 1.** Can the satisfaction of the family-professional relationship, as perceived by parents, be predicted from their ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

**Research Question 2.** Can the levels of parental stress of parents of children with autism be predicted from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

**Research Question 3.** Can the satisfaction of family quality of life as perceived by parents be predicted from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

**Research Question 4.** Does the perceived parental stress level have a direct effect on the parental satisfaction concerning family quality of life?

**Research Question 5.** Is the effect of the perceived parental stress level on parental satisfaction concerning family quality of life moderated by family-professional partnerships?

**Research Question 6.** Does the parental satisfaction concerning family quality of life have a direct effect on the perceived parental stress level?

**Research Question 7.** Is the effect of the perceived parental satisfaction concerning family quality of life on parental stress level moderated by family-professional partnerships?
Significance of the Study

When a family includes a child with a disability, the whole family is impacted, including the child, parents, siblings, and extended family (Turnbull et al., 2011). Family quality of life provides a multi-dimensional picture of a family in that a child is best served within the context of their family, particularly a child with a disability (Brown et al., 2006; Summers et al., 2005). Although many studies have been conducted concerning the parental stress of parents of children with autism, there is little literature concerning family quality of life and family-professional relationship for this population.

This study evaluated the relationship among parental stress, family-professional partnerships, and family quality of life. Two hypothesized models (see Appendix A) depict the relationship that the family-professional partnership plays as a moderator between the level of stress experienced by parents and the overall family quality of life. That is, how the family-professional partnership affects the direction and/or strength of the relation between parental stress and family quality of life.

The results of this study may be used to determine the factors that impact the quality of life of families of children with autism. Interventions as well as professional support could be developed to enhance family quality of life with a focus on parental stress and partnerships according to the results of this study.

Limitations of the Study

The limitations of this study were:

1. A survey method was used in this study. A diagnosis of autism was reported by parents. However, the assessment for diagnosis was not identified. Thus, the definition or assessment by which a child was diagnosed was not known.
2. Parents who were interested in the topic may be more likely to complete the survey. Thus, the configuration of the population was a limitation of the study.

3. The survey was implemented through an online system. Therefore, only parents with internet access were able to complete the survey.

4. Because the survey was implemented via an online system, which lacks face-to-face contact with the participants (parents), the participation rate could be low.

5. Social desirability could be a mediator. Thus, participants might have responded to questions in a manner that they feel they should, not the way they actually believe. Participants might have answered the survey depending on what they thought the answer should be.

**Definition of Terms**

Following is a list of terms used in this study. The definitions provided here were used in the context of the study.

**Autism.** Autism is a developmental disability which is characterized by social interactions, verbal and nonverbal communication skills, and restricted repetitive behavior (APA, 2000).

**Disability-related support.** Disability-related support refers to the services received by the family with a child with a disability in order to facilitate the child’s progress at home, school, workplace, or in their social life (Summer et al., 2005).

**Emotional well-being.** Emotional well-being involves positive thinking, identity, personal harmony, adaptability, control, and stress management (Turnbull et al., 2004).
**Family interaction.** The concept of family interaction involves the role played by each member of the family unit. It includes the relationship and communication among family members and how family members handle problems (Summers et al., 2005).

**Family-professional partnership.** A mutual supportive relationship built among families (not only parents) and professionals with the goal to meet the needs of both children and their families (Summers et al., 2005).

**Family quality of life.** Family quality of life is personally defined and informs the dynamic sense of well-being of the family, collectively, and subjectively (Zuna et al., 2010). The five main domains of family quality of life include family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support (Summers et al., 2005).

**Moderator.** A moderator variable can be either qualitative or quantitative and has an effect on the direction and/or the strength of the relation between the independent variable and the dependent variable (Baron & Kenny, 1986).

**Parenting.** The concept of parenting focuses on the teaching/guiding, supervising, and disciplining in a family by the adult(s) in charge of the unit (Turnbull et al., 2004).

**Parental stress.** Parental stress is the manner in which parents perceive available resources for meeting the demands of their tasks of parenting. It often results when there is a mismatch between expectations and perceptions of available resources (Deater-Deckard, 1998).
Physical/material well-being. Physical and material well-being are tangible entities (e.g., medical care, dental care, transportation, finance) that impact the family unit positively or negatively (Summers et al., 2005).

Quality of life. Quality of life is defined as a reflection of an individual’s satisfaction with home, community living, employment, social interactions, and health functioning (Schalock, 1994).
CHAPTER TWO

REVIEW OF RELATED LITERATURE

Family plays an important role in the development of children and youth. The role of family relationships, especially parental/marital and parent-child relationships, are critical. The literature indicates that parent-child relationships are highly correlated with adaptive behavior in childhood and adolescence (Cowan & Cowan, 2002; Davies, Cummings, & Winter, 2004; Davies, Sturge-Apple, Winter, Cummings, & Farrell, 2006). These relationships also indirectly influence children outside of the family, such as at school or in peer-relationships, as parental interactions serve as a model for children (Cowan & Cowan, 2002; Guajaro, Snyder, & Petersen, 2009; Sturge-Apple, Davies, & Cumming, 2010). The relationship between parents also impacts the adjustment of their children both inside (e.g., sibling relationships) and outside of the family (e.g., school) (Cowan & Cowan, 2002).

While the family is considered a system or whole unit, family members are interdependent with each other (Sturge-Apple et al., 2010). The children in the family also influence and contribute to the well-being or resilience of the family (Ungar, Theron, & Didkowsky, 2011). When an individual with disabilities is present in the family system, the whole family unit is impacted (Blacher & McIntyre, 2006; Havens, 2005; Meadan, Halle, & Ebata, 2010; Perry, Harris, & Minnes, 2005; Trute, Hiebert-Murphy, & Levine, 2007). A common theme in the research literature indicates the importance of support and services for the family as well as the child with a disability (Eskow, Pineles, & Summers, 2011; Hall & Graff, 2011; Havens, 2005; Meadan et al., 2010; Schieve, Blumberg, Rice, Visser, & Boyle, 2007).
Family quality of life (FQOL) is used as an indicator to measure the effectiveness of service programs for families (e.g., health, social service, and education), and also to assess the effectiveness of the familial interventions (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Park et al., 2003; Poston et al., 2003; Zuna, Summers, Turnbull, Hu, & Xu, 2010). Because families repeatedly indicate the importance of supports and services, research relating FQOL to other indicators is timely. Other indicators impacting FQOL are parental stress and family-professional partnerships (Summers et al., 2007; Stoner & Angell, 2006). Thus, to explore the current status of family and professional partnerships and the factors contributing to this relationship is critical (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Summers et al., 2005, Summers et al., 2007).

The Family System in Child/Youth Development

Family systems theory maintains that boundaries or implicit rules for assessing materials, resources, and support within the family govern the interdependencies among relationships (Sturge-Apple et al., 2010). When parents experience discord or parenting problems, their children have more difficulties in meeting developmental milestones (Sturge-Apple et al., 2010). Previous research indicates that patterns of family functioning are associated with the adjustment of children (Davies et al., 2004; Sturge-Apple et al., 2010). Although studies show mixed results, parental stress is another factor affecting a child’s social-cognitive development (Guajardo, Snyder, & Petersen, 2009).

The Family System and Typical Children/Youth

Current family systems research has begun to expand beyond only examining the parent-child relationship into the collective experiences of the family (Davies et al., 2004;
Sturge-Apple et al., 2010). While still adhering to the constructs of family systems theory, the research is now focusing more on child development and adjustment (Cowan & Cowan, 2002; Davies et al., 2004; Davies et al., 2006; Sturge-Apple et al., 2010).

Davies et al. (2004) designed a study to examine the pathways through which system profiles of family functioning affect a child’s security and psychological adjustment. Specifically, the purpose of the study was to assess the forms of family functioning (e.g., cohesive families, disengaged families, enmeshed families, and adequate families) to determine the contributions of different profiles to the security of children and any psychological symptoms within a family-wide model. Davies et al. (2004) believed that children in enmeshed and disengaged families would experience higher insecurity, which is associated with psychological problems.

Participants of this study were drawn from a larger project that was designed to explore the relationship among family processes, child coping, and adjustment. The original sample included 236 kindergarten children and their families. A total of 221 kindergarteners (124 girls and 97 boys) and both of their parents completed all the measures required in this study. The families (mothers, fathers, and children) visited the research center twice, with one year between each visit. The center had an observation room for observing family interactions and interview rooms for completing surveys.

A Simulated Phone Argument Task (SPAT) (Davies et al., 2004) was performed to observe the child’s reaction during an interparental conflict and a subsequent resolution. Each mother followed the script and conveyed different emotions (e.g., mild irritation, frustration, and anger) toward their partner as they normally would at home during conflict. At the end of the simulation, each mother communicated understanding,
caring, and warmth in her tone of voice. Each SPAT lasted one minute with a three-minute free period following. The free period was used to measure each child’s immediate and delayed reaction to the SPAT.

Specific distress behaviors (e.g., freezing, anxiety, whining, anxious smiling, loss of control, anger, sadness, and interpersonal hostility) as well as avoidance and involvement behaviors (e.g., shouting out and social withdrawal) were recorded during the four-minute period of the SPAT (conflict and resolution). The children also answered questions from the Interparental Conflict Scale for Young children (CPIC-Y; Grych, 2000), and their parents completed surveys regarding their functioning in spousal, coparental, and parent-child interactions. The surveys used included the O’Leary-Porter Scale (Porter & O’Leary, 1980) for interparental conflict, the Love and Affection Subscale of the Managing Affect and Differences Scale (Arellano & Markman, 1995) for interparental affection, the Child-Rearing Disagreements Scale (Jouriles et al., 1991) for coparental disagreements, the Parental Acceptance Subscale of the Parental Acceptance and Rejection Questionnaire (Rohner, 1990) for parental acceptance, three subscales of the Child Report of Parenting Behaviors Inventory (Margolies & Weintraub, 1977; Schluderman & Schluderman, 1970) for parental psychological control, and the Alabama Parenting Questionnaire (Shelton, Frick, & Wootton, 1996) for parental behavioral control. Both parents also completed the symptoms subscales from the Child Behavior Checklist (Achenbach, 1991a). The Teacher Report Form of the Achenbach (1991a) was completed by the kindergarten and first grade teachers of the participating children.

Descriptive data (e.g. means, standard deviations, and intercorrelations) of the measures of family process, child insecurity, and psychological adjustment were reported.
The profiles of family functioning were identified by hierarchical agglomerative cluster analyses (with squared Euclidian distance) and non-hierarchical cluster analyses. Four family clusters were identified: (a) cohesive families, (b) enmeshed families, (c) disengaged families, and (d) adequate (but not optimal) families. A series of analyses of covariance (ANCOVAs) were conducted to examine the association between the profiles of family functioning and dimensions of child insecurity. A series of repeated measures multivariate analyses covariance (MANOVAs) were conducted to examine the associations between family profiles and child adjustment across the two visits to the research center. A series of repeated-measures multiple regression analyses were conducted to examine the relationships between the insecurity of the children and their psychological adjustment across the two visits. Finally, structural equation modeling (SEM) was conducted to determine the role of insecurity with the children between the profiles of family functioning and child adjustment, including internalizing and externalizing symptoms.

Compared to children from cohesive families, children from enmeshed and disengaged families displayed greater levels of insecurity in the marital relationship concurrently. However, children from adequate families were very similar to those in cohesive families. Results of the structural equation models showed that insecurity of the children in the interparental relationship was a mediator between family functioning (i.e., family enmeshment and disengagement) and their psychological problems one year later. Davies et al. (2004) concluded that the study expanded the understanding of how interparental relationships and family relational patterns (e.g., marital, coparenting, and parent-child subsystems) impact children’s emotional security. Davies et al. (2004)
recommended future research replicates findings of the study using different assessment techniques.

Sturge-Apple et al. (2010) conducted a multimethod, 3-year longitudinal study to identify family typologies (e.g., family functioning across multiple systems or family relationship patterns) across multiple family contexts to examine how the typologies were related to the adjustment of young children in school. The participants included families with one child in kindergarten, with parents who had lived together for at least three years. The participants were 234 kindergarten children and their parents. The families visited the research center twice a year with one week in between the two visits. The parents (both mothers and fathers) and their child played an interactive game for 15 minutes, and the parents participated in an interparental interaction task.

The subscales of the System for Coding Interactions in Dyads (SCID) (Malik & Lindahl, 1996) were used to evaluate the interparental relationship (e.g., interaction behaviors and maternal/parental hostility) between the mothers and fathers. The SCID is a 5-point Likert scale ranging from 1 (very low) to 5 (high) on the level of hostile and aggressive behaviors and verbalizations as well as displays of anger, frustration, and tension, and repeated, prolonged, and tense forms of detachment and avoidance. In order to assess the parent-child relationship, the Iowa Family Interaction Rating Scales (IFIRS) (Melby & Conger, 2001) was used and the Relatedness Scale (Davies, 2002) was used to evaluate child behaviors. The adjustment of the children was assessed by several scales: (a) The Teacher Report Form (Achenbach, 1991b) to assess child internalizing and externalizing symptoms, (b) the hyperactivity/distractibility subscale of the Child Behavior Scale (CBS) (Ladd & Profilet, 1996), (c) the cooperative participation subscale
of the *Teacher Rating Scale of School Adjustment* (TRSSA; Birch & Ladd, 1997) to assess the classroom engagement of the children, (d) the school avoidance and school liking subscales from the *TRSSA* (Birch & Ladd, 1997), and (e) the prosocial behavior subscale of *CBS* (Ladd & Profilet, 1996) were used to assess difficulties in emotional adjustment of the children.

Latent Profile Analysis (LPA) was used to determine family profiles (e.g., family typology) and latent growth curve analyses were used to examine the adjustment trajectories of the children in the school context. Three primary typologies of family functioning were extracted from the latent profile analysis: (a) cohesive families, (b) enmeshed families, and (c) disengaged families. The family patterns were differentially associated with adjustment trajectories of the young children in school. Sturge-Apple et al. (2010) concluded that the study highlighted the developmental utility of incorporating pattern-based approaches from three family relationship contexts (i.e., interparental, parent-child, and triadic) to typologies of family functioning. Sturge-Apple et al. (2010) recommended that longer assessment windows be incorporated to examine how family typologies affect adjustment of the children over time. They also suggested that assessment of family typologies be done to ascertain how stability and change in the typologies impact the adjustment trajectories of the children over time.

Davies et al. (2006) conducted a multi-method, one-year longitudinal study to identify parameters of developmental change and stability of child reaction patterns to conflict between their parents in the context of family relations. They assessed the association between multiple forms of interparental conflict, family processes, and child reactions during the early school years. A total of 223 families, with a child in
kindergarten and parents who had lived together for three years were recruited for the study.

Data were collected twice during the study, with one year between each session. During each session the families came to the research center twice a week. For the first session, both parents and child visited the center and participated in interparental interaction tasks and parent-child tasks. A simulated phone argument task was conducted to assess the young child’s emotional reactivity. For the second visit, only the mother and the child participated. The mothers participated in a simulated phone argument task in front of the child. The *Revised MacArthur Story Stem Battery* (Bretherton, Oppenheim, Buschsbaum, Emde, & The MacArthur Narrative Group, 1990) was completed by the child for the second visit to assess the representations of family relationships. A series of repeated measure ANOVAs were used to examine whether child reactivity to interparental conflict changed across time. Structural Equation Modeling (SEM) was used to test the conceptual model. Longitudinal, autoregressive analyses were used to examine the associations between the multiple domains of child response and time.

Results of the study indicated that interparental hostility was associated with a greater child sensitization and negative internal representations of interparental conflict concurrently, but not over time. Parental warmth was not a mediator of the paths between interparental conflict and child reactivity, but it was significantly related to lower subjective distress reactions of the children to the simulated interparental conflict task. The data also supported that the differences between individuals was a factor of the children’s forms of reactivity to conflict. Davies et al. (2006) concluded that the study showed the value of formulating multivariate developmental models to find the
parameters of child reactivity to interparental conflict. They recommend that the methods
and design of the study serve as the foundation for conducting new developmental
assessment to evaluate child adjustment.

Melby and Conger (1996) conducted a longitudinal study to examine the
association among parental behaviors (e.g., parenting, hostility) and adolescent academic
performance across time. Specifically, Melby and Conger (1996) proposed that family
per capita income and parent educational level would influence both variables of parental
families through local school systems. A total of 347 families that included adolescents in
the seventh grade volunteered to participate over the four years of the study.

In each year of data collection, the families were interviewed twice. The
interviews focused on beliefs about parenting, goals, values, friends, and future plans.
The family members also completed questionnaires regarding family processes,
characteristics of each family member, and demographic information during the first visit.
For the second visit, the family members participated in structured interaction tasks
lasting 30 minutes to assess the interaction among family members. These tasks were
videotaped. The videotapes were coded using the Iowa Family Interaction Rating Scales
(Melby et al., 1989). The schools attended by the adolescents provided official records
(e.g., grade points average) as the academic performance of the adolescents.

Descriptive statistics (e.g., means and standard deviations) were reported. Zero-
order correlations between all of the variables were conducted to analyze the
relationships between variables. Structure equation modeling was conducted to test the
conceptual model regarding the relationships among parental behaviors (involved
parenting and hostility), adolescent academic performance, family per capita income, and parent educational level. The analysis demonstrated that there was an association between parent behavior and academic performance. For both parents, involved parenting (e.g., setting goals, positive reinforcement, appropriate behavioral standards) increased the academic performance of the adolescents while parental hostility (a dimension of negative emotional affect) decreased academic performance. Parent educational level was associated with positive parental involvement and to academic performance.

Melby and Conger (1996) concluded that parental behaviors played an important role in changing school academic performance either positively or negatively, starting from early to middle adolescence. The data were consistent across gender for both parents and adolescents. They recommended future research to examine the role of other possible important variables (e.g., parental employment, parental depression, peer relationships, and adolescent personality) in relation to adolescent academic performance.

Ungar et al. (2011) conducted an exploratory qualitative study to examine the contributions of adolescents to the well-being and resilience of their families in five countries. A total of 16 adolescents (8 males and 8 females) age 13 to 16 were recruited from five countries (e.g., Canada, China, India, South Africa, and India) for this study. These adolescents were considered to be developmentally doing well regardless of facing considerable levels of risks (e.g., poverty, racial minority, refugee status, disability).

This study consisted of six phases. The first phase was to identify participants and collect consents forms. The second phase was to investigate themes related to resilience by conducting semi-structured interviews with the youth. The third phase was to film a day in the life of the youth. For the fourth phase, the adolescents were given a disposable
camera to take pictures on various aspects of their lives and asked to provide explanations of their coping with adversity and experiences with transition. Phase five involved selecting video clips and creating a 30-minute compilation of pictures that demonstrated aspects of protective processes associated with resilience. The last phase involved a second interview with the adolescents that focused on the photos taken.

Ungar et al. (2011) applied a constructivist grounded theory approach to analyze the data. The adolescent participants were involved in the interpretations of their own data. Final data sets including interviews, observations, photos, and videos were analyzed for each participant and then analyzed across adolescents. Results showed that precocious and developmentally appropriate behavior exhibited by the adolescents contributed to the well-being and resilience of their family. The precociousness of each adolescent was distinguished by the nature of the parent-child hierarchy in each family. An inverted hierarchy indicated that some adolescents were required to function in the role of the parent and resulted in the child assuming responsibility for the physical well-being of the family. A Fattened Hierarchy indicated that the relationship between the youth and parent(s) was peer-like and interdependent. That is, the youth contributed to the family to help unburden the responsibilities of the parents, but without taking the position of the parent. Adolescents who exhibited developmentally appropriate behavior contributed to the well-being of the family by facilitating access to resources. Ungar et al. (2011) noted that the use of multiple qualitative methods, advisory committees, and reciprocity in the design as well as the length of engagement with each adolescent were the strengths of the study. They recommended that further studies include a larger sample size, be conducted across time, and explore more specific patterns of within-family contribution.
Researchers have conducted studies to examine the influences of family systems, such as parent-child relationships, marital/interparental relationship, and other variables within the subsystems of the family unit to ascertain the impact on emotional, social, and academic development (Davies et al., 2004; Davies et al., 2006; Melby & Conger, 1996; Sturge-Apple et al., 2010). The results indicate the importance of the family system for the development of children and youth. In addition, the literature shows that the relationships between children/youth and parents are bi-directional, meaning older children in a family also contribute to the well-being of the family (Ungar et al., 2011).

**The Family System and Children/Youth with Disabilities**

Because a family system is considered to be a whole unit, a child with a disability in the family can impact the system (Havens, 2005). Therefore, it is important to understand how the presence of a child with a disability influences as well as contributes to the system as a whole.

Pelchat, Lefebvre, and Perreault (2003) conducted a qualitative study to explore the point of view of mothers and fathers concerning the differences and similarities of parenting a child with a disability (e.g., Down syndrome in the study). A total of nine parents (five mothers and four fathers) from five families with a child with Down syndrome participated in the study. The children were between two-to-five years old.

Two focus groups were conducted simultaneously in separate rooms for 90 minutes, one for mothers and one for fathers, to avoid crossover effects. Each focus group was conducted by researchers reflecting the gender of the group. During the focus group, one researcher led the discussion while the other observed and took notes. The discussion was guided by open-ended questions concerning the differences and
similarities of personal experiences and personal explanations of participants with their partners in parenting a child with Down syndrome. Each group was video-taped.

A coding system and content analysis (Merton, Fiske, & Kendall, 1990) were used for data coding and theme extracting. Two broad themes appeared from the analysis: (a) actual and expected roles and (b) the normalization/stigmatization of the child with Down syndrome. Concerning the actual and expected roles, the fathers focused on their roles in parental and extended family issues, while the mothers addressed their roles in the marital and parental subsystems. The parents expressed different views concerning the normalization/stigmatization of their child. The mothers were more willing to ask for help and support, more involved, and more devoted to their child. The fathers expressed discomfort with their child’s special needs for care. Plechat et al. (2003) concluded that families with children with disabilities are similar to families with children without disabilities. However, the presence of a child with a disability accentuated the difficulties parents experienced within the family system. They recommended that the relationship between parents in their roles as individuals, parents as partners, and parents as members of the family as a whole should be further examined with a focus on normalization and stigmatization and social roles of both parents.

Perry, Harris, and Minnes (2005) conducted a study to explore the effects of the severity, age, and type of developmental disability of the child on family environments and family harmony. The purpose of the study was to: (a) examine parental perceptions of the family environment; (b) ascertain the relationship between the family environment and the child’s age, severity, and type of developmental disabilities; and (c) explore the effect of several variables on parent perceived family harmony. Parents of a child with
developmental disability were included in the study. Twenty-eight children of the parents had Down syndrome, 17 children had Fragile X syndrome, 48 children had Rett syndrome, 79 children had Autism, and 33 children had a developmental disability of unknown etiology.

The 90-item *Family Environment Scale* (FES) (Moos & Moos, 1981) was used to measure family environment. This scale includes 10 subscales within three domains. The subscale of *relationships* was used as a general measure of family harmony. The mean scores and standard deviations of the FES subscales were reported, graphed, and compared to the distressed and typical norms. A series of ANOVAs were used to analyze the data and examine the relationship between parent perceptions of family harmony and the type and the severity of the disabilities as well as the age of the child. The results showed that the family environment of families with children with developmental disabilities was not different from those of typically developing children. There also was no difference between mothers and fathers across all ten FES subscales. However, there was increased diagnostic ambiguity associated with lower levels of family harmony. Perry et al. (2005) concluded that the identification of factors that serve as protective factors for families at risk for stress is an important line of research and further research is required.

Blacher and McIntyre (2006) designed a study to examine whether behavior problems and adaptive behavior of young adults with intellectual disabilities and the well-being of their family varied by diagnostic syndrome (e.g., intellectual disability only, cerebral palsy, Down syndrome, autism) and by cultural group (e.g., Anglo, Latino). A
total of 282 parents of young adults with moderate to severe intellectual disabilities participated (150 were Anglos, and 132 were Latinos).

Several instruments were used to collect data. Measures of family well-being, included the 50-item *Family Impact Questionnaire* (Donenberg & Baker, 1993), the 20-item *Center for Epidemiologic Studies—Depression* (Radloff, 1977), and the 17-item *Philadelphia Geriatric Center Morale Scale* (Lawton, 1972). The parents completed the surveys and were interviewed. The parents also completed: (a) *The Family Data Sheet* (demographic data), (b) *Acculturation Scale for Hispanics* (Marin, Sabogal, Marin, Otero-Sabogal, & Pérez-Stable, 1987) (to assess language, media, and ethnic social relations), (c) *Vineland Adaptive Behavior Scale* (VABS; Sparrow, Balla, & Cicchetti, 1984) (to obtain overall adaptive behavior), (d) *Scales of Independent Behavior – Revised Problem Behavior Scale* (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996) (to measure maladaptive behavior), and (e) the *Reiss Screen for Maladaptive Behavior* (Reiss, 1994, 2nd ed.) (to identify mental health problems).

Data were analyzed by a series of ANOVAs and hierarchical regression analyses. The results indicated that the diagnostic syndrome of autism showed the highest scores in multiple behavior problems and Down syndrome was associated with the lowest behavior problem score. Regarding family well-being, parents of young adults with autism reported lower levels of well-being, compared to parents of young adults with Down syndrome who indicated the highest levels of well-being. When behavior problems were controlled, the well-being of families did not vary by diagnostic syndrome. Concerning cultural group, the patterns of behavior problems and well-being were not varied by cultural group. Latino mothers experienced higher levels of depression and lower morale.
than did their Anglo counterparts. However, Latino mothers scored higher on positive impact of feelings about parenting on the *Family Impact Questionnaire* (Donenberg & Baker, 1993). Blacher and McIntyre (2006) concluded that informal supports and formal services should be made available to all mothers of young adults with intellectual disabilities, especially for those with challenging behaviors. They recommended that researchers continue to examine the factors associated with the Latino culture that accounts for the more positive maternal perceptions as well as include a variety of cultural groups in further studies.

Trute, Hiebert-Murphy, and Levine (2007) designed a study to explore parental cognitive appraisals of the family with a child with an intellectual or developmental disability and the impact of the appraisal on the adjustment of the family. The purpose of the study was to examine gender differences across time for dependent variables (e.g., appraisal of family, impact of disabilities, parental self-esteem, and family well-being), stability of parents scores across time on the dependent variables, and the effect of parental self-esteem on positive and negative appraisals of family impact of disability. A total of 103 families of children with disabilities participated in the study.

The parents were interviewed separately at home twice, after their children had entered and received childhood disability services for six months, and one year after the first interviews. Three measures were used to conduct interviews. The *Family Impact of Childhood Disability Scale* (True & Hiebert-Murphy, 2002) was used to assess positive and negative appraisals of the impact of childhood disability on the family. Five additional items were added to the scale to address positive family impact in order to balance the weight of both negative and positive impact in the overall score. The 10-item
Rosenberg Self-Esteem Scale (Rosenberg, 1965) was used to measure parental esteem, and the 50-item Family Assessment Measure III- Brief Form (Skinner, Steinhauer, & Santa-Barbara, 1983, 1995) was used to rate family organization and functioning.

Paired t tests were used to compare the scores of the mothers and fathers on self-esteem, appraisal impact of disability on the family, and family well-being. For both parents, the level of negative appraisal of the impact of disability on the family and the level of self-esteem were the predictors of family well-being. For mothers, early family well-being was related to positive appraisal of the child with a disability and enhanced self-esteem. For fathers, their mean score on positive appraisal increased over time. However, since the sample of fathers was relatively small in the study, Trute et al. (2007) noted that the prediction of the parental self-esteem of the fathers and their perceived family well-being should be considered as tentative. Trute et al. (2007) concluded that there were differences in parental appraisal of the impact of disability on the family. The parents of the children with disabilities had both positive and negative appraisals and these appraisals were predictors of perceived overall family well-being for both parents. They recommended that further studies be conducted with a larger sample of families with young children with specific disabilities and with families from diverse groups.

Knestrick and Kuchey (2009) designed a descriptive study to explore the resiliency factors that families develop while raising a child with a severe disability. The purpose of the study was to compare and contrast how families address and manage additional responsibilities and to identify the key characteristics of resilient families. The families recruited for the study were two-parent families that had at least one child with a diagnosed severe disability. A total of 20-paired couples participated in the study. The
disabilities of the children included intellectual disabilities, emotional and behavioral disabilities, learning disabilities, and Asperger syndrome. The parents rated the disabilities as either severe or severe and profound.

The study was conducted in three stages. The first stage was a 2-hour interview with each pair of parents. The interviews focused on characteristics of resiliency in their families, such as rhythm, hardiness, and general attitude. The second stage was a 2-hour focus group with all participants. The third stage was to observe families in their home with the entire family present. Data analysis was guided by the ecological model (Bronfenbrenner, 1979). Themes were identified from the data in two categories: (a) reconstruction and (b) an affirmation of the importance of social economic status. Reconstruction was considered as the time and the ability of the families to reflect on their vision of family, of the disability, and their child. The relationship between resilience and level of socio-economic status and access to services also was found. In addition, development of rhythm in the family also enhanced the development of resiliency. The component of rhythm included consist rules, rituals, and routines. Knestrick and Kuchey (2009) concluded that there are many factors that contribute to family resiliency. It appears that however a family struggles with basic needs, there is little time for them to be reflective and reconstruct their values of family, child, and disability. Knestrick and Kuchey (2009) recommended that adequate supports from service programs, schools, and health services be provided for families that include a child with a disability.

The presence of a child with disability in a family is not necessarily devastating for members in the family or the family subsystems (Havens, 2005). The research
indicates both positive and negative impacts on the family unit. Parents have both positive and negative appraisals concerning the family impact of disability (Trute et al., 2007). However, when adequate supports are provided, families of children with disabilities do thrive and become a resilient family (Havens, 2005; Knestrick & Kuchey, 2009).

**The family system and children/youth with autism.** Individuals with autism spectrum disorders (ASD) are identified by their limited verbal and nonverbal communication, social interaction impairments, and repetitive patterns of behavior (American Psychiatric Association, 2000; Meadan et al., 2010). These characteristics are factors that influence their immediate and extended family (Meadan et al., 2010). However, Meadan et al. (2010) maintain that a child/youth with ASD impacts each person in the family in different ways. There may be bidirectional relationships between individuals with ASD and their different family members (Brobst, Clopton, & Hendrick, 2009; Fein & Dunn, 2007). Therefore, it is important to understand how the presence of a family member (child/youth) with ASD affects the family in which they live.

Cassidy, McConkey, Truesdale-Kennedy, and Slevin (2008) conducted a large-sample size study to explore the impact of preschoolers with ASD on their families. The purpose of the study was to report the demographic characteristics of the parents and their young children with ASD, explore perceptions of the parents concerning difficulties of their child, identify the influence the child had on the family, and to outline the supports that families received and other supports needed. A total of 104 parents with a child with ASD were interviewed in the study. Among these families, the mothers served as the
informants for most families (71% of the families), both parents participated for 25% of the families, and only fathers participated for 4% of the families.

Cassidy et al. (2008) used a semi-structured questionnaire and standard rating scale to conduct individual interviews. The interviews were conducted in the home and took 90 minutes. The semi-structured questionnaire included open and closed questions developed for the study. Standard rating scales were also used and included: (a) the *Vineland Adaptive Behavior Scale* (Sparrow et al., 1984), (b) the *Gilliam Autism Rating Scale* (Gilliam, 2001), and (c) the *Questionnaire on Resources and Stress* (Friedrich, Greenberg, & Clinic, 1983).

Descriptive statistics (e.g., means, standard deviations, percentage, and range) were reported. Although the children all had the same confirmed diagnosis (ASD), their difficulties in development and the characteristics of their families were different. The parents reported developmental problems in language, play, and relating to others as well as combinations of issues. Most families in the study experienced increased levels of stress. However, the amount and type of professional support each family received were not associated with the characteristics of the child and family. Cassidy et al. (2008) concluded that family-centered interventions and support services should be available and accessible to families. They recommended that future studies expand beyond the impacts of therapeutic interventions to the impacts of a variety of professional supports on families.

Quintero and McIntyre (2010) examined the differences in sibling adjustment (social, behavior, and academic) and maternal well-being in families with and without a child with ASD. The purpose of the study was to compare social, behavioral, and
academic adjustment in older siblings of children with ASD to older siblings of typically developing children and examine the relationships between parental well-being and sibling adjustment. A total of 43 families participated in the study. The families had a young child, age 2-5 years, and a child in elementary school age 6-10 years. Among these families, 20 had a child with an ASD and 23 had a child without disabilities.

Parental well-being variables were collected by two measures. Parental daily stress associated with childrearing activities for all children in their household was measured by the 20-item Parenting Daily Hassles Scale (Crnic & Greenberg, 1990). The depressive symptomatology of the parents was assessed by the 20-item Center for Epidemiologic Studies—Depression Scale (Radloff, 1977). Sibling adjustment was reported by parents and teachers and the Child Behavior Checklist for Age 6-18 (Achenbach & Rescorla, 2001) was used for parents to report the behavior problems of the older siblings. The Teacher’s Report Form of the Achenbach and Rescorla (2001) was used by teachers to report the older siblings’ behavior problems. Regarding social skills, parents and teachers completed the Social Skills Rating System (Gresham & Elliott, 1990), Elementary Parent Version and Elementary Teacher Version, respectively. Teachers of the older siblings also reported their academic competence using the 9-item Academic Competence Subscale of the Social Skills Rating System—Elementary Teacher Version (Gresham & Elliott, 1990).

Both descriptive and inferential statistics were used to analyze the data. Chi-square and t tests were used to examine the difference in demographic variables between both groups, and t tests and analysis of covariance (ANCOVA) were used to examine the differences on maternal well-being and sibling adjustment between both groups.
Compared to mothers of preschoolers without ASD, mothers with a child with ASD experienced more daily hassles, life stress, and depression. The adjustment of older siblings in social, behavior, and academic did not show significant differences from the reports of parents and teachers. However, the behavioral adjustment of the siblings was highly related to maternal well-being. Quintero and McIntyre (2010) concluded that since the behavioral adjustment of siblings was significantly associated with maternal well-being and it is more likely that parents of children with ASD experience more parental stress and depression, siblings of children with autism may be more vulnerable to the cumulative risks over time. They recommended to further examine how the behavior problems and adaptive functioning of children with ASD influence adjustment of their siblings in future research.

Brobst, Clopton, and Hendrick (2009) conducted a study to compare the relationships between couples with children with ASD and those whose children did not have a developmental disorder. More specifically, they examined the variables of stress (e.g., child’s behavior problem) and relationship satisfaction. A total of 45 couples participated in the study with 25 couples having children with ASD (e.g. autism, Asperger syndrome, or pervasive developmental disorder not otherwise specified) and 20 couples with children without ASD or other developmental disorders.

The couples completed several questionnaires: (a) the 36-item Parenting Stress Index—Short Form (Abidin, 1986), (b) the 36-item Eyberg Child Behavior Inventory (Eyberg & Pincus, 1999), (c) the 7-item Relationship Assessment Scale (Hendrick, 1988), (d) the 6-item Social Support Scale (Sarason, Sarason, Shearin, & Pierce, 1987), (e) the 6-item Respect Toward Partner scale (Hendrick & Hendrick, 2006), and (f) the selected
4-item from *Commitment Scale* (Hendrick & Hendrick, 2002; Lund 1985). The data from the scales were the dependent variables and were analyzed by a series of analyses of variance (ANOVAs) to ascertain the differences between the ASD group and the comparison group and the difference between husbands and wives. Correlational analyses were applied to ascertain the relationships among variables. The data indicated that parents of children with ASD encountered more serious child behavioral problems, experienced higher levels of parental stress, and were less satisfied with their partner relationship. However, there were no significant differences on perceived spousal support, respect, and commitment for their partners between both groups of couples. Brobst et al. (2009) concluded that continuing examining a variety of child and parent variables helps to identify the most critical factors on life quality of families of children with ASD or other developmental disabilities. Thus, they recommended that future studies be conducted to examine the relationship between ASD and behavior problems and how to address these issues at home, at school, and in counseling. They suggested that research examines a variety of aspects of the marital relationship for parents of children with ASD and with other disabilities.


The 101-item *Parenting Stress Index* (Abidin, 1995) (a 5-point Likert scale) was used to measure stress in parent-child systems. The scale includes six subscales:
Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, and Acceptability. The Gilliam Autism Rating Scale, Second Edition (Gilliam, 2005) was used to assess children on three domains of autism: (a) stereotyped behavior, (b) communication, and (c) social interaction. An independent samples t test was conducted to examine the difference on parental stress between both groups. A series of multivariate analyses of variance (MANOVAs) were conducted to examine the differences in mean scores on the six subscales of the Parenting Stress Index (Abidin, 1995) for girls and boys. Pearson correlations were used to examine the relationships between the level of autism and maternal stress.

Based on the scores of the Parenting Stress Index (Abidin, 1995), mothers of children with autism experienced greater stress than mothers of typically developing children. Mothers of children with autism scored higher than their counterparts in the comparison group on 13 out of 14 subscales of the index. Mean Child Domain Subscale scores for mothers of children with autism were at the 99th percentile. The scores for the Attachment Subscales were the only scores that did not show differences between two groups of mothers. For both groups, mean scores on this subscale were at about the 50th percentile. That is, even though mothers of children with autism showed higher levels of stress, they still had close relationships with their children. Hoffman et al. (2009) recommended development of specific interventions for mothers of children with autism to reduce their parental stress.

Rao and Beidel (2009) conducted a study to examine the impact of children with high-functioning autism (HFA) on parental stress, sibling adjustment, and family functioning. A total of 29 families of children age 8-to-14 years participated in the study.
Parents (12 mothers and 3 fathers) and siblings (4 sisters and 3 brothers) of 15 children with HFA comprised the targeted group. The other 14 parents (12 mothers and 2 fathers) and siblings (2 sisters and 6 brothers) of 14 children without any psychological disorders were the comparison group.

A packet of materials (e.g., a postage prepaid self-addressed envelope and questionnaire) was sent to parents who participated in the study. Six scales were included in the questionnaire: (a) the Parenting Stress Index (Abidin, 1995) (to measure parental stress); (b) the Family Environment Scale (Moos & Moos, 1986) (to assess family functioning); (c) the Symptom Checklist-90-Revised (Derogatis, 1994) (to assess parental psychological problems and psychopathology); (d) the Short Form 36 Health Survey (Ware & Sherbourne, 1992) (to measure general physical and mental health of parents); (e) the Piers-Harris Children’s Self-Concept Scale, 2nd edition (Piers & Herzberg, 2002) (to assess sibling adjustment); and (f) the Child Behavior Checklist (Achenbach, 1991a) (to collect data regarding child behavior problems). Independent samples t tests were conducted to examine whether there were significant differences between families of children with HFA and families without children with any disabilities.

Parents of children with HFA reported significantly higher levels of parental stress than parents of the matched control children. Thus, indicating that parental stress was associated with characteristics of the children. Even though children with HFA had higher intellectual functioning, it did not compensate for the stress related to parenting a child with ASD. Rao and Beidel (2009) concluded that the treatments provided for the children with HFA did not necessarily improve the symptoms of the children. They
recommended that interventions for families targeting parental stress must be provided to enhance outcomes of both family and the child.

Studies examining the different relationships in a family system that are affected by the presence of children with ASD, including children with HFA show mixed results. Families may have similar experiences as those families of typically developing children (Hoffman et al., 2009). Generally, families of children with ASD report higher parental stress and lower satisfaction with their relationships with spouse or cohabitating partner (Brobst et al., 2009; Cassidy et al., 2008; Hoffman et al., 2009; Quintero & McIntyre, 2010; Rao & Beidel, 2009). Because of the lack of consistent data, further research is needed to provide appropriate support services specific to families of children with ASD.

**Family Quality of Life**

Quality of life (QOL) is an important indicator of the effectiveness of service programs (e.g. health, social service, and education) as well as research interventions/treatment (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). The direction of research in the field of disabilities has gradually changed from exclusive focus on individual QOL to a broader conception of the whole family unit (Gardiner & Iarocci, 2012). Although research indicates that the family plays an important role for individuals with disabilities, the examination of family quality of life (FQOL) is a relatively new field that has just emerged within the last ten years (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Samuel, Rillotta, & Brown, 2012; Turnbull, Summers, Lee, & Kyzar, 2007; Zuna, Summers, Turnbull, Hu, & Xu, 2010). The focus on FQOL incorporates the concepts of QOL within the field of intellectual disabilities (Brown et al., 2006). Studies on FQOL explore the influence of different life domains when there is a
member in the family with a disability as well as the perceptions of family members about their life in general (Brown et al., 2006).

**Family Quality of Life with Typical Children/Youth**

Since family is considered a critical social unit, family quality of life is considered an important indicator of overall life quality, reflective of the concepts and characteristics of a society at large (Rettig & Leichtentritt, 1999). Therefore, to explore family quality of life and the factors that influence it becomes an issue of social justice.

Rettig and Bubolz (1983) used resource exchange theory to develop perceptual indicators of quality of family life. This theory included six classes of resources for maintaining some level of life quality: love, status, services, information, goods and money. The study examined whether familial perspectives on resources received in the family contributed to their satisfaction of family life quality and whether the order of resources on domains would be correlated to family life satisfaction. Rettig and Bubolz (1983) proposed that if a variable within any resource class is more particularistic, that variable would be more important for explaining satisfaction. A total of 224 husband-wife couples participated in the study and completed the study questionnaire.

The dependent variable of the study was perceived quality of family life, measured by a global item regarding feelings about their own family life. The question was rated using a 7-point Delighted-Terrible Likert scale (ranging from *terrible, unhappy, mostly dissatisfied, mixed, about equally satisfied and dissatisfied, mostly satisfied, pleased, to delighted*). The independent variables included the perceived evaluation of and the frequency of received resources. Items regarding evaluation of received resources were rated by the 7-point Delighted-Terrible scale. Items regarding
perceived frequency of received resources were rated by 8-point Likert scale (from never to about 2-3 times a day). The agglomerative method of hierarchical complete-linkage clustering was used to identify hierarchical clustering of the six classes of resources and their contributions to perceived quality of family life. Also, multiple regression analyses were applied to examine whether feelings about the particularistic resources received from the family contributed to family life satisfaction for both wife and husband.

Data analyses indicated that both social-psychological and economic resources were important predictors of quality of family life. When more particularistic resources (e.g., love, status) were received, the participants reported higher levels of satisfaction with quality of family life for both wife and husband. Rettig and Bubolz (1983) concluded that the study contributed to the literature regarding the situation of a family as the dominant factor predicting quality of family life. They recommended further studies focus on other predictors of quality of family life.

Voydanoff, Fine, and Donnelly (1994) examined the association between family organization and family quality of life in different types of families. The types of family included parents in first marriage, remarriages with biological children, and step families. They used data from the 1987-1988 National Survey of Families and Households in the United States to examine this association. The original national data set included data from 13,017 households. The data in this study included 1560 married couples who had children under the age of 19. The primary respondent in a household was interviewed. His or her spouse or cohabitating partner completed a self-administered questionnaire. The data collected included the composition of families and the relationship of household members (e.g., marriage, separation, history of divorce, adoption, arrangement of child
custody). The questionnaire also included items concerning relationships with family members (e.g., parents, children, in-laws). Economic well-being and demographic variables also were investigated.

Data were analyzed by multiple regression analyses to determine contributions of family demographics (e.g., race, education, and income), family structure (e.g., first marriage, remarriages with biological children, and step families), and family organization (e.g., task/role division in work and household tasks). The participants in different family structures perceived their quality of parent-child relationships differently. However, the variable of family structures was not related to family organization. The data indicated that some aspects of family organization were related to quality of parent-child relationships and marital relationships. Voydanoff et al. (1994) concluded that family structure and family organization were not consistently associated with quality of family life. They recommended future studies be conducted to examine the effects of shifts in family organization as well as the provider role on quality of family life.

Rettig and Leichtentritt (1999) applied Foa and Foa’s Resource Theory (1974) to develop a self-report, multi-dimensional instrument for measuring family well-being and family life quality. The resource theory consisted of six classes of resources (e.g., love, status, information, money, goods, and services) believed to be important to maintain quality of life. The purpose of the study was to examine whether family is an important environment for individual well-being. This study was part of a large project that was conducted to identify individual responses to economic hardship. A total of 560 participants completed the survey in the study.
Data were collected using a 32-item survey across six resources received from family. The items were rated using a 7-Likert point Delighted-Terrible scale (from terrible, unhappy, mostly dissatisfied, mixed, about equally satisfied and dissatisfied, mostly satisfied, pleased, to delighted) (Andrews & Withey, 1976), to represent the content of family life. The perceived quality of family life was measured by a global item regarding feelings about their own family life. This question was rated by 7-Likert point Delighted-Terrible scale as well. Rettig and Leichtentritt (1999) used mapping sentences to evaluate individual perceptions of resources on predicting family well-being. They also used multidimensional scaling analysis to determine the underlying circular structure of resource classes proposed by the resource theory. Based on the results of the analysis, the circular structure was confirmed for the study sample and across gender. That is, the construct validity of the circular structure of the resource classes on the model was demonstrated. Model differences between male and female were shown in the position of four resource classes (e.g., goals, services, status and information). That is, men and women perceived value priorities for their family life differently, regarding goods, services, information, and status.

Rettig and Leichtentritt (1999) concluded that the scale should continue to be refined. They recommended that further research is necessary using populations with a variety of demographic characteristics to explore the applicability of the items on the survey.

Zabriskie and McCormick (2003) conducted a study to investigate the association between family leisure involvement and family life satisfaction from the perspectives of parents, children, and family level (e.g., joint perspectives). They believed that there
would be a positive relationship between family leisure involvement and family life satisfaction. A total of 179 families with middle school children ages participated in the study.

Zabriskie and McCormick (2003) used two instruments in the study. One instrument was the 5-item *Satisfaction with Family Life Scale* (SWFL), modified from the *Satisfaction with Life Scale* (Diener, Emmons, Larsen, & Griffin, 1985). The other instrument was the 42-item *Family Leisure Activity Profile* (Zabriskie, 2000), used to measure family leisure involvement across 16 activity categories. In addition, sociodemographic questions were included. Responses of the parents and youth, resulted in a family mean score for each family (i.e., family level responses) that were analyzed by Pearson correlations and multiple regression analyses.

Pearson correlations were used to identify possible controlling factors in subsequent analyses for multiple regression analyses. Multiple regression analyses were conducted to examine the contributions of family leisure involvement to family life satisfaction from the three perspectives (e.g., parents, children, and family). There was a strong relationship between perceived family leisure involvement of parents and families and their satisfaction with family life. From the perspective of the children, this relationship was not significant. However, the results also showed a difference between female and male youth. Female youth reported less satisfaction with their family life, compared to male youth. From the perspectives of parent, children, and family, a history of divorce was significantly negatively related to family life satisfaction. That is, when the family had a history of divorce, the mean family satisfaction was lower.
Zabriskie and McCormick (2003) concluded that their study contributed to the literature by collecting data from both the perspectives of parents and children as well as analyzing the data from the joint perspectives. They recommended that future research use pre-tests as well as different levels and types of family leisure involvement, post-tests, and follow-ups over time to examine the causal effects of family leisure involvement on family life satisfaction. They believed that qualitative methods (e.g., in-depth interviews and observations) would provide more in-depth findings.

Zuna, Selig, Summers, and Turnbull (2009) designed a study to expand the usability of the *Family Quality of Life Scale* (Hoffman et al., 2006), a psychometric validated measurement for families of children with disabilities. The purpose of the study was to test the measurement properties of the scale for families of kindergarteners without disabilities. This study was part of a statewide Kindergarten School Readiness Study conducted by the State Department of Education in Kansas. A total of 566 parents of kindergarten children without disabilities, who completed at least 85% of the survey and returned the surveys were included in the data analysis.

Zuna et al. (2009) implemented the 21 nondisability-related items of the *Family Quality of Life Scale* (Hoffman et al., 2006) that crossed four domains: family interaction, parenting, emotional well-being, and physical/material well-being. Demographic data were collected as well. The data were analyzed by a confirmatory factor analysis (CFA) to examine the factor structure of the scale. Results of the analysis indicated there was an adequate fit to the sample of families of kindergarteners to the theoretical model. That is, the hypothesized family quality of life model that had four factors (e.g., family
interaction, parenting, emotional well-being, and physical/material well-being) was confirmed.

Zuna et al. (2009) concluded that to further assess scale validity for the study population, more data would be needed (e.g., convergent validity of the scale for families of kindergartener without disabilities). They recommended that further research be conducted to examine the measurement invariance across two groups (with families of children with and without disabilities) and to investigate the family quality of life on more than one family member.

Researchers have used different measures to assess family quality of life. Some used a global question item for participants to rate their family life quality (Rettig & Bubolz, 1983; Rettig & Leichtentritt, 1999), some used several global indicators (Voydanoff et al., 1994; Zabriskie & McCormick, 2003), and some used a more comprehensive survey across various domains (Zuna et al., 2009). Research has identified resources received from family, family structure, family organization, and family leisure involvement as factors that contribute to FQOL.

**Family Quality of Life with Children/Youth with Disabilities**

Significant progress has been made in conceptualizing and measuring individual quality of life for people with disabilities (Poston et al., 2003). However, scholars note that individual quality of life is related to the quality of life of those around them; therefore, the quality of life of those around individuals must be considered to address individual quality of life (Park et al., 2003). In the disability field, the family-centered service delivery model is a strong focus (Poston et al., 2003). However, family quality of life is just emerging as a construct in the field.
Poston et al. (2003) conducted a qualitative study to conceptualize and develop different domains of family quality of life from a grounded theory. The purpose of the study was to explore the major domains, subdomains, and indicators within each domain of family quality of life. A total of 187 individuals participated in the study, including family members of children with disabilities (e.g., parents, siblings), families of children without disabilities, service providers, and administrators.

Six focus groups were conducted, including two groups of families of children with disabilities, two groups of families of children without disabilities, one group of service providers, and one group of administrators. The focus groups met twice. Individual interviews were conducted using semi-structured questions, with family members of children with and without disabilities and professionals. They were asked to define family quality of life and describe the factors that help things go well and those that contribute to difficult times within the family. The interviews were recorded.

A constant comparative method was used to analyze the data collected from the focus groups and interviews. From the data, domains, subdomains, and codes of family quality of life were generated. After the codes were agreed upon, all transcripts (e.g., 35 transcripts from focus groups and 30 transcripts from individual interviews) were entered into Ethnograph (5.0), a software program for qualitative analysis, to sort data by categories. Three qualitative techniques (e.g., data triangulation, peer debriefing, and member checking) were used to accurately report the data.

A total of 139 indicators across 10 domains of family quality of life were identified to measure quality of life for families. These 10 domains included six that have an individual orientation (e.g., advocacy, emotional well-being, health, environmental
well-being, productivity, and social well-being) and four that have a family orientation (e.g., daily family life, family interaction, financial well-being, and parenting).

The results indicated that parents of children with disabilities had higher level of concerns. Among the six individually oriented domains, perspectives of the parents of children with and without disabilities were different substantially in the domains of advocacy, emotional well-being, and social well-being. Parents of children with disabilities generally expressed more needs and stronger concerns regarding these three areas. Among the four family-oriented domains, parents of children with disabilities spoke strongly for the needs of more support and information to enable them to interact with other family members (i.e., family interaction) and to help them control their child’s behavioral issues (i.e., the domain of parenting).

Poston et al. (2003) concluded that in order to enrich the rhetoric of family-centered services and enhance outcomes for families of children with disabilities, it is important to provide a conceptual framework to guide research and family support. They proposed to establish a psychometrically-based scale to measure family outcomes in future research using exploratory and confirmatory factor analyses, item analyses, and structure equation modeling. In addition, they also want to use a participatory action research approach to ensure the scale will be meaningful for family support.

Park et al. (2003) conducted a study to develop and validate an instrument to measure FQOL (i.e., the *Family Quality of Life Survey*). The purpose of the study was to examine the empirical structure of the family quality of life survey, revise items on the scale, and assess the psychometric properties of each domain. A total of 1197 respondents from 459 families (across 13 states from diverse geographical areas of the
United States) participated in the national field test, including 194 adolescents or young adults with a disability.

Before the field test, Park et al. (2003) developed the preliminary survey items and conducted a pilot test to revise the scale. In order to involve as many as possible family members to assess their perception of the whole FQOL, four versions of the scale were developed, including versions for adult/adolescent members of the family in which there is a person with a disability and a version for individuals with a physical or cognitive disability. The participants of the pilot test included 16 family members, 6 service providers, and 5 researchers. After the pilot study, the survey was reduced to two versions, including one version for individuals with a disability and a version for family members of a child with a disability. The survey was finalized into a 112-item scale, and the wording of the scale was rewritten to a six-grade reading level. The final version of the survey was also translated into Spanish. The finalized 112-item survey was then administered in the national field test. A package of materials was sent to the families who agreed to participate.

Because the scale was a research tool and an evaluation tool for programs, items rated as low importance were removed. Exploratory factor analyses were conducted to refine the overall scale, develop subscales, and reduce the number of items. Instead of a 10-domain structure in the preliminary study (Poston et al., 2003), through factor analysis, the scale was refined to a five-domain structure, comprised of 41 items. Park et al. (2003) also refined the wording of items. The results of exploratory factor analyses revealed a five-factor resolution, including four general factors addressing family as a social unit (e.g., family interaction, parenting, general resources, health and safety), and
one factor specific to families who had children with disabilities (i.e., support for persons with disabilities) with each factor consisting of at least eight items.

Park et al. (2003) concluded that the study was one of the beginning efforts to address and expand the need of a family quality of life measure. As families, service providers, researchers, and policy makers work together, this could enhance quality of life of families. They maintained that this validated family quality of life scale can be used to measure outcomes of service delivery, to identify the needs of a family, and to develop staff training and personnel preparation to serve families. They recommended future studies involve families in the research, discover the role of individual differences in the perception of family quality of life, and collect data from multiple family members within a family unit.

Hoffman et al. (2006) conducted two studies to complete the development of a reliable scale for assessing the construct of family quality of life. They considered the two studies as the third phase of developing the instrument for measuring family quality of life, specifically for families with children with disabilities. The purpose of the first study was to examine if items within each subscale had a conceptual and statistical fit. A total of 208 families with a child with a disability (one respondent per family) participated in the study. The disabilities of the children included ADD/ADHD, autism spectrum disorder, developmental delay, emotional disorder, intellectual disability, learning disability, and other physical and health disabilities.

Information about the scale was presented at parent meetings at national, state, and local levels. Parents completed the scale in both importance rating and satisfaction rating and returned it. Confirmatory factor analyses (CFA) were used to examine the
factor loadings and overall model fit in order to conduct item analyses within each domain of the scale. Problematic items and items not rated greater than 4 on the 5-point importance scale were removed. The modified scale included five subscales: Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability-Related Support. Each subscale consisted of four to six items.

Hoffman et al. (2006) concluded that all subscales appeared to be unidimensional and internally consistent with regard to importance ratings. The subscales of Family Interaction and Emotional Well-Being were also unidimensional and internally consistent regarding satisfaction ratings. However, the subscales of Parenting and Disability-Related Support were less so, and the subscale of Physical/Material Well-Being were not related to satisfaction rating. This indicated that the parents were not satisfied with each item of the subscale.

The purpose of the second study Hoffman et al. (2006) conducted was to examine the psychometric characteristics of the five revised subscales from their first study, and refine the overall factor structure of the scale and to evaluate further psychometric properties (e.g., reliability and validity). A total of 280 families with children with disabilities participated. Copies of the scale were mailed to the parents.

The revised Beach Center Family Quality of Life Scale (Hoffman et al., 2006) from the first study was administered. Participants rated the survey in both importance and satisfaction rating. The Family APGAR Scale (Smilkstein, Ashworth, & Montano, 1982) and the Family Resource Scale (Dunst & Leet, 1985) were selected as convergent validity measures and implemented to separate subsamples of subjects. The Beach Center
Family Quality of Life Scale was readministered three months later to a subsample of the parents to examine the test-retest reliability of the instrument.

Items within each domain/factor and the overall scale structure were found to have a good to excellent fit for ratings in both importance and satisfaction. Also, the Family APGAR Scale (Smilkstein et al., 1982) and the Family Resource Scale (Dunst & Leet, 1985) (i.e., the convergent validity measures) were significantly correlated with the hypothesized subscales of the Family Quality of Life Scale. The test-retest reliability correlations were significant across all subscales for both ratings.

Hoffman et al. (2006) concluded that, based on the two empirical studies, the final version of the Beach Center Family Quality of Life Scale comprised of a total of 25 items across five domains (Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability Related Support), unidimensional and internally consistent. Hoffman et al. (2006) recommended that the scale could serve as a research tool to explore the dimensions of family dynamics and as an evaluation tool to examine the effectiveness of family-oriented programs and policies.

Wang et al. (2004) conducted a study to examine the relationships among family income (total household income), level of severity of a child’s disability, and satisfaction of parents with their family quality of life. The purpose of the study was to explore whether family income or the severity of a child’s disability predicted satisfaction with FQOL for both parents as well as to ascertain if there was an interaction effect of the two variables for predicting parental satisfaction with FQOL. A total of 130 fathers and 234 mothers of children with disabilities from 280 families completed the survey. The disabilities represented by the children included ADD/ADHD, autism spectrum disorder,
developmental delays, emotional and behavioral disorders, hearing impairments, intellectual disabilities, physical disabilities, speech or language impairments, visual impairments, health impairments, and not specified disabilities.

Survey packets with a return envelope were sent to a total of 1,409 families. Each package of the survey contained one survey for Dad, and one for Mom. The survey packet included 15 demographic questions and the 25-item Beach Center Family Quality of Life Scale (Hoffman et al., 2006), including five subscales: Family Interaction (6 items), Parenting (6 items), Emotional Well-Being (4 items), Physical/Material Well-Being (5 items), and Disability-Related Support (4 items). The parents completed the Family Quality of Life items on both importance and satisfaction using a 5-point Likert scale. However, only the satisfaction rating was used for the data analysis in this study. Structure equation modeling was used to examine the hypothesized associations between family variables (e.g., family income and severity of a child’s disability) and parental satisfaction with FQOL.

The results of the analysis showed that the severity of a child’s disability was a negative significant predictor for both parents in terms of their satisfaction ratings of family quality of life. As the severity of the child’s disability increased, the parents reported lower levels of FQOL. Family income was a weak, but significant positive predictor of the mothers’ satisfaction ratings of FQOL. As the mothers reported higher levels of income, they reported higher levels of satisfaction. However, income was not a predictor of satisfaction with FQOL as reported by the fathers. The interaction effect of family income and severity of disability was not significant regarding satisfaction as reported by both parents with their FQOL.
Wang et al. (2004) concluded that although family income was not found to be a statistically significant predictor for father satisfaction, the findings do indicate important predictors of overall parent satisfaction and thus have important implications for future research, policy, and practice. Wang et al. (2004) recommended further studies examine the effect of the levels and types of services and specific characteristics of disabilities on parental satisfaction with family quality of life. They also encourage further research on a larger and diverse population and incorporating qualitative components.

Overall, the construct of FQOL for families of children with disabilities and the scale used to measure this concept has been developed through a series of studies (Park et al., 2003; Poston et al., 2003; Hoffman et al., 2006). This scale is being used to examine families of children with disabilities regarding different factors contributing to their FQOL (Wang et al., 2004).

**Family quality of life with children/youth with autism.** Studies on FQOL with children/youth with autism are beginning to emerge. Johnson, Frenn, Feetham, and Simpson (2011) proposed that since there was no cure for ASD, improved QOL is crucial for families of children with autism as it is a recognized metric of successful outcomes. Family quality of life can also be a meaningful indicator of the effectiveness of services that these families and their children with autism need.

Brown et al. (2006) conducted a study to explore the similarities and differences in FQOL among families that had a child with Down syndrome, families that had a child with autism, and families of typical developing children. The household composition of the families was similar. They investigated the responses of primary caregivers to the FQOL Survey and how these responses related to each domain of FQOL. They compared
the results among the families. The study also examined the differences in parental perceptions of services, if the perceptions related to FQOL, and the reported percentage of family satisfaction within the domains of FQOL.

Fifty-one parents of children with disabilities participated in the study (33 families with a child with Down syndrome and 18 families with a child with autism). Follow-up interviews were conducted. Data also were collected from 18 families with children without disabilities.

The *Family Quality of Life Survey* (Brown, Neikrug, & Brown, 2000) was used to collect data, focusing on the nine domains of FQOL: (a) health; (b) financial well-being; (c) family relations; (d) support from other people; (e) support from disability-related services; (f) spiritual and cultural beliefs; (g) careers and preparation for careers; (h) leisure and enjoyment of life; and (i) community and civic involvement. The parents were instructed to consider the whole family.

Correlations, univariate analysis of variance, and allied tests were conducted to analyze the data. Also, percentage of satisfaction within the domains reported by the families was reported. Correlation between each domain and the total of FQOL were examined for each disability group. Five domains were significantly correlated to the total FQOL for the autism group and seven domains were significantly correlated for the Down syndrome group. The domains of family relations, leisure and enjoyment of life, career and career planning, and health had the higher correlation to overall FQOL. The domain of support from disability-related services had the lowest and insignificant correlation in both groups. Univariate analysis of variance showed that there were statistically significant differences in domains among the three types of families with the
FQOL satisfaction of the families without a child with a disability being significantly higher than the two disability groups across all domains (except for the domain of support from disability-related services). The percentage of satisfaction (including very satisfied and satisfied) in five domains for this group ranged from 80% to 89%. For the Down syndrome group, five domains (e.g., health, family relations, spiritual and cultural beliefs, careers and preparation for careers, and leisure and enjoyment of life) showed a percentage satisfaction above 50%. For the autism group, only three domains showed a percentage satisfaction above 50% (e.g., health, family relations, and spiritual and cultural beliefs). The qualitative data indicated that the autism group had higher counts of negative interview statements than did the Down syndrome group.

Brown et al. (2006) concluded that all domains, with the exception of disability-related support services, contributed significantly to overall FQOL. And, that some domains contributed more significantly than others in terms of family type. They also found that families without a child with a disability had higher satisfaction scores than the two disability groups. They recommended that further studies should explore the domains in which parents reported the most dissatisfaction (e.g., disability-related services, respite support, career development, and education opportunities).

Lee, Harrington, Louie, and Newschaffer (2008) used data from the National Survey of Children’s Health (NSCH) (Blumberg, Olson, Srinath, & Giambo, 2005) to evaluate QOL and parental concerns for families of children with autism and compared those to families of children with ADHD and to families of typically developing children. The NSCH data (Blumberg et al., 2005) contains parent report data for 102,353 children,
ages 0 to 17, in three groups: (a) autism (483 children), (b) ADD/ADHD (6319 children), and (c) a comparison group (13,398 children).

Ten items were analyzed and treated as separate outcome variables (e.g., caring burden, times of family outing in the past week, number of family meals together in the past week, frequency of religious service attendance, quit job, after school participation, repeated a grade, independence, and community service). Parental concerns were measured by asking parents their level of concern with their child’s achievement, self-esteem, stress-coping, learning difficulties, and being bullied by their classmates.

Parents of children with autism reported higher levels of caring burden and parental concerns in all five domains than did the other two groups of parents. Parents also reported that their child with autism was more likely to repeat a grade, miss more days of school, and less likely to attend after-school or weekend club/organization activities.

Lee et al. (2008) concluded that parents of children with autism reported a higher level of caring burden, a lower frequency of attending religious services, and a greater possibility of quitting their job due to child care problems. Their child with autism missed more days of school, repeated grade more often, participated less in after school events or community services. Parents of children with autism also had serious concerns about their child’s learning difficulties and being bullied. Lee et al. (2008) recommended longitudinal studies be conducted to examine quality of life outcomes overtime.

In a study designed to determine if parents of children with high functioning autism spectrum disorders (HFASDs) reported lower health-related QOL as compared to parents of children without a disability and to identify the relationship among various
demographic and psychosocial variables and health-related QOL, Lee et al. (2009) recruited 135 parents of children with HFASD and 46 parents of children without disabilities to complete surveys. Demographic variables between the two parent groups were compared using independent samples $t$ tests and chi-square tests of independence. Except for the age of the parents, the comparisons of other demographic characteristics were not significant. Since parental age was not considered a critical variable, the two groups were considered as comparable groups.

Five self-report measures including a demographic form soliciting information on parents and their children were included in survey packet. The packet included the *Family Crisis-Oriented Personal Evaluation* (McCubbin, Olson, & Larsen, 1981) (to assess problem-solving attitudes and behaviors of families when responding to problems or difficulties), the *Family Inventory of Resources for Management* (McCubbin, Comeau, & Harkins, 1981) (to measure family perceptions of their available social, psychological, community, and financial resources), the *Parenting Stress Inventory-Short Form* (Abidin, 1995) (to assess parent perceptions on the level of stress relating to parenting), the *Perceived Severity of Child’s Condition* (to report the severity of their child’s disability), and the *MOS 36-Item Short-Form Health Survey* (Version 1.0) (Ware & Sherbourne, 1992) (to measure health related QOL).

Results of $t$ tests showed all variables were significantly different between parents of children with HFASD and those of typical children. Parents of the children with HFASD reported significantly lower physical and mental health scores compared to parents of typically developing children. They also reported higher levels of stress, lower levels of adaptive coping, and fewer available resources. These results indicated that
parents of children with HFASD experienced a significantly lower level of QOL. The results of hierarchical regression analyses for parental physical health indicated that demographic variables were significant in predicting both the physical health and mental health of parents of children with HFASD. For parents of children with HFASD, income was a significant predictor of both physical and mental health QOL, and the number of children in the family was a significant predictor of physical health QOL. After controlling for demographic variables, only stress was found to be significant in predicting the physical and mental health summary scale.

Lee et al. (2009) concluded that having a child with a HFASD may negatively influence the physical and mental health of the parents. Lee et al. (2009) maintain that a child with HFASD in a family contributes to a lower overall QOL for parents. Lee et al. (2009) recommended that further studies be conducted to examine sibling age and its impact relative to the child with the HFASD.

Johnson et al. (2011) conducted a study to ascertain the relationship among parenting stress, support from family, and the health-related quality of life (HRQOL) (including both physical and mental health) for parents of children with ASD. The goal of the study was to ascertain if parenting stress was associated with physical or mental health and if the discrepancy between expectation and satisfaction of family functioning were correlated with lower mental or physical health and if that discrepancy mediated the relationship of parental stress on HRQOL. Johnson et al. (2011) formulated two hypotheses for this study: (a) when parents had higher discrepant scores between “what is” and “what should be” in family functioning within spouse perceptions, they would report lower mental and physical health; and (b) mothers would have significantly higher
discrepancy scores between their expectation and current situation in family functioning than fathers. A total of 128 parents participated in the study.

Johnson et al. (2011) applied a non-experimental, cross sectional, correlation design. Demographic questions and three surveys were used to measure the three key constructs of the study on parenting stress, supportive family functioning, and HRQOL. Health-related QOL (physical and mental health) was measured by the *Rand SF 36-Item Health Survey* (Ware, Kosinski, & Keller, 1994), the *Parenting Stress Scale: Autism* (PSS) (Phetrasuwan, 2003) was used to measure parenting stress, and support from family functioning was measured by the *Feetham Family Functioning Survey* (Feetham & Humenick, 1982). Data were analyzed using a Wilcoxon signed-ranks test to ascertain if the mothers’ discrepant scores between expectation and current situation of family functioning were higher than the fathers’ scores. Stepwise linear regression was conducted to examine the relationship among the three variables (e.g., parenting stress, discrepancy score in family function, and physical and mental health).

Regarding parenting stress, the personal/family life subscale of the PSS (Phetrasuwan, 2003) was correlated with poor mental health of both the mothers and fathers. The caregiving stress of the mother was related to their lower physical health, but not mental health. The stress of personal and family life of the fathers was related to their physical and mental health. Results of the study indicated that the mothers’ discrepant scores in family functioning had a significantly wider range than did the fathers’ scores. The discrepant scores of the mothers and fathers were associated with each other positively. The personal and family life stress of both parents was related to their discrepant scores. Therefore, the discrepant scores in family functioning mediate the
relationship of personal and family life stress on mental health of both parents.

Concerning the two hypotheses, the first hypothesis was partially supported, because the discrepant scores of the fathers were correlated with their mental health, but not physical health. However, discrepant scores of the mothers were correlated with both their mental and physical health. The second hypothesis was supported by the study. Mothers of children with ASD had higher discrepant scores than fathers.

Johnson et al. (2011) concluded that their study provided a guide for health care professionals to assess and plan interventions concerning parental stress, family functioning, and physical and mental health for parents of children with ASD. They recommended that future studies explore the differences in the perceptions of mothers and fathers on family functioning.

Studies in the area of family quality of life with children/youth with autism still focus on quality of life of parents, especially the aspect related to their health (e.g., Johnson et al., 2011; Khanna et al., 2011; Lee et al., 2009). Lee et al. (2008) addressed quality of life of families of children with autism, but the measures of quality of life in the study did not sufficiently represent individuals (since most items were counted as frequency) nor address each family unique enough (Gardiner & Iarocci, 2012). Only few studies ask the participants to consider their entire family (Brown et al., 2006; Eskow et al., 2012). Therefore, to explore more on the FQOL of families of children/youth with ASD is worthy.

**Parental Stress within the Family System**

The imbalance between the parental perceptions and the demands of childrearing compounded by the perceived lack of available resources is defined as parental stress
Parental stress is one of the many factors contributing the effectiveness of parenting (Guajardo et al., 2009). It is virtually unavoidable for parents to experience some degree of stress (Putnick et al., 2010). However, according to the family stress model, when parents experience higher levels of stress and are busy responding to stress, the parent-child subsystems in the family are affected (Guajardo et al., 2009; Raphael et al, 2009). Parents with higher levels of stress may become less responsive and affectionate in the relationship with their children and use more power-assertive techniques, thus, negatively impacting their parenting (Guajardo et al., 2009). Unfortunately, stress can lead to the inability to seek appropriate supports for their child and ultimately impacting the social-cognitive development of the child (Guajardo et al., 2009; Raphael et al, 2009).

**Parental Stress with Typical Children**

Since parental stress in the family system can be one factor related to the development of children, it is important to examine the variables that contribute to parental stress and the interaction of these variables. Understanding parental stressors can lead to appropriate interventions and supports that will provide services for the parents and child.

Raphael et al. (2009) used the 2003-2004 National Survey of Children’s Health (Blumberg et al., 2005) to examine the relationship between high parenting stress and the use of child healthcare. Specifically, Raphael et al. (2009) reported the prevalence of parenting stress and assessed variables (e.g., socio-demographic variables and healthcare utilization) related to parenting stress in families in the United States. The data of 86,895 respondents from the 2003-2004 National Survey of Children’s Health (NSCH)
(Blumberg et al., 2005) were used in this study. A total of 102,353 computer-assisted telephone interviews were conducted, during January 2003 to July 2004. The respondents to the telephone interviews were those had the most knowledge about the health and health care of the randomly-sampled child.

Raphael et al. (2009) used four questions from the survey as the measure of parenting stress. These questions were rated by 4-point Likert scale. Two questions focused on intervening factors of parental stress, including a question regarding parental self-efficacy and a question regarding social support. Other variables specific to the characteristics of children (e.g. age, gender, race/ethnicity, health status, special needs status, immigration status, and health care status) and variables specific to the characteristics of families (e.g., primary language spoken at home, parental education, income level, number of children in the household, family structure, status of health, insurance and health status of parents) were also used as independent variables for data analysis. Three questions addressed emergency care, sick visits to primary care, and preventive care were selected to represent the variable of healthcare utilization. A battery of analyses were conducted. Descriptive statistics were used to report the characteristics of the children. A Chi-squared analysis was used to examine the differences between proportions. Bivariate and multivariate weighted logistic regression also was applied to ascertain the relationships between parenting stress and utilization of healthcare with controlling parental psychosocial and socio-demographic variables, such as parental health and parental coping. Variables included parenting stress, parental mental health, parental coping, and social support as the major independent variables. Utilization of
healthcare (e.g., emergency care, primary care, and preventive care) in the past 12 months was the dependent variable.

Overall, 12% of the parents reported high parenting stress. Parents who reported worse mental health, who had less effective coping skills, and who did not have emotional support experienced higher level of parental stress. Parents who were African American, whose first language was not English, and who had children with disabilities reported a higher level of parental stress. After controlling for other parental psychosocial factors and socio-demographic variables, parents with higher parental stress were more likely to use emergency care for their children compared to parents with lower parental stress. In addition, utilization of primary care for sick visits was significantly associated with low parental self-efficacy, lack of social support, and poor parental health. Parental emotional support was the only variable associated with the utilization of preventive care.

Raphael et al. (2009) concluded that the study was the first report regarding the positive relationship between parenting stress and utilization of pediatric emergency care based on a national population sample. They suggested future studies examine the factors contributing to this association. They also recommended the development of interventions focused on parental stress to provide support for families that need emergency care.

McBride, Schoppe, and Rane (2002) conducted a study to examine the relationship among child temperament, parental stress, and the amount of parental involvement in childrearing activities. The study was designed to ascertain the effect of child characteristics on the quantity of parental involvement to bridge the gap in the
literature concerning father involvement. The interactions between mothers and fathers also were assessed. Participants in the study were 100 two-parent families.

A two-hour interview was conducted with each family in their home. Self-report and interview data were collected to measure parental involvement. The variables of parental involvement were measured using the Interaction/Accessibility Time Diary Interview Protocol (McBride & Mills, 1993). The Parental Responsibility Scale (McBride & Mills, 1993) was used to measure parental responsibility. Parental stress was measured using the Parenting Stress Index—Short Form (Abidin, 1990). Child temperament was measured using the parent form of the Temperament Assessment Battery for Children (Martin, 1988). Student t tests were conducted to examine the differences of child gender on the parental perceptions of child temperament in three temperament dimensions (e.g., activity level, emotional intensity, and sociability). Regressions were used to examine the association among child characteristics (e.g., child temperament and gender), parental stress, and parental involvement.

The results indicated that when children displayed less emotional temperament, the parents experienced lower level of stress. The gender of the child and parents affected the relationship between child temperament and parental stress. This relationship appeared especially for mothers of boys and fathers of girls. When fathers were less involved in their parental role, their daughters were less sociable. The relationship between child temperament and parental involvement was stronger than the relationship between child temperament and maternal involvement. McBride et al. (2002) concluded that it was important to understand the transactional process of the father-child relationship in order to encourage fathers to engage in behaviors that benefit their
children. They recommended future research use both interview and observational assessments of parental involvement to discover more information concerning father involvement.

Guajardo et al. (2009) conducted a study to examine the relationship among parental behavior, parental stress, child internalizing and externalizing behavior, and social-cognitive development (e.g., theory of mind and emotion understanding). The goal was to ascertain whether parental stress related to parental behavior in responsiveness and discipline and whether these predict child social-cognitive development. They also tested whether child social-cognitive development related to internalizing and externalizing behaviors. A total of 83 parents and their children participated in the study. Due to technical difficulties, only observational data for 47 of the parent-child dyads were coded.

This study was conducted at a university. The parent-child dyads participated sessions that included two parents. For the first part, parents completed questionnaires regarding parental stress (the Parenting Stress Index, Abidin, 1995), parental practicing behavior (the Parenting Scale, Arnold, O’Leary, Wolff, & Acker, 1993), and child behavior (CBCL 1.5-5 years, Achenbach, 1991b), and a demographic survey. The children completed a language assessment (Test for the Auditory Comprehension of Language—Third Edition, Carrow-Woolfolk, 1999), and tasks regarding theory of mind (seven tasks to assess desires, beliefs, knowledge, contents false belief, explicit false belief, belief emotion, and real-apparent emotion) (Wellman & Liu, 2004) and emotional understanding (Cassidy, Parke, Butkovsky, & Braugart, 1992). For the second part, three consecutive, 10-minute parent-child free play interactions, a parent-busy task, and a clean-up task were videotaped. Parent verbal response/statements, parental instruction,
child compliance, and noncompliance were coded. Descriptive statistics and intercorrelations among the variables were analyzed. Guajardo et al. (2009) examined the correlation among theory of mind, emotional understanding, age, language, parental age, education, household income, and number of siblings. Four hierarchical regression analyses were conducted to test the hypotheses (whether parental stress related to parental behavior, whether parental stress and parental behavior related to child social-cognitive development, and whether child internalizing and externalizing behavior related to children’s theory of mind and emotional understanding).

Age, language, and household income were related to social-cognitive development (e.g., performance of theory of mind and understanding of emotion). Therefore, these variables were controlled in the subsequent analyses. Lax parenting and parental stress were associated with child performance of theory of mind. Parenting imitation, considered to be an aspect of responsiveness, was a negative predictor of children’s emotional understanding. Both child externalizing and internalizing behaviors were not related to theory of mind performance. However, externalizing behavior was related to emotional understanding. Overall, Guajardo et al. (2009) concluded that the results of the study supported direct and indirect relationships between parent-child interactions and child social-cognitive development. They recommended future studies be conducted to examine more dynamic relationships among the variables.

Belcher, Watkins, Johnson, and Ialongo (2007) conducted a study to examine the effects of socioeconomic status, parental mental health, and parental knowledge of child development on parenting styles and parental stress. A total of 125 caregivers of children, enrolled in an Early Head Start Program participated in the study.
Belcher et al. (2007) conducted structured one-on-one interviews with the parents. Several scales were administered during the interviews. The 75-item Knowledge of Infant Development Inventory (KIDI) (MacPhee, 1981) was used to assess parent knowledge of infant development. The 30-item Psychiatric Symptom Index (PsySI) (Ilfeld, 1976) was used as a measure for parental mental health. Three subscales of Parenting Style Expectations Scale (Sommer et al., 2000; Sommer et al., 1993), including Responsiveness/Empathy, Abuse/Neglect, and Authoritarianism, were used to examine parenting style and behaviors. The 36-item Parenting Stress Index—Short Form (Abidin, 1995) was used to assess parenting stress. Correlation coefficients were used to analyze the relationships among variables. Univariate linear regression analyses were conducted to examine the association among measures of parenting style, behaviors, parenting stress, and the knowledge of development. Multivariate regression analyses were conducted to ascertain the effects of parenting behavior and parenting stress on knowledge of development.

Mean scores of the Psychiatric Symptom Index (Ilfeld, 1976) of participants in the study was in the top 15% of the normative population. When parents had more knowledge of child development, they had lower levels of parent-child dysfunctional interaction and experienced lower levels of parental stress. The socioeconomic status of a family was related to elevated knowledge of child development positively. The larger the size of the household was related to younger caregivers and more severe psychiatric symptoms. However, psychiatric symptoms were not related to less optimal parenting behavior and higher perceived parental stress, but were associated with more dysfunctional interactions between parent and child. Belcher et al. (2007) concluded that
the study documented the relationships among knowledge of child development, parenting behavior, perceived parenting stress, and provided support of the importance of effective parent education on child development and mental health support. They recommended that further study is necessity to evaluate strategies that could enhance parent involvement in early education.

Putnick et al. (2010) conducted a study to ascertain how the parent, the child, and the interaction between the parent and child contributed to parental stress across the transition years to adolescence. They also compared perceived parenting stress of mothers and fathers from the same families and to examine how their parental stress affected each other. A total of 222 parents were included in the study. They completed questionnaires separately when their child was 10-years-old and 14-years-old as they transitioned to adolescence.

The 36-item Parenting Stress Index—Short Form (PSI) (Abidin, 1995) was used to assess sources of stress resulting from the parent, the child, and interactions between the parent and the child. The Jackson Personality Inventory—Revised (Jackson, 1994) and the Social Desirability Scale—Short Form (Reynolds, 1982) were only administered when the child was 14-years-old. The Mothers completed the Parenting Stress Index—Short Form (Abidin, 1995) the first time during a home visit, when their child was 10-years-old. Descriptive statistics of variables and coefficients were performed for the variable of parenting stress. Zero-order correlations were conducted to test the stability of parenting stress across child age and the mother-father agreement in relative standing. Several generalized linear mixed models were computed to assess continuity across child age, agreement in mean level between both parents, and stress across gender from 10 to
14 years. Partial correlations were used to examine the correlations of mother and father parenting stress across age, the relationships cross-age, and cross-parenting among parenting stressors.

The parental stress experienced by the parents across their child’s transition to adolescence (between 10 to 14 years old) was highly stable. The parental stress increased across time due to increased dysfunctional interactions between parents and child, not due to child behavior. Both parents agreed moderately in their relative standing and in the average levels of parental stress across three different domains of parenting stress at both data points. Parenting stress for both mothers and fathers across domains was somewhat related. Putnick et al. (2010) concluded that the increase of perceived parental stress of the mothers and fathers across the transition to adolescence was related to parent-child interaction. Therefore, it is important to find ways to maintain communication and closeness between parents and children to prevent elevated stress during the transition period. They recommended future studies be conducted to explore the qualities of parent-adolescent relationships that may lead to parenting stress and evaluate ways to address the challenges faced by parents and adolescents during the transition period.

Literature concerning parental stress has not only provided an overview of the prevalence parental stress (Raphael et al., 2009), and examined the effects of different variables either within the family system or outside the family system on the stress experienced (Belcher et al., 2007; Guajardo et al., 2009; McBride et al., 2002; Putnick et al., 2010; Raphael et al., 2009). The literature supports the need for specific supports for parents to decrease the levels of parental stress.
Parental Stress with Children/Youth with Disabilities

When there is a child/youth with disabilities present in a family, the whole family system is affected. Parents of children with disabilities also are influenced specifically. Research indicates that parents of children with disabilities report greater levels of parental stress than those of children without disabilities (Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008).

Gupta (2007) compared parental stress among parents of children with different types of disabilities or illness. The participants included parents of children with four different types of special needs (e.g., ADHD, developmental disabilities, HIV, asthma), and typically developing children. The children with HIV and asthma were grouped together and labeled as group with chronic medical conditions. The 120-item Parenting Stress Index (PSI) (Abidin, 1995) was administered to assess parenting stress. Demographic information was collected as well.

A one-way analysis of variance (ANOVA) was conducted to compare the scores of the four groups (e.g., ADHD, developmental disabilities, chronic medical conditions, and typical developing). The parents of children with ADHD and parents of children with developmental disabilities reported a higher overall rating of parenting stress than did parents of the children with asthma, HIV, or children without disabilities. Gupta (2007) concluded that the parenting stress in families of children with disabilities was accounted for by the overall nature of the disabilities of the children. Gupta (2007) maintained that comprehensive medical services could reduce parenting stress. Gupta (2007) recommended to conduct further research be counted using more sophisticated tools with a larger-sample of diverse participants.
Lopez et al. (2008) conducted a study to compare parental stress and coping strategies (e.g., problem focused, emotion-focused, and appraisal-or perception-focused coping) in families of young children with and without developmental delays. A total of 46 parents of young children participated in the study. There were 29 children with developmental delays and 17 children without delays.

This study was part of a longitudinal project regarding transition into school for young children with developmental delays. Three one-hour telephone interviews were conducted with each parent. However, only data from the first interview was used in this study. Demographic information was collected. The Scales of Independent Behavior—Revised Early Development Form (Bruininks et al., 1996) was used to measure adaptive and maladaptive behavior of the children. The Family Stress and Coping Interview (Nachshen, Woodford, & Minnes, 2003) was used to assess parental stress. The Ways of Coping Scale—Revised (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; revised by McColl & Skinner, 1995) was used to examine the coping strategies used by parents when they encountered issues related to their child.

A series of multivariate analyses of variance (MANOVAs) were conducted to compare the level of stress reported by the parents and the other variables (e.g., children’s adaptive and maladaptive behaviors) across the two groups (parents of children with and without developmental delays). When compared to parents of young children without developmental delays, parents of children with developmental delays reported a higher level of parental stress and their children displayed more maladaptive behavior. Regardless of these differences, both groups of parents implemented similar amounts and styles of coping. Lopez et al. (2008) concluded the study demonstrated that parents of
children with developmental delays experienced higher levels of parental stress due to issues related to development and/or the specific diagnosis of their child. Lopez et al. (2008) recommended further study to examine the relationship between different coping styles and how these may decrease parental stress.

Baker, Blacher, Crnic, and Edelbrock (2002) designed a study to investigate behavior problems in three-year-old children with and without developmental delays and the impact of the behavior problems and cognitive delays on parental stress. A total of 225 families participated in the study. Ninety-two children classified as having developmental delays were recruited from community agencies. The comparison group was recruited from preschools and daycare programs.

A phone interview was conducted to explain the research to parents and schedule home visits. A two-hour home assessment was conducted and the Bayley Scales of Infant Development II (Bayley, 1993) administered to assess mental and motor development of the children. At the same time, parents completed a demographic questionnaire and the Child Behavior Checklist for Ages 1.5-5 (Achenbach, 1991a), and Family Impact Questionnaire (Donenberg & Baker, 1993) to measure the impact of the child on the family. A series of analyses of variance (ANOVAs) were conducted to examine the child behavior scores by delay status (delayed vs. nondelayed) and examine the effects of delay status and behavior problems (e.g., high, medium, and low behavior problems) on parental stress. Regression analyses were used to examine the predicted variables of parental stress.

In both scales, completed by staff and parents, children with developmental delays showed more behavior problems than children without delays. Parents of children
with developmental delays reported higher parental stress in their families. The extent of behavior problems exhibited by the children with developmental delay accounted more than cognitive delay in relation to parental stress. Baker et al. (2002) concluded that social skill development and behavior problem management should be integrated into the core curriculum for early intervention programs. They also believed future research should focus on parent programs that work with families to develop strategies to improve problem behaviors and cope with stress.

Baker et al. (2003) conducted a study to explore the early manifestation and continuity of problem behaviors in preschoolers with and without developmental delays. Specifically, Beaker et al. (2003) examined whether children with developmental delays exhibit more problem behaviors than those without developmental delays, and if the problem behaviors change over time. The goal was to ascertain the relationship between child problem behavior, the differences between parents (mother and father) concerning their assessment of problem behavior, and the relationship between child problems and stress. This study was part of a 2-year longitudinal study. A total of 205 families participated in the study. Eighty-two young children with developmental delays (Down Syndrome, cerebral palsy, and not specified diagnosis) and young children without developmental delays participated in the study.

A phone interview was conducted before the home visit. At the home visit, the BSID-II (Bayley, 1993) was administered to assess mental and motor development of the children. At the same time, parents completed a demographic questionnaire and the Child Behavior Checklist for Ages 1.5-5 (Achenbach, 1991b). The Family Impact Questionnaire (Donenberg & Baker, 1993) was also completed by parents to measure the
impact of the child on the family. The *BSID-II* and the *Family Impact Questionnaire* were administered a second time during another home assessment session.

A correlation was conducted to examine the behavior of the child across time points. A series of analyses of variance (ANOVAs) were conducted to analyze data: (a) a 2 x 2 ANOVA to examine child behavior scores by delay status and time; and (b) a 2 x 2 ANOVA to examine the family impact by delay status and time. Two sets of hierarchical multiple regressions were used to examine the relationship between child characteristics and parental stress over time. Over the age of 3-to-4 years, behavior problems were quite stable. Children with developmental delays exhibited more behavior problems than their non-delayed peers and their scores on the *BSID-II* were three times as likely to fall into the clinical range. Mothers and fathers of children with developmental delays showed high agreement in their rating of their child’s problems. They also experienced higher parenting stress. The variable of parental stress was related to the extent of behavior problems rather than to the developmental delay of the child. Baker et al. (2003) concluded that the relationship between parenting stress and behavior problems was transactional over time. That is, parental stress contributed to increased child problem behavior over time and increased child problem behavior contributed to higher parental stress over time. The findings were similar between mothers and fathers. They recommended early intervention programs be developed focused on social skill development and behavior problem management as well as the development of parent programs to teach coping strategies.

Guralnick, Hammond, Neville, and Connor (2008) designed a longitudinal study to examine the association between the sources and functions of social support and the
dimensions of child and-parent-related stress for parents of children with developmental delays. Guralnick et al. (2008) wanted to identify social support dimensions that would contribute to child-and parent-related domains of stress. Young children who had mild developmental delays, a current IEP, difficulties in peer-related social skills, a primary female caregiver, and a score between 50 to 80 on the full Scale IQ of the *Wechsler Preschool and Primary Scale of Intelligence-Revised* (Wechsler, 1989) participated in the study. A total of 73 families of young children with developmental delays participated in the study and 63 families remained for the second year.

A packet of materials was sent to the families. Several measures were administered in the study to assess intelligence, adaptive behavior, language, vocabulary, and behavior problems of the children. The *Hollingshead Four Factor Index of Social Status* (Hollingshead, 1975) was used to measure social status of the family, the *PSI* was used to assess child-related and parent-related stress (Abidin, 1995), and the *Inventory of Parental Experiences* (IPE) (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983) was used to measure the social support of mothers. The mothers were interviewed. Guralnick et al. (2008) repeated the same procedure after 2 years.

A MANOVA was conducted to examine changes over time, stability of support, and stress. Two hierarchical regressions were used to examine the predictive relationship between social support for the first year and the overall stress measure scores for the second year. Regardless of the source, parenting support during early childhood was a consistent predictor of most dimensions of parent stress. General support such as primarily emotional support and validation from different sources had less widespread influences on parental stress. Guralnick et al. (2008) concluded that the findings of the
study suggest a need for more parenting support to decrease both child-and parent-related stress for mothers of children with developmental delays. Guralnick et al. (2008) recommended that the long-term effectiveness of parenting support and respite care options in reducing parent stress be examined.

Concerning parental stress with children/youth with disabilities, researchers have conducted studies to compare the levels of parental stress experienced by parents of children with disabilities and without disabilities (Baker et al., 2002; Baker et al., 2003; Gupta, 2007; Lopez; 2008). The results of the studies indicate that parents with a child with disability experience higher levels of stress. They also stress that parental stress is related to different variables, such as children’s problem behavior (Baker et al., 2002; Baker et al., 2003) and social support for parents (Guralnick et al., 2008).

**Parental stress with children/youth with autism.** To raise a child with autism can be a demanding and challenging task for some parents (Tomanik, Harris, & Hawkins, 2004). Parents of children with autism consistently report elevated levels of stress (Cassidy et al., 2008; Hoffman et al., 2009; Meadan et al., 2010; Rao & Beidel, 2009). Therefore, to identify specific factors that relate to the high levels of stress is timely and important.

Tomanik et al. (2004) conducted a study to examine the relationship between the adaptive and maladaptive behaviors of children with ASD and the parental stress experienced by their mothers. A total of 60 mothers of children with autism were recruited to participate in the study. Their children with autism ranged in age from 2-to-7 years old.
The mothers completed a questionnaire that included informed consent and four survey instruments. A 26-item demographic questionnaire was used to collect background information concerning the mother and her child with ASD; the 36-item Parenting Stress Index-Short Form (Abidin, 1995), a 58-item symptom checklist Aberrant Behavior Checklist (Aman & Singh, 1986), and the AAMR Adaptive Behavior Scale—School, 2nd edition (ABS-S:2; Nihira, Leland & Lambert, 1993) were administered.

Descriptive data were collected and reported. A regression analysis was performed to examine the relationship between the adaptive and maladaptive behaviors of the children with ASD and maternal stress. Mothers of children with ASD reported that significantly elevated level of parental stress. The regression analysis showed that the adaptive and maladaptive behaviors were highly correlated to maternal stress. Tomanik et al. (2004) concluded that there was a significant relationship between behavior of children with autism and maternal stress. They recommended future studies examine the relationship between intellectual functioning of children with autism and parental stress.

Schieve, Blumberg, Rice, Visser, and Boyle (2007) examined the relationship between parenting a child with autism and parental stress. Schieve et al. (2007) used the 2003 National Survey of Children’s Health to conduct the analysis. This national survey was conducted using parents or other adult respondents who knew the targeted child. For this study, 459 participants reported that their child had autism. The data of these parents were used to compare with the responses of 4,545 parents of children with health care needs and other emotional, developmental, or behavioral problems.
Parents of children with autism reported that their child had been labeled by a doctor or health care professional. Four questions from the survey addressed parenting stress and aggravation among parents. Descriptive data of demographic, health care characteristics, and parental social characteristics were reported. Descriptive data of parental self-reported feelings related to coping, stress, and aggravation also were reported. In order to represent the noninstitutionalized population of children nationally, the researchers weighted all data. Also, $\chi^2$ tests were used to assess the differences between the autism and comparison groups by using SUDAAN software (Research Triangle Institute, 2004).

Among the four groups, parents of children with autism scored the highest for aggravation, followed by parents of children with developmental problems other than autism, followed by parents of children with special health care needs without developmental problems, and, finally, parents of children without special health care needs. Specifically, for parents with high aggravation, over half of their children needed special services. That is, parents of children with autism and with recent special service needs were much more likely to have higher aggravation than the other three groups whose children needed special services. However, parents with children with autism, but without special service needs, did not have as high aggravation as parents of children with other developmental problems. Schieve et al. (2007) concluded that parents of children with autism may face unique stressors and may need family-centered treatment. They suggested that further research concentrate on specific stress and examine the impact of the stress on the families of children with autism.
Davis and Carter (2008) conducted a study to ascertain the stress experienced by mothers and fathers of toddlers who were newly diagnosed with ASD. They examined the associations between child behavior and parenting stress in both the mothers and fathers. Specifically, they explored parenting stress related to the new diagnosis of ASD of their toddler, identified the similarities and differences between mothers and fathers, and examined the associations among the children’s disabilities, problem behavior, cognitive level, and parental stress. A total of 108 parents (54 paired couples) participated in the study. Their young children with autism had a mean age of 26.9 months at the time the study was conducted and received some early intervention services.

Davis and Carter (2008) mailed the surveys to the parents and conducted one at-home session and one center-based session. During the first session, a parent interview was conducted using the *Autism Diagnostic Inventory-Revised* (ADI-R) (Lord, Rutter, & LeCouteur, 1994). The second session was conducted in a research center and the children were video-taped to assess their developmental and cognitive functioning. Scales used for the second session included the *Autism Diagnostic Observation Schedule-Generic* (ADOS-G; Lord et al., 2000), the *Mullen Scales of Early Learning* (Mullen, 1995), and the *Infant Toddler Social Emotional Assessment* (ITSEA; Carter & Briggs-Gowan 2006). The parents also completed the *Beck Anxiety Inventory* (BAI) (Beck, Epstein, Brown, & Steer, 1988), the *Center for Epidemiologic Studies Depression Inventory* (CES-D) (Radloff, 1977), and the *Parenting Stress Index—Short Form* (PSI/SF) (Abidin, 1990).

Descriptive data were analyzed. Several regression analyses were used to predict the overall parenting stress experienced by the mothers and fathers, the maternal stress,
and the fathers’ parenting stress. Both parents reported high levels of parental stress. A relationship was found between deficit/delays in the social relatedness of the children with overall parenting stress, parent-child relationship problems, and distress for both parents. Regulatory problems were associated with mothers’ parenting stress, while externalizing behaviors were related to paternal stress. However, cognitive functioning, communication deficits, and atypical behaviors were not significantly related to parental stress. Davis and Carter (2008) concluded that the results of the study document high levels of stress and depressive symptoms present in both mothers and fathers of very young children with ASD. They recommended that clinical assessment focusing on the different experiences of both parents is needed.

Lyons, Leon, Phelps, and Dunleavy (2010) examined the impact of the severity of autism disorders and the coping styles of parents of children with ASD on the resulting stress. Specifically, the autism symptoms of the children and parental coping styles (e.g., task-oriented, emotion-oriented, social diversion, and distraction) were evaluated to predict four types of parental stress. The four types of parental stress included parent and family problems, pessimism, child characteristics, and physical incapacity. A total of 77 primary caregivers (68 mothers, 4 fathers, 2 grandparents, and 3 others) of children with ASD participated in the study.

Questionnaire packets were mailed and 77 were completed. Each packet included several measures: (a) demographic Information, (b) the Childhood Autism Rating Scale – Parent Version (CARS-P) (Schopler, Reichler, DeVellis, & Daly, 1980) to assess the severity of autism symptoms, (c) the Questionnaire on Resources and Stress—Friedrich Short Form (QRS-F) (Friedrich et al., 1983) to examine resources and stress, and (d) the
*Coping Inventory for Stressful Situations* (CISS) (Endler & Parker, 1990) to assess coping styles of the caregivers.

Mean, standard deviations, and correlations between variables were reported. Hierarchical ordinary least squares multiple regression analyses were employed to examine the effect of autism severity, coping style, and the interaction between these two variables on parental stress. The emotion-oriented coping style was associated with more parent and family problems and the task-oriented coping style was associated with lower physical incapacity. The severity of a child’s autism symptom was the strongest and consistent predictor of parental stress. The emotion-oriented coping was a moderator of the relationship between pessimism and child symptom severity and distraction coping moderated the relationship between parent and family problems and the autism symptom. Lyons et al. (2010) concluded that their findings expanded the understanding of the effectiveness of coping styles for this group of parents with direct implications for parent education. They suggested future research use a longitudinal design to examine the causal relationships of autism severity and coping strategies on parental stress over time and with a diverse sample.

Hall and Graff (2011) designed a descriptive, correlational, cross-sectional study to examine the views of parents of children with autism concerning adaptive behaviors of their children, family support networks, parental stress, and coping patterns, to ascertain the relationships among the adaptive behaviors of children with autism, family support, parental stress, and coping. A total of 73 parents or primary caregivers whose children were diagnosed with autism participated in the study.
The participants either completed the surveys alone or in a semi-structured format. The measurement instruments in the study included the *Coping Health Inventory for Parents* (McCubbin, McCubbin, Nevin, & Cauble, 1981) to measure parental coping behavior, the *Family Support Scale* (Dunst, Jenkins, & Trivette, 1984) to measure perceptions of family support, the *Parenting Stress Index—Short Form* (Abidin, 1995) to assess stress, and the *Vineland Adaptive Behavior Scales, Second Edition* (Sparrow et al., 2005) to assess the adaptive behaviors of the children with autism. Descriptive data of the variables were reported. Hall and Graff (2011) conducted an Univariate, Pearson product-moment correlation, independent-samples $t$ test, and multiple regression analyses to analyze the data.

The results of the analyses indicated that parents reported their children with autism had low levels of adaptive behavior in the areas of socialization, communication, and daily living. The parents experienced high levels of stress, had difficulties in coping, and needed elevated levels of family support. An association was found between the low adaptive behavior of the children with autism and increased levels of parental stress, the need for additional family support, and a lack of effective coping strategies. Hall and Graff (2011) concluded that the parents in the study reported they had not received beneficial family support. They suggested that professionals should provide valuable support for families with children with autism.

Compared to parents of typical developing children and parents of other developmental disabilities, parents of children with ASD report higher parental stress (Schieve et al., 2007). Researchers have examined various factors related to the high levels of parental stress, including characteristics of children and parents. Parental stress
is related to the characteristics of the children, such as adaptive and maladaptive behaviors (Davis & Carter, 2008; Hall & Graff, 2011; Tomanik et al., 2004) as well as the symptom severity (Lyons et al., 2010). It appears that parental coping styles (Hall & Graff, 2011; Lyons et al., 2010) and family support networks (Hall & Graff, 2011) also are related to parental stress. Therefore, to provide support or parental education for parents to address their child’s problem behaviors and, thus, learn more effective coping strategies is important and beneficial for families of children with ASD.

**The Role of Family and Professional Partnerships in Child/Youth Development**

Family plays an important role in the social, behavioral, and academic development of all children (Cowan & Cowan, 2002; Guajaro et al., 2009; Sturge-Apple et al., 2010). Children benefit from family involvement at home and at school (Hindman & Morrison, 2011). Connections between educators/professionals and families must be established to optimize the competence of children with and without disabilities (Giovacco-Johnson, 2009; Hindman & Morrison, 2011; Pryor, 1995; Spann, Frank, Kohler, & Delann, 2003; Stevenson & Baker, 1987). These connections involve the triad of parents, teachers, and students. As parents, teachers, and students change individually, their mutual relationships also change (Pryor, 1995). Strong partnerships are the result of professional initiation and depend on both families and educators for their growth and maintenance (Giovacco-Johnson, 2009).

**Family and Professional Partnerships for Typical Children/Youth**

Family-professional partnerships are critical for all students for academic success (Giovacco-Johnson, 2009; Hindman & Morrison, 2011; Stevenson & Baker, 1987).
However, in the field of education, there has been more focus on parental involvement, rather than family-school partnerships (Spann et al., 2003). The importance of reciprocal positive partnerships between families and professionals should be recognized in education.

Stevenson and Baker (1987) examined the association between the family-school partnership and the child’s school performance. Specifically, they focused on parental involvement in school and examined variables related to the involvement and its impact on children’s school performance. This study used a nationally representative sample of American households from an omnibus data set, the *Time Use Longitudinal Panel Study* (Juster, Hill, Stafford, & Unknown, 1975-1981). Data of 179 children and their teachers were drawn from the original data set.

Demographic information, such as age and sex of the children and education level of the mothers were included in the study. Data of parental involvement and school performance of the children were collected via a teacher questionnaire. Parental involvement was measured by the question “To what extent did his/her parents get involved in the activities of the school such as PTO and parent-teacher conferences?” The question items regarding these two variables were rated on a 5-point Likert scale. A cross-sectional analysis was performed to analyze the data related to parental involvement. A multiple regression analysis was conducted to examine the contribution of parental involvement to the prediction of school performance.

The results of the analyses confirmed all three hypotheses. First, the educational level of the mothers was related to the degree of parental involvement. That is, when a mother had more education, the degree of parental involvement in school activities was
higher. Second, when children were younger, the level of parental involvement was greater. When parents of children were involved in school activities more, the child’s school performance was better than children of parents who were less involved. However, there was no direct effect of maternal educational status on child’s school performance without considering parental involvement in school activities. Stevenson and Baker (1987) concluded that their study had explored important variables related to family-school relations. They recommended further study to examine how parents invest in and manage their child’s school career contribute to the relationships between parents and the school.

Pryor (1995) conducted a study to explore the perceptions of students, parents, and teachers concerning parent involvement. Pryor (1995) examined the existing relationships between families and schools. A total of 516 ninth-grade students, 305 parents, and 38 teachers participated in the study. They responded to questionnaires and/or participated in focus groups and telephone interviews.

Pryor (1995) employed four techniques to collect data to get a full picture of family-school relationships. These included surveys, focus groups, telephone interviews, and case studies of schools. The survey, a 20-item questionnaire focused on parental involvement in their child’s education and school, was mailed to the parents. The parents were asked about the changes they would make to improve the methods families and schools used to help children with their education. The parents also participated in focus groups. The students completed an 18-item questionnaire to measure their school bonding and attitudes toward parental involvement. One open-ended question was asked regarding the changes students would make to their school for a better education. The teachers
completed a 31-item questionnaire concerning their attitudes toward parental involvement. Only the relationship between family-school relations and parental education was examined by correlation.

Ninth-grade students were reluctant to have their parents involved in their education initially. However, they also indicated if they were faced with issues in school, they wanted their parents to be involved. The parental view of school varied significantly from one district to another and the attitudes of the parents also were related to parent involvement practices of the school and the bonding between student and school. Parents expected to receive more communication from the school, rather than just receiving a phone call when their child got into trouble. They also wanted to be involved in their child’s education in more meaningful ways. The teachers wanted more parental involvement, especially in the area of academics. Pryor (1995) concluded that parents, teachers, and students need to work together to make good education happen. Pryor (1993) recommended that further research be conducted in school/family partnerships, specifically in the development of interventions for school personnel and parents.

Hindman and Morrison (2011) designed a study to explore the contributions of educator outreach and the impact on family involvement in the academic and social literacy in the Head Start Program. They investigated the nature and extent of family involvement (at home, in school, and through communication) and educator outreach to the home during the first year of Head Start. A total of 3,100 children and their families participated in the study. A total of 286 classroom teachers also participated in the study.

The children’s academic skills were collected using Woodcock-Johnson R Letter-Word Subtest (Woodcock, McGrew, & Mather, 2001) and Peabody Picture Vocabulary
Test-III (Dunn & Dunn, 1998) in the fall and spring. The parents answered a 7-item scale to rate their child’s approaches to learning. Interviews were conducted with the parents regarding their home involvement and involvement with the center directors focus on center outreach to parents in the fall. The parents reported their in-school involvement and communication in the spring. The nature and extent of family involvement and educator outreach were reported using descriptive data (mean, standard deviation) and the relations between types of family involvement and between types of educator outreach practices were analyzed using correlations. Hierarchical linear models were used to analyze the contributions of family and center outreach to child outcomes.

The families reported regular and frequent involvement at home and school. The centers also created involvement opportunities for families. The extent to which family involvement contributed to the children’s learning varied by the activities in which parents were involved. For example, a parent teaching about letters was related to decoding and parents reading books related to vocabulary. The frequency of in-school involvement invitations were related to family in-school involvement. Hindman and Morrison (2011) concluded that their study provide groundwork for future research to develop a comprehensive and specific model for family and educators to work together and thus foster literacy and related skills. Hindman and Morrison (2011) recommended future research was direct observations of educator outreach and family involvement, direct assessment to investigate how children approach learning, and gather outreach data from various people involved with the children and families.

Giovacco-Johnson (2009) applied a narrative inquiry to expand understanding of the complexity of family involvement. Seventeen families participated in semi-structured
interviews. The interviews were videotaped, transcribed, and shared with the families to ensure the correctness of the content. In addition, visual documentation of the family also was collected. Photos of interactions of family members with each other were taken and one photo was selected by the family to enlarge for an exhibition with the narratives.

All interview transcripts were reviewed and a content analysis technique used to analyze the data. Key ideas generated from the family data were coded and used as themes to organize the data. Individual statements were color-coded and sorted to reflect the themes generated. The themes showed family priorities in forming partnerships, depending on the value they placed on the importance of belonging to the school community, family involvement, respecting and honoring diversity, and participating in their child’s future. Giovacco-Johnson (2009) concluded that even though the findings of the study might be unique to this program, it helped to understand the importance of redefining family partnerships in early care and education to include family values and priorities. Giovacco-Johnson (2009) recommended teachers use the results of the study to recognize and value the various ways that families choose to be involved in their child’s education.

Research indicates over and over the importance of family and professional partnerships for a child’s school academic performance (Hindman & Morrison, 2011; Stevenson & Baker, 1987). In order to develop family and professional partnerships, families, professionals (e.g., teachers, administrators), and even students must work together as a team and strengthen their bonds (Dotson-Blake, 2010; Giovacco-Jonhson, 2009; Pryor, 1995).
Family and Professional Partnerships for Children/Youth with Disabilities

In order to provide effective services for children with disabilities, the collaborative partnering between family and professionals has been recommended for decades (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). This concept has been incorporated in one of six principles of the Individual with Disabilities Education Act (IDEA, 2004) in developing and implementing special education programs (Blue-Banning et al., 2004; Summers et al., 2005). However, it is not easy to develop collaborative partnerships between parents and professionals (Blue-Banning et al., 2004). The lack of empirical understanding of the components of interpersonal partnerships may be one of the problems in this area (Blue-Banning et al., 2004).

Blue-Banning et al. (2004) conducted a qualitative study to identify the empirical indicators of professional behavior that facilitate collaborative partnerships. A total of 190 participants and 53 professionals participated in the study.

Blue-Banning et al. (2004) conducted 34 focus groups with the adult family members of children with and without disabilities, service providers, and administrators. Guided by an interview protocol, the participants were asked their experiences with professionals and families, both successful and unsuccessful partnerships. In the second focus group session, the participants were asked to verify and check their responses and resolve unanswered questions. Individual interviews were conducted with 18 families of children with disabilities and with the 14 direct service providers of these families. Data from the focus groups and interviews were transcribed. After the content of the transcripts were reviewed and errors of the transcripts were corrected, the transcripts were entered into a qualitative analysis software program, Ethnograph. The interviews
were reviewed for themes. The themes were defined and given code names. When new themes emerged, the data were revised. Through this analysis procedure, a total of 39 categories/indicators were generated from the results of the qualitative inquiry. These indicators were then organized into six broader domains: (a) communication, (b) commitment, (c) equality, (d) skills, (e) trust, and (f) respect. Indicators of collaborative partnership were identified from the qualitative inquiry and categorized into six broad domains: (a) communication, (b) commitment, (c) equality, (d) skills, (e) trust, and (f) respect.

Blue-Banning et al. (2004) concluded that the study identified the indicators of professional behavior that would support the collaborative partnership between parents and professionals. They recommended that the results be used to develop a measure of positive partnerships. They also suggested that future research should examine if enhancing specific interpersonal skills and attitudes of professionals would improve parent involvement in educational settings.

Summers, Hoffman, Marquis, Turnbull, and Poston (2005) conducted a study to examine the effect of the age differences of children with disabilities on the perceptions of their parents concerning the importance of and satisfaction with partnerships with professionals who worked with their children. The satisfaction of parents with children of different ages was compared, as family needs and expectations may change due to the change in demands across the family life cycle. A total of 147 parents of children with disabilities participated in the study.

The *Beach Center Family-Professional Partnership Scale* (Summers et al., 2005) was implemented in the study. This 18-item scale was comprised of two subscales: Child-
Focused Relationships and Family-Focused Relationships. Each scale had nine items. Participating parents completed the scale in both importance and satisfaction ratings on a 5-point scale. For the importance scale, the parents rated each question ranging from 1 (a little important) to 5 (critically important). For the satisfaction scale, parents rated each question ranging from 1 (very dissatisfied) to 5 (very satisfied). Descriptive statistics were reported. Means of the overall scale and each subscale were calculated. Independent analyses of variance (ANOVAs) were conducted to examine the differences in both importance and satisfaction ratings across age groups. Exploratory analyses concerning satisfaction levels across other demographic variables also were conducted. Two-way independent analyses were used to examine the characteristics of parents concerning their satisfaction rating. Regarding the importance rating, parents of children from different age groups did not rate the importance of scale differently. That is to say, parents in the study did not have different perceptions concerning the importance of the partnerships with professionals. Regarding the satisfaction rating, there were differences among satisfaction levels of partnerships. Parents of children age birth to 3 years, reported the highest satisfaction with their partnerships with professionals, while parents of children age 6 to 12 years were the least satisfied.

Summers et al. (2005) concluded that to judge the quality of partnerships between families and professionals according to family satisfaction is a helpful method for researchers, practitioners, and policy makers to develop programs that fully address the needs of a family. Summers et al. (2005) recommended that future research examine if the interactions identified in this study could be replicated with other samples.
Summers et al. (2007) designed a study to ascertain the relationship of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programs. Summers et al. (2007) also explored if parents received adequate levels of services for themselves and for their children, their ratings of satisfaction and importance of parent partnerships with professionals, and the parents’ rating of satisfaction with aspects of their family quality of life. One hundred and eighty families of young children with disabilities who received early childhood services across four geographic regions participated in the study.

Three instruments were used to collect data on adequacy of services, family-professional partnerships, and FQOL. The Service Inventory (Summer et al., 2007) was administered to assess the perceptions of the families with children with disabilities regarding the services they needed and the services they received. The Family-Professional Partnership Scale (Summer et al., 2005) was used to assess parental perceptions concerning the importance of partnerships and their satisfaction with the family-professional partnership (e.g., child focused and family focused). The Family Quality of Life Scale (Hoffman et al., 2006) was used to measure family perceptions of their quality of life. This scale had a total of 25 items, across five domains (e.g., family interaction, parenting, emotional well-being, physical well-being, and disability-related support).

Descriptive data (e.g., number and percentage of respondents for the service needs and adequacy rating; mean and standard deviation of importance and satisfaction rating on the Partnership Scale and the FQOL scale were reported. The relationship between service adequacy, partnership satisfaction, and FQOL satisfaction were examined using a
mediation test model developed by Sobel (1982). Most parents reported that they received adequate services for their child, but they believed that they did not receive enough services for their family. Overall, parents responded that they were satisfied with their partnerships with their primary service provider. However, the provider’s ability to meet their child’s individual needs and to provide information about services was rated lower. For their FQOL, parents were more satisfied with their material/physical well-being than their emotional well-being. Regarding the relationship among the three variable, service adequacy was a strong predictor of family quality of life and the partnerships were a partial mediator of the relationship between adequate services and family quality of life. Summers et al. (2007) concluded that adequate levels of service should be a major focus of partnerships. They recommended more training for service providers in order to deliver quality services.

Due to the lack of empirical evidence concerning the specific components of partnerships impacting the relationships between families and professionals, researchers are working to develop a scale to measure family and professional partnerships for families of children with disabilities (e.g., Family-Professional Partnership Scale) (Blue-Banning et al., 2004; Summers et al., 2005). The scale has been used in the field, but only with families with younger children (Summers et al., 2005; Summers et al., 2007). Therefore, using the Family-Professional Partnership Scale with a broader range of families (e.g., older children or adults with disabilities) as well as families from cultural and linguistically diverse backgrounds should be focus of future research (Summers et al., 2005).
Family and professional Partnerships for children/youth with autism. To establish partnerships between families of children with autism and educational professionals is a critical issue (Stoner et al., 2005). The provisions of the IDEA (2004) are fundamental regarding the legal rights for parents of children with disabilities to be involved in their child’s education (Stoner & Angell, 2006). As the prevalence of ASD increases, the demands for educational professionals to provide services for this group of students rises as well (Stoner et al., 2005; Stoner & Angell, 2006). However, parents of children with ASD usually believe that they are viewed as adversarial, demanding, and hostile by the educational system (Stoner & Angell, 2006). Therefore, to understand parental perceptions concerning their experiences and relationships with educational professionals as well as to explore the factors that contribute to positive relationships becomes extremely important.

Fish (2006) conducted a case study to investigate how parents of students with autism perceived IEP meetings, being valued by the educator during the process, and to identify factors that resulted in the belief that their children were not properly served through the IEP meeting. Fish (2006) also measured parental input regarding actions that both parents and educators can take to better serve the child. Seven families participated in the study, including three single-parent and four two-parent families. Only one parent from each family participated. Their children, with a diagnosis of autism, were all enrolled in public schools.

Fish (2006) used quantitative measures as well as semi-structured interviews to collect the data. Five interview questions concerning parental perceptions toward the quality of services received by their child, how they were treated and perceived by other
IEP team members, the change they desired to make in their child’s IEP meeting were asked, and what the school could do to improve the IEP meeting. Each interview was audio-recorded and transcribed. A constant comparative method was used to analyze the data. The data were constantly compared, categories generated from the transcripts, and the categories integrated. Color-coding was applied to label and distinguish the categories. The data were organized based on the emergent categories.

Analysis of the data indicated that the parent believed that their child did not receive quality service and as parents they had negative experiences in the initial IEP meeting. Most parents did not agree with educators regarding the services to be provided for their children. They also believed that their children would be better served through periodic interaction with their general education peers. The parents did not feel the IEP team members treated them as an equal partner as they felt blamed for their child’s behavioral problems and academic deficits. However, when an advocate was present at the IEP meeting, parents believed they were treated better. Parents felt educators lacked knowledge and understanding of disabilities. They also proposed that they, as parents, should be more active participants in IEP meeting. Fish (2006) concluded that parents wanted to be treated as equal contributors in their child’s IEP meeting and wanted things discussed in the meetings to be fully implemented for their child. They recommended further study to examine the perceptions of parents from different demographic variables.

Stoner et al. (2005) conducted a study to explore the perceptions of parents of young children with ASD concerning their interaction with educational professionals. Specifically, Stoner et al. (2005) were concerned about the influences on parent-professional interactions, parents’ experiences, roles, and relationships with education
professionals. Eight parents of four children with ASD were recruited to participate in the study. All of their children with ASD were boys. Two of them attended preschool, and two attended elementary school.

A total of 24 semi-structured interviews (three per participant) were conducted to collect data. The first interviews were guided by broad, open-ended questions, and analyzed before the interviews. Each of the first interviews took approximately 60-90 minutes and the next set of interviews lasted approximately 90 minutes. There was a 3-month time period between the first and second, and the second and third interviews. The data were reviewed; and the issues raised by the parents were probed in the subsequent interviews. Cross-case analysis was used to analyze the data. Data were analyzed as a whole entity using a flexible standard of variable categories. The categories that emerged were used to analyze the data more in depth. Finally, a constant comparative method was used to compare categories across cases and the categories were refined, expanded or deleted. Several approaches, such as triangulation, respondent validation, and member checking were used to confirm the results.

Results of the analysis revealed that struggling to obtain a diagnosis of their child, intense self-education, external problem-focused behavior, transitions between interventions, and fighting to obtain services for their child influenced the interaction between parents of children with ASD and educational professionals. This struggle negatively impacted the trust parents felt toward educators. The parents expressed a need for frequent, open, and honest communication from teachers. Stoner et al. (2005) concluded that the need for educational professionals to understand parental perceptions is great. They recommended professionals who work with parents of children with ASD...
use open communication, effective intervention practices, and service delivery specifically focus on the needs of the child are imperative.

Stoner and Angell (2006) designed a qualitative study to explore the roles played by parents of children with ASD in school and their interactions with school professionals. The participants were four married couples with children with ASD. Three face-to-face, semi-structured individual interviews were conducted to collect data from each parent, resulting in a total of 24 interviews. Each interview lasted approximately 90 minutes. Before the second and third interviews, the information from previous interviews were transcribed and analyzed. A cross-case analysis with line-by-line coding, followed by a comparative analysis was used to analyze the data. Categories identified were used to analyze each case in depth. Data were organized by a qualitative data management software program, Nvivo. Finally, triangulation, respondent validation, and member checking were performed to confirm the findings.

Four categories of parental roles in their child’s education were consistently reported by the parents: (a) negotiator; (b) monitor, (c) supporter, and (d) advocate. All parents negotiated at IEP meetings regarding issues of placement, related services, and individual assistance for their child. Preparation for negotiation, provision of rationales, and use of consultants for their requests were considered to be effective negotiation strategies by the parents. The parents also consistently checked the quality and content of their child’s educational program in both formal (e.g., IEP meetings, parent-teacher conferences) and informal communications. The parents reported that they supported the school system, just as parents of typically developing children did. The parents tended to trust the educator when they perceived professionals as competent and having best
interests of children in mind. Parental trust in educational professionals impacts their
engagement in their roles of negotiator, monitor, and supporter. Stoner and Angell (2006)
concluded that the study identified the correlations among personal life experience, trust,
building of interpersonal relationships, and the various roles played by parents and
professionals. They recommended future research be done focused on promoting
professional understanding of the construct of trust, and its impact on mutual
collaboration between parents and professionals.

Spann, Kohler, and Soenksen (2003) conducted a study to examine the
involvement of families of children with ASD and the perceptions of parents regarding
special education services received by their child. Parents of children with autism and
related pervasive developmental disorders participated in the study. Phone interviews
were conducted with 45 parents.

There were a total of 15 questions on the survey that addressed: (a) the amount
and nature of special education services their child received from the school; (b) the
frequency and quality of communication among parents, teachers, and other school
personnel; (c) the nature of parental knowledge about and involvement in the IEP
process; and (d) parental priorities for their child and overall satisfaction with school
services. Each interview lasted 40-60 minutes and was tape-recorded.

Descriptive data were reported. Results indicated that 73% of the children spent
part of the day in the general education setting and received one to two special education
services (e.g., paraprofessional, speech therapy, occupational therapy, physical therapy).
Approximately half of the parents (51%) reported that they communicated with school
personnel daily with the communications focused on sharing information, discussing
information, or solving conflicts. The parents believed they had a moderate or higher level of knowledge of their child’s needs than did their child’s teacher. They indicated that they had a moderate or higher level of parental involvement and a moderate or higher level of satisfaction with IEP process. However, many parents also reported that the school did not do enough to address the most pressing needs of their children. Spann et al. (2003) concluded that the study supported and extended existing research regarding the perceptions of parents of children with ASD. They recommended that future research continue to examine parental relationships with school personnel using multiple measures.

Starr and Foy (2012) designed a study to investigate parental perceptions of and satisfaction with the education their child with ASD was receiving. Specifically, the study addressed the factors that contributed to suspension of children with ASD from school. The study also measured the extent of fear, resentment, or prejudice from other parents as well as school personnel experienced by the parents and their child. The participants were 144 parents who completed the survey.

The survey consisted of 116 items, including Liker-type and open-ended questions. The open-ended questions were analyzed and the written comments were transcribed. A general inductive approach was used to categorize the comments. Similar themes were integrated under broader categories.

A total of 15 % of the children had been suspended from school. All parents believed that this was due to the inability of school personnel to address the child’s behavior. Many parents reported they or their child had experienced fear, resentment, or prejudice from school personnel and other professionals. Nearly half of the parents were
“somewhat satisfied” or “dissatisfied” with their child’s education. The overall themes identified across the questions focused on the ability of school personnel to effectively address behavior, teacher training, and understanding of disability as well as effective communication and collaboration between families and school. Starr and Foy (2012) concluded that views of parents must be taken into consideration by educators. They recommended future research explore whether the age/grade level of the child impacts parental perceptions of and satisfaction with their child’s education.

It is important to build partnerships between families of children with ASD and educational professionals. However, families continue to express dissatisfaction with the school services provided to their children and had negative experiences in the IEP meeting (Fish, 2006; Starr & Foy, 2012; Stoner & Angell, 2006). Moreover, the parents also indicated they were not viewed as equal partners in the IEP process (Fish, 2006; Starr & Foy, 2012). These factors may influence the education of children with autism. Future studies should examine a broad population of parents of children with autism and focus on enhancing trust and partnerships among parents, teachers, and school personnel.

Summary

Family systems theory maintains that a family is a whole unit (Parke, 2004; Pinkus, 2006). Internal relationships among family members can influence each other. When there is an individual with a disability in the family, this influences the whole system. The features of children with autism are very unique and considered to be factors that impact their immediate and extended family (Headan et al., 2010).

Compared to children without disabilities and children with other type of disabilities, parents of children with autism have reported elevated parental stress (Brobst
et al., 2009; Gupta et al., 2007; Headan et al., 2010; Hoffman et al., 2009; Lee et al., 2009). They also report significant lower satisfaction of FQOL than families of typical children and families of children with Down syndrome (Brown et al., 2006). This indicates that the presence of a child with autism in a family does influence the family system.

Partnerships between families and professionals are critical for the success of all students (Giovacco-Johnson, 2009; Hindman & Morrison, 2011; Stevenson & Baker, 1987). However, parents of children with autism consistently report negative experiences or dissatisfaction with their interactions with educational professionals (Fish, 2006; Starr & Foy, 2012; Stoner & Angell, 2006). Because the sample size of most studies regarding family-professional partnerships is relatively small, the current study expanded its participant pool to investigate the current status of partnerships between families of children with autism and teachers as perceived by parents. This study also evaluates the relationship between different variables (e.g., educational level, age of the child with autism, type and length of services received) and family-professional partnerships.

This study also used structural equation modeling to ascertain the relationships among the FQOL, parental stress, and family-professional partnerships. Partnerships have been identified as a mediator of the effects of service adequacy on family quality of life in an early childhood service (Summers et al., 2007). The current study examined the relationship with families of children with autism.
CHAPTER THREE

METHOD

Overview

The stress experienced by parents (especially mothers) with a child with autism has been well documented in the literature (Brobst et al., 2009; Dabrowska & Pisula, 2010; Hoffman et al., 2009; Koegel et al., 1992; Mancil et al., 2009; Meadan et al., 2010; Mori, Ujiie, Smith, & Howlin, 2009; Phetrasuwan & Miles, 2009; Pisula, 2006; Rao & Beidel, 2009; Schieve et al., 2007). The stress level of parents of children with autism, parents of typical developing children, and parents of children with other disabilities have been explored in the research (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Brobst et al., 2009; Dabrowska & Pisula, 2010; Hoffman et al., 2009; Pisula, 2007).

Family quality of life is a concept that has recently emerged in the special education literature (Wang & Kober, 2011; Zuna et al., 2010). Studies concerning family quality of life have primarily focused on families with children with intellectual disabilities (Bertelli et al., 2011; Samuel, Rillotta, & Brown, 2012; Werner et al., 2009). Research focusing on the quality of life of a family that has at least one child with autism is sparse.

It is important to establish positive partnerships among families and professionals (Summers et al., 2005; Blue-Banning et al., 2004). However, research concerning the perceptions of parents of children with autism regarding their partnerships with professionals is lacking in the field of special education.

This study investigated the quality of life of families that have at least one child with ASD, parental stress level, and partnerships between the family and professionals.
Also, parent perceptions of parental stress, family quality of life, and family-professional partnerships were assessed to ascertain if there were differences across different variables (e.g., ethnic backgrounds, educational levels, income levels, and relationship status, etc.). Moreover, the study examined the relationship among these three variables (e.g., family quality of life, parental stress, and family-professional partnership). Thus, the results of this study may be used to identify the factors that impact the parental stress of parents of children with autism and the quality of life of families of children with autism. Accordingly, interventions or professional support may be developed to improve family quality of life with a focus on parental stress and partnerships.

Convenience sampling of parents was employed in the study through the selection of center and service provider sites. However, the respondents were representative of parents of children with autism in a large southwestern school district. The parents were invited to participate in the study by completing an online questionnaire (see Appendix B).

**Research Questions**

This study addressed the following seven questions:

**Research Question 1.** Can the satisfaction of the family-professional relationship, as perceived by parents, be predicted from their ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

It was predicted that parental perceptions of their family-professional relationship were based on their ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received.
Research Question 2. Can the levels of parental stress of parents of children with autism be predicted from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

It was predicted that the levels of parental stress of parents of children with autism were based on ethnicity, education level, income level, relationship status of parent(s), age of the child with autism, and type and length of services.

Research Question 3. Can the satisfaction of family quality of life as perceived by parents be predicted from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

It was predicted that parents would perceive their satisfaction with family quality of life based on ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received.

Research Question 4. Does the perceived parental stress level have a direct effect on the parental satisfaction concerning family quality of life?

It was predicted in the hypothesized model 1 (see Appendix A) that the perceived parental stress level would have a direct effect on parental satisfaction concerning family quality of life. That is, when parents of children with autism perceived a higher parental stress level, they would have a lower level of satisfaction concerning family quality of life.

Research Question 5. Is the effect of the perceived parental stress level on parental satisfaction concerning family quality of life moderated by family-professional partnerships?
It was predicted in the hypothesized model 1 (see Appendix A) that the effect of the perceived parental stress level on parental satisfaction concerning family quality of life would be moderated by family-professional partnerships. That is, family-professional partnerships would serve a moderating function and thus buffer the negative effects of high parental stress.

Research Question 6. Does the parental satisfaction concerning family quality of life have a direct effect on the perceived parental stress level?

It was predicted in the hypothesized model 2 (see Appendix A) that parental satisfaction concerning family quality of life would have a direct effect on perceived parental stress level. That is, when parents of children with autism reported a higher level of satisfaction concerning family quality of life, they would have a lower perceived parental stress level.

Research Question 7. Is the effect of the perceived parental satisfaction concerning family quality of life on parental stress level moderated by family-professional partnerships?

It was predicted in the hypothesized model 2 (see Appendix A) that the effect of the perceived parental satisfaction concerning family quality of life on parental stress level would be moderated by family-professional partnerships. That is, family-professional partnerships would affect the strength of the relation between family quality of life and parental stress.

Participants

The participants in this study were parents of children with autism who participated in services or training from an autism center located at a state university, a
state autism organization, a regional autism organization, or a local autism service provider. All participants received an email describing the study and inviting them to complete the online questionnaire. When the participants clicked the link of the questionnaire, the first screen was the protocol describing the purpose of the study and the approximate length of completing the online questionnaire (see Appendix C). The second screen was the digital consent form (see Appendix D). The prospective participants completed the digital informed consent form before they accessed the online questionnaire (see Appendix E). Demographic information was collected from all parent participants (see Table 1). A total of 236 parents completed the questionnaire. The mean age of the first child with autism in the family was 10.7 (SD = 5.9).

**Setting**

An autism center located at a state university, a state autism organization, a regional autism organization, and a local autism service provider agreed to participate in this study (see Appendix F). All were located in a large, southwestern city in the United States.

**Center A**

Center A for Autism Spectrum Disorders is located at a university in a southwestern state and provides training and workshops to the community (e.g., families, teachers, and service providers). The purpose of the training and workshops is to increase awareness of autism and strategies to work with individuals with ASD. This center also focuses on effective assessment and interventions for people with ASD.
Table 1

*Parent Demographic Information*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number of Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
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<tr>
<td>Male</td>
<td>33</td>
</tr>
<tr>
<td>Female</td>
<td>203</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
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<tr>
<td>White (non-Hispanic)</td>
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<tr>
<td>African American</td>
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</tr>
<tr>
<td>American Indian or Alaska Native</td>
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</tr>
<tr>
<td>Asian</td>
<td>12</td>
</tr>
<tr>
<td>Native Hawaiian/Pacific Islander</td>
<td>4</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
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</tr>
<tr>
<td>Two or more races</td>
<td>19</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
</tr>
<tr>
<td><strong>Relationship Status of Parent(s) in Household</strong></td>
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</tr>
<tr>
<td>Married</td>
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<tr>
<td>Widowed</td>
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</tr>
<tr>
<td>Divorced</td>
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<tr>
<td>Separated</td>
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</tr>
<tr>
<td>Never married</td>
<td>10</td>
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<tr>
<td>Living with a Partner</td>
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(continued)
Table 1

*Parent Demographic Information*

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<tr>
<th>Characteristics</th>
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<tr>
<td><strong>Educational Background</strong></td>
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<tr>
<td>No high school diploma or GED</td>
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<tr>
<td>High school graduate (diploma or GED)</td>
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<tr>
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<td>Bachelor’s degree</td>
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<td>Graduate degree</td>
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<td>$ 10,000- $ 19,999</td>
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</tr>
<tr>
<td>$ 20,000- $ 29,999</td>
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</tr>
<tr>
<td>$ 30,000- $ 39,999</td>
<td>17</td>
</tr>
<tr>
<td>$ 40,000- $ 49,999</td>
<td>19</td>
</tr>
<tr>
<td>$ 50,000- $ 59,999</td>
<td>28</td>
</tr>
<tr>
<td>$ 60,000- $ 69,999</td>
<td>27</td>
</tr>
<tr>
<td>$ \geq 70,000</td>
<td>100</td>
</tr>
<tr>
<td><strong>Number of children with autism</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>221</td>
</tr>
<tr>
<td>Female</td>
<td>46</td>
</tr>
<tr>
<td>Total</td>
<td>267</td>
</tr>
</tbody>
</table>
Table 1

**Parent Demographic Information**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number of Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Therapy Received at Home</strong></td>
<td></td>
</tr>
<tr>
<td>ABA (Lovaas, DTT, etc.)</td>
<td>67</td>
</tr>
<tr>
<td>Floor Time/RDI</td>
<td>9</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>51</td>
</tr>
<tr>
<td>Denver Early Childhood</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>47</td>
</tr>
<tr>
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<td>0-5 hours</td>
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<tr>
<td>6-15 hours</td>
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<tr>
<td>16-25 hours</td>
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<tr>
<td>26-40 hours</td>
<td>6</td>
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<tr>
<td>&gt; 40 hours</td>
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</table>

(continued)
Table 1

*Parent Demographic Information*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number of Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Therapy Received in School</strong></td>
<td></td>
</tr>
<tr>
<td>ABA (Lovaas, DTT, etc.)</td>
<td>47</td>
</tr>
<tr>
<td>Floor Time/RDI</td>
<td>9</td>
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<tr>
<td>Speech Therapy</td>
<td>145</td>
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<tr>
<td>Denver Early Childhood</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
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</tr>
<tr>
<td>None of The Above</td>
<td>59</td>
</tr>
<tr>
<td><strong>Length of Therapy Received in School Weekly</strong></td>
<td></td>
</tr>
<tr>
<td>0-5 hours</td>
<td>130</td>
</tr>
<tr>
<td>6-15 hours</td>
<td>23</td>
</tr>
<tr>
<td>16-25 hours</td>
<td>9</td>
</tr>
<tr>
<td>26-40 hours</td>
<td>14</td>
</tr>
<tr>
<td>&gt; 40 hours</td>
<td>1</td>
</tr>
</tbody>
</table>
Organization A

Organization A is an advocate organization that provides support to individuals with ASD and related neuro-developmental disorders as well as their families. This organization has established a state-wide network for all ASD groups/organizations/families to meet. The organization also works to raise public awareness of autism, provides information concerning conferences, and offers a variety of training seminars.

Organization B

Organization B is a non-profit organization comprised of parents and professionals that provides treatment, resources, and a support network for families with children with ASD. The organization offers opportunities for families to meet each other, share and discuss issues, and network. Also, the organization trains tutors for a family home-based program to serve children with ASD.

Service Provider A

Service provider A is a board certified behavior analyst and speech language pathologist in this specific southwestern state. This provider specializes in the treatment of families of children with autism and other related disabilities. The services provided include speech therapy and applied behavior analysis for school and in-home settings for children with autism and their families. Workshops and hands-on training are provided to school staff and educational tutorials are provided to students with autism.

Instrumentation

The questionnaire used in this study was a compellation of three surveys. The final questionnaire was designed to investigate the perceptions of parents who have at
least one child with autism concerning family quality of life, parental stress, and partnerships with professionals. The combined surveys were: (a) the *Beach Center Family Quality of Life Scale* (Hoffman et al., 2006), (b) the *Parental Stress Scale* (Berry & Jones, 1995), and (c) the *Beach Center Family-Professional Partnership Scale (Family Version)* (Summers et al., 2005). Permission to use these surveys was granted by the authors (see Appendix G).

The *Beach Center Family Quality of Life Scale* (Hoffman et al., 2006) initially was developed from extensive literature reviews and a qualitative study that was conducted to conceptualize the concept of family quality of life through focus groups and individual interviews (Poston et al., 2003). An exploratory factor analysis (Park et al., 2003) and confirmatory factor analyses (Hoffman et al., 2006) were conducted to validate the factor structure of the scale. The *Parental Stress Scale* (Berry & Jones, 1995), through various research studies, was found to be a highly reliable measure of stress and exhibited good convergent validity with many related measures (Berry & Jones, 1995). The *Beach Center Family-Professional Partnership Scale (Family Version)* (Summers et al., 2005) was developed from an extensive literature review. Focus groups were conducted to develop the components of interpersonal partnership (Blue-Banning et al., 2004) and factor analyses were conducted in two national studies to refine the scale (Summers et al., 2005). Overall, these three scales are highly reliable measures and they all have satisfactory convergent validity with other validated measures. They were selected for use in this study based on these measures.
**Beach Center Family Quality of Life Scale**

*The Beach Center Family Quality of Life Scale* (Hoffman et al., 2006) was developed to assess the level of satisfaction experienced by parents concerning the quality of life of their family. A total of 25 items are on the scale. The survey has five subscales: (a) family interaction, (b) parenting, (c) emotional well-being, (d) physical/material well-being, and (e) disability-related support. Each subscale is comprised of four to six items, with each item rated on a 5-point Likert-type scale (1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4 = satisfied, and 5 = very satisfied). The scale has adequate internal consistency with an alpha of .88 (Hoffman et al., 2006). Test-retest reliability of each of the subscales has been established, ranging from .60 to .77 (significant at the .01 level) (Hoffman et al., 2006). Good convergent validity also has been demonstrated with other family measures (Hoffman et al., 2006).

**Parental Stress Scale**

The *Parental Stress Scale* (Berry & Jones, 1995) is an 18-item, self-report measure that assesses positive components (e.g., emotional benefits, self-enrichment, and personal development) and negative components (e.g., resource demands, opportunity costs, and limitations) of parenthood. All items are rated on a 5-point Likert-type scale (1 = strongly disagree, 2 = disagree, 3 = undecided, 4 = agree, and 5 = strongly agree). Identified questions are reverse scored (e.g., Question 1, Question 2, Question 5, etc.). Higher scores indicate greater parental stress. Data on the scale indicate satisfactory levels of internal reliability (.83), test-retest reliability (.81) and convergent validity with various measures of stress, emotion, and role satisfaction (Berry & Jones, 1995).
Discriminant analyses supported the differentiated parental stress between parents of children with typical development and with both developmental and behavioral issues (Berry & Jones, 1995).

**Beach Center Family-Professional Partnership Scale (Family Version)**

The *Beach Center Family-Professional Partnership Scale* (Summers et al., 2005) was used to examine the perceptions of the parents concerning their satisfaction with their relationships with professionals (e.g., teachers). The scale contains a total of 18 items that measure two domains of relationships (child-focused relationships and family-focused relationships), with nine items in each domain. Each item is rated on a 5-point Likert scale, ranging from 1 (very dissatisfied) to 5 (very satisfied). High internal consistency of the two subscales and the total scale were demonstrated to be .94 of the domain of Child-Focus, .92 of the domain of Family-Focus, and .96 for the total scale (Summers et al., 2005).

**Materials**

**Questionnaire**

For the purpose of this study, a 61-item questionnaire was developed that was comprised of questions from the *Beach Center Family Quality of Life Scale* (Hoffman et al., 2006), the *Parental Stress Scale* (Berry & Jones, 1995), and the *Beach Center Family-Professional Partnership Scale (Family Version)* (Summers et al., 2005) (see Appendix B). Permission was granted by the authors to adapt the scales to a digital format for use in this study (see Appendix G). Items in the two sections of the questionnaire dealing with family quality of life and family-professional partnership were rated on a 5-point Likert scale (1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied,
nor dissatisfied, 4 = satisfied, and 5 = very satisfied). The third section of the questionnaire dealt with parental stress and the items also was rated on a 5-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = undecided, 4 = agree, and 5 = strongly agree). The questionnaire was posted online through a dedicated IP address. A hyperlink, was established on the first page of the dedicated website linking the participants to the questionnaire.

**Website**

The questionnaire was developed using *Qualtrics* (Qualtrics Labs Inc., 2009). *Qualtrics* is a web-based survey software. The first version of the software was released in 2005 and the most recent version in 2009. It is a research-based survey tool and has been adopted by many universities, enterprises, government and non-profit organizations to conduct online surveys and experimental research. Some unique features of this tool include: (a) more than 100 different types of questions can be chosen, (b) data can be displayed in more than 30 different types of graphs, and (c) data can be downloaded or exported to Excel, SPSS or XML or HTML formats.

To maintain confidentiality, the center, organizations, and service provider emailed the parents a dedicated web address to access the online questionnaire. The parents accessed the web-based questionnaire following the process outlined in Appendix E.

The website was accessible to participants for a three-month period. All questionnaire responses were categorized and maintained digitally. Access to the information compiled from the questionnaire on the dedicated website was limited to one
person. Information obtained was used solely for the purpose of statistical analysis and dissemination of information pertaining to the purpose of this study.

**Design and Procedures**

This study was conducted over a three-month period. This study consisted the following phases: developing the online questionnaire, soliciting participants and distributing the online questionnaire, collecting the data, and analyzing the data.

**Phase One**

The Beach Center on Disability, located at the University of Kansas, was contacted and permission requested to use the *Beach Center Family Quality of Life Scale* (Hoffman et al., 2006) and the *Family-Professional Partnership Scale (Family Version)* (Summers et al., 2005) in this study. Permission also was granted to convert the two scales into an online format (see Appendix G). Dr. Judy O. Berry, one of the developers of the *Parental Stress Scale* was contacted and permission granted to use the scale and convert it into an online format (see Appendix G). The final questionnaire contains a total of 61 items, in three different sections: (a) Family Quality of Life, (b) Family-Professional Partnership, and (c) Parental Stress.

These surveys were converted from the paper format to the online format using *Qualtrics* (Qualtrics Labs Inc., 2009), a online survey/research tool. The website was designed to allow up to 1500 parents to access the website. The request for informed consent appeared on the first page of the website before participants entered the questionnaire (see Appendix C). Digital consent was considered to be legal consent for an online survey (C. Esparza, personal communication, May 16, 2012). Once participants agreed to participate in the study, by clicking the button to give their consent, they
accessed the online questionnaire. That is, they selected the button, “Yes, I have read the above information and agree to participate in this study. I am at least 18 years of age,” to access the online questionnaire (see Appendix D). However, they were able to terminate the survey at anytime if they wished to by closing the window (see Appendix E).

To ensure that the questionnaire was transferred from the paper format to the digital format correctly, two reliability checkers reviewed the digital questionnaire. Reliability was set at 100%. The questionnaire was transferred to the online environment with 100% accuracy.

**Phase Two**

An autism center located at a large southwestern university, a state autism organization, a regional autism organization, and a local autism service provider were contacted and agreed to participate in the study (see Appendix F). To maintain confidentiality, they sent out the email to parents in their databases concerning completion of the online questionnaire. All potential parent participants received the initial email from the center, organizations, and service provider that generated the questionnaire process outlined in Appendix E.

A detailed explanation of the study was included in the email with a link to the online questionnaire. If the receivers of the email were professionals or teachers, they were asked to forward the email to parents they knew or served. The email indicated that participation in the study was voluntary and that not participating in the study would not impact the services they receive. Once parents gave their informed consent, they accessed the online questionnaire. The protocol contained a randomly assigned coded IP address to
code participant access to the online questionnaire. Once a parent completed the questionnaire, they were unable to access the website again.

**Phase Three**

The online survey website was accessible for three months. After the first email was sent, the first reminder email was sent two days later. The second reminder was sent out five days later after the first reminder. The third reminder was sent seven days after the first reminder. Thus, parents who had not completed the survey received four e-mail contacts within 10 days. Parents who had not completed the survey received four contacts over the three-month period.

When converting the questionnaire into the online format, items were coded. Responses of participants were exported into the Statistical Package for the Social Sciences (SPSS) for analysis.

**Phase Four**

Once the responses were exported into the SPSS, descriptive statistics and tests were conducted to analyze the data. Also, the responses were exported into AMOS to examine the structural equation modeling.

**Data Collection**

Emails from the center, two organizations and service provider were sent to prospective parent participants. Demographic information and parent responses from the questionnaire were collected for a three-month period. The data collected from the questionnaire and demographic information were exported into SPSS for analysis.
Treatment of the Data

Responses of the parents were analyzed to answer the following research questions:

**Research Question 1.** Can the satisfaction of the family-professional relationship, as perceived by parents, be predicted from their ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

**Analysis:** A multiple regression analysis was conducted to predict satisfaction of the family-professional relationship, as perceived by parents from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received. Alpha level was set at .05.

**Research Question 2.** Can the levels of parental stress of parents of children with autism be predicted from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

**Analysis:** A multiple regression analysis was conducted to predict levels of parental stress from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received. Alpha level was set at .05.

**Research Question 3.** Can the satisfaction of family quality of life as perceived by parents be predicted from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

**Analysis:** A multiple regression analysis was conducted to predict satisfaction with family quality of life from ethnicity, educational level, income level, relationship
status of parent(s), age of the child with autism, and type and length of services received. Alpha level was set at .05.

**Research Question 4.** Does the perceived parental stress level have a direct effect on the parental satisfaction concerning family quality of life?

**Analysis:** Structural equation modeling was used to examine the effect of the perceived parental stress level on the parental satisfaction concerning family quality of life. The evaluation of model adequacy was based on the chi-square statistic, normed fit index (NFI), comparative fit index (CFI), and root mean square error of approximation (RMSEA). Alpha level was set at .05.

**Research Question 5.** Is the effect of the perceived parental stress level on parental satisfaction concerning family quality of life moderated by family-professional partnerships?

**Analysis:** Structural equation modeling was used to examine if the relationship between the perceived parental stress level and parental satisfaction concerning family quality of life was moderated by family professional partnerships. The evaluation of model adequacy was based on chi-square statistic, normed fit index (NFI), comparative fit index (CFI), and root mean square error of approximation (RMSEA). Alpha level was set at .05.

**Research Question 6.** Does the parental satisfaction concerning family quality of life have a direct effect on the perceived parental stress level?

**Analysis:** Structural equation modeling was used to examine the effect of the parental satisfaction concerning family quality of life on the perceived parental stress level. The evaluation of model adequacy was based on chi-square statistic, normed fit
index (NFI), comparative fit index (CFI), and root mean square error of approximation (RMSEA). Alpha level was set at .05.

**Research Question 7.** Is the effect of the perceived parental satisfaction concerning family quality of life on parental stress level moderated by family-professional partnerships?

**Analysis:** Structural equation modeling was used to examine if the relationship between the parental satisfaction concerning family quality of life and the perceived parental stress level was moderated by family professional partnerships. The evaluation of model adequacy was based on chi-square statistic, normed fit index (NFI), comparative fit index (CFI), and root mean square error of approximation (RMSEA). Alpha level was set at .05.
CHAPTER FOUR

RESULTS

The presence of a child with autism spectrum disorder (ASD) in a family influences the family system (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008; Meadan, Halle, & Ebata, 2010). Parents of children with ASD report elevated parental stress (Brobst, Clopton, & Hendrick, 2009; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009). Compared to children without disabilities and children with Down syndrome, parents of children with ASD also indicate a lower satisfaction with their family quality of life (Brown, MacAdam, Wang, & Iarocci, 2006). In addition, partnerships between families and professionals may impact a family’s quality of life (Davis & Gavidia-Payne, 2009). Because of the potential interaction of these three variables, research is needed to assess the relationship among the variables.

The purpose of this study was to determine the relationship among family-professional partnerships, parental stress, and family quality of life for families in which at least one child had autism. An online questionnaire was developed for use in this study and distributed through Qualtrics (Qualtrics Labs Inc., 2009), a web-based online software. Demographic information was collected and three scales (e.g., the Beach Center Family-Professional partnership Scale, the Parental Stress Scale, and the Beach Center Family Quality of Life Scale) were used to collect parental perceptions of family-professional partnerships, parental stress, and family quality of life, respectively, for families of children with ASD. Four non-profit autism organizations in a southwest region of the United States distributed the questionnaire link to parents of children with ASD. A total of 236 questionnaires (see Table 1) were completed. However, only 230
and 231 were analyzed due to missing data. Data were collected across a three-month period and quantitative analyses were used to analyze the data.

**Family Questionnaire**

The questionnaire (see Appendix B) used for this study included three scales. The *Parental Stress Scale* (Berry & Jones, 1995) was used to collect information concerning parental stress experienced by parents of children with ASD. This scale has a total of 18 statements. For each statement, parents indicated on a 5-point Likert scale: (1) strongly disagree, (2) disagree, (3) undecided, (4) agree, and (5) strongly agree. Identified questions were reverse coded (e.g., Question 1, Question 2, Question 5, etc.). Therefore, when parents scored higher on the scale, the score indicated greater parental stress. The *Beach Center Family-Professional partnership Scale (Family Version)* (Summers et al., 2005) was used to investigate parental satisfaction with the relationship(s) with their child’s teacher(s). The *Beach Center Family Quality of Life Scale* (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) was used to ascertain parental satisfaction with their family quality of life as a unit. For the two Beach Center scales, the parents used a 5-point Likert scale for each item: (1) strongly dissatisfied, (2) dissatisfied, (3) neither dissatisfied nor satisfied, (4) satisfied, and (5) strongly satisfied.

The online questionnaire consisted of a total of 71 items, including 10 demographic items. The data from the questionnaire were analyzed to answer the following questions:
Research Question 1. Can the satisfaction of the family-professional relationship, as perceived by parents, be predicted from their ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

It was predicted that parental perceptions of their family-professional relationship was based on their ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received.

A multiple regression analysis was conducted with data from 230 completed surveys of the Beach Center Family-Professional partnership Scale (Family Version) to analyze questionnaire data to predict perceived family-professional partnerships based on (a) ethnicity, (b) educational level, (c) income level, (d) relationship status of parent(s), (e) age of the first child with autism, and (f) type and length of services received. Dummy coding was employed to recode categorical variables: ethnicity (White vs. non-White), educational level (postsecondary, but no degree and undergraduate vs. associate’s degree and above), relationship status of parent(s) (parents who were married or living with a partner vs. one-parent family). Age of the first child with autism and the type of services received at home and in school were treated as continuous variables. Income level and length of therapy received at home and in school were recoded. Total household income level from $\leq 19,000$-$49,999$ was recoded as one, from $50,000$-$69,999$ was recoded as two, and $\geq 70,000$ was recoded as three. Length of services received at home and in school was recoded. When the family received no service, it was recoded as one, 0-15 hours was recoded as two, and 16 hours and above was recoded as three. Alpha level was set at .05.
The results of the stepwise multiple regression analysis indicated that the two variables that contributed significantly to the family-professional relationship were age of the first child with autism and type of school services received (see Table 2). As the age of the child with autism got older, the satisfaction of family-professional partnerships decreased. As the family of the child with ASD received more types of services at school, the perceived satisfaction of the family-professional relationship increased. The overall percent of variance explained by these two variables was 6.4%, which is a very small portion of variance.

Research Question 2. Can the levels of parental stress of parents of children with autism be predicted from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

It was predicted that the levels of parental stress of parents of children with autism was based on ethnicity, education level, income level, relationship status of parent(s), age of the child with autism, and type and length of services.

A multiple regression analysis was conducted to predict levels of parental stress from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received. Alpha level was set at .05.

The results of the stepwise multiple regression analysis indicated that the only variable that contributed significantly to the level of parental stress was the relationship status of parent(s) (see Table 3). When the relationship status of the parent(s) was a one-parent family (e.g., widowed, divorced, separated, or never married), it predicted higher levels of parental stress. The overall percent of variance explained by this variable was 2.1%, which is a very small portion of variance.
**Research Question 3.** Can the satisfaction of family quality of life as perceived by parents be predicted from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received?

It was predicted that parents would perceive their satisfaction with family quality of life based on ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received.

A multiple regression analysis was conducted to predict satisfaction with family quality of life from ethnicity, educational level, income level, relationship status of parent(s), age of the child with autism, and type and length of services received. Alpha level was set at .05.

The results of the stepwise multiple regression analysis indicated that the two variables contributed significantly to the satisfaction with family quality of life. They were total household income and the age of the first child with autism (see Table 4). As the total household income increased, the perceived satisfaction of family quality of life increased. As the age of the child with autism got older, the satisfaction of family quality of life decreased. The overall percent of variance explained by these two variables was 14.4%, which is a small portion of variance.
Table 2

*Significant Predictors for Perceived Satisfaction of Family-professional Partnerships*  
(*n = 230*)

<table>
<thead>
<tr>
<th>Significant Predictor</th>
<th>Standardized Coefficients</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of the first child with autism</td>
<td>-.177</td>
<td>-2.725</td>
<td>.007*</td>
</tr>
<tr>
<td>Types of services received in school</td>
<td>.153</td>
<td>2.354</td>
<td>.019*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>$R^2 = .064$</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* *p* < .05

Table 3

*Significant Predictors for Perceived Parental Stress (n = 231)*

<table>
<thead>
<tr>
<th>Significant Predictor</th>
<th>Standardized Coefficients</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two-parent (married or living with a partner) vs. Single-parent (widowed, divorced, separated, or never married)</td>
<td>.146</td>
<td>2.227</td>
<td>.027*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>$R^2 = .021$</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* *p* < .05
Table 4

**Significant Predictors for Perceived Satisfaction of Family Quality of Life (n = 231)**

<table>
<thead>
<tr>
<th>Significant Predictor</th>
<th>Standardized Coefficients</th>
<th>$t$</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total household income</td>
<td>.351</td>
<td>5.728</td>
<td>.000*</td>
</tr>
<tr>
<td>Age of the first child with autism</td>
<td>-.137</td>
<td>-2.232</td>
<td>.027*</td>
</tr>
<tr>
<td>$R^2 = .144$</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* $*p < .05$

**Research Question 4.** Does the perceived parental stress level have a direct effect on the parental satisfaction concerning family quality of life?

It was predicted in the hypothesized model 1 (see Appendix A) that the perceived parental stress level would have a direct effect on parental satisfaction concerning family quality of life. That is, when parents of children with autism perceived a higher parental stress level, they would have a lower level of satisfaction concerning family quality of life.

Structural equation modeling was used to examine the effect of the perceived parental stress level on the parental satisfaction concerning family quality of life. The evaluation of model adequacy was based on the chi-square statistic, normed fit index (NFI), comparative fit index (CFI), and root mean square error of approximation (RMSEA). Alpha level was set at .05.

The factor of family quality of life has five indicators: (a) family interaction, (b) parenting, (c) emotional well-being, (d) physical/material well-being, and (e) disability-
related support. The subscale-only model was conducted for the factor of family quality of life (see Figure H1). After using the modification indices to adjust error covariances, this model had an excellent fit, $\chi^2 (3) = 4.88, p = .18$, NFI = .99, CFI = 1.00, RMSEA = .052. The sum of parental stress was treated as one observable factor. The full model of the hypothesized model 1 is presented in Figure H2 (at Appendix H). This model had a good fit, $\chi^2 (229) = 546.30, p < .01$, NFI = .92, CFI = .95, RMSEA = .08 (see Figure H3). Since the path coefficient of the effect of family-professional partnerships on parental stress was not significant ($\beta = -.10, p > .05$), the parameter was dropped and the final model was re-tested again. The re-rested model had a good fit, $\chi^2 (230) = 548.74, p < .01$, NFI = .92, CFI = .95, RMSEA = .08. The perceived parental stress level had a direct effect on the parental satisfaction concerning family quality of life, $\beta = -.46, p < .05$ (see Figure H4).

**Research Question 5.** Is the effect of the perceived parental stress level on parental satisfaction concerning family quality of life moderated by family-professional partnerships?

It was predicted in the hypothesized model 1 (see Appendix A) that the effect of the perceived parental stress level on parental satisfaction concerning family quality of life would be moderated by family-professional partnerships. That is, family-professional partnerships would serve a moderating function and thus buffer the negative effects of high parental stress.

The factor of family-professional partnerships has 18 indicators. The item-level factor model was conducted for the factor of partnership. After using the modification indices to adjust error covariances, this model had a good fit, $\chi^2 (105) = 259.66, p < .01$, \ldots
NFI = .95, CFI = .97, RMSEA = .079 (see Figure H5). The full model of the hypothesized model 1 is presented in Figure H2 in Appendix H. This model had a good fit, $\chi^2 (229) = 546.30, p < .01$, NFI = .92, CFI = .95, RMSEA = .08 (see Figure H3). Since the path coefficient of the effect of family-professional partnerships on parental stress was not significant ($\beta = -.10, p > .05$), the parameter was dropped, and the final model was re-tested again. The re-tested model had a good fit, $\chi^2 (230) = 548.74, p < .01$, NFI = .92, CFI = .95, RMSEA = .08. The perceived parental stress level had a direct effect on the parental satisfaction concerning family quality of life, $\beta = -.46, p < .05$ (see Figure H4). While the parental satisfaction concerning family-professional partnerships had a direct effect on the parental satisfaction concerning family quality of life, $\beta = .35, p < .05$, the parental satisfaction concerning family-professional partnership did not have a significant direct effect on the perceived parental stress level. Therefore, the effect of the perceived parental stress level on parental satisfaction concerning family quality of life was not moderated by family-professional partnerships. That is, family-professional partnerships did not serve a moderating function and thus did not buffer the negative effects of high parental stress.

**Research Question 6.** Does the parental satisfaction concerning family quality of life have a direct effect on the perceived parental stress level?

It was predicted in the hypothesized model 2 (see Appendix A) that parental satisfaction concerning family quality of life would have a direct effect on perceived parental stress level. That is, when parents of children with autism reported a higher level of satisfaction concerning family quality of life, they would have a lower perceived parental stress level.
The hypothesized model 2 was tested through structural equation modeling. The full model had a good fit, $\chi^2 (222) = 484.72, p < .01, NFI = .93, CFI = .96, RMSEA = .07$ (see Figure H6). The parental satisfaction concerning family quality of life had a direct effect on the perceived parental stress level, $\beta = -.51, p < .05$ (see Figure H7). Since the path coefficient of the effect of family-professional partnerships on parental stress was not significant ($\beta = .08, p > .05$) and the path coefficient was positive rather than negative as proposed by the hypothesis, the path between them was deleted and the final model was re-tested again. The re-tested model had a good fit, $\chi^2 (223) = 486.24, p < .01, NFI = .93, CFI = .96, RMSEA = .07$. The perceived parental satisfaction concerning family quality of life had a direct effect on the perceived parental stress level, $\beta = -.48, p < .05$ (see Figure H8).

**Research Question 7.** Is the effect of the perceived parental satisfaction concerning family quality of life on parental stress level moderated by family-professional partnerships?

It was predicted in the hypothesized model 2 (see Appendix A) that the effect of the perceived parental satisfaction concerning family quality of life on parental stress level would be moderated by family-professional partnerships. That is, family-professional partnerships would affect the strength of the relation between family quality of life and parental stress.

The parental satisfaction concerning family quality of life has a direct effect on the perceived parental stress level, $\beta = -.48, p < .05$ (see Figure H8). While the parental satisfaction concerning family-professional partnerships had a direct effect on parental satisfaction concerning family quality of life, $\beta = .35, p < .05$, the parental satisfaction
concerning family-professional partnership did not have a significant direct effect on the perceived parental stress level. Therefore, the effect of the perceived parental satisfaction concerning family quality of life on parental stress level was not moderated by family-professional partnerships. That is, family-professional partnerships did not affect the strength of the effect of the family quality of life on parental stress.
CHAPTER FIVE

DISCUSSION

There has been extensive research focused on the stress experienced by parents (especially mothers) who have a child with autism spectrum disorder (ASD) (Brobst, Clopton, & Hendrick, 2009; Dabrowska & Pisula, 2010; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Koegel et al., 1992; Meadan, Halle, & Ebata, 2010; Phetrasuwan & Miles, 2009; Pisula, 2006; Rao & Beidel, 2009; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). However, little research exists to describe family quality of life for families of children with autism that considers the whole family unit (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Eskow, Pineles, & Summers, 2012). And, only a few studies focus on the relationships/partnerships between families and professionals who provide services to children with ASD (Fish, 2006; Starr & Foy, 2012; Stoner & Angell, 2006; Stoner et al., 2005).

The purpose of the study was to examine parental satisfaction with their family-professional relationship(s), parental perception of stress, and parental satisfaction with their family quality of life for families of children with ASD. This study also attempted to determine the relationship among family-professional partnerships, parental stress, and family quality of life. Data were collected using an online questionnaire that was comprised of three scales (Beach Center Family-Professional Partnership Scale, Parental Stress Scale, and Beach Center Family Quality of Life Scale) (Summers et al., 2005; Berry & Jones, 1995; Hoffman et al., 2006, respectively) as well as family demographic information.
The questionnaire included demographic information on ethnicity, relationship status of parent(s), educational background, total household income level, age of the child with autism, and type and length of services received at home and in school. Specifically, the *Beach Center Family-Professional Partnership Scale* was used to examine parental satisfaction with their family-professional relationship (Summers et al., 2005), the *Parental Stress Scale* was used to examine parental perceptions of their stress level, and the *Beach Center Family Quality of Life Scale* (Hoffman et al., 2006) was used to measure parental satisfaction with their family quality of life.

**Satisfaction with Family-Professional Relationship**

Question One was analyzed to examine the variables that were predictors of parental satisfaction with their family-professional partnerships. The results showed that two demographic variables were statistically significant predictors of family-professional partnerships. The first variable was the age of the first child with autism in the family. That is, as a child with autism gets older, parental satisfaction with their family-professional partnership(s) decreased. This finding supports the research that parents of older children with disabilities report lower levels of satisfaction with their partnerships with professionals (Summers, Hoffman, Marquis, Turnbull, & Poston, 2005).

The other significant predictor of family-professional partnership(s) was the type of services received in school. As the child with autism received more school services, the parents rated their family-professional partnerships at a higher level. This result aligns with the study by Summers et al. (2007) in which the data indicated that the adequacy of service provision in early childhood programs was a significant predictor for family-professional partnerships.
However, in the current study, these two variables (e.g., age of the child with autism, school services received) accounted only for a small portion of variance (6.4%). This indicates that there are other factors related to family-professional partnerships that may impact the relationship more. Further research is needed to identify these factors.

**Parental Stress of Parents of Children with Autism**

Question Two centered on the variables that were predictors of parental stress of parents of children with ASD. The results from this study indicated that the relationship status of the parent(s) was a predictor of parental stress. That is, single parents (e.g., widowed, divorced, separated, or never married) indicated a higher level of stress, while parents in two-parent families (e.g., married or living with a partner) showed a lower level of parental stress. This may because single-parent households are at a higher risk of living in poverty (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). This finding supports earlier studies in which single-mother families with children with disabilities experienced greater levels of stress (Beckman, 1983; Boyce, Miller, White, & Godfrey, 1994; Holroyd, 1974).

However, even though the variable relationship status of parent(s) was statistically significant, it explains a very small portion of variance (2.1%). This finding is similar to the study by Boyce et al. (1994) in which multiple studies concerning stress levels of single-parent and two-parent families of children with disabilities were reviewed and mixed results found. Boyce et al. (1994) found that if maternal education and income were controlled, the differences in stress levels between single-and-two parent families often were not significant (Boyce et al., 1994). Therefore, for parents of children with
ASD, other variables should be identified and explored. It appears that variables, other than those identified in this study, may serve as predictors of stress for these parents.

**Satisfaction with Family Quality of Life**

Research Question Three examined the variables that were predictors of parental satisfaction with their family quality of life. The results showed that two demographic variables were statistically significant predictors of family quality of life. The first variable was the total household income. When a family had a higher total household income, the parent(s) reported a more satisfactory family quality of life. This mirrors the work of Wang et al. (2004) in which they found that family income is one of the most significant predictors of the satisfaction of mothers (not fathers) with family quality of life while the child is young.

The other significant predictor of family quality of life in this study was the age of the first child with autism in the family. As the child with autism grew older, the parental satisfaction with family quality of life decreased. These results are similar to those in a study by Perry, Harris, and Minnes (2005) in which parents of young children with developmental disabilities rated their family harmony higher than parents of elementary and secondary age children. While the two predictors (e.g., family income, age of the child with ASD) identified in this study were significant, both of them together accounted for only a small portion of variance (14.4%). It appears that more variables may serve as predictors of family quality of life and should be explored in future research.
The Relationship Among Family-Professional Partnerships, Parental Stress, and Family Quality of Life

Question Four, Five, Six, and Seven were analyzed to ascertain the relationship among the three main factors: (a) family-professional partnership(s), (b) parental stress, (c) and family quality of life. The relationship among the three main factors were depicted in two hypothesized models (see Appendix A) and were analyzed using structural equation modeling.

Both Question Four and Question Six dealt with the relationship between parental stress and family quality of life. Question Four examined if parental stress had a direct effect on family quality of life as hypothesized in model 1 (see Figure A1) and Question Six examined if family quality of life had a direct effect on parental stress (see Figure A2). The results for Question Four indicated that parental stress had a direct effect on family quality of life. When parents of children with ASD perceived a higher level of parental stress, they reported a lower level of satisfaction with their family quality of life.

Conversely, the results for Question Six showed that family quality of life had a direct effect on the parental stress. This finding is similar to the study by Lee, Hwang, Chen, and Chien (2009). In their study, they found that the quality of life of primary caregivers has a direct effect on parental stress. In addition, this parental stress has a direct effect on the quality of life of the child.

To date, there have been no studies investigating the effects of parental stress on the satisfaction with family quality of life within families of children with ASD that considers the whole family unit. However, the relationship between these two variables may be interpreted in light of previous studies that found parents of children with autism...
usually report significantly higher levels of stress than do parents of children with other disabilities or without disabilities (Brobst et al., 2009; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Quintero & McIntyre, 2012; Rao & Beidel, 2009), as well as a lower level of family quality of life (Brown et al., 2006). Lee et al. (2009) also identified parental stress as one of the significant predictors contributing to health-related quality of life for parents of children with ASD. The results of this current study extended the concept of quality of life to the whole family unit (i.e. family quality of life) and found that the variables of parental stress and family quality of life have a direct effect on each other.

Question Five and Seven examined if family-professional partnerships moderated the relationship between the perceived parental stress levels and parental satisfaction concerning family quality of life. While the parental satisfaction concerning family-professional partnerships had a direct effect on the parental satisfaction concerning family quality of life, the parental satisfaction with the family-professional partnership(s) did not have a significant direct effect on the perceived parental stress level. Therefore, the results showed that family-professional partnerships neither moderates the effect of the perceived parental stress level on parental satisfaction concerning family quality of life (Question Five) nor the effect of the perceived parental satisfaction concerning family quality of life on the parental stress level (Question Seven).

The parental satisfaction concerning family-professional partnerships had a direct effect on the parental satisfaction concerning family quality of life. This finding supports the research that perceptions and experiences of parents of young children with disabilities are associated with family quality of life (Davis & Gavidia-Payne, 2005). The
parental satisfaction concerning family-professional partnership did not have a significant direct effect on the perceived parental stress level. This result is both similar to and different from a study conducted by Guralnick, Hammond, Neville, and Connor (2008). The result of the current study differs from Guralnick et al. (2008) because in their study general support from various sources was related to parental stress, specifically child-related stress, for families of children with mild developmental delays. The result of the current study is similar to Guralnick et al. (2008) in that after controlling for child-related variables (e.g., age, children, levels of cognitive and language, behavioral problems of the child) and family social status, parental support was related to both child-and parent-related stress. Thus, the relationship between supports for family (i.e., family-professional partnerships in this study) and parental stress should be further examined.

**Conclusions**

Based on the collected quantitative data, seven conclusions may be drawn from this study. These conclusions should be viewed in light of the limitations of the study.

1. Two significant predictors of family-professional partnerships are age of the first child with autism and type of services the child receives in school. While accounting for a small portion of variance, investigation of other variables that may provide an explanation is needed.

2. The only significant predictor of parental stress was the relationship status of parent(s). However, once again, this variable accounts for a very small portion of variance, but it does identify a factor to be considered when working with parents of children with ASD.
3. Two significant predictors of family quality of life were identified in the study. While the predictors, household income and age of the first child with autism, account for a small portion of variance, they do provide some insight into the quality of life experienced by the family as a unit rather than as individuals.

4. In the structural equation model for the effect of family-professional partnership(s) and parental stress on family quality of life, parental stress had a direct effect on family quality of life. When parents of children with autism perceive a higher parental stress level, they experience a lower level of satisfaction with their family quality of life. This provides educators who work with these parents a better understanding of the impact of parental stress on family quality of life in terms of family functioning and specific supports that may or may not be in place at home for the child.

5. In the structural equation model for the effect of family-professional partnership(s) and parental stress on family quality of life, the family professional partnership did not moderate the effect of the perceived parental stress level on parental satisfaction concerning family quality of life. This indicates family-professional partnerships do not buffer the negative effects of high parental stress.

6. In the structural equation model for the effect of family-professional partnership(s) on parental stress through family quality of life, family quality of life had a direct effect on parental stress. This indicates that when parents of children with autism perceive a higher level of satisfaction concerning
family quality of life, they will have a lower perceived parental stress level. Again, this provides educator some indication of family functioning.

7. In the structural equation model for the effect of family-professional partnership(s) on parental stress through family quality of life, family professional partnership(s) did not moderate the effect of parental satisfaction concerning family quality of life on the perceived parental stress level. This indicates that family-professional partnerships did not affect the strength of the relation between family quality of life and parental stress. However, family-professional partnership(s) has an effect on parental stress through family quality of life.

**Recommendations for Future Research**

Studies have consistently shown that parents of children with ASD experience elevated levels of stress (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008; Hoffman et al., 2009; Meadan, Halle, & Ebata, 2010; Rao & Beidel, 2009). Research on the quality of life within a family in which at least one child/youth has autism has just started to emerge. Enhancing family quality of life for these families is crucial as it is a meaningful indicator of the types of services needed (Johnson, Frenn, Feetham, & Simpson, 2011). Furthermore, establishing collaborative partnerships between family and professionals is imperative to provide effective services for children with disabilities (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). However, parents of children with autism continue to report negative experiences or unsatisfactory interactions with educational professionals (Fish, 2006; Starr & Foy, 2012; Stoner & Angell, 2006). Therefore, research is needed to determine the predictors of these three
variables as well as examine the relationships among these three important aspects for families of children with autism. Based on the results of this study, the following recommendations are suggested for further study.

1. Using data from this study, further analysis of family quality of life should be conducted to determine if there are significant differences among the five main domains of family quality of life (e.g., family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support).

2. Using data from this study, further analysis of family-professional partnerships should be conducted to examine if there is a significant difference between two domains of family-professional partnerships (e.g., family-focused and child-focused relationships).

3. A replication of the present study should be conducted that includes a larger number of parents of children with ASD from different regions of the United States.

4. A replication of present study should be conducted that includes parents of children with ASD who are not associated with formal autism organizations (e.g., school-based programs).

5. A replication of the current study should be conducted that includes parents of children with various disabilities, parents of typically developing children, and parents from culturally and linguistically diverse groups.

6. Further research should be conducted to include more child-related variables (e.g., severity of child disability, behavior problems, child function) or other
variables (e.g., coping style) to determine the relationship of these child variables with family quality of life and family-professional partnerships.

7. Further research should be conducted to compare the perceptions of parents and teachers concerning family-professional partnerships to identify the gap between the two parties.

8. Further research should be conducted to compare the perceptions of various family members concerning family-quality of life.

9. Further research should be conducted to compare parental perceptions of family quality of life and family-professional partnerships across age groups (e.g., early intervention, elementary education, and secondary education).

10. Further research should be conducted to identify different types of training and support for special education teachers to develop positive partnerships with the families they serve.

Summary

Prior to this study, limited research has been conducted concerning parental satisfaction with family quality of life and family-professional partnerships in families with children with ASD. No research has been conducted to examine the relationship of the two variables to parental stress for this population of parents. This study incorporated the three variables (e.g., parental stress, family-professional partnerships, family quality of life) to examine the significant predictors for these variables and ascertain the relationship of parental stress, family-professional partnerships, and family quality of life for families of children with ASD.
Results of this study showed that several demographic variables are predictors of family-professional partnerships, parental stress, and family-professional partnerships and these results are supported by previous studies (Beckman, 1983; Boyce et al., 1994; Holroyd, 1974; Perry et al., 2009; Summers et al., 2005; Summers et al., 2007; Wang et al., 2004). However, even though the predictors (age of the first child with autism, type of services the child receives in school, relationship status of parent(s), household income) were found to be significant, they explained only a small portion of variance for these outcome variables. Therefore, more items should be identified and surveyed to ascertain if they can predict these variables.

This study contributes to the literature in that it appears to be one of the first studies designed to ascertain the relationship among parental stress, family-professional partnerships, and family quality of life for the population of families of children with ASD. The results showed that parental stress had a direct effect on family quality of life. Although family-professional partnerships did not moderate the effect of the perceived parental stress level on parental satisfaction concerning family quality of life, or the effect of parental satisfaction concerning family quality of life on the perceived parental stress level, family-professional partnerships did have an effect on parental stress through family quality of life. That is, educators can enhance satisfaction with family-professional partnerships between teachers and parents of children with ASD and, thus, improve the satisfaction with family quality of life. Through improving satisfaction with family quality of life, educators indirectly decrease the levels of parental stress. These findings have direct implications for teacher education as well as parent/educator collaboration. Teacher education must include coursework to enhance the understanding of the inner
workings of families that include a child/youth with autism. This training should include the components needed to form successful parent/educator collaborative teams. It is through the formation of strong family-professional partnerships that outcomes for children with autism will be improved.
APPENDIX A

HYPOTHESESIZED MODELS
Figure A1. Hypothesized Model 1.
Figure A2. Hypothesized Model 2.
APPENDIX B

QUESTIONNAIRE
SECTION 1:

Demographic and Background Information

Please answer the following questions:

1. Gender: 1.1 □ Male  1.2 □ Female

2. Ethnicity:
   2.1 □ White (non-Hispanic)
   2.2 □ African American
   2.3 □ American Indian or Alaska Native
   2.4 □ Asian
   2.5 □ Native Hawaiian/Pacific Islander
   2.6 □ Hispanic or Latino
   2.7 □ Two or more races
   2.8 □ Other (Please specify):
       ________________________________________________

3. Relationship Status of Parent(s) in Household.
   3.1 □ Married
   3.2 □ Widowed
   3.3 □ Divorced
   3.4 □ Separated
   3.5 □ Never married
   3.6 □ Living with a Partner

4. Educational Background
   4.1 □ No high school diploma or GED
   4.2 □ High school graduate (diploma or GED)
   4.3 □ Postsecondary, but no degree
   4.4 □ Associate’s degree
   4.5 □ Bachelor’s degree
   4.6 □ Graduate degree

5. Total Household Income
   5.1 □ ≤ $ 19,999
   5.2 □ $ 20,000 - $ 29,999
   5.3 □ $ 30,000 - $ 39,999
   5.4 □ $ 40,000 - $ 49,999
   5.5 □ $ 50,000 - $ 59,999
   5.6 □ $ 60,000 - $ 69,999
   5.7 □ ≥ $ 70,000
6. Number of Children with Autism:
   Male, Age: _____________   Female, Age: _____________
   (write number of your child(ren) with autism in the box)

7. Type of Therapy Received at Home
   7.1 ABA (e.g., Lovaas, DTT, etc.)
   7.2 Floor Time/RDI
   7.3 Speech Therapy
   7.4 Denver Early Childhood
   7.5 Other (Please specify): _____________________________

   7.6 None of the Above

8. Length of Therapy Received at Home Weekly
   8.1 0 - 5 hours
   8.2 6 - 15 hours
   8.3 16 – 25 hours
   8.4 26 – 40 hours
   8.5 > 40 hours

9. Type of Therapy Received in School
   9.1 ABA (e.g., Lovaas, DTT, etc.)
   9.2 Floor Time/RDI
   9.3 Speech Therapy
   9.4 Denver Early Childhood
   9.5 Other (Please specify): _____________________________

   9.6 None of the Above

10. Length of Therapy Received in School Weekly
    10.1 0 - 5 hours
    10.2 6 - 15 hours
    10.3 16 – 25 hours
    10.4 26 – 40 hours
    10.5 > 40 hours
SECTION 2:

**Family Quality of Life**

Directions:

This survey is about how you feel about your life together as a family. Your “family” may include many people – mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as:

1. Those people who you think of as part of your family (even though they may or may not be related by blood or marriage), and
2. Those people who support and care for each other on a regular basis.

For this survey, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The items on the next screen are things that hundreds of families have said are important for a good family quality of life. We want to know how **satisfied** you are with these things in your family.

Please check the boxes on the following screens that reflect your level of satisfaction with each item.

- Clicking the first box means you are **very dissatisfied**.
- Clicking the second box means you are **dissatisfied**.
- Clicking the third box means you are **neither satisfied nor dissatisfied**.
- Clicking the fourth box means you are **satisfied**.
- Clicking the fifth box means you are **very satisfied**.

Thank you so much for sharing your opinion!
### Family Quality of Life

<table>
<thead>
<tr>
<th>How satisfied am I that:</th>
<th>1 Very Dissatisfied</th>
<th>2 Dissatisfied</th>
<th>3 Neither</th>
<th>4 Satisfied</th>
<th>5 Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>My family enjoys spending time together.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My family members help the children learn to be independent.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My family has the support we need to relieve stress.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My family members have friends or others who provide support.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My family members help the children with schoolwork and activities.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My family members have transportation to get to the places they need to be.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My family members talk openly with each other.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My family members teach the children how to get along with others.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My family members have some time to pursue our own interests.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My family solves problems together.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My family members support each other to accomplish goals.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
## Family Quality of Life

<table>
<thead>
<tr>
<th>How satisfied am I that:</th>
<th>1 Very Dissatisfied</th>
<th>2 Dissatisfied</th>
<th>3 Neither</th>
<th>4 Satisfied</th>
<th>5 Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>My family members show that they love and care for each other.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>My family has outside help available to us to take care of special needs of all family members.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Adults in my family teach the children to make good decisions.</td>
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<td></td>
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<tr>
<td>My family gets medical care when needed.</td>
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<tr>
<td>My family has a way to take care of our expenses.</td>
<td></td>
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<tr>
<td>Adults in my family know other people in the children's lives (friends, teachers, etc.).</td>
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<td></td>
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<tr>
<td>My family is able to handle life's ups and downs.</td>
<td></td>
<td></td>
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<tr>
<td>Adults in my family have time to take care of the individual needs of every child.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>My family gets dental care when needed.</td>
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<td></td>
</tr>
<tr>
<td>My family feels safe at home, work, school, and in our neighborhood.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How satisfied am I that:</td>
<td>1 Very Dissatisfied</td>
<td>2 Dissatisfied</td>
<td>3 Neither</td>
<td>4 Satisfied</td>
<td>5 Very Satisfied</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>My family member with a disability has support to accomplish goals at school or at workplace.</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
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<td>[ ]</td>
</tr>
<tr>
<td>My family member with a disability has support to accomplish goals at home.</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
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<td>[ ]</td>
</tr>
<tr>
<td>My family member with a disability has support to make friends.</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
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</tr>
<tr>
<td>My family has a good relationship with the service providers who provide services and support to my family member with a disability.</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
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</tbody>
</table>
SECTION 3:

Family-Professional Partnership

Directions:

This survey is about how you feel about the main person who works with you and your child. There may be many teachers who work with your child with autism. Think about the teacher who has worked THE MOST with your child with autism over the last six months.

Please rate each item by marking the appropriate box to indicate your level of satisfaction with each item below. The options range between “Very dissatisfied” (1) to “Very satisfied” (5).

Clicking the first box means you are very dissatisfied.

Clicking the second box means you are dissatisfied.

Clicking the third box means you are neither satisfied nor dissatisfied.

Clicking the fourth box means you are satisfied.

Clicking the fifth box means you are very satisfied.
<table>
<thead>
<tr>
<th>Family-Professional Partnership</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How satisfied are you that your child's teacher:</strong></td>
</tr>
<tr>
<td><strong>1</strong> Very Dissatisfied</td>
</tr>
<tr>
<td>Helps you gain skills or information to get your child's needs.</td>
</tr>
<tr>
<td>Has the skills to help your child succeed.</td>
</tr>
<tr>
<td>Provides services that meet the individual needs of your child.</td>
</tr>
<tr>
<td>Speaks up for your child's best interests when working with other staff.</td>
</tr>
<tr>
<td>Lets you know about the good things your child does.</td>
</tr>
<tr>
<td>Is available when you need him/her.</td>
</tr>
<tr>
<td>Treats your child with dignity.</td>
</tr>
<tr>
<td>Builds on your child's strengths.</td>
</tr>
<tr>
<td>Values your opinion about your child's needs.</td>
</tr>
<tr>
<td>Is honest, even when there is bad news to give.</td>
</tr>
<tr>
<td>Keeps your child safe when your child is in his/her care.</td>
</tr>
<tr>
<td>How satisfied are you that your child's teacher:</td>
</tr>
<tr>
<td>------------------------------------------------</td>
</tr>
<tr>
<td>Uses words that you understand.</td>
</tr>
<tr>
<td>Protects your family's privacy.</td>
</tr>
<tr>
<td>Shows respect for your family's values and beliefs.</td>
</tr>
<tr>
<td>Listens without judging your child or family.</td>
</tr>
<tr>
<td>Is a person you can depend on and trust.</td>
</tr>
<tr>
<td>Pays attention to what you have to say.</td>
</tr>
<tr>
<td>Is friendly.</td>
</tr>
</tbody>
</table>
SECTION 4:

**Parental Stress**

Directions:

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(ren) with autism. Please indicate the degree to which you agree or disagree with the following items by marking the appropriate number.

Clicking the first box means you strongly disagree.

Clicking the second box means you disagree.

Clicking the third box means you are undecided.

Clicking the fourth box means you agree.

Clicking the fifth box means you strongly agree.

<table>
<thead>
<tr>
<th>Parental Stress Statements</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am happy in my role as a parent.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>There is little or nothing I wouldn't do for my child(ren) if it was necessary.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
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</tr>
<tr>
<td>Caring for my child(ren) sometimes takes more time and energy than I have to give.</td>
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<td>□</td>
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</tr>
<tr>
<td>I sometimes worry whether I am doing enough for my child(ren).</td>
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<tr>
<td>I feel close to my child(ren).</td>
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<tr>
<td>I enjoy spending time with my child(ren).</td>
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<tr>
<td>My child(ren) is an important source of affection for me.</td>
<td></td>
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</tr>
<tr>
<td>Having child(ren) gives me a more certain and optimistic view for the future.</td>
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<tr>
<td>The major source of stress in my life is my child(ren).</td>
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<tr>
<td>Having child(ren) leaves little time and flexibility in my life.</td>
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<tr>
<td>Having child(ren) has been a financial burden.</td>
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<tr>
<td>It is difficult to balance different responsibilities because of my child(ren).</td>
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<tr>
<td>The behavior of my child(ren) is often embarrassing or stressful to me.</td>
<td></td>
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</tr>
<tr>
<td>If I had it to do over again, I might decide not to have child(ren).</td>
<td></td>
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</tr>
<tr>
<td>Statements</td>
<td>1</td>
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<tr>
<td>I feel overwhelmed by the responsibility of being a parent.</td>
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<tr>
<td>Having child(ren) has meant having too few choices and too little control over my life.</td>
<td></td>
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<tr>
<td>I am satisfied as a parent.</td>
<td></td>
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<tr>
<td>I find my child(ren) enjoyable.</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
SECTION 5:

Any Comments that You Want to Add:
APPENDIX C

PROTOCOL DESCRIPTION

(COVER SHEET)
Dear Prospective Participant:

You are being invited to participate in a research study. The purpose of this study is to find out your perceived level of parental stress, your satisfaction with your family quality of life, and your satisfaction with your partnerships with teachers of your child with autism.

Your input is very important to contribute to the knowledge base of how parents of children with autism feel about their parental stress, family quality of life, and their partnerships with teachers. Your participation in this study is voluntary. If you decide not to participate, there will no effects on any services you currently receive.

This study involves the completion of an online questionnaire, which will take about 25-35 minutes. If you are willing to participate, please go to the following URL address: http://unlv.qualtrics.com/SE/?SID=SV_0AMXRFZyYhULX8M. Once you click the link, you will be directed to the homepage of the questionnaire.

If you have any questions or concerns, you may contact Dr. Kyle Higgins (at 702-895-1102) or Yun-Ju Hsiao (at 702-895-2464).

Thank you very much for your time!
APPENDIX D

INFORMED CONSENT
EXEMPT RESEARCH STUDY
INFORMATION SHEET
Department of Educational and Clinical Studies

TITLE OF STUDY: Parental Stress, Family-Professional Partnership, and Family Quality of Life in Families of Children with Autism Spectrum Disorder

INVESTIGATOR(S) AND CONTACT PHONE NUMBER:
Kyle Higgins, Ph.D. (702-895-1102) and Yun-Ju Hsiao, M.A. (702-895-2464)

The purpose of this study is find out your perceived level of parental stress, your satisfaction level on your family quality of life, and your satisfaction level on the relationship with teachers of your child with autism.

You are being asked to participate in the study because you meet the following criteria:
You are a parent of a child with autism spectrum disorder.

If you volunteer to participate in this study, you will be asked to do the following:
Complete an online questionnaire.

This study includes only minimal risks. The study will take about 25-35 minutes of your time. You will not be compensated for your time.

For questions regarding the rights of research subjects, any complaints or comments regarding the manner in which the study is being conducted you may contact the UNLV Office of Research Integrity – Human Subjects at 702-895-2794, toll free at 877-895-2794, or via email at IRB@unlv.edu.

Your participation in this study is voluntary. You may withdraw at any time. You are encouraged to ask questions about this study at the beginning or any time during the research study.

Participant Consent:

☐ Yes, I have read the above information and agree to participate in this study. I am at least 18 years of age. (By clicking here, you will be directed to the questionnaire).

☐ No, I do not want to participate at this time.
APPENDIX E

FLOW CHART OF THE PROCESS
Protocol Description (Cover Letter) (see Appendix C)

Informed Consent Form (see Appendix D)

Demographic Information (see Appendix B Questionnaire Section 1)

Questionnaire (see Appendix B Section 2, 3, and 4)
APPENDIX F

LETTERS OF ACCESSIBILITY TO THE FACILITIES

- CENTER A
- ORGANIZATION A
- ORGANIZATION B
- SERVICE PROVIDER A
Office of Research Integrity – Human Subjects
University of Nevada, Las Vegas
4505 S. Maryland Parkway, Box 451047
Las Vegas, NV 89154-1047

Subject: Letter of Acknowledgement of a Research Project at Center for Autism Spectrum Disorders, UNLV (CASD)

Dear ORI – Human Subjects:

This letter will acknowledge that I have reviewed a request by Dr. Kyle Higgins and Yun-Ju Hsiao to conduct a research project entitled, Parental Stress, Family-Professional Partnership, and Family Quality of Life in Families of Children with Autism Spectrum Disorder at CASD.

When the research project has received approval from the UNLV Institutional Review Board, and upon presentation of the approval letter to me by the approved researcher, as Center Director for CASD, I agree to allow access for the approved research project.

If we have any concerns or need additional information, the project researcher will be contacted or we will contact the UNLV Office of Research Integrity – Human Subjects at 895-2794.

Sincerely,

[Signature]

Authorized Facility Representative Signature 6/11/12 Date

[Print Representative Name and Title]
Office of Research Integrity – Human Subjects
University of Nevada, Las Vegas
4505 S. Maryland Parkway, Box 451047
Las Vegas, NV 89154-1047

Subject: Letter of Acknowledgement for a Research Project at ACON

Dear ORI – Human Subjects:

This letter will acknowledge that I have reviewed a request by Dr. Kyle Higgins and Yun-Ju Hsiao to conduct a research project entitled, Parental Stress, Family-Professional Partnership, and Family Quality of Life in Families of Children with Autism Spectrum Disorder.

When the research project has received approval from the UNLV Institutional Review Board, and upon presentation of the approval letter to me by the approved researcher, as Executive Director for ACON, I agree to allow access for the approved research project.

If we have any concerns or need additional information, the project researcher will be contacted or we will contact the UNLV Office of Research Integrity – Human Subjects at 895-2794.

Sincerely,

Authorized Facility Representative Signature

Date

Print Representative Name and Title

Michelle Scott-Leung, Executive Director

Autism Coalition of Nevada
Office of Research Integrity – Human Subjects
University of Nevada, Las Vegas
4505 S. Maryland Parkway, Bex 451047
Las Vegas, NV 89154-1047

Subject: Letter of Acknowledgement of a Research Project at FEAT of southern Nevada

Dear ORI – Human Subjects:

This letter will acknowledge that I have reviewed a request by Dr. Kyle Higgins and Yun-Ju Hsiao to conduct a research project entitled, Parental Stress, Family-Professional Partnership, and Family Quality of Life in Families of Children with Autism Spectrum Disorder at FEAT of southern Nevada.

When the research project has received approval from the UNLV Institutional Review Board, and upon presentation of the approval letter to me by the approved researcher, as Executive Director for FEAT of southern Nevada I agree to allow access for the approved research project.

If we have any concerns or need additional information, the project researcher will be contacted or we will contact the UNLV Office of Research Integrity – Human Subjects at 895-2794.

Sincerely,

Authorized Facility Representative Signature

Print Representative Name and Title

Date

6-10-12
Tandem Therapy Services, LLC
Chris Holcomb, M.Ed., CCC-SLP, BCBA
Board Certified Speech Language Pathologist
Board Certified Behavior Analyst
6887 W. Charleston Blvd.
Las Vegas, Nevada 89117
Office (702) 396-0101
Fax (702) 222-2012
Tandemtherapyservices.com

Office of Research Integrity – Human Subjects
University of Nevada, Las Vegas
4505 S. Maryland Parkway, Box 451047
Las Vegas, NV 89154-1047

Subject: Letter of Acknowledgement of a Research Project at Tandem Therapy Services, LLC

Dear ORI – Human Subjects:

This letter will acknowledge that I have reviewed a request by Dr. Kyle Higgins and Yun-Ju Hsiao to conduct a research project entitled, Parental Stress, Family-Professional Partnership, and Family Quality of Life in Families of Children with Autism Spectrum Disorder at Tandem Therapy Services, LLC.

When the research project has received approval from the UNLV Institutional Review Board. and upon presentation of the approval letter to me by the approved researcher, as site administrator Board Certified Behavior Analyst/Board Certified Speech Language Pathologist for Tandem Therapy Services, LLC I agree to allow access for the approved research project.

If we have any concerns or need additional information, the project researcher will be contacted or we will contact the UNLV Office of Research Integrity – Human Subjects at 895-2794.

Sincerely,

[Signature]
Authorised Facility Representative Signature

[Signature]
Date

[Signature]
Print Representative Name and Title
APPENDIX G

PERMISSION LETTERS FOR USE OF

- THE FAMILY QUALITY OF LIFE SCALE
- THE FAMILY-PROFESSIONAL PARTNERSHIP SCALE
- THE PARENTAL STRESS SCALE
May 16, 2012

Jean Ann Summers, Ph.D.
Beach Center on Disability
Life Span Institute
1200 Sunnyside, Room 3144
University of Kansas
Lawrence, KS 66045

Dear Dr. Summers:

I am completing a doctoral dissertation at University of Nevada, Las Vegas entitled “Parental Stress, Family-Professional Partnership, and Family Quality of Life in Families of Children with Autism Spectrum Disorder.” I would like your permission to reprint in my dissertation excerpts from the following:


The excerpts to be reproduced are: Family Quality of Life Survey.

The requested permission extends to any future revisions and editions of my dissertation, including non-exclusive world rights in all languages, and to the prospective publication of my dissertation by ProQuest Information and Learning (ProQuest) through its UMI® Dissertation Publishing business. ProQuest may produce and sell copies of my dissertation on demand and may make my dissertation available for free internet download at my request. These rights will in no way restrict republication of the material in any other form by you or by others authorized by you. Your signing of this letter will also confirm that the Beach Center on Disability owns the copyright to the above-described material.

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

Sincerely,

Yulin Ju Hsiao

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE:

The Beach Center on Disability
By: Jean Ann Summers
Jean Ann Summers, Ph.D.
Title: Associate Director
Date: May 31, 2012
May 16, 2012

Jean Ann Summers, Ph.D.
Beach Center on Disability
Life Span Institute
1200 Sunnyside, Room 3144
University of Kansas
Lawrence, KS 66045

Dear Dr. Summers:

I am completing a doctoral dissertation at University of Nevada, Las Vegas entitled "Parental Stress, Family-Professional Partnership, and Family Quality of Life in Families of Children with Autism Spectrum Disorder." I would like your permission to reprint in my dissertation excerpts from the following:


The excerpts to be reproduced are: Family-Professional Partnership Scale (Family Version).

The requested permission extends to any future revisions and editions of my dissertation, including non-exclusive world rights in all languages, and to the prospective publication of my dissertation by ProQuest Information and Learning (ProQuest) through its UMI® Dissertation Publishing business. ProQuest may produce and sell copies of my dissertation on demand and may make my dissertation available for free internet download at my request. These rights will in no way restrict republication of the material in any other form by you or by others authorized by you. Your signing of this letter will also confirm that the Beach Center on Disability owns the copyright to the above-described material.

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

Sincerely,

Yui-Ju Hsiao

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE:
The Beach Center on Disability
By: Jean Ann Summers, Ph.D.
Title: Associate Director
Date: May 21, 2012
May 16, 2012

Judy Orth Berry, Ed.D.
Department of Psychology
The University of Tulsa
800 S. Tucker Dr.
Tulsa, OK 74104

Dear Dr. Berry:

I am completing a doctoral dissertation at University of Nevada, Las Vegas entitled "Parental Stress, Family-Professional Partnership, and Family Quality of Life in Families of Children with Autism Spectrum Disorder." I would like your permission to reprint in my dissertation excerpts from the following:


The excerpts to be reproduced are: Parental Stress Scale.

The requested permission extends to any future revisions and editions of my dissertation, including non-exclusive world rights in all languages, and to the prospective publication of my dissertation by ProQuest Information and Learning (ProQuest) through its UMI® Dissertation Publishing business. ProQuest may produce and sell copies of my dissertation on demand and may make my dissertation available for free internet download at my request. These rights will in no way restrict republication of the material in any other form by you or by others authorized by you. Your signing of this letter will also confirm that you own the copyright to the above-described material.

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

Sincerely,

Yun-Ju Hsiao

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE:

Judy Orth Berry, Ed.D.

Date: 5/21/12
APPENDIX H

STRUCTURAL EQUATION MODELS
Figure H1. The measurement model of family quality of life
Figure H2. The full initial model of hypothesize model 1
Figure H3. The initial structural equation model of the effect of family-professional partnership and parental stress on family quality of life.
Figure H4. The structural equation model of the effect of family-professional partnership and parental stress on family quality of life
Figure H5. The measurement model of family-professional partnership
Figure H6. The full initial model of hypothesized model
Figure H7. The initial structural equation model of the effect of family-professional partnership and family quality of life on parental stress.
Figure H8. The structural equation model of the effect of family-professional partnership on parental stress through family quality of life
References


disability: Parental cognitions in relation to child characteristics and family support.

Journal of Intellectual Disability Research, 53, 969-980.

Hindman, A. H., & Morrison, F. J. (2011). Family involvement and educator outreach in
Head Start: Nature, extent and contributions to early literacy skills. The

Elementary School Journal, 111, 359-386.

from a national sample of eighth-grade students. Exceptionality, 5, 71-81.


Parenting stress and closeness: Mothers of typically developing children and
mothers of children with autism. Focus on Autism and Other Developmental


family outcomes: Psychometric evaluation of the Beach Center family quality of


Yale University, Department of Sociology. New Haven.

Holroyd, J. (1974). The questionnaire on resources and stress: An instrument to measure
family response to a handicapped member. Journal of Community Psychology, 2,
92-94.


Padak, N., & Rasinski, T. V. (2010). Welcoming schools: Small changes that can make a big difference. Reading Teacher, 64, 294-297.


Yun-Ju Hsiao  
Curriculum Vitae

University of Nevada, Las Vegas  
4505 S. Maryland Parkway  
Box 453014 Las Vegas, NV 89154  
yunjuhs@gmail.com

Current Position

2008-present  
PhD Doctoral Student (anticipated graduation date: May 2013)  
Department of Educational and Clinical Studies (Special Education)  
College of Education, University of Nevada, Las Vegas

2008-present  
Graduate and Research Assistant  
Department of Educational and Clinical Studies  
College of Education, University of Nevada, Las Vegas

2009-present  
Editorial Assistant  
Intervention in School and Clinic Journal (a ranked journal in Special Education, published by the Hammill Foundation and Sage Publications)

Education

2008 August-present  
PhD Doctoral Student, Special Education, University of Nevada, Las Vegas  
Disability Areas: Autism, Early Childhood Special Education, and Emotional Behavioral Disorders  
Leadership Areas: Statistics and Research Design  
Passed Doctoral Comprehensive Exams with Honors and Distinction  
Title of Dissertation: Parental Stress, Family-Professional Partnerships, and Family Quality of Life: Families of Children with Autism Spectrum Disorder  
GPA: 3.96/4.0
2008 August
Master of Arts in Special Education, Arizona State University, Tempe, Arizona
Title of Thesis: Preservice Teachers’ Beliefs about Their Preparedness in Culturally Responsive Teaching
GPA: 4.0/4.0

2005 June
Bachelor of Education, National Taichung Teachers College, Taichung, Taiwan
Major: Special Education
Minor: Language and Literacy Education
GPA: 3.92/4.0 (89.10/100)

Certification
Evaluator, *Wechsler Intelligence Scale for Children* (Chinese Edition), Department of Special Education, National Taichung Teachers College, Taiwan

General Education Teacher, Elementary School, Ministry of Education, Taiwan

Special Education Teacher, Elementary School, Ministry of Education, Taiwan

Honors and Awards

2013 April
Received TED Kaleidoscope Student Research Poster Award for Quantitative Research
Title Poster: *Perceptions of Parents of Children with Autism Spectrum Disorders towards Partnerships with Teachers*

2011 May
Passed Doctoral Comprehensive Exams with Honors and Distinction
Department of Educational and Clinical Studies
College of Education, University of Nevada, Las Vegas

2009-present
Member, Golden Key International Honor Society

2001
Elite of the Year
National Taichung Teachers College, Taiwan
Professional Experience

University Experience

2009-present  Editorial Assistant
*Intervention in School and Clinic Journal*

2008-present  Graduate and Research Assistant
Department of Educational and Clinical Studies
University of Nevada, Las Vegas

Grant Affiliations

2012-present  Formative Evaluator
*Project Grow: Making Data-Based Decisions in the Science Content Area*
NeCoTIP Projects
Nevada System of Higher Education

2011-present  Project Director
*Parental Stress, Family-Professional Partnerships, and Family Quality of Life: Families of Children with Autism Spectrum Disorder* (in progress)
Doug Sperber Foundation, $500.00
Center for Autism Spectrum Disorders
University of Nevada, Las Vegas

2011-present  Fieldwork Supervisor
*Project Connect Autism and Intellectual Disabilities*
U.S. Department of Education
Office of Special Education Programs
Personnel Development

2011-present  Research Assistant
Highly Qualified, High Quality (HQ2) Special Educators:
A 325T Project
U.S. Department of Education
Office of Special Education Programs
Public School Experience

2005-2006  Student Teacher
            Self-Contained Special Class
            Changhua Jhong Siao Elementary School
            Changhua, Taiwan

2004-2005  Internship
            5th Grade General Class
            Municipal Dongsing Elementary School,
            Taichung, Taiwan

2004-2005  Internship
            Resource Class Program
            Sheen-San Elementary School
            Taichung, Taiwan

Spring 2005 Internship
            1st-2nd Grade Self-Contained Special Class
            Taichung East District Le-Ye Elementary School
            Taichung, Taiwan

Fall 2004  Internship
            Self-Contained Gifted Class
            Tai-Ping Elementary School
            Taichung, Taiwan

Related Educational Experience

2012-present Volunteer Job Coach
            Teenworks Program
            Grant a Gift Autism Foundation
            Las Vegas, Nevada

2003  Volunteer Camp Counselor
            The 4th Adolescent Weekend Life Skills
            Development Camp
            Taichung Autism Education Association
            Taichung, Taiwan
2001-2002  Volunteer Tutor
Daniel A. Poling Memorial Babies Home
Taichung, Taiwan

Research and Scholarship

Publications

Refereed Articles


In Press


In Preparation


Presentations


Hsiao, Y. J. (2009, November). Preservice teacher’s beliefs about their preparedness in culturally responsive teaching. Paper presented at the meeting of the 32nd Annual Conference of Teacher Education Division of the Council for Exceptional Children, Charlotte, NC.


**Participation in Large Scale Data-Collection Projects**

2010-2012 Project Evaluator and Member of Research Team  
*The Miley Achievement Project: Alienation, Social Skills, Resilience, and Problem Solving*  
University of Nevada, Las Vegas/Clark County School District

Research team comprised of university faculty from New Mexico State University, University of North Carolina - Greensboro, California State University - Fullerton, and University of Nevada - Las Vegas. Project assessed four components (alienation, social skills, resilience, and problem solving) with students with emotional behavioral disorders and their teachers. N = 51 students and 18 teachers.

2012-present Formative Evaluator and Data Analysis  
*Project Grow: A NeCOTip Project*  
University of Nevada, Las Vegas/Clark County School District

Research team investigating the unwrapping of State of Nevada biology standards, teaching general and special educators to unwrap the standards to facilitate the inclusion of students with disabilities in general education 9th grade biology, collecting data on teacher implementation, and student outcomes over the course of a year. N = 18 teachers and approximately 500 students.
2012-present

Project Evaluator and Member of Research Team

The Fremont Project: Alienation, Social Skills, Resilience, and Problem Solving

University of Nevada, Las Vegas/Clark County School District

Research team comprised of university faculty from New Mexico State University, University of North Carolina - Greensboro, California State University - Fullerton, and University of Nevada - Las Vegas. Project is assessing four components (alienation, social skills, resilience, and problem solving) with Latino middle school students and their teachers. Projected N of 1500 students.

Teaching

University Courses Developed

Undergraduate

EDSP 411 Special Education Techniques in Inclusive Settings

Working with an instruction and design team to create an online version of the introduction to special education course for general education preservice teachers. Course covers history of special education, laws and processes, characteristics of learners, and strategies for supporting students with disabilities in classroom environments. Beta version implemented summer 2012. Final version implemented fall 2012.

University Courses Taught

Undergraduate

<table>
<thead>
<tr>
<th>Course Number and Title</th>
<th>Course Description</th>
<th>Semester(s) Taught/Co-Taught</th>
</tr>
</thead>
</table>
| EDSP 411: Special Education Techniques in Inclusive Settings | Course designed to provide general education preservice teachers an overview of special education, including legal aspects, characteristics of disabilities, accommodations for learning, and collaborative skills. | Fall 2011
<p>|                     |                    | Summer 2012 (online) |
|                     |                    | Fall 2012 (online) |</p>
<table>
<thead>
<tr>
<th>Course Number and Title</th>
<th>Course Description</th>
<th>Semester(s) Taught/Co-Taught</th>
</tr>
</thead>
</table>
| EDSP 432/ESP 483: Parental Involvement in Special and General Education | Course designed to addresses the legal requirements related to parent rights and responsibilities for their infants, toddlers, children, youth, adult children with disabilities in educational and community programs and settings. | Spring 2011 (co-taught)  
Spring 2012 (co-taught) |

**Graduate**

<table>
<thead>
<tr>
<th>Course Number and Title</th>
<th>Course Description</th>
<th>Semester(s) Taught/Co-Taught</th>
</tr>
</thead>
</table>
| ESP 701: Introduction to Special Education and Legal Issues | Course designed to introduce the characteristics, training, and educational needs of students with disabilities and gifts and talents. Prerequisite to all subsequent courses in special education. | Summer 2011 (co-taught)  
Spring 2013 (online) |
<p>| ESP 722: Multicultural Perspectives in Special Education | Course designed to introduce students to trends and issues in special education relative to students who come from culturally and linguistically diverse backgrounds. | Summer 2012 |
| ESP 730: Parental Involvement in Special and General Education | Course designed to addresses the legal requirements related to parent rights and responsibilities for their infants, toddlers, children, youth, adult children with disabilities in educational and community programs and settings. | Summer 2011 (online; two sections) |
| ESP 733: Management and Modification of Students with Special Needs | Course designed to provide an introduction to applied behavior analysis as it applies to teaching and managing students with special needs, as well as an introduction to the development of quality classroom management programs. | Spring 2012 (co-taught) |</p>
<table>
<thead>
<tr>
<th>Course Number and Title</th>
<th>Course Description</th>
<th>Semester(s) Taught/Co-Taught</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESP 772: Family Education in Early Childhood Special Education</td>
<td>Course designed to provide students an overview of average family structure and interaction patterns, roles, expectations and conflicts; mother-infant, family-infant bonding patterns; general and specific problems and needs of families of children with disabilities; programs developed for family involvement and education; national, state/local program models and evaluation. Course includes discussion of strategies for involvement of families in Part C and Part B (P.L. 108-446) services.</td>
<td>Spring 2011 (co-taught)</td>
</tr>
</tbody>
</table>

**Field Supervision**

<table>
<thead>
<tr>
<th>Course Number and Title</th>
<th>Course Description</th>
<th>Semester(s) Supervised</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESP 720: Field Experience in Special Education</td>
<td>This is the field experience at the graduate level and involves supervising students while they teach. Areas include: intellectual disabilities and autism.</td>
<td>Fall 2011, Spring 2012, Fall 2012, Spring 2013</td>
</tr>
</tbody>
</table>

**Statistical Analysis Expertise**

- z-test
- t-test
- Chi-square test
- Multiple regression and correlation methods
- Analysis-of-variance methods
- Multivariate statistics
- Factor analysis
- Structural equation modeling
Service

University

2011-2012
Membership Chair
UNLV Student Chapter of Council for Exceptional Children
Appointed position

2010-2011
Treasurer
UNLV Student Chapter of the Council for Exceptional Children
Elected position

2009-2010
Secretary
UNLV Student Chapter of the Council for Exceptional Children
Elected position

Professional

2012-present
Committee Member
Technology Committee
Council for Learning Disabilities

2009-present
Editorial Assistant
*Intervention in School and Clinic Journal* (a ranked journal in Special Education, published by the Hammill Foundation and Sage Publications)
Professional Organizations

Council for Exceptional Children
   Division for Culturally and Linguistically Diverse Exceptional Learners
   Division for Early Childhood
   Division for Research
   Division on Autism and Developmental Disabilities
   Teacher Education Division

Council for Learning Disabilities