

FAMILY EXPERIENCES AND IDENTIFIED  
MENTAL HEALTH ISSUES AS DEFINED BY PARENTS  
OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

A DISSERTATION

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BY

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## DEDICATION

To my mother,  
Your faith, prayers, and encouragement have been endless.  
I cannot thank you enough.

and

In memory of my father,  
You helped prepare me for this task and so many others.  
Your presence is felt every day.

## ACKNOWLEDGEMENTS

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## ABSTRACT

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### FAMILY EXPERIENCES AND IDENTIFIED MENTAL HEALTH ISSUES AS DEFINED BY PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

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This qualitative study conducted from a phenomenological perspective examined parents' perceptions of their families' experiences when the family included a child identified with an autism spectrum disorder (ASD). The study also explored parents' perceptions of services received by the child and family, including family therapy. Finally, the family's experiences with service providers were examined in an effort to determine what these experiences suggest to family therapists interested in meeting the mental health needs of families dealing with ASDs. Face-to-face interviews were conducted with parents of children between the ages of 6 and 21 who had been identified with an ASD. Each interview was audio-taped and transcribed. Transcriptions were then read and analyzed in an effort to explore the themes that developed from participants' descriptions of their own experiences and those of family members. Special attention was given to understanding the experiences of families dealing with an ASD and how the information shared by parents could inform the work of family therapists interested in meeting the mental health needs of the family. Parents who participated in this study wanted professionals to understand the vast differences found

on the autism spectrum and the uniqueness of every child identified with an ASD. Parents shared their beliefs that ASDs are family conditions. Parents also shared information about the services they have received and need.

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## CHAPTER 1

### INTRODUCTION

The number of individuals diagnosed with an autism spectrum disorder (ASD) has increased greatly in recent years. Robert Beck, president and CEO of the Autism Society of America (ASA), calls autism “the fastest-growing disability in our nation” (Federal Document Clearing House Congressional Testimony, 2004, Body section, ¶ 1). Ozonoff, Dawson, and McParland (2002) state, “Estimates of the prevalence of autism spectrum disorders have soared in the last two decades” (p. 37). According to McAfee (2002), the rate of diagnoses of Asperger’s Syndrome and high-functioning autism “is rising at such a rapid rate that it is outstripping the availability of quality programming for these individuals” (p. xix).

Lorna Wing (2001) provides three possible explanations for the increasing number of ASD diagnoses. First, changes in the definition of autism and autism spectrum disorders, including the addition of Asperger’s to the list of spectrum disorders, have made current definitions of these disorders broader than in the past. Second, there has been a growing interest in autistic disorders by parents and professionals, increasing the chance that an individual will be diagnosed with an ASD. Third, there may be a real increase. Wing adds that while there are three possible reasons for the recent increase, the increase may actually be due to a combination of those reasons.

Regardless of the reason for the increase in the number of ASD diagnoses, there is an increased need for effective services for families and individuals with an ASD. The complex needs of children with an ASD often require a variety of interventions, yet in many areas of the country, parents have difficulty locating professionals who are familiar with ASDs (Bashe & Kirby, 2001; Powley, 2004; Taylor, 2003). Services needed for an individual with an ASD may include behavioral interventions, social skills training, speech therapy, occupational therapy, and medical services (Dykens & Volkmar, 1997). Counseling and family therapy have also been suggested for some individuals diagnosed with an ASD and members of their family (Forrester & Aston, 2002; Lozzi-Toscano, 2004; Powers, 2003; Sperry, 1997; Wing, 2001).

#### Statement of the Problem

Many professionals have a limited understanding of ASDs, including counselors and family therapists. Counseling and family therapy literature contains little information about this population. This lack of attention to ASDs may help explain the frustration of parents when attempting to locate professionals that are knowledgeable about ASDs. The recent growth in the number of individuals diagnosed with an ASD suggests that an increasing number of families will experience the challenges that accompany these conditions – and more than ever, professionals such as family therapists, with an understanding of family systems and ASDs, will be needed to assist these families.

If mental health professionals are to effectively meet the needs of individuals with an ASD and their family members, more information is needed about the experiences of families when a family member has been diagnosed with an ASD. The parent's perspective of these experiences can be especially important because of the critical role the parent plays in seeking services that address the needs of the family. An understanding of how ASDs impact the family can guide therapists who work with the family to alleviate or reduce the distress that brought the family to therapy.

#### *Autism Spectrum Disorders Defined*

The term ASD or "autism spectrum disorder" refers to a group of neurodevelopmental disorders that are characterized by the following characteristics: (a) impairment in social interaction, (b) impairment in verbal and nonverbal communication, and (c) restricted and repetitive patterns of behavior (American Psychiatric Association, 1994). Autism spectrum disorders are listed in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* (1994) under Pervasive Developmental Disorders and include (a) Autistic Disorder, (b) Rett's Disorder, (c) Childhood Disintegrative Disorder, (d) Asperger's Disorder, and (e) Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). The most common ASDs are Autism Disorder, Asperger's Disorder, and PDD-NOS (National Institute of Mental Health [NIMH], n.d.). The terms autism spectrum disorders and pervasive developmental disorders are often used interchangeably to refer to the full spectrum of disorders (Wetherby & Prizant, 2000).

## *Characteristics*

Most individuals diagnosed with an ASD do not appear physically different (Attwood, 1998). The diagnosis is based on behavioral observations and information about behavior patterns that begin in early childhood (Wing, 2001). Characteristics of an ASD can vary greatly from one individual to another, but all individuals diagnosed with a disorder on the autism spectrum will have some of the characteristics described below.

### *Social Interactions*

One of the most distinguishable characteristics of ASDs is social difficulties. The DSM-IV (American Psychiatric Association, 1994) lists specific social behaviors to consider when diagnosing an ASD. These include an impairment in the use of multiple nonverbal behaviors; failure to develop peer relationships appropriate to the individual's developmental level; "a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people"; and a lack of social or emotional reciprocity (p. 70). Observable nonverbal traits include (a) little or no eye contact, (b) an unusual gaze, and (c) limited or unusual facial expressions.

While the individual with autism may seem uninterested in others, many individuals diagnosed with Asperger's Disorder want to fit in but do not know how (Autism Society of America, n.d.). The child may not be able to figure out the unwritten social rules or may want to control the play of his or her peers. An individual with an ASD may not use or understand nonverbal behavior (Wing as cited

in Sicile-Kira, 2004, p. 20). The individual may use gestures in an unusual way (Sicile-Kira). Persons with an ASD may eventually learn social rules but generally do so through direct instruction or by intellectual analysis of situations rather than by natural intuition (Attwood, 1998).

When explaining the social difficulties of individuals on the autism spectrum, Wing (2001) divides these individuals into four groups: (a) the aloof group, (b) the passive group, (c) the “active but odd” group, and (d) the group that displays impairments in communication. Individuals in the aloof group act as if others do not exist, show no interest in others, and are not sympathetic to the experiences of other people. The passive group is not completely cut off from others, but these individuals do not initiate social interaction (Wing). Behavior problems are not generally seen in children who fit into the passive group, except possibly in adolescence. Individuals in the “active but odd” group do actively approach others, but the people they approach are usually those in charge or, for children, someone older. Their conversations are often one-sided, and they pay little attention to the feelings and needs of those with whom they are talking. Persons in the last group have difficulty with communication. They may or may not have impairments in language, but it is the way they use language that sets them apart.

### *Routines*

Routines make life more predictable for individuals with ASDs while changes in routines or the environment may be especially stressful (Attwood, 1998; Sicile-

Kira, 2004). In some cases, changes in family routines may result in behavioral difficulties. When attempting to manage challenging behaviors, it can be important to understand a child's attempt to use routines to introduce order into their chaotic world (Wing, 2001).

### *Communication*

An important factor in ASDs is communication. Individuals diagnosed with Autistic Disorder may never develop speech, may lose the ability to speak after beginning to develop early signs of speech (Sicile-Kira, 2004), or may be delayed in their acquisition of speech. The diagnostic criteria for Asperger's Disorder states, "There are no clinically significant general delays in language" (American Psychiatric Association, 1994, p. 75). A diagnosis of PDD-NOS allows for flexibility in this area.

Regardless of the specific autism spectrum diagnosis, it is important to consider communication when working with a person on the autism spectrum and his or her family. Some children on the spectrum need to be spoken to in very specific ways (Norton & Drew, 1994), making it necessary for parents and professionals to alter their communication with the child. Pragmatics, how language is used in social context, is often difficult for a person with an ASD. This individual may not know how to begin or end conversations, may approach a stranger and start a conversation on a special area of interest, or may ask or state something that is embarrassing to the other party (Sicile-Kira, 2004). Families may isolate themselves for fear of being embarrassed by their child's behaviors (Sicile-Kira).

## *Cognition*

The type of social knowledge that seems to be most impaired in autistic children is the “recognition that other people have thoughts and feelings of their own” (Sigman et al., 1997, p. 259). This ability to “recognize other people’s feelings, thoughts, beliefs, and intentions and to respond to the person accordingly” (McAfee, 2002, p. xxxii) is referred to as “theory of mind.” According to Powers (2003), “children are remarkably consistent in the age they acquire the ability to make distinctions between their own thoughts and the thoughts of another person” (p. 26), an ability that develops at about age four in most children. Baron-Cohen considers the lack of theory of mind to be the core deficit of autism (Volkmar, Carter, Grossman, & Klin, 1997).

A number of difficulties have been attributed to the phenomenon known as “mind blindness.” Citing Baron-Cohen, Volkmar et al. (1997) write, “Just as blind children cannot see, children with autism are unable to recognize mental states” (p. 185). People diagnosed with Asperger’s may find it difficult to predict other people’s behavior (Cumine, Leach, & Stevenson, 1988), leading to a fear and avoidance of people as well as a lack of empathy, conscience, and motivation to please others. These individuals may find it hard to take into account what other people know or can be expected to know. The ability to anticipate what others might think of one’s actions and to understand deception may be missing or limited. Individuals with an ASD may have difficulty reading the intentions of others and understanding their motives. This

mindblindness can affect the relationships of individuals with an ASD including relationships within the family. It can also be a source of concern for parents who fear that their child's inability to discern the intentions of others may place the child at greater risk for abuse.

### *Sensory*

While those with an ASD can be overly or under sensitive to sensory input, the tendency for most individuals with an ASD is to overreact (Powers, 1989). Individuals with an ASD may be extremely sensitive to touch or to things that touch their bodies. Certain foods may be avoided due to the taste or texture of the food. An unusual perception of color may be noted, and, in some cases, there may be perceptual distortion. Some individuals with an ASD are extremely sensitive to smell. In many cases, individuals with an ASD have very high pain tolerances (Attwood, 1998).

Gutstein (2002) suggests that children with high-functioning autism or Asperger's syndrome live in a universe where the noises constantly invade their brain and threaten to overwhelm them. These children learn to avoid this chaos by shutting down and avoiding most elements of variability and novelty. They focus on those aspects of the environment that remain the same and are obsessed by their search for stable patterns and unchanging relationships.

### *Motor Clumsiness*

The individual diagnosed with an ASD may exhibit repetitive motor movements, low muscle tone, and uneven fine and gross motor skills (Sicile-Kira,

2004). These individuals may appear clumsy or awkward (ASA: Aspergers, n.d.). For some individuals with an ASD, legible handwriting is a challenge, often requiring the use of compensatory strategies such as the use of a word processor. Such difficulties can make homework a challenge for children with an ASD and their parents.

### *The Need for Information*

Characteristics associated with ASDs impact the lives of individuals on the autism spectrum and their families. The needs of children identified with an ASD may “overwhelm the functioning of the family as a system, creating a dysfunctional marriage, distressed siblings, and/or individual symptoms of discomfort” (Harris, Gill, & Alessandri, 1991, p. 277). Autism can affect almost every area of family life and “needs to be treated as a family problem, not just a problem of the individual with autistic behaviors” (Norton & Drew, p. 73). Professionals need to be aware of the challenges faced by individuals on the autism spectrum and their families. Recommendations for counseling and family therapy must be accompanied by information about the experiences of families dealing with ASDs, families’ experiences in seeking services, and an understanding of the factors to be considered when working with these families.

### *Purpose of the Study*

The purpose of this study was to examine how parents/guardians perceived family life when a son or daughter had been identified as having an autism spectrum disorder and the experiences of parents/guardians in accessing services including

family therapy. The study also explored what the experiences of participants suggest to family therapists interested in meeting the mental health needs of families dealing with an ASD.

The objectives of this study were accomplished by interviewing 21 parents of children from 6 to 21 years of age. Interviews were recorded and transcribed. Transcripts were analyzed in order to identify the themes and patterns that emerged from participants' responses to interview questions and to determine how these themes and patterns related to the interview questions that guided this study. Participants provided demographic information (Appendix D) that was examined for patterns that might provide information useful to those working with individuals having an ASD and their family members.

### Research Questions

To fulfill the purposes of this study, the following research questions were examined (see Table 1):

1. How do parents/guardians experience family life when a son or daughter has been identified as having an autism spectrum disorder?
2. What experiences have parents/guardians had in accessing services that may include family therapy?
3. When parents/guardians have a child with an ASD, what do families' experiences with service providers suggest to family therapists interested in meeting the mental health needs of the family?

Table 1  
Research and Interview Questions

Research Questions	Interview Questions
1. How do parents/guardians experience family life when a son or daughter has been identified as being on the autism spectrum?	1. Tell me about your experience of family life with a (son/daughter) identified with an ASD.
2. What experiences have parents/guardians had in accessing services that may include family therapy?	2. What types of services has your child (identified with an ASD) received? 3. What types of services or assistance have you received as a family (related to your child's ASD)? 4. What have been your experiences in working with mental health professionals (related to an autism spectrum disorder)?
3. When parents/guardians have a child with an ASD, what do the family's experiences with service providers suggest to family therapists interested in meeting the mental health needs of the family?	5. Are there services that you or a member of your family (including a family member diagnosed with an ASD) have not received but that you believe would be (or would have been) beneficial? 6. What would you like mental health professionals to know about working with individuals with autism spectrum disorders and their families? 7. Based on your experiences and observations, what types of mental health services do you believe may be helpful in meeting the needs of individuals and families dealing with issues related to an ASD? 8. What is your knowledge of/or experience with family therapy? 9. What suggestions do you have for improving mental health services for individuals who have been diagnosed with an ASD and members of their family?

## Research Theoretical Framework

This qualitative study was conducted from a phenomenological perspective. Studies conducted from this perspective examine human experiences “through the detailed descriptions of the people being studied” (Creswell, 1994, p.12). Certain concepts or phenomena are explored, and the meaning of the lived experiences for several individuals is described. When conducting a phenomenological study, the researcher must set aside all prejudgments, bracketing his or her own experiences in order to understand the experience of the participant (Creswell).

### Definition of Terms

1. Pervasive Developmental Disorders: In this study, use of the term “pervasive developmental disorders” referred to the group of disorders included in the DSM-IV under the category of Pervasive Developmental Disorders. These disorders are “characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities” (American Psychiatric Association, 1994, p. 65).
2. Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS). In this study the terms “Pervasive Developmental Disorders Not Otherwise Specified” and “PDD-NOS” referred to the specific disorder listed under the category Pervasive Developmental Disorders.

3. High-functioning autism: A condition whereby an individual “fits the diagnosis criteria for autism but has near normal cognitive and learning abilities. Even though the person may have had difficulty acquiring language, he or she does develop language skills that are close to those expected at his or her age” (Ozonoff et al., 2002, p. 9).

### Assumptions

The following assumptions were made in conducting this study:

1. Participants were truthful during the interview process.
2. Participants were able to adequately articulate their own experiences and the experiences of other family members as they perceived them.

### Delimitations

This study was subjected to the following delimitations:

1. This study was limited to parents of children ages 6 to 21 years identified with an ASD willing to participate in audio taped interviews that were transcribed.
2. This study took place in specific areas of North and West Texas.
3. The information obtained in this study was limited to that which could be obtained during the time allotted for the interviews.

### Summary

An increase in the number of individuals diagnosed with an ASD has resulted in an increased need for services for these individuals and members of their families. Counseling and family therapy have been suggested for some individuals and families

that have a child with an ASD, yet little information is available about such services. If effective services are to be provided to this population, more information is needed about the experiences of parents/guardians that include an individual with an ASD; the experiences of parents/guardians in accessing services, including counseling and family therapy; and how an understanding of these experiences can inform family therapists who work with individuals and families dealing with ASDs.

This qualitative study explored perceptions of parents by interviewing 21 parents of children diagnosed with an ASD. Each interview was audio taped and transcribed. Transcriptions were studied and analyzed in an effort to explore recurrent themes found in the responses of participants to the interview questions. Demographic information (Appendix D) was also obtained from parents/guardians. Themes and patterns were documented. The researcher explored ways in which these themes and patterns related to the interview questions that guided this study.

## CHAPTER II

### REVIEW OF THE LITERATURE

Counseling and family therapy have been recommended for some individuals and families dealing with autism spectrum disorders (ASD), yet there is little published information about counseling and family therapy with this population. Literature can be found in a number of related areas including (a) general recommendations for individual and family-centered services when an individual has been diagnosed with an ASD, (b) information about the needs of the family when a family member has a disability, (c) information about the needs of the family when a family member has an ASD, (d) information about services offered to those diagnosed with an ASD and their family members, and (e) research related to ASDs and the family. A review of the literature related to these topics is presented in this chapter.

#### Recommended Individual and Family-Centered Services

Dunlap and Fox (1999) suggested that comprehensive family support is a needed element of early intervention for families of children with autism and is most effective when it is family-centered and collaborative. These authors recommended that family-centered services (a) enhance family competence and confidence, (b) address support from a life-style perspective, (c) arrange for stability and continuity in support relationships, and (d) provide for stability and consistency across time and circumstances. Dunlap and Fox also stressed the need for families to be familiar with

available services, know how these services can be accessed, and act as effective advocates for the child and family. According to these authors, “Children with autism do well when their families acquire skills and knowledge along with the confidence that they can use these competencies to solve problems and create desirable and productive environments for their child’s development” (p. 51). Dunlap and Fox stated, “Family support providers can provide valuable assistance if they are able to help families gain confidence in carrying out effective interactions with their children, as well as in their attempt to acquire information and use the information to their families’ advantage” (p. 51).

Harris (1984) suggested three broad categories of families that can benefit from an integration of instruction and family treatment when the family includes a child on the autism spectrum. The first group includes families that might never have been considered for family therapy if they had not been faced with the additional stress of raising an autistic child. Although these individuals are generally well-functioning and healthy, they can benefit from relatively short-term interventions intended to help them understand how the child with autism may impact the family and how family issues may affect their ability to help this child. The second group includes families that experience some type of difficulty that arises independently of the needs associated with the child who has autism. The needs of these families extend beyond the needs of the child, and, in many cases, these families would have been in need of help even if they did not have a child with special needs. The third group of

families has specific needs within the family that create stress for family members but would have never come to the attention of a therapist had the family not had the added stresses of a handicapped child.

Wing (2001) pointed out that higher-functioning adolescents and adults with an ASD may be aware that they are different from others in their age groups and may benefit from counseling provided by professionals who understand the nature of their disability. Therapy was also recommended for individuals identified with ASDs when they experience the loss of loved ones (Wing). Parents may benefit from the support of an experienced counselor when an ASD is first diagnosed. Some families need assistance when an individual diagnosed with an ASD starts school, reaches adolescence, or goes through other transitions (Sicile-Kira, 2004; Wing).

Counseling and family therapy were not suggested in place of treatment plans that focus on teaching skills and addressing behavioral difficulties (Harris, 1984; Wing, 2001). Instead, recommendations for counseling and family therapy focused on the need for professionals to recognize the many facets of the problems families encounter when faced with an ASD. Harris stressed the need for appropriate referrals when the demands of clients extend beyond a professional's expertise.

#### Families with a Disabled Child

Although this study focused on families with children on the autism spectrum, the literature about children with disabilities and their families provided information applicable to families dealing with ASDs. Theories of development and the family

have been adapted to provide a better understanding of how families function when they have a child with a disability. This section reviews literature related to children with disabilities and their families that may be applicable to ASDs.

### *The Impact on the Family*

Seligman (1991) stated, “A focus on children with disabilities ignores other family members who may be affected by the presence of the child” (p. 27). He added that focusing on the child ignores the dynamic nature of family functioning. According to Seligman, “A disability of one family member affects the entire system and in turn affects the disabled person” (p. 27).

Darling (1991) took a symbolic interactionist view of families with a disabled child. This author noted that most parents have limited experience with individuals with disabilities prior to the birth of a disabled child and are poorly prepared for the birth of a child with a disability. Darling (1991) discussed how interactions with family and friends before the birth of a child can affect parents. Concerns voiced by potential parents about the health of their child are often discounted by family and friends who assure them that everything will be fine (Darling). According to Darling (1991), one of the most difficult tasks facing new parents of children with disabilities is telling other family members and friends about their child’s problems for the first time.

## *Modified Theories as Applied to Families with a Disabled Family Member*

### *Parental Stages for Accepting a Child's Disability*

The stages a parent goes through when learning of and dealing with a child's disability have been compared to the stages used to understand the acceptance of dying and death. According to Solnit and Stark (1961), parents must mourn the loss of the normal child they wished for before they can accept their child who has a disability (as cited in Darling, 1991). Drotar, Baskiewicz, Irvin, Kennell, and Klaus (1975) found that parents of children with congenital malformations experienced a common sequence of reactions (as cited in Darling). These reactions were shock; denial; sadness, anger, and/or anxiety; adaptation; and reorganization. The most common reaction was sadness, a reaction that either accompanied or followed denial.

### *Family Life Cycle*

The family life cycle presented by Duvall (1957) provided a series of developmental stages that families experience over time (as cited in Seligman, 1991). During these stages, the family's lifestyle is relatively stable as each member of the family engages in developmental tasks related to a specific stage. When disruptions occur in traditional family patterns, new subphases and additional tasks are added to the family life cycle (Elman, 1991).

Olson et al. (1984) identified five developmental stages experienced by families with a disabled child and the stress factors associated with each stage (as cited in Seligman). The first of these stages, the childbearing stage, is a time for obtaining

an accurate diagnosis, making emotional adjustments, and informing other family members of the child's condition. The second stage begins when the child reaches school age. Parents must clarify their personal views related to mainstreaming versus segregated placements. They may also have to deal with the reactions of the child's peers. The third stage, adolescence, requires parents adjust to the chronic nature of the child's disability and the need to plan for the child's future. Parents may also have to deal with issues of sexuality, peer isolation, and rejection. The fourth stage is the launching period. Olson et al. suggested that during this stage, the family must recognize and adjust to their continuing responsibilities, consider residential placement, and think about socialization for the disabled family member. The last stage, the postparental period, was described as a time for spouses to re-establish their relationships and interact with the disabled family member's residential service providers.

It is important to note the date of publication when reviewing the developmental stages presented by Olson et al. (1984). The articulation of these stages provides useful information relevant for today's families; however, societal changes and changes in the educational system since the 1980s must be considered when referring to the references made by Olson et al. to residential placements and residential service providers. The launching period, as described by Olson et al. is often different for many of today's families, with a wider range of services and less emphasis on residential placements.

### *The Social Ecology Model*

Seligman (1991) emphasized the need to understand the family with a disabled child within the context of the larger social, economic, and political realities. Ecological studies considered the family members in the context of relationships and the family environment while recognizing that families can only be understood within the context of the community and society (Connard & Novick, 1996). Ecological models stressed the interaction between people and their changing environment (Merrick, 1995).

Ecological models based on principles of human development were proposed by Bronfenbrenner who divide environmental systems into four levels: (a) microsystem, (b) mesosystem, (c) exosystem, and (d) macrosystem (Bubolz & Sontag, 1993). Bronfenbrenner (1979, p. 3) described an individual's environment as ". . . a set of nested structures each inside the next, like a set of Russian dolls" (as cited in Bubolz & Sontag, p. 423). According to Bronfenbrenner, the family functions as the primary microsystem (Bubolz & Sontag). The mesosystem consists of interrelations involving two or more major settings that contain the developing person (Merrick, 1995) such as day care and school (Bubolz & Sontag). The exosystem, an extension of the mesosystem, includes both formal and informal social structures that do not contain the developing person. Examples of the exosystem are the world of work, the neighborhood, mass media, and the distribution of goods and services

(Merrick). The macrosystem involves the broad patterns of cultural “blueprints” for the culture’s ecology of human development (Bubolz & Sontag, p. 423).

Mitchell (1983) applied Bronfenbrenner’s concepts to families with disabled children (as cited in Seligman, 1991). The microsystem was described by Mitchell as the roles, interpersonal relationships, and patterns of activities experienced by the family. Problems faced by families with a disabled child impact these relationships. The relationship between a mother and father may be affected by how well the parents coped before the birth of the child and the degree to which the couple is able to accept the child’s disability. Mitchell suggested that mothers and fathers need to be aware of how much attention the nondisabled child receives and the impact on other relationships. Mitchell also discussed the importance of “whether the father withdraws or is psychologically and instrumentally present for the disabled child and the family” (p. 38). Interactions between the disabled child and nondisabled child may be similar to any other sibling relationships but can be affected by the degree to which nondisabled children are asked to help with the disabled child as well as their fears and concerns related to the disability (as cited in Seligman).

The microsystem functions within the mesosystem. According to Mitchell (1983), the mesosystem contains a variety of individuals and services including medical and health-care workers, extended family, friends and neighbors, work and recreation associates, early intervention programs, other parents, and the local community. The family may not be directly involved with many elements of the

exosystem, but these elements affect the family. Families may be dependent on the health-care system as well as the social-welfare system. Educational services may benefit the child and provide respite and help for the family. Mass media can impact attitudes about disabled persons (as cited in Seligman).

According to Mitchell (1983), the macrosystem, the ideology or belief systems inherent in our social institutions, impacts the family of a disabled child. Ethnic, cultural, and religious values influence family members' views of a disability and these family members interact with the service-delivery system. The health of the economy and political atmosphere can also impact programs for people with disabilities, while the family's socioeconomic status may determine the availability of the family's resources (as cited in Seligman, 1991).

### *Family Stress and Coping*

In a discussion of families that include a family member with a disability, Elman (1991) presented a variety of perspectives related to family stress and coping (McCubbin et al. 1980; Olsen, Sprenkle, & Russell, 1979; Pratt, 1976; Russ & Oliveri, 1980), including McCubbin et al.'s (1980) research on coping styles, strategies, and families. According to Elman, the research of McCubbin et al. is of particular use to the family therapist. Five coping strategies are used by the family to manage interactions within the family and transactions between the family and the community. The first two strategies, reframing and passive appraisals, are internal. Reframing is defined as "the family's ability to redefine stressful experiences in a way that makes

them more acceptable and manageable” (p. 380). The second strategy, passive appraisals, is described as “defining the problem as one that the family cannot or need not control or something that will take care of itself” (p. 380). The last three strategies are external strategies: (a) acquiring social support, (b) seeking spiritual support, and (c) mobilizing the family to acquire and accept help from others.

### *Family Systems Theory*

Seligman (1991) and Elman (1991) presented a systems perspective of families with a disabled family member that were based on Structural Family Therapy. Minuchin and his colleagues created the concepts of structural family therapy while working with disorganized families from inner-city slums. Concrete and powerful restructuring techniques were developed and used to bring about changes in these families (Nichols & Schwartz, 1995). According to Nichols and Schwartz, the most important principle of this approach were that every family has a structure that is revealed only when the family is in action. The focus of this model is on changing the organization of the family (Minuchin, 1974). Structural family therapy emphasized the balance between stability and change, and between openness and closedness (Becvar & Becvar, 1996).

Important concepts of structural family therapy are structure, subsystems, boundaries, alignments, and complementarity (Nichols & Schwartz, 1995). According to Minuchin (1974), structure refers to the invisible set of functional demands or patterns that organize the way the family interacts (as cited in Becvar & Becvar,

1996). Structural family therapy considers the family as a whole while recognizing family subsystems (Becvar & Becvar). These subsystems have been described as “units of the family based on function” (Nichols & Schwartz, p. 240). Family subsystems include the spouse subsystem, parental subsystem, sibling subsystem, individual subsystem, and extra-familial subsystem (Becvar & Becvar; Minuchin & Fishman, 1981 as cited in Elman, 1991; Seligman, 1991).

Boundaries are “the invisible barriers that surround individuals and subsystems” (Nichols & Schwartz, 1995, p. 214). Emotional boundaries regulate the amount of contact the individual, subsystem, and family have with others. These boundaries serve to protect the autonomy of the family and its subsystems. Interpersonal boundaries range from rigid to diffuse. Rigid boundaries are overly restrictive, permit little contact with outside systems, and result in disengagement. Diffuse boundaries result in enmeshment. Enmeshed subsystems offer an increased sense of support but interfere with independence and autonomy (Nichols & Schwartz). Weak boundaries between subsystems can result in over-involved and overprotective relationships (Seligman, 1991).

Applying Minuchin’s concepts to families with disabled children, Seligman (1991) suggested that for overprotective families, letting go of their child may increase anxiety and prevent the child from participating in activities that would promote independence. Disengaged families with rigid subsystem boundaries have interactions that may be characterized by minimal involvement. In such families, a father may be

disengaged, deny the disability, and withdraw from marital and parental interactions. Well-functioning families, those characterized by a balance between enmeshment and disengagement, represent the middle of the continuum (Seligman).

Elman (1991) wrote, “What is predictable in many families with a disabled child, particularly where the family is having persistent difficulty in adapting, is that the family is too enmeshed or over-involved in response to the child, the disability, and the required care and treatment” (p. 384). Elman stated that it is normal for parents of young disabled or ill children to be over-involved in their care, but added that developmentally, it is appropriate for that over-involvement to decrease. According to Elman, families most likely to be dysfunctional are those that repeat the same pattern over and over, regardless of whether their response is appropriate in a given situation.

Seligman (1991) stressed the importance of adaptability for families with a disabled family member, stating that rigid families may have difficulty adjusting to the demands of caring for an impaired child. Seligman offered an example of how rigidity can impact the family. He described a father whose rigid breadwinner role prevented him from helping with domestic chores or assisting with a child and stated that such a rigid role placed a disproportionate burden on the mother and can leave the family in jeopardy of becoming dysfunctional. According to Elman (1991), “Families with the most flexibility are most likely to accomplish the changing tasks and needs of the family over time” (p. 383).

While some families that include a child with a disability function in a dysfunctional manner, many of these families are “normal” families struggling with the specific needs and challenges of a disabled child (Elman, 1991). Elman presented an alternate view to pathology in such situations by stating, “The family is attempting to cope with a critical situation that interferes with normal development” (p. 373). Elman suggested that for families that are relatively healthy but dealing with challenges that accompany a disability, therapy should be educational and supportive while helping the family proceed with developmental tasks and “deal with the often unpredictable course of the child’s disabilities” (p. 373).

#### Autism Spectrum Disorders and Family Stressors

All families experience stress, yet some stressors are more common in families with a child on the autism spectrum. Norton and Drew (1994) suggested that professionals need to be aware of family stressors when working with families who have a child on the autism spectrum. A review of the literature provided information about some of the stressors encountered by these families.

##### *Diagnostic Confusion*

Marcus, Kuncze, and Schopler (1997) suggested that one of the first stressors for families dealing with an ASD is the diagnostic confusion experienced when parents are not given accurate, clear, and informative information about their child’s problem. In most cases, the formal diagnosis of an ASD is not obtained until after a child’s second birthday (Dunlap & Fox, 1999), though a diagnosis can take much

longer. Misdiagnosis is a common problem, with symptoms of ASDs often being attributed to other known health conditions, medication, psychiatric, or family problems (Waltz, 2002).

### *Overwhelming Information*

While obtaining a diagnosis can be stressful, information about the disability and its treatment can also be overwhelming for some families (Dunlap & Fox, 1999). Parents must deal with the confusion that comes when different terms are used to describe and define pervasive developmental disorders (Marcus et al., 1997). Disagreements between professionals only complicate the situation, with professionals from various disciplines suggesting treatments that reflect their own perspectives. Parents may find it difficult to set priorities when trying to decide which areas of function should be addressed first (Waltz, 2002).

### *Uneven and Unusual Course of Development*

A stressor often associated with ASDs is the uneven and unusual course of development (Marcus, 1997; Shuntermann, 2002). Development that appears normal may be followed by plateaus and regression. Deficits exist in some areas while skills in other areas are age appropriate or advanced for the child's age. Developmental inconsistencies can be confusing as parents attempt to determine whether the child is unable to do something or is refusing to do it. Marcus et al. suggested that appropriate interventions can help parents recognize which behaviors result from a lack of understanding or ability and which are oppositional.

### *Normal Appearance Accompanied by Unusual Behaviors*

The “normal appearance” of individuals with an ASD has been described as a stressor for parents. According to Marcus et al., (1997), this normal appearance “creates expectations of average social and communicative behavior that are rarely met” (p. 635). When in public, parents may worry about what others think when their child who looks normal displays behaviors that are unusual or considered socially unacceptable (Marcus et al.).

Parents with a child on the autism spectrum also deal with numerous other stressors. Children with ASDs may have difficulty processing facial gestures, eye contact, and body language. The child may push away or cry when a parent tries to hold him or her. Some parents find it difficult to nurture a child when their attempts to show love and give attention are rejected. The erratic sleep patterns of the child with autism may prevent parents from sleeping for more than a few hours each night. The slightest change in routine can cause serious difficulties for some families. The challenges faced by families with a child on the autism spectrum can play a role in family decisions such as relocation and job changes. Additionally, respite care and special financial considerations may be needed (Norton & Drew, 1994).

### *Interventions Used with Individuals and Families*

#### *Impacted by Autism Spectrum Disorders*

Numerous interventions were used to address concerns related to ASDs. Some approaches focused on the individual with an ASD. These approaches concentrate on

skill development, behaviors, or sensory needs of the individual. Other approaches include family members as part of the intervention process, but also focus on the child's skill development or behavior issues. The following section reviews some of the more common interventions that focus on the individual as well as methods that include parents and families.

### *Individual Approaches*

Individual approaches are often used to address social and behavioral issues in children with ASDs. These skill-based treatments focus on the specific needs of individuals on the autism spectrum. Some of the more common services received by these individuals are social skills training, speech therapy, physical therapy, occupational therapy, medication, and special diets.

#### *Applied Behavioral Analysis (ABA)*

Applied Behavioral Analysis, better known as ABA, is a behavioral approach used with children on the autism spectrum to teach skills related to academics, self-help, speech and language, and social behaviors (Sicile-Kira, 2004). The Lovaas method, an intense ABA program developed by Dr. O. Ivar Lovaas, is known for its use with children on the autism spectrum. Verbal behavior therapy is an ABA approach that addresses language. These approaches are based on the work of B. F. Skinner, who is considered the grandfather of ABA (Sicile-Kira).

### *Social Skills*

Individual and group approaches are often used for teaching social skills. Social stories, an approach developed by Carol Gray, are narratives specifically written to provide directions for appropriate behaviors and responses. Comic strip conversations, also developed by Gray, show what people say and do but also use “thinking bubbles” to emphasize what they may be thinking in a specific situation (Sicile-Kira, 2004). Social skills groups allow children on the autism spectrum to participate in small groups for the purpose of learning the interpersonal skills appropriate in social situations. Adults teach and prompt appropriate interactions in these groups.

### *Communication*

Speech therapy is a common service for children on the autism spectrum. The objective for some children is to increase language. For others, the focus is on pragmatic language. Alternative communication programs may also be used including Picture Exchange Communication System (PECS) and Facilitated Communication (FC). PECS, a program co-developed by Andy Bondy and Lori Frost, allows the child who has difficulty using language to use pictures to communicate, motivating interactions with others. FC, an approach originally developed for those unable to control or use their muscles, requires that a facilitator hold the communicator’s hand or arm in a way that allows the individual to point to letters on a board. This method has been controversial due to the lack of research showing that the efforts to

communicate come from the disabled individual rather than from the facilitator (Sicile-Kira, 2004).

### *Occupational Therapy and Physical Therapy*

Children with an ASD can have the same needs as other children; therefore, the need for services from an occupational therapist or physical therapist may be the same as for other children. There are some needs, however, that are more likely to be seen in the child with an ASD than in the general population. These needs include sensory needs and motor coordination.

### *Approaches that Involve Parents*

#### *Parent Training*

Parent training focuses on teaching parents the skills needed to help their child master social and behavioral objectives. According to Briesmeister and Schaefer (1989), the goal of parent training is for parents to become agents of change and take on the role of co-therapists. Parents are taught new parenting techniques and child-management skills. Parent training is grounded in behavioral modification constructs and principles of learning theory (Briesmeister & Schaefer). The behavioral approach was recognized by Marcus et al. (1997), but these authors also recognized other approaches to parent training including the educational approach, relationship enhancement approach, and the cognitive approach.

Marcus (1997) found that the majority of parent training programs shared certain assumptions and procedures. These programs emphasized the collaborative

nature of the relationship between parents and professionals, tended to understand parent-child relationships from an interactional or transactional perspective, and viewed patterns of parent and child behavior as becoming established and maintained over time. Issues of blame were put aside, and the focus was on how parents can interact more effectively with their child.

Parents trained in the use of behavioral techniques have been successful in the treatment of a variety of problems including self-injury, self-stimulation, and aggression. Self-help behaviors such as eating and dressing have been taught using behavioral approaches (Harris, 1984). According to Harris, parent training and the use of behavioral approaches do not “cure” autism but allow parents and their autistic child to cope more effectively with the effects of the condition.

#### *Relationship Development Intervention*

Relationship Development Intervention (RDI) is a parent based clinical treatment program operated by Steven Gutstein and his wife, Rachelle Sheely. Gutstein and Sheely are co-directors of The Connections Center for Family and Personal Development in Houston, Texas. Using a cognitive and developmental systems approach, these psychologists have worked to address the social and emotional deficits found in those with an ASD and other relationship-based disorders. The primary focus of RDI has been to remediate experience-sharing deficits (Gutstein, 2000; RDI, n.d.)

According to Gutstein (2000), there are two major reasons for social interactions: experience sharing and instrumental interactions. Experience sharing occurs when people interact for no purpose other than for sharing their mutual world. Instrumental interactions involve deliberate actions taken to achieve specific objectives. Novelty and variation are valued in experience sharing but not in instrumental interactions (Gutstein). Gutstein believed that a deficit in experience sharing is one of the hallmarks of all types of autism.

Before beginning a RDI program, a comprehensive diagnostic evaluation is required for the individual suspected of being on the autism spectrum. Parents must attend an introductory seminar or view a three-hour videotape, attend an intensive four-day parent seminar, and participate in the Relationship Development Assessment (RDA). The RDA has been designed to evaluate the child's experience-sharing competencies and limitations. From this assessment, potential child and parent obstacles are identified and appropriate treatment objectives are developed (RDI).

Once parents are familiar with the program and the assessment process has been completed, parents begin to work with a Certified RDI Program Consultant or someone who is supervised by staff or designees of the Connections Center. The consultant works with the family on a regular basis, setting clear intervention objectives based on the RDA evaluation. The consultant evaluates and implements modifications based on the child's individual needs; tracks and evaluates intervention

objectives; and regularly reviews and provides feedback on videotapes of parent-child interaction sessions conducted by parents in the home (RDI, n.d.).

Parents function as the primary facilitators for their child's program at least 50% of the time, applying RDI principles throughout the day (RDI, n.d.). Parents "learn to set clear limits, minimize distractions, and develop an 'emotionally attuned' relationship before leading the child through the elements of social choreography" (Gutstein, 2000, p. xxi). As long as the child is on level one, parents either spend or work toward spending three to five hours per week in "lab" time. The rest of the time is spent in "lifestyle." As the levels increase, this amount of time can decrease. Once a child is developmentally ready, he or she is placed in a peer dyad with a peer matched by stage, according to the RDI program. When a child masters all functions through stage 10, the child may be put in a small peer group with peers who are matched by stage (RDI).

In an RDI program, the child works on self and social development objectives. The program is considered the primary intervention for the child, but other services are received as needed. These services include, but are not limited to, medication, diet, occupational therapy, speech and language intervention, and behavior management (RDI, n. d.).

### Research on Autism Spectrum Disorders and the Family

Research on ASDs has grown at a phenomenal rate, yet research on families having a family member on the autism spectrum is relatively scarce. Studies involving

families dealing with an ASD have been conducted in the areas of sibling relationships, parental perceptions, family interactions, social support, and characteristics of the parent. These studies provide information that can help in understanding ASDs and their impact on the family.

### *Siblings*

A study described by Glasberg (2000) examined 63 siblings' understanding of ASDs. An interviewing method described by Bibace and Walsh (1979, 1980) was used by the researchers (as cited in Glasberg). This method of interviewing had been used previously to measure cognitive sophistication in thinking about illness. In the study described by Glasberg, parents were interviewed and asked how they thought typically developing siblings of children with an ASD would respond to interview questions about ASDs. The researchers found that "parents tended to overestimate their child's understanding of the disorder's impact" (p. 143). Although siblings' reasoning became more mature with age, responses of typically developing siblings indicated that their understanding of ASDs developed more slowly than the norms for concepts related to illness (Glasberg).

Hastings (2003) reported a study that explored the behavioral adjustment of siblings of children with autism when the child with autism received applied behavior analysis as an intervention. The study yielded the following results. First, mothers of the children reported no increases in behavioral adjustment problems as a result of the applied behavioral analysis. Second, social support was found to function as a

moderator of the impact of autism severity on sibling adjustment rather than as a mediator or compensatory variable. Third, siblings in families with a less severely autistic child had fewer adjustment problems when more formal social support was also available to the family.

Family systems theory was used to examine sibling relationships in 50 families that included a child with autism, Asperger's, or PDD (Rivers & Stoneman, 2003). Researchers hypothesized that marital stress and coping by seeking social support would influence the quality of sibling relations when one sibling had an ASD. Each family triad participating in the study included a child with autism, Asperger's, or PDD; a typically developing sibling; and a parent. Typically developing siblings and parents in each family completed the Sibling Inventory of Behavior and a modified version of the Satisfaction with the Sibling Relationship Scale. Parents also completed a family information form, a modification of the Marital Strains subscale of the Family Inventory of Life Events and Changes (FILE), and The Family Crisis Oriented Personal Evaluation Scales (F-COPES).

In this study, typically developing children rated the relationship with their siblings with an ASD as positive. The relationship was rated more positively by typically developing siblings than by their parents. Parents' and siblings' reports of the quality of sibling relationships were positively correlated, but there were no significant correlations between siblings' measures and the demographic characteristics of

participants. Typically developing peers expressed greater satisfaction when the sibling with autism was younger (Rivers & Stoneman, 2003).

Marital stress appeared to influence sibling relationships in the families participating in this study. For families with low levels of marital stress, sibling satisfaction was high regardless of whether the family accessed informal social support. As marital stress increased, the quality of the sibling relationship deteriorated. An unexpected result was that when levels of marital stress increased, the negative behaviors of siblings increased at a faster rate if the family accessed informal social support. Based on the findings of this study, Rivers and Stoneman stressed the need to consider family context “as a contributor to the quality of the sibling relationship” (p. 383).

### *Parental Perceptions of Their Child with an ASD*

#### *Parental perceptions of children with autism and child-adult interactions*

Kasari and Sigman (1997) studied the relationship between parental perceptions, parental stress, and observed parent-child interactive behavior. Three groups of children were included in the study: normally developing children, children with autism, and children with mental retardation. The group of children with mental retardation included children with Down syndrome; therefore, this group was divided into a Down syndrome group and a non-Down syndrome mental retardation group when the characteristics of these two groups were different in ways that could impact the results of the study. The normally developing children and children with mental

retardation chosen for this study were of comparable mental age to the children with autism. The researchers matched the autism and nonretarded samples as closely as possible in the areas of ethnicity and socioeconomic status (SES). Factors such as birth order of the children, number of parents in the home, and maternal education level were also considered.

Children and parents participating in the study were seen for two sessions. During the first session, a test was administered to each child to obtain a cognitive measure. Parents completed a set of questionnaires including the Behavior Style Questionnaire and the Parenting Stress Index. Parents were then interviewed with the ABC (Krug et al., 1979) to obtain a measure of caregiver perception of autistic symptomology (as cited by Kasari & Sigman, 1999). "A caregiver-child interaction session" (Kasari & Sigman, p. 44) was also conducted. During the second visit, the child's receptive and expressive language was measured, and the child was involved in an interaction session similar to the first session except that the adult in this session was the examiner instead of the caregiver. Graduate students in education and psychology who were blind to the condition and earlier test performance of the child coded the interaction sessions (Kasari & Sigman).

The results of this study were divided into two sections. The first set of results focused on the questionnaire data and differences found between the two groups while the second set of results was concerned with the association between perceptions and interactions. The autistic group was found to differ significantly from the other groups

in respect to the symptomology associated with autism. Caregivers of children with autism perceived their children as more difficult temperamentally than caregivers of children in the Down syndrome group and the nonretarded group. The non-Down syndrome mentally retarded group was perceived by parents to be similar to the group with autism. According to Kasari and Sigman (1999), parents' responses on the child characteristics domain of the Parent Stress Index indicated that caregivers of autistic and non-Down mentally retarded children experience more stress associated with child characteristics than caregivers of Down syndrome and non-retarded children.

Observations of the child-adult interaction sessions revealed no statistically significant differences among the autistic, mentally retarded, and non-retarded groups; however, there was a statistically significant difference for all groups when comparing the children's interactions with caregivers to the children's interactions with the unfamiliar experimenter. The results of this study revealed that parents who perceived their children to be more difficult temperamentally had children who were less engaged with the parent during a social game and less responsive to the experimenter. Parents of autistic children who reported greater stress also had children who were less responsive in social interactions.

#### *Parents' perceptions of educational placement for their child*

Karsari, Freeman, Bauminger, and Alkin (1999) examined parental perceptions of educational placements for children who had either autism or Down syndrome. The researchers were interested in whether the children's diagnoses and ages would

influence parents' perceptions of the best educational placement for their children. They also wanted to determine what the parents viewed as advantages of their children's current placements and which placements parents viewed as ideal. Children with autism and Down syndrome were chosen for this study because of their different responses to social situations.

Kasari et al. (1999) found that the two groups of parents were equally satisfied with their children's educational placements at the time of the study, and there was no statistically significant difference in the two groups of parents' desires to change their children's placement. In both groups, parents of younger children were more satisfied than parents of older children. The results of this study also revealed that parents of children with Down syndrome were more likely to choose full-time placement in general education while parents of children with autism were more in favor of consistent part-time placement in the general education setting.

#### *Parental perception of cognitive functioning*

Geiger, Smith, and Creaghead (2002) conducted a study comparing the extent of agreement between parents and professional evaluators when considering the cognitive functioning of children with autism. Questionnaires were used to examine the parents' view of their child's cognitive level while standardized intellectual measures were used to obtain age equivalencies. Significant differences were found between the parents' perceptions of their child's level of cognitive functioning and the professional assessment of the child's cognitive level; however, as the level of

cognitive functioning increased, the level of agreement between parents and professionals increased as well.

### *Family Interactions*

A study examining play interactions of family members and children with autism was reported by El-Ghoroury and Romanczyk (1999). Nine families participated in the study that involved three visits to the home of participants. During each visit, researchers videotaped interactions between family members. An analysis of the taped interactions revealed that mothers and fathers displayed more play behaviors with the child diagnosed with autism than were displayed by siblings and the diagnosed child; however, children with autism initiated more interactions with their siblings than with their parents.

### *Social Support or Gender as Related to Parental Stress, Anxiety, and Depression*

Sharpley and Bitsika (1997) described a study designed to determine whether parental stress, anxiety, and depression associated with parenting an autistic child was related to gender or alleviated by social support. Information was received from a confidential and anonymous survey of 219 parents of children with autism. The independent variables used for this study included (a) gender of parents, (b) age of child, (c) age of onset, (d) parental health, (e) access to other family members, and (f) level of understanding of the child's problem by other family members. Dependent variables included (a) the nature of the child's disorder, (b) parental well-being as determined by measures of anxiety and depression, (c) parents' daily level of stress

arising from parenting, (d) parents' confidence in handling their child's major difficulty, and (e) parents' report regarding the frequency of times they felt stretched beyond their limits. Sharpley and Bitsika indicated that the meaning of social support in this study was taken from the following definition used in previous studies: "The presence/absence of a clear understanding of the child's disorder by those immediate family members who provide respite from the day-to-day demands of parenting" (para. 6).

Parents of children with autism completed the Zung Self-Rating Anxiety Scale, the Zung Self-Rating Depression Scale, three additional questions added to the scales to determine parental stress, and a demographic questionnaire. The questionnaire included questions related to various aspects of the child's disorder, parents' illnesses or disability and medication taken, forms of assistance provided from within and outside the family, whether the assistance was provided by people with a clear understanding of the child's difficulties and needs, the major difficulty that parents experienced with their child, and parents' major concern for their child's future.

Almost half of parents returning information reported that their major current child-management difficulty was behavioral. The majority of parents, 81.9%, reported that they were sometimes stretched beyond their limits. Of those who sometimes felt stretched beyond their limits, almost half reported that they felt this way from one to five times a month. Another 11.1% of parents reported feeling this way more than 15 times per month. Half of the parents who participated felt a "high" or "very high"

level of stress while 36.9% felt an “average” level of stress. Females reported higher levels of parenting stress than males, but females also reported higher levels of confidence in handling their child’s major problem. Parents reporting a major illness or disability also reported higher levels of anxiety, depression, and daily stress as well as higher levels of feeling stretched beyond their limits. Parents suffering from an illness or disability which in their view hindered their ability to be an active parent to their child with autism had significantly higher SAS scores, SDS scores, and daily level of stress from parenting than parents with no such illness or disability.

Almost two-thirds of the parents who participated in this study had access to family members for assistance in childcare. Parents with access to assistant caregivers who were perceived by the parent as having a “clear understanding of the child’s difficulties and needs” had SAS and SDS scores indicating significantly lower levels of anxiety and depression. These parents also had significantly higher levels of confidence in their own ability to handle their child’s major difficulties.

#### *Relationship Development Intervention Versus Other Approaches*

Gutstein (2005) described a preliminary attempt to study the effectiveness of Relationship Development Intervention (RDI) with children on the autism spectrum. For this study, two measures of progress were chosen to indicate effectiveness: (a) improvement on the Autism Diagnostic Observation Schedule (ADOS) and (b) increased independent functioning in the educational setting as measured by educational placement. The participants were children with an ASD who ranged in age

from two to nine years. The families of 17 children participated in RDI while the other 14 children participated in other treatments. The children in the two groups were similar in diagnoses, ages, and cognitive and language functioning. Gustein reported that the RDI and non-RDI children did not differ in educational placement when the study began. At that time, only one child in each group functioned independently in a regular education classroom.

Over a 16-month period, the RDI group averaged a little over five hours per week of therapist contact, while the non-RDI group averaged over 25 hours per week of therapist contact. After 16 months, 70% of the RDI children had improved in at least one diagnostic category on the ADOS while the children in non-RDI group did not improve in any diagnostic category. Also, 13 children from the RDI group were attending regular education settings without significant support. In the non-RDI group, no child had moved from a special education placement to a regular education setting during this same period (Gutstein, 2005).

#### *Parental, Service, and Cost Impacts*

A study conducted in England served as a preliminary examination of a research instrument developed to collect cost information for individuals with an ASD. This study presented by Jarbrink, Fombonne, and Knapp (2003) yielded information that could be used to further modify the instrument but also provided information about the costs associated with ASDs. The research instrument, a questionnaire developed from the Client Service Receipt Inventory (CSRI), has been

used in evaluations of interventions for needs related to mental health, learning disability, physical disability, and child and family problems (Beecham & Kapp, 1992, 2001 as cited in Jarbrink et al.). The CSRI was modified so it could be used in a postal survey and could be completed by a person caring for a child with an ASD. Fifteen parents participated in the study. Two families had more than one child on the spectrum, so there were 17 children on whom information was obtained. Information about the time spent by caregivers on informal care was obtained through two questions on the questionnaire and a diary survey to be completed by the caregiver for 14 consecutive days.

The first question asked caregivers about the average amount of time spent in different care-giving activities as a result of their child's disorder. Six participants were unable to answer the question because they found it difficult to separate the time between the activities, were unable to determine the number of hours of care that were due to the disorder, or indicated that the child's needs took all of their available time. The average amount of time spent on such activities by parents who did answer the questions was nearly 60 hours. The second question asked caregivers to categorize the time-loss due to their child's disorder in the areas of paid work, unpaid work, or leisure. On average the caregivers estimated that they would have spent 40 hours per week on other activities if their child did not have an ASD. Some parents stated that they would have spent more time, an estimated 22 hours, on paid work. The number of unpaid hours spent in work varied greatly for the caregivers, some of whom were

involved in volunteer groups that they said they would not have been involved in had their child not been on the autism spectrum. Parents estimated an average loss of 17 hours a week in leisure time (Jarbrink et al., 2003)

The researchers found that out-of-pocket expenses recorded in the diary were higher than the expenses indicated in the questionnaire. This was attributed to the tendency of parents to forget expenses when asked to remember expenses over the last six months. Some of the expenses reported by parents included costs for education, therapy, health services and medication, adaptation costs, the cost of assessments, extra help, transport, and the costs of damages. All parents reported that their child's disorder had negatively impacted their career and/or income, but only 11 were able to estimate the income loss that could be attributed to having a child with an ASD (Jarbrink et al., 2003).

This preliminary study helped researchers better understand the costs associated with ASDs and the challenges associated with obtaining information about these costs. They were able to identify the types of information that most likely to be obtained by the questions added to the questionnaire and the types of information that could be obtained from the diary. The study also helped researchers identify several problems with the modified questionnaire. Although the purpose of the study was to evaluate the modified questionnaire for use with caretakers of children on the autism spectrum, the study provided useful information to be considered in any study related to the costs associated with ASDs (Jarbrink et al., 2003).

## Summary of the Literature

Counseling and family therapy have been recommended for some individuals and families dealing with ASDs, yet there is little published information about counseling and family therapy with this population. Suggestions for counseling and family therapy have focused on the need for family support, competence, and confidence. Counseling has been recommended for higher-functioning adolescents and adults with an ASD provided by professionals who understand the nature of their disability when these adolescents and adults are aware of the ways that they are different from others in their age groups. Therapy was also recommended for individuals identified with ASDs when they experience the loss of loved ones.

Counseling or family therapy have been suggested for some parents when an ASD is first diagnosed and during times of transition such as when an individual diagnosed with an ASD starts school, reaches adolescence, or goes through other transitions. Counseling and family therapy have not been suggested in place of treatment plans that focus on teaching skills and addressing behavioral difficulties. Instead, recommendations for counseling and family therapy have focused on the need for professionals to recognize the many facets of the problems families encounter when faced with an ASD.

While there is limited information about ASDs in the counseling and family therapy literature, information can be found about the stressors that are common in families when the family includes a child on the autism spectrum. Information about

children with disabilities and their families is also available. Theories of development and the family have been adapted to provide a better understanding of how families function when they have a child with a disability and models of therapy used by family therapists have been adapted for use with families that include a child with a disability.

## CHAPTER III

### METHODOLOGY

The purpose of this qualitative study was to examine parents’/guardians’ experiences of family life when a child in the family had been identified with an autism spectrum disorder (ASD) and the parents’/guardians’ experiences in attempting to access services that may include family therapy. This study also explored what parents’/guardians’ experiences suggest for family therapists interested in meeting the mental health needs of individuals and families dealing with an ASD. This chapter explains the methods used in conducting this study, the efforts taken to minimize risks related to confidentiality, and the treatment of data.

#### Research Design

A qualitative design was chosen for this study, allowing participants to share the information they believed to be important. Using their words, parents painted what Creswell (1998) refers to as a “complex, holistic picture” (p. 15), presenting “multiple dimensions” (p. 15) of the complexities associated with ASDs. This approach allowed participants to describe their own experiences rather than respond to variables chosen for investigation by the researcher. According to Daly (1992), qualitative methods facilitate holistic studies of families that allow interactions, dynamics, and contexts to be investigated rather than an investigation of “variables that isolate particular fragments of family experience like an attitude or a behavior” (p. 4).

A phenomenological approach served as the framework for this study. A phenomenological approach attempts “to understand empirical matters from the perspective of those being studied” (Creswell, 1998, p. 275). This approach provided a useful framework for addressing the key objectives of this study: (a) to examine parents’ perceptions of family life when a son or daughter had been identified with an ASD, and (b) to explore parents’ experiences in accessing services for their child and other family members.

### Participants

This study was designed to include 20 parents/guardians of individuals identified with an ASD from age 5 to 21. Those who actually participated in this study were 21 parents of individuals identified with an ASD who ranged in age from 6 to 21 years. No guardians participated in this study, and no parent of a five year old expressed a willingness to participate during the time allotted for the study. The final number of parents participating was 21 because when the researcher arrived to conduct the final interview, both parents expressed a desire to participate in the study, and both were interviewed. The children represented in this study who had been identified with an ASD numbered 19. Two reasons existed for the difference in the number of parents participating and the number of children represented: (a) First, the number of participants included three couples who each had one child on the autism spectrum. (b) Second, one parent had twins, and both of these children had been identified with an ASD.

This study was designed to include parents of children who were in the “high-functioning” range of the autism spectrum. For this reason, participation in this study was limited to parents of children with some self-help and communication skills. Parents who participated in this study were known to have a child who attended or had attended (in the case of high school graduates) at least some mainstream classes. The only child represented in this study who did not attend mainstream classes was the twin of a child who attended mainstream classes for part of the school day.

## Procedure

### *Selection of Participants*

Individuals who participated in this study were recruited from two different sources. The first source was a North Texas school district. The primary researcher worked with school district personnel to access the addresses of students who received special education services in this district according to the eligibility criteria for autism. The researcher, an employee of the district, had access to confidential student information, but the information accessed for this study included only the information necessary for letters to be sent to parents.

Letters were sent to parents believed to meet the criteria for participation in this study. These letters (Appendix A) included a postcard (Appendix B), a stamped envelope addressed to the researcher, and the researcher’s telephone number. The researcher was responsible for all cost incurred in the mailing of these letters. Recipients interested in participating in this study were asked to call the researcher or

return the postcard in a self-addressed envelope enclosed in the letter. Once the researcher had been contacted by the parent, an appointment was scheduled by telephone. Interviews were scheduled for a time and location that was convenient for the parent.

A second method of recruitment was to contact persons known to the researcher to have a child identified with an autism spectrum disorder who had previously expressed interest in this study. These parents were also contacted through a letter that provided details about the study (Appendix A). Instructions for contacting the researcher were the same for this group as the group previously described. Interviews for this group were also scheduled by telephone.

#### *Location of Interview*

Interviews took place at a private location agreed upon by the participant and the researcher. The majority of interviews were conducted in the home of the participant. Two interviews were conducted in a private room at a school.

#### *Interview Process*

A semi-structured, face-to-face interview was conducted with each participant. Interviews lasted from 30 minutes to one-and-a-half hours. An interview guide was used during the interview process (Appendix F). Each interview was comprised of three parts. During the first segment of the interview, the researcher reviewed the purpose of the study, and discussed the consent form with the potential participant. Questions about the study and consent form were answered. The researcher explained

that a summary of the results of this study would be sent to the participant if he or she indicated an interest by providing an address at the bottom of the consent form.

Participants were given a copy of the consent form to keep. The last step during the first segment of the interview session was to ask participants to complete the demographic data form (Appendix D).

The second segment was the actual interview. Participants were reminded that a number would be used during the interview instead of names. Participants were also reminded that they could stop the interview at any time, could discuss any questions that made them uncomfortable with the researcher, or could choose not to answer a question.

The third segment of the interview took place once the actual interview had been completed. Participants were given an opportunity to ask questions. Once all questions were answered, the researcher thanked the participants and gave them \$25.00 as compensation for their time.

#### *Storage and Handling of Confidential Information*

In order to protect the confidentiality of participants, a number was used in place of participants' names on audio tapes, demographic data forms, transcripts, and notes taken during interviews. Consent forms were the only source to contain the names of participants. These consent forms were stored separately from audiotapes, interview transcripts, demographic forms, interview notes, and other sources of information about participants and members of their family.

Access to audiotapes of interviews, computer disks used during the transcription of the audiotapes, and interview notes were limited to the primary researcher and two transcribers. The primary researcher was the only person to have access to the demographic data forms. The only individuals to have access to interview transcripts were the primary researcher, research advisor, two transcribers, and a reviewer. Each of these persons completed the on-line course regarding ethics and research as required by the Institutional Review Board at Texas Woman's University prior to their involvement in this study. All tapes, interview transcripts, demographic data forms, and computer disks were kept in a locked closet in the home of the primary researcher.

All audio tapes, transcripts, demographic forms, and computer disks will be destroyed no later than one year after the completion of this study. At this time tapes will be cut into small pieces. Transcripts and demographic forms will be shredded and computer disks will be destroyed.

#### *Pilot Study*

A pilot study was conducted with one parent prior to interviews with other participants. A video camera was used during this pilot study, allowing the primary researcher to observe her own body language and tone of voice. The camera was directed only at the researcher. This pilot study served to increase the researcher's awareness of how her own body language and voice might alter the information provided by participants. The parent who participated in this pilot study was included

in the final number of participants since the camera was focused on the researcher and did not seem to interfere with the information shared by the participant.

### *Treatment of Data*

Following each interview, an audiotape of the interview was transcribed by the primary researcher or a transcriber. Notes taken during the interview were used by transcribers to ensure the accuracy of transcripts. These notes included words used by participants that were anticipated to be unclear on the audio tapes. Completed transcripts were read the first time for accuracy. Corrections were made when needed. Transcripts were then read again to get a sense of the overall meaning of the participants' experiences.

Once each transcript had been read for accuracy and overall meaning, interview transcripts were analyzed by the researcher in a manner consistent with the suggestions of Smith, Jarman, and Osborn (1999). As transcripts were read, the margin on one side of the paper was used to note things of interest or significance. The margin on the other side of the paper was used to document emerging themes. These emerging themes were highlighted and underlined with colored markers. Different colors were used to indicating different emerging themes. Possible emerging themes from interview transcripts were recorded on separate sheets of paper, along with the interview number and the location of each emerging theme in the transcript. Transcripts were reviewed separately for the purpose of identifying the services received by the child and family. Services were noted on a separate piece of paper

according to whether the services were received by the child or the family. Any services that included family members were marked as a family service. One example of this was home-training. Notes were made as to which services were provided by the school system and which services were provided by other sources such as health care facilities, individuals in private practice, and community groups.

Two reviewers read and analyzed the transcripts in addition to the primary researcher. The second reviewer was the researcher's major advisor. The third reviewer had recently completed a doctoral program in family therapy at Texas Woman's University. All reviewers read and analyzed interview transcripts then met to discuss their findings. The three reviewers found a number of themes in common, but one reviewer identified a theme that was inconsistent with the findings of the other reviewers. After some discussion, it was determined that this theme was not consistent with a phenomenological approach. For that reason the theme in question was omitted.

The last phase of data analysis involved translating the themes into a narrative account. This was done with input from the primary researcher's major advisor. Demographic information was also analyzed to determine patterns related to the participants responses and demographic data.

#### The Researcher

Sherill Davis is a doctoral student in Family Therapy at Texas Woman's University at Texas Woman's University, a Licensed Professional Counselor, and a Special Education Counselor for a North Texas school district. She has taught in

public schools in both the general and special education settings, worked for social services in Texas and Nebraska, and completed internship programs with Mental Health/Mental Retardation and juvenile probation. Sherill enjoys working with children, adolescents, and families. Her interests include adolescent issues, learning differences, and autism spectrum disorders.

Sherill's interest in autism spectrum disorders has grown during her 12 years as a Special Education Counselor. Inclusion of Asperger's Disorder in the DSM-IV and changes in the way the educational system addresses the needs of this population have allowed Sherill an opportunity to work with a wide spectrum of students and families dealing with the challenges presented by ASDs. Her pursuit of a doctorate in family therapy has increased her awareness of the needs of these families and the need for resources that address the needs of the entire family. Sherill has also developed an interest in learning more about the experiences of families impacted by ASDs and how current services for families can be improved.

### Credibility

According to Goldstein, Safarek, Reiboldt, Allbright, and Kellet (1996), "Qualitative data are inherently subjective, dynamic, and changeable over time" (p. 313). The following procedures were implemented in order to assure credibility and trustworthiness of this study. A pilot study was conducted using a video camera that focused on the researcher. This was done to increase the researcher's awareness of

how her own body language and voice tone might influence the responses of participants.

Triangulation, “corroboration with other data sources” (Goldstein et al., 1996, p. 313), was also utilized in this study. First, data was obtained from a variety of participants in the form of an interview. Second, multiple sources of data were reviewed and analyzed including interview transcripts, demographic data forms, and interview notes. Lastly, two reviewers in addition to the primary researcher examined and analyzed interview transcripts.

In an effort to suspend her own experiences with individuals identified with an ASD and members of their families, the primary researcher made an effort to limit interview questions and probes to those chosen in advance. These questions and probes were reviewed by the primary researcher’s research committee and Institutional Review Board prior to any contact with any participants. When the researcher was asked by participants to clarify questions, an attempt was made to answer participants in such a way that any information a participant wished to share was relevant. An example of this was when participants asked if interview question number two was asking about services the child received in the school setting or services received outside of school. The researcher attempted to respond to questions by participants so as to indicate that all information was relevant.

The primary researcher limited data analysis to information provided by participants during the actual interview and on the demographic data form. This

helped to ensure that the findings of this study would be based on information provided by the participants, increasing the credibility of this study. It also allowed the primary researcher's understanding of the themes that emerged in this study to be questioned by additional reviewers.

### Transferability

This study was developed to have some transferability but should not be generalized to other groups or settings. Parents who participated in this study were from two specific geographical areas in Texas. The majority of participants were from the same geographical area, had children who attended schools within the same district, and had access to similar types of services both through the school district and outside of the school setting. The experiences of parents in this study may be different than those of parents with children in other school districts and in other areas of the state or country.

### Summary

The purpose of this research study was to examine parents' perceptions of family life when a child had been diagnosed with an ASD and to explore the experiences of parents in accessing services, including family therapy. A semi-structured interview format was used with 21 parents of children on the autism spectrum that ranged in age from 6 to 21. These face-to-face interviews were audio-taped then transcribed. Transcripts from interviews with parents and demographic

information obtained prior to the interview were analyzed to determine the themes that emerged from participants' responses. These themes were documented in a narrative.

## CHAPTER IV

### FINDINGS

The purpose of this study was to examine parents' perceptions of family life when a son or daughter had been identified as having an autism spectrum disorder (ASD), to investigate parents' experiences in accessing services, including family therapy; and to explore what parents' experiences suggest to family therapists interested in meeting the needs of individuals and family members dealing with an ASD. This chapter contains the results of interviews with parents who participated in this study and their children identified with an ASD.

#### Participants

A total of 21 parents participated in this research project while the number of children represented was 19 (see Figures 1, 2, 3, and 4). The difference in the number of participants and children represented was due to (a) the participation of three couples who had a child identified with an ASD, and (b) the participation of one mother who had two children on the autism spectrum. Children with an ASD represented in this study ranged in age from 6 to 21 years old.

All but two parents who participated in this study had children who attended or had attended schools in a large North Texas school district. All but one of these students were currently receiving services through special education. The student who was not currently receiving Special Education services was a recent high school

graduate who had previously received Special Education services. The remaining two participants were from a rural area in West Texas. One of these participants had a son in college and the other had twins received Special Education services.

Participants completed a demographic data form that provided information about themselves and their children (see Appendix D). Parents were asked to indicate whether their children had been identified as having autism, Asperger's, PDD-NOS, Rett's Disorder, or Childhood Disintegrative Disorder. There was also a place for parents to mark if their child had been evaluated by the school system and found to meet eligibility for Special Education services as a student who met the educational criteria for autism. Some parents marked more than one disorder, stating that their child had been given different diagnoses by different professionals. According to the information provided by parents, five children had been identified as having autism, nine children had been identified as meeting the criteria for Asperger's, six children had been identified as meeting the criteria for PDD-NOS, and two children had been identified as eligible for Special Education services as a student meeting the criteria for autism (see Figures 5, 6, 7, and 8).

Parents provided information about their child's educational placement. Of the 19 children represented in this study, 12 attended mainstream classes, 6 attended some mainstream classes, and 1 was placed in a self-contained classroom. The number of students represented in this study that were fully mainstreamed may be the result of procedures used for this study (see Figure 7).

Figure 1  
Parents Participating

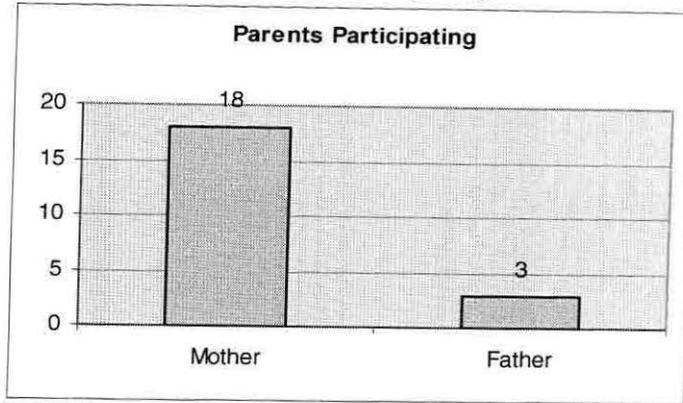


Figure 2  
Parent's Highest Level of Education

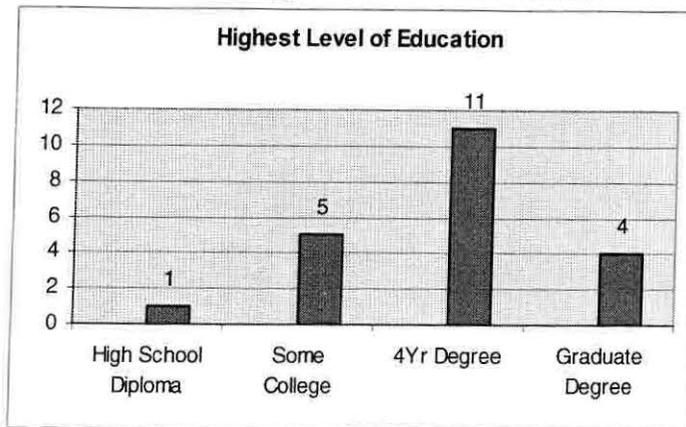


Figure 3  
Race of Parents

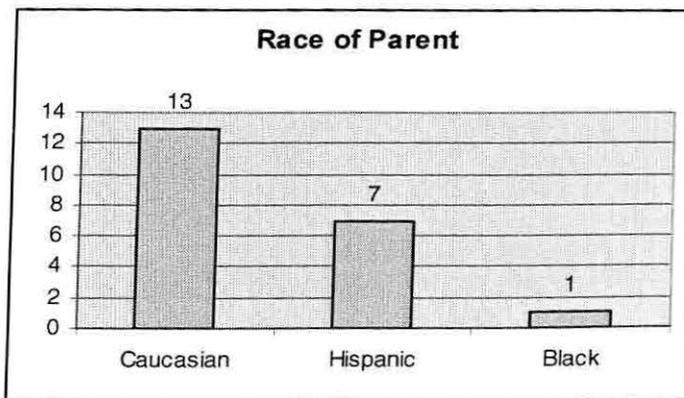


Figure 4  
Male/Female Distribution of Children

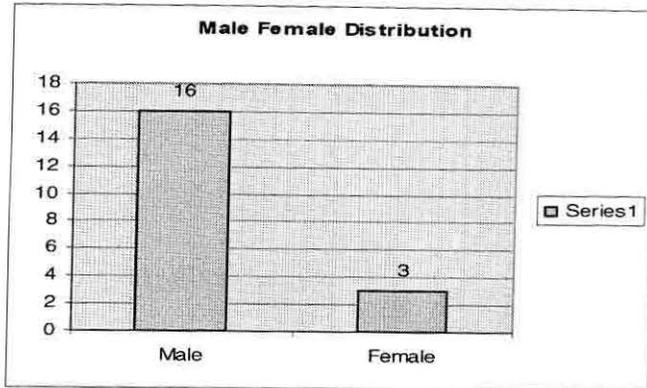


Figure 5  
Source of Disorder Identification

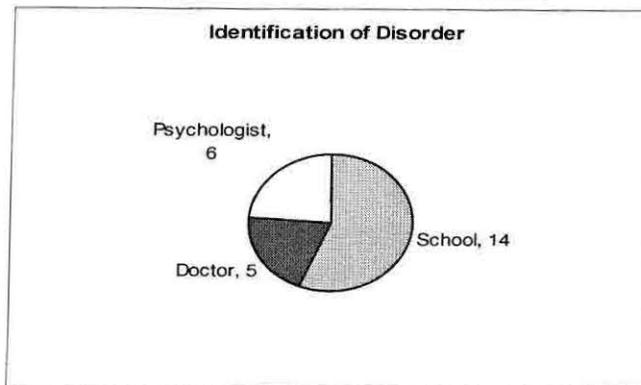


Figure 6  
Category of Autism Spectrum Disorder

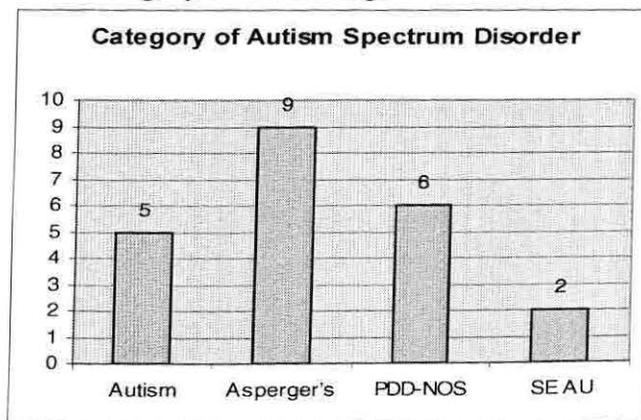


Figure 7  
Educational Placement of Children

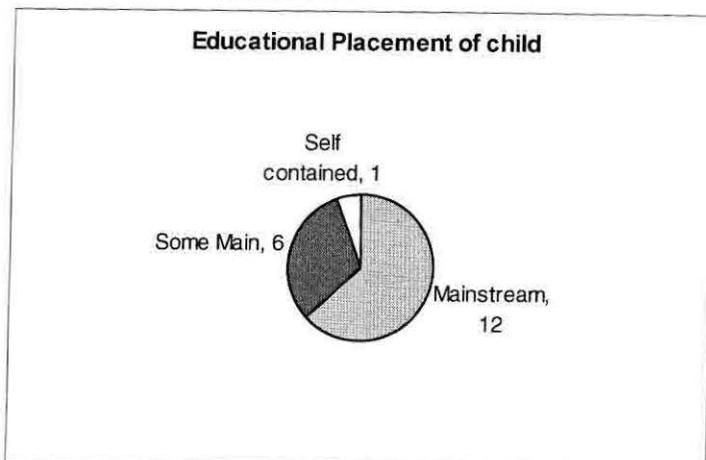
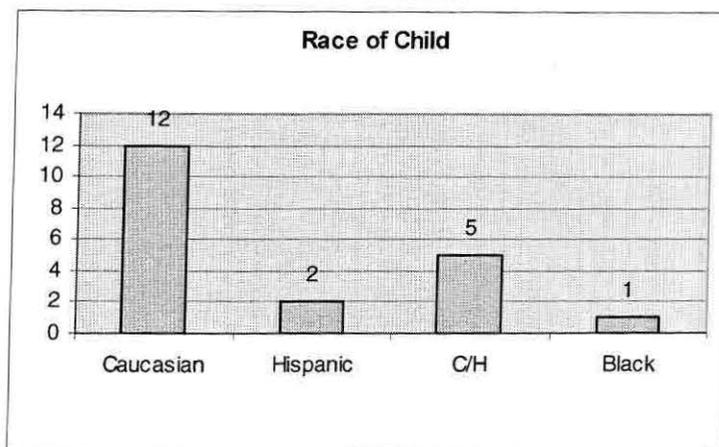


Figure 8  
Race of Child



researcher called parents to schedule interviews as soon as possible after receiving cards indicating that parents were willing to participate in this study. The order in which letters were mailed may have affected the number of these students who were in mainstream classes.

### Findings

The findings of this study are based on the responses of participants to nine questions asked during interviews with 21 parents of children identified with an ASD. As participants' responses were analyzed using interview transcripts, common themes and sub-themes began to emerge. These themes and sub-themes provided information useful in answering the three research questions that guided this study:

1. How do parents/guardians experience family life when a son or daughter has been identified as having an autism spectrum disorder?
2. What experiences have parents/guardians had in accessing services that may include family therapy?
3. When parents/guardians have a child with an ASD, what do families' experiences with service providers suggest to family therapists interested in meeting the mental health needs of the family?

The themes and sub-themes that emerged from parents' responses can be divided into three categories: (a) parents' perceptions of family life, (b) parents' experiences in accessing services, and (c) parents' perceptions of services needed. These themes provided answers to the first and second research questions. The third

research question was answered by considering the information obtained from all interview questions.

*Family Life as Perceived By Parents of a Child Identified with an ASD*

The first research question asked how parents/guardians experience family life when a son or daughter has been identified with an ASD. Two parents of young children stated that their child's ASD had had little impact on the family. Other parents indicated that characteristics of their child's ASD had impacted their entire family.

“If you have a child with this disorder, depending upon the age, everything in the family has to be structured around the child.” [#2]

“It complicates things. You are basically challenging chaos at every turn. . . extremely challenging. . . the stress level, the expectations that you feel – that you need to live up to in order to help your kid . . .” [#10]

“You have to adjust your family life to what they need.” [#5]

“It impacts the whole family.” [#16]

“He [child with an ASD] has definitely set the tone in our family for much of his life.” [#11]

Most parents gave specific examples of how their child's spectrum disorder affected day-to-day family life. Common themes developed from parents' descriptions of family life with a son or daughter identified with an ASD. These themes included (a) the impact of ASDs on family members' every-day lives, (b) the impact on family relationships, (c) adjustments,

strategies, and coping as a part of family life, (d) family life and school, and (e) the challenge of communicating.

### *The Impact of Characteristics of Autism Spectrum Disorders on the Family*

As parents gave examples of family life with a child on the autism spectrum, each story was different, yet at the same time, each story was the same in regards to how the family was affected by the child's communication differences, sensory issues, cognitive differences, and need for routine – all common characteristics of ASDs.

“[Name] was interested in cars or anything with wheels. . . . He would actually take those cars and line them up in certain areas of the kitchen to where I would find his cars in the microwave, in the freezer, across my stove. . . . but they had to be in a certain line and the wheels – where he could watch the wheels. When I would have to cook, I would have to try to remove these cars which caused anger – frustration on his part. He couldn't understand why I was moving these things. . . . It was just very hard to get him to change to something else. . . . He would complain at home that he could hear TV sets being . . . turned on very early in the morning, say at 5 o'clock. I would turn it on to listen to the news, but my room is downstairs, and his was upstairs in the corner. He would complain about the impulses he felt in his head and said, 'It's like lightening in my brain. I feel lightening going through my brain.' . . . I had trouble when I took [name] shopping with me. . . . He would not enter a store or a building if it didn't have the right smell – which complicated things because I couldn't leave a young child outside. . . . so it made it very difficult for us to do outings together as a family.” [#1]

“Everything in the family has to be structured around the child. My son had to have a specific time to do everything. We had to pretty much live our life by the clock.” [#2]

“When he was younger . . . we did have to tell him if we were going on a trip - where we were going, how long we were going, what we were doing – to get him prepared, so he would not stress out.” [#21]

“We have very many restrictions on our social life . . . because he is so sensitive to noise and crowds and heat and lights . . . an outing is restricted . . . even if it is to go get ice cream which he loves. Something that is minor is even difficult for a [teenage] straight “A” student. . . . As far as social life, I am unable to have friends in the house. I am unable to talk on the phone without being like, ‘Who waltzed into my house?’” [#11]

“When he was younger, we’d say like, ‘Can you pick up your shoes, and put them in your room?’ He’d look at you like, ‘What did you just say?’ and you’d have to figure out another way to say the same thing. You’d figure out two or three different ways, and then it would click. ‘That’s what she wants me to do.’” [#5]

“For the most part, now, to me the hardest thing to deal with is him not understanding that certain situations are supposed to be humorous.” [#14]

Many parents described how characteristics of their child’s ASD affected family relationships. Three types of family relationships were mentioned by participants: (a) the marriage relationship, (b) sibling relationships, and (c) extended family relationships. The marriage relationship and sibling relationships were mentioned most often. Only one parent spoke of extended family relationships.

*The marital relationship.* Most parents did not speak of their marriage during this study, but parents who did mention their marriage indicated that the characteristics of their child’s ASD had resulted in an increased strain on their marriage. Two of the parents who participated in this study were divorced.

“Asperger’s has definitely been a strain on our marriage. We are divorced now. We may well have been divorced if we didn’t have an Asperger’s child, but it definitely was a strain in the household.” [#11]

“This made it very difficult in the family dynamics as you had one parent who can accept it and move on, but you have another who’s in denial.” [#1]

“During his early years, it was hard. Men don’t think, you know . . . they don’t think they can have an imperfect child, so a little frustration went on there between us, I guess.” [#5]

“I didn’t agree with what my husband wanted us to do, and he didn’t agree with what I wanted to do. It made for a rough time there.” [#18]

*Sibling relationships.* In this study, 15 of the 19 children represented in this study had at least one sibling. Some parents reported sibling relationships that were primarily positive, giving examples of how sibling relationships had been helpful to the child with an ASD.

“He has a sister. . . . Just since last year they have really been playing well together. She will tell him what to do and he’ll do it. . . . He’s getting a lot better at playing with other kids.”[#15]

“He [sibling identified with an ASD] did not want to interact. He did not want to follow directions. He wanted to play by himself . . . His brother has been, I know God - I swear – he knows what people to put together because his brother from the day that he was born, he was in his face - ‘You will notice me. You will play with me. You will talk to me. You will not get out of it’ . . . and [name] doesn’t have an option except to respond.” [#12]

“He gets along very well with his sister. He very rarely fights with her.” [#9]

Other parents spoke of how their child’s ASD made it difficult for the child’s sibling(s) to have a normal social life. They spoke of the behaviors of the child identified with an ASD that affected the sibling relationship and the response of the sibling who had not been identified with an ASD. Parents of older children reported that siblings sometimes felt embarrassed by their sibling with an ASD. Differences in

the way situations were handled between siblings seemed to be a factor in the way non-identified siblings responded.

“Most of the attention had to go to her which took a lot of attention away from the others. There was a lot of stress.” [#18]

“Now, several times a day, his brother will talk about how difficult it is to have an Asperger’s brother and how much it influences his life and how unfair it is.” [#11]

“If I had it to do all over again, I would’ve made sure that I had paid more attention to my daughter than I did. I didn’t ignore her, but I didn’t realize how much effort and time I was putting into redirecting my son. . . . She became upset as she began to realize or began to think that things he had - it was unfair – advantages. . . . and she was becoming more embarrassed about her brother’s action, about the way he reacted when her friends came over. He would stand at the top of the balcony and say, ‘They can’t come in here. This is my house. Don’t let anybody in here.’” [#1]

“That’s hard on the siblings because he is held to a different standard than they are. His brother is younger, and we have to ask him to kind of watch out for [name] to be sure that the important things get done. Sometimes he is very much embarrassed by his brother. If I drop him out at school, he gets out of the car really fast and goes in a different door. He doesn’t want anyone to know that [name] is his brother.” [#17]

“He’s different, you know? His brothers and sisters love him, but sometimes they just don’t ‘get’ him. . . . Sometimes the older kids don’t quite understand why his rules are a little different – not lower standards but different standards.” [#13]

*Extended family relationships.* The impact of ASDs on extended family relationships has received little attention in the literature. One parent share information about her extended families reaction at the mention of her daughter being diagnosed with an ASD.

“I have found instances within my own family where if you mention, ‘My daughter has Asperger’s,’ they panic.” [#10]

### *School and the Family*

Although no interview questions asked directly about school dynamics affecting the ASD child and the family, the topic of school was an ongoing theme throughout many of the interviews with parents. Some parents spoke positively about their experiences in dealing with the school system, while others spoke negatively about their child’s experiences related to school and their own experiences in dealing with school staff and faculty. Some described both positive and negative experiences. Some of the positive things parents had to say are as follows:

“The school staff has been very helpful – the school psychologist, the diagnostician – all those people there have been very helpful in working with [name] and figuring out what it is exactly that is going on with him – and I just could not ask for a better PPCD teacher over at [name of school]. I just love her to death. . . .” [#13]

“Thank you [name of school district]. I really give them more credit than any other thing that I’ve done with my children as far as services.” [#11]

“Working with the staff at his former school has been outstanding from day one. They’re such dedicated people and even though there were times when it was hard, maybe for them to understand where I was coming from or for me to understand where they were coming from, we were always able to come back to some common ground – which was always the child.” [#12]

“I don’t think there is anything that we should have that we are not getting.” [#15]

*School as a stressor for family members.* Parents' descriptions of negative experiences with school related issues could usually be put into one of three categories: (a) their child's difficulties with social situations at school, (b) parents' experiences in dealing with faculty and staff, and (c) the amount of time the child spent on homework.

"My son cannot go into a classroom and mind his own business. He's a magnet for trouble. He's the behavior issue if he decides to say no or stand his ground. . . . He's the behavior issue. He likes to learn. He said if they'd only leave him alone, he'd be really happy, but that's not what life's about." [#7]

"During an ARD, I sit on one side of the table and everybody sits on the other side of the table, so I feel like I'm in front of a firing squad. . . . I think I cried at the ARD in seventh grade. I couldn't go to the second one. I had my husband go." [#6]

"She had some really good teachers, but I can remember one year she got a relatively new teacher who basically didn't even accept that she had some problems or that she was different. She just thought that it was her attitude or that she just wasn't trying to organize or whatever." [#10]

"Homework's been a nightmare. It gets harder every year . . . a total nightmare." [#8]

*The child at school is not necessarily the same child at home.* A number of participants reported that their child is different at school than at home. Some parents reported that their child responds better to family members than to teachers and peers. Other parents said their child tries to please teachers at school but displays aggressive behaviors at home.

“I think there needs to be an element of education to parents in general - that what your child is at home is not what your child is at school.”  
[#10]

“He follows the little rules and tries to please the teacher. . . . We have major stress in our home if something unpleasant happens during the school day. I know the teachers do not see the person I see. I know they don’t. They don’t understand. I find that the school – they’re justifiably unaware of how bad the problem is because they don’t see it at school. . . . even though it’s a school problem that he’s bringing home to our house.” [#18]

“When he goes to school, literally, he goes to do battle. When he steps out of the car, I literally see the smile on his face disappear to be replaced with a look of resolve – strong resolve. . . .A façade that he puts on like a suit of armor when he steps out of the car, and when we pick him up, we see that look on his face and when he throws his book in the car. We always think he had a fight with somebody on the way out, but as soon as he throws the book bag in the car, sits down, and closes the door, it’s like, ‘Hi, Mom/Dad, what’s going on?’ He’s this great jovial kid again. He’s happy, so it’s um, it’s a survival mode.”  
[#7]

### *Strategies and Coping within the Family*

An analysis of interview transcripts provided a glimpse of not only the challenges faced by participants but also of how they coped. Parents described a variety of situations that required family members to adapt to the needs of the child with an ASD. They also described strategies for dealing with a child identified with a spectrum disorder.

“What I learned is to prepare him ahead of time for changes, and I’ve learned to try to keep things very smooth at the beginning of the school year because I know that’s a change – a big change.” [#6]

“Laughter has been my one source of – if I can make him laugh about it – it has been one of his strengths – to bring him back . . . I try to come down to his level . . .” [#8]

The easiest way to get her to respond to anything is to put your hand out – stretch it out to her to see if she wants to take your hand and ask her if she would like a hug. Hugs are the only thing that open her up. But you have to offer it, extend it, and she has to say ‘yes’ and initiate it. But I’ve been able to accomplish great things by doing that with her, but it’s been trial and error. . . [#10]

“Humor . . . and I learned that fairly early on – to make him laugh kind of de-fuses the tension, and I’m able to get through to him. . . . some of the coping skills I’ve acquired with him throughout - setting consequences, very clear limited consequences.” [#6]

“In many ways, we have become very accustomed to living with Asperger’s, but we have had to make adjustments, and I have made them without noticing that I just made them. Something will transpire, and I will – ‘Oh, I just accommodated for this,’ and I did it without even thinking.” [#11]

“I think I have read more from the internet than I have from books – how to prepare them for things and how to keep a schedule and say things a certain way like, ‘First we’re going to do this, and then you can come back and do what you want to do’ . . . . You always have to plan a step ahead. . . . My husband is learning too – and I’ve had to teach my parents. They know he’s different, but they know how to talk to him, and we talk about it. . . . We do the social stories whenever he needs it then he repeats it back to me – what is expected of him in new situations.” [#15]

“I joined the local county autistic society here to gain information for myself. I wanted to be around other parents to learn about their experiences and see how we all have things in common. . . I found that very, very helpful.” [#1]

“So I have learned to carry my own files. I carry [name’s] list of medications. I have learned to take his whole medical history with me. When I go to certain meetings at school, I take my notebook.” [#8]

## *The Challenge of Communicating*

An unexpected theme that evolved as transcripts were analyzed was that of the challenge of communication. Participants used words, phrases, and acronyms unfamiliar to many people, including some professionals. The language used by participants was often the language used by schools when a child receives services in accordance with the Individuals with Disabilities Act (IDEA). An understanding of the language used by parents – or at least a willingness to learn the language - can be important when professionals work with the parent of a child on the autism spectrum (see Table 2).

“He has speech and O.T. and . . . he went to PPCD” [#9]

[Services received] “adaptive P.E. . . .He doesn’t do a lot of stemming. . . .We went through Tri-Care. [#4]

“Our first ARD meeting . . . He did spend time in P.A.S.” [#1]

“You know there’s Early Childhood . . . There’s ECI that can help you.” [#15]

“. . . so she referred us to ITIP. . .” [#13]

“Like on his IEP at school....They moved him to Developmental 1”  
[# 14]

Table 2 Acronyms and Language Used by Participants

Acronyms and Words Used By Participants	Meaning of Acronyms	Definitions and Explanations
ARD	Admission, Review, and Dismissal	A committee meeting of educational staff and a child's parent(s) wherein an IEP is created or reviewed, instructional setting code and speech therapy indicator are set, and, all required related services are determined.
D-1	Developmental First Grade	Children who are not developmentally ready for first grade may be placed in a D-1 classroom.
ECI	Early Childhood Intervention	Programs and services provided to infants and toddlers with developmental delays from birth through age two.
IEP	Individualized Education Plan	Individualized Educational Program (IEP) describes the special education and related services specifically designed to meet the unique educational needs of a student with a disability.
ITIP	Infant and Toddler Intervention Program	Early Childhood Intervention (ECI) supports young children ages birth - 3 who have developmental delays or disabilities. Support is provided by promoting nurturing relationships, healthy development, positive learning experiences, and community involvement.
PAS	Principal's Alternative to Suspension	A classroom setting in which students complete assignments from their regular teachers under the supervision of the PAS teacher. . . . Students who do not maintain acceptable behavior in the PAS room will be suspended from school (LISD.net – hhs.

Acronyms and Words Used By Participants	Meanings of Acronyms	Definitions and Explanations
PPCD	Preschool Programs for Children with Disabilities	A special education program that offers a continuum of services to preschool children ages 3-5, identified through the Admission, Review, and Dismissal committee process. The program offers a free appropriate education to children identified with a disability, beginning on their third birthday. (Region 14: Education Service Center)
P.T.	Physical Therapy	The treatment of physical dysfunction or injury by the use of therapeutic exercise and the application of modalities, intended to restore or facilitate normal function or development. Also called physiotherapy.
TRICARE	Department of Defense's managed health care	Managed health care program for active duty military, active duty service families, retirees and their families, and other beneficiaries (Office of the Assistant Secretary of Defense, 2005)
WIC	Women, Infants, Children	Serves to safeguard the health of low-income women, infants, & children up to age 5 who are at nutritional risk by providing nutritious foods to supplement diets, information on healthy eating, and referrals to health care.
Adaptive P.E.	Adaptive Physical Education	Diversified programs of developmental activities, games, sports and rhythms suited to the needs, interests, capacities, and limitations of students with disabilities

### *Parents' Experiences in Accessing Services*

The second research question used to guide this study asked, “What experiences have parents/guardians had in accessing services that include family therapy?” Parents were asked the following questions in an effort to obtain information that could provide answers to this question: (a) “What types of services has your child (identified with an ASD) received?” (b) “What types of services or assistance have you received as a family (related to your child’s ASD)?” and (c) “What have been your experiences in working with mental health professionals (related to an autism spectrum disorder)?” According to the information provided by parents, most of the services received by children with an ASD and members of their family were obtained from the following sources: (a) the schools, (b) private providers (c) medical and treatment facilities, (d) community services, and (e) conferences.

Parents’ responses to questions about services revealed that most services received by children and families related to the child’s ASD were provided by the school district. All parents who were interviewed reported that their child has received some services through the schools to address characteristics associated with the child’s autism spectrum disorder. Some children also received services outside of the school system.

### *Individual, Child Focused Services*

The most common services received by children with an ASD were speech, occupational therapy, counseling, and social skills. It was difficult to determine exactly which services each child received because some parents had difficulty remembering the services their child received at school. The researcher was familiar with the services offered in the school setting, but some parents' descriptions of services were too vague for the researcher to determine exactly what services the child received. Parents who stated that their child received services outside the school setting referred to psychological or counseling services more often than any other service. When parents were asked about the services their child received, all but two of the parents interviewed referred to educational placements. Some of the placements parents mentioned were D-1 (developmental first grade), Resource, PPCD, CM, Bridging, and Inclusion.

### *Family Services*

Parents of children recently identified with an ASD seemed less aware of the services offered by the school district and the community. Several participants made reference to programs provided by the school district for parents of children on the autism spectrum but stated that they had not attended. A few parents stated that they had not needed any type of services for the family. Few parents indicated that they had participated in programs

outside the school system such as the autism society, support groups, or conferences. The most commonly named service received by parents was in-home training. This service was provided to families by the school system when specific criteria were met.

### *Parents' Experiences in Working with Mental Health Professionals*

When asked about their experiences with mental health professionals, the responses of parents varied. Some parents described very positive experiences, while others described negative experiences. Mental health professionals who were described favorably by participants were knowledgeable of ASDs, respectful of the parent's opinions and feelings, and willing to serve as an advocate for the child and family with the school system. Some psychologists and counselors employed by the school district also served as advocates for the child by working with staff who did not have an adequate understanding of ASDs. Regardless of parents' experiences, a common theme was that parents' experiences with professionals can be important to the child's development and family's welfare.

“Actually it's been very positive. I'll give you that. You know, they've had some great ideas that, you know, we've used. I'm pretty creative when it comes to stuff, so I usually take what they say and what I know and put them together and come up with a solution, you know, on what is best for him.” [#5]

“Very interesting. I've had everything. . . . Our family doctor actually diagnosed our daughter with pervasive development disorder two years prior to our accepting that it was a medical condition and was even related to the Asperger's/autism spectrum, and then I've been to neurologists that just pass it off as ADHD with non-hyper. . . because she wasn't severe - disregarded it . . there were so many things that we

could have done to help her earlier that just weren't done because we had professionals telling us, 'Why are you even here?' So I've had a whole range of things, and even the family doctor that said it may be pervasive development disorder was, 'Well there's nothing you can do about it,' so you know, kind of the same attitude. . . .and no one told me at that time there might be some information I could get that could help me unlock how to communicate with my daughter. . . .and then I've run into [school psychologist] within the school district that helped me realized that my daughter doesn't even read non-verbals. I did not understand that because she memorized me well enough that I didn't see that. He was extremely helpful in analyzing that, . . . so he was much more truly concerned with helping her rather than, 'You're not severe enough to worry about doing anything with.' So I've had a wide array of experiences . . . ." [#10]

"At one time, we were involved with a psychiatrist in this area and the psychiatrist, unfortunately, was not well-trained in the field of autism and felt like we had done an injustice to our son in the fact that he was labeled this. . . . I had a lot of difficulty with this man due to his negative attitude towards the diagnosis." [#4]

"Um. The second individual - this was not through the school - she didn't think anything was wrong with him. There was some incident at school, and I had to take him in, and we kind of had some talks and stuff. I think she talked more to me than she did to him. So there wasn't - she didn't see anything. She kind of went 'I think the staff is kind of over-reacting. He's a great kid. I don't see the problem that they are seeing,' and went to me wanting him to perfect and stuff like that, so it was not good. You know I didn't get anything from it, and I don't think he did either. The first individual counselor he went to see was a um, I think it was called play therapy. He really enjoyed that time. I felt he could really talk to her about things that he couldn't to us necessarily, or he could just play with the stuff, and she would talk to me after about what she had seen and what he was doing and things like that. That, to me, provided more information than the second counselor did. We didn't go back to that second counselor. It was very uncomfortable." [#6]

"Oh! They don't communicate with the school. The school doesn't communicate with them. It's like they don't communicate with each other. You're sent to a specialist. 'Why are you here?' 'Didn't you get the file?' It's like starting from ground zero each and every time. . . . Some of them have been exceptionally good because they have let [name] talk. They have let [name] tell what's going on. Others don't

want to hear it from a child. When you tell the child, 'Tell the doctor what's going on.' They look at you like, 'You're the parent.' Yeah, I'm the parent but he's the patient, and the patient has feelings. The patient has a say so, and many of them look at me when they give me a diagnosis or they give me my choices, and I turn to [name] and I kind of tell him. 'Well what do you think, [child's name]?' It's like, 'Well you're the parent,' but, he's the patient, and I try to involve him in everything. Some of them have been very understanding. Others don't like it to much." [#8]

Parents' responses emphasized the role of the mental health professional as an advocate for the child and the family.

"I felt like the district had taken many steps to anticipate future problems, especially when my son was moving from grade to grade. . . . At the beginning of every school year in grade school, someone—a psychologist or someone from the district would come and notify my son's teacher and talk to them about him coming in and what difficulties they might encounter and how they might approach this in the classroom to make his transition as easy as possible. I find these things very helpful, and, unfortunately, when they get in the older grades this is not as easy to do." [#1]

"With Dr. \_\_\_\_\_, it's been a very positive experience. Our pediatrician was the first one who put us in touch with her, and she was the only person she wanted us to see. . . . She was very thorough, very professional. All her testing was very thorough, and I think her diagnosis is accurate. I've read a lot of stuff on Asperger's Syndrome, and I know my son, and I approve of her diagnosis. Our relationship with her has been very positive and open. It's been a very positive experience. . . . I have found Dr. \_\_\_\_\_ to be a wonderful advocate for us, and that is what I wanted from her. I wanted somebody who knew what my son needs and was able to say and actually put it in writing - that this is what I would like to see in the ARD . . . and in that respect, she was extremely helpful because now it's there. It's law. If I walk into the cafeteria, and he is not sitting at the end where he has some elbow room and doesn't have to smell another child's food, you know - if someone brings pickles for lunch and it's a big disaster . . . and so that's what I want and I think other parents would like to have - another individual who would advocate for them and who knows how the ARD system works and would also be willing to be in the ARD with them if needed. . . . she was a wonderful advocate for us." [#9]

### *Families' Experiences and Family Therapy*

The third research question used to guide this study was, “When parents/guardians have a child with an ASD, what do the family’s experiences with service providers suggest to family therapists interested in meeting the mental health needs of the family?” Participants were asked to respond to five interview questions related to this research question: (a) Are there services that you or a member of your family (including a family member identified with an ASD) have not received but that you believe would be (or would have been) beneficial? (b) What would you like mental health professionals to know about working with individuals with autism spectrum disorders and their families? (c) Based on your experiences and observations, what types of mental health services do you believe may be helpful in meeting the needs of individuals and families dealing with issues related to an ASD? (d) What is your knowledge of/or experience with family therapy? (e) What suggestions do you have for improving mental health services for individuals who have been diagnosed with an ASD and members of their family?

An analysis of participants’ responses revealed a great deal of overlap in parents’ responses to three interview questions. Questions that resulted in overlapping data asked about the services parents had not received but believed would be beneficial, mental health services parents believed would be beneficial in meeting the needs of individuals on the autism spectrum and their families, and suggestions for improving services. As a result of the overlap in responses, parents’ responses were

combined for the purpose of analysis. Parents expressed numerous needs, but common themes emerged in the areas of (a) training and education, (b) support for parents, (c) social skills training, (d) counseling and family therapy, and (e) services and educational placements in the schools.

### *Autism Spectrum Disorders: Training and Education*

As parents shared their own lived experiences, they spoke frequently of the challenges they had encountered due to the lack of information about ASDs. Participants expressed interests in training and education for the public in general and for parents but were especially interested in training for professionals. Parents wanted the public to understand about their children.

“The perception people have of autism is a totally non-participating person in society, and that’s not at all the case. Many of your Asperger’s kids are actually more intelligent and have gone on to do great things, and so I think public education arena would be very helpful for anyone with Asperger’s.” [#10]

“. . . for parents that don’t understand what their child is going through, I think there should be classroom instruction for that family.”

“Sometimes we don’t want to accept that something is different with our child . . . but I think there should be some classroom instruction to deal with this.” [#14]

“Parent education because it took me years to figure out how to deal with her, how to approach her, how to discipline, how to communicate with her, . . . I still don’t feel comfortable with how to motivate her in situations – so there’s an element of – I would say education.” [#10]

“Share everything you’ve learned – success stories, coping strategies, books, anything like that . . . share resources. If the counselor knows of any resources or whatever, or if they could recommend this web site or this group . . . anything that you run across . . . maybe compile a list.

... I also wish the teachers would receive information or training at some point as to what Asperger's is. ... I don't think teachers understand. An Asperger's Syndrome kid looks normal. He looks like I look. ... They think he is lazy or rebellious or different. Teachers don't know how to respond." [#6]

"I wish there could be training or something brought in for school personnel or with the family to help train the family to go into the schools themselves and approach this maybe with an administrator or with the teachers to try to educate or make the general ed. teachers more knowledgeable about this." [#4]

"I think in general if the regular teachers ... they need to be more educated about what it is and not just have that term thrown at them ... you know, a paragraph about what it is." [#3]

"All their teachers – I'm talking about high school now, but all their teachers should understand that they are different. Their thinking is different from most kids in the class ... " [#14]

"Teachers need to know something about this disorder because that's where the child is spending the majority of his time. That where he's socializing. That's where he's interacting. That's where he's going to have a lot of the problems he's having. My son's problems were even more pronounced at school because he was around other kids that didn't understand him. He was around teachers that didn't understand him. ... They didn't notice that he was obsessing. They just thought he was out of control. ... So I think the first step is to train teachers, and school personnel, and pediatricians." [#2]

"I think pediatricians need to know more than they do, and they need to be able to say, well maybe he's a late talker. You need to go see an audiologist – instead of waiting till three and you've already lost a year and-a-half ... ECI. ... I didn't know about that until my son was four, and I thought, "Why didn't anyone ever tell me this?" [#15]

"... every police officer should go through some type of mental health program so that they can recognize the signs of people who have these concerns at all levels. ... So the mental health world needs to train the people that deal with our children in society at a high level, not just in passing." [#20]

### *Support Needed for Parents*

The need for support was expressed in many ways. Parents wanted to meet other parents who had a child on the autism spectrum. Some participants suggested support groups and mentors. The parents who participated in this study wanted other parents to know that they were not alone.

“Maybe even family support groups. I don’t know if they have those or not. I haven’t heard of any.” [#12]

“I think that parents need mentors . . . somebody that we can talk to and maybe share our ideas and feelings on something because I think if you have a person who is more knowledgeable maybe in one area, if they could share their resources and their knowledge with you...” [#1]

“I think a family group thing where you have . . . other families that have the same problems is helpful to the parents . . .”

“To know that there are people out there. . . . They’re not alone.” [#1]

### *Social Skills Training*

Throughout this study, parents spoke of the need for social skills training for their children. They wanted this training to help their children both at school and at home. Some parents wanted counseling that would include social skills training.

“I would like to see some sort of counseling in some sort of group, maybe in his school with other children with Asperger’s, with other children who – who are just not getting this stuff – who need to be taught.” [#3]

“I know he received a lot of help in dealing with the social aspects and the social skills. Sometimes I feel like he might have needed more help in that area – with the social interactions.” [#1]

“. . . something where they learn how to read situations and read facial expressions. They are very important in our family . . . Now he knows the faces by rote and knows expressions by rote and it calms him. . . .

any type of service that can calm us because it has been difficult.”  
[#11]

Several parents spoke of counseling received by different family members. Few spoke of family counseling, although many of the issues parents described were family issues. Two parents clearly articulated their desire for family counseling.

“ . . . I dream of family counseling with parents . . . counseling on how you handle the most absurd situations you find yourself in. . . . I think that family counseling is almost as important - or more important than individual counseling for the kid because the parents are the ones that direct that kid and you know if you constantly hitting a brick wall, you just give up.” [#10]

“So I have been looking for another counselor who can give us family counseling and I have found it’s very difficult. . . .” [#11]

### *Suggestions for Therapists*

“I have often wished that they had it specialized. You know how they have family counseling or Christian counseling or sex and marriage counseling. You know, Asperger’s counseling would be nice. If I knew that his counselor was educated in it . . . I think that would be helpful.” [#11]

“I think that if there are people that specialize in that [counseling]. They need to advertise themselves, and if there is someone who specialized in that I would definitely look into that.” [#15]

Not only did some parents express a need for family therapy, but they articulated their needs – specific unmet needs that could be addressed in therapy.

“ . . . I have an answer that wants to jump out. It’s to help the child and the parents let go of the shame. The child is aware of being a burden and the parent . . . a sense of loss. . . . Help them resolve any issues of

guilt. Our belief, currently, is that we have contributed to this condition by voluntarily submitting to baby inoculations when at the time everything inside of me was telling me not to let him have the cocktails. . . . what if I had fought a little harder and could've prevented this. . . . I'm thinking about helping parents to deal with . . . there's nothing abnormal about these feelings – to some degree – at some points, I felt shame. It took me a while to get over that, but there is nothing to be ashamed about – that I couldn't produce a healthy offspring . . . m-m-m . . . because in my eyes now, look at it, there is nothing abnormal about my son. He's just the way he is. Back to the questions – the counseling profession could help the parents get over that. Once you get past that, those layers of mixed emotions, you can face and deal with what you've got head on without having to deal with it through the layers of emotions. That's what I think would really help. As far as counseling goes – other parents - to let them know that this condition – if their child does indeed have similar characteristics – is that they can get better, there is a light at the end of the tunnel, and it is a journey that does have an end, you know, a favorable end that can be directed.” [#7]

“Collectively with the parent – come up with a game plan – a game plan that will establish purpose for the child and the means for the parent to support that purpose. To establish the roles in how they are going to face their future. It is the unknown that scares all of us. The mental health people can help parents and the child . . . ‘This is what we are going to do – we don't know what you have, but we think we can help you like this.’” [#8]

“. . . to find out that it's not their fault that their child's that way.” [#1]

As parents talked about what they wanted and needed, some had more recommendations than others. All participants had some something to say. One parent talked about what he felt his son needed then ended with the following statement:

“I want health professionals to know that sometimes we don't know what we want. We don't know what we need. Sometimes the communication of what is offered doesn't make any sense and you just say, ‘I don't want that. I don't need that.’ . . . ‘What do you need?’ . . . ‘I don't know,’ . . . and, even though I'm sure of it as far as wanting

something, I don't know what it is. It is hard for me to communicate to them what I want . . ." [#20]

### *What Parents Want Mental Health Professionals to Know*

Numerous themes were abstracted from interview transcripts but none was more apparent than the theme that developed in response to the question asking parents what they wanted mental health professionals to know about working with individuals with autism spectrum disorders and their families. Independently of each other and without prompting, the majority of parents responded that they wanted mental health professionals, teachers, and other people involved with their child to understand that each child on the autism spectrum is unique.

"I would like them to be aware of the extreme range of symptoms that they are going to see . . . the extreme diversity in these people." [#10]

"I would like for them to really understand the vast spectrum."

"Every case is individual . . . what may work for some – or 10 – may not work for my particular child." [#4]

". . . I still see individuals - when you mention autism, they think of non-verbal, head-banging, or self-injurious people." [#1]

"You can't lump everyone in one category. You have to treat their specific problems that deal with what they've got." [#2]

"I think that some of them [mental health professionals] have this cookie cutter image in which very child fits . . . each child is an individual." [#8]

"The cookie cutter approach can be more detrimental than helpful . . . I have noticed a want to force a fit into a category for the sake of efficiency. . . . There is no such thing as a typical case, but that also means that there is not a typical solution either, and from a manager's perspective, how do you support that?" [#20]

“I would hope that they know that there are so many different levels.”  
[ #9]

“With the individual, it is so individualized. You can’t put them in a box. Everybody’s different and to different degrees.” [#12]

“. . . the conventional wisdom is not appropriate in our situation.” [#11]

“Each person is an individual . . . so it’s so hard to say one thing is gonna work for one ‘cause it won’t or it might . . .” [#21]

### *Knowledge of and Experience with Family Therapy*

In order to understand what participants’ experiences suggested for family therapists, parents were asked, “What is your knowledge of or experience with family therapy?” Four participants responded, “None.” Four parents responded that they had not had family therapy. Three participants responded with words such as “limited” or “very little” One participant replied, “You’re about it.”

Two participants stated that they had participated in family therapy. Two others had been exposed to family therapy through psychology classes. One participant’s response indicated some knowledge of family therapy based on a spouse’s educational program and “plans to do family counseling.”

Additional responses by participants to the question asking about the parent’s knowledge of or experience with family therapy indicated that these participant’s understanding of family therapy may be somewhat vague or inaccurate. Their responses were as follows:

“Don’t have any other than the play therapy and then that individual [therapy] . . .” [#6]

“My [child] . . . has seen a psychologist or psychiatrist since he was in [grade]. When we saw Dr. \_\_\_\_\_, he always met with [name] the first 30 minutes then with us for 15 minutes.” [#17]

“[Parent’s employer] offered counseling support or family counseling services, so I called and signed up the family and went [to the counselor] for six visits to talk about \_\_\_\_\_. He spent some time alone with [child] – a couple of sessions – and a couple of sessions with us [parents] alone – and counseled us to sue the school district.” [#7]

### Summary

The findings of this study are based on interviews with 21 parents of children with an ASD. In these interviews, parents shared their perceptions of family life with a son or daughter identified with an ASD and discussed their attempts to access services that addressed the needs of their child and other family members. Those parents also shared suggestions for services, their knowledge of or experience with family therapy, and what they wanted mental health professionals to know. The findings of this study provided information about the impact of ASDs on family life, the impact of the school experience on the family, and the need for services that consider the uniqueness of every child on the spectrum and the needs of the family.

## CHAPTER V

### DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS

The purpose of this study was to examine family life from the parent's perspective when a son or daughter had been identified with an autism spectrum disorder (ASD). Parents' experiences in accessing services for both the child and family were explored. Finally, this study examined what parents' experiences suggest for family therapists interested in meeting the needs of individuals on the autism spectrum and members of their family. This chapter includes a discussion of the findings and implications of this study. Recommendations for family therapists and for future research are provided. The limitations of this study are also presented.

#### Discussion

Parents who participated in this study provided information about family life when a son or daughter had been identified with an ASD. Although parents' experiences varied, common themes emerged as interview transcripts were read and analyzed. Most parents viewed their child's ASD as a family condition and concern. These parents shared how the characteristics of their child's ASD impact every-day family life and relationships. Participants described challenges related to changes and routines, school related issues, social situations, and sensory issues. The resiliency of those who participated in this study was evident. Parents shared strategies they had

used in dealing with the challenges of their every-day life. They also described ways of coping with the stressors that frequently accompany an ASD.

As parents shared their experiences of family life with a child on the autism spectrum, they also spoke of their child's strengths. Parents' descriptions of their children included phrases such as "kind and caring," "very sensitive," "very sweet-natured," "loving and outgoing," "a lot of fun," "compassionate," and "honest and reliable." One mother said of her son, "He is my hero. He is very strong in character. He is a very honest person. I admire him a lot. He's been a gift."

Participants described the services their children had received. The majority of services described by parents were provided by the school district. Other than educational placements and modifications, the most common services received by children identified with an ASD were speech therapy, occupational therapy, and counseling. Several parents expressed an interest in social skills training for their child while others indicated that their son or daughter received training in this area but wanted their child to receive additional social skills instruction. A number of parents seemed confused about whether their child was receiving social skills training and who was providing these services.

Parents provided information about the services family members had received. The most common service received by families was in-home training, a service provided by the school district in specific types of situations. Some family members had also taken advantage of other services offered by the school district for family

members. These services included family counseling and group meetings for parents, siblings, and the child on the autism spectrum.

Many of the participants in this study depended largely on the services offered by the school district to meet the needs of their child identified with an ASD and other family members, but some parents did access services outside the school system. It seemed to the researcher that three factors were related to whether parents sought outside services: (a) whether the parents perceived a need for services other than those provided by the school system, (b) whether parents seem to feel that the school system was responsible for meeting the needs of their child, and (c) whether parents were aware of services that might be available in addition to the services provided by the school system.

Parents were asked about their experiences in working with mental health professionals (related to their child's ASD). Some parents described very positive experiences with mental health professionals while other parents described less helpful experiences. In some cases, parents had had both positive and negative experiences. Some of the things parents described as helpful were (a) ideas and suggestions shared by the professional, (b) information that helped the parent understand their child (i.e., informing the parent that their child was unable to read non-verbal cues), (c) knowing that their child was able to share concerns with the professional, (d) the professional allowing the child to talk, and (f) the professional serving as an advocate for the child

(i.e. communicating with the schools, putting recommendations in writing for ARD committees, and letting teachers know what to expect from the child).

Concerns shared by parents when asked about their experiences with mental health professionals were often the same concerns that these and other parents expressed about other professionals such as physicians. The experiences parents found troubling were (a) inaccurate diagnosis and information, (b) conflicting information from professionals, (c) inadequate information about possible interventions, (d) blame of parents for the child's problems, (e) a negative attitude towards the diagnosis of an ASD, (f) not listening to the child, (g) blaming the school for the difficulties the child was experiencing, and (h) not communicating with the school.

When parents were asked what they wanted mental health professionals to know, the majority of parents stressed the need for mental health professionals to understand the uniqueness of each child on the autism spectrum. Parents emphasized the need for professionals to understand the wide range of conditions found on the spectrum. They wanted professionals to understand that children identified with the same condition can have characteristics that differ and are unique to the individual. Although not every parent responded in the same way to this question, the majority of parents provided responses that were amazingly similar regardless of the age of their child, the severity of their child's condition, or the challenges faces by the family.

When asked about the services they would like to see and their ideas for improving mental health services, some participants had numerous suggestions while

others had little to say. One thing that all parents agreed on was the need for “training.” Participants wanted to see more training and education for parents, professionals, and the community at large, but the most common request was for teacher training.

Parents were asked about their knowledge of or experience with family therapy. Although a few participants were knowledgeable about family therapy, responses to this question indicated the limited knowledge most parents had of family therapy. Several participants indicated the need for services that family therapists provide but did not seem to be aware of the availability of such services.

Finally, this study considers what parents’ experiences suggest for family therapists interested in meeting the needs of individuals on the autism spectrum and their family members. Throughout this study, parents conveyed the importance of professionals having a thorough knowledge of ASDs. Family therapists need to be aware of the ways characteristics of an ASD can impact the individual on the autism spectrum and his or her family members. Therapists also need to have an understanding of the types of services and interventions that may be helpful in meeting the needs of this population. Communicating with parents of a child on the autism spectrum may require some understanding of the terms and acronyms used when referring to sensory issues, early childhood and special education programs, and common interventions for children identified with an ASD.

Parents who participated in this study referred to ASDs as a family condition. These parents articulated their need for services, describing the types of services they wanted. Participants spoke of the need for services that address the need of the individual with a spectrum disorder and family members, yet most participants had limited knowledge of or experience with family therapy. Some parents suggested that it would be helpful if professionals who are knowledgeable about ASDs advertise their services.

### Implications

The number of ASDs diagnosed in recent years has soared. While the reasons for this increase are unknown, it is clear that ASDs impact the entire family. Some families cope well with the challenges that accompany an ASD, but others face immense obstacles. The reasons that some families dealing with ASDs function better than others are unclear, but the severity of the ASD and the specific characteristics that accompany the ASD may be partial explanations for this variation.

Many families dealing with ASDs need help. School systems are required to provide some services when an individual on the autism spectrum meets the criteria for special education services. These services are provided under the eligibility criteria for autism, but in many cases, families have needs that extend beyond the services available through the schools. These families need the help of competent professionals who are prepared to address their unmet needs.

Family therapists are trained to understand not only the dynamics of the family but to understand families as they function in the context of society. This understanding can be helpful when looking at how a child's needs impact the family and how the interaction between the family and the school system impacts family life. Many individuals and families dealing with ASDs require a variety of services. Family therapy has received little attention as a possible service for these individuals and families, but should be considered as appropriate for some families.

While family therapy may be an appropriate service for some families dealing with an ASD, most parents of children with an ASD who participated in this study had little, if any, knowledge of or experience with family therapy. Fifteen of 21 parents who participated in this study had at least one college degree, indicating that these parents are a well educated group of participants. Family therapists need to consider ways of educating the public as to the services they offer.

### Recommendations

Parents depend on the knowledge and competence of professionals in their areas of expertise. Parents of children on the autism spectrum must often deal with many different types of professionals. The ability of these parents to help their child with an ASD develop his or her potential often depends on the parent's ability to locate competent professionals who have the knowledge and skills needed for their particular profession. Parents of children with an ASD also need professionals with some understanding of the autism spectrum. Family therapists need to become

knowledgeable about ASDs. The characteristics of each child on the autism spectrum are unique, but through education and experience, family therapists can learn to recognize the characteristics of ASDs and to work effectively with these individuals and their families.

Based on the findings of this study, recommendations can be made for family therapists interested in working with individuals on the autism spectrum and their family members (Appendix H). Many of these recommendations have come directly from the information shared by parents. Parents have much to say about what they need, and their recommendations are worthy of careful consideration. One father expressed the needs of families this way:

“I’d like to add to how mental health professionals can help. Once they realize that this type of situation is unique – that they embrace the thought – if they don’t already . . . that they . . . need to treat the whole family as a unit and not the individual - because it doesn’t work that way. You treat the child by himself without an understanding of his support structure – it is bound to fail. You’re planting the seeds in unfertile soil. The soil is the family unit and the support structure, so it cannot happen without the support structure. If you’re not getting it from both ends, you are wasting your time and you’re most likely hurting the situation.”

### Research Considerations

An understanding of the experiences of the primary researcher in conducting this study may be helpful to those interested in conducting similar research in the future. Obtaining demographic data for this study presented certain challenges that may need to be considered when planning such research in the future. Some parents had difficulty remembering the child’s age when he

or she was first identified as having an ASD. Parents who had a child in school at the time of identification were more likely to remember the grade level of the child than the child's age. Some parents had difficulty answering whether their child had been identified with Autism Disorder, Asperger's Disorder, or PDD-NOS, stating that they had received more than one diagnosis. Due to varying opinions and diagnoses by professionals, some parents also found it difficult to provide information about the source of initial diagnosis or identification (physician, psychologist, school, etc.). Parents were unsure as to when a diagnosis was made when a professional had mentioned that a child might have a pervasive developmental disorder but had provided specific information related to the possible disorder. Future researchers may want to take these factors into consideration when planning their own research.

#### Future Research

Some research has been conducted on how ASDs impact the family; however, this research is limited in scope. Little research has focused on the characteristics of ASDs as they relate to family therapy and the use of family therapy in addressing the needs of family members who are dealing with an ASD. The following recommendations are made for future research that focuses on ASDs, their impact on the family, and the implications for family therapists:

1. Additional studies of family life as it relates to family therapy are needed with larger numbers of participants from various geographical locations.

2. Studies are needed that include the perspective of the child identified with an ASD and/or the perspective of siblings that have not been identified with an ASD.
3. Studies are needed that focus on the specific characteristics of ASDs and their impact on the family (i.e. how the need for routines and sameness impacts family life).
4. Studies are needed that explore which characteristics commonly associated with an ASD are most likely to affect family functioning.
5. Research is needed that explores the types of interventions most effective for dealing with family issues when a child has an ASD?
6. Studies are needed that help to answer the question, “When is family therapy an appropriate service for family members dealing with a child on the autism spectrum?”
7. Research studies are needed to determine how the needs of families differ based on the age and developmental stage of the child identified with an ASD?
8. Studies are needed to determine what school experiences most positively/negatively impact home life for the student with an ASD?
9. Research studies are needed to determine what aspects of home life most positively/negatively impact a students’ academic success and social functioning in the school setting?
10. Research is needed to determine which models and approaches are most effective in dealing with individuals identified with an ASD and members of their family.

## Limitations

The following limitations of this study prevent the generalization of the information obtained in this study to samples other than the one used in this study.

1. A random sample of participants was not used for this study.
2. The participants in this study had children who had some communication and self-help skills; therefore, transferability of the findings of this study are limited to situations where children have similar skills as those represented in this study.
3. Parents who participated in this study may not be representative of all parents of children with an ASD.
4. Audio recordings of the interviews conducted for this study may have influenced the responses of participants.

## Summary

This research study examined the family's experience of family life from the parent's perspective when a son or daughter had been identified with an autism spectrum disorder (ASD). Parents' perceptions of services received by both the child and family members were explored. Finally, this study examined what parents' perceptions of family life and their experiences in accessing services suggest for family therapists interested in meeting the needs of individuals on the autism spectrum and members of their family.

Parents participating in this study viewed their child's ASD as a family condition. They shared information about how the characteristics of their child's ASD

impacted the every-day lives of family members. They shared information about the services they have received and about the types of services they need. Parents stressed the need for mental health professionals to understand the vast differences found on the autism spectrum and the uniqueness of every child. They also wanted training for professionals and the community at large. Finally, parents participating in this study expressed the need for mentors, support groups, education for parents, counseling, and family therapy.

Family therapists are encouraged to develop a greater understanding of the characteristics of ASDs. Family therapy is suggested as an appropriate service for some families dealing with an autism spectrum disorder. Research is also recommended to better understand the impact of ASDs on the family, effective treatment options for families dealing with the family issues related to ASDs, and the role of family therapists in the treatment of individual and family issues related to ASDs.

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## APPENDICES

APPENDIX A

Letter of Invitation to Participate

Sherill Davis  
P. O. Box 271415  
Flower Mound, TX 75027  
[Date]

[Name and Address of Potential Participant]

Dear \_\_\_\_\_,

I would like to ask for your help with a research project that will focus on the experiences of individuals and families affected by autism spectrum disorders and the services they receive, including but not limited to counseling and family therapy. I am a doctoral student in Family Therapy at Texas Woman's University, a Special Education Counselor, and a Licensed Professional Counselor. I will be conducting this study this summer and will be interviewing parents and guardians of individuals between the ages of 5 and 21.

Participants will be limited to those who have or are responsible for the care of children between the ages of 5 and 21 who have been identified as being on the autism spectrum. When possible, participants will be parents of children who are believed to be in the high-functioning range of autism, parents of children with Asperger's Disorder, or parents of children who meet the criteria for Pervasive Developmental Disorder Not-Otherwise-Specified. This may result in the exclusion of parents of children with low-functioning autism but will allow for the project to focus on a sample of the population that is more likely to have certain experiences, needs, and concerns in common. Parents with children on the autism spectrum who will be excluded in this study will be those who have children who are unable to communicate, and have little or no self-help skills.

Interviews will be conducted at a private location that is agreed upon by you and the researcher. The interview is expected to last between one hour and one-and-a-half hours. These interviews will be audio-taped, but instead of using your name or the name of your child, a number will be used to identify all tapes, transcripts, and notes. You will be asked to provide information about your child such as the age and grade of your child and his or her specific diagnosis. The form will also ask for other information such as the relationship of the person completing the form to the child and about family composition. This information will take approximately 5 minutes to complete and will also be identified with a number instead of a name. The maximum time commitment required from you is estimated to be no more than three hours, but

in most cases will be less. Should you decide to participate, at the end of the interview you will be compensated \$25.00 for your time.

Participation in this study will be entirely voluntary. Your decision to participate or not to participate will not affect any services that you or your family may be receiving. Participation in this study can be terminated at any time.

If you would be willing to participate in this study or have any questions, please contact me by calling (214) 392-6253 or by returning the enclosed postcard in the envelope that is provided. If you have any questions about your rights as a participant in this research or the way this research is being conducted you may contact the Texas Woman's University Office of Research and Sponsored Programs at (940) 898-3378 or via email at [IRB@twu.edu](mailto:IRB@twu.edu).

Cordially,

Sherill Davis

APPENDIX B

Response Card

## Response Card

Card to be Signed and Returned by Participant  
to Indicate Interest in Study

You are being asked to participate in a research project conducted by Sherill Davis, a doctoral student at Texas Woman's University. This project will focus on the experiences of individuals and families affected by autism spectrum disorders and the services they receive (including but not limited to counseling and family therapy). If you would be willing to participate in this project, please sign your name below, provide a phone number where you can be reached and the best time to reach you, and return this card to Ms. Davis in the envelope provided.

I am interested in participating in this research project.

\_\_\_\_\_  
Name

\_\_\_\_\_  
Phone number

Best time to reach me \_\_\_\_\_

PLEASE MAIL TO RESEARCHER IN THE ENVELOPE PROVIDED.

APPENDIX C

Consent to Participate

TEXAS WOMAN'S UNIVERSITY  
CONSENT TO PARTICIPATE IN RESEARCH

Title: Family Experiences and Identified Mental Health Issues as Defined by Parents of Children with Autism Spectrum Disorders

Investigator: Sherill Davis.....(972) 539-6662  
Advisor: Linda Metcalf, Ph.D. ....(940) 898-2687

### Explanation and Purpose of the Research

You are being asked to participate in a research study conducted by Sherill Davis, a doctoral candidate at Texas Woman's University in Denton, Texas. The purpose of this research is to investigate parents' perceptions of their family's experiences of having a child or adolescent with an autism spectrum disorder as well as the family's experiences in accessing services, including counseling and family therapy. Parents/guardians will be asked about services that might be helpful to the individual on the autism spectrum as well as other members of their family.

### Research Procedures

For this study, the investigator will conduct face-to-face interviews with parents/guardians of children on the autism spectrum. This interview is anticipated to last between one and one-and-a-half hours. You will be audiotaped during this face-to-face interview. The purpose of audiotaping is to provide a transcription of the information discussed during the interview and to assure the accuracy of the reporting of that information. The researcher may take written notes during the interview for research purposes only. You will be asked to complete a form providing information about your child and your family. It is expected that this form will take about 5 minutes to complete. Your maximum total time commitment in this study is estimated to be no more than three hours.

### Potential Risks and Measures to Minimize Risks

*Loss of Confidentiality:* A potential risk related to your participation in this study is the release of confidential information. Measures will be taken to reduce these risks. Interviews will take place at a private location agreed upon by you and the investigator. A numeric code will be used instead of your name on the demographic form, audiotape, interview notes, and transcription of the audiotape. Signed consent forms will be stored separately from audiotapes, transcripts, interview notes, and demographic forms. Only the investigator, her advisor, and transcriber will have

access to interview tapes and transcripts. The only persons with access to the demographic information provided by participants will be the researcher and her research advisor.

Consent forms, audiotapes, transcriptions, demographic forms, and research notes will be stored in a locked file or closet in the investigator's home. The transcriber will be provided with a locking container for the storage of audiotapes, interview transcripts, and computer disks. Within a year of the completion of this study, audiotapes will be destroyed by cutting the tapes into small pieces, transcription diskettes will be erased and/or destroyed, and hard copies of transcriptions will be shredded.

It is anticipated that the results of this study will be published in the investigator's dissertation and possibly in other research publications. No names or other identifying information will be included in any publication.

Confidentiality will be protected to the extent that is allowed by law. Confidentiality is not protected in situations such as but not limited to those involving child neglect or abuse, disclosure of intent to harm oneself, or disclosure of intent to harm someone else.

*Fatigue:* A potential risk related to your participation in this study is fatigue during the interview. To avoid fatigue, you may take a break (or breaks) during the interview as needed.

*Emotional Discomfort:* You may find it uncomfortable to answer some questions asked during the interview. If you experience emotional discomfort related to the interview questions, you are invited to discuss this with the researcher. Also, you may take breaks, choose not to answer any questions that make you feel uncomfortable and/or stop the interview at any time. Any cost acquired as a result of your participation in this study will be your responsibility.

*Loss of Time:* The interview is estimated to last between one hour and one-and-a-half hours. The maximum time commitment anticipated from participants is three hours. This includes time spent scheduling an appointment, rescheduling if needed, discussing the research study with the investigator, reading and signing the consent to participate form, completing the demographic form, participating in the interview, and discussing any questions.

You will choose a day and time for the interview that is convenient for you. You may stop the interview at any time due to time constraints or for any other reason.

*Coercion:* A potential risk of this project is that you may feel coerced to participate in this project. There is no penalty for choosing not to participate. Your participation or lack of participation in this project will not affect, positively or negatively, any services that your child receives or that any member of your family receives. If you choose to participate, you may choose not to answer a question and/or stop the interview at any time.

### Participation and Benefits

Your involvement in this research study is completely voluntary, and you may discontinue your participation in the study at any time without penalty.

Direct benefits of this study will be limited to the following:

- A brief summary of the results of this study will be mailed to you upon the completion of this study.
- Compensation: At the end of the interview, you will receive \$25.00 as compensation for your time.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

### Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via email at [IRB@twu.edu](mailto:IRB@twu.edu).

Please indicate your consent to be included in this study by signing and dating this form in the space indicated below.

---

Signature of Participant

---

Date

---

If you would like to receive a summary of the results of this study, please list the address to which the summary should be sent.

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APPENDIX D

Demographic Information

Demographic Information

Interview Number \_\_\_\_\_ Date of Interview \_\_\_\_\_

Information about the child:

\_\_\_\_\_ Male \_\_\_\_\_ Female

Current age and grade of child on the autism spectrum:

Age - \_\_\_\_\_ Grade - \_\_\_\_\_

Age and grade of child when first identified as having an autism spectrum disorder:

Age - \_\_\_\_\_ Grade - \_\_\_\_\_

Specific autism spectrum disorder

- \_\_\_\_\_ Autism
- \_\_\_\_\_ Asperger's
- \_\_\_\_\_ PDD-NOS/Pervasive Developmental Disorder – Not Otherwise Specified
- \_\_\_\_\_ Rett's Disorder
- \_\_\_\_\_ Childhood Disintegrative Disorder
- \_\_\_\_\_ School district determined that child qualified for special education under the eligibility criteria of autism (specific autism spectrum disorder unknown or

Other diagnosis/diagnoses by physician: \_\_\_\_\_

Other educational eligibilities: \_\_\_\_\_

Initial identification of an autism spectrum disorder was determined by

- \_\_\_\_\_ School
- \_\_\_\_\_ Doctor
- \_\_\_\_\_ Psychologist
- \_\_\_\_\_ Other: (Please explain) \_\_\_\_\_

Educational placement of child:

- \_\_\_\_\_ All general education / mainstream classes
- \_\_\_\_\_ Some mainstream classes
- \_\_\_\_\_ Self-contained class (all day)

Race of child:

- \_\_\_\_\_ Caucasian \_\_\_\_\_ Hispanic
- \_\_\_\_\_ Black \_\_\_\_\_ Asian
- \_\_\_\_\_ Other \_\_\_\_\_

Information about the Participant:

Relationship of participant to child with an autism spectrum disorder

Mother       Father       Guardian       Other

The child on the autism spectrum disorder lives with his or her

Biological mother and father

Biological mother

Biological father

Biological mother and step-father

Biological father and step-mother

Adoptive parents

Adoptive mother only

Adoptive father only

Guardian

Other: Please explain: \_\_\_\_\_

Family Composition:

Please give the relationship of individuals living in the household (not name) to the child with an autism spectrum disorder. Also give the age of these individuals.

Relationship of Persons Living in the Household	Age
(Example:) <u>Brother</u>	<u>14</u>
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Highest Level of Education of Parent Participating

Some high school

High school diploma

Some college

4 year college degree

Graduate degree

Race of parent

Caucasian

Hispanic

Black

Asian

Other \_\_\_\_\_

## APPENDIX E

### Research Questions and Probes

## Interview Questions and Probes

### Interview Questions:

1. Tell me about your experience of family life with a (son/daughter) identified with an autism spectrum disorder.
2. What types of services has your child (identified with an ASD) received?
3. What types of services or assistance have you received as a family (related to your child's ASD)?
4. What have been your experiences in working with mental health professionals (related to an autism spectrum disorder)?
5. Are there services that you or a member of your family (including a family member identified with an ASD) have not received but that you believe would be (or would have been) beneficial?
6. What would you like mental health professionals to know about working with individuals with autism spectrum disorders and their families?
7. Based on your experiences and observations, what types of mental health services do you believe may be helpful in meeting the needs of individuals and families dealing with issues related to an ASD?
8. What is your knowledge of/or experience with family therapy?
9. What suggestions do you have for improving mental health services for individuals who have been diagnosed with an ASD and members of their family?

## Probes to be Used During the Interview

### Verbal Probes

Tell me more about that

Could you tell me more about that?

Is there any thing you would like to add?

Could you give me an example?

And by that you mean?

Anything else?

Could you elaborate on that?

### Non-Verbal Probes

Smiling

Laughing with participant

Leaning forward

APPENDIX F

Interview Guide

## Interview Guide

Hi! Thanks for coming! [Brief conversation to establish rapport]

I am conducting a study designed to learn more about the experiences of families when a child in that family has an autism spectrum disorder. The study also explores the experiences of family members in accessing services including counseling and family therapy and suggestions parents have for improving mental health services that address the needs of individuals on the autism spectrum and members of their family.

Before we begin, I would like to go over this form with you. It is a form that provides information about the study and asks for your consent to participation in this study. It gives information about people you can call if you have questions and how these individuals can be reached.

[Provide potential participant with a consent form]

I would like for you to read this form. I will answer any questions you have.

[Allow participant time to read the form]

Do you have any questions?

[If participant has not signed form ask if they are willing to participate in the study and if so, ask if they will sign the form. Remind them to check whether or not they would like to receive a summary of the results of the study.]

[If and when the consent form has been signed, thank the participant and provide the person with a Demographic Information form. *See next page.*]

This form asks for information about your child, your family, and yourself. It should take only about five minutes to complete - or less - then we will be ready to start the interview.

[When demographic form has been completed]

Remember, a number will be used instead of your name on the audiotape and other information. There will be no need to use names or identifying information during the interview. If you should do so, this will not be included in the transcript. Please let me know if you need to take a break, and remember that you may stop the interview at anytime. If a question makes you uncomfortable you can let me know, choose not to answer that question, or can stop the interview.

Let's begin.

[See next page]

[START TAPE]

Interview Number: \_\_\_\_\_

Date: \_\_\_\_\_

### Interview Questions and Probes

#### Interview Questions:

1. Tell me about your experience of family life with a (son/daughter) identified with an autism spectrum disorder.
2. What types of services has your child (identified with an ASD) received?
3. What types of services or assistance have you received as a family (related to your child's ASD)?
4. What have been your experiences in working with mental health professionals (related to an autism spectrum disorder)?
5. Are there services that you or a member of your family (including a family member identified with an ASD) have not received but that you believe would be (or would have been) beneficial?
6. What would you like mental health professionals to know about working with individuals with autism spectrum disorders and their families?
7. Based on your experiences and observations, what types of mental health services do you believe may be helpful in meeting the needs of individuals and families dealing with issues related to an ASD?
8. What is your knowledge of/or experience with family therapy?
9. What suggestions do you have for improving mental health services for

individuals who have been diagnosed with an ASD and members of their family?

### Probes to be Used During the Interview

#### Verbal Probes

Tell me more about that

Could you tell me more about that?

Is there any thing you would like to add?

Could you give me an example?

And by that you mean?

Anything else?

Could you elaborate on that?

#### Non-Verbal Probes

Smiling

Laughing with participant

Leaning forward

#### Closure

That is all in terms of the interview questions. Do you have any questions for me?

Answer any questions, listen to any thoughts that participants may wish to share related to the interview, and thank the parent for his or her participation.

Give participant \$25.00 for participating in the study.

## APPENDIX G

### Research Questions, Interview Questions, and Themes

### Research Questions, Interview Questions, and Themes

Research Questions	Interview Questions	Themes
1. How do parents/guardians experience family life when a son or daughter has been identified as being on the autism spectrum (ASD)?	1. Tell me about your experience of family life with a (son/daughter) identified with an ASD.	ASDs impact the entire family system. ASDs impact family routines/activities. ASDs impact family relationships/marriage School related to challenges Families may have difficulty communicating needs to professionals when child has an ASD.
2. What experiences have parents/guardians had in accessing services that may include family therapy?	2. What types of services has your child (identified with an ASD) received? 3. What types of services or assistance have you received as a family (related to your child's ASD)? 4. What have been your experiences in working with mental health professionals (related to an autism spectrum disorder)?	Child: Speech, O.T., & Counseling Family: In-home training Experiences with mental health professionals: knowledge & advocacy as positive experiences Professionals' lack of understanding as negative
3. When parents/guardians have a child with an ASD, what do the family's experiences with service providers suggest to family therapists interested in meeting the mental health needs of the family?	5. Are there services that you or a member of your family (including a family member diagnosed with an ASD) have not received by that you believe would be (or would have been) beneficial? 6. What would you like mental health professionals to know about working with individuals with autism spectrum disorders and their families? 7. Based on your experiences and observations, what types of mental health services do you believe may be helpful in meeting the needs of individuals and families dealing with issues related to an ASD? 8. What is your knowledge of/or experience with family therapy? 9. What suggestions do you have for improving mental health services for individuals who have been diagnosed with an ASD and members of their family?	Education & training as helpful and necessary. Support for parents through counseling & family therapy Social Skills training for ASD child: needed and beneficial. Mental health professionals need to see the uniqueness of every child Little knowledge of or experience in family therapy for majority of parents.

APPENDIX H

Autism Spectrum Disorders and  
Recommendations for Family Therapists

Autism Spectrum Disorders and  
Recommendations for Family Therapists

1. Recognize the wide range of behaviors and the different levels of severity associated with autism spectrum disorders.
2. Recognize the uniqueness of each individual on the spectrum.
3. Develop an understanding of each person's specific characteristics related to communication, interests, routines, social awareness, cognitive functioning, sensory issues, and motor coordination.
4. Obtain information about the person's experiences in a variety of settings.
5. Consider the impact of the ASD on each member of the family.
6. Recognize the strengths often associated with an ASD.
7. If the individual has a special interests, consider using this interest as a way of "connecting" with the individual.
8. Recognize that the individual may have a need for routines and that this need may impact the way he or she responds in a therapy setting.
9. Consider the individuals need for routines when assessing family function.
10. Prepare individuals with an ASD in advance for change (i.e., meeting in a different location).
11. Be aware of common communication obstacles when working with a person on the autism spectrum (i.e. difficulty or inability to "read" non-verbal cues;

difficult with abstract language, metaphors, and figurative language; literal interpretations of what is said such as “always tell the truth”).

12. Avoid words such as “always”, “never”, or “must” unless the use of the word can be taken literally.
13. Check for understanding of what has been discussed.
14. Do not assume that the individual understands what is expected in social situations. Be prepared to explain social situations and social rules.
15. Provide information in a written form when possible.
16. Consider the individual’s sensory needs in assessing situations and in working with an individual (i.e. ability to hear things that others may not hear; sensitivity to smells such as perfumes and lotions, sensitivity to bright lights). Remember that each individual will have different sensory needs.
17. Family therapists unfamiliar with the language parents’ use may need to
18. clarify the meanings of acronyms and terminology with parents and locate information to improve their understanding of the terms used by parents.
19. Family therapists need to be knowledgeable in the area of ASDs so as to assist in the identification of possible spectrum disorders, make appropriate referrals, and help families dealing with the characteristics of these conditions.