The Quality of the Sibling Relationship of Children Diagnosed with Autism

Kelly C. O'Laughlin
kellyol@pcom.edu

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THE QUALITY OF THE SIBLING RELATIONSHIP
OF CHILDREN DIAGNOSED WITH AUTISM

By Kelly C. O'Laughlin, MA, MS, MAMT-BC
Submitted in Partial Fulfillment of the Requirements of the Degree of
Doctor of Psychology
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PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
DEPARTMENT OF PSYCHOLOGY

Dissertation Approval

This is to certify that the thesis presented to us by Kelly C. O’Laughlin on the 9th day of April, 2009, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

Committee Members' Signatures:

Beverly White, Psy.D.

Robert Di'Tomasso, PhD., ABPP

Kathryn Soeder, Ed.D.

Robert A. DiTomasso, Ph.D., ABPP, Chair, Department of Psychology
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Benigno numine Ab uno discer omnes
By the favor of the heavens from one learn all
Abstract

Seldom has the quality of the sibling relationship between children with disabilities and their siblings without disabilities been explored, particularly via firsthand accounts from the non-disabled sibling, rather than from parental observations and reports. Furthermore, research has shown mixed results regarding whether or not the siblings of children with disabilities have increased internalizing (anxiety, depression, and obsessive compulsive disorder) or externalizing (attention deficits, hyperactivity, and oppositional) behaviors, psychosocial maladjustment, or impaired developmental stages, as opposed to siblings of children without disabilities. This study attempted to determine whether or not there was a correlation between the severity of autism disability, as measured by the Gilliam Autism Rating Scale-II and the Vineland Adaptive Behavior Scale-II Communication and Socialization domains, the quality of the sibling relationship, as measured by the Sibling Relationship Questionnaire, and perceptions of social and familial support in siblings of children with autism. Social support and familial support were measured by the Social Support Scale for Children. The only significant correlations identified were between the VABS-II Communication domain and SRQ Conflict domain. In addition, both VABS domains correlated with the SRQ Rivalry domain. A correlation between the non-autistic siblings' feelings of parental support and decreased communication abilities of the child with autism were significant.
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Chapter 1

Statement of the Problem

Sibling relationships afford unique opportunities for child development (Dunn, 2005). Siblings are developmentally important because of their emotionally uninhibited relationships, the impact of sharing their parents, and their daily contact and familiarity (Dunn). Research has provided evidence for associations between the quality of sibling relationships and children's externalizing (i.e., attention deficits, hyperactivity, oppositional, and conduct) behaviors and various aspects of deviance and antisocial behaviors (Criss & Shaw, 2005; Feinberg, Reiss, Neiderheiser, & Hetherington, 2005; Kramer & Kowal, 2005). There is also evidence for contributions of sibling relationship quality to depressive behavior and internalizing behaviors (Lobato, Kao, Plante, 2005; Richmond, Stocker, & Rienks, 2005). Positive effects of the sibling relationship, specifically increased empathy and stronger sibling bonds, have also been identified (Pike, Coldwell, Dunn, 2005; Pomery, Gibbons, Gerrard, Cleveland, Brody, Wills, 2005). As a result, understanding the quality and dynamics of a sibling relationship is important towards identifying positive development and adjustment problems (Dunn).

In the past, sibling research has focused on sibling spacing, family size, and sibling order, with variable outcomes and conclusions identified (Hetherington, 2005). Within the past twenty years, however, researchers of siblings have focused on four issues. First, research has explored the connections between sibling relationships and other social relationships, such as friendships and partnerships (Bryant, 1992 Dunn, 1988). Second, research has correlated the effects of sibling relationships on an individual's personality, and on social, and cognitive development (Hetherington &
Clingempeel, 1992; Patterson, 1982). Third, sibling research considered the roles of genetic and environmental factors upon sibling developmental outcomes and differences (Hetherington, Reiss, & Plomin, 1994). Finally, research has identified the developmental course of sibling relationships (Furman & Buhrmester, 1992; Buhrmester, 1992). These four research dimensions provide a systematic framework to organize and research sibling relationships (Dunn, 2005).

In the United States, approximately six percent of all children under the age of eighteen years have some type of disability (National Health Interview Survey, 2006). According to the United States Association of Retarded Citizens (2006) an estimated seven million "typically developing" American children have siblings with disabilities. These statistics support a potentially growing population of siblings of a child with a disability (NHIS) and also the need for sibling studies to incorporate this variable into research. The only clear conclusion is that when one child has a disability, the entire family unit is impacted, as a whole and as individuals.

On one side of disability research, a number of studies (Breslau & Prabucki, 1987; Dyson, Edgar, Crnic, 1989; Fisman, Wolf, Ellison, Gillis, Freeman, & Szatmari, 1996; Hastings, 2003; Lobato, Barbour, Hall, & Miller, 1997; McHale & Gamble, 1989; Nixon & Cummings, 1999; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, Shalev, 2004; Roberts & Lawton, 2001; Tew & Laurence, 1973; Tritt & Esses, 1988; Verte, Roeyers, & Buysse, 2003) confirm that the non-disabled siblings have a higher occurrence and/or potential for behavioral and conduct problems, social and/or emotional impairments and/or increased levels of depression or anxiety.
Other studies, however, (Bischoff & Tingstrom, 1991; Cuskelly & Gunn, 2006; Dyson, 2000; Ferrari, 1984; Giallo & Gavidia-Payne, 2006; Hannah & Midlarsky, 1999; Kaminsky & Dewey, 2002; Rivers & Stoneman, 2003) have failed to find any impact upon the non-disabled sibling. Furthermore, these siblings do not appear to experience higher levels of maladjustment and/or internalized or externalized behavioral and/or social problems than siblings of children without disabilities. Seligman and Darling (1989) reported that some siblings seem to benefit emotionally by having a sibling with a disability.

These outcome inconsistencies demonstrate a need for further studies on sibling outcomes to limit the scope to one specific disability, such as autism, rather than to attempt to generalize across the entire disability spectrum.

*Purpose of the Study*

The purpose of this study is to determine whether or not there is a correlation between the severity of autism disability and the quality of the sibling relationship. These differences will be identified via quantifiable measures that explore the quality of the sibling relationship and the perceptions of social and familial support as experienced by non-disabled siblings. This study seeks to obtain these results through the personal accounts of the individual siblings rather than through the accounts of parents as in previous studies (Kaminsky & Dewey, 2002; Rivers & Stoneman, 2003). Hastings (2003) suggested the need for further research to obtain these first-hand accounts because parents, specifically mothers, tend to be more negative when describing interactions and social qualities of the sibling without a disability.
The review of the literature will identify and explore the purpose and the role of siblings. Specifically, the literature will identify the impact of a child's disability and the possibilities that exist concerning the role of disability on sibling members of the family. Research will also define autism and its unique diagnostic features, and will address the impact that these unique issues have upon the sibling relationship as well as the feelings of social support.
Autism

Autism is a complex developmental disability that affects the normal functioning of the brain, which impacts a child's ability to communicate, understand language, play, and relate to others. Autism is one of five disorders that fall under the umbrella of Pervasive Developmental Disorders (PDD); these include Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Approximately two to six of one thousand children, ranging from one in five hundred to one in one hundred-fifty, have some form of autism/PDD (NIMH and CDC, 2007).

Diagnosis

In the Diagnostic and Statistical Manual of Mental Disorders-IV TR (American Psychiatric Association, 2000), Autistic Disorder, under the heading of Pervasive Developmental Disorders, is characterized by severe and pervasive impairment in reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities. Generally these impairments are evident during the first two years of life; however, many diagnoses are not made until ages four through five (NICHCY, 2007).

A diagnosis of autistic disorder is made when an individual demonstrates six or more of twelve symptoms across three major areas: (a) social interaction, (b) communication, and (c) behavior (APA, 2000). Impairment in social interaction may be manifested by the use of nonverbal behaviors such as eye contact, facial expressions, and
social interaction gestures. Impairment in communication may be manifested by a delay in or lack of spoken language development, difficulty initiating and/or sustaining speech, the use of stereotyped or repetitive language, and the demonstration of good speech skills with deficits in maintaining conversation. Because of communication deficits, children with autism have difficulty engaging in developmentally appropriate make-believe play or social imitative play. Children with autism also demonstrate limited stereotyped and repetitive patterns of behavior, interests, and activities that may be manifested by a preoccupation with a topic or item of interest. These children have an extreme inflexibility towards non-routine activities and likely need to follow a specific schedule at home and school. Many children with autism engage in repetitive movements such as rocking, twirling, or hand flapping. They may also engage in self-abusive behavior such as biting themselves or head-banging. Often they have a reduced sensitivity to pain, but are abnormally sensitive to sound, touch, or other sensory stimulation. Other behavioral challenges for these children include: physical inactivity or an appearance of passivity; highly selective eating habits, limiting of foods with similar textures or type; frequent temper tantrums, often for no known reason; and increased aggression, such as physically attacking or injuring others without seeming intent (Powers, 2000).

There are no medical tests available for diagnosing autism. An accurate diagnosis is based on the observation of an individual's communication, behavior, and developmental levels. Medical tests may be used to rule out other medical differential diagnoses. On initial observation, some individuals with autism may appear to have mental retardation, hearing impairments, behavioral disorders, or "eccentricities" (Autism Society of America, 2007). Individuals with autism may have these issues in addition to
a diagnosis of autism; however, a comprehensive assessment should identify the possibility of multiple concurrence and dual diagnosis. It is important for the clinician to distinguish autism from other medical or behavioral issues because intervention and educational programming for individuals with autism is unique in determining an accurate autism diagnosis (Autism Society of America, 2007).

*Autism Assessment*

In order to obtain a diagnosis of autism, one should obtain a comprehensive assessment from a multidisciplinary assessment team. Often the multidisciplinary team includes the following: a developmental pediatrician, child psychiatrist, and/or clinical or neuro-psychologist. Frequently consultations are also obtained from speech/language, physical, and/or occupational therapists. Most autism support agencies or groups can provide assistance with locating an assessment team or practice. In general, many referrals from general care pediatricians are made for children to be assessed further by developmental pediatricians. Most large universities and children’s hospitals have autism centers that can provide the initial diagnosis and/or ongoing treatment, or diagnosis referrals can be obtained from an individual’s local educational intermediate unit, child study team, or early intervention service provider. In 2000, the Centers for Disease Control funded several Centers for Autism and Developmental Disabilities Research and Epidemiology Network (CADDRE). The CADDRE Network is currently working on the Study to Explore Early Development (SEED) to help identify factors that may put children at risk for autism (CDC, 2007).
Screening tools and diagnostic instruments

Although a brief observation in a single environment should not be used to obtain a true picture of an individual's abilities and behaviors, a parent or caregiver's input and the developmental history of the child are important contributions to make an accurate diagnosis. Often during an initial assessment, a screening instrument may be used to assist in making an accurate diagnosis. The following are the most often used screening tools:

Gilliam Autism Rating Scale (GARS), Childhood Autism Rating Scale (CARS), Modified Checklist for Autism in Toddlers (CHAT), Autism Diagnostic Observation Schedule (ADOS), or Screening Test for Autism in Two Year Olds (STAT).

Although not necessary for an autism diagnosis, some psychologists may also administer an Intelligence Scale, in order to obtain an IQ score, and an Adaptive Behavior Scale, a scale of personal and social skills, in order to rule out a differential diagnosis or identify the best educational placement. The differential diagnosis of autism involves comparing the autistic behavior with non-autistic behavior. Other diagnoses that may need to be ruled out include mental retardation or speech/language impairments and medical problems associated with autism such as Fragile X syndrome or Phenylketonuria (PKU). The most common disorders that should be distinguished from autism include: mental retardation, language disorder, obsessive compulsive disorder, social anxiety disorder, and/or selective mutism.

Currently there is not a known cause of autism; however, research has provided etiological indicators. Genetics may be linked to autism origins (Ingram, Stodgell, Hyman, Figlewicz, Warkamp, & Rodier, 2000). It is not clear if it is solely genetics or if
it is a possible family-based characteristic (Constantino, Lajonchere, Lutz, Gray, Abbacchi, McKenna, Singh, & Todd, 2006). Some family studies have identified autism-like behaviors in family members other than in the child with autism (Constantino, et al, 2006 and Ingram, et al., 2000). Most recently, it has been suggested that the measles-mumps-rubella (MMR) vaccine may be linked to the development of autism. The Immunization Review Committee conducted a review of research on this topic and subsequently denied a causal connection between vaccinations and autism (Kaye, Melero-Montes, & Jick, 2001). Furthermore, The British Medical Journal reported that “the data provide evidence that no correlation exists between the prevalence of the MMR vaccination and the rapid increase of autism overtime” (Kaye, et al, 2001, p.2).

Disability Affects Family

Because of increases in population growth, overall life expectancy, and medical advances, the population of individuals who experience disabilities is likely to multiply. As this population increases, it is important to explore the effects of disability on family members, specifically parents and siblings. Presently the World Health Organization (July, 2007) estimates that ten percent of the world’s population experiences some form of disability. In fact, approximately six hundred-fifty million of the world’s population lives with a disability; two hundred million of these are children (WHO, 2007). In the United States, five to thirty percent of all children experience moderate to severe levels of chronic illness or disability during childhood (NICHCY).

The arrival of a child with a disability can either strengthen the family’s bond or completely dissolve the family unit (Shelton, Jepson, & Johnson, 1987). Families of children with disabilities tend to be more susceptible to emotional problems, have
increased feelings of guilt, and are extremely sensitive to criticism (Featherstone, 1980). The WHO (2007) reports that the manner in which society reacts to and understands disability further affects a family’s response to a child’s disability. This reaction may include the experience of or the perceived physical and/or verbal responses or criticism from strangers. Families of children with disabilities often experience financial hardships, social isolation, educational constraints, strained personal relationships, decreased participation in external activities, and lost opportunities for family members as well as for the child with the disability (McCubbin & Patterson, 1983).

Family systems theory provides “…a good foundation for the understanding and examination of dynamics within the family that has a child with [a disability such as] autism” (Berkell Zager, 1999). In general, all families are diverse and unique; each individual member affects other members and the family unit as a whole (Berkell Zager). According to family systems theory, children are embedded within multiple layers of these systems, all of which have indirect and direct effects on behavior (Bronfenbrenner, 1979). Within the family system itself, subsystems such as marital, parental, and sibling systems exist. Family members are interrelated; therefore, any event that impacts one member will affect all family members. Family systems theory also accounts for the outcome and response differences demonstrated by seemingly similar families. Family systems theory enables researchers to explore how the impact of subsystems, ripple effects, and multiple relationships affect overall outcome and development (Rivers & Stoneman, 2003).

From a cognitive therapy perspective, five interrelated factors such as, interpersonal/environmental context, an individual’s physiology, emotional functioning,
behavior, and cognition, are involved in conceptualizing human psychological development (Beck, 1985; Beck, 1995). All of these elements develop independently and interdependently among family members. This model is also inclusive of systemic, interpersonal, and cultural perspectives as variables that impact these previously stated, five interrelated factors (Friedberg & McClure, 2002). The manner in which children interpret these factors and their experiences shapes their emotional functioning. This interpretation is often impacted greatly by their parents’ or by caregiver’s own experiences and feelings (Beck, 1985).

Parents play an important role in the socio-emotional development of their children because children observe and model their parents’ behaviors and responses (Gibbs, 1993). As part of the modeling process, children observe a parental response, and depending on their own developmental stage, they process this response and make it their own (Stoneman & Brody, 1993). According to a family systems perspective, in order to identify and define the experiences of siblings of children with disabilities, an exploration into the effects upon parents should also be explored (Stoneman, 1995). A cognitive behavioral perspective further specifies that the cognitive schemas and subsequent behavioral responses is not created in a vacuum but is influenced by other family members, especially parents (Friedberg & McClure, 2002).

One of the greatest stresses experienced by parents is the “loss” of a child either through disability or through death (Rivers & Stoneman, 2003). Parental stress, experienced by having a child or children with a disability, is increased because parents often see their children who have disabilities as a symbol of “shared failure.” The presence of a medical disorder can potentially exacerbate this stress and lead to increased
conflict between parents that can significantly impact the other children in the family (Gray, 1998). The manner in which a parent reacts and responds to these stresses impacts the entire family unit by providing the response model for the entire family (Singers & Powers, 1993). It seems obvious that the parental acknowledgement and acceptance of a child with a disability (Gibbs, 1993) will provide a subsequent baseline for their other children and family members.

Family communication tends to be hindered when one member has a disability. In general all members have difficulty expressing their emotions for fear of exposing self-perceived “ugly emotions” (Featherstone, 1980). In order to understand more fully the effect of a child’s disability on parents and siblings, addressing the role of the child’s diagnosis is essential.

*Initial Disability Diagnosis*

When children are initially diagnosed with a disability the impact upon the family is similar to that of a family member’s death. Most families go through the stages of grief and loss as identified by Kubler-Ross (Shontz, 1965). “Loss is typically perceived when the reality of life is changed in such a way as to make it less preferred than wanted or expected. Such is typically the case for families when a member is diagnosed with a disability or health challenge” (Singer & Powers, 1993, p. 237). Family members must work through the stages of grief. When grieving an individual with a disability, it is not always possible for sorrow to be openly expressed. There may be responsibilities that need to be undertaken or arrangements that need to be implemented. Other people need to be supported, such as the other children in the family; this is in addition to the individual undergoing the grieving process. For example, social expectations often make
weeping unacceptable and the conventional wisdom that “men don’t cry” makes it very
difficult for many men to shed tears. “Other people may be embarrassed or impatient by
tears and see bravery as an admirable trait” (Beardley, 1997). Fear of the grieving
process stems from the fear of hearing “the worse news or having to hear what is being
denied” (Beardley, 1997). There is also the fear of losing control, hurting others, being
seen as a bad person, rejection, and the guilt associated with the fear of retribution for
these feelings (Beardley). After parents grieve the potential losses, such as their child’s
not attending college, not getting married, not having children, and/or not living
independently, they are able to move forward and cope with other challenges that may
come (Naseef, 1989).

**Denial**

In order for mothers to develop healthy attachments to their children with a
disability, they must resolve their own emotional feelings regarding the disability (Pianta,
Marvin, Bitner, & Borowitz, 1996). Maternal or paternal denial has a huge impact upon
the family unit. Essentially, if a parent is in denial about a child’s disability, chances are
that the sibling will also be in denial (Gibbs, 1993). When parents feel denial or feelings
of shame, their child will ultimately limit his or her own emotional expression of feelings
(Jaffe-Ruiz, 1984). Also, parents who do not come to terms with their child’s disability
or refuse to acknowledge the disability’s existence provide little support to their other
children. Parental denial impairs the lines of family communication and leaves the
sibling with questions and concerns unresolved and unanswered. Denial affects the entire
family, not just the member experiencing the denial (Powell & Ogle, 1985).
To counteract denial within the family, it is important to keep all family members informed, to support a sibling’s free expression and to respond to questions associated with the disability, with individual roles, and with responsibilities. “The extent and openness of parental communication with the siblings is an important factor that contributes to positive [sibling] adjustment [and outcome]” (Singer & Powers, 1993). There is an absolute necessity to be open and to explain information completely to the siblings of a child with a disability (Jaffe-Ruiz, 1984).

*Need for open communication*

More importantly, free self-expression and restricted family conflict actually limit the likelihood of the development of problematic behaviors between the sibling and the child with a disability (Dyson, Edgar, & Crnic, 1989). Parents who do not support open communication within the family unit may negatively impact and influence the well being of the siblings without a disability. Unsubstantiated fears and worries can be created and supported when misinformation or a lack of information about a disability is presented (Powell & Ogle, 1985). Family communication provides accurate information and the self-expression of feelings and anxieties. Family communication can be provided within the immediate family unit or from the support of other families that are managing a child with the same or similar disability (Jaffe-Ruiz, 1984). Older children should be provided with the best and most accurate information so that they can make informed decisions about their own futures, about levels of responsibility for the child with a disability, and about potential genetic considerations (Steiner, 1984).
Social supports

The existence and utilization of social and parental supports are necessary to ensure that the family unit is not negatively impacted (Boyd, 2002; Hanline & Daley, 1992). Social supports are known to improve family function (Hanline & Daley). Informal social supports, such as help from immediate and extended family, friends, and neighbors, are more effective than formal social supports that include help from professionals and agencies (Boyd, 2002). Parents who receive informal social supports, “relate better emotionally to their children and their children’s needs” (Boyd, 2002). Social supports not only have “direct, mediation and moderating influences on the behavior and development of children with disabilities,” but these social supports also have the “greatest positive effect on behavioral functioning.” Support is most effective when provided in response to the families’ or to an individual’s specific or individualized needs (Dunst, Tribette, and Jodry, 1997). Lazarus & Folkman (1984) report that problem-focused coping strategies towards stress are necessary in order to access needed social supports. For example, African-American families may enlist the informal social supports of their extended family members and therefore they may exhibit positive, correlated outcomes on behalf both of their family strengths and of this positive restructuring. In Latino families, informal social support from family and friends is not always beneficial to the competency of the family (Hanline & Daley, 1992).

Autism Effects

The complex features of autism and pervasive developmental disorders present unique challenges to parents, siblings, and families. Most notably, autism impacts communications, bonding, and scheduling, all of which affect the flow and structure of
routine family life. Specifically, children with autism often experience irregular sleep patterns, including sleeping fewer than four hours a night. These sleep difficulties are stressful on family members' emotional and physical states, and on the general safety of unsupervised children. Children with autism prefer consistency and can become easily attached to personal objects, making outings and changes in routine impossible (Lovaas, 1987). They also demonstrate odd and erratic behaviors, which often put family members at greater risk for psychological dysfunction (Rodrigue, Geffken, & Morgan, 1993). Families of children with autism tend to participate in fewer recreational opportunities, may have impaired family function, and increased feelings of distress about their children (Bebko, Konstantareas, & Springer, 1987).

Parents

Parents find it particularly difficult to nurture an unresponsive child and have difficulties tolerating the perceived rejection from their child with autism (Gilliam & Smith, 1983). Parents report that their most challenging problems were communicating with their children with autism, inappropriate or extreme behaviors in public settings, destruction of property in the home, obsessions about eating, toileting issues, improper sexual expression, and levels of aggression or violence (Gray, 1992). Employment challenges for parents and/or caregivers are also common among parents of children with autism (Bolman, 2006).

With divorce rate estimates for parents of children with autism in the eighty percent range (Bolman, 2006), it is not surprising that autism, more than any other disability, increases stress in parents and families (Bristol & Schopler, 1984). Specifically, parents frequently endure an extreme amount of stress as their children’s
developmental differences become more pronounced, not only while seeking an accurate diagnosis, but also after treatment services are obtained on behalf of their children (Gray, 1994). Until diagnosis is made, there is little that parents can do for their children with autism and also for their children without disabilities, which lead to parental feelings of helplessness. Adding to these feelings of helplessness are the parents' intense stress and concerns for the well-being of their other children. Parents also state that one of the worst effects upon their families is a decrease in family socialization and recreational experiences (Rivers & Stoneman, 2003). The added pressure of learning that early intervention and treatment tend to make behavioral change more favorable increases these feelings of hopelessness (Rivers & Stoneman).

Mothers

Mothers, more than fathers, are more likely to report severe levels of distress. This distress is due to their increased involvement in child-rearing, increased experiences on the receiving end of social reactions to their children’s public behaviors, and often, a decreased opportunity for escape through work or employment (Gray). Gray’s study also found that more than fifty percent of mothers reported that their children’s autism prevented them from attending work or employment in general. Fathers were less likely impacted, with only minimal effects upon work. The levels of maternal stress and behavioral problems of children with autism is one of the most significant stressors for families and couples (Hasting & Brown, 2002).

Post diagnosis

Feelings of stress are not limited only to the time periods leading up to diagnosis. After diagnosis is made and parents obtain an appropriate educational placement,
children's social skills, emotional regularity, and attention span tend to stabilize, and the levels of families' and of parental stress greatly decrease. However, when children with autism enter adolescence, parents tend to re-experience emotional instability as their children mature sexually and physically. Often, as children age and increase in size and strength, levels of violence become an even greater concern for families and parents. Gray (1994) noted that levels of aggression and violence tended to decrease during adolescence for individuals who demonstrated higher levels of aggression/violence during childhood. The reverse is true for children who were more calm, tranquil, and placid during childhood; they become more violent during adolescence.

The period of adulthood provides new challenges for families and parents because long-term care and future placement must be considered. Special education services end at the age of twenty-one years (Individuals with Disabilities Education Act). Although parents may maintain high expectations that their children will develop skills to live semi-independently and obtain some type of supervised employment, it is not always the case (Gray, 1993). In addition, individuals with autism demonstrate vast skill ability and functional behavior levels, making a parent's assessment of their own child's abilities frequently higher than they actually are. Factors further complicating this period are aging parents, adult siblings' responsibilities to their own families, and the loss of previously utilized extended family member.

Couples

With so many demands placed on parents throughout their children's life spans and the increased attention required of children with autism, the marital relationship tends to become a less serious priority. Furthermore, known stresses cause "strain and eventual
splintering” (Bolman, 2006). Additionally, it is also not clear if coping strategies utilized by parents, such as “religion, social withdrawal, individual attainment, and activity” are conducted within the couple pairing or are conducted separately (Gray, 1998). Of additional concern are reports that parent conflict and marital dissatisfaction leads to poorer adjustment in siblings of children with autism (Dyson, Edgar, & Crnic, 1989).

Family needs

Suggestions to avoid such stress on marital couples of children with autism should be family based. Families should be given social services such as financial counseling and placement options, both residential and outpatient services, throughout the life spectrum of their children with autism. As therapeutic needs for these children change over the life span, so does the need for specialized care. Care over the life span further supports the siblings without disabilities, because they can feel confident that their sibling with autism can have their needs met after the death of their shared parents. If appropriate planning for their children’s needs is achieved, parents and families, in the future, do not worry about housing for their children with autism. Furthermore, because routine is essential, transitions to alternative residential or education placement should be completed prior to absolute necessity (Norton & Drew, 1994).

Respite care is also an important service for parents of children with autism. Respite care for the primary care giver, typically the mother, is essential for the parent’s well being (Holmes & Carr, 1991). Grandparents can provide respite care services, but some grandparents can be overcritical of their child’s parenting skills and may deny that their grandchild has any type of disability (Gray, 1998). It is frequently recommended that siblings be utilized to provide respite care services for parents (Gilliam & Smith,
1983). However, power struggles within families may ensue when older siblings assume power, including care, because a parent’s attention is drawn primarily to the children with disabilities (Harman, Drew, Egan, & Wolf, 1993). In some cases, older female siblings may harbor feelings of anger and resentment towards their sibling with autism (Stoneman, Brody, Davis, & Crapps, 1988).

Sibling Relationships

Siblings can serve as an important social support and have functions distinct from parents, friends, and romantic partners (Buhrmester, 1992). However, until approximately fifteen years ago, sibling studies in family and developmental research was lacking (Dunn, 2005). Most sibling studies, during the 1980’s, linked the role that siblings have upon the development of individual differences in children. Since then, research has demonstrated more specifically that the sibling relationship is essential in social development (Kramer & Kowal, 2005), emotional development (Brown & Dunn, 1996), and socio-cognitive development (Howe, 1991). Siblings also provide an opportunity for exploration and advancement of social skills, emotional expression, and empathy building (Hanline & Daley, 1992). These types of interactions are essential to help siblings learn to deal effectively with relationships in general (Randall, Peter, & Parker, 1999). Because siblings spend considerable time together, the qualities of their sibling interactions play a key role in child development (Brody, Stoneman, & McCoy, 1992). Furthermore, sibling relationships tend to be more influential than parent relationships because there is greater overlap in life spans between siblings than parents (Lobato, Faust, & Spirito, 1998). According to Siegel & Silverstein (pp. 152, 1994)
"...relationships between siblings serve as the prototype for all sorts of later consensual relationships."

Siblings are also perceived as a unique source of emotional support, beyond that of parental support and peer acceptance (Seigner, 1998). This relationship is an integral component in providing an opportunity for learning and practicing social skills, emotional regulation and expression, interpersonal skills, and empathy training (Buhrmester & Furman, 1990; Furman & Buhrmester, 1992). The intimacy of sharing common experiences and background cannot compete with that of very close friends (Knott, Lewis, & Williams, 1995). Siblings also provide companionship for one another (Modry-Mandell, Gamble, & Taylor, 2006). Older siblings frequently act as caregivers, teachers, and models for their younger siblings. Siblings acquire and practice these skills within the family construct (Broderick & Smith, 1979) and the quality of these interactions influence the internalized and externalized behaviors demonstrated by children (Brody, et al., 1992).

Variance in sibling relationships

Sibling relationships vary in terms of power, status, and levels of intimacy, competitiveness, and levels of cooperation (Furman & Buhrmester, 1985). These qualities are not set and are fluid over time, during developmental changes and as wants and needs vary. For example, in terms of power and status, some relationships can be nurturing or domineering. In closeness and intimacy, sibling relationships can be distant or close, as well as amicable or hostile. In the conduct and rivalry arena, siblings can be antagonistic and/or competitive, and may imbue (??) parental partiality. Certain constellation variables may also impact the sibling relationship (Lampert, 2007). Same
sex siblings report increased feelings of companionship, intimacy, and affection than siblings of the opposite sex (Fuhrman & Buhrmester, 1985). Siblings closer in age tend to perceive greater feelings of conflict than siblings with a greater age difference (Fuhrman & Buhrmester). Combinations of constellation variables, siblings close in age and of the opposite sex have decreased feelings of closeness/warmness (Fuhrman & Buhrmester).

_Sibling relationships during adolescence_

The role of the sibling relationship changes from childhood to adolescence. It has an effect on adolescent development, specifically during the early and middle adolescence periods. Adolescents' close siblings ranked higher in functional importance than mothers and fathers, but lower than best same-sex friends in the attributes of companionship, intimacy, and nurturance (Lempers & Clark-Lempers, 1992). However, Cicirelli (1995) reported that siblings were frequently more available and accessible over time than friends when dealing with family-based problems or concerns. Woodward & Frank (1988) also reported that siblings are often the ones that adolescents turn to when needing comfort for feelings of loneliness. In general, adolescents are more likely to be understood and respected by their siblings and frequently share similar views (Moser, Paternite, & Dixon, 1988). Also during the adolescent stage, siblings experience increasing levels of equality with their sibling and feelings of power decrease and subside.

_Positive relationships_

Adolescents who identify positive sibling relationships tend to have better friendships and higher self-esteem, which in turn is associated with decreased feelings of
loneliness, depression, and delinquent behaviors (Yeh & Lempers, 2004). Positive sibling relationships also increase levels in self-esteem, social competence, self-control, independence, and life skills (Amato, 1989). These positive relationships can serve as a source of social support to overcome distress and help adolescents remain connected with family during this stage of individuation. Sibling relationships frequently become less “asymmetric” and more “egalitarian” during this period. Adolescents also report decreased amounts of interaction, companionship, intimacy, and affection with their siblings. Despite these decreases, the sibling relationship does not become less important to the adolescent.

Close sibling relationships also serve to demonstrate and manage adolescent opportunities to learn and practice social skills and desired positive behaviors. Dunn (1992, 1993) found that close sibling relationships also provide a framework for adolescents to generalize what they learn from sibling interactions to create and foster good relationships successfully with close friends, necessary to adolescent adjustment. These close sibling relationships can create positive adolescent developmental outcomes indirectly, by helping adolescents construct positive friendships. In later adolescence, siblings’ negative and positive behaviors and feelings regarding each other in childhood were correlated with the quality of sibling relationships (Dunn, 1996).

**Siblings of Children with a Disability**

The amount of research on having a sibling with a disability is rather scarce. Most research that explores the impact of having a sibling with a disability suggests inconclusive data and can appear misleading (Hastings, 2002). It is assumed that siblings of children with a disability are likely to demonstrate psychological maladjustment more
often than siblings of healthy or normally developing children (Rodrique, et al, 1993). However, Cuskelley & Gunn (2006) found no significant differences between the siblings of children with Down syndrome and siblings of children without disabilities on adjustment measures. These measures included parent perceptions of externalizing and internalizing behaviors, parent perceptions of sibling competence, and sibling perceptions of their own competence and self-worth. There was an association between parental reports of externalizing behaviors and sibling relationships with the brother/sister closest in age, but this was likely because of variables of sex and developmental age, rather than because of group association.

Positive effects and outcomes

Both Ferrari (1984) and Mates (1990) found that siblings of children with disability are generally well-adjusted, both with positive social competence and with self-concepts. Giallo & Gavidia-Payne (2006) found that parent and family factors were stronger predictors of sibling adjustment difficulties in siblings of children with disabilities, than the siblings' own experiences of stress and coping. Influencing family factors which predict sibling adjustment difficulties include: socio-economic status, past attendance at a sibling support group, parent stress, family time and routines, family problem-solving and communication, and family hardiness. Finally, the results revealed that the family level of risk and resilience factors were better predictors of sibling adjustment than the siblings' own experiences of stress and coping resources, highlighting the importance of familial and parental contributions to the sibling adjustment process.

McMahon, Noll, Michaud, & Johnson (2001) found no depression differences between siblings of children with acquired brain injury and their peers. Dyson (2000) and
Hannah & Midlarsky (1999) report that family variables, such as the sibling's sex and age, affect sibling adjustment more so than having a sibling with a disability. Kaminsky & Dewey (2002) found slight increases in levels of loneliness in siblings of children with disabilities, but that increase was shown only in siblings of children with Down syndrome. Some siblings seem to benefit emotionally by having a sibling with a disability (Seligman & Darling, 1989).

Some research has suggested that siblings have been positively influenced by their siblings' disabilities. Derouin & Jessee (1996) reported that some siblings enjoy having less parental attention and increased independence. For example, one sibling stated that “I'm more independent and able to do things on my own” (Derouin & Jessee, 1996). Some siblings are more protective and caring of their siblings with disabilities and demonstrate increased empathy for others (Faux, 1993). Mandleco, Olsen, Dychess, & Marshall (2003) identified positive coping responses by siblings of children with disabilities.

**Negative effects and outcomes**

In a meta-analysis of twenty-five studies of sibling relationships, there was a slight negative impact only upon the siblings of children diagnosed with mental retardation (Rossiter & Sharpe, 2001). A meta-analysis of forty-three studies on siblings of children with a chronic illness, conducted between 1970 and 1995, revealed that sixty percent reported increased sibling risk for internalizing and externalizing behaviors and lower social competence (Williams, 1997). These behaviors include difficulty in school, jealousy, decreased self-esteem, and social isolation. Dyson, Edgar, Crnic (1989) found that siblings of children with mental retardation may be at greater risk for adjustment
problems because of family stress related to the needs of the child with mental retardation. However, self-concept was positively associated with family cohesion, and social competence was positively associated with family promotion of independence. Only studies with the siblings of children with mental retardation showed that family conflict was inversely related to social competence, and family organization was positively related to sibling self-concept. Fisman, Wolf, Ellison, Gillis, Freeman, & Szatmari (1996) and Fisman, Wolf, Ellison, & Freeman (2000) found that siblings of children with developmental disabilities experience more adjustment difficulties than do control groups with non-disabled siblings. Lobato, Barbour, Hall, & Miller (1987) suggest that specific evidence suggests that girls whose younger siblings have chronic conditions are more likely to experience internalizing problems such as depression and anxiety. McHale & Gamble (1989) suggested that increases in sibling externalizing behavior were due to increased childcare responsibilities of their sibling with disabilities. However, Nixon & Cummings (1999) indicated that the siblings of children with disabilities are more sensitive to conflict within the family unit. Verte, Roeyers, & Buysse, 2003 found that the siblings of children with disabilities do have an increased occurrence and potential for behavioral and conduct problems, social and/or emotional impairments. Siblings of children with disabilities frequently experience less parental attention both in quantity and in quality (Howlin, 1988). Siblings of children with disabilities may also fear “catching” the disability themselves because of a lack of information presented to them about the disability. Further concerns include the fear that their own potential children may “inherit” the disability (Powell & Ogle, 1985). Siblings often fear for their own future survival, as well as the future outcomes of the child with a
disability (Gladstone & Montgomery, 1990). Siblings also fear that the care and responsibility for their siblings will fall upon them after the parent ages or dies. Alleviating this fear is extremely difficult because of its levels of entrenchment and personalization (Featherstone, 1980).

In general, the more ambiguous the children's disabilities (i.e., DSM IV-TR Not Otherwise Specified-NOS diagnosis) the more likely the siblings will have poorer psychological outcomes (McHale, Simeonsson, & Sloan, 1984).

**Constellation variables**

Gold (1993), Mates (1990), McHale et al. (1986), Rodrigue et al. (1993) reported that birth order, family size, and the gender of the sibling without a disability were not related to adjustment outcome. In general gender, age, birth order does not have a strong impact on sibling adjustment (Eisenberg, Bake, & Blacher, 1998; Gold, 1993; Hannah & Midlarsky, 1999; Lampert, 2007; Mates, 1990; McHale, Sloan, & Simeonsson, 1986; Roeyers & Mycke, 1995). However, it is reported that females and siblings from two-child families are at increased risk for poor adjustment when compared with control groups. The reason for this may be that larger families can disperse potential burdens, such as childcare, chores, and excessively high expectations among several children rather than upon only one child. Furthermore, larger families allow for the occurrence of alternative sibling relationships (Mates, 1990). Ferrari, 1984 and Kaminsky & Dewey, 2002 report that siblings in families with more than two children are more likely to be well adjusted than families with only two children. Siblings, in general, may develop a greater emotional bond if they are the same sex, share activities, and are close in age; this connection is often being established early in childhood (Harris, 1994). Within typical
siblings’ relationships, younger children tend to imitate older siblings and older siblings tend to initiate positive and negative interactions with their younger siblings; however, these roles are frequently blurred in families with children with disabilities (Knott, et al., 1995). Often the children with disabilities are perceived as the youngest developmentally, making the youngest child, chronologically, having to accept the role and responsibilities of being the oldest sibling (Kaminsky & Dewey, 2001).

Constellation variables, specifically within autism research, denote that the overall effects upon the sibling “rely heavily on their ages and the extent to which autism disrupts family routines” (Targ Brill, 1994). Kaminsky & Dewey (2001) found that siblings younger than the child with a disability tend to have “more rejecting feelings towards their disabled sibling than did older siblings”.

*Siblings of Children with Autism*

Siblings of children with autism have a unique perspective on their sibling relationship compared with siblings of children with other disabilities (Hastings, 2003). Siblings of children with autism experience communicative, social, and behavioral challenges that are uniquely different from those of children with other disabilities (Bagenholm & Gillberg, 1991). Autism is also considered “invisible” because children with autism do not have the physical markers as do those with visible physical disabilities or with specific types of mental retardation (Howlin, 1988). Further, the nature of behaviors demonstrated by children with autism may seem “inexplicable and unpredictable”, thus creating siblings who have “unique” feelings of frustration or embarrassment (Morgan, 1988). The overall adjustment of siblings of children with autism varies on a continuum from the extremes of positives to the most negative.
Positive effects and outcomes

Despite the demonstration that the sibling relationship affords a unique opportunity to learn and practice social development and interpersonal skills, most autism research neglects to identify whether or not having a sibling with autism impacts these skill developments. Furthermore, present research outcomes are inconsistent about whether or not the sibling experiences social or emotional maladjustment or negative effects because of potential limits within the quality of the sibling relationship. Kaminsky and Dewey (2003) found no differences in loneliness between siblings of children with autism and comparison children. Rivers & Stoneman (2003) found, that despite families of children with autism reporting increased levels of parental stress, the outcome on sibling maladjustment was null. Hastings (2003) also found that the parent’s psychological adjustment and behavior problems of the child with autism did not predict sibling maladjustment.

In fact, siblings of children with autism frequently describe their sibling relationship more positively than siblings of children without disabilities (Bagenholm & Gillberg, 1991). Specifically, siblings tend to report more positive relationships with and attitudes towards their sibling (McHale, Sloan, Simeonsson, 1986). Some siblings report increased self-concept and overall quality of the sibling relationship than peers of siblings without disabilities (Berger, 1980). Some siblings even report less overall sibling conflict (Kaminsky & Dewey, 2001). Furthermore, siblings can also be positive role models for children with autism (Gilliam & Smith, 1983).

Siblings are also important social facilitators on behalf of children with autism. Children with autism tend to make increased verbal initiations towards their siblings
more so than toward their parents (El-Ghoroury & Romanczyk, 1999). However, Knott, et al., in a 1995 study, found that autistic sibling dyads tended to respond to each other “...less frequently to...initiations and imitated...less often, than children in Down syndrome dyads”. Many siblings even reported that they were “proud” of teaching their siblings with autism new things. An increased positive regard and nurturance towards siblings with autism did not impact levels of marital satisfaction (Fisman, Wolf, Ellison, Gillis, Freeman, & Szatmari, 1996).

**Negative effects and outcomes**

However, research concerning siblings of children with other disabilities are inconsistent and provide varying outcomes; the same is true of research concerning siblings of children with autism. Studies demonstrate that siblings of children with autism are as socially and behaviorally competent as siblings of children without disabilities; these studies also show that older siblings appear to have a greater difficulty with behavior coping skills, and emotional stability (Rodrigue et al, 1993). Hastings (2003) reported that in a sample of school-aged children (four to sixteen years old), siblings of children with autism reported increased behavioral problems and fewer prosocial behaviors than children in the normative samples. Older siblings also demonstrated increased rates both of internalized and of externalized behavior problems (Rodrigue, et al).

Because of the nature of autism impairment, some siblings have difficulty sharing thoughts, emotions, and ideas with their siblings who have autism (Rutter & Schopler, 1987). Siblings of children with autism also report decreased levels of intimacy, of prosocial behavior, and of nurturance within their sibling relationships; these are qualities
were based on Buhrmester and Furman’s Sibling Relationship Questionnaire-Revised (1990) (Kaminsky & Dewey, 2001). Frequently siblings of children with autism demonstrate similar impairments with their other siblings, thus suggesting that other factors may influence these qualities (Kaminsky & Dewey).

Genetic factors, rather than disability itself, may be responsible for social deficits in sibling pairs when one sibling has autism (Constantino, Lajonchere, Lutz, Gray, Abbacchi, McKenna, Singh, & Todd, 2006). It is possible that impaired social reciprocity, communication, and pragmatics may be genetic, and a catalyst for further genetic research in autism (Klin, Jones, Schultz, Volkmar, & Cohn, 2002).

Because siblings are expected to care for their other sibling and do more household chores because of the limited abilities of the child with autism, feelings of resentment may develop (Randall & Parker, 1999). Siblings of children with autism may also be resentful of the child with autism because of the perceived “control” which that child has over the entire family (Gray, 1998). This control affects activity involving familial participation, scheduling desires, and potential flexibility in daily life. These feelings of resentment may impact the siblings’ overall social development and further hinder the quality of their sibling relationship.

Some research has found that these siblings have fewer friends than siblings of children with other disabilities or of typically developing children (Glasberg, 2000). However, it is not clear if these social limitations are due to the rigidity and decrease of social outings experienced in families with an autistic child, the limitations placed on the siblings because of a parent’s need for additional support or assistance with the child who has autism, or because of feelings of resentment, and/or embarrassment (Powell, et al.,
For example, siblings may be embarrassed by the child’s extreme temper tantrums that result in the siblings not inviting friends to their home or not participating in extracurricular activities. This may ultimately lead to decreasing social opportunities and subsequently to resentment (Gray, 1994).

Children with autism may also demonstrate a “non-caring” attitude towards family members and unintended destruction of a family member’s property. “Do I love her? It’s hard. Sometimes I do when she acts nice for a while. But it’s difficult to love someone when they don’t do anything pleasant” reports an older brother of a child with autism (Binkard, Goldberg, & Goldberg, 1987). Gold (1993) also found increased depression among siblings. Increased feelings of anxiety, phobias, and neurosis may be due to fears associated with having a sibling with a disability. “Their distress may be underestimated and they should be included in counseling from an early age” (Coleby, 1995).

Breslau & Prabucki (1987) found significantly more behavioral difficulties in the siblings of children with Pervasive Developmental Disorder (PDD) when compared with children having other disabilities. These findings underline the potential risks for the siblings of children with PDD and suggest the importance of a transactional mechanism rather than the identification of single risk or protective factors in predicting sibling adjustment (Hastings).

_Need for Current Study_

This review of literature demonstrates the inconsistencies exhibited in current studies. These varied outcomes may be due to methodology issues such as the use of parent reports rather than first hand sibling accounts. Hastings (2003) found that mothers
reported increased behavioral problems and fewer pro-social behaviors in siblings of children with autism, than those that were actually demonstrated. This study’s use of maternal ratings of sibling adjustment, rather than first-hand reports of sibling adjustment, suggests potential impartiality. Ferrari (1984) and Lobato et al. (1987) have reported that parents’ reports, specifically mothers’ reports differ from siblings’ reports. Parents report siblings without disabilities as having increased levels of depression and aggressive behaviors (Gold, 1990; Lobato et al). It is important to acknowledge the differences between self-reports and the second-hand reports when conducting a study on siblings of children with disabilities. Specifically, these studies relied on parental reports to identify the children’s diagnosed disabilities and to quantify and define the levels of impairment, including the overall effects on the sibling relationship (Fisman, Wolf, Ellison, Gillis, Freeman, & Szatmari, 1996; McHale, Sloan, & Simeonsson, 1986; McKeever, 1984). This study used parental reports to obtain levels of impairment from autism, as well as communication and socialization adaptive behaviors; however, the non-disabled sibling provided general demographic information, input on the quality of the sibling relationship, and perceptions of social support.

Study Measures

Furman and Buhrmester have identified four common dimensions of children’s sibling relationships such as warmth/closeness, conflict, rivalry, and status/power. These aspects have been reported consistently in other sibling studies, utilizing self-reports of sibling relationship quality from children and adolescents (Furman & Buhrmester; 1985; Hetherington & Clingempeel, 1992; Stocker & McHale, 1992), parent reports of young children’s sibling relationships (Kramer & Baron, 1995; Volling & Elins, 1998) and more
recently, with self-reports of adult sibling relationship quality (Cole & Kearns, 2001; Graham-Bermann & Cutler, 1994; Stocker, Lanthier, & Furman, 1997). The most commonly used questionnaires to assess the quality of the sibling relationship include: the Sibling Relationship Questionnaire (SRQ: Furman & Buhrmester, 1985), the Sibling Relationship Inventory (SRI: Stocker & McHale, 1992) and the Sibling Qualities Scale (SQS: Cole & Kearns, 2001). All of these measurements have been used predominantly with elementary school-aged children and adolescents. Other available questionnaires include the Sibling Relationships in Early Childhood questionnaire (SREC: Volling & Elins, 1998), Parental Expectations and Perceptions of Children’s Sibling Relationships questionnaire (PEPC-SRQ: Kramer & Baron, 1995) and the Sibling Behaviors and Feelings questionnaire (SBFQ: Mendelson, Aboud, & Lanthier, 1994), all of which must be completed by parents in order to assess very young children in the toddler and preschool years.

To assess siblings in late adolescence to early adulthood, The Adult Sibling Relationship Questionnaire (ASRQ: Stocker, Lanthier, & Furman, 1997); The Lifespan Sibling Relationship Scale (LSRS: Riggio, 2000) and the Brother-Sister Questionnaire (Graham-Bermann & Cutler, 1994) were used. Generally the adult questionnaires are more prevalent in research because of less stringent consent requirements for adult participants.

Harter’s Social Support Scale for Adolescents (SSSA, 1985) is a series of subscales within Harter’s Self-Perception Profile for Children (SPPC, 1985) that have been used to qualify perceptions of social support. The SSSA is designed for children ages 12-18 years and includes a general self-worth subscale and five separate subscales:
(a) scholastic competence, (b) athletic competence, (c) peer social acceptance, (d) physical appearance, and (e) behavioral conduct. Research with this scale supports greatest stability with children who perform at the level of at least an eight year old (Harter, 1990; Marsh & Holmes, 1990). The internal consistency, coefficient alpha, for the subscales ranges from .75-.84 for the social scales (Harter, 1982). The United States Department of Education, 2000 and 2001, has frequently utilized this support when assessing the socio-emotional development and overall perceptions of support, specifically from teachers. In 2001, test-retest reliability with a sample of 208 Colorado students was .80 and a larger sample from New York, N=810, yielded slightly lower but similar correlations with a range from .69-.80 (US Department of Education). Relative to the four sources of social support, internal consistency reliability estimates range from .72 (Friend) to .88 (Parent) (Harter, 1986; Grebenkemper, 1993). In addition, factor analytic studies of the SSSA have found that parent, teacher, and peer support are differentiated by elementary school children, and that all four sources of social support (parent, teacher, peer, close friend) are differentiated by middle school children (Harter; Grebenkemper; Chapman, 2003). Correlations between classmate support and the Social Acceptance/Popularity subscale of the SPPC ranged from .62 to .69 (Harter; Grebenkemper) and correlations between the close friend subscale and a child’s perceived ability to confide and disclose feelings with peers, was .46 (Harter). Finally, the correlation between the parent support subscale and a measure of congruence of values among children and parents using the five competency areas on the SPPC was .48 (Harter).
Harter's measure involves a response format designed to minimize socially acceptable response biases (Harter, 1982) with children being asked to choose between two ends of a response continuum and to rate whether or not the statement chosen is "really true for me" or "sort of true for me." Each item is then scored on a Likert scale of 1-4. Children use the entire scale in this type of format, yielding greater variability and normal distribution of the scores (Harter, 1982). However, Marsh & Gouvernet, 1989; Marsh & Holmes, 1990, criticized this format because of its complexity and of difficulties for children with limited cognitive abilities (Silon & Harter, 1985; Marsh & Holmes, 1990).
Chapter 3: Hypothesis

Aims of the Current Study

The purpose of this study is to identify whether or not there is a correlation between the severity of autism disability and the quality of the sibling relationship and differences regarding non-disabled siblings’ perception of social and familial support.

Hypothesis of the Current Study

Severity of the autism disability will likely impact the non-disabled sibling’s perceptions of the quality of the sibling relationship.

1a. Siblings of children with less severe levels of autism will report more positive qualities within the closeness/ intimacy domain of the sibling relationship.

1b. Siblings of children with less severe levels of autism will report decreased levels of power within the sibling relationship.

1c. Siblings of children with less severe levels of autism will report decreased levels of conflict within the sibling relationship.

1d. Siblings of children with less severe levels of autism will report decreased levels of rivalry within the sibling relationship.

Rationale: This hypothesis is supported by Kaminsky and Dewey (2001), who indicated that siblings of children with autism reported “less intimacy with their reference sibling than participating siblings with Down Syndrome”. Furthermore, Knott, Lewis, and Williams (1995) reported that children with autism tend to spend less time with their siblings and demonstrated limited pro-social initiations toward their siblings.

According to Furman and Buhrmester’s (1990) Sibling Relationship Questionnaire (SRQ-Revised), the subscale of Rivalry is measured by perceived levels of
maternal and paternal partiality. This specific measure within this hypothesis is supported by Hannah and Midlarsky (1995), stating that parents tend to devote more physical time and emotional energy towards the child with a disability; therefore, the siblings of the disabled child receives a decreased amount of attention from both parents.

2. The severity of the autism disability will negatively impact the non-disabled siblings’ perceptions of social support; specifically, the non-disabled siblings of children with severe levels of autism will report decreased feelings of social support from family members and from outside social networks.

Rationale: This hypothesis is supported by Breslau, Weitzman, and Messenger, (1981); Lobato, (1983); McHale, Simeonsson, and Sloan, (1984); Meyer and Valdasy, (1994); Rodrigue, Geffken, and Morgan, (1993); Seligman, (1983); and Simeonsson and McHale, (1981), all of whom reported that parents must devote more time to the sibling with a disability; therefore, the non-disabled sibling is often overburdened with household chores and responsibilities. This increase in home-based responsibilities limits the siblings’ social interactions and opportunities outside of the home. Because of limits on the siblings’ social and extracurricular interactions, the siblings most likely view these limitations as a result of lack of social and familial support.
Chapter 4: Method

Design

A quasi-experimental research design between participants was utilized because random assignment was not possible. The independent variables within this experiment were the diagnosis of autism and subsequent levels of impairment. The independent variable was operationally defined by scores on the Gilliam Autism Rating Scale, Second Edition (GARS-2, 1995) and the communication and socialization domains of the Vineland Adaptive Behaviors Questionnaire (VABS-II). The dependent variables within this experiment will be the perceived quality of the sibling relationship and perceptions of social and familial support. The quality of the sibling relationship was measured by Furman and Buhrmester’s SRQ-Revised (1990). The specific qualities of Closeness and Intimacy, Power, Conflict, and Rivalry were isolated. Harter’s Perceptions of Social and Familial Support (SSSA, 1988) will be used to qualify perceptions of social support.

Participants

To obtain the targeted research population this study employed non-random, purposive samples techniques. Participating families were recruited from Pennsylvania and New Jersey by means of public notice at specialized education settings, residential facilities, medical and psychological agencies, and parent support groups. To limit developmental stage variability, siblings between the ages of twelve through eighteen were sought.

Families who were interested were asked to participate in a parent interview, either on the telephone or in-person. The interview consisted of an oral format of the GARS-2 and Communication and Socialization domains of the VABS-II. An oral format
was utilized in order to control threats to the validity of the GARS-2 and VABS-II. Possible threats include parents’ reading levels and parents’ understanding of testing terminology and jargon. The interviewer developed a standard script in order to probe for responses. Upon completion of the interview, scores from the GARS-2 and VABS-II were obtained. Only children that met the diagnostic scoring criteria for autism were considered for the next level of the study; children who met the criteria for a PDD-NOS or Asperger’s diagnosis were disqualified.

The next level of the study pertained only to the siblings of children with autism. The siblings were provided a sibling questionnaire packet. The packet included: (a) a sibling demographic questionnaire, (b) the SRQ-Revised, and (c) the SSSA. The sibling completed and returned the packet in a pre-paid postage envelope.

**Inclusion criteria**

In order to be eligible to participate in this study, participants must have been between the ages of twelve through eighteen years old and have had a sibling diagnosed with autism. Participants must not have had a formal diagnosis or classification of disability themselves, defined as any type of pervasive developmental disorder and/or level of mental retardation. They must currently have shared the same residence as their disabled sibling and must have been between the ages of twelve and eighteen. The size of the family, parent’s relationship status (i.e. married, divorced, widowed), parent’s sexual orientation, and/or sibling gender did not affect inclusion within this study.

**Exclusion criteria**

Participants who had a sibling with a diagnosis of PDD-NOS, Asperger’s, and/or Rett’s disorder were not eligible for this study. In addition, participants who, personally,
had a formal diagnosis or classification, defined as any type of pervasive developmental disorder and/or level of mental retardation were not eligible for participation. Participants who did not currently share the same residence as their siblings and were not between the ages of twelve and eighteen were not eligible to participate in this study.

Measures

The Gilliam Autism Rating Scale, Second Edition (GARS-2, 2006) is a behavioral checklist that aids in identifying the presence and severity of autism in individuals between the ages of three and twenty-two years. Items are based on the Autism Society of America and the Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition-Text Revision (DSM-IV-TR) definitions of autism. Each subtest (Stereotyped Behaviors, Communication, and Social Interaction) contains fourteen items. The total of the subtest scores yields an Autism Index. The estimated completion time is ten to fifteen minutes. It is normed on a representative sample of 1,107 persons with autism from 48 states within the United States. All of the coefficients of reliability for the subscales and for the entire test are large in magnitude. The validity of GARS-2 was demonstrated by confirming: that the items of the subscales are representative of the characteristics of autism; that the subscales are strongly related to each other and to performance of other tests that screen for autism and that standard scores discriminate persons with autism from persons with other severe behavioral disorders, such as persons with mental retardation and multi-disabilities.

The Vineland Adaptive Behaviors Scale, Second Edition (VABS-II) is a one hundred thirty-three item survey; sixty-seven items in Communication and sixty-six items in Socialization, were taken directly from the VABS-II Parent Survey Form. The
purpose of this questionnaire is to obtain basic information about the adaptive behavioral levels and levels of behavioral severity of the child with autism. The communication and socialization domains are being utilized to further substantiate autism severity levels. The communication domain contains three sub-domains: receptive, expressive, and written communication. The socialization domain contains three sub-domains: interpersonal, play and leisure time, and coping skills. On the survey, parents were asked about the frequency and severity of their child’s autism related behaviors. The estimated completion time is fifteen minutes. The reliability coefficients for the communication domain range from median values of .73 to .94 for the composite. Only 6 of the 15 coefficients equal or exceed .90. The reliability coefficients for the socialization domain range from median values of .78 to .94 for the composite. Only 2 of the 15 coefficients equal or exceed .90. Domain scores can be transformed to standard scores (mean = 100; standard deviation = 15), percentile ranks, age equivalents, and adaptive levels. The original Vineland exhibited low to moderate correlations with the ABIC, the K-ABC, and the PPVT-R, with higher coefficients obtained when comparisons were made on populations with handicapping conditions.

The Demographic Questionnaire obtained information about the sibling’s age, sex, family’s size, birth order, and presence of other children with disabilities in his or her home. Siblings were also report the ages of the siblings and of the child diagnosed with autism. The estimated completion time is five minutes.

The Self-perception of Sibling Relationship Questionnaire (SRQ-Revised, 1990) was devised by Furman & Buhrmester (1990); it consists of fifteen scales, each containing 2-3 items, for a total of 39 items that assess children’s perceptions of their
siblings. These perceptions were divided into four dimensions: Closeness/Intimacy, Power, Conduct, and Rivalry. The Closeness/Intimacy subscale is made up of seven individual scales that include: pro-social behavior, companionship, similarity, admiration of sibling, admiration by sibling, and affection. The Power factor is calculated by adding the nurturance of sibling and dominance over sibling scales, minus the nurturance by sibling and dominance by sibling scales. The conflict factor consists of "quarreling", antagonism", and "competition". The Rivalry factor consists of scales of maternal partiality and paternal partiality. Furman and Buhmester (1990) report test-retest reliability ranges from .58 to .86 with a mean of .71. Internal consistency coefficients range from .71 -.81 for children in the third, sixth, ninth, and twelfth grades. Of the 60 alpha coefficients calculated for the 15 scales in each age group of children, 55 alpha coefficients were greater than .60. The SRQ can be used with children as young as second grade. The estimated completion time is ten to fifteen minutes.

The Social Support Scale for Adolescents (SSSA, 1988) was developed by Harter (1988). This twenty-four item self-report scale assesses children's perceptions of support from parents, teachers, classmates, and close friends. The Adolescent's scale is appropriate for ages twelve through eighteen years. Scores range from 1 to 4 for each item and from 24-96 for the entire scale. Higher scores indicate greater perceived levels of social support. Harter (1988) reports internal consistency reliabilities ranging from .72 to .88 across subscales for children in grades three through eight. Factor analytic studies have found that parent, teacher, and peer support are differentiated by elementary school children, and all four sources of social support (parent, teacher, peer, close friend) are differentiated by middle school children. Individual subscales were correlated with
theoretically relevant measures to demonstrate construct validity. Correlations between classmate support and the Social/Acceptances/Popularity subscale from the SPP-C ranged from .62 to .69. The correlation between the parent support subscale and a measure of congruence of values among children and parents using the five competency areas was .48. The estimated completion time is five to ten minutes.

**Procedure**

Participating families were provided with a Questionnaire Packet, either through email or postal mail at the time they contacted the student co-investigator for information. The Questionnaire Packet included: a letter of introduction that included contact information in case of questions, copies of the Form of Consent and Assent, Sibling Questionnaire packet, Parent Questionnaire packet, and a return-addressed, postage paid envelope, if the packet was not delivered electronically. The Sibling Packet included: a letter of assent, a Demographics Questionnaire, Self-perception of Sibling Relationship Questionnaire (SRQ-Revised, 1990), Social Support Scale for Adolescents (SSSA, 1988), and instructions for completing the questionnaires. The neuro-typical sibling completed each set of questionnaires. Each participant completed the questionnaires independently. The sibling’s response was encouraged and obtained via follow-up contacts such as reminder emails. Siblings were directed to return their completed questionnaire packet within fourteen days of receipt of these materials. The estimated completion time for the Questionnaire Packet was approximately ten to fifteen minutes for siblings and twenty to thirty minutes for the parents.
In order to further encourage the participant to respond, each packet contained a postcard for the participant to submit, with his or her name and contact information. This postcard was separated manually from completed questionnaires in order to maintain anonymity of the participant. These postcards were then submitted into a raffle drawing for a fifty dollar gift card. The raffle was open to all participants who completed the questionnaire packet and submitted the postcard. The winner of the gift card was randomly selected and the gift card was mailed to the winner by the researcher. If requested, participants could also obtain aggregated data results upon completion of the data analysis portion of this study.

Each family that agreed to participate was assigned a number, and all names were removed from all data to ensure the confidentiality of participants. Identification numbers were used to monitor and track data. The parent packet and sibling packet were assigned the same numbers in order to identify the sibling appropriately with the correct parent.
Chapter 4: Results

Demographics

Thirty-four families participated in this study. Families were recruited cross-country through state chapters of the Autism Society of America and SibShops®, a curriculum-based series of workshops for siblings of children with special needs. Families were also recruited throughout school districts and throughout schools for children with autism across Pennsylvania.

Seventy percent of participating families had both parents living in the home. Families with step-parents were coded separately. Not surprisingly, 94% of the children with autism were male because autism strikes males four times more often than females (Autism Society of America). The children with autism ranged in age from 6 - 22 years; the mean age was approximately fourteen-years old.

Over one-third of the sibling sample was thirteen years old and reportedly in grades seventh and eighth. The mean age of participating siblings was fourteen-years. Slightly more than one-half of the sample was female. Almost 65% of siblings were from two child families.

Autism Measurement Tools

The GARS-II was used to quantify the severity of autism, specifically identified as the final autism index. The higher the number of the GARS final autism index, the more severe the disability of autism. The final autism index is created by obtaining the sum of three subscales, communication, social interaction, and stereotyped behaviors. The GARS final autism index range was 64 – 121, with a standard deviation 17.9. The GARS-2 is used as an autism diagnostic tool; therefore, the interpretation guide identifies
the fact that an autism index of 85 or higher has a “very likely probability of autism”, 70 - 84 has a “possibly probability”, and 69 or less as “unlikely”. There were five families who had siblings with autism scores in the “unlikely” range (??) these families were included in the study because inclusion criteria, provided to participating families, stated that children had to have an existing diagnosis of autism. It is possible that these participants carried a diagnosis of Asperger’s or PDD-NOS, which were exclusionary diagnoses for this study; however, based on “good faith” information provided by participating families, this fact was not ascertained. Additionally the GARS-2 should never be used as the sole diagnostic tool for autism. Autism should be diagnosed through a battery of assessment tools, as well as through behavioral observations, case histories, and parent interviews (GARS-2, 2006).

The VABS-II subscales of Communication and Socialization were further utilized to assess the levels of impairment within these realms. The lower the scores on these subscales the greater the impairment within these areas. The VABS-II communication standard score ranged from 29 to 99, with a standard deviation of 13.7. The VABS-II socialization scores ranged from 20 to 104, with a standard deviation of 16.2. According to the VABS-II Domain Score Profile, standard scores that range from 85 to 115 fall within the average, 70 to 84 within the moderately-low, and 69 and below within the low range of ability. At least two siblings with autism fell within this average range in the domain of communication and two fell within the average range in the domain of socialization. Additional descriptive statistics are provided within Table 1.
Table 1

*Descriptive Statistics of the GARS-II and VABS-II Standard Scores*

<table>
<thead>
<tr>
<th>Statistics</th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>GARS Autism Index</td>
<td>34</td>
<td>64</td>
<td>121</td>
<td>92.4</td>
<td>17.9</td>
</tr>
<tr>
<td>GARS Communication</td>
<td>30</td>
<td>4</td>
<td>17</td>
<td>8.9</td>
<td>3.0</td>
</tr>
<tr>
<td>GARS Social Interaction</td>
<td>34</td>
<td>4</td>
<td>16</td>
<td>9.9</td>
<td>3.7</td>
</tr>
<tr>
<td>GARS Stereotyped Behavior</td>
<td>34</td>
<td>4</td>
<td>14</td>
<td>7.7</td>
<td>3.3</td>
</tr>
<tr>
<td>VABS Communication</td>
<td>34</td>
<td>29</td>
<td>99</td>
<td>67.0</td>
<td>13.7</td>
</tr>
<tr>
<td>VABS Socialization</td>
<td>34</td>
<td>20</td>
<td>104</td>
<td>62.7</td>
<td>16.2</td>
</tr>
</tbody>
</table>

* The GARS-II communication subscale can be omitted if the individual does not talk, sign, or use any other form of communication.

Correlations between the GARS-II and the VABS-II subscales of Communication and Socialization are shown in table 2. The preferred scoring correlation between the two scales should be that as the GARS-II scores increase the VABS-II scores should decrease.
Table 2

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

Hypothesis 1 of the Current Study

Severity of the autism disability will likely impact the non-disabled sibling’s perceptions of the quality of the sibling relationship as shown in Table 3.
Table 3

Correlations between Level of Autism Impairment and SRQ Subscales

<table>
<thead>
<tr>
<th>SRQ</th>
<th>Warmth/Closeness</th>
<th>GARS Autism Index</th>
<th>VABS Communication</th>
<th>VABS Social Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pearson Correlation</td>
<td>-.072</td>
<td>.163</td>
<td>.038</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.687</td>
<td>.357</td>
<td>.831</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Power</td>
<td>Pearson Correlation</td>
<td>.000</td>
<td>.158</td>
<td>.010</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.999</td>
<td>.374</td>
<td>.954</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Conflict</td>
<td>Pearson Correlation</td>
<td>-.026</td>
<td>.550**</td>
<td>.396*</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.885</td>
<td>.001</td>
<td>.020</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Rivalry</td>
<td>Pearson Correlation</td>
<td>.068</td>
<td>.452**</td>
<td>.480*</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.706</td>
<td>.008</td>
<td>.005</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>34</td>
<td>34</td>
</tr>
</tbody>
</table>

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

1a. Siblings of children with less severe levels of autism will report more positive qualities within the closeness/intimacy domain of the sibling relationship.

1b. Siblings of children with less severe levels of autism will report decreased levels of power within the sibling relationship.

Both Hypothesis 1a and 1b could not be supported, because the correlation statistics were not statistically significant.

1c. Siblings of children with less severe levels of autism will report decreased levels of conflict within the sibling relationship. The GARS-II Final Autism Index did not provide statistically significant correlations. However, the VABS-II Communication domain did demonstrate a significant correlation with the conflict quality of the sibling relationship.
relationship. This correlation was positive, which means that as the communication
levels decreased, representing an increased level of autism communication impairment,
the levels of conflict also decreased. According to Table 3, the correlation between
VABS-II Communication domain and SRQ Conflict was statistically significant, $r (35) = .55$, $p = .001$. In addition, the VABS-II socialization domain also demonstrated a positive
correlation with the conflict variable. As the level of socialization impairment decreases,
which again represent increased levels of autism disability, the level of conflict increases.
This correlation was statistically significant, $r (35) = .396$, $p = .02$. Despite these
significance levels, they do not support the hypothesis as stated, but rather indicate that
siblings of children with more severe levels of autism, as defined by decreased standard
scores on the VABS-II communication and socialization domains, report decreased levels
of conflict within their sibling relationships.

1d. Siblings of children with less severe levels of autism will report decreased
levels of rivalry within the sibling relationship. As in the previous hypothesis, the
GARS-II Final Autism Index did not provide statistically significant correlations.
However, both the VABS-II Communication and Socialization domains did demonstrate
a significant correlation with the rivalry quality of the sibling relationship. Both of these
correlations were positive, which means that as the domain levels decreased, representing
an increased level of autism communication and socialization impairment, the levels of
rivalry also decreased. According to Table 3, these correlations can be reported as $r (35) = .45$, $p = .008$ and $r(35) = .48$, $p = 005$ respectively. Despite these significance levels,
they do not support the hypothesis as stated, but rather indicate that siblings of children
with more severe levels of autism, as defined by decreased standard scores on the VABS-
II communication and socialization domains, report decreased levels of rivalry within their sibling relationships.

With hypotheses 1c and hypothesis 1d, the most significant mediating variables are both communication and social interaction, because the VABS-2 measured these specific domains and the GARS-2 measures a conglomeration of multiple variables, communication, socialization, and stereotypical behavior. The VABS-2 communication domain correlated most highly with the conflict and with the rivalry domains. It is possible that because communication is limited between siblings, there is less to argue about, there are decreased communalities to lead to rivalry, there is overall avoidance of the dyad as a whole, or there is a decision to give up participating in conflict because it is a fight that cannot be won.
Hypothesis 2 of the Current Study

Table 4

Levels of Autism and Feelings of Social Support

<table>
<thead>
<tr>
<th></th>
<th>GARS Autism Index</th>
<th>VABS Communication</th>
<th>VABS Social Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>SSS-C Parent Support</td>
<td>Parent Correlation</td>
<td>.389*</td>
<td>.161</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.023</td>
<td>.362</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Classmate Support</td>
<td>Classmate Correlation</td>
<td>-.293</td>
<td>-.030</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.093</td>
<td>.867</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Teacher Support</td>
<td>Teacher Correlation</td>
<td>-.285</td>
<td>.201</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.102</td>
<td>.254</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Friend Support</td>
<td>Friend Correlation</td>
<td>-.191</td>
<td>.029</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.279</td>
<td>.869</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>34</td>
<td>34</td>
</tr>
</tbody>
</table>

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

2. The severity of the autism disability will negatively impact the non-disabled sibling’s perceptions of social support; specifically the non-disabled sibling of children with severe levels of autism will report decreased feelings of social support from family members and from outside social networks. The only statistically significant correlation was demonstrated between the GARS-II Final Autism Index and the Parent Support Subscale of Harter’s SSSA, with a negative correlation. Specifically, as scores on the GARS-II Final Autism Index increased, meaning increased levels of autism impairment, the sibling reported decreased feelings of parent support. This correlation was statistically significant, *r* (35) = -.389, *p* = .023. In addition to the GARS-II Final Autism Index.
Index and Classmate and Teacher Support Subscale, these levels approached clinical significance with \( r(35) = -0.293, p = 0.09 \) and \( r(35) = -0.29, p = 0.10 \) respectively.

**Additional Analyses**

There are several additional, notable correlations demonstrated in Table 5 that do not pertain directly to the study hypotheses.

Table 5

*Correlation is significant at the 0.05 level (2-tailed).**Correlation is significant at the 0.01 level (2-tailed).

<table>
<thead>
<tr>
<th>SSS-C Subscales</th>
<th>Parent Support</th>
<th>Classmate Support</th>
<th>Teacher Support</th>
<th>Friend Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Pearson</td>
<td>1</td>
<td>.497**</td>
<td>.440**</td>
<td>.517**</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.003</td>
<td>.009</td>
<td>.002</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>34</td>
<td>34</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Classmate Pearson</td>
<td>.497**</td>
<td>1</td>
<td>.244</td>
<td>.566**</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.003</td>
<td>.164</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>34</td>
<td>34</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Teacher Pearson</td>
<td>.440**</td>
<td>.244</td>
<td>1</td>
<td>.174</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.009</td>
<td>.164</td>
<td>.325</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>34</td>
<td>34</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Friend Pearson</td>
<td>.517**</td>
<td>.566**</td>
<td>.174</td>
<td>1</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.002</td>
<td>.000</td>
<td>.325</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>34</td>
<td>34</td>
<td>34</td>
<td>34</td>
</tr>
</tbody>
</table>

These positive intercorrelations are between the levels of parent support and levels of classmate, teacher, and friend support. These correlations denote the fact that as levels of parent support increase, levels of classmate, teacher, and friend support increase. These correlations are noted as follows: \( r(35) = .497, p = .003; r(35) = .44, p = .009; r(35) = .517, p = .002 \) respectively. The intercorrelations between the levels of classmate...
support and friend support are clinically significant with $r(35) = .57$, $p = .00$. What cannot be identified in this study is whether or not increased social support from parents imbued the support from classmates, teachers, and friends. For example, the parent attempts to overcompensate for limits possibly placed on their neuro-typical child by getting this child involved in additional activities, sports, and/or social events, therefore increasing opportunities for outside support.
Chapter 5: Discussion

The guiding purpose of this study was to provide a voice to a population that is seldom acknowledged, the siblings of children with autism. Despite the low response rate and limited statistical support for the research hypotheses, this voice was heard within this study. Based on additional, unsolicited comments provided by parents and siblings through recruitment communications and based on written statements on the submitted sibling questionnaires, most siblings were reportedly “cooperative” with the study and comfortable acknowledging the difficulties/differences within their sibling relationships. One participant commented, “He [the child with autism] can’t talk and can’t really do much with me, but I love him.” This recognition of the limits within their sibling relationships was often countered with feelings of care and love for their siblings with autism. Only one sibling expressed negative feelings toward the study. Specifically this sibling wrote, “I, in actuality, refuse to participate. My mother made me do this survey against my choice. Please acknowledge that all answers are given grudgingly.” Other negative comments from siblings were limited to the lack of monetary compensation for participants, as well as parents reporting difficulty to get their “teenager” to take the time to complete their questionnaires. This “difficulty” was anticipated by the researcher because of the psycho-developmental considerations of teenagers.

This negative comment may lead to the conclusion that some participants may have felt coerced into participating in the study. The child was given the opportunity not to give assent to his or her participation, even if the parent provided consent. In the provided example, this child did give assent and completed the questionnaires in entirety.
with the addition of several handwritten comments identifying a “dislike” for the use of repetitious language within questionnaires. In issues of coercion, participants tend to “fake good” or “inflate pathology” across the board; therefore, the parent responses would have been consistent with their child’s responses. In the example cited, both participants appeared to be providing honest responses, especially because the child’s added comments did not coincide with their parent’s questionnaire output.

Difficulty with recruitment was also a major limitation with this study. After multiple delays in obtaining IRB approval, the study recruitment period was limited to fewer than ninety days from recruitment to data input. Access to this population was obtained through “word of mouth” via teachers, parents, therapists, and special education administrators. This study relied greatly on electronic dissemination of recruitment materials. Many of the local chapters of the Autism Society of America were receptive to posting information about the study on their websites or within their newsletters, but often created only bi-monthly newsletters, which were not compatible with the time frame of this study. The researcher also obtained support from local chapters of Sibshops®, a curriculum-based sibling support group for siblings of children with disabilities. Not all chapters had siblings of children with autism within their networks, but those that did tended to forward recruitment information to potential families. In addition, the researcher attempted to obtain a snowball effect when recruiting, by asking families interested in participation to provide the contact information for another family that would be willing to participate. Unfortunately, this technique was seldom effective.

Based on the range of GARS-II Autism Index scores, 64 - 121 with a standard deviation 17.9, it is highly likely that children with Asperger’s and/or PDD-NOS were
included within the study’s sample, despite the expressed exclusion criteria of both these diagnoses. Because the hypotheses addressed the “severity of autism disability,” rather than accepting the child’s diagnosis at face-value, the specific label of the impairment did not seem as important as the quantitative criterion. However, this may be a huge criticism of this study.

An additional criticism of this study is the accessibility of the questionnaires to participants. The researcher received approximately ninety email and ten telephone requests for questionnaire packets. The electronic requests were accommodated by the scanning of questionnaires in PDF formats; however, this still meant that the materials needed to be printed out and submitted to the researcher via United States postal service or fax. Several of the participating families rescanned completed questionnaires and consents and emailed them back to the researcher; others mailed or faxed them back to the researcher. One complaint was that when the completed packet was printed out, it was often over twenty pages long, making the questionnaires appear more daunting and time consuming than they actually were. Based on feedback from participants, the preference for electronic, such as “Survey Monkey,” styled questionnaires would have been preferred and would possibly have increased the overall response rate. According to a 2007 study conducted by Pew Internet and Community Life Project, in the United States nearly eighty-six percent of thirteen to seventeen year olds have handheld electronic devices with internet access. Currently nearly sixty-four percent of teenagers ages twelve through seventeen engage in at least one type of internet content creation and/or participation (Pew Internet and Community Life Project, 2007). The numbers of teenagers engaging in electronic media seem to be increasing and electronics are often
identified as this generation’s preferred media type; therefore, it is a consideration that should be taken into account when recruiting individuals of that age group for research studies.

Because of the small sample size it was very difficult to obtain enough information to identify statistically significant correlations. Two null hypotheses were supported in this study, including: decreased levels of communication of the child with autism related to decreased feelings of conflict within the sibling relationship and decreased levels of communication and socialization of the child with autism related to decreased feelings of conflict in the sibling relationship. The other two hypotheses associated with sibling relationship quality did not reach statistical significance. In regard to the feelings of social support, part of that hypothesis was supported, specifically the more severe autism impairment correlated with decreased feelings of parental support. Feelings of decreased support from classmates and teachers approached only statistical significance. It is possible that a more powerful sample size could have provided more support for these hypotheses.

The demographic questionnaire focused on obtaining direct information from the sibling; therefore, it did not ask about socio-economic status, living environment (i.e. urban or rural), and parent’s education levels. It also failed to ask siblings about their racial identities. This additional information would have been helpful in answering criticism in autism research that such research is often limited to a very homogenous group of families. These families are often Caucasian, with higher educational levels, and identified as being in middle to upper-level income brackets. These families, more
often than other families, have greater accessibility to specialized services and private school settings (Rivers & Stoneman, 2003).

Interestingly, the majority of the sibling participants were around thirteen and fourteen years old and tended to report more favorable opinions of their sibling relationships. Developmentally, this does not coincide with a population that is egocentric and more concerned with “what’s in it for me.” Individuals who are more self-serving would not seem to be as likely to participate in a study that will not directly impact them or provide them with incentives, but this did not seem to be the case with this study. An additional developmental concern is that children in this age group are very limited with what is or is not within their control and participated because their parents asked them to participate. This might also have contributed to their making increasingly favorable comments about their siblings diagnosed with autism. Because their worldview and access to additional life opportunities is limited, they would rate many things within this view as favorable because they have little else with which to compare that experience. For example, if the sibling is exposed to little more than school and home, they then do not miss out on regular outings to the mall or movies, spending the night at a friend’s house, or Saturday night dates. Siblings’ experiences are the basis for their worldview, so that if they do not know that additional opportunities are available to them, they do not see this as a problem when they suddenly are no longer available to them.

Based on the literature review, understanding how individuals are affected by another sibling’s disability is important in order to best address their needs. By addressing these needs, the family unit will be further affected and impacted. When
speaking with parents during the recruitment process, there appeared to be a great deal of concern about their neuro-typical children. Parents often commented that they “[felt] it’s important to talk to and help [them].” In addition, the parents often expressed the fact that their neuro-typical children were “more mature than other kids their age,” “very smart and high-achieving,” and were “more kind and loving than their peers.” Parents also expressed concern that their neuro-typical children “deserved more” in their family lives, often identifying social and educational opportunities, parent time, personal choices, and “just more...more than the limitations that our family life has.” Several sibling respondents added a similar, unsolicited comment on their questionnaires, sharing the fact that they do not blame their brothers or parents for the limits in their lives; they just accept this as being their lives. These comments provide an excellent argument for the need for further qualitative studies in order to identify family concerns and address these concerns appropriately through psychoeducational or therapeutic programming or services for all family members.
References


Binkard, Goldberg, & Goldberg (1987). Brothers and sisters talk with PACER. Minneapolis: PACER Center.


Autistic Siblings

*Issues in Comprehensive Pediatric Nursing, 19 (2).*


Dyson (2000). Sibling relationships of non-disabled school-age children to their siblings with disabilities. *Journal of Intellectual Disability Research, 44 (3 & 4).*


Faux (1993). Siblings are important too. *Journal of Pediatric Nursing, 8 (5).*


Lempers & Clark-Lempers (1992). Young, middle, and late adolescents’ comparisons of
functional importance of five significant relationships. *Journal of Youth and Adolescents, 21.*


Rivers (1999). Siblings' relationships when a child has autism: Temperament, family stress and coping. *Dissertation Abstracts International Section A: Humanities and Social Sciences, 60* (2-A), 0560. (UMI No. 9920084)


Rodrigue, Geffken, & Morgan (1993). Perceived competence and behavioral adjustment


Siegel & Silverstein (1994). *What about me? Growing up with a developmentally*


of Mental Retardation, 93 (2).


Appendix
DEMOGRAPHIC QUESTIONNAIRE

Please answer the following questions about yourself.

**How old are you?**  
- [ ] 12  
- [ ] 13  
- [ ] 14  
- [ ] 15  
- [ ] 16  
- [ ] 17  
- [ ] 18

**Are you:**  
- [ ] male  
- [ ] female

**What grade are you in:**  
- [ ] 6  
- [ ] 7  
- [ ] 8  
- [ ] 9  
- [ ] 10  
- [ ] 11  
- [ ] 12  
- [ ] Post High School

**Who lives in your home:**  
- [ ] Mom  
- [ ] Dad

- [ ] Brother (age:_______)  
- [ ] sister (age:_______)

- [ ] Brother (age:_______)  
- [ ] sister (age:_______)

- [ ] Brother (age:_______)  
- [ ] sister (age:_______)

- [ ] Brother (age:_______)  
- [ ] sister (age:_______)

**Does anyone else live in your home?**  
- [ ] Yes  
- [ ] No

If yes, please list how they are related (Example: Grandmother)

---

**Which sibling is diagnosed with autism?**  
- [ ] AGE:_______  
- [ ] SEX: [ ] male  
- [ ] female

**Is anyone else in your family diagnosed with autism?**  
- [ ] Yes  
- [ ] No

If so please list sex and how they are related (Example: Female Cousin):  

---
<table>
<thead>
<tr>
<th>ID #</th>
<th>Sibling Relationship Questionnaire - Revised (Child) 3/90</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Some siblings do nice things for each other a lot, while other siblings do nice things for each other a little. How much do both you and this sibling do nice things for each other?</td>
</tr>
<tr>
<td>2.</td>
<td>Who usually gets treated better by your mother, you or this sibling?</td>
</tr>
<tr>
<td>3.</td>
<td>How much do you show this sibling how to do things he or she doesn't know how to do?</td>
</tr>
<tr>
<td>4.</td>
<td>How much does this sibling show you how to do things you don't know how to do?</td>
</tr>
<tr>
<td>5.</td>
<td>How much do you tell this sibling what to do?</td>
</tr>
<tr>
<td>6.</td>
<td>How much does this sibling tell you what to do?</td>
</tr>
<tr>
<td>7.</td>
<td>Who usually gets treated better by your father, you or this sibling?</td>
</tr>
<tr>
<td>8.</td>
<td>Some siblings care about each other a lot while other siblings don't care about each other that much. How much do you and this sibling care about each other?</td>
</tr>
<tr>
<td>9.</td>
<td>How much do you and this sibling go places and do things together?</td>
</tr>
<tr>
<td>ID #:</td>
<td>Question</td>
</tr>
<tr>
<td>------</td>
<td>--------------------------------------------------------------------------</td>
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</tbody>
</table>
|      | 10. How much do you and this sibling insult and call each other names?   | [ ] Hardly at all  
[ ] Not too much  
[ ] Somewhat  
[ ] Very much  
[ ] EXTREMELY MUCH |
|      | 11. How much do you and this sibling like the same things?               | [ ] Hardly at all  
[ ] Not too much  
[ ] Somewhat  
[ ] Very much  
[ ] EXTREMELY MUCH |
|      | 12. How much do you and this sibling tell each other everything?         | [ ] Hardly at all  
[ ] Not too much  
[ ] Somewhat  
[ ] Very much  
[ ] EXTREMELY MUCH |
|      | 13. Some siblings try to out-do or beat each other at things a lot, while other siblings try to out-do each other a little. How much do you and this sibling try to out-do each other at things? | [ ] Hardly at all  
[ ] Not too much  
[ ] Somewhat  
[ ] Very much  
[ ] EXTREMELY MUCH |
|      | 14. How much do you admire and respect this sibling?                     | [ ] Hardly at all  
[ ] Not too much  
[ ] Somewhat  
[ ] Very much  
[ ] EXTREMELY MUCH |
|      | 15. How much does this sibling admire and respect you?                   | [ ] Hardly at all  
[ ] Not too much  
[ ] Somewhat  
[ ] Very much  
[ ] EXTREMELY MUCH |
|      | 16. How much do you and this sibling disagree and quarrel with each other? | [ ] Hardly at all  
[ ] Not too much  
[ ] Somewhat  
[ ] Very much  
[ ] EXTREMELY MUCH |
|      | 17. Some siblings cooperate a lot, while other siblings cooperate a little. How much do you and this sibling cooperate with other? | [ ] Hardly at all  
[ ] Not too much  
[ ] Somewhat  
[ ] Very much  
[ ] EXTREMELY MUCH |
|      | 18. Who gets more attention from your mother, you or this sibling?       | [ ] My sibling almost always gets more attention  
[ ] My sibling often gets more attention  
[ ] We get about the same amount of attention  
[ ] I often get more attention  
[ ] I almost always get more attention |
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. How much do you help this sibling with things he or she can't do by him or herself?</td>
<td>[ ] Hardly at all, [ ] Not too much, [ ] Somewhat, [ ] Very much, [ ] EXTREMELY MUCH</td>
</tr>
<tr>
<td>20. How much does this sibling help you with things you can’t do by yourself?</td>
<td>[ ] Hardly at all, [ ] Not too much, [ ] Somewhat, [ ] Very much, [ ] EXTREMELY MUCH</td>
</tr>
<tr>
<td>21. How much do you make this sibling do things?</td>
<td>[ ] Hardly at all, [ ] Not too much, [ ] Somewhat, [ ] Very much, [ ] EXTREMELY MUCH</td>
</tr>
<tr>
<td>22. How much does this sibling make you do things?</td>
<td>[ ] Hardly at all, [ ] Not too much, [ ] Somewhat, [ ] Very much, [ ] EXTREMELY MUCH</td>
</tr>
<tr>
<td>23. Who gets more attention from your father, you or this sibling?</td>
<td>[ ] My sibling almost always gets more attention, [ ] My sibling often gets more attention, [ ] We get about the same amount of attention, [ ] I often get more attention, [ ] I almost always get more attention</td>
</tr>
<tr>
<td>24. How much do you and this sibling love each other?</td>
<td>[ ] Hardly at all, [ ] Not too much, [ ] Somewhat, [ ] Very much, [ ] EXTREMELY MUCH</td>
</tr>
<tr>
<td>25. Some siblings play around and have fun with each other a lot, while other siblings play around and have fun with each other a little. How much do you and this sibling play around and have fun with each other?</td>
<td>[ ] Hardly at all, [ ] Not too much, [ ] Somewhat, [ ] Very much, [ ] EXTREMELY MUCH</td>
</tr>
<tr>
<td>26. How much are you and this sibling mean to each other?</td>
<td>[ ] Hardly at all, [ ] Not too much, [ ] Somewhat, [ ] Very much, [ ] EXTREMELY MUCH</td>
</tr>
<tr>
<td>27. How much do you and this sibling have in common?</td>
<td>[ ] Hardly at all, [ ] Not too much, [ ] Somewhat, [ ] Very much, [ ] EXTREMELY MUCH</td>
</tr>
<tr>
<td>Q.</td>
<td>Description</td>
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<tr>
<td>28.</td>
<td>How much do you and this sibling share secrets and private feelings?</td>
</tr>
<tr>
<td>29.</td>
<td>How much do you and this sibling compete with each other?</td>
</tr>
<tr>
<td>30.</td>
<td>How much do you look up to and feel proud of this sibling?</td>
</tr>
<tr>
<td>31.</td>
<td>How much does this sibling look up to and feel proud of you?</td>
</tr>
<tr>
<td>32.</td>
<td>How much do you and this sibling get mad at and get in arguments with each other?</td>
</tr>
<tr>
<td>33.</td>
<td>How much do both you and your sibling share with each other?</td>
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<tr>
<td>34.</td>
<td>Who does your mother usually favor, you or this sibling?</td>
</tr>
<tr>
<td>35.</td>
<td>How much do you teach this sibling things that he or she doesn’t know?</td>
</tr>
<tr>
<td>36.</td>
<td>How much does this sibling teach you things that you don’t know?</td>
</tr>
<tr>
<td></td>
<td>Question</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>37.</td>
<td>How much do you order this sibling around?</td>
</tr>
<tr>
<td>38.</td>
<td>How much does this sibling order you around?</td>
</tr>
<tr>
<td>39.</td>
<td>Who does your father usually favor, you or this sibling?</td>
</tr>
<tr>
<td>40.</td>
<td>How much is there a strong feeling of affection (love) between you and this sibling?</td>
</tr>
<tr>
<td>41.</td>
<td>Some kids spend lots of time with their siblings, while others don’t spend so much. How much free time do you and this sibling spend together?</td>
</tr>
<tr>
<td>42.</td>
<td>How much do you and this sibling bug and pick on each other in mean ways?</td>
</tr>
<tr>
<td>43.</td>
<td>How much are you and this sibling alike?</td>
</tr>
<tr>
<td>44.</td>
<td>How much do you and this sibling tell each other things you don’t want other people to know?</td>
</tr>
<tr>
<td>45.</td>
<td>How much do you and this sibling try to do things better than each other?</td>
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</tbody>
</table>
ID #: 

<table>
<thead>
<tr>
<th>Question</th>
<th>Choices</th>
</tr>
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<tbody>
<tr>
<td>46. How much do you think highly of this sibling?</td>
<td>[ ] Hardly at all</td>
</tr>
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<td></td>
<td>[ ] Not too much</td>
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<td></td>
<td>[ ] Somewhat</td>
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<td></td>
<td>[ ] Very much</td>
</tr>
<tr>
<td></td>
<td>[ ] EXTREMELY MUCH</td>
</tr>
<tr>
<td>47. How much does this sibling think highly of you?</td>
<td>[ ] Hardly at all</td>
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<td></td>
<td>[ ] Not too much</td>
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<td>[ ] Somewhat</td>
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<td></td>
<td>[ ] Very much</td>
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<tr>
<td></td>
<td>[ ] EXTREMELY MUCH</td>
</tr>
<tr>
<td>48. How much do you and this sibling argue with each other?</td>
<td>[ ] Hardly at all</td>
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<td></td>
<td>[ ] Not too much</td>
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<td>[ ] Somewhat</td>
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<td>[ ] Very much</td>
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<td></td>
<td>[ ] EXTREMELY MUCH</td>
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</tbody>
</table>
Social Support Scale for Children and Adolescents (Harter, 1985)

INSTRUCTIONS

This questionnaire is interested in several kinds of people in your life. This is a survey, NOT a test. There are no right or wrong answers! Since kids are very different from one another, you will be putting down something unique to yourself.

There is a sample question at the top of the page. This question talks about two kinds of kids, and we want to know which kids are most like YOU.

1. What I want you to decide first is whether you are more like the kids on the left side who would rather do fun things with a lot of other people, or whether you are more like the kids on the right side who would rather do fun things with just a few people.

2. Now the second thing I want you to think about, now that you have decided which kind of kids are most like you, is to decide whether that is only sort of true for you, OR really true for you. If it’s only sort of true, then put an X in the box under sort of true; if it’s really true for you, then put an X in that box, under really true.

3. For each sentence you only check one box. Sometimes it will be on one side of the page, another time it will be on the other side of the page, but you can only check ONE BOX for each sentence. You DON’T check both sides, just the ONE side most like you.

Sample Item:

<table>
<thead>
<tr>
<th>Really True for Me</th>
<th>Sort of True for Me</th>
<th>Sample Item</th>
<th>Really True for Me</th>
<th>Sort of True for Me</th>
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<tbody>
<tr>
<td>X</td>
<td></td>
<td>Some kids like to do fun things with a lot of other people.</td>
<td>BUT Other kids like to do fun things with just a few people.</td>
<td></td>
</tr>
</tbody>
</table>

“Some kids like to do fun things with a lot of other people” is “Really True of Me” so it is checked off.
<table>
<thead>
<tr>
<th>ID #: ____________________________</th>
<th>Really True for Me</th>
<th>Sort of True for Me</th>
<th>Really True for Me</th>
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</thead>
<tbody>
<tr>
<td>3.</td>
<td>☐ ☐ ☐</td>
<td>Some kids have a teacher who helps them if they are upset and have a problem</td>
<td>BUT Other kids don’t have a teacher who helps them if they are upset and have a problem</td>
</tr>
<tr>
<td>4.</td>
<td>☐ ☐ ☐</td>
<td>Some kids have a close friend who they can tell problems to</td>
<td>BUT Other kids don’t have a close friend who they can tell problems to</td>
</tr>
<tr>
<td>5.</td>
<td>☐ ☐ ☐</td>
<td>Some kids have parents who don’t seem to want to hear about their children’s problems</td>
<td>BUT Other kids have parents who do want to listen to their children’s problems</td>
</tr>
<tr>
<td>6.</td>
<td>☐ ☐ ☐</td>
<td>Some kids have classmates that they can become friends with</td>
<td>BUT Other kids don’t have classmates that they can become friends with</td>
</tr>
<tr>
<td>7.</td>
<td>☐ ☐ ☐</td>
<td>Some kids don’t have a teacher who helps them to do their very best</td>
<td>BUT Other kids do have a teacher who helps them to do their very best</td>
</tr>
<tr>
<td>8.</td>
<td>☐ ☐ ☐</td>
<td>Some kids have a close friend who really understand them</td>
<td>BUT Other kids don’t have a close friend who understands them</td>
</tr>
<tr>
<td>9.</td>
<td>☐ ☐ ☐</td>
<td>Some kids have parents who care about their feelings</td>
<td>BUT Other kids have parents who don’t seem to care very much about their children’s feelings</td>
</tr>
<tr>
<td>10.</td>
<td>☐ ☐ ☐</td>
<td>Some kids have classmates who sometimes make fun of them</td>
<td>BUT Other kids don’t have classmates who make fun of them</td>
</tr>
<tr>
<td>ID #</td>
<td>Really True for Me</td>
<td>Sort of True for Me</td>
<td>Really True for Me</td>
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<td>11.</td>
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<td>12.</td>
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<tr>
<td>19.</td>
<td>[ ]</td>
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</tr>
</tbody>
</table>

**11.** Some kids do have a teacher who cares about them. **BUT** Other kids don’t have a teacher who cares about them.

**12.** Some kids have a close friend who they can talk to about things that bother them. **BUT** Other kids don’t have a close friend who they can talk to about things that bother them.

**13.** Some kids have parents who treat their children like a person who really matters. **BUT** Other kids have parents who don’t usually treat their children like a person who matters.

**14.** Some kids have classmates who pay attention to what they say. **BUT** Other kids have classmates who usually don’t pay attention to what they say.

**15.** Some kids don’t have a teacher who is fair to them. **BUT** Other kids do have a teacher who is fair to them.

**16.** Some kids don’t have a close friend who they like to spend time with. **BUT** Other kids do have a close friend who they like to spend time with.

**17.** Some kids have parents who like them the way they are. **BUT** Other kids have parents who wish their children were different.

**18.** Some kids don’t get asked to play in games with classmates very often. **BUT** Other kids often get asked to play in games by their classmates.

**19.** Some kids don’t have a teacher who cares if they feel bad. **BUT** Other kids do have a teacher who cares if they feel bad.
<table>
<thead>
<tr>
<th>ID #</th>
<th>Really True for Me</th>
<th>Sort of True for Me</th>
<th>Really True for Me</th>
</tr>
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<tbody>
<tr>
<td>20.</td>
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<td>21.</td>
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<tr>
<td>24.</td>
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</table>
INFORMED CONSENT FORM

TITLE OF STUDY

THE QUALITY OF THE SIBLING RELATIONSHIP
OF CHILDREN DIAGNOSED WITH AUTISM

TITLE OF STUDY IN LAY TERMS

What is it like to have a brother/sister with autism?

PURPOSE

The purpose of this research is to find out whether there is a correlation between the severity of autism disability and the quality of the sibling (brother/sister) relationship and differences regarding non-disabled siblings’ perception of social and familial support.

You are being asked to be in this research study because you have another child with a diagnosis of autism. If your other child has a diagnosis of Asperger’s, Rett’s, or Pervasive Developmental Disorder-Not Otherwise Specified, and your participating child, without autism, has a diagnosis of mental retardation, you can not be in this study.

INVESTIGATOR(S)

Principal Investigator: Beverly White, PsyD
Philadelphia College of Osteopathic Medicine
Department: Psychology
Address: 4170 City Avenue
         Philadelphia, PA 19131
Phone: 215-871-6497

Co-Investigator: Institution:
Department:
Address:
Phone:

Responsible (Student) Investigator: Kelly C. O’Laughlin

The survey you are being asked to volunteer for is part of a research project.

If you have questions about this research, you can call Dr. White at (215) 871-6497.
If you have any questions or problems during the study, you can ask Dr. White, who will be available during the entire study. If you want to know more about Dr. White’s background, or the rights of research subjects, you can call the PCOM Research Compliance Specialist at (215) 871-6782.

DESCRIPTION OF THE PROCEDURES

If you decide to be in this study, you will be asked to complete a Gilliam Autism Rating Scale (GARS-II) and Communication and Socialization Domains of the Vineland Adaptive Behavior Questionnaire (VABS-II). Only one parent is needed to complete this questionnaire, it does not matter if the father or the mother participate, however, the parent participant should be the primary caregiver for the child with autism in order to provide the most accurate information for the questionnaires.

The study will take about 20-30 minutes for each session. There will be 2 session(s) over the course of 30 days, for a total of 20-40 minutes of your time.

POTENTIAL BENEFITS

You may not benefit from being in this study. Other people in the future may benefit from what the researchers learn from the study.

RISKS AND DISCOMFORTS

There are no known risks to the parent from being in this study.

ALTERNATIVES

The other choice is to not be in this study.

PAYMENT

You will not be paid for being in this study. However your child will be eligible to participate in a raffle for a $50 gift card.
CONFIDENTIALITY

All information and records relating to your participation will be kept in a locked file. Only the researchers, members of the Institutional Review Board, and the U.S. Food and Drug Administration will be able to look at these records. If the results of this study are published, no names or other identifying information will be used.

REASONS YOU MAY BE TAKEN OUT OF THE STUDY WITHOUT YOUR CONSENT

If health conditions occur that would make staying in the study possibly dangerous to you, or if other conditions occur that would damage you or your health, the researchers may take you out of this study.

In addition, the entire study may be stopped if dangerous risks or side effects occur in other people.

NEW FINDINGS

If any new information develops that may affect your willingness to stay in this study, you will be told about it.

INJURY

If you are injured as a result of this research study, you will be provided with immediate necessary care.

However, you will not be reimbursed for care or receive other payment. PCOM will not be responsible for any of your bills, including any routine care under this program or reimbursement for any side effects that may occur as a result of this program.

If you believe that you have suffered injury or illness in the course of this research, you should notify the PCOM Research Compliance Specialist at (215) 871-6782. A review by a committee will be arranged to determine if the injury or illness is a result of your being in this research. You should also contact the PCOM Research Compliance Specialist if you believe that you have not been told enough about the risks, benefits, or other options, or that you are being pressured to stay in this study against your wishes.
VOLUNTARY PARTICIPATION

You may refuse to be in this study. You voluntarily consent to be in this study with the understanding of the known possible effects or hazards that might occur during this study. Not all the possible effects of the study are known.

You may leave this study at any time.

If you drop out of this study, there will be no penalty or loss of benefits to which you are entitled.

I have had adequate time to read this form and I understand its contents. I have been given a copy for my personal records.

I agree to be in this research study.

Signature of Subject: __________________________

Date: _____/_____/______ Time:___________ AM/PM

Signature of Witness: ____________________________

Date: _____/_____/______ Time:___________ AM/PM

Signature of Investigator or Designee, ____________________________
(circle one)

Date: _____/_____/______ Time:___________ AM/PM
The Quality of the Sibling Relationship of Children Diagnosed with Autism

You are being asked to be in a research study about your feelings about your relationship with your brother or sister with autism. This study is being conducted by Kelly O’Laughlin, who is a student at Philadelphia College of Osteopathic Medicine (PCOM). She is doing the study to earn a degree.

If you agree to be in this study, you will be asked to fill out a packet of questionnaires. These questionnaires will take about 10-15 minutes. NO names will be on the forms, but you will be asked to write your age, sex, and list the birth order of your brother(s) and sister(s) on a separate form.

You will only be identified by a number on your questionnaire packet. Your name will NOT be on any of the materials used in this study. You will NOT be asked to provide your name at any time. Please do NOT use or write your name anywhere at anytime during this study. Ms. O’Laughlin will not be able to link your name with your forms.

Your family members will not be given any of the answers that you provide. You will not benefit from being in this study. However, this study may provide information on what brothers or sisters of children with autism think about their relationship and their feelings of support from their parents and other adults.

You can say no or stop your participation at any time with no penalty or loss of benefits. All forms and other study records will be kept in a locked file. Only the researcher(s), members of the PCOM Institutional Review Board, and the U.S. Food and Drug Administration will be able to look at these records. If the results of this study are published, no names or other identifying information will be used.

One or both of your parents have already given permission for you to be in the study. They have a phone number for Ms. O’Laughlin, in case you or your parents have any questions about the research. They also have a phone number for the chairperson of the Institutional Review Board at PCOM, in case there are any questions about your rights as a research subject. You will be given a copy of this form to keep.
I was given enough time to read this form and ask questions. I understand the study.

I have been given a copy of this form to keep.

I agree to be in this research study.

Child Signature ___________________________ Date ____________

Child Name (printed) ___________________________ Date ____________

Investigator Signature ___________________________ Date ____________

Witness Signature ___________________________ Date ____________

The person being asked to be in this study can not give legal consent because he/she is under the age of 18. ___________________________ has my permission to be in this research.

(Please print child's name)

Signature of Parent or Legal Guardian ___________________________ Date ____________