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SIBLINGS OF INDIVIDUALS WITH AUTISM: PERCEPTIONS OF THE SIBLING
EXPERIENCE, PSYCHOLOGICAL FUNCTIONING, AND THE DEVELOPMENTAL
TASKS OF YOUNG ADULTHOOD

by

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ABSTRACT OF THE DISSERTATION

Siblings of Individuals with Autism: Perceptions of the Sibling Experience,
Psychological Functioning, and the Developmental Tasks of Young Adulthood

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Previous research has suggested siblings of individuals with autism are more likely to have adjustment problems during childhood than are other youngsters and is important to explore whether adult siblings are at increased risk for similar problems. The present study asked 25 young adult siblings of individuals diagnosed with an autism spectrum disorder (ASD siblings) and 25 control siblings of individuals without a chronic disability or illness to complete measures relevant to the overall functioning of a young adult. These included assessments of family functioning (quality of attachment to parents and psychological separation from parents), career development (both confidence in and satisfaction with career decisions), and evidence of psychological distress (i.e., symptoms of anxiety and depression). Respondents were also asked about their perceptions of the impact of their siblings on their family during childhood and at the present time. Overall,

the findings in the present study supported the hypothesis that ASD siblings would differ from control siblings particularly in the areas of family functioning, career goals, and perceptions of the impact of their sibling on their experiences with their family. Specifically, ASD siblings were more likely to report a less positive attachment to their parents, more likely to indicate their sibling impacted their development and career aspirations, more likely to report the desire to pursue a service career, and more likely to report negative childhood experiences due to their sibling. No differences between sibling groups were found on measures of psychological distress or separation from parents. The implications of the present study and recommendations and directions for future research on adult siblings of individuals with autism spectrum disorders are also discussed.

Dedication

For my father, who is very proud of his little girl.

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Siblings of Individuals with Autism: Perceptions of the Sibling Experience,
Psychological Functioning, and the Developmental Tasks of Young Adulthood

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Siblings of Individuals with Autism: Perceptions of the Sibling Experience, Psychological Functioning, and the Developmental Tasks of Young Adulthood Sibling Relationships across the Lifetime

The sibling relationship is an important, unique, and complex bond. Several particular characteristics of the sibling relationship distinguish it from all other types of interpersonal connections (Cicirelli, 1995). The sibling relationship can begin very early in life and is often the longest relationship a person will experience. Since it typically begins so early, it generally has a longer time course than relationships with parents, children, spouses, and friends. Siblings usually share genetic characteristics and a long history of shared environmental influences that can result in similar attitudes, knowledge, beliefs, and personality traits (Cicirelli, 1995). The sibling relationship is also obtained by birth (or parental decision) rather than selected by choice. Even if siblings choose to have little contact, they are nevertheless related. The sibling relationship is also characterized by relatively reciprocal and equivalent status when compared to other significant family relationships (e.g., parents or children).

The literature on siblings has, not surprisingly, suggested that relationships between typically developing siblings can vary significantly in terms of closeness, commitment, and warmth. The sibling relationship can be characterized by conflict, competition, and resentment and/or serve as a tremendous source of support. Since the sibling bond is such an important and enduring relationship and the nature of the relationship can vary significantly, it is thought to significantly impact an individual's psychological functioning and thus is becoming a frequently studied family relationship (Dunn, 1992). To examine the impact of different types of sibling relationships,

researchers generally examine the pattern of interactions between the individuals (e.g., frequent/infrequent or positive/negative) and the subjective attitudes each has about the other (e.g., nature of cognitions about sibling) (Cicirelli, 1995). According to the literature, both of these aspects of the sibling relationship can influence a child's outcome (Dunn, 1992). For example, the sibling relationship has been noted to be related to the development of internalizing and externalizing disorders, self-esteem, and interpersonal abilities.

Since the sibling relationship begins so early in life and is present throughout all periods of development, it is important to consider the distinct impacts of the sibling relationship at different periods of development (Harris & Glasberg, 2003). The sibling relationship is likely to have distinct impacts during early childhood, middle childhood, adolescence, and adulthood. Most children become a sibling at birth or during the early childhood years. For an older sibling, there is a period of adaptation which begins whenever a new baby is born or a new child is brought into the family (Cicirelli, 1995). Since an infant or young child requires significant attention from caregivers, some siblings have difficulty with the adjustment. When the older sibling becomes aware of the impact the new child can have on the family, most siblings will seek some form of reassurance from their parents while others may develop behavior problems. This process of adapting to a new sibling can be easier if the child already has a sibling or if parents have been preparing the child by talking about changes that will occur when the new child arrives (Cicirelli, 1995). Although this can be a difficult period for some children, an attachment or bond between the siblings is also developing very early in their relationship (Cicirelli, 1995). Evidence of this is apparent when young siblings are

separated from their parents, they tend to be drawn towards each other and older siblings will tend to comfort younger distressed siblings.

Early childhood interactions between siblings are generally initiated and maintained by the older sibling (Feiges & Weiss, 2004). When the younger child is an infant or young toddler, these interactions tend to be brief. As the younger child grows into a potential playmate around three or four years of age, older children become more interested in interacting with their younger brothers or sisters (Harris & Glasberg, 2003). These early interactions are thought to be important learning opportunities for both children. The older sibling is serving as a social and language model for the younger child while the older child makes gains in social skills by learning to adjust her language and play to the abilities of her younger sibling. During early childhood, children with siblings are exposed to early social learning concepts such as fairness and sharing (Feiges & Weiss, 2004).

Higher levels of conflict are typically observed between siblings as they move from early to middle childhood. As children develop, their sibling relationships become more egalitarian and the older sibling becomes both less dominant and less nurturing (Dunn, 1992). As a result, hostility and conflict can increase due to increasing efforts by the younger sibling to assert him/herself. This pattern of change in dominance is observed until adolescence, when sibling relationships become largely egalitarian. However, subtle levels of dominance of one sibling can still be seen in adult siblings (Cicirelli, 1995).

Middle childhood is also characterized by the increasing role of peers as playmates. During early childhood, parents and siblings are the most important sources

of emotional support. However, as children age, they depend less upon their families as they begin to depend more upon their peers. Buhrmester (1992) found emotional disclosure to siblings decreased during middle childhood and was surpassed by disclosure to peers between the second and fourth grade, indicating the beginnings of individuation and separation from the family. Despite the growing independence of children in middle childhood, sibling relationships are likely still playing a major role in the development of interpersonal skills. Some evidence of this has been found in research linking hostile relationships between siblings to problems with social reasoning and behavior problems in school (Dunn, 1988).

Adolescent sibling relationships are characterized by decreasing levels of conflicts and increasingly equivalent roles (Cicirelli, 1995). Conflicts between siblings tend to peak in late childhood and then decrease throughout adolescence as separation from the family continues. Adolescent siblings are less likely to take on a nurturing role towards a younger sibling when the siblings are close in age. During adolescence, sibling relationships are heavily influenced by the individual characteristics of the family and the siblings themselves. For example, same-sex and closer in age siblings tend to report greater intimacy and affection, but are also more likely to have antagonistic and relationships filled with conflict (Feiges & Weiss, 2004). Parental influences upon sibling relationships include the tendency for siblings to be closer when there is a lack of parental involvement and the tendency for siblings to act with hostility toward one another when they perceive differential treatment from their parents (Boer, Goedhart & Treffers, 1992).

Although the degree of contact between adult siblings varies greatly, most siblings remain in some form of contact and continue to feel close to their sibling into old age (Cicirelli, 1996). As adults, the nature of the relationship with a sibling is most heavily influenced by choice as siblings are no longer required to interact with their sibling because they can choose not to live together. Further, it is evident that sibling relationships do not remain constant throughout adulthood and are likely to experience multiple evolutions. For example, young adult siblings are less likely to remain in contact with and draw support from one another as they attend college or focus on developing their own careers and families. Some of the variables that likely influence how much time siblings spend together and the nature of their relationship include events such as marriage/divorce, employment, relocation, differences in achievements, and family illness or death.

Adult sibling relationships continue to be influenced by sibling and parent characteristics. For example, older adult siblings are more likely to report a close relationship, maintain contact with, and benefit from having a relationship with a sister (Cicirelli, 1995). Further, involvement with a parent may facilitate a closer relationship by such things as passing on information about the sibling and arranging family occasions.

During adulthood, siblings are highly utilized sources of support during periods of crisis or loss. Maintaining a close relationship with a sibling in adulthood, especially a sister, is associated with less depression and greater life-satisfaction (Cicirelli, 1996). Sibling closeness or conflict is especially influenced by the need to manage a parent's health and resources and cope with a parent's death (Cicirelli, 1996). With the greater probability of

divorce and remarriage, a longer life span, and a smaller family, the sibling relationship may be taking on a larger role in the support system of an adult (Harris & Glasberg, 2003).

Stressors Associated with Autism

There is clear evidence in the literature that researchers are increasingly recognizing the role of the sibling relationship on development (Dunn, 1992) and there has been a corresponding increase in the appreciation of the experience of having a sibling with autism. Brothers and sisters of individuals with autism have to cope with the unique set of challenges placed upon the entire family and they undoubtedly have a distinctive sibling experience.

The features of autism pose rigorous challenges to families. Autism is a pervasive developmental disorder characterized by a triad of impairments: deficits in social functioning, deficits in communication, and a restricted repertoire of activities or interests (Mesibov, Adams, & Klinger, 1997). Autism is associated with a variety of other characteristics including mental retardation, seizure disorders, difficulty with attention and concentration, lack of play skills, and behavior problems such as aggressions and self-injury. The degree of impairment associated with autism varies significantly. Some individuals need relatively little support in academic or employment environments while others will require a significant amount of assistance throughout their lives. Consequently, the effects of autism differ significantly from other frequently studied disorders such as childhood cancer, diabetes, cerebral palsy, or Down's syndrome and are unique to each family.

Lobato, Faust, and Spirito (1988) outlined six characteristics that differ among the illnesses and disabilities commonly addressed in the literature: onset, etiology, course, prognosis, visibility, and functional impairment. These characteristics change the way a disorder impacts upon family members. For instance, a late onset disorder can impact the sibling relationship differently than an early onset disorder perhaps due to a period of normal relationship development that occurred prior to the late onset disorder. As a result, the sibling may have more difficulty coping at the time of the onset of the disorder since they may be experiencing a more sudden loss (Lobato, Faust, & Spirito, 1988). In contrast, children with a sibling with an early onset disorder are likely to have never known the sibling before the onset of the disorder and thus may not experience a loss associated with a change in their relationship. However, they may experience the effects of the disorder during a number of crucial developmental periods or be influenced by the perception of a loss at a time other than the onset of the disorder.

Autism and the other pervasive developmental disorders are characterized by an early onset, a typically genetic basis a stable or fluctuating course, a nonfatal prognosis, unaffected physical appearance, and implications for behavioral, emotional, cognitive, and communicative functions. The early onset associated with autism implies that most siblings have always known their sibling with the disability and are less likely to experience loss. However, parents are likely to be experiencing the loss of their hopes for a particular type of child and/or guilt associated with the genetic and/or environmental determinants of the disorder (Lobato, Faust, & Spirito, 1988). Features such as behavior problems and seizures can fluctuate, resulting in temporary and unpredictable increases in the stress experienced by the family. Since autism is not a visible disorder, siblings

might have to answer questions from their peers about the disorder and fear having their friends come over to the house. Further, an invisible disorder might be more difficult for young siblings to understand than a disorder associated with a readily observable physical illness (Glasberg, 2000). Finally, the pervasive effects of autism on functioning imply day-to-day life will be influenced for siblings and their families.

The unique social, communication, and play deficits of autism are also expected to significantly influence the development of sibling relationships. Individuals with autism often have difficulty with skills important for forming interpersonal relationships such as pretend play, joint attention, social reciprocity, perspective-taking, initiating conversations, and displaying affection (Knott, Lewis, & Williams, 1995; Mesibov, Adams, & Klinger, 1997). Young siblings of children with autism may initially be interested in playing and interacting with their brother or sister but find their sibling a frustrating or disappointing playmate (Harris & Glasberg, 2003). This may lead to decreased interactions between siblings and less development of a social bond during childhood. Further, it is known that parents of children with autism or other disabilities are more likely to have increased stress and suffer from depression or marital distress (Fisman, Wolf, Ellison, & Freeman, 2000; Rivers & Stoneman, 2003). The increased stress experienced by parents of individuals with autism is also likely to contribute to the functioning of a sibling.

The Impact of Autism on Siblings

The greater appreciation of the distinct stressors associated with autism has led to an increase in research focusing exclusively on siblings of children with the disorder. However, the study of siblings of individuals with autism is still a relatively new research

area and there is considerably more research on the general effects of having a sibling with a disability. Thus, the present review includes studies of siblings of children with developmental disabilities or mental retardation when examining outcomes important for children but not well investigated in siblings of children with autism. Research on the impact of having a brother or sister with autism or other developmental disability has focused on two main outcomes: the nature of the sibling relationship and the adaptation of the sibling to the disorder.

The sibling relationship. Research on the sibling relationship when one child has a disability has addressed both the pattern of interactions between the individuals and the subjective attitudes of a sibling towards their brother or sister with a disability (Cicirelli, 1995). The nature of interactions between siblings has been examined using both direct observation and interview methods.

Only a few direct observations of children's interactions with their siblings with autism have been conducted, but findings have been relatively consistent (El-Ghoroury & Romanczyk, 1999; Knott, Lewis, & Williams, 1995). Knott, Lewis, and Williams (1995) compared interactions between children and their siblings with autism or siblings with Down's syndrome. They observed the frequency of initiations and responses between the children and coded them as either pro-social or antagonistic. They found that sibling pairs involving a child with Down's syndrome made more pro-social and antagonistic initiations towards each other and used a wider variety of initiation strategies than sibling pairs involving a child with autism. Similarly, they found that children with Down's syndrome responded more positively to their sibling's initiations than children with autism. El-Ghoroury and Romanczyk (1999) conducted observations of family

members' interactions toward children with autism. They found that mothers and fathers were more likely than siblings to exhibit play behaviors towards the child with autism. This is evidence for the notion that siblings might be less likely to find their sibling a reinforcing playmate. These findings that siblings interact less are not unexpected given the nature of the social and communication impairments associated with autism.

There have also been observational studies comparing sibling interactions when one child had been diagnosed with mental retardation. Stoneman, Brody, Davis, and Crapps (1987) found that siblings of a child with mental retardation were more likely than other children to be involved in activities associated with manager/guidance and teacher/helper roles. Siblings of children with mental retardation were also engaged in different activities than siblings of typically developing children. Siblings appeared to be accommodating the disability of their sibling by engaging in activities such as rough and tumble play rather than engaging their siblings in more socially difficult activities such as games. However, the amount of time spent interacting did not differ between groups (Stoneman, Brody, Davis, & Crapps, 1987). This finding is inconsistent with observations of sibling pairs when one has autism, suggesting that less frequent interactions could be a unique phenomenon of autism (Knott, Lewis, & Williams, 1995). Thus, it is unknown whether the caretaking and type of activity findings from this study should be generalized to children with autism.

Interviews with children and their parents about the types of activities siblings engage in together indicate siblings are more likely to take on caregiver roles in their interactions. Lobato, Barbour, Hall and Miller (1987) found that increased childcare responsibilities can be found even in preschool aged siblings of children with disabilities.

Stoneman, Brody, Davis, and Crapps (1988) interviewed siblings of children with and without mental retardation about childcare responsibilities, household tasks, activities, and friends. They found that girls in both groups were more likely to be engaged in caretaking responsibilities than boys. However, they found childcare responsibilities increased for brothers of children with a sibling with mental retardation to levels similar to those of sisters of children without a disability. In this sample, increased childcare responsibilities were associated with greater sibling conflict, decreased opportunities for interactions with peers, and fewer out-of-home activities. Some have suspected that childcare activities may provide some benefit for children including opportunities for social development (Feiges & Weiss, 2004; Lobato, Barbour, Hall, & Miller, 1987). However, these findings suggest that increased responsibilities might be associated with contextual variables that can lead to depression. Many of these findings were supported by McHale and Gamble's (1989) examination of siblings of children with and without disabilities. Using interview methods, they found similar rates of interaction in two groups of children. Both girls and boys were more likely to have caretaking and household chore responsibilities if they had a sibling with a disability. These results parallel previous findings about siblings of children with mental retardation, but less is known about whether these patterns exist in siblings of children with autism. In one study that included children with autism, lower levels of pro-social and nurturing behavior were found between siblings when one child had autism than in comparison groups of siblings of children with Down's syndrome or typically developing children (Kaminsky & Dewey, 2001).

Variable trends have been observed in children's descriptions of their siblings with autism or another disability. Overall, it has been found that siblings of children with a disability tend to rate their sibling very positively (McHale, Sloan, & Stoneman, 1986; Pilowsky et al., 2004; Stoneman, 2001; Stoneman, Brody, Davis, & Crapps, 1987).

Some have found that children with siblings with a disability have more positive descriptions of their siblings than other children (Kaminsky & Dewey, 2001; Stoneman, 2001). For example, Kaminsky and Dewey (2001) found that siblings of children with a disability (autism or Down's syndrome) reported more admiration of and less rivalry with their sibling than a comparison group of children. However, a few studies have found that siblings of children autism tended to have more negative views about their sibling than children of siblings with other disabilities (Bagenholm & Gillberg, 1991).

In some samples, there was considerably more variability in the reports by siblings.

McHale, Sloan, and Simeonsson (1986) found little overall difference between siblings of children with autism, children with mental retardation, and children without a disability.

However, they reported tremendous variability among siblings of children with a disability when compared to siblings of typically developing children. Some children described very positive attitudes and relationships and some described very negative ones. This pattern has led later researchers to focus on factors that contribute to the variability in children's reports. Some of these differences may be explained by the age of the siblings. Pilowsky et al. (2004) found sibling age was associated with a positive description of their brother or sister with autism. Older children were more likely to describe their sibling positively, perhaps due to a growing awareness of the nature of the disorder and increasing empathy towards their sibling.

Sibling adaptation. Research on sibling adaptation to having a brother or sister with a developmental disability suggests a somewhat increased risk of adjustment problems. A few studies have found no evidence of problems with behavioral adjustment using measures of behavior problems or symptoms of anxiety and depression. For example, Hastings (2003b) found no increases in emotional problems, conduct problems, or peer relations when compared to normative data. Similarly, Pilowsky et al. (2004) compared rates of social-emotional adjustment, behavior problems, and social skills in siblings of children with autism, siblings of children with mental retardation, and siblings with developmental language disorders. No notable differences were found among groups.

However, a number of other studies have found significant increases of internalizing and externalizing disorders in siblings. Gamble and McHale (1989) found that siblings of children with a disability reported more symptoms of anxiety and depression than siblings of children without a disability. Research conducted by Gold (1993) found that siblings of children with autism scored higher on measures of depression than siblings of children without a disability. Using parent and teacher report measures, Fisman et al. (1996) examined rates of externalizing and internalizing disorders in siblings of children with a pervasive developmental disorder, siblings of children with Down's syndrome, and a control group of siblings. They found higher rates of parent reported externalizing and internalizing disorders and teacher reported internalizing disorders in siblings of children with a pervasive developmental disorder than in either of the control groups. Similarly, Hastings (2003a) reported increased

parent reported behavior problems in siblings of children with autism when compared to normative data.

A few studies have found increased adjustment disorder rates that persist over time. In a five-year longitudinal study, Breslau and Prabucki (1987) found that parent's initial ratings of aggressive behaviors were higher in siblings of children with a disability than control children. At the five year follow-up, they found depression and aggressive behaviors had increased in siblings of children with disabilities but did not find similar increases in controls. In a three-year follow-up to an earlier study (see above; Fisman et al., 1996), Fisman, Wolf, Ellison, and Freeman (2000) found that siblings of children with pervasive developmental disorders maintained increases in parent reported externalizing behaviors and teacher reported internalizing disorders. However, they found that parent reported rates of internalizing disorders were no longer significantly different than controls.

There are also a number of mixed reports that suggest other variables may be responsible for the range of poor adjustment findings. For example, Lobato, Barbour, Hall, and Miller (1987) found more differences on parent report measures of their children's depressive and aggressive behaviors than in ratings by the siblings themselves. This speaks to the methodological problems with report measures, especially when completed by parents who may be experiencing distress themselves. In another study, Rodrigue, Geffken, and Morgan (1993) found higher scores on measures of internalizing and externalizing problems but found these scores were in normal ranges. This suggests that many children are experiencing greater amounts of stress but that these stressors are not resulting in significant adjustment problems (Hastings, 2003a). Finally, Dyson

(1989) found little differences between siblings of children with and without disabilities on measures of self-concept, behavior problems, and social competence. Yet, there was notable variability in the groups, indicating the potential greater importance of other variables interacting with the stressor of having a sibling with a disability. As previously mentioned, variability has also been found in siblings' attitudes towards the child with a disability (McHale, Sloan, & Simeonsson, 1986).

The literature on a child's adaptation to a chronic disability or illness in a sibling is not limited to developmental disabilities. There is considerable evidence that having a sibling with any one of a number of chronic conditions can increase the likelihood of adjustment difficulties such as behavior problems or peer difficulties. For example, siblings of children with Attention Deficit Hyperactivity Disorder have been reported to have more peer difficulties and emotional problems than their peers (Jones, Welsh, Glassmire, & Tavegia, 2006; Smith et al., 2002). Siblings of individuals with chronic illness such as cancer or diabetes have also been found to have increased adjustment problems including conduct disorders and academic problems (Barlow & Ellard, 2006; Bellin & Kovacs, 2006).

While the literature on school-aged siblings of children with autism or other disabilities has expanded considerably in the past few decades, very little research has focused on adolescents or adults and almost none of it addresses siblings of individuals with autism. As previously mentioned, adolescence is characterized by increasing independence from family members, increasing focus on peer relationships, and the development of a more egalitarian relationship with siblings (Cicirelli, 1995). Since many of the same processes in school aged children were disrupted as a result of having a

sibling with a disability, it would be expected that that this disruption would continue into adolescence. The growing recognition of the unique concerns and demands associated with being an adolescent or adult sibling will hopefully lead to more knowledge about whether the positive or negative effects of having a sibling with autism will persist into later adolescence or adulthood (Eisenberg, Baker, & Blacher, 1998; Harris & Glasberg, 2003; Opperman & Alant, 2003). In one study, Breslau and Prabucki (1987) found that adolescent siblings reported more oppositional behaviors including breaking minor rules, disobedience, arguing, and stubbornness than children obtained from a geographic sample.

Others have hypothesized that the cognitive changes associated with adolescence may also lead to concerns and cognitions about the future (Eisenberg, Baker, & Blacher, 1998; Harris & Glasberg, 2003). During this period, adolescent siblings are likely becoming aware of the roles and responsibilities they might have to take on as they grow into adults. Eisenberg, Baker, and Blacher (1998) interviewed adolescent siblings of children with mental retardation who lived at home, children with mental retardation who were placed out of the home, and children without mental retardation. The authors did not find differences between the groups on measures of psychological adjustment, self-esteem, or family environment. Further, siblings of children with mental retardation reported that the experience had a positive impact on them. However, the authors did find that siblings of children with mental retardation expressed concern about the future (Eisenberg, Baker, & Blacher, 1998). Most siblings worried about where their brother or sister will live in the future, who will take care of them in the future, believed they would

responsible for care giving in the future, and stated that their sibling will influence their later decisions about career and family.

Even less is known about adult siblings of individuals with autism. Very few studies have examined the experience of having a sibling with a disability or the impact upon adjustment in adulthood. Seltzer, Greenberg, Wyngaarden, Gordon, and Judge (1997) found that siblings of adults with mental retardation were more likely to have face-to-face contact with their sibling than siblings of adults with severe mental illness. Siblings of adults with mental retardation were also more likely to perceive their relationship with their sibling as positive, perceive that the sentiment was reciprocated, and report that their sibling had a significant impact upon their career choices, decisions to have children, romantic relationships, plans for the future, and attitudes towards individuals with disabilities. Having a close relationship with a brother or sister with mental retardation also predicted better psychological functioning. Unfortunately, this study did not employ a control group of siblings so it is not known whether either of the groups differs from siblings of adults without a disability or illness.

Having a sibling with a disability is likely to impact upon adult psychological functioning due to the impact on decisions about career and family. Life events such as marriage, moving, and deciding to have children may be more stressful if a sibling is concerned about the individual with autism, needs of their family, or the possibility of having a child with autism. Further, loss of a parent may also be particularly difficult if increased caretaking responsibilities are associated with the loss and the siblings with autism is not able to provide the emotional support often provided by siblings in times of

loss. It is of obvious clinical importance to know if the minor risk of adjustment problems reported in childhood persists into adulthood.

Also as interesting are the potential positive effects of having a sibling with autism. Siblings of adults with autism could be more likely to keep in contact with their sibling and report a more positive overall sibling experience. Clinical researchers have suggested that siblings of children with developmental disabilities might be more likely to choose careers in education or psychology (Harris & Glasberg, 2003).

This review of the literature on siblings of children with autism or other developmental disabilities suggests that having a sibling with autism significantly affects sibling relationships and can lead to adjustment problems in some populations of children. When one child has a developmental disability, sibling relationships in childhood might be characterized by fewer typical interactions and additional childcare responsibilities for the sibling without a disability. Further, adolescent and adult siblings of individuals with autism may also worry about their brother or sister's future and make decisions about career and family based upon their needs of their sibling. Obvious directions for future research include investigations of adolescent and adult siblings of individuals with disabilities and the specific impact of autism (versus other diagnoses) on a sibling.

Rationale for the Present Study

Since previous research has suggested siblings of individuals with autism are more likely to have adjustment problems during childhood than are other children, is important to explore whether adult siblings are at increased risk as well. To date, no studies have specifically addressed this potentially valuable area of research. If there is an

increased risk of adjustment problems or other major concerns in adulthood, this would have important implications for researchers and clinicians. Not only would this support the need for researchers to develop appropriate interventions for older siblings, it would identify a need for methods to prevent the prolonged impact that having a sibling with autism has upon an individual. If these difficulties can be prevented, this may reduce the burden of autism upon families and society.

The present study explored the effect of having a sibling with autism on psychological functioning during young adulthood. The study compared siblings of individuals with autism spectrum disorders and siblings of individuals without a chronic disability or illness on various measures relevant to the development of a young adult. These included the nature of relationships with parents, career development, and psychological functioning. Based upon previous research, it was hypothesized that siblings of individuals with autism spectrum disorders would differ from other siblings in all of these major areas of development. Specifically, siblings were predicted to have increased problems with parental attachment, separation, and psychological functioning. Further, it was anticipated that siblings would perceive their sibling would have a greater impact upon their career decisions and be more likely to pursue a service career. The present study also compared groups of siblings on their perceptions of the impact of their sibling on their family life. It was hypothesized that siblings of individuals with autism spectrum disorders would report more negative emotions and experiences due to their sibling and that their sibling had a more significant impact upon their development than control siblings.

Method

Participants

Participants were 50 young adults between the ages of 18 and 24 years old. They included 25 siblings of individuals diagnosed with an autism spectrum disorder (referred to as “ASD siblings” in this paper) and 25 control siblings of individuals without a chronic disability or illness. Each participant had a biological sibling born within 7 years of their birth so that the sibling was more likely living with the participant during much of early childhood. Siblings of individuals with autism were recruited by contacting families who receive services at well-known autism treatment programs in New Jersey and California as well as families who are members of a statewide New Jersey autism advocacy organization. Approximately 1400 unselected families of individuals with autism were given fliers or packets about participation. It is unknown how many of these families had a young adult sibling. Participants who were siblings of individuals without a chronic disability or illness were recruited by handing out fliers about participation at malls, coffee shops, and airport waiting areas in New Jersey and California. Control siblings were recruited after ASD siblings so the investigators could target young adults for participation with similar demographic characteristics as the ASD siblings. This was done because it was predicted that given the nature of autism spectrum disorders, ASD siblings would differ on certain characteristics. For example, autism is more common in males so ASD siblings might be more likely to have a brother than a sister. Since there are known gender differences in sibling relationships, it would be important to make sure that differences between groups was not due to the control group benefiting from having more sisters. Although there was no formal matching or randomization used in this study,

the primary investigator handed out more fliers to individuals who endorsed some similar characteristics as the ASD siblings (e.g., females who stated they had a brother).

Approximately 650 fliers were passed out to potential participants in public areas.

Procedure

After expressing interest in participation (e.g., replying to a flier by contacting the primary investigator through email), a potential participant was given a packet containing study materials. The packet included a letter to participants describing the study, consent forms, a demographic data form, study questionnaires, and a stamped return envelope addressed to the primary investigator. Demographic information collected from each participant included the participant's age, ethnicity, gender, number of siblings, age of siblings, and parental marital status. Participants were instructed to review the consent form, complete the questionnaires, and return the materials within 14 days of receiving the packet. Approximately 60% of ASD siblings who indicated interest in participating and approximately 31% of control siblings who indicated interest returned completed surveys. One survey from an ASD sibling was returned without complete information and was not included in the data analysis leaving 25 participants in that group.

Participants were not supervised during completion of the questionnaires since the majority of the questionnaires were completed by participants in their homes. However, prior to the start of the study, a group of volunteer undergraduate psychology students completed the questionnaires and were asked to provide feedback to the researchers about length of the questionnaires, any fatigue, and the clarity of the instructions provided with each measure. Using this feedback from the volunteer students, specific instructions for

participants were developed to address any issues that might arise during completion of questionnaires.

Measures

Parental Attachment Questionnaire (Kenny, 1987). The Parental Attachment Questionnaire (PAQ) is a 55-item instrument designed to measure the quality of the attachment between young adults and their parents (See Appendix A). The PAQ contains items answered on a 5-point Likert scale and consists of three scales: Affective Quality of Relationship with Parents, Parents as Facilitators of Independence, and Parents as Source of Support. The instrument has been reported to have alpha coefficients of .96, .88, and .88 for the affective quality, source of support, and fostering independence scales and test-retest stability coefficients of between .82 and .91 (Lopez & Gover, 1993).

Sample items from each scale include: Affective Quality of Relationship with Parents – “In general, my parents understand my problems and concerns”; Parents as Facilitators of Independence – “In general, my parents try to control my life”; and Parents as Source of Support – “In general, my parents are available to give me advice or guidance when I want it”.

Psychological Separation Inventory (Hoffman, 1984). The Psychological Separation Inventory (PSI) is a 138-item instrument designed to measure the process that underlies psychological separation from parents (See Appendix A). Different aspects of separation/individuation are examined in four scales including: Functional Independence, Attitudinal Independence, Emotional Independence, and Conflictual Independence. The PSI contains separate mother and father scales and consists of items answered on a 5-point Likert scale. The scales have been reported to have internal consistency

coefficients (Cronbach alpha) that range from .84 to .92 and test-retest correlations that range between .49 - .96 (Hoffman, 1984).

Sample items from each scale include: Functional Independence - “When I am in difficulty, I usually call upon my mother/father to get me out of trouble”; Emotional Independence - “Sometimes I call home just to hear my mother/father’s voice”; Attitudinal Independence - “My religious beliefs are similar to my mother’s/father’s”; and Conflictual Independence - “I have to be careful not to hurt my mother’s/father’s feelings”.

Beck Depression Inventory & Beck Anxiety Inventory (Beck, Ward, Mendelson, Mock & Erbaugh, 1961; Beck & Steer, 1990). The Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI) are widely used instruments designed to measure symptoms of depression and anxiety (See Appendix A). The BDI is a 21-item instrument in multiple choice format that yields a total score between 0 and 63. A higher total score indicates greater symptoms of depression. The BAI contains 21-items which each describe a symptom of anxiety and ask the participant to rate on a 4-point scale how much they have been bothered by the symptom. Total score ranges between 0 and 63, which a higher total score reflecting increased symptoms of anxiety. The BDI has test-retest correlations generally in the range of .48 to .86 (Groth-Marnat, 1990) and the BAI has test-retest correlations generally in the range of .75 (Beck & Steer, 1990).

Education and Career Information. An education and development form was developed to provide information about a young adult’s stage in and satisfaction with the choosing a career (See Appendix A). Additional questions address the young adult’s

perceptions of the influence of his/her parents and siblings upon making a career decision.

Subjective Sibling Experience. Fifteen questions were developed to inquire about each participant's subjective experience of being a sibling (See Appendix A). Each of these items was answered on a 5-point Likert scale. Sample questions include:

“Compared with your peers, do you think you spent more time in caretaking roles with your sibling as a child?” and “To what extent do you think you have overcompensated for your sibling's failure to achieve goals?”.

Data Analysis

Differences between the groups on scores on each scale of the Parental Attachment Questionnaire (PAQ) and the Parental Separation Inventory (PSI) were compared using one-way analysis of variance. Any differences between groups on scores on the Beck Depression Inventory (BDI) and the Beck Anxiety Inventory (BAI) were compared using the t-test for two population means.

The education and career and sibling experience questionnaires were developed by the primary investigator, are not standardized measures, and do not yield overall scores that easily lend themselves to comparison. Each questionnaire contains a number of Likert scale questions that provide information about career development or the sibling experience. T-tests for two population means was run on individual questions to determine whether there are differences between the groups on responses to the questions. Further, the education and career questionnaire asked participants to provide information about nature of their career goals. Undergraduate students were asked to rate whether they considered each career a “service career” or a “non-service career”

depending upon whether they believed the occupation involved “helping others in need on a daily basis”. Examples of service careers provided to the raters included clinical psychology, nursing, medicine, or teaching.

Results

Demographic Information

Demographic information as reported by participants is presented in Table 1. Participants were on average 20.96 years of age (range 18 to 24 years), more likely to be female (62%), largely identified themselves as Caucasian (86%) with 6% African American, 2% Asian, 2% Indian, 2% Hispanic and 2% other. The majority of participants reported their parents were married (68%). The respondents were likely to be students (70%) and had on average completed almost 3 years of higher education (range 0-6 years). Using t-tests to compare means, no group differences were found when comparing ASD and control siblings on participant age, participant gender, ethnicity, parental marital status, student status, number of years of education, number of siblings, age of siblings, gender of siblings, or whether they were living with their sibling (Table 1).

ASD siblings also provided information about their sibling not applicable to control siblings. When asked about the autism diagnosis of their sibling, 80% of ASD siblings responded that their sibling was diagnosed with Autistic Disorder, 12% reported diagnoses of Asperger's Disorder, and 8% noted a diagnosis of Pervasive Developmental Disorder – Not Otherwise Specified. ASD siblings reported 76% of their siblings were receiving specialized autism services and 48% of their siblings were receiving applied behavior analysis services. The type of services being provided to those siblings who were not receiving ABA is not known.

Sibling Experience Questionnaire

Table 1. Demographic Information

	Siblings of Individuals with ASDs (n=25)	Control Siblings (n=25)	t(49) value	P value
Age	Mean = 20.80 years Range = 18 - 24 years SD 2.02	Mean = 21.12 years Range = 18 - 24 years SD 1.90	-0.5770	0.57 (NS)
Gender	56% Female; 44% Male	68% Female; 32% Male	-0.5790	0.57 (NS)
Ethnicity	88% Caucasian; 4% African American; 4% Pacific Islander; 4% Indian	84% Caucasian; 8% African American; 4% Hispanic, 4% Other	-1.1150	0.27 (NS)
Parental Marital Status	72% Married; 20% Divorced; 4% Separated; 4% Never Married	64% Married; 32% Divorced; 4% Separated	<0.0001	>0.99 (NS)
Student Status	68% Students	72% Students	0.3030	0.76 (NS)
Years Education	2.84 years	3.12 years	-0.6020	0.55 (NS)
Number of Siblings	Mean = 1.48 Range = 1-3 SD 0.71	Mean = 1.68 Range = 1-4 SD 0.85	-0.8990	0.37 (NS)
Sibling Diagnosis	80% Autistic Disorder; 12% Asperger's Disorder; 8% Pervasive Developmental Disorder- Not Otherwise Specified			
Sibling Age	Mean = 19.36 years Range = 13 - 32 years SD 4.46	Mean = 21.40 years Range = 13 - 34 years SD 5.14	0.9760	0.33 (NS)
Sibling Gender	84% male; 16% female	76% male; 24% female	-0.6960	0.49 (NS)
Live with Sibling	48% Live with Sibling	36% Live with Sibling	0.8490	0.40 (NS)
Sibling Receiving Autism Services	76% Receiving Services			
Sibling Receiving ABA Services	48% Receiving ABA Services			

To compare siblings on responses to questions about their experience as a sibling, a series of t-tests to compare means were utilized (Figure 1). ASD siblings reported more negative experiences with peers due to their sibling ($M=2.48$, $SD=1.29$) than control siblings ($M=1.36$, $SD=0.91$); ($t(49)=3.542$, $p<.001$), more caretaking responsibilities (ASD $M=3.88$, $SD=0.88$; Control $M=1.36$, $SD=0.44$; $t(49)=14.012$, $p<.001$), more overcompensation for siblings failure to achieve goals (ASD $M=2.68$, $SD=1.35$; Control $M=1.24$, $SD=0.60$; $t(49)=4.891$, $p<.001$), and more guilt about having abilities that their sibling lacks (ASD $M=2.48$, $SD=1.42$; Control $M=1.60$, $SD=0.58$; $t(49)=8.704$, $p<.001$). ASD siblings reported more worry about their sibling on a daily basis ($M=3.44$, $SD=1.16$) than control siblings ($M=1.72$, $SD=0.61$); ($t(49)=6.564$, $p<.001$), more worry about their sibling's future (ASD $M=4.00$, $SD=0.87$; Control $M=1.96$, $SD=0.79$; $t(49)=8.704$, $p<.001$), and more worry about having a child with autism in the future (ASD $M=3.40$, $SD=1.29$; Control $M=1.68$, $SD=0.69$; $t(49)=5.874$, $p<.001$). In addition, ASD siblings indicated their brother's or sister's needs were a greater focus within the family relative to their own during childhood (ASD $M=4.12$, $SD=0.73$; Control $M=2.84$, $SD=0.75$; $t(49)=6.149$, $p<.001$) and at the present time (ASD $M=3.88$, $SD=.83$; Control $M=2.44$, $SD=1.04$; $t(49)=5.392$, $p<.001$).

ASD siblings also reported their sibling was more of an influence on decisions about career and family (ASD $M=3.40$, $SD=1.08$; Control $M=2.32$, $SD=1.35$; $t(49)=3.130$, $p=.003$), had more of an impact upon decision about where to live (ASD $M=2.68$, $SD=1.25$; Control $M=1.52$, $SD=0.71$; $t(49)=4.031$, $p<.001$), and also has had a greater impact upon helping form who they are (ASD

M=4.44, SD=0.71; Control M=2.88, SD=0.83; $t(49)=7.120$, $p<.001$). There was a small but significant difference between groups on level of involvement they expected to have in the future with their sibling (ASD M=4.24, SD=0.66; Control M=3.80, SD=0.76; $t(49)=2.175$, $p<.001$). However, ASD siblings were not more likely to report pressure from parents to be involved with their sibling's life (ASD M=2.36, SD=1.04; Control M=2.32, SD=1.46; $t(49)=0.112$, $p=0.912$). Also, ASD siblings were not more likely to have participated in support groups of therapy that focused on issues related to being a sibling (ASD M=1.48, SD=0.96; Control M=1.08, SD=0.28; $t(49)=1.997$, $p=.052$).

Parental Attachment Questionnaire

ASD and control siblings' average scores on the Parental Attachment Questionnaire are presented in Figure 2. ASD participants reported a less positive affective quality to their relationship with their parents (ASD M=102.44, SD=18.57; Control M=114.36, SD=14.76; $F(1,48)=6.310$, $p=.015$), reported their parents did less to facilitate their independence (ASD M=47.00, SD=9.08; Control M=55.80, SD=10.21; $F(1,48)=10.367$, $p=.002$), and reported their parents were less of a source of support (ASD M=40.64, SD=7.63; Control M=51.40, SD=12.75; $F(1,48)=13.112$, $p<.001$).

Psychological Separation Inventory

As depicted in Figure 3, no notable differences were found between sibling groups on any of the scales of the Parental Separation Inventory. On the mother scales, no differences were found on attitudinal independence (ASD M=22.28, SD=9.94; Control M=18.96, SD=7.10; $F(1,48)=1.847$, $p=0.180$),

Figure 1. Perceptions of the Sibling Experience: Siblings of Individuals with Autism Spectrum Disorders and Control Siblings

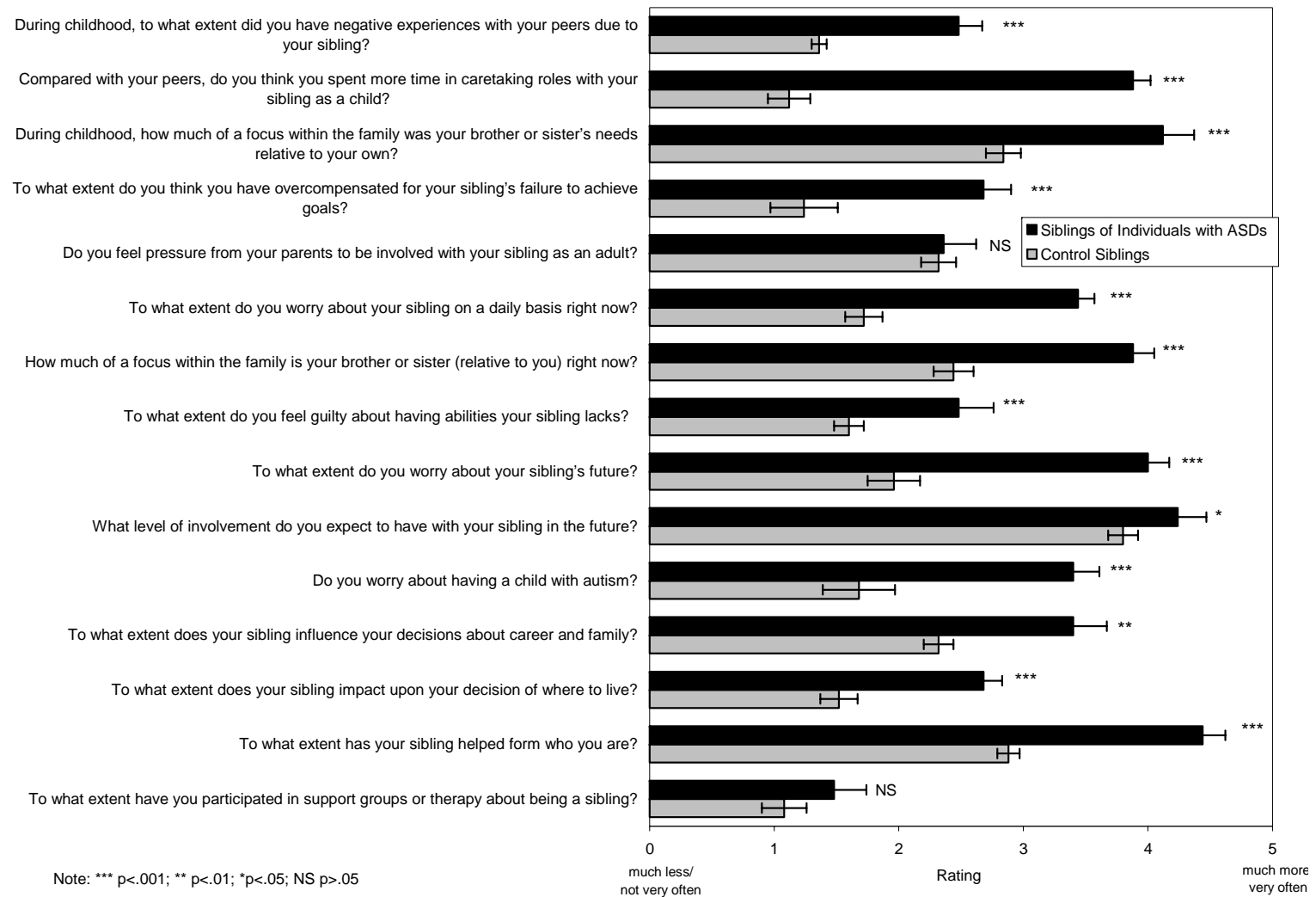
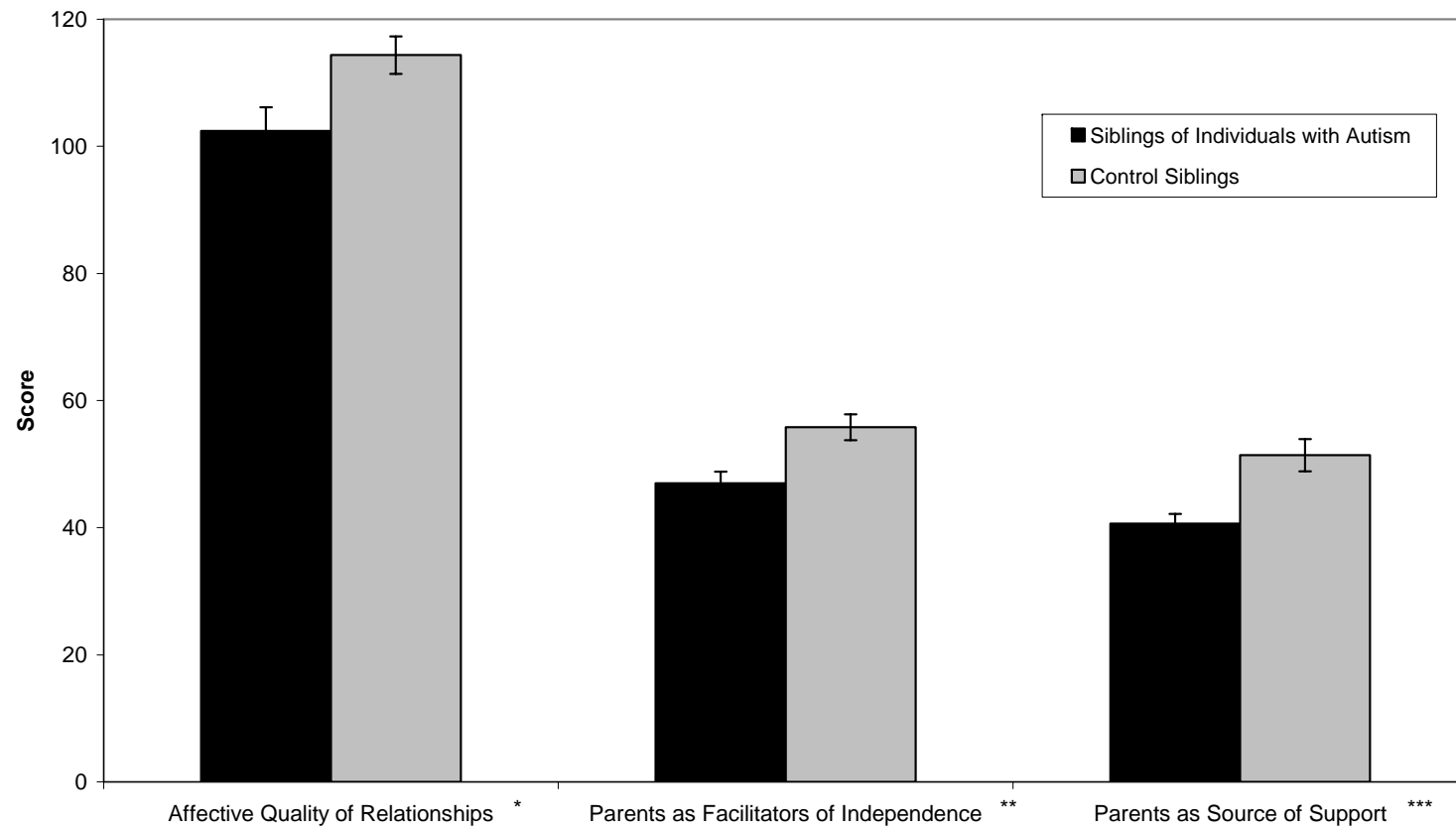
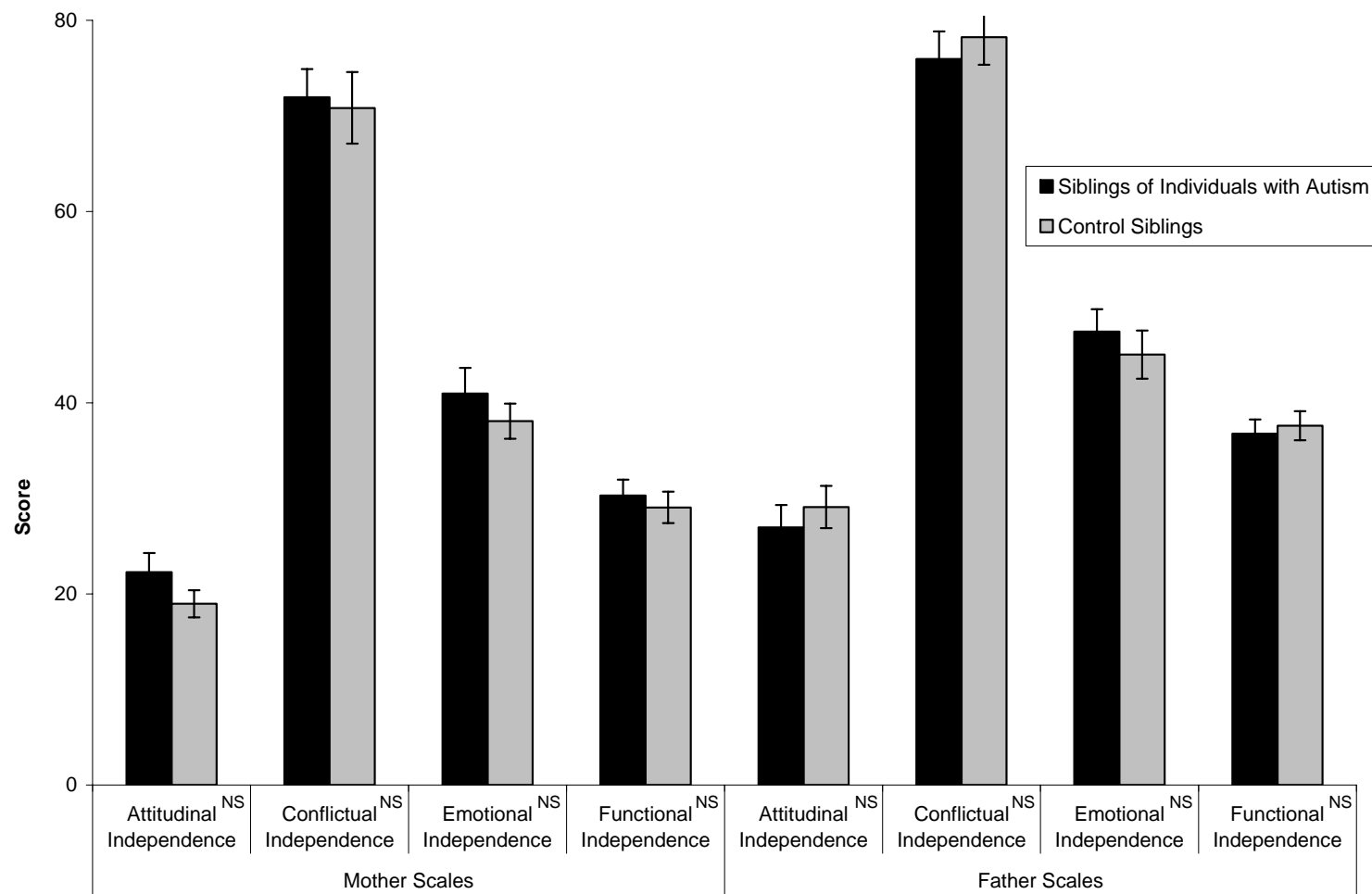


Figure 2. Parental Attachment in Siblings of Individuals with Autism Spectrum Disorders and Control Siblings



Note: *** $p < .001$; ** $p < .01$; * $p < .05$

Figure 3. Parental Separation in Siblings of Individuals with Autism Spectrum Disorders and Control Siblings



Note: NS p>.05

conflictual independence (ASD $M=71.96$, $SD=14.75$; Control $M=70.84$, $SD=18.76$; $F(1,48) = 0.005$, $p=0.815$), emotional independence, (ASD $M=40.92$, $SD=13.37$; Control $M=38.08$, $SD=9.22$; $F(1,48) = 0.764$, $p=0.386$), or functional independence (ASD $M=30.28$, $SD=8.31$; Control $M=29.04$, $SD=8.25$; $F(1,48) = 0.280$, $p=0.599$). Similarly on the father scales, no differences between groups were found on attitudinal independence (ASD $M=26.96$, $SD=11.71$; Control $M=29.08$, $SD=11.05$; $F(1,48) = 0.433$, $p=0.514$), conflictual independence (ASD $M=75.96$, $SD=14.47$; Control $M=78.24$, $SD=14.48$; $F(1,48) = 0.310$, $p=0.580$), emotional independence, (ASD $M=47.44$, $SD=11.76$; Control $M=45.04$, $SD=12.58$; $F(1,48) = 0.486$, $p=0.489$), or functional independence (ASD $M=36.76$, $SD=7.40$; Control $M=37.60$, $SD=7.66$; $F(1,48) = 0.156$, $p=0.695$).

Beck Anxiety Inventory & Beck Depression Inventory

Results from the Beck Anxiety Inventory (BAI) and the Beck Depression Inventory (BDI) are depicted in Figure 4. On the BAI, ASD siblings reported slightly more clinical symptoms of anxiety but this difference was not statistically significant (ASD $M=9.48$, $SD=9.48$; Control $M=7.68$, $SD=7.34$; $F(1,48)=0.641$, $p=0.427$). On the BDI, ASD siblings did not report more symptoms of depression (ASD $M=4.84$, $SD=4.84$; Control $M=5.20$, $SD=5.44$; $F(1,48)=0.019$, $p=0.891$). However, on both of these measures, there were notable outliers that significantly elevated the means for each of these groups. Due to the small sample size and the presence of outliers in both groups of siblings, these scores were not removed from the data set for this analysis. However, to further explore whether symptoms of anxiety and depression were different between groups, the number of

participants with “clinically significant” symptom profiles was examined.

“Clinically significant” was defined according to the recommendation of the developers of the scales (Beck, Ward, Mendelson, Mock & Erbaugh, 1961; Beck & Steer, 1990) and included any score that fell in the “moderate” or “severe” symptom ranges. As depicted in Figure 4, there was no difference between groups on number of participants who fell in these clinical ranges.

Education & Career Development

Figures 5 & 6 present findings from the education and career questionnaire. As illustrated in Figure 5, no group differences were found on participants confidence in career direction (ASD $M=4.48$, $SD=1.83$; Control $M=5.08$, $SD=1.50$; $t(49)=1.269$, $p=0.210$), satisfaction with career choice (ASD $M=5.56$, $SD=1.08$; Control $M=5.76$, $SD=0.97$; $t(49)=0.668$, $p=0.495$), or perception of their parent’s influence upon their career choice (ASD $M=3.60$, $SD=1.50$; Control $M=3.76$, $SD=1.09$; $t(49)=0.431$, $p=0.668$). However, ASD siblings reported that their sibling had a greater impact upon their career choice (ASD $M=4.32$, $SD=2.25$; Control $M=2.64$, $SD=1.93$; $t(49)=2.832$, $p=.007$). Figure 6 presents the percentage of participants pursuing service careers such as health care, psychology, or teaching. ASD siblings were more likely to indicate an intent to pursue a direct service career (76% of respondents) than control siblings (28% of respondents), ($t(49)=3.795$, $p<.001$).

Figure 4. Symptoms of Anxiety and Depression in Siblings of Individuals with Autism Spectrum Disorders and Control Siblings

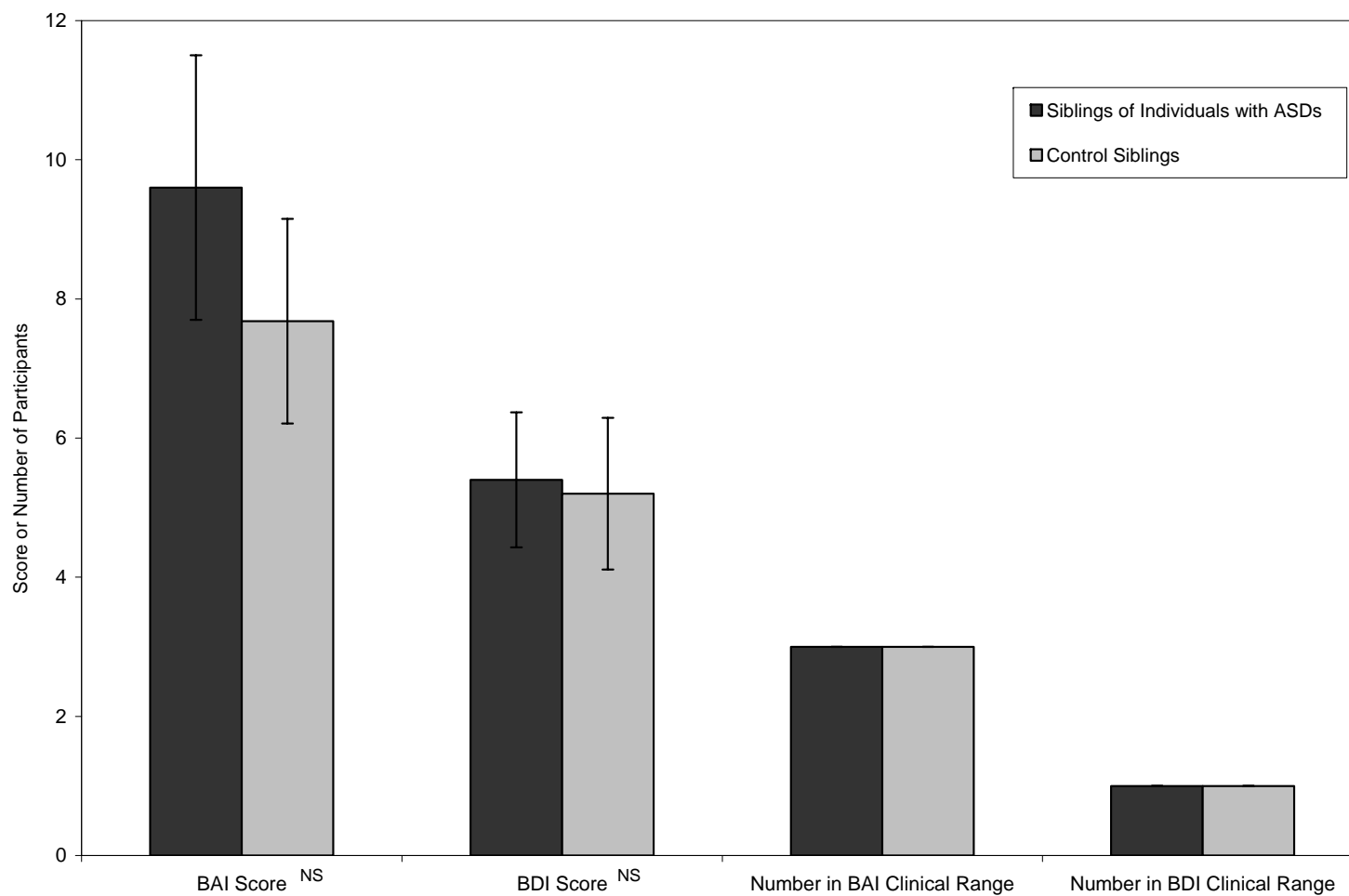
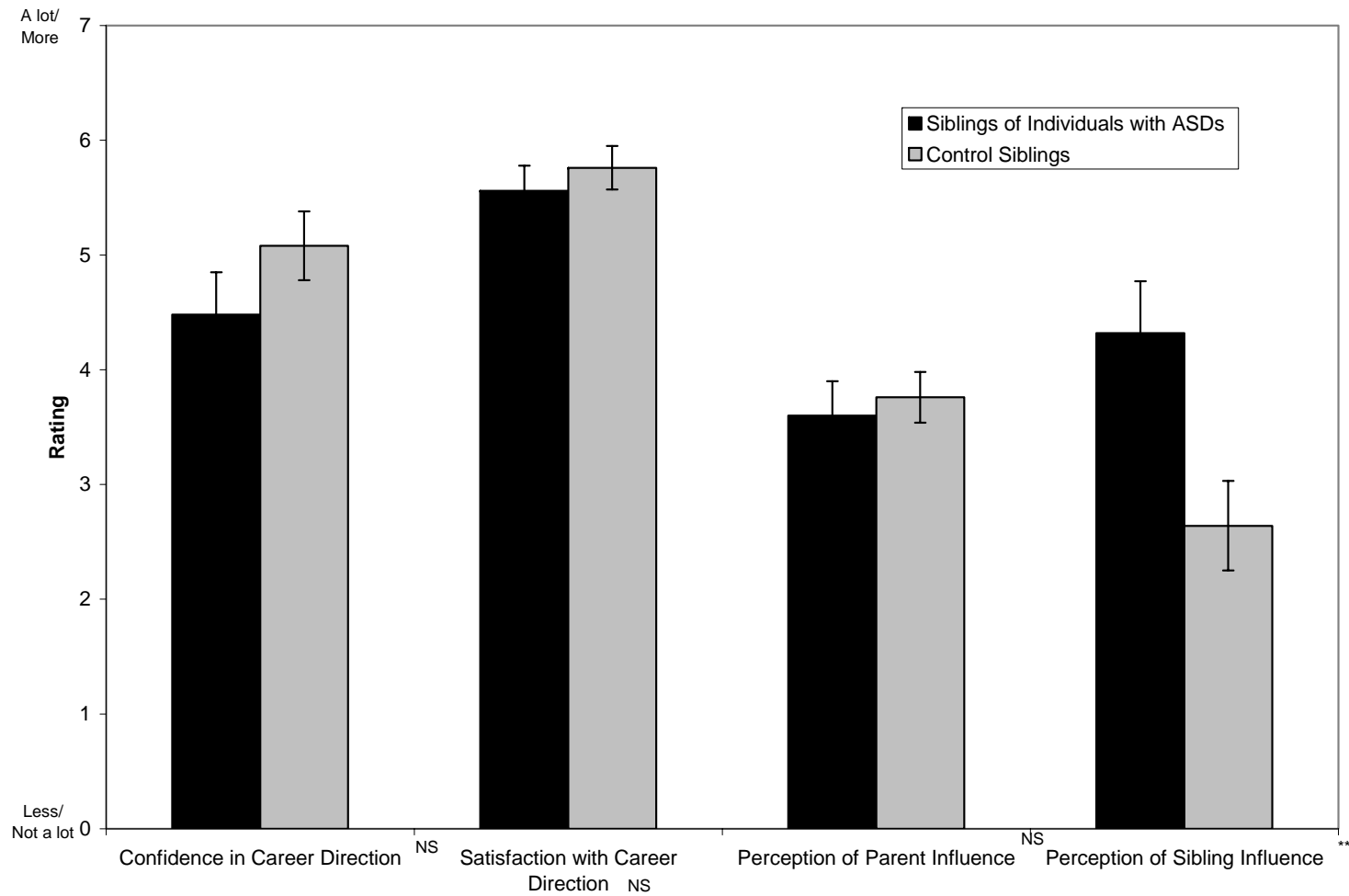
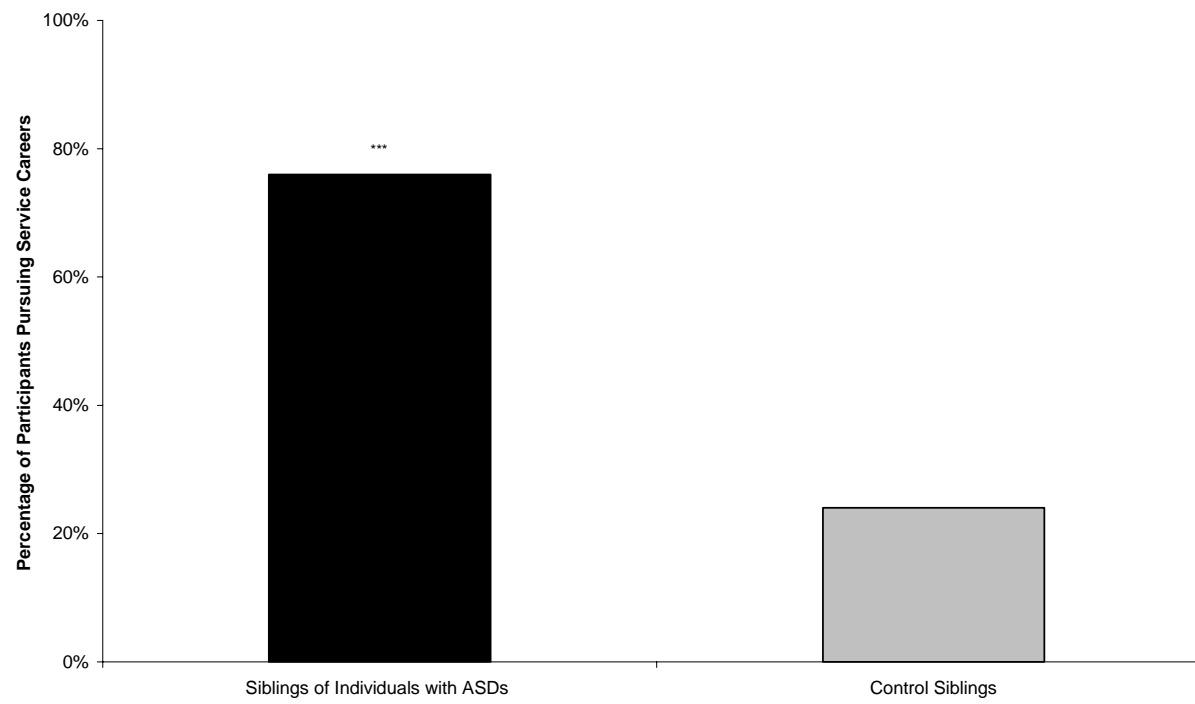


Figure 5. Confidence/Satisfaction with Career Development and Perception of Parent/Sibling Influence on Career Development in Siblings of Individuals with Autism Spectrum Disorders and Control Siblings



Note: ** $p < .01$; NS $p > .05$

Figure 6. Percentage Siblings of Individuals with Autism Spectrum Disorders and Control Siblings Pursuing Service Careers



Note: *** $p < .001$

Discussion

The present study is the first report to date to specifically examine the psychological functioning of young adult siblings of individuals with autism spectrum disorders. ASD siblings were compared to control siblings on measures relevant to the overall functioning of a young adult including family functioning (quality of attachment to parents & psychological separation from parents), career development (both confidence in and satisfaction with career decisions), and evidence of psychological distress (i.e., symptoms of anxiety and depression). Given previous research on ASD siblings during childhood (e.g. Eisenberg, Baker, & Blacher, 1998; Fisman et al., 1996; Freeman, 2000; Gamble & McHale, 1989; Gold, 1993) it was predicted that these siblings would likely show differences in some of these areas of functioning when compared to young adults who grew up with siblings without autism. Since it was hypothesized that any differences in functioning would be largely due to the unique experiences associated with being a sibling of an individual with an autism spectrum disorder (e.g., Lobato, Faust, & Spirito, 1988; Harris & Glasberg, 2003; Feiges & Weiss, 2004), respondents were asked about their perceptions of the impact of their siblings on their family during childhood and at the present time.

Overall, the findings in the present study support the hypothesis that ASD siblings would differ from control siblings particularly in the areas of family functioning, career goals, and perceptions of the impact of their sibling on their experiences with their family. Each of these areas of functioning is discussed below. The discussion also includes critiques of the methods used in the present

study and how these methodological issues impact generalizations that can be made from the study findings. Finally, recommendations and directions for future research on adult siblings of individuals with autism spectrum disorders are presented for each area examined in this study.

Parental Attachment and Separation from Parents

Study findings support the hypothesis that ASD siblings differed from control siblings in the area of relationships to their parents. First, ASD siblings differed significantly from controls on quality of attachment to parents in all three areas examined in this study: affective quality of relationship, parents as facilitators of independence, and parents as sources of support. ASD siblings reported a less positive affective quality to their relationship to their parents, indicated that their parents did less to facilitate their independence, and conveyed their parents were less of a source of support for them than did the control group. However, the two groups of siblings did not differ on measures of psychological separation from their parents. ASD siblings were not different from control siblings on measures of attitudinal independence, conflictual independence, emotional independence, and functional independence from either their mother or father.

At first glance, it might appear inconsistent that ASD siblings' scores on the parental attachment measure were lower than controls while scores on a psychological separation measure were not significantly different. For example, ASD siblings report a less positive affective relationship with their parents on the Parental Attachment Questionnaire (PAQ; Kenny, 1987) but do not show

differences in conflictual or emotional independence from either their mother or father on the Psychological Separation Inventory (PSI; Hoffman, 1984).

Comparing the items used in these measures might shed some light as to why ASD siblings show differences on the parental attachment measure and not the psychological separation measure. Some of the items that fall on the affective quality of relationship to parents scale on the PAQ include: “In general, my parents are sensitive to my feelings and needs”; “In general, my parents are too busy to help me”; “During recent visits or time spent together, my parents were persons towards whom I felt cool and distant”; and “During recent visits or time spent together, my parents were persons whose company I enjoyed”. Items on the emotional independence scale on the PSI include: “I like to show people pictures of my mother”, “I sometimes call home just to hear my mother’s voice”, “When home on a vacation, I like to spend most of my time with my mother”, and “I like to hug and kiss my mother”. While these scales clearly evaluate some similar constructs, the PAQ affective quality of relationship to parents scales primarily asks questions about the respondents’ attitudes and views of their parents whereas the emotional independence scale of the PSI asks more questions about the behavioral characteristics of the respondents’ relationship with their parents. Thus, study findings concerning the family measures are not necessarily inconsistent, as a young adult’s report of their attitudes and views of their parents’ behavior can be different from their the behavior towards their parents.

Education and Career Development

There was also some support for the hypothesis that ASD siblings would differ on amount of education or career development when compared to the control group. While siblings did not differ when asked about their confidence in or satisfaction with their career direction or student status, ASD siblings were much more likely to be pursuing a career in a service field such as psychology, healthcare, or teaching. There were also differences between groups concerning the impact of various family members on their career decisions. While sibling groups did not differ on how much they perceived the general influence of their brother or sister to be, ASD siblings were much more likely to report that their sibling had a significant impact upon their career decisions. These findings are consistent with previous research findings indicating that early childhood experiences have a significant impact upon career aspirations (e.g., Nikevic, Kramolisova-Advani, & Spada, 2007; Paris & Frank, 1983). Paris and Frank (1983) found that medical students were more likely to have had an illness in the family than law students and law students were more likely to have had legal problems in their family. Similarly, Nikevic, Kramolisova-Advani, and Spada (2007) reported that psychology students with clinical aspirations were more likely to report negative childhood experiences (e.g., sexual abuse and childhood neglect) than psychology students with no clinical aspirations or business students.

The present study did not explore the means through which having a sibling with autism impacts career decision. There are a number of reasonable hypotheses about why so large a number of ASD siblings in this group are

pursuing service careers. Perhaps it is because they have directly experienced the benefit of these services for their family and thus value these types of careers. However, it might also be that ASD siblings have a long history of reinforcement for caretaking responsibilities, that their parents particularly value careers in service, or that they want to “fix” for others the kinds of challenges they encountered (Seligman & Darling, 2007). Interestingly, the findings from the present study conflict the few other research findings about siblings of individuals with disabilities that have not found them more likely to pursue a service career (Seligman & Darling, 2007). However, none of these studies specifically examined siblings of individuals with autism spectrum disorder. Further research is necessary to explore why the experience of having a brother or sister with autism would lead to an increased likelihood of pursuing a service career.

In the present study, ASD siblings were more likely to be pursuing service careers. It is often presumed that service careers lead to greater satisfaction than other occupations because the professional has the daily experience of helping someone in need. Interestingly, the ASD siblings in this study were not more satisfied with their career than the control group even though they were more likely to be pursuing service careers. The reason for this might be that the majority of the respondents in this study were students at the time of the study. Thus, while many of them were pursuing helping careers, they might not be working in that career at the present time. Plus, it makes sense that someone who is actively pursuing a career in any field is expecting to find that

career satisfying. Thus, both groups might have been likely to be highly satisfied with their career at the present time since most of the individuals in the study were still working toward their career. It will be useful to ask these questions of ASD siblings who are at a later stage life stage than the current participants.

Psychological Distress

The finding that ASD siblings were not more likely to have symptoms of anxiety or depression is likely reassuring for both families and clinicians working with this population. However, any conclusion that ASD siblings do not truly have greater symptoms of anxiety or depression should be quite tentative given the variability of findings from previous research (Gamble & McHale, 1989; Gold, 1993; Hastings, 2003b; Pilowsky et al., 2004), the small sample of siblings, and the possibility of sampling bias. Further, the present study employed brief measures that are best used for examining the severity of symptoms and not as reliable indicators of the presence of an anxiety or depressive disorder.

The recruiting strategies utilized in the present study ensured that the groups did not differ on certain variables (e.g., more females with brothers), it is still likely that some of the methods could have resulted in sampling bias. The majority of the ASD siblings were recruited for participation through their parents, who were associated with major autism advocacy organizations or autism treatment centers. This group of siblings might differ significantly from the general population of siblings for many reasons. These siblings could be more likely to have a sibling who is accessing appropriate services and their

family might have a better history of support from these organizations than do other families. Further, since these participants were recruited by contacting their parents, it might be more likely that the parents and their children are in regular contact and have a stronger relationship. Both of these could be significantly related to the presence of stress within the family. It is not unreasonable to suspect that measures of the problems with family functioning and psychological distress might generated underestimates of the presence of these problems in the general population of ASD siblings because of sampling bias.

In future studies, siblings might be asked directly whether they had ever been diagnosed with a psychological disorder as well as asking them to complete standardized measures of anxiety and depression. Although a standardized measure is certainly a more reliable method than relying upon the reporting of community diagnoses, the present study only examined two symptom categories in order to limit the number of measures participants were required to complete. In the present study, participants were excluded if they had a history of any developmental or learning disorder to control for having some symptoms of an autism spectrum disorder. However, it is possible that siblings might have a greater likelihood of other disorders that have resulted from the environmental stressors associated with autism. Further, the BAI (Beck & Steer, 1990) primarily asks about the physical symptoms of anxiety disorders (e.g., dizzy/lightheadedness, heart pounding, hands trembling) and an individual may have an anxiety disorder with very few physical symptoms. Even though the difference between groups was not significant, siblings in the ASD group had

more physical symptoms of anxiety and it might be worth exploring more thorough methods for evaluating the presence of an anxiety disorder such as the Anxiety Disorder Interview Schedule (ADIS-IV; Brown, DiNardo, & Barlow, 1994) or a wider range of brief screening measures including scales like the Penn State Worry Questionnaire (Meyer, Miller, Metzger, & Borkovec, 1990).

Interestingly, young adulthood is the time when siblings might be least likely to experience the direct impact of their sibling on their daily lives. This is first major period of their life in which they are not forced to live with their sibling. They are at a point in development when they are largely spending their time focusing on their own career development and personal development and the major caretaking responsibilities that older siblings of people with autism usually take on as parents age have not yet begun in most cases. Thus, this might be the period in a sibling's life in which they have fewer daily stressors related to their sibling and thus they might be least likely to present with anxiety or depression during this time. It will be important to examine the functioning of older adult siblings in future research on siblings. Many older siblings take on the major caretaking roles as their parents age, might need to assume financial responsibilities for their sibling, and have the increased stress of making major decisions about the future of their sibling. Longitudinal research on the functioning of siblings throughout adulthood and during major life transitions (e.g., marriage, loss of a parent) might be a useful method for identifying the times of increased stress for siblings.

Perceptions of the Sibling Experience

When compared to control siblings, ASD siblings reported a great deal more negative experiences related to their siblings, including negative experience with peers, worry about their sibling and future events, and guilt about having abilities their sibling lacks. This is potentially quite concerning, although not surprising given the strain that autism is known to cause for families. These findings are quite consistent with what clinicians have reported from their experiences with siblings (Feiges & Weiss, 2004; Harris & Glasberg, 2002). The present study is important because it provides empirical evidence that young adult siblings perceive their experience of childhood is different from others.

The ASD sibling experience questions were designed to gather specific information that was hypothesized to be less likely to happen in other families. Since a questionnaire method was used to collect this information, the questions might have been suggestive and perhaps the higher ASD siblings' ratings were the result of this suggestion. Control siblings who were aware of the intention of the study might also have detected that they were not "supposed" to be rating themselves as likely to have had these experiences. This is a general problem with questionnaire methods but is certainly a potential limitation of the methods used in this study. This might have been tempered by interspersing these questions with many more questions about families in the future. However, these questions were designed by the primary investigator in consultation with researchers who have with significant personal experience with siblings of individuals with autism. Thus, it is appropriate to take these findings as at least

preliminary confirmation of what those with clinical expertise in this area report about young adult siblings.

Limitations & Future Research

The relatively small sample size in the present study did not allow for the use of statistical methods to compare the influence of one variable on another variable (e.g., whether the increased caretaking responsibilities as a child contributes to the increased likelihood that ASD siblings will pursue service careers or whether the perception that their family spends more time focused on their sibling leads to a less positive affective relationship with parents). Due to the lack of direct evidence linking these variables, the findings of the present study can only hypothesize that relationships such as these exist, but no conclusions can be made in this area. This is a significant limitation of the present study and certainly an important direction for future research on young adult siblings. In future studies, it would also be useful to consider whether there are certain factors that predict resiliency in siblings (e.g., adequate services, close relationships with extended families, or presence of another sibling in the family).

Another major limitation of the present study was that no information about the functioning level of the individuals with autism was collected. This seriously limits the ability to generalize the findings of this study to the general population of ASD siblings because it is not known whether the respondents in the present study are representative of that group. It might be expected that individuals with a “lower functioning” sibling or one with severe behavior

problems may have experienced greater distress since an individual with a more severe disability might have a larger impact on the daily lives of their family.

Generalization of these findings is also limited by the likelihood that all respondents are probably more altruistic than the general population. This bias should be assumed to be present in both groups as all respondents were willing to volunteer a significant amount of time to participate without compensation.

While this might not impact whether differences between groups can be attributed to the presence of sibling with autism spectrum disorder, it might be a problem for generalizing to the general population of siblings. This question might be somewhat resolved by comparing the rates of certain characteristics of the control group (e.g., parent marital status, number of years of education, number of siblings) with published information from other studies that included much larger samples of young adults.

Future studies might also benefit from the addition of another control group. This control group should include siblings of individuals from a different clinical population (e.g., a language disorder, learning disabilities, ADHD or mental retardation). It is not known whether the findings in the present study are unique to autism or would apply to siblings of individuals with any significant childhood disorder. Such controls have been used in many studies with children who have a brother or sister with autism and generally have sometimes found differences between these groups (Knott, Lewis, & Williams, 1995; Bagenholm & Gillberg, 1991; Fisman et al., 1996).

It is also important to acknowledge that the present study cannot conclude that the differences between ASD siblings and controls are due to the experience of having a sibling with autism. It can be reasonably hypothesized that differences between groups could be due to genetic differences. It is generally believed that there are a number of genes involved in autism and several studies have found increased rates of learning and language disorders in the siblings of individuals with autism (reference). Although all participants in the present study were excluded if they had a history of language disorders, developmental delays, or learning disabilities to minimize the impact of genetics, it is still likely that some of the participants have some of the genes associated with autism. Thus, some of the differences between groups might be due to genetic differences. One strategy that might assist with teasing out these differences could be comparing ASD siblings who have only one siblings to ASD siblings who also have a sibling without a diagnosis.

Conclusions

Despite its limitations, this study is the first to explore the functioning of young adult siblings and thus makes a meaningful contribution to the literature on families of individuals with autism. This study empirically demonstrates that which clinical researchers and parents have long suspected: that the development of a young adult can be significantly impacted by having a brother or sister with autism. Young adult ASD siblings differed on measures of their relationship with their parents and are likely to choose different career goals from other siblings. Further, siblings of individuals with autism do perceive their sibling had a

greater impact upon their family life and development than other siblings. It is hoped the findings of this study emphasize the need for more research in this area.

It is essential to highlight that these findings do not suggest having a brother or sister with autism necessarily leads to a negative outcome. It simply might be a different sibling experience with its own benefits and challenges. While ASD siblings in this study were more likely to have a less positive relationship with their parents and more negative experiences due to their siblings, ASD siblings did not report greater anxiety or depression, did not indicate more difficulties with separation from parents, did not indicate less satisfaction or confidence in their career goals, and did reveal they are more likely to be pursuing service careers. Based upon these findings, clinicians should be on the lookout for problems with the relationships between young adults siblings and their parents, but should not necessarily assume these young adults are experiencing significantly greater psychological distress. These are potentially valuable findings for clinicians working with families of individuals with autism who are definitely interested in identifying the needs of the clients they serve.

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Attachment A

Parental Attachment Questionnaire

The following pages contain states that describe family relationships and the kinds of feelings frequently reported by young adults. Please respond to each item by circling the number on a scale of 1 to 5 that best describes your parents, your relationship with your parents, and your experiences and feelings. Please circle only a single rating to describe your parents and your relationship with them.

If only one parent is living, respond with reference to your living parent. If your parents are divorced and you feel closer to one parent, please respond with reference to the parent with whom you feel closer.

In general, my parents . . .

- | | | | | | |
|----|---|----------|-------------------|-------------|-----------|
| 1. | are persons I can count on to provide emotional support when I feel troubled. | | | | |
| | 1 | 2 | 3 | 4 | 5 |
| | Not at all | Somewhat | A Moderate Amount | Quite A Bit | Very Much |
| 2. | support my goals and interests. | | | | |
| | 1 | 2 | 3 | 4 | 5 |
| | Not at all | Somewhat | A Moderate Amount | Quite A Bit | Very Much |
| 3. | live in a different world | | | | |
| | 1 | 2 | 3 | 4 | 5 |
| | Not at all | Somewhat | A Moderate Amount | Quite A Bit | Very Much |
| 4. | understand my problems and concerns | | | | |
| | 1 | 2 | 3 | 4 | 5 |
| | Not at all | Somewhat | A Moderate Amount | Quite A Bit | Very Much |
| 5. | respect my privacy. | | | | |
| | 1 | 2 | 3 | 4 | 5 |
| | Not at all | Somewhat | A Moderate Amount | Quite A Bit | Very Much |
| 6. | restrict my freedom or independence. | | | | |
| | 1 | 2 | 3 | 4 | 5 |
| | Not at all | Somewhat | A Moderate Amount | Quite A Bit | Very Much |
| 7. | are available to give me advice or guidance when I want it. | | | | |
| | 1 | 2 | 3 | 4 | 5 |
| | Not at all | Somewhat | A Moderate Amount | Quite A Bit | Very Much |

8. take my opinions seriously.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

9. encourage me to make my own decisions.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

10. are critical of what I do.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

11. impose their values on me.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

12. have given me as much attention as I have wanted.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

13. are persons to whom I can express differences of opinion on important matters.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

14. have no idea what I am feeling or thinking.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

15. have provided me with the freedom to experiment and learn things on my own.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

16. are too busy or otherwise involved to help me.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

17. have trust and confidence in me.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

18. try to control my life.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

19. protect me from danger and difficulty.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

20. ignore what I have to say.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

21. are sensitive to my feelings and needs.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

22. are disappointed in me.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

23. give me advice whether or not I want it.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

24. respect my judgment and decisions, even if different from what they would want.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

25. do things for me, which I could do for myself.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

27. treat me like a younger child.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

During recent visits or time spent together, my parents were persons . . .

28. I looked forward to seeing.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

29. with whom I argued.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

30. with whom I felt relaxed and comfortable.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

31. who made me angry.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

32. I wanted to be with all the time.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

33. towards whom I felt cool and distant.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

34. who got on my nerves.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

35. who aroused feelings of guilt and anxiety.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

36. to whom I enjoyed telling about the things I have done and learned.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

37. for whom I felt I feeling of love.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

38. I tried to ignore.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

39. to whom I confided my most personal thoughts and feelings

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

40. whose company I enjoyed.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

41. I avoided telling about my experiences.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

Following time spent together, I leave my parents . . .

42. with warm and positive feelings.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

43. feeling let down and disappointed by my family.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

When I have a serious problem or an important decision to make . . .

44. I look to my family for support encouragement, and or guidance.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

45. I seek help from a professional, such as a therapist, college counselor, or clergy.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

46. I think about how my family might respond and what they might say.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

47. I work it out on my own, without help or discussion from others.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

48. I discuss the matter with a friend.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

49. I know that my family with know what to do.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

50. I contact my family if I am not able to resolve the situation after talking it over with my friends.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

When I go to my parents for help . . .

51. I feel more confident in my ability to handle the problems on my own.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

52. I continue to feel unsure of myself.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

53. I feel that I would have obtained more understanding and comfort from a friend.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

54. I feel confident that things will work out as long as I follow my parents advice.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

55. I am disappointed in their advice.

1	2	3	4	5
Not at all	Somewhat	A Moderate Amount	Quite A Bit	Very Much

PSYCHOLOGICAL SEPARATION INVENTORY

Instructions: The following list of statements describes different aspects of students' relationships with both their mother and father. Imagine a scale ranging from 1 to 5 that tells how well each statement applies to you. In the space next to the statement, please enter a number from "1" (Not at all true of me) to "5" (Very true of me). If the statement does not apply enter "1". Please be completely honest. Your answers are entirely confidential and will be useful only if they accurately describe you.

If only one parent is living, respond only to questions that reference to your living parent. If you do not have contact with one parent, please respond only to questions that reference the parent you are close to.

Not at all true of me	A little bit true of me	Moderately true of me	Quite a bit true of me	Very true of me
1	2	3	4	5

- ___1. I like to show my friends pictures of my mother.
- ___2. Sometimes my mother is a burden to me.
- ___3. I feel longing if I am away from my mother for too long.
- ___4. My ideas regarding racial equality are similar to my mother's.
- ___5. My mother's wishes have influenced my selection of friends.
- ___6. I feel like I am constantly at war with my mother.
- ___7. I blame my mother for many of the problems I have.
- ___8. I wish I could trust my mother more.
- ___9. My attitudes about obscenity are similar to my mother's.
- ___10. When I am in difficulty I usually call upon my mother to help me out of trouble.
- ___11. My mother is the most important person in the world to me.
- ___12. I have to be careful not to hurt my mother's feelings.
- ___13. I wish that my mother lived nearer so I could visit her more frequently.

- ___14. My opinions regarding the role of women are similar to my mother's.
- ___15. I often ask my mother to assist me in solving my personal problems.
- ___16. I sometimes feel like I'm being punished by my mother.
- ___17. Being away from my mother makes me feel lonely.
- ___18. I wish my mother wasn't so over protective.
- ___19. My opinions regarding the role of men are similar to my mother's.
- ___20. I wouldn't make a major purchase without my mother's approval.
- ___21. I wish my mother wouldn't try to manipulate me.
- ___22. I wish my mother wouldn't try to make fun of me.
- ___23. I sometimes call home just to hear my mother's voice.
- ___24. My religious beliefs are similar to my mother's.
- ___25. My mother's wishes have influenced my choice of major at school.
- ___26. I feel that I have obligations to my mother that I wish I didn't have.
- ___27. My mother expects too much from me.
- ___28. I wish I could stop lying to my mother.
- ___29. My beliefs regarding how to raise children are similar to my mother's.
- ___30. My mother helps me to make my budget.
- ___31. While I am home on a vacation I like to spend most of my time with my mother.
- ___32. I often wish that my mother would treat me more like an adult.
- ___33. After being with my mother for a vacation I find it difficult to leave her.
- ___34. My values regarding honesty are similar to my mother's.

- ___35. I generally consult with my mother when I make plans for an out of town weekend.
- ___36. I am often angry at my mother.
- ___37. I like to hug and kiss my mother.
- ___38. I hate it when my mother makes suggestions about what I do.
- ___39. My attitudes about solitude are similar to my mother's.
- ___40. I consult with my mother when deciding about part-time employment.
- ___41. I decide what to do according to whether my mother will approve of it.
- ___42. Even when my mother has a good idea I refuse to listen to it because she made it.
- ___43. When I do poorly in school I feel I'm letting my mother down.
- ___44. My attitudes regarding environmental protection are similar to my mother's.
- ___45. I ask my mother what to do when I get into a tough situation.
- ___46. I wish my mother wouldn't try to get me to take sides with her.
- ___47. My mother is my best friend.
- ___48. I argue with my mother over little things.
- ___49. My beliefs about how the world began are similar to my mother's.
- ___50. I do what my mother decides on most questions that come up.
- ___51. I seem to be closer to my mother than most people my age.
- ___52. My mother is sometimes a source of embarrassment to me.
- ___53. Sometimes I think I am too dependent on my mother.

- ___54. My beliefs about what happens to people when they die are similar to my mother's.
- ___55. I ask for my mother's advice when I am planning my vacation time.
- ___56. I am sometimes ashamed of my mother.
- ___57. I care too much about my mother's reactions.
- ___58. I get angry when my mother criticizes me.
- ___59. My attitudes regarding sex are similar to my mother's
- ___60. I like to have my mother help me pick out the clothing I buy for special occasions.
- ___61. I sometimes feel like an extension of my mother.
- ___62. When I don't write my mother often enough I feel guilty.
- ___63. I feel uncomfortable keeping things from my mother.
- ___64. My attitudes regarding national defense are similar to my mother's.
- ___65. I call my mother whenever anything goes wrong.
- ___66. I often have to make decisions for my mother.
- ___67. I'm not sure I could make it in life without my mother.
- ___68. I sometimes resent it when my mother tells me what to do.
- ___69. My attitudes regarding mentally ill people are similar to my mother's.
- ___70. I like to show my friends pictures of my father.
- ___71. Sometimes my father is a burden to me.
- ___72. I feel longing if I am away from my father for too long.
- ___73. My ideas regarding racial equality are similar to my father's.
- ___74. My father's wishes have influenced my selection of friends.

- ___75. I feel like I am constantly at war with my father.
- ___76. I blame my father for many of the problems I have.
- ___77. I wish I could trust my father more
- ___78. My attitudes about obscenity are similar to my father's.
- ___79. When I am in difficulty I usually call upon my father to help me out of trouble.
- ___80. My father is the most important person in the world to me.
- ___81. I have to be careful not to hurt my father's feelings.
- ___82. I wish that my father lived nearer so I could visit him more frequently.
- ___83. My opinions regarding the role of women are similar to my father's.
- ___84. I often ask my father to assist me in solving my personal problems.
- ___85. I sometimes feel like I'm being punished by my father.
- ___86. Being away from my father makes me feel lonely.
- ___87. I wish my father wasn't so over protective.
- ___88. My opinions regarding the role of men are similar to my father's.
- ___89. I wouldn't make a major purchase without my father's approval.
- ___90. I wish my father wouldn't try to manipulate me.
- ___91. I wish my father wouldn't try to make fun of me.
- ___92. I sometimes call home just to hear my father's voice.
- ___93. My religious beliefs are similar to my father's.
- ___94. My father's wishes have influenced my choice of major at school.
- ___95. I feel that I have obligations to my father that I wish I didn't have.
- ___96. My father expects too much from me.

- ___97. I wish I could stop lying to my father.
- ___98. My beliefs regarding how to raise children are similar to my father's.
- ___99. My father helps me to make my budget.
- ___100. While I am home on a vacation I like to spend most of my time with my father.
- ___101. I often wish that my father would treat me more like an adult.
- ___102. After being with my father for a vacation I find it difficult to leave him.
- ___103. My values regarding honesty are similar to my father's.
- ___104. I generally consult with my father when I make plans for an out of town weekend.
- ___105. I am often angry at my father.
- ___106. I like to hug and kiss my father.
- ___107. I hate it when my father makes suggestions about what I do.
- ___108. My attitudes about solitude are similar to my father's.
- ___109. I consult with my father when deciding about part-time employment.
- ___110. I decide what to do according to whether my father will approve of it.
- ___111. Even when my father has a good idea I refuse to listen to it because he made it.
- ___112. When I do poorly in school I feel I'm letting my father down.
- ___113. My attitudes regarding environmental protection are similar to my father's.
- ___114. I ask my father what to do when I get into a tough situation.
- ___115. I wish my father wouldn't try to get me to take sides with him.

- ___116. My father is my best friend.
- ___117. I argue with my father over little things.
- ___118. My beliefs about how the world began are similar to my father's.
- ___119. I do what my father decides on most questions that come up.
- ___120. I seem to be closer to my father than most people my age.
- ___121. My father is sometimes a source of embarrassment to me.
- ___122. Sometimes I think I am too dependent on my father.
- ___123. My beliefs about what happens to people when they die are similar to my fathers.
- ___124. I ask for my father's advice when I am planning my vacation time.
- ___125. I am sometimes ashamed of my father.
- ___126. I care too much about my father's reactions.
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- ___134. I call my father whenever anything goes wrong.
- ___135. I often have to make decisions for my father.
- ___136. I'm not sure I could make it in life without my father.

___137. I sometimes resent it when my father tells me what to do.

___138. My attitudes regarding mentally ill people are similar to my father's.

Career Information Form

Number of Years of Education Following High School Completed Thus Far:

Have you decided upon a desired career path? Yes / No

How confident are you that you will be working in this career path in the next 5 years?

Very Confident		Confident		Not Confident
1 2 3 4 5 6 7				

How satisfied are you with the career path or major you have chosen?

Very Satisfied		Satisfied		Not Satisfied
1 2 3 4 5 6 7				

Which of the following fields is your career found in?

- _____ Arts, Design, Entertainment, Media
- _____ Accounting/Financial
- _____ Community, Psychology, Social Services
- _____ Computer, Mathematical
- _____ Education, Teaching, Training, Library Services
- _____ Science
- _____ Engineering, Architecture
- _____ Farming, Fishing, Forestry
- _____ Food Preparation, Chef, Food Server
- _____ Healthcare, Doctor, Nursing, Pediatrics
- _____ Construction, Installation, Maintenance, Repair
- _____ Legal, Lawyer
- _____ Environmental, Physical Sciences
- _____ Management, Business, Real Estate
- _____ Biotech, Pharmaceutical, Laboratory Medical
- _____ Office, Administrative Support
- _____ Protective Service
- _____ Sales, Marketing
- _____ Transportation, Moving
- _____ Military Service
- _____ Other: _____

Please further describe the career you have chosen. Be as specific as possible.

Do you think others would consider this career one that serves others? Yes /No

If yes, please describe the nature of the service.

How much influence do you believe your parent(s) had upon choosing your career path?

A Lot of Influence	Some Influence			No Influence		
1	2	3	4	5	6	7

How much influence did your sibling have upon choosing your career path?
(Note: If you have more than one sibling, please answer in relation to your sibling with autism or the sibling that you feel closest to)

A Lot of Influence	Some Influence			No Influence		
1	2	3	4	5	6	7

Beck Anxiety Inventory

Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past week, including today, by circling the number in the corresponding space in the column next to each symptom.

	Not At All	Mildly but it didn't bother me much.	Moderately - it wasn't pleasant at times	Severely – it bothered me a lot
Numbness or tingling	0	1	2	3
Feeling hot	0	1	2	3
Wobbliness in legs	0	1	2	3
Unable to relax	0	1	2	3
Fear of worst happening	0	1	2	3
Dizzy or lightheaded	0	1	2	3
Heart pounding/racing	0	1	2	3
Unsteady	0	1	2	3
Terrified or afraid	0	1	2	3
Nervous	0	1	2	3
Feeling of choking	0	1	2	3
Hands trembling	0	1	2	3
Shaky / unsteady	0	1	2	3
Fear of losing control	0	1	2	3
Difficulty in breathing	0	1	2	3
Fear of dying	0	1	2	3
Scared	0	1	2	3
Indigestion	0	1	2	3
Faint / lightheaded	0	1	2	3
Face flushed	0	1	2	3
Hot/cold sweats	0	1	2	3

Beck Depression Inventory

Choose one statement from among the group of four statements in each question that best describes how you have been feeling during the past week. Circle the number beside your choice.

1. 0 I do not feel sad.
 1 I feel sad.
 2 I am sad all the time and I can't snap out of it.
 3 I am so sad or unhappy that I can't stand it.

2. 0 I am not particularly discouraged about the future.
 1 I feel discouraged about the future.
 2 I feel I have nothing to look forward to.
 3 I feel that the future is hopeless and that things cannot improve.

3. 0 I do not feel like a failure.
 1 I feel I have failed more than the average person.
 2 As I look back on my life, all I can see is a lot of failure.
 3 I feel I am a complete failure as a person.

4. 0 I get as much satisfaction out of things as I used to.
 1 I don't enjoy things the way I used to.
 2 I don't get any real satisfaction out of anything anymore.
 3 I am dissatisfied or bored with everything.

5. 0 I don't feel particularly guilty.
 1 I feel guilty a good part of the time.
 2 I feel quite guilty most of the time.
 3 I feel guilty all of the time.

6. 0 I don't feel I am being punished.
 1 I feel I may be punished.
 2 I expect to be punished.
 3 I feel I am being punished.

7. 0 I don't feel disappointed in myself.
 1 I am disappointed in myself.
 2 I am disgusted with myself.
 3 I hate myself.

8. 0 I don't feel I am any worse than anybody else.
 1 I am critical of myself for my weaknesses or mistakes.
 2 I blame myself all the time for my faults.
 3 I blame myself for everything bad that happens.

9. 0 I don't have any thoughts of killing myself.
 1 I have thoughts of killing myself, but I would not carry them out.
 2 I would like to kill myself.
 3 I would kill myself if I had the chance.
10. 0 I don't cry any more than usual.
 1 I cry more now than I used to.
 2 I cry all the time now.
 3 I used to be able to cry, but now I can't cry even though I want to.
11. 0 I am no more irritated by things than I ever am.
 1 I am slightly more irritated now than usual.
 2 I am quite annoyed or irritated a good deal of the time.
 3 I feel irritated all the time now.
12. 0 I have not lost interest in other people.
 1 I am less interested in other people than I used to be.
 2 I have lost most of my interest in other people.
 3 I have lost all of my interest in other people.
13. 0 I make decisions about as well as I ever could.
 1 I put off making decisions more than I used to.
 2 I have greater difficulty in making decisions than before.
 3 I can't make decisions at all anymore.
14. 0 I don't feel that I look any worse than I used to.
 1 I am worried that I am looking old or unattractive.
 2 I feel that there are permanent changes in my appearance that
 make me look unattractive.
 3 I believe that I look ugly.
15. 0 I can work about as well as before.
 1 It takes an extra effort to get started at doing something.
 2 I have to push myself very hard to do anything.
 3 I can't do any work at all.
16. 0 I can sleep as well as usual.
 1 I don't sleep as well as I used to.
 2 I wake up 1-2 hours earlier than usual and find it hard to get back
 to sleep.
 3 I wake up several hours earlier than I used to and cannot get back
 to sleep.
17. 0 I don't get more tired than usual.
 1 I get tired more easily than I used to.
 2 I get tired from doing almost anything.

- 3 I am too tired to do anything.
18. 0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now.
3 I have no appetite at all anymore.
19. 0 I haven't lost much weight, if any, lately.
1 I have lost more than five pounds.
2 I have lost more than ten pounds.
3 I have lost more than fifteen pounds.
(Score 0 if you have been purposely trying to lose weight.)
20. 0 I am no more worried about my health than usual.
1 I am worried about physical problems such as aches and pains, or upset stomach, or constipation.
2 I am very worried about physical problems, and it's hard to think of much else.
3 I am so worried about my physical problems that I cannot think about anything else.
21. 0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

Sibling Questions

1. During childhood, to what extent did you have negative experiences with your peers due to your sibling?

Not at all	A little bit	Sometimes	Quite a bit	Very often
1	2	3	4	5

2. Compared with your peers, do you think you spent more time in caretaking roles with your sibling as a child?

Not at all	A little bit	Sometimes	Quite a bit	Very often
1	2	3	4	5

3. During childhood, how much of a focus within the family was your brother or sister's needs relative to your own?

Less of a focus	A little less	About the Same	A little more	Much more of a focus
1	2	3	4	5

4. To what extent do you think you have overcompensated for your sibling's failure to achieve goals?

Not at all	A little bit	Sometimes	Quite a bit	Very often
1	2	3	4	5

5. Do you feel pressure from your parents to be involved with your sibling as an adult?

None	A little bit	Sometimes	Quite a bit	Very often
1	2	3	4	5

6. To what extent do you worry about your sibling on a daily basis right now?

Not at all	A little bit	Sometimes	Quite a bit	Very often
1	2	3	4	5

7. How much of a focus within the family is your brother or sister (relative to you) right now?

Less of a focus	A little less	About the Same	A little more	Much more Of a focus
1	2	3	4	5

8. To what extent do you feel guilty about having abilities your sibling lacks?

Not at all	A little bit	Sometimes	Quite a bit	Very often
1	2	3	4	5

9. To what extent do you worry about your sibling's future?

Not at all	A little bit	Sometimes	Quite a bit	Very often
1	2	3	4	5

10. What level of involvement do you expect to have with your sibling in the future?

None	A little bit	Occasional	Frequent	Very frequent
1	2	3	4	5

11. Do you worry about having a child with autism?

Not at all	A little bit	Sometimes	Quite a bit	Very often
1	2	3	4	5

12. To what extent does your sibling influence your decisions about career and family?

Not at all	A little bit	Sometimes	Quite a bit	Very often
1	2	3	4	5

13. To what extent does your sibling impact upon your decision of where to live?

Not at all	A little bit	Moderate	Quite a bit	A lot of impact
1	2	3	4	5

14. To what extent has your sibling helped form who you are?

Not at all	A little bit	Moderate	Quite a bit	A lot of impact
1	2	3	4	5

15. To what extent have you participated in support groups or therapy about being a sibling?

Not at all	A little bit	Sometimes	Quite a bit	Very often
1	2	3	4	5

Curriculum Vita

MEGAN PATRICIA MARTINS

Education

- 2004 Rutgers, The State University of New Jersey; Department of Psychology; Master of Science
- 2001 Claremont McKenna College; Departments of Psychology & Biology; Bachelor of Arts

Occupations

- 2006-2007 University of California, Los Angeles; Semel Institute for Neuroscience and Human Behavior, David Geffen School of Medicine; Clinical Psychology Intern, Developmental Disabilities
- 2001-2006 Rutgers, The State University of New Jersey; Research & Training Division, Douglass Developmental Disabilities Center; Research Coordinator / Behavioral Consultant

Publications

Kelley, M. E., Shillingsburg, M. A., McKnight, K., Castro, J. M., Addison, L., LaRue, R., & Martins M.P (in press). Assessment of the functions of vocal behavior in children with developmental disabilities. *Journal of Applied Behavior Analysis*.

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