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What's It Really Like?

A Qualitative Study of

The Experiences of Siblings

Of Children with Autism
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Chapter I

Review of the Literature

As its classification as a pervasive developmental disorder would suggest, autism is a disorder that affects individuals across all domains of functioning. According to the most recent diagnostic criteria, impairments in social interaction, communication, and behavior are the requisite characteristics of autism (American Psychiatric Association, 1994). The diagnostic criteria have changed only slightly since the disorder was first identified by Kanner in 1943. What has remained constant, and what is often immediately identifiable to observers, is that individuals with autism are generally severely impaired in social interactions and general relationship skills (Travis & Sigman, 1998).

Recent research has documented an alarming increase in the prevalence of autism (Charman, 2002; Wing & Potter, 2002). Many theories exist to explain this increase. There are proponents of theories that vary from environmental toxins to vaccinations, genetic causes to changes in diagnostic criteria and understanding. While there may be a degree of credibility to each of these ideas, researchers have been unable to conclusively state the cause of this disorder. A recent study of the increase of autism in California determined that many of the current theories of causality could not sufficiently account for the increase in that state (Byrd, 2002).

The increase in prevalence of autism has led to renewed interest in interventions. In many cases, individuals with autism require life-long care and educational assistance. Although individuals with autism are often severely impaired, there are well-established interventions that can be utilized to produce positive changes. Most widely used
treatment methodologies involve basic behavior modification to guide and reinforce individuals with autism. One of the most critical elements of successful interventions is consistency. Interventions that are delivered consistently across school and home settings, for example, are more likely to lead to positive outcomes.

To ensure maximum therapeutic outcomes for children with autism, support and consistency from family members are essential. The parents of the child with autism are often highly involved with the child’s treatments, attending meetings at school and helping to monitor progress. While parents play an integral role in the success of their children, they are not the only individuals to interact with their child on a daily basis. Other family members are sometimes overlooked in the lives of children with autism. Siblings and other members of the extended family play a large role in the lives of children with autism.

*The Sibling Relationship*

The current investigation is concerned with the siblings of children with autism. Longitudinal research on the constancy of close relationships indicates that siblings often have some of the longest, most intimate relationships (Wenger & Jerrome, 1999). The nature of the pervasive impairments in children with autism necessarily impacts their sibling relationships. As a result, siblings of children with autism report lower levels of intimacy and nurturance with their siblings (Kaminsky & Dewey, 2001). In a quantitative study of sisters of individuals with developmental disabilities, Begun (1989) found the sibling relationship to be characterized by less intimacy and lower perceived sibling similarity. Using the Sibling Relationship Questionnaire, Begun also found the relationship with a developmentally disabled sibling to be different than that with a
typically developing sibling, most notably in the areas of admiration and nurturance. These findings led Begun to describe the relationship between siblings when one has a developmental disability as "affectively neutral" (p. 571). This description comes from the fact that "it is difficult to interact intimately with a person of limited language and social competence" (p. 571).

This disruption in the typical sibling relationship has implications for both the child with the disability and for their siblings. The sibling relationship forms the basis for future peer relationships and is often one of the first and most enduring friendships that an individual will have (Wenger & Jerrome, 1999). In many ways, the sibling relationship and sibling interactions early in life are a microcosm of future relationships and interactions. One learns how to give and receive love, a precursor to mature romantic relationships. One learns how to effectively deal with conflicts and to respect the opinions and wishes of others, abilities that are necessary in future interactions with other adults. In this sense, the sibling relationship provides the earliest social learning environment for an individual (Frank, 1996). Competitiveness, altruism, nurturance, and aggressiveness are just some of the behaviors that have their roots in the sibling relationship (Siegel & Silverstein, 1994).

*Research Trends*

As the number of empirical investigations of siblings of children with disabilities has grown, several research trends have emerged. For many years, researchers operated on the assumption that having a handicapped sibling was a negative occurrence in one's life. While research has borne out the idea that there are potentially negative implications of having a handicapped sibling, a growing body of literature suggests that siblings of
children with handicaps may experience a number of positive outcomes. Meyer and Vadasy (1994) review sibling issues in their handbook for workshops for siblings of children with disabilities. They describe several potential negative sibling issues including overidentification, embarrassment, guilt, isolation, loneliness, loss, resentment, increased responsibilities, and pressure to achieve. However, they acknowledge the strengths that they have encountered in siblings of children with handicaps, and list maturity, improved social competence, insight, tolerance, pride, vocational opportunities, advocacy, and loyalty as potentially positive outcomes for siblings.

The work by Meyer and Vadasy (1994), while informed by the research literature, is not an empirical investigation of these issues. However, the conclusions they reach are supported by published reviews of the literature pertaining to siblings of children with disabilities. A review by Correa, Silberman and Trusty (1986) refers to increased stress and poor adaptation as potential negative outcomes, but notes that it is imperative that researchers consider potential positive outcomes. In order to examine the relative amounts of positive and negative outcomes in the literature, Summers, White and Summers (1994) compiled and rated 13 studies. Results indicated that 25% of studies reported negative outcomes while only 9% reported positive outcomes. While this finding is interesting, it is important to note that 66% of the studies found no difference between siblings of children with disabilities and siblings of typically functioning children. Although these results may indicate a true tendency towards negative outcomes, the authors note “it is apparent that previous reviewers may have overstated the effect based on the available data” (p. 178). Although the percentage of positive outcome
studies is smaller, the authors report that the statistical support for increased prosocial behaviors is just as robust as for negative outcomes.

A more recent meta-analysis supported the Summers, et al. findings. A compilation of 25 studies was examined and a small, but statistically significant, negative effect emerged (Rossiter & Sharpe, 2001). The authors of this analysis included a cautionary statement that echoes that of Summers et al., noting that a small effect “suggests the generalized concern about the social and psychological development of the siblings of individuals with mental retardation has been overstated” (p. 76). There are several possibilities raised by the results of the meta-analyses by Summers, et al. and by Rossiter and Sharpe. The first is that having a handicapped sibling necessarily leads to at least some small negative outcomes. Another possibility is that the studies reviewed reflect a research bias towards negative outcomes in this population. It is easy to assume that negative outcomes would predominate in such a family situation. Some have directly called for a shift in this perspective (Cuskelley, 1999), but this idea dominated the research milieu for many years and old theories are sometimes slow to lose favor.

An innovative analysis by Helff and Glidden (1998) scrutinized 60 studies in order to analyze trends in the research on families of children with developmental disabilities. This paper considered studies published from 1971 to 1993, making it the most thorough review to date. The results indicate a decrease in the negativity of the research literature, but without a concurrent increase in positivity. It is likely that some of the decrease in negativity was related to the increased utilization of appropriate comparison groups and improvements in the research methodologies. However, many of
the reviewed studies had hypotheses that seemed to operate on the assumption of negativity.

Though this assumption of negativity persists, studies continue to report on positive outcomes of having a sibling with autism. In addition to the positive traits anecdotally described by Meyer and Vadasy (1994), empirical investigations have concluded that there are positive outcomes for siblings. In a recent study of siblings of children with autism, Verté, Roeyers and Buysse (2003) found that adolescent sisters of children with autism have a higher self-concept as compared to a control group. In addition, siblings of children with autism generally report feeling well supported in their lives by a variety of sources (Kaminsky & Dewey, 2002), possibly contributing to increases in self-concept. Another recent positive finding, which the author notes requires more study, is that having a sibling with autism has stronger effects on prosocial behavior than on negative behaviors (Hastings, 2003a). It is likely that research focusing on positive outcomes for siblings will continue to be published, and this increasing body of positive literature will impact the design of future studies as well as the overall perception of siblings of children with autism.

It is difficult to accurately ascertain trends in the literature on siblings of children with autism, as much of the previous research has been hampered by flawed methodologies. Perhaps the most often cited methodological flaw in this literature is the failure to use appropriate comparison groups (Cuskelley, 1999; Summers, et al., 1994). Summers and his colleagues note that many early studies, which likely set the tone for subsequent studies, “have no reference group by which to compare these siblings (p. 171).” Several interesting potential variables in this line of study have been proposed.
Lobato, Faust and Spirito (1988) propose five characteristics of a disability that would impact research findings: onset, etiology, course, prognosis and functional complications. These characteristics make intuitive sense; for example, a sibling of a child with cancer, with a commonly fatal course, would undergo different reactions than the sibling of a child with a behavior disorder. To date, these characteristics have not been systematically examined in siblings of children with autism. Other variables that have not been consistently taken into account include birth order and age-spacing (Begun, 1989; Breslau, 1982; Crnic & Leconte, 1986), gender interactions (Stoneman, 1989; Stoneman, Brody, Davis & Crapps, 1987), family characteristics (Kaminsky & Dewey, 2001), and sources of information utilized (Cuskelley, 1999; Summers, et al., 1994).

While it is unlikely that a single study could appropriately control for all of these variables, the best studies are those that endeavor to control for at least some of them (Cuskelley, 1999).

The lack of a cohesive theory of sibling outcomes complicates this research. Research is still inconclusive as to what aspects are most important to consider. Sibling relationships and family environments are complex, and formulating a cohesive theory that incorporates all of these variables is a daunting task. Daunting though it may be, if the subjects in these studies “continue to be seen as victims and their positive outcomes viewed with skepticism, services and interventions will be inappropriate (Helff & Glidden, 1998, p. 461).”

**Personal Experiences**

Several studies have concluded that having a brother or sister with autism or other disabilities impacts siblings in many ways. Previous research has concluded that there
can potentially be both positive and negative outcomes. A recent meta-analysis concluded that there is a small overall negative effect (Rossiter & Sharpe, 2001), but many authors caution that the results must be considered in light of any moderating family circumstances. Potential stressors felt by families of children with autism include, but are not limited to, the unpredictable behavior of the child, changes in routine, and the financial implications of education and treatment (Norton & Drew, 1994). Another variable that moderates the personal impact on siblings is the relative age of the affected child. Breslau (1982) found that younger brothers and older sisters of disabled children are at higher risk for psychological impairment. Although there are potentially negative outcomes for these siblings they tend to rate their sibling relationships as positive (Bagenholm & Gillberg, 1991; McHale, Sloan & Simeonsson, 1986), even with the presence of obvious stressors.

An important element of the personal experiences of siblings of children with autism is their understanding of autism. Siblings have a strong need for information about their brother or sister’s condition (Meyer & Vadasy, 1994). A recent study utilizing a detailed survey of family needs revealed that when a child with a developmental disability is present, the need for information is most often cited as a concern (Ellis, et al., 2002). It is important that siblings obtain information about their brother or sister’s condition, as increased knowledge of how to deal with the condition has been shown to be a predictor of how positive the sibling relationship is rated by both mothers and siblings (McHale, et al., 1986). Despite the importance of learning about the condition, siblings of children with autism attain an understanding of the condition at a slower rate than siblings of children with other conditions, possibly reflective of the slow
development of the professional understanding of autism (Glasberg, 2000). In one study, 55% of siblings of children with autism “had no words to explain why their brother or sister was different from others” (Bagenholm & Gillberg, 1991, p. 304). The information needs of siblings should be given increased attention by the professionals working with families of children with autism. In a qualitative study, Bagenholm and Gillberg (1991) found that many siblings of children with autism report that they can only talk with someone outside of the home about their sibling’s condition. Professionals working with families are therefore in a good position to offer information to siblings of children with autism.

Another aspect of the personal life of siblings that may be impacted by having a sibling with autism is their social life and interactions with peers. Again, research has been inconclusive as to whether siblings of children with autism have impaired social lives or if their social lives remain relatively unaffected by their sibling’s condition. Studies that have demonstrated impaired socialization in siblings of children with autism describe fewer contacts with peers (Coleby, 1995), and a trend towards difficulty in relating with peers (Cadman, Boyle & Offord, 1988). In the Bagenholm and Gillberg (1991) study, more than one-third of siblings of children with autism described themselves as lonely, having no friends, and preferring to stay home, and all of these descriptions were confirmed by parent reports. Siblings of disabled children have also been shown to demonstrate higher levels of interpersonal aggression with peers (Breslau, Weitzman & Messenger, 1981). An important limitation of these studies, however, is that they do not take into account the degree to which siblings of children with autism are genetically similar. Some recent research has suggested that this overlap may have some
implications for the personality and behavioral characteristics of unaffected siblings (Hughes, Plumet, & Leboyer, 1999; Briskman, Happé, & Frith, 2001).

Conversely, there are some studies that report typical socialization in siblings (Hannah & Midlarsky, 1999). Bischoff and Tingstrom (1991) used several sibling-specific questionnaires to conclude that siblings of children with disabilities “do not exhibit differential levels of social competence (p. 317)” when compared to siblings of children without disabilities. A similar conclusion was reached by Kaminsky and Dewey (2002) in a study specifically of siblings of children with autism. The authors used a battery of quantitative measures and confirmed that siblings of children with autism do not display impaired socialization. In addition, one result of interviews conducted by Stoneman and her colleagues (1988) was that “as a group siblings of mentally retarded children spend at least as much time with friends as do their agemates, and no disadvantage seems to come to these children from diminished opportunities for contact with friends (p. 180).” Other research has demonstrated that the similarity in social competence between siblings of children with handicaps and controls remains stable over time (Dyson, 1999). Other studies have shown that having a brother or sister with autism has stronger effects on prosocial behavior than on behavior problems (Hastings, 2003a). While it has not been widely studied, another aspect of socialization is the preferred location for peer interactions. The assumption would be that having a disabled sibling would make one less likely to invite friends to the home. Again, this is not a well-researched area, but interviews by Stoneman, et al. (1988) found that siblings of children with mental retardation had frequent peer contacts in the home.
It is likely that socialization patterns and frequency of in-home peer interactions are closely related to the sibling’s comfort with revealing the diagnosis to peers. In a study of siblings of children with chronic health conditions, more than 40% of the respondents said that they would hesitate to reveal their sibling’s condition to others (Gallo, Breitmayer, Knafl & Zoeller, 1991). Gallo and her colleagues conducted individual interviews with children aged 6 to 14 who had a sibling with a chronic health condition and, while it is reassuring to know that approximately 60% of respondents would feel comfortable revealing their sibling’s condition, the 40% who would not offered some interesting insights into their restraint. The most cited reason was that the affected child would be the subject of ridicule, while others mentioned fear that peers would share the knowledge of the child’s condition. In this study, adolescent respondents were more willing to reveal the condition of their sibling, suggesting that age is a moderating factor in the level of comfort with the sibling’s condition. Revelation of the condition of a sibling can be trying for a child. However, peer acceptance of the affected sibling has been shown to impact the sibling’s perception of their sibling relationship. Positive peer reactions relate to more positive sibling relationships with the handicapped child (McHale, et al., 1986). While some research has focused on socialization and peer relations in siblings of children with handicapping conditions, more work is needed to more accurately describe peer interactions concerning the affected child, and to study the revelation of the condition to peers and others.

**Family Experiences**

It is impossible to separate the experiences of the sibling from the context of his or her family. Within that context there are a variety of roles to be played and a variety
of family factors that will impact both the affected child and his or her siblings. Research shows that families of children with disabilities generally experience higher levels of stress (Bouma & Schweitzer, 1990; Dyson, 1993; Gray, 1997; Sanders & Morgan, 1997), and that this level of stress is unlikely to decrease over time (Dyson, 1993; Gray, 2002). Siblings are not immune to the effects of such chronic stressors on the family.

As they are generally close in age, siblings are often the first playmates of autistic children. Several studies have examined the interactions and play styles of siblings with their brother or sister with a disability. Research has shown that siblings of children with autism allow their affected sibling to initiate play situations and social interactions (El-Ghoroury & Romanczyk, 1999). In this study, the authors noted “siblings appear to be approaching the observed interactions with children in a manner similar to a typical play situation rather than a teaching situation (p. 256).” These results support those found by Knott, Lewis and Williams (1995) that, while the play interactions between children with autism and their siblings were somewhat impoverished, they closely resembled the interactions between typically developing children, especially in initiations and responses. By interacting in this manner, siblings are offering their affected brothers and sisters the opportunity to learn and practice skills that are generally delayed in autism. Siblings of children with disabilities also engage in more parallel play and social play (Lobato, Miller, Barbour, Hall & Pezzullo, 1991), also skills that are characteristically difficult for children with autism to obtain. While the quality of these interactions is important, it has also been demonstrated that siblings of mentally retarded children interact with their affected sibling at relatively high rates (Stoneman, Brody, Davis & Crapps, 1987). The observations reported by Knott and her colleagues (1995) showed a higher frequency of
play interactions among siblings when one child has autism than would be expected in typical peer play. El-Ghoroury and Romanczyk (1999) found that siblings of children with autism interacted less frequently with their affected brother or sister than did their parents, but that this less frequent interaction actually provided the child with autism with more opportunities for learning. Future research should seek to more systematically examine the role of sibling play in the skill development of children with autism.

Another important aspect of family life is the role the sibling of the child with autism plays in the family. The added pressures applied to the family by the behaviors and symptoms of the child with autism often lead to alterations in individual family roles. The unaffected siblings of children with disabilities often take on increased responsibilities and care-giving roles (McHale & Gamble, 1989; Wilson, Blacher & Baker, 1989). In the Wilson et al. study, interviews of siblings found that teaching, dressing, feeding, babysitting, and disciplining were the most frequently mentioned types of care-giving. Siblings interviewed in the McHale and Gamble study reported twice as much time spent on care-giving as compared to control siblings without handicapped brothers or sisters. While a study by Bagenholm and Gillberg (1991) concurred with these findings, they added that increased responsibility was only reported by siblings and not by their parents. High and consistent levels of stress may impact parents abilities to recognize the increased pressures that are placed on their other children.

Several variables relating to sibling stressors have been studied, including the age and gender of the siblings of affected children. Sisters of children with disabilities consistently report more home and childcare responsibilities than do brothers (Damiani, 1999), but brothers of children with disabilities have been found to be more involved in
childcare than siblings of typically developing children (Stoneman, et al., 1987). It does appear, however, that at a young age, the care-giving expectations placed on sisters of children with handicaps may act as a buffer against feelings of depression (Lobato, Barbour, Hall & Miller, 1987), although these findings do not continue into adulthood.

While typical sibling interactions are described as symmetrical, sibling interactions with children with disabilities have been shown to become less symmetrical over time, as the cognitive and social capacities of the typically developing sibling outpace those of the affected child (Stoneman, 2001). As these relationships become less symmetrical, increased care giving responsibilities are more likely to cause difficulty for the unaffected sibling. While these increased responsibilities may be necessary for the family to cope with the presence of a child with autism, some have cautioned that the extreme helpfulness, hyper-responsibility, and pseudo-maturity exhibited by some siblings may be accompanied by a flip-side clinical picture of depression, shame, excessive guilt, unrelenting worry, social isolation, psychosomatic problems, and conduct disturbances that characterize the parentified child (Lamorey, 1999, p. 76).

Increasing the responsibilities of siblings of children with autism may help the family cope in the short-term, but may have long-term detrimental effects on the siblings themselves.

One of the most important family variables is the relationship between the sibling and his or her parents. This relationship is necessarily moderated by the stress and coping of the parents. In addition, how well parents balance their resources among their children is important for the child with autism as well as for their siblings. Research has also shown that chronic disorders like autism can contribute more to family stress than chronic physical disorders (Bouma & Schweitzer, 1990). The effects on
parents of having a child with a disability have been well documented. For example, mothers of children with developmental disorders report high levels of doubt in their competence as parents (Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari, 1996). In addition, marriage difficulties may often be present, and marital dissatisfaction can also have detrimental implications for sibling relationships (Stoneman, 2001). The mechanism for this impact may have been best described by Nixon and Cummings (1999) as the result of increased levels of concern about family related conflicts in siblings of children with disabilities. Another explanation for the mechanism of impact on siblings of the marital relationship is offered by Martin and Cole (1993) who found that “fathers who were involved in cohesive marital relationships were also involved in cohesive father-child relationships (p. 191).” These results suggest that fathers who are more involved in their marriages possess characteristics that make them more engaging fathers, and more invested in their children. A similar finding was reported for mothers, but was not as strong.

Children’s self-concept is also related to the quality of their parents’ relationship. Children of parents who report more stress generally have a lower self-concept (Dyson, Edgar & Crnic, 1989). The level of parental stress has also been shown to influence parents’ ratings of behavior problems in unaffected siblings (Fisman, Wolf, Ellison & Freeman, 2000). Parental ratings of externalizing problems in the Fisman, et al. study were higher in families with developmental disorders as compared to families of children with Down’s syndrome and controls. Parental stress may be seen as a consistent moderator of reports of sibling behavior and concerns. In some cases, however, this effect may be negative and may indicate that some concerns of siblings are overlooked by
parents, likely as a result of the stressors that accompany parenting a child with autism or other disabilities. In the Bagenholm and Gillberg (1991) interviews, siblings reported having to help out more with their affected sibling, a finding that was only reported by siblings and not mentioned as problematic by parents. Parent reports of problems faced by siblings of children with autism tend to decrease over time (Gray, 2002). There are several possible explanations for these ratings by parents. They may reflect a simple developmental trend towards appreciating the independence of siblings, or, more troubling, a misunderstanding of the issues that are problematic for siblings. Some literature exists that may be supportive of the second possibility. Over 60% of siblings in Bischoff and Tingstrom’s (1991) study reported a desire to discuss concerns about their affected sibling with someone. This result is troubling when combined with findings that siblings of children with autism often feel that they can only talk about their sibling with someone outside of the home (Bagenholm & Gillberg, 1991). These results would seem to indicate that parenting a child with autism causes increased family stressors, and that family and marital stressors can negatively impact unaffected siblings, possibly to the extent that they do not feel comfortable discussing their sibling within the family context. This sequence of events points to the need for open communication within the family as well as for the provision of services outside of the family that are focused on the unique needs of siblings.

Support Services

As the needs of siblings have increasingly become a focus of empirical investigation, services specifically for siblings of children with autism have become correspondingly more common. While some siblings may require intensive interventions
like counseling or psychotherapy, many siblings benefit from being allowed to discuss their situation and meet others who have the same experiences. Even this type of structured support is not always necessary, as siblings of children with autism report feeling supported by parents, teachers, classmates, and close friends (Kaminsky & Dewey, 2002). Professionals, however, need to be aware of the possibility that siblings of children with autism may need more intensive interventions. The assumption that all siblings need such attention, however, has been shown to be dated and untrue. Cadman and his colleagues (1988) offer the advice that “siblings should be assessed as individuals, without any expectation bias, and should be offered treatment only when sound clinical indications are found (p. 120).” Some studies have found that siblings may be at risk for the development of conditions that may require treatment. Siblings may show more depressive symptoms than controls (Breslau & Prabucki, 1987; Cadman, et al., 1988). Siblings of children with autism may also show social and learning difficulties and other psychiatric diagnoses (Lainhart, 1999). Professionals should take care to attend to the needs of siblings, as this group likely harbors some resentment towards their handling by professionals historically. Siblings report anger at professionals as a result of their lack of understanding of sibling needs, as well as their historical “handicap-as-illness mentality (Edmundson, 1985, p. 50).” This does not suggest that siblings as a group are angry at professionals in general, but is likely reflective of the historically negative opinions of families and siblings of children with disabilities, most strikingly those of children with autism.

As noted above, more than 60% of siblings of children with disabilities express a desire to talk with someone about their sibling’s condition (Bischoff & Tingstrom, 1991).
This may take a variety of forms, from informal social contacts with peers, to structured support groups, to psychotherapy. In a more broad sense, social support has been found to moderate the impact of the symptom pattern of children with autism on their siblings (Hastings, 2003b). In this study, families reporting higher levels of social support also report more positive adjustment in unaffected siblings. One of the most recommended types of social support is support groups specifically designed to address the unique issues of siblings of children with autism.

Few studies have specifically examined the outcomes of sibling support groups, but those that have demonstrate several positive effects of participation. Uniformly, participating siblings enjoy the group experience (Dyson, 1998; McLinden, Miller & Deprey, 1991; Phillips, 1999). Some of the outcomes that have been examined include higher levels of social support, and improvements in behavior towards affected siblings (McLinden, et al., 1991). In the Phillips (1999) study, a support program was designed for siblings of children with disabilities. The author reports decreased levels of depression, anxiety, and sibling related stress, and increases in the self-esteem and perception of social support of the siblings as measured by a pre- and post-test design. Dyson (1998) also designed and evaluated a support group, but used participant evaluations as the data. The author simply asked the participants to list their most and least favorite components of the program, from activities, to snacks, to meeting times. Sibling participants most frequently reported enjoying learning about their sibling’s condition, and having the opportunity to meet and socialize with other siblings with similar experiences. These results are consistent with the literature suggesting that needs for information and socialization are important for siblings of children with autism.
While there are few empirical investigations of the effects of sibling support programs, there is no shortage of suggestions and curricula for such groups. Perhaps the most widely know and used curriculum for sibling support groups is the Sibshops model developed by Meyer and Vadasy (1994). This model has been compiled into a book detailing discussion and support activities as well as recreational and social activities. To date there are not any systematic evaluations of the Sibshops program, but it is widely used generally viewed positively. In an encouraging trend, other curricula for sibling support programs are available in literature spanning from pediatrics (Cruz, Andron & Sammons, 1984) to occupational therapy (Unruh, 1992), to education (Stewart, Benson & Lindsey, 1987; Summers, Bridge & Summers, 1991) and psychology (Newson & Davies, 1994). While not supported by data, it is likely that the lack of more recently published curricula is reflective of the widespread adaptation of the Sibshops model.
Chapter II
Rationale and Research Objectives

As the above review shows, there are many inconsistent findings in the sibling literature. There are many ways that researchers can seek to remedy the discrepancies and methodological concerns in this literature. The continued use of control groups will enable researchers to have more confidence in their findings. Accounting for the variability in the family situations and age and sex considerations will provide more accurate data on the outcomes of siblings of children with autism. Another suggestion would be to go directly to the source to gather data (Cuskelley, 1999). Many studies utilize parent and teacher report data, while fewer studies actually use sibling self-report data. If we are attempting to analyze the lives and outcomes of siblings of children with autism, their subjective input is likely to be the most relevant (Hannah & Midlarsky, 1985). Some researchers have considered the subjective, qualitative responses of siblings of children with disabilities (Bågenholm & Gillberg, 1991; Dyson, 1998; Gallo, et al., 1991; Glasberg, 2000; McHale, et al., 1986; McHale & Gamble, 1989; Stoneman, et al., 1988; Wilson, et al., 1989), but many more studies rely on questionnaires and standardized measures.

Of the studies mentioned above, only the McHale, et al. (1986), Bågenholm and Gillberg (1991) and Glasberg (2000) studies include a large number of siblings of children with autism. Much of what we know about the lives of siblings of children with autism comes from observations (e.g., El-Ghoroury & Romanczyk, 1999; Knott, et al., 1995), and standardized measures. Even those studies that use standardized measures...
seem to rely as much on parent report (e.g. Ellis, et al., 2002; Hastings, 2003a; 2003b) as on the self report of siblings (e.g. Kaminsky & Dewey, 2001; 2002; Verté et al., 2003).

While there is certainly much to be gained from a strictly quantitative look at siblings of children with autism, the lives of these siblings and their families are necessarily extremely variable. Largely reflective of the idiosyncratic nature of the symptoms of autism, families of children with autism may be more different than similar (Ramey, Krauss, & Simeonsson, 1989). While responses to questions on a particular scale may be reflective of the immediate thoughts of siblings, it is likely that their thoughts and feelings about their brother or sister with autism vary with their day-to-day experiences. Open ended questions offer siblings a chance to discuss their thoughts and feelings and how they vary over time. As Berg (2001) notes, certain experiences cannot meaningfully be conveyed through numbers.

Qualitative interviews with siblings of children with autism can provide an important level of depth to the existing empirical literature. Ramey and her colleagues (1989) recommend the incorporation of multiple methodologies, "especially given the compelling evidence that different methods have yielded major insights (p. iii)." Specifically, siblings of children with autism are appropriate for qualitative inquiry as they see the effects of autism everyday. Particularly, "they see the effect of their sibling's disability on their own lives" (Glasberg, 2000; p. 152). Using interview methodology allows the participant to openly discuss his or her experiences, more specifically, semi-structured interviews allow for a freer exchange of ideas (Esterberg, 2002).
Only by asking the experts, the siblings themselves, can we hope to ascertain the issues that they see as relevant, and the inner experiences that relate to these issues. By offering to listen directly to siblings and to relate the experience in their words, new insights may be gained that can have profound influence on the lives of children with autism, their parents, and their siblings.

With this goal in mind, the following are the objectives of the current investigation:

First, this study will investigate the personal experiences of siblings of children with autism to gain insights from the siblings themselves about the impact of autism on their social relationships.

Secondly, participants will provide more internal information such as their understanding of autism and the feelings that they identify as related to having a brother or sister with autism.

Considering the participants in the context of their families, a third objective is to gather data on siblings’ perceptions of their roles in the family, including any added pressures that result from having a brother or sister with autism. The study also seeks to acquire an understanding of siblings’ perceptions of how well their parents handle having a child with autism and how well their parents understand the sibling point of view.

A fourth objective is to learn about siblings’ involvement in various support services. Data to be gathered here includes a sibling perspective on what aspects of support services are most helpful to them, information that could have implications for parents, teachers, and professionals.
As a final objective, siblings of children with autism will be given the opportunity to respond to questions that do not seem to have been posed to them in past literature. Questions will be asked about the hopes, wishes, and fears that siblings harbor for their brother or sister with autism. Also, understanding that positive outcomes frequently occur, the study will investigate what the participants have learned from their sibling and what their sibling relationship has taught them about themselves. Finally, siblings will be offered the chance to relay what they wish others knew about being a sibling of a child with autism, and will offer advice to other siblings of children with autism.
Chapter III

Method

Overview

This study uses qualitative methodology with data being collected in interview format. The use of this type of methodology in the area of autism and sibling adjustment allows the respondents to be more open to reply to questions as they see fit. By allowing for free responses, this project aims to provide siblings with a means of expression that is not often afforded them in research.

Participants

Participants in this study will be children who have one sibling with a DSM-IV diagnosis of Autistic Disorder (299.00; A.P.A, 1994). Siblings of children diagnosed with other developmental disorders will not be included. Participants will be between the ages of 6 and 18 years old, and the sibling with autism must also be between the ages of 6 and 18 years old. All eligible and interested siblings will be included unless they are unable to respond to interview questions or otherwise participate fully in the study. Step-siblings, adoptive siblings, siblings residing outside of the home, and other types of sibling relationships will be included provided that the participants spend a majority of their time in the home in which their autistic brother or sister spends the majority of his or her time. In addition, efforts will be made to recruit children from families with underrepresented demographic characteristics. The target number of participants in this study is between 20 and 25. Previous qualitative studies of children with disabilities have relied on a range of participants, Wilson, et al. (1989) interviewed 24 siblings and Gallo and her colleagues (1991) had 27 participants. The most common number of subjects,
however, is approximately 60 (Stoneman, et al. (1988); McHale & Gamble, (1989); Bågenholm & Gillberg (1991); Glasberg (2000)). These studies focused on only one, or a limited number, of aspects of the sibling experience and could include more siblings as the amount of time spent with each was relatively short.

Participants will be recruited as part of a larger study of families of children with autism. Recruiting will be from autism-related organizations in the Greater Cincinnati area, as well as from local school settings and churches. Schools and churches are included in recruiting in the hopes that families who are not actively involved in support organizations may be contacted. Minority families and families with other demographic profiles (low SES, urban, rural, etc.) are underrepresented in the research literature. A recruitment advertisement (see Appendix A) will be placed in the newsletters of the local organizations, and schools and churches will be contacted directly. A letter (Appendix A) will be sent through the schools to parents of children with autism. Contacts with local churches will help to identify potential participants within the congregations.

*Measures*

*Interview form.*

The interview questionnaire (see Appendix B) to be used was created specifically for this investigation, and is based on a thorough review of the literature. It will, however, be piloted on several families who will offer suggestions for improvement. These are families who are familiar to the interviewer from work experiences and who are willing to complete the interview and offer constructive criticism about the content, wording, and delivery of the interview. Meeting with these families will provide the opportunity to field-test the interview prior to beginning data collection.
Numerical rating scales.

Four items in the interview are supplemented by 5-point numerical rating scales. These items deal with the impact of an autistic sibling on the participant’s social life, whether they feel added pressures as a result of their sibling, their perception of how well their parents handle their autistic sibling, and how helpful support services are to them. When the rating scale questions are asked, participants will be presented with a graphic representation that includes the anchors for each end of the scale. Research has shown that between 5 and 9 points on a rating scale will provide the optimal amount of data while not offering participants excessive distinctions (Whitley, 1996).

The Gilliam Autism Rating Scale.

Parents will be asked to complete the Gilliam Autism Rating Scale (GARS; Gilliam, 1995) regarding their child with autism. The purpose of including the GARS is twofold. First, the GARS provides a rating of the severity of the child’s autistic presentation. This will allow us to compare responses as they correspond to the level of severity of the child with autism. The second purpose of the GARS is to act as a check on the appropriateness of the inclusion of the family and the siblings in the project. We are focusing on siblings of children with autistic disorder, as opposed to other developmental disorders. Parent report would be our only confirmation of the diagnosis; including the GARS will provide us with corroboration of that diagnosis.

The GARS is a brief report form that can be completed by parents, teachers or other caregivers. It is used to identify autism in individuals 3-22 years of age and to provide an estimate of the difficulties faced by the child (Kabot, Masi, & Segal, 2003). The GARS has four subscales (Stereotyped Behaviors, Communication, Social...
Interaction, and Developmental Disturbances) that yield an overall Autism Quotient. The GARS has good reliability and validity, but a recent analysis suggests that it may not have sufficient sensitivity, resulting in a high rate of false negatives (South, Williams, McMahon, Owley, Filipek, Shernoff, et al., 2002). As our purpose is corroboration of diagnosis, not determination of diagnosis, the sensitivity of the measure is sufficient.

The GARS has been used previously in studies involving siblings of children with autism. In a series of studies using the same participants, Kaminsky and Dewey (2001, 2002) had parents complete the GARS as a measure of the severity of the child with autism. This measure was used in analyses of the sibling relationship (2001) and the psychosocial adjustment (2002) of the siblings of children with autism.

**Demographic Data**

All participants will provide demographic information prior to the interview. Information to be gathered includes the marital status of parents, living arrangements of the siblings, racial/ethnic background, parents' education, employment, and whether there is any family history of developmental disorders (see Appendix C). The final piece of demographic information to be gathered is a checklist of services that the child with autism is currently receiving and a similar checklist for the siblings.

**Procedure**

Families who agree to participate in the study will initially be mailed a demographic information questionnaire (Appendix C) with the informed consent forms for the parents and assent forms for the siblings (Appendix D), whichever is appropriate. Also at this time the families will receive a short summary of the study with an overview of the topics to be discussed (Appendix E). Families will also be asked to complete the
Gilliam Autism Rating Scale (Gilliam, 1995). At the outset of the interview this information will be discussed and all consent and assent forms will be reviewed.

All interviews will be conducted in the participant’s homes at times that are mutually acceptable to the families and the researchers. The interviewers will strive to build a collaborative relationship with the participants, as the interview is intentionally structured in a conversational format. There are several broad areas to be covered in the interview, and there are additional specific questions that will be asked if they are not addressed in the responses to the more general questions. The general categories for siblings are Personal Experiences, Family Experiences, Support Services, and Conclusions. In addition, several of the questions are supplemented with 5-point numerical rating scales. Participants will be provided with a visual aid to ensure their understanding of the scales.

The data to be collected are the responses to general questions and the responses to the numerical rating scale supplemental items. All data from the interviews will be audio recorded using standard cassette tape recording equipment. As interviews are completed, all recordings will be transcribed by an independent transcription service. A professional transcription service with expertise in medical transcriptions will be employed to ensure familiarity with the content of the interviews and appropriate transcription.
Chapter IV

Proposed Data Analysis

All interview data will be audio recorded and transcribed by an independent transcription service. Data analysis will be undertaken to determine emergent themes and issues as provided by the subjects. The transcribed data will be coded and categorized by independent raters, using a procedure described below. Coding refers to the process of defining, categorizing, and giving meaning to the body of responses that make up the larger data set (Charmaz, 2000). As the content areas of the interview necessarily impact the general categories of responses, the focus of the coding will be to elucidate the ways in which siblings of children with autism describe their experiences within these larger content areas.

Interview data will be reviewed by independent raters who will compile and describe themes and issues that are recurrent in the data. These raters will be blind to the research objectives of the project and the basis for the development of the interview questions. The raters will be given an overview of the project and specific instructions for coding the data, based on both the empirical (Barbour, 2000) and theoretical (Fossey, et al., 2002; Charmaz, 2000; Ryan and Bernard, 2000) literature regarding qualitative analysis.

Prior to analysis by the independent raters, the researcher will divide the interview data into the content areas that were the basis for the interview questions. Data to be analyzed by the raters will be the verbatim responses of the subjects to interview questions, with these responses grouped by content area. The specific information to be gathered from the raters will be distinct categories or classes of responses that emerge
from coding the data. Inter-rater reliability will be calculated using Cohen’s Kappa (Following descriptions from Howell (1997) and Ryan & Bernard (2000)).

Data to be reported will be the number of subjects whose responses were grouped into each distinct category (reported in percentages). The numerical rating scales that accompany several questions will also be analyzed and reported as frequencies of ratings. The final step of data analysis, to be carried out by the researcher, will be the narrative synthesis of the categories in order to accurately portray the subjective lives of the subjects. As noted by Smith and Short (2001), ensuring that the data are accurately represented by the categories “that gave rise to theoretical notions eases the researcher’s task of demonstrating to an audience of colleagues that what is proposed is a reasonable interpretation of the data (p. 407).”
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Appendix A

Recruitment Letters

*Autism Organization Newsletters*

A Study of Families of Children with Autism

What's it really like? Have you ever wished you could tell people all about your life with a child with autism? Would you like to share both the good and bad experiences? A new study seeks to understand the daily life experiences of families of children with autism, as told by the families. We have a semi-structured interview for parents and siblings of children with autism that covers a wide range of life experiences. We would like to meet with you in your home and discuss your experiences. The information that we hope to gather will enable others to better appreciate the impact of a child with autism on the family. If you are interested in sharing your experiences and wish to receive more information on this exciting study, please contact . . .
School Recruitment Letter

A Study of Families of Children with Autism

What's it really like? Have you ever wished you could tell people all about your life with a child with autism? Would you like to share both the good and bad experiences? A new study seeks to understand the daily life experiences of families of children with autism. We would like to discuss a wide range of life experiences of both parents and siblings of children with autism. The information gathered will be helpful to and individuals who work with or are interested in autism, including teachers, therapists, and other professionals.

We would like to meet with you in your home and discuss your experiences. We will work to find times that accommodate your schedule. Memberships in autism organizations or use of any type of therapies are not requirements for this study and, in fact, we hope to talk with families who are not actively involved with autism organizations. If you are interested in sharing your experiences and wish to receive more information on this exciting study, please contact . . .
Appendix B

Interview

Sibling interview

**General Category – Introduction**
- Tell me about your family
  - Family members
  - Members of the immediate family who do not live at home (college, etc.)
  - Pets

**General Category – Personal Experiences**
- What is it like having a (brother/sister) with autism?
- What does autism mean to you?
  - Where did you get your information; how did you learn about autism?
  - Are there people you can talk to if you have questions about autism?
    - Who are they and what do they tell you?
    - Do you find that they are willing to talk to you about it?
- What kinds of feelings do you have about having a (brother/sister) with autism (resentment, guilt, embarrassment, fairness, attention differences)?
- How do you talk to your friends/classmates/neighbors about (name)?
  - How do they usually respond?
  - If they are not supportive or understanding, how do you react?
- Does (name) affect your social life? *(rephrase for younger kids)*
  (1-no, not really....5-yes, a lot)
  - Do you have friends over to your house?
  - If so, how does (name) react?
  - What do your friends say about (name) when they come over?
    - How do they treat him/her, or react to him/her?
- Has having a (brother/sister) like (name) changed the way you think about other people?
- What do you hope to do when you get older?
  - Has (name) had an impact on this decision?

**General Category – Family Experiences**
- What kinds of things do you do with (name)?
- What is your role in the family?
  - Are you happy with this or do you wish it could be different?
- Do you feel added pressures because of (name)? *(rephrase for younger kids, i.e., are things harder because of (name))*
  (1-no, not really....5-yes, a lot)
  - If so, where do these pressures come from?
- How do you think your parents handle having a child like (name)?
  - Do you think they do a good/bad job with (name)?
    (1-not really/bad job....5-yes, a great job)
- Do you think your parents understand how you feel about your brother/sister?
  - Do you think they understand and accept these feelings?
- Do you talk with your parents specifically about being (name)’s (brother/sister)?
- How do you feel overall about (name) being a part of your family?
- How do you think things would be different if (name) wasn’t autistic?

**General Category – Support Services**
- What sorts of things have helped you through tough times?
  - Have you ever talked to a doctor or been a part of a group?
  - Are you involved in any of these services now?
  - If yes, do you like them?
    - How much? (1-I don’t like them….5-I really like them)
  - Do they help you?
    - If yes, in what ways?
    - If no, what types of things would be helpful to you?
- What makes these things helpful?
- What do you think you have gained/learned from being involved in these services?
- Do you or would you like to be a leader in any of the groups or services that you’re involved in?

**General Category – Conclusions**
- What’s the worst thing about having a (brother/sister) with autism?
- How would your life be different if (name) was not autistic?
- What are your hopes/wishes/fears for (name)?
- What kinds of fun stuff do you do with (name)?
  - How do you feel about (name) during these special times?
- What have you learned from (name)?
- What have you learned about yourself from being the brother/sister of a child with autism?
- What do you wish people knew about being a (brother/sister) of a child with autism?
- What would you tell other kids who have a brother or sister with autism?
- What’s the best thing about having a (brother/sister) with autism?

- Is there anything else that we have not talked about that you would like to discuss?
Appendix C

Demographic Data Form

Families of Children with Autism
Family Information Sheet

- Parents’ names and ages (please include step-parents and any other guardians):
  - 
  - 
  - 
  - 

- Marital status of individuals listed above:
  - 
  - 

- Names and ages of all siblings of the child with autism (please indicate place of
  residence as it relates to the child with autism (at home with the child, at college, etc)):
  - 
  - 
  - 
  - 

- How do you describe the racial or ethnic background of the child with autism?
  - 

- Address:
  - 
    - Length of time at current address: 
    - Previous address(es) (if applicable):
      - 
      - 

- Parents’ education levels (please check highest attained):
  - [ ] High School
  - [ ] College
  - [ ] Graduate School
  - [ ] Other (please describe) 

- Parents’ or guardians’ employment (type of work):
  - 
  - 
  - 
  - 

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- Are there any other people in the extended family of the child with autism who have autism and/or any other handicapping conditions (please include family relationship to the child):
  - 
  - 
  - 

- Please indicate any services or treatments that your child is currently receiving:
  - Special Education
  - Speech Therapy
  - Occupational Therapy
  - Physical Therapy
  - School Counseling
  - Home-Based Services
  - Medications
  - Special Diets
  - Art Therapy
  - Music Therapy
  - Play Groups
  - Psychotherapy
  - Other (describe) ________________________________
  - Other (describe) ________________________________
  - Other (describe) ________________________________
  - Other (describe) ________________________________
  - Other (describe) ________________________________

- Please indicate any services or treatments that other family members currently receive (include names of family members involved):
  - Individual Psychotherapy ________________________________
  - Group Psychotherapy ________________________________
  - Support Groups ________________________________
  - Special Education ________________________________
  - Speech Therapy ________________________________
  - Occupational Therapy ________________________________
  - Physical Therapy ________________________________
  - School Counseling ________________________________
  - Medications ________________________________
  - Other (describe) ________________________________
  - Other (describe) ________________________________
  - Other (describe) ________________________________
  - Other (describe) ________________________________
Appendix D

Consent and Assent Forms

INFORMED CONSENT DOCUMENT

Study Title: What's it like? A study of siblings of children with autism

Investigator: T.J. Nestheide, M.A. (859) 781-9637

Contact Information: Janet R. Schultz, Ph.D. Xavier University (513) 745-3248

You are being asked to allow your child/children ___(insert name/s)___ to participate in a project conducted through Xavier University. The University requires that you give your signed consent to allow your child/children to participate in this project. The investigator will explain to you, in detail, the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask him any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the investigator any questions you may have. If you decide to allow your child/children to participate in the project, please sign below in the presence of the person who explained it to you. You should be given a copy of this form to keep.

This project involves an interview about your child/children’s life as a sibling of a child with autism. The information gathered will help teachers, therapists, professionals and other siblings of children with autism to better understand their experiences. The interview will take place in your home, and all siblings will be interviewed separately. Our discussion will be audio recorded and the information transcribed. I will be keeping the information gathered from our interview, but it will in no way be associated with your child/children’s name/s or other identifying information.

There are no foreseeable risks associated with your child/children’s participation in this study. However, some people get upset when discussing personal issues. The potential benefits to your child/children include the opportunity to help others better understand their life as a sibling of a child with autism, and the chance to talk with someone openly about their sibling.

All information gathered will be kept confidential and names or other identifying information will not be associated with responses. Tapes and transcriptions will be kept separately from consent and demographic forms, and no effort will be made to identify the source of any information. Tapes may be used for professional or educational purposes but will at no time be matched with any identifying information. You have the right at any time to refuse to allow your child/children to participate in this study, and you are free to withdraw your child/children from the study at any time without penalty.

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I understand also that it is not possible to identify all potential risks in a research procedure, and I believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

______________________________  ______________________
Signature                       Date

______________________________  ______________________
Witness                         Date
ASSENT TO PARTICIPATE

Study Title: What's it like? A study of siblings of children with autism

Investigator: T.J. Nestheide, M.A. (859) 781-9637

Contact Information: Janet R. Schultz, Ph.D. Xavier University (513) 745-3248

You are being asked to be involved in a project from Xavier University. This form will explain your rights about the project. The person doing the research will talk with you and explain the project and tell you about any possible risks from being involved. Read, or listen carefully, to the information about the study, and if you have any questions please ask the person doing the research. You will get to keep a copy of this form.

This project is about your life with your brother or sister with autism. We will discuss your experiences with your brother or sister and your answers will help other children with a brother or sister with autism, and teachers, doctors and other people who work with kids with autism. We will talk in your home, and if you have other brothers or sisters who are in the study, we will talk to each of you by yourselves. Our talk will be audio recorded and I will keep the tapes. No one will be able to know who is on the tape, and I will not put your name on it.

There are not any risks in this study, but some people may get upset talking about their thoughts and feelings. Your answers in this study could help a lot of other people. All of your answers and other information will be kept secret so no one will be able to identify you or know that you were in the study. You have the right to refuse to be in this study, and you can stop at any time, without any penalty.

I have been told about this study and agree to be in it. I know that if I have any questions at any time I can ask the person doing the research.

Signature ____________________________     Today’s Date ____________________________

Witness ____________________________     Today’s Date ____________________________
Appendix E

Description of Study for Participants

Hello! Thanks for your interest in our study of families of children with autism. This letter is to follow up on our phone conversation about the study. We will give you a brief description of the areas we are interested in talking about, but please don’t feel limited to talking only about these things. We hope to better understand your daily life experiences, and, while we feel that these broad categories cover much of the experience, we want to learn from you, not limit you.

We would prefer to interview parents together when possible and siblings individually. The interviews will be audio recorded. Please read the consent and assent forms for more about our use of the information you provide. It is ultimately our hope that the information that you and others provide us will be helpful to teachers, therapists, professionals, and you, as the family of a child with autism.

The general categories of interest for the parents (things for you to be thinking about) are: your experience with getting the diagnosis of autism, adjusting to and living with a child with autism, the impact of a child with autism on the family, your experience with support services (schools, therapies, support groups, etc.), concerns for the future, and opportunities for growth. These are only broad categories, we have more specific questions within each area, but again, we want you to guide us. We will address the specific questions if they don’t come up in our discussion.

Siblings should be thinking about the following areas: your personal experiences as they relate to having a brother or sister with autism, your family experiences, your thoughts on doctors, groups, and other support services, and finally, you will get the
chance to offer advice and help to professionals and other kids who have brothers or sisters with autism.

We will review the procedures and consent forms when we arrive at your home. Again, no special preparations need to be made for our visit. If you should have any questions about the categories for discussion, or about any other part of the study, please feel free to contact us. Thank you again for your interest, we look forward to meeting with you.
Chapter V
Dissertation

Abstract

Twenty-one siblings of children with autism were interviewed about a variety of elements of their lives. Participants discussed their personal and social lives, described their understanding of autism, their family experiences, involvement with support services, and responded to several additional questions that had not been addressed in previous literature. Participants described both positive and negative implications of this sibling relationship. Responses are described in detail and, when possible, in the participant’s own words. Limitations of the current study and suggestions for future research are discussed.
As its classification as a pervasive developmental disorder would suggest, autism is a disorder that affects individuals across all domains of functioning. According to the most recent diagnostic criteria, impairments in social interaction, communication, and behavior are the requisite characteristics of autism (American Psychiatric Association, 1994). The diagnostic criteria have changed only slightly since the disorder was first identified by Kanner in 1943. What has remained constant, and what is often immediately identifiable to observers, is that individuals with autism are generally severely impaired in social interactions and general relationship skills (Travis & Sigman, 1998).

Recent research has documented an alarming increase in the prevalence of autism (Charman, 2002; Wing & Potter, 2002). A recent study in California determined that many of the current theories of causality could not sufficiently account for the increase in that state (Byrd, 2002). The increase in prevalence of autism has led to renewed interest in interventions. Although individuals with autism are often severely impaired, there are well-established interventions that can be utilized to produce positive changes. To ensure maximum therapeutic outcomes for children with autism, support and consistency from family members are essential. The parents of the child with autism are often highly involved with the child's treatments, attending meetings at school and helping to monitor progress. While parents play an integral role in the success of their children, they are not the only individuals to interact with their child on a daily basis. Other family members
are sometimes overlooked in the lives of children with autism. Siblings and other members of the extended family play a large role in the lives of children with autism.

The Sibling Relationship

The current investigation is concerned with the siblings of children with autism. Longitudinal research on the constancy of close relationships indicates that siblings often have some of the longest, most intimate relationships (Wenger & Jerrome, 1999). The nature of the pervasive impairments in children with autism necessarily impacts their sibling relationships. As a result, siblings of children with autism report lower levels of intimacy with their siblings (Kaminsky & Dewey, 2001). In a quantitative study of sisters of individuals with developmental disabilities, Begun (1989) found the sibling relationship to be characterized by less intimacy and lower perceived sibling similarity. These findings led Begun to describe the relationship between siblings when one has a developmental disability as "affectively neutral" (p. 571). This description comes from the fact that "it is difficult to interact intimately with a person of limited language and social competence" (p. 571).

This disruption in the typical sibling relationship has implications for both the child with the disability and for the sibling(s). The sibling relationship forms the basis for future peer relationships and is often one of the first and most enduring friendships that an individual will have (Wenger & Jerrome, 1999). In addition, the sibling relationship provides the earliest social learning environment for an individual (Frank, 1996). Competitiveness, altruism, nurturance, and aggressiveness are just some of the behaviors that have their roots in the sibling relationship (Siegel & Silverstein, 1994).
Research Trends

As the number of empirical investigations of siblings of children with disabilities has grown, several research trends have emerged. For many years, researchers operated on the assumption that having a handicapped sibling was a negative occurrence in one's life. While research has borne out the idea that there are potentially negative implications of having a handicapped sibling, a growing body of literature suggests that siblings of children with handicaps may experience a number of positive outcomes. Meyer and Vadasy (1994) reviewed sibling issues in their handbook for workshops for siblings of children with disabilities. They described several potential negative sibling issues including overidentification, embarrassment, guilt, isolation, loneliness, loss, resentment, increased responsibilities, and pressure to achieve. However, they acknowledged the strengths that they have encountered in siblings of children with handicaps, and list maturity, improved social competence, insight, tolerance, pride, vocational opportunities, advocacy, and loyalty as potentially positive outcomes for siblings.

A review by Correa, Silberman and Trusty (1986) referred to increased stress and poor adaptation as potential negative outcomes, but noted that it is imperative that researchers consider potential positive outcomes. In order to examine the relative amounts of positive and negative outcomes in the literature, Summers, White and Summers (1994) compiled and rated 13 studies. They concluded that 25% of studies reported negative outcomes, and only 9% reported positive outcomes; the majority of the studies (66%) found no difference between siblings of children with disabilities and siblings of typically functioning children. Although these results may indicate a true tendency towards negative outcomes, the authors noted, “it is apparent that previous
reviewers may have overstated the effect based on the available data" (p. 178). A more recent meta-analysis supported the Summers et al. findings. A compilation of 25 studies was examined and a small, but statistically significant, negative effect emerged (Rossiter & Sharpe, 2001). The authors of this analysis included a cautionary statement that echoes that of Summers et al., noting that a small effect "suggests the generalized concern about the social and psychological development of the siblings of individuals with mental retardation has been overstated" (p. 76). There are several possibilities raised by the results of the meta-analyses by Summers, et al. and by Rossiter and Sharpe. The first is that having a handicapped sibling necessarily leads to at least some small negative outcomes. Another possibility is that the studies reviewed reflect a research bias towards negative outcomes in this population. It is easy to assume that negative outcomes would predominate in such a family situation. Some have directly called for a shift in this perspective (Cuskelley, 1999), but this idea dominated the research milieu for many years and old theories are sometimes slow to lose favor.

An innovative analysis by Helff and Glidden (1998) scrutinized 60 studies in order to analyze trends in the research on families of children with developmental disabilities. This paper considered studies published from 1971 to 1993, making it the most thorough review to date. The results indicated a decrease in the negativity of the research literature, but without a concurrent increase in positivity. It is likely that some of the decrease in negativity was related to the increased utilization of appropriate comparison groups and improvements in the research methodologies. However, many of the reviewed studies had hypotheses that seemed to operate on the assumption of negativity.
Though this assumption of negativity persists, studies continue to report on positive outcomes of having a sibling with autism. In addition to the positive traits anecdotally described by Meyer and Vadasy (1994), empirical investigations have concluded that there are positive outcomes for siblings. In a recent study of siblings of children with autism, Verté, Roeyers and Buysse (2003) found that adolescent sisters of children with autism had a more positive self-concept compared to a control group. In addition, siblings of children with autism reported feeling well supported in their lives by a variety of sources (Kaminsky & Dewey, 2002), possibly contributing to increases in self-concept. Another recent positive finding, which the author noted requires more study, is that having a sibling with autism had stronger effects on prosocial behavior than on negative behaviors (Hastings, 2003a). It is likely that research focusing on positive outcomes for siblings will continue to be published, and this increasing body of positive literature will impact the design of future studies as well as the overall perception of siblings of children with autism.

The lack of a cohesive theory of sibling outcomes complicates this research. Research is still inconclusive as to what aspects are most important to consider. Sibling relationships and family environments are complex, and formulating a cohesive theory that incorporates all of these variables is a daunting task. Daunting though it may be, if the subjects in these studies “continue to be seen as victims and their positive outcomes viewed with skepticism, services and interventions will be inappropriate (Helff & Glidden, 1998, p. 461).”

*Personal Experiences*
One important element of the personal experiences of siblings of children with autism is their understanding of autism. Siblings have a strong need for information about their brother or sister's condition (Meyer & Vadasy, 1994). A recent study utilizing a survey of family needs found that the need for information was most often cited in families with a child with a developmental disability (Ellis, et al., 2002). It is important that siblings obtain information about their brother or sister's condition, as increased knowledge of how to deal with the condition has been shown to be a predictor of how positive the sibling relationship is rated by both mothers and siblings (McHale, et al., 1986). Despite the importance of learning about the condition, siblings of children with autism attain an understanding of the condition at a slower rate than siblings of children with other conditions, possibly reflective of the slow development of the professional understanding of autism (Glasberg, 2000). In one study, 55% of siblings of children with autism “had no words to explain why their brother or sister was different from others” (Bagenholm & Gillberg, 1991, p. 304). In a qualitative study, Bagenholm and Gillberg (1991) found that many siblings of children with autism feel that they can only talk with someone outside of the home about their sibling’s condition.

Another aspect of the personal experiences of siblings that may be impacted by having a sibling with autism is their social life and interactions with peers. Studies that have demonstrated impaired socialization in siblings of children with autism described fewer contacts with peers (Coleby, 1995), and a trend towards difficulty in relating with peers (Cadman, Boyle & Offord, 1988). In the Bagenholm and Gillberg (1991) study, more than one-third of siblings of children with autism described themselves as lonely, having no friends, and preferring to stay home, and all of these descriptions were
confirmed by parent reports. Siblings of disabled children have also been shown to
demonstrate higher levels of interpersonal aggression with peers (Breslau, Weitzman &
Messenger, 1981). Conversely, some studies report typical socialization in siblings
(Hannah & Midlarsky, 1999). Bischoff and Tingstrom (1991) used several sibling-
specific questionnaires and found that siblings of children with disabilities “do not exhibit
differential levels of social competence” (p. 317) when compared to siblings of children
without disabilities. A similar conclusion was reached by Kaminsky and Dewey (2002)
in a study specifically of siblings of children with autism. The authors used a battery of
quantitative measures and confirmed that siblings of children with autism do not display
impaired socialization. In addition, one result of interviews conducted by Stoneman and
her colleagues (1988) was that “as a group, siblings of mentally retarded children spend
at least as much time with friends as do their agemates, and no disadvantage seems to
come to these children from diminished opportunities for contact with friends” (p. 180).
Other research has demonstrated that the similarity in social competence between siblings
of children with handicaps and controls remains stable over time (Dyson, 1999). Other
studies have shown that having a brother or sister with autism has stronger effects on
prosocial behavior than on behavior problems (Hastings, 2003a). While it has not been
widely studied, another aspect of socialization is the preferred location for peer
interactions. Having a disabled sibling may make one less likely to invite friends to the
home. However, interviews by Stoneman, et al. (1988) found that siblings of children
with mental retardation had frequent peer contacts in the home.

It is likely that socialization patterns and frequency of in-home peer interactions
are closely related to the sibling’s comfort with revealing the diagnosis to peers. In a
study of siblings of children with chronic health conditions, more than 40% of the respondents stated that they would hesitate to reveal their sibling's condition to others (Gallo, Breitmayer, Knafl & Zoeller, 1991). Gallo and her colleagues conducted individual interviews with children aged 6 to 14 who had a sibling with a chronic health condition and, while it is reassuring to know that approximately 60% of respondents would feel comfortable revealing their sibling's condition, the 40% who would not offered some interesting insights into their restraint. The most cited reason was that the affected child would be the subject of ridicule, while others mentioned fear that peers would share information about the child's condition with other peers. Peer acceptance of the affected sibling has been shown to impact the sibling's perception of their sibling relationship. Positive peer reactions related to more positive sibling relationships with the handicapped child (McHale, et al., 1986). While some research has focused on socialization and peer relations in siblings of children with handicapping conditions, more work is needed to more accurately describe peer interactions concerning the affected child, and to study the revelation of the condition to peers and others.

Family Experiences

It is impossible to separate the experiences of the sibling from the context of his or her family. Research shows that families of children with disabilities generally experience higher levels of stress (Bouma & Schweitzer, 1990; Dyson, 1993; Gray, 1997; Sanders & Morgan, 1997), and that this level of stress is unlikely to decrease over time (Dyson, 1993; Gray, 2002).

Siblings are often the first playmates of autistic children. Several studies have examined the interactions and play styles of siblings with their brother or sister with a
disability. Research has shown that siblings of children with autism allow their affected sibling to initiate play situations and social interactions (El-Ghoroury & Romanczyk, 1999). In this study, the authors noted, “siblings appear to be approaching the observed interactions with children in a manner similar to a typical play situation rather than a teaching situation” (p. 256). These results support those of Knott, Lewis and Williams (1995) who found that while the play interactions between children with autism and their siblings were somewhat impoverished, they closely resembled the interactions between typically developing children, especially in initiations and responses. Siblings of children with disabilities also engaged in more parallel play and social play (Lobato, Miller, Barbour, Hall & Pezzullo, 1991), skills that are characteristically difficult for children with autism to obtain. While the quality of these interactions is important, it has also been demonstrated that siblings of mentally retarded children interact with their affected sibling at relatively high rates (Stoneman, Brody, Davis & Crapps, 1987). The observations reported by Knott and her colleagues (1995) showed a higher frequency of play interactions among siblings when one child has autism than would be expected in typical peer play. El-Ghoroury and Romanczyk (1999) found that siblings of children with autism interacted less frequently with their affected brother or sister than did their parents, but that the less frequent interactions actually provided the child with autism with more opportunities for learning.

There are often added pressures applied to the family by the behaviors and symptoms of the child with autism that may lead to alterations in individual family roles. The unaffected siblings of children with disabilities often take on increased responsibilities and care-giving roles (McHale & Gamble, 1989; Wilson, Blacher &
Baker, 1989). In the Wilson et al. study, interviews of siblings found that teaching, dressing, feeding, babysitting, and disciplining were the most frequently mentioned types of care-giving. Siblings interviewed in the McHale and Gamble study reported twice as much time spent on care-giving as compared to control siblings without handicapped brothers or sisters. A study by Bagenholm and Gillberg (1991) concurred with these findings, but they added that increased responsibility was only reported by siblings and not by their parents.

Several variables relating to sibling stressors have been studied, including the age and gender of the siblings of affected children. Sisters of children with disabilities reported more home and childcare responsibilities than brothers (Damiani, 1999), but brothers of children with disabilities have been found to be more involved in childcare than siblings of typically developing children (Stoneman, et al., 1987). At a young age the care-giving expectations placed on sisters of children with handicaps may act as a buffer against feelings of depression (Lobato, Barbour, Hall & Miller, 1987), although these findings did not continue into adulthood.

While typical sibling interactions are described as symmetrical, sibling interactions with children with disabilities have been shown to become less symmetrical over time, as the cognitive and social capacities of the typically developing sibling outpace those of the affected child (Stoneman, 2001). As these relationships become less symmetrical, increased care-giving responsibilities are more likely to cause difficulty for the unaffected sibling. These increased responsibilities may be necessary for the family to cope with the presence of a child with autism, and some have cautioned that the extreme helpfulness, hyper-responsibility, and pseudo-maturity exhibited by some siblings may be accompanied by a flip-side clinical picture of depression, shame,
excessive guilt, unrelenting worry, social isolation, psychosomatic problems, and conduct
disturbances that characterize the parentified child (Lamorey, 1999, p. 76).

Increasing the responsibilities of siblings of children with autism may help the family
cope in the short-term, but may have long-term detrimental effects on the siblings
themselves.

One of the most important family variables is the relationship between the sibling
and his or her parents. Research has also shown that chronic disorders like autism
contribute more to family stress than chronic physical disorders (Bouma & Schweitzer,
1990). The effects on parents of having a child with a disability have been well
documented. Mothers of children with developmental disorders reported high levels of
doubt in their competence as parents (Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari,
1996). In addition, marriage difficulties may be present, and marital dissatisfaction can
also have detrimental implications for sibling relationships (Stoneman, 2001). The
mechanism for this impact may have been best described by Nixon and Cummings (1999)
as the result of increased levels of concern about family related conflicts in siblings of
children with disabilities. Another explanation for the mechanism of impact on siblings
of the marital relationship is offered by Martin and Cole (1993) who found that “fathers
who were involved in cohesive marital relationships were also involved in cohesive
father-child relationships” (p. 191). These results suggested that fathers who are more
involved in their marriages possess characteristics that make them more engaging fathers,
and are more invested in their children. A similar finding was reported for mothers, but
was not as strong.

In the Bagenholm and Gillberg (1991) interviews, siblings reported having to help
out more with their affected sibling, a finding that was only reported by siblings and not
mentioned as problematic by parents. Parent reports of problems faced by siblings of children with autism tend to decrease over time (Gray, 2002). These ratings may reflect a simple developmental trend towards appreciating the independence of siblings, or, more troubling, a misunderstanding of the issues that are problematic for siblings. Some literature exists that may be supportive of the second possibility. Over 60% of siblings in Bischoff and Tingstrom's (1991) study reported a desire to discuss concerns about their affected sibling with someone. This result is troubling when combined with findings that siblings of children with autism reported that they can only talk about their sibling with someone outside of the home (Bagenholm & Gillberg, 1991). These results would seem to indicate that parenting a child with autism causes increased family stressors, and that family and marital stressors can negatively impact unaffected siblings, possibly to the extent that they do not feel comfortable discussing their sibling within the family context. This sequence of events points to the need for open communication within the family as well as for the provision of services outside of the family that are focused on the unique needs of siblings.

Support Services

As the needs of siblings have increasingly become a focus of empirical investigation, services specifically for siblings of children with autism have become correspondingly more common. While some siblings may require intensive interventions like counseling or psychotherapy, many siblings benefit from being allowed to discuss their situation and meet others who have the same experiences. Even this type of structured support is not always necessary, as siblings of children with autism reported feeling supported by parents, teachers, classmates, and close friends (Kaminsky & Dewey,
It may be possible, however, that siblings of children with autism need interventions that are more intensive. The assumption that all siblings need such attention, however, has been shown to be dated and untrue. Cadman and his colleagues (1988) offered the advice that “siblings should be assessed as individuals, without any expectation bias, and should be offered treatment only when sound clinical indications are found (p. 120).” Some studies have found that siblings may be at risk for the development of conditions that may require treatment. Siblings of children with chronic health conditions had more depressive symptoms than controls (Breslau & Prabucki, 1987; Cadman, et al., 1988). Siblings of children with autism have also shown social and learning difficulties and other psychiatric diagnoses (Lainhart, 1999).

As noted above, more than 60% of siblings of children with disabilities express a desire to talk with someone about their sibling’s condition (Bischoff & Tingstrom, 1991). This may take a variety of forms, from informal social contacts with peers, to structured support groups, to psychotherapy. In a more broad sense, social support has been found to moderate the impact of the symptom pattern of children with autism on their siblings (Hastings, 2003b). In this study, families who reported higher levels of social support also reported more positive adjustment in unaffected siblings.

One of the most commonly recommended types of social support is support groups specifically designed to address the unique issues of siblings of children with autism. Few studies have specifically examined the outcomes of sibling support groups, but those that have demonstrate several positive effects of participation. Uniformly, participating siblings reported enjoy the group experience (Dyson, 1998; McLinden, Miller & Deprey, 1991; Phillips, 1999). Some of the outcomes that have been examined
include higher levels of social support, and improvements in behavior towards affected siblings (McLinden, et al., 1991). In the Phillips (1999) study, a support program was designed for siblings of children with disabilities. The author reported decreased levels of depression, anxiety, and sibling related stress, and increases in the self-esteem and perception of social support of the siblings as measured by a pre- and post-test design. Dyson (1998) also designed and evaluated a support group, but used participant evaluations as the data. Sibling participants most frequently reported enjoying learning about their sibling’s condition, and having the opportunity to meet and socialize with other siblings with similar experiences. These results are consistent with the literature suggesting that needs for information and socialization are important for siblings of children with autism.

While new findings are being reported on all aspects of the lives of siblings of children with autism, there remain many inconsistent findings in the literature. One suggestion to help unify the literature would be to go directly to the source to gather data (Cuskelley, 1999). Many studies utilize parent and teacher report data, while fewer studies actually use sibling self-report data. In attempting to analyze the lives and outcomes of siblings of children with autism, their subjective input is likely to be the most relevant (Hannah & Midlarsky, 1985). Some researchers have considered the subjective, qualitative responses of siblings of children with disabilities (Bågenholm & Gillberg, 1991; Dyson, 1998; Gallo, et al., 1991; Glasberg, 2000; McHale, et al, 1986; McHale & Gamble, 1989; Stoneman, et al., 1988; Wilson, et al., 1989), but many more studies have relied on questionnaires and standardized measures.
Of the studies mentioned above, only the McHale, et al. (1986), Bågenholm and Gillberg (1991) and Glasberg (2000) studies included a large number of siblings of children with autism. Much of what we know about the lives of siblings of children with autism comes from observations (e.g., El-Ghoroury & Romanczyk, 1999; Knott, et al., 1995), and standardized measures. Those studies that used standardized measures seemed to rely as much on parent report (e.g. Ellis, et al., 2002; Hastings, 2003a; 2003b) as on the self report of siblings (e.g. Kaminsky & Dewey, 2001; 2002; Verté et al., 2003).

While there is certainly much to be gained from a strictly quantitative look at siblings of children with autism, the lives of these siblings and their families are necessarily extremely variable. Largely reflective of the idiosyncratic nature of the symptoms of autism, families of children with autism may be more different than similar (Ramey, Krauss, & Simeonsson, 1989). Open ended questions offer siblings a chance to discuss their thoughts and feelings and how they vary over time. As Berg (2001) noted, certain experiences cannot be meaningfully conveyed through numbers.

Qualitative interviews with siblings of children with autism can provide an important level of depth to the existing empirical literature. Siblings of children with autism are appropriate for qualitative inquiry as they see the effects of autism everyday. Particularly, “they see the effect of their sibling’s disability on their own lives” (Glasberg, 2000; p. 152). Using interview methodology allows the participant to openly discuss his or her experiences, more specifically, semi-structured interviews allow for a freer exchange of ideas (Esterberg, 2002).

Only by asking the experts, the siblings themselves, can we hope to ascertain the issues that they see as relevant, and the internal experiences that relate to these issues. By
offering to listen directly to siblings and to relate the experience in their words, new insights may be gained that can have profound influence on the lives of children with autism, their parents, and their siblings.

With this goal in mind, we set the following objectives for the current investigation:

First, we asked the siblings of children with autism to describe their personal experiences to gain insights about the impact of autism on their social relationships.

Secondly, the siblings provided information about their understanding of autism and the feelings that they identify as related to having a brother or sister with autism.

Considering the participants in the context of their families, a third objective was to gather data on siblings’ perceptions of their roles in the family, including any added pressures that result from having a brother or sister with autism. The study also sought to gain an understanding of siblings’ perceptions of how well their parents handle having a child with autism and how well their parents understand the sibling point of view.

A fourth objective was to learn about siblings’ involvement in various support services. Data gathered here included what aspects of support services they perceived to be most helpful to them, information that could have implications for parents, teachers, and professionals.

As a final objective, siblings of children with autism were given the opportunity to respond to questions that do not seem to have been posed to them in past literature. Questions were asked about the hopes, wishes, and fears that siblings harbor for their brother or sister with autism. In addition, understanding that positive outcomes frequently occur, the study investigated what the participants have learned from their
sibling and what their sibling relationship has taught them about themselves. Finally, siblings were offered the chance to relay what they wish others knew about being a sibling of a child with autism, and to offer advice to other siblings of children with autism.

Method

Participants

Participants were 21 children who have one sibling with a DSM-IV diagnosis of Autistic Disorder (299.00; A.P.A, 1994). All siblings with autism had been previously diagnosed by local medical professionals. Participants ranged in age from 6 to 15 with a mean age of 9.57 years. Eleven participants were female (age range=6-15 years, mean=9.54 years) and 10 were male (age range=7-15 years, mean=9.6 years). All of the siblings with autism were boys (N=13, age range=6-14 years, mean=8.46 years). The participants represented 13 unique families with eight families having one participant, two families having two participants and three families having three participants. All participants were biological siblings of the child with autism. Refer to Table 1 for demographic information. All participants were Caucasian and were middle class based on combined family income data provided (Family income range=30-60,000$ to 180,000+$). Participants were recruited through the newsletter of the local autism society and its affiliated website, through contacts at a local organization providing therapeutic horseback riding, or were referred by other participating families. Attempts to recruit participants through local schools and other organizations (i.e. church groups) were unsuccessful. Several families initially agreed to participate but did not because of scheduling difficulties or losing contact with the researcher.
Measures

Interview form.

The interview questionnaire (see Appendix A) used was created specifically for this study, and is based on a review of the literature. In addition, the questionnaire was piloted on one family who offered suggestions for improvement. Among the suggestions was simplification of wording of the questionnaire and consent and assent forms.

Numerical rating scales.

Four items in the interview were supplemented by 5-point numerical rating scales. These items deal with the impact of an autistic sibling on the participant’s social life, whether they feel added pressures as a result of their sibling, their perception of how well their parents handle their autistic sibling, and how helpful support services are to them. Participants were presented with a graphic representation of the scales that included the anchors for each end of the scale. Due to differences in interviewer style and uncertainty in some participants, not all participants assigned numbers to each question. Refer to Table 2 for all numerical responses.

The Gilliam Autism Rating Scale.

Parents of each participant completed the Gilliam Autism Rating Scale (GARS; Gilliam, 1995) regarding the child with autism. The GARS was used for two reasons; to provide a rating of the severity of the child’s autistic presentation, and to serve as a verification of the child’s autism diagnosis. The GARS was completed for each sibling with autism (N=13, Range=78-113, Mean=96.07). All siblings with autism scored at or above cutoff scores for autism on the GARS.
**Demographic Data.**

Parents of all participants completed a demographic information sheet (see Appendix B) prior to the interviews. Information gathered includes the marital status of parents, living arrangements of the siblings, racial/ethnic background, parents’ education, employment, family history of developmental disorders and a listing of current services that the child with autism and the participating sibling might receive.

**Procedure**

Families who agreed to participate in the study were initially mailed the demographic information questionnaire (see above) as well as the informed consent forms for the parents and assent forms for the siblings (Appendix C). The GARS was also completed prior to the interviews. At the outset of the interviews, this information was discussed and all consent and assent forms were reviewed with the participants.

All interviews were conducted in the family’s homes and were audio-recorded. All recorded interviews were transcribed by an independent medical transcription service.

**Data Analysis**

Data were analyzed using a combination of methods. Transcribed interviews were divided into responses to individual questions and all responses to each question were grouped. Two independent raters, graduate students in psychology who were otherwise not involved in the project, rated the responses and grouped them into thematic categories. The raters worked independent of each other and therefore developed categories that were labeled differently but were consistent in content. Finally, the researcher used a forced agreement procedure to produce the final category descriptions. This was done by combining similar categories from each rater (e.g. Rater 1’s category
‘Fun/Cool’ and Rater 2’s category ‘Nice/Affectionate’ were combined to create the final category of ‘Positive Responses.’

Results

At the outset of the interview, participants were asked to talk about their families (Question 001; Tell me about your family). This initial question was included as a segue into the interview. All participants named their family members and pets and described a variety of family situations, from their parents’ marital status to daily activities.

Participant’s personal experiences were addressed by five questions (Questions 002, 005, 006, 007, and 008, see Appendix A for a full list of questions). In response to Question 002 (What is it like having a (brother/sister) with autism?), 48% of participants expressed positive reactions, including

I always think about him when I’m not with him. (6-year-old female)

I play and hug him sometimes. (7-year-old male)

Seventy six percent of participants provided negative responses, including

It’s really hard. Sometimes he gets on my nerves. (9-year-old female)

It’s kind of embarrassing sometimes. Like when you’re out to eat somewhere and he’s causing a scene or something. (15-year-old female)

Participants described their interactions with peers in regards to their sibling with autism (Question 005, How do you talk to your friends/classmates/neighbors about (name)?). More participants (62%) reported talking with their peers about their sibling with autism than did not (48%) and one participant described getting into confrontations with peers regarding his sibling with autism.
I don’t get into any physical fights, but sometimes I yell at them. (13-year-old male)

When asked specifically about the impact that their sibling with autism has on their social life (Question 006, Does (name) affect your social life?), 38% of participants acknowledged a detrimental impact on their social life.

Like we’ll go to a restaurant and I might want to go to this one or he might want to go to another one, we have to go where he wants. (11-year-old male)

Sometimes he bugs me when I’m having someone over. We just have to, I have to keep telling him to get away and stuff. (13-year-old male)

More participants (67%) stated that having a sibling with autism does not affect their social life. Ninety five percent of participants acknowledged that they do have friends over to their homes to play.

I’ve had friends over here before. He plays with them and stuff. They just say, ‘hey buddy, do you want to go play a video game with us?’ (7-year-old male)

Yeah, I have friends over to my house. Sometimes they even spend the night. (8-year-old male)

Question 006 was supplemented by a 5-point rating scale where participants were asked if their sibling with autism affected their social life (1=no, not really….5=yes, a lot). Twenty participants responded to the question with a mean rating of 2.42 (Range=1-5, SD=1.19). This score is commensurate with the percentage of participants (67%) who did not describe any detrimental impact on their social life.

Most participants (67%) stated that living with their sibling with autism has not changed the way they feel about other people (Question 007, Has having a (brother/sister)
like (name) changed the way you think about other people?), while some (33%) acknowledged that their view of others has changed because of their sibling relationship.

They look different and they act different, but they’re still the same person. (11-year-old male)

Definitely. Because sometimes I see people saying stuff about other people like at school who have disabilities and I probably would be too if [he] wasn’t my brother. (11-year-old male)

Participants were asked about the impact their sibling has had on their future ambitions (Question 008, What do you hope to do when you get older? and, Has (name) had an impact on this decision?). Participants talked about desired future professions including helping professions, veterinary medicine, and other careers. Many participants (67%) reported no sibling impact on career decisions, while others (33%) reported some sibling impact.

I might want to be a teacher or a psychologist. I think I might want to work with autistic kids. (9-year-old female)

I want to work with handicapped children like people with autism and stuff. I was going to get dogs and train them to be therapy dogs. (10-year-old female)

To achieve the second objective, participants were asked about the meaning of autism and their feelings about their sibling (Questions 003, 0031 and 004, see Appendix A). In response to Question 003 (What does autism mean to you?), 43% of participants described autism as a different way of learning.

A disease of the brain that causes someone to learn differently. (10-year-old female)
Twenty four percent of participants equated autism with communication difficulties.

Well, I know it’s a disability and it’s like, it’s hard for them to communicate. (11-year-old male)

Other participants (43%) used a variety of descriptions of autism, reflecting a range of sophistication.

Like, um, when somebody’s brain works different. (6-year-old female)

I think that word means like their talents and the stuff they cannot do and can do. (8-year-old male)

I’m thinking it means, like, he gets something that it makes you go wild and get an asthma attack. (7-year-old female)

Participants reported getting information about autism from a variety of sources (Question 0031, Where did you get your information; How did you learn about autism?), including their parents and other family members (86%), as well as other professionals (29%) with whom the participant is familiar (i.e. doctor, psychologist).

In response to a question about their feelings regarding their sibling with autism (Question 004, What kinds of feelings do you have about having a (brother/sister) with autism?), 57% of participants described positive feelings.

I mostly feel like he’s special with my family because most families don’t have families like that. It feels really special to have someone in my family who has difficulties. (9-year-old female)

He doesn’t do any mean things like some brothers do. (9-year-old female)

More participants (81%) listed negative feelings about their sibling with autism.

Sometimes it’s frustrating. Sometimes he gets really physical. Like he’ll
jump on top of me and wrestle me. (11-year-old female)

Kind of mad sometimes. Because sometimes you build towers and he knocks them down. (8-year-old male)

To address objective three, participants were asked a series of seven questions (Questions 009, 010, 011, 012, 013, 014 and 015, see Appendix A) regarding their family life, family roles, and parent reactions to the family dynamic. When asked about how they spend time with their sibling with autism (Question 009, What kinds of things do you do with (name)?), 95% of participants described positive interactions.

Sometimes we jump on our trampoline. We watch TV. He likes me to help him with the movies, so I do. (10-year-old female)

Play with him. Sometimes we have races in the house, but mom really doesn’t like it. (8-year-old male)

We get ice cream and stuff. It’s more just to hang out than get the ice cream or whatever. (15-year-old male)

Participants were asked about their roles in the family and their thoughts on their role (Question 010, What is your role in the family, and, Are you happy with this or do you wish it could be different?). All participants described roles that varied from childcare to household chores.

Doing the dishwasher and cleaning up my room. (6-year-old female)

Well since I’m the oldest, I have to watch out for everybody else. (11-year-old female)
The majority of participants (57%) reported liking their role in the family, while only 10% specifically stated that they did not like their role. Thirty three percent of participants did not have an opinion on their current family role.

In response to a question about additional pressures that derive from having a sibling with autism (Question 011, Do you feel added pressures because of (name)?), 38% of participants described some added pressures.

My step-dad is like ‘[he] is sick in the head and we expect more from you.’ So, its’ pretty hard. (11-year-old male)

More participants (62%) did not describe any added pressures that stem from having a sibling with autism.

There isn’t really pressure that much, other than once in a while he kind of runs around. (9-year-old female)

Question 011 was supplemented with a 5-point rating scale where participants were asked if they felt any added pressures stemming from their sibling with autism (1=no, not really….5=yes, a lot). Nineteen participants responded to the question with a mean rating of 2.18 (Range=1-4, SD=1.03). This number is consistent with the fact that 62% of participants did not describe feeling any added pressures.

Participants were asked to discuss how they felt their parents handled having a child with autism (Question 012, How do you think you parents handle having a child like (name)?). Most participants (86%) felt that their parents did a good job with their sibling with autism. Many participants elaborated on how their parents help their sibling.

She tries to learn more about [him] and she tries to, like, give him special classes and stuff. (11-year-old male)
They give him special therapies. They give him lots of attention. They make sure he’s not hurt or anything. (9-year-old female)

A++. They care a lot about him. They’d do anything to make him talk. (10-year-old female)

Other participants (29%) described situations that they felt illustrated difficulties with handling their sibling with autism.

My mom is really, really, really soft on [him] because sometimes he’ll come down with a fake illness. Any my dad, he’s pretty tough on [him]. (11-year-old female)

I think my dad does a bad job because he doesn’t hold on to my brother’s hand instead of letting it go and not holding on to it. (7-year-old female)

Question 012 was supplemented with a 5-point rating scale where participants were asked if their parents do a good or bad job with their sibling with autism (1=not really/bad job....5=yes, a great job). Seventeen participants responded to the question with a mean rating of 4.41 (Range=2.5-5, SD=.7453). This score reflects the responses, described above, that most participants (86%) felt that their parents did a good job with their sibling with autism.

Participants were asked whether they felt their parents understood their feelings regarding their sibling with autism (Question 013, Do you think your parents understand how you feel about your (brother/sister), and, Do you talk with your parents specifically about being (name)’s (brother/sister)?). Forty eight percent of participants noted that they do talk with their parents about their sibling with autism, while 52% do not. Overall,
62% of participants felt that their parents understand their feelings about their sibling with autism.

I think my mom understands how I feel about [him]. I think she knows it's kind of embarrassing for me sometimes because she had a brother with autism. (9-year-old female)

Yeah. My mom always tucks me in at night and sometimes she lays down with me. We talk about where he's going to go and what he's going to do when he grows up and we just say the possibilities of where he's going to go and stuff. (9-year-old female)

They don't understand anything else, but they understand that. (13-year-old male)

Other participants (33%) felt that their parents did not understand how they feel about their sibling with autism.

No. They don't accept the way I respond to him, so it's not their choice. (15-year-old male)

Participants were asked a question about their feelings for their family (Question 014, How do you feel overall about (name) being a part of your family?). Most participants (67%) made positive statements about their sibling with autism being a part of their family.

I think he's a good member of our family. He does what he's told most of the time. He's really nice and friendly. (9-year-old female)

I'm glad he's in the family. I think it's kind of neat having an autistic brother. (10-year-old female)
Thirty three percent of participants provided other responses that included a range of feelings and reactions to having a sibling with autism in their family.

Sometimes I feel good, sometimes [he] can be pretty mean and sometimes [he] can be pretty annoying. (7-year-old male)

In response to a question asking them to consider life if their sibling did not have autism (Question 015, How do you think things would be different if (name) wasn’t autistic?), 52% of participants thought that things would be better if their sibling did not have autism.

It would be a tiny bit better. He wouldn’t break any of my toys. He would talk to me about what he wants. (8-year-old male)

We’d do a lot of stuff together. I’d do a lot more stuff with him. (10-year-old female)

Many participants (48%) felt that things would be worse if their sibling was not autistic.

I’d feel so bad because he would probably be really, really mean to me. He wouldn’t let me come into his room. (6-year-old female)

I’d probably get in more trouble more often because I’d have somebody to get in trouble with. (15-year-old male)

Objective four examined participants’ experiences with support services through four questions (Questions 016, 017, 018 and 019, see Appendix A). Participants were asked about their experiences with support services (Question 016, What sorts of things have helped you through tough times?). The majority of participants (67%) reported having no history of involvement with any support services. The remaining 33% of participants reported some involvement with support services. Of this 33% (N=7), 71%
(N=5) found their experiences to be helpful. Types of services described included structured support groups, individual counseling and informal supports through community organizations or other families.

And with the school psychologist, she helped me by saying in my file she said she had me sign a paper that said anything that’s in this room stays in this room. She was really nice. I could say anything. It kind of makes me feel more comfortable. (11-year-old male)

We have parties with the Autism Society. It’s fun. Just because when I go there, other people are there and you kind of learn from that. (9-year-old female)

The remaining participants with some history of involvement with support services (29%, N=2) reported that their experiences were not helpful.

Sibshops. They just discuss about the issues, which I think is really boring. Well they take up your time in the summer and they are really boring. (10-year-old female)

Question 016 was supplemented with a 5-point scale where participants were asked how much they liked the support services they had been involved with (1=I don’t like them….5=I really like them). Six participants responded to the question with a mean rating of 3.25 (Range=1-5, SD=1.60). This is consistent with the finding that most participants with a history of involvement with support services (71%) reported that these experiences were helpful.

Objective five consisted of several questions that did not appear in previous literature (Questions 020, 021, 022, 024, 025, 026, 027 and 028, see Appendix A) and were designed to allow the participants to consider other aspects of their experiences.
Question 020 (What's the worst thing about having a (brother/sister) with autism?) allowed participants to discuss the negative aspects of having a sibling with autism.

Some (24%) participants described their sibling as annoying.

He breaks toys. He comes in my room. It gets really annoying. (8-year-old male)

Well he's really annoying. He teases me about stuff. (10-year-old female)

Other participants (14%) described embarrassing situations involving their sibling with autism.

I said this a lot of times, it's really embarrassing to tell my friends why he doesn't go to my school. And I just pretend I don't know because it's embarrassing why to tell them. (9-year-old female)

Just explaining to everybody what's wrong with him. It's kind of hard to explain and being embarrassed. (15-year-old female)

The majority of participants (62%) described difficulties regarding their sibling.

Sometimes it gets really scary. He has seizures. (11-year-old male)

Sometimes my parents are busy and they don't want to play games with me so I talk to [his] therapist person. (10-year-old female)

The worst thing is probably being....Like kids that are making fun of him. I don't really like that. (11-year-old male)

Participants were asked for their thoughts about the future for their sibling with autism (Question 022, What are your hopes/wishes/fears for (name)?). The majority (62%) of participant responses reflected a desire for their sibling to lead a normal life.

I hope he gets a good job and leads a good life. (10-year-old female)
I hope he doesn’t have something that he doesn’t deserve, that he doesn’t do it just because he’s autistic. I don’t think that should stop him from having a good life. (11-year-old male)

Other participants (43%) expressed a desire that their sibling’s behavior would improve.

That he’d talk and do a lot more stuff. (10-year-old female)

He’ll understand talk and he won’t scream. (8-year-old female)

I wish he would stop biting and pinching. (7-year-old male)

Participants were asked what they had learned from their sibling with autism (Question 024, What have you learned from your sibling?). Some participants (43%) did not feel that they had learned anything from their sibling with autism. However, many participants (57%) reported that they had learned acceptance and understanding from their sibling.

Some people are different. You’ve got to accept them for who they are and they might be friendly and fine and sometimes, most of the time, they are. (9-year-old female)

That there are a lot of people in this world that have disabilities and stuff and we need to try to help them and to learn patience. (10-year-old female)

Participants were also asked what they had learned about themselves from being the sibling of a child with autism (Question 025, What have you learned about yourself from being the (brother/sister) of a child with autism?). Twenty nine percent of participants reported that they had not learned anything about themselves from their sibling relationship. Many (57%) participants stated that they have learned how to better relate to others.
If I meet someone with a brother or sister with autism, I know how they feel and I could probably, we could probably talk about our brother or sister. (9-year-old female)

Everything isn’t always about me. That I’m going to have to make some changes for him and I’m going to have to be there for him. (15-year-old female)

Participants were asked what they would like others to know about having a sibling with autism (Question 026, What do you wish people knew about being a (brother/sister) of a child with autism?). In response, 38% of participants stated that they wished others would be accepting of their sibling.

I wish they knew how it feels and I don’t know, like, to accept them. (9-year-old female)

That even though he might be autistic, they should still take care of him. (8-year-old male)

Some participants (24%) wished others knew that having a sibling with autism was not very different from having a typically developing sibling.

It’s not very different. Well, because I’ve been over to my friend’s house who has a younger brother [his] age who is normal and he acts the same way. (10-year-old female)

I’m sure people, when they first see him, they are always, they think he’s a weird kid or whatever, but he’s not. He’s normal. (15-year-old female)

Additionally, 38% of participants provided responses that reflected a range of desires.
I would tell them that sometimes they want their way and you should learn to put your foot down and I don’t think my parents have learned that yet. (11-year-old female)

It’s kind of like a mystery that you have to find what he likes. (10-year-old female)

Participants were asked what advice they would give to other siblings of children with autism (Question 027, What would you tell other kids who have a brother or sister with autism?). The majority of participants (71%) offered helpful and positive advice to other siblings.

I would tell them that it’s ok to have an autistic brother because you can learn some things about how they feel and how their feelings are even if they can’t talk. (10-year-old female)

That they need to be patient with him and try to understand that they need help and you try and let them fit in and make them feel comfortable and make them feel not so different from everybody else. (10-year-old female)

Other participants (29%) offered advice that included negative situations and described personal experiences.

Be ready for your brother to have seizures. And be ready for lots of tantrums. Like they get really hysteric and stuff. And sometimes there are family problems. (11-year-old male)

I would tell them some stuff that my brother does sometimes. (7-year-old male)

Finally, participants were given the opportunity to describe the best things about having a sibling with autism (Question 028, What’s the best thing about having a
(brother/sister) with autism?). Many participants (38%) described having fun playing with their sibling.

He usually likes to play games and stuff. It’s really fun playing with him. (8-year-old male)

He likes to do the things that I do and I really enjoy that. (9-year-old male)

Other participants (33%) talked about having a sibling with autism as a learning experience.

That you can experience more stuff. Um, like going to new places and stuff. (10-year-old female)

Learning how to deal with other people and understand them better like that kind of thing. (11-year-old male)

Other participants (29%) offered a variety of responses that reflected positive experiences and situations.

The best thing is that he’s not as annoying as usual brothers. (10-year-old female)

Um, just that he can really bring our family together sometimes. (13-year-old male)

Um, him being different and making us laugh. Yeah, it wouldn’t be the same without him. (15-year-old female)

Discussion

The current study was designed to allow siblings of children with autism to describe their experiences in their own words. Previous studies have not often afforded this population the opportunity to speak candidly. While based on previous studies, the current study seeks to add depth and realism to the existing body of literature.
Participants were asked questions regarding the following elements of their lives; personal and social experiences, their understanding of autism, family experiences, involvement with support services, and, finally, a series of questions that do not seem to have been asked in previous literature.

Participants offered a mixed picture of their personal and social experiences. The majority of participants (76%) made negative overall statements about their siblings with autism, but most participants also indicated that their sibling did not significantly affect their social life, their view of others, or their career aspirations. When asked what the worst thing was about their sibling with autism, participants described their siblings as annoying ("It gets annoying.") , embarrassing ("It’s kind of hard to explain, and being embarrassed.") , or described situations from their experience ("They go up to him and stare at him and make fun of him and stuff."). When asked about feelings that they associated with their sibling with autism, 81% of participants made negative statements. The responses generally reflected feelings about particular situations with their sibling, such as how they feel when they are fighting with their sibling or when their sibling takes their toys. Participants were not asked, however, about feelings toward their other, typically developing siblings and it is unclear whether their responses are purely reflective of the sibling’s autism or of broader family dynamics.

Taken together, the results described above have several implications. More practically, they indicate a need for increased public education about autism that may improve relations with others as described by participants of the current study. Additionally, adults should provide siblings of children with autism with accurate, age appropriate information. Many siblings could also benefit from simple coping strategies.
for difficult situations, such as walking away from confrontations or learning to seek additional information when necessary.

Participants in the current study were willing to speak openly about their sibling with autism, including making negative statements about their sibling. Results of previous studies (McHale, et al., 1986; Bågenholm & Gillberg, 1991; Glasberg, 2000) may have been impacted by social desirability of responses. In the current study, participant interviews were conducted individually, in separate rooms from other family members. While the results may have been solely impacted by the nature of the interviews, it is also possible that these negative responses reflect an increasing trend toward comfort with talking about their sibling with autism. Therefore, while the reported results are negative, the simple ability to relate negative experiences may, in itself, be a positive finding.

In contrast to the negative statements described above, all participants also made positive statements about their siblings. Participants described having fun playing ("It's really fun playing with him."); looking at the situation as a learning experience ("You can experience more stuff."); and other positive statements ("It wouldn't be the same without him.") that stand in contrast to previous literature (Correa, Silberman & Trusty, 1986; Summers, White & Summers, 1994; Rossiter & Sharpe, 2001) that discuss the overall negative effect of having a sibling with autism. Responses from participants in the current study support previous literature (Verte, Roeyers & Buysse, 2003; Kaminsky & Dewey, 2002, Hastings, 2003a) that finds, in addition to some negative implications, positive outcomes (i.e. higher self-concept, improved social competence) for siblings of children with autism.
Additionally, the finding that 95% of participants socialize with peers in their own homes is consistent with several previous papers (Kaminsky & Dewey, 2002; Bischoff & Tingstrom, 1991; Stoneman, et al., 1988) that found no evidence for impaired socialization in siblings of children with disabilities. The current qualitative results on socialization complement the results of the Kaminsky and Dewey (2002) report that found, quantitatively, normal levels of social competence in siblings of children with autism.

Previous research on siblings of children with chronic health conditions (Gallo, et al., 1991) indicated that approximately 60% of participants would talk with peers about their sibling’s condition, although a smaller number reported actually having talked with their peers about their sibling. Results of the current study, with 62% of participants saying that they talk to their peers about their sibling with autism, extend these results to siblings of children with autism. While this consistency is an important finding, one might expect that, with the increase in autism and the increased public knowledge about autism, more children would be comfortable discussing their sibling’s condition with peers. Additional research should examine, in more detail, the dynamics that surround the revealing of a sibling’s disability to peers.

Participants’ stated hopes for their sibling with autism included living a normal life (“I hope he gets a good job and leads a good life;” “I hope he progresses more and can read and gets a job and has a girlfriend and gets married.”) and recognizing symptom improvements (“That his brain gets a lot better;” “That he’d talk and do a lot more stuff.”). Part of any education of siblings of children with autism should include realistic appraisals of outcomes, provided at age-appropriate levels. While it would be
important to remain optimistic, certain expectations may not be appropriate and siblings could be led to develop hopes that are more appropriate for the future.

Participants were asked to describe autism and relate feelings that they had about their sibling with autism. Participant’s definitions of autism reflected a range of sophistication and comprehension (“You can’t do some stuff that regular people can do;” “A disease of the brain that that causes someone to learn differently.”). That most participants were able to develop a response to this question is a positive finding, given that, in one previous study, 55% of siblings of children with autism “had no words to explain” the condition (Bagenholm & Gillberg, 1991). This finding may be reflective of the increased information regarding autism available to families. While the descriptions of autism provided by participants were likely influenced by the age of the participants, they were also likely based on information provided by parents. The current study found that 86% of participants would ask a family member for information about autism, an improvement from the results of the Bagenholm and Gillberg (1991) study that found that 35% of siblings of children with autism felt that they could only talk with someone outside the house about their sibling’s condition.

Ninety five percent of participants in the current study reported positive interactions with their sibling with autism, consistent with the findings of Knott, Lewis and Williams (1995) that play interactions when one sibling has autism are similar to those of typically developing siblings. Participants described playing (“We play a game and it’s pretty fun.”), helping (“He likes me to help him with the movies, so I do.”), and teaching their sibling with autism (“I get to help him with his math, which is kind of fun.”). The interactions described by participants in the current study likely benefit both
the sibling with autism as well as the participants, consistent with the findings of El-Ghoroury and Romanczyk (1999) that frequent interactions with siblings allow the child with autism more opportunities for learning.

Participants also provided insights into their experiences regarding their family as a whole. Participants’ responses indicated that they have a variety of roles within their families. Many talked only about chores, but some participants described care-giving roles similar to those reported in previous literature (McHale & Gamble, 1989; Wilson, Blacher & Baker, 1989; Bagenholm and Gillberg, 1991; Damiani, 1999). To elaborate on these roles, participants were asked their opinion of their roles, a question that does not appear to have been asked in previous studies. Most participants, 57%, reported liking their roles, 33% had no opinion and only 10% (2 participants) did not like their roles. Despite having a variety of family roles, the majority of participants did not report feeling any additional pressure because of their sibling with autism.

Participants in the current study also reported relying on their parents for information and support. The majority of participants (62%) felt that their parents understand how they feel about their sibling with autism. In addition, 82% of participants felt that their parents do a good job dealing with their sibling with autism. These results are promising when compared to previous literature on high levels of stress and relationship problems when a family member has a disability (Bouma & Schweitzer, 1990; Fisman et al., 1996; Nixon & Cummings, 1999; Stoneman, 2001). The current results on parental interactions may also be affected by increased knowledge about autism that is available to families.
The majority of participants in the current study (67%) reported no history of involvement with support services. This finding can be interpreted in several ways. First, siblings of children with autism may not require intensive supports. Previous research that had assumed negative outcomes for siblings of children with autism has been shown to be outdated (Cadman, et al., 1988), and this result is consistent with the theory that siblings of children with autism are generally well adjusted. A second interpretation could be that support services for siblings of children with autism are not readily available.

Of those participants who had been involved with support services (N=7), 71% reported that the interventions were helpful. Services described by participants included SibShops, talking with counselors, and more informal gatherings sponsored by the local autism society. The positive ratings are consistent with previous research that the majority of participants evaluate social supports positively (McLinden, Miller & Deprey, 1991; Dyson, 1998; Phillips, 1999). While previous authors have described a need for information in siblings of children with disabilities (Meyer & Vadasy, 1994; Ellis, et al., 2002), no participants in the current study expressly described asking for information, but several mentioned learning about their sibling as being a helpful part of support services.

There are several limitations of this study which future research should seek to remedy. The number of participants (N=21) is smaller than many other studies of siblings of children with autism, although many more questions were asked of participants in this study as compared to previous qualitative reports (Stoneman, et al., 1988; Bagenholm & Gillberg, 1991). Additionally, because of the breadth of the current interview, detailed information was not gathered on specific aspects of the participant’s
lives, but rather broadly assessed many elements of the experiences of siblings of children with autism. Future research should examine elements of the current study in more depth. Specific groupings of participants (by age, gender, birth order, etc.) would allow for statements on the lives of the participants through development. The inclusion of parent corroboration of participant's information would also lend weight to their statements and the derived conclusions. Additionally, the use of a well-matched control group of siblings with other disabilities or typically developing siblings would allow further comparisons to be made.

Developmental differences emerged in response to several of the questions. Younger participants provided concrete answers or may not have fully understood the implications of particular questions (Question 010, What is your role in the family? and Question 015, How would things be different if (name) was not autistic?). In addition, younger participants may not have been capable of the abstract thinking required by some of the questions (Question 007, Has having a brother like (name) changed the way you think about other people?, Question 024, What have you learned from your sibling?, and Question 025, What have you learned about yourself from being the sibling of a child with autism). While the interview questions were piloted prior to use, future research should seek to develop more age-appropriate wording to such questions.

As reported above, all participants in the current study were Caucasian and middle class. Attempts made to include participants from under-represented demographic groups (i.e. low SES, non-Caucasian) by recruiting through the public school system and from inner-city churches were unsuccessful. Any future research
should attempt to include these under-represented groups in order to develop a more representative picture of the lives of siblings of children with autism.

What the results of the current study provide, in addition to the information described above, are a glimpse into the inner thoughts and feelings of siblings of children with autism in regards to their lives. While family members are given increasing attention by the research literature and by those who implement interventions, more can be done to incorporate siblings. Some siblings may not necessarily want to be involved directly with interventions, but many do. Whether they are involved in a hands-on manner or not, the recognition that siblings play an important role in families of children with autism is essential for those working with these families.

In addition to a broad understanding and appreciation for the role of siblings of children with autism, professionals should seek to work directly with this population. While two thirds of the participants in this study were not involved in support services, it cannot be assumed that this was because they did not require intervention. Supports for siblings are scarce in most areas, but do not need to be complex and structured to be of benefit to participants. Siblings in Kaminsky and Dewey's (2002) study reported feeling supported by a variety of sources. Designing information sessions on autism for schools would benefit siblings by increasing awareness of the condition, and may also benefit the children with autism themselves, by leading to better social experiences with more understanding typically developing peers. Providing age-appropriate information to parents and siblings can help foster open communication and problem solving in these families. Professionals simply talking with the siblings of children with whom they work would likely be supportive and informative.
Participants stressed that learning acceptance and understanding were important across a variety of domains. They stated that they had learned these qualities from their sibling and they noted that they wished others would also learn to accept and relate to their siblings with autism. While teaching others to accept individuals with autism is certainly not responsibility of their siblings, siblings who are well informed and who feel comfortable talking about their sibling with peers can do much to improve understanding of the condition.

The participants in the current study emphasized that siblings of children with autism are vital members of their families, and that no element of their family’s experience escape them. Those who work with children with autism would do well to incorporate siblings and their experiences. This population requires the attention and support of the professionals who are already involved with their families.
References


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* - Bold lines indicate participants from separate families.
Table 2

**Numerical Rating Scale Scores**

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Table 2 (continued)

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* - Numbers in parentheses represent the average when two numbers were given.

** - N/A = Not applicable (i.e. no history of involvement with support services).

*** - (--) = No response given.
Appendix A

Interview

Sibling interview

General Category — Introduction
001 Tell me about your family

General Category — Personal Experiences
002 What is it like having a (brother/sister) with autism?
003 What does autism mean to you?
0031 Where did you get your information; how did you learn about autism?
004 What kinds of feelings do you have about having a (brother/sister) with autism?
005 How do you talk to your friends/classmates/neighbors about (name)?
006 Does (name) affect your social life? (rephrase for younger kids)
(1-no, not really...5-yes, a lot)
007 Has having a (brother/sister) like (name) changed the way you think about other people?
008 What do you hope to do when you get older?
Has (name) had an impact on this decision?

General Category — Family Experiences
009 What kinds of things do you do with (name)?
010 What is your role in the family?
Are you happy with this or do you wish it could be different?
011 Do you feel added pressures because of (name)?
(1-no, not really...5-yes, a lot)
012 How do you think your parents handle having a child like (name)?
(1-not really/bad job...5-yes, a great job)
013 Do you think your parents understand how you feel about your brother/sister?
Do you talk with your parents specifically about being (name)’s (brother/sister)?
014 How do you feel overall about (name) being a part of your family?
015 How do you think things would be different if (name) wasn’t autistic?

General Category — Support Services
016 What sorts of things have helped you through tough times?
(1-I don’t like them...5-I really like them)

General Category — Conclusions
020 What’s the worst thing about having a (brother/sister) with autism?
022 What are your hopes/wishes/fears for (name)?
024 What have you learned from (name)?
025 What have you learned about yourself from being the brother/sister of a child with autism?
026 What do you wish people knew about being a (brother/sister) of a child with autism?
027 What would you tell other kids who have a brother or sister with autism?
028 What’s the best thing about having a (brother/sister) with autism?
Appendix B

Demographic Data Form

Families of Children with Autism
Family Information Sheet

- Parents' names and ages (please include step-parents and any other guardians):
  - 
  - 
  - 

- Marital status of individuals listed above:
  - 
  - 

- Names and ages of all siblings of the child with autism (please indicate place of residence as it relates to the child with autism (at home with the child, at college, etc)):
  - 
  - 
  - 
  - 

- How do you describe the racial or ethnic background of the child with autism?
  - 

- Address:
  - 
    - Length of time at current address:
    - Previous address(es) (if applicable):
    - 
    - 

- Parents' education levels (please check highest attained):
  ☐ High School    ☐ College    ☐ Graduate School
  ☐ Other (please describe)______________________________________

-Parents’ or guardians’ employment (type of work):
  - 
  - 
  - 

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- Are there any other people in the extended family of the child with autism who have autism and/or any other handicapping conditions (please include family relationship to the child):
  - 
  - 
  - 

- Please indicate any services or treatments that your child is currently receiving:
  - Special Education
  - Speech Therapy
  - Occupational Therapy
  - Physical Therapy
  - School Counseling
  - Home-Based Services
  - Medications
  - Special Diets
  - Art Therapy
  - Music Therapy
  - Play Groups
  - Psychotherapy
  - Other (describe) 
  - Other (describe)
  - Other (describe)
  - Other (describe)
  - Other (describe)

- Please indicate any services or treatments that other family members currently receive (include names of family members involved):
  - Individual Psychotherapy
  - Group Psychotherapy
  - Support Groups
  - Special Education
  - Speech Therapy
  - Occupational Therapy
  - Physical Therapy
  - School Counseling
  - Medications
  - Other (describe)
  - Other (describe)
  - Other (describe)
  - Other (describe)
Appendix C

Consent and Assent Forms

INFORMED CONSENT DOCUMENT

Study Title: What’s it like? A study of siblings of children with autism

Investigator: T.J. Nestheide, M.A. (859) 781-9637

Contact Information: Janet R. Schultz, Ph.D. Xavier University (513) 745-3248

You are being asked to allow your child/children (insert name/s) to participate in a project conducted through Xavier University. The University requires that you give your signed agreement to allow your child/children to participate in this project. The investigator will explain to you, in detail, the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask him any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the investigator any questions you may have. If you decide to allow your child/children to participate in the project, please sign below in the presence of the person who explained it to you. You should be given a copy of this form to keep.

This project involves an interview about your child/children's life as a sibling of a child with autism. The information gathered will help teachers, therapists, professionals and other siblings of children with autism to better understand their experiences. The interview will take place in your home, and all siblings will be interviewed separately. Our discussion will be audio recorded and the information transcribed. I will be keeping the information gathered from our interview, but it will in no way be associated with your child/children’s name/s or other identifying information.

There are no foreseeable risks associated with your child/children’s participation in this study. However, some people get upset when discussing personal issues. The potential benefits to your child/children include the opportunity to help others better understand their life as a sibling of a child with autism, and the chance to talk with someone openly about their sibling.

All information gathered will be kept confidential and names or other identifying information will not be associated with responses. Tapes and transcriptions will be kept separately from consent and demographic forms, and no effort will be made to identify the source of any information. Tapes may be used for professional or educational purposes but will at no time be matched with any identifying information. You have the right at any time to refuse to allow your child/children to participate in this study, and you are free to withdraw your child/children from the study at any time without penalty.
I understand also that it is not possible to identify all potential risks in a research procedure, and I believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

______________________________       ________________
Signature                      Date

______________________________       ________________
Witness                        Date
ASSENT TO PARTICIPATE

Study Title: What's it like? A study of siblings of children with autism

Investigator: T.J. Nestheide, M.A. (859) 781-9637

Contact Information: Janet R. Schultz, Ph.D. Xavier University (513) 745-3248

You are being asked to be involved in a project from Xavier University. This form will explain your rights about the project. The person doing the research will talk with you and explain the project and tell you about any possible risks from being involved. Read, or listen carefully, to the information about the study, and if you have any questions please ask the person doing the research. You will get to keep a copy of this form.

This project is about your life with your brother or sister with autism. We will discuss your experiences with your brother or sister and your answers will help other children with a brother or sister with autism, and teachers, doctors and other people who work with kids with autism. We will talk in your home, and if you have other brothers or sisters who are in the study, we will talk to each of you by yourselves. Our talk will be audio recorded and I will keep the tapes. No one will be able to know who is on the tape, and I will not put your name on it.

There are not any risks in this study, but some people may get upset talking about their thoughts and feelings. Your answers in this study could help a lot of other people. All of your answers and other information will be kept secret so no one will be able to identify you or know that you were in the study. You have the right to refuse to be in this study, and you can stop at any time, without any penalty.

I have been told about this study and agree to be in it. I know that if I have any questions at any time I can ask the person doing the research.

__________________________  _______________________
Signature                           Today's Date

__________________________  _______________________
Witness                           Today's Date
Appendix D

Xavier University IRB Approval Form

May 11, 2005

Thaddeus J. Nestheide, M.A.
43 Hollywoods Dr., #3
Ft. Thomas, KY 41075

Dear Mr. Nestheide:

The IRB received your Progress Report on Protocol #0276-4, Experiences of Families of Children with Autism. Your research is approved for an additional year. This approval will expire 5/5/06. Please submit a Progress Report by that date. A form is included for your convenience. The form may also be found at http://www.xu.edu/IRB/IRBForms.

Sincerely,

Robert C. Baumiller, S.J.
IRB Chair and Administrator

RCB:nm

cc: Dr. Janet Schultz, ML 6511

Enclosure: Progress Report

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