Excerpted from *Beyond the Autism Diagnosis: A Professional's Guide to Helping Families* by Marion O'Brien, Ph.D, and Julie A. Daggett, Ph.D.

9

The Rest of the Family

When a child is diagnosed with an autism spectrum disorder, the entire family makes many accommodations to allow the child to participate as fully as possible in family, school, and community activities. These accommodations can take a toll on all members of the family, sometimes leading them down paths they never expected to travel. Although the needs of the child with an ASD initially may seem paramount to parents, exclusive focus on a single family member creates difficulties across the rest of the family system. Therefore, for the well-being of every family member, it is crucial that parents consider their own needs, the needs of their other children, and the needs of extended family members to be as important as those of the child with an ASD.

In this chapter, we examine family issues that often arise when a child has an ASD. We first look at the marital relationship and how it can be placed at risk. Next, we describe the experiences of children who have a sibling with autism. We then consider the feelings of grandparents and other extended family members who are often somewhat removed from the daily life of the family but who may have extensive influence on family adjustment. We also touch on friendships and their importance to parents. Finally, we suggest approaches to dealing with the sometimes intrusive reactions of strangers and acquaintances.

MARITAL RELATIONSHIP

In many families, the roles of mother and father tend to eclipse the roles of wife and husband, at least during the period of time when children are young and need a lot of care. This is even more true in families of children with ASDs, who demand constant attention and assistance. Yet, our experience in talking with families, as well as research into the functioning of families who have children with disabilities, strongly indicates that the kind of intimate support that spouses receive

Brookes Publishing | www.brookespublishing.com | 1-800-638-3775

from each other is extremely important to everyone in the family (Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003). Most professionals who work with children with ASDs have not been trained to provide marital counseling and need to recognize their limitations in discussing family relationships with parents. If parents suggest that their family is experiencing a great deal of stress, it can be helpful to offer a referral to a family counselor. In all situations, professionals who are knowledgeable about the issues couples face when raising a child with an ASD can support parents in their relationship with each other and with their child.

Family Roles

When a child has a disability, it is common for mothers to assume a large portion of the child's care. Frequently, mothers in this situation choose not to be employed outside the home or limit their hours of employment (Booth & Kelly, 1999; Gray, 2002). As a result, fathers assume a greater responsibility for the financial well-being of the family. These decisions about how to divide the family workload are often made on practical grounds, in response to immediate demands, and without a lot of thought about their long-term ramifications. Many couples find themselves in a traditional family pattern (husband employed and wife at home), however, that they had not anticipated and that does not fit their image of their relationship with each other. Furthermore, as the two partners' roles become more separate, each may come to feel unsupported by the other. Mothers who are responsible for the majority of the care and intervention for a child with an ASD can become exhausted with the never-ending demands and be dissatisfied when their husband is not available to provide respite. Fathers who are so worried about the family's financial position that they take on added responsibilities at work or even a second job can also be exhausted and be dissatisfied with the attention paid to their needs at home. Without making judgments about the lifestyle choices parents make, professionals can help parents realize that they *are* making choices that affect all aspects of the family's relationships and can advocate for respite care services to help relieve family stress.

Disagreements Over Services

There are many sources of potential conflict between spouses when a child has an ASD. Conflicting information about types of educational and intervention services and especially alternative treatments may be interpreted differently by mothers and fathers. Often, mothers are the family members who participate most actively in parent support groups and, therefore, hear the stories about validated interventions and "miraculous cures." In some families, fathers may be skeptical about the value of certain intervention approaches. In others, fathers may find it reduces family conflict if they simply withdraw and let their wife be in charge of their child's intervention. Either situation presents many opportunities for miscommunication and a lack of connection between parents. Professionals can promote open consideration of all intervention options by providing families with reliable written information about available services and alternative approaches, as well as by making active efforts to discuss the child's intervention program with both parents. When professionals arrange meetings with families, they can try to schedule them at times when fathers are able to attend or can suggest telephone conferences rather than face-to-face meetings. Many families have access to e-mail, so sending messages to the e-mail addresses of both mothers and fathers can help to ensure that fathers are in the loop.

When families use home-based services, they often find family life to be disrupted. With preschool-age children, it is not uncommon for in-home intervention services to consume 40 or more hours per week. This means that the family has a nonfamily member in the household most of the time the child is awake. For some families, this is a welcome distraction from their own continual focus on and involvement with the child. For others, having an outsider around all the time is intrusive and makes them feel that they cannot relax but must be on their best behavior. Parents need to consider their families' personalities and comfort level in deciding on the type and extent of home-based services. Professionals can help families think through these issues in advance, and they should avoid pressing families to adopt any one particular service model. Parents are the best judge of what will work for their families, and professionals need to trust parents' judgments.

Ways of Coping

Raising a child with an ASD is difficult and requires many adjustments and personal sacrifices on the part of all family members. Often, there are crisis periods that must be weathered, and every parent feels overwhelmed at times. Each family member has his or her own way of coping with stress and challenges. Some people are problem focused in their approach to difficulty, using problems as motivators for action. Others are emotion focused, with a need to express their feelings openly and to be heard. Some people believe their family problems, including those surrounding the care of a child with an ASD, are private and should be kept that way, whereas others are quick to seek support from family, friends, neighbors, their faith community, and professionals. Some individuals find that exercise, yoga, meditation, or massage relieves stress. In responding to a child's ASD, parents may differ in their focus and interpretation of the disorder. As noted in Chapter 2, some will focus largely on what might have been, others on what is, and some on what could be. Fathers and mothers may have differing beliefs about the cause of their child's ASD and the likely prognosis. These different approaches can lead down different paths toward adjustment and suggest different strategies for the family.

When there are differences in the ways spouses approach a situation, the possibility for conflict and misunderstanding is great. Because personalities and coping styles are very difficult to change, the best hope is that couples keep the lines of communication open and talk through their feelings with each other. Again, it is inappropriate for professionals who are not licensed as family therapists to intervene in family conflict. Professionals can help by encouraging parents to talk about their ways of coping with the difficulties they face, listening carefully, acknowledging the reality of these difficulties and the need to find a successful way to cope, and suggesting counseling when it would be helpful.

When Parents Separate

In some families, the stress of raising a child with an ASD combines with other factors to lead to separation or divorce. There has been little study of single-parent families of children with ASDs, but it is reasonable to assume that the difficulties only multiply. In divorced families, it is more common for mothers to have custody of and responsibility for children (Clarke, 1995); it is also more common for single mothers to have fewer financial and social resources than their former husbands. Mothers who are raising children with ASDs on their own especially need support from extended family, friends, community members, and professionals.

Nonresident fathers may find it particularly difficult to maintain a relationship with a child who has an ASD. Often, the father may feel that the child's situation was at least in part responsible for the disruption in the marriage. In addition, ASDs are defined by difficulties with social relationships, and because ASDs have a genetic component, some of these symptoms may be present in the father as well as the child. It may appear that a child with an ASD is not concerned about maintaining a relationship with his or her father. Like all children,

Excerpted from *Beyond the Autism Diagnosis: A Professional's Guide to Helping Families* by Marion O'Brien, Ph.D, and Julie A. Daggett, Ph.D.

however, children with ASDs benefit greatly from consistent contact with people who truly care about them. Following separation or divorce, fathers can be encouraged to develop a regular routine for spending time with their children and to keep to that routine no matter what. Children with ASDs will likely prefer to do the same thing every time they see their fathers, and this consistency will actually help to cement the relationship. Professionals can help to keep nonresident but involved fathers informed about their children's educational program and progress and can make arrangements for father participation whenever possible.

Points to Remember

Mothers and fathers of children with ASDs are also wives and husbands. It is easy for professionals to overlook these important roles in the family and focus entirely on parent–child issues. Recognition of the key support role that each parent plays for the other can help professionals take a broader view of family adjustment.

SIBLING RELATIONSHIPS

Sibling relationships are the longest-lasting family bonds many individuals will have in their lives. Yet, it is also true that there is great variability in how brothers and sisters get along with each other, both during childhood and as adults. Many siblings have wide differences in personalities, interests, values, and career paths. These may be evident early on, so that some siblings almost appear to be from different families. Others develop close relationships that are maintained over their lifetimes. Many factors contribute to the nature of sibling relationships, and an ASD is only one of those factors. Thus, parents who have a child with an ASD cannot assume that any pattern of sibling relationships is standard. Just as in all families, the relationships between siblings will develop individually, outside of parents' control.

This is not to say that parents cannot establish a family environment that encourages respect and caring among all members of the family. Such an environment teaches children much about social relationships in general and family responsibilities in particular. Problems can arise when parents focus on the needs of the child with an ASD to the unintended neglect of the needs of other children or when they insist that siblings assume major responsibilities for care and teaching of the child with an ASD. Professionals who are informed about sibling relationship issues in families of children with ASDs can help families balance their efforts on behalf of all of their children.

Brookes Publishing | www.brookespublishing.com | 1-800-638-3775

Helping Siblings Understand Autism Spectrum Disorders

Autism spectrum disorders are difficult to understand. Many parents have problems grasping the disorder's complex nature, and most people who have not had direct experience with ASDs have inaccurate views of their symptoms and outcome. It is therefore not surprising that siblings of a child with an ASD are often mystified. When confused, children develop their own explanations for events. Frequently, given young children's tendency to interpret events with regard to themselves, they will feel they are in some way responsible for their sibling's difficulties (Harris & Glasberg, 2003). It is therefore important that parents do their best to help children understand how an ASD is expressed in their sibling's behavior.

Siblings need to have ASDs explained to them frequently, in terms that match their current level of understanding. Preschoolers can accept explanations such as, "Gloria doesn't like it when there's a lot of noise. It makes her feel bad and she cries." As children grow, they can learn to relate to the differences between their own responses in certain situations and those of their sibling with an ASD: "Brendan had a really bad time today at lunch, didn't he? He fell off his chair and shouted and kicked the wall and the furniture. He did that because he didn't want to eat what we were having. When he doesn't want something, he doesn't have any other ways of telling us that. You would just say, 'I don't want this,' but he can't do that." As they reach adolescence, siblings can be encouraged to read and learn about ASDs independently and to discuss with their parents what they learn. At each stage, parents often need to take the lead in bringing up the topic of ASDs rather than waiting for children to ask questions. The complexity of ASDs can make it difficult for children to frame questions that they think are acceptable, so they may think the topic is off limits if parents do not introduce it. Siblings may also feel they cannot express their anger when their sibling with an ASD breaks a favorite toy, their embarrassment at the sibling's misbehavior in public, or their wish for a "normal" sibling. Parents who are open and forthright with their children and who accept their fears and frustrations as natural and healthy take major steps toward positive adjustment of siblings (Bauminger & Yirmiya, 2001; Hauser-Cram & Howell, 2003).

Respecting the Individuality of Each Child

When a family includes a child with an ASD, siblings who are typically developing may believe that their needs are not as important or urgent as those of their siblings with ASDs and therefore should not be expressed. Furthermore, siblings of children with ASDs sometimes do not view themselves as having an identity outside of their sibling role. Others may feel the need to overachieve at school or in sports to compensate parents for their sibling's disabilities (Harris & Glasberg, 2003). Even when parents are overwhelmed with the emotional and physical strain of caring for a child with an ASD, they must ensure that all of their children's psychological needs are met. Professionals can help parents understand the need for and obtain respite care so they can spend individual time with each child, investing this time with as much importance as the care and education of the child with an ASD. Time away from the sibling with an ASD is especially important when a child is developing his or her own skills and abilities through school-based or extracurricular activities. When a child with an ASD is in the stands at the softball game, he or she will often be the center of attention. If that child's sibling is pitching a perfect game, that achievement may be eclipsed by the chaos and confusion caused by the child with an ASD. Thus, families can be encouraged to arrange alternate care for the child with an ASD while they attend sports and school events that involve their other children.

Children are particularly vulnerable to being embarrassed in front of their peers, and parents need to be sensitive to these feelings. Parents and professionals can help siblings develop ways of explaining ASDs to their friends in age-appropriate ways and can encourage them to enlist support from and share confidences with close friends. Parents who talk openly about ASDs and accept them as a part of life tend to encourage their children to be open and accepting as well. When children do not feel responsible for their sibling's odd behavior and when they know their own feelings and needs are honored and supported, they are able to develop strong and healthy relationships with others inside and outside the family.

Promoting Positive Relationships

Most parents hope their children will get along and develop strong relationships with one another. Parents of children with ASDs have the same hopes. The research literature on siblings of children with disabilities, and with ASDs in particular, tends to portray these siblings as having adjustment difficulties and psychological problems (Hastings, 2003). By contrast, surveys of adults whose siblings have disabilities indicate that many believe they gained a great deal of compassion and care for others through their childhood experiences (Hauser-Cram & Howell, 2003). Although parents cannot dictate what family relationships will be like, they can promote shared experiences between siblings.

Excerpted from *Beyond the Autism Diagnosis: A Professional's Guide to Helping Families* by Marion O'Brien, Ph.D, and Julie A. Daggett, Ph.D.

Young children usually want to include a sibling with an ASD in their play. The difficulty lies in the fact that the child with an ASD is often not interested in social play, has few and limited play skills, and does not communicate well. Siblings cannot be expected to overcome these difficulties on their own. They need support and help in developing play situations that will engage their sibling with an ASD. Adults who know the child with an ASD well and understand his or her interests and abilities can design games and activities that build on the strengths of the child with an ASD and, therefore, encourage his or her active play with siblings (Hauser-Cram & Glasberg, 2003). For example, one researcher developed an adaptation of a popular children's game that capitalized on the specific interests of individual children with ASDs (Baker, 2000). Not only did the adapted game lead to successful sibling play, but siblings expressed more favorable attitudes about the children with ASDs when they were able to share this activity.

Parents can also take an active role in teaching their child with an ASD specific ways to play with certain kinds of toys. Good candidates are foam or fabric balls; trucks, cars, and a garage; a dollhouse and figures; soft dolls or puppets with some accessories; and other uncomplicated toys that do not require advanced fine motor skills (Harris & Glasberg, 2003). Parents need to spend time with both the child with an ASD and the sibling, developing the same play routine separately with each child. This experience gives the children shared knowledge, or a common base for interaction with a specific set of toys, and will promote successful play. Siblings can also be taught ways to interact successfully with their brother or sister who has an ASD. For example, especially as children get older, they can learn to give clear and direct instructions as to what they want their sibling with an ASD to do and to praise any approximation of the desired response (El-Ghoroury & Romanczyk, 1999; Harris & Glasberg, 2003). The same kinds of teaching interactions that promote learning of all skills in children with ASDs can be used to promote play. Knowing these skills can reduce frustration on the part of siblings as well as increase the level of interaction between children.

Determining Sibling Responsibilities

Although siblings of children with ASDs can participate actively in the life of their brother or sister, they should not be expected to take on major responsibilities for physical care or intervention. Such a role, when it consumes much of the child's free time, upsets the equilibrium of sibling relationships as they are defined in U.S. society. Unlike parent–child relationships, which are hierarchical by their very nature, sibling relationships are parallel in power and influence (Dunn, 2002). When a child has an ASD, the nature of this relationship is altered, although generally not to the extent that one sibling takes over responsibility for the other. In some families of children with ASDs, one sibling is recruited into a caregiving role, becoming the second-in-command (Bauminger & Yirmiya, 2001). In other cases, siblings are expected to be interventionists and handle difficult behavior when it arises (Harris & Glasberg, 2003). Research suggests that siblings who are required to take on such roles tend to be resentful and ultimately to have more adjustment problems themselves (McHale, Simeonsson, & Sloan, 1984).

As siblings of children with ASDs enter adolescence, there are new concerns for parents to consider. A major developmental task of adolescence is the achievement of independence from the family while maintaining connection and closeness. With their increasing maturity, adolescents begin to understand their family's situation in more depth. At this point, most siblings have the ability and desire to take on some caregiving responsibilities for the child with an ASD, and this is an appropriate sign of increasing maturity. A potential difficulty arises when siblings also begin to see themselves as responsible for providing the kind of emotional support to their parents that is more commonly provided by other adults (Harris & Glasberg, 2003). If allowed to travel down this path, adolescents can postpone their own development of independence and autonomy. Parents need to encourage adolescents in their family to explore their own interests and activities separate from the family. Adolescents also have the ability to take a long-term view and realize that their parents will not always be able to provide for their sibling with an ASD. It is important at this point for parents to put into place a long-term care and assistance plan for their child with an ASD so that adolescents do not believe that they are personally responsible for the lifetime care of their sibling. Finally, adolescents who are looking ahead to the formation of their own families may begin to express concerns about the genetics of ASDs and the likelihood that their own children will be affected. As these concerns arise, professionals can refer families to a genetic counselor for information about the potential heritability of the disorder.

Addressing Destructive or Violent Behavior

Probably the most difficult family situation arises when a child with an ASD is consistently destructive or violent. Siblings cannot be expected to control this behavior, nor can they constantly be exposed to situations in which they could be injured. Their belongings need to be kept

Excerpted from *Beyond the Autism Diagnosis: A Professional's Guide to Helping Families* by Marion O'Brien, Ph.D, and Julie A. Daggett, Ph.D.

in a secure location, and their interactions with their sibling need to be closely supervised. Children who are living under these conditions also need a great deal of adult support and guidance, opportunities to express their fears and worries in a safe and open situation, and encouragement to pursue interests and activities outside the family.

When there are other children in the family, parents need to give careful consideration to the appropriate living situation for a child with an ASD who is consistently destructive or violent. Often, these children benefit from a highly structured living environment with 24-hour supervision. Without this level of support, children with ASDs can begin to exhibit violence toward themselves, endangering their own health and well-being. Out-of-home placements are often discouraged given the emphasis on natural environments for all individuals with disabilities, but this societal value needs to be balanced against the safety and psychological health of individuals in a family. Professionals can help families in these situations confront the reality of the needs of all family members and consider alternative placements if necessary.

Offering Support for Siblings

In many U.S. communities, organizations supporting individuals with disabilities organize Sibshops, which provide excellent supports for siblings of children with special needs (Meyer & Vadasy, 1994). Sibshops are based on the idea that brothers and sisters of children with disabilities benefit from knowing other children in the same situation and with whom they can share stories and concerns without seeming different or having to defend themselves or their sibling. Effective Sibshops are organized around fun activities for children of different ages, so they are more likely to resemble an afternoon in the park than a group therapy session. In the context of playing and getting to know each other, participating children can talk about the pleasures and pains of having a sibling with a disability and share their successes and disappointments. Adult leaders also provide age-appropriate information about disabilities and the implications of a sibling's condition. See the Resources section for a web site that lists registered Sibshops around the United States.

Points to Remember

Although there has been a lot of speculation that siblings of children with disabilities experience adjustment problems, researchers have learned that siblings of children with ASDs commonly report benefits

Brookes Publishing | www.brookespublishing.com | 1-800-638-3775

in terms of their emotional well-being and concern for other people. In all families, some sibling pairs develop strong and supportive relationships and others do not. In families of children with ASDs, the same is true. Siblings are most likely to adjust well when their parents adjust well, their parents' marriage is strong and supportive, and the family is involved with all the children. Supports for siblings from outside the family can help children normalize their experiences and share their feelings with others in similar situations.

RELATIONSHIPS WITH GRANDPARENTS AND OTHER EXTENDED FAMILY MEMBERS

Many parents who learn that their child has an ASD are still young enough themselves that they rely on their own parents as important sources of support and information. A diagnosis of an ASD can change the family dynamic and even lead to intergenerational conflict. *ASD* is a relatively new term for a set of disorders that has always been evident but has not been widely recognized. Thus, it may be completely unfamiliar and very confusing to grandparents. If a child is generally functioning well or has relatively mild symptoms, grandparents and other family members may be critical of the family's decision to seek a diagnosis; they may believe that the parents are unfairly labeling the child as having a disability. It can even happen that each set of grandparents blames the son- or daughter-in-law for either over-reacting to what they believe is normal variation in development or just a difficult stage or, if they accept the diagnosis, for bringing the faulty genes into their family.

Young parents in the 21st century are more tuned in to and accepting of individuals with disabilities than are many older people. With increasing visibility of individuals with disabilities and support for the inclusion of all people into the full life of U.S. communities, acknowledgement of differing abilities has become more commonplace. Many of today's parents went to school with children who had special needs. In earlier eras, this was not the case. Disability was stigmatized and treated as a secret. Individuals who had a physical or intellectual disability were either institutionalized or kept at home, largely hidden from sight. Many grandparents were raised in such a social environment, and although they may recognize and value inclusion, they probably also never thought that disability would come to their family. Thus, when parents learn that a child has an ASD, one of their major concerns may be how to tell the news to their own parents (Shea, 1993).

Professionals can help parents by determining, at the time of diagnosis, if this is a concern. If it is, parents can be provided with written information that is presented in an uncomplicated and direct style;

that way, the child's parents are not responsible for interpreting the meaning of ASDs to their parents. Professionals can also be open to receiving telephone calls from grandparents who want to understand more about ASDs and the implications for their family and their grandchild. Professionals who have continuing involvement in the intervention and educational programs of children with ASDs can also help by checking in periodically to find out how family relationships are going. It can be useful to invite grandparents to school so they can see their grandchild interacting with other children and can talk with other parents and grandparents.

Finally, if professionals learn that the diagnosis of ASDs has inserted a wedge into the family, they can help parents think about ways to resolve conflicts. Some grandparents appear to be angry because they are overcome with fear and distress about their beloved grandchild (Glasberg & Harris, 1997). Sharing their fears and sorrow—and maybe even a good cry—with their own children can help to repair hard feelings. Grandparents who live at a distance or do not see their grandchild on a regular basis may simply think that the child is fine and a big fuss is being made over nothing. Their constant criticism can undermine a family's confidence and even cause marital difficulties if blame is placed on one parent. Professionals can provide support and resources to be shared with the grandparents, but this is one situation in which spousal support is probably the most important element in resolving the problems.

When grandparents are accepting and want to help, they can provide an enormously valuable support system for young families. Often, grandparents have more financial resources than parents do, and have a network—or time to find a network—that can help the family locate information and services for the child. Grandparents can visit schools with advance warning, observe the child in the classroom, and provide feedback to the special services staff and principal about the child's performance and needs. Grandparents can provide support for parents during IEP meetings, where their maturity, experience, and status may ensure that their voices are heard, whereas those of parents may not be. Grandparents can provide parents needed respite by taking care of the child with an ASD on a regular basis so the parents can devote time to themselves or to another child in the family. In these situations, grandparents might be encouraged to receive training in the best ways to interact and gain cooperation from the child with an ASD. Professionals who work with families of children with ASDs can provide an important service by offering grandparent workshops on occasion.

If grandparents are often perplexed by ASDs, other extended family members may be even more confused and resistant. Aunts, uncles, cousins, and other relatives may have many questions and concerns, not to mention vast quantities of advice that they wish to offer. Supportive grandparents can play an important role between these family members and the parents of the child with an ASD. Grandparents can make telephone calls, send information, refer others to useful books and web sites, and make notes about the good and bad advice that is received. By serving as "information central," grandparents relieve parents of the emotionally exhausting task of explaining ASDs to everyone and hearing seemingly endless stories about other children who had similar symptoms. Once everyone in the family is informed and has had a chance to adjust to the new reality, the parents of the child with an ASD will also be ready to share their experiences and seek support from those they love.

Families are fantastic, and they are vital sources of love and connection to most of us. For children with an ASD, however, families are best taken in small doses. Many children with ASDs neither function well in crowds nor enjoy physical affection or verbal attention. Thus, family reunions and large holiday gatherings can be disastrous situations for a child with an ASD (Harris & Glasberg, 2003). It is often best for parents to invite small groups of family members to visit their home, so the child feels comfortable and safe, and to prepare their guests for the child's somewhat limited involvement. It can be helpful to obtain the services of a respite care worker who is familiar with the child to keep the child occupied and, if possible, to involve the child's cousins and siblings in an activity while the adults talk or eat. Children with ASDs should not be hidden away or isolated from family, but they also do not have to be in the spotlight at family gatherings.

FRIENDSHIPS

For most people, close friends are key contributors to self-esteem and safe outlets for expressions of negative feelings, such as fear and depression. True friends can be trusted not to share confidences with spouses, co-workers, or professionals working with a child. When parents learn their child has an ASD, they often find themselves cut off from friends. Part of this discontinuity has to do with the emotional distress that many parents feel at this time, and part is related to a lack of time for anything other than finding help for their child. Another big part is a sense of difference, a separation from the way life used to be. It is true that many young parents count as their friends other young parents, and when a child receives a diagnosis of an ASD, the activities that these families used to share may no longer be enjoyable. Interests also diverge. For example, as the father of a child with an

ASD becomes invested in learning about educational programs that fit his child's needs, his friends may not understand why he no longer joins their Friday night poker games. Life has changed, and often it is difficult for old friends to come along.

Many communities have organized parent support groups or have formed parent networks in an effort to promote communication and contact and, thus, to prevent parents of children with disabilities from feeling isolated and alone. These are vital components of some parents' support systems. Other parents wish not to be identified primarily as the parent of a child with an ASD and seek friends who can love and accept their child even if they do not have a child with a disability. Parents must find the way that best fits their needs and vision of the future, both for themselves and for their child.

STRANGERS AND ACQUAINTANCES

Parents of children with ASDs often find themselves in situations where they feel called upon to defend their child and their parenting in public. Most parents whose children have autism have had experiences of being publicly criticized or chastised over their child's behavior. Such events are, at best, awkward, and can escalate into truly unpleasant incidents. Families of children with ASDs, including other children in the family, need a repertoire of responses to the intrusive and inappropriate comments of perfect strangers who are unable to mind their own business. Without such a repertoire, families may find themselves unwilling to take their child out in public, further restricting their own social and personal opportunities.

It is of course helpful for parents who have a child with an ASD to rehearse with the child what will happen during the morning of shopping at the mall, or to practice in advance how to hold mother's hand while standing in line at the post office. But no one can foresee that this is the very day the mascot of the local community college, a huge bulldog, will be at the mall, or that the post office heating system will emit a constant loud, high-pitched sound. It is the unexpected that creates chaos.

One big reason that the difficult or out-of-control behavior of children with ASDs attracts so much attention is that the children themselves do not look different from other children. A child who has a visible disability—who wears leg braces or is blind—elicits empathy and concern. A child who has an ASD, whose disability is visible only as challenging behavior, elicits criticism and blame, often loudly and always rudely. Parents of children with ASDs quickly come to realize that the "fault" in the situation is not theirs nor their child's, but lies in the ignorance of the stranger.

Some parents, wishing to avoid direct confrontation in these situations, print up index cards with a statement describing ASDs and how they affect children's behavior. They can hand one of these to anyone who appears to be building up enough steam to become vocal. Professionals can develop samples of such cards and make them available to parents who prefer this approach. Other parents develop a simple but very professional-sounding statement, such as, "Dorian has a neurological impediment that causes muscular spasms and uncontrolled vocalizations. I'm sure you would want people to be considerate if you had this condition." Fortunately, the thoughtless staring and rude comments of strangers are most upsetting to parents in the early stages of adapting to autism. With time and experience, most parents say that although it still happens, it is less bothersome. Thus, parents should be encouraged to continue to take their child to public places and not to let others' lack of knowledge and courtesy interfere with their lives.

Children also need to know how to respond when their sibling behaves badly in public. Depending upon their personalities and their sociability, children can quite openly defuse adults' criticism simply by smiling and saying, "Morgan has autism. What do you have?" Siblings should not, however, be put in the position of having to defend their family if they are uncomfortable or if the rudeness of others makes them angry. Parents can simply suggest that the sibling, if he or she is old enough, return to the family car, or wait at the front door of the building. When siblings are present during confrontational situations with strangers, parents should make a point of discussing the situation with them later, explaining it, laughing with them over it, and reassuring them that what the stranger says is based on a lack of information and a lack of good sense.

SUMMARY

Professionals who work with children with ASDs tend to see the family through a narrow lens that is focused on that child and his or her challenges. At best, they usually know the child's mother. Given how much is known about the importance of the entire family system—marriage, siblings, extended family—to everyone's well-being, it is time for professionals to expand their view to include all the relationships that affect the child. Professionals who are knowledgeable about family dynamics can help parents prepare for and cope with the impact autism will have on the lives of all members of their family.

Excerpted from *Beyond the Autism Diagnosis: A Professional's Guide to Helping Families* by Marion O'Brien, Ph.D, and Julie A. Daggett, Ph.D.

RESOURCES

Books that Address Sibling Issues

Harris, S.L., & Glasberg, B.A. (2003). *Siblings of children with autism: A guide for families* (2nd ed.). Bethesda, MD: Woodbine House.

Meyer, D.J. (1997). *Views from our shoes: Growing up with a brother or sister with special needs.* Bethesda, MD: Woodbine House.

Meyer, D.J., & Vadasy, P.F. (1994). *Sibshops: Workshops for siblings of children with special needs.* Baltimore: Paul H. Brookes Publishing Co.

Powers, M.D. (2000). *Children with autism: A parents' guide* (2nd ed.). Bethesda, MD: Woodbine House.

Sibshops Web Site

http://www.thearc.org/siblingsupport/sibshops-about

Order Form

BROOKES PUBLISHING • P.O. Box 10624, Baltimore, MD 21285-0624

ABOUT YOU (write in your specialty and check one field that best applies)

Specialty

○ Birth to Five ○ K–12 ○ Clinical/Medical Personnel ○ 4-year College/Grad. ○ Comm. College/Vocational ○ Association/Foundation ○ Comm. Services

Name

Address

○ residential ○ commercial

City State

ZIP Country

E-mail

○ Yes! I want to receive e-mail about new titles and special offers. (Your e-mail address will not be shared with any other party.)

We auto-confirm all orders by mail; please provide an email address to receive confirmation of order and shipping.

Qty	Stock #	Title	Price

Subtotal

6% sales tax, MD only

5% business tax (GST), CAN only

P.O. customers: 2% of subtotal

Shipping (see chart below)

Total (in U.S. dollars)

PAYMENT METHOD

○ Check enclosed (payable to Brookes Publishing Co.)

○ Purchase Order attached (bill my institution)
*Add 2% to product total for P.O. handling fee

○ American Express (15 digits)

○ Discover (16 digits)

○ MasterCard (16 digits)

○ Visa (13 or 16 digits)

Credit card account number __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __

Security code (3 or 4 digit code on back of card): __ __ __ __

Expiration date __ __ /__ __ Signature

Convenient ways to order:

CALL toll-free 1-800-638-3775 M-F, 9 a.m. to 5 p.m. ET.; **FAX** 410-337-8539;
MAIL order form to: Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624:
ON-LINE www.brookespublishing.com

Money-back guarantee! Ordering with Brookes is risk-free. If you are not completely satisfied, you may return books and videotapes within 30 days for a full credit of the purchase price (unless otherwise indicated). Refunds will be issued for prepaid orders. Items must be returned in resalable condition. All prices in U.S.A. dollars. Policies and prices subject to change without notice. Prices may be higher outside the U.S.A.

STANDARD GROUND SHIPPING & HANDLING

(For other shipping options and rates, call 1-800-638-3775, in the U.S.A. and Canada, and 410-337-9580, worldwide.)

Continental U.S.A.[**] territories & protectorates[†]; AK, HI & PR[‡]

For subtotal of	Add*
US$55.00 and under	$6.49
US$55.01 and over	12%

[**]Continental U.S.A. orders ship via UPS Ground Delivery.
[†]U.S.A. territories & protectorates orders ship via USPS.
[‡]AK, HI, and PR please add an additional US$12.00. Orders ship via UPS Air.
Please call or email for expedited shipping options and rates.

Canada

For subtotal of	Add*
US$67.00 and under	$9.99
US$67.01 and over	15%

Orders for Canada are consolidated for shipping twice each month. For minimum shipping time, please place your orders by the 9th or 24th of each month.

**calculate percentage on subtotal*