The Affects of Autism in Families and Partner Relationships

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AUTISM—IT’S A FAMILY THING

It has been estimated that the divorce rate is in the 80% range in families with children who have an autism spectrum disorder (ASD) (Bolman, 2006). Despite high rates of marital conflict, many couples do not reach out for couples therapy. Lack of respite is a major reason. For most, finding a babysitter with whom they can safely leave an autistic child who has toileting issues, little communication skills, aggression and other inappropriate behaviors on a regular basis is difficult (Sicile-Kira, 2004). Another reason is their lack of belief that they will find a therapist understanding of their particular circumstance who can offer any true guidance, thus preferring to use the precious time away from the child to confide in a good friend.

Marital stress around the child usually starts when one or both of the parents realize the child is not developing properly. Couples with a child who does not seek their attention in the usual way (i.e., eye contact, reaching out for or giving affection, seeking comfort when hurt) find it hard not to feel rejected or unimportant to the child. For those whose child develops normally and then regresses around 18-24 months, there is the added loss of the child they knew slipping away. Consider also that a couple looks forward to having a child, and each person had an idea of what the expected child would be like. When the child does not match the expectation, or regresses, there is a loss and anguish felt by the parent not unlike the stages of grief that people who lose a loved one experience (Sicile-Kira, 2004).

Other stages of added stress are getting a diagnosis (family physicians are reluctant to make a diagnosis on a condition, once rare, for which they have no set treatment plan to prescribe); getting services (a constant struggle); dealing with adolescence (sexual development appears, uncontrolled tantrums can be dangerous as the teen gets bigger); and post high school (the realization that few adult services are available) (Sicile-Kira, 2006).

Keeping any marriage healthy takes time, and all too often, time gets swallowed up by the autistic child’s needs. Many children with an ASD have difficulty sleeping, meaning that at least one of the parents is sleep deprived. Usually, a role division takes place as one parent, usually mom, becomes the autism expert, while dad works harder to earn money or opts out. Differences of opinion exacerbate an already difficult situation—how much time, energy and money is to be spent on helping the child is based on personal philosophy, and this is where the couple may clash. Over time, dad becomes frustrated at the demands of the mother to interact or play with a child who does not know how, and moms become frustrated at the lack of involvement of their partners.

As well, a common pattern among moms is to wonder what they did wrong—drinking or taking medications during pregnancy, exercising too much, allowing the child to be vaccinated; thus adding feelings of guilt to an already stressful situation. Also, the couple eventually feels isolated because they feel it is hard to take an autistic child to people’s homes and are uncomfortable inviting people over.

Sometimes the couple becomes closer than ever, bonded in their shared circumstances. Unfortunately, the stress of dealing with autism and all it entails (the constant and necessary advocacy at school, fighting for services and support, added financial burden, trying to handle behaviors and meltdowns at home) becomes a wedge pushing the parents further and further apart. Overwhelmed, stressed and exhausted, the couple’s communication becomes impaired and even autistic-like, lacking emotion and reciprocity. This can affect other children in the family.
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Siblings
The challenges of having a brother or sister on the spectrum can have both positive and negative effects on a sibling. The factors that affect how a sibling adapts include family size, severity of the brother or sister’s impairment, age of the sibling at the time of the diagnosis, gender and age of sibling, and their place in the birth order. The parents’ attitudes and expectations have a strong bearing on how a sibling adapts.

Many siblings develop a maturity and sense of responsibility greater than that of their peers, take pride in the accomplishments of their brother and sister, and develop a strong sense of loyalty. Siblings of ASD children are usually more tolerant of differences in people and show compassion to others with special needs. However, many siblings feel resentment at the extra attention the child with autism receives, and some feel guilty over the well-being of their own health. When young, they may think they can “catch” autism from their sibling. They may also feel saddled with the responsibility of helping their parents cope with the diagnosis. A sibling may seek out a therapist with complaints of a cold, uncaring, and unemotional husband, although she may have chosen her mate because he appeared calm and reliable. As an adult, she might be depressed, divorced, and without the ability to empathize. Other siblings of ASD children are usually more tolerant of differences in people and show compassion to others with special needs. They may be depressed, single, or divorced with necessary support in the way of childcare, financial support, and advocacy. But, they may also contribute to stress because of conflict regarding behavioral symptoms and treatment (Hillman, 2007). Sometimes grandparents also feel the blame-game about the possible causes of the child’s autism, which can be particularly troublesome if the couple splits up and there are disputes over custody.

Grandparents
Unlike the parents who are totally focused on their autistic child’s needs, grandparents are concerned about the effects of autism on their adult children (the parents), other grandchildren and future generations. They also suffer stress similar to that of parents and siblings. Grandparents are concerned about the difficult situations they see their own children experiencing. They may provide the autistic child’s parents (who may be depressed, single, or divorced) with necessary support in the way of childcare, financial support, and advocacy. But, they may also contribute to stress because of conflict regarding behavioral symptoms and treatment (Hillman, 2007). Sometimes grandparents also feel the blame-game about the possible causes of the child’s autism, which can be particularly troublesome if the couple splits up and there are disputes over custody.

Grandparents may want to help by babysitting, but most do not have the training in behavior management or may not have the physical strength required to handle behavior episodes. They may just want to play with the child and spoil him or her, and end up feeling rejected by the lack of typical exchange.

An Asperger Marriage
As an autistic parent has been recognized since 1994, there are many adults with ASD who have been diagnosed and treated for mental illness. Although traditionally three out of four children diagnosed with an ASD are male, there is growing consensus that there may actually be more females with ASD who have been misdiagnosed with other conditions. The following information is based on heterosexual partnerships, although it occurs in same-gender relationships just as it does in the population at large.

Sometimes the diagnosis of an adult follows that of the offspring; sometimes it follows marital therapy; and sometimes problems at work finally force a diagnosis. A partner may seek out a therapist with complaints of a cold, uncaring, and unemotional husband, although she may have chosen her mate because he appeared calm and reliable. As an adult, she might be depressed, divorced, and without the ability to empathize. One of them is anger at missing out on a aspects of a marriage to which the partner was looking forward. Another feeling is relief that the partner is not trying to shut the other one out, he is just unable to provide the emotional response needed (Slater-Walker & Walklin, 2002). For children, the reaction is similar. The positive aspects of having a spouse with Asperger’s can include the realization that they are in most cases loyal, honest, and dependable. Those who are diagnosed as adults who knew they were different feel empowered and relieved once they receive the diagnosis, as now they have a starting point for finding strategies that are helpful (Carley, 2008).

How Therapists Can Help
There many ways in which therapists can help the family unit with an autistic member. For help to individuals who need more information, or need access to a support group, the Autism Society of America has local chapters that can be helpful (see the resource directory in this issue). Couples need to be encouraged to acknowledge and face the emotions of the grief cycle (i.e., denial, grief, depression, anger) and the loss of the child they were expecting, and to work through these emotions. Misdirected anger is often released at school personnel in Individualized Educational Program (IEP) meetings or taken out on service providers, thus alienating the very people who are there to help.

Encouraging couples to regularly schedule time together without the children is important. However, this suggestion is useless unless there is support for the partner to whom the child is the top priority. The positive aspects of having a spouse with Asperger’s can include the realization that they are in most cases loyal, honest, and dependable. Those who are diagnosed as adults who knew they were different feel empowered and relieved once they receive the diagnosis, as now they have a starting point for finding strategies that are helpful (Carley, 2008).

Finding out that a partner has an ASD can provoke different feelings. One of them is anger at missing out on aspects of a marriage to which the partner was looking forward. Another feeling is relief that the partner is not trying to shut the other one out, he is just unable to provide the emotional response needed (Slater-Walker & Walklin, 2002). For children, the reaction is similar. The positive aspects of having a spouse with Asperger’s can include the realization that they are in most cases loyal, honest, and dependable. Those who are diagnosed as adults who knew they were different feel empowered and relieved once they receive the diagnosis, as now they have a starting point for finding strategies that are helpful (Carley, 2008).

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the age level necessary, and suggest children’s books which are available on ASD. The sibling may also benefit from joining a support group for siblings of special needs children. This can be extremely beneficial in helping the child realize they are not the only one going through this.

Siblings need to be reminded often that they have just as much of their parents’ love as their autistic sibling, even if parents may need to give more time and attention to the brother or sister with autism. It is important that the non-autistic sibling have a private, autism-free zone to call their own, and a secure place to keep their precious objects. They also need to see that the sibling with ASD is given consequences if he wrecks their things, and that he is expected to improve his behaviors over time.

In a partnership between a person with Asperger’s syndrome and a non-autistic partner, each partner must recognize the differences they have and why. If the partner with AS refuses to acknowledge that his behaviors and actions have and why. If the partner with AS refuses to acknowledge that his behaviors and actions are unacceptable, then there is little hope for the relationship.

Understanding the deficits, reinforcing the strengths, and acknowledging the needs of each partner is helpful. Teaching the willing AS partner behaviors that are important to the partner is effective. My research indicates that those willing to learn can be taught expected behaviors and strategies. Some of these include teaching the “hidden curriculum” (i.e., what non-autistics automatically learn and take for granted, making lists for visual learners). For more social competence at work, having a mentor there who can explain the non-autistic expectations, and writing a list or drawing a map of the hierarchy and expected communications at each level can be well worth the effort. The Global and Regional Asperger Syndrome (GRASP) is a good online network for people on the spectrum; information for partners and families can be found at Asperger Syndrome Partners & Individuals, Resources, Encouragement and Support, and Families of Adults Affected by Asperger’s Syndrome. All of these resources are included in the directory at the back of this issue.


References

Sicile-Kira, C. (2004). "I definitely believe the service has enhanced my practice. People who use the service tell me that they appreciate being able to get an idea of my background and areas of expertise." Nancy K. Gardner, Ph.D.