

**High Functioning Autism/Asperger Syndrome: DIAGNOSTIC DILEMMAS AND  
IMPACT ON THE FAMILY**  
**By Sarita Freedman, PhD**

Whether a child receives a diagnosis of Autism or Asperger Syndrome, it changes that child's family forever. The level of impact on each individual family—parents, siblings, grandparents, and extended family members—varies tremendously. However, I've never worked with a family where there has been no change as a result of their child's diagnosis and the resultant, inherent difficulties that ensue for everyone involved. It has been my experience that in most cases, however, children with HFA/AS can bring a tremendous amount of joy to their families. From their child or children on the "spectrum," their families learn about the miracles of development—much more so than many families of neurotypical children. And if the family can stay intact and "weather the storms" of HFA/AS, they come out of it with a unique sense of inner strength and unity that I have not encountered in many other families.

The HFA/AS diagnoses are often lumped together by many professionals and non-professionals. In diagnosing adults, the differences do appear to become less clear, and making diagnostic distinctions is difficult because the diagnosis is based on early development. For example, most parents cannot remember what type of infant and toddler their son or daughter was when they are now 47 years old. What was their language like? How did they play with other children, did they have friends? Forty-seven years ago, a child with HFA or AS might have simply been viewed as "mentally retarded, lazy, shy, or different." Without any *glaring* symptoms our past ability to identify and provide for these individuals was very limited.

In a recent review of the literature, I have found little that addresses the emotional impact on the family, specifically related to HFA versus AS. There are many important issues, and this paper will address them from this author's perspective. The following areas impact families (marriages, siblings, extended family members): onset of symptomatology, time of diagnosis, clarity of diagnosis, uncertainty about prognosis, personal associations, acceptance in the community, education concerns and co-morbid (other medical or psychiatric) conditions and their treatment.

**Onset of Symptoms, Clarity and Time of Diagnosis**

In most cases, the onset of symptoms in children with autism appears much earlier than in children with AS. Even in the mildest of cases, a good diagnostician can sometimes detect symptoms of autism in babies as young as 15 months. The struggles that most families initially face revolve around finding an individual to validate the parents' perceptions and recognize their child's symptoms as important enough to make an appropriate referral. The pediatrician is usually consulted first, and often parents are told not to worry. Fortunately, pediatricians are becoming better educated about developmental disabilities in general. Being told not to worry creates doubt and confusion in

parents about their perceptions, which in fact, are usually quite accurate. It also delays the diagnostic process sometimes for several months, even years, especially because no parent wants their child to have delays. There is an unconscious collusion oftentimes between parents who fear the truth and professionals who are naturally uncomfortable relaying “bad news” to parents. Hopefully within 5 years all pediatricians will be routinely screening for Pervasive Developmental Disorders as a general practice when a child is two years old. My advice to parents who have been told not to worry, is to trust your instincts and get a second and third opinion if you have to. It is current public knowledge that early intervention leads to better prognosis.

Early diagnosis can be traumatic for many parents and their families. However, the “hope” and good fortune of having discovered the problem early on often mitigate some of the family’s worst nightmares. Nevertheless, most families experience loss and grief, denial, general discord, and fear about the future. A diagnosis of HFA does not preclude conjuring up old stereotypes of autism—head banging, rocking, institutions—these are terrifying images. However, in many cases parents are relieved to have a diagnosis, to know that there is in fact, something—it has a name, there are treatments for it, and many parents feel as if now they have a direction. Knowledge is always more empowering than helplessness.

No matter what the family’s reaction is, they know deep down that their lives will never be the same. I always encourage families to seek professional guidance and refer them to support groups following the initial diagnosis so that they do not feel alone, ashamed, lost, and so they can begin early on to connect with other families in their same position. Often this is one of the most healing experiences for a family. Most families of children with autism are receptive to this idea, although some may not be ready right away.

Hopefully, the time of diagnosis in autism occurs at least by the time the child is three, if not earlier. The clarity of the diagnosis is fairly certain, given a good diagnostician with extensive experience in this area. Parents’ reactions are mitigated by these factors, although they may seek several different opinions. What is most important for parents to hear from the diagnostician is the importance of early intervention. For me the most unfortunate situations arise when parents desperately seek (and find) another opinion—primarily one that negates the diagnosis—and lose precious time, sometimes even one year or more. Unfortunate for the child, but more importantly, parents later feel a tremendous sense of guilt over having “lost” this time.

Conversely, the onset of AS symptoms occurs in a somewhat different pattern, and there are not as many diagnosticians familiar with the diagnosis so it may be difficult to attain. Many of the child’s “symptoms” initially appear to be personality styles/quirks. Most children with AS are quite verbal, which throws many parents and diagnosticians off. Especially at an early age, their special interests may include age appropriate toys such as cars, planes, trains, bugs, etc. Although they may appear excessive to the family, parents hear from other

parents that their children also love to watch their favorite videos over and over. Nevertheless, most typically developing children do not use the scripts from their favorite videos when interacting with other people. They aren't necessarily "married" to their favorite video/subject inasmuch as everything they talk about, do, or have, **has** to be related to their favorite video/subject. Thus, an early diagnosis of AS is rare. The average age of diagnosis for most children with AS is approximately 7 years (Klin, Volkmar, & Sparrow, 2000).

Without an early diagnosis, families of young children with AS ultimately make many accommodations in their home and lifestyles. The child's rigidity and intense focus on special interests may become more and more disruptive to the family, although I am continually amazed at how very adaptive some families can be. Ultimately, either the child's unusual interests, behavior and/or the child's more obvious social difficulties, set in motion the family's search for specialists. However, until this point, the family has believed that their child is "normal."

Although a diagnosis of AS is definitely a shock to the family, it is a relatively "new" syndrome, and its association with autism is somewhat of a conundrum because those stereotypical images don't fit most AS children. This makes it somewhat more palatable. In my experience, when I tell a family that AS is related to the spectrum of autism, the family feels confused because their child in no way fits that image. Parents often fear that their child will suddenly become "autistic," but once reassured that this is unlikely and that the prognosis is usually quite good, parents of children with AS typically feel more hopeful. There is also another advantage that these families have, and that is that not many non-professional people have ever heard of AS, so when a family prepares to tell others about it the impact is not as strong as if they had to use the "autism" label.

In my experience, parents of children with AS may not initially be as receptive to counseling and support groups. I believe that this occurs first of all because they have spent so many years accommodating to their child and believing that their child's is "normal." Furthermore, it takes parents of an older child time to get adjusted to the implications of this diagnosis. Finally, many parents have expressed concerns about joining family support groups because they fear that their child's functioning level may not match the functioning levels of the other children, and thus they will not get anything out of it.

For both sets of parents (HFA and AS), I believe there are two main areas of impact: the loss of the child they dreamed they would have, and pain about their child's current and potential difficulties in the world. There is a natural grieving process that occurs, after which parents still don't know what to dream of for their child. No one can predict what the prognosis will be. At some point, most parents re-evaluate their preconceived notions about what is "normal" to them and what appears to be acceptable to their child. One father wrote that his son with autism is "completely content and forever happy with his life" (Tsai, 2000, p. 204). However, that life may not be what parents envisioned.

The lessons parents of children on the spectrum have reportedly learned from their experience are profound. Dr. Tsai wrote that his son “seems to remind me that I have been driven and controlled by individualism, materialism, and sensationalism...[his] total dependence on and trust in me teaches me an important human relationship...challenges me to see that compassion is the only way to fulfill our human vocation...to give my love when I am strong and to receive the love of others when I am weak” (Tsai, 2000, pp. 204-205).

### **Marriage, Family, Sibling and Community Issues**

The effect of a diagnosis of HFA/AS and the child's lifelong difficulties pervades the marriage, siblings, and extended family. Unfortunately, the divorce rate among families of children with autism spectrum is higher than among families of children with other disabilities. Factors that complicate a marriage may include guilt and blame—either self-blame or one spouse blaming the other, denial, financial burdens, parenting issues.

Guilt and blame significantly impact the marital relationship. There is “genetic blame”—whose side of the family did this come from. Self-blame is related to past personal indiscretions as being causal. In turn, partners may each feel a sense of guilt about their own possible genetic contribution and may also feel as if they are being punished for past indiscretions. Guilt and blame are destructively divisive and should be dealt with early on in the diagnostic process, usually with professional guidance. They crop up periodically throughout the child's life, and if the partners can learn to deal with them effectively they will not continually chip away at the individuals' and the relationship's evolution.

The subtler the child's symptoms, the more denial families tend to experience. Denial negatively impacts the family and marriage in many ways. Primarily, when one parent is in denial, s/he leaves their partner in the situation alone. The unsupported partner lives with a tremendous amount of stress but pushes forward nevertheless. The unsupported partner suddenly feels like a single parent in an extremely difficult situation. This is not what either partner bargained for, that is for sure. A marriage cannot be sustained in this manner.

Financial burdens also place stress on the marriage. It is difficult to have a child on the spectrum and not incur unexpected and significant financial expenditures. Furthermore, it is difficult to sustain a two-income family with a child on the spectrum because of the child's need for additional services either before or after school.

Finally, parenting issues impact a marriage in that consistency is important and most often the primary working parent, by necessity, cannot take part in the child's therapies. The burden falls on one parent to “instruct” the other parent based on what s/he has learned from the professionals. This engenders a variety of emotional reactions in the working parent. All of the above factors occur in varying combinations and intensities, further complicating the picture.

If there are no siblings, the couple is faced with the decision of whether or not to have another child. Many couples are driven to do so because they so desperately want to fulfill their lost fantasies of having a "typical" child. Many couples fear having another child on the spectrum and decide against it. Finally, some couples have another child prior to their first child's diagnosis. After the diagnosis, they live in fear of whether the second child will also have a spectrum disorder.

When there are already siblings the disruption of the sibling's personal space and belongings by a young child who does not understand boundaries, is unable to read social cues, and is biologically unable to control his/her impulses, feels intrusive. They often feel embarrassed by their sibling's behavior, especially in adolescence. Siblings typically spend much of their time in waiting rooms and may often feel it is their responsibility to care for their sibling—a burden that can elicit resentment and derail the sibling's natural course of emotional development. This occurs when siblings take on roles that they are not developmentally prepared for (Kremen, personal communication). When the sibling relationship is properly sustained, it is often the child's siblings who make the greatest difference in the child's life. Siblings have written the following: "Having...as a brother has helped me to develop a strength of character that I believe would be lacking if he had not come into my life...taught me to never underestimate the power of optimism and hope...[and] that labels are quite meaningless when it comes to predicting the ability of people to create magical and powerful lives" (Donnelly, et. al., 2000, p. 199).

Extended family plays a pivotal role. If they can accept the diagnosis without blaming the child's parents, they can be a source of strength and support for the family. However, extended family members may take longer to reach a point of acceptance. Acceptance for family members of AS children may be easier than for those of HFA children because the child's profile does not match up with the old stereotypes associated with autism. This may also be the case for children diagnosed with HFA, although their symptoms can eventually be recognized as "watered down" versions of the behaviors associated with classic autism. On the flip side, the more subtle expression of both HFA and AS symptoms may make it more difficult for extended family to accept, which may result in extended denial and blaming child's parents for the child's misbehavior.

Parents face their own sense of loss, and they feel pain around the difficulties their child faces. Grandparents face the loss of the grandchild they imagined they'd have, and also feel the pain and suffering their own children face as parents of a child with autism spectrum. Other family members may experience these emotions, and may also feel a form of survivor guilt if their children are neurotypical.

Finally, the family's perceptions of their child's acceptance in the community can lead to isolation. Although in both HFA/AS they know their child is bright, sometimes unusual habits and behavior problems can cause a family to avoid public places. However, in many cases both sets of families do not typically

experience the type of social isolation that families of children with classic autism face.

### **Co-morbid Conditions**

The literature is ripe with other medical conditions that often accompany autism spectrum disorder. These conditions are referred to as "co-morbid" conditions, and their expression can be mild to severe, regardless of where the child's level of autism spectrum lies. It is not uncommon to find any of the following conditions co-existing with autism spectrum disorders. Please note, however, that mental retardation, Fragile X, Tuberous Sclerosis Complex, and Down Syndrome, are more serious conditions usually associated with some level of mental retardation. By definition, an individual who falls into the "high functioning" end of the spectrum would have average to above average intelligence and cognitive ability. Obviously, the existence of some of these other conditions would impact any family, with the level of impact being dependant on the severity of the condition, and on the level of interference in the child's and the family's life.

- ❑ Mood disorders
- ❑ Anxiety disorders
- ❑ Seizure disorders
- ❑ Otitis Media (chronic ear infections)
- ❑ Attentional difficulties (not typically true ADHD)
- ❑ Regulatory dysfunction
- ❑ Nonverbal Learning Disability (NLD)
- ❑ Obsessive Compulsive Disorder (OCD)
- ❑ Tourette's Syndrome
- ❑ Mental retardation
- ❑ Fragile X
- ❑ Tuberous Sclerosis Complex
- ❑ Down Syndrome

### **Education issues**

All families of special needs children are exposed to undue stress resulting from the need to advocate for their child's education, and to acquire and retain other necessary services. For families of individuals with high functioning autism or Asperger Syndrome, the stress level appears to be higher as a result of a lack of knowledge and substantiated research in the field as to the most effective methods to educate these individuals.

Another roadblock that all families of special needs children face relates to the expectations and understanding of the family versus the school district's ability and willingness to provide the type of programming that the child's parents believe would benefit the child most. Special education law states that a school district must provide a child with "FAPE," a free and appropriate education. Not the BEST, but what the district deems is appropriate. This determination varies

from district to district, and even from school to school within a district. Typically districts resist providing what has recently been supported in the literature as the most appropriate and successful treatments for a variety of reasons. This need to advocate, or what is sometimes felt as "fight" for one's child, including the need to hire attorneys and supplement with their own finances the child's public education with services that the parents believe are important but the school district is unwilling to fund, creates undue stress on the family. Considering how difficult it is to maintain a two-income family once a child has been diagnosed, these emotional and financial burdens weigh heavily on the family. Furthermore, the family must always focus on making the determination about which therapies would be most effective for their child and also consider the need to create a balance in the child's life between therapies, leading a regular childhood, and sufficient family time. In the understandable frenzy to secure as many services as possible to treat the child's autism, what families sometimes lose sight of is that their child is first, and foremost a child. Not only does the child need time to be a child, but the child's family must also allow themselves time to enjoy one another. The balance between services and family down time is often lost in many families of children with autism spectrum disorder, no matter what the child's functioning level.

Autism spectrum disorders create a situation for families that is out of the realm of normal experience. Clearly the most important factors that lead to positive outcome include family support, appropriate intervention for the child, and maintaining healthy family relationships. Often times this will require professional help, not only for the child but also for significant family units. It is my firm belief that if only by virtue of sharing the burden, families who learn to accept assistance feel generally less burdened than families who are more isolated, and this is supported in the research literature. If you have a child with autism spectrum, do not feel embarrassed or ashamed to ask for help, from anyone. Reaching out will only help you be better able to reach your own inner strength.

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