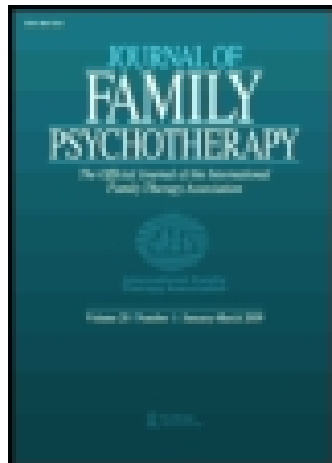


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Supporting Families Dealing with Autism and Asperger's Disorders

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INTERVENTION INTERCHANGE
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**Supporting Families Dealing with Autism
and Asperger's Disorders**

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Autism and related disorders are becoming more common (Centers for Disease Control and Prevention [CDC], 2009), and family therapists are likely to encounter families with a member with some form of this disorder. The parents of children with these disorders often need considerable support in terms of information and intervention because the disorders are lifelong and multifaceted. In addition, autism has impact on the family as well as the individual, and so there is a growing need for family-centered intervention and support services (Lozzi-Toscano, 2004). Family therapists can play an important role in helping to ease the stress that accompanies life with autism. Autism is a complex disorder, and its treatment requires attention to many facets. Thus, rather than focusing on a specific intervention, this brief article discusses components of treatment important for individuals and families dealing with autism spectrum disorders (ASDs). The article touches on issues of prevalence and diagnosis of autism and then focuses on basic needs of families dealing with an ASD, including family-based treatment.

WHAT IS AUTISM? DEFINITIONS AND PREVALENCE

Autism is a lifelong, neurobiological developmental disorder. Autism is marked by impairments in social interaction and communication, possible impairments in cognitive functioning, and often impairments in fine and gross motor skills. The signs and symptoms often differ greatly from person to person, and the disorder in one person can seem very different from the

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disorder in another because symptoms may be manifest in varying degrees. The CDC indicated in 2007 that autism occurs in 1 of 150 children in the United States, but 2009 estimates indicate that roughly 1 in 90 U.S. children ages 3 to 17 have a type of the disorder (CDC, 2009; National Institute of Mental Health [NIHM], 2009). Autism is approximately four times more common in boys than girls (CDC, 2009). It affects individuals differently and to varying degrees. For this reason, the term *autism spectrum disorders* (ASDs) is used. Autism is also known as *pervasive developmental disorder* because of its impact on many areas of functioning (NIMH, 2009). The most common pervasive developmental disorders tend to be Asperger's disorder and autism.

Asperger's disorder and autism are seen as two different disorders on the same spectrum. However, there is now evidence that the two disorders are not *qualitatively* distinct but are different *quantitative* manifestations of the same disorder (Sanders, 2009), that is, the disorder may only differ in terms of severity. Perhaps the most important distinctions for general clinicians to keep in mind are the differences between Asperger's disorder and autism. Asperger's is typically the least severe of the ASDs. Like autism, it is characterized by impairments in social skills and interactions, repetitive routines and interests, difficulty in interpreting nonverbal communication, and often clumsy motor skills (National Institute of Neurological Disorders and Stroke [NINDS], 2009). However, the severity of these symptoms is less than with autism.

A person with autism has difficulty in social interactions (e.g., lack of social or emotional reciprocity), struggles to engage in reciprocal conversation, and usually has few if any friendships. Regulating emotion can be difficult for those with ASDs, and outbursts or behavior problems can result from this difficulty (NINDS, 2009). Those with more severe autism may never develop speech, or may lose the ability to speak, and language comprehension is often delayed (American Psychiatric Association [APA], 2000). Autism can include cognitive impairment (as opposed to Asperger's, which is characterized by normal or even high IQ; Sanders, 2009). The focus on repetitive behaviors (e.g., body movements, hand flapping) and repetitive and narrow interests and activities is more marked than with Asperger's disorder. Autism often includes sensory sensitivities, so sounds may be too loud, touch irritating, and interactions overwhelming.

Screening and Diagnosis of ASDs

A person with an ASD is more likely to already be diagnosed if the symptoms are evident. There is evidence that professionals such as pediatricians and family therapists often miss or mistake ASDs—especially when the symptoms are not severe (Carlson, McGeorge, & Halvorson, 2007; Whittingham, Sofronoff, Sheffield, & Sanders, 2008). High-functioning autism

or Asperger's, which may be the same (Ritvo, Ritvo, Guthrie, & Ritvo, 2008), may be mistaken for common behavioral or academic problems (e.g., rebellion, stubbornness, poor grades). To further cloud the issue, depression and anxiety occur more often than average in individuals with ASDs and their family members (Drahota, 2009; NINDS, 2009). To ensure proper diagnosis and treatment, periodic screening of children's normative developmental milestones is recommended (CDC, 2009).

For children up to 5 years old, a general screening tool such as the Ages and Stages Questionnaire (ASQ, 3rd edition; Bricker & Squires, 1999) may be used. The Parents' Evaluations of Developmental Status (Glascoe, 1997) also helps identify children with developmental delays. Assessment tools specifically for autism include the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 2001) for toddlers 16 to 30 months, the Social Communication Questionnaire (SCQ; Eaves, Wingert, Ho, & Mickelson, 2006) for children 4 years and older, and the Autism Diagnostic Interview (ADI-R; Lord, Rutter, & Le Couteur, 1994) for children up to 10 years. The Ritvo Autism and Asperger's Diagnostic Scale (Ritvo, Ritvo, Guthrie, Yuwiler, et al., 2008) is for use with adults.

TREATMENT COMPONENTS

Whether the diagnosis comes as a surprise or as the result of a long search for an accurate diagnosis, the process of treatment can be difficult in terms of emotional toll for the family and the diagnosed individual. ASDs are multifaceted, and treatment should likewise be multifaceted, which typically means assembling a treatment team of various providers. Finding, accessing, and paying for services can be difficult, and parents often need education about ASDs, guidance in accessing services and treatment, and continuing support. Treatment must be tailored specifically to each individual. Following are important types of intervention and support that family therapists can offer.

Provide Education

The first and most pressing need is for reliable information about ASDs, especially those whose children are newly diagnosed (Hillman, 2006). Family therapists can play an important role in providing education for parents of children with an ASD and in linking parents to other knowledgeable professionals. Helpful information includes typical signs and symptoms of the ASD (even though each case differs), and treatments such as social skills training (for Asperger's and autism), and applied behavior analysis (ABA) and educational interventions such as TEACCH (Mesibov, Shea, & Schopler, 2004) for those with moderate to severe autism. Locating developmental

pediatricians and psychiatrists who have knowledge of and experience with ASDs is important. Education about pharmacological and dietary interventions is also needed. Local universities sometimes have programs for children with ASDs through departments of special education, psychology, or psychiatry.

INTERNET RESOURCES

A wealth of information is accessible through the Internet, and family therapists can guide parents toward credible sources based on empirical findings. Two different institutes within the National Institutes of Health have Web sites devoted to information on ASDs: www.nimh.nih.gov/health/publications/autism (the NIMH publication on ASDs) and www.ninds.nih.gov/disorders/autism and www.ninds.nih.gov/disorders/asperger (sites from the NINDS). These sites provide information on definition, prevalence, and diagnosis and on treatments, prognosis, and research programs on ASDs. The Autism Society of America (www.autism-society.org) is the nation's largest grassroots autism organization. Using the *autism community* link, local chapters can be found throughout the United States. These chapters are volunteer-led by parents and provide information on ASDs and on services specific to local areas. Local chapters often form important support networks for parents and families. Other sites such as www.autismeducation.net provide information on best practices in treatment options and provide links to many other sites such as the Autism Research Institute (www.autism.com/ari), a major group of professionals and parents devoted to empirical research of ASDs.

Help Parents Assess School-Based Services

The school system is typically a key system for access to services. The Individual with Disabilities Education Act (IDEA) of 2004 is a federal law and funding stream that mandates early intervention and special education services to children with disabilities (see the U.S. Department of Education's site, <http://idea.ed.gov>; U.S. Department of Education, 2009). Thus, to some extent, diagnosis and some treatment may be offered through the school, including counseling, social skills groups, and occupational therapy. IDEA requires that the school create an individualized education program (IEP) for each student diagnosed with an ASD. This plan specifies modifications tailored to the individual needs of the child and sets discrete goals in terms of cognitive development, academic achievement, and social interaction. Of course, schools differ in staffing and in training in interventions relevant to those with ASDs; thus, there is wide variation in services offered and modes of delivery.

Families may need additional therapeutic support not available through the school. Moreover, parents are frequently in the position of advocating

for their child and may benefit from professional support in identifying and insisting on services from the school and from other sources not currently available through the school. Parents may also benefit from help in devising strategies for educating teachers, classmates, and neighbors about the ASD or in thinking through the rationale of not doing so.

Provide Systemic Family Therapy

Treatment for ASDs should address the main areas of deficit, including social and communication skills, and mood disorders and repetitive routines (NINDS, 2009). Family therapists are often well trained in providing these treatments. Treatment should be tailored to specific needs. In cases of more severe symptoms, individualized treatment is often administered through specialized programs, with schools, clinics, and agencies providing adjunctive services. In cases of milder symptoms, treatments are more likely to be offered by professionals through schools and family treatment centers. Regardless of severity of the ASD, the systemic and contextual understanding of a family therapist can be used to help families understand and navigate the complexities of the treatment team. Moreover, the treatments commonly offered by family therapists constitute an important facet of the treatment for an ASD. The neurological limitations innate to ASDs may require slight modification to common treatments, but several are appropriate for these disorders.

IMPROVE ADAPTIVE BEHAVIORS

Children with ASDs may be referred due to behavioral problems. Research suggests that parents may attribute ASD-related behavior to intentional misbehavior (Whittingham et al., 2008). In the case of mild autism or Asperger's, family therapists can help the individual to recognize negative emotions, expand array of behavioral choices when frustration and anger occur, and take advantage of the resources available to them (e.g., time away, modes of prosocial conflict resolution). Individuals with moderate to severe autism typically need relatively intensive and sustained intervention such as ABA or other behaviorally based interventions. Parents' involvement in this treatment has long been advocated (Benson, Karlof, & Siperstein, 2008), and more programs for children with autism are training parents to do this therapy at home (NIMH, 2009). Behavioral interventions are also effective in reducing repetitive and restricted behaviors (Hillman, 2006).

PROVIDE SOCIAL SKILLS TRAINING AND ADDRESS MOOD DISORDERS

ASDs are characterized by deficits in interpersonal interaction among family members, peers, and teachers. Thus, training in social skills is usually needed and is particularly appropriate for children with high-functioning autism and

Asperger's. Such children may need services beyond those offered through school and may benefit from outside support in developing and practicing social skills. An advantage to family therapy is that interpersonal skills may be fostered in conjunction with the whole family, and therapists can facilitate the transfer of these skills to peer interactions. An important modification to typical social skills training is additional practice in reading emotions expressed through verbal and nonverbal language and other issues like recognizing idiosyncratic figures of speech. Social skills groups can provide additional in vivo opportunities for practice. Role plays of social interactions are useful, as is training parents to role play such interactions. It is beneficial for the child to interact regularly with typically functioning children (Baker, Wang, & Walberg, 1994).

Training in social skills is important for those in mainstream school because children with ASDs may have difficulty picking up on and deciphering verbal instructions. Therapists can help parents remember that poor management skills are not intentional and can strategize with the family about methods of communication in the class (e.g., use written instructions, sit close to the teacher) and facilitate communication with the special education staff and with teachers outside of class (e.g., through daily planners, regular e-mails, or even via the school's peer tutoring program). Ultimately, however, children in mainstream or inclusive settings need help in developing the ability to successfully interact socially and discern instructions.

Individuals and families dealing with ASDs are relatively more likely to have depression and anxiety (NINDS, 2009); for example, there is evidence that anxiety affects one third of those with ASDs (Drahotá, 2009). Common therapeutic models can be effective for these problems (e.g., cognitive-behavioural therapy, solution-focused brief therapy). Those with Asperger's disorder have normal to high levels of intelligence (Sanders, 2009) and thus may be very aware of ways in which they are socially different. Depending on the situation, treatment of the mood disorder may include techniques such as social skills training, externalizing symptoms, reframing situations, and strategizing behavioral solutions individually and among family members. In addition, antidepressants are sometimes used to treat depression, decrease anxiety (e.g., paroxetine), decrease repetitive behaviors, and treat sleeplessness.

PROVIDE THERAPY TO FAMILY MEMBERS

Families may present with a variety of issues surrounding the ASD. Family therapists may help the family respond to the grief and confusion of the diagnosis, as it becomes clear that one of the family members will be carrying a lifelong disability. Couple therapy may be indicated due to the stress inherent to parenting a child with an ASD (Abbeduto et al., 2004). Family

therapists can help siblings know more about autism, strategize in dealing with the daily stress of living with a sibling with an ASD, and allow the sibling to talk openly with a nonparent about the challenges of living with a sibling with an ASD (Hirakawa, 2004). Family therapists can facilitate conversations with the diagnosed child about the implications of their disorder, as the child is ready and developmentally able. Many with ASDs become aware of their abilities and disabilities relative to other children, and it is important that parents and other responsible adults give them accurate information about the disorder in straightforward terms and allow them to question, grieve, and adjust gradually.

ASDs have impact on the family as well as the individual, and family therapists can provide important facets of treatment for all who live with an ASD. Caring for and coordinating the treatment for a child with an ASD is demanding to the point that parents may feel chronic trauma, develop aspects of hypervigilance, and may feel further traumatized rather than supported when help is offered (Alvarez & Reid, 1998). Naturally, any family treatment must give attention to the therapeutic relationship and the specific needs of the family.

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