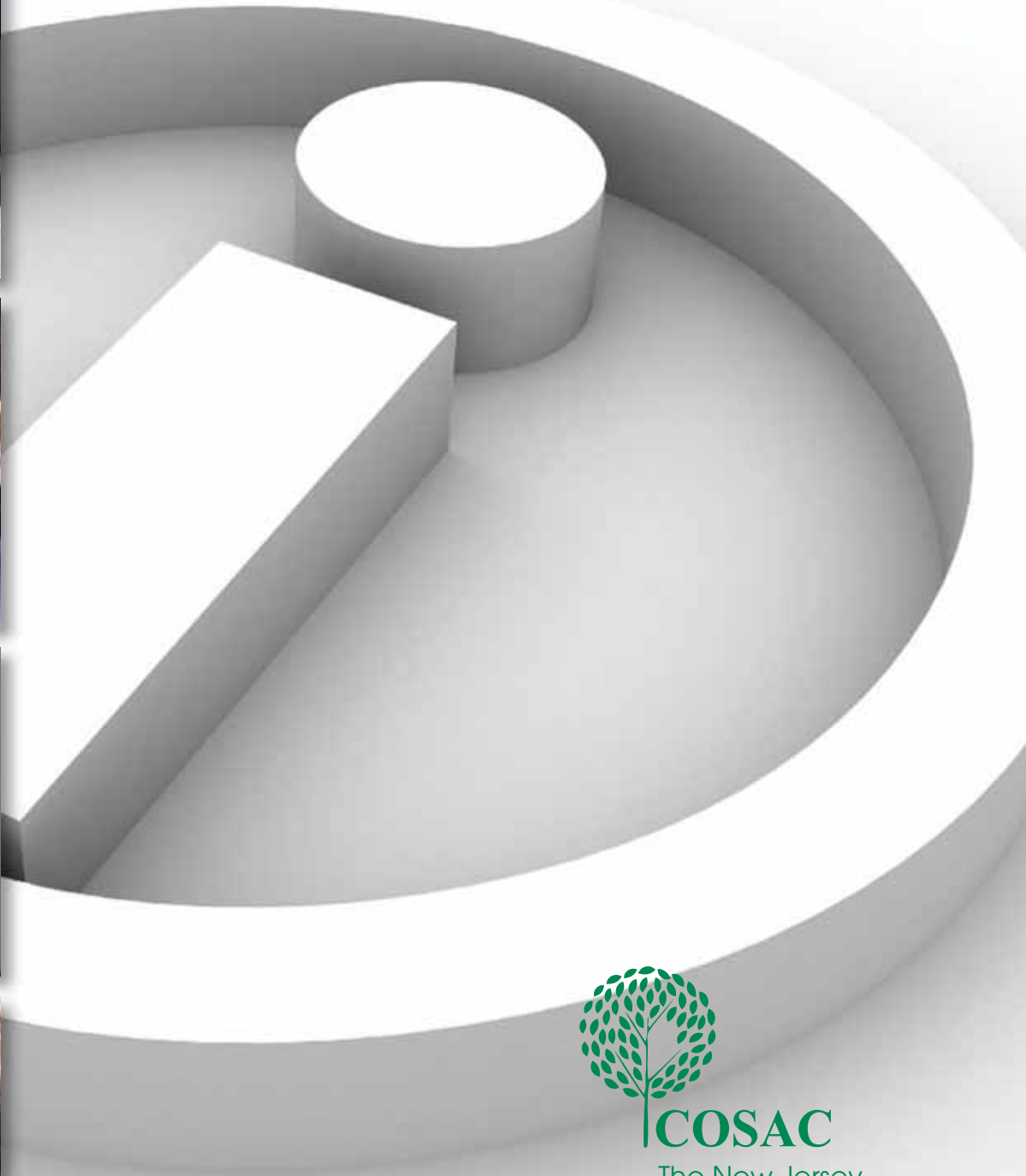




# Autism

BASIC INFORMATION



**COSAC**

The New Jersey  
Center for Outreach  
& Services for the  
Autism Community

# Foreword

Since the publication of the last edition of this booklet in 2004, the autism community has published many studies that advance our understanding of the causes and treatment for autism spectrum disorders (ASDs). Due to the collaboration between researchers and educators, much of this information has advanced our understanding of how to best improve the lives of people with autism spectrum disorders. Unfortunately, there also is a wealth of information that is confusing, misleading, and without firm scientific basis. What has not changed is the need for early identification by pediatricians and other professionals, information and options for families, and understanding and support from the general public. We are confident that this publication will help fill that need.

Contained in this booklet is the widely accepted diagnostic criteria as published in the Diagnostic and Statistical Manual – Fourth Edition, Text Revision; objective criteria to use when deciding on a treatment approach; and a list of resources to further your knowledge about ASDs. It is our intent for this booklet to be a beginning resource guide to help you navigate the roads ahead that pertain to diagnostic issues, individualized treatment options, medical testing, and available resources. You will, and should, continue to look for further, more specialized resources, but we hope that you will continue to use this publication after your first reading. Make notes in the margins, use the sample forms, and file it away for further reference.

We wish to thank the authors who have contributed to this booklet and the many families and professionals who have given us feedback since our last publication. We urge you to continue your quest for appropriate, effective, and scientifically-validated interventions. Effective intervention combined with family and community support is the key to a more fulfilling life for people with autism and their families. Much success to all of you!

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# Pervasive Developmental Disorders

## Autism Spectrum Disorders (ASDs)

Autistic Disorder

Asperger's Disorder

Pervasive Developmental Disorder Not  
Otherwise Specified (PDDNOS)

## Other

Rett's Disorder

Childhood Disintegrative Disorder

# Autism Spectrum Disorders

Autism Spectrum Disorders (ASDs) are classified under the category of Pervasive Developmental Disorders (PDDs). These include: Autistic Disorder (Autism), Asperger's Disorder, PDDNOS (Pervasive Developmental Disorder Not Otherwise Specified), Rett's Syndrome, and Childhood Disintegrative Disorder. Diagnosticians have suggested that Autism, Asperger's Disorder, and PDDNOS are related disorders. While these three disorders are the focus of this booklet, more information on all PDDs can be found in the Diagnostic and Statistical Manual excerpt beginning on page 33.

## Diagnosis

ASDs are behaviorally defined and diagnosed. The three hallmark impairments in autism are: social interaction, communication and behavior. In Asperger's Disorder, social communication and the pragmatic use of language are affected, but it does not typically involve delays in the development of communication skills. PDDNOS involves a combination of characteristics that are similar to autism and Asperger's Disorder but do not exactly match the criteria. Developmental and symptom patterns among individuals with an ASD can be quite variable. Each individual with an ASD is unique.

## Onset

Autism is usually diagnosed in the first three years of life. Asperger's Disorder and PDDNOS may be diagnosed years later. For example, when a child enters school, social difficulties and delays may become more apparent.

## Gender

ASDs are more common in males than females by a ratio of approximately 4:1.

## Prevalence

ASDs affect approximately 1 in 150 individuals nationally and 1 in 94 in New Jersey (CDC, 2007), in families of all racial, ethnic and socio-economic backgrounds.

## Associated Medical Problems

Approximately one third of individuals with autism develop a seizure disorder in early childhood (around age 5) or in early adolescence. The prevalence of seizures in individuals with Asperger's Disorder and PDDNOS is unknown.

## Cognitive Ability

Many individuals with autism learn more slowly than their peers. Currently, the specific percentage of individuals with mental retardation is under question. Researchers estimate that the majority of individuals with autism and the minority of those with Asperger's Disorder and PDDNOS meet these criteria for mental retardation. It is important to note a few things. First, accurately assessing the IQ of individuals with ASDs can be difficult, especially with young children and those with significant communication impairment. Second, results from assessments completed before and after an individual has participated in intervention may differ dramatically. Finally, an IQ score is only a snapshot of a person's abilities. Therefore, all individuals deserve every opportunity to learn and reach their fullest potential.

## Cause

While research into the causes of these disorders advances our understanding of ASDs as biologically-based disorders, as of this writing, no consistent biological markers have been identified. In the 1960's, some believed that negative interactions between the parents and the child were the cause of ASDs. However, current research suggests that there are no factors in the child's psychological environment that cause ASDs.

## Prognosis

Individuals with ASDs live a normal lifespan. There is no cure for ASDs but they are treatable. Early diagnosis and appropriate intervention are vital to the future development of the child. Outcome research strongly suggests that the behavioral treatment approach known as Applied Behavior Analysis offers the most educational benefit.

### What is autism?

Autism is a problem in the brain that makes it hard to talk, get along with other people, and learn new things.

### How do you get autism?

You are born with autism, just as some people are born with brown hair and some people are born with freckles. Many special adults, called researchers, are trying to figure out exactly how autism happens and how to teach people with autism to learn more.

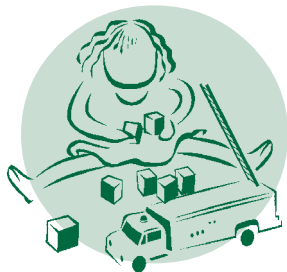


### Why can't people with autism talk like other people?

Most people with autism have a hard time using words and may even say the same word or sentence over and over again. Some people don't talk with their mouths; instead, they use their hands and pictures. There also are other people with autism who can talk just like you.

### How do kids with autism play?

Children with autism might play in a different way than other kids. They may like to stare at something for a long time, twirl a piece of string, or spin a toy car around and around. Kids with autism may play by themselves because they don't know how to play with other kids. They might need to learn how to play. If you know someone with autism, how does he or she play?



### Do some kids with autism have tantrums?

Yes. Some kids with autism might be happy and then become sad or mad. They might even have a tantrum. It might be because they have a hard time telling people what they need and want.

## Are all people with autism the same?

No. People with autism have many different things that they like to do and are good at. Every person in the world is unique in his or her own special way. How are you special? If you know someone with autism, how is he or she special?

## Do children with autism go to school?

Yes. Children with autism go to school to learn just like you. A kid with autism may be in your class or a school just for kids with autism.



## What are people with autism like when they grow up?

People with autism can learn to do all sorts of things when they grow up. They might have a job at a grocery store, as an artist, or working on a computer. Many people with autism learn to make friends, have a job, and lead a happy life.

## How should I act around someone with autism?

Great question and there's an easy answer! You should always try to be a caring person. Act like you usually would. If you don't know how to hang out with kids with autism, maybe a grown-up could show you how to get their attention. Even if someone with autism acts differently than you, they can still have feelings and care about you. Just be yourself when you are with someone with autism. You may even make a new friend!



# Your Child Has a Diagnosis of Autism, Asperger's Disorder or PDDNOS

Carolyn Thorwarth Bruey, Psy.D.

## Introduction to Pervasive Developmental Disorders

You may have never heard the phrases "Autism Spectrum Disorders" (ASDs) or "Pervasive Developmental Disorder" (PDD) until a professional used it when describing your own child. The general population has little knowledge regarding these children and adults, and even professionals who have specialized in this field for many years are gaining new information every day. Try not to be overwhelmed by all the terms and jargon; rather, keep focused upon your child's needs and abilities while learning as much as you can through reading and talking to other parents or professionals.

The key word when understanding autism spectrum disorders is "disorder." In comparison to other children with developmental delays, an autism spectrum disorder reflects a disordered developmental trend. Whereas an eight-year-old child with mental retardation may function at the level of a three-year-old child across a broad spectrum of skill areas (e.g., social, language, motor), a child with an autism spectrum disorder will show notable peaks and valleys both across and between developmental areas. An example of a child who exhibits different developmental abilities across skill areas may show clear strength in the areas of motor development and coordination, but demonstrates little social awareness of others. An example of disordered development within a given skill area would be a child who can label all types of foreign and domestic cars but not be able to hold a simple conversation. The unusual array of strengths and weaknesses inherent to autism spectrum disorders can be especially difficult for parents because they repeatedly wonder, "If she can do this, why can't she do that?" The sequence in which your child learns various skills may seem confusing and "wrong;" however, try to merely recognize, appreciate, and build upon your child's relative strengths.

Although children with an autism spectrum disorder will show relative peaks and valleys in development, the three major areas of concern inherent to any Pervasive Developmental Disorder are social skills, language development, and the presence of stereotyped behavior, interests, and activities. When determining how these diagnostic criteria relate to your own child, keep in mind that there is a wide variation within all children who have been diagnosed as having a autism spectrum disorder. While one child with autism may be completely nonverbal and spend most of the day engaged in repetitive behaviors, another child may be able to participate in a relatively sophisticated conversation and show minimal stereotypic behaviors.

Another general characteristic across autism spectrum disorders discussed in this chapter is that the onset of symptoms needs to be apparent at a very early age (e.g., before approximately age three). Parents often do not recognize these symptoms at first, especially if the child with an autism spectrum disorder is their first child. For example, they may report, "He was a wonderful baby. He never cried to be picked up," or "She was always so careful, lining up her blocks over and over." However, upon

retrospect, parents frequently begin to recognize the signs which had been evident all along but became more apparent as the child grew older. The first “red flag” for many parents is a delay in speech development, and their first step is often to have the child’s hearing tested to rule out a hearing impairment. As more professionals are contacted and the child’s developmental history is assessed more carefully, a diagnosis of one of the autism spectrum disorders is eventually obtained.

An important point to be made regarding autism spectrum disorders is that they are clearly neurobiologically-based. In contrast to old-fashioned and unproven notions that parents “caused” these disorders, more recent research has indicated that the neurological system, biochemical makeup, genetic material and/or brain structures of these individuals are often different as compared to typically developing children and adults. Although there are no definitive answers or consistent physiological underpinnings yet, many research studies continue to address the question of cause with the hope of leading to both prevention and treatment strategies for the future. The most important theme for you to remember is that parents are not the cause.

## **The Pervasive Developmental Disorders**

### **Umbrella**

Although the American Psychiatric Association has defined five subcategories within the general heading of Pervasive Developmental Disorders, the present chapter will be limited in scope to describing the three autism spectrum disorders: autism, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) as these are the most common types of Pervasive Developmental Disorders. For your knowledge, the other two subcategories are Childhood Disintegrative Disorder and Rett’s Disorder. Generally speaking, the frequency of autism spectrum disorders is 1 in 150 nationally and 1 in 94 in New Jersey (CDC, 2007).

### **Autism**

The term “autistic” was first coined in the 1940s by a man named Leo Kanner. He began to see a pattern of behaviors in some of the children he treated and felt that they constituted a separate psychiatric disorder.

Although his diagnostic criteria have been modified to some extent through the years, the emphasis upon social and language deficits as well as repetitive stereotypic behaviors was reported within Kanner’s observations.

Autism can occur in any family. Although it was once thought that autism occurred in families where both parents worked and were relatively affluent, this contention has since been abandoned. The ratio of boys to girls is approximately 4:1. Autism is often coexistent with mental retardation. When there is one child with autism in the family, the chance of having another child with autism or another type of communication disorder is heightened; however, most siblings of individuals with autism show normal development.

As with any autism spectrum disorder, the major areas of concern with autism are poor social skills, limited communication development, and a limited repertoire of interests and activities. In terms of social skills, children and adults with autism may show minimal ability to respond to family members in a preferential manner. This tendency is often difficult for parents who feel “rejected” by their child. Remember that this inability is not a choice on your child’s part, but rather a reflection of autism. Other common characteristics of social interactions in an individual with autism are limited development of friendships and peer-to-peer play activities. Individuals with autism often play by themselves and rarely initiate interactions with peers. A third example of poor social skills would be children or adults who rarely attempt to share items of interest with others. In contrast to typically developing children who frequently bring toys or objects to show their parents, children with autism do not seem to be motivated to do so.

The second major area of concern in individuals with autism is difficulty with both receptive and expressive communication. Speech acquisition is often delayed if it develops at all, and many children and adults with autism show unusual speech patterns such as echolalia (repeating words which are spoken by others), pronominal reversal (referring to themselves as “you” instead of “I”), and perseverative speech (repeating the same words or sounds in a noncommunicative fashion). Although a given

individual may have the vocabulary to hold a conversation, he or she may be unable to do so.

The third diagnostic area for autism is restricted and stereotyped patterns of behavior, interests and activities. For example, an individual with autism may become overly upset if routines are changed even slightly. Another person with autism may collect hundreds of samples of an unusual item (lint, broken pieces of china) but show no interest in more typical hobbies. A third example of this diagnostic category would be an individual who spends a great majority of time engaged in stereotypic behaviors (e.g., rocking, staring at his fingers, flipping blinds).

### **Asperger's Disorder**

In 1994, the American Psychiatric Association's Diagnostic Statistical Manual-Fourth Edition (DSM-IV) added a new subcategory of Pervasive Developmental Disorders: Asperger's Disorder. Before describing the diagnostic criteria for Asperger's Disorder, let us review what knowledge exists regarding demographic patterns and general characteristics. Most individuals with Asperger's Disorder do not show the cognitive deficits evident in someone with autism. Language development is rarely delayed and in fact expressive speech is within the normal range. Unfortunately, since the disorder is relatively new there is limited research regarding the prevalence of Asperger's Disorder. Similarly, little is known regarding any familial patterns, although it does appear that there is an increased chance of more than one family member having Asperger's Disorder.

Generally speaking, the diagnostic criteria for Asperger's Disorder are equivalent to those listed for autism with the exception of delays and peculiarities in language development. Individuals with Asperger's Disorder show marked impairment in social interactions such as poor relationships, lack of spontaneous sharing of items of interest, and more subtle aspects of human interaction such as limited eye contact and use of gestures. They also demonstrate the types of repetitive and stereotyped behaviors which are evident in autism, as well as a restricted range of interests and insistence on following certain routines and rituals without

modification. It is not uncommon for young children with Asperger's Disorder to remain undiagnosed until they are five years old or older due to their normal speech development.

Many individuals with Asperger's Disorder are able to eventually lead relatively independent lives. Due to the absence of cognitive impairment, many hold competitive employment and can live in a supervised apartment or even independently. However, the social "quirks" and ritualistic behaviors may persist throughout their lifetime, which may in turn hinder their personal relationships.

### **PDDNOS**

Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) is a subcategory of Pervasive Developmental Disorders which in many ways ends up being somewhat of a catch-all group for individuals who exhibit "autistic like" behavior. As with all Pervasive Developmental Disorders, the major areas of concern are social and language development as well as stereotyped behaviors. In contrast to other subcategories of Pervasive Developmental Disorders, however, PDDNOS does not list specific, detailed behavioral characteristics which must be present for a diagnosis. Instead, PDDNOS is a diagnostic category defined by the absence of sufficient symptoms to warrant one of the other Pervasive Developmental Disorder categories.

As a consequence of this rather vague diagnostic criteria for PDDNOS, it is difficult for professionals to agree when diagnosing these children. Parents are often confused and frustrated when their child is labeled as "autistic" by one professional and having "PDDNOS" by another. Some professionals and parents have proposed that autism be divided into gradations of severity, such that individuals who are "classically autistic" be defined as having "severe" autism while individuals who would currently be labeled PDDNOS be diagnosed as having "mild" autism.

One of the difficulties about having a child with PDDNOS is the lack of information and literature which is available to parents. If your child has been diagnosed as having "PDDNOS," it is important to recognize that much of the literature which is available

regarding autism may very well be relevant to your child. Your best bet is to modify any strategies which are presented in these “how-to” books according to your own child’s developmental and behavioral profile rather than waiting for information which is specific to children with PDDNOS.

### **A Final Word about Diagnosis**

It is important to keep in mind that all autism spectrum disorders are diagnosed purely through behavioral characteristics. As of this writing, there are no blood test, MRI, EEG, or other physiologically-based formats for confirming a diagnosis. As a consequence, there is certainly room for subjective interpretation of the behavioral descriptions listed in diagnostic tools. Therefore, if your child has only recently been diagnosed as having an autism spectrum disorder, it makes sense to seek a second opinion so you can be assured that the diagnosis is valid. Regardless of the final diagnosis, attempt to see your child as a child first and a child with an autism spectrum disorder second.

## **About the Author**

Carolyn T. Bruey, Psy.D., received her doctorate in psychology from Rutgers University Graduate School of Applied and Professional Psychology in 1982. She has worked with children and adults with autism for over twenty years. Her professional experiences related to autism include being the Coordinator of Training and Evaluation for the Teaching Family Homes for Autistic Children, as well as the Program Coordinator for four group homes for children with autism. She served as the supervisor for the Assistant Director of The New Jersey Center for Outreach and Services for the Autism Community, Inc., as well as being a board member for this agency for many years. Publications include “Daily Care of Your Child with Autism” in the book *Children with Autism: A Parent’s Guide* (2nd ed.). She is currently the Managing Partner of Developmental Disabilities Resources in Lititz, PA., an agency that provides psychological services and training to individuals with developmental disabilities, their families, and direct care staff.

# Related Medical Tests: An Overview

Kapila Seshadri, M.D., and Audrey Mars, M.D.

## Who should be referred?

Failure to meet any of these developmental milestones is an absolute indication to proceed with further evaluation:

- No babbling by 12 months
- No gesturing (pointing, waving bye-bye, etc.) by 12 months
- No single words by 16 months
- No two-word spontaneous (not just echolalic) phrases by 24 months
- Any loss of any language or social skills at any age

## What tests should be performed?

Although there is no diagnostic laboratory test for autism spectrum disorders, tests are often recommended for the following reasons: 1) to search for a cause for having autism 2) to rule out other medical problems that might look like autism (for example, hearing loss), and 3) to detect medical problems that might be co-existing with the autism spectrum disorders.

Any child with delayed language or at risk for autism should be provided with a referral for **audiologic** testing. A child who does not speak or respond to others' speech may have autism or may actually have a hearing problem or some other problem which interferes with speech.

**Cognitive** testing by a psychologist, a speech/language pathologist (including functional communication) and an evaluation of sensorimotor skills by an occupational or physical therapist will give a greater understanding of the child's learning strengths and weaknesses. Such evaluations will be useful in planning an appropriate educational program.

**Metabolic** testing should be considered when there is a history of lethargy, cyclic vomiting, early seizures, intellectual disability, or unusual facial features. Untreated phenylketonuria (PKU) is an example of a metabolic disorder.

Children with pica should have their lead level monitored. They may also have their ferritin level checked if there are concerns of anemia.

An **EEG** (electroencephalogram) may reveal brain wave abnormalities indicative of epilepsy and is generally only done if seizures are suspected clinically or if there is a history of regression (significant loss of social and communicative function).

**Neuroimaging** may be indicated by an abnormal neurologic examination not explained by the diagnosis of autism, such as non-symmetrical motor examination, cranial nerve abnormalities, microcephaly, and hypo/hyper pigmented skin (neurocutaneous) lesions. Routine clinical neuroimaging, such as Magnetic Resonance Imaging (MRI), is not indicated in the diagnostic evaluation of autism at the present time.

**Additional** testing to be considered is based on history and physical examination.

### **What causes autism?**

The cause of autism is not fully understood. When first described in 1943 by Dr. Leo Kanner, it was thought that autism was caused by a lack of warmth and love on the part of the parents. We now know that a child with autism is born with a developmental disability and the parents are not in any way to blame.

Neurological damage (with or without a biochemical basis) is now believed to be the cause of autism. Autism occurs more often in children who have had other conditions which affect the brain before birth such as German Measles (Rubella), phenylketonuria (PKU, a defect in body chemistry) and infantile spasms (a form of epilepsy). There is a higher prevalence of seizures (epilepsy) in children with autism, especially around adolescence. Some rare metabolic imbalances have also been linked to autism. Thus, there are several findings that point to an abnormality in the brain itself or a disturbance in the body chemistry which affects the brain.

Recently, researchers have focused attention on the actual structure of the brain in people with autism. Using a procedure called Magnetic Resonance Imaging (MRI), researchers have found that there may be a structural difference in the cerebellum part of the brain in people with autism. However, at this time, these findings are not specific enough for MRI to serve as a diagnostic test for autism.

### **What about genetic factors?**

There are a number of genetically transmitted and familial factors which have been linked to autism. It is likely that genes inherited from both parents combine

with other factors, such as injury to the brain before birth or an illness in early infancy. It may be that what is inherited is an increased susceptibility to develop autism.

Researchers have found that a couple with one child with autism has a greater risk of having a second child with autism than a couple without a child with autism. This risk is greatly increased when there is an identified genetic disorder, such as Fragile X syndrome. Because inheritance patterns differ from family to family parents who plan to expand their family may wish to seek genetic counseling services to determine their own relative risk.

## About the Authors

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# The Road Less Traveled: Charting a Clear Course for Autism Treatment

David Celiberti, Ph.D., BCBA, Suzanne Buchanan, Psy.D., BCBA,  
Felicia Bleecker, Psy.D., David Kreiss, Psy.D., and David Rosenfeld, Psy.D.

The current landscape of treatment options for parents of children with autism can be a confusing and unsettling one. To help explore this challenge, let us offer the following scenario:

*Your child has been diagnosed with cancer. While searching for medical treatment for your child, you come across a variety of medical providers. Some practice 1980s style medicine and others practice state-of-the-art medical techniques. The first group appears unaware of the latest scientific advances in treatment, whereas the second group is embracing and making the most of recent scientific advances within the field of pediatric cancer care. Given the tremendous stakes at hand and your concern for the health and well-being of your child, virtually all of you would choose those doctors who provide the most current, scientifically-validated medical approach to treat your child's cancer.*

*Fortunately, the "treatment of choice" for cancer is fairly well-defined. In pediatric cancer care, there is a shared commitment to using science to guide treatment. Although experimental drug trials are a slow process, once drugs and drug protocols are approved, the treatment of choice is clear. Furthermore, there are a variety of negative consequences for those physicians who ignore and fail to integrate science-based advances in their treatment of cancer (e.g., sanctions from licensing boards, malpractice lawsuits). Although there is certainly a range of expertise among cancer specialists, well-established medical training programs and licensing criteria help ensure a high-level of competence from all. Parents of children diagnosed with cancer do not need to exert painstaking efforts to acquire information about cancer treatment and locate appropriate medical providers, and children diagnosed with cancer are typically able to avoid waiting lists and access timely treatment. Finally, the professional community and society at large do not fault parents for pursuing the most current, scientifically validated intervention for their child's cancer.*

Now let's turn to the experiences of parents of children diagnosed with autism and related disorders. In contrast to the above scenario, parents of children with autism will certainly encounter providers with a range of commitment to the latest scientific advances. Unfortunately, there are many providers who are unaware of scientifically-validated technology, as well as others who are aware but choose to reject this technology outright. It is our view that scientific evidence represents the best source of information to guide treatment selection. Parents of children with autism often have to sift through much literature to locate information about scientifically-validated intervention. With the increasing

demand for services, parents often encounter a shortage of providers and extensive waiting lists for treatment. This often occurs when their child is at an age when timely intervention is of the essence. Even among the pool of providers who claim to embrace scientifically-validated treatment for autism, there exist tremendous differences in quality and expertise. Currently, the gap between what is known about effective autism treatment and what is practiced is quite wide. Sadly, that is the reality of autism treatment.

It is our view that embracing a scientific method is the foundation of providing state-of-the-art treatment for autism and a reliable source of hope. Those of you who question this notion should consider the scenario above again. By respecting the scientific method, physicians who provide cancer care can differentiate between effective and ineffective treatments and make choices carefully and responsibly. In cancer treatment this process has been conducted through careful analysis of the types of cancer, the types of treatment, and the variable outcomes for children. This process includes the following: knowledge of current best practice; hypotheses to improve the course of treatment and the children's prognoses; direct observation and data collection to test the hypotheses; and finally, the publication of the results, their implications for the field, and their directions for future research. This scientific process has also advanced the treatment of autism.<sup>1</sup>

Although research has suggested a biological basis for autism,<sup>2</sup> there are currently no scientifically-validated medical treatments to address the core deficits of autism. Unfortunately, many parents of newly diagnosed children believe that medical treatments do exist that may eliminate most, if not all, of the symptoms or manifestations of autism, perhaps even proving to be a cure. This expectation may be due in part to the fact that the medical model for many other disorders is well established. As an example, the treatment for strep throat may involve a very specific class of antibiotics administered three times per day for 10 days. Although the cause of this infection is rather clear, autism, by contrast, is widely believed to have multiple causes that vary across individuals. Nonetheless, drug interventions for individuals with autism have been widely attempted targeting a vast array of symptoms associated with autism. These trials

have included such medications as antihypertensives, anxiolytics, anticonvulsants, antipsychotics, antidepressants, antihistamines, and stimulants.<sup>3</sup>

In their search for science-based treatment for autism, parents will certainly encounter Applied Behavior Analysis (ABA). The field of ABA has evolved considerably over the last few decades.<sup>4</sup> Technologies to address learning difficulties and to target challenging behaviors have become increasingly effective, refined, and precise. It cannot be overstated that the data-based literature supporting interventions for individuals with autism based on the principles of ABA is indeed abundant. Every year the technology is expanded and enhanced through research that is carefully documented, scrutinized by professional reviewers and ultimately published in scientific journals.<sup>5</sup> As a result of this ever-increasing body of scientific support, a number of state and federal agencies have looked at the wide array of available treatment for autism and have determined that ABA is the only treatment approach that is scientifically validated.<sup>6</sup> It is disheartening that so many providers in the field ignore these recommendations of these agencies. (On a practical note, you will find that information about ABA is also available in books that provide an overview of the ABA model and teaching strategies derived from ABA.<sup>7</sup>)

It is important to note the treatment of autism using ABA does not produce overnight results, nor is ABA a cure for autism. Rather, ABA requires a strong and intensive commitment with respect to time, structure, and consistency.<sup>8</sup> Despite this commitment, "recovery" may be a viable outcome for only some individuals with autism. Furthermore, high-quality ABA services are not widely available and are often difficult to access. The shortage of qualified and competent ABA providers has created a breeding ground for less qualified individuals to fill the gap between supply and demand. In other words, not all behavior analysts are "created equal," and there is great variability in the training and supervision of these professionals.<sup>9</sup> Consequently, not all ABA programs are consistent with best practice and the commitment to ongoing assessment of progress can vary widely. Yes, individuals with autism are likely to benefit from comprehensive and state-of-the-art ABA programs because many of the techniques used within an ABA program have strong scientific support. Yet,

how “comprehensive and state-of-the-art” a program is often depends on the qualifications of the behavior analyst and the teaching staff. Parents should not believe that once their child with autism is participating in an ABA program, the questions about treatment are answered. While one major question regarding the type of educational program has been answered, there are countless other questions to ask in order to effectively monitor the quality of the treatment provided (e.g., what is being targeted, how is it being targeted, are the desired outcomes being achieved?). Thus, parents should always be active participants in the decision-making process within an ABA program for their child.

As stated above, ABA is not an intervention with a track record of “overnight” success. Unfortunately, there are no quick and easy treatments for autism that have been proven to be successful through research. As a result, both parental and professional interest in alternative treatment approaches has remained strong partly due to their often promised success and ease through which they are carried out. The term “magic bullet” is often associated with a straightforward and precise intervention for a specific condition. The search for the “magic bullet” to treat autism is elusive, as it has been with other disorders.

*In the 1970s, Ritalin was touted to be the miraculous “magic bullet” for Attention Deficit Hyperactivity Disorder (ADHD). To date, however, the published research supporting the efficacy of this medication has suggested some positive changes, but there has not been an abundance of data documenting long-term elimination of the symptoms associated with ADHD. The last few decades have revealed that Ritalin is not a “magic bullet.” While it helps many children with ADHD attend, it should not be assumed that children will then automatically know when, where, and to which aspects of the environment they should attend. Nor will medication result in the appearance of missing academic content areas and prerequisite skills. Furthermore, it is not realistic to expect dramatic changes in the social arena. Peers may not automatically embrace a child with ADHD who a week prior*

*was significantly disruptive to the class and unable to wait his or her turn on the playground. Psychostimulants such as Ritalin may be part of the treatment for an individual with ADHD, but not the solution in and of itself.*

This example suggests that even effective pharmaceutical interventions for autism may not be sufficient in and of themselves. Progress may be maximized only when combined with a comprehensive approach to teaching new behaviors (such as behavioral intervention drawn from ABA) to address the development of important skills that do not automatically appear through the use of medication.

For one parent, the example above may reaffirm his/her commitment to science-based treatment approaches. Another parent may take a different perspective – believing that some of the various treatment options could be helpful in treating autism. So, let us now take a look at what other treatments exist - as there are currently dozens of other intervention options. These approaches include, but are not limited to, extensive dietary modifications, medications, vitamin therapy, hormone therapy, facilitated communication, gentle teaching, biofeedback, electromagnetic therapy, infusion or injection of immunological substances, sensory manipulations such as auditory integration, massage of the scalp, specialized prism lenses, complex rhythmic drumming patterns, exposure to fluorescent lights, the Miller Method, significant manipulations in parent-child interactions such as holding therapy and Option therapy, as well as treatments involving therapeutic contact with animals such as dolphins and horses.

There is no reason to doubt that the number of intervention options will only increase with time. In fact, every year new interventions to treat autism are proposed. The internet is filled with ongoing dialogue and volumes of anecdotal information advocating the use of these alternative treatments. Interventions such as secretin and facilitated communication have received substantial and widespread media coverage prior to the emergence of adequate scientific evidence supporting their use. Testimonials boasting vast improvement or even a cure for autism can be extremely enticing to parents or caregivers, raising their hopes and expectations. Unfortunately, with the

exception of some medications, it has been noted repeatedly that the advocates of these treatments to date have not generated adequate scientific support for such interventions.<sup>10</sup>

It is our opinion that the responsibility to demonstrate efficacy lies with the providers of that particular intervention. This position has been shared by others.<sup>11</sup> Unfortunately, many have abandoned this important responsibility and have instead asked consumers to rely only on anecdotal reports, descriptive published reports, or poorly designed research. It is important to alert our readers that there have actually been published articles and policy statements discrediting the use of many interventions including facilitated communication,<sup>12</sup> auditory integration training,<sup>13</sup> and sensory integration training.<sup>14</sup>

Nonetheless, the abundance of possible treatments for autism continue to be a source of temptation for some parents and professionals trying to maximize the overall functioning and quality of life for their child or client. The enormous list of possible approaches is partially because numerous disciplines are involved in autism treatment. For some parents, the availability of such a wide range of alternative treatment approaches can be reassuring. For others, an increasing number of options can lead to false hopes that may result in disappointment, frustration, and burnout. Parents may come to regret not considering or trying a treatment approach that others have claimed to be beneficial. Parents may also find themselves second guessing their decisions or feeling unsure about whether they are doing what is best for their child. In the absence of scientific support for alternative treatment approaches, parents of individuals with autism often have to rely on their own investigation of various treatment options in order to determine which would be the best course of action for their child. We feel that this is a very unfortunate and even unsettling role for parents to assume.

It is understandable that parents have various reactions and perspectives regarding how to make treatment decisions. For example, many parents are not tempted by the vast number of treatment options that are available. These parents are naturally skeptical of those treatments that do not have scientific support. They may cautiously view alternative treatments as

experimental and not as a viable option. Other parents may have explored one or more alternative treatments and found themselves unimpressed or even disappointed with the outcome. Yet, still other parents have worked with and become influenced by applied behavior analysts who are rather forthright in their criticisms and dismissal of alternative interventions. The persuasive arguments by these professionals have discouraged some parents from pursuing treatment approaches that lack scientific support.

Unfortunately, such strong positions have alienated other parents and have led many to pursue these alternative interventions secretly and with little to no professional guidance. Such concealed efforts run counter to the concept of parent-professional communication that is essential to any effective ABA program. A valid and objective evaluation of a child's skill acquisition and behaviors is also negatively impacted when parents and caregivers do not feel comfortable reporting their child's involvement and participation in alternative treatments. As a result, teaching staff may be at a loss to understand a sudden change in classroom behavior that may indeed be an adverse reaction to another treatment (e.g., a dietary intervention). These professionals may lose sight of the notion that parents and caregivers are driven to help their children get better. While they want to make informed decisions regarding alternative treatments for their child, parents understandably may be willing to try any techniques which offer the hope of improving their child's outcome.

At the other extreme, there are professionals who misrepresent, minimize, or outright dismiss scientifically supported treatments and the scientific method. We have observed that not all professionals in the field rely on scientifically-validated information when endorsing and/or providing interventions. One rationalization for this flexible approach is based on the belief that no one approach, including ABA, works for all individuals. Yet, a "try everything" mindset may lead a parent to believe that the treatment of autism should be based upon the quantity of interventions, as opposed to quality of the interventions. As a result, parents may spread their available resources too thinly in their efforts to create a multi-layered treatment program for their child. In addition, unforeseen negative

interactions may occur from the combination of two or more interventions that should not be implemented at the same time.

There is a possible silver lining here: perhaps the provision of multiple services may benefit the child. This situation calls for even greater attention to treatment evaluation and an assessment of the unique contribution of each method. A similar evaluation process may also be necessary when one method relies on an array of components as many treatments for autism do. It is in the child's and the family's best interest to evaluate these services to ensure that each one is a worthwhile endeavor. Doing so will enable parents to make the most of their time and resources. When faced with such complicated questions, many parents take a best-odds approach. The child participates primarily in an ABA program and the parents cautiously introduce and evaluate treatments that have not yet been scientifically validated. Again, having to make such important decisions with little support, resources, and information is a difficult task, however, it is hoped that the considerations detailed in this document may alleviate some of this burden.

We believe it is important to provide parents and caregivers of children with autism with a step-by-step approach to the investigation of treatment options, thereby enhancing their chances of making the most informed and effective decisions for their child. It is our view that the scientific practices and high standards used within of Applied Behavior Analysis offer all of us very useful tools for negotiating the variety of treatment approaches available in the field.

We recognize that our readers possess varying familiarity with ABA. Many may not be aware that the assessment and evaluation methods utilized within ABA can actually provide parents with a useful way of exploring various treatment choices for their children. We can identify and clearly define the behaviors that we wish to target for change.

- Once a definition of a target behavior is created, we can track the frequency, intensity, and/or duration of the target behavior's occurrence before the treatment is ever implemented (baseline data). If it is not known how frequently the target behavior occurred before treatment, it will be

impossible for us to assess the effectiveness of the treatment in increasing or decreasing the behavior.

- Next, we can collect data on an ongoing basis as the treatment is implemented to observe trends in the target behavior. Are behaviors increasing, decreasing, or remaining unchanged?
- After the treatment has been implemented for a sufficient amount of time, we can make a determination regarding the effectiveness of the treatment. At this point, it may be necessary to maintain, alter, or discontinue treatment.

These evaluation procedures above are integral components of interventions based on ABA and are routinely carried out within well-run ABA treatment programs. However, all interventions should be subjected to the same scrutiny when it relates to something as precious as the safety, well-being, and potential of an individual with autism. The responsibility to objectively assess progress should not diminish with the implementation of alternative treatment options. In fact, interventions that lack a sound body of scientific support should actually be evaluated even more rigorously.

We have included a series of questions for consideration when evaluating treatment approaches for autism. It is followed by a summary of the key questions that can readily be used when interviewing prospective service providers including those who offer ABA and those who do not (see Appendix A). As can be seen in Figure 1, information gathering and decision making can be a sequential process:

- Phase I explores whether the intervention in question is a viable, safe, and potentially worthwhile intervention. Published scientific evidence will likely address many of the questions included in this phase of inquiry. More specifically, when looking to published research for these answers, the introduction section of the research article will be most helpful as it lays out the research that supports and leads up to the current study.
- Phase II explores whether the intervention in question is appropriate for an individual with autism and whether the service provider is

suitable. When looking to published research for these answers, two sections of an article will be most helpful: the method and discussion sections. The method section describes the participants. To the extent that an individual is similar to the participant in the study, it is reasonable to expect that he/she may have a similar response to that particular treatment. The discussion section of an article lists the contributions and limitations of the treatment and the study itself.

- Phase III describes assessing outcomes objectively and whether the risks are outweighed by the potential benefits. The results and discussion sections provide helpful information to answer these questions regarding target behaviors (often called the dependent variables), how they are measured, the amount of behavior change, and an analysis of the advantages and disadvantages. We hope it is clear to the reader that in the absence of published scientific evidence that a particular intervention is effective, consumers must be particularly cautious and these questions should be considered even more carefully.

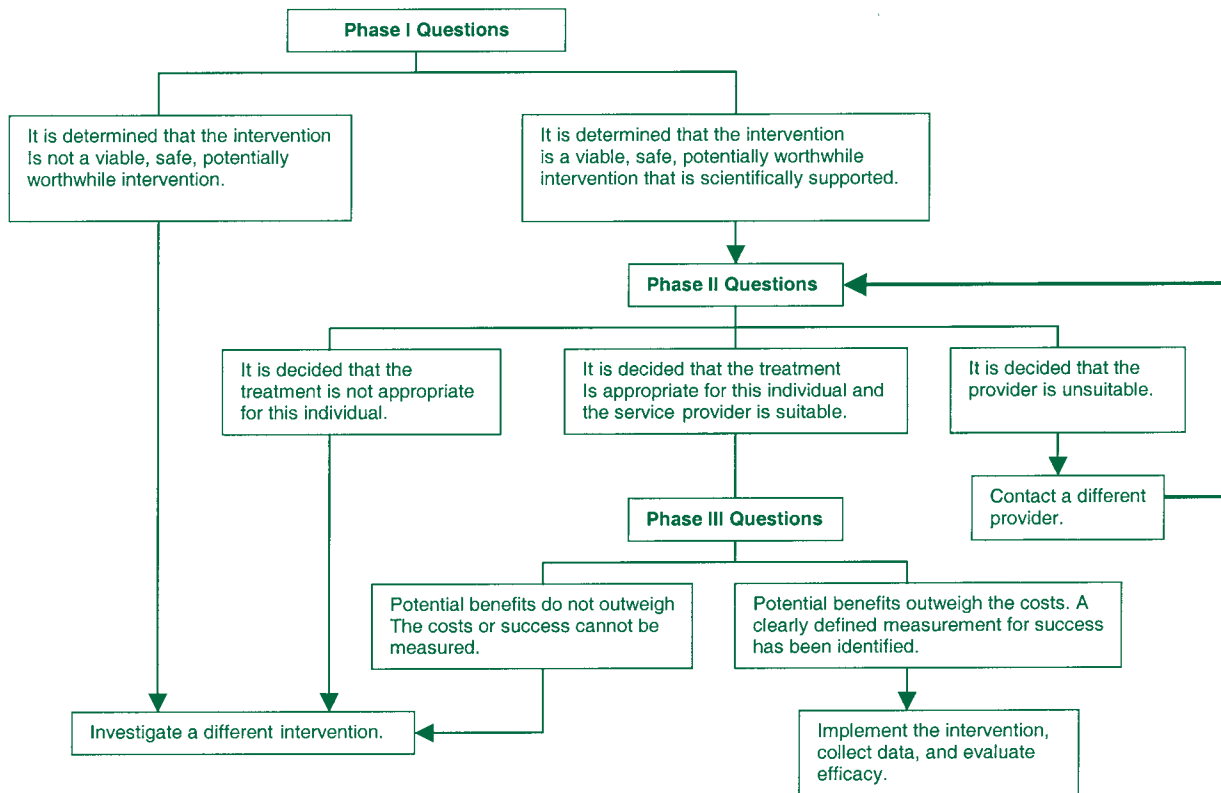


Figure 1. Decision-Making Flow Chart for Evaluating Alternative Interventions for Individuals with Autism

## Phase I

### Exploring the viability and appropriateness of a treatment approach

#### Research

- First and foremost, what research is available in the professional literature that confirms the effectiveness of this approach? Is there research that does not support the effectiveness of this approach?
- In the absence of published research supporting the effectiveness of this approach, how do the proponents of the approach justify their advocacy in the face of no published, scientific support? (See Green, 1996a)
- What percentage of individuals with autism has experienced positive effects with this treatment approach? Are there any characteristics that differentiate the individuals who experience positive effects from those who do not?
- How important are these positive effects? Are they statistically significant (i.e., data obtained in a scientific investigation to suggest that the desired change is not due to chance)? Are they clinically significant (i.e., observations suggest a noticeable and desirable change in one or more important area of concern)?
- Do the results appear in published research, or are they presented as estimates in a case study or narrative report? What is the size of the group upon which these estimates are based? If they are estimates, who are they based upon?
- Does the published literature represent objective, empirical research (i.e., scientifically driven and data-based)? Or is it descriptive research that describes someone's impressions over time?
- What is the theory/rationale that drives this treatment approach? Does this theory make intuitive sense? Does this theory have scientific support?
- Are there individuals examining this approach who are committed to science-based research? How many researchers are currently investigating this treatment approach?
- How can this supporting literature be obtained?

#### Treatment

- What areas of functioning and specific behaviors are being targeted by this approach? In other words, how exactly does this treatment impact upon individuals with autism?
- How does this treatment approach work? Is there a planned and documented sequence of assessment and intervention strategies?
- How will skill gains made in treatment sessions generalize to everyday settings in a functional manner?
- What are the risks and benefits of this treatment approach? Do the potential benefits outweigh the risks? Are there other approaches that may provide the same benefits with fewer risks?
- Are there adverse effects associated with this treatment approach?
- How long has this approach been available?
- Are there multiple service providers with whom this treatment approach can be discussed?

If this treatment approach appears to be a viable, safe, potentially worthwhile intervention that has sufficient scientific support, then Phase II questions should be explored. If unsatisfactory responses are obtained, if multiple incomplete responses are offered, or appropriate answers could not be located, then consumers are discouraged from pursuing the approach in question.

## Phase II

### Assessing the appropriateness of the intervention under the supervision of a specific service provider for a specific individual with autism

- Why is this specific individual with autism a good candidate for this treatment approach? Upon what information is this determination based (e.g., analysis of immune functioning, behavioral observation, data from blood work, standardized testing)?
- Does every individual with autism receive the exact same treatment? If not, how will this treatment be individually tailored and based on what factors? In other words, how can this treatment approach be adjusted to meet the needs of the specific individual?
- How does this approach fit in with the individual's existing treatment? Can it complement existing interventions? Is it compatible? Is it counterproductive or will it interfere with the existing treatment? In what ways? How can such interference be prevented, avoided, or minimized?
- What are the necessary credentials and experiences to carry out this treatment approach safely and effectively? Does the potential service provider have the necessary credentials and experiences to carry out this treatment approach safely and effectively?
- Is there a system of procedural safeguards providing oversight and accountability for this service provider in the case of malpractice? (Examples include licensing and certification boards.)
- How does this treatment approach as it is outlined in the available research literature differ from the actual treatment approach used by the service provider?
- How costly is this treatment approach for the specific individual? In terms of financial resources? In terms of time accessing services? In terms of disruption to other services? In terms of parental effort? In terms of impact on family life?
- What are the start-up expenses? What are the ongoing expenses? Will the expenses be covered by insurance? Will the expenses be covered by the school district (if the individual with autism is enrolled in school)? Are there external sources of funding for this treatment approach?
- What is the parents' and caregivers' role in implementing or supporting this treatment approach? What support or oversight is needed?
- What is the school's role in implementing or supporting this treatment approach? What support or oversight is needed?

If it has been decided that this treatment approach may be appropriate for the specific individual with autism and a particular service provider is suitable to offer the treatment approach, then proceed to the Phase III questions. If the potential provider is not able to answer questions satisfactorily or does not have the necessary credentials or experiences, then another provider should be sought and Phase II questions should be reconsidered. If it appears that the individual with autism is not a suitable candidate, then consumers are encouraged to explore other approaches or continue their inquiry with another provider (to obtain a second opinion).

## Phase III

### Monitoring the implementation of the treatment and evaluating effectiveness

- How will success be measured for the specific individual?
- What specific areas of behavior or physiological functioning are being used to measure effectiveness? Have these areas been defined objectively, clearly, and concisely?
- What baseline data are requested by the service provider (i.e., information collected prior to an intervention in order to provide an objective standard for evaluating change)? This is an important question to ask because many service providers fall short in this area.
- Does the service provider discuss ongoing data collection? If not, how does the provider anticipate making an objective judgment about the success of the intervention in the absence of data?
- Does this treatment approach lend itself to a reversal (i.e., the treatment is briefly discontinued to see if the rate of target behavior returns to original levels)?
- How will the service provider measure the effectiveness of the intervention if there are concurrent interventions that may be targeting the same areas? How can unique contributions of the concurrent interventions be determined?
- Do the potential positive benefits outweigh the costs?
- Are there any potential side effects that should be anticipated for this individual? How should the side effects be managed? Which side effects warrant a call to the service provider? Which side effects warrant immediate discontinuation of the treatment?
- What will the length of this intervention be for the individual? What time period is necessary for this approach to begin to show positive effects?
- How frequently does the individual need to be seen by the service provider? What will the re-evaluation involve?
- At what point can one expect to stop this intervention? How will it be discontinued or faded?
- How frequently does the parent need to communicate with the service provider? What kind of information should the parent be reporting to the service provider?
- What should the school's role in monitoring this treatment approach be, if any? Would there be any benefit to restricting information about the intervention to only a select few staff persons (i.e., in order to minimize a biased evaluation of change)?

## Conclusion

The above list of questions is not intended to be exhaustive, nor is it necessary to use the entire list when exploring alternatives. Instead, this list is provided in the hopes of expanding the range of considerations available to parents and caregivers when pursuing any treatment approach, even an approach that enjoys significant scientific support such as ABA. Parents who possess greater knowledge and a framework for evaluating treatments can feel more confident in making sound treatment decisions. As consumers of these services and perhaps the strongest advocates for their children's safety and well-being, parents have not only the right, but also the responsibility to protect their children. Parents and caregivers should be informed as to what they can expect from any given treatment and should be knowledgeable about whether there are any potential risks associated with that treatment.

Professionals who offer or market interventions to individuals with autism have the obligation to fully explain their treatment methods, to clearly identify the nature and range of possible treatment effects, and to provide a means for evaluating the effectiveness of their interventions objectively. Professionals should not be offended when asked such questions concerning their services, and

parents should not be made to feel intimidated for seeking such information.

We look forward to the day when parents need not work so hard at sifting through the enormous number of approaches available and when service providers have a broader array of scientifically-validated procedures to draw upon when addressing the many needs of children with autism. It is hoped that by empowering parents with the tools needed to negotiate the maze of interventions and to be more knowledgeable consumers, the quality of services available to individuals with autism will be enhanced and the road to effective treatment will be clearer.

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## Endnotes

1. Crosland, Zarcone, Lindauer, Valdovinos, Zarcone, Hellings & Schroeder, 2003; Green, 1996a; Green, 1996b
2. Assumpcao, 1998; Cook, 2001; Courchesne, 1995; Courchesne, Carper, & Akshoomoff, 2003; Eigsti & Shapiro, 2003; Kemper & Bauman, 1993; Kemper & Bauman, 1998; Mazzocco, Kates, Baumgardner, Freund, & Reiss, 1997; Mesibov, Adams, & Klinger, 1997; Nicolson & Szatmari, 2003; Shastri, 2003
3. Barnard, Young, Pearson, Geddes, & O' Brien, 2002; Cohen, Ihrig, Lott, & Kerrick, 1998; Cook, Rowlett, Jaselskis, & Leventhal, 1992; DeLong, Teague, & McSwain, 1998; Fatemi, Realmuto, Khan, & Thuras, 1998; Gringus, 2000; Hammock, Schroeder, Levin, 1995; Langworthy-Lam, Aman, & Van Bourgondien, 2002; Kwok, 2003; McDougle, Holmes, Carlson, Pelton, Cohen, & Price, 1998; Sweeney, Fomess, & Levitt, 1998
4. Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996; McClannahan, MacDuff, & Krantz, 2002; Rossenwasser & Axelrod, 2001; Rossenwasser & Axelrod, 2002
5. Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Birnbrauer & Leach, 1993; Eikeseth, Smith, Jahr, & Eldevik, 2002; Fenske, Zalenski, Krantz, & McClannahan, 1985; Harris & Handleman, 2000; Harris, Handleman, Gordon, Kristoff, & Fuentes, 1991; Lovaas, 1987; Luiselli, Cannon, Ellis, & Sisson, 2002; Smith, Groen, & Wynn, 2000
6. Collaborative Work Group on Autistic Spectrum Disorders, 1997; Maine Administrators of Services for Children with Disabilities Autism Taskforce, 1999; New York State Department of Health, 1999; U.S. Department of Health and Human Services, 1999
7. Buchanan & Weiss, in press; Fovel, 2002; Harris & Weiss, 1998; Koegel & Koegel, 1995; Leaf & McEachin, 1999; Lovaas, 2003; Maurice, Green, & Luce, 1996; Maurice, Green, & Foxx, 2001
8. Freeman, 1997; Maurice, Green and Luce, 1996
9. For more information on professional standards, you are referred to the Consumer Guidelines published by the Autism Special Interest Group of the Association for Behavior Analysis (1998) at [www.abainternational.org](http://www.abainternational.org) and the Behavior Analyst Certification Board [www.bacb.com](http://www.bacb.com). A revised version of the Consumer Guidelines will be available in the summer of 2004
10. Green, 1996a; Green, 1996b; Smith, 1996; Maine Administrators of Services for Children with Disabilities Autism Taskforce, 1999; New York State Department of Health, 1999; U.S. Department of Health and Human Services, 1999
11. Fox, 1999
12. American Psychological Association, 1994; Cardinal, Hanson, & Wakeham, 1996; Green & Shane, 1994; Jacobson, Mulick, & Schwartz, 1995; Wheeler, Jacobson, Paglieri, & Schwartz, 1993
13. American Academy of Pediatrics, 1998; American Speech-Language-Hearing Association, 2004; Gravel, 1994
14. Arendt, MacLean, Baumeister, 1988; Hoehn & Baumeister, 1994; Mason & Iwata, 1990; Ottenbacher & Short, 1985

# Appendix A

## Sample Form to Evaluate Treatments for Autism

### Phase I Treatment approach

Does this approach have empirical support in peer-reviewed journals?  yes  no

How can I obtain this and other relevant literature? \_\_\_\_\_

According to this literature, what percentage of individuals makes objective and meaningful progress? \_\_\_\_\_

How does this treatment work? \_\_\_\_\_

How can I obtain a written copy of the procedures? \_\_\_\_\_

Are there risks or adverse side effects? \_\_\_\_\_

What are the criticisms and limitations of this approach? \_\_\_\_\_

How do the proponents respond? \_\_\_\_\_

### Phase II Specific service provider for a specific individual

How will the treatment be individualized? \_\_\_\_\_

What are the necessary experiences and credentials to carry out this treatment approach safely and effectively? \_\_\_\_\_

What experiences and credentials does this service provider have (years of supervised and independent experience, number of individuals with autism, types of behaviors treated, etc.)? \_\_\_\_\_

What mechanisms are in place for oversight of this service provider such as a licensing board, professional board, or provider agency? \_\_\_\_\_

What are the costs in terms of finances, time, materials, etc.? \_\_\_\_\_

What roles do the parents, other family members, and school personnel play? \_\_\_\_\_

# Appendix A

## Sample Form to Evaluate Treatments for Autism

### Phase III

#### Monitoring implementation and evaluating effectiveness

How will progress or lack thereof be evaluated? \_\_\_\_\_

Are target behaviors stated in observable and measurable terms? \_\_\_\_\_

Are the assessment strategies logical and thoroughly described?  yes  no

Are the intervention strategies logical and thoroughly described?  yes  no

How will gains in treatment generalize to everyday settings? \_\_\_\_\_

How will we know when to change specific and general strategies? \_\_\_\_\_

How long is the individual expected to need treatment? \_\_\_\_\_

With this service provider? \_\_\_\_\_

Others? \_\_\_\_\_

How often should the parent and the service provider communicate? \_\_\_\_\_

What types of information would be helpful to the service provider? \_\_\_\_\_

# Tables

**Table 1**  
Partial list of peer-reviewed journals

While not an exhaustive list, the following journals are well-regarded sources of information. Publication in these journals involves a process known as peer review in which a study is evaluated, critiqued and eventually determined by a group of experts to be scientifically and clinically valuable.

- *Analysis and Intervention in Developmental Disabilities*
- *Analysis of Verbal Behavior*
- *Autism*
- *Behavioral Interventions*
- *Behavior Therapy*
- *Child and Family Behavior Therapy*
- *Focus on Autism and Developmental Disorders*
- *Journal of Applied Behavior Analysis*
- *Journal of the American Academy of Child and Adolescent Psychiatry*
- *Journal of Autism and Developmental Disorders*
- *Journal of the Association for People with Severe Handicaps*
- *Journal of Consulting and Clinical Psychology*
- *Journal of Positive Behavior Interventions*
- *Journal of Speech and Hearing Disorders*
- *Research in Developmental Disabilities*

**Table 2**  
Partial list of associations that provide information about autism treatment

American Occupational Therapy Association	<a href="http://www.aota.org">www.aota.org</a>
American Speech-Language-Hearing Association	<a href="http://www.asha.org">www.asha.org</a>
Association for Behavior Analysis (ABA)	<a href="http://www.abainternational.org">www.abainternational.org</a>
<i>Autism Special Interest Group</i>	<a href="http://www.autismsig.org">www.autismsig.org</a>
<i>Parent-Professional Partnership Special Interest Group</i>	<a href="http://www.pppsig.org">www.pppsig.org</a>
<i>State, Regional, and International Chapters of ABA</i>	
Association for Science in Autism Treatment (ASAT)	<a href="http://www.asatonline.org">www.asatonline.org</a>
Autism Speaks	<a href="http://www.autismspeaks.org">www.autismspeaks.org</a>
Behavior Analyst Certification Board (BACB)	<a href="http://www.bacb.com">www.bacb.com</a>
Cambridge Center for Behavioral Studies	<a href="http://www.behavior.org">www.behavior.org</a>
The Interdisciplinary Council on Developmental and Learning Disorders	<a href="http://www.icdl.org">www.icdl.org</a>
The New Jersey Center for Outreach and Services for the Autism Community (COSAC)	<a href="http://www.njcosac.org">www.njcosac.org</a>
Organization for Autism Research (OAR)	<a href="http://www.researchautism.org">www.researchautism.org</a>

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# Diagnostic and Statistical Manual, Fourth Edition, Text Revision

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Pervasive Developmental Disorders are characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities. The qualitative impairments that define these conditions are distinctly deviant relative to the individual's developmental level or mental age. This section contains Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. These disorders are usually evident in the first years of life and are often associated with some degree of Mental Retardation. The Pervasive Developmental Disorders are sometimes observed with a diverse group of other general medical conditions (e.g., chromosomal abnormalities, congenital infections, structural abnormalities of the central nervous system). Although terms like "psychosis" and "childhood schizophrenia" were once used to refer to individuals with these conditions, there is considerable evidence to suggest that the Pervasive Developmental Disorders are distinct from Schizophrenia (however, an individual with Pervasive Developmental Disorder may occasionally later develop Schizophrenia.)

## **299.00 Autistic Disorder**

### **Diagnostic Features**

The essential features of Autistic Disorder are the presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests. Manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual. Autistic Disorder is sometimes referred to as early infantile autism, childhood autism, or Kanner's autism.

The impairment in reciprocal social interaction is gross and sustained. There may be marked impairment in the use of multiple nonverbal behaviors (e.g., eye-to-eye gaze, facial expression, body postures, and gestures) to regulate social interaction and communication (Criterion A1a). There may be failure to develop peer relationships appropriate to developmental level (Criterion A1b) that may take different forms at different ages. Younger individuals may have little or no interest in establishing friendships. Older individuals may have an interest in friendship but lack understanding of the conventions of social interaction. There may be a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., not showing, bringing, or pointing out objects they find interesting) (Criterion A1c). Lack of social or emotional reciprocity may be present (e.g., not actively

participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or “mechanical” aids) (Criterion A1d). Often an individual’s awareness of others is markedly impaired. Individuals with this disorder may be oblivious to other children (including siblings), may have no concept of the needs of others, or may not notice another person’s distress.

The impairment in communication is also marked and sustained and affects both verbal and nonverbal skills. There may be delay in, or total lack of, the development of spoken language (Criterion A2a). In individuals who do speak, there may be marked impairment in the ability to initiate or sustain a conversation with others (Criterion A2b), or a stereotyped and repetitive use of language or idiosyncratic language (Criterion A2c.) There may also be a lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level (Criterion A2d). When speech does develop, the pitch, intonation, rate, rhythm, or stress may be abnormal (e.g., tone of voice may be monotonous or inappropriate to context or may contain question-like rises at ends of statements). Grammatical structures are often immature and include stereotyped and repetitive use of language (e.g., repetition of words or phrases regardless of meaning; repeating jingles or commercials) or idiosyncratic language (i.e., language that has meaning only to those familiar with the individual’s communication style). Language comprehension is often very delayed, and the individual may be unable to understand simple questions or directions. A disturbance in the pragmatic (social use) of language is often evidenced by an inability to integrate words with gestures or understand humor or non-literal aspects of speech such as irony or implied meaning. Imaginative play is often absent or markedly impaired. These individuals often tend not to engage in the simple imitation games or routines of infancy or early childhood or do so only out of context or in a mechanical way.

Individuals with Autistic Disorder have restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. There may be an encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus (Criterion A3a); an

apparently inflexible adherence to specific, nonfunctional routines or rituals (Criterion A3b); stereotyped and repetitive motor mannerisms (Criterion A3c); or a persistent preoccupation with parts of objects (Criterion A3d). Individuals with Autistic Disorder display a markedly restricted range of interest and are often preoccupied with one narrow interest (e.g., dates, phone numbers, radio station call letters). They may line up an exact number of playthings in the same manner over and over again or repetitively mimic the actions of a television actor. They may insist on sameness and show resistance to or distress over trivial changes (e.g., a younger child may have a catastrophic reaction to a minor change in the environment such as rearrangement of the furniture or use of a new set of utensils at the dinner table). There is often interest in the nonfunctional routines or rituals or an unreasonable insistence on following routines (e.g., taking exactly the same route to school every day). Stereotyped body movements include the hands (clapping, finger flicking) or whole body (rocking, dipping, and swaying). Abnormalities of posture (e.g., walking on tiptoe, odd hand movements and body postures) may be present. These individuals show a persistent preoccupation with parts of objects (buttons, parts of the body). There may also be a fascination with movement (e.g., the spinning wheels of toys, the opening and closing of doors, an electric fan or other rapidly revolving object). The person may be highly attached to some inanimate object (e.g., a piece of string or a rubber band.)

The disturbance must be manifest by delays or abnormal functioning in at least one (and often several) of the following areas prior to age 3 years: social interaction, language as used in social communication, or symbolic or imaginative play (Criterion B). In most cases, there is no period of unequivocally normal development, although in perhaps 20% of cases parents report relatively normal development for 1 or 2 years. In such cases, parents may report that the child acquired few words and lost these or seemed to stagnate developmentally.

By definition, if there is a period of normal development, it cannot extend past age 3 years. The disturbance must not be better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder (Criterion C).

## Associated Features and Disorders

**Associated descriptive features and mental disorders.** In most cases, there is an associated diagnosis of Mental Retardation, which can range from mild to profound. There may be abnormalities in the development of cognitive skills. The profile of cognitive skills is usually uneven, regardless of the general level of intelligence with verbal skills typically weaker than nonverbal skills. Sometimes special skills are present (e.g., a 4 ½-year-old girl with Autistic Disorder may be able to “decode” written materials with minimal understanding of the meaning of what is read [hyperlexia] or a 10-year-old boy may have prodigious abilities to calculate dates [calendar calculation]). Estimates of single-word (receptive or expressive) vocabulary are not always good estimates of language level (i.e., actual language skills may be at much lower levels).

Individuals with Autistic Disorder may have a range of behavioral symptoms, including hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behaviors, and, particularly in younger children, temper tantrums. There may be odd responses to sensory stimuli (e.g., a high threshold for pain, oversensitivity to sounds or being touched, exaggerated reactions to light or odors, fascination with certain stimuli). There may be abnormalities in eating (e.g., limiting diet to a few foods, Pica) or sleeping (e.g., recurrent awakening at night with rocking). Abnormalities of mood or affect (e.g., giggling or weeping for no apparent reason, an apparent absence of emotional reaction) may be present. There may be a lack of fear in response to real dangers, and excessive fearlessness in response to harmless objects. A variety of self-injurious behaviors may be present (e.g., head banging or finger, hand, or wrist biting.) In adolescence or early adult life, individuals with Autistic Disorder who have the intellectual capacity for insight may become depressed in response to the realization of their serious impairment.

### Associated laboratory findings

When Autistic Disorder is associated with a general medical condition, laboratory findings consistent with the general medical condition will be observed. There are group differences in some measures of

serotonergic activity, but these are not diagnostic for Autistic Disorder. Imaging studies may be abnormal in some cases, but no specific pattern has been clearly identified. EEG abnormalities are common even in the absence of seizure disorders.

**Associated physical examination findings and general medical conditions.** Various nonspecific neurological symptoms or signs may be noted (e.g., primitive reflexes, delayed development of hand dominance) in Autistic Disorder. The condition is sometimes observed in association with a neurological or other general medical condition (e.g., fragile X syndrome and tuberous sclerosis).

Seizures may develop (particularly in adolescence) in as many as 25% of cases. Both microcephaly and macrocephaly are observed. When other general medical conditions are present, they should be noted on Axis III.

## Specific Age and Gender Features

The nature of the impairment in social interaction may change over time in Autistic Disorder and may vary depending on the developmental level of the individual. In infants, there may be a failure to cuddle; an indifference or aversion to affection or physical contact; a lack of eye contact, facial responsiveness, or socially directed smiles; and a failure to respond to their parents' voices. As a result, parents may be concerned initially that the child is deaf. Young children with this disorder may treat adults as interchangeable, may cling mechanically to a specific person, or may use the parent's hand to obtain desired objects without ever making eye contact (as if it were the hand rather than the person that is relevant.) Over the course of development, the child may become more willing to be passively engaged in social interaction and may even become more interested in social interaction. However, even in such instances, the child tends to treat other people in unusual ways (e.g., expecting other people to answer ritualized questions in specific ways, having little sense of other people's boundaries, and being inappropriately intrusive in social interaction.) In older individuals, tasks involving long-term memory (e.g., train timetables, historical dates, chemical formulas, or recall of the exact words of songs heard years

before) may be excellent, but the information tends to be repeated over and over again, regardless of the appropriateness of the information in social context. Rates of the disorder are four to five times higher in males than in females. Females with the disorder are more likely, however, to exhibit more severe Mental Retardation.

## Prevalence

The median rate of Autistic Disorder in epidemiological studies is 5 cases per 10,000 individuals, with reported rates ranging from 2 to 20 cases per 10,000 individuals. It remains unclear whether the higher reported rates reflect differences in methodology or an increased frequency of the condition. For more up-to-date information on the prevalence rates of autism, please see page 6.

## Course

By definition, the onset of Autistic Disorder is prior to age 3 years. In some instances, parents will report that they have been worried about the child since birth or shortly afterward because of the child's lack of interest in social interaction. Manifestations of the disorder in infancy are more subtle and difficult to define than those seen after age 2 years. In a minority of cases, the child may be reported to have developed normally for the first year (or even 2 years) of life. Autistic Disorder follows a continuous course. In school-age children and adolescents, developmental gains in some areas are common (e.g., increased interest in social functioning as the child reaches school age). Some individuals deteriorate behaviorally during adolescence, whereas others improve. Language skills (e.g., presence of communicative speech) and overall intellectual level are the strongest factors related to ultimate prognosis. Available follow-up studies suggest that only a small percentage of individuals with the disorder go on as adults to live and work independently. In about one-third of cases, some degree of partial independence is possible. The highest functioning adults with Autistic Disorder typically continue to exhibit problems in social interaction and communication along with markedly restricted interests and activities.

## Familial Pattern

There is an increased risk of Autistic Disorder among siblings of individuals with the disorder, with approximately 5% of siblings also exhibiting the condition. There also appears to be risk for various developmental difficulties in affected siblings.

## Differential Diagnosis

Periods of developmental regression may be observed in normal development, but these are neither as severe or as prolonged as in Autistic Disorder. Autistic Disorder must be differentiated from other Pervasive Developmental Disorders. Rett's Disorder differs from Autistic Disorder in its characteristic sex ratio and pattern of deficits. Rett's Disorder has been diagnosed only in females, whereas Autistic Disorder occurs more frequently in males. In Rett's Disorder, there is a characteristic pattern of head growth deceleration, loss of previously acquired purposeful hand skills, and the appearance of poorly coordinated gait or trunk movements. Particularly during the preschool years, individuals with Rett's Disorder may exhibit difficulties in social interaction similar to those observed in Autistic Disorder, but these tend to be transient. Autistic Disorder differs from Childhood Disintegrative Disorder, which has a distinctive pattern of severe developmental regression in multiple areas of functioning following at least two years of normal development. In Autistic Disorder, developmental abnormalities are usually noted within the first year of life. When information on early development is unavailable or when it is not possible to document the required period of normal development, the diagnosis of Autistic Disorder should be made. Asperger's Disorder can be distinguished from Autistic Disorder by the lack of delay of deviance in early language development. Asperger's Disorder is not diagnosed if the criteria are met for Autistic Disorder.

Schizophrenia with childhood onset usually develops after four years of normal, or near normal, development. An additional diagnosis of Schizophrenia can be made if an individual with Autistic Disorder develops the characteristic features of Schizophrenia with active-phase symptoms of prominent delusions or hallucinations that last for at least 1 month. In Selective

Mutism, the child usually exhibits appropriate communication skills in certain contexts and does not have the severe impairment in social interaction and the restricted patterns of behavior associated with Autistic Disorder. In Expressive Language Disorder and Mixed Receptive-Expressive Language Disorder, there is language impairment, but it is not associated with the presence of a qualitative impairment in social interaction and restricted, repetitive, and stereotyped patterns of behavior. It is sometimes difficult to determine whether an additional diagnosis of Autistic Disorder is warranted in an individual with Mental Retardation, especially if the Mental Retardation is

Severe or Profound. An additional diagnosis of Autistic Disorder is reserved for those situations in which there are qualitative deficits in social and communicative skills and the specific behaviors characteristic of Autistic Disorder are present. Motor stereotypes are characteristic of Autistic Disorder; an additional diagnosis of Stereotypic Movement Disorder is not given when these are accounted for as a part of the presentation of Autistic Disorder. Symptoms of overactivity and inattention are frequent in Autistic Disorder, but a diagnosis of Attention-Deficit/Hyperactivity Disorder is not made if Autistic Disorder is present.

### Diagnostic criteria for 299.00 Autistic Disorder

(A) Total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
  - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
  - (b) failure to develop peer relationships appropriate to developmental level
  - (c) lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
  - (d) lack of social or emotional reciprocity
- (2) qualitative impairments in communication as manifested by at least one of the following:
  - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)
  - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
  - (c) stereotyped and repetitive use of language or idiosyncratic language
  - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - (a) encompassing preoccupation with one or more stereotyped patterns of interest that is abnormal either in intensity or focus
  - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
  - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - (d) persistent preoccupation with parts of objects

(B) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

(C) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

## 299.80 Rett's Disorder

### Diagnostic Features

The essential feature of Rett's Disorder is the development of multiple specific deficits following a period of normal functioning after birth. Individuals have an apparently normal prenatal and perinatal period (Criterion A1) with normal psychomotor development through the first five months of life (Criterion A2). Head circumference at birth is also within the normal limits (Criterion A3). Between ages five and forty-eight months, head growth decelerates (Criterion B1). There is a loss of previously acquired purposeful hand skills between ages five and thirty months, with the subsequent development of characteristic stereotyped hand movements resembling hand-wringing or hand washing (Criterion B2). Interest in the social environment diminishes in the first few years after the onset of the disorder (Criterion B3), although social interaction may often develop later in the course. Problems develop in the coordination of the gait or trunk movements (Criterion B4). There is also severe impairment in expressive and receptive language development, with severe psychomotor retardation (Criterion B5).

### Associated Features and Disorders

Rett's Disorder is typically associated with Severe or Profound Mental Retardation, which, if present, should be coded on Axis II. There are no specific laboratory findings associated with the disorder. There may be an increased frequency of EEG abnormalities and seizure disorder in individuals with Rett's Disorder. Nonspecific abnormalities on brain imaging have been reported.

### Prevalence

Data are limited to mostly case series, and it appears that Rett's Disorder is much less common than Autistic Disorder. This disorder has been reported only in females.

### Course

The pattern of developmental regression is highly distinctive. Rett's Disorder has its onset prior to age 4 years, usually in the first or second year of life. The duration of the disorder is lifelong, and the loss of skills is generally persistent and progressive. In most instances, recovery is quite limited, although some very modest developmental gains may be made and interest in social interaction may be observed as individuals enter later childhood or adolescence. The communicative and behavioral difficulties usually remain relatively constant throughout life.

### Differential Diagnosis

Periods of developmental regression may be observed in normal development, but these are neither as severe or as prolonged as in Rett's Disorder. For the differential between Rett's Disorder and Autistic Disorder, see page 36. Rett's Disorder differs from Childhood Disintegrative Disorder and Asperger's Disorder in its characteristic sex ratio, onset, and pattern of deficits. Rett's Disorder has been diagnosed only in females, whereas Childhood Disintegrative Disorder and Asperger's Disorder appear to be more common in males. The onset of symptoms in Rett's Disorder can begin as early as age 5 months, where in Childhood Disintegrative Disorder the period of normal development is typically more prolonged (i.e., at least until age 2 years). In Rett's Disorder, there is a characteristic pattern of head growth deceleration, loss of previously acquired purposeful hand skills, and the appearance of poorly coordinated gait or trunk movements. In contrast to Asperger's Disorder, Rett's Disorder is characterized by a severe impairment in expressive and receptive language development.

## Diagnostic criteria for 299.80 Rett's Disorder

- (A) All of the following:
- (1) apparently normal prenatal and perinatal development
  - (2) apparently normal psychomotor development through the first 5 months after birth
  - (3) normal head circumference at birth
- (B) Onset of all of the following after the period of normal development:
- (1) deceleration of head growth between ages 5 and 48 months
  - (2) loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)
  - (3) loss of social engagement early in the course (although often social interaction develops later)
  - (4) appearance of poorly coordinated gait or trunk movements
  - (5) severely impaired expressive and receptive language development with severe psychomotor retardation.

## 299.10 Childhood Disintegrative Disorder

### Diagnostic Features

The essential feature of Childhood Disintegrative Disorder is a marked regression in multiple areas of functioning following a period of at least 2 years of apparently normal development (Criterion A). Apparently normal development is reflected in age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior. After the first 2 years of life (but before age 10 years), the child has a clinically significant loss of previously acquired skills in at least two of the following areas: expressive or receptive language, social skills or adaptive behavior, bowel or bladder control, play, or motor skills (Criterion B). Most typically, acquired skills are lost in almost all areas. Individuals with this disorder exhibit the social and communicative deficits and behavioral features generally observed in Autistic Disorder (see page 70). There is qualitative impairment in social interaction (Criterion C1) and in communication (Criterion C2), and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (Criterion C3). The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia (Criterion D). This condition has also been termed Heller's syndrome, dementia infantilis, or disintegrative psychosis.

## Associated Features and Disorders

Childhood Disintegrative Disorder is usually associated with Severe Mental Retardation, which, if present, should be coded on Axis II. Various nonspecific neurological symptoms or signs may be noted. There seems to be an increased frequency of EEG abnormalities and seizure disorder. Although it appears likely that the condition is the result of some insult to the developing central nervous system, no precise mechanism has been identified. The condition is occasionally observed in association with a general medical condition (e.g., metachromatic leukodystrophy, Schilder's disease) that might account for the developmental regression. In most instances, however, extensive investigation does not reveal such a condition. If a neurological or other general medical condition is associated with the disorder, it should be recorded on Axis III. The laboratory findings will reflect any associated general medical conditions.

## Prevalence

Epidemiological data are limited, but Childhood Disintegrative Disorder appears to be very rare and much less common than Autistic Disorder. Although initial studies suggested an equal sex ratio, the most recent data suggest that the condition is more common among males.

## Course

By definition, Childhood Disintegrative Disorder can only be diagnosed if the symptoms are preceded by at least 2 years of normal development and the onset is prior to age 10 years. When the period of normal development has been quite prolonged (5 or more years), it is particularly important to conduct a thorough physical and neurological examination to assess for the presence of a general medical condition. In most cases, the onset is between ages 3 and 4 years and may be insidious or abrupt. Premonitory signs can include increased activity levels, irritability, and anxiety followed by a loss of speech and other skills. Usually the loss of skills reaches a plateau, after which some limited improvement may occur, although improvement is rarely marked. In other instances, especially when the disorder is associated with a progressive neurological condition, the loss of skills is progressive. This disorder follows a continuous course, and in the majority of cases, the duration is lifelong. The social, communicative, and behavioral difficulties remain relatively constant throughout life.

## Differential Diagnosis

Periods of regression may be observed in normal development, but these are neither as severe or as prolonged as in Childhood Disintegrative Disorder. Childhood Disintegrative Disorder must be differentiated from other Pervasive Developmental Disorders. For the differential diagnosis with Autistic Disorder, see page 36. For the differential diagnosis with Rett's Disorder, see page 76. In contrast to Asperger's Disorder, Childhood Disintegrative Disorder is characterized by a clinically significant loss in previously acquired skills and a greater likelihood of Mental Retardation. In Asperger's Disorder, there is no delay in language development and no marked loss of developmental skills.

Childhood Disintegrative Disorder must be differentiated from dementia with onset during infancy or childhood. Dementia occurs as a consequence of the direct psychological effects of a general medical condition (e.g., head trauma), whereas Childhood Disintegrative Disorder typically occurs in the absence of an associated general medical condition.

### Diagnostic Criteria for 299.10 Childhood Disintegrative Disorder

- (A) Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.
- (B) Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
  - (1) expressive or receptive language
  - (2) social skills or adaptive behavior
  - (3) bowel or bladder control
  - (4) play
  - (5) motor skills
- (C) Abnormalities of functioning in at least two of the following areas:
  - (1) qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
  - (2) qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
  - (3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypies and mannerisms
- (D) The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

## Asperger's Disorder

### Diagnostic Features

The essential features of Asperger's Disorder are severe and sustained impairment in social interaction (Criterion A) and the development of restricted, repetitive patterns of behavior, interests, and activities (Criterion B). The disturbance must cause clinically significant impairment in social, occupational, or other important areas of functioning (Criterion C). In contrast to Autistic Disorder, there are no clinically significant delays or deviance in language acquisition (e.g., single non-echoed words are used communicatively by age 2 years, and spontaneous communicative phrases are used by age 3 years) (Criterion D), although more subtle aspects of social communication (e.g., typical give-and-take in conversation) may be affected. In addition, during the first 3 years of life there are no clinically significant delays in cognitive development as manifested by expressing normal curiosity about the environment or in the acquisition of age-appropriate learning skills and adaptive behaviors (other than in social interaction) (Criterion E). Finally, the criteria are not met for another specific Pervasive Developmental Disorder or for Schizophrenia (Criterion F). This condition is also termed as Asperger's syndrome.

The impairment in reciprocal social interaction is gross and sustained. There may be marked impairment in the use of multiple nonverbal behaviors (e.g., eye-to-eye gaze, facial expression, body postures and gestures) to regulate social interaction and communication (Criterion A1). There may be failure to develop peer relationships appropriate to developmental level (Criterion A2) that may take different forms at different ages. Younger individuals may have little or no interest in establishing friendships. Older individuals may have an interest in friendship but lack understanding of the conventions of social interaction. There may be a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., not showing, bringing, or pointing out objects they find interesting) (Criterion A3). Lack of social or emotional reciprocity may be present (e.g., not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids) (Criterion A4). Although the

social deficit in Asperger's Disorder is severe and is defined in the same way as in Autistic Disorder, the lack of social reciprocity is more typically manifest by an eccentric and one-sided social approach to others (e.g., pursuing a conversational topic regardless of others' reactions) rather than social and emotional indifference.

As in Autistic Disorder, restricted, repetitive patterns of behavior, interests, and activities are present (Criterion B). Often these are primarily manifest in the development of encompassing preoccupations about a circumscribed topic of interest, about which the individual can amass a great deal of facts and information (Criterion B1). These interests and activities are pursued with great intensity often to the exclusion of other activities.

The disturbance must cause clinically significant impairment in social adaptation, which in turn may have significant impact on self-sufficiency or on occupational or other important areas of functioning (Criterion C). The social deficits are restricted patterns of interests, activities, and behavior are the source of considerable disability.

In contrast to Autistic Disorder, there are no clinically significant delays in the early language (e.g., single words are used by age 2, communicative phrases are used by age 3). (Criterion D). Subsequent language may be unusual in terms of the individual's preoccupation with certain topics and his or her verbosity. Difficulties in communication may result from social dysfunction and the failure to appreciate and utilize conventional rules of conversation, failure to appreciate nonverbal cues, and limited capacities for self-monitoring

Individuals with Asperger's Disorder do not have clinically significant delays in cognitive development or in the age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood (Criterion E). Because early language and cognitive skills are within normal limits in the first three years of life, parents or caregivers are not usually concerned about the child's development during that time, although upon detailed interviewing they may recall unusual behaviors. The child may be described as talking before walking, and

indeed parents may believe the child to be precocious (e.g., with a rich or “adult” vocabulary). Although subtle social problems may exist, parents or caregivers often are not concerned until the child begins to attend a preschool or is exposed to same-age children; at this point the child’s social difficulties with same-age peers may be apparent.

By definition the diagnosis is not given if the criteria are met for any other specific Pervasive Developmental Disorder or for Schizophrenia (although the diagnoses of Asperger’s Disorder and Schizophrenia may coexist if the onset of Asperger’s Disorder clearly preceded the onset of Schizophrenia) (Criterion F).

## Associated Features and Disorders

In contrast to Autistic Disorder, Mental Retardation is not usually observed in Asperger’s Disorder, although occasional cases in which Mild Mental Retardation is present have been noted (e.g., when Mental Retardation becomes apparent only in the school years, with no apparent or language delay in the first years of life). Variability of cognitive functioning may be observed, often with strengths in areas of verbal ability (e.g., vocabulary, rote auditory memory) and weaknesses in non-verbal areas (e.g., visual-motor and visual-spatial skills). Motor clumsiness and awkwardness may be present but usually are relatively mild, although motor difficulties may contribute to peer rejection and social isolation (e.g., inability to participate in group sports). Symptoms of overactivity and inattention are frequent in Asperger’s Disorder, and indeed many individuals with this condition receive a diagnosis of Attention Deficit/Hyperactivity Disorder prior to the diagnosis of Asperger’s Disorder. Asperger’s Disorder has been reported to be associated with a number of other mental disorders, including Depressive Disorder.

### Specific Age and Gender Features

The clinical picture may present differently at different ages. Often the social disability of individuals with the disorder becomes more striking over time. By adolescence some individuals with the disorder may learn to use areas of strength (e.g., rote verbal abilities) to compensate for other areas of weakness. Individuals with Asperger’s Disorder may experience victimization

by others; this, and feelings of social isolation and an increasing capacity for self-awareness, may contribute to the development of depression and anxiety in adolescence and young adulthood. The disorder is diagnosed much more frequently (at least five times) in males than in females.

## Prevalence

Definitive data regarding the prevalence of Asperger’s Disorder are lacking.

## Course

Asperger’s Disorder is a continuous and lifelong disorder. In school-age children, good verbal abilities may, to some extent, mask the severity of the child’s social dysfunction and may also mislead caregivers and teachers. That is, caregivers and teachers may focus on the child’s good verbal skills but be insufficiently aware of problems in other areas (particularly social adjustment). The child’s relatively good verbal skills may also lead teachers and caregivers to erroneously attribute behavioral difficulties to willfulness or stubbornness in the child. Interest in forming social relationships may increase in adolescence as the individuals learn some ways in responding more adaptively to their difficulties—for example, the individual may learn to apply explicit verbal rules or routines in certain stressful situations. Older individuals may have an interest in friendship but lack understanding of the conventions of social interaction and may more likely make relationships with individuals much older or younger than themselves. The prognosis appears significantly better than in Autistic Disorder, as follow-up studies suggest that, as adults, many individuals are capable of gainful employment and personal self-sufficiency.

## Familial Pattern

Although the available data are limited, there appears to be an increased frequency of Asperger’s Disorder among family members of individuals who have the disorder. There may also be an increased risk for Autistic Disorder as well as more general social difficulties.

## Differential Diagnosis

Asperger's Disorder must be distinguished from the other Pervasive Developmental Disorders, all of which are characterized by problems in social interaction. It differs from Autistic Disorder in several ways. In Autistic Disorder there are, by definition, significant abnormalities in the areas of social interaction, language, and play, whereas in Asperger's Disorder early cognitive and language skills are not delayed significantly. Furthermore, in Autistic Disorder, restricted, repetitive, and stereotyped interests and activities are often characterized by the presence of motor mannerisms, preoccupation with parts of objects, rituals, and marked distress in change, whereas in Asperger's Disorder these are primarily observed in the all-encompassing pursuit of a circumscribed interest involving a topic to which the individual devotes inordinate amounts of time amassing information and facts. Differentiation of the two conditions can be problematic in some cases. In Autistic Disorder, typical social interaction patterns are marked by self-isolation or markedly rigid social approaches, whereas in Asperger's Disorder there may appear to be motivation for approaching others even though this is then done in a highly eccentric, one-sided, verbose, and insensitive manner.

Asperger's Disorder differs from Childhood Disintegrative Disorder, which has a distinctive pattern of developmental regression following at least 2 years of normal development. Children with Childhood Disintegrative Disorder also display marked degrees of Mental Retardation and language impairment. In contrast, in Asperger's Disorder there is no pattern of developmental regression and, by definition, no significant cognitive or language delays.

Schizophrenia of childhood onset usually develops after years of normal, or near normal, development, and characteristic features of the disorder, including

hallucinations, delusions, and disorganized speech, are present. In Selective Mutism, the child usually exhibits appropriate communication skills in certain contexts and does not have the severe impairment in social interaction and the restricted patterns of behavior associated with Asperger's Disorder. Conversely, individuals with Asperger's Disorder are typically verbose. In Expressive Language Disorder and Mixed Receptive-Expressive Language Disorder, there is language impairment but no associated qualitative impairment in social interaction and restricted, repetitive, and stereotyped patterns of behavior. Some individuals with Asperger's Disorder may exhibit behavioral patterns suggesting Obsessive-Compulsive Disorder, although special clinical attention should be given to the differentiation between preoccupations and activities in Asperger's Disorder and obsessions and compulsions in Obsessive-Compulsive Disorder. In Asperger's Disorder these interests are the source of some apparent pleasure or comfort, whereas in Obsessive-Compulsive Disorder they are the source of anxiety. Furthermore, Obsessive-Compulsive Disorder is typically not associated with the level of impairment in social interaction and social communication seen in Asperger's Disorder.

The relationship between Asperger's Disorder and Schizoid Personality Disorder is unclear. In general, the social difficulties in Asperger's Disorder are more severe and of earlier onset. Although some individuals with Asperger's Disorder may experience heightened and debilitating anxiety in social settings as in Social Phobia or other Anxiety Disorders, the latter conditions are not characterized by pervasive impairments in social development or by the circumscribed interests typical of Asperger's Disorder. Asperger's Disorder must be distinguished from normal social awkwardness and normal age-appropriate interests and hobbies. In Asperger's Disorder, the social deficits are quite severe and the preoccupations are all-encompassing and interfere with the acquisition of basic skills.

## Diagnostic criteria for 299.80 Asperger's Disorder

- (A) Qualitative impairment in social interaction, as manifested by at least two of the following:
- (1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
  - (2) failure to develop peer relationships appropriate to developmental level
  - (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
  - (4) lack of social or emotional reciprocity
- (B) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
- (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - (2) apparently inflexible adherence to specific, nonfunctional routines or rituals
  - (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - (4) persistent preoccupation with parts of objects
- (C) The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- (D) There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- (E) There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- (F) Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

## Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder.

For example, this category includes "atypical autism"-presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

# Additional Resources

## COSAC Publications

COSAC provides a wide variety of autism-related resources and referral lists to both parents and professionals: basic information about autism, lists of books, schools, camps, residential services, special education attorneys, dentists, pediatricians, and much more. We also maintain files on various topics including research, treatment, and family issues. In addition, we also produce several newsletters as a benefit to our members. For more information on obtaining any of these resources, visit [www.njcosac.org](http://www.njcosac.org), or mail in the publication order form located on page 47 of this booklet.

## Resources for Additional Reading

Harris, S. L., and Glasberg, B. (2003). *Siblings of children with autism: A guide for families* (2nd ed.). Bethesda, MD: Woodbine House. ISBN: 1890627291.

Harris, S. L., and Weiss M. J. (2007). *Right from the start: Behavioral intervention for young children with autism* (2nd ed.). Bethesda, MD: Woodbine House. ISBN: 189062702X.

Howlin, P. (1996). *Autism: Preparing for adulthood*. London: Routledge. ISBN: 0-415-11532.

Klin, A., Volkmar, F. R., & Sparrow S. S. (2000). *Asperger's Syndrome*. New York: Guilford Publications, Incorporated. ISBN: 1-57230-534-7.

Maurice, C. (1994). *Let me hear your voice: A family's triumph over autism*. New York: Random House, Inc. ISBN: 0-449-90664-7.

Maurice, C., Luce, S. C., & Green, G. (1996). *Behavioral intervention for young children with autism: A manual for parents & professionals*. Austin, TX: PRO-ED. ISBN: 0890796831.

Meyer, D. (1997). *View from our shoes: Growing up with a brother or sister with special needs*. Bethesda: Woodbine House. ISBN: 0933149980.

Powers, M. (2000). *Children with autism: A parents' guide* (2nd ed.). Bethesda, MD: Woodbine House. ISBN: 1890627046.

Sundberg, M., & Partington, J. (1998). *Teaching language to children with autism or other developmental disabilities*. Pleasant Hill, CA: Behavior Analysts, Inc. ISBN: 0968098509.

## Where to Find More Information About Autism Spectrum Disorders

### Your Local Library

Ask the librarian to help you find more information about a specific diagnosis. In order to access the most accurate information, check to see that the resources at the library are recent.

### A University Library

University libraries house professional journals and other publications that include the most up-to-date information about diagnosis, cause, and treatment of various disorders. Ask the librarian how to find this information. A medical school library, a graduate school of psychology, or a graduate school of education would be most likely to contain the publications that would be helpful for you.

### Bookstores

Many large bookstores carry recent publications about specific diagnosis and treatment. Ask a salesperson to point you in the right direction. Online bookstores may carry even more titles. Try using keywords to search these stores.

### The Internet

Searching various online databases may lead you to a wealth of information on a specific topic. However, the information on the web is not necessarily reviewed or approved by professionals. Therefore, you must be a cautious consumer of information that has been found online. Be careful, especially of information with no clear authorship or from organizations not affiliated with trusted or recognizable sources.

### Conferences

Attend a conference arranged by an organization that promotes scientifically-based information on autism spectrum disorders. Conferences are an excellent source of current information. Often, conference attendees have a variety of workshops to choose from and may be able to ask specific questions of experts in a field. (Contact COSAC for more information on our annual conference and to be placed on the registration brochure mailing list.)

### Learning Resource Centers (LRCs)

There are four federally funded LRCs in New Jersey. These centers offer information, loan of materials, consultation and production services to educators and parents of special education students in New Jersey. To find out the location and telephone numbers of the LRC closest to you, please call COSAC or refer to our Resource Packet.

### Support Groups

Parents of individuals with autism spectrum disorders often have gathered volumes of information through either research or experience. Support groups are a great place to meet parents and find out what they know about a specific diagnosis or treatment.

### COSAC

As the premier organization in New Jersey concerned with autism, COSAC offers a wide variety of information, referrals, workshops, conferences, parent support, and professional education. Please contact COSAC at 609-883-8100, 1-800-4-AUTISM, [information@njcosac.org](mailto:information@njcosac.org), or visit [www.njcosac.org](http://www.njcosac.org) for more information on these services or to download many of COSAC's publications and referral lists.

# Publication Order Form

Many of these publications are available to download from COSAC's website, [www.njcosac.org](http://www.njcosac.org).

## Agency Information *The following are free of charge.*

**COSAC Agency Brochure** - Describes goals and services of COSAC.

**COSAC Fact Sheet** - Brief description of COSAC services.

## General Information

The following are available for a nominal fee after the first free copy.

**Autism: Questions & Answers** - A brochure for laypeople, written in non-technical terms, giving general facts about autism spectrum disorders.

**What to look for in a Specialized Program** - Guidelines for selecting a specialized school or program for children with autism.

**Employment Options for Adults with Autism** - Describes work options for adults with autism and guidelines for selecting a program.

**Issues in Autism: Residential Options** - Guidelines for selecting a community residential placement for individuals with autism.

## Newsletter

The following is available only to COSAC members. See below for membership information

**UpDate** - A bi-monthly newsletter for parents of individuals with autism, service providers and other professionals who are interested in autism.

## Booklets

The following are available for a nominal fee after the first free copy.

**Autism: Basic Information** - Please consider sharing with others how valuable this resource has been for you.

**Applied Behavior Analysis & Autism: An Introduction** - An overview of Applied Behavior Analysis for parents and professionals.

**Introduction to Autism Services: A New Jersey Guide** - A guide to services for parents of children with autism.

**Consumer Guidelines** - A guide for identifying, selecting and evaluating behavior analysts and working with individuals with ASDs.

## Additional Information Available

COSAC produces a number of fact sheets, referral lists, reading lists, and other publications for the autism community (including information in Spanish). Please note that many of these publications only refer to New Jersey-based services. These publications are as follows:

Referral lists (*Adult Employment Programs, Agency Providers of Behavior Intervention, Camps, Community Residential Placements, Diagnosticians & Neurologists, Dentists, Lawyers, Pediatricians, Presenters, Psychiatrists/Psychologists/Social Workers/Counselors, Recreation/Adult Vacation/Travel, Respite/After-school/Childcare, Schools, Speech/Occupational/Physical Therapy, Support Groups*)  
Autism Spectrum Disorders Fact Sheet  
IEP Packet (based on New Jersey law)  
Kids Booklet  
The Next Step  
NJ Division of Developmental Disabilities (DDD) Packet  
Reading List for Kids  
Resource Packet  
Transition IEP Packet (for children 14 and over)  
Sibling Pen Pal Program Sign-Up

## Membership

Please consider becoming a member. Your membership fees help ensure that our services are available to families and professionals throughout New Jersey. Add your membership fees to any publication fees or donations below. Visit our website, [www.njcosac.org](http://www.njcosac.org), or call 1-800-4-AUTISM for more information about the benefits of membership. Corporate and agency memberships also are available.

## To Order...

Please circle the items you wish to receive and write the quantity in the margin.

Duplicate or volume order requests **must be accompanied by a check or money order** made payable to COSAC for the owed amount. We welcome and appreciate your tax deductible contributions as well.

Please Print Clearly or Type

Ms. Mr. Mrs. \_\_\_\_\_

Address \_\_\_\_\_ County (if NJ) \_\_\_\_\_

Are you a Service Provider? Yes No If yes, please specify

Are you a parent of a child or adult with autism? Yes No What are your child's age & sex? \_\_\_\_\_

Phone ( ) \_\_\_\_\_

Publication fees \$ \_\_\_\_\_ Membership fees \$40(Basic) \$75(Silver) \$150(Gold)

Tax Deductible contribution enclosed \$ \_\_\_\_\_ Total Amount \$ \_\_\_\_\_

Would you like to be added to our mailing list? Yes No

## Please send check (if applicable) and completed form to:

The New Jersey Center for Outreach & Services for the Autism Community (COSAC)

1450 Parkside Avenue, Suite 22, Ewing, NJ 08638

1800.4.AUTISM, 609.883.8100, 609.883.5509 fax

information@njcosac.org, www.njcosac.org









