

Screening and Diagnosis

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It was 11:32 p.m. I was changing my 4-month-old daughter's diaper when I noticed her characteristic movements. I knew that look, the expression of a blank stare, wrists and ankles circling as arms and legs flapped. Parents of kids with autism know it as self-stimulating behavior or "stimming."

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I called our pediatrician and voiced my concerns as I tried to manage my emotions. That red flag was all too familiar. My son, who was 8 years older than his sister, had been diagnosed with autism five years earlier (two years and several specialists after the first signs were detected). The pediatrician told me that there was nothing he could do, for there was no known testing or screening for my daughter until she was at least 18 months of age. I was dumbfounded, since I knew how important early intervention was.

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Nevertheless, I couldn't make an appointment until my daughter was 18 months, and then it took an additional 4 months for her to be seen by the diagnostic team at the local hospital.

Developmental delay was her first diagnosis. Even though all the signs of autism were present, the main evaluator did not believe that autism ran in families or that it could be shared by siblings. My daughter was only mimicking my son, it was suggested. After checking further, she was diagnosed with PDD-NOS. She still exhibits self-stimulating behavior seven and a half years later. The difference is that now I am not the only one to notice it. Others see it too.

There is no blood test to determine if a child has an autism spectrum disorder. The diagnosis is referred to as a *descriptive diagnosis*, meaning the diagnosis is based on observation of the child's behavior. This chapter covers early signs that parents might notice and screening and diagnostic instruments that professionals may use to make the diagnosis of autism spectrum disorder.

Early Signs

The characteristic behaviors of ASD may or may not be obvious in infancy (12-18 months), but usually becomes more apparent during early childhood (18 months to 6 years). Children with high functioning ASD may not be identified until much later because they often show no delay in the development of fundamental language skills.

"Red Flags" of Autism

- Does not babble or coo by 12 months
- Does not gesture (point, wave, grasp) by 12 months
- Does not say single words by 16 months
- Does not say two-word phrases on his own by 24 months
- May lose language or social skills after having acquired them

“Red Flags” of High Functioning ASD

Sometimes children with High Functioning ASD may not be diagnosed until after the age of 5 and parents may notice some of the following symptoms.

- Clumsy
- Hyperactive
- Language processing speed (may be slow to understand and respond to requests or may not be able to say what she needs)
- Social skills (may make inappropriate comments, may talk to everyone about a topic of interest)
- Early reading and math skills (may read early but not comprehend what’s read, or acquire math skills long before same-age peers)

Demonstrating more than one of these red flags does not necessarily mean your child has an ASD. However, it does indicate a need for further evaluation. Many of the behaviors associated with ASD are shaped by other disorders, such as intellectual disabilities or behavioral disorders. Various assessments may be necessary to rule out or identify other possible explanations for symptoms being exhibited. It is important to distinguish ASD from other conditions, since an accurate diagnosis and early identification provide the basis for building an appropriate and effective program.

Where to Turn for an Evaluation

If you’re concerned about your child’s development, talk to your child’s pediatrician. He or she may be able to refer you for further evaluation. If your pediatrician does not share your concerns, consider seeking a second opinion from a professional who specializes in ASD.

If your child is in preschool or elementary school, talk to his teacher. If your child is not yet in school, you may still contact your local school district. The school district is responsible for identifying all children with disabilities.

If your child is under 3 years of age, you may also contact Ohio’s early intervention program called *Help Me Grow*. The program is designed for parents of newborns, infants, and toddlers, and it provides both health and developmental services. *Help Me Grow* connects families with the resources they need, including assessment services. Call (800) 755-GROW (4769).

For further information on the process of determining eligibility for special education services, see Appendix E.

Help Me Grow is Ohio's federally mandated early intervention program. It provides services to children birth through age 3 who have identified disabilities or are at risk for developmental delays. It ensures that children with developmental delays and disabilities have access to and receive needed intervention services.

Any family, regardless of income level, with a concern about the development of their infant or toddler, is entitled to an evaluation and assessment to determine eligibility for services. Any child under the age of 3 who has a specified developmental delay or medical condition that is likely to result in a delay is eligible for *Help Me Grow* services.

Help Me Grow brings together parents and health, education, and social service professionals. This team writes an Individualized Family Service Plan (IFSP) based on the family's priorities and the child's developmental needs. The IFSP becomes the road map for the services the family and their young child will receive.

An evaluation can also be obtained at a children's hospital or clinic with a developmental psychiatrist or psychologist, or other appropriate, licensed professional.

An ASD is diagnosed by observation of the child's communication, behavior, and developmental levels. A brief observation in a single setting cannot present a true picture of the child's abilities and behaviors. Parental (and other caregivers' and/or teachers') input and the child's developmental history are important components in making an accurate diagnosis. See Appendix A for the Diagnostic Criteria for ASD from the DSM 5.

Ideally, an evaluation is completed by a team of professionals from various backgrounds, which may include a combination of any of the following:

- **Developmental pediatrician** – Treats health problems of children with developmental delays or handicaps. (A pediatric neurologist may be used in place of, or in addition to, a developmental pediatrician.)
- **Child psychiatrist** – A medical doctor who can prescribe medication and provide help in behavior, emotional adjustment, and social relationships.
- **Clinical psychologist** – Specializes in understanding the nature and impact of developmental disabilities, including ASD. May perform psychological and assessment tests, as well as help with behavior modification and social skills training.
- **Occupational therapist** – Focuses on practical, self-help skills that will aid in daily living, such as dressing and eating. May also work on sensory integration, coordination of movement, and fine-motor skills.
- **Physical therapist** – Helps to improve the use of bones, muscles, joints, and nerves to develop muscle strength, coordination, and motor skills.
- **Speech/language pathologist** – Involved in the improvement of communication skills, including speech and language.

- **Social worker** – May provide counseling services or act as case manager helping to arrange services and treatments.

The evaluation process may include a variety of assessment tools, such as:

- Childhood Autism Rating Scale (CARS)
- The Modified Checklist for Autism in Toddlers (M-CHAT)
- The Social Communication Questionnaire (SCQ)
- The Autism Diagnostic Observation Schedule (ADOS)
- The Autism Diagnostic Interview – Revised (ADI-R)
- Gilliam Autism Rating Scale (GARS)
- Psychoeducational Profile, 3rd Edition (PEP-III)
- Parent Interviews for Autism (PIA)

According to the Individuals with Disabilities Education Act (IDEA), if a child has a disability, the child is entitled to a free and appropriate public education (FAPE). FAPE means an individualized educational program (IEP) that is designed to meet the child's unique needs. FAPE includes special education and related services that are provided for the child's educational benefit. In Ohio, the medical diagnosis of autism is not required for a child to be identified under the category of autism by the school team and to receive special education services. For more information about educational identification and accessing special education services, see Chapter 5.

Seek out other parents and discuss your child's situation with them. Learn about their experiences. Often other parents are one of your best sources of information. In addition, remember that you are allowed to invite any individual (e.g., extended family member, friend, or neighbor) to participate in your child's IEP meeting. Bring people who can help develop an IEP for your child.

What Will Happen During the Diagnostic Assessment Process?

You will very likely have to wait some time, from several weeks to several months, to obtain an appointment at an autism clinic or with a professional who performs autism assessments. Each diagnostic process will differ based on the practices of the professionals involved and the assessment(s) they are using.

When you make the appointment, be sure to ask the following:

- How long is the waiting period to obtain an assessment?
- What professionals will be involved?
- What assessments will be performed?
- What records will be required from you?
- What will you need to do to prepare for the appointment?
- How many adults will be in the room with your child during the appointment?
- What will happen with your child during the appointment?
- Will you accompany your child during the assessment process?
- How long will the assessment process take?
- How long will it be until you will hear the results of the assessment?
- How long will it be until you have a written report?

Dealing with Professionals

When the doctor told me that my son had autism, I was devastated. "Will he end up living at Bittersweet Farms (a residential facility for adults with autism)?" I asked. The doctor looked at the social worker and rolled her eyes. "No way," she said. I was about to breathe a sigh of relief when she added with a laugh, "They have 100 people on their waiting list. There's no way he'll ever get in!" I had just been told that my second child, like my first, had autism. I completely shut down, grabbed my child and ran out to my car. I was reeling from the news. Do you think anyone from the doctor's office called me? Well, actually, the social worker did, but only to tell me that I had better get my son involved in a home program. Not a word was said to address how I was feeling.

As soon as your child is diagnosed with autism, and possibly before, you will most likely begin dealing with a number of professionals.

The following are some of the professionals you may encounter:

- **Medical professionals** – pediatrician, developmental-behavioral pediatrician, neurologist
- **Mental health professionals** – psychiatrist, psychologist, neuropsychologist, social worker, caseworker
- **School personnel** – special education teacher, general education teacher, school psychologist, counselor, special education director, school principal
- **Therapists** – behavioral therapist, speech therapist, occupational therapist, physical therapist, play therapist, music therapist
- **Service coordinators** – early interventionist, DODD (developmental disabilities) service and support specialist, Family and Children First Council (FCFC) specialist

It can be intimidating to have to deal with so many different professionals. Professionals often speak in their discipline’s “jargon”, which helps them speak shorthand to each other. It can also serve to distance them from their patients/clients. This distance can sometimes seem like arrogance and insensitivity, and can seem particularly painful the first time a family is told their child has autism. Families remember this moment for the rest of their lives. Many have horror stories, like the ones in the vignette above, about remarks and behaviors of professionals at these meetings.

It is not that the professionals are uncaring; after all, they chose careers helping children. It is usually because they do not have the training (or the time) to help families process their feelings about the information they are receiving. It is unrealistic to think families will not have strong reactions to receiving a diagnosis of ASD for their child.

Suggestions for Dealing with Professionals

- First, allow yourself to have the feelings you experience. It is not necessarily a bad thing to show emotion in front of professionals. It will help them develop empathy and a better understanding of what you are going through.
- Communicate your level of stress by sharing actual examples of what you are going through. For example, let the IEP team know that your child is locking himself in the bathroom for three hours every night to avoid doing his homework or that your child (and you) are only sleeping three hours a night.

- Do not be intimidated by the expertise of professionals. They are the “experts” in their field, but remember that you are the expert on your child. You have information that is just as valuable and you deserve to be treated with respect.
- If possible, both parents should attend meetings. Even if you are a single parent, it is in your child’s best interest for parents to work together. Each parent may request a separate parent teacher conference, but schools are only required to conduct one set of Multi-Factored Evaluation (MFE) or IEP meetings. Both parents should have access to information about their child unless the court has prohibited one or the other parent from being involved.
- Everyone filters out some information, especially information that arouses intense feelings. Bring a friend or advocate to meetings to help you hear and remember what is being said.
- Make a list of questions when you think of them. Bring the list with you to appointments. Write down the answers as soon as you can or have a friend take notes.
- Ask professionals to explain what they have said in plain English until you understand it.
- If there is not time for them to explain everything to your satisfaction, ask to schedule another meeting.
- Find out how you can communicate with a professional if you have questions later on.
- Clarify early on what (services) you can expect from the professional. For example, find out if the particular doctor provides diagnosis or assessments for the disability you suspect. Some pediatricians cannot or will not diagnose ASD.
- Communicate often.
- Keep communication open. Discuss problems as soon as they arise. Be honest. Give the professional a chance to address any problems.
- Be prepared. Professionals have limited time. Appointments will go more smoothly if you have done your homework and are ready with questions.
- Keep appointments or call if you can’t keep them.
- Put everything in writing. Keep notes of every appointment and phone call. (See Parent Record-Keeping Worksheet in Appendix B.)
- View professionals as resources in their fields. Continue to ask questions until you understand their position. Sometimes the professional does not have the most current information. Parents of children with autism are often in a position of knowing more than the professional.
- Remember that everyone has biases. Ask and understand what they are. For example, a surgeon’s solution to a medical problem is usually to cut. A medical doctor’s may be to use medication. Ask for data to support their recommendations.
- Don’t assume that professionals are only interested in what is best for your child. They may have competing interests. For example, a school system is only required to provide your child an “appropriate program,” not necessarily the best program. They are trying to use their dollars most efficiently for many children. You want the best program for your child.
- Learn your rights.

- Be a good consumer. To advocate for a particular treatment method or service, do your homework and bring the research with you.
- Figure out what you really want for your child and state it as a goal. Instead of demanding a particular treatment or service, ask the professionals how they propose to help your child to achieve the goal. Then ask if what they propose is going to work and how they know that.
- Demand accountability. Professionals should have data and research to show what works.
- Ask for periodic reports so you can monitor your child's progress.
- Ask for a meeting to discuss if a treatment or therapy is not working.
- Remember it is okay, and you have the right, to disagree with professionals and, ultimately, to decide what is right for your child and family.
- Be respectful, even if you disagree. Explain your point of view in a calm, courteous way.
- If a relationship with a professional breaks down and is beyond repair or you just don't feel comfortable, you have the right to leave.
- Beware if you are continually jumping from one professional to another. Ask yourself if you have some unresolved feelings you need to deal address.
- Nurture and cultivate relationships with professionals, especially those who are working directly with your child. Your child will need all the advocates he can get.
- Consider bringing brownies to a meeting. Chocolate makes everyone feel better.
- Thank professionals in writing when they have helped you. Also write to their supervisors about how they have helped your child.

You and your child will most likely be dealing with a host of professionals for his entire life. You will get more help for your child if you can learn to build strong relationships with those who are in a position to help him. This will start with you believing that you are an equal partner in parent-professional collaborations and continue as you nurture those relationships.

Dual Diagnosis or Comorbidity

Little by little we began to ask everyone who knew him if they thought there was something else going on with Peter Ben. Didn't some of the things he did look autistic? Was this possible? Down Syndrome I knew really well. I had lived and worked with many people with Down Syndrome, both children and adults. My son Peter Ben wasn't behaving like any I had known. Could it be autism? Autism I didn't know.

Our wonderful pediatrician confessed he didn't see the purpose in adding more labels to our son, but he too was very surprised that Peter Ben's language had almost stopped. No one from school wished to commit to the possibilities of a second diagnosis, but many characteristics our son had were so telling after a while.

It was the other parents who tipped our hand for us. There was the mom who saw us struggling with Peter Ben at a school function and asked, "How come I haven't seen you at the Autism Society meetings?" Another woman said, "I know he has Down Syndrome. What else is going on with him?" Finally, we got an appointment at Children's Hospital with a psychologist who was able to evaluate Peter Ben. Yep. He met the criteria by several counts. He had autism.

People with ASD can have two or more separate diagnoses, including mental health, medical conditions, or other developmental disabilities. This is referred to as *dual diagnosis*, *comorbidity*, or *co-existing conditions*.

... With Specific Developmental Disabilities

It can be difficult to identify and diagnose symptoms and traits of ASD as distinct from other developmental disabilities that can cause speech and communication delays, low muscle tone, sensitivities to/unawareness of light, sound, or different kinds of touch, or demonstration of repetitive movements. It is important to understand the difference between symptoms in children who only have other conditions and those who also have ASD, because it could impact the treatment and services a child receives.

It is well documented that ASD can co-exist with many other conditions. Each year more parents are getting accurate diagnoses of ASD among their children who also have:

- Fragile X syndrome
- Epilepsy and seizure disorders
- Visual impairment/blindness
- Hearing impairment/deafness
- Down Syndrome
- Tuberous sclerosis
- Cerebral palsy
- Angelman's Syndrome
- Eating disorders
- William's Syndrome
- Prader-Willi Syndrome
- Fetal alcohol syndrome or effect

It is not the intent to describe each condition in detail here. However, if you suspect autistic behaviors or traits in your child who has another developmental disability, please pursue an evaluation from a qualified professional. Having an accurate diagnosis of ASD for a child with a co-existing disability can help make important decisions for treatment and education.

(For example, behaviors may be misinterpreted without a proper diagnosis. Sometimes an adult may declare that a child is "choosing" to ignore verbal directions, when that child is, in fact, too overwhelmed by environmental noises as a result of her ASD. In such a case, using pictures or written words instead of verbal directions is recommended, but such interventions are often not considered for a child who has normal hearing and can say some words.)

Some disability support organizations, such as those for Fragile X, Down Syndrome, and sensory impairments (visually impaired, hearing impaired) offer specific resources and support for the dual diagnosis that includes ASD. These include organizations like the Upside of Downs, the National Association of the Deaf, National Federation for the Blind, and Disability Solutions.

If anyone from whom you are seeking help says “there is no such thing as a dual diagnosis, you’re just in denial about your child,” seek another opinion!

... With Other Diagnoses – Common Disorders That Occur with ASD

Just as a child with epilepsy can suffer from anxiety, depression, motor difficulties, speech delays, or any other condition, an individual with ASD can suffer from other symptoms or disorders. Though these conditions can and should be treated, their treatment does not address the distinctive symptoms of ASD, such as impairment in social interaction, restricted repetitive and stereotyped patterns of behavior or interests, and so on, and thus the primary diagnosis of ASD should not be ignored.

Examples of co-occurring/dual diagnoses include the following:

Mental Health

- Bipolar disorder
- Generalized anxiety
- Obsessive compulsive disorder
- Oppositional-defiant disorder
- Depression
- Schizophrenia
- Mood disorder

Neurological

- Seizure disorder (estimated at up to 25 percent of individuals with ASD)
- Tourette’s Syndrome
- Sleep disorders
- Learning disabilities
- Attention deficit disorder (ADD or ADHD)
- Sensory integration disorder
- Executive functioning disorder

Physical

- Cerebral palsy
- Muscular dystrophy
- Abnormal gait
- Poor coordination

Medical

- Diabetes
- Asthma
- Heart conditions
- Vision loss
- Hearing loss
- Allergies
- Gastrointestinal conditions
- Hypoglycemia

In addition to the specific diagnoses above, unusual responses to sensory stimuli, sleep problems, and low muscle tone can occur in individuals with ASD.

While generalized anxiety or panic disorders are frequently co-occurring disorders in their own right, anxiety is also an inevitable outcome for individuals on the spectrum who try to fit into neurotypical society (Gutstein, 2004). Other symptoms of living with ASD may also look like a separate disorder, although they are an expression of ASD.

Resources

Autism Spectrum Disorders:

Autism Society of America: <http://www.autism-society.org>

Holtz, K., Ziegert, A., & Baker, C. (2004). *Life journey through autism: An educator's guide*. Silver Springs, MD: Organization for Autism Research, Danya International.
Also available at www.autismresearch.org.

Dual Diagnosis:

Riverbend Down Syndrome: <http://www.riverbendds.org/index.htm?page=home.html>

Deafness and Autism:

About.com: deafness.about.com/cs/multiplendisab/a/autism.htm

Visual Impairment and Autism:

Texas School for the Blind: <http://www.tsbvi.edu/143-mivi-general/965-autism-and-visual-impairment>

Fragile X and ASD:

National Fragile X Foundation: <https://fragilex.org/fragile-x-associated-disorders/fragile-x-syndrome/autism-and-fragile-x-syndrome/>

Autism and Epilepsy:

Autism Research Institute: http://www.autism.com/symptoms_seizures

Epilepsy Foundation: <http://www.epilepsy.com>

Down Syndrome and Autism:

Chromosomal abnormalities and autism: <http://www.medicalnewstoday.com/releases/63408.php>

National Down Syndrome Society: <http://www.ndss.org/Resources/Health-Care/Associated-Conditions/Dual-Diagnosis-of-Down-Syndrome--Autism/>

Down syndrome & autistic spectrum disorder. *Disability Solutions*, 3 (5 & 6).

International Rett Syndrome Association: www.rettsyndrome.org

Riverbend Down Syndrome: www.riverbendds.org/index.htm?page=autism.html

This Yahoo group (an electronic mailing list) provides more information on autism and Down Syndrome: groups.yahoo.com/group/ds-autism click on "Join this Group"

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