

I Suspect My Child Has Autism:

A Four-Step Guide for Ohio Parents on What to Do Next

When parents have concerns about their child's development, there is almost always a valid reason for their concerns. Research supports that parents are accurate reporters of early signs of developmental delays or autism. A short encounter or interaction between your child and a physician may not be enough time for the physician to accurately observe the collection of symptoms that you see day in and day out. Parents need to be prepared with a list of specific observations, including times, places, and frequency, to paint an accurate picture of their worries. In the past, 80 percent of physicians told parents to "wait and see".¹ Early intervention works. Act now!

1) Medical/Clinical Evaluations

¹Autism Society. Retrieved March 1, 2009.

STEP 1 Asking for Evaluation *There are three types of evaluations.*

- Talk to your child's doctor; be specific about your concerns.
- Ask your doctor to evaluate your child for autism or make a referral to a professional who can (developmental psychologist, developmental pediatrician, pediatric neurologist). It's okay to ask that action be taken immediately.
- To pay for the evaluation, check these sources:
 1. **Private insurance:** Check your whole insurance plan to see if it pays for a medical/clinical evaluation for developmental disabilities or autism.
 2. **Bureau for Children with Medical Handicaps (BCMh):** BCMh is a part of the Ohio Department of Health that provides funding for evaluations through their approved providers. To find out what is covered, call the state office toll free at (800) 755-4769 or visit www.odh.ohio.gov and search for BCMh.

Early medical signs:

- Problems with communication
- Resistant to change
- Difficulty playing with peers
- Little or no eye contact
- Unusual reaction to noises, lights, touch, smell, and taste
- Handflapping, rocking, walking on toes
- Frequent or extreme tantrums (meltdowns)

Websites to check your child's development:

- www.concernedaboutdevelopment.org
- www.firstsigns.org
- www.cdc.gov (Learn the Signs, Act Early)

3. **Medicaid:** Check with your county's Jobs and Family Services (JFS) agency to see if your child is eligible for funding for an evaluation through a Medicaid provider. Find your county's JFS by calling toll free (877) 852-0010 or visit jfs.ohio.gov/county/cntydir.stm.

4. **County Board of Developmental Disability Services (CBDDS):** Some county boards pay for a medical/clinical evaluation. Check with your county board to see if they will provide funding for a medical/clinical evaluation. Find your county board contact information toll free at (877) 464-7633 or visit <http://dodd.ohio.gov/CountyBoards/Pages/default.aspx>.
5. **County Board of Mental Health:** Some mental health boards subsidize the cost of an evaluation. Check with your County Board of Mental Health for a referral for a medical/clinical evaluation. Contact them toll free (877) 275-6364 or visit <http://mha.ohio.gov>.

2) Education Evaluations

- If your child is approaching age 3 or older and you would like services for him in school, you need to get an educational evaluation.
- A medical/clinical evaluation does not necessarily qualify a child for special educational services. For this, an educational evaluation is needed.
 1. **Contact your local school district special education office in writing** to request an initial Multi-Factored Evaluation (MFE). Districts are required by law to respond within 30 days.
 2. **You will be asked to attend a meeting to plan the evaluation** if the district agrees to evaluate your child. Parents should request assessments in all of the following areas: communication, social, motor, sensory, emotional, behavioral, functional and academic performance. If your request for an evaluation is denied, consult Appendix C or call Autism Society of Ohio at (614) 487-4726.
 3. **Review the Evaluation Team Report (ETR)** to see if your child qualifies for services. If so, the team will then write an Individual Education Program (IEP) for him. (To learn more about the special education process, read Chapter 5 of Ohio's Parent Guide to Autism Spectrum Disorders).

School-Age Signs

- Lack of appropriate eye contact
- Behavioral problems, meltdowns
- Lack of friends
- Difficulty with changes in schedule
- Problems completing work
- Poor motor skills, poor handwriting
- Anxious and inflexible

3) Evaluation for Additional Services

1. **County Board of Developmental Disability Services:** This agency provides funding and services for individuals with developmental disabilities, including autism. (For a description of those services, see pages 124-125) The evaluation process will vary depending on the age of your child.
 - **0-3 years of age** – The county board will do play-based assessment to see if your child is eligible for services.
 - **3-16** – Request your child be evaluated to determine eligibility for county board funding and services. This evaluation is called the Children's Ohio Eligibility Determination Instrument (COEDI).

- **16 and up** – Request your child be evaluated to determine eligibility for county board funding and services. This evaluation is called the Ohio Eligibility Determination Instrument (OEDI).

You can call toll free (877) 464-7633 or visit <http://dodd.ohio.gov/IndividualFamilies/Pages/default.aspx> to find your county board’s phone number.

1. **Help Me Grow:** If your child is younger than 3 years old, check your local *Help Me Grow* program to determine if he or she is eligible for *Help Me Grow* services. For a description of this program, see pages 11-12, 121. To find your local office, call toll free (800) 755-4769 or visit www.ohiohelpmegrow.org.

For more information about evaluation see Chapter 2.

Learn more about autism spectrum disorders and how you can support your child while the evaluation process is being completed.

STEP 2 Educating Yourself

The Ohio’s Parent Guide to Autism Spectrum Disorders which was developed by parents for parents, is a great place to start.

If you’re feeling overwhelmed and need support, the following websites can provide information that

will help and connect you to local autism groups and resources in your area:

- Autism Society www.autism-society.org
- Autism Society of Ohio www.autismohio.org
- Your local Autism Society Chapter (linked from the Autism Society of Ohio website)

For additional information about autism, check these websites:

- Organization for Autism Research www.researchautism.org
- Autism Speaks www.autismspeaks.org

Remember . . .

- Don’t feel pressured.
- The services you choose must meet the needs of your child and family.
- Be mindful of programs that promise a cure.
- Check out available options before making a decision.
- Network with professionals and other parents to gather information.

STEP 3 Getting Services

Getting services is an ongoing process as your child develops and matures. Various service providers will interact with your child throughout his/her life. Your child's team may consist of your child's teachers and other school personnel, doctors, psychologists, therapists, behavioral consultants, neurologists, etc.

Each individual with autism is "uniquely autistic." There is no "one-size-fits-all" treatment. The job of determining what will work best falls on the family and the professionals who work with them. However, the National Academy of Sciences recommends early and intensive intervention of at least 25 hours per week and year-round interventions for young children with autism. See Chapter 4 for more information on types of interventions.

Your child may be eligible for the following range of services, including, but not limited to:

1. Case management/service coordination
2. Behavioral intervention services
3. Speech, occupational and physical therapies
4. Respite, summer programs
5. Waiver services
6. Medical and medication management services
7. Social work services
8. Psychology services
9. Counseling
10. Nutritional services

STEP 4 Record Management

These services may be provided by state or local agencies or private providers through the child's insurance plan. For more information on these services and which agencies may provide them, see Chapters 5 and 6.

You will be gathering a lot of information that you will want to keep handy. (There are sample forms in Appendix B that will help.) Here's how to do it:

- **Create a filing system that you can maintain** and update. For example, use a 3-ring binder, an expandable file folder, a filing cabinet or box.
- **Keep records of the following:**
 1. Business cards of the various agencies and professionals you are in contact with.
 2. A phone log that documents the person, the agency, and one sentence describing the topic and results of the discussion.
 3. Reports such as medical records, evaluation reports, service plans, educational records, home-school communication forms, and travel records of trips to doctors and therapies.
 4. Articles and autism information, etc.
- **Collect ongoing data of your child's progress.** This can be done by keeping a video log, samples of school work, therapy notes, grade cards, progress notes, behavior plan notes, etc.
- **Set aside a time to maintain your file on a regular basis.**