

First Diagnosis Tool Kit



This kit is designed to take you through the steps of first diagnosis, from concern about your child's development through knowing what to do if you receive a diagnosis of autism. There is no particular order to these steps – use whatever information is applicable to your family.

Milestones provides consultation services to all family members, professionals, and self-advocates. Services include connecting participants to resources and providing general information and assistance. We also offer a free Autism Help Desk. If you have any questions or concerns, please contact us at (216) 464-7600.

1. I am concerned about my child's development. What should I do?

- Review the warning signs for autism spectrum disorders.
- Document at what age your child reaches developmental milestones. Use this checklist: <https://www.autismspeaks.org/resource-guide>
- Record any behaviors that are not typical, making sure to date each entry.
- If your child is under the age of 3, contact Bright Beginnings (formerly Help Me Grow) at <http://www.esc-cc.org/BrightBeginnings.aspx> for an informal evaluation. If your child is nearing the age of 3 or older, contact your school's Director of Pupil Services or Special Education Coordinator – they help families with school-aged children with special needs to determine what assistance your child needs to succeed in their learning environment.
- Schedule an appointment with someone who can evaluate and diagnose your child. A pediatric neurologist, child psychologist, child psychiatrist, or developmental pediatrician can evaluate and diagnose. See our Resource Center at <https://www.milestones.org/resources/community-resource-center> for some names of local specialists.
- Prior to your child's appointment read what the diagnostic testing can entail at <https://www.autismspeaks.org/learn-signs>

2. I am waiting for a diagnosis for my child, is there something I should do in the meantime?

- Contact Bright Beginnings, <http://www.escneo.org/BrightBeginnings.aspx>, if your child is under age 3 to receive developmental services.
- If you are not yet enrolled in your school district, reach out to your school district's Director of Pupil Services or Special Education Coordinator. They help families with school-aged children (ages 3 to 21) with special needs to determine what assistance the child needs to succeed in his learning environment.
- Research and make an appointment with a speech and language pathologist (SLP), who can help your child work on language and communication skills.
- Learn all that you can about autism spectrum disorders (ASD) and what you could expect in the future. There are many guides in our Resource Center: <https://www.milestones.org/resources/community-resource-center>

- Seek out support groups or people you may know who have children with special needs to share resources and ideas at <https://www.milestones.org/resources/community-resource-center>
- Learn about respite opportunities at <https://www.milestones.org/resources/community-resource-center>
- Start Building Your Team so you can have supports in place for you, your family and your child. Learn how to build your team: <https://www.milestones.org/get-started/families/siblingsextended-family>

3. My child has just been diagnosed with ASD. What do I do now?

- Learn about the different evidence-based therapies at <https://www.milestones.org/get-started/all-about-asd/evidence-based-interventions> and decide which ones you will incorporate.
- If you haven't already, contact Bright Beginnings (formerly Help Me Grow), <http://www.esc-cc.org/BrightBeginnings.aspx>, if your child is under age 3 to receive developmental services.
- Reach out to your school district's Director of Pupil Services or Special Education Coordinator—they help families with school-aged children (ages 3 – 21) with special needs to determine what assistance your child needs to succeed in his learning environment.
- Initiate a request to the principal at your child's school for a formal Multi-Factored Evaluation (MFE) to determine any learning adjustments that might be needed. Review this page from Disability Rights Ohio to learn more about an MFE: <https://www.disabilityrightsohio.org/letter-writing-requesting-multi-factored-evaluation>
- Alternately, research the different specialty schools in Ohio (preschool, primary, or secondary) that offer a specialized educational experience for children on the autism spectrum if you are not interested in public education. Visit each school of interest using this checklist as a guide: <https://www.autismspeaks.org/resource-guide>
- If your child qualifies for special services according to the MFE, the next step is drafting an Individualized Education Program (IEP) or Section 504 plan. This will need to be in place before your child can receive special services through school.
- Contact your local county board of developmental disabilities for an assessment of your child's eligibility for services and for possible assistance with recreational therapies, supplies, and other needs. (<http://www.oacbdds.org/>)
- Research opportunities for funding necessary therapies or special schools through scholarships and waivers. The Ohio Department of Education's Autism Scholarship, education.ohio.gov/Topics/Other-Resources/Scholarships/Autism-Scholarship-Program, and the Jon Peterson Special Needs Scholarship, www.scoho.org/SCO_specialEd.html, can help pay for specialized education starting at age 3. Some waivers such as the SELF Waiver, viewable at <https://www.disabilityrightsohio.org/medicaid-self-waiver>, can help pay for needed therapies or other equipment at any age.
- If you are eligible, Medicaid, medicaid.ohio.gov, is also a financial resource to pay for possible medical or other disability-related care services. You can apply for assistance by contacting your county's Department of Job and Family Services. You can review the criteria for Medicaid eligibility here: <https://medicaid.ohio.gov/FOR-OHIOANS/Who-Qualifies>
- Learn all that you can about IEPs or Section 504 plans, to determine what is applicable for your child. Some good online resources are Wrightslaw.com and OCALI, www.ocali.org.

4. My child is over the age of 12 and has just been diagnosed. What do I do?

- If your child is over the age of 18 and you are wondering if autism may be an appropriate diagnosis get a referral from your primary care physician for a specialist who can determine a diagnosis, such as a psychiatrist, psychologist or neurologist, or refer to our Resource Center at <https://www.milestones.org/resources/community-resource-center>. You can also contact Milestones Helpdesk (<https://www.milestones.org/services/helpdesk>) for further assistance.
- Initiate a written request to the principal at your child's school for a formal Multi-Factored Evaluation (MFE) to determine any learning adjustments that might be needed. Review this page from Disability Rights Ohio, <https://www.disabilityrightsohio.org/>, to learn more about an MFE: <https://www.disabilityrightsohio.org/letter-writing-request-mfe>
- Start Building Your Team so you can have supports in place for you, your family and your child. Learn how to build your team: <https://www.milestones.org/get-started/families/siblingsextended-family>
- Learn all that you can about IEPs or Section 504 plans, to determine what is applicable for your child. Some good online resources are Wrightslaw.com and OCALI, www.ocali.org. You can learn about the difference between an IEP and a 504 plan here: <https://www.verywellfamily.com/how-does-a-504-plan-differ-from-an-iep-3104707>
- If your child qualifies for special services according to the MFE, the next step is drafting an Individualized Education Program (IEP) or Section 504 plan. This will need to be in place before your child can receive special services through school.
- Alternately, research the different specialty schools in Ohio (preschool, primary, or secondary) that offer a specialized educational experience for children on the autism spectrum if you are not interested in public education. View a list of schools in our Resource Center at <https://www.milestones.org/resources/community-resource-center> Visit each school of interest using this checklist as a guide: <https://www.autismspeaks.org/resource-guide>
- Contact your local county board of developmental disabilities for an assessment of your child's eligibility for services and for possible assistance with recreational therapies, supplies, and other needs. For a list of the Ohio Association of County Boards, visit www.oacbdd.org.
- If you are eligible, Medicaid, medicaid.ohio.gov, is also a financial resource to pay for possible medical or other disability-related care services. You can apply for assistance by contacting your county's Department of Job and Family Services. You can review the criteria for Medicaid eligibility here: <https://medicaid.ohio.gov/FOR-OHIOANS/Who-Qualifies>
- Learn about the different evidence-based therapies at <https://www.milestones.org/get-started/all-about-asd/evidence-based-interventions> and decide which ones you will incorporate.
- Research opportunities for funding necessary therapies or special schools through scholarships and waivers. The Ohio Department of Education's Autism Scholarship, education.ohio.gov/Topics/Other-Resources/Scholarships/Autism-Scholarship-Program, and the Jon Peterson Special Needs Scholarship, www.scoho.org/SCO_specialEd.html, can help pay for specialized education at age 3. Some waivers such as the SELF Waiver, viewable at <https://www.disabilityrightsohio.org/medicaid-self-waiver>, can help pay for needed therapies or other equipment at any age.
- Seek out resources that cater to teens and adults with autism through our Resource Center, <https://www.milestones.org/resources/community-resource-center>. Note that you can refine your search by age group, as well as category such as Social & Recreation, Medical, and Educational resources.

Additional Resources

Milestones has Guiding Questions (<https://www.milestones.org/resources/guiding-questions-for-a-new-resource>) that can help when you are interviewing new services for your child. These printable guides can go with you to an appointment and prompt you with questions that can help you make a decision.

Contact Milestones at (216) 464-7600 if you need more direction or you are interested in coaching or consultation services.

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