

# Autism Fast Start Checklist

This Fast Start Checklist was created to help parents who are concerned that their child is exhibiting signs of an Autism Spectrum Disorder. It serves as a general guideline for obtaining support through the evaluation and initial treatment process and is not intended to be all-inclusive. Work with your physician, service provider, and other knowledgeable people to determine the best route for your family. Don't worry about trying to do everything on this list, as they are provided as points to consider. You know your family's capabilities best and you should try only those interventions and treatments that make sense to your family.

**DISCLAIMER: The information contained in this checklist should not be construed as medical advice. Please consult a professional to help guide you in your decision-making process.**

## *Early Detection*

- Read information regarding how to detect first signs of possible autism spectrum disorders.** A comprehensive review is found on the First Signs website at [www.firstsigns.org](http://www.firstsigns.org).
- Watch videos** available on the *Autism Speaks* website to help you detect red flags or diagnostic features that your child may exhibit (<http://www.autismspeaks.org/video/glossary.php>).

## **If your child is 2 years old or younger:**

- Contact your local Early Intervention Agency for an evaluation** ([www.utahbabywatch.org](http://www.utahbabywatch.org)). These agencies are government-funded and serve all eligible infants and toddlers who have developmental delays and/or disabilities. They conduct a wide variety of tests to determine the strengths and challenges the child is experiencing, then, if the child qualifies, the team develops an Individual and Family Service Plan (IFSP), which guides service delivery.
- Complete a developmental checklist** such as the *Communication and Symbolic Behavior Scales Developmental Profile Infant/Toddler Checklist* available free from the *First Words Project* (<http://firstwords.fsu.edu/toddlerChecklist.html>) and discuss it with your child's pediatrician. This Checklist is used by pediatricians, parents, or childcare providers as a screening instrument to decide if a communication evaluation is needed for infants/toddlers. It is available in several languages.

If your child is between 16-30 months of age, you may want to complete the Modified-Checklist for Autism in Toddlers (M-CHAT) and go over the results with your pediatrician. The M-CHAT can be found at: <http://www.firstsigns.org/downloads/m-chat.PDF>.

## **If your child is 3-4 years old:**

- ❑ **Contact your local Early Childhood Special Education program.** Each school district has a program for preschoolers with developmental delays or disabilities (ages 3-5). Early Childhood Special Education professionals will work with you to evaluate your child’s development and determine whether he/she is eligible for a free and appropriate public education under the Individuals with Disabilities Education Act (early childhood special education and/or related services). If your child is eligible for services, the team will develop an Individualized Education Program (IEP) which will determine what services your child will receive.

**If your child is 5 years or older:**

- ❑ **Contact your local school district, which will have a program for students with disabilities ages 5-22.** A multidisciplinary team of professionals will work with you to evaluate your child’s strengths and weaknesses and determine whether he/she is eligible for a free and appropriate public education under the Individuals with Disabilities Education Improvement Act (special education and/or related services). This team will not provide a diagnosis; they will provide an “educational classification” of autism for those who meet the educational definition, whose autism negatively impacts education, and who require specialized instruction. The team may also refer you to a child psychologist, psychiatrist, neurologist, or other medical professional for a diagnostic evaluation.

***Evaluation and Treatment***

- ❑ **Obtain diagnostic testing and/or assessment:** Make an appointment to see a child psychologist, psychiatrist, neurologist, or other medical professional who specializes in diagnosing children with Autism Spectrum Disorders (ASD). This may be the physician that your local early intervention, early childhood, or special education program has referred you to, or it may be a physician referred by a friend, family member, or another parent of a child with ASD. These assessment services may be provided by private or government-funded professionals (such as Valley Mental Health [www.vmh.com](http://www.vmh.com) and Wasatch Mental Health [www.wasatch.org](http://www.wasatch.org)). For a list of several diagnosticians in Utah, visit [http://www.utahparentcenter.org/docs/resources/Autism\\_Doctors\\_Clinics.htm](http://www.utahparentcenter.org/docs/resources/Autism_Doctors_Clinics.htm). To access detailed information about the diagnostic process and other resources visit the Utah MedHome Portal at [www.medhomeportal.org](http://www.medhomeportal.org).

Along with testing for the symptoms of an Autism Spectrum Disorder, the diagnostic testing should include:

- a. *Full neurodevelopmental evaluation*, including testing to rule out genetic disorders such as Fragile X, Rett’s Syndrome
- b. *Social skills assessment*
- c. *Communication assessment* (receptive/expressive language and social language)
- d. *Adaptive behavior assessment*
- e. *Hearing screening*
- f. *Occupational therapy evaluation* (fine/small motor skills)
- g. *Physical therapy evaluation* (gross/large motor skills)

- ❑ **If your child is diagnosed with an Autism Spectrum Disorder, obtain a 100-Day Kit from *Autism Speaks*.** The 100 Day Kit includes basic information about autism and dealing with the news of a diagnosis. The personalized kit lists local service providers, support groups, recreational activities, sources of legal information, conferences, local autism and disability organizations and information about the local chapter of Autism Speaks. It provides insight into getting services for a newly diagnosed child and explains various available treatment options. A week-by-week action plan helps walk a family through the steps it needs to take to ensure that it is on the right track. The kit also includes a glossary of terms associated with autism, as well as a safety plan and a list of recommended books and informational web sites. The kit can be accessed at: [http://www.autismspeaks.org/press/100\\_day\\_kit.php](http://www.autismspeaks.org/press/100_day_kit.php).
- ❑ **Obtain the DVD *My Next Steps: A Parent's Guide to Understanding Autism*,** or view the videos at <http://depts.washington.edu/uwautism/video/video.html> to learn techniques for engaging your child and working with your school system.
- ❑ **Solicit help and support from family, friends, and autism support groups.** Several support groups exist to assist parents through the evaluation, diagnosis, and treatment processes. These support groups may function by holding regular meetings, providing telephone support, or communicating electronically. Support groups may be found by contacting the Utah Parent Center at (800) 468-1160, (801) 272-1051, or ([http://www.utahparentcenter.org/docs/resources/Parent\\_Support\\_Groups\\_Autism.pdf](http://www.utahparentcenter.org/docs/resources/Parent_Support_Groups_Autism.pdf)).
- ❑ **Create a filing system for compiling important information and documents** (e.g., personal documentation, developmental milestones, diagnostic history, education history, social skill development). For example, *Record Book for Individuals with Autism Spectrum Disorders* by Wheeler, M., & Pratt, C. (2000). Bloomington: Indiana: Indiana Institute on Disability and Community. Available from (812) 855-6508 or <http://www.iidc.indiana.edu/irca/fpublications.html>. Include information about what your child likes/dislikes, how he/she is motivated, and his/her strengths and interests. Share this document with your service providers.
- ❑ **Contact the Division of Services for Persons with Disabilities (DSPD).** DSPD intake workers will evaluate your child for eligibility for their home and community-based services such as community living, day services, supported employment services, and support for people with disabilities and their families. There is a waiting list to access these services, so it is recommended that you contact them shortly after receiving the diagnosis. Visit [www.dspd.utah.gov](http://www.dspd.utah.gov). You may obtain assistance with completing paperwork for needed supports contacting the Disability Support Center for Families ([www.disabilitysupportcenter.org](http://www.disabilitysupportcenter.org)). They also provide information and referral assistance, parent trainings and support groups, and Spanish interpreters.
- ❑ **Apply for Social Security and Supplemental Security Income.** The Social Security and Supplemental Security Income (SSI) disability programs are Federal programs that provide monthly assistance to people with disabilities. While these two programs are different in many ways, the Social Security Administration administers both and only individuals who have a disability and meet medical criteria may qualify for benefits under either program.

SSI is a federal program that provides monthly cash payments to people in need. SSI is

for people who are 65 or older, as well as for people with disabilities of any age, including children. Visit [www.ssa.gov](http://www.ssa.gov) or call (800-772-1213)

- ❑ **Videotape your child.** Many parents have found that reviewing videotapes of their child with service providers assists in the diagnostic process. It also serves to show progress over time.
- ❑ **Review various service delivery options.**
  - a. *Publicly-funded treatment.* Your local publicly-funded agency (early intervention, early childhood special education, K-12+ special education in both district and charter schools) will provide services based upon an Individualized Family Service Plan (IFSP; 0-3 years) or an Individualized Education Program (IEP; 5-22 years), a legal document which outlines the services they will provide. The IFSP also outlines goals determined for the child and his/her family.
  - b. *Private treatment.* You may consider contacting a private agency which serves infants, toddlers, and children with ASD. These agencies charge fees for their services, often on a sliding-scale, based upon family income. Check with your health insurance provider to ascertain whether they cover treatments for children with autism.

Know that you can supplement your publicly-funded treatment with private treatment. Some families choose to fund speech therapy, home-based programming, community-based training, and other services beyond what the school provides. Furthermore, consultation groups exist which help coordinate services, serve as advocates in school or other meetings, and they may also provide direct services to families.

- ❑ **Review various treatment options**
  - a. The Autism Society of America webpage includes information regarding various treatment options:  
[http://www.autism-society.org/site/PageServer?pagename=life\\_treat](http://www.autism-society.org/site/PageServer?pagename=life_treat)
  - b. Guidelines for effective treatment can be found at:  
<http://www.autismcouncilofutah.org/treatmentoverview.htm>
  - c. Common Educational Treatments (see descriptions of these treatments at <http://www.autismspeaks.org/whattodo/index.php#aba>; Also, see the Autism Society of America webpage for a discussion regarding educational issues: [http://www.autism-society.org/site/PageServer?pagename=life\\_edu](http://www.autism-society.org/site/PageServer?pagename=life_edu))
    - Applied Behavioral Analysis (ABA)
    - Floortime (Greenspan's Developmental Process)
    - Picture Exchange Communication System (PECS)
    - Relationship Development Intervention (RDI)
    - The SCERTS<sup>®</sup> Model
    - Social Skills Training (e.g., Social Stories)
    - Structured Teaching (TEACCH; Training and Education of Autistic and Related Communication Handicapped Children)
    - Verbal Behavior Intervention
  - d. Common Therapies
    - Speech/Language Therapy
    - Occupational Therapy (Sensory Integration)

- Physical Therapy
  - Auditory Integration Therapy
  - Relaxation Therapy
- e. Common Health Care Treatments
- Nutrition/Dietary: Wheat/Milk Free Diets, Vitamin/Mineral Supplements, Biomedical Treatment through a DAN! (Defeat Autism Now) practitioner
  - Psychopharmacological
- Determine which treatments are available in your area, most viable and beneficial** given your unique family situation, your child’s circumstances, and results from the medical/psychological testing.

*Autism Source* is the Autism Society of America's on-line referral database of autism related services and supports. Autism Source is free, searchable by location or service type, and provides resource listings throughout the United States. Listings include: many types of service providers, ASA Chapters, support groups, medical professionals, educational facilities, legal services, government agencies, research centers, and more. Available at: <http://www.autismsource.org/>. Other lists of services in Utah are available from the Utah Parent Center ([http://www.utahparentcenter.org/resources\\_autism.htm](http://www.utahparentcenter.org/resources_autism.htm)) and the Autism Council of Utah: <http://www.autismcouncilofutah.org/resources.htm>.

- Take an online introductory course** such as the Autism 101 course sponsored by the Autism Society of America (<http://www.autism-society.org/site/PageServer?pagename=course>).
- Learn about the law and your rights in your child’s education.** If your child is being served by a publicly-funded organization, they will give you a document detailing your “Parents’ Rights.” This may be a lengthy document accompanied by a brief summary. You may also access information about education law at sites such as: [www.wrightslaw.com](http://www.wrightslaw.com). Also, the Utah Parent Center provides one-on-one consultations, workshops, trainings, and information (800-468-1160) or (801) 272-1051 or [www.utahparentcenter.org](http://www.utahparentcenter.org).
- Implement as quickly as possible**, observing one intervention at a time to measure effectiveness.
- Collaborate with professionals to monitor and evaluate progress** by taking careful notes and daily logs of behavior to discern which interventions are providing the best results. Collaborate with agency/school personnel (e.g., teacher, physician, psychologist, speech-language pathologist) to compare how your child is doing. Work together to help your child transfer or generalize skills across different environments, people, materials, time of day, and instructional cues.
- Make necessary changes** in your child’s treatment plan for optimal response.

Don’t get discouraged! Getting a diagnosis of autism for your child can change your family’s life. Many parents have experienced the stages of grief while going through the diagnostic and treatment process: denial, bargaining, anger, depression, then acceptance. Realize that this is a marathon, not a sprint. Take care of yourself and your other family members, and let others help you for the benefit of your child and your family.

Since we don't know the exact cause of autism and we don't have a definite cure, many families have found that treating the symptoms using a multi-faceted approach to treatment is the most beneficial. Each child is a unique puzzle. Finding the pieces to your child's puzzle will need to be tailored to his/her needs and response rates for each intervention. What may work for one child, may not work for another. Be persistent in finding the specific pieces that fit together for your child.

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[www.autismcouncilofutah.org](http://www.autismcouncilofutah.org)