



Newly Diagnosed? If You Have Just Been Told Your Child Is On the Autism Spectrum, Here's Some Advice from Parents Who Have Been in Your Shoes.

Most parents feel overwhelmed and are not sure where to start when their child is first diagnosed with an Autism Spectrum Disorder. Here are some recommendations from “seasoned” parents.

- ✓ **POAC-NoVA** is a local, parent-volunteer run organization that offers an active listserv, support groups, and informational meetings for members, in addition to social occasions for families. We want to help and we're free to join! Just visit www.poac-nova.org/join-poac-nova/.
- ✓ **Other Advocacy Groups:** Local chapters of national organizations such as the ARC of Northern Virginia (<https://thearcofnova.org/>) and the Autism Society of Northern Virginia (www.asnv.org) are staffed and offer a wide variety of programs to help you understand the complicated array of services your child may need. Autism Speaks is another national organization that offers conferences, funds local grants and funds research. Parents Education and Advocacy Training Center (www.peatc.org) is a quasi-governmental organization that provides access to training and resources for parents.
- ✓ **Child Find:** Run by county school systems, this is the gateway to determining eligibility and placing your young children (20 months to 5 years old) in special education services. Google Child Find for your county to access services.
- ✓ **Local Screening Panels:** If your child is already enrolled in public school, the school will determine eligibility for special education services. Even if your child is performing at or above grade level, he or she may still be eligible.
- ✓ **Parent Resource Centers:** Local county school systems have PRCs to educate families about a variety of issues, including special education and autism.
- ✓ **Formal Diagnosis:** You will need a formal clinical diagnosis (**not** from the schools) to get insurance coverage for most types of rehabilitative and other services related to autism and to be eligible for Medicaid services. In our area, Kennedy Krieger Institute (www.kennedykrieger.org) and Children's National (www.childrensnational.org) are the places you can get comprehensive diagnoses and “prescriptions” for services, including applied behavioral analysis (ABA) and speech, physical and occupational therapy. There is often a lengthy wait for these evaluations, so contact them as soon as possible.

- ✓ **Therapies and Related Services:** Applied behavioral analysis is the evidence-based educational practice found to work for our children. Get as much as you can afford as early as possible. If you're not seeing results, find a new provider, but there are often waiting lists. Speech and language pathologists help with development of language and communication skills. Occupational therapy helps with sensory issues and fine and gross motor skills development. Physical therapy is generally for children with physical disabilities beyond autism or for those recovering from injuries or surgeries.
- ✓ **Medicaid Waiver:** Even if your family income is over the threshold limit for eligibility for Medicaid, which covers basic medical and dental care, you can still apply for "waiver" services. Early and Periodic Screening and Detection Services and Developmental Delay waiver services are available to eligible participants through local community service boards. Another waiver that some children with autism qualify for is the CCC+ waiver; while it doesn't cover as many services, it does offer in-home personal attendant care and there is no wait list. In VA, it often takes years for your child to receive services. There are currently 12,000+ people waiting for services under the DD waiver in Virginia. If you intend to live in Northern VA for any length of time, get your child on the waiting list as soon as possible. The Arc of Northern Virginia is a great resource to help you navigate the waiver programs, especially now, as there have been many changes and new names.
- ✓ **IFSP Grant.** Being on the Medicaid waiver waiting list does entitle you to grant funding under the Individual and Family Services Program. The IFSP grants of \$1000 or less are generally available to families once a year through an application process. More information is available at <https://ifsponline.dbhds.virginia.gov/>.
- ✓ **Medical Care:** Some of our kids have medical issues, such as gastrointestinal issues or seizures. Many will also eventually require some type of medication for commonly associated conditions, such as anxiety, mood disorders or attention-related disorders. Having a pediatrician with some knowledge of and experience with these issues will make your life easier. Many of us use developmental pediatricians. Many pediatric groups have a provider who is their resource person on autism spectrum disorders. Ask around. Neuropsychiatrists, psychiatrists, gastroenterologists, neurologists, dentists, dieticians/nutritionists and ENTs are frequently used specialists.
- ✓ **And finally...breathe.** Your child is still the same child you loved yesterday regardless of his or her new label. With the right services, you are likely to see a lot of change and progress. Take care of yourself as you begin this journey.