



## ***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 with hundreds of parent/guardian participants, 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 [our website](#).
- ✓ **Other Advocacy Groups:** Local chapters of national organizations such as the [ARC of Northern Virginia](#) and the [Autism Society of Northern Virginia](#) are staffed and offer a wide variety of programs to help you understand the complicated array of services your child may need. The [Parent Educational Advocacy Training Center](#) is a quasi-governmental organization that provides access to training and resources for parents and offers outreach and programs in Spanish. All school jurisdictions are required to have Special Education Advisory Committees (in Fairfax County it's called the Advisory Committee for Students with Disabilities). These groups advise local school boards on policies affecting special education and programming for students with disabilities. Some jurisdictions, including [Fairfax County](#), also have a Special Education Parent and Teacher Association.
- ✓ **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 or check our website for local resources in some of our school jurisdictions.
- ✓ **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, they may still be eligible.
- ✓ **Family or Parent Resource Centers:** Local county school systems have FRCs or PRCs to educate families about a variety of issues, including special education, autism and other related conditions.
- ✓ **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](#) and [Center for Autism Spectrum Disorders | Children's National Hospital](#) are two of the largest sites to get comprehensive diagnoses and “prescriptions” for services, including applied behavioral analysis (ABA), assistive technology, 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 one of the foremost evidence-based educational practices that works for many of our children. We advise seeking ABA early and working with school-based programs to coordinate services at home. POAC-NoVA has also endorsed the Unstuck and On Target curriculum to enhance certain executive functioning skills. The curriculum was developed by Children’s National’s Dr. Lauren Kenworthy, who is on our Advisory Board. 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. There are often waiting lists for these services.
- ✓ **Medicaid Waivers:** Even if your family income is above the threshold 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. There are three waiver programs specifically for people with developmental disabilities, including the Building Independence Waiver (BI), the Family and Individual Supports Waiver (FIS), and the Community Living (CL) Waiver. Unfortunately, Virginia has a long waiting list for these waivers. Each individual determined to be eligible for waiver services is assigned a priority level, based on their individual needs, and each of the waivers meets different needs. Contact your local Community Services Board for more information and to apply for your child. Also learn about the waivers at [Waiver Services - Virginia Department of Behavioral Health and Developmental Services](#).
- ✓ **IFSP Grant.** Being on the Medicaid waiver waiting list does entitle you to apply for 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.
- ✓ **Division of Aging and Rehabilitative Services (DARS):** For students transitioning from school-based to community services, DARS can offer lots of support in identifying and training teens and adults for employment options and enhancing independent living skills starting in high school. They provide access to programs such as driver’s education, and offer training in self-advocacy and soft skills to make people with disabilities better candidates for long-term employment. Most high schools have an employment training representative (ETR) familiar with DARS and its many programs or you can contact them directly.
- ✓ **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 their 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. POAC-NoVA is here to help you each step of the way.