Do you or your child's provider suspect that your child may have an

AUTISM SPECTRUM DISORDER?

What is Autism?

Autism or autism spectrum disorder (ASD) is a neurodevelopmental disability that can be associated with social, communication, and behavioral challenges. Children diagnosed with autism may communicate, interact, behave, and learn in ways that are different from people without autism. You can visit the **Centers for Disease Control and Prevention (CDC)** autism webpage to learn more about how autism is defined.

DC AUTISM COLLABORATIVE

How Common is Autism?

The Centers for Disease Control and Prevention (CDC) estimates that about 1 in 31, 8-year-old children have been identified with autism.

How is Autism Diagnosed?

A diagnosis of autism is made based on your description of your child's development, a review of your child's history and observations of certain behaviors by your child's primary care provider and an autism expert. You can learn more by reading the American Academy of Pediatrics' article, **"How is Autism Diagnosed?"**

The criteria for diagnosing autism include:

- ☑ challenges with social communication and interaction
- ☑ restricted or repetitive behaviors or interests

What are the Early Signs of Autism?

It is important to note that most children with autism engage in just some, but not all, of the behaviors listed. The CDC has a list of the signs of autism that can be found **here**.

The American Academy of Pediatrics has a similar list, **"What are the Early Signs of Autism?"** that includes examples of how to tell the difference between a child with autism and a typically developing child. Autism Navigator developed the **Baby Navigator Lookbook: 16 Early Signs of Autism by 16 Months**.

Kennedy Krieger Institute has developed a free **9-minute video tutorial** to improve recognition of the early signs of autism. The tutorial consists of 6 video clips comparing toddlers who show no signs of autism to toddlers who show early signs of autism.

If I Suspect Autism, What Do I Do Next?

If you suspect autism, there are several options for next steps. It is often helpful to pursue multiple pathways at the same time. This includes seeking out an Early Intervention or educational evaluation (Infant & Toddler Connection of Virginia or your county's Child Find Program). Seek out an evaluation within the medical setting. Talk to your child's primary care provider about these options. If your child's primary care provider has told you to "wait and see," but you feel uneasy about that advice, you can **self-refer** to **Infant & Toddler Connection of Virginia** or your county's Child Find Program

Early Intervention/Educational Evaluations

Early Intervention/Educational Evaluations Guided by the **Individuals with Disabilities Education Act (IDEA) Part C** and **Part B, Infant & Toddler Connection of Virginia and Child Find** are free to all families within Virginia. An evaluation is done to determine if the child is eligible for services

- For children under the age of 3 years, **The Infant & Toddler Connection of Virginia** provides early intervention supports and services to infants and toddlers who are not developing as expected or who have a medical condition that can delay normal development. Early intervention supports and services focus on increasing the child's participation in family and community activities that are important to the family. In addition, supports and services focus on helping parents and other caregivers know how to find ways to help the child learn during everyday activities. These supports and services are available for all eligible children and their families regardless of the family's ability to pay.
- For children 2 years (whose birthday falls on or before September 30) through age 5, **Early Childhood Special Education** services are provided through your **local school division**. Your local school division's Child Find evaluations are used to determine if a child meets criteria for one of the 14 IDEA-specified disabilities which includes autism. Child Find can create and recommend Individualized Education Plan (IEP) services. IEP services are implemented in school settings.

Evaluations of Autism within the Medical Setting

Children can receive a comprehensive autism evaluation in the medical setting by a medical provider (pediatrician, psychologist, or another medical specialist). These evaluations are usually covered by your child's health insurance. Providers use your description of your child's development, developmental history, observations, and assessments to determine if your child meets the **DSM—5 diagnostic criteria for ASD**. If your child meets these criteria, the provider will give your child a **medical diagnosis of autism**.

What are the Differences Between a Medical Diagnosis and an Educational Classification of Autism?

Usually made by a medical provider in a healthcare setting using **DSM—5 diagnostic criteria**, a medical diagnosis of autism will not always lead to eligibility for early intervention/special education services. A medical diagnosis of autism can be helpful to make sure a child has additional access to services through their health insurance plan. A medical provider may be able to recommend other therapies and services that are not a part of the IFSP or IEP.

For children 2 years, 8 months of age and older, an educational classification of autism identifies autism as a disability under IDEA and determines eligibility for special education services. An educational classification of autism can be helpful to make sure a child has access to needed supports in school.

Why is it important to pursue both a Medical Diagnosis and an Educational Classification of Autism?

Families can have better access to services in school and in the community and may be able to support their child's development more comprehensively.

How do I Access Early Intervention/Educational Evaluations?

Your child's primary care provider may refer you or you can self-refer to Infant & Toddler Connection of Virginia or your county's Child Find Program.

- If your child is birth to 2 years, 11 months: Call the **Infant & Toddler Connection of Virginia** Hotline at 703-246-7180
- If your child is 2 years, 8 month and 5 years, or 10 months: Call your county's Child Find program. Phone numbers can be found by searching Google for Child Find followed by the name of your county.

Please note that the early intervention/special education evaluation process will only begin after a parent/guardian has provided written consent.

Parent Tips on How to Access Autism Evaluations:

- ☑ Waitlists are long for medical evaluations (3 months-2 years), but do not get discouraged
- ☑ Call multiple clinics and submit paperwork, you can always call to cancel once you get an appointment
- ☑ Medical evaluation and early intervention/educational evaluations can happen at the same time, and it is often a good idea to pursue both at the same time
- ☑ Ask questions if you do not understand
- ☑ Work with your medical provider to arrange further diagnostic evaluations if needed

WHERE CAN I GET MY CHILD EVALUATED FOR A MEDICAL DIAGNOSIS OF AUTISM?

You can call your insurance provider or ask your child's doctor to help you find a health care provider who can diagnose autism. Below is also a list of clinics that evaluate for autism:

- **Ally Behavior Centers** 240-342-2666
- **As You Are** (Virtual evaluations, not in person)
- **Autism Spectrum Center at Mount Washington Pediatric Hospital** 410-367-2222
- **Center for Autism Services, Science and Innovation at Kennedy Krieger Institute (CASSI)** 443-923-7630, option 2
- **Children's National Hospital: Various Autism Clinics**
- **Inova Children's Developmental Pediatrics** 571-472-4300
- **Inova Kellar Center** 703-218-8500
- **Pathways Autism Assessments at Behavioral Framework** 301-578-5935
- **Sparks ABA** 240-297-3550

DC-AC does not endorse any resources or services. These resources are for informational purposes only.

If you need support in accessing or navigating these services, contact The Parent Educational Advocacy Training Center.

The American Academy of Pediatrics has created a resource, **"If Autism is Suspected, What Next?"** which provides information on what happens during an autism evaluation, as well as a list of medical tests that are not recommended.

What should I do after an evaluation?

Parents should keep records of conversations and communications with providers and agencies. The Center for Parents Information and Resources created this **Sample Record Keeping Worksheet**. Parents should get a copy of the evaluation and share this with their child's health and education providers.

It also will be important to connect with other parents/caregivers of children diagnosed with autism and connect with community resources. Check out this blog post entitled **"The First Three Things to Do When Your Child is Diagnosed with Autism"** to help get you started.

Autism Resources for Families:

Parent Training and Information Center: Each state has at least one Parent Training and Information (PTI) Center funded under the Individuals with Disabilities in Education Act (IDEA). The goal of the PTI is to support families of children birth-22 with disabilities by providing free information to maximize their child's education. Virginia's PTI is **The Parent Educational Advocacy Training Center**.

Family-to-Family Health Information Center (F2F): **The Center for Family Involvement** is Virginia's F2F, which is a family-led center funded by the Health Resources and Services Administration. There is one F2F in each state, and each F2F is staffed by highly skilled, knowledgeable family members who have first-hand experience and understanding of the challenges faced by families of Children and Youth with Special Health Care Needs.

Parent to Parent (P2P): Parent to Parent USA is a national network of P2P programs to ensure access to quality emotional support for families of individuals with disabilities and/or special health care needs. Through a one-to-one "match," experienced Support Parents provide emotional support to families of individuals with special health care needs and assist them in finding information and resources. **Parent to Parent of Virginia** is the parent-to-parent program for Virginia parents and caregivers of children with disabilities.

Developmental Disabilities (DD) Council: **Virginia Board for People with Disabilities** is an independent, state agency that is led by people with developmental disabilities and family members of people with developmental disabilities. It is funded by a federal agency called the Administration on Disabilities, Office of Intellectual and Developmental Disabilities. The DD Council seeks to strengthen the voice of people with developmental disabilities and their families in support of greater independence, inclusion, empowerment, and the pursuit of life as they choose..

Partners in Policymaking (PIP): PIP is a program that prepares adults with intellectual/ developmental disabilities (I/DD), parents, and family members of children and adults with I/DD to be effective advocates at the local, state, and federal levels. This program is currently available in over 30 states, including DC. **Virginia Board for People with Disabilities** is Virginia's PIP Program. Virginia Board for People with Disabilities is a leadership training program designed for self-advocates and family members of individuals with intellectual and/ or developmental disabilities as well as professionals working with people with disabilities.

DC AUTISM COLLABORATIVE

Developmental Monitoring, Screening, and Evaluation Subgroup:

Emily Aaron, Azeb Adere, Shanter Alexander, Jane Anderson, Trina Anderson, Rachel Brady, Tori Bronaugh, Ivy Giserman-Kiss, Leandra Godoy, Yolanda Graves, Samantha Hamburger, Amanda Hastings, Diane Jacobstein, Shalinee Khurana, Stacie Lamour, Becky Lane, Melissa Long, Michael Mintz, Yetta Myrick, Allan Phillips, Jordanne Reader, Karla Reid-Witt, Liz Rihani, Cathy Scheiner, Audrey Thurm, Yagnash Vadgama, Mary Wozniak. Gali Laska