

# First Steps

After a Medical Diagnosis of Autism

Being told that your child has a medical diagnosis of autism can either be expected or come as a surprise. In either situation, you may feel unsure, scared, or lost. Understanding what to do next can ease worries, and help you feel more confident with the path forward. In this document, you will find information and resources to help guide you through the first couple of weeks following a diagnosis.



## First Steps

## After a Medical Diagnosis of Autism

1.

#### **Seek Support**

Remember, you are not alone. Your child's teacher, pediatrician, other parents or caregivers, and organizations within the community may be able to help you understand the resources and support that are available for you and your child. For example, DC Autism Parents (DCAP) is a parent volunteer-led non-profit organization that offers resources, a video series, and monthly newsletters. The DC Parent Training & Information (PTI) Center, Advocates for Justice & Education, can support you with free information and resources related to your child's education and healthcare needs.





#### **Explore Insurance and Intervention Options**

Receiving a medical diagnosis of autism may allow your child to receive more specialized health-related services and interventions. One health-related service is specialized insurance. Health Services for Children with Special Needs, Inc. (HSCSN) is a health care plan provider that can manage your child's medical care and behavioral health services. You can visit their website to see if you qualify or to receive the contact information to speak with an enrollment specialist. Your child will also have access to interventions specific to autism, which include different forms of therapy, such as behavioral, speech, occupational and physical therapy. If you are interested in learning more about therapy offered for autistic children, speak with your child's pediatrician or contact your health insurance company to identify therapists and service providers.

#### **Explore Early Intervention and Specialized Education Services**

While only having a medical diagnosis of autism is valid and crucial for accessing healthcare and specialized services, **obtaining an educational classification as well can provide vital school-based support and resources to further enhance your child's educational experience.** 

If your child is not already receiving specialized services in the school system, they can benefit from having an educational classification of autism in addition to a medical diagnosis. An educational classification of autism identifies autism as a disability under the Individuals with Disabilities Education Act (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.

If your child is enrolled in public school, they may benefit from an Individualized Education Program (IEP) or a 504 Plan, which can offer your child specific support or accommodations at school. To learn more about what your child might be eligible for, there are evaluation centers that may be able to help. For children birth to 2 years, 10 months, Strong Start provides services by an Individualized Family Service Plan (IFSP) if there is a 25% delay in 1-5 areas of development. Even though they do not diagnose or classify children as having autism, they do provide important intervention services that many children with autism need, such as speech therapy, occupational therapy, and applied behavior analysis. For children 2 years, 8 months to 5 years, 10 months, Early Stages' evaluations are used to determine if a child meets criteria for one of the 14 IDEA-specified disabilities which includes autism. Early Stages will create and recommend IEP services. IEP services are implemented in a DC public school setting or DC Public Charter School. Additionally, we encourage you to reach out to your child's school or healthcare provider to learn more about these specific offerings.

## Resources

#### **ORGANIZATIONS:**

- Advocates for Justice & Education serves as both the Parent Training and Information Center (PTI) and the Family-to-Family Health Information Center (F2F) for the District of Columbia:
  - o **Parent Training and Information Center (PTI):** Each state has at least 1 PTI Center funded under 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.
  - o **Family-to-Family Health Information Center:** The 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 and Disabilities.



- DC Autism Parents (DCAP): DCAP supports families in navigating the autism journey through a video series and monthly newsletter. DCAP is a 501(c)3, parent volunteer-led non-profit organization created by parents of autistic children and youth for parents of autistic children and youth.
- <u>DC Special Education Hub:</u> The DC Special Education Hub helps families understand special education in the District of Columbia. Their knowledgeable team connects families with tools, information, and 1:1 support so families can make informed decisions to guide their child's learning.
- The Ethiopian Eritrean Special Needs Community (EESNC): EESNC is a 501(c)(3) nonprofit dedicated to empowering individuals with special needs and their families. EESNC adopts a family-centered approach, offering culturally sensitive and linguistically appropriate information, training, tailored guidance, and referrals. Serving as a dynamic community hub and information-sharing platform, EESNC ensures easy access to vital resources and expertise.

#### **PARENT TRAININGS:**

- <u>ADEPT</u> (Autism Distance Education Parent Training): Developed by UC Davis MIND Institute/Center for Excellence in Developmental Disabilities, ADEPT Interactive Learning is a 10-lesson interactive, self-paced, online learning module providing parents with tools and training to teach their child with autism and other related disorders functional skills using applied behavior analysis (ABA) techniques.
- <u>Caregiver Skills Training:</u> A free online training program from Autism Speaks and the World Health Organization that teaches caregivers day-to-day skills to help boost the wellbeing and development of children ages 2-9 with autism and other developmental delays.
- <u>Help is in Your Hands:</u> An online interactive resource, developed by UC Davis clinical psychologists, Sally Rogers and Aubyn Stahmer, for families with young kids with symptoms of or diagnosed with an autism spectrum disorder. It is a free website with 16 web-based video modules to help parents add simple intervention practices to their everyday routines at home.

#### **ADDITIONAL RESOURCES:**

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- Rest to Create Change Toolkit: A resource created by DC Autism Parents to support parents and caregivers to adopt rest within their daily lives.
- <u>Sesame Street and Autism:</u> The Sesame Workshop's autism resources page offers educational and engaging materials tailored for families of children with autism, featuring videos, activities, and the introduction of Julia, a Muppet with autism, to promote understanding and inclusiveness. The site provides practical tools and tips to help navigate daily challenges and supports the nurturing of connections and empathy within the autism community.
- Association for Science in Autism Treatment Learn More About Specific Treatments: A
  comprehensive resource for parents of children with autism, offering information on a wide
  range of autism treatments. It aims to empower families with knowledge to make informed
  decisions regarding therapeutic options, emphasizing the importance of scientifically
  validated methods for improving the lives of individuals with autism.