Down syndrome and autism spectrum disorder (DS-ASD): What you need to know

Autism spectrum disorder is a common condition in people who also have Down syndrome. In this handout, you will learn about autism and Down syndrome, including the signs of autism, how it is diagnosed, and where to find more information.

What is autism spectrum disorder?
Autism spectrum disorder (ASD, or simply autism) is a developmental disorder in which a person has challenges with social interaction and communication as well as patterns of repetitive and/or restrictive behaviors (behaviors that are limited in terms of a person’s focus, interests or activities).

What is autism spectrum disorder?
About 16-18 out of every 100 people with Down syndrome have ASD. Doctors believe there may be even more people with Down syndrome who also have ASD because of diagnostic overshadowing (when behaviors are attributed to Down syndrome rather than to another possible diagnosis, like ASD).

What are some signs that my child with Down syndrome might have ASD?

- Difficulty or disinterest in social interaction and communication. This may look like fewer spoken words, poor eye contact or avoiding peers.
- Repetitive or restrictive behaviors, often completed with intense focus. This could be hand flapping, body rocking, twirling of objects, lining up objects or head-banging. You may also hear this called stimming.
- Significant challenges with expressive language (language that expresses needs and wants). Some people with ASD may be non-speaking. Instead, they may use other ways to communicate, such as through sounds, gestures or electronic devices, like a tablet.
- Increased or decreased sensitivity to stimulation, including sounds, textures and physical touch. Feeling indifference (neutral) to pain is also common.
- Difficulty with change or transitions

It is important to note that many children with Down syndrome without ASD have some of these behaviors, too. You/your family, teachers or doctors may suspect that your child with Down syndrome also has ASD if they have more of the above characteristics.

How is ASD diagnosed in people with Down syndrome?
ASD can be diagnosed through a formal evaluation by an experienced provider, such as a neuropsychologist (someone trained to assess and care for people who experience challenges with language, learning or understanding) or a developmental pediatrician (a pediatrician trained to care for children with behavioral and learning challenges). They can use a variety of tests and surveys to figure out whether your child has ASD.

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What should I expect if my child is diagnosed with ASD?

ASD is a common and manageable condition. It is important to diagnose ASD early so you and your child can start to learn to manage their behavior and meet their needs as soon as possible. The overall goal of learning to manage ASD is to help your child develop techniques and skills to interact, communicate and regulate (manage or control) behavior in their own unique way.

Once diagnosed, your child may receive one or more of the following:

- Care from a **psychiatrist** (doctor who can prescribe medications for mental or behavioral health challenges), developmental-behavioral pediatrician and/or doctor specializing in ASD. While there is no cure for autism, medications can help manage your child’s symptoms and behavior. It is important that they also continue to receive care from their pediatrician and/or the Down Syndrome Program to ensure their needs related to Down syndrome are met.

- A referral for **Applied Behavior Analysis (ABA)**, a type of behavior therapy that can help your child learn to change their behavior and improve their communication

- Additional genetic testing and a medical evaluation for ASD. This is important to rule out another diagnosis that may cause signs or behaviors that look similar to ASD.

Where can I find additional resources on ASD and Down syndrome?

There are many organizations and resources available to support parents and families who are caring for a loved with DS-ASD:

- The Down Syndrome Program at Mass General for Children (MGfC) and Massachusetts General Hospital massgeneral.org/downsyndrome
- The Lurie Center for Autism at MGfC and Mass General massgeneral.org/children/autism/lurie-center
- Down Syndrome-Autism Connection®
ds-asd-connection.org/who-we-are/frequent-questions.html
- Autism Speaks® in partnership with the Down Syndrome Medical Interest Group® autismspeaks.org/down-syndrome-and-autism-spectrum-disorder-ds-asd
- National Down Syndrome Society®
ndss.org/resources/dual-diagnosis-syndrome-autism
- Autism Alliance®
autismalliance.org
- Down Syndrome Center® podcast directory.libsyn.com/episode/index/id/15256988