

Down Syndrome & Autism

Down syndrome and autism are both equal opportunity conditions— meaning that anyone, anywhere, regardless of race, creed or socio-economic status, can have a child with either condition. It is believed that up to 18%¹ (some research suggests up to 39%²) of individuals with Down syndrome also have autism spectrum disorder. Both Down syndrome and autism can be challenging disabilities separately, without the combination, however when combined the challenges are multiplied and can be quite complex.

Behaviors to Notice

Before 3 years old:

- Repetitive motor behaviors
- Fascination with and staring at lights, ceiling fans, or fingers
- Episodic eye movements
- Extreme food refusal
- Unusual play with toys or other objects
- Receptive language impairment
- Little or no meaningful spoken language, gestures or signs

3 years and older:

- History of developmental regression
- Hyper or hypo-activity, short attention, impulsivity and poor organization
- Unusual vocalizations
- Unusual sensory responsiveness
- Difficulty with changes in routine or familiar surroundings
- Extreme anxiety, fearfulness or agitation
- Sleep disturbances
- Disruptive behaviors



Teens and Adults:

- Significant lack of social response or relatedness with family or friends
- Lack of interest or ability to develop relationships with peers
- Antisocial, anxious, or fearful in the presence of people they don't know
- Intensified stereotypic and repetitive motor behaviors
- Obsession or fascination with inanimate objects
- Lack of ability or interest in creative play
- Manipulation of objects in rigid ways
- Intensified sensitivity to certain types of sensory input
- Frequent tantrums and outbursts, as well as verbal or physical aggression
- Great difficulty in adjusting to transitions
- Dropping to the ground and refusing to move

Please note that many of these behaviors are normal for children with Down syndrome at certain points of development. Also, a child with Down syndrome may experience relatively normal development but then regress by developing these behaviors between the ages of three and seven. When one or two of these behaviors become predictable, extreme, or resistant to change, your child may benefit from a thorough evaluation for autism spectrum disorder performed by a professional who is experienced in working with children with Down syndrome.

¹ JFK Partners, University of Colorado Denver, <http://jfkpartners.org>.

² When Down Syndrome and Autism Intersect, A Guide to DS-ASD for Parents and Professionals, P.1, Woodbine House, 2013.

Down Syndrome & Autism, continued

What to do if you suspect ASD

If you feel an evaluation is in order, observe closely, take notes, and arm yourself with current information. Some parents have been persistent and in time they finally get the answers to their questions. When seeking an evaluation, be sure to ask if the provider has experience with evaluating autism in a person/child with Down syndrome. Many families seek an appointment with an AUCD center (Association of University Centers on Disabilities), a developmental pediatrician, a neuropsychologist, Children's Hospital in their area, or their local Down syndrome clinic -- and others have been able to obtain an educational diagnosis of autism from their school system.

It's also important to do the following to take care of yourself as a care giver:

- Increase your circle of support, ask for help from family, friends, support staff from school, church family, etc.
- Pursue a Personal Care Attendant (PCA) or respite services
- Those who find themselves struggling with their emotions regarding the second diagnosis may benefit from working with a professional counselor such as a grief, marriage, or family counselor, psychologist, or a spiritual leader
- Join the Down Syndrome-Autism Connection
 - Facebook Support Page
 - Monthly on-line chat support group

Benefits of Knowing

Many parents have expressed that once their child received the additional diagnosis of autism, it became the most important issue. A lot of parents and professionals will tell you that the autism almost always "trumps" the Down syndrome, with difficult behaviors and educational challenges being the main issues in their lives.

A formal diagnosis could:

- Help get needed school and community services that are tailored to children with autism
- Explain why a child with Down syndrome and autism develops and acts differently
- Help parents and extended family members to better understand, support and guide their child

While parents of children with DS-ASD may sometimes feel alone, there are expanding efforts to make support and help available. There is growing awareness of the needs of those with DS-ASD, and efforts are underway in different parts of the country to meet those needs.

There are many reasons to remain hopeful about the future. As more is learned about the intersection of Down syndrome and autism, better health and education strategies will likely become clearer, paving the way for brighter futures to come!

Resources

- **"When Down Syndrome and Autism Intersect"**
by Margaret Froehlike and Robin Zaborek
- **The Down Syndrome Autism Connection**
(www.ds-asd-connection.org)
- **Autism Speaks** (www.autismspeaks.org)
- **Autism Society** (www.autism-society.org)
- **Kennedy Krieger Institute** (www.kennedykrieger.org)
- **The Association of University Centers on Disabilities**
(www.aucd.org/directory)
- **Children's Hospital Association's Directory**
(www.childrenshospitals.org)
- **JFK Partners** (www.jfkpartners.org)