

When Autism and Down Syndrome Co-Occur



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DOWN SYNDROME
CONGRESS

Parent Webinar Series



Speakers

- ▶ Tamara Pursley, National Down Syndrome Congress
- ▶ Kim Musheno, Autism Society of America
- ▶ Joe Joyce, Board chair, Autism Society of America
- ▶ Kerim Munir, MD, MPH, DSc, Boston Children's Hospital



National Down Syndrome Congress (NDSC)

- ▶ Oldest national organization serving the DS community
- ▶ Provide accurate and up-to-date information for families and professionals, across the lifespan
- ▶ Work with more than 250 parent support organizations around the globe
- ▶ NDSC Annual Convention (inc. DS-ASD track)
- ▶ Policy & Advocacy Team in Washington, DC and collaboration with other disability organizations



Autism Society of America

- ▶ Largest, oldest grassroots organization on ASD
- ▶ 80 affiliates nationwide
- ▶ Over 617,000 served across our network in 2018
- ▶ 2,000 community events this year
- ▶ 224,000 inquiries for information and referrals
- ▶ 7,000 first responders trained
- ▶ Provide national advocacy on health, long term services, education, employment, and civil rights



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Policy & Advocacy Resources

- ▶ [NDSC legislative Priorities](#)
- ▶ [NDSC Action Center](#)
- ▶ [Advocacy Resources](#)

- ▶ [Autism Society Public Policy Agenda](#)
- ▶ [Autism Society Action Center](#)
- ▶ [Ignite Policy Newsletter](#) – subscribe for free
- ▶ [Annual conference and Hill Day, July 9-11](#)



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Co-occurring DS and ASD: What do we know?

- ▶ DS is the most common genetic condition, at 1 in 700 babies born each year
- ▶ Autism affects 1 in every 60 births, or about 1% of the world's population
- ▶ DS and ASD are equal opportunity conditions
- ▶ It is believed that 18% of the DS population also have ASD



Behaviors to Notice

- ▶ Unusual response to sensations (especially sounds, lights, touch or pain)
- ▶ Food refusal (preferred textures or tastes)
- ▶ Unusual play with toys and other objects
- ▶ Difficulty with changes in routine or familiar surroundings
- ▶ Little or no meaningful communication
- ▶ Disruptive behaviors (aggression, throwing tantrums or extreme non-compliance)
- ▶ Hyperactivity, short attention and impulsivity
- ▶ Self-injurious behavior (skin picking, head hitting or banging, eye-poking or biting)
- ▶ Sleep disturbances
- ▶ History of developmental regression (especially language and social skills)

Benefits of Knowing

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



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It can be difficult to diagnose

- ▶ Some of the same symptoms which occur in DS-ASD are also seen in stereotypic movement disorder, major depression, post-traumatic stress disorder, acute adjustment reactions, obsessive-compulsive disorder, anxiety disorder, or when children are exposed to extremely stressful and chaotic events or environments.
- ▶ Sometimes when children with Down syndrome are experiencing medical problems that are hidden—such as earache, headache, toothache, sinusitis, gastritis, ulcer, pelvic pain, glaucoma, and so on—the situation results in behaviors that may appear “autistic-like” such as self-injury, irritability, or aggressive behaviors.



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Obstacles to Dual Diagnosis

- ▶ Failure to Recognize Dual Diagnosis
- ▶ Confusion with other behavioral or psychiatric conditions such as ADHD, OCD, or depression
 - **Result: Parents may feel forced into demanding a costly referral for another medical evaluation at a Down syndrome clinic or Child Development Center.**
- ▶ Lack of acceptance by professionals that ASD can coexist in a child with Down syndrome who has cognitive impairment.
 - **Result: Parents become frustrated and may give up trying to obtain more specific medical treatment or behavioral intervention.**



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Why is it important?

- ▶ Understanding the correct diagnosis is important to effective interventions that help children thrive
- ▶ Including:
 - correct pharmaceutical interventions
 - Educational interventions
 - Behavioral interventions



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Evaluation & Diagnosis

- ▶ Many families seek an appointment with an AUCD center, a developmental pediatrician, or Down syndrome clinic -- and others have been able to obtain an educational diagnosis of autism from their school system.



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Parent Perspective



Joyce Family:

Elise

Joe

David

Matthew



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What does the science say?

Research & clinical perspective

- ▶ Kerim Munir, MD, MPH, DSc, Boston Children's Hospital



Sources & Resources:

- ▶ [DS-ASD Connection](#)
- ▶ [Association of University Centers on Disabilities \(AUCD\)](#)
- ▶ [George T. Capone, DS and ASD: A Look at What We Know](#)
- ▶ [Sue Buckley, How many children with DS also have Autism and how do we meet their needs?](#)
- ▶ [Cook and Quinn, Expressive Communication in Individuals with a Dual Diagnosis of Autism Spectrum Disorder and Down Syndrome](#)
- ▶ [Colin Reilly, Autism spectrum disorders in Down syndrome: A review](#)



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Questions?

- ▶ Thank you so much for joining us today!

If we can be of further assistance, please contact us

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