

Down Syndrome and Autism

April is Autism Acceptance Month! The DSAGSL is committed to serving, supporting, and celebrating all individuals with Down syndrome and their families. Around 16-18% of the Down syndrome community will receive a dual diagnosis of Down syndrome and Autism Spectrum Disorder (DS-ASD). We have gathered some resources and information that may be helpful for families who have received a DS-ASD dual diagnosis, and for those who may be seeking an autism diagnosis. DSAGSL celebrates our members with Autism and Down syndrome in the month of April, and all year long!!

NEW HEALTHCARE GUIDELINES & SCREENING RECOMMENDATIONS



In October of 2022, the Healthcare Information for Families of Children and Adolescents with Down Syndrome were revised and one of the revisions includes screen for autism.

For Children Between 1-5 Years Old

Developmental services (early intervention):

Review your child's development with your doctor. Your child should be referred to local early intervention services. Additional options for therapy may be needed. Speech progress can be slow in Down syndrome, but after some delays, many will learn to talk. Until speech is easier for your child, he or she might need help finding other ways to communicate, such as using sign language, pictures, reading, or using electronic communication tools.

Behavior problems are often linked to problems with communication, but may reflect other issues, including ADHD and autism. Ask your doctor to screen for autism because it occurs more commonly in children with Down syndrome.



SUPPORT

Free Support & Resources through [DSAGSL DS ASD Dual Diagnosis Community Group](#)

Local support for families who have a dual diagnosis of DS-ASD
Private Facebook Group where families can exchange information and resources with other families in your community
Events hosted by DSAGSL and other local organizations with sensory-friendly environments
Contact Linda@dsagsl.org for more information

Visit the DSAGSL Blog to hear directly from families in the community whose child has received a DS-ASD dual diagnosis

[2022 Blog Post](#): My Thoughts & Journey with the Dual Diagnosis of Down Syndrome and Autism Spectrum Disorder, by Kim Youngberg

[2021 Blog Post](#): Our Journey with Down Syndrome and Autism: The Missing Puzzle Piece, by Kristi Denner

[2020 Blog Post](#): Our DS-ASD Journey, by Mary Hart

[2020 Blog Post](#): A Parent's Perspective on Dual Diagnosis, by Jeff Ponder

Free Online Support through the [Down Syndrome Autism Connection](#)

Serves over 2300 members worldwide
Families with loved ones with DS-ASD are invited to join other families in the world-wide community via their [private Facebook support page](#)
DSAC offers a monthly Zoom support meeting on the last Tuesday of each month at 7pm CST.
Ask questions and share experiences with other who are also looking for support and resources in a caring DS-ASD community.
Post photos, videos, and share the journey!
Contact DSAC for more information - dsasinfo@gmail.com

RESOURCES



- When Down Syndrome and Autism Intersect: A Guide for Parents and Professionals
 - [\(available on Amazon\)](#)
 - DSAGSL has a few copies of this book we can provide to families for free. If you are interested in a copy of this book, please contact Linda@dsagsl.org.
- Autism-like Behaviors in Children with Down Syndrome
 - [Frequent Questions](#)
- Down Syndrome and Autism
 - [A Look at What We Know](#)
- DS-ASD Connection Newsletter
 - [Quarterly e-newsletter with updates and information](#)
- National Down Syndrome Congress Webinar
 - [DS-ASD: Recognizing Signs and Tailoring Interventions](#)
- National Down Syndrome Congress PowerPoint
 - [When Down Syndrome and Autism Co-Occur](#)
- DSAGSL DS-ASD Dual Diagnosis Resources
 - [\(scroll down to Dual Diagnosis\)](#)

Commonly agreed upon core features on ASD include:

- Impairment in relating to people in social circumstances (social-disinterest, poor eye-contact, anxiety, social avoidance, or withdrawal).
- Impairment in communication such as initiating or understanding spoken words, signs, and/or gestures.
- Lack of imaginative play.
- Repetitive body movements and/or a persistent pattern of repetitive or ritualistic behavior. Focus on these activities is usually intense.

If a dual diagnosis of ASD is suspected, what should a parent do?

- Speak with your child's primary care physician and seek a referral to a knowledgeable professional who can help guide you.
- If a diagnosis of ASD is confirmed, you may wish to discuss possible treatment options with each of the different professionals you choose to consult with.
- Work with professionals who will help you understand, evaluate, and prioritize your various options.
- Work with professionals who are not overtly critical or threatened by attempts to design a program that is best for your child.

Benefits of Knowing

- In most cases, ASD (not Down syndrome) is the more functionally impairing developmental disorder.
- ASD in the setting of intellectual disability needs to be recognized when creating a meaningful educational treatment plan.
- A diagnosis of ASD could entitle your child to more specialized educational and intervention services.

Medicaid Home & Community Based Waivers

Under Home and Community-based waivers, a state may use Medicaid funding for home and community-based services provided only to a target group of people who have intellectual and developmental disabilities.

- [Missouri Dept. of Mental Health Waiver Program](#)
- [Illinois Healthcare and Family Services Waiver Program](#)

WHERE TO GET A DIAGNOSIS



The following Centers provide diagnosis, treatment, and training in Missouri

- MU Thompson Center for Autism and Neurodevelopmental Disorders
 - [573-882-6081 or 1-888-720-0015](#)
- SSM Cardinal Glennon Children's Medical Center - Knights of Columbus Developmental Center
 - [314-577-5609](#)
- Kansas City area Children's Mercy Hospital and Clinics - Developmental & Behavioral Sciences
 - [816-234-3674](#)
- Southeast Missouri State University - Autism Center for Diagnosis & Treatment
 - [573-986-4985](#)
- Washington University - Autism Clinical Center
 - [314-286-1700, Option 2](#) or psychiatryscheduling@psychiatry.wustl.edu
- Mercy Kids - Autism Center
 - [314-872-3345](#)

The following Centers provide diagnosis, treatment, and training in Illinois

- Center for Autism Spectrum Disorder - SIU Carbondale
 - <https://casd.siu.edu>
- The Autism Program of Illinois - Carbondale, IL
 - <https://tap-illinois.org/southern-illinois-university>
- University of Illinois Autism Clinic - Champaign, IL
 - <https://psc.illinois.edu/autism-spectrum-assessment-services>
- Autism Society of Southern Illinois
 - <https://www.autismsocietysi.org>
- Illinois Center for Autism - Fairview Heights, IL
 - <https://illinoiscenterforautism.org>
- The Autism Collective - Peoria, IL
 - <https://theautismcollective.org>
- Easter Seals of Central Illinois
 - <https://www.easterseals.com/ci/our-programs/ASD/autism-services/autism-diagnostic-clinic.html>
- The Autism Clinic at Hope, O'Fallon IL
 - <https://www.theautismclinic.org>



LOCAL PROGRAMS & RESOURCES

- Easter Seals Midwest
 - www.easterseals.com/midwest/our-programs/autism-services
- Judevine Center for Autism
 - www.judevine.org
- Autism Speaks
 - www.autismspeaks.org
- Missouri Dept. Of Mental Health's Division of Developmental Disabilities
 - www.dmh.mo.gov/dev-disabilities/regional-offices
- Illinois Dept. of Healthcare and Family Services
 - www.dhs.state.il.us
- Illinois Center for Autism in Fairview Heights, IL
 - <https://illinoiscenterforautism.org>

HAS YOUR CHILD BEEN DIAGNOSED WITH AUTISM?



The DSAGSL keeps a database that stores information about everyone connected with the organization, including families who have a loved one with a dual diagnosis of Down syndrome and autism. Recently, our Director of Family Support, Linda Kamphorst, sent out an email to the families in the dual diagnosis community.

IF YOU DID NOT RECEIVE THAT EMAIL, then we do not have this information recorded in our database for your child with Down syndrome.

Please contact Linda@dsagsl.org or 314-833-8214 if you would like to be included in mailings and emails about resources and events for families of a child with a DS-ASD dual diagnosis.

SAVE THE DATE! In June, DSAGSL will partner with the Down Syndrome - Autism Connection, and hear from their Executive Director, Charlotte Gray. Be on the look out for more information coming soon.

The DSAGSL also maintains a list of experienced parents who are happy to speak with other parents whose child has received a DS-ASD dual diagnosis.
