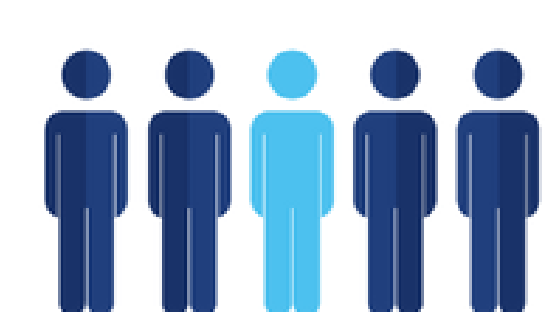


Background

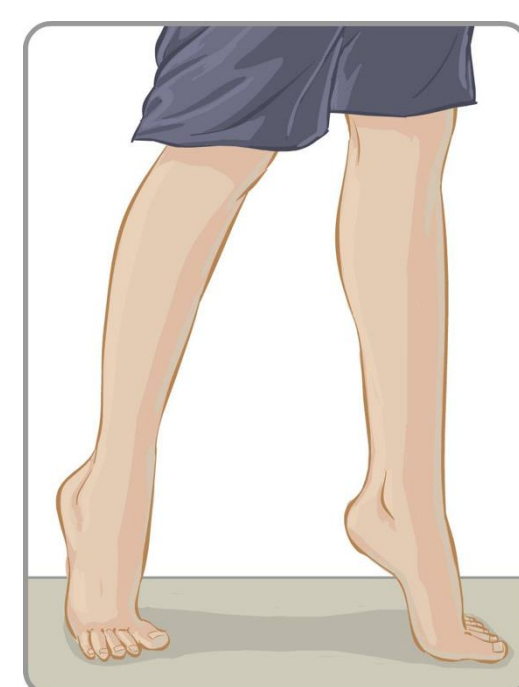
Autism (ASD) is often underdiagnosed in children with Down Syndrome (DS).



Based on current literature, about **1 in 5** children with Down

Syndrome also meet criteria for Autism, which is a higher prevalence than the general population. However, research on the dual diagnosis is limited, and the exact rate of comorbidity varies by study.

Research continues to examine behaviors that differentiate children with DS from children with the dual diagnosis. One of the main characteristics of Autism is lacking social interest.



Children with the dual diagnosis also may have more pronounced communication delays, sensory differences, and repetitive body movements (e.g., hand flapping, spinning, toe walking).

It is important to know which ASD characteristics to look for in a child with DS who will experience developmental delays in the context of their DS diagnosis. Early identification of the dual diagnosis allows families access to necessary treatments and community supports.

Methods and Results

Literature review conducted using PubMed and Google Scholar

- Relevant articles were summarized into one word document for comparison

Canva.com used to create a two-page flyer

- Collated information gathered during literature review procedures

Nemours Down Syndrome Clinic members reviewed flyer and provided edits, as needed

- Self and parent advocates were included in the editing team

Edits incorporated into draft, and final copy reviewed in person with team members

Next Steps

1. Continue to speak with contacts at the Down Syndrome Association (DSA) of Delaware as well as the Down Syndrome Clinic at Nemours to make any additional content edits to the flyer
2. Work with the Delaware Network for Excellence in Autism (DNEA) to update formatting of the flyer for virtual dissemination on their webpage
3. Hand out the printed flyer to families during DS Clinic days at Nemours (the second and fourth Thursdays of month)
4. Make the flyer accessible online through several webpages: 1) Nemours DS Clinic, 2) Swank Autism Center, 3) the DNEA, and 4) the DSA of DE.
5. Gather information from families who see the flyer to 1) determine if the information is new and helpful, 2) see if they were able to get an autism evaluation for their child, and 3) determine at what age families get a diagnosis (if relevant)

Relevant References

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The Dual Diagnosis: Autism and Down Syndrome

About 1 in 5 children with Down Syndrome also meet criteria for Autism



What to Look For?

Seeing any of the symptoms below in your child with Down Syndrome is reason to ask your providers about an autism evaluation.



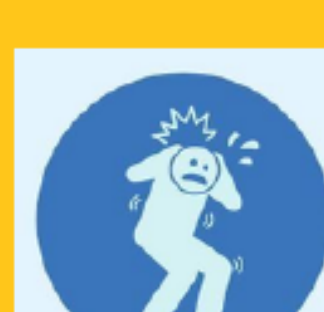
Communication

- Not saying any words or phrases by 3 years old
- Using other people's hands to do tasks
- May have loss of speech
- Little use of gestures such as pointing, nodding, waving, or blowing a kiss



Social Skills

- Does not respond to their name or share interests
- Avoids other children
- Has disruptive behaviors including aggression, extreme non-compliance, tantrums
- Does not make eye contact as expected



Repetitive Behaviors and Sensory Differences

- Frequent body movements (e.g., hand flapping, spinning, jumping, toe walking)
- Plays with toys and objects in unexpected ways
- Makes sounds repeatedly towards self while playing
- Has meltdowns with changes in their schedule
- Dislikes loud noises or physical touch





The Dual Diagnosis: Autism Evaluation and Treatment

Why get an evaluation?

Getting an evaluation can help families better understand their child and get access to additional community resources and support!!

How to get an evaluation:

There are several pathways to get a child evaluated for autism both by providers in the community and at school. There is a medical diagnosis of autism as well as an educational classification. Both evaluations require working with a trained professional. They will use assessment tools including parent and teacher questionnaires, parent interview, and structured observation. A good place to start asking questions is at the Down Syndrome Clinic at Nemours! You can find the link for more information on Down Syndrome clinic below.

Find Community:

Connecting with the Down Syndrome Association can help you find other families of children with the dual diagnosis in your area!

Additional Therapies:

With an autism diagnosis, your child is now eligible for behavior therapy (such as Applied Behavioral Analysis (ABA)) through insurance. This type of therapy focuses on the development of early social communication, language, and play skills in your young child with autism.

I got a diagnosis, now what?

Community Resources and Literature:

Delaware Organizations:

- Down Syndrome Association (DSA) of Delaware (dsadelaware.org)
- Autism Delaware (<http://delautism.org>)
- Swank Autism Center at Nemours (<https://www.nemours.org/services/swank-autism-center.html>)
- Nemours DS Clinic (<https://www.dsadelaware.org/for-families/medical/childrens-clinic/>)

Literature:

- Autism Speaks DS/ASD webpage (<https://www.autismspeaks.org/down-syndrome-and-autism-spectrum-disorder-da-asd>)
- When Down Syndrome and Autism Intersect: A Guide to DS-ASD for Parents and Professionals by Margaret Froehle and Robin Sattel

Select Relevant References:

- Diniz, N. L. F., Parlo-Oliveira, E., Pimenta, P. G. A., Araújo, L. A., & Valadares, E. R. (2022). Autism and Down syndrome: early identification and diagnosis. *Arquivos de neuro-psiquiatria*, 80(6), 620–630. <https://doi.org/10.1590/0004-282X-ANP-2021-0156>
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