

Resource Directory



Resources listed are not endorsed by DSAWM, but are a list of options that are available. If you know of additional West Michigan resources, please let us know at 616-956-3488 or director@dsawm.org. For more information, visit dsawm.org/resources.



DS-ASD Dual Diagnosis Resources

Autism spectrum disorder is a neurological disorder that affects the brain's development of social and communication skills. As research of developmental disabilities advances, studies are now showing that people with Down syndrome are more likely to have autism than their neurotypical peers. When a person is diagnosed with both Down syndrome and autism, that person is often referred to as having a dual diagnosis or DS-ASD.

Getting & Understanding a Diagnosis

Research into DS-ASD is a relatively new field of study and, as result, many people with Down syndrome and autism remain undiagnosed with the latter. The more information is shared and relationship between Down syndrome and autism is understood, the sooner an individual with DS-ASD can be diagnosed after autistic characteristics first begin to present. Once an individual receives a dual diagnosis, additional resources for support, such as ABA (Applied Behavior Analysis) therapy, are often made available to families.

The **NDSS Down Syndrome and Autism pamphlet** offers a concise overview of what to do if you suspect your child may have a dual diagnosis and the behaviors that may indicate ASD (see below). The pamphlet can be viewed at ndss.org. Comprehensive information is also available from the **Down Syndrome-Autism Connection** (ds-asd-connection.org or 720-757-7007), the only nonprofit organization dedicated solely to DS-ASD in the United States. Additional reading can be found at the websites for the **National Down Syndrome Society** (ndss.org) and **Down Syndrome Resource Foundation** (dsrf.org).

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
- **3 Years and Older**
 - 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

If you believe your child should be evaluated for ASD, the West Michigan providers listed below are available to provide testing and a diagnosis to families.

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| <p>BRAINS brainspotential.com 616-365-8920 Grand Rapids</p> | <p>Mary Free Bed Kids – Autism Spectrum Disorder Program maryfreebed.com/conditions/autism 616-840-8807 Grand Rapids, Traverse City, Bay City</p> |
| <p>Helen DeVos Behavioral Health Clinic – Spectrum Health spectrumhealth.org/services/helen-devos-childrens-hospital/behavioral-medicine-and-psychiatry 866-989-7999 Grand Rapids</p> | <p>Pine Rest Christian Mental Health Services pinerest.org 800-678-5500 Grand Rapids</p> |
| <p>Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia</p> | <p>WMed Pediatric Autism Center med.wmich.edu/node/701 269-337-6077 Kalamazoo</p> |

Blue Cross Blue Shield maintains a list of approved **autism evaluation centers (AAECs)** across the state that may be helpful in identifying an evaluation site outside of West Michigan. The list can be viewed on their website at bcbsm.com.

Additional information about diagnosis can be found at the website for the Autism Alliance of Michigan at autismallianceofmichigan.org/diagnosis or by calling 877-463-2266.

Community Supports

Ds-ASD Support

- **Down Syndrome-Autism Connection** (ds-asd-connection.org or 720-757-7007) provides education and support to individuals facing the unique challenges caused by co-occurring Down syndrome and autism.
- **Ds-ASD Listserv** is managed by the Down Syndrome Network of Montgomery County for the purpose of providing friends, relatives, and caregivers of people with dual diagnoses with a place where they can connect to share information. To join the Listserv, email dsasd+subscribe@groups.io.
- **DSDN Dual Diagnosis – Down syndrome and Autism** (facebook.com/groups/DSDNDUALDIAGNOSISAUTISMandDS) is a Facebook group for parents of children diagnosed with Down syndrome and Autism created by the Down Syndrome Diagnosis Network.

Autism Support

- **Autism Society of Michigan** (autism-mi.org or 517-882-2800) is committed to empowering individuals with autism and their families by offering educational resources and materials, workshops, seminars and other services.
- **Autism Alliance of Michigan** (autismallianceofmichigan.org or 877-463-2266) leads efforts to raise expectations and expand opportunities for people touched by autism across the lifespan.
- **Autism Support of Kent County** (autismsupportofkentcounty.org or 616-752-8577) works to provide services that make it possible for individuals with autism to lead healthier and more productive lives.
- **Autism Support of West Shore** (asws.org or 616-395-3222) advocates and supports meaningful participation in all aspects of life for individuals with Autism Spectrum Disorder and their families in West Michigan.
- **Hope Network Center for Autism** (hopenetwork.org/autism or [844-969-0252](tel:844-969-0252)) a multi-disciplinary team of experts specialized in treating learners on the autism spectrum as young as 18-months-old.

Michigan Alliance for Families shares additional resources on their website specific to residents with autism in the state of Michigan at michiganallianceforfamilies.org/autism-spectrum-disorder.

For more information about DS-ASD Dual Diagnosis, visit the DS-ASD Dual Diagnosis Resources page of our website at dsawm.org/dual-diagnosis-resources.

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Two Punches on the Disability Card

by Amy Wigger, Hudsonville

Your son is autistic. I let out a sigh of relief, at the same time feeling like someone had knocked the wind out of me with so few words again.

Three years before, almost to the day, another medical professional looked me in the eye and said five words, your son has Down syndrome. I was prepared for that diagnosis, even without a prenatal diagnosis. I had literal dreams about our third born child having Down syndrome, had mother's intuition, and I believe a divine message somehow letting me know that Owen would be born with Down syndrome. So while the rest of our family and friends felt the world shift completely from under their feet, I was standing tall and strong. I prided myself on the way I gracefully handled this diagnosis that no one else expected and Owen soon began to thrive.



Owen began to say words around age 2. Simple words like mom and dad or cookie rolled off his tongue. Again, we were so impressed and excited. Life marched on.

Around age 2 and a half, we noticed Owen was getting lost in his own world more times than not. He was attracted to lights and anything he could hold in his hands and shake simultaneously. I would later be informed at his autism testing that this was in fact him flapping, a characteristic of autism. He was becoming more and more angry and his words had all disappeared, really before I noticed, they were gone. He didn't try to sing along with songs anymore and the light we used to see in his eyes was almost gone.

As parents we began to wonder what we were doing wrong. We hadn't changed any routines or the way we interacted with Owen. His environment was consistent, and we kept basically the same daily schedule. We were at a loss. We were frustrated and sad, mostly because we wanted to help Owen, but we had no idea how. I was watching other kids with Down syndrome surpass Owen's developmental milestones. Their temperament was drastically different than Owen's. I quit going to playdates, not just with typical kids, but with families who had kids with Down syndrome. We had to be failing him somewhere. Why was our child the only one not moving forward?

Owen's teaching team were the ones who told us that they thought it would be beneficial for Owen to be screened for autism. I was confused and sad, but all of a sudden a bit hopeful as well. Maybe we weren't terrible parents, maybe there was more going on.

His screening took place at our local Children's hospital. It took about 4 hours and part of us wondered if we would go and they would dismiss his behavior as "low functioning" Down syndrome. We had heard from other families who had gone through testing 5-10 years before that it wasn't an uncommon phrase when they inquired about a dual diagnosis. At the end of the appointment, we heard the words, he has autism. They would of course have to write up the report and file all the paperwork, but we had our disability punch card punched again.

It took me longer to accept this diagnosis. It didn't feel fair that Owen would get another diagnosis. One that would complicate his life further. One that may limit him further. I allowed myself to stay

in that place. I still allow myself to feel those feelings, to mourn that our son no longer “just” has Down syndrome. These days we see autism characteristics come through into our daily lives more dominantly than Owen’s Down syndrome characteristics.



As a parent I still feel like I don’t quite fit at either party. I don’t totally fit in with the Down syndrome crowd and the same goes for the autism community. Owen doesn’t fit in either box either. I’ve decided that I may not be the only parent feeling this way. My goal is to be as transparent about our dual diagnosis life as possible, while still respecting our son’s autonomy. I also want to share our story to encourage any parent who is feeling what we were feeling that you are not alone. That statistics are showing that more and more people with Down syndrome also have autism. And if you suspect your loved one does, it’s always worth looking into.

We also see light again. Owen began ABA therapy and has been attending what may be an actual utopia of therapy centers for 5 years. He is fully included in a general education setting where his school welcomes his behavior techs with open arms. The team he has works together to make sure everyone is on the same page, and we are all working together to meet Owen’s needs so he can thrive. He also is gaining some verbal language back and successfully uses a device to communicate with those around him.

We still have difficult days, sometimes difficult seasons. We are all learning and growing and figuring out how to support Owen and one another as we move down this road. But we have hope again. The light is back in Owen’s eyes. He is a wonderful son, brother, and friend. He makes us laugh every day. He is blazing his own path and we could not be more proud of him.

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
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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 Froehlke 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)