



The Van Schoyck Family recently moved to the Greater Cincinnati area and immediately made connections with the DSAGC Community through our community groups. This is their family's journey with learning about co-occurring diagnoses of Down syndrome and Autism

The day we received our daughter Sienna's diagnosis of autism, my husband and I felt a huge sense of relief. Leading up to the appointment we kept asking ourselves, if she doesn't have autism (in addition to Down syndrome) then what? Or if the developmental pediatrician doesn't agree that some of the markers we see are an obvious indication that she's on the spectrum, then what? Because despite Sienna having an entire village of therapists and specialists, she had plateaued with speech for two years. I think the assumption was all roads point to Down syndrome, but we had a feeling there had to be more. Our hope was if Sienna did have ASD (Autism Spectrum Disorder), then finally, we could open a door to better understanding our daughter's behavior and start on a path to truly addressing her specific needs. Between the ages of four to six, Sienna was doing very well at school. She was out of diapers. She was emerging in

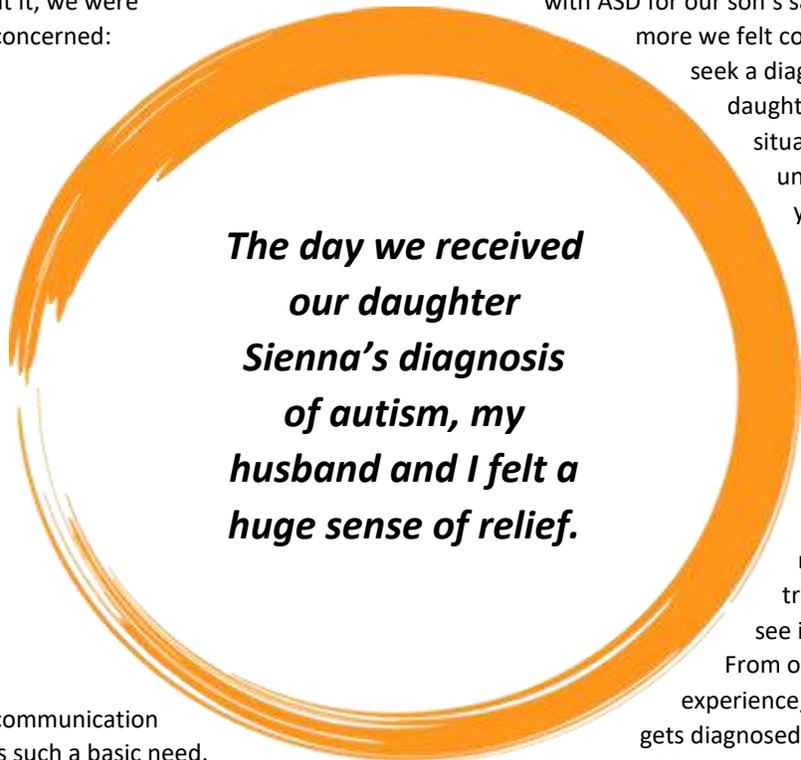
reading. And for the most part seemed content. But there was this pressing concern, one that would be very obvious when we would meet with other kiddos her age that also had Down syndrome...our sweet little kiddo wasn't really talking. Sienna also wasn't as interested in waving hello, giving out hugs or joining peers at play. She actually seemed more like an aloof teenager, wanting to spend all her time in her room alone, flipping through books and listening to music. My husband and I tried reminding ourselves that not all kids with Down syndrome are the same. We tried not to compare. We tried focusing on her strengths. But however we looked at it, we were concerned:

correct consonant sound at the beginning or end of a word. Although important, there was a bigger concern not being addressed. She was unable to communicate if she was hungry, hurt, or happy - something was missing from our village. It was actually our son who started to shed some light to the possibility that Sienna could be autistic. The same year she was diagnosed, our son had received his diagnosis eight months prior. Like many diagnostic tools, there's a parent portion to be completed based on observations of your child. Question after question of my son's evaluation, it was like a light bulb being switched on - this sounds like Sienna. And the more we became acquainted with ASD for our son's sake, the more we felt compelled to

seek a diagnosis for our daughter. Our situation may be unique, but if you suspect your child may have autism or have been told by a teacher or therapist that there are some markers or traits that they see in your child, From our experience, after a child gets diagnosed with Autism

communication is such a basic need. Her peers with DS were stringing two to three-word phrases, some speaking in sentences and/or answering basic questions. Sienna's speech goals were still focused on consistently making the

Spectrum Disorder parents usually seek behavior therapy. Typically, this means families either a) Investigate and pursue ABA therapy (Applied Behavior Analysis - a systematic type of therapy



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that focuses on improving specific behaviors in areas such as social skills, communication, hygiene, academics, etc. or b) Seek other supports. It was the decision of our family to do ABA. In many ways, it's like other therapies: do your homework and find a place that works for you and your child. However, unlike most therapies that we were accustomed to; ABA therapy usually requires a minimum 10 hours a week commitment. In our case, the recommendation for our daughter was 20 hours a week. This was by far the most challenging aspect of adjusting to this additional diagnosis. We as a family had to make major changes to our schedule. For us, it meant withdrawing our daughter from school and doing homeschool in the morning and therapy in the afternoon. For other families, it could be finding a therapy center that does after school hours. There's also the option to look into schools such as the Cincinnati Center for Autism and using the Autism Scholarship Program of Ohio. We noticed changes in my daughter almost immediately. The therapy was always based around activities she enjoyed. The therapy team sought and included parent input which was extremely important to us. And finally, her AAC device (Augmentative and Alternative



Communication) was being used. Sienna was communicating and we were listening. The other door that a formal diagnosis opened for our daughter was in school. Before the diagnosis, I remember once sitting after an IEP meeting in an assistant principal's office arguing over 15 minutes of time being spent in Gen Ed versus pull out resource. After the diagnosis, my husband and I really had to sit down and ask ourselves what skills could Sienna work on in behavior therapy and are these skills more important at this time than learning how to do word problems in math and learning to read with phonics. The reality for us was that those things could wait. Our new priority was helping our daughter find her voice, advocate her needs, and encourage her to explore and share her interests. And so, we shifted completely to make ASD her primary qualifier for special education services on her IEP. If you fear that an additional diagnosis such as Autism could be interpreted as your child having higher needs which could be used against your argument for inclusion, keep in mind the argument could work in reverse. If your child was well supported and making progress before the diagnosis, then why would anything change. Or perhaps the

question to ask yourself, could my child be struggling with behaviors that are disruptive to his learning that once addressed could expand opportunities for more inclusive opportunities? I guess what I'm saying is that I think it's okay to step out of the "more alike than different" mind set and get comfortable with the wide spectrum of interesting differences that we all encompass as individuals. It may feel a bit overwhelming to consider an additional diagnosis. It's like you're just getting a grasp on all that's Down syndrome, only to be handed a new set of information books. My husband and I definitely felt that way. We still have moments of great uncertainty. What will this mean for our kids' future? Will she be able to work and live independently? Where are all the adults with DS and Autism? We continually have to refocus our energy on the question demanding an answer today - how can we help our daughter at this moment? And if there's one thing I've learned from the DS community it's this: we chart a path to success for our amazing kids one step at a time.

For more information visit:

DSAGC:

<https://www.dsagc.com/resources1/information-by-topic/co-occurring-conditions/>

NDSS:

<https://www.ndss.org/resources/dual-diagnosis-syndrome-autism/>