

Transcript Details

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ReachMD

www.reachmd.com
info@reachmd.com
(866) 423-7849

The Parent's Perspectives on Autism Spectrum Disorder

With the national incidence rate of 188 individuals under the age of 18 diagnosed with autism spectrum disorder in the United States, the CDC categorizes this disease as a significant public health issue. If you haven't met, or know someone impacted by autism spectrum disorder yet, with incident rates this high you're guaranteed to know many during your lifetime.

You're listening to ReachMD. I'm Paul Rokuskie, your host, and with me today is Mercedes Ignasiak and Vanessa Vega, both parents of a child on the autism spectrum. Today we're discussing the parent's perspective of autism spectrum disorder, and how it impacts, not only their children diagnosed with autism, but their entire family. Welcome ladies.

Mercedes Ignasiak:
Thank you.

Vanessa Vega:
Thank you.

Paul Rokuskie:
So I'm going to just jump right into this. So Mercedes, give us a little bit of background about you and your family.

Mercedes Ignasiak:
Okay. I'm married and I have two children. I have a 24-year-old young man who is the one that's diagnosed with an autism spectrum disorder and I have a 21-year-old daughter who is now college age. So my home consists of just the four of us and my father lives with us as well. My son at 24, years ago when we had him diagnosed, the autism spectrum disorder was not something that was really made aware of in the community. Years ago when we had noticed that he had had some developmental delays, we had had him taken to various physicians and different things but we really didn't know that this is what he had. So we've been really on quite a journey, and now at 24, he's done really well, made a lot of strides and our household, we're always learning every day.

Paul Rokuskie:
That's great. So Vanessa, tell us a little bit about yourself and your family.

Vanessa Vega:
Sure. In our family, we have one child, seven and a half years old on the autism spectrum and we are both challenged by the diagnosis a little bit because we're both full time working parents in corporate America. Our child in our case was diagnosed at a time when the awareness of this thing called autism was a little bit more prevalent. He was diagnosed at age three and I had noticed symptoms of developmental delay or potential developmental delay as early as about 16 months. So in my case I was very proactive in terms of trying to find answers for what might be affecting our son and worked very, very closely partnering with the various physicians in various specialties that worked with him to arrive at that diagnosis.

Paul Rokuskie:
Mercedes, what prompted you to seek answers many years ago when your son was much younger obviously?

Mercedes Ignasiak:
Well many years ago and as Vanessa had pointed out, the time my son was diagnosed with a developmental delay, there really wasn't an awareness of autism, or the spectrum, or Asperger's syndrome. We had just noticed that when he was about two years old, he really wasn't reaching the milestones that we expected. He wasn't speaking. His gross motor was a little bit impaired as well as his fine motor skills and we had pretty much gone to the pediatrician and they had kept a watch on it but they really weren't as, I guess, aware

themselves what this could be, and in some cases, they said just watch it and maybe he'll grow out of it and unfortunately, sometimes you hear things that boys are a little bit slower in their development. So it was kind of something like that that we were looking at.

When we saw that our son was not progressing as we watched. We had pretty much then became proactive and said to, at the time our pediatrician that we really wanted to go seek out another professional just to find out what our gut had told us that we definitely had something that we needed to get addressed because it was more than just a slow development. There was certainly a problem and some of those things that really made us seek this out was not only was his language delayed, but we did really see that our son was developing great anxiety and had socialization issues whenever we were in the public or even around other extended family gatherings. So this is pretty much where then at that time we became proactive to seek out a medical professional, but at that time, there really weren't specialists to go see and we weren't sure where to go.

And in addition to that, years ago when my son was diagnosed, this was going back around like '91, '92, you didn't even have the internet out. So most of the time parents like myself, we were calling hospitals or we were looking in the phonebooks, looking for directories to see who else we could find. I mean we would get referrals from our pediatrician but you know, sometimes we just needed other options as well. So it was really a challenging time like that and as I see now, which is nice is that there a lot more resources available to parents and one thing I have to say, the internet is really truly a Godsend. It does help in education for parents as well as professionals too.

Paul Rokuskie:

So when exactly did you get the diagnosis of autism spectrum disorder? How old was your son when that happened and did you get diagnoses prior to that?

Mercedes Ignasiak:

No. What happened with my son back then in the early 90's, they weren't really diagnosing anyone with Asperger's or autism. We actually were just getting what I call 'vegetable soup diagnoses' every time we went to a physician and we did end up going to a neurodevelopmental pediatrician who was wonderful, but each time we went with an issue, if it was a language problem, fine motor skills problem, we would get the diagnosis of say expressive receptive language disorder. We would get fine motor disorder and that would be added to his diagnoses there and then as he was maturing and getting older, we noticed that we were actually seeing some attention deficit disorder with our son. So that ended up to be another diagnosis our son had.

So by the time he was about ten and eleven, we did have some medication into our son just to address some of the attention deficit disorder and also some anxiety, but what came out then was obsessive-compulsive disorder. Once that final component at that time I'm going to say when my son was about eleven, once that was diagnosed, the pediatrician or neurodevelopmental pediatrician then said to us, 'He has an autism spectrum disorder' and I looked at her and I said what is that and again, this is the early like mid 90's. She said all the components of all of his diagnoses over the years has been autism spectrum disorder but I didn't give that to him until he received the final component or we noticed ____ (7:09) obsessive-compulsive disorder.

So back then in the 90's, they didn't really recognize it as it quickly or at least gave that diagnosis and so now like I said, you know, it's nice to see that physicians are recognizing it more that when they see these components, they're not waiting. It seems like they're addressing it right away and actually recognizing these symptoms.

Paul Rokuskie:

Excellent. So Vanessa, your son was diagnosed by your pediatrician, developmental pediatrician, who and at what age?

Vanessa Vega:

My son was diagnosed by a developmental pediatrician at age two with a different diagnosis. This diagnosis then was developmental language delay and then when he was formally three years old because he had some challenges with transitions and with change in general the pediatrician switched the diagnosis to PDDNOS, which is on the autism spectrum.

Paul Rokuskie:

If you're just joining us, you're listening to ReachMD. I'm Paul Rokuskie and I'm speaking with Mercedes Ignasiak and Vanessa Vega. We're talking about a parent's perspective on autism spectrum disorder.

So very different times that your sons were diagnosed at very different times one in the mid 90's and one just a few years ago. After you get that diagnosis, what was the next thing that your physician guided you to do and Mercedes will have you start with that.

Mercedes Ignasiak:

Actually what our pediatrician, our neurodevelopmental pediatrician suggested is that we have an IEP written and that we be proactive in obtaining for our son the various services he needed such as speech therapy, occupational therapy, and to deal with some of his

anxiety, they also recommended that we maybe have him get some individual psychotherapy to help deal with some of the anxiety. What I really had liked about our neurodevelopmental pediatrician is that she wanted to address all of our son's issues by not just medication but also therapies and she looked at his diagnosis and wanted him treated as a whole and in addition to that, the school district was...it was imperative that he receive these services for himself so that he could become a success.

So what we did was we partnered with our school district and we created the IEP's to address the needs that he had. He was put into smaller group settings in school and at the time in the 90's, what they did with our children is they put them in learning support, language support programs so that they were in small groups and they were able to get that almost individualized attention in that smaller group and together with the Special Ed teacher, they also had a teacher's assistant in the classroom as well to follow through which was nice.

We were also very proactive in getting our child speech therapy both in the school district and privately. One of the things that we made sure we did was through the state system, we made sure that we actually filed out an application for an access card and that allowed us to get our son services through Keystone Mercy Insurance and that helped get and pay for the services both in the school district as well as privately. So all of this aggressive treatment really helped and it was intense therapy treatment for at least five, six years, and it really made a change in our child. So partnering not only just with the physician but with our school district and also with all our therapists that really was the key and we worked as a team both the parents and the professionals to really develop a plan and follow through to ensure the success.

Paul Rokuskie:

And just for our listeners that medical access card is something specific to individuals residing in Pennsylvania. That's going to vary state by state, and some people's medical benefits may cover these things, and some things may be out of pocket and that'll vary from state to state. So Vanessa similar question to you, where did you start your path of navigating the system after you got your initial diagnosis.

Vanessa Vega:

Well, as you can imagine Paul, I mentioned that my son had a different diagnosis that was not at all autism related at age two and when his neurodevelopmental pediatrician actually came with the autism diagnosis, we were a little shell-shocked. I have to share that as a parent. I think one of a parent's greatest fears is when someone particularly somebody in a medical profession comes to you and says 'Your child may never be able to.' Those are the seven words that I can almost guarantee most parents will never want to hear. So our initial reaction was okay, so what does this mean in terms of limitations, in terms of potential, in terms of, you know, any question that comes to mind at the time and we had the benefit that our neurodevelopmental pediatrician is very, very focused specifically in autism and she very patiently answered questions and encouraged us to, as Mercedes referenced, go on the internet and read more about the diagnosis, read more about the options that are available for therapies.

So that's really where we went. With her advice, she mentioned occupational therapy. She mentioned speech therapy. In his case, he didn't have a significant gross motor delay. So physical therapy wasn't something that we pursued initially. But we went to the internet just to learn more about 'So I have this diagnosis. What now?' and that really helped me as a parent, and my husband as well. Whenever we took him to follow up physician to be prepared to bring up specific questions that we wanted answers from our physician so that we can work as a team and guide that therapy, guide that treatment protocol in a way that's beneficial to our son and we really have seen nice gains from that. We've started extensive speech therapy and occupational therapy going on about four years now and have seen tremendous progress to the point where God willing our child will be able to be independent to some degree.

We've got a long way to go before we get to that stage but through hard work, through dedication, it's possible, and my advice to parents would be to not get so hung up on the diagnosis but to really kind of mobilize and advocate for your child and try to get as much of the supports that are available to help your child develop to his or her fullest potential. Along those same lines, my advice to a physician would be, you know, recognize that when you do hear that A word that autism that it can be a shell-shocker to parents to the extent that medical professionals can help parents cope with that diagnosis and what it means, offer resources, offer insight, and a lot of it is available right now. It really does set the tone for this is a partnership and we really do feel that all of the medical professionals that are treating our son whether they see him on a weekly basis or whether they see him two times a year are part of a team and really kind of working toward a common goal.

Paul Rokuskie:

And that sounds like it's a very important aspect. We see physicians today partnering with a general practitioner, with a specialist, or various specialists coming together to come up with a mutual diagnosis in that the parent is a key component in that team. Many thanks to our guests, Mercedes Ignasiak and Vanessa Vega. We've been discussing autism spectrum disorder. Be sure to visit our website at ReachMD.com featuring podcasts of this and other series and thank you for listening.