

A case description of autism- Alexis' story

Alexis' Story

Alexis Wineman is the first woman with autism spectrum disorder (ASD) to participate in the Miss America competition. Alexis was in middle school when officially diagnosed with PDD-NOS (Pervasive Developmental Disorder- Not Otherwise Specified), but felt "different" from an early age. As she got older, she struggled with some of the challenges that come with having ASD, such as a speech impediment, communication difficulties, and being sensitive to loud sounds, and other sensory-related issues. Alexis also had to deal with bullying that occurred because of her differences. Fortunately, her family has always been a source of strength and inspiration for her. We interviewed Alexis, her mother Kimberley, her older brother Nicholas, and her older sister Danielle, and her twin Amanda to hear more about the unique role that siblings play in families living with ASD.



Alexis' Perspective

Prior to being diagnosed with autism, neither I nor my family had an explanation for my meltdowns and other issues. After the diagnosis, it was incredible how my siblings reacted. They were superheroes. They took me everywhere and pushed me into activities. They helped me with homework. It was just amazing how they sprang into action after years of not knowing what was going on.

My advice for other individuals with autism would be to have patience for your siblings just like they have patience for you. It's good to try and figure out what's going on from their perspective rather than focusing on yourself.



Kimberley's Perspective

Once Alexis was diagnosed and we knew what we are dealing with, her siblings took control. They shoved her into things and got her involved. They wouldn't let her use autism as a crutch or excuse for not being involved. Her brother got her into cross-country and her sisters got her into cheerleading. All three siblings got her into speech and drama. Had she not been involved in those activities, she wouldn't have been able to accomplish all that she has accomplished. Alexis was able to find activities where she was accepted, and she wouldn't have found those on her own.

Her siblings also became very protective and helped with the teasing and bullying. Siblings can be such a positive force for combatting bullying. They can educate the peer group. That's something a sibling can be much more effective at than a parent.

My advice for someone who has a sibling with autism would be to engage them and help them find their niche.

"My advice for other individuals with autism would be to have patience for your siblings just like they have patience for you."

Nicholas' Perspective

Before Alexis was diagnosed, we just didn't understand why she was acting out. It was very confusing and frustrating. After the diagnosis, things made a lot more sense. Being able to help and take preventive measures, it was a whole new world. It has made us all better people. We learned patience.

It was a common occurrence that we would get into fights, but being able to make up and process what happened was different for Alexis compared to the rest of us. With Alexis, when the fight was over, the board was erased clean. In other words, five minutes later everything was completely back to normal. It seemed like she was doing it to annoy you, but she wasn't. Not understanding why it was so easy for her to get over a fight was hard. Going through experiences like this makes you have to be more understanding. You learn that people handle things differently.

My advice for someone who has a sibling with autism would be to practice empathy. I consider myself to be empathetic and living with Alexis was a huge part of that.

Danielle's Perspective

My brother and I had to do some growing up fast. You have to take on a parenting role when you're trying to understand what's going on. From the time she was diagnosed, it opened our eyes to understanding people with disabilities. We have openness to people with differences and are able to maintain that empathy. We've grown up having to deal with all levels of ups and downs.

I played a second mom when Alexis was younger. If she didn't listen to mom, I'd go in and say the same thing. Sometimes it's easier to have someone on her level explain things or give her the opportunity to vent.

My advice for someone who has a sibling with autism is that you have to become a solid shadow for your sibling. They might not fully understand how much you are putting in to be there for them. At the end of the day, each success, no matter how small, is part of you. You deserve to celebrate too. When you're diagnosed with autism, it's a diagnosis for the entire family and not just that person. It's really a test of family.

Amanda's Perspective

Having a twin is how we figured out there was a problem. There was a direct comparison to a neuro-typical child, and they could see that Alexis wasn't meeting milestones the way I was. When I was little, whenever I came home from school, I tried to teach her to do things that I had learned so that she could keep up with me.

We are now roommates in college. But I still have to wake her up and help keep her on a schedule. It's been interesting to see how people in college react to our interactions. They don't understand that I'm acting in a couple of different roles—sometimes as a sibling and sometimes more as a mother.

My advice for someone with a sibling with autism is to be patient. As stressful as the role you have to play is, it's also rewarding. If you try to be patient, you get to share in success. Alexis' America's Choice Award during the Miss America competition ranks as one of the highlights of my life because I got to share in that success. Never give up on trying to help.

Source:

<https://www.cdc.gov/ncbddd/autism/stories.html>