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*Ending the Stigma*

My name is Kristie Carlsen. I'm a 30-year-old self-advocate originally born in Racine WI. When I was five years old, I moved with my family to Evansville, Wisconsin. Evansville a small community just outside of Madison that was even smaller when I was growing up than it is now. To give a little perspective on size, my graduating class had roughly 100-120 students. Growing up in a small town didn't provide a lot of diversity because of its lower population and rural location.

When I was 5 years old I was diagnosed with epilepsy and a learning disorder but my formal autism diagnosis didn't happen until I was much older. This meant that I was in special education classes but wasn't really getting supports accurate to my needs. Middle school was probably harder than high school because of how separated I was from my peers. I worked tirelessly to get into the regular education English class which took time but I did accomplish! High school was a little bit better because of the routine but overstimulation from noise made it almost impossible to concentrate. After I graduated from High School I attended the Madison Media Institute, which sadly closed some years ago. I was lucky enough to have a supportive counselor from DVR who helped me fight to get the accommodations that reflected my needs as closely as possible, since this was still before my Autism diagnosis.

I went through another neuropsychology evaluation when I was 21. At that time the doctor said I presented a lot like a person with Autism but that they didn't want to put that label on me at that time.

This is when my label turned from “nonverbal learning disorder” to “developmentally disabled”. This still didn’t feel correct to me so I continued to talk this over with many of the people in my personal and medical circle. My therapist at the time even told me once that she didn’t think I had autism because I was too smart. Around this time I was looking up a lot of things and found a lot of videos online of girls talking about how autism made them feel and that’s when it all really clicked for me. It was as if they were talking about my life. I again spoke with my psychiatrist and after hearing me out he gave me some homework. He asked me to go through the updated DSM-5 and list examples of any of the 5 categories under the diagnosis that I’ve experienced. By doing this homework I was able to show specific circumstances that I had experience in not one or two of the categories but all five. After presenting this to my psychiatrist, he completely agreed and I received my Autism diagnosis shortly thereafter.

I think women are very often misdiagnosed with other things instead of Autism because of how society views Autism but also women in general. The channel *Invisible I* on *YouTube* has a video called *Autism in Females* I would recommend watching. My Autism diagnosis has really helped myself and others around me to learn how I process, understand and a lot about me as a person. It has brought my immediate family closer and it has helped them understand me a bit better. I’ve always been the person to stand up for other people but I’ve never felt confident to stand up for myself. After getting a diagnosis it validated my feelings and has empowered me to be a better advocate for myself and ultimately others.

In 2006 I was a delegate for the Youth Leadership Forum. I decided to come back as staff in 2015. After my first year as staff, I realized that I had new goals to be more independent. The first thing I decided to do was refill my own weekly pill box rather than have it done for me. Each year after, I just kept adding goals to the list on ways I could be more independent. In 2016, I became good friends with two other YLF staff/board members which led to them prompting me to join YLF’s board. Last year (2019) I became the Vice President of WI Youth Leadership Forum and it has been a great experience.

I don’t remember how I originally found out about YLF but I think it was an aide in high school or a case manager gave information about it to my parents. My parents were not overly fond of me leaving for more than a night or two with a ton of new things being thrown at me. I didn’t realize it was a camp for people with disabilities until later on in the camp and I think that’s why my parents were so good with it, as they knew there would be accommodations made for my needs. For me it was just cool being out on my own for an extended amount of time.

During my high school years my Dad had many health concerns and finally needed a bone marrow transplant to live, which brought him closer to his faith. The rest of the family was just struggling a bit with faith at the time. Simultaneously, my grandma who I was close with died which led me to also struggle with my faith. After some time had passed, my Dad got me to start going back to church initially to keep him company. During the Lent season we decided to go together to every service and event. The pastor was younger, and it seemed a bit less formal. I felt so much more comfortable being myself and church seemed to better fit me. The message seemed to have changed to promote love and acceptance.

Church should be about accepting everyone. In the bible there are several stories about healing and in the nursery at our church, there was a book about healing a blind man. It made me often wonder, what if he didn't want to be healed? What If he didn't have shame for who he was? Why do we need to "cure" things that society tells us are wrong with people? This is when I talked with my Pastor and finally understood that my "cure" was not getting rid of my autism but getting a diagnosis. My cure was accepting who I was. If there was a cure available for Autism I wouldn't even think about taking it. There isn't anything wrong with me and I shouldn't feel ashamed.

My dream is for the world to stop forcing me to accommodate but rather for the world to be understanding enough to know how to accommodate for others who are different and need different things. Autism Awareness has been around for a while but what we need more of is Autism Acceptance. Do not judge people for walking around with headphones or stimming in public. It's frustrating having an invisible disability because people don't understand I have a disability and they hold me to a different standard that I can't always meet because of that. That different standard is a large part of the stigma around having a disability and to move forward, it needs to end.