

## An Orange Socks Story – Will: Three Impacted Siblings, Down Syndrome and Autism

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I met Will at a conference and was so glad that he agreed to an Orange Socks interview by phone about his experiences as a sibling of someone with disabilities. Will is the youngest of four children, and his perspective is very unique. His oldest sibling is a woman with Down syndrome, and his two older brothers are on opposite ends of the autism spectrum.

Gerald: Will, I'm honored that you would take the time to do an Orange Socks interview with me. As the first sibling to be part of the Orange Socks project, could you tell me your story about your family? Where you fit in and some of the diagnoses of your siblings.

Will: Absolutely, I'm originally from St. Louis, Missouri. I am the youngest of four, and all three of my older siblings have disabilities. My sister is 28, she has Down syndrome, and my two older brothers are 25 and 23, respectively. One has high-functioning autism, and the other has low-functioning autism. It was definitely interesting to get that type of perspective growing up. There's a lot of talk at the Sibling Leadership Conference about not being as high on the priority list as other people.

Gerald: As a sibling?

Will: As my siblings.

Gerald: Okay.

Will: There's a Ted Talk about it where they're considered to be a glass child, not meaning that we're fragile like glass, but that our parents see right through our needs to directly address the needs of my siblings. That was something that really hit me when I was watching it, realizing that my needs weren't necessarily addressed because they were so focused on my siblings. That actually gave me a lot of opportunities because I started to seek outlets in recreation and sports. I was really big on basketball and cycling. Basketball has taken me where I am today, and I love the game. I love to bike everywhere, my brother, Beret, and I would bike pretty much anywhere. It was not only a great opportunity for me to express myself through that kind of outlet, but also it empowers me and helps empower my siblings as well, in ways that I never really could have imagined. All three of my siblings participated in the Special Olympics growing up, so I had a really close association with them. My brother did track and field, my sister did swimming, and my brother, Beret, did basketball and swimming. From an early age I was immersed in sports and the disability community, and it gave me perspective in terms of how I can really make my mark now in the industry.

Gerald: That's an interesting concept of being a glass child. Obviously, being the youngest probably for a period of time, my assumption is you assumed that every family was like that because you didn't know any different, right?

Will: Absolutely, I didn't know what life outside of it was like.

Gerald: About how old were you when you realized that your older siblings were, perhaps, not like your friends' older siblings?

Will: That's funny that you ask that because I don't know if there was a turning point for me when I started to realize that because I was really sheltered growing up. I guess it was because they didn't want to be, "exposed to the world," in that sense. So, for a while it seemed they were embarrassed of the fact that I had to deal with all of this growing up, and they didn't necessarily want me to share that part of my life.

Gerald: They, as in your parents?

Will: Yes, but as I got older, I think the turning point was when I started high school. That was probably when I started to come into my own, because you're going through puberty and all those different things. From there, I started getting more involved with the females, and starting to go out more with my friends. Once I started seeing other people's families, I thought that I didn't really have a childhood to a degree because so much of it was focused on taking care of my siblings. I guess to formally answer your question, it was more of when I started through puberty early on in high school.

Gerald: Interesting, as you think back, what was the hardest part for you? Being a sibling of three people with disabilities, including high-functioning on the autism spectrum, low-functioning on the autism spectrum and someone with Down syndrome. What do you think was the hardest part?

Will: I think the hardest part was in trying to embrace it. What I mean by that is I always would remember my dad trying to take us to different activities like a, "normal," family would do. Such as going to the zoo, but time and time again, I have a million stories about what didn't go right every time we went somewhere, and every time my brother would run away. He almost ran into an enclosure one time at the zoo. Seeing the looks we got from the other patrons was something that really kind of stuck with me, that people didn't necessarily understand, and were really quick to judge. I hate to say it, but I tried not to associate myself with my family while we were in these circumstances. I would walk behind them because I wouldn't really know what to do. I would try to help handle the situation if my dad asked me, but to a degree, it was more like I was embarrassed. As I started getting older, I started realizing the importance of putting them into the right environment to succeed because they had a different way of thinking for things.

Gerald: I think that's great. I appreciate your candor with your experiences. Can you tell me about some of the joys you might have experienced with three siblings with very different disabilities?

Will: It's funny that you mentioned that as well because there are varying levels, and I maybe lived vicariously through my mother, who has been so excited when these successes do happen to them. I could see them thrive in an environment like the Special Olympics, where my sister would get a gold medal for doing her events, or when my brother won eight gold medals from the Special Olympics. In an iconic picture of him, he looks just like Michael Phelps, and he

experienced great pride from that. Whenever they accomplish something that great, like graduating from the Special School District, or accomplishing the goal of being a part of the Special Olympics, you could see how much joy it brought my mother who worked so hard to make sure that my siblings succeeded. Right now, my brother, who is low-functioning, lives in assisted living. And that was a very long process, getting someone to lift him for the major needs that he has. There has to be a person on call for that. I'm a pretty large individual at 6'5" and 220, but my brother is 6'7" and 350.

Gerald: Oh boy.

Will: He's massive, so I always kind of joke that if he didn't have a disability, he would be an offensive lineman or something like that. It was such a great joy to see all the hard work that my father put in, getting my brother placed like that. My sister currently works in a sheltered workshop and is part of a dance program, getting to express herself through art, dance and humanities. Probably one of the best moments I've experienced is when she met her boyfriend, who also has Down syndrome. They've been dating for five years, which is absolutely incredible. They're the cutest couple ever, which is so nice to see, and seeing the genuine love and affection that they have for each other has had an impact on all of us. It lets you really appreciate the smaller things in life. My brother who has high-functioning autism has made tremendous strides, and I'm really proud of him for it, because after graduating from school, he just stayed in his room, gained a lot of weight and spent all day on his computer. All of the problems with that are not just emotional, but physical as well. He was getting significantly overweight. Then my mom really helped him turn his life around by getting him a job, by having him get a gym membership and starting to learn independence skills so that he could eventually move out on his own. He had his own car and ended up totaling it. My dad was completely opposed to his having a new car, but my mom reasoned, "If you give him the right environment, like not driving on the highway, he should be given a chance." So, my mom went against my dad's wishes and ended up buying him a new car. He actually saved up money to buy that car, which is incredible, but he has been driving solely on the side roads and not on the highway, and he hasn't had an accident in over two years. It's a testament to what I was saying before, that it's mainly about the environment that you put them in, and if you're able to tailor that towards their specific needs, then I don't understand why we don't do that. I guess that was the biggest joy that I've had with my brother. I found it really fascinating. It's the little victories with my sister, and it's the victories that I see with my brother through my mother, and then it's the amazing growth that my brother has experienced growing and learning these independent skills, and really becoming a functioning member of society. I've seen those joys through three different avenues, and if anything, it has given me a lot of perspective as to what I should appreciate in this life.

Gerald: I appreciate that you obviously are a very competent adult. You're on track for your life, you've got plans for the future, and you are centered and know who you are. You've got a plan. With your experience growing up and being the youngest of a family with all of your siblings having developmental disabilities, how do you think it shaped you as a person? Would you trade that experience with the life of one of your friends, knowing what you know now? Granted, you're not in the teenage years anymore, so all that stuff is gone, but with that shaping you had growing up and the person that you've become, would you have traded that experience?

Will: I'll answer your second question first, I wouldn't trade it for anything in the world. In high school, I was in psychology class, and we were presented with a big topic at the time of genetically modifying the loop. Now, of course you can change the eye color, or maybe determine the sex and those types of things. Our professor asked a really interesting question, if during the process you were to discover that your baby was going to have a disability, and you had the ability to genetically modify and change it, would you? I was the only one in my class who said no. it made me start thinking about how people view disability in life, and it gave me a lot more perspective on the term of respect for how I was raised. I'm living in NYC right now, and I'm sure you know as well as anybody the general perception of New Yorkers as very stand-offish, rude and set in their own ways. But the way that I was raised allowed me to understand where everybody is coming from. It has given me a sense of knowing my place in life now because of how I was raised. Tying back into your question about my development as a person, I wouldn't trade it. I really wouldn't, because even though it was a tough childhood, it really shaped me by giving me that perspective in terms of what I really wanted to do in life. If I had never found basketball, I really don't know where I would be at this point. Those are the kinds of things that I think about in terms of life, growth and development as a person.

Gerald: You made a really interesting comment about your psychology class, that's really an interesting thing to me. Do you happen to know if you were the only one in the class who had siblings with disabilities?

Will: Yes, I can say that confidently.

Gerald: That's interesting that the only person in the room with experiences first-hand with people with disabilities wouldn't change it, whereas the others who had no experience would. I find that a really powerful construct, a very powerful experience that you had.

Will: Definitely, I completely agree.

Gerald: I am very grateful to Will for taking the time for an Orange Socks interview, and for being the first to do so. His circumstances are unique, and his insights are very profound and very valuable.