

Another Type of Human

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It was at a restaurant that I came across the most remarkable person I'd ever met. Even though Daddy was exhausted from serving in the army, he took Mommy and I to a Cajun restaurant. Cajun is his favourite type of food. We had just finished our meal. It was delicious. I went up to thank the chef, which is what nice people do, and that is how I met Danny. Many, many thoughts went through my head at that time, which I now attempt to reproduce below:

The cook looks handsome. He looks very different to me. A lot of people look different to me. If he doesn't have the upturned nose, the droopy skin, the big upper lip, he doesn't have William's Syndrome. He's like other people then- he's normal. He's also my new friend! I am excited to talk to him! Maybe we'll be best friends. Oh! That fire looks scary! I hope he doesn't burn himself.

"I hope you don't burn yourself, mister cook. Your food is very good. My name is Heidi, by the way. Very nice to meet you. What is your name?"

He looks very confused. Why does he look so dumbfounded? Does he not understand what I am saying? Why is he making all these fast hand movements? Can't he speak?

"Can you speak?"

Let me point to my mouth so that he can understand better what I am saying. He's shaking his head. He's pointing to his ears, shaking his hand and his head again. Ohhh- he must have problems in his ears...

"He's deaf."

The waiter next to him is now speaking to me. The chef can't hear- that explains it!

"Oh. I hope I didn't hurt his feelings. I'm Heidi, by the way, very nice to meet you. What is your name?"

"I'm Miguel."

"How does one talk to him, Miguel? I really want to talk to him and thank him for making this delicious food for us. Is there any way I can talk to him?"

"Well, if you wait just three more minutes, the restaurant will close, and we can come talk to you for some time. Hold on- let me just ask him if he'd be fine with that."

Miguel is now making the same type of fast hand movements that the chef was making earlier. I hope mister chef talks to me. He needn't be scared: I'm a small girl and he's a grown man. Besides, I'm a very nice person. I should smile so that he isn't scared.

"He'd love to talk to you for a few minutes after we close. His name's Danny, by the way. I can interpret for you- that means I will tell him what you're saying."

"I know what an interpreter is."

"You're so young! That's very impressive! Alright, see you in a few minutes then."

[After some time.]

They're walking towards us! Oh Lord! I'm so excited to be able to finally talk to Danny! I have never been able to communicate with a deaf person before. I have so many questions!

Danny looks happy. He's looked happy throughout our brief exchange. He

must be a happy person.

Danny looks around our table, moving his eyes rapidly, tilting his head. He sits down. Miguel pulls up a chair and places it in front of Danny, right next to mine. He then readjusts my chair. The arrangement isn't very different to the last one. Miguel still looks critical though. Odd.

"Danny can't see very well. He needs us to be in very specific positions relative to his eyes so that he can shift between seeing each of us easily. He can't see a lot of things on the sides of his eyes- his eyes can only focus on the middle. He needs to be able to see me, because I will tell him what you are saying in sign language."

Sign language! That's what those rapid hand movements were! No wonder there was so much similarity between their movements- they were speaking a language!

"-but he also needs to be able to see you, because he is ultimately talking to you, and needs to see your expressions. From now on, what I say is what Danny is saying, okay?"

"Okay. Can you please translate this for me? 'Hello Mr. Danny. I'm so happy that you agreed to talk to me. My name is Heidi, and I just wanted to tell you that your food is extremely tasty!'"

Danny laughs. His laugh is a short burst, and stops very abruptly. He continues smiling. He is not conscious that it's awkward. "Thank you very much, Heidi. Do you want to see something cool?"

"Yes!"

"I can tell what you ate even though I was in the kitchen and did not know which one was your order. You ate creole rice."

I am astonished. The kitchen is not close to where we were sitting, and there is no way Danny could have seen who had asked for what.

"How do you know?"

"My nose is sharp."

He smiles. Unbelievable! I can't believe he just guessed what I ate using his nose! But I have limited time. I should ask my questions soon.

"I have some questions to ask you, if you don't mind."

"Go ahead."

"How come you have hearing problems as well as problems with your sight? Did something happen to you?"

"I have Usher Syndrome. There was a problem in my genes and I was born deaf. As I grow older though, my vision also progressively declines at the periphery. Imagine looking through a narrow pipe. That is how I see. Ultimately, I will go blind."

"I have a problem with my chromosomes too! I have William's Syndrome, which is why I look like this."

"You're very pretty."

This is the first time anyone has said that about me. Children my age tell me that my face looks like a grandma's face, and that I look weird. I like Danny. He doesn't mind people who look different.

Something just occurs to me.

"You've always been deaf-does that mean you can't hear music?"

"I've never heard anything. I don't know what it's like to hear."

I can't process this. I have always had a connection with music. I've grown up with tunes in my head. I create rhythms on the floor when I'm bored.

I sing for fun. Music is what helps me connect with people. It keeps me happy. I can't believe Danny doesn't have that.

"Music is my life. I can't imagine what that's like for you."

I am concerned for Danny. Being so different from everyone else, and only being able to communicate a certain way, how does he find friends?

"Do you get lonely, since you can communicate only using sign language?"

"You would think so, but no. There's a whole community of people with Usher's syndrome here in the US. We meet up often, and we're here for each other. We support each other. They're like a large family for me. Looking at my blind friends in the group, and the support they get, I am less afraid of losing my sight completely. Knowing there are many of us out there that have gone through this helps me stay strong."

I'm relieved, and also inspired. This reminds me of how I felt when my parents took me to a music day camp for people with William's syndrome. There were people of all ages- and the children there looked just like me. We all enjoyed ourselves thoroughly. I felt at home there, at ease the moment I walked in.

Danny and Miguel had to leave at that point, and my parents were also glad to be able to go back home. But I often think about Danny and our conversation. We have very different conditions, yet we are similar in many ways. People call them genetic diseases but so many extraordinary abilities are a result of these 'diseases'. It's amazing how we are all human, and yet so different. As for Danny and I, I think we're superheroes in our own right.

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