

## OCALI | Podcast - Episode 5 Interview with Michelle

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**TERESA KOBELT:** Welcome to From My Perspective. This is OCALI Family Center's weekly podcast. Each week you'll hear from people with disabilities, their families, friends, and others in their lives. You'll hear about everyday life, their passions, their interests and opinions. You'll be inspired. You might laugh or cry. But most importantly, we hope you'll better understand what life is like from our perspective.

On this week's podcast, we'll hear from Michelle, a young adult who is deaf and blind. She'll share her perspective on the importance of self-advocacy, as well as how much her family has meant throughout her life. If you could start just by maybe describing yourself a little bit, how would you describe yourself?

**MICHELLE MOTIL:** Hmm. How would I describe myself? One interesting question. I would describe myself as a person who is determined, who strives to persevere through challenges. I would like to believe that I'm well articulated and I'm smart. I'm fairly confident when I'm comfortable and around familiar people. I really like reading and writing and learning new things. One can never be completely done learning. You can never learn too much. Yeah. I'm nice.

**BOTH:** [LAUGH]

**TERESA:** Yes. You are nice. It's true.

**MICHELLE:** Well, good. I'm glad you think so.

**TERESA:** So nowhere in there did you say that you are deaf or blind, which--

**MICHELLE:** Interesting. Yeah, I didn't. When I think of describing myself, I guess that doesn't really come to mind, just because I don't think about it all the time, every day. It's like everyone has hands, right? But no one says, oh, by the way, I also have hands. It's kind of like that. It's just not something that I would think to describe.

Also visually, everyone can see that. Well, if I have my cane, people can tell that I can't see. And so that really does become my identity to everyone who doesn't know me. Oh, there's the blind girl.

But the idea is once you actually get to know me, that doesn't become the main thing you think about when you meet me, hopefully. You think of, oh, this is Michelle, and you know, she went to college, and she really likes to talk and she likes learning, and stuff like that. I would hope

that someone would identify me from something just aside from my disabilities.

**TERESA:** Often when people think about disabilities, they think about people who have kind of these extraordinary stories or really sort of tragic stories. And when I thought about you, I thought, Michelle is just ordinary. And that's the part that I mean no offense by being ordinary. You want to be married. You meet people on Tinder. You use Uber.

**BOTH:** [LAUGH]

**MICHELLE:** So that's the thing you remember about me.

**TERESA:** Yes.

**BOTH:** [LAUGH]

**TERESA:** You make zoodles in your kitchen, in your apartment that you live in by yourself. I mean, you are a pretty average, typical,

**MICHELLE:** I'm just an ordinary person who just happens to not be able to see or hear very well.

**TERESA:** Yeah.

**MICHELLE:** But yeah. Sometimes-- I always find this to be a really good compliment. My friends will forget that I can't see. Like, they'll get out the car, and they'll start walking towards the restaurant doors or something, and I'll just be left standing there. And they're like, Michelle? Aren't you coming? Oh, oh, oh yeah, that's right.

**BOTH:** [LAUGHTER]

**MICHELLE:** Sorry, I forgot. Yeah.

**TERESA:** That's great. Can you tell people your story?

**MICHELLE:** . When I was about 18 months old, I got this persistent case of pink eye, so my parents took me to the eye doctor. And they found out that it wasn't pink eye after all. It was something called uveitis, which is inflammation of the eye.

And it was discovered that I was born with an autoimmune disease, which is where a person's immune system attacks parts of the body as if they were foreign organs that don't belong. So my immune system was trying to destroy my eyes, and that was discovered when I was 18

months old.

When I was three years old, I got hearing aids. My mother noticed that I wasn't talking very well, so that was her first clue. And then also, I threw a lot of tantrums. That's not unusual for kids to throw tantrums and throw fits if they don't understand what people are saying around them, what's going on around them. And also, it's frustrating to not be able to communicate with others around you. So once I got my hearing aids, I threw much less tantrums.

[LAUGH]

And I could hear a lot better. And my parents got me a private speech therapist, and I also went to Columbus Speech & Hearing for their preschool program. I did speech therapy until I was

about eight years old. So several intensive years of speech therapy. And here we are. Now I can talk much better.

[LAUGH]

It was discovered after a time, maybe I was eight or nine-- that my hearing impairment and my vision impairment were related. At first, it was treated as two separate symptoms, but it came to light that my immune system was attacking both my eyes and my ears as a system.

Eventually, my eyesight got worse and my hearing got worse. You know, it was progressive loss. I could see well enough to drive until I was about, oh, a sixth grader. And then after that, when I was in eighth grade, my immune system disease flared up really badly, and I spent a lot of time in the doctor's office and in hospitals, missing school because I needed some pretty intense medication to suppress my immune system.

In the past, medicine and surgeries were enough to preserve my vision or to even increase my vision, but when I turned 15, it was just all too much. And so I lost my vision.

And then I went to the Ohio State School for the Blind when I was a freshman and a sophomore, and I learned how to be blind. So I learned how to use a cane and how to read Braille and how to use assistive technology, the stuff like that.

And then I went back to public school for my junior and senior year of high school. And then I went off to college to become a high school English teacher. I also got two cochlear implants

because I lost my vision and I lost my hearing, eventually. So I am a fully bionic [INAUDIBLE].

**TERESA:** When did you get your cochlear implants?

**MICHELLE:** I got my first one when I was 15. So kind of soon after I lost my vision. And then I got my second implant when I was a junior in college. I was a lot more adventurous when I could see, because you know, I didn't have to be quite as cautious. I'm definitely more cautious now, but I'm still a thrill seeker. So I do stuff like, oh, I don't know, I've gone jet skiing a few times. I went to circus school once. That was kind of crazy.

[LAUGHTER]

What else? Well, I'm kind of a boring adult now.

**BOTH:** [LAUGHTER]

**MICHELLE:** When I was a youth, I did a lot of interesting stuff.

**TERESA:** Yeah. What was your family's reaction when you started to lose your vision and your hearing?

**MICHELLE:** It was very hard on everyone. My mom was definitely really depressed. I don't even think she knows this, but there was this one time where I saw this email that she sent to one of her friends, because we had one of those computers where you could just leave the screen, I guess.

Well, basically I came to the computer, and my mother had this email up, and it was this email she had just sent to her friend. And of course, I had the computer blown up to enormous proportions print-wise. It was right when I was right in the middle. I could still see. Very, very difficult to see unless I blew everything up. Everything was very foggy.

But I remember I was reading this email that my mother sent to her friend. She was like, I don't know what to do. My heart is breaking. I feel so helpless. There's nothing I can do for my child. And you know what? It made me cry.

[LAUGH]

But yeah. It was very stressful and very hard for everyone at the time, especially because we didn't know what to do next. Yeah. We didn't know what kind of life that I was going to have.

My mom is really the one who made most of the decisions concerning me. You know, my dad

was supportive, but he pretty much told my mom to do what she thought was best. And so obviously, my father and my sister were upset as well, but it definitely hit my mother the most, because she was the one taking me to school and taking me to all these doctors' offices. And she knew she was going to be the one helping me out in the future.

**TERESA:** I think anybody who met you now or interacted with you now would not know that you've ever had a hard time.

**BOTH:** [LAUGH]

**TERESA:** I mean, you just tend to be a really-- even everybody around here, always talking about how positive you are. And yet you said earlier that when you first started to lose your vision and then when you lost it altogether, that was a really hard time.

**MICHELLE:** It was a really hard time. I was definitely very depressed, because I have spent all my life being able to see, and now all of a sudden, I couldn't. And I didn't know how to do anything. So I thought, great. I'm going to have this life where I'm going to be this worthless burden to everyone, not able to contribute or do anything by myself. Always going to have to rely on other people. It was not a good feeling at all.

And I also lost my vision and my hearing at one point. These were two separate incidents. That also was very hard, before I got my cochlear implants and such. So yeah. I have definitely gone through some challenging experiences, but we worked hard to figure out what to do next.

We talked to a lot of people. And You know, we didn't just stay home and cry to ourselves all the time. We went out and we tried to do what we could to fix the situation. And eventually, I learned how to be blind and how to be independent, and that really gave me my life back.

**TERESA:** I'm not sure that everybody would know what-- said that. What does that mean, how to be blind? You learned how to be blind.

**MICHELLE:** Yeah. Well, first of all, when you first go blind, you're-- you're-- oh, this is so hard to explain. When I first went blind, I wasn't as accustomed to it as I am now, obviously. But now I can see the world through all my other senses.

Whereas when I first went blind, I was still getting used to it, so I wasn't getting a lot of information from my other senses, because I didn't know how to use them just yet. But now

that I've been blind for a while, I know how to use my other senses to see the world and to interact with it. I have really good mental mapping skills. For instance--

**TERESA:** Will you tell people what that is, mental mapping?

**MICHELLE:** Yeah. So this is very interesting, because since I was able to see, I grasp visual concepts maybe a little more easily than someone who was born blind. But I know, for instance, the bathroom is across from the bookcases, or this hallway is going to lead to these rooms.

Basically, when I make a mental map in my mind, I know how that map feels in reality. So when I'm walking down the hall, I know what each door is, and I know what's across from each door, And I know my landmarks and stuff like that. So you have to create a mental map of places when you travel.

**TERESA:** So talking about things that keep you safe, we talked earlier about kind of your cane. And can you tell people-- I'm not sure everybody understands what your cane does and doesn't do for you.

**MICHELLE:** Yeah. So what people should know is the cane doesn't have a magic GPS inside of it. It doesn't tell me where I'm going. All it really does-- it protects me. It keeps me safe. But I have to know where I'm going without the cane. The cane is only there to help me get there more quickly and to protect myself.

So for instance, this building that I'm in right now, I can get everywhere in the building without my cane. It just might take me a little bit longer. And also other people won't be aware that I'm blind, and so they might crash into me or I might crash into them.

The cane is-- its main purposes are for protection and also to let other people know that you are blind. I mean, that I am blind, and that they should get out of my way. Because if you don't have the cane, you tend to look pretty normal, so people won't know that you're blind, and that they should accommodate you.

**TERESA:** Will you talk a little bit about the technology you use?

**MICHELLE:** Mm-hmm. So I use an iPhone. I'm able to text and I'm able to call people and to use apps. You know, like Uber. Thank goodness for Uber and UberEATS and stuff. I also have a refreshable Braille display, which I can pair through Bluetooth with my phone. So if I can't hear the

voiceover very well, which does sometimes happen, I can read it on my refreshable Braille display.

I also use a Braille note taker, which is basically in laptop in Braille. I use that mostly to take notes and do other laptop-type stuff. I also have a regular laptop, the kind that everyone else uses, but it has a screen reader software program on it, and that program is called JAWS, which stands for Job Access With Speech.

Although really, I think it should stand for [INAUDIBLE] Active Word System, because you can make it talk as quickly or as slowly as you want. You can make it talk in different languages, you can make it talk in a British accent. It's pretty neat. And I tell the screen reader program what to read through the use of keystrokes. And so that lets me do most of the things that everyone else can, such as using the internet, social media, email.

**TERESA:** You mentioned social media, and I know you have lots of friends and a pretty active social life.

**MICHELLE:** Hmm.

**BOTH:** [LAUGHTER]

**TERESA:** Or at least it's active compared to mine. Maybe I should say that.

**MICHELLE:** Yeah, but you're married with kids. That becomes your social life.

**TERESA:** That's right. So what do you do after you leave work? What's your usual routine?

**MICHELLE:** Oh, gosh. Honestly, I don't want to do anything after work.

[LAUGHTER]

Well, yeah. I check my social media. And I might read some articles, because, well, I'm a bit of a nerd, and I enjoy reading articles. Ha ha. Or novels or books or whatever. I kind of do that to relax. I might have a glass of wine. Ha ha. I might listen to music. I have an Alexa, Alexa Echo, so she makes listening to music really easy. And then I might have a friend or two over, and then I go to bed.

**BOTH:** [LAUGHTER]

**TERESA:** What do you envision in your future? What are you going to do or be or what problems are

you going to solve in the world?

**MICHELLE:** Oh, god. Why'd you have to ask me that? Well, I hope to be really good at my job. I guess that's my ultimate goal. And I would really like to be, like-- what do they call it? A social advocate maybe for people with disabilities. I'd like to see more equality and access for disabled people, and also just for minorities in general.

**TERESA:** Are there other people, as you think just kind of about this journey that you've been on, some of the people that have really sort of meant the most to you along the way, or had the most impact on you?

**MICHELLE:** Yeah. I think teachers had the biggest impact on my life, to the point where I wanted to become a teacher because I wanted to also have that kind of impact on students. You know, I had a Braille teacher. I had an American Sign Language instructor. I had an orientation and mobility instructor. Taught me how to get around with a cane. I had an assistive technology teacher.

I had an English teacher who told me that I was smart and talented in English. And I had a speech therapist. And I've had teachers who taught me how to use my cochlear implants and how to listen, listening therapy. So I've had all kinds of teachers throughout my life. And without them, there's no way that I could be the person that I am today. So I think that's very important.

And of course, my parents. Like, without my parents, I don't even think I would have gotten those teachers, or I wouldn't have cared to be taught as much. But yeah. My parents have really been the ones to give me this great life that I have right now. They made the best decisions that they could in terms of raising me and providing me what I needed for a good education and to be successful and independent. Yeah. Without them-- yeah.

I want to, like, talk about my parents and what they've done for me. But basically, they've just been really supportive, and they've always expected me to go to college and to be successful and to have an independent life and a career. And I think the fact that I knew they expected that from me, it helped me fulfill those expectations.

They've just been very supportive, and they've always been good about telling me that I have to make a plan. So they've always encouraged me to plan for the future. They taught me that. And they helped me when it comes to executing my goals. And they're just-- my parents are



good teachers in themselves.

**TERESA:** Did their expectations change at all when you lost your vision or your hearing?

**MICHELLE:** I mean, you know, during that dark time when we first found out, for a few months, it was just general despair. So maybe. It's not something I really asked. It's not something they offered, like, information-wise either. They didn't say, well, Michelle, well, all right. I guess you can't go to college. I guess we're going to have to hire you a nanny. Like, they didn't do that. No.

**TERESA:** What do you think turned the despair around?

**MICHELLE:** I think it was the fact that when I went to the blind school, it really changed my perspective and my thinking and my attitude. They saw that I was happy and that I was learning how to be independent, and I think that's what they needed. My happiness and my independence and my success made them happy. It made them hopeful. It made them believe that I could.

**TERESA:** Can you tell me a little bit about things that you're passionate about?

**MICHELLE:** I'm definitely passionate about equality and access for everyone. I'm pretty passionate about being open-minded and trying not to cling to preconceived notions and prejudice about people and situations.

I know that it can't be helped to have those preconceived notions, because that's just how your brain is wired. You have to have some preconceived notion, because your brain is busy categorizing everything. I mean, that's just going to happen. But I'm pretty passionate about giving everyone a chance to show me who they are without me trying to impose my beliefs.

I'm also passionate, I think, about education. Yeah, definitely education. I know it sounds cliché, but I do think education is the big equalizer. The education system needs work, and it could be debated that the education system is not an equalizer.

But being well educated in general is definitely an equalizer. The more knowledge and information that people have, the better their lives can become, because they can make better choices and decisions. So yeah. Those are some things I'm passionate about. I also really like English.

**BOTH:** [LAUGHTER]

**MICHELLE:** And let's see.

**TERESA:** I have heard you talk too about self-advocacy.

**MICHELLE:** Yes. That's definitely what I'm passionate about. Sometimes it's really hard to think of, what are you passionate about? I'm better at writing out my thoughts sometimes than talking about them.

Self-advocacy is huge. I am very passionate about when you are conversing or helping people with disabilities, please talk to the person with the disability. Don't talk to the person next to them, whether that be their aide or the interpreter or their parents or their caseworker.

Because I have noticed that a lot, and that does not benefit or help the disabled people in any way.

The only thing that does for them is it gets them used to not thinking, not making decisions, not doing things for themselves. So that when they do have to do all those things by themselves, they don't know how to do it, because they were too used to letting everyone else do it for them.

**TERESA:** Now did you have that experience at all? Where do you think-- like, where that passion come from?

**MICHELLE:** For instance, I've never paid a bill in my life until just recently. So I didn't know how to do that. When I went to college, I had to get used to advocating for myself, telling other people, this is what I need. This is what I want. And also educating other people about my disability.

In the past, it was always my mother who was telling other people, this is what my daughter needs, or this is what my daughter's disabilities are. That was very uncomfortable at first, realizing that I was the only one on the college campus who was blind.

And I was the only one I knew. I only knew myself. I didn't know anyone else. And so that was very uncomfortable. But I pushed through it, because you're not going to get any better or learn anything new or get comfortable if you don't do those things that make you uncomfortable, and you don't practice.

Doctors appointments. Like, making doctors appointments. I mean, logically, you would think, oh, well, you just call them up and say, hey, I want a doctor's appointment. But for some people, that's really nerve wracking if they've never done that before. Or let's see. What else? Taxes. You know, those big, long forms that we have to fill out. I still don't know what the heck

that's about.

**BOTH:** [LAUGHTER]

**TERESA:** You're probably in good company.

**MICHELLE:** Yeah.

**TERESA:** Is there anything else that you would want to say to people or tell people? Something people should know about you?

**MICHELLE:** I just want you to keep in mind that people with disabilities, they're normal. They just happen to be disabled. And everyone wants to be treated with normalcy and respect. If you have a hard time thinking about how to treat people with disabilities, just think, how would you want to be treated if you got into an accident tomorrow and you got a disability?

So for instance, it doesn't bother me when people ask me questions about my disability, because I mean, I want to talk about it. It's a huge part of my life. But also, it's not the only aspect of my identity. There are more parts to myself than being disabled. But most disabled people want to talk about themselves in any way.

So if you genuinely want to know the answer to something, then ask. It's always OK to ask. The worst that will happen is they might be like, I'm sorry. I'd rather not talk about it.