

Disability Exchange Podcast, Season 5, Episode 5

Roxie in Color with Stacy Cervenka and Diane Debrovner

Judy Warth: Welcome to Disability Exchange. We are a podcast from the University Center of Excellence and Developmental Disabilities here at the University of Iowa.

Our purpose is to center and elevate the voices of people with disabilities and those who support them. My name is Judy Warth, and I'm one of the hosts I'm here today with Mike Hoenig. Mike, you wanna say hello?

Mike Hoenig: Sure. My name is Mike Hoenig. I am fortunate to be co-host of Disability Exchange with Judy and with our producer, Joanna Sahba.

We really are excited today to have two guests. Some of you may remember Stacy Cervenka, who is now the officially confirmed director of the Iowa Department for the Blind in Des Moines.

Judy Warth: Congratulations, Stacy.

Stacy Cervenka: Oh, thank you.

Mike Hoenig: She was on earlier talking about her role at the department and what brought her here and kind of her vision for the department.

One of the things that she told us was that she had co-authored a book entitled *Roxy in Color* with Diane Debrovner. Today we have the opportunity to talk with Stacy about it and also to meet Diane.

So, Diane and Stacy, welcome to Disability Exchange!

Stacy Cervenka: Well, thank you for having us.

Diane Debrovner: Thank you so much.

Judy Warth: Would you mind sharing with us kind of what, how you guys got started on this project?

Stacy Cervenka: Sure. In 2018, Diane was working as the deputy editor of Parents magazine and she was doing a story on blind parents and it ended up actually being the cover story. She won all sorts of awards. She had deep conversations with probably about a dozen blind parents and

we stayed in touch. When she had an idea for a middle grade novel, she reached out to me and we began working together.

Judy Warth: What's your story, Diane?

Diane Debrovner: I was an editor for a long time, and I met a blind mom and realized that I didn't know very much about the experience of blind parents, I decided to write a story and I didn't really know where it was going to take me. But I met so many interesting people: Stacy and her husband and, and others across the country. I heard a lot, a lot of unique stories and a lot of similarities in stories about ways they had not always been treated fairly. And assumptions had been made about their parenting skills. That, that was, uh, upsetting to hear. And I, I wanted our audience of, I think we had 11 million parents at that point, to have a better sense of, of what that experience was like.

I had already been writing middle grade fiction. I hadn't published a book yet, but when I was talking to Stacy and the other parents I met, I started imagining what a story could be like from that perspective. Once this story grabbed onto me, I, I just couldn't stop thinking about it.

I started writing it by myself from the perspective of Roxy, who sighted, like I am, and also from the perspective of her, of her mother's guide dog, who is the secondary narrator in the story. I just realized that I wasn't able to tell the story authentically by myself. So, I called Stacy and I asked her if she would be interested in working on it with me, and I was just very grateful and, and excited when she said yes.

Mike Hoenig: Tell us a little bit more about the general plot.

Stacy Cervenka: Sure. Roxy Glass, is a 12-year-old girl who moves to a new town on Long Island, and is starting at a new school in seventh grade. She has two parents who are blind. She and her little brother are sighted. Roxy has lived largely a pretty happy life. But she has experienced some bullying so when she starts at a new school, she just wants to start over.

First, she is trying to decide, whether to tell her friends that her parents are blind. She wants them to get to know her first and to not make assumptions. As

the plot develops, we see lots of different aspects of living as a person who's blind, whether that is, “uber denial” because of guide dogs to website inaccessibility to the over involvement of Child Protective Services.

Roxy is also deciding whether to take the genetic test to determine whether she will inherit retinitis pigmentosa. While all this is happening, she is joining in the school mural contest because Roxy is an artist and hence the name of the book, *Roxie in Color*.

She really kind of, sees the world in a very artistic way.

Judy Warth: And, you know, I was curious how did you decide to use art as her main form of self-expression?

Diane Debrovner: When she had a hard time at her old school, she retreated into her family life. She has a very close relationship with her mother's guide dog Nash, who when he is off duty is just the regular dog. When I started thinking about the book, a sighted character who had a particularly visual approach to the world, seemed like it might create some tension and would contrast with how her parents experienced the world.

Stacy Cervenka: My husband and I are both blind and we have two sighted kids and my daughter does gymnastics. That's a very visual thing. Me and my husband have never tried to steer her away from that. Funny story, Josie had a gymnastics performance at the end of a camp, and Greg unfortunately got stuck at work with an emergency and so he had to miss the performance. She wouldn't go on. She wanted Greg to be there so much. And Greg is totally blind. He would've been there out of pride and support.

Leo, for a while, he was doing competitive chess. There is nothing more boring for a blind parent to go and watch than competitive chess. There is nothing to see or hear. Neither Greg or I are super into chess. And we were really proud that Leo was. So, I think you know, Roxy's parents don't try to discourage her from art and in fact they are very proud of her art.

Mike Hoenig: On the first day of school in seventh grade, that was the first fun fact that came to her mind. So, she talked about painting on the walls.

Stacy Cervenka: Most parents might not allow that, whether they're blind or sighted.

Diane Debrovner: I mean, I think that there are probably lots of, lots of ways in which unique families do things differently and kids discover that along the way. Just habits that you don't realize that your family does something differently.

And um, until you're in a situation where it, you're confronted with that. The very first scene when she's little and she goes to her friend's house and she draws on the wall. It's actually a very tender scene where she's so excited to go to this girl's house and she's having a play date, and she draws a heart on the wall for her potential new friend and the whole thing doesn't end well. Because the girl and her mom are not happy, and unfortunately the girl goes back to school and says, "Oh my goodness, you're not gonna believe what happened." Poor Roxy only wanted to make a friend.

Judy Warth: Speaking of friends I found it interesting and enjoyable to hear the story from Nash's perspective. What inspired you to do that?

Stacy Cervenka: I think one really cool thing that Nash adds to the book is another perspective. Roxy is a typical 12-year-old, and 12-year-olds are very dramatic. Nash doesn't see her family the way that she does. Through Nash, you see that, look, this is a loving family. It allows you to be in places that Roxy isn't. Whether it's when mom goes to the convenience store or later when CPS pays a visit.

Diane Debrovner: I'm very aware that the minority of blind people use guide dogs but as somebody who was learning about both guide dogs and blind parenting, I was fascinated by the bond that exists between handlers and dogs and that what's required of a dog to go through the incredible training that's necessary to become an expert, reliable guide dog. It requires that dogs ignore some of the "doginess" that is part of their nature, right? Like they can't have a treat on the street. They can't go up to people when they're working.

Diane Debrovner : And so it was nice to think about ways that we could incorporate some of his dog perspective on the world in other ways. He's still thinking like a dog in certain ways, even though he's working,

Mike Hoenig: For those of you that are listening to the podcast for the first time, I'm blind too. All of those experiences and stereotypes, I think that is going to resonate so well with people and I hope that parents will read this book along with their kiddos.

Stacy Cervenka: It's kind of funny because when, when blind and low vision people read the book, they always talk about the restaurant chapters. And it, one thing that was really important to me was that it be clear that Roxy's parents are not the only two blind parents in the world, and that there is an entire blind community out there. It's not just about mom and dad are super different, they're just, they're part of a different community. With the restaurant chapter, at first when I wrote it, I was thinking, you know, when I go out to a restaurant, like nothing necessarily always happens.

And Diane was like, 'Stacy, stuff has to happen.' I don't know. I mean, So, their guide dog gets denied and the little brother spills something and they don't have a braille menu and the waiter is rude. This stuff does happen. It's very realistic. And so I didn't want it to come across as that every time a blind person goes outside, it's a disaster. At the same point, these, these experiences that happen to them are very true to life.

Judy Warth: There were just these common themes that, you know, how we see, how we feel, how we all come together. We're all living in the same world with maybe slightly different perceptions and experiences, but there are common themes, um, which I think is helpful for people to see that we are more alike than we are different.

Diane Debrovner: We've been asked before what, you know, what we hope people will take away from the story. And that is typically what I say. Stacy and I are very different. We have different backgrounds, we have different lives, and yet we really share the belief that everyone has more in common. I think kids will enjoy the story on a variety of levels and that, that they'll relate to different parts of the story depending on who they are and, and what their family structure is like, and what their background is like.

But I, I hope that bigger message rings true for everyone.

Stacy Cervenka: I think a lot of kids who are from families that are considered different from those around them, whether it's because, you know, maybe their family is a different race or a different religion or you know, their parents are immigrants or, um, they just have a different family, constellation.

I think any kid who's ever felt like their family is different from those around them will be able to resonate with this book. She just feels like, why is my family so different?

Judy Warth: Middle school is a time of reckoning where nobody fits in. Were there friendship dynamics or school moments that were inspired by real experiences you've had or seen?

Diane Debrovner: Judy, I would agree that middle school is a tough time for everyone. All of the, the social challenges that Roxy and her friends go through were very familiar to me. It's been decades since we were in seventh grade, but those experiences stay with us. They all want to fit in and blend in and yet still stand out for what makes them special.

Stacy Cervenka: I thought it was really funny that Diane wrote this piece where mom shows it up at school wearing a fanny pack. I used to be so embarrassed when my mom would wear a fanny pack in the nineties. I was like, "Oh my gosh."

Judy Warth: Never forget, Stacy, it is the role of our mothers to keep us slightly embarrassed.

Stacy Cervenka: Yes.

Mike Hoenig: Can I ask Stacy or Diane if they would be up for reading a passage from Roxy in color.

Diane Debrovner: Stacy's had a lot of positive feedback reading that restaurant scene, and I think your audience might enjoy it.

Stacy Cervenka: Okay.

So, Chapter 19.

To set the scene Roxy's parents are Penny and Joe, and Roxy's little brother is Theo. They are going out to dinner with another family that includes two blind parents Scott and Grace, and two sighted kids and one who is blind, Charlie, Mina, and Violet.

Okay, let's see. They get to the restaurant and Charlie holds the door open for everyone. Mom and Nash approach the hostess stand. The hostess looks over mom's shoulder, apparently searching for a real adult, but sees only Dad, Scott and Grace with their white canes.

"Is someone with you?" She asked Mom. Seriously?

“Yes. We're all together.” Mom says. “We have a reservation, Glass, party of nine.”

“Oh, okay.” The hostess looks at her computer screen, then she glances down at Nash and puts her index fingers on her temples as if she's wishing away a headache.

“I mean, unfortunately, ma'am, we don't allow dogs here.”

“Excuse me.” Mom says to the hostess.”

“Sorry. It's a health code thing. People aren't allowed to bring pets into restaurants.” Roxy's stomach drops. She knows what's coming next.

“Miss, Nash is a guide dog, not a pet.” Her mom reaches into her purse for her ID card with a picture of her and Nash, and hands it to the woman. “According to the Americans with Disabilities Act Guide, dogs are allowed in any place of public accommodation denying this access is against federal law.” The hostess looks at the card like it's monopoly money.

“I don't know.”

“I'd like to speak with the manager.” Mom says.

“I'll be right back.” Roxy feels her entire body turning red. She hates when people discriminate against Nash and Mom, but does there always have to be such a scene? She glances at a couple waiting behind them. The woman looks at her phone as if she hasn't been listening to the whole conversation and the man checks his watch. They're probably wondering why Roxy's family doesn't just find someplace else to eat. A bald man with a beard walks out of the dining room with the hostess.

“Hey there folks. I'm Enzo the manager.”

“Hello” Mom says, “There seems to be a misunderstanding. We were told we're not allowed to eat here because of my guide dog.”

“I'm sorry ma'am. Haley here is new. We don't allow pets in the restaurant, but of course you and your service dog are welcome.”

“Thank you. I hope you'll take this opportunity to educate your staff.”

“We absolutely will. Let us just push a few tables together.” He and the hostess disappear into the dining room.

“Well, that's a relief,” Scott says, “I thought we'd have to call the NFB Guide dog division there for a second.” The adults laugh, but Roxy doesn't think it's funny.

“Sorry about my mom.” She says to Charlie low enough so their parents can't hear. “She can be kind of...”

“Your mom's a total boss.” He says, “I would've flipped out at that lady.”

“We were about to say something too.” The man behind them says, “Doesn't everybody know about service dogs by now?”

Mike Hoenig: Very true to life.

Judy Warth: One thing I like too about that scene is, is as mom stands up for herself as well and is like, “Hey, you can't just tell us, we can't come in here.”

Mike Hoenig: I really liked Charlie speaking up, maybe mentoring Roxy because it feels like a little bit like Roxy is, well, she's ashamed.

At one point she asked Charlie, what do your friends think about having blind parents? Well, they're fine with it, she is so hung up on that.

Stacy Cervenka: I don't think that Roxy's ashamed of her parents, like organically. I mean, I don't think she thinks that mom and dad aren't good parents or shameful. I think she just feels like they're so different and I'm tired of being different and I'm tired of people not understanding mom and dad. You know what I mean?

Mike Hoenig: Yeah.

Judy Warth: When I kind of try to pull out the moral of the story, Roxy's experience comes from being open and willing to accept who you are and who your family is, no matter what they're made of, and not hiding. She was able to have deeper friendships with Charlie and more confidence and, and kind of overcomes that risk

Stacy Cervenka: With Charlie, she's not worried that he's going to find out this secret. He already knows. There's this level of comfort where, you know, with her friends, like, there's always this part of her that's like, okay, I can't say this. that does prevent them from, you know, sort of getting to that next level of closeness and authenticity.

Mike Hoenig: This book is going to be published soon. Tell us a little bit about that.

Stacy Cervenka: It is coming out from Candlewick Press on June 2nd, and, we're going to be, uh, doing a book premiere event right here in Des Moines at Beaverdale Books on June 7th. And so, we invite all of you, to come out to Beaverdale books on June 7th and come to our book premiere. We would love to see you.

Diane Debrovner: Stacy, you wanna tell them a little bit about the audiobook?

Stacy Cervenka: Yes. We, of course, it's coming out in typical print and we're actually using a font called Atkinson Hyper Legible that was developed by the Braille Institute to be particularly legible and easy-to-read by people with low vision. There will be a large print version coming out in September. In June, an audio book version is coming out. It's going to be narrated by Aria Mia Loberti. She's a blind actress and she was actually in Netflix's *All the Light We Cannot See* and *Grey's Anatomy*. Jeff Ebner, who is award-nominated for some Audies, which are apparently audible book awards doing Nash. That will be on Audible and, you know, everywhere audio books are sold. It will also be on NLS BARD in both Braille and audio. And you know, of course you can get it on your Kindle, so it will be available in a variety of accessible formats, so hopefully one that works for everyone.

Mike Hoenig: One last question for you guys. What do you most hope that readers, especially kids, um, who are unfamiliar with disabilities, walk away understanding after reading this book?

Stacy Cervenka: Well, for kids without disabilities, I hope that they walk away understanding that blind and, and disabled people, become adults and are real adults just like their parents, and that they have careers and relationships and kids and houses.

I hope that the blind and low vision kids and kids with other disabilities read it and realize that you know, they too can grow up to have joy filled futures with

careers and relationships and kids. In Iowa we have blind kids who are the only blind kid in their county.

When you're growing up as a blind kid, and I think Mike, you'll, you know, agree with this, you can't always envision what being a blind adult is like, because most of the adults around you, if not all, are sighted.

Mike Hoenig: Absolutely.

Diane Debrovner: And I think it's really important for kids to see their lives and their family's lives reflected on the pages of books that they're reading and that their classmates are reading. You know, I hope that kids who are sighted realize that there are just certain people who do things differently and that people with disabilities are doing things differently. We can assume the best about people and give people the benefit of the doubt. 'Cause no one really wants to be labeled or have assumptions made about them that aren't, that aren't accurate.

Mike Hoenig: We want to thank, both Stacy and Diane, for your time talking with us and thank you for, for authoring the book. And a special thanks to all of you, our listeners, for checking us out, and we look forward to coming to you again very soon.

Narrator: Thank you for joining us today on Disability Exchange. Disability Exchange is produced by the University Center for Excellence in Developmental Disabilities, which is housed at the Center for Disabilities and Development at the University of Iowa. Special thanks to Kyle Delve for the music contribution.