Down to the Struts

Season 7, Episode 4: Going Beyond Awareness with Diana Pastora Carson

Guest: Diana Pastora Carson

Host: Qudsiya Naqui

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“going beyond awareness is really looking at disability as normal and natural part of the human experience. It's looking at disability as a valuable part of diversity.”

**Introduction**

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Hi, this is Qudsiya Naqui—creator and host of Down to the Struts, the podcast about disability, design, and intersectionality. Believe it or not,

We’re halfway through Season 7, and today, we’ll be listening in on my conversation with Diana Pastora Carson. Diana has been an elementary school and university level educator for more than 30 years. She now serves as a consultant on diversity as it relates to disability, urging families and educators to go beyond awareness to achieve true inclusion and belonging for disabled people. Diana and I talked about her own journey to embracing disability inclusion as she battled to free her brother, Joaquin from long-term institutionalization so that he could live in his community. Diana also shared the tools she has developed

to help parents, students, and educators practice disability inclusion. Ok, let’s get down to it.

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Thank you so much for joining me, Diana. It's really a pleasure to have you and to return the invitation that you so generously offered me to be on your podcast.

Diana Pastora Carson:

Thank you, Qudsiya. i am so excited to be here. Thank you for this invitation.

**Qudsiya Naqui:**

Let's start off by having you introduce yourself to our listeners and share a little bit about the role that disability has played in your life.

Diana Pastora Carson:

Sure, so my name is Diana Pastore Carson. I am a retired elementary and special education teacher most of my time was teaching general education with an emphasis on inclusion. I did that for roughly 25 years in the public school system. I currently co-teach a disability and society course at San Diego State University. I am an author of a book called beyond awareness, bringing disability into diversity work in K 12, schools and communities. I also wrote a children's book that is not just for children. It's called “Ed Roberts, Champion of Disability Rights.” I'm a podcast host like you are. It's called “Beyond Awareness: Disability Awareness That Matters.” I'm a keynote speaker and consultant on inclusive instructional strategies. I'm also a sibling, advocate for my brother and with my brother Joaquin, who is autistic and who spent 15 years of his adult life in an institution. And after a three year court battle, he has now been my next door neighbor for 11 years, yay. And I think it's really important to for listeners to know that Joaquin has helped me create keynotes. And He's participated during keynote presentations with me when he's been able. And he has given me permission to share our story with others. And then finally, in the last couple of years, I also began to identify as a disabled person. And you and I were speaking earlier about Judy Heumann, and she's actually the person who encouraged me to claim my disabled identity. And so I've been doing that ever since then, May her memory be a blessing.

**Qudsiya Naqui:**

Thank you, Diana, what is it that you don't do? That's just incredible. You wear so many hats, and you are an excellent podcaster. I highly recommend Diana’s podcast to my listeners and we'll share a link to all of those resources in the show notes. What led you from being an educator for so many years to really becoming a Disability Justice and disability rights champion in the way that you are today?

Diana Pastora Carson:

when I was getting my master's in special education, I learned lots of different strategies for doing quote unquote, doing disability awareness. And I learned them from mentor teachers. I learned them in my coursework, and I did the simulations, I did the inspiration porn, I did all that stuff. And as a sibling, I started, this journey towards advocacy with my brother to get him out of this horrible institution. And, I thought, Why did this have to happen? Why did my brother have to, first of all end up there? Why did he have to be in segregated education? Why did he have to end up in an institution? Why did he not have access to meaningful relationships and to communication and why didn't he have access to, to being a valued participant in his community? Why was he judged? And why was he excluded? And, I couldn't figure it out, but I wanted to find out. And so I kept doing these disability awareness things, thinking I was doing the right thing. And then I started teaching disability and society classes. I was asked to teach these classes at a community college College since I was such a disability rights advocate at the time, they thought I would be a good candidate. And I said, Sure, but you know, I didn't really know the subject matter. And so I said, I may know a lot about disabilities, because that's I got my master's in special education. But I didn't know a lot about disability, I didn't know a lot about the experience of being disabled by one’s society, I was trying to figure it out, in terms of the story that my brother and I shared as family, trying to find equity in and inclusion in his life. But I didn't know about it in terms of other stories. And so I started reading books, and I started listening to people who are disabled. And I started to, and I started listening to disability studies, scholars and Disability Studies in Education. And I said, Oh, my gosh, we've been doing this all wrong. we're spreading messages that are so outdated and so counterproductive. And that's when I started modifying, and totally, I mean, it up ended my world, it taught me so much. And I realized, I've got to do something. And I've got to share this with other educators, because we're all doing I know, the hearts. I mean, most of my educator, friends, are incredible allies, for the disability community, and are just really good people. And they want to do the right thing. But we have been taught so incorrectly. and then we're part of a culture that's very ablest and very much, into inspiration, porn But most of us who are not part of this disability community don't know. And so my mission has been to transform access awareness. Belonging, awareness.

**Qudsiya Naqui:**

And that begs my next question, which is, from your perspective, Diana, what does it mean to go beyond awareness?

Diana Pastora Carson:

it's not looking at what's quote unquote, wrong with people's bodies and minds. it's not looking at how inspiring people are, because their quote, unquote, overcoming their disabilities, it's, it's really looking at how we as a society, both as individuals, and systemically, as a society, have been the barriers that disabled people have had to overcome. going beyond awareness is really looking at disability as normal and natural part of the human experience, that phrase that we all know and love. It's looking at disability as a valuable part of diversity, especially when we're talking about Dei, which, traditionally leaves out disability. beyond awareness means looking at Access awareness. It's looking at belonging, it's listening to the voices of disabled people. It's not bringing in the psychology, the school psychologist to talk to the kids about autism. It's not bringing in experts in disability, you know, quote unquote experts in disability if those experts are not people who experienced disability who lived the experience of disability, and beyond awareness means amplifying the voices of people with this abilities. I'm not, I'm not saying that I'm the expert at all of these things, and I probably never will be. But I'm wanting to learn and grow by reading and listening to the disability community. And I'm sharing what I have learned with my educator colleagues, and hoping that what we learn together will have a lifelong effect on students in schools, and that will create truly inclusive communities, and build access intimacy within those communities.

[Contemplative guitar strumming]

**Qudsiya Naqui:**

I'm curious if you could provide some examples of when you go into a school, or you work with educators, and families and schools, what are some strategies that you've developed to help them go beyond awareness?

Diana Pastora Carson:

I have a framework that I use, I call them the five keys or the five fundamentals, it's ableism, then access and inclusion, then assistive technology, then disability history, disability rights, and disability justice. And then the last one is respectful language. So those are the topic areas that when people invite people to come to their schools to share, these are the topic areas that we want them to tie into their, their share, they might be sharing about, you know, their artwork, they might be sharing about what they love to do in terms of adaptive sports, they might be sharing about their family, their kids, you know, they may be parents, just anything that's of interest to them, that's going to be of interest to the students, bringing people in who are multimodal communicators who may be used assistive technology to communicate.

**Qudsiya Naqui:**

I think that example is, is really illustrative of what you're talking about, because the person isn't coming in to do a show and tell about their disability. They're just coming in to talk about their life and how they live their life in different and interesting ways that kids can have exposure to.

Diana Pastora Carson:

Absolutely, absolutely.

**Qudsiya Naqui:**

You recently wrote a piece for ABILITY Magazine about this concept that you describe as durable accommodations. And this strikes me as similar to one of your are related to your principle around access and assistive technology in some ways. What what is a durable accommodation? And how can a durable accommodation help us design a better world?

Diana Pastora Carson:

Yes, so durable accommodations is a concept that my parents perfected in our home when we were growing up. And that was just having an environment where my brother Joaquin could be Joaquin, where he could be himself. And we didn't have to worry about him hurting himself or hurting any part of the environment. And so when we, when we created a home for him, we made sure that it was durable in nature. And we realized, you know, we got we may have gotten him out of the institution, and he may have a wonderful life in the community now, but in 2020 We live in a rural neighborhood in San Diego, on the outskirts of San Diego, and in 2020, we had two wildfires that we had to evacuate from. And this was during COVID. So everything was pretty much shut down, including public restrooms. And we had nowhere to go. We had no durable place to go, we couldn't take Joaquin to a hotel. Because there was a lot that he could hurt himself on if he were having a bad day. we've had to evacuate three times now, since then, a total of three times twice in 2020. And once in 2021. And we never had a place to go. And even when we reached out to an adult day program that was shut down. And I knew the people that were in charge there because I'm part of that community. As far as teaching classes on their campus, I knew that they had a durable environment, I knew that Joaquin would be safe there. And I knew that they were shut down and nobody was using the facility. And I reached out to them. And I asked if we could take Joaquin and his staff over there to wait out the fire. We were told no. we'd never felt so alone. And helpless. When Joaquin was in an institution. He had everything he needed to if he needed a doctor in that moment, he had one if he had, if he needed some safe place to be, you know, by all intents and purposes in terms of durable accommodations, he had it. But when once we got him out of the institution and into the community, those were the forgotten things. we've had many situations where we couldn't get him the health care he needed when he needed it. So I've been reaching out to federal and state organizations and agencies and making people aware of the need for access to durable accommodations, and we're hoping that we make some progress.

**Qudsiya Naqui--**the concept of access and negotiating access and thinking critically about design of spaces. Those are terms that are really used in the framework of disability politics, and they enable us to create environments that are beneficial to everybody.

Diana Pastora Carson:

in the article I write about how it would be a dream come true to have, the hotel industry, hop on board. And it's not just about autism, or people with emotional or behavioral dysregulation, even mental health disabilities that may need certain types of durable accommodations. But it's about everybody working together, no matter what your needs are, and really taking a look at who are we including, and who are we not including? And how can we be more inclusive in the design of our hotels? I mean, they're redesigning hotel rooms all the time. And sometimes they're really funky designs, you know, but what if we looked at what if we sought consultation from a variety of disability groups and advocacy groups, and said, How can we make this more accessible not just to you, but to everybody?

Qudsiya Naqui:

I will certainly also link folks to your peace in ABILITY Magazine in the show notes as well. Diana, you, you do so much. Is there? Is there a project, a new initiative or something you're working on that you're excited about? What's next for you?

Diana Pastora Carson:

the durable accommodations is the newest thing on my agenda. I just want to get the word out. That's what's new for me figuring out how to get the word out, especially to educators who don't know, spreading the message, having people you know, sign up for, for some of my free resources and spread and sending them out to people that they know so more and more people can go beyond awareness.

**Qudsiya Naqui:**

That's fantastic. And where can our listeners find you and your work, Diana?

Diana Pastora Carson:

Well, for educators interested in disability awareness with a Disability Studies in Education take on it, they can get my free resource called “The Five Keys to Going Beyond Awareness.” And that can be found at gobeyondawareness.com/keys. I also have a free resource called “How to Talk About Disability with Kids.” And that can be found at gobeyondawareness.com/talk. And then, dianapastoracarson.com is where you can find many other resources including my blog, my books, and my digital Beyond Awareness Basics course, as well as a beyond disability awareness educators guide, recently published by NPR Inc., which is National Professional Resources, Inc. and I'm really excited about it actually, it's “Beyond Disability Awareness: An Educators Guide” which is a trifold laminated resource, kind of like a cheat sheet for educators who just want the quick and easy resource to make sure they're staying away from outdated, obsolete ways of doing disability awareness.

**Qudsiya Naqui:**

That's fantastic. Thank you so much, Diana, for being on the podcast. It was really great to be in conversation with you.

Diana Pastora Carson:

Thank you so much, Qudsiya.

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Down to the Struts was produced by Ilana Nevins and me. Our social media manager is Avery Anapol. With special thanks to Claire Shanley for designing our logo, and to Eiffel Gangsta Beats for our theme music. Remember to subscribe, rate, and review the podcast on your favorite podcast platform, And follow us on Twitter and Instagram at Down to the Struts. You can also get the latest updates by joining our Facebook group, Down to the Struts Podcast, and by subscribing to our newsletter, Getting Down to It on SubStack. We also love hearing from you directly! You can always drop us a line at downtothestruts@gmail.com. All of these ways of connecting with us are linked directly from our website, downtothestruts.com. And of course, stay tuned for our next episode, so we can get back down to it!