



The Think Inclusive Podcast

Season 9, Episode 13

Diana Pastora Carson | Beyond Awareness

Tim Villegas (00:00):

Steak is coming. If you don't know what that means, you will in a minute. And if you want a preview of our conversation with Diana Pastora Carson, watch her Ted talk, "Walking with Joaquin" about her family's journey to bring Joaquin home after 15 years of living in an institution. We'll put a link in the show notes. But to set up this conversation with Diana, I wanted to play a clip from her Ted talk. The moment she tells Joaquin that he's coming home.

Diana Pastora Carson (00:34):

When we were in the process of fighting to get Joaquin released from the institution, a fight that took three years. My mother asked Joaquin, "what would you like to be your homecoming meal when we finally get you out?" And he said, "steak." And I don't know why he said steak. We didn't really eat steak growing up. We were more of a rice and chicken kind of family. But he said steak. And we later realized for those three years, he kept saying, I want steak. I like steak. Steak is coming. Steak is coming. And I'm wearing the necklace that says steak is coming right now. He kept saying that and we realized that was his metaphor for what he knew he needed and what he deserved. And that was life quality. So here's the day we announced to him that he was gonna finally get that steak.

Diana Pastora Carson (01:22):

What happened at your meeting, Joaquin? Listen for a second. What happened is it was decided that you get to come home on November 4th, which is 21 days. Oh, what do you think?

Joaquin (01:46):

Are you ready? What the hell, bi#\$h.

Diana Pastora Carson (01:46):

What do you think?

Joaquin (01:46):

I want steak. I want steak.

Friends (01:46):

Congratulations buddy, that's less than a month away.

Diana Pastora Carson (02:04):

Joaquin also learned some choice adult words in the institution.

Tim Villegas (02:10):

My name is Tim Villegas and you are listening to the think inclusive podcast. This podcast exists to build bridges between families, educators, and disability rights advocates to create a shared understanding of inclusive and what inclusion looks like in the real world. To find out more about who we are and what we do, check us out at thinkinclusive.us or on the socials, Facebook, Instagram, or Twitter. Today on the podcast, I interview Diana Pastora Carson, the host of the Beyond Awareness podcast. We talk about what her journey has been like as an educator who advocated for inclusive education. What it's like now that Joaquin has been home for close to 10 years. And why she started the beyond awareness podcast. I'm so glad you're here. Thanks for listening, subscribing and rating us on Apple podcast or Spotify. And now our interview with Diana Pastora Carson.

Tim Villegas (03:13):

Okay. Today on the podcast, we have Diana Pastora Carson who has been an educator for over 30 years, teaching both at the elementary school level and the university level. She is a consultant and trainer on diversity as it relates to disability. And is the author of several articles and books, including Beyond Awareness: bringing disability into diversity work in K12 schools and communities. As well as her children's book Ed Roberts: champion of disability rights. She is the host of beyond awareness: disability awareness that matters podcast. Welcome to the think inclusive podcast. Diana, it's a pleasure to have you.

Diana Pastora Carson (03:54):

Thank you, Tim. It's really exciting to be here today. Thanks for the invite.

Tim Villegas (04:00):

Yeah. Yeah. So we're like, you know, swapping guest spots on our podcast. This is awesome. Yes.

Diana Pastora Carson (04:08):

It was lovely to have you on my, thanks for stepping out into my new world of podcasting and braving the territory and being a guest for me. I loved your interview with me.

Tim Villegas (04:18):

Of course. Yeah. Yeah. Very happy you to do it. So I'm excited for our audience to hear your story. So I, you know, I know that you wrote, you wrote your book and I just, like I said before, we started taping recently saw your Ted talk, which we will link to the show notes. But why don't you just introduce yourself to our audience and say like who you are and, and we can kind of jump off from there.

Diana Pastora Carson (04:47):

Sure. Well, you, you mentioned all my, my teaching experience and that I'm a public speaker and have a Ted talk. I also am a community activist and advocate. I've served two terms on the board of directors of disability rights California. And currently I serve on the board of directors of disability voices United. But one thing that's not in the introduction is that I am a fierce sibling advocate. And my brother Joaquin is one of my closest, my closest relationships in life. And he always has been, I've often said that I feel like we are twins, even though we're a year apart. And I have to say this, anytime that I speak and I share the

story of our journey together, our journey towards inclusion, I have to say, I have Joaquin's blessing. And I have his consent to be able to share this with the audience.

Diana Pastora Carson (05:53):

He wants me to share the story, he has made that well known. He's been in the audience at conferences. He has helped me and co-presented with me. And if he's not co-presenting with me, he's out in the audience saying right on baby. You know, he, he loves to hear his story shared. And even with the podcast that he's been listening to, he's been encouraging me to keep going. So Joaquin was the product of a system, a school system that had no clue back in the 1970s when IDEA was passed. No clue about what inclusive education would look like. He was placed in a special classroom that did a lot of aversive conditioning methods. It was all about compliance training and control until a day when he was in the timeout closet for way too long and had too much time and had a bowel movement inside the closet.

Diana Pastora Carson (06:54):

And my mother was called and told she had to come get her son and that he couldn't go to school there anymore. And so my mom came and cleaned the room, the timeout room. She cleaned up my brother and she walked home with Joaquin and Joaquin was then placed in a non-public school for children with autism. And he was there for 10 years. It was all that was offered. It was all there was available. And for 10 years they, they had all kinds of modern, quote unquote, "modern techniques." They had the timeout rooms, of course, but they also used spray bottles to squirt him in the face with the water bottle if he was not compliant. If he tried to aggress, if he to bite somebody for instance because they were treating him in ways that were not dignifying they would spray him in the mouth with vinegar.

Diana Pastora Carson (07:49):

They also did restraints with him. We know the head down procedure where they would have him sit crisscross apple sauce with his hands behind his back and in his head touching the floor. And if he didn't do it voluntarily, they would forcibly keep him in that position with two people or three people. And sometimes five people holding him down. So he was basically tortured throughout his childhood education every day in order to help him, you know, fit, to quote unquote "help him." and then he ended up at age 17 and I'll make the short, this long story very short. But his school gave my parents an ultimatum that if he didn't start taking psychotropic medications to control his behavior, because they couldn't control him anymore. He was six feet tall weighed 200 pounds. And they said, we can't control him.

Diana Pastora Carson (08:46):

You need to put him on medications. And my parents finally relented after about a, a year or two of the school begging them to do so. And my brother had this horrible reaction to these medications. They were horse tranquilizers basically, Thorazine, and Joaquin, who is a man who loves to ride bikes and run and skateboards, skates, swim. Like he's coordinated as can be. He was on the floor having seizures as a result of these medications. And my dad and, and so my parents tried to, there was nowhere to call nobody they could turn to, to ask, how do we, how do we help our son? What medication do we remove him? You know, take off of his medication protocol. Nobody. And there was no internet resources. And so they started to play around with his meds, thinking that they would be able to help him.

Diana Pastora Carson (09:46):

And it didn't work. It just, this young, beautiful man became psychotic and dangerous as a result of these medications. And at one point I came home from high school and I saw my mother who was ill laying on the sofa crying. And my father was straddled over Joaquin and Joaquin was naked. He was sweating profusely. And my dad was sweating so heavily that drips of sweat were rolling off of his nose onto Joaquin. And my dad was holding his hands in place. And he had been in this position for two hours trying to keep Joaquin from destroying the house and hurting himself and hurting our mother and my dad. I'd never seen my dad cry, but my dad was crying and he said, Diana, I need you to go to the garage and I need you to go get a rope. So I went and I got a rope and my dad tied Joaquin's hands and feet together.

Diana Pastora Carson (10:46):

And he then proceeded to call Joaquin's social worker at, in California we have the regional center system and he called us and there was nobody available except for a man who was also a father of a young man with autism. And they cried on the phone together. And my dad said, I need help. My son needs help. And he said, Mr. Carson, I'm so sorry to have to tell you this, but you're gonna have to, untie your son. And I'm gonna have to all child protective services. And first thing in the morning, you have to drive your son to the state hospital, which is two hours away. And so that was our family's first trip to the institution in orange county, California. And for Joaquin actually lived there twice in his life once for eight years, and once for seven years with a group home stay in between.

Diana Pastora Carson (11:46):

So a total of 15 years in an institution, that's what Joaquin has lived through. And as I got older, you know, back then I was a teenager, but as I got older, I decided I wanna be a teacher. And I wanna make a difference for kids like Joaquin. I know there has to be something that I can do that would change the future of somebody else. And at the same time, I started educating myself, started getting to know a lot of people in the space of autism and autism self advocacy, and just dignity and disability studies. And I became, I became one of the people my parents kind of steps aside so that I could support Joaquin, learn about alternative communication, learn about supported, typing, see what Joaquin really wanted in his life and learning to honor his communication, not just hear it, but actually say, okay, Joaquin doesn't wanna live here.

Diana Pastora Carson (12:51):

We're gonna find a way that works for him. And I remembered as a kid, we always loved the country. I mean, our family would drive to the country cause it was really the only place we could go without people staring without people making rude comments. And it was where Joaquin felt like he could be free. And so I knew, okay, I'm gonna get him outta the institution, no more group home, we've been there, done that. We need Joaquin to have his own place. We need a supported living option. And that's what we went for. And we did it in a country area. So my husband and I bought a home in a rural area with a barn and we renovated the barn and it's Joaquinified. It is custom built for Joaquin. So if he has a rough day, he can't hurt himself on anything it's indestructible.

Diana Pastora Carson (13:40):

And then on those good days, you know, either way he's at home, this is home for him. We, our favorite song and we have a YouTube video about it is "country roads take me home," you know? Yeah. We sing that together. You've seen it. Yeah. So, and at the same time as I was working on getting my brother out of an institution, I started diving into what, why did this have to happen? What's going on in our society,

in our education system that routed him this way? And, and I, I just, by chance, a friend of mine asked me to, co-teach a disability studies class with her when she was going on maternity leave at a local community college. And so if I wanna do that, I'm gonna have to learn a lot there. I mean, I may have a master's degree in special education and I may know a lot about disabilities, but I realized the, and there, I didn't know a lot about disability, about the experience of disability.

Diana Pastora Carson (14:44):

And so I started diving in, I started reading books and when I did, oh my gosh, it up ended my world. I had been doing all these simulation activities in schools to try to create sensitivity for students. I used to, I was really excited about disability awareness because I thought it was gonna make a difference for kids, right. Aside from my inclusion efforts with my own students in my classroom, I knew that disability awareness was a must. But once I started teaching a disability studies class, I realized that I had it all wrong. Tim, I realized that what I was doing was causing more harm than good and that I needed to create a different way of doing disability awareness and it needed to come from disability studies perspective. It needed to come from a person-centered perspective. It needed to be from the voices of people who actually experienced disability, not me, you know, putting Vaseline on glasses and having them try them on and say, oh, now, you know what it's like to be vision impaired or blind right? No, because we don't know what it's like in that. You know, five minutes, 10 minutes, even an hour that way, you're not gonna know what the experience of being disabled by societal barriers is like, until you've walked that walk as a person.

Tim Villegas (16:05):

Oh, I love that. I let's camp out on that for just, just a second, because that is, that is so interesting. I've never actually, I don't think I've made that connection before because these, the activities that you plan to simulate disability. It automatically assumes that that is the barrier. Right, right.

Diana Pastora Carson (16:34):

Yeah. Yeah. And it's a person's physical body or me or their brain that is the problem. Right. And we're not looking at them as the problem, we're looking at society is the problem. The barriers are the problem. The ableism is the problem.

Tim Villegas (16:53):

Yes. Yes, absolutely. Yeah. I mean I, I don't think I've ever heard it put, so succinctly, you know, I mean, I think that, I think that, yeah, of course that like those activities don't, you know, in the long run don't do a whole lot, right. But just the fact that like, if, if we really wanted to simulate what it was like having a disability, the world would have to actually completely change for abled people like so that they wouldn't be able to access anything. Right.

Diana Pastora Carson (17:31):

Right. And the word access is key. Access is everything. You know, when you look, when you have a person sharing their story, when you amplify their voice and their story about not having access, about encountering ableism, about the effect of having access to assistive technology or the effects of having access to a voice and having your voice be honored. When you, when you have people sharing their history, when you learn about disability history in not just modern disability history and the, you know, and legislation for I'm the sixties and seventies on, but if you go back thousands of years and how people have been perceived, and you correlate that with how we treat people now things change for

students, you know, students' eyes open up, they get it. Probably more quickly than a lot of adults get it. But it makes a difference for adults too.

Diana Pastora Carson (18:32):

And so that's what I've learned, you know, that, that, you know, we were doing, we were, we had the best of intentions. I always had the best of intentions. I thought I was doing the right thing. But I wasn't. And I realized that if I really wanna make a difference for the Joaquins of the world, then I had to approach disability awareness in a different way. I had to approach being a sibling in a different way. You know, I, I, I'm a big griper about some of the stances that some of my fellow siblings take when it comes to their brothers or sisters. And, you know, we, we have to look at it from a social model and a social justice perspective. Are we going to be an ally for people, whether they're blood related or not whether there are students or not, how much of an ally are we committed to being for all people?

Diana Pastora Carson (19:29):

And that necessarily includes people with disabilities, whether it's communication disabilities, cognitive disabilities, physical disabilities, mental health disabilities, whatever, learning disabilities, whatever type of disabilities they are. Learning what the journey is, what the barriers are and how we can take societal barriers out of the way, you know, how can we actually implement universal design for learning? And, and in terms of everyday interactions, not just, you know, the, the building or the environment in a classroom. But how we address people, how do we design our, our, our conversations with our students so that we are designing those conversations to be inclusive and nurturing for everyone.

Tim Villegas (20:21):

So tell us tell us about Joaquin now, like, you know, oh, where is he now? Like, or maybe, maybe you wanna finish that story of, of him getting out and then kind of like what he is doing right now.

Diana Pastora Carson (20:35):

Yes. So for the last three years of him being at the institution. So the institution, one thing they did really well is they had medical professionals and their goal was to titrate him off of the medications, because both times he stayed there, it was a direct result of these psychotropic medications that he's highly allergic to. Took four years to titrate him off those medications. Once we got him off of those, the last time I said to the regional center and the state hospital, okay. We, we have a place for Joaquin. Joaquin wants to move out. We want supported living. And the regional center said, no, he doesn't qualify for it. And that's when we had to fight. So we actually went to court for a year and a half and we lost, and it was a devastating blow. And, and we decided we're not giving up, cause we're kind of that way.

Diana Pastora Carson (21:31):

Spanish Italian families don't give up easily. That may be a generalization, but this is just how it is. So we went back and my mom asked him Joaquin, "when, when you get, when you come home, what do you want, mommy to make you for dinner?" And he said, steak. We didn't grow up eating a lot of steak. I don't remember ever eating steak, but he said steak. And for the rest of that time in the state hospital, he kept saying, steak is coming. Steak is coming. Steak is coming repeatedly. I like steak, steak coming, you know? And so we kept, that's his motto now. Steak is coming. I love steak. He still says it to this day. I love steak. And we don't even eat steak still. Cause it gives it's, it gets him constipated. And he knows that.

Diana Pastora Carson (22:24):

But anyway, so for three years we kept looking forward to steak and finally that day came, we won that case and he got to get out and I said, how do you feel? And he said, I want steak. I want steak. And we moved from orange county to where we live in the outskirts of San Diego in a little community called Hummel on eight acres. And Tim, last month we celebrated 10 years, 10 years he's been home. And we were told it couldn't happen, that he was a danger to society. He was a danger to himself and others. We were told it would never work and we made it happen. And he we've got steak every day, even, you know, but we have... Joaquin hasn't changed him. That's the thing. You know, when I think of my students who were in my general classroom, you know, there were good days and there were bad days.

Diana Pastora Carson (23:15):

They, they were the same student, no matter what, but it was a relationship that carried us through, you know, and Joaquin, he has good days and he has really bad days and some days are really, really bad. But Joaquin has the opportunity to have them in a place where he's loved and honored. And he's with a community that he knows loves him and where it's of his choosing. And he knows we're on his team. He has friendships. He has neighbors that love him and bring him gifts and, and brownies and, you know, stop by to say hi and honk the horn at him. Cause he loves that. Give him a ride on their Harley Davidson. Cause he loves that. You know, he, he has a community.

Diana Pastora Carson (23:58):

He could have had that so much sooner. Tim, he could have had friends so much sooner if he hadn't been shipped off to a school so far away from his community. If he had had teachers who understood. And I'm not blaming the teachers because they were part of a system and it was top down and you know, we didn't have as much as much research back then, but you know, with good intentions, we oftentimes isolate students thinking we're doing the right thing and we are not. If we're not committed to them having life quality for their entire life, then we're not gonna understand the impact of them being separated, segregated, and not having a sense of belonging in their younger years in school. And that's why it's so. That's why I'm so passionate about this. That's why it's so important to me that my students, no matter who they are, that they all feel loved and that they're all feeling welcomed in the classroom by me as the model of that love and by their peers because the peers pick up on how we feel about each and every student.

Tim Villegas (25:11):

So what would've made a difference for Joaquin, you know, in a, in elementary school. Cause from what I understand about his story, right? He was never included. Never, right. He was always in a separate segregated classroom working on, you know, things that probably didn't align with grade level standards. Not at all, not at all. I'm just guessing. Yeah.

Diana Pastora Carson (25:43):

He was it wherever he went to school, it was always about compliance. It was like dog, dog training for kids. Right. And so yeah, what would've made a difference was Joaquin knowing that his voice mattered. What would've made a difference, I see autistic self advocates who type now at a young age and I'm like, this is what Joaquin needed. Yeah. Yeah. You know, if they had just known, if anybody had known, I mean, I can't blame anyone in particular because people in our, in our world just didn't know at the time, but gosh, we know now we have no excuse. There are little kids running around with no way to

amplify their voices, nobody who believes in their competence and we need to start presuming competence from the get go. I don't care what the cognitive assessments tell us. They could be correct.

Diana Pastora Carson (26:45):

But we have to presume that students are competent and treat them as if they're competent and provide them ways to communicate. Not just the little things, you know, not just, you know, what do you want the hot dog or do you want the hamburger for lunch in the cafeteria line? That's important. That's definitely a start, but so many other things that we could all day long be asking people what they want, giving them a voice and honoring their voice. And getting, and prioritizing having professionals in communication with any student who doesn't have reliable communication. Early on. We need to focus on that and we need to have... Joaquin. I remember when he first came home, one of the things that was so incredibly profound to me was reading a book with him, called eyes on the prize. I sat down and read this book with him.

Diana Pastora Carson (27:41):

It's about the black civil rights move. And Joaquin sat there for an hour, at least, listening and looking at all these pictures. He had never learned about history before. Mm. And he could relate to discrimination, not in this, not a, not the same type of discrimination of course, but you know, if he had been a, a part of history classes in high school, he may not have been able to present the same level of understanding that the other students did. He may never have been able to demonstrate what his comprehension was, but wow. Giving him the opportunity to learn about science and history and reading and writing and math. What, what a disservice we did by not empowering him with those all those years. And not, not just the academic part of education, but the relationship part with your peers.

Tim Villegas (28:42):

Yeah. Yeah. So I want to the last part of our time together talking about your podcast. So you have a podcast called beyond awareness and it's, it's new, it's new. Again, I had the pleasure of being, being on it. But I I'd like for you to, to share with our audience, number one, why a podcast? Why, you know, why did you wanna use this mode of communication and then two, like what do you hope for, to it to accomplish and like kind of your dream for the podcast.

Diana Pastora Carson (29:27):

Yeah. Thanks for bringing it up. Yeah. The podcast is brand new, started in December. And the reason that I wanted to do the podcasting format is because I really like talking to people and I, I've learned, I've met so many amazing people. I have this incredible network of people that I'm connected to that, you know, every day I go to my classroom and I would be the one teacher on my campus that everybody knew I was the inclusion teacher. You know, if there's this kid that the parents want him included, oh, take him to Diana's room. And I don't, and I don't think it's because I was more capable. I think it was just because I was more at ease about it because I knew so many people I'd heard so many stories I'd attended when I was on this quest for Joaquin.

Diana Pastora Carson (30:15):

I immersed myself in all kinds of spaces online and in books, in podcasts. And so I really wanted to provide that level of comfort and ease and peace of mind to my colleagues. And when I had to, I actually left teaching last year during the pandemic, I had a medical crisis and I realized, with all the online, I couldn't be online. I just, and I, it was doing a disservice to my students and my families to not be able to

show up to work because of my own medical issues related to online teaching. And so I, at first I was devastated. I had so much shame associated with that. I felt guilt for leaving my peers, my colleagues, and my families, but I worked through that and I found this silver lining, oh my gosh, here's my opportunity. This is what I need to do.

Diana Pastora Carson (31:15):

And so I started, you know, learning more about podcasting. I got myself a coach who's been helping me and, and I'm really excited about it. I want for teachers who are interested in inclusive education, who are interested in diversity, equity and inclusion. Diversity, equity, access, and inclusion. And who with a good heart have always wanted to do dis awareness stuff on their campuses but weren't quite sure how to, this is, this is the answer. This is, these are the guests who will talk about it. These are the guests who talk from the heart in a safe zone where we can learn, well, what can you do for disability awareness instead of doing simulations, what actually matters and what actually will make a difference long term for your students and for your staff. So that's what, that's what it's about. It's called beyond awareness, disability awareness that matters.

Tim Villegas (32:18):

So Diana, I I'd love for you to share with our audience, like where can they find more about you? Go beyond awareness. If you have any online courses, plug your book, whatever you'd like to talk about, just let people know where they can get more information.

Diana Pastora Carson (32:35):

All right. Well, I do have a free downloadable ebook called the five keys to going beyond awareness. And that can be found at <https://www.gobeyondawareness.com/keys>. And also I have a digital course for anybody who wants to learn how to do, quote unquote, do disability awareness on their campus. From a perspective of a disability studies perspective, a research based perspective, a dignifying perspective. They would go to go beyondawareness.com and you'll find information there about that course. I do have my book [Beyond Awareness: bringing disability into diversity work in K12 schools and communities](#). That's on Amazon. And also a children's book, an illustrated children's book called [Ed Roberts: champion of disability rights](#). That's also on Amazon. So those are the main things. And then of course, the podcast. [Beyond awareness, disability awareness that matters](#). And you can find that anywhere where you can find podcasts.

Tim Villegas (33:45):

All right, well, Diana Pastora Carson, it's been a pleasure to have you on the podcast. We appreciate your time.

Diana Pastora Carson (33:51):

Thank you, Tim.

Tim Villegas (33:54):

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