OCALI | Podcast – Episode 15

ADA Anniversary

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SIMON BUEHRER: Welcome to Inspiring Change from OCALI, our forum of stories and connections from our ongoing work of inspiring change and promoting access for people with disabilities. I'm Simon Buehrer.

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DIANA MAIROSE: But what I don't understand is why is it so hard for people with disabilities to live? And have their own rights and have their own choices, and what they believe in, and what they feel is important?

MARK SEIFARTH: It was my mother and my father. I'm going to lose my composure. Because of that. That's the history you have to understand about how important the ADA is.

D'ARCEE NEAL: And see in America, I don't got to do none of that. Because in America, if people are doing something and you find it to be distasteful or inappropriate, I mean all you really gotta do in the day of social media is take a photo.

SIMON BUEHRER: July 2020 marks the 30 year anniversary of the Americans with Disabilities Act, otherwise known as the ADA. This is the civil rights law signed by the first President Bush and intended to prohibit discrimination against individuals with disabilities in all areas of public life.

We wanted to get a better sense of the role the ADA plays and the impact it has had and continues to have on our society, our culture, and the lives of people with or without disabilities, and also talk about where the ADA misses the mark and the work that still needs to be done.

So we invited three people from three different generations to share some of their thoughts, stories, and personal experiences with the ADA. We'll first let them introduce themselves, and then roll into our conversation. We started the day out by asking each of them to share their name, where they're from, and who they are.

DIANA MAIROSE: My name is Diana Mairose and I am from Cincinnati, Ohio. And who am I? I'm going to say I am an advocate, artist, and aunt.

D'ARCEE NEAL: My name is D'ARCEE Neal. I live in Columbus. I'm a recent transplant from Washington DC. And I would call myself an activist as well as an academic. So I'm a second year doctoral student at The Ohio State University. And I do a lot of work at the intersection of race theory and disability, specifically through the lens of popular culture and Afrofuturism.

MARK SEIFARTH: I'm Mark Seifarth. I live in Columbus. Who am I? Well, I'm a person with a disability. I have cerebral palsy. And I have worked on public policy issues on the local, state, and federal level for over 40 years. And issues of empowerment and disability and advocacy seem to have been part of my existence for as long as I can remember. And I'll probably impart a couple of stories that go along with that run. So that's a quick beginning.

SIMON BUEHRER: So we have an advocate artist, an activist academic, and a leader who's worked on issues of disability and empowerment for a long time. As Mark said, he's championed disability policy at the local, state, and national level for over four decades. He was almost the same age that D'Arcee is now when the ADA was passed in 1990. So as the senior member of the group, we ask Mark to start us off and help provide some historical context and explain the importance and significance of the ADA.

MARK SEIFARTH: The ADA was and is a civil rights law for people with disability. Without it, you had no recourse. Without it, you could be fired as a person with a disability and have no recourse. You could go to a public building, not get in, not have an interpreter, not have anything you need, not have any accessibility. You could go to the movie theater and be turned away.

And you need to understand that history. It's just seminal. It's just the most important thing to understand that before the ADA, you could be told "no," and there was nothing you could do.

SIMON BUEHRER: That's hard for a lot of us to imagine, especially in 2020. We're used to doing things. We're always doing things. So to think about a time when there was, as Mark puts it, "nothing you can do," seems very distant from where we are today.

Which gives us some good historical context to understand the role and impact of the ADA. As we continue the conversation, it also helps to have a baseline understanding of the specific areas covered by the ADA. We'll again let Mark explain this.

MARK SEIFARTH: The easiest way is that the four main areas, employment, public services, which also includes government, local government, and transportation, public accommodation all places, all private entities and then telecommunication. It's got to be accessible. You've got to have telecommunication accessible. So whether you're a person that has communication needs, that those are met. Those are the four basic pillars of the ADA.

SIMON BUEHRER: For Diana, part of the impact of the ADA coincided with her personal and professional development as an advocate for people with disabilities,

DIANA MAIROSE: People with disabilities went from being segregated to learning their own voice. And we have to remember that each of us have our own story. I feel it's important to tell other people's stories. Because that's how I learned about advocacy. And it's not just about me. It's helping those who are important to me.

SIMON BUEHRER: When you tell or share other people's stories, especially those stories that may have historically been hidden, untold, or even lost, when you share those stories through social media, traditional media, policy work, et cetera, you create a stronger, enriched, more complete picture of what it means to be a person. Though as D'Arcee explains, results and success hinge on work at the foundational level and the continued need to address root causes and systemic issues.

D'ARCEE NEAL: And it was told to me so eloquently, several years ago, I was at an internship with the American Association of People with Disabilities in Washington DC. And we had Leah Katz-Hernandez She's the first the deaf person to ever work at the White House.

And she was amazing. President Obama hired her. She was awesome. And she came in and we were talking about the successes and the failures of the ADA. And while we agree that it is a resounding success, writ large, the nuances of the specificities, she compared it to-- Like for example, I'm also gay. I'm queer. And so we compare it to the gay rights movement.

She said the groundwork that they laid has been so effective in the queer community because they attacked the foundation of the issue, which was homophobia. They went door to door and basically told people gay folks are people first, bottom line.

We're not talking about this the specificities of what they do in the bedroom and when the door is closed, or when the lights is off. None of that is relevant. What people are doing, those are side conversations that are not relevant to the bottom line of people's fundamental right to exist.

SIMON BUEHRER: That fundamental right to exist is what civil rights legislation like the ADA is intended to address. Sometimes it works really well and does exactly what it's intended to do. Diana shared a brief story about a friend of hers.

DIANA MAIROSE: I had a very close friend who passed away unfortunately. He had CP as well, but he made his own decision every day. And he spoke up every day. But we have a long way to go.

SIMON BUEHRER: But even though her friend made his own decisions and spoke up every day, as Diana says, "we still have a long way to go."

D'ARCEE NEAL: I'm looking at the systemic problems that necessitated the ADA to begin with, and I just honestly feel like those aren't being dealt with at all. People are doing stuff that is surface level. And that's what is gonna keep this rotating in a circle that will never change unless folks start getting at the root. They got to go deeper than what it is now.

SIMON BUEHRER: OK. So let's unpack this a bit. How do you go deeper than where things are now? For D'Arcee, part of it is a conversation about media and representation, about how we as a society view and depict people with disabilities, and the platform that is or is not provided to them.

D'ARCEE NEAL: Jerry Lewis may not be around anymore. The telethon may be over, but people still feel the echoes of what he did. They feel the echoes of this whole point. And everything leads back to wanting to be in the charity model. They want to feel bad because bottom line, folks with disabilities embody other people's nightmares. If I'm just going to be real, people look at disability as though it is the embodiment of a nightmare.

And medical shows as much as I love Grey's Anatomy and The Good Doctor it don't help. Because every single time you see a person with a disability on TV or media, it's always funneled through this idea of like, "oh god, that's my worst nightmare, my worst experience." I can't ever end up in a wheelchair. So that's the mess that when I see it, I'm just like the ADA is meant to deal with these things. It's meant to try to help shape these things, but people still talk about buses.

I get that like both parts of it are really important, but like I said, I'm up here trying to do the work intellectually to talk about the other side of the equation, which is equally as important, media representation, the flip side of what happened when you get off the bus. It's the advertising that you see on the bus. It's what you're looking at on your cell phone why you gettin' from point A to point B.

SIMON BUEHRER: We all have inherent biases and we all make convenient assumptions about each other every day.

MARK SEIFARTH: I'll tell you an older story. I've been married for 33 years come this fall. I married somebody that I met in the State House. I married up. She's smarter than I am. I was smart enough to marry somebody smarter than me. But I cannot tell you how many times after I got married, people who I did not know, the first thing out of their mouth was, "Well does your wife have a disability?"

There was an automatic assumption that I had to marry somebody with a disability. Because only people with disabilities spend time with people with disabilities. Heaven forbid you should want to spend time with different kinds of people. I can't tell you how many times over the years, we'd go out to eat and the server would look at my wife and ask her what I wanted. And as you can tell, I'm not a very quiet guy.

SIMON BUEHRER: And so while the ADA was intended to allow people with disabilities the opportunity to live and participate more fully in all areas of public life. That black and white legislation signed 30 years ago by the first President Bush is colored by the complexities, subtleties, and reality of ... well, life.

DIANA MAIROSE: And we do have our own rules and our own guidelines, which some of it I understand. But what I don't understand is why is it so hard for people with disabilities to live? And have their own life and have their own choices and what they believe in and what they feel is important?

MARK SEIFARTH: And one of the challenges in the disability community for years has always been not only choices, but informed choices. Do I actually know what my choices are? Have I gotten to do an internship? Or are they just saying, well this was the only job you get the have because this is the one we think you're qualified for? Well, I never had an internship. I never got to travel and see other places and all those things. So that's one of those big issues is being able to have informed choices.

D'ARCEE NEAL: I went to Costa Rica. I lived there for a month, it was like, six, seven, eight weeks, and it was a group of us. It was a group of students with Mobility International that were just traveling, living our best lives. And when I tell you, it was actually disconcerting. People were getting out of their cars to take pictures of us, film us.

It was like a zoo. It felt like a zoo exhibit. And folks were, I mean, we literally were stopping traffic. People were getting out of their cars to take photos, because it was like three wheelchair users and three blind folk and some deaf people, and they were just like, what are they doing? And we're just like, "We're on vacation. Like, do you mind?" But just the concept of people living their whole lives, their full, unadulterated, embodied lives in public freaked people out so much that they didn't know what to do. And this was-- we're not talking 1969. This was 2009.

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SIMON BUEHRER: I attended a webinar back in January, and one of the speakers dropped the kind of phrase you might find yourself copying to a sticky note and leaving on your desk or near your computer as a kind of daily affirmation or reminder or inspirational nugget. The phrase is, you own your life.

And I remember, it was one of those significant, perhaps life-changing moments that hit me square in the face and knocked me out of my daily stupor. And just as I was cozying into the doldrums of winter. You own your life. Yes. Exactly. It's my life. I own it. It's my responsibility. My thoughts, my words, my actions all of it. I wrote that phrase on a sticky note and left it near my computer.

But is it true? Is it true for everyone? Does everyone own their own lives? Or is that ownership limited to those of a certain privilege? A certain class? Or race? Or sexual orientation? Or ability? And whether or not you own your own life, at the very least, how do you live it on your own terms? Or in your own way? Is it even up to you? Or is your life shaped, defined, and controlled by the society, culture, norms, and rules that surround you?

I don't have any answers to any of these questions. These were just some of my thoughts, and some of the questions that were rolling around in my head as we continue the conversation about the 30th anniversary of the ADA, with D'Arcee Neil, Diana Mairose, and Mark Seifarth.

MARK SEIFARTH: When it was time for me to start to go to school, to go to kindergarten, there was one school in the entire county that I lived in for everybody with a disability. Didn't matter what your disability was. You had to go to this one school in the whole county. And this was the very early 60's. Well, my mother would have none of this. So she and I went-- and I was a wee one, this is before kindergarten.

And we met with the principal. It was a long meeting. I don't remember all of it. But at the end of the meeting, the principal came out and said, "We don't have an elevator. He has to climb a flight of stairs." So with my leg braces on, I clanked up a flight of stairs, clanked back down a flight of stairs, looked at the principal, and he said, "He can come."

Now remember, in 1975 we passed the Education All Handicapped Children Act, which was the precursor of IDEA. I know this is boring, but it's important. If that principal had said no, I had no recourse. There was nobody to appeal to, no law, no nothing. It was my mother and my father. I'm going to lose my composure because of that. That's the history you have to understand, about how important the ADA is.

D'ARCEE NEAL: So one thing I love about the ADA, if I'm being perfectly honest, and I say this from personal experience, because I have had the great fortune to live outside of the United States a couple of times. And I lived in Germany in my undergrad, and I did my first master's degree in London. And so I know what I'm talking about when I say ... no, one thing I love about the ADA is that it gives you teeth.

Other countries treat disability like it is a suggestion. Like, so in London, for example, huge mega transport system, but if people with disabilities, if wheelchair users want to get on their bus, it's like a piece of metal, no kidding, it's like a piece of metal that just comes sliding out of the side of the bus. It just like clanks to the ground. And the first time I saw it I was like, "what is that?" And they were like, "It's the ramp." And I was just like, there is no gradient on that. There is no bracing. Huh?

And so to like literally get into the bus, you literally have to take like a running leap. I have to back up and like speed my way up, and literally use inertia to go up what is basically like, a 45 degree angle. And it's very dangerous. And like sometimes I didn't always get it, and sometimes people would be trying to grab onto you. None of that should be required.

And see in America, and I don't got to do none of that. Because in America, if people are doing something and you find it to be distasteful or inappropriate, I mean, all you really gotta do in the day of social media is take a photo.

DIANA MAIROSE: And there is some politics and some policy, and then that's where I struggle, because I had a couple jobs. I had one job where I had to take six buses a day just to work four hours. And I don't want to say I got fired from this job, because I take it as a learning experience. I learned I do not like working by myself.

Why can't people with disabilities have the same opportunity? And I think it's opportunity, it's job coaching, it's understanding community, helping people and finding things you need, and meeting people. If you don't have the opportunity to meet people and to job shadowing. We need a lot more job shadowing. And creativity, we need a lot more creativity.

SIMON BUEHRER: Diana's right. We need a lot more community and creativity when it comes to employing people with disabilities. But we also need more community and creativity as we plot the next steps and the future of the ADA.

MARK SEIFARTH: This is a journey. I can talk about what ADA did and the laws before it, and the fact that my mother had to go argue with a principal for a couple of hours and I had to clank up a flight of stairs to prove I could go to school. Now we're past that. But does that mean we're done? Not by a long sight.

What about folks with mental illness and mental health issues? We're not even scratching the surface with people's mental health needs. You know, because that's an invisible disability that maybe you can't see. There are all kinds of questions about how inclusive we can be with disabilities and how we're going to move everybody forward, because one of the challenges to getting the ADA passed was everybody had to work together. That's really hard. Because sometimes my issue's got to be the most important issue. How can we help everybody move forward?

D'ARCEE NEAL: It's like, people are starting to get it, but then you've got to give them the nuance that goes with it. And so I think that if the ADA needed to do a next step, it would be that. Now that we know we're at 30, now that we know what it is, folks have had it for an entire generation plus. Gen Z is now getting the vestiges of the next next part of it, so now people need to start talking about nuance.

It's like, yes we have audio narration, yes AMC movie theaters will let blind folks come to the theater with the equipment and stuff that they have, but it's like, how are you training folks? What is the training regimen? What does that look like? Who is doing it?

DIANA MAIROSE: And if they don't believe in what I do, or don't understand what I do, I educate them, because not everybody knows everything.

[MUSIC PLAYING]

SIMON BUEHRER: You're so right, Diana. Not everyone knows everything. There is always more to learn, and always more to understand. The journey continues. And if you'd like to continue your journey, further your own knowledge and understanding, and fuel your ADA actions and activities during this 30th anniversary, you can go to adaanniversary.org. That's all one word. adaanniversary.org.

They have a whole host of free materials for you and your business or school. There's a media kit and logos and sample social media posts, a whole bunch of things that you can use to communicate and celebrate 30 years of the ADA. Again, it's at adaanniversary.org. And it looks like they're using the hashtags #ADA30 and #ThanksToTheADA.

And speaking of thanks, I'd like to thank our guests for this episode. D'Arcee Neil and Mark Seifarth from Columbus, and Diana Mairose from Cincinnati. We did a Zoom interview for almost two hours, and they shared so many great stories and experiences. Unfortunately we couldn't fit them all into this episode, but we really appreciate their time and generosity.

If you want to follow any of them on social media, you can find Mark at Mark Seifarth, that's M-A-R-K, S as in Sam, E-I-F-A-R-T-H, @MarkSeifarth. And D'Arcee Neil is @DrChairington C-H-A-I-R-I-N-G-T-O-N. And you can find Diana Mairose on Facebook. Facebook.com/diana, D-I-A-N-A, dot Mairose, M-A-I-R-O-S-E.

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Thanks again for listening to Inspiring Change, because the need for change is everywhere, and inspiration can come from anywhere. I'm Simon Buehrer. See you soon.

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