

Disability Perspectives Podcast Part 2
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>> CALEB BERKEMEIER: Welcome to ADA Today, a podcast of the Mid-Atlantic ADA Center. My name is Caleb, training specialist for the Center. In this episode, we have part two of our disability perspectives roundtable from the 2019 ADA conference.

All right. You guys have raised some very interesting points here. I think what I want to do now is do a round of questions. I think I'm going to start with what Josie was talking about. A question had occurred to me as I was listening to what you were saying. This is for anybody, too, of course, if you want to jump in on this. There are a lot of efforts now to try to cure blindness. I see these stories sometimes about the technology that's out and they will be testing it on blind people. A blind person will participate in the effort to cure. There will typically be a news story that's written about it. When I go on Facebook groups where blind people are discussing these issues, some of them will be very critical of the fact that a blind person participated in an effort to cure blindness because they think that, for one thing, it sends a bad message that blindness is something that should be cured, and also they will sometimes question the level of consciousness that the person participating in the study has because they'll say if this person really desires a cure, then they must not realize that blindness is not the problem. It's something else. I guess my question basically is: Is it wrong to desire a cure if you are disabled?

>> JOSIE BADGER: That's so deep, Caleb. I told him to do that. I think if we're going off of the concepts that I believe America was based off of, life, liberty, and pursuit of happiness, if we're looking at our ethical rights to autonomy, to dignity, I think that we all have the right to choose whether we want to pursue a cure or not. However, I think that we need to be cognizant that seeing or, for me, walking and breathing can be overrated. I think that, once again, we might assume that

me being able to breathe or walk is going to solve all my problems. It probably will not. My body has become adjusted to my disability, as has my mind. We're looking at changing not only people but potentially society's view of people with disabilities, assuming, once again, that people would all want to have this cure. Although I ultimately believe we all should have that choice, I do believe that as a community, as a diverse population, those of us who feel pride in our disability need to be out in the community, need to show that our lives matter, and that they are not less because of disability. The balance needs to be out there, but the freedom does, too.

>> CALEB BERKEMEIER: Anyone else want to take that up?

>> JOSIE BADGER: Jessica should comment.

>> JESSICA BENHAM: Okay. I'll jump in on this, too, because I think the concept of the cure is controversial in the autistic community as well. On one hand, you have autistic folks saying, no, this is who I am. Don't change the person. Let's change culture. Let's change expectations. Let's accommodate all of those things. On the other side, you have what are frequently portrayed as parents, but sometimes our autistic people themselves as well, saying, no, I hate this, make it go away, make it stop. There is a tendency on both sides of that debate to look at the other side and say, oh, that person isn't - like devalue the perspective of the person and the autonomy and self-determination of the person who is making the statement. I'll get frustrated when parents jump into the debate just because they don't have as much at stake in the idea of the cure as actually autistic people do.

When you're talking about something like autism, which you can't separate from the person, right, it's not like cancer. You can't point to the autism and say that's the thing I want to get rid of. What it means for autistic people to talk about a cure is elimination of people like me. It means we tested your baby and they have the autism gene. Much like in other disabilities that can be determined with prenatal testing, it's not even a choice. It's a strong suggestion from the medical professional to terminate the pregnancy. I think the concern, especially for folks with disabilities like autism where it's much harder, I think, to separate from somebody's personhood and humanity, people worry about eugenics. But I also think you can extend that to the rest of the disability community. There is this temptation to separate body and mind and it's artificial. Right? Josie was saying her brain and her body are used to her

disability in the same way that my brain and my body are as well. If you took those things away from me, if you took them away from Josie, from any of us, we wouldn't be the same person.

And so the question of a cure is not do I want to exist without autism or without Ehlers-Danlos syndrome, the question of the cure is do I want to exist, or would I rather be another person entirely? For me, that's the ultimate ethical question. Some people would prefer to be another person entirely, and that's their right, but my concern is that if that's the narrative we're pushing and if that's the narrative that people who are not autistic or not disabled are pushing, there is this social pressure and you become - that becomes part of you, too. Right? If you grow up being told we want to cure you. Who you are is horrible. You shouldn't be the way that you are. If that's what you grow up with, you believe that about yourself. If that is the lesson that society is teaching us about autistic people and about people with disabilities, that we can just wave a magic wand and that will all go away, then for the people who don't choose that, for the people like me who say, you know, sometimes being autistic is really annoying because of the people around me, because of the environment that I'm in, and I would not choose to take a cure, but then there's no pressure in society to accommodate somebody like me. Because if the vast overwhelming narrative is, oh, we can just cure you, and if you don't take it, it's your fault, you could take that, it's your fault, then why would somebody accommodate somebody like me? I agree. It absolutely is a personal choice. We need to be careful because what can be construed as a personal choice could very much stem from what society and culture tells us to believe about ourselves.

>> JOSIE BADGER: Okay. I'm going to add one more because you're nerding me out here. I'm getting excited. You hit on this huge part of whose choice is it. When we start putting the choice into the hands of insurance companies, of maybe accommodating service providers, maybe of parents who are deciding whether to carry a child with a disability or not, that's where I get extremely concerned. Just as Jessica said, we might think that this decision is being made by the person, I want the cure, whatever that might be, but when we're saying that insurance in certain states will pay for physician assisted suicide but not appropriate treatment, what are we getting at? Who is actually making that choice? When we're talking about doctors saying your child's life is going to be poor quality, you might as well abort them because they have Down syndrome, who is actually making that choice? And so although we assume

that we are making it, there are so many pressures around us that take us out of the equation.

>> JESSICA BENHAM: Yeah. To add to that case in point, my insurance company will not cover anything related to autism for people older than 18 years old. It's an exemption. Won't cover it. Right. What happens when the insurance company will cover the cure but not anything related to accommodations, any of those? What happens? Where is the real choice? It's not a real choice. I think, Josie, you're exactly right about that.

>> MARIAN VESSELS: As someone who developed a disability in college, there is an interesting dichotomy in my community of pre and post, remembering what it was like without the disability, then the overlay of the current reality. But I think most of the people that I know, if you gave them the choice to be overnight cured, I think many of us would still say I'll take what I've got but with hopefully some accommodations and supports to make this life help in work because it's who we are and it's who we've become and it's who we have developed into. It wouldn't have happened without that intervention and without that disability. But a lot of it is still that perception being broken versus being whole, whether society feels that we need to be fixed as opposed to providing the supports to allow us to live in the bodies we currently have and the brains and the countenance that we currently have to be successful and effective in our current lives and as we move forward.

>> CALEB BERKEMEIER: I'm going to move to a new question. This is stemming from comments that Jessica and Marian were making. It's about disability politics. There are those in the disability community who criticize the ADA for being a failure because it has not - it wasn't radical enough. It didn't do enough to address all the problems that exist for disabled people. One of the reasons it was a failure is because of the way that it had to be passed. A massive coalition had to be assembled. They say that when you go about trying to pass a piece of legislation in that way with all these different groups of people, the legislation necessarily has to get watered down. And so there are some disability specific groups who are resistant to broad coalitions because they think that it waters down their political power. What do you guys make of that?

>> JESSICA BENHAM: I think that marginalized people operating through cross movement solidarity as the founders of the Disability Justice Movement, Sins Invalid, would tell us that that kind of broad coalition can be incredibly successful. I

think that when marginalized people take back power, when they work together across movements, understanding the similarities and differences between the variety of oppressions or lack of civil rights that all of us face, that we're able to move forward and do better things together. Where I think broad coalitions fail is when the people who are leading the coalitions are not the ones who are facing the civil rights struggle, which is why, for me, it's critical that we not only see disabled folks in power in places of elected leadership or other leadership positions, but that we also see folks who are black, indigenous, people of color, LGBTQ people, the list goes on, because it is through coalitions of people who have been historically oppressed in this country, which includes people with disabilities, but it goes far beyond that, that we'll see real lasting and systemic change.

>> MARIAN VESSELS: I agree. I can't really enhance more than that. I think that it was only through a coalition, and the first time, quite frankly, I think the only time, because I don't think we've seen it again in such strength that we saw across the board people with disabilities. Traditionally, we are segmented. We have the blind coalition. We have the deaf coalitions. We have the this and the that. It was the first time that we actually had consensus from all different kinds of disabilities to make the ADA happen. It was the strength in that that actually forced the ADA to become into existence because you had so many people, and even though we all had disagreement about what should be in. Of course, it had to be watered down. That was the only way it got passed. But would I take a watered-down version on a broad coalition versus the reality that nothing would have happened? In a heartbeat. But I think we need to still remember that there are challenges when you get such a broad coalition and knowing you're going to give up. That means you still need individual activism and coalescing among a large group of people that you bring in other marginalized groups to help you fight your battles so that you are working together to enhance that milieu to assure that civil rights, no matter who is being affected by it, can be strengthened by many of us as opposed to a few of us.

>> JESSICA BENHAM: I agree. And I think, to your point, too, we need to talk about more ways to involve young people in these coalitions. You mentioned earlier the ADA generation. I've got to tell you, as someone who is teaching college students and was also trying - I was a student myself, I was a graduate student, part of Students for Disability Activism group, and undergraduates didn't want to be involved. They don't want to

label themselves as disabled. I try so hard to tell them do you not understand that after you leave this university, you lose all of these things that you're guaranteed under these things that only apply to educational settings? You need to know how to advocate for yourself. You're right. We face these challenges. The only way to move forward is together. I really hope we can get more young folks involved.

>> CALEB BERKEMEIER: Good. Kind of jumping off of what you just said, Jessica, it has to do with disability pride, the difference between accepting disability as a personal description and actually being proud of disability. There are also some disability groups who oppose disability pride because they think that the ultimate goal is for disabled people to eventually be so thoroughly integrated into society that disability almost becomes invisible. Disability pride, they think, actually works against that end goal because the disabled person themselves is the one who really wants to highlight the fact that they are disabled. My question is: Is there a problem with disability pride in that way?

>> JESSICA BENHAM: If so, we're in trouble.

>> JOSIE BADGER: Okay. I was pointed to. Disability pride. You know, I have this really interesting situation. I was Miss Wheelchair America 2012. I have a Miss Wheelchair Pennsylvania ambassador in the back, Katie. I was Miss Wheelchair America and I was speaking to a class, special ed teachers, I believe, and the question was brought up: Wouldn't it be great if some day there wouldn't need to be a Miss Wheelchair pageant and it would just be Miss America? I thought about it. I said, you know, honestly, it would be great. Maybe it might happen soon where Miss America, Miss USA is inclusive to anyone with a disability, but I think that there is also a place for our own pride, our own identity, and to be with people who get us. And so just like whether we are in a different minority population or we're women or we go to church, we have a right to be with people who we agree with, who get us. And so I think we need both. I want every one of us to be able to go get a job at a restaurant, a store, a college, but I also want all of us to feel that we have another home where we are understood in the disability community. And so, for me, pride is about allowing myself to find my family, both my real family but my disability family, and to recognize that I'm not broken, and that took a really, really long time to do. And so we need both. Number one, I'm all about the pride, but sometimes pride is just being able to go

forward and knowing that we're not wrong and we're not broken and standing up for what is right.

>> JESSICA BENHAM: I'm happy to eat my words on this one at some point in the future, but I've got to disagree with the premise of the question. I have said before, like I live for the day when my cane is seen the same way as the glasses that I sometimes wear. It's a thing that helps me walk, much in the same way that those help me see, as a fashion statement, but not as anything distinctive. I've said that before. But the reality of it is I'm not going to see in my lifetime, nor will our children or our children's children see, a world in which disability becomes invisible in the fabric of humanity. It's not going to happen. That's maybe pessimistic of me, but I think it's real. Right? It's been 30 years since the ADA, and while we've accomplished a lot, where are we? If anything, sometimes it feels like we're going backwards. When we talk about institutions for disabled people, one of the things I've written about is the history of institutions in Pennsylvania, and we started movements to close these in the 1940s and '50s. And here we are in Pennsylvania at the end of 2019 and people are still telling me that folks with an intellectual and developmental disabilities can't live in the community.

As much as I hate to say it - I mean, I hope I'm wrong maybe. Maybe I'm wrong. I don't think anytime soon, if at all, we're going to see a world in which disability vanishes into the fabric of humanity. But to talk about pride more generally, at the end of the day, pride is about reclaiming something that people say we shouldn't have. Right? People have used all kinds of slurs to describe me. People have told me that someone like me doesn't belong in a room making a decision, that somebody like me - I remember my second grade teacher in front of me told my parents that I was a bad kid that would amount to nothing. Right? And so pride is a response to that. It's an intentional choice to say screw you. I belong. I deserve to exist. People who are more visibly disabled, more visibly different even than I am, they deserve to belong, too. And so when I talk about pride, when I am visibly and openly a multiply disabled person, what I'm saying is to all the little kids who are growing up like me or disabled in ways that are not like me, that they belong and that there is a place in this world for them. And so, for me, that's what pride means.

>> CALEB BERKEMEIER: We'll wrap up on one more question here. We've been mentioning that education is important. I was at a panel like this recently and the topic was what do you do when

you have a bad interaction with someone who is not disabled? I was sharing that sometimes when somebody asks my wife what I want to eat or if someone grabs my cane, sometimes I get upset and I let them know that I'm upset. Sometimes I don't respond in ways that are - I mean, if I were trying to educate them and not make them feel bad, I would approach it in a very different way. Now somebody on the panel was in autism activism and also coming out of the LGBT advocacy world and she was saying that she does not feel the obligation to respond in a way where she has to hide her anger. But on the other hand, of course, if you respond in an angry way, perhaps you've lost the opportunity to educate a person, and maybe in the future, they will just think that someone who is disabled, they should just avoid them. Do you guys on the panel feel an obligation to respond in a particular way to educate other people when they do something that is really disrespectful?

>> MARIAN VESSELS: Being an educator, I'm trained as a health educator, I've educated in a variety of ways, so that's my core is to want to bring that person along so they understand because most of the time I think it is pure ignorance. If I felt that someone was doing it spitefully, I might respond differently. But I think most of the times that I see it, it's pure ignorance. I want them to be able to appreciate how to do it differently and why that was not a good thing to do because I want to pay it forward. I may never encounter them again, but I would love to see down the future that they were then respectful to people with disabilities, willing to engage. If I let loose on them and talk about how rude and insensitive and offensive they were to me, I don't know that they would ever approach - and I have heard from people that they've had that happen and are literally at times tearful when they've gotten around people with disabilities because they were so afraid that they were going to get this avalanche of hatred and spewing of anger. I can understand it. I feel it. But I usually try and vent it other ways and not to that person, hoping that they will indeed have a good reaction, learn, maybe go back and share that with other people, and start the ball rolling so that we got more people being more sensitive. But I think that's my nature. Other people probably have different thoughts.

>> JESSICA BENHAM: I think I'll add two things. The first is to say that your everyday disabled person is under no obligation to be nice or to educate the person who said the thing. But as someone who, like you, is an educator and has chosen a very public outspoken life of advocacy, I personally feel under a bit of obligation to either do one of two things. First, be nice and

patiently educate, or second, deploy rudeness strategically. By that, I mean as somebody who is autistic, there is a little bit of a free pass which is founded in other people's ableism about autism that I can strategically employ for my own devices, which is that if I am rude, they don't think I did it on purpose.

I'm at dinner with a bunch of other folks who work on developmental disability policy issues. I'm the only person at the table with a developmental disability. They're talking about the importance of friendship for people with developmental disabilities. Now I have been trying to say something for the past, oh, 15 minutes or so and I keep getting talked over, as often happens to disabled folks at a table with non-disabled folks. After a while, I decide, okay, I tried. This is my time to deploy rudeness strategically. And so I pipe up quite loudly in this very nice Italian restaurant I don't want any of your f-ing friends. You could have heard a pin drop. And then I could say my nice little piece. But in their minds, it doesn't reflect on me at all as a human being because she's autistic. Yeah. It wasn't Jess. It was the autism talking, as though it's something different from me.

I think there are two things that I kind of tend to do. One, when possible, patiently educate, but two, when not, take advantage of ableist biases that give me a little bit more wiggle room around rudeness.

>> JOSIE BADGER: Very good. Just for me, I think I've had to approach most things with humor because there are times that, if I didn't use humor, I would say things that would not be super educational. Just like Caleb, I still have a lot of people who ask my husband what would she like for dinner? I might say I want a cheeseburger and I'd like to shove this fork up your nose. That is the ideal thing that I would like to say; however, it's more - I agree that, normally, it is much more effective to joke, to make light of it, and to then teach. Because sometimes even at the moment that we are teaching, people shut down. They are like, oh, I insulted them. Oh, I'm embarrassed. But if there is a way to make people feel comfortable while teaching them, to have them laugh and recognize that you too are a human, then we come to a more mutual understanding. It can be pure education rather than an insult. I can't tell you that that's always how it happens, but that's what I try to do.

>> CALEB BERKEMEIER: I think that's a great place to wrap up. Thank you, everyone, for the discussion.

>> SPEAKER: ADA Today is produced by the Mid-Atlantic ADA Center. For questions about the Americans with Disabilities Act, phone the ADA National Network tollfree at 1-800-949-4232. And visit our website at ADAinfo.org. The Mid-Atlantic ADA Center is a grant-funded project operated by TransCen Incorporated whose mission is to improve the lives of people with disabilities through meaningful work and community inclusion. Find out more by visiting Transcen.org.