

Disability Perspectives Podcast Part 1
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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. And in this episode, we have part one of a disability perspectives roundtable that took place last year at our annual conference.

Now the audio quality in this recording is not very good, but we wanted to release it anyway because we think there is a lot of good content here. Hopefully it's not too distracting. Without further ado, please enjoy.

Good afternoon, everybody. My name is Caleb Berkemeier. I'm the training specialist for the Mid-Atlantic ADA Center. I'm going to be moderating our discussion for this session.

The way that this is going to work is I've asked my three friends up here to kick us off with a topic that they think is important right now in the disability community. I'll have each of them introduce themselves. They'll talk a little bit about their topic. And then after that, we will start to discuss what they've brought up. We'll introduce other things as well. That's how this session will go.

We're going to start with Josie. I'll let her introduce herself. She is going to talk about health care ethics and disability rights justice.

>> JOSIE BADGER: Okay. Can people hear me? Yes. Okay. If I start sounding like Darth Vader, let me know. That means the microphone is hitting my ventilator and not my mouth. Let me know.

Hi, everyone. I am Dr. Josie Badger. I am a certified rehab counselor and a health care ethicist, but that doesn't mean much in real life. In real life, I have my own business where I

provide consulting services. I worked for the Rehab Service Administration and I also work on a political campaign where we work to improve the employment of people with disabilities. Just recently, and very cool, got to start working with a large health system on improving their accessibility for women with disabilities in their OB-GYN. I'm really excited about that. I'll actually use my degree for once.

Actually, Jessica and I up here, we have a lot of similar interests. We're trying to stay out of each other's space. A little bit hard, though. With my doctorate, being in health care ethics, so many people are like why did you do that? It sounds like a terrible topic. But I think that as an individual with a disability, health care ethics are around us, whether it's from birth or later in life, and will probably get more significant if we are fortunate enough to get older. And so for me, health care ethics was where my life began.

I was born with my disability called congenial myasthenic syndrome. There is only about 10 to 20 people with my exact mutation, so, obviously, there was no - no one knew what was going on. I was born in the '80s, and so it wasn't like going and getting a blood test and be able to get your DNA mutation that is now possible. I spent many years of my life in children's hospital. With that being part of life, then also being in the intercourse of research and science and actual beneficial medicine was where I lived. For many years, I was being tested over and over for the same condition because it looks like something else, and it was wrong every time, obviously. And then I, for some reason, show up for botulism, which is what Botox is made out of. And so at that point, the University of Pittsburgh was trying to make Botox, and so they would secretly try to take samples from me to figure out why I had botulism, which I hope that I screwed up their tests. I really do because they certainly were not doing it for my benefit and they were doing it secretly. And so it was an issue that really shaped who I am as a person.

A huge reason that I am sitting here today is not only good people in the health care field that understand what ethics means, but then on the flip side why I am so passionate about these issues. But in disability and health care ethics, there is often a really strong divide between those two fields and that's misfortunate because I think that there should be a major connection. However, in a lot of the field of health care ethics, people assume that disability is sickness. It means that it's a lower quality of life. And so they assume that the

eradication of disability is often better than life with a disability. And so as we're moving through the progression of science, of testing, of genetic tests, of the possibility of cures, then there's going to be more pressure to figure out as individuals living with disabilities, as people who may be proud of their disability, do we have a right to remain people with disabilities when there is a cure that might be available. That is something that we as a population, as a diversity group, we're going to have to figure out. Are we allowed to be who we are, or is that against every medical belief and against the betterment of society, which I would disagree with?

We're also looking at - I mentioned it briefly - the difference between disability and suffering. It's often considered synonymous and it's not. I do believe that there should be eradication of suffering, but often those are created by the situations around us, by our environment, and not necessarily at all by our disability. And so when we're talking about anything from treatment to curing disability to potentially physician assisted suicide, we're taking a route that assumes that disability is the worst outcome, that we need to pursue any treatment possible to get rid of disability, instead of looking at environmental changes, medication changes that could improve or get rid of the suffering aspect of our lives. Most of the time for me, my suffering comes from a lack of access, a lack of adequate support, not from my ventilator or wheelchair. And so I think that we, within the health care realm, need to start thinking about what does it mean to live well with a disability.

Under the field of health care ethics, we talk about the top principles of dignity, autonomy, beneficence, non-maleficence, which I don't know if you guys are interested in the Disney movies, but they have Maleficent. As a health care ethicist, I really want to wear her horns and get like a big circle with a line through it and just hold her around me for Halloween. But there's very few people that would give that up. Forget it. Anyhow, I'm a nerd. But I think we're forgetting that the primary principles of ethics are dignity, beneficence, autonomy. We're assuming that it is eradicating conditions. When you're looking at a person with a disability and protecting their ethical rights, although the rights are the same for people with or without disabilities, there has to be additional protections for those individuals, especially for people who might struggle with communication or problem solving or decision making. Those individuals are at a greater risk of having their rights not protected. That is where my heart is.

I'm going to jump over to Caleb to see who he's going to next.

>> CALEB BERKEMEIER: Yeah. Thanks, Josie. It's very important to return to those in a little bit.

Let's go to Jessica next. She is going to talk about disabled political and electoral activism.

>> JESSICA BEHHAN: Like Caleb said, my name is Jessica. I'm from an organization called the Pittsburgh Center for Autistic Advocacy. We're an organization that's entirely run by people on the autism spectrum, which means all of our staff and our bylaws say at least 50% of our board, but I think we're closer to like 80% of our board right now. The reason that myself and a friend of mine, Cori Frazer, founded this organization was because we saw that in the greater Pittsburgh area, and oftentimes in Pennsylvania at large, there were not autistic voices at the table when decisions were being made about us.

I do want to highlight a couple things today. Like Josie said, my background is in health care ethics, like Josie's is. My research has been about supported decision making in the context of health care for people with developmental and intellectual disabilities. I want to talk a little bit about one of the big controversies in Pennsylvania right now, which is the closure of two state centers for people with intellectual and developmental disabilities.

Part of why I want to talk about this is because I've also been one of the folks who has been union organizing at the University of Pittsburgh. There is this tension between folks who are union folks and people who are fighting for their rights to live in an integrated community setting because the jobs at a lot of these institutions are union jobs, whereas at private providers who provide most of home health care services, those aren't union jobs. The wages and the benefits just aren't as good. And so there is this inherent tension between the needs of workers and the right of people with disabilities to live in the community like anybody else.

And so one of the things that we have striven to do at the Pittsburgh Center is to ensure that folks are at the table when decisions are being made about them. I see myself as someone with a union organizing background who is also a person with a developmental disability as someone who is uniquely positioned

to bridge those gaps, to find ways to work in solidarity with the unions, but also to respect the rights of people with disabilities to live in the community. And so that's been kind of one way at the Pittsburgh Center that we've worked to highlight and lift up the voices of other folks with developmental and intellectual disabilities.

But like Caleb said, what I want to talk about today is the growing electoral activism in politics that's happening with people with disabilities. I did not think in my lifetime that I would see presidential candidates putting out disability policy platforms, that that would be something that not only they would do but that would get national news coverage. We've so often been lumped under health care policy as though the lives of people with disabilities are only about health care needs. But this cycle, we're seeing something exciting and different and I'm really happy about that. I think that speaks to where we're at as a disability activist movement. For so long, we've been working outside the system, whether that's climbing up the capital steps or chaining ourselves together in the rotunda.

I think it's interesting to me to watch the sort of inside/outside activism that disabled folks and movements have been able to do, kind of come of age a little bit as we hit, I think, ADA at 30. And so things that we're seeing, there have been for a long time organizations that are run by folks with disabilities that do some more conventional lobbying, I think, that the Autistic Self-Advocacy Network would be an example of an organization like that, though they certainly do work that is not conventional lobbying as well. But to see a presidential town hall on disability, to see disability policy plans introduced by I think at least - there are at least three presidential candidates, Kamala Harris, Pete Buttigieg - I said it right - and Julián Castro. There may be more. I know that Bernie Sanders and Elizabeth Warren have included disability rights within other policies that they have proposed. That's just really exciting. But we're also seeing the hiring of campaign workers with disabilities by presidential campaigns. As someone who has done some electoral and campaign work myself, and who knows a lot of folks with disabilities who do that work, it's exciting to see those organizers getting a national profile. I know at least, I think, Elizabeth Warren and Pete Buttigieg have hired campaign staff with disabilities. I think there may be others as well, but it's surprisingly hard to find that information. It's just what I know through being a person with a disability who has done some of this work.

We're also seeing a growing number of candidates and elected officials who have disabilities. When we're talking about folks being at the table where decisions are being made about them, it's no longer on the outside looking in. It's being the folks who sit at the table in the first place. I think as we're thinking about the ways in which activists with disabilities can make change, there are so many ways, but one of them is by running for office. The National Council on Independent Living has started to keep track a list of elected officials with disabilities, candidates with disabilities, and most recently has started to provide campaign training for folks with disabilities who are interested in running or working on campaigns as well. And so from my perspective as someone who is younger than the ADA and obviously does not remember a time without it, it's fascinating to see in my lifetime the change from growing up in the '90s when no one was really sure entirely what the ADA meant to now where we're still fighting all of those same old fights of not only how do we get into the building and then do we get to use the bathroom, but we're seeing new fights and new platforms and positions of leadership as well. As much as I'm frustrated that we're seeing the same fights of closing state centers, ensuring access and equity and all of those things, I think I have a lot of hope for what the future holds for people with disabilities. I'm excited that I get to be part of that.

>> CALEB BERKEMEIER: Thank you, Jessica.

And then lastly, we'll go to Marian. She is going to talk about the ADA and also some of her experiences recently overseas. Right?

>> MARIAN VESSELS: Well, it's a nice segue from what Jessica was just talking about.

I've spent much of my adult life working in disability issues, and the last 30-some-odd years working on the ADA issues. I thought as we're coming up to the 30th anniversary, to be able to reflect on, for me, and I think maybe for others in the room, there are a few that have been in the fight for a long time as well, to kind of reflect on where we've been and hopefully engage with you as to where we should be going and what battles are still left to fight. As somebody who was not born during the ADA generation, but can remember fighting for the ability to go to classes in college because they were inaccessible, and luckily there was a disabled student center that was the first in the country, or one of the firsts in the

country, that helped me do that. Reflecting back, we've come a long way.

I think one of the things that I wanted to highlight a little bit is some of our successes and some of our challenges. I think across the board, we have seen improvement. I think, if nothing else, when we leave today, I want people to feel very good about some of the issues that all of you have been involved with and your role in assuring that there have been and there continue to be incremental successes in what the ADA is. I remember sitting on the White House lawn watching the signing of the ADA, and Marsha and I don't know anybody else here. Okay. There are two of us. Marsha can reflect on hers as well. It was an incredible day. It was the largest gathering of people with disabilities in the country. There were people from literally all over the country with all different kinds of disabilities who had been involved in making sure that the ADA passed and believed passionately in it. It was a miserably hot day, but there was so much joy and enthusiasm. I really felt like it was the 4th of July for people with disabilities because it was really the beginning of our civil rights, because up until then, 504, a lot of other things really were not effective and really didn't live up to the expectation and the mandate that they had. I think most of us, hopefully more than most of us, realize that ADA, like any civil rights law, is a process. It's not a guarantee of rights, as we look back 30 years and know that we're not anywhere near where I would have hoped we would be in terms of that day thinking about all of the wonderful potential and promise that the ADA gave us at that moment. But it truly was the beginning of what we can look back with pride that has been a model throughout the world and people constantly look to as a potential for greater things for the inclusion of a variety of people with disabilities.

In the employment arena, employers are talking, for the most part, about providing reasonable accommodations. They're still not very good at it. They're still not very aggressive at it. But without the ADA, I'm convinced that we would not be having any discussion about it. Has it worked for many people? No. We look at our employment rates. They're still almost as bad as they were 30 years ago. Does that mean that the employment provisions were a failure? No. Not at all. But I think a lot of the measurements that we do are not capturing a lot of the people with disabilities that have gotten accommodations because they're not raising their hands and saying I have a disability, so they're being accommodated as a part of the routine process now. We're finding that still, consistently, people with severe

disabilities, people with intellectual disabilities, people on a variety of disability spectrums that may be harder to accommodate, they may not have had the ability to get into the workforce due to transportation, housing, resources available to get them into the workforce. But we are seeing that there are a lot of people with disabilities who continue to maintain in the workforce because of the provisions of the ADA.

Under state and local government, all of the services the state and local government provide, and there are many, things like transportation, education, voting, making sure that our voting places are accessible so our voices are heard and we can support candidates with disabilities getting out there, our social services, parks and recreation, all the programs that are available, our streetscapes. We're seeing marginal and incremental successes in those areas. Transportation is a limited but kind of interesting success story in that almost all busses in the U.S. are now accessible for people with disabilities on the whole. The problem is ramps don't work, training is nonexistent on how to use them, how to maintain good customer services, how to call out stops for people with visual disabilities, and how to holistically look at people with disabilities who need transportation. The limitations of three-quarters of a mile, ability beyond fixed route is a real limitation for many people being able to use a bus system and be able to successfully get not only to work and education but social and religious opportunities, shopping, et cetera. We have a long way to go in state and local government, but we are making progress there. Many programs are now accessible. They're looking at providing interpreters. More and more, you see interpreters at any national disaster, local disaster. They don't do a good job of focusing in on those when they're doing the television at the local, but they're having them there. It's a start.

Public accommodations. We continue to see that businesses, if they feel it's in their best interest, are including people with disabilities. People who have been sued are now providing more accommodations to people with disabilities and allowing them. We're seeing more activism in the communities in assuring that people with disabilities are getting into, getting up that step, or getting over that threshold and that barrier to get in and purchase goods and services and to participate in the mainstream. But we have a tremendously long way to go before people are fully included. Telecommunications. Thirty years ago, the advent of a relay system that was free to everyone was a huge accessibility feature for folks who are deaf and have

hearing disabilities and communication disabilities to allow them for the first time to actually call and get that pizza or change a doctor's appointment. It still has relevance, although much more minimal today, because we have other forms of technology that allow people to do that. But there still are complex issues that people still feel they would like to do that one-on-one communication. Even the relay continues to be somewhat relevant today as one of the issues around telecommunications.

Where do we go from here? We have tremendous challenges, in my opinion, in assuring that there is full inclusion of people with disabilities. We have a huge still lack of awareness. There are still businesses that I talk to that said, ADA, you mean I have to do this? I'm stunned after all of these years that they are still genuinely unaware and have actually, upon education, have been willing to make some changes. Did not know. That scares me that after all these years of a mandate that seems to be in the public eye constantly, people don't know about it. We have large groups of people who still don't know they are covered under the ADA. We have veterans who don't know they have a disability even though they have a significant disability. They consider themselves veterans and not people with disabilities and not taking advantage of the rights and responsibilities under the ADA. We've got folks who are recovering alcoholics and drug addiction who are covered under the ADA and have no idea that those are covered disabilities and could be taking advantage of them to be able to get back into the mainstream, get back into employment. IT is a huge, huge issue. Most websites are not accessible. Many technologies were never designed for the inclusion of people with disabilities to allow them into the marketplace and into the workplace and into the information stream. Many, many people are excluded from what is considered to be mainstream access this day and age. The web is a huge long way before we ever get to even minimal access for many, many people.

I had the unique opportunity about a month ago to be in Zurich and Vienna and traveling around the city and was really dismayed to see how in a very liberal country, in very expensive cities with well-funded government, there was little that was made accessible for people with disabilities. There seemed to be no concern in general for people with disabilities. The museums, the trains, the cultural opportunities all had discounts for people with disabilities, which was wonderful. It allowed people to participate and such. They actually let attendants go free. There were some interesting concepts there if you could get

there. If you could make it to that door, they were going to let you in and you wouldn't have to pay. That just doesn't make sense to me. I mean, quite honestly, I took advantage of all the opportunities because it was very expensive to be there. I didn't say, thank you, no. I said thank you very much and I appreciate the consideration. But there was nothing on the streets that allowed people to do it. Their train system is minimally accessible. They are moving toward it. We are so much further ahead. I have not been asked or heard the comments so often as I did on this last trip, what does she want to eat? What does she need? Here in the U.S., actually, I have to admit, two weeks ago someone did that to me and it was the first time I'd heard it here in a very, very long time. We did a little education. That person will never do it again. But very kindly. But I have never consistently person after person. There was obviously not an expectation that people with disabilities are out and about and would be able to conduct their own affairs.

As challenging as the ADA is today, I think we have a lot going for us. It is our mandate, all of our mandate, to assure that the ADA stays strong, viable, continues to grow and be updated, and to prevent it from being nonexistent in the future.

>> CALEB BERKEMEIER: Okay. Thank you, Marian.

>> 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.