

FHEO Table Talks Series: Changing Perceptions to Change Lives: Disability Rights and the Barriers that Still Exist

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Speakers: **Dr. Sachin Pavithran**, Executive Director of the U.S. Access Board; **Jennifer Mathis**, Deputy Legal Director and Director of Policy and Legal Advocacy at the Bazelon Center for Mental Health Law

James M. Roberts: Hello, welcome to another episode of FHEO table talk series. I'm your host, James M. Roberts. In July 2021, we celebrated the 31st anniversary of the signing of the Americans with Disabilities Act, or the ADA. And this month on September 26 we commemorate over 40 years since the enactment of Section 504 of the Rehabilitation Act of 1973, which was one of the first federal civil rights laws that provided protection for people with disabilities. With more than 40 years of progress to improve disabilities rights, there is still a lot of work to be done to remove the barriers that still exist. Today I am talking with individuals that actively advance important issues related to disability rights, accessibility, and civil rights. Joining me for this table talk is Dr. Sachin Dev Pavithran, the Executive Director of the U.S. Access Board. Welcome Dr. Sachin Pavithran and thank you for participating on the panel. I want to also welcome Jennifer Mathis, Deputy Legal Director and Director of Policy and Legal Advocacy at the Bazelon Center for Mental Health Law. We're glad you both are contributing to today's table talks discussion.

Let's jump right into the questions. This first question is for the panel. How does the work you do relate to the Americans with Disabilities Act, the Fair Housing Act, and other disability rights laws? I'll start with you, Dr. Sachin Pavithran.

Dr. Sachin Pavithran: Thank you, James, and thanks for inviting me to be part of this conversation which is an important conversation to have. So under the Americans with Disabilities Act, the access board we set the minimum guidelines for facilities, for transportation, and buildings. We also provide technical assistance and training on how to best implement these guidelines. We also provide guidelines on the Americans, sorry, the Architectural Barriers Act, which is one of the first piece of legislation that was passed that addresses accessibility.

The difference between the A.B.A. which is the Architectural Barriers Act and the A.D.A. which is the Americans with disabilities act, is the A.D.A., which is often confused by most people, only applies to federal buildings. So the U.S. access board, we set guideline for the Architectural Barriers Act but we also enforce the A.D.A., so if we receive any complaints from any individual about any federal facilities whether it's federal buildings, national parks or any area that federal dollars flows through, we enforce those standards. But we also provide technical assistance and training as well for the A.B.A. as well. Along with that, the Relocation Act, we provide training and set standards for section 508, which is pretty well known for the web accessibility side of things, the information technology component. Then as of late we've been providing guidelines for the medical diagnostic equipment, which is under the section 510 of the rehabilitation act. So, there's a lot of different areas we focus on. We set standards and guidelines that have direct impact for people with disabilities.

James M. Roberts: excellent. It's evident, Dr. Pavithran, the work that you do impacts many lives here in America. Jennifer, please tell us how the work that you do relates to the A.D.A., the Fair Housing Act, and other disability rights laws.

Jennifer Mathis: Nearly all of what the Bazelon Center and I do is closely tied to the A.D.A. and other Disability rights laws. Most of the Bazelon Center litigation involves claims under the A.D.A. and section 504, sometimes also under the Fair Housing Act. But challenging discrimination based on disability is really at the core of our work, whether it's about health care or education, employment, community living, voting, parental rights, or other areas. Most of our litigation seeks to challenge how public service systems operate in discriminatory ways, for example, we fought many cases seeking to have systems stop overlying on institutional care and instead offer opportunities for people with disabilities to receive services in their own homes and communities. We've also brought a lot of litigation seeking to have school systems provide an equal education to children with disabilities. Some of those use the I.D.E.A., Individuals with Disabilities Education Act, but many also have claims under the A.D.A. Our policy advocacy also advances the A.D.A. and the other disability rights laws, some of that work involves trying to secure regulations, guidance, other statements of the law from federal agencies that flesh out the laws applications to different areas and clarify people's rights under those areas. Often we also seek to have congress pass laws that advance compliance with A.D.A. and the other nondiscrimination laws. For example, we might ask congress to enact changes in Medicaid programs that encourage states to adopt and expand their own community-based services in order to expand opportunities for people with disabilities to live in their own homes and promote compliance with the A.D.A.'s integration mandate. So those are some of the ways that our litigation as well as our policy work really revolve around these disability discrimination laws.

James M. Roberts: It's encouraging to hear how the work that you all do relates to various disability rights laws and also continues to move disability rights to the forefront. As I mentioned, it has been 31 years since the A.D.A. was passed, and in more than 40 years for the section 504 rehabilitation Act. Throughout the years there have been other disability and civil rights laws that have expanded upon many of the provisions of the A.D.A. and section 504. Dr. Pavithran, this next question is for you. What advancements have you seen throughout your career?

Dr. Sachin Pavithran: Since the A.D.A. and other legislation that has been passed, you know, obviously a lot of accessibility improvements have come into place. There's been a lot of attention given to what accessibility should look like, whether it's a building, whether it's transportation, whether it's websites. All those areas have been given lots of attention. But one thing that we've learned over the years of doing accessibility is if you don't define what accessibility it should look like, people really don't understand what is good accessible product, what the end result should look like. Because if you don't define accessibility, everyone is going to do it their own way thinking this is what accessibility should be. So when we work on our standards, when we work on our guides, we make it very clear when we say accessible buildings, when we say accessible pathways, accessible buses, there's a certain threshold it needs to meet. Now, everyone can go above and beyond what the minimum standards we set. But if, in order to meet the minimum standard we define, this is what is accessibility look likes. Early in the years when engineers and other designers when they're working on products or buildings or building different parts, whether it, whatever it might be, the question was always "why do we need to do this?" Because an understanding of what is inclusion, accessibility was not really understood by a lot of these designers because they didn't see the value of creating a fully inclusive environment for everyone. Always the price tag was the biggest, the bigger conversation and also the conversation around, "does it really make a difference?" But with all the training, technical assistance, not just the Access Board, many entities have been providing around accessibility, it has changed the mindset of the importance of full community inclusion. I'm not saying we're there where we need to be, I think there's still a long ways to go. But there is dialogue happening where people are more engaged in the conversation and willing to

be more inclusive and create accessible products. We still have a long ways to go. There are still barriers that exist. But from the early 90's through now, there has been significant improvements. Hopefully, we passed 31 years since the ADA passed, hopefully by the next 31st anniversary, accessibility becomes not a conversation that happens on the side but it's something that's baked into everything that we design.

James M. Roberts: I completely agree. We need to continue to build inclusive communities, hopefully we'll continue to see more advancements being made as we move forward. Jennifer, can you tell us what advancements you have seen throughout your career?

Jennifer Mathis: Sure. So, I would say one advancement, I think that has been really significant, is the evolution of the A.D.A.'s integration mandate and how service systems have responded to that in terms of how they serve people with disabilities. So when I came to the Bazelon Center in 1999, the Supreme Court had just agreed to hear the Olmsted case, I spent the first six months of my time here working on the briefing in that case. And then I've spent 22 years after that working on community integration work and watching attitudes slowly evolve as the law evolved. And at the time that the court was hearing Olmsted, the conversation was really about institution bad, community good. As the law and policy have evolved there has been a lot more opportunity to focus on what does the community look like. What is true integration. People have also begun to apply the integration mandate to all kinds of service systems, including employment services, educational services, and criminal justice systems, especially as those relate to mental health service systems. There's still obviously a long way to go in shifting how disability service systems operate, but the law is often an important way to shift attitudes. And another big shift that I saw, this is from a legal frame or legal rights frame, was the passage of the A.D.A. amendments act, or the A.D.A.'s child in a way. Because of some problematic Supreme Court decisions, lower court decisions, interpreting those, the law had really gotten to a point where so many people with disabilities who congress had intended to protect under the A.D.A. were no longer considered protected by the law. And so for people with diabetes, epilepsy and to some extent people with psychiatric disabilities and others, the A.D.A. had become at least in employment cases almost a dead letter. There was a massive undertaking to go back to congress to say fix this problem, this was not what you intended, and that involved intensive negotiations with business community for many months and a joint effort with them to secure passage of an amendment to the A.D.A. And that really restored congress' intent to have the A.D.A. apply broadly to all people with disabilities.

And then finally one other thing that I would highlight, as a big shift or advancement that I've seen over time, is that I would say for lots of reasons people with disabilities are increasingly recognized as a voting block and as a political force. And we have now begun to see more attention, I would say not enough, but a lot more attention paid to disability issues in political campaigns and particularly presidential campaigns. And I think that tells us that we are starting to be heard.

James M. Roberts: I couldn't agree more, Jennifer. I also believe the advancements in disability rights laws throughout the years have improved the daily lives of so many people with disabilities. However, many people with disabilities are discriminated against because of their disability. The misconceptions that some may have about those with physical and/or mental health disabilities can detrimentally impact lives.

Jennifer, this next question is for you. In what ways do public knowledge and attitudes affect where and how people with mental health disabilities live?

Jennifer Mathis: Sure. So public attitudes play an enormous role in what the lives of people with disabilities look like and where they live. And frankly, part of the reason we have civil rights laws is to limit how those attitudes have sometimes adversely affected the lives of people with disabilities, including people with mental health disabilities. I would say the law affects public attitudes, and public attitudes also affect how the law is implemented and whether it is implemented. And one way that happens is those attitudes have often resulted in the needless segregation of people with mental health disabilities. And even when there has been litigation to enforce the ADA's integration mandate, to enforce the Fair Housing Act, attitudes about where people with mental health disabilities should live and how they should live are so deeply engrained at every level of service system that even when you have states entering settlement agreements to change practices, change how things are done, it's often a challenge to shift the way that people think about and what they know about who can live in their own place, with supports. When service systems have operated for decades and decades by serving people with mental health disabilities in large congregate settings, then the people who assess their needs, the people who serve them, the people who run the systems often tend to think this is where they belong because that's how it's always worked and that's what we know. And it's really hard to get people to think outside of that box. And in addition to that, there's also another layer, there's widespread discrimination against people with disabilities, in housing. And HUD did a study a few years ago finding that people with mental health disability as well as intellectual disabilities routinely face discrimination by landlords, housing providers, and that, I think on top of all the service system issues that we face, really creates a lot of challenges in ensuring that people with mental health disabilities have the opportunities to live in mainstream housing, in their own communities, regular buildings, just like everybody else.

James M. Roberts: Yes, we definitely need to continue to keep changing perceptions. Thank you, Jennifer. Discrimination definitely does affect someone's life in many ways. Having access to fair housing plays a large part in being able to live independently for people with disabilities. I am in total agreement that we must eradicate any misconceptions about those who have a physical or mental disability. Having access to safe and affordable housing plays an integral role in living independently for people with physical and/or mental health disabilities.

Jennifer, this next question is for you. What changes are needed when it comes to housing for people with mental health disabilities who need services and supports? And, could you discuss the type of services and supports that people with mental health disabilities may need to live independently?

Jennifer Mathis: Sure. So I would say that certainly one of the biggest changes we need is more housing subsidies. We don't have enough subsidies to make housing affordable for so many people with disabilities. And as you know, disabilities often for many reasons associated with lower incomes and poverty because of discrimination. So many people with disabilities, particularly mental health disabilities, are stuck in congregate care settings that serve them poorly and deprive them of choice and autonomy in daily aspects of life, primarily because these are the only housing options available to them, either because of the insufficiency of the housing that's available to them or because of the insufficiency of community-based services. So, the lack of affordable housing has increasingly, I would say, become the biggest barrier to community living. Some states have their own rental subsidy programs, that can be used for people with disabilities. Sometimes they are targeted specifically to people with disabilities, sometimes they are broader. But either way, those are never big enough to meet the need. Most states rely primarily on federal housing subsidy programs, which are incredibly helpful, incredibly important, but also meet only a small fraction of need for affordable housing. So that's certainly one huge need.

And then secondly, we need more and better community-based services. You asked about the types of community-based services that people with mental health disabilities will often need, and I would say those include supported housing, which is a rental subsidy, essentially, a place to live, a house or apartment, in a regular building, not a special building for special people. And an individualized set of supports that are typically provided by Medicaid. For example, people often need a case manager to help ensure that their needs are being met and that the person is getting the services he or she needs, help with housing-related needs. So, for example, help finding housing that the person wants and securing it, and keeping that housing, making sure that people aren't evicted, that they can work out problems with landlords that may come up. People often need supportive employment services, which help people find jobs, identify what kinds of employment works for them, and that they want to do, and keeping jobs. And another really important thing I think increasingly recognized by states and covered by Medicaid is peer support services. Services provided by people with lived experience in mental health service systems who can say 'I've been in your shoes, I've done this, you can do it', and help people navigate, and help educate people. And help people really advocate for themselves. And mobile crisis services. Mobile crisis services are often necessary, if somebody has a crisis, particularly at off hours, having somebody come with a mobile team, often just a mental health clinician or peer support worker, sometimes there's a medic or something, sometimes there's not. But to help someone deescalate in a crisis situation. Those are some of the core services that people need. And sometimes, for people who need a lot of help, they may have a mobile team, a community support team, or sometimes an ACT team – assertive community treatment team – that offers really all of these services that are combined and provided by a team that's closely coordinating with each other. So, there will be a housing specialist, an unemployment specialist, a case manager, and peer support worker, and somebody to ensure that person can get their medical needs met. And all of those people are closely coordinated. That's what it often looks like, that sort of range of services for people who need services and supports.

And I guess I would say, lastly, the other thing that really needs to happen aside from more housing subsidies to make housing more affordable and more and better services, is just more aggressive and widespread enforcement of the disability rights laws, including the A.D.A. and the Fair Housing Act.

James M. Roberts: Thank you, Jennifer, for your response. HUD has been a leader in the enforcement of the Fair Housing Act and uniform accessibility standards that ensures people with disabilities are provided reasonable accommodations necessary for independent living. We are committed to making the needed changes to support those with mental health disabilities.

Earlier on in the show, I mentioned there have been other disability and civil rights laws that have also ensured access for people with disabilities. One of those laws is the Architectural Barriers Act of 1968. Dr. Pavithran, this next question is for you. At the access board, you enforce the Architectural Barriers Act. What does the act cover and what is your enforcement mechanisms?

Dr. Sachin Pavithran: So, the Architectural Barriers Act, as you said, as I stated earlier, is one of the oldest acts that addresses accessibility. Passed in 1968, it covers any facilities including housing, the design... built, altered, and if any alteration is done when the housing facility is being designed or built, or any federal building which is leased or owned by the federal government, if there's any federal dollars flowing into these areas, the Architectural Barriers Act will cover that. What the act says is that it needs to be accessibility to these facilities, there should not be any physical barriers when accessing any of these facilities or buildings or housing that the federal dollars have flowed through. So, we do enforce the A.B.A., and the way that works is any individual that sees a physical barrier in any of these federal

facilities, they can file a complaint to complain with us, using our online complaint form. And once we receive that complaint, we verify whether the complaint falls under the A.B.A. Often there's confusion whether it falls under the A.B.A. or the A.D.A. So we verify to make sure this is appropriately falls under the jurisdiction of the A.B.A. Once that part is done, we contact the entity that has the accessibility barrier and try to have corrective action to remove the barrier. It's a process that does take time at times, but it is very important piece of legislation that people need to be aware of because our federal government has accountability on accessibility. All our federal facilities need to be accessible. Not saying all our federal spaces are accessible, but there is ways to make sure those facilities are accessible by enforcement. So, I encourage anyone who comes across federal spaces that are not accessible, to contact us so we can rectify and make sure those barriers are removed.

James M. Roberts: Thank you. The access board is making a difference in providing inclusivity and accessibility for all. There have been many advancements in modern technology that are being used to help people with disabilities thrive, in the home and in their public lives, and most importantly in the workplace. For instance, there is the G.P.S. that leads the blind, cochlear implants for hearing, and a phone for people with auditory impairments. Dr. Pavithran, this next question is for you. How are new technologies impacting access for people with disabilities?

Dr. Sachin Pavithran: The advancement in technology has made a significant difference in the lives of people with disabilities. As a blind person myself, I rely on my technology for various functions, not just for professional but also in my personal life. Earlier in the days when technologies were being developed or designed, it used to be specialized for the person with the disability. So, for a blind person they used to have specialized equipment, specialized software that was built on, built to be used with a unique device that's only designed for that population. Which was good, which was nice to have because it gave us technology that we could use in different settings. But the problem was it was very expensive. For example, an example of technology I used to own, which is called a braille mill, it's a braille display I can also take notes on. It's a basic device I can take notes on that has an operating system, but it costs me over \$6,000. No special features other than note taking. With advancement in technology and using mainstream technologies like Apple devices, android devices, that conversation has significantly changed because the mobile platform has opened doors for people with disabilities to have access to technology within the mainstream space. So, the technology that used to be developed, specialized for people with disabilities, now you're finding those transitioning into app forms, so you can download an app that you can just download to your smart phone, your tablet, whatever product you're using, and be able to be independent by using the technology. The reason that's important is, the price and affordability. Another device, to give an example. Back in the day if I wanted to get a money identifier, so something that helps me identify the bills that I have, the dollars I have in my wallet, the piece of technology was probably in the \$200 range. Now I can get an app that's just a few dollars that not just identify the U.S. dollars but several other currencies, 30, 40 other currencies. And I paid probably \$2 for the app. So, a huge difference. And I don't even need to carry a separate device with me, it's all on my phone. So just a few different examples how technology has evolved, and especially using the mainstream technology like products put out by Apple, Google, Microsoft, using that technology and embedding accessibility into it makes a significant difference. Screen reading software, for example, what I use as a blind person, if I buy a Mac it comes built in, I can use it right out of the box, I don't need to pay hundreds of dollars to use it. I turn on my Apple tv, I have a voiceover, I can use it right away. So, of all this is different devices, communication devices used to be significantly expensive. Now, there still are those special... but you can get apps which are significantly cheaper, download to your tablet and children can use those devices in the classroom or wherever they might be using it. So that's where the technology has changed. It's improved in what it can do, but it also has made it significantly more

affordable for most individuals, which was hard to come by because several thousand dollars for a small piece of technology, not everyone can get it. And not everyone can use it in different settings.

But technology is not the only solution. Technology is great to have, but we also need to think about accessible, when we think about accessibility we need to make sure everything is designed with accessibility so technology is not the way we accomplish accessibility, technology is just another tool to do the work. But it's not a solution for the accessibility. Accessibility is something that we need to really engrave into how we design products and how we think about what and why it should look like for everyone, not just people with disabilities.

James M. Roberts: Thank you for your response on that, too. Technology can definitely lower barriers that people with disabilities encounter in their daily lives. I look forward to seeing how modern technology will continue to allow them to participate and enjoy the benefits of the digital society. My final question is for both Dr Pavithran and Jennifer. As we look forward, what do you believe is the best way we can make a substantial difference in access for individuals with disabilities and build on the foundation that currently exists? We'll start with you, Jennifer.

Jennifer Mathis: So, I would say shifting public attitudes is key. So much of the exclusion and unequal treatment of people with disabilities happens because either there are unfounded assumptions that they are not capable, or because of what the Supreme Court once called benign neglect. Not thinking about the impact of certain policies, practices, on people with disabilities. For example, building inaccessible buildings or creating inaccessible websites. I am not a big believer in what in the mental health world are often called anti-stigma campaigns. These campaigns try to persuade people to treat people with disabilities better or see them in a better light, they generally have not been that effective. Other types of public advocacy are important, and I do think that, for example, drawing public attention to people with disabilities as being in the same roles as everybody else, is key. But I guess I believe at heart that enforcing the civil rights laws is often the best way to start that happening. And attitudes start shifting when people realize that people with disabilities are their coworkers, their employers, their neighbors, their family members, their leaders, and that they're as capable as anybody else. Maybe more capable in many cases. So, I think you can't legislate or litigate your way, all the way to full and fair and equal access in all walks of life. But I do think the civil rights laws are one of the most powerful tools we have to get people with disabilities access to all the things we take for granted. And having people with disabilities in visible roles when they have access is the key to shifting attitudes that keep them back, that result in building those inaccessible buildings and sidewalks and fears of having people with disabilities as employees and tenants and neighbors and students.

James M. Roberts: I agree, Jennifer. More focus should be placed on the initiatives that grass roots organizations or other partnering agencies have committed to furthering through communication and cross collaboration. Dr. Pavithran, please share with us your thoughts on this.

Dr. Sachin Pavithran: I agree with what was just said. I also think we need to continue to push accessibility as a priority in policies and in designs, and in education also. Where at universities and other areas where we are talking about design, accessibility needs to be part of the conversation, it needs to be embedded into the culture. There needs to be a culture shift on how people think about design. Until there is a change in how people embrace inclusion, and especially full community inclusion, there's always going to be this conversation about accessibility and how to make things accessible. We are not going to get to a point where full community inclusion becomes the norm until the culture embraces that whole concept. So, we need to continue to keep pushing good policies and practice that

embraces and embeds accessibility into it. But we also need to have the right tools for all the entities that's working on designs, whether it's architects, engineers, whether it's educators, they also need to have the right tools so they know what good accessibility looks like and they understand what needs to go into designing good products.

Technology is continuing to change, there's new trends always in technology, there's new ideas coming up. There's conversations around what transportation looks like, for example, autonomous vehicles, it's a big topic of conversation, what does that mean for people with disabilities. Transportation is always a big barrier for people with disabilities. People with disabilities choose where to live because transportation is always the biggest concern. So, what does that mean for accessibility and design? We need to really be on top of those conversations, we need to be at the table where these new trends are popping up. And also when it comes to housing, when a house is being built, one of the architects, one of those different groups working on the design for building new houses and homes that individuals are moving into, what design standards are being followed that have accessibility in mind. So, the conversation needs to continue, the conversation is important, and the conversation will only be successful if there's a cultural shift. And we need to continue to push for that culture shift so that accessibility becomes embedded into everything that we do.

James M. Roberts: I whole heartedly agree with you, Dr. Pavithran, on that. This is an important issue that we all should be aware of. And work towards implementing. Your words are very inspirational, and I think I speak for everyone that we all play a very important role in making a more accessible and inclusive world for all. I want to thank each of the panelists for sharing their perspectives on the progress that disability rights laws have made. Remember, everyone has the right to fair housing and we can all do our part in changing perceptions to change lives. This concludes our program. Until the next FHEO table talk, take care, everyone.