Disability Visibility Podcast

Episode 18: Accessibility and the ADA

Guests: Lia Seth and Dara Baldwin

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the Disability Visibility Podcast with your host, Alice Wong.

ALICE WONG: Heyyyyy, this is the Disability Visibility Podcast, conversations on disability politics, culture, and media. I'm your host, Alice Wong. Today's episode is about accessibility with my two guests Lia Seth and Dara Baldwin. You'll first hear Lia's experiences navigating public spaces in the San Francisco Bay Area as a person with an invisible disability and a specific instance with a business where accessibility and customer service went hand-in-hand. Next, Dara, a policy analyst, will tell us about the latest threat to accessibility and disability rights: A bill called the ADA Education and Reform Act of 2017. Dara shares what's at stake with this bill and what we can do to oppose it. Are you ready? Away we go!

[electronic beeping]

ELECTRONIC VOICE: 5, 4, 3, 2, 1.

Introduction to Lia's interview

ALICE: So, Lia, thank you so much for joining with me on the podcast today. Why don't you tell me a little bit about yourself, if you don't mind?

LIA SETH: Definitely, thanks. And again, I'm really glad to be on the podcast. I'm excited that you asked me to be here.

So, my name is Lia Seth. I work in Human Resources in the Bay Area. I've been disabled my whole life but really only realized and adopted that identity when I was around 20 or 21. The symptoms and the pain started early in high school, but I didn't have a name for it, didn't know that anything was wrong until much later, after college. I was really lucky to be introduced to the online disabled community through Tumblr and to find all these disabled and otherwise marginalized individuals like me in the last five or six years to relate to and learn from. And since meeting these people and being surrounded by them, my goal has always been education and awareness, especially for people like me with invisible disabilities.

Physical and social accessibility and barriers

ALICE: That's awesome. So, I guess, since the topic today is about accessibility, do you mind kind of describing some of what your experiences are like in terms of navigating spaces, whether it's physical or social? And just any kind of barriers you might've encountered as you just go about your daily life.

LIA: Sure. Well, I mean, as you said, there's physical barriers, and there's social barriers, you know. As someone who is generally invisibly disabled, but I do have a wheelchair and a cane that I use on occasion on high-pain days, it really, it can change depending on what state I'm in and what mobility device I may be using or not using. I've had people stare at me in parking lots when I put up my tag and then walk out of my car. I've had people judge me for laughing too much when I'm in my wheelchair, as though disabled people can only ever be sad and angry. Or they can only be hopeful and inspiring. They seem to forget that there's in-betweens, that we're people with every range of emotions.

I've had people spit on me on public transportation for taking one of the blue seats.

ALICE: Oh, my goodness. Really?

LIA: Yes. That was one of the worst experiences. It was incredibly embarrassing. No one else on the bus said anything. No one talked to me. No one came to my defense. I think that day I ended up getting off the bus early and just waiting for a different bus just because I was so mortified.

[mellow guitar music]

And a couple of years after that, once I was taking the bus to work every week, I bought a cane, not because I needed the cane. In fact, it tends to get in the way when I'm walking. It's really difficult to walk with a cane when I don't need it. It's useful when I'm standing, kind of gives me more stability; it gives me kind of a tripod stance. But it gets in the way otherwise. But I bought that cane really to make the invisible disability visible when I'm in public. So, when I'm on public transit, if I get on a bus with a cane, people are more likely to give me their seat than if I just get on looking perfectly healthy, because this is apparently not what disability looks like to most people.

ALICE: And that's really messed up, don't you think? It's like, there isn't enough understanding or at least flexibility in people's understanding of disability is not static, it's not always apparent, and the fact that people harass and humiliate you and making you kind of have this outward signifier is pretty horrible.

LIA: Definitely.

Experiences with advocating for accessibility

ALICE: Do you mind sharing some experiences you've had let's say, in public or let's say, at a restaurant or some sort of place where you had to request or advocate for accessibility and some examples of things that worked out fantastically or other things that were not so positive?

LIA: Sure. I mean, I've had good and bad experiences. When I first got my wheelchair in 2013, I got it anticipating that I would be able to use it on my high-pain days. I wasn't planning on using it every day. I didn't think I would be a full-time wheelchair user.

There was one time I was going out to see a comedy show, and I didn't want to drive because I knew parking was gonna be hard in that neighborhood. So, I tried to request a Lyft, but I wanted to take my wheelchair to the comedy club. And at the time, there was no way to request a car that I could guarantee would have room for my chair in the trunk or anything. So, I tried to call for a standard taxi cab, but I found out that there were only three accessible taxi cabs across all of San Francisco on a Saturday night. So, I had to just test my luck, get a regular taxi cab, and hope that if they have space for a suitcase, they would have space for a wheelchair. And I did get lucky. But that was kind of frustrating.

But on the other hand, that same night, I had called the comedy club ahead of time, and they were great. They had put a reserved sign on two folding chairs, moved one out of the way when I arrived. They shook my hand when I arrived, treated me like a person. They were really communicative. They were just really thoughtful about the way they treated me. So, I mean, you can have a good and bad experience back to back like that.

[mellow guitar music]

The toll of laboring for accessibility

ALICE: And all of this, I think what is, not just as a person with an invisible disability, but there's so much invisible labor that people with disabilities have to do just to do the same things that our non-disabled counterparts do. Can you talk a little bit about the toll of all this labor that you do every day that most people either take for granted or just have absolutely no clue that all the effort it took just for you to get to that venue?

LIA: Yeah. I mean, I have to plan ahead. Luckily, planning does come pretty easily to me, but I really have to plan ahead. If I'm gonna be going out, I need to say, OK, what is this venue? Let me look up reviews and see what people have said about the venue. Let me look up pictures. Is the bathroom down a narrow hallway? I'm gonna have to call and hope that I get someone who's understanding or hope that I get someone on the phone at all who can tell me about their accessibility options and what I can expect. I have to then think about things like, OK, what am I gonna wear that's gonna be the most comfortable? What's the weather that day? If I'm going to a concert or a show or something that's really high energy, what am I doing in the days leading up to that, to make sure that I'm preserving energy but also not using no energy? Because with my condition, my muscles can atrophy really fast. So, staying too stationary is also not great for me. So, there's a ton of planning that goes into it, and it's really hard for anyone who doesn't have a condition like this to even fathom the level of planning that goes into doing anything.

ALICE: And I don't know about you, but sometimes, I mentally have to prepare for expecting a sub-par experience so that when people do treat me with respect and like a person, it's such a refreshing thing, even though that should be the norm. Do you find that most of the times you've had pretty decent experiences accessing with a disability? Or do you feel like it's very random?

LIA: Frankly, I think I tend to go in with a negative view a lot of the times. I tend to assume I'm not gonna get help. I tend to assume that people are going to be judgmental. Or they'll me that everything will be fine, and I'll show up, and no one will know what I'm talking about. So, I tend to be kind of negative. But I've been really lucky with the last couple of times that I've called venues to ask about their accessibility, I've had some really great accessibility experiences just in the last year.

Just in the last two or three months, I've gone to two concerts where the venue had pre-thought about accessibility. They were willing to work with me to make sure that I had a good time at a show instead of just telling me how I was allowed to act or where I was allowed to be. One of those was at a small venue in Berkeley where just at this venue, by asking questions, every single person we talked to was helpful. The person working at the ticket desk gave us the names of everyone who would be on staff that night and then alerted those people that I would be there and would need some accessibility help. There were chairs just at the side of the venue, and I asked—because again, it doesn't hurt to ask— "Hey, can I just take this chair and drag it right to the floor of the stage," so I basically kind of create my own front row where I'm sitting, and then everyone's just standing behind me. And the bartender and the bouncers were not only on board with that, but they said, "Hey, if you have a problem, if someone's giving you a problem about this, if someone's getting in your way, come find us or send someone to come find us. And we will personally talk to them and tell them they can't get in your way." And that was outstanding to me, that I was treated in such a way that was just respectful, and I was able to have such a great time.

And yeah, on one hand, that's something really amazing, and I wanted to celebrate that. But on the other hand, it's a little frustrating that that's not the norm.

Shout-out to Cornerstone in Berkeley for their positive attitude in providing access

ALICE: And if it's OK, I mean, maybe we can just give them a shout-out. Because the venue that you went to is called Cornerstone Berkeley?

LIA: Yeah. So, it was the Cornerstone music venue in Berkeley. I went to a show there in September. The entire staff was amazing, and I would love to give a shout-out. So, it was Jenny, who was at the box office. She asked what I needed. She didn't ask any insulting questions. She just asked, "What do you need? What can we do for you?" Cory was also at the box office. He promised that the staff would take care of us. He promised that I'd have seating with a clear view of the stage. And I know that there's some venues where clear view of the stage can mean, "Well, it's clear if no one's standing in front of you."

ALICE: Mmhmm.

LIA: "But otherwise, tough luck." And the last person was TJ, who was the bouncer at Cornerstone, who was the one who was saying, "Anyone gives you problems, you come straight to me." And at the end of the night, TJ came and found me, and he said, "Did you have fun," high-fived me. He was super on my side, and that felt amazing. And that really should be the norm for anyone working with any customers because you don't always know who's disabled. You don't always know who needs help. So, it doesn't hurt to treat people as humans.

ALICE: And you wrote about this experience with this venue in October of 2017 in a piece you wrote called "Accessibility and the Kids Who Go to Shows." When I read that piece, I knew I immediately wanted to interview you about this subject. And I think, if you don't mind, I'm gonna read a quote from you. You wrote something that I just loved.

LIA: Sure.

ALICE: So, you said, "Accessibility is more than ramps and parking spots; accessibility is also about basic human decency that goes beyond the law—the kind that the staff at Cornerstone showed to me, and then kind that allowed me to have one of the greatest concert-going experiences of my life. Accessibility is about *people*."

So, you know, I think most people often have a very narrow idea of what accessibility is. What are your thoughts about what accessibility, what do you want it to be, from people who don't, who maybe kind of completely listening to this podcast and not really knowing much about accessibility? What do you wanna share to folks?

LIA: Sure. I mean, again, it's really, it's beyond compliance, it's beyond enforcement of ramps, parking spaces, elevators, image descriptions, audio captions: That should all be standard by now, and it's still not, which is a problem. But accessibility's also about human connections. It's about not othering disabled people. It’s about not making us jump through hoops to get what we need out of the world. It’s, again, asking those questions without being insulting. Finding out what we actually need, rather than trying to make those decisions for us.

And it’s, you know, we spend a lot of time and energy, like I said, thinking ahead and pre-planning. So, a great thing a venue can do is to do some of that pre-planning for us. Have accessibility information up on your website. Have an accessibility specialist, if you’re able to. I went to a concert just a couple of weeks ago where, again, I called the venue and said, “I wanna ask about accessible seating.” And they said, “We’re gonna transfer you to our accessibility person.” And they had someone on staff who it was their job to make sure that people with disabilities and people with certain needs for being in a public space like that were able to still have a great time. I think that’s something that any venue could work towards if not do right away.

Final thoughts on the ADA

ALICE: Is there anything else you’d like to share in terms of things like the ADA? Is there anything else you wanna share with us?

LIA: Yeah. I mean, a lot of people don’t realize that the ADA is kind of an imperfect law. I think it’s a really great starting point, but compliance is just not strictly enforced. It’s not uniformly enforced. Businesses can use this legal loophole of finding accessibility incorporation “an undue hardship” to avoid making any changes. So, you end up with historic buildings refusing to add elevators or widen doorways. You have small shops saying they can’t shoulder the costs of removing entrance stairs or adding a ramp. There are times that I’ve been treated worse than one of those rolling garbage bins when I’m in my wheelchair, and that’s totally legal, according to the ADA. So, there’s a lot to do there that’s far from perfect. Any disabled person can tell you that, but it is a starting point.

And recently, Congress has been trying to create a new bill that would change the way that businesses are required to comply with the ADA. HR 620 is really not the answer either. Instead of putting the burden on the businesses and requiring them to comply and making the ADA stronger or more structured, it’s putting that burden on the community of people with disabilities. It’s putting that burden squarely on the shoulders of the those who, frankly, don’t have the time or energy to handle that.

ALICE: Well, Lia, I am so thankful for your story and your voice and your presence. And thank you for all that you do.

LIA: Thank you! You’re an amazing part of this community, and I’m so honored that I got to talk to you today.

[laid back acoustic guitar music]

Introduction to Dara’s interview

DARA BALDWIN: Thank you, Alice, for having me. It is a honor to finally talk to you and to do this special podcast on a very important issue.

ALICE: Absolutely. And why don’t you tell me a little bit about yourself? You are the Senior Public Policy Analyst at the National Disability Rights Network. Tell me a little bit about NDRN and what you do there and anything you wanna share about yourself.

DARA: Sure, Alice. Thank you. I live and work in Washington D.C. I'm honored and blessed to do the work that I do. I am a disability rights advocate as well as, as you said, a Senior Public Policy Analyst, that's at National Disability Rights Network. I'll talk about the network first and then myself.

So, NDRN is the national office for the protection and advocacy programs around the country. They are the civil rights lawyers for people with disabilities. They were founded in the late '70s after the Geraldo Rivera, his first investigative report around the horrific situation and way in which they treated people with disabilities at Willowbrook in New York. And then Senator Jacob Javits—anyone who's been to New York, Javits Center, it was named after him—he created the P and A system in 1976. We—when I say we, the P and A systems—they are under DHHS, Department of Health and Human Services. They are non-competitive, annually-granted through federal funds. The only criteria for a person to use a protection and advocacy program is that they must be a person with a disability, and they must admit to that disability. You know, we can't help people who won't. We have some people who— You know, you don't have to disclose or anything, but you have to disclose to the P and A in order to get some help. And so, that's the network, and that's what they do there.

NDRN is the national office, and we do training and technical assistance for the network. And I've been there since 2014. Prior to that, I worked for TASH. Then I worked for NCIL, the National Council for Independent Living. And I was also the ADA Compliance Specialist for Mayor Gray, Mayor of the District of Columbia. I've been doing disability policy since 2009. I came right before the passage of the Hate Crimes Act, in which we helped to make sure that disabilities was included in that. And then, I've been doing social justice and equity work probably all of my life. I grew up with it. My family is very involved in voting rights and school, education rights. So, I grew up around that with both my parents being very active in their community, and my grandparents. So, that's where it comes from for me. It's a passion and a love to do this work.

ALICE: Mmhmm. And I really do appreciate all of your email alerts, the information that you share about the latest going on, on the Hill.

HR 602: Legislation designed to weaken the ADA

ALICE: And today's episode is about the ADA and accessibility. And specifically, I wanna talk to you about HR 620, which is also known as the ADA Education and Reform Act of 2017. So, for people who have never heard of this bill, why don't you tell our listeners what the bill is and what it will mean for people with disabilities?

DARA: The bill, as you said, is HR 620, the ADA Education and Reform Act. And HR, if you're ever doing federal policy, HR is the House of Representatives. So, it is in the House, where this bill stands. And every Congress is numbered since 1776. So, we are in the 115th Congress, and for the 115th Congress, every time a Representative puts in a bill to be looked at and made into a law, it gets a number. And so, this was the 620th bill. So, a lot of people don't understand that, so I just wanna make sure they know that. It's kind of the same as if you do state work, it's the same thing: H in your state, you just don't have the R, probably, next to it.

So, anyway, it was introduced by Representative Ted Poe of Texas—he's a Republican from Texas—along with Representative Scott Peters, Democrat from California. And so, it is considered an ADA notification bill. They've been around, unfortunately, since the early 2000s, I would have to say.

[atmospheric, bell-ringing sound]

DARA: In 1990, when they did the ADA—almost 28 years ago, now—the disability community, the business community, and the Hill (meaning all of Congress, both the Senate and the House) came together and made a deal. One of the part was, right, any building built before 1990 is not in; you don't have to be accessible unless you touch the building. And then after 1990, you have to be accessible. You have to make the ramps and the doors wide enough, anything after that. And any building built after 1990 had to be accessible, right? Because you weren't gonna go back and do all of those things.

Another agreement was that also, they knew the buildings that were built before 1990 weren't accessible or that people wouldn't follow, right? It's very hard to enforce laws, so this is where we come in. People are building buildings, still, that are not accessible. And so, you have a process where you can file a complaint. If you won the case, which you probably would, you would get what's called injunctive relief, which is fix the door, right? Make the ramp. You have to do that. And attorneys' fees. Which, this really, I mean, we've seen around the country, maybe $500. 'Cause attorney just really has to fill out a form. And that was fine.

What they did not put in was damages. You could not get personal damages for that, which was fine. And there are certain states who passed the ADA law— You can pass your own state laws, right? You can't weaken a federal law. You can strengthen it, and some people, some states have put in damages. So, you could get damages as well. So, those states have done that, and it is in those states where you find this run amok is what we call it, I call it, attorneys who go around and say to the 7-11s, "You're not accessible. We're gonna sue you." But it seems like, when it comes to this, they just cut a check to these attorneys because it's more damages. Like, we just see the complaint; you don't see a whole lot of lawsuits being filed. It's just the threat of being sued.

And then, what also these attorneys do is come back over and over and over and over again and do this. From that, many businesses have been complaining about it and say it's bankrupting them, when it can't possibly. The highest we've seen is about a $8,000 payout. And let me tell you, if you're a small business, and you're gonna go out of business 'cause of $8,000, you weren't doing too well from the beginning! So, let's be real, here, right?! It's really a pushback of them just not wanting to be accessible. And it's been 28 years, and when are you going to do this?

They also, when you look at the title of the bill, it says, "ADA Education and Reform Act." So, it's real interesting. There's no need for all of that. And so, Ted Poe in Texas decided to introduce this bill. So, here we are in 115th, the new bill has been introduced, and unfortunately, not only do we have a Democrat who introduced this bill, but we now have democrats who are on the bill as co-sponsors.

The main elements of the bill, civil rights, and integration

ALICE: And what are the main elements of the bill?

DARA: So, the other issues about the bill: One is that the shopping centers basically don't want to have to address your complaint if you come to their place of business with a complaint or filing a complaint against the damages of them not being accessible. And I'm using shopping centers because it is the shopping centers' lobbyists who are pushing this. But if you go and read their letter, you'll see it's many people: Realtors; unfortunately, now grocery stores have joined in. And so, they don't want to do this.

And so, what notification is, is that you may come up to the 7-11, you can't get in, there's stairs, that's a barrier, architectural barrier. So, you would have to find out that 7-11, which usually, it may not be the gentleman or woman or person inside running it. So, you have to find out who they are, file a complaint, and it gets sent to them. They can 60-90 days—actually, it's 90 days—to get back to you about it and let you know what's going on. And in fact, in the bill, it says to present substantial progress. There's no definitely of what substantial progress is, but that surely doesn't mean fix the barrier, like get rid of the stairs. And then, if they don't do it—and they may not have enough time, there may not be a contractor who can come and do it—so, they get another 60 days. [chuckles] And so, it goes to 180 days, which is almost six months, before you, as a person with disability can get into that 7-11. Which is not what the ADA does right now.

The ADA, right now, as I told you, file your complaint, they're supposed to take care of it, and things happen to them. DOJ, you can file your complaint with DOJ. You can file your complaint with a lawyer. And they have to address this immediately. Most people with disabilities and their family members don't wanna file a complaint, right? They wanna get into the store. They want their— Right? And so, they also want to not only be a customer, but they also want to work in those stores. And it's not just the entrances to the stores. Many stores, if you can get in, their bathrooms aren't accessible, right? Or their fitting rooms aren't accessible. So, they need to be fully accessible. And so, that's a problem.

So, the bill will push that off, which also does not give an incentive to businesses to be accessible, right? Why do it when, oh, I could just wait. You know, I could just keep doing it: 60, 90, 180. I just could keep doing it over and over again because all I need is substantial progress. Which is not defined. So, this is wrong.

[atmospheric, bell-ringing sound]

DARA: And any other civil right case, or anything other thing, me, I am an African American woman, and I don't have a disability. But say I went to that 7-11, and they said, "You can't come in. You can't shop here," I have immediate relief. If this law passes, this will create a separate class of people who can't do, right? So, people with disabilities don't have that anymore. When they have a civil right, which is called the ADA. That is what the ADA is about: Community integration and civil and human rights. Communities of color will tell you no, right? You can't do this to Muslims. You can't do this, right? You can't do this to religious groups. So, why is it OK to do it to people with disabilities? So, that's the basis of that part of the bill.

And then the education side, they're saying, these business owners are saying, "Oh, we need more education. We need to be educated more," when that's not true either. Because two years after the ADA was passed, in the implementation of the ADA, they created what is called ADA Resource Centers. So, they're trying to say they don't get the education, which is not true. What we have seen is they don't use the ADA Resource Centers.

How to take action to stop HR 620

ALICE: Yeah. And I just wanna segue into action. What can people do who want to stop HR 620?

DARA: Well, what you can do is look at this House Judiciary Committee. You can go to the website. Just Google, "House Judiciary Committee." The members' names will come up. If you have a member in your state, you make sure you make a phone call to them and say, "I oppose this bill." As well as your own member. Even if that member is not on the Judiciary Committee, please call all of your Representatives in your state—so, you have multiple Representatives in your state—and tell them, “I oppose this bill,” and tell them why.

And you can go to CCD, Consortiums for Citizens with Disabilities’ website. Just Google, “CCD disability,” and click on. It’ll come up. Right on the front page it says, “Save the ADA.” And you can find all kinds of information there. Look at the Myths and Facts sheet. That will help you out a lot.

So, call your Representatives. And don’t call them once. Please. Call them once a week. Every week, like every Wednesday. Or get a little round going on in your neighborhood and in your community, wherever you go and have fun and mix and mingle with people. Have your neighbors call, your coworkers call on Monday, on Tuesday, on Wednesday. And call them and say, “We opposed this bill.”

Right now, the bill is not moving, thank goodness. We’re almost at the end of this first session, and we don’t see it going anywhere, which is great. We also have not seen a Senate bill being introduced. So, that’s great as well. There’s also a Change.org petition. As you were saying, for every day, and what I do is every Monday morning, I send that Change.org petition to the Hill with the new numbers. We’re up to about 1,680-something. It’d be great to have some more on there. So, if you go on there, you go to Change.org, it says, “Don’t Tread on My ADA.” Make sure you call your Representative. If they’re a Democrat, our ask is, “Get off of the bill because you’re on record saying you support weakening the ADA.”

ALICE: Thank you for that, Dara. And I’m gonna definitely add links to your Change petition and more information about the bill on the website so folks immediately get that information. So, Dara, I really appreciate you giving me this update and overview of this bill and what it means in terms of accessibility and basic human rights for 57 million-plus Americans with disabilities.

Final thoughts on HR 620

ALICE: Do you have any final thoughts you’d like to share?

DARA: That we can stop this bill. And the last thing I’ll say: When we do stop this bill, we’re planning it will not pass 115th as long as you guys do what we asked you guys to do. Because we need you to call in and keep on them. And then we need to go to the next step and have those conversations with the small businesses. That’s the other side. If you encounter a business that’s not accessible, then do that and say, “We wanna work with you. We wanna talk with you.” And contact ICSC, which is International Council on Shopping Centers. Google them, and call their office and say, “Hey! We wanna help.” So, we need to let legislators and people know, “We wanna resolve this problem because we don’t want you to weaken the ADA. We don’t want that to happen.”

And the last thing I wanna say is, again, thank you, everyone out there who has helped out and continues to help out. I know you have been stressed and pulled in all different ways this year with all the different things. But get some rest and get yourselves together, and then get back out there. Because the fight’s not over.

ALICE: It sure isn’t. Well, thank you again, Dara. I really appreciate you, where you go and your expertise.

DARA: Thank you.

ALICE: Thank you.

[hip-hop music]

Wrap-up

This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes including text transcripts are available at https://disabilityvisibilityproject.com/podcast/.

You can also find links to Lia’s story and more about HR 620 on our website.

The audio producer for this episode is Sarika D. Mehta. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Thanks for listening and see ya on the Internets! Byyeeeeeee!

♪ how far will they go? ♪

♪ oh yeah ♪

♪ how far will they go? ♪

♪ oh yeah ♪