

## **Down to the Struts**

Episode 1: Getting Wise About Disability

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Guest: Arielle Silverman

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### **Introduction**

[jazzy piano chords, bass strumming with hip-hop beats]

QUDSIYA NAQUI: Hi this is Qudsiya Naqui and I am excited to welcome you to the first episode of “Down to the Struts.” Today we’ll listen in to my conversation with Arielle Silverman, Arielle is a consultant who works to promote a fuller understanding of the disability experience. She participates in research and training designed to improve public perceptions and understanding of disability. We talked about what it truly means to understand disability, the history of the Disability rights movement and how much further we have to go till we achieve full inclusion for disabled people. I learned a lot during this conversation, and I look forward to sharing Arielle’s wisdom with you.

Okay let's get down to it...

[nice little jazzy piano pause]

QUDSIYA NAQUI: Well, thank you for joining me today! So, I was just hoping you could start off by just introducing yourself, telling us a little bit about your disability journey and how it’s affected the work that you are doing now.

ARIELLE SILVERMAN: Alright well, thank you for listening everyone! My name is Arielle Silverman and as far as my disability journey, I've been totally blind since birth. So, I've always identified as a person with a disability, and I never thought of being blind as any kind of negative part of myself. It was just a part of who I am, as much as my being female or my height or my skin color or my hair color is.

But I realized, eventually, as I was growing up that other people thought blindness as -- a very bad thing. And in fact, blindness is one of the most feared diseases that people fear. So, I kind of had to go through the process of understanding why -- or accepting the fact that a lot of people think of blindness as a bad thing, or think I am less capable because of my blindness. And then as a part of that process, I started interacting with other blind people. First, I had peers at a local blindness day camp that I attended. Then I joined the National Federation of the Blind. So, I started meeting blind people of all ages, from all over the world, and developing that community. And I started to notice a lot of issues that are affecting not only blind people, but people with all different types of disabilities, that are preventing us from achieving full equality.

I actually decided to study social psychology, specifically, because I wanted to better understand where a lot of these inequalities come from. And what kinds of systems, beliefs and emotions kind of, maintain that second class status of people with disabilities. You know, with the understanding that where a behavior comes from is the first step to figuring out how to change it. So that was my motivation for completing a doctorate in social psychology, I got my doctorate in 2014 from the University of Colorado Boulder and then I did two years of postdoctoral research in the rehab-medicine department at the University of Washington. So that was a little bit of a different perspective. But we focused on positive psychology and resilience in living with physical disabilities.

So, my world started to expand from the world of blindness to different types of disabilities. And I realized, as I was doing this work, that I didn't want to spend the rest of my career in the ivory tower, talking to other academics. I wanted to talk to people who could actually directly benefit from my research. So, I started writing plain language summaries of research to make it more digestible to members of the public. I also started doing training, kind of locally for groups that invited me to do training for them on inclusion. And eventually decided to set up my own freelance business doing a combination of disability related research and disability related training. So that is what I have been doing for the past four year since I have moved to the Washington D.C. area with my husband, is working on different kinds of research projects that involve learning more about the disability experience, and then also providing training especially to non-profits, really any type of organization that wants to figure out how to be more inclusive of people with disabilities.

QUDSIYA: Thanks for that Arielle! And I remember you telling me about the work you were doing in training airport personnel and I remember being very personally grateful, as a blind/low vision person myself. Travelling and navigating through airports is one of the most challenging things, and not because airports are particularly complicated or difficult, but because of the lack of training of airport personnel and just kind of bad design, which we'll talk about in future episodes. But I just remember being personally grateful for that work you were doing to train airport folks about how to work effectively with people with different types of disabilities.

So, the name of your consulting company is Disability Wisdom. Can you tell us, what is Disability Wisdom?

ARIELLE: Well that's a great question and I see- I like the phrase "Disability Wisdom," because it has two meanings. So, you can think of the more literal meaning of wisdom as experience, kind of insider knowledge that you gain over a long period of time. And so the goal of disability wisdom as practice is to cultivate and synthesize all of the wisdom, the first hand wisdom, that the people with disabilities gain in our everyday lives. Like so much of policy and practices is influenced by people without disabilities making decisions on our behalf. We need to have a more direct involvement in the policies affecting us. And the wisdom that we've developed through problem solving and figuring out how to access the world, it needs to be cultivated and shared with other people in our community as well as outside of our community. So I think that is kind of the first meaning of Disability Wisdom, wisdom through the lived experience of people with disabilities.

But also, the term "wise," was used by the sociologist Erving Goffman to describe people who are a part of the majority group, but who have important relationships with members of minority groups. So specifically he wrote about gay people in the 1950s, who were very highly stigmatized, and they would refer to their straight allies as the Wise or Wise People, because they treated them as if they did not have a stigma. So, one of the main objectives of Disability Wisdom was to help educate allies. To teach people without disabilities to be wiser and to build empowering, respectful relationships with people who have disabilities and treating us as if we were members of the majority group. So that's kind of the second meaning of Disability Wisdom.

QUDSIYA: That's really helpful! And is a perfect segue into my next question. Which is, this podcast will really focus on two things, and I will ask you two questions that kind of relate to both in your own experience. But one is answering the question of, why should we factor in disability when we are trying to improve the structures and systems that affect our lives? And

the second aspect of what does the disability identity-- how can that help us inform how we think about other types of systemic inequalities? So, to that first point, you've done a lot of work training different types of groups on how to be inclusive of disabled people, and how to factor in disability related issues when developing policies or designing structures and systems. So to your mind, what is the value of that? Why should we care about factoring in disability when we design things in the world around us?

ARIELLE: Well, so I think a lot of people don't realize how common disability is, and by some estimates, one in four, one in five people worldwide has a disability. Then of course if you factor in all of the immediate family members of people with disabilities, it is a huge percentage of the population that is directly impacted by either living with a disability or being in a very significant relationship with a disabled person. So quite frankly, it is important to care about people with disabilities, because otherwise a lot of people get left out. So, from a business perspective, if your business is inaccessible your customer base is going to be significantly reduced. There are also benefits, a little bit less direct, of hiring people with disabilities in terms of creating better morale, having more diversity of opinions and experiences, and that is also parallel with the importance of inclusion of other minority groups who have different experiences.

And a lot of innovations come from or are things that started out as disability related accommodations, and it turned out they had benefits for other people. So a couple of like really obvious examples, curb cuts were originally intended for wheelchair users, and they are actually essential for wheelchair users to be able to navigate in a lot of places. But they're also really handy if you're pulling a stroller or a grocery cart. Text messaging, I believe, started out as an accommodation for deaf people and a lot of the talking GPS uses a lot of the same technology that blind people use to access computers. So, when we develop innovations to help people with disabilities access things, we are actually promoting access for everyone.

QUDSIYA: I really like the example of the curb cut! That's a great one. And you know, I didn't really think about it until you said it now. But there are moments where if you're driving and you can't see your phone, being able to hear the auditory instructions from, say for example Google Maps is hugely beneficial. I mean there are so many instances where sighted people are not able to use their eyes, because they are doing something else or -- there's lots of reasons why having a non-sighted way to do something for example, or a way to do something that doesn't involve using your legs is beneficial for others. So, yeah, some of those I thought of but others I haven't. So those are really interesting examples.

So on the second point, in addition to being a person with a disability, which is a way that I identify as well, we have so many other aspects of our identities. And I was wondering if you could talk a little bit about those other aspects of your identity: What they are? How they have an impact on your life in ways that are related and sometimes not related to your disability?

ARIELLE: [Hums in agreement] So my other, I guess I would say minority group identity, is that I'm Jewish and only about two percent of Americans identify as Jews. So, I would say that is definitely a minority identity. And that means the intersection of my two identities of being disabled and Jewish, or blind and Jewish, is really small. So one interesting thing when you have two or more either minority identities or negatively stereotyped, stigmatized identities, is that sometimes they can compete with each other.

So I was reflecting on yesterday -- I was actually looking at a blog post (someone/ they) wrote about this and I was reflecting on a couple of times when I was in -- especially as a child and an adolescent, where I was in a group... So for example I went to a Jewish Youth Group retreat for a weekend and we went to a place -- we went to an arcade that was completely inaccessible to me as a blind person, because they were all video games or go-cart races. It was very difficult for me to participate. So I felt isolated from my Jewish peers, even though we shared Judaism in common. There were times in the weekend where I felt very close to them when we were singing Jewish songs and doing Israeli things and stuff like that. And other times it just felt completely isolating because of my disability. And conversely there have been times I have been with blind peers, where I have a very strong disability connection with them, but our religion and cultural beliefs are completely different. Or they all celebrate Christmas and I didn't grow up celebrating Christmas, so during Christmas time I would feel isolated because of that. And I think sometimes when that happens, you can have a competition between the two identities. Like you feel like you have to choose one or the other, so that you don't feel left out. And what's been really cool actually is that some of my favorite consulting clients have been Jewish organizations, like the Jewish Federation of Greater Washington, the Foundation for Jewish Camp and Union for Reform Judaism, and a couple of synagogues I have worked with. They are very much dedicated to promoting full inclusion, as an imperative, as a way of improving their entire process, not just as a charity thing. It's been very healing for me, because both of my identities are celebrated in those kinds of environments. And I can really feel like the next generation of disabled Jews might have a better time reconciling those two identities, than maybe I did when I was growing up. So that is something I think that can happen when you're disabled, and you have some other minority group identity.

I mean, I know in disability spaces, a lot of work still needs to be done to include LGBTQ and racial and ethnic minorities and gender minorities. And by the same token a lot of the time the diversity groups that try to promote diversity for some of those other identities don't always understand disability. I had a friend who was taking some kind of diversity training through her

employer, and the training was completely inaccessible. There was like a video with text and she's blind, and she couldn't access the text, so she was left out of this diversity and inclusion training. Those kinds of things happen quite a bit. And so, we need to be more mindful of making disability spaces more inclusive to other groups. And then making those other groups' spaces more accessible and inclusive to people with disabilities.

QUDSIYA: So much of what you just said really resonated with me. You know, I'm Muslim and South Asian American, and also identify as having low vision and being blind. I feel the same. I maybe know one other person who is both South Asian and blind, I think we both might know the same person actually. [chuckles]. So that's really helpful, but I definitely feel like I have to do a little code switching between those two communities.

Also sometimes, and I'm curious if you've had this experience, when you're in a workplace or you are struggling -- I haven't really worked as much in a disability workspace. I'm an attorney, but I've done lots of different types of work that are necessarily disability related, and in those environments I'm never sure, you know is it because I'm a woman? Is it because I have a disability? When I am being treated a different way or feel that I am being discriminated against or excluded, based on what factor that is happening? How do those things interrelate to one another? I'm curious if you've also felt similarly. Not being sure what the source of any type of exclusionary behavior or discriminatory behavior is coming from.

ARIELLE: Yeah, the only example I can think of is a little bit different. But I think as a woman, I've definitely been socialized to be more kind of gracious toward people who are being overly helpful and toward men who are being overly helpful. I think I definitely experience more of the patronizing, like grabbing and condescending behavior from men, than I necessarily would if I were a guy. A lot of my male friends don't have quite the same level of that interaction, so I think that is one way the identities can kind of intersect. But I think blind men probably have challenges that I didn't have related to not being accepted in sport activities, or like not being able to drive and not being stigmatized in certain kinds of roles they might fulfill. So I think either gender identity can intersect with ableism in interesting ways.

QUDSIYA: Yeah, I think for men who have different types of disabilities, I think they're not complying with the gender expectations of a man in some way. Because our concepts of ability are so tied to what is considered able for a cis gendered white male, which I think is very interesting, But that is a totally different topic for an entire podcast episode probably. So we might have to have you back for that. [laughs].

So I wanted to switch gears a little bit, speaking of a topic that could take up an entire podcast episode or maybe even an entire series, we could spend a long time talking about the Americans with Disabilities Act. I was hoping you would be able to share with me and with the listeners a little bit about what is that legislation? How did it change the game for people with disabilities? And just give us a little background about the ADA.

ARIELLE: Well so of course if we go back a century or two in American history, a lot of these patterns were duplicated around the world. People with disabilities were often placed in institutions, like nursing homes or group homes, and not really expected to participate in their communities. Around kind of the middle of the 20th century, disabled self-advocates started to unify. And it's interesting to look at some of the trends in medicine that ended up kind of increasing the rate of certain types of disabilities, like polio outbreaks in the 40s and 50s led to a lot of people who are survivors of polio and were physically disabled. They were kind of the ring leaders of those movements, and there was kind of a parallel in the blind community, more premature infants being saved but then developing blindness, and of course after World War II there were a lot of veterans with disabilities. So the disabled voice kind of changed and it got louder in the middle of the 20th century. And disabled people started advocating for the right to participate in the community and rights to access public transportation, to get jobs, to go to college. There were a couple of laws that were really landmark laws, the Rehabilitation Act of 1973 had some provisions in it that predated the ADA, but required that entities that were receiving federal government funds be accessible to people with disabilities and not to discriminate against people with disabilities. So colleges and universities that were funded by the federal government, federal government offices of course, and other sorts of agencies had to be accessible. Of course that didn't cover a lot of private businesses that disabled people could not, literally could not access, could not get into in their wheelchairs. Or could not access the information that was provided. So there was a lot of additional advocacy to bring about the ADA in 1990, which basically requires any entity that is serving the public, and there are some exceptions like religious organizations can be exempt. But most of what we consider a business or service organizations that are serving the public, are required to be accessible, provide reasonable accommodations. That means for example if I go into the grocery store, I can't find the items I need without a sighted person who can read the labels. So the store has to make a reasonable effort to accommodate me, like providing a staff member to help me with that. Instead of saying "no you need to bring someone with you". Of course a lot of businesses had with mobility disabilities could access them, and discrimination is also prohibited in the basis of disabilities, so this also extends to other civil rights laws that protect racial, ethnic, sexual, gender minorities from discrimination are now extended to disabled people. So employers can't say we won't hire you because of your disability, service organizations like child-care centers can't turn away a disabled child merely because they have a disability and so on.

Now of course there are a lot of limitations of the ADA, which I think is the next question. But in theory, the ADA is meant to prevent discrimination on the basis of disability.

QUDSIYA: So that's really an interesting background and thank you for summing that up! There is so much in there, but you distilled it in a really succinct way, so I really appreciate that. So basically, what you're saying is the ADA made sure that disabled people had to have access to the things that abled people have access to, right? So now, fast forwarding to today, I think we are having this conversation around a lot of other contexts, just around the country and the world. But when it comes to disability. What do you think the ADA left out? And if you could design an ADA 2.0, would it look similar, would it add on to the current iteration of the ADA, has done or would you change things more fundamentally? In terms of how we think about disability and inclusion now.

ARIELLE: Yeah, so I'm not a legal expert so I'm not sure how many of these things are things that can be added to the law... Or if it's more of a question of what changes require fixes other than legislation. Because, you can say legislatively that businesses have to be rebuilt for accessibility, which has not happened to the extent that it should, if the law were properly enforced. You can use legislation to ban discrimination, on the basis of disability but it's still happens a lot. And my understanding of that is when people discriminate, they often do it in a more surreptitious way. So it's harder to identify that they are discriminating on the basis of disability. So pre-ADA, someone could just say, "oh you're blind you can't do that job, sorry better luck next time." Whereas now, an employer might not say that but they might say "oh we've already filled the position," or "we're not hiring for this position anymore," and in fact they are making a discriminatory judgement. There are also cases where language will be written into the job descriptions basically saying that ability is an essential function of the job even if it's not, and that is a way to kind of get around the ADA.

So a couple things come to mind, one is I think the ADA sometimes scares people more than it actually creates reform. So for example, employers are not permitted to ask questions about disability in job interviews, and it's understandable why that provision is there, because it helps to prevent blatant discrimination. And of course, applicants have the right to not disclose if they have a disability. But sometimes that prohibition I think also leads to a lot of assumptions being made about disabilities. So the employer isn't allowed to ask any questions, but they feel uncomfortable, they don't know what to do and they just end up not making the hire. So I wonder if there's a way to allow dialogue to occur between an employer and employee about disability related needs, without having to go through a lot of bureaucracy on part of the employee. So that some of those misconceptions can be resolved.



I think the main issue is that prejudice is still going to exist. We can pass all the laws in the world, but people are still going to have prejudices and they're still going to find more creative ways to know if we need some kind of companion process in addition to the ADA. But in addition to banning discrimination legally we need to find a way to educate the non-disabled public about disabilities. And it really kind of amazes me, for example how many parents have a disabled child and just have no idea what to expect and are just shocked and surprised that they had a disabled child. And if they had been kind of educated on how common disabilities are, how normal they are as a part of society, you know, just basic principles of inclusion, parents won't be so overwhelmed, employers won't be so overwhelmed when they're confronted with disability. Even making some kind of universal disability education in the high school curriculum or in the college curriculum, I think ideally in the high school curriculum because a lot of people don't go to college, and still might end up having a disabled child or having a disabled person want to work for them. But we need to get the education more systematic, and we need to have it run by people with disabilities. So people can let go of a lot of these automatic implicit discomforts they kind of feel about disabilities.

QUDSIYA: If I think about it, in school we -- you know, you learn about the Civil Rights Movement and you learn about the Women's Rights Movement and the Disability Rights Movement, was a movement and it was quite an extensive movement, but we don't learn about the ADA in school the way we learn about the Voting Rights Act. I don't know if you had that in your curriculum...

ARIELLE: I don't even remember when I first learned about the ADA, but I didn't learn about most of the disability activism until I was in college. And most of what I initially learned was blindness-centric because that was information that I sought out about blind people. I didn't even know there was this whole "Cross-Disability Movement," until fairly recently.

QUDSIYA: I'm a person who lost their vision later in life, and was raised by an entirely, you know, my entire family is sighted and there is no one else in my family that has the condition that I have, that resulted in my vision loss. So I really was sort of not acclimated to a lot of this. I got rehabilitation services through the state where I lived but, you know, I didn't come to this experience until much later in my life either. I mean I think for two of us, that in of itself is kind of interesting. And as someone who is a lawyer themselves, I'm a lawyer by training and I would agree with you wholeheartedly. It's more than laws, it's about cultural shift, there needs to be legal protections but also a cultural shift for things to really move. So to that end, I'm really curious what you think about -- what do you view as sort of the difference, if any, between

accommodation and inclusion? Accommodation often in my experience is like, here's a separate way for you to do something and it's not exactly the same, but it's a way, and it might not be as good, a little separate but equal or separate but not equal in a way I guess. [laughs]. For example, if you have a structure and there's stairs going to the entrance, but the wheelchair entrance is in like a really inconvenient location. Yes you've provided access to the building, but you've put the access in a place that is difficult to get to in the first place, and also kind of segregated from the mainstream use of the structure. So I'm curious whether we have further to go and how we can go from accommodation to actual meaningful inclusion, if you think there's a difference between those two things?

Arielle : Well accommodation is kind of like a band aid, it's just kind of temporarily fixing it for one case. And sometimes, that's the best you can do in the short term. It's interesting to think about it if the roles were reversed, right? If something were only accessible to blind people, like maybe an audio described movie that was only in audible format, and then say maybe my husband (who is sighted) wanted to watch the movie with us. We would have to accommodate him by adding on some kind of visual component so that he could enjoy it, as well as we could enjoy it. And that seems kind of silly, really accommodation is just making something available to whoever is in the minority of the group. Whereas inclusion, ideally is making something equally accessible to everyone. And so in your example, just having a ramp and stairs side-by-side, or even just having the ramp, would be an instance of full inclusion. Or presenting something in a way that's screen-reader accessible that's also visually accessible, without having to make a lot of last-minute changes for specific cases. I know also with deafness, a lot of deafness related accommodations can be expensive. Like ASL interpreters or captioners, they require a lot of human capital. But writing something like a transcript of a presentation that's written by the presenter, which can automatically be there for everyone without having to be requested ahead of time. That would be a more inclusive solution to that problem.

QUDSIYA: Yeah so the idea is thinking ahead, considering those design elements from the beginning at the inception of the project or design--

ARIELLE: Right!

QUDSIYA: --be the best way. Yeah exactly.

ARIELLE: I think the idea is that if you invest a little bit of effort upfront, you won't have to go back in later and keep fixing it.

QUDSIYA: Right, exactly. And I think, in some instances we are getting a little closer to that, but still have a ways to go in acclimating people. But I think your point about education from an early age, and introducing these concepts to people early on so they think about them in their day-to-day life in a different way, in more meaningful ways, is definitely a place to start.

So I was wondering if there were any other thoughts you had about what people should know about disability and why we should care about it? And why it's important not just to the disabled community but to just people in everyday life. You've said a lot about it, but I wanted to open it up and see if you had any more parting thoughts you wanted to share.

ARIELLE: Well I think it's just important to keep in mind that everyone has something to offer, and everyone has a different set of strengths and challenges. I don't necessarily like this whole idea of "oh we're all a little bit disabled, or we all have disabilities." I think we all have advantages and disadvantages in different environments. Everybody has something to offer and we shouldn't cast anyone aside as too disabled or too different to be a part of whatever community it is we are creating, or whatever work it is we are doing.

[nice jazzy piano and hip-hop beats pause]

## **Outro**

QUDSIYA: So if you're up for it Arielle, I'd love it if you could tell folks where to find your writing and tell them about the work that you are doing.

ARIELLE: Yeah that's easy. So if you go to [www.disabilitywisdom.com](http://www.disabilitywisdom.com) you will find a little bit about my services, and you will also find my blog if you go to the blog in the navigation bar at the top of the page. I've also included, of course, my contact information on that website and I admin a discussion group on FaceBook called "[The Disability Wisdom Discussion Group](#)." So you can find that by doing a FaceBook search as well, and that's a forum for people with and without disabilities to talk about disability related issues.

QUDSIYA: Thanks Arielle, that sounds great! And I hope our listeners will check out [www.disabilitywisdom.com](http://www.disabilitywisdom.com) and also the [Disability Wisdom FaceBook group](#). I am a member and I find it tremendously rich in terms of the diversity of the group, and the discussions. I'll share this information with everyone in the show notes. And thank you again to Arielle for joining us!

ARIELLE: Alright. Thank you!

[soothing jazz piano, hip-hop beat pause]

QUDSIYA: Thank you for joining me for the first episode of Down to the Struts. If you want to learn more about the podcast and find future episodes, go to [www.downtothestruts.com](http://www.downtothestruts.com). You can also subscribe to "Down to the Struts" on Apple Podcasts, Spotify or Stitcher. I'd love to hear from you if you have questions, feedback, or ideas for future episodes, please email me at [downtothestruts@gmail.com](mailto:downtothestruts@gmail.com). A very special thanks to Anna Wu, Avery Anapol and Adriane Kong, and to all the friends, family and supporters who have helped me along this journey. Without your advice and guidance this podcast would not be possible.

Thank you all again for listening, I'm looking forward to our next episode so we can get back down to it!

[ends with the soothing jazz piano, hip-hop beat]