# **Down to the Struts**

Episode 3: Unfair Nation – “Access Ability”

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Guest: Qudsiya Naqui

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For more information:  [www.downtothestruts.com](http://www.downtothestruts.com)

**Introduction**

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

QUDSIYA NAQUI: Hi this is Qudsiya Naqui, and welcome to episode three of *Down to the Struts*! This week I'm excited to share with you *my* moment in the hot seat, giving an interview with my friend, Ehsan Zaffar host of the podcast [*Unfair Nation*](https://www.unfairnation.com/about). Ehsan is a civil rights lawyer educator and policymaker dedicated to fighting structural inequality. When I sat down with Ehsan, we talked about my experiences with structural inequality as a disabled person. I hope that many of you can relate to my story. The battle against inequity and inequality has never been more important. I encourage everyone to listen to *Unfair Nation*, Ehsan’s latest episode on worker power was fascinating and so important you can visit unfairnation.com to learn more about this project and to subscribe to Ehsan’s weekly newsletter. You can also subscribe, rate and review the *Unfair Nation* podcast, wherever you love to listen.

Okay, let's get down to it!

[whimsical, light piano chords]

EHSAN ZAFFAR: I’m Ehsan Zaffar and welcome to another episode of *Unfair Nation*, the podcast that discusses our nation's rising inequity and social, political and economic inequality. What it means for you, and what you can do about it. Every week we interview one person for 25 minutes to understand their lived experience with structural inequality, and today I'm joined by Qudsiya Naqui, an attorney who lives in Washington DC.

Hi Qudsiya, thanks for being here--

QUDSIYA: Thanks for having me Ehsan.

EHSAN: --on a rainy Washington evening, in fact. Why don't we just start with you telling us a little bit about yourself?

QUDSIYA: Sure! Thanks. So as Ehsan mentioned, I am an attorney and I live in Washington DC. I've been living in the city for about five years now. I'm originally from New Jersey, so I've done work around immigration law as well as Civil Justice Reform.

EHSAN: And one of the reasons why you're here to talk with us today is about your experience of losing sight. Can you tell us a little bit about that?

QUDSIYA: Sure. So I have a congenital retinal condition, it's known as Leber's congenital amaurosis. Congenital means that I was born with it, so I've had this condition since birth. And it causes vision loss over time and, you know, I think that the experience of vision loss for me, and I should-- I should say that, you know people-- blindness is really very much a spectrum. There are people who are born with little to no vision or have light perception. Visual impairment can run the gambit, everyone's experience is very very very different and unique, and I am speaking today about my particular experience. Although I think some of the principles I'll talk about are common-- can be common among other people but mostly I'll just be speaking about my own experiences.

I think the experience for me was sort of two fold. There was the physical experience of the vision loss, and so grappling with, you know, your vision changing. You-- you have to learn to do things differently or certain things that were easy, suddenly become harder. And I think I grew up in a time and in a paradigm where the idea around, sort of, assistive technology was to maximize the use of one's vision. So using aids like magnifiers and high contrast and other types of things that would facilitate the use of the eyes. And that can be very challenging when you-- you know that's becoming really hard, it's very exhausting, but you're trying to hang on to your vision. So those are some of the physical aspects of vision loss. At the same time there's a psychological effect, and I often explain it to people like... dealing with the loss of a loved one or with-- or with death. You kind of go through the grieving process, the denial, the anger, the sadness. And you're-- you're dealing with the loss of this “thing” that you relied on, and it allows you to live your life in a certain way that can no longer do that for you. And it's very-- it’s an emotional experience that you're going through, along with the logistics of figuring out how to live with the physical loss of your vision.

EHSAN: And when did your vision loss start?

QUDSIYA: I started to really lose a lot of vision... I was pretty functional enough through high school. I use some assistive technology. I got extra time on exams. So I definitely wasn't-- I was mainstream schooled. I didn't go to a blind school or anything like that, but I definitely needed some adaptations, but I could still see quite well during the day. I was always night blind, but I didn't get to use a mobility cane in the day. I could, sort of, pass in a certain way. I could pass as sighted. And then in my mid-20s I lost a significant amount of vision. I think beginning the senior year of college and going into the year I was working after college as a paralegal, and then starting law school. I really started to lose a lot of vision, and it’s very very gradual. So you don’t really know that it’s happening or realize. I didn’t fully understand I was going to lose vision like that, until I met a specialist in my mid-20s, who basically kind of walked me through the prognosis and the process. And that was quite shocking to me, because I just wasn’t anticipating that.

EHSAN: So let's talk a little bit about your experience in law school. How was that experience Visa V like law school? Did you-- I imagine you start experiencing some difficulties in terms of doing your daily work and classes. How did the power dynamics shift? Did you feel like you have less power, more power to get stuff done? Was your school helpful, in providing you some of the tools that you needed to get work done?

QUDSIYA: Yeah that's a really good question, but I need to start that story a step earlier.

EHSAN: Sure.

QUDSIYA: So I think my first real experience with, sort of, the injustice of the system as related to a person with a disability, or the first time that I encountered a barrier-- I'd always been a very very fortunate person. I grew up with a very supportive family. I went to very good schools. I did very very well in school. I took a lot of pride in my intellectual development, in my academic success. And that was something very important to me, I worked really hard. And I the first time ever encountered a barrier in that regard-- And I always had very supportive teachers and mentors, people around me who gave me things I needed when I asked for them. And I was very very very lucky, not everyone has that experience. And then the first time that I really encountered a barrier to my success was with the LSAT. Which is a law school entrance exam. So I had experienced a lot of changes in my vision. And the types of accommodations for testing that I was requesting for the LSAT were different from what I had needed in past standardized testing, like the SAT or the undergraduate entrance exam. And so because at the time, the LSAT had a policy that you had to get the same accommodations that you had previously. So they didn’t really account for people who had degenerative conditions. And so they denied my request for accommodations, because those accommodations were not consistent with what I had in the past.

And though I tried to appeal that decision. My appeal was denied. And so I went forward with the accommodations that they gave me, which was 18-pt font and time-and-a-half (1.5x more exam time). So not that double time and a comfortable font size, the 14-point font size that at the time was comfortable for me. Now, I can't read print it all. But at the time that was what was comfortable to me. So with the LSAT, for those who aren't familiar, there's a section that's called the logic games. And they're basically like these mind puzzles, and they involve a lot of numbers and they can be very visual. And in the exam, the logic games are set out on one page. And it's really important to be able to see everything on one page, but with an 18pt font test, the games were not on one page. They were-- they were--I had to flip back and forth. And I have random eye movement, so I can't focus. If I-- if I move away from a page and I look back, I can't find my place easily. So I wasn't able to finish the exam and I scored really poorly.

So I tried it again. And the second time I just asked for the standard font size, thinking, you know, this might be able to work for me. And again I ask for double time but only got time-and-a-half. And of course, as I probably should have known... or you know, as was inevitable, the regular 10-point font size or whatever they used was too small and I couldn't read the exam again. And you know at the time I-- I didn't understand how to advocate for myself. And so I just assumed that this circumstance, and my poor LSAT scores were my own fault. And that, you know, there was nothing I could do! And so I did the best that I could, and I got-- I was lucky I got into a very decent law school.

And again, had very supportive-- You know, going back to the original question Ehsan, I had a lot of support from my school. They really helped me some transitioning I-- I really couldn't read anymore. In the first year I didn't understand that. And so I just didn't do well, because I couldn't keep up with the volume of reading. Not because I didn't understand or comprehend it. But because it was physically exhausting to read hundreds and hundreds of pages a week, which is what you had to do in law school. And so they helped me through a transition where I moved from learning visually by reading to learning auditorily by listening, which took me a long time. But, again, I was very supported through that process. It took me a year to really master it. But-- but I had a really positive experience, and a positive experience again with the bar [exam], which is the licensing exam that you take at the end of law school so you can get your law license.

But that LSAT experience had really reverberating effects on my life: in where I went to law school and the opportunities that resulted from where I went to law school. And then also just on my-- on my, like I said there's a psychological component, you know, the feeling of defeat or the feeling that I-- you know, that this is my failure. Just having a complete lack of knowledge that I could’ve been able to advocate for myself.

EHSAN: You mentioned you didn’t challenge the decisions or, kind of, the setup, right? Or the system. This is a podcast of a structural inequality. And one of the reasons why structural inequalities is, kind of, so endemic is that a lot of people don't challenge it. It's part of a system, it's structured, feels like you can't change it, you're just one person. Do you feel like, in addition to what you were experiencing in terms of vision loss-- Do you feel like any other part of your identity -- you’re South Asian like I am -- or any other part of your identity, do you think that played a role in you choosing, at least initially, not to challenge it? I know later on you've been advocating a lot more. But at that point, maybe your age, because you're a younger person, do you think any of that played an impact or had a role?

QUDSIYA: Oh I definitely think so! I think all of those things factor into the decision. But I think, most importantly when I reflect back on that time… Yes, I think it was definitely my age, my lack of experience, my lack of understanding of the law and like whatever protection could have potentially been available to me. And just yeah, I mean-- I think, you know, I just didn't know what I didn't know, you know. But mainly I think, you know, the thing that was the biggest barrier for me is that at the time I… In my identity I still identified, and I think this is common with-- again I can't speak for everyone’s experience-- but I think it's often common with people who suffer vision loss versus people who have been blind since birth or very young childhood, I still identified very much as being sighted. And I was still trying to pass.

I often explained it, you know, as sort of being in the closet. In a type of closet, and sort of trying to pass as being sighted and, you know, being-- having... Being blind, or visually impaired, or having low vision, or whatever words you want to use, that was not part of my identity. That was something I hid when I could, and, you know, was trying to deny or ignore about myself. And I think *that*, above all else, was a huge reason why I didn't advocate for myself, because I didn't view myself as a person with a disability in the way that I do now. And *that* has been a paradigm shift in my life. And a journey that I've taken over a long time, and it's taking me a long time to get there. But I think most of all, leaving aside the age and maybe some of the cultural things you're referencing, I think that was the biggest block for me in terms of understanding how to advocate for myself. Because I didn't understand what I was advocating for, in the sense that this was not part of my identity.

EHSAN: And since then when you’ve kind of accepted that part of yourself, how has-- how have your interactions with like systems, whether his professional or personal or social or political, how have they kind of shifted since then?

QUDSIYA: Oh it's just been an incredible sea change. I mean, I think, you know, once I sort of, you know... There were a series of events in my life that led me to change the way that I think about myself and the world around me. And that has been an incredible paradigm shift, you know. It's very liberating and very empowering for me to finally realize that, you know, I'm not the-- My vision loss is not the problem, I don’t have a problem. The problem is that the world is not designed for me. And in that knowledge, I feel that I can advocate for myself. Because I can say “you know what this thing is not accessible” or “this isn't designed for my use and I demand to be able to participate in the world and to have the world be designed for me and I deserve that as a human being.” And being able to-- and I'm-- I am I'm proud of my blindness in my vision loss.

And I feel that once I started to embrace being blind and doing things as a blind person... So I mentioned earlier, you know, when I was young that the paradigm was to use the specific technology that maximizes the use of your vision. So since then, because I have shifted the way that I think about this, I find assistive technology that allows me to get things done. Oftentimes without using my vision at all. And you know I think that is so powerful, you know. I'm able to be so much more independent and so much more empowered and such a better advocate for myself, because I am solid in who I am and I'm very comfortable with my blindness, and it’s part of who I am. And I think, you know, going back to your question. I think that the way that the world is structured doesn't allow people to do that. You have to fight against the structures that don’t accept your blindness.

EHSAN: And be innovative, right? Like maybe carry around a small carry-on luggage from the metro to the podcast studio, right?

QUDSIYA : [chuckles] Yeah! it's creativity and it's also... You know, it's funny people just-- I think--

EHSAN: Do you want to tell people what I'm referring to? [laughs]

QUDSIYA: Yeah! So Ehsan and I were walking to the metro and I had a luggage with me. And I told him you grab one end of the luggage, I'll grab the other end of the luggage. And then we can walk together, and that's how you can guide me. I mean I had my cane, but I just didn't know where I was going, so it was helpful to have him do that. But yeah! You get really creative, and you become more free to do that. But it's funny I mean, I read an article a few years ago in the New York Times, I think it was an op-ed. The title was very provocative, it was ”Why People Fear the Blind.” And you know, I think that for people, sight feels so fundamental they cannot fathom that one can function without it. And I think when you--

EHSAN: They’re scared, right?

QUDSIYA: Yeah, and there's another concept in their-- that is-- You know, that that kind of permeates our society and our social and cultural and economic structures. Which is ableism, which is this idea that “I am-- I am sighted, I am more able than you, and therefore, you know, I know how to do this better than you can.” And I experienced that, and my blind friends and colleagues experience it everyday. This presumption that if you're doing something differently than someone else-- I'll give you an example that’s more concrete.

Ehsan: Sure.

QUDSIYA: So you know oftentimes what we're trained to do is-- you know, there's a lot of escalators in DC in the metros and everywhere around. So for safety you're supposed to reach out and touch the banister to feel whether it's going up or down, and that's how you check to make sure you're going the direction you want to go. And so sometimes people will see me do that, and they’ll grab the arm that I use my cane with, or like grab me, or try to pull me back if they think that I'm going down the escalator. They're not understanding what I'm doing. And as a result of that, if you take someone's arm that they're holding their cane with, you take away their whole sense of orientation. Which actually makes them less safe, and I don't believe that people are malicious or trying to do something out of any ill intention. But it's this ableism, this idea that, you know, “I have ability above yours, and therefore I know better than you.”

EHSAN: I mean I’m thinking about that just now trying to imagine that, and I'm getting scared. Because I’m seeing visions of myself like falling down the escalator, because somebody jerked me, right? Because it’s unpredictable.

QUDSIYA: Yeah.

EHSAN: And now every time I'm trying to reach out and touch the banister, I'm a little afraid that somebody will see that and like grab my arm, right. I can't-- I can't imagine how like-- and it’s making me anxious just thinking about it.

QUDSIYA: Yeah and it's just it's interesting, people's notions. You know, you would never go grab a random person in the street, but I think people think that's okay, because of this idea that just is so deeply ingrained in our society. And like I said I don't ascribe ill intention to any one individual person who does these things. They’re conditioned in that way, in the same way that we're conditioned by structural racism and lots of other things, and sexism and all those things. And this is just another one of those things, and it’s very challenging to kind of work against it. But I feel very hopeful, you know. I think as technology becomes so advanced, there’s more-- the world starts to be designed more accessible to people with different types of conditions, with different sorts of needs, and different ways the world needs to be designed for them. I have hope that eventually, you see a blind person in the street who seems to know what they’re doing, you keep on walking! And so, and also our assumptions change. I believe it’s possible I have a lot of hope for that. But there’s a lot of work to do.

EHSAN: Now I know you work on immigration issues as a lawyer. And so, kind of working on these issues is not really your professional background. But like what would you... You know, if you're speaking with somebody, a policy-maker, and she, kind of, has some mandate to work on these issues, and she doesn't have a lived experience like you do. What kind of your viewpoint? Like what’s the kind of advice you wanna give her? What’s something you want her to think about? As she's creating policy for blind people or trying to create a world that is accessible.

QUDSIYA: So the biggest thing I would say is-- again I am not another disability rights or disability law scholar--

EHSAN: Well nobody's perfect.

QUDSIYA: [chuckles] But I’m a person in my own experience. But I think that the Americans with Disabilities Act or the ADA-- It was passed in 1990 under the first Bush Administration, it was a, you know, really the culmination of a lot of work that a lot of disability rights advocates did for a long long long time. And it was really a watershed piece of legislation.And it really changed the game, because it opened the door for people with disabilities to have access to housing, have access to employment, to have protection mechanisms against discrimination. So it was really really groundbreaking. And it established the concept of reasonable accommodation, which is really important. But I think that in the world we live in now, I think there's a little bit further to go. So I think there's a difference between accommodation and inclusion.

EHSAN: [hums in agreement]

QUDSIYA: So if I was talking to a policy-maker, I would want them to take that step forward. So not the idea that, you know, we should provide reasonable accommodation because someone is disabled. It's that we should design a world that's inclusive of everyone regardless of what's up with their life. So a good example I use is-- a policy example is curb cuts. You know, curb cuts were, I guess, originally designed for people in wheelchairs and they were life altering. Made it a lot easier for someone in a wheelchair to get around and it was a really important thing. But they also help people with strollers...

EHSAN: Help people with back pain.

QUDSIYA: Or people with back pain, like you. And so if we think about that world in this broader way and we think about accommodating everyone. There's a certain I think-- a little bit of a, sometimes, a separate but equal idea in this idea of reasonable accommodation. So I'll give you another example, the company that -- I don't recall the name -- but the company that makes Uno cards was really lotted, and I think it was wonderful, they came out with a set of Uno cards that have Braille on them. So [Braille Uno cards](https://www.mattelgames.com/games/en-us/uno-braille), which is super fantastic. But, you know, I would love to live in a world that went one step further, which is that every deck of Uno cards you buy has Braille on them

EHSAN: Sure, yeah.

QUDSIYA: So everyone's getting a Braille set of cards. So no matter what circumstance you're in... So you’re randomly with someone who needs Braille Uno cards, and you’re playing Uno. There’s Braille Uno cards.

EHSAN: My business cards have Braille on them, but I would want all business cards to have Braille on them. It’s kind of cool actually...

QUDSIYA: Just by default! Right?

EHSAN: Yeah!

QUDSIYA: Again, I'm speaking about one type of disability because that's my lived experience. But ditto for all of the different kinds of, you know, neurodiverse conditions, physical disabilities, all different sorts of things.

EHSAN: Sure.

QUDSIYA: If we think about the world in this way, as opposed to saying to someone…

EHSAN: “You figure it out.”

QUDSIYA: “You figure it out.” Or asking-- Instead of saying, you know, “what’s your disability?” or whatever, or saying “would this be helpful, would that be helpful?” And being sort of proactive. As opposed to making the disabled person do all the work of, sort of, having to constantly advocate for themselves and have to explain to people what they need.

EHSAN: So last question. What-- you know-- Especially over the last 10 years, when you said like, kind of, your identity’s kind of solidified a little bit, for lack of a better word. What's something surprising you've experienced? Or something that, you know, when you started kind of on this journey let's say after the LSAT, you had a vision of like this is where my life’s headed. Maybe it wasn't a happy vision, maybe it was. And now 10 or so years have passed, anything interesting, unexpected, surprising that you experienced during the last like decade or so?

 QUDSIYA: Yeah! So I’m 35 now, not scared to admit it. [laughs] If I had to have a chat with my 25-year-old self, you know, I would tell them that, you have a lot to look forward to. And, you know, I honestly would not have it any other way.

EHSAN: Right. Awesome.

QUDSIYA: I think my life is totally enriched by this, and I- I think it's it's it really changed the course of my life. And I think it's-- you know, everyone has their own sort of disability inclusion journey. And, you know, some people get to a certain point or shift the way they think, some people don’t. And, you know, everyone’s experience is valid for what it is ‘cause that's the experience. But I love my-- I'm really happy that I have a blindness community that I'm a part of, and a broader, kind of, disability community that I'm a part of. And I feel that this experience has only added things to my life and not taken away. And I honestly feel like in respecting myself, I feel that I have greater respect of others and I think that *that* is really empowering and enables me to just be a better human in general.

EHSAN: Well, thanks for schlepping out here in the rain on a really cold Washington DC evening. We will put some of the stuff you've talked about in our show notes, like maybe a [link to the Uno website](https://www.mattelgames.com/games/en-us/uno-braille). Happy Holidays! Since we're close to the holidays. Safe travels, Qudsiya. I don't know if you're traveling anywhere. And with that we are near the end of another episode of *Unfair Nation*. We're probably not going to record anything over the holidays, so tune in next year for another episode of *Unfair Nation* and until then, Happy Holidays!

[whimsical, light piano chords]

**Outro:**

QUDSIYA: Thanks for listening to episode three of *Down to the Struts*! This podcast would not be possible without the energy and creativity of Anna Wu, Adriane Kong, Ilana Nevins and Avery Anapol. Special thanks to Ehsan Zaffar for sharing the audio to *Unfair Nation*. If you want to learn more about the *Down to the Struts* podcast you can visit www.downtothestruts.com, and connect with us on Twitter, Facebook, and Instagram. Also remember to subscribe, rate and review *Down to the Struts* on Apple Podcast, Spotify and Stitcher.

Thanks again for listening! And join me for episode four coming in two weeks, so we can get back down to it.

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