Down to the Struts

Season 6, Episode 6: Access and Empowered Interdependence with Haben Girma

Host: Qudsiya Naqui

Guest: Haben Girma

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**Introduction**

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[jazzy piano chords, bass strumming with smooth R&B]

**Qudsiya Naqui:**

Hi, this is Qudsiya Naqui, and welcome to the season finale of Down to the Struts—the podcast about disability, design, and intersectionality. Thank you for joining me over the last few weeks in my conversations with artists, researchers, and activists—all path-breaking visionaries who have helped us imagine a more inclusive, accessible, and just world for disabled people. It is my honor to share this final interview of Season 6 with Haben Girma. Haben is a human rights lawyer advancing disability justice.

She is the author of the memoir, *Haben: The Deafblind Woman Who Conquered Harvard Law*, and President Barack Obama named her a White House Champion of Change. A fitting end to our season, Haben and I talked about why centering access is the key to achieving empowered interdependence to tear down the ableist social and physical structures that surround us. I hope you are able to soak in Haben’s wisdom, as I did, during this interview. Ok, let’s get down to it.

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

I'd like to begin by thanking you so much, Haben, for joining me today.

Haben Girma:

Oh, absolutely. Thanks for having me on your program.

**Qudsiya Naqui:**

It's such an honor to have you, and I wanted to start by asking you to introduce yourself and, and share a little bit about your disability journey.

Haben Girma:

My name is Haben, and I was born and raised in Oakland, California. My parents are from Eritrea and Ethiopia. I'm deafblind. There's a spectrum of deaf blindness. I was taught Brail early on, and that really helped me in gaining access to the written word, and later, digital content. So I would love for listeners and readers to know that I'm not hearing and instead I'm reading the words in Braille on a Braille display and there might be a bit of a delay between when she speaks and when I respond. And that's because the typing and the Braille is still coming through. Part of accessibility is patience, holding space for all the different ways we voice and listen.

**Qudsiya Naqui:**

Thank you, Haben—those are very wise and important words and, and I think we all could benefit from slowing down and having a little bit of patience in general. I wanted to start off by asking you something, um, that sort of came to my mind after reading your wonderful, wonderful memoir, which is also called *Haben*, and I highly recommend it to all of my listeners out there. In the memoir, you start off by talking about your family's origins and Ethiopia and Eritrea, and I wondered if you could share a little bit about how your cultural background and the experience of growing up in a family of immigrants has shaped your perspective on disability?

**Haben Girma:**

There are so many layers to that question. I was born in California. I identify as a Californian and an American first and foremost, but because of my name, Haben, and my skin color and how I look when people ask me, where are you from? They don't really wanna hear California and they're never satisfied with the answer, California. So there are so many layers to what is my culture? How do I explain my culture? I am kind of a mix of what I've learned from my parents who grew up in Ethiopia and Eritrea, but I'm also very much also a mix of where I grew up in Oakland, California. So do you get that question a lot? Where are you from based on your name?

**Qudsiya Naqui:**

Absolutely. I am from New Jersey, but I am of South Asian origin. My parents immigrated to the United States from India, and also the added layer of complication with the fact that I am Indian, but I'm Muslim and half of my family migrated to Pakistan during independence and partition on the, on the South Asian subcontinent. So that, that question where you are from is complicated, but the simple answer is always New Jersey and it's, and nobody wants to accept that answer.

**Haben Girma:**

Right. Another layer to that for me is a lot of Eritreans get frustrated with me because I'm not fluent in the language and I know it's not just me. A lot of other Eritrean Americans have these guilt inducing conversations with elders who are like, why don't you speak the language? Why didn't you learn? And being deaf makes it more difficult, not impossible, but more difficult to learn additional languages.

Qudsiya Naqui:

Yes, I can. I can imagine that, that that is the case. And I imagine also growing up in California, in Oakland in particular, just in this epicenter of the, sort of the disability rights movement and disability culture, and then also at the same time, having grown up in a household where your parents immigrated from another country resulted in some, you know, just sort of interesting dynamics. I'm curious if, if that's something that you experienced and, and what that was like

**Haben Girma:**

Where to even begin. So, my parents did not know about Braille or sign language or even Helen Keller. They were learning about a lot of that at the same time I was learning about it. And I don't think that's really an Eritrea versus America thing. It's more of an access thing. Because I know there are also families in the United States who have still not heard about braille or still don't really understand what American Sign language is. And I know people also struggle to gain access to that kind of information around the world. Did your family, did your parents know about Braille?

**Qudsiya Naqui:**

That is such a great point. my, my parents did not know about Braille because I had low vision, I had quite a bit of usable vision when I was younger. The school system never offered me the option of learning Braille, so I never learned Braille. to this day, I have never learned braille and nor did my parents understand that that was available or an option or could be beneficial to me because they did not have access to that information. And I think you're absolutely correct in saying…A lot of times in the US because we have these civil rights laws and we often, uh, you know, Americans believe themselves to be very forward thinking or, or, or white Americans in some ways about disability. They sort of, Explain the fact that people of other cultures or immigrant families don't know about accessibility because of cultural barriers, but I don't think that's true. I think it's, it's not culture. It's access to information.

**Haben Girma:**

Yeah. So if I had grown up in New Jersey, there's a chance I too never would've learned Braille. By Luck I was born in Oakland and the Bay Area is the heart of the disability rights movement. I had enough vision to read print when I was in elementary school and really all through high school, but my teachers decided, let's teach her Braille. Her vision may continue to decrease, and if she has this extra tool, it could be helpful down the line. So even though I could read print through a lot of headaches and straining and struggling and very inefficiently and with a lot of stress, they still taught me Braille. And yeah, that probably wouldn't have happened in New Jersey. Other places, even in other areas of California. I've heard of deafblind students and blind students who are not taught Braille.

Qudsiya Naqui:

the fact that, I don't know Braille has, has been something that Has been on my mind for a while now and I actually ordered my first Braille learning kit. So I'm going to try to teach myself Braille through some online courses through the Hadley program, which I'm really excited about because I know I've heard from your book and from other blind friends how critical Brail literacy is, and I've really seen that as well as my vision has declined and I found myself not able to read Braille, and I'm really hoping I can change that.

Haben Girma:

Yes, yes, yes! It is hard. Your, your brain is adjusting, your fingertips are adjusting, but you tandem bike if you can tandem bike, learning to read Braille is just like learning to ride a bike.

**Qudsiya Naqui:**

That is very encouraging and a very comforting way to put it. I appreciate that.

Haben Girma:

You're welcome. That's gonna be super exciting. It'll open up so many things to you, and you'll be surprised by what you'll find yourself doing with Braille.

[Breezy musical beats with snapping fingers]

**Qudsiya Naqui:**

In the US we often think about a solution or a pathway or a way of access as advancing independence. Laws like the ADA and the Rehab Act are set up to advance independence, which often we interpret as being able to do everything yourself. But for you and I who grew up in, um, you know, uh, we are American, but we grew up in different, uh, different cultures cuz our parents came from different places and different parts of the world. Uh, we grew up in cultures that really prize and value interdependence, which as you know, is one of the principles of disability justice. What do you, what do you think the relation is between dependence and interdependence when it comes to disability?

Haben Girma:

There are some people in the disability community who shame other disabled people for not being 100% independent. That is toxic. And I, I wish that would stop. There are these notions that you are a person deserving dignity only if you can do something entirely on your own. And it's, it's a very unhealthy world. On the other hand, there are advocates in the disability justice movement who recognize that in fact, all of us are interdependent. We're all depending on other people and each other to live and, and get through our communities. There are cultures that are more focused on independence. And then there are cultures that are so focused on interdependence that people are discouraged and prevented from developing skills they could have. So for example, someone might only move around their community with sighted assistance because they've never learned how to do things on their own. I think it needs to be a choice. We shouldn't be shaming blind people who use cited assistance. We should make sure that every blind person has that choice, that they get access to orientation and mobility skills, and then get to choose, today I'd like cited assistance for this activity and not be shamed for that and recognize it's, it's a personal cultural choice.

**Qudsiya Naqui:**

I completely agree. I, I feel that once I had more, Mobility skills, more blindness skills in general, I was able to make those choices more easily, and they were conscious choices as opposed to coming from a position of disempowered dependence versus empowered interdependence. Was that your experience as you developed your, your deafness and blindness skills?

**Haben Girma:**

I had access to orientation and mobility from day one, especially starting at first grade, and I was too young to really understand what the point of it all was. But over time, those skills, developing blindness skills, cane travel skills getting comfortable talking to strangers and asking, what street is this? What bus is this? That turned out to be very, very helpful.

**Qudsiya Naqui:**

So in that sense, you were using your independent skills because you knew how to use your cane and get around, but your interdependent skills and recognizing that there's information you just couldn't get to that someone else could, could help you find like what bus it was or what street you were on.

**Haben Girma:**

A lot of that is often called independent skills, and I feel like we should drop that phrase. So for example, navigating as a quote unquote independent blind person, you're often talking to people and, and asking a bus driver what bus is this? So you're, you're working within your community. You're interacting and being interdependent with audio information from bus drivers or relying on programmers to build apps that can give you accurate g p s information on, on where you are. So you are interdependent. With your entire community blindness skills, came, travel skills orientation and mobility skills. I feel like that is more accurate compared to independent skills, which is. What it was usually called when I was growing up.

**Qudsiya Naqui:**

Yeah. I had the same experience where that was all oriented around this word independence. But I think you're absolutely right that it doesn't, that doesn't quite capture what's actually happening, um, in those interactions as you move around in space. So sort of related to interdependence, independence, and this whole conversation Over the last three years, especially, I feel like we, with the pandemic and sort of the. Racial reckoning. We've experienced the economic and financial crises over the past three years, since 2020. Um, have really rocked the world and for many people, including myself, really made me reconsider what community is and, and how I think about how interdependent the world is in general. And I wondered if you could share a little bit about how those experiences over the last three years have sort of shaped your perspective, if at all, about disability and access.

**Haben Girma:**

For one thing, I feel like the pandemic has taught us to be more stubborn and vocal in demanding for accessibility solutions. There are accessibility solutions like remote work and flexible work that some disabled people had been asking for for years, and employers would say, sorry, can't be done. Not possible. Then overnight, it seems like everyone made remote work possible during the pandemic, and that taught us a lot of things people are saying, that's impossible. It's actually not impossible, and we need to continue urging employers, schools, institutions to start implementing accessibility features.

**Qudsiya Naqui:**

Absolutely. I think that is something really hopeful and exciting that came out of this, you know, really difficult last few years that have been so challenging is this, this new commitment to thinking about the world in a new way and reshaping what we thought was just the way it Needs to be all the time. And, um, you know, as part of that, a lot of organizations have started focusing on disability, equity and inclusion. And one thing I've observed is diversity, equity, and inclusion haven't always incorporated these concepts you were just describing about access. So from your point of view, as someone who has championed access for their entire career, how does access factor into efforts towards diversity, equity, and inclusion?

Haben Girma:

You probably noticed that for the most part, when programs are talking about diversity, they're not thinking about disability, and it's frustrating that that's still happening. I remember being invited to speak at a diversity conference and I encouraged them to have captioning at the event. And then at the day of the conference, there wasn't captioning. That was very frustrating, and things like that still keep happening. What's your experience with the word diversity?

Qudsiya Naqui:

I've noticed the same thing that diversity, equity, and inclusion conversations often don’t consider access or included as a value unto itself. I would argue that access is the bedrock of diversity, equity, and inclusion. And I wondered if you had some ideas about how organizations can, can be more mindful about putting access at the forefront.

**Haben Girma:**

I wanna unpack, why aren't they putting access at the forefront? I think for some communities they feel their community deserves value on the basis of being seen as strong and a long list of physically based strong characteristics that community has contributed to society, and there's a reluctance to bring up disability. Of ableist shameful notions that just see disability as weak, unbroken, and one only gets value as being framed as strong. So I think those types of feelings and ideas keep people from really diving into disability and accessibility. And my response to that would be, We can't build up a culture that says one has value based on some notion on being strong. And if you unpack the word strong or similar words like strong, it comes down to productivity and what you can do in traditional type. In, in terms of traditional forms of work and traditional forms of productivity, that's what it's all coming down to in one's worth a community and individual's worth is being tied to productivity. So diversity programs need to unpack all of that shame and stigma and assumptions that's happening under the surface. And once we can deal with. Then we can start getting those organizations to really understand ableism and in removing ableism and fighting ableism, amplify disabled voices, particularly those working on disability justice.

**Qudsiya Naqui:**

That's a really helpful and interesting way of putting it, and it ties back to what you were saying earlier. Oftentimes access involves slowing down, having patience, and in some ways, perhaps that is sort of antithetical or the opposite of sort of the way organizations think about productivity. It's always about speed and intensity and impatience. And so I think your, your advice is really, really wise.

**Haben Girma:**

Do you have any tips, suggestions, ideas on how to get more organizations to unpack these assumptions and beliefs they have about productivity? And what kind of communities deserve attention and deserve the spotlight?

**Qudsiya Naqui:**

That's a really good question. It's a hard question. It feels like a mountain of a question. Um, but I think it. Like you said, the first step is when you have people like you and me being hired and intentionally recruited into organizations, and that doesn't mean just getting their foot in the door, but making sure that they have everything they need to be successful. I know, you know, we were talking earlier before we started recording about my work on access to court. And how I'm able to bring a disability perspective there. And, um, you know, one example is I was working on a project about, um, looking, studying in an online dispute resolution system where a court created this online platform where you could resolve your dispute without having to set foot inside a courtroom. And I realized, We were doing an evaluation of the platform, but no one was looking at whether it was actually accessible for people with disabilities, and eventually—it took a little bit of time, but the court system invested in doing a full accessibility assessment of this platform to make sure that all parties to litigation could meaningfully access and use it in the way that was intended. So, I think, when you bring in those perspectives, it forces everybody to slow down and think about access, and think about who’s missing, who isn’t getting access. And in that way, everyone is included, and also treated equitably.

Haben Girma:

Thank you for encouraging the organization to make sure they were also reviewing for digital accessibility to make sure that disabled people could also have access to justice.

**Qudsiya Naqui:**

Yeah, and and I think that you, you're right that we change that culture when more of us are present and there's more ways of being in the room.

**Haben Girma:**

We definitely do. I do wish more non-disabled allies would help shoulder the burden. It's exhausting always being the one to say, Hey, why aren't you thinking about digital accessibility? There should be more non-disabled people asking that same question.

**Qudsiya Naqui:**

I absolutely agree, Haben, and I'm always excited when I find someone who does not identify as disabled for example, providing alt text for an image without having to be asked or thinking about making sure a meeting. Live captioning without having someone who needs that live captioning have to sort of ask for it. So, um, I hope that we can eventually live in a world where we can see access without having to ask, without having to fight all the time.

**Haben Girma:**

Agreed, and it shouldn't just be in the work world. It should also be in the play world. Do you have access to opportunities to play in Washington, DC for example? I read that you go tandem biking. What other fun things do you do?,

**Qudsiya Naqui:**

I love to tandem bike and I, I also, I enjoy. In your book when you talked about your love of hiking and rock climbing, those are things that I also very much enjoy. And I am part of a wonderful organization here in DC called The Metro Washington Association of Blind Athletes, and our mission is to create those adaptive sports opportunities for blind folks in the area. So that is something that's very much a passion of mine. I also, I really. Theater and the arts, and I agree that's another area. Frankly, the art space feels to me sort of ahead of the curve when it comes to, um, making art accessible. I know the Smithsonian Museums here in DC have whole programs and departments dedicated to art access. So those are, those are just, just some things and it's always so exciting when you can go to a theater performance and have a live audio describer or go to a museum and have someone provide an accessible tour. So those are some things that I love to do for play. So I know you love the outdoors Haben, but what else do you love to do for play at where you are in the Bay Area?

**Haben Girma:**

We have a lot of great hiking out here. So I really enjoy going on trails and taking in nature. I also really like the water and activities like surfing, standup, paddle boarding.

**Qudsiya Naqui:**

That's so cool. I've never surfed before. That must feel amazing. I've always wanted to try it.

**Haben Girma:**

If you come out to California, I can recommend some awesome instructors.

**Qudsiya Naqui:**

I would love that. That would be so much fun. So havin as we, as we wrap up, I would love it if you could share where our listeners can find more about you, your book and, and anything else you want to share.

**Haben Girma:**

My book is, *Haben: The Deafblind Woman Who Conquered Harvard Law*, a lot of people have said to me, wow, you're so inspiring. You overcame your disability to go to Harvard. So I wrote my book to help teach people. I'm still disabled. I did not overcome my disability. It was Harvard that had to overcome years and years of ableism and racism and sexism, and they still have more work to do. And so there are lots of great stories in the book. It's available at most bookstores. It's available on Kindle. It's available with the National Brail and Talking Book Library and Bookshare, and many local libraries as well. I share a lot on social media. My username is @HabenGerma, and I also have a website, habengirma.com.

**Qudsiya Naqui:**

Amazing. And we'll share your social media handle and link to your website and link to where people can find the book on the episode page and show notes for this episode. So thank you so much, Hain. It's been such a pleasure chatting with you. I, I've learned a ton and you've given me a lot to think about.

**Haben Girma:**

Good luck with your Braille learning!

Qudsiya Naqui:

Thank you so much.

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

This episode was produced by Ilana Nevins and me. Our social media manager is Avery Anapol. Special thanks to Claire Shanley for designing our logo, and to Eiffel Gangsta Beats for our theme music. If you like what you’re hearing and reading, be sure to subscribe or drop us a review on Apple Podcasts, Spotify, Sticher, or wherever you love to listen, follow us on Twitter and Instagram at Down to the Struts, and join our Facebook group, Down to the Struts podcast. If you want a monthly update from me, including news from the disability community, sign up for our newsletter, Getting Down to It on Substack. If you have disability news or thoughts to share, drop us a line at [downtothestruts@gmail.com](mailto:downtothestruts@gmail.com). Thanks for listening, and see you in a couple of weeks so we can get back down to it!

I end this season with deep gratitude for all of the listeners out there.

I hope that these conversations will serve as an archive,

forever preserving the stories of the incredible disability justice champions whose existence makes the world a better place every day.

The team and I are hard at work on Season 7, which will drop into your feeds this summer.

Until then, take care, stay in touch,

and I cannot wait to get back down to it with you in a few short months.