

# Down to the Struts

Episode 2:

Host: Qudsiya Naqui

Guest: Sara Acevedo

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## Introduction

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

QUDSIYA NAQUI: Hi this is Qudsiya Naqui, and welcome to the second episode of Down to the Struts! Today we'll listen in on my conversation with Sara Acevedo. Sara is a scholar and activist and assistant professor at Miami University in Ohio. She is an expert in linguistics and her work lies at the intersection of anthropology and social change. This was a fascinating conversation about disability and the power of language.

Okay, let's get down to it...

[nice little jazzy piano pause]

QUDSIYA NAQUI: Thank you so much, Sara for joining us! I am really delighted to have you on Down to the Struts today. I wanted to start by asking you to share a little bit about yourself, your disability journey, how it led you to your interest in linguistics and your work at the intersection of anthropology and social change.

SARA ACEVEDO: Thank you so much for having me Qudsiya! I think that's a great project. I'll do my best to answer your questions. So my journey with disability -- I like to talk about my journey with disability studies, I think that makes more sense for me. I was studying French Linguistics in Spain, I was born and raised in Columbia, but I went to Spain for my undergraduate. And while I was there I had the opportunity to come to the United States to a summer camp that served disabled adults from 18 all the way to 80 or something like that. And I did that for 5 years. And then at the end of those 5 years or a little before that, I thought "you know I've you want to do justice to this hands on experience that I've had, working with the

disabled people in this sort of recreational setting.” And based on conversations I had with people who went to camp, I just really wanted to know more and actually be fully educated -- I mean to the extent possible, you're never fully educated. But I really wanted to be educated on the topic, and I decided to change the course of my professional career and I applied for a graduate degree in disability studies at a bunch of different places, but I decided to come to Philadelphia Temple University. I had wonderful professors there, and they really radicalized me. It was not difficult to become radicalized around disability politics but that's where I started, I'll say. So then my journey continued to get a Masters in Liberal Arts with a focus on Disability Studies, and that was also at Temple. Then I moved to San Francisco where I got my doctoral degree in anthropology and social change with a focus on disability justice. So that's kind of how things started.

QUDSIYA: That's a really incredible story and so much of it really resonates with me. As someone who's pretty involved in adaptive sports, I recognize the power that recreational activity can have in bringing people together in general, but also a disability community. I think as we've discussed previously when we had spoken, I graduated from Temple Law School so that's an institution that I spent some time at, as well.

So can you tell us a little bit about your activism and your scholarship, and how that was informed by the experience that you had in your education and in your life up to that.

SARA: Like I said I became very into disability politics very early on when I first encountered disability studies. It wasn't long before I was building a community and reaching out and building networks and, you know, communicating with others across disability and across other identities that are marginalized. So I started that journey in 2009, so it's been a while that I've been doing this, and I love it. I wouldn't have it any other way. I think that before really coming onto my own disability identity, I did a lot of work-- groundwork to then get me to a point where I was really ready to understand my own disability. I always knew I was neurodivergent, I just didn't have the language for it. And so I saw myself reflected in so many of my peers and in so many ways. And finally when I was conducting research with autistic community scholars and educators in Berkeley, I finally came to identify myself as an autistic person. And then pursued a formal diagnosis, mostly to have access to accommodations and services that I wouldn't have had access to if I didn't pursue a diagnosis.

And that is very controversial, right? Because it really is seeking validation from a quote on quote, “medical expert” when we ourselves know ourselves better, so much better than what somebody else could know about us based on a book, you know or a textbook or an anatomy class. I'm-- I mean I'm not saying that medical experts are completely clueless, but they are sometimes! When it comes to other people's lived experience, and especially listening, you know, listening to your own experiences in how you-- how you reflect those and how you experience those and relate them and convey them. And I had already started doing work on neurodiversity before I started my dissertation process, so I became more and more involved.

And right now my work is really fully drawing from critical autism studies and of course critical disability studies.

QUDSIYA: That's really helpful Sara. There's so much to unpack in what you just described so you-- you use the term autistic and neurodivergent a few times and I want to get back to those terms, you know, because this is a conversation about language and disability. And how we talk about disability, both within our disability communities in and also when relating to non-disabled people. And you really also touched on something else that's really important, it is that idea of the medical model of disability. Which relates to the scientific or medical aspect of a disease or condition, that people have versus the social model of disability. So for example, using my own experience, if you were to describe by medical condition an accurate description of that would be visually impaired. As I'm not fully blind and I have some usable vision so that's accurate. However, increasingly, in my own journey I have come to identify myself as blind. And I use the term blind, because it is a, sort of, sociopolitical choice that I'm making. It is an identity that I have, it's a community I'm a part of. So I noticed the same, sort of, way in which you are using these terms that, kind of, go beyond the medicalization of whatever our respective conditions may be. So I think that's really interesting.

That leads me to my next question, which is why is language important for disabled people in having autonomy and agency for themselves.

SARA: In our world in general, language is really taken for granted as just a bunch of symbols coming together to form representations of -- what it means to be human, and what it means to be alive, and what it means to exist in the world, and navigate the world. But really language has so much power, language really is an institution of power. It carries a lot of weight, it carries potential for liberation, as it has been, you know, undertaken and reclaimed by disabled communities. And it has a potential for fertilization of communities, you know. And our history is really being impacted by these labels... that are now so casually thrown around by non-disabled people in the non-disabled world, who are mostly unaware of the histories of these terms. And really have established some sort of linguistic distance from the history of these terms, which is really like a way of understanding language is a disembodied sort of phenomenon. Or-- as opposed to language being a-- being something that is grounded in history, and it's grounded in culture, and it's grounded in the different ways in which we have approached struggle and have fought against oppression.

QUDSIYA: Those are all really great points, and lead me to my next question, which is in a sense asking to provide some examples of what you were describing.

So I'm curious if you can share a little bit with our listeners about the history of the word "disability" itself, and what role is played in the Disability Rights Movement?

SARA: You know, it goes back to what you're discussing before, in terms of this stark difference between focus on the medicalization of the body, medicalization of impairment versus really a focus on the structures that really make meaning of impairment, and turn it into a negative social category through the use of labels, that are mostly, of course, medical and diagnostic. So the history of any term is not really cut and dry. It's not that easy to really look for a quote on quote, "origin of a word" or term. It has so many, you know, there are so many elements to it that are unknown to us, as with everything else in the world. But I would say that there is this transition from the medical model of disability to the social model of disability, and we are way beyond the social model of disability right now. But I would say that the first distinction that was made by disabled sociologists -- who were the ones following community efforts thinking about the social experience of disability in the UK -- was this idea that there is a distinction between the body understood as an individual problem. So a biological individual problem, and the idea of disability being a process. So there is this process of disablement that occurs when they argue the negative socialization of impairment.

But then the word, of course, is being reclaimed by our communities in ways that-- for instance the word "crip" has been reclaimed by a community. So in that sense, there is a historical transition. It's not very clear when it occurred, but it took place around the-- I would say the 80s when this difference was really made, sort of, clear. Even in activist circles and scholarly communities as well.

QUDSIYA: So most people are not as familiar with the term "crip." Can you talk a little bit about-- again as you mentioned, it's really hard to trace the history of these words to a single source. So you talk about this process of reclamation, right? So I imagine, if I understand you correctly, with "crip" it started out as being sort of a term that was used negatively, that was then reclaimed or re-appropriated by the disability communities. So say a little bit about the word "crip," what it meant in the past, what it means today. And tell us a little bit about that, because I think folks are a little less familiar with that term.

SARA: Of course! It's an abbreviation of "crippled," which refers more specifically to a physical disability. Then it's being reclaimed in such amazing ways, and then it's derived into these amazing compound words. Such as "cripdom" or "cripistemology" or so many other really iterations of the word that really disempower that negative historical connotation. And really invest the word with so much cultural meaning, and even in sensual and erotic meaning too. And it's been the components of performance art. So you think about Sins Invalid for instance, the troop of artists of color who really emphasizes or centers gender-nonconforming experiences and non-binary experiences. So it is to claim of the body, the disabled body as a sensual, sexual, erotic side of pleasure as well. So you know "crip" is really related to the Arts. It has a lot of history rooted in the Arts, as we know the term today is being reclaimed by disabled artists.

QUDSIYA: That's really interesting! I didn't recognize the connection between the word "crip" being used in an artistic concept. I've also heard of it in a political context in campaigns for example, #CriptheVote, I understand essentially connotes making voting accessible for people with disabilities.

SARA: I would say that the way in which artistic iterations of "crip" really manifests is utterly political. It is utterly political. So you know, the artistic, the political, the sensual, the body, they're all part of our history. They're an active part of the way that we appear in the world, and the way that we gather together in collectivity around our various identities. And I would say any identity that is contested is political, and of course disability is a very contested identity.

QUDSIYA: Yes! And that is a great segue into another topic that I wanted to cover with you, which is there is a lot of debate between the concept of person first language and identity first language. So for listeners not familiar with those concepts that-- that is a difference between for example, the term "person with a disability" and "disabled person."

SARA: [hums in agreement]

QUDSIYA: Likewise, when we talk about what you and I have been referring to as the "non-disabled world" or "non-disabled people," there's a debate between using that term versus "able-bodied." So can you talk a little bit about these debates, and what they mean for disability rights and for the disability culture.

SARA: Sure! I do want to say that I move away from the [disability] rights discourse, I work within the [disability] justice discourse; so disability justice more than disability rights. And yeah, sure, so you know this debate, you know, it's pretty old and it's pretty steeped in our community's history. And I've written about this before and I am constantly teaching this to my students, who come from helping professions' backgrounds that take this class in disability studies as part of their minor. And they encounter this idea that reclaiming a disability identity isn't something wrong or bad, and that disability is not a bad word that we need to get away from or hide from. Actually the contrary and, you know, this came about with the autistic movement of the 90s here in the United States, really foregrounding the idea of a process of the disablement with the force of the social model within that framework. And really thinking about how these processes are not natural or-- or transcendent but they are actually rooted--- they are constructed as opposed to just existing in a vacuum with no impact from social agents, right? So emphasizing on this idea of disablement as a process really brings this idea to the center stage that we are not disabled by our bodies themselves, but actually by the structures, and policies, and interactions, and personal and at the systemic level that really disabled us.

You know, that's also an idea that's being contested, because, you know, the very idea that disability does not reside in our bodies is actually something that is being contested by other models. Such as, the post-modern model or that psycho-social model of disability, which really understands disability as a construct but also as an embodied lived experience. So for instance, I live with chronic illness. I wouldn't say that my chronic illness would disappear if the world was more accessible. It would -- it might make it easier for me to navigate the world as someone who lives with chronic pain, but the chronic pain wouldn't just automatically just go away, right? So disability studies has really gone back to really embrace this idea of a body that is vulnerable, and that is, you know, that it feels, that it senses, that it experiences pain and pleasure and joy and sadness and all of these things that really makes us human. So there was this move to leave aside this material or corporal or carnal experiences of the body. And at a time-- at a political time that was so imperative and important to really reclaim the humanity of disabled people, that this engagement with the body or the cardinality of the body was really set aside for a bit. And then really-- really embraced it once again really forcefully within our disability studies scholarship.

QUDSIYA: So in other words, what you're saying is that the person first language is this idea of "I want you not divorced my identity, but I am a person but I have this disability." Versus identity first language, which is this embrace of "I am a disabled person, this is part of my body that I am not ashamed of."

SARA: Yeah it is and it isn't. I mean both. So with "person first" which is -- yes, it wasn't it came at a time of political unrest when actors were really trying to reassert, or even assert the bare humanity of disabled people, where we were not recognized as fully human. So that was a time to really emphasize on the human aspect of our lives. And then it came a time -- when it was really time to emphasize cultural and political aspects of our identity and our embodied experiences, because they're not separate. They work in tandem and are entangled, right? So "person first" really was historically weaponized, in a sense, to really bring awareness to the idea that disabled people were people. Wow! What a realization! And then the move to -- towards using "identity first" language was really to emphasize on disability as a process, as opposed to some sort of transcendent identity.

QUDSIYA: I really like that, because it leaves space for both of these terms, and it places everything in its historical context. So I really appreciate that explanation. And then likewise turning to the other set of terms I was mentioning earlier. I'm curious if you have a similar perspective, or could explain the idea of talking about able-bodied people versus the move to talking about non-disabled people.

SARA: Sure, sure! So this comes from the idea that, the more that we center ability as the ideal of humanity, yeah?

QUDSIYA: [hums in agreement]

SARA: The more we are than going to move away from the existence of bodily difference and bodily variation as an inherent part of the human experience, right? So, talking about able-bodied recenters disability thinking in terms of disabled and non-disabled bodies. And those can be polarizing categories, and they are. And the disability experience is so fluid, that to really claim non-disability versus disability in this stark opposition! I am wary of that. I think that our bodies are fluid, and identities are fluid. So the explanation, or one of the explanations of the push for using a non-disabled versus able-bodied, is decentering ability as the ideal of humanity.

QUDSIYA: This really tracks with my own personal experience as someone -- you used the word "fluidity," I think that's very accurate. So I am someone who has a degenerative condition, so I lost vision over time. And the way I talked about that morphed over time. And part of that was my own coming into consciousness and my own radicalization, if you will. And part it was also that my actual experience of the world was a fluid thing, and changing over the course of many years. So I think that's a really nice way of putting it and I appreciate the idea of the decentering of the able-bodied center. I think there's a parallel in our discussions of racial justice in terms of decentering whiteness as the center point of our culture.

SARA: Absolutely.

QUDSIYA: So I think there's a lot of parallels there. I wanted to turn back to something you were talking about earlier, because I think it's really important and it didn't fall into the initial scope of this conversation but I think it's a really key point and it relates to language. You talked about the distinction between rights and justice, and talking about disability rights versus justice, can you cap that a little bit more.

SARA: Sure, I mean there are so many differences and they're all so historical and it's all a matter of histories. It's not this one's better and that one's worse and this one... No! They come in certain political times within specific historical periods in which one or the other iteration of disability politics has been needed. So at the time where disability rights were really being championed by early activists, it was at a time again that our rights were not even considered to be as important as other people's rights. So it was really important to pursue that line of activism, where there would be this negotiation with the State and with the government in terms of really asserting rights that were "naturally" quote on quote "organically" granted to citizens, you know, across the board except for disabled citizens. It was important at the time to

really emphasize on this idea of recognition and rights within a structure and a legal and a policy system.

Whereas at the time where we are-- and the Disability Justice Movement has been around for a while now. And it was initiated by queer disable activists of color performers, and you know Sins Invalid group were the initiators the movement. And then it has expanded exponentially in the United States and in some other places, as well. So there is a difference between what it means to have access to rights, which exist within the political arena that relates to law and policy, and to identify with justice at every single level of our existence. So not only access to rights, but access to culture, to our own definition of culture and to our own definition of ourselves within that culture, you know. And access to political experiences and to political self-identification and togetherness and collective action, those elements are really not considered within the rights narrative. And one of the most, most important things at the center of disability justice, is that it recognizes multiple-issue politics, as was coined by Audre Lorde. She said we do not lead single-issue lives, so our politics, you know I'm paraphrasing of course, we do not lead single-issue lives so our politics cannot be single-issue politics. Disability justice really emphasizes disability at the intersection of other marginalized identities, such as a race and gender expression and identity and sexual orientation and expression ethnicity, citizenship status, religious practice, political affiliation, you know. And so many other identities that fall within those that are marginalized from conversations, not only in terms of rights but in terms of culture.

QUDSIYA: That absolutely makes sense, Sara. And resonated very much with what this podcast is trying to accomplish, which is to help people view disability as part of a multi-faceted intersectional lens, by which to look at the world. So I think that's a really great articulation and I am really glad that we were able to touch on this, and talk about the Disability Justice Movement a little bit more as it has evolved. So with all of that said, what advice would you give to a non-disabled community about using language and building a vocabulary around inclusion for disabled people?

SARA: That's another thing I'm not very much-- I don't work very much within the context of inclusion. I work with the context of access, once again because the idea of inclusion is limited to those rights, right? And to be included in a system that is set to be *the system*, right? So sitting within a structure that we did not participate in building, and in deciding. And participating as autonomous agents to me is-- it's something that I want to move away from. Not from not from the acts that further inclusivity, but this idea of inclusion as the top thing for us to achieve, versus access in every aspect of everyday life is what I really stand for, you know. And this iteration of disability justice/activist like Alice Wong, Mia Mingus and Sandy Ho, who coined the hashtag #accessislove. Access is so much more than inclusion. It goes way beyond the built environment and again it is access to political affiliation, and to constructing our own knowledge and sense of meaning and what our histories really tell about the story and the -- and the lives of disabled people in different parts of the world.



So I would say that the advice that I -- that I would give to my students as really read from disabled people. Seek materials authored by disabled people. Seek content, whether at the level of grassroots activism or the scholarly world. Pursue information that you are getting directly from the source, so to speak. There's so much mediation of disability and disability identity out there. There's always this filtering effect that disability has, because it's understood as something shameful, or we still are dealing with these understandings of disability. They're not a matter of the past, right? So there's a lot of euphemisms around the word "disability" too, which are so very offensive, you know. But these come from ignorance, you know, sometimes willful ignorance. So I do tell my students, it is so important for people who currently identify as non-disabled to seek out this-- to educate themselves, really to not rely on disabled people to educate them at every step of their journey, so to speak, into consciousness. But really to seek out the sources that will inform you, and those will be those authors by disabled people ourselves.

QUDSIYA: That's really excellent advice and your comments really were a moment of awakening for me. I think the common language of today has been, you know, has been the DEI, so the Diversity Equity Inclusion. And I love your exposition of the term inclusion as, again, inclusion into an able-centric system. And the idea of access more acknowledging that, that system that is able-centric and then creating access as an act of love. So I really-- I really like that framing. I think it makes a lot of sense. And then I just wanted to also reference the earlier about that sort of euphemistic language. So examples of that include "differently-abled" and things like that. So for non-disabled people there's actually a hashtag #saytheword. It's not scary, it's not it is a political identity and it has meaning that is powerful in a positive way and so I'm really glad you pointed that out as well. So on the point of reading, I think there is definitely a balance, people should go and seek out the information and be proactive. But I would like to ask a question, because you are a scholar and because you have such a bird's-eye view of this space, is there anything in particular at this moment you would recommend to people, any recommended reading from Sara Acevedo.

SARA: Absolutely, the first thing I recommend you go read are the [10 Principles of Disability Justice](#) by Sins Invalid and everything else that is on their website. One of their books, which is now under 2nd Edition, [Skin, Tooth and Bone: The Basis of Movement is Our People](#), is really fundamental reading for anyone who really wants to know about disability beyond what the world thinks disability is or should be.

I also recommend [Care Work: Dreaming Disability Justice](#) by Leah Lakshmi Piepzna-Samarasinha, I hope I said it right. I will also recommend the work of Mia Mingus and [Leaving Evidence](#), her blog Leaving Evidence. And Alice Wong of course. Alice Wong has a new book out there. And I mostly -- I always recommend materials by disabled people of color, because that's my closest community. I'm part of that community, and I just find that full and complete alignment with their disability politics.

QUDSIYA: Yeah and the book by Alice Wong is called [\*Disability Visibility\*](#), I recently read it at the collection of essays and it is incredibly, incredibly powerful.

SARA: Yeah, yeah and the title *Disability Visibility* right, and Alice had a huge project and it still exists in a podcast format, it existed as a FaceBook group many many years, and now the book is out there and I can't wait to read it. I cannot wait to have some space of some sort to briefly and read that book, but yeah. Thank you so much for sharing the title!

QUDSIYA: We will definitely share links to these resources that Sara has mentioned in show notes, so that folks can go back and access those materials or know where to find them and purchase them, etcetera.

SARA: So in the beginning I was like kind of warming up, and trying to get into those topics. So there's a lot of "uhhh" it's because my brain goes everywhere. Not that I have to justify, but just to share it with the people who are listening to this. You know, I also went on a tangent, which is what I do, that just-- my brain works that way. And you asked me about autism and neurodivergence and I -- I think that I answered partially, somewhat you wanted to know. But if you want to ask me one last thing about that, I can absolutely touch on that.

QUDSIYA: Wonderful! I will take you up on that. So can you tell us about the term neurodivergent and its origin and what it means to you?

SARA: Yes absolutely. So, you know, neurodivergent, specifically was coined by an autistic activist called Cassiano Sa Su Mas , and I hope I said it correctly because I have never heard it uttered by somebody else. And the term really pointing to how neurodiversity exists in the world as much as-- and it's akin to biodiversity. There is this proven scientific research that demonstrates that all of our brains are wired differently, and so the idea that the world is neurodiverse, that's just what it is. Our world is understood in terms of biodiversity and so neurodiversity is akin to that understanding. Neurodivergent, refers to the specific individual experience of that neurodiversity, if that makes sense, right? So I am neurodivergent as opposed to I am neurodiverse, this is what this activist coined and many other autistic activists have followed on that. Others simply prefer the term neurodiverse and to me that's perfectly valuable and valid, everybody gets to choose. I mean if they are part of the community I think they get to choose how to identify. And there are things I wouldn't agree with but that's not my place to tell another disabled person how to identify. That's the origin of it. And neurodiversity as a term coined by sociologist Judy Singer in the late 1980s one of the first coinages is of the word, in understanding of neurological differences, or neurological divergence. So that's where neurodivergent comes from. I say I'm multiply neurodivergent, because I'm not only autistic, I'm other things. And they're an integral part of my identity so I don't have it. I don't have them. I am it. I am them, if that makes sense.

QUDSIYA: Yeah, I'm really glad we went back and talked about that a little more. Thank you for sharing that! I personally learned a great deal from that explanation and I hope that others do as well. So with that, thank you again Sara! I will link to the materials that you referenced and to your bio as well in the show notes so that people can learn a little bit more about you. And thanks again for joining me.

[soothing jazz piano, hip-hop beat pause]

QUDSIYA: Thank you for joining me for the second episode of Down to the Struts. You can find more information about the podcast, including transcripts at [www.downtothestruts.com](http://www.downtothestruts.com). You can also follow us on Facebook, Twitter and Instagram, and please remember to subscribe wherever you get your podcasts. Special thanks to Anna Wu, Avery Anapol, Adriane Kong, Claire Shanley and Ilana Nevins.

Thanks again for listening and 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]