**Down to the Struts**

Season 3, Episode 6: Accessing the Halls of Government

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Guest: Stephanie Deluca

Transcript by Qudsiya Naqui

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**Introduction**

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

Qudsiya Naqui:

Hi, this is Qudsiya Naqui and welcome to the sixth and final episode of Down to the Struts season three. After this episode, we're going to take a break so we can create more powerful stories about disability design and intersectionality. Before we get started, I wanted to give a very big shout out to our very first Down to the Struts Foundation Patron, Jessie Lorenz. Jesse's support will help us sustain the manpower and resources to bring you many more disability stories to come. Patreon is a platform where you can support content creators, and help them continue to make the content you love. I'll share some more details later in the episode. But if you're interested, you can follow the link in the show notes or simply go to www.patreon.com/downtothestruts to join Jessie as one of our amazing patrons. Today, we'll listen in on my conversation with Stephanie DeLuca. Stephanie is a Legislative Assistant in the office of Senator Tammy Duckworth, where she works on health care and disability policy. Stephanie and I talked about her journey as a disabled scientist to the halls of Congress, how her experiences as a disabled person have informed her approach to public policy, and the need to break down barriers and expand opportunities for disabled people to inform the laws and policies that affect all of our daily lives. Stephanie's perspective is powerful and not often heard, and I hope you feel as energized by our conversation as I did. Okay, let's get down to it.

Qudsiya Naqui:

Well, thank you so much, Stephanie, for joining us for this final episode of Season Three of Down to the Struts. I'm so excited to have you today.

Stephanie Deluca:

Well, it's nice to be here. I didn't realize this is gonna be your last episode of the season. So yeah, particularly honored.

Qudsiya Naqui:

Got to go out with a bang, right. So I wanted to start off by asking you to introduce yourself. And I'd love for you to share a bit about your journey of how you went from being a scientist to working on healthcare and disability policy in our nation's capital.

Stephanie Deluca:

Yeah, definitely. It's definitely a round about journey. Okay, so first of all, I’ll say up front that even though I work in the Senate, and I work on health care and Disability Policy for senator Duckworth, I’m doing this interview on my own time with my own resources, and the thoughts and opinions expressed in this interview are my own and they in no way represent the senator or her office or any of our policies or positions. That being said, I can actually answer your question though. My name is Stephanie DeLuca. And I use she her pronouns. And I will give a brief description of myself. So I'm Korean American, and I am albino. So I have, you know, a very round face and almond shaped eyes, but my skin is very white and my hair is white, although it has some orange from a dye job from like, last year. And I'm also blind. Or some might say I'm visually impaired because actually, I've quite a bit of usable vision. So in terms of how I got from being a scientist to working on the hill, I don't know, I think it's actually interesting to think about, like how I became became a scientist to begin with. It was funny, I think I was maybe 11 or 10, or something like that. My mom was like, Oh, I know. You should be an astrophysicist. And I'm, like, had no idea what that was. And so I was like, that sounds great. She was envisioning like a life where I was like a research professor or something like that. And I really ran with that idea for like, a long time. I was like, Okay, I'm gonna be an astrophysicist. And then I took astronomy and physics in high school. And I was like, I really hate this. I hate physics so much. And then also in my astronomy class, I I was just having a really hard time with like, star charts and doing some of the homework assignments and stuff. And I didn't at the time know what accommodations to ask for, or that I should ask for them or anything like that. So I was just like, I don't think astronomy is for me, I have no idea how to do this, even though I know other blind astronomers, Oh, well. So it also at the same time, turned out that I liked chemistry better anyway. And I was also really interested in genetics. And so I was like, Okay, well, I'm still gonna try to be a research professor, but I'm going to do it, I'm going to do like biochemistry or like molecular genetics or something like that. So then, I kind of like switched course, in a way, where I like, switched my focus, but then was still aiming to go, you know, and get my PhD become a professor until about my second year of grad school, where I was like, actually, I really hate this too. And I won't go into all the details of like, why is why I hated it decided to leave academia, but through a lot of research and self reflection and informational interviews, just decided that, you know, instead of academic research, public policy seemed like a much better match for my interests, and my skill sets and like what I was good at, and then, you know, my personality, just like how I like to work. And so I did decide to stick it out and get my PhD, largely for the training just because it's so unique. But then also, there are these fellowship programs that are specifically for scientists who want to get into public policy. And most of them require you to have a PhD. And so that was kind of like my entry point into the policy world was through one of these fellowships at the American Chemical Society. And that was back in like, 2014. So ever since then, I've been just bouncing around from various policy or politics job to another until I landed in my current office back in November 2020. In terms of health care policy, in particular, that was like, largely happenstance. So I think what happened was during these these fellowship programs, they have this like placement process, and you interview with a bunch of offices, and they're like, Oh, well, what do you want to work on? And I will tell them, like, I'm, I can do whatever, you know, I could do environment, to climate to health care, you know, just, I'm here for the experience. And I think at the time, everyone just wanted someone to work on healthcare. So that's kind of how I how I ended up working on healthcare. So that just was more of a more of, by chance than anything else. Really.

Qudsiya Naqui:

Wow, that's a great story. And I think it goes to show you how people can take very circuitous paths that do lead them to the right place. And oftentimes, it's about the journey and not the destination. And I just also have to say, I also despised physics, I was physics, I could never understand physics, mad respect for the physicists of the world, because I have no idea how they do it.

Stephanie Deluca:

Yeah, definitely, definitely have mad respect for all the physicists, because chemistry is about. I think chemistry is like my sweet spot. But I don't want to go any lower, like any lower level, in that in terms of the types of particles we're talking about.

Qudsiya Naqui:

Could you tell us a little bit about how your personal story and your identity have shaped your approach to working on Capitol Hill on you know, especially on the issues that you work on?

Stephanie Deluca:

Yeah, I think we often like to think of ourselves, like as staffers as being totally objective. And we're not impacted by, we just do our jobs without like thinking about our own paths, or lived experiences. And like, I just really don't see how that's 100% true. And I don't think that's necessarily true in any job. For me, I think it plays a pretty big role in some ways. Like, I'm the type of person who likes to bring my whole self to, to the job. So I'm Korean American, I'm a woman, I'm blind. I'm a scientist. And like, I like to bring all of that to the table. And then I also it's important for me that like I work on the things that I that align with the things that I care about, I think it kind of manifests in a few different ways. So in the mornings, I'll be like, reading the news or whatever, and the things that catch my eye, or that I'm paying particular attention to or the things that like, I read them, like we should really do something about this. I'm gonna write a letter, like something like that. I think that my background and my lived experience like totally feeds into, into that that it’s kind of part of the process, if That makes sense. And then also, that view or that framing or that perspective also comes into play like, on other things, not just on the projects that we cook up for ourselves and things like that. But also, part of my job is to like review social media posts, or press releases, or op eds, and things like that. And having that lens of who I am and the experiences I've gone through, kind of, I imagined, they must, in some way inform how I filter through those communications. And, you know, also like, you know, my day job in terms of like, what I'm hearing in the news, and what I'm like hearing for constituents stuff does as well, but you can't escape, you know, who you are, when you're, when you're doing this, that sort of work. And then the other piece of it is no, like, largely internal facing. So in the policies and procedures and priorities in the office, I think this is one of the situations where it really does matter who's in the room, or who's at the table making decisions. Because, you know, as a staff, we help set priorities for the office or weigh in on what we think is important, for objectives for the next Congress and things like that. And certainly your professional once professional experience was, you know, it was probably carries more weight or the most weight in those conversations. But also, this is, you know, why we people will often say personnel is policy, because you're also setting the tone for like, these are the things that we should be caring about and should be doing as an office that employs people, and then also as an office that represents the the American people as well,

Qudsiya Naqui:

that's really interesting. And so true. I also am a believer in bringing all aspects of yourself to your work.

To that end, are there physical barriers to access you encounter while working in the Capitol building itself?

Stephanie Deluca:

to your question on accessibility, it's not just a matter of accessibility for staff, it's it's a, it's a matter of accessibility for, for members of Congress, for staff for the press for constituents, you know, it's your, as a constituent, it's your constitutional right to come petition, your member of Congress and make your voice heard. And if it's inaccessible to you than that, that's a problem. Right? You know, it's a problem when a hearing room isn't accessible to the members who are there to hear testimony or for the people who are coming in to testify. And it's a problem if, you know, there's no or no sign language, interpreters for what's happening on the on the Senate floor. And you know, it's a problem if like, constituents come in to have a meeting, and their doorways to the office are not wide enough for like power wheelchairs, and there's like, no avail available, accessible room in the Capitol, like, you know, what are you going to do in that situation? But unfortunately, these are all problems we have. I think there's a lot of issues with barriers that stem from the fact that people with disabilities just aren't often thought about with regards to like discussions on civil rights, or on diversity, equity inclusion, it's almost like, it's like, we don't exist, like people forget. And I actually kind of experienced this in a way because like I was saying earlier, I'm blind, but I have quite a bit identifies a person who is blind, but I have quite a bit of usable vision, and people have literally said, not not in my workplace, but just in general, like, Oh, I forgot you are blind. And they, I guess, in some way have may have like, internalized some practices in my life to hide the fact that I can't see well, which is kind of sad. So so in some ways, like, we're invisible to a lot of people. And then also, I think some of us at least have a lot of us have taught ourselves to make to make our disabilities kind of like not a thing to kind of diminish them. So I think that's one reason why we have all these problems. I was just reading this article in Roll Call recently, it's like a really super inside the beltway outlet. But it was saying that there was, you know, we still have a long way to go when it comes to access, like, I think they said, over 2000 barriers to accessibility on the on the Hill, just like a lot. They range from things like hand like soap dispensers that require two hands to use, doors that don't open to, you know, lack of wheelchair ramps and things like that, although that I think that article was like, last year or something. So this, this number of barriers might be lower now. And you know, we're still struggling with like website accessibility and social media accessibility as well. Not only externally facing both things, like a lot of our internal tools aren't there. accessible either for someone who say uses a screen reader and things like that. So you know, it's just, there's just a lot there. But then like outside of the physical barriers, there's also like, how would you phrase this like, it's like a cultural barrier, or a societal barrier or social barrier, where there are practices that we could benefit by changing. So for example, in the recruitment process, or in the onboarding process for people with disabilities, like saying, like, people with disabilities are welcome to apply. And if you need accommodations at any step in the process, like please let us know is like a really good thing to do, I think, you know, reaching out to groups that, you know, have a wide network of people with disabilities who might be interested in applying is also, you know, another way that we could improve access. And then there's like, a staff training component of this too, where it's like, we don't get a lot of training on how to interact with people with disabilities, and in a respectful way. I think also, there's a lack of data. So it's like, we don't even really going back to my first point about kind of being invisible, like, we don't even really know, how many people with disabilities work on the Hill. You know, I think in terms of addressing these problems, I think it's like, collecting data, and then like, appropriating funds to fix these barriers to access. And I think, you know, just raising awareness that this is a group that we should care about, and that when we're talking about diversity, inclusion efforts that people with disabilities need to be taken into account.

Qudsiya Naqui:

Yeah, those are really great concrete solutions. And and before we recorded this episode, you had shared some of those articles and roll call with me, which we can also share on the page for this episode when it releases and I was stunned at the number of barriers, and also the fact that we don't really have a clear sense of how many staff are disabled in Congress. And it's so interesting, the fact that that article, the last one you sent me, came out in 2020, which is the 30th anniversary anniversary of the Americans with Disabilities Act. And so many of the principles of that act are not implemented in Congress. And I think there's also this sort of underlying just the underlying ableism of the idea that we will make policy and legislate issues related to disabled people, but they don't belong in our halls in our offices at our decision making tables, or they don't, you know, and I think that there's a real gap there. And I think there's, there's a reason for that slogan of the disability rights movement, nothing about us without us, because it literally still is happening. Everything about us is happening without us the importance of people like you, you know, having a seat at the table and being there is so key, but there needs to be, you know, more of you. So, I mean, I think I think that's those are all really great, concrete solutions. But I think you need a coalition of people that are willing to implement them and to fight for them. And that needs sort of political will, inside and outside. I think for sure,

Stephanie Deluca:

when we're making policy, or seeking input stakeholder input, you know, we have, you know, our go to groups or people that we trust to reach out to like, what is your perspective? What is your view on this bill? Or on this letter? Or can you help me think through or make sense of this or that, but a lot of these things that we're talking about are very, like internal facing in a way, although I do think that those articles that that you're talking about, did mentioned some groups, a bit of an uphill battle to deal with a long standing internal structure. And then it's difficult to because like, the Capitol is, like, has a lot of is a historic building. And there's a lot of like, you know, folks might say, like, Oh, well, this is a historic staircase or something. And like, we can't do anything about that. Yeah, that sort of thing. So there's just a lot of bureaucracy and a lot of like, cultural barriers are to kind of overcome as well, at the end of the day, it really is like a privilege to to be working now in the US Senate on the issues that I care about. And even though on the other side, there also is like this responsibility to try to try to make it better.

[Short, cheerful beats]

Intermission:

Hi, it's Qudsiya. . I hope you're enjoying the episode so far. I want to tell you a little bit more about supporting Down to the Struts on Patreon. This podcast is a labor of love, but it also requires resources, like our audio production equipment, transcription software, our website, and most importantly, the team of talented, dedicated humans who make it all happen. With your donation, you'll be able to help us with these expenses. And you'll also become part of our community, and another voice in the movement for Disability Justice, you can support us at three different tiers starting at just $5 a month. In exchange, you'll receive access to bonus content, personalized messages from me, and exclusive Down to the Struts mirch. If you can't give right now, that's okay, too. You can still support us in other ways, like rating and reviewing us on Apple, podcasts, Spotify, Stitcher, or wherever you love to listen, you can also follow us on social media, or just share the episodes with a friend. Okay, now back to the episode.

[Short, cheerful beats]

Qudsiya Naqui:

What are your hopes for what is possible if we bring a disability conscious framework into policymaking?

Stephanie Deluca:

This is a really, really good question. You know, one of the things that really excites me about my current job is that I work on both, for example, healthcare and disability policy. And it's like, on one hand, like, why do we even classify those as two separate things? Obviously, there's like a ton of overlap. But you know, I think that I'm lucky to be in a position where I can think intersectionally, like that, I think a lot of this came out during the covid 19 pandemic, where those lines between the health care policy bucket and the disability bucket, like got very blurred. So I can't really talk about explicitly like the things that I'm working on in that space, but I will just say like, there's a lot of long standing issues, say that in this intersection of health care and disability policy, for example, where that, you know, may have been exacerbated if not exacerbated, but, but like, brought to light by the pandemic. And, for example, like access to health care, no, we heard a lot in the news about, you know, the disparities for black and brown communities and their access to health care and the racism in the healthcare system, but a lot less so about people with disabilities and the barriers that they faced, and continue to face I mean, like, physical barriers, like, you know, vaccine sites not actually being physically accessible to websites to sign up for the vaccine not being accessible to a lack of information, things like that. And then, and then, you know, there's a lot of barriers around, or concerns or issues around, you know, where people's rights, the rights of people with disabilities being respected. Another thing that's interesting is like, thinking about this intersection between healthcare and disability, like we're seeing a lot with the so called long hauler. So people are, who are, you know, have COVID infections and are now have been experiencing symptoms of like, brain fog, or fatigue and things like that for like, months after their initial infection. That's another clear intersection with both how do we improve access to health care, provide the support they need in terms of like multidisciplinary care, but also, you know, making sure this new group again, so people with disabilities are have the supports and the education that they need to know how to advocate for themselves and be like, have this where they need if they need workplace accommodations, and things like that. So being able to kind of think across these areas of policy, in a more holistic way, is something that I'm kind of starting with in the healthcare disability space, but I hope it like spills over into other spaces as well.

Qudsiya Naqui:

Yeah, that's great. And I think there are so many issues like that, you know, we had an episode, you know, from our second season with Dr. Lisa Iezzoni from Harvard, who talked about the survey that she did of physicians and their negative perceptions of disabled people. And, you know, that was really shocking that data was shocking, and I think relates to a lot of the things you were describing about access to care for disabled people, and you can't sort of separate the disability issue from the health issue. And it's, there's so many issues like that, you know, immigration, policing, it's so important to make those intersections visible to the people who make decisions about those issues. And so I think those are some really, really good examples. So, so winding down here a little bit what What advice would you have for a disabled person who wants to work in politics and policy? Now that you've been doing it for some time?

Stephanie Deluca:

I mean, I think in the end, it's, you just have to do it. Just do it, you know, if it's something that you're contemplating and don't know how to how to get started, just reach out to me, it takes some courage, right? You need to like, kind of work yourself up to it. But then like, think about all the people that you know, or who you might know, or who might be able to help you. And they might be total strangers. But, you know, you might be surprised by reaching out to folks on social media, how responsive they are. If you're saying like, hey, I want to get involved in XYZ, can you help provide advice or you know, things like that. So, I think this podcast is also a great start to kind of think through what you might need to do or do to take into account. But I think it's just the first step is not psyching yourself out, and keeping yourself from doing it. And then I think, you know, sometimes it can be helpful to think in a finite steps or kind of break it up into chunks or pieces. So, you know, you could start out small, like, getting involved in a local organization, I started getting involved with the National Federation of the Blind, like I don't, I don't know, maybe it was a decade ago or something, you know, they have all these local chapters and just start going to chapter meetings and things like that. So if there's like a organization that you identify with, see if they have local chapters, or local folks that you can reach out to and just kind of talk to them about the work that they do. That could be a good entry point to. And then if you're, you know, thinking about running for office, it's not like one office is more important than the other in a way. in DC, for example, we have tons of local advisory committees and things like that some of them are just appointed, like you're appointed to them, and you just need to reach out to your local elected official and say, like, Hey, I would like to serve on this Advisory Committee for, you know, our local neighborhood commission, or I think we, our local elementary school has like an advisory committee. I don't remember what it's actually called. And people can run for those positions that community members can run for those positions. So that can also be a good way to start. And then you can, if you want to run for federal office, you should because it's a very daunting, I think, to think about to do, but at the end of the day, you might be the first person with the disability to do it. But if you don't, then who will? So you might as well.

Qudsiya Naqui:

Well, Stephanie, this has been a delight. Thank you so much for sharing your wisdom. Thank you for your work. I'm so happy that you represent constituents in Congress, and that you have a seat at the table and you represent these issues. And it's kind of crazy to imagine that by the time this episode airs, you will have a baby. So I wish you all the best with that as well.

Stephanie Deluca:

Yeah, thank you. That'll be a whole other whole other journey.

Qudsiya Naqui:

Maybe we'll do a podcast episode about it. Again, I--

Stephanie Deluca:

There's a lot of there's so many things, I’ve been reading about parenting and things like that. And people with disabilities have their own challenges there too. And I admit I haven't read up on that as much because I guess I haven't gotten around to it. But that's like a really good one to think about. Just because it's an it's another intersection.

Qudsiya Naqui:

We'll have to have you back then.

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

Thanks for listening to this season of Down to the Struts. This podcast would not be possible without the energy and creativity of our audio producer Ilana Nevins and our digital and social media manager, Avery Anapol . A big shout out to Claire Shanley, for designing our logo and to Eiffel Gangsta Beats, for our awesome theme music. And of course, most importantly, thanks to you for continuing to listen and support the work of this podcast. Remember, you can subscribe rate and review the podcast on Apple podcasts, Spotify, Stitcher, or wherever you love to listen. You could follow us on Twitter and Instagram at Down to the Struts. And join our Facebook group Down to the Struts podcast for news special between seasons content, and to join together with other listeners in our growing community. And if you're able, you can also become a patron by visiting www.patreon.com/downtothestruts. You can also do none of that and just enjoy the conversations that you find here. Stay tuned for more fascinating episodes about disability design and intersectionality when we return for season four, until then, be well so we can get back down to it.

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