Down to the Struts

Season 7, Episode 1: New Disabled South

Guest: Dom Kelly

Host: Qudsiya Naqui

Transcript by: Qudsiya Naqui

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“oftentimes, people don't create these spaces for us as disabled people. So we have to create these spaces ourselves.”

**Introduction**

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

Qudsiya Naqui:

Hi, this is Qudsiya Naqui—creator and host of Down to the Struts, the podcast about disability, design, and intersectionality. Welcome to Season 7! Over the next several weeks,

We’ll hear from disabled activists, organizers, and media makers about their approaches to creating disability community, building power within the framework of disability justice, and storytelling as a tool for dismantling ableism. We’re kicking off this exciting series of conversations with Dom Kelly. Dom is the co-founder, president, and CEO of New Disabled South, a nonprofit organization that aims to achieve justice and liberation for all disabled people in the south. Dom and I talked about the road that led him to political activism, the birth of New Disabled South, its grounding in the principles of disability justice, and its innovative regional organizing approach. Ok, let’s get down to it!

Qudsiya Naqui:

thank you so much, Dom, for joining us on the podcast. I'm so delighted to have you.

Dom Kelly:

Thank you so much for having me, this is the best way to spend my evening.

Qudsiya Naqui:

I'm so happy and flattered to hear that. I’d love it if we could start off by having you introduce yourself and share a little bit about your story and what compelled you to this life of disability activism and organizing.

Dom Kelly:

Sure, so my name is Dom Kelly. He him pronouns. I feel like I've been in the disability advocacy space in one way or another, since I was like four years old. I have joke that my mom dropped my triplet brothers and I in front of a roomful of high school seniors and said good luck, which is like half true. She did put us in front of a room of high school seniors with a lot of support. But really, she wanted to empower my brothers and I to tell our stories as disabled kids so that other people wouldn't tell our stories for us. And the three of us were diagnosed with cerebral palsy a year old. So I feel like I was kind of thrown into the advocacy space in some way. And throughout all of the, like, different turns that my career has taken. Over the years, I've always had some, part of my work part of my my time spent in, talking about my disability, talking about the disability community trying to educate folks. And then, , at some point, in my 20s, I realized that, I really had a passion for progressive politics and passion for organizing, and that I could actually turn that passion in the work I was doing on the side as a volunteer into full time work and, figure out an actual career in this space. So that's kind of it kind of led me all to New Disabled South, and this, this organization that I just started dreaming about a few years ago and was able to actually get off the ground.

Qudsiya Naqui:

That's awesome. And your mom sounds like a total badass. So that leads me to the big question, can you tell us, what is New Disabled South? And how did you will this dream into being?

Dom Kelly:

So we are the first regional disability organization in the country, which is, I think, sad to say, we've really needed a regional approach to this work. And when I found out that there were no groups that were doing this work, from that perspective, it got me thinking, Okay, how do we solve that, that problem like, like, the problem that I saw was that so many times in this space, disability focused organizations were sort of working in silos, like they're doing great work at the state level, they're doing great work locally, or they're doing great work at the federal level. But there's often not that those connectors between them. And living in the South in the United States, I saw firsthand, my own experience in watching others in my community that, like, so many of the issues that disabled people face in this country, were worse in the South for a number of reasons. And so in a conversation with a friend, we talked about how there's no Southern strategy, we need a Southern strategy specifically. And so that that is really kind of how it started to get my gears turning. And I spent the last few years thinking about that question of how do we take a regional approach? And what is the size of the Southern Strategy look like and for disability rights and disability justice, and, you know, throughout that time was working at a voting rights organization based here in Georgia, where I got to create our disability portfolio. My first day of work there, I asked what they did around disability and there was no actually specific work to, you know, helped decrease barriers to voting and voter suppression as it relates to disabled people. And so I got to kind of build that out. And then I worked on a political campaign where I got to have a actually create an entire department devoted to disability engagement and disabled voters. And through that was building New Disabled South, putting the pieces together. And about a year ago, I started working on it part time until this past November when the election was over. And a week to the day I announced it officially. our work is really focused on creating policy change and narrative change around disability in the south, we've got an entirely disabled staff and entirely disabled governing board. Everyone has roots in the south or lives in the south. And you know, we are we are focusing on disability rights, policy work and Disability Justice, organizing, you know, focusing on a few different priority buckets, policy buckets, looking at disabled poverty and care in the south, the criminalization of black and brown and other disabled people of color, and looking at tearing down barriers to voting for disabled people in the south. So it's an orc we're organizing, we're doing policy advocacy, we're investing in research all towards this mission of Liberation and Justice for all disabled people in 14 states in the South.

[Twangy bluegrass notes]

Qudsiya Naqui:

I want to dig a little bit deeper with you DOM around this regional approach, because it's so novel and interesting, and what are the advantages of taking this type of approach? And how do you build an infrastructure around it when you're working, across state legislatures, when it comes to policy, for instance, or just across different states that might be similar in some ways, but different in others? What are the advantages of that approach? And how do you actually build it out?

Dom Kelly:

We find ourselves working in silos so often, you know, we'll have an organization in Georgia that's focused solely on Georgians. And then we have an organization in Texas working focus solely, solely on Texans and, you know, state by state, and or there's, you know, organizations working in specific cities, right. what I know to be true, and what is a principle of disability, justice is, is this idea of interdependence, and that we, we have to work together, we have to help each other. And so when I think about, okay, like the issues we have here in Georgia are not just Georgia, like, Georgia has not expanded Medicaid, I know that there are tens, if not hundreds of thousands of people in the coverage gap for Medicaid, in Georgia who are disabled, maybe they don't have a diagnosis, because we have had, you know, however many dozen hospitals close here across the state of Georgia, and maybe they don't have maybe they're in one of the nine counties in Georgia that doesn't have a single doctor, right. So like, they might not have the ability to get to a doctor if they don't have accessible affordable transportation. So like, they may not have a diagnosis. They can't get Medicaid, they can't get, you know, SSDI like there's there's they don't have the ability to have access to those kinds of services. So when I think about that, I think Well, that can't just be that can't just be in Georgia by were the were the other states that haven't expanded Medicaid. It is right now 10 states that haven't expanded Medicaid, and seven out of the 10 of them are here in the south. And that's when the light bulb went off, it was, Wow, we have an opportunity to, you know, people have been doing really good work toward Medicaid expansion, or really good work toward home and community based services funding for, you know, people with IDD in their states, but like we've only gotten so far. So how do we how do we take that to the next level? How do we actually become more effective, it's by working together. And, and I know that, you know, a person in Mississippi, their experience may be different than someone in Louisiana, they're, you know, different states. But we have very similar demographics, we have very similar, very similar makeup of state legislatures. So oftentimes, it's the same barriers that we have to that we have to get through. And so being able to bring people together, I think is really critical. with our research, right now, we're really focusing our research on this idea of, criminalization of black and brown disabled people in rural parts of, of our region. And, you know, we're thinking through what our, couple of hypotheses are around this particular issue. But, what, what we know to be true is that, you know, more policing doesn't actually help disabled people, it doesn't actually improve outcomes for specifically, just black and brown disabled people and their interactions with the criminal legal system, right. And like, we can look to data in different southern states to show that, the incarceration rate is much higher, that disabled people are, brutalized by the police at much higher rates. So we want to look at that research and be able to come up with solutions that take into consideration our entire region or similar parts of our region, so that we can start to think what are the solutions to these problems, and what's the data that can back it up? So that's kind of how we're thinking about our regional approach, it's like, we are really better together than separate, and we can solve problems better when we look at it from this through this lens.

[Twangy bluegrass notes]

Qudsiya Naqui:

I love that you, mentioned the Disability Justice principle of interdependence. So often, social and political movements and the organizations that move them forward often don't hold space for disability, culture and disabled ways of being and I wondered if you could share in terms of your internal organizational structure and way of operating how you have brought disability justice principles into the ways in which you have built your organization.

Dom Kelly:

Yeah, well, that was crucial to, to how myself and my co founder, Kehsi Iman Wilson, when we started to, think through what our culture would be, it was, it was crucial for us to have the disability justice principles right there in front of us. So we could start to build our culture off of these principles, because those are the principles that are driving our work. So, outside of interdependence to start, like, for us, it is rest, restoration, healing is all critical to disability justice and critical to having a disabled led organization with hiring disabled folks like we we know, especially in movement spaces, that burnout is just, it is it is across the board, but especially with disabled and chronically ill and neurodivergent folks like, burnout is real. And we we leave these spaces often because especially in progressive spaces, like you are expected to work around the clock you are expected to, you know, leave it on the field, so to speak, to you know, the detriment of your own health and well being and we know that that's not feasible for most of us in disability communities. So, I really was thinking about this idea. The Disability Justice principle of having an anti capitalist politic and what does that look like, in a company culture. And for us, it was, this idea of we don't put a value on someone's productivity and that their body being productive is them, it means that there are more of a valuable employee like productivity is not the goal. And we know that we can do good work, but that we don't have to kill ourselves doing it. And like we've all been, we've all come from I all staff comes from these spaces where we have literally almost killed ourselves doing this work. So we have a four day workweek where we don't work 40 hours in four days, we work 32 hours. Sometimes if that, you know, we have like, super flexibility around our schedule, we do not make people stick to a nine to five schedule, people have lives, people have things they need to do, we have unlimited PTO, that's like not just a thing that, you know, some companies do it because they you don't want people to take it like we're like, take the PTO, please take the PTO. our benefits are, fully paid health benefits, like all the things that I would want to feel like a valuable employee we implement for our employees. And that's just crucial to creating that culture and really living by our values, in terms of interdependence, like we talk about this almost every day internally in our organization that we are here to help each other. So while I am, you know, my bike by title, the President and CEO and Kehsi Iman by title is the Chief Operating Officer, I do not feel that I have any more power than anyone else in my organization that my views are weighted the same as anyone else’s. That, we are completely transparent about every single aspect of the organization, we share financial information with our employees, because we feel like it's crucial to creating trust, and all of that helps us work better together. Because that is critical to our success. So it's for us to be able to rely on each other and help each other and be interdependent, rather than independent.

[Twangy bluegrass notes]

Qudsiya Naqui:

I wondered, Dom If you had any advice for folks who want to sort of create, replicate what you've done and develop this regional model of disability research, advocacy and organizing?

Dom Kelly:

Yeah, I mean, I think it is crucial right now it is it is needed. And my advice would be advice that was that was given to me by Rebecca Coakley, a few years ago, which was that oftentimes, people don't create these spaces for us as disabled people. So we have to create these spaces ourselves. don't be afraid to create it yourself. and that was really, life changing for me. And I took that to heart because it gave me the confidence to actually not only put my ideas out down on paper, but like, actually act on them and, and my first piece of advice is like find those people who can be in your corner and help you get to the next stage. Whether that's like, I want to start a 501 C three, right? Like, I don't know how to do that. So, like, reach out to folks on Twitter, reach out to me, reach out to anyone who's done it, you know, hey, where do I start? Maybe it's Fiscal Sponsorship. Right? Like maybe it's maybe you actually do start your own seed three and you find the $600 you crowd fund it whatever you do, to get it or you find a fiscal sponsor, like there are different ways to do it. But I think it's starting with finding those those cheerleaders. Maria Towne who heads the American Association of People with Disabilities, she was you know, the first one, when i i Just like casually mentioned that I was working on my own thing. And she was like, wait, go back to your own thing. Tell me more about that. And then she was mentoring me at the time. And we just focused squarely on me putting these these plans in place for NDS and a plan for how we were actually I was actually going to, like, get this moving. And like that was just so necessary. So that's just like a, you know, that might be more general advice. And then I think if if you're really considering a regional approach, we're in what we're kind of still doing right now is like those relationships with people. You know, if you're on the West Coast, and you're like, I want to find my ally, I want to find my allies, like, you go to Cal, you talk to people in California, you talk to people in Oregon, talk to people in Washington, like, find those folks who are doing good work, ask them how they've do ne it, talk to them about your idea. Talk to them, like ask them what they need, ask them where they think the gaps are, like, bring those people into the conversation. And then do a little power mapping, like the power mapping has been critical for me as an organizer to kind of just see like, who are the players? What are my goals? How do we get those goals done? Who do we go to to get them done? In in this region? I think that's been a that was a good starting point for me.

Qudsiya Naqui:

Can you explain a little bit more what power mapping is?

Dom Kelly:

It's a it's a tool for organizing where essentially, you put, you know, you put a circle or some something in the center where like, here's the person that I want to influence, like, maybe it's a policymaker, or maybe it's the President of the United States. And then from there, I like draw a line, and I'll put another, you know, thing, and I'll put like, the President's pastor, right, it's like someone who has direct influence over him. And then I draw another couple lines. And I, like, Who do I who has access to the President's pastor, right? And then from there, you're just kind of like mapping out? Who has the power? Who has the relationships? And how can I? How can I influence those people? So in the case of NDS, it was like, you know, here's, here's my, my goal here, here are the people I want to influence. Who are the players that are out there doing this in each state? And then how do I get to those people? How do I build relationships? You know, who do I know in my rolodex that knows this person? So it's just a good way to like, kind of put your organizing strategy out on a piece of paper and think through who has the power? And and how do I get to them to be able to solve this this problem?

Qudsiya Naqui:

Dom, you mentioned a couple of the things that you're working on, what are some of your other key priorities moving forward?

Dom Kelly:

a critical issue for us right now is home and community based services, which I think I touched on briefly. So right now, there are specifically waiting lists around home and community based services. There are over 500,000 people in across our southern states who are on waiting lists for Medicaid waivers that would give them these services in their homes or communities. That's out of 656,000 nationally, so it's a huge number that are here in our region. We have been really focused on like, what are the issues around HCBS waiver waiting lists around waiver implementation? And what is our role and a getting more funding for waiver waiting lists and be I guess, sort of whistleblowing on, on some of the some of the issues that are going on in states around implementation? I know in some states people have been retaliated against people have had their services taken away from them when they did get a waiver, because so and so in this department didn't like, you know, what they had to say or didn't like something about them, like, we're trying to look at the racial disparities in how waivers are actually given out people are, are given services and taken off the waiting list. So we're really looking at HCBS, holistically, but super focused right now on trying to get more funding so that people can get off waiting lists. And coupled with that is making sure that the care workers who are actually providing the care for folks, specifically people with intellectual and developmental disabilities like that they can get, actually living wages, because here in Georgia, for example, the reimbursement rate for care worker wages for DSPs is $10 an hour and that's just not livable. And so we worked this legislative session in Georgia to try to get an increase in both waiver funding and DSP wage funding. And we were able to make some really good progress with that. Thankfully, this this session, we're not where we need to be in Georgia, but we were able to make some progress. And we launched around $90,000 paid media campaign across the state of Georgia and every major media market, to really make sure that everyone, people who probably don't even know about a waiver waiting list could understand the issue and give them an opportunity to mobilize and get involved. So I said it's a big priority for us. And then we also launched a 501 C four, called New disabled South rising. And that 501 C four allows us to do really unlimited lobbying, direct lobbying, but also just a little bit more political work. We are working through plans for next year, the presidential election year, major election year in this country, for how we get organizers on the ground in our states, how we ensure that disabled people can vote in the election next year. So we're kind of putting our a lot of our plans together, we hired an amazing assistant director who kind of is leading our C four strategy, their name is ek Hoffman, they're in South Carolina. And, and we're working through what that strategy looks like for for next year. And then, you know, overall, kind of trying to make sure that we are telling stories of disabled people across the south. So we can help change the narrative around disability, it's another big focus of ours, and giving opportunities for storytelling for people to say, what their experience as a disabled person in the South has been and what they are needing and demanding from those in power.

Qudsiya Naqui:

And for our listeners, particularly those who are in the south themselves. How can folks, where can folks find NDS and how can they get involved?

Dom Kelly:

Yeah, so newdisabledsouth.org is the New Disabled South website and newdisabledsouthrising.org is for New Disabled South Rising. And so on both of those websites, there's information on how to get involved on the NDS website, specifically, there is a an opportunity to volunteer. We're also looking for people to share their stories. So if you live in the south, and you want to share your story, we're going to try to use those stories in a bunch of cool ways. Maybe podcasts, maybe getting people to tell their stories through media, op, eds, things like that. We want to work with people to be able to actually, you know, talk about their experiences in public, if that's what they choose to do. So we're collecting stories. And then yeah, we're always going to need people who are willing to be on the ground and help organize and people who want to be a part of our coalition can sign up to do that on the NDIS website. So there are lots of opportunities to get involved. But newdisabledsouth.org is where to do it. And then we're on social media too.

Qudsiya Naqui:

thank you so much, Dom for taking the time out of all of the many things that you're doing. And on a Friday night to speak with me.

Dom Kelly:

Thank you so much. Thank you so much for having me.

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

Qudsiya Naqui:

Down to the Struts was produced by Ilana Nevins and me. Our social media manager is Avery Anapol. With special thanks to Claire Shanley for designing our logo, and to Eiffel Gangsta Beats for our theme music. Remember to subscribe, rate, and review the podcast on your favorite podcast platform,

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