**Down to the Struts**

Season 6, Bonus Episode: Judy Heumann - Reflections on the Disability Revolution

Host: Qudsiya Naqui

Guest: Judy Heumann

Transcript by Qudsiya Naqui

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

**Introduction**

[The episode opens with the sound of water rushing through a mountain stream]

Qudsiya Naqui:

Hi, it’s Qudsiya. On March 4, 2023, the disability community lost one of its most significant leaders—Judy Heumann left us to carry on her legacy of demanding that disabled people

Have the right and the opportunity to live in their communities, access employment, go to school, and so much more. And beyond being a dedicated and savvy international disability rights advocate, she was a beautiful and kind soul, a connector, and a bridge-builder. I’d like to share my deepest condolences to all who knew Judy well—those she loved, and those who worked alongside her on her lifelong journey to achieve disability rights for all. I met Judy once,

When she generously agreed to join me for an interview on Down to the Struts. We ended up chatting for several hours, and those hours were some of the most memorable of my life. She told me stories, we laughed, she introduced me to various people over email, and she encouraged me in all of my pursuits. It is my honor and pleasure to share part of this conversation as our Season 6 bonus episode. Please enjoy Season 4, episode 1, “Reflections on the Disability Revolution.” Rest in power, Judy.

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

Qudsiya Naqui:

Hi, this is Qudsiya Naqui and welcome to season four of down to the struts, the podcast about disability design and intersectionality. We're so excited to bring you six new episodes featuring guests who will share their insights about the building blocks for a more accessible, inclusive world. The first three guests of our new season were featured in Grace Bonney's new book, Collective Wisdom, a rich, multi layered collection of interviews, conversations and photographs featuring 100 trailblazing women who share the lessons they've learned by carving their own unique paths. As someone who cherishes their relationships with older women and old souls in general, I adored this book and encourage you to grab a copy from your favorite bookseller. It is my great honor to share with you all the first of three conversations with three amazing disabled women featured in Collective Wisdom. Today you'll listen in on my conversation with Judy Heumann. Judy is an International Disability Rights activist and author of the book Being Heumann: An Unrepentant Memoir of a Disability Rights activist. And one of the central figures in the film, Crip Camp. Judy and I talked about the many lessons she learned from her decades of tireless advocacy on behalf of disabled people around the world, and her vision of the future for disabled people. Okay, let's get down to it. Thank you so much, Judy, for joining me, it's

Qudsiya Naqui:

Judy, it’s really an honor to have you on the podcast, and I'm really looking forward to our conversation.

Judy Heumann:

Me, too.

Qudsiya Naqui:

So you know, in a lot of ways, your reputation precedes you, but I would love it if you could introduce yourself and tell us a little bit about some of the most important lessons you've learned in your role as part of the disability civil rights movement?

Judy Heumann:

Thank you for the question. And it's not easy to answer because there are many different answers, I'm going to be 74. So I had polio when I was 18 months old. That was in 1949. And so there are many changes that have occurred over the course of my life, some of which have been influenced by me, my friends, other colleagues, both here in United States in Brooklyn, New York City, California, around the country and internationally. One thing I would say is, I've learned that there are so many different types of disabilities. And we for too many years, and still today are not working collaboratively enough. And by that, I mean, the causes of our disability are obviously varied, even if we have the same type of disability, like physical disability or blindness, or whatever. And I've learned that if we can trust each other and learn and work together, that we're able to make advances more than if we don't work collaboratively. And that it is very important for us to be able to build trust, that we understand the types of discrimination that people may be facing, because of disability, disability and race, disability, race and gender, whatever the intersectionality may be. And that we are fighting together to end discrimination. And to be able to create a society which is really able to be trusting and valuing everyone, I think in disability also, you know, we're different than many other communities because people acquire their disabilities, short term or long term over the course of their lifespan. And I think that really has an impact on how people see themselves. Because if you've grown up in a society, or as we are all growing up in a society, which discriminates against many, but right now let’s discuss disability, you may have been one of those people who either discriminated against or didn't value or was afraid of whatever the negative thinking was. And now you're one of us. And how you begin to adapt, maintain or regain your sense of self awareness and dignity, I think, is different than when we become disabled when we're younger. When did you acquire your disability?

Qudsiya Naqui:

I was born with my condition, but it was degenerative. So I lost a lot of vision over time, most of which I lost in my 20s.

Judy Heumann:

Okay, so do you resonate to anything that I've just been saying?

Qudsiya Naqui:

Oh, yes, absolutely. Absolutely. It's definitely a process of deconstructing your own, I guess, internalized ableism. And your sense of the way the world is supposed to be or should be. And that's a journey, I definitely went through having lost a lot of vision as an adult.

Judy Heumann:

And I presume you're still going through it?

Qudsiya Naqui:

Yes, yes, definitely.

Judy Heumann:

I mean, ableism is very interesting, because I continue, you know, I'm giving a lot of presentations, because of the movie Crip Camp and my book, Being Heumann. And I find that one of the values of doing these presentations, is continuing to reflect on how I may answer questions differently. As I reconnect with some memory, some experience that I had, and ableism you know, oppression, I'm feeling less valued than others, and how I reacted as I was growing up. And I think, you know, the resilience that I've needed to develop, you know, over the years to be able to come back when someone is being disrespectful, disregarding me. And I don't mean just me, but us as a group, it's how you find that internal strength to be able to, for me respond as quickly as possible. And also, I think what's been very important is, as we do come more together, both in our categories of disability and across disability. And I think communication, in both ways is very important. Because, you know, there are experiences, and I'll just use the issue of blindness right now, because you have, you're blind, but you may, you will be experiencing certain things differently, or the types of ableism that you may be experiencing, may be similar or the same, but may also be different. And I think it's important. I think another thing that I've learned over these years, is that storytelling is really important. You know, for me, storytelling has been important for me personally, to really, as I've been saying, dig deep and really, not only articulate, but emotionally feel things that have happened to me. And I, I feel that it's important for people to know their own stories. This is not just obviously disability related. But you know, things that have been painful that have made us feel less than being able to understand what the incidences were how we how I felt, how I reacted, did I react the way I wanted to react, would I have done something differently if that same thing happened today. Those are all important and also really sharing those stories with other people. Because I think it's learning from the experiences that other people have had that also gives us new individual ideas, and collective ideas and ways of you know, organizing. And so for me over the years as we've been really strengthening our movement, it's been very valuable to learn about common issues that people face and also about ways people respond. And I think being able to provide support for people to allow people emotionally to recognize that there are other people there to help them.

Qudsiya Naqui:

Those are really valuable lessons. And I would completely agree in my own story, part of what resulted in transformation for me, coming to terms with my blindness as an adult was interacting with other blind people, other people with different types of disabilities and feeling a sense of community and you feel a sense of power in that community. And so then you feel in a safer place when you want to advocate for yourself. So I think there's, there's so much you know, truth to that, and what the thing that kind of brought us together, that led to our introduction was your contribution to Grace Bonney's book, Collective Wisdom, and you were interviewed by, you know, another disability, Kaitlyn Yang, who's another disability activist and your advice, being, you know, being bold, taking risks. And also, you know, you talked just as you did now, about the value of, you know, community, you also spent a lot of a good chunk of your life working in public service in the government, and you brought a lot, you know, you know, I read your book Being Heumann, and it was illuminating to learn more about your story, and all the people that you worked with, and when you were inside the government, from the book, you use those same principles of community, being bold, taking risks, and working in a community organizing kind of mode, what did that experience kind of reveal to you about how we can reshape and change public policy to be more accessible, more inclusive, think more intersectionally about people's lives and how to make them better?

Judy Heumann:

I think we need more disabled people and more people who are truly knowledgeable about what the barriers are that we are experiencing, the ableism the discrimination, what laws exist, how those laws are, or are not being effectively implemented. I feel that we are still not having the effects and impact in public policy, because there are not yet enough disabled people who have experienced what it means when public policy that doesn't exist, or is not as strong as it should be, or is not being appropriately implemented. I always when I was working in the Clinton administration, as the Assistant Secretary, in the Department of Ed, really talking about how every day of school lost for a disabled child, or non disabled child was a day that would never be brought back. You know, when I was asked if I was interested in working in government, in the Clinton administration, and I said that the one position I was interested in was that the Assistant Secretary for the Office of Special Education and Rehabilitative Services, I was interested in that position, in part, because there are three major areas impacting disabled people, education for children, early childhood through rehab services administration, major program dealing with employment, education, job placement, development, and what was then called the National Institute on Disability and Rehabilitation Research. All of those organizations, all of the components of OSERS dealt with major public policies, implementation of laws, funding for states, and accountability. And for me, it was a way of bringing the voices of disabled people and parents and practitioners who had a vision for how we wanted these laws to positively impact children and adults. And what was very, you know, clear to me is, there were many people who were working these government jobs, who really understood the importance of their jobs. And I would say in OSERS, we had the majority of disabled people who work in the Department of Education, work in OSERS, and that was very valuable because those of us with disabilities and many without really had a commitment. But I think for those of us with disabilities, there was this steady drumbeat of recognizing a couple of things. One thing that we recognized as political appointees, was we had a finite amount of time, that we would be in our jobs, because we were political. And that meant when President Clinton left office, and you know, you know, he's in for four years, but he could have lost and we could have been gone, there was this real urgency of being able to identify not only what we thought were critical issues, but working with the Congress on a regular basis on appropriations, and policy, legislation and practices. So bringing all of that together, was an exciting time and also scary, because at the senior level, meaning the Secretary and the other assistant secretaries, I was the only one who was an active advocate on disability, and had a disability. And so, you know, there were many ways and times that I had to figure out how, because I, I believed it was really important, that disability be addressed, not just in OSERS, but across the Department of Ed, as well as other agencies. So looking at how we can get disability integrated in in many ways, how to finesse and let people understand the importance and how we could be persistent and consistent to make this happen more.

Qudsiya Naqui:

In your, in your book, you also give an example. Give some examples of, you know, how you brought the community kind of into the decision making process while you were inside of government? I was curious what your thoughts are about that? Or how if you could tell the listeners a little bit about how you were able to do that?

Judy Heumann:

Yes, so my view was, and still is, There are things in government that you, you want to be able to get input from people. And for me, it was meaningful impact from the community, if they felt that they could be honest and open about what was happening, what was happening in the area of education for disabled children, when they were going to school, and whether they were getting the right services or not, what struggles families were having when dealing with local school districts, or what successes they were easily having. Because you know, it's both extremes, and then everything in the middle. And likewise, in the area of rehab, the agency component that works on employment, and neither the work that we're doing in research, so making things authentic and real and valuable, so that the work that we were doing, would be seen as improving outcomes for disabled children and adults. And that's really, what all of this is about is improving outcomes, advancing rights, enabling people to have their dreams and be able to realize those as much as possible. So when there are not enough disabled people who are working, now we're discussing government, but it can be foundations, corporations, wherever it's difficult to come to the table, and be able to feel an assurance that people will not only listen, but they understand what you're talking about. And in many cases, you know, really having to spend a lot of time explaining to people that though I may say this, but in reality, this is what's happening. And what responsibility do we have to try to ensure that the law is implemented effectively, to improve results? On a regular basis, I would have staff in my office, and other parts of the Department of Education. I've taught to meet with other lawyers and advocates and disabled individuals to understand what more we needed to do what the issues were, but also to learn, for example, about what was going on with Centers for Independent Living with other organizations like parent groups, the National Association of the Deaf and the National Federation of the Blind and many, many others. We would have meetings a couple of times a year with many of the national organizations to be kept informed of what was going on and to also allowed people to be critical and constructive for what we need to do better. So I think this is not just a disability issue. But people need to understand how government is working at the local level, the township, the city, the county, the state and the federal, and not to feel alienated. That was one of my jobs and my team, we all believe that we wanted people to participate. And in order to participate, they needed to feel like they were welcomed. We didn't have to agree on everything at all. And there might have been a lot of reasons where I might have agreed with something, but we couldn't get as much as we wanted for various reasons. But you want people to trust, I think trust is really one of the most critical words.

Qudsiya Naqui:

Yeah, that's so true. And I feel like that is, you know, increasingly difficult in our, our current political environment, which sort of leads me to my, the next thing I wanted to ask you, and so, you know, you your, your book, you know, being human, it really, when I read it, it read to me, almost like a community organizing manual, you know, you describe and in so much detail, which is wonderful about what it took in terms of logistics in terms of cooperation in terms of communication, to advance and to change the regulations and the laws to dismantle you know, sort of systemic discrimination against disabled people. And you know, now you've seen, you know, we've seen over the last, like 50 years, the Disability Justice Movement, kind of really pick up where the disability civil rights movement left off in many ways, and bring in all sorts of new intersecting issues that you were talking about at the top of this interview, you know, around immigration, around policing, and how those issues also affect particularly disabled people of color in a disproportionate way. And so, my question would be, you know, what advice do you have for the disability activists today who are operating in this incredibly divided polarized politics that we live in?

Judy Heumann:

First of all, I believe it's important that we, as disabled people, not only engage with our organizations, but we get other organizations, civil rights organizations, human rights organizations, etc., to really understand that the discrimination that we experience as disabled people, that people from all the black community, the Latin community, indigenous community, on and on, there are disabled people in all of those communities. And we need to have all of the communities working together, learning together and advancing our voices together. Because when we look at things like school to prison pipeline, school to prison pipeline, which shows that 60% or more individuals in juvenile facilities, for example, have disabilities, we need to have all these communities working together to ensure that children are getting services they need earlier on, that they're not dropping out of school, that they're getting the support they need, so that they can move forward, that as a group, we can be working together to be able to look at what some of the issues are around individuals who have mental health disabilities, whatever other groups that come from, look at police training and interventions that need to be used, not including the police to address issues of people who have various forms of disabilities. Ultimately, it is very important that we are at of time right now, where we seriously are looking at the issues that we're all discussing, you know, in the area of disability, were dealing with many people who have biases about those of us with disabilities. And I feel that is significantly because people are afraid of becoming like us. And when people are afraid of becoming like us, I think they are not engaging as seriously as we would like them to. And I think if we can, in the work that we're doing, help people to see that disability is a normal part of life. And that in many cases we're not. It shouldn't be seen as the disability being the problem that we need to see the problem as society and lack of laws or funding or implementation are all the above that those are the causes for our different communities, an education, employment community integration.

Qudsiya Naqui 25:06

Thank you so much, Judy, for this conversation, all of what you're saying, I agree with wholeheartedly. And I think, you know, we're in the midst of this real sort of cultural Reckoning and kind of needing to change our culture and how we think about our bodies kind of overall. You know, and I think one of one of the good examples that I always I always think about is, you know, you were talking about earlier, the, you know, how you have come to reflect on your past life and how you responded to experiences of discrimination. And I find myself doing that a lot as well. And think about how much my view about those experiences has changed over time. But one of the things I never really even thought about or noticed is that when I was in school, I didn't, I didn't learn about you. You know, I learned about a lot of things in history class, but I never really learned about the disability civil rights movement until much later on in life. It wasn't taught in my school. Also, I never had examples of strong, you know, disabled or blind characters in the literature we read, there were no, I couldn't, I didn't see myself in my education. And I think that's part of the problem, too. And nor did my non-disabled peers, I was I was in a mainstream school. And I think like if, if we, if we sort of embed and normalize, as you said, images of people who are disabled, that kind of living in the world and being successful in it, and working through the challenges of life, I think everyone would just be better off.

Judy Heumann:

Your point is really important. And that is that the lack of visibility of issues impacting disabled people from all backgrounds, not only is adversely affecting us, and our families with disabilities, because absence doesn't usually mean, there's something great, it means there's something you don't want to show something you're hiding. So basically, the limited representation. And even with the limited representation, which I want to say, on the one hand, we are beginning to see some important changes. I don't want us to get overly enthusiastic, that the little changes that we're seeing are where we need to be, because they're not. So we need to be able to recognize the numbers of people with disabilities who have been working, advancing documentary filmmaking, inclusion of disabled people in television programs, inclusion of disability in the news, you know, radio, television, social media in general. Those are all very positive things that are slowly happening. But, you know, the comment that you made, is one that I still hear over and over again, people who have majored in human rights, who say, I never said anything about disability. People who saw crip camp, when we were in Utah, for Sundance, there were thousands of people who saw the film. And the most common comment that people made was, how come we don't know this story? And my comment to them was your filmmakers, you’re documentary filmmakers? How come you haven't told the story? What I think is very important now is that we as a movement are definitely maturing. We're benefiting from laws that didn't exist before 1972. It is resulting in more disabled children, going to schools getting better education's having greater opportunities for employment, employers who are hiring, transportation systems, technology, all these things that are improving, but in saying that, we know that the unemployment rate for disabled people is twice as high as for non disabled people. We know that the benefits that many people need are inappropriately designed, because they force you to earn limited amounts of money in order to not lose your benefits, when in fact you may have additional expenses as a disabled person, and you need those benefits, but getting the general public and politicians to understand this for me over and over Again, it means we've got to tell our story. We've got to get our story out there. What do we need to organize more, we need not just only to be working with the disability groups that we believe we can work with, because we agree with their objectives. But we also need to be looking at what are our other areas of interest? Are there other organizations that we may want to be involved with in the local community, normalizing disability, and also, speaking up and out when things aren't being done the way we want, I want to emphasize the fact that I feel we need to really be looking at the intergenerational issues that we faced as disabled people. Because we look at the number of 61 million disabled people, many of those people are over 30. And many of those people may be me, because now I'm going to be 74. But you know, your mothers, your grandparents. And when, for example, my mother was a very strong advocate, when my mom got cancer, and needed a wheelchair to go outside, she didn't want to go outside in a wheelchair. And I remember how astonished I was. And I think I'm certainly not unique in this. So all of what we've been discussing today is the kinds of changes and representation in media and our jobs and laws being enforced more effectively, in legislation, like Build Back Better, being able to get money for home and community based services. And there is a problem, these are all very important. And so the same stories that I've been discussed discussing, are being repeated now, in many, many, many different nonprofits, for profits, media, markets, etc. Because as we get in, hopefully, we can overcome a fear of discussing not only our disability as it is part of our lives, it's not our whole life, but to allow people to see what changes needed to be need to be made, in order to ensure that our voices can also be amplified by having more people hired by engaging in the community, getting a better understanding of what added value can we make? And why is that half not happening now? What changes do we need to be making in order to really give visibility to the breath of the disability community, and to be able to get people to feel and recognize that we all have to be a part of this? You know, this is not something that only disabled people need to be engaged with? It's a societal change. And it also goes, as I've been saying, it's not just a disability issue. It's a systemic issue.

Qudsiya Naqui:

Yeah, I think that's, that's all very correct. Also, like getting people to think more holistically. I think there's like a lot of really good literature and kinda like the disability Legal Studies space, like kind of like, critical disability theory, that sort of very related to and aligned with critical race theory about just like, we all live in bodies, they all have stuff that happens to them. And like, we're all the same in that humanity. And like, as a result, we should give each other grace and show empathy and try to give everyone equitable access, I think is like, that's kind of like the message I always send to wherever I work, whatever I do, and I kind of try to weave it into whatever it is that we're talking about.

Judy Heumann:

I also want to make things simple. I think it's very important that disability is becoming a part of academic thought. But I want the average person on the street, to be able to engage in these discussions, to be able to understand these issues in a personal way, in a family way and a community way so that people can, in BASIC language, be able to talk about what we know they can talk about, right? What does it feel when someone grabs your arm to pull you across the street?

Qudsiya Naqui:

Yep.

Judy Heumann:

You know, what does it feel like when someone doesn't speak to you and speaks to somebody else instead of You, I think we need to really allow people to have a better understanding of what are we talking about?

Qudsiya Naqui:

Yeah.

Judy Heumann:

And yes, I think it is very important to be analytical and legal and all these things. And I believe very much in disability studies and all of these areas of thought. But I also feel really strongly that I want the majority of people to be able to understand more of what we're talking about. So that things like disability studies are recognized as something that should be going on, not just at the university level. But as you were saying earlier, it needs to be appearing in our children's books, and our classroom texts, in elementary school, in middle school and high school, and those things will not happen until there are more people who recognize that and lead by us that we are no longer accepting of exclusion. And there are various ways that we express that. Some of it is like you and like me, when I worked in government and nonprofits continuing to push on various issues. But it also is really getting other people. Like if we look at the 504demonstrations, one of the important aspects of the 504 demonstrations in the bay area in particular, was that many of the groups that were working on that were in the building that were coming to rallies every day, we had support from the Black Panthers, and Glide Memorial Church and all these local organizations that didn't necessarily have much to do with disability yet. But we had been working with them to support issues that they were advancing, and they were working with us. And so the average person on the street might more likely understand that what 504 was not what he did or didn't allow, but what they understood is we were talking about not being able to get into a building discrimination in employment. And seeing that, yes, that's a problem. But equally seeing that, oh, I know someone that's affected, or I have an invisible disability, and I'm afraid to talk about it. And if I have depression, what's happening? How do I deal with it? So it really, I think that's what we're really where we're needing to go is to get more and more people to want to be a part of this movement, to not feel afraid of adversity happening to them, because they speak out about injustice.

Qudsiya Naqui:

Yeah, and I think, especially with the mental health disabilities, there is so much stigma, I can't tell you how many colleagues, friends, people I talked to who are so afraid of, you know, the harms that could come to them by disclosing mental health disability in a workplace, for example. And I think, you know, that, and that has, that has so much to do with I mean, both with physical and mental disabilities, you know, how work is even structured, you know, does the nine to five kind of factory factory style, labor market design, we have really even work and just kind of breaking down our understanding of these systems and how they can be harmful or not actually advance productivity at all. For certain people, I think, I think we still have some mountains to climb, but I have to tell you in, in creating this podcast, even, you know, some of my family members who I never like I, you know, tried for years, who just like don't understand, they've actually heard the stories of all of my guests. And the other day, my cousin was telling me like her mom, my aunt said something like about some some situation, oh, it was like a fire pit in her house that my cousin had built. And my aunt said, This is not accessible in any way. And I don't think I had heard there was like those words out of her mouth ever in life. And so I was, like I say, I was like, I count that as a win.

Judy Heumann:

And that's exactly what I'm talking about when you're aunt, other people have learned what accessible even means, right? And to be able to identify it. And then to be able to look at what can be done not only to fix it, but to prevent it.

Qudsiya Naqui:

Because yeah, and how they can become part of the solution. Exactly. Yeah.

Judy Heumann:

And that's what I'm saying. Yeah, not all gonna be going to the classroom to learn about these theories. But programs like this are very important. because it simplifies, it allows people to engage, and to process like your aunt, and thousands and thousands of other people. They feel threatened, as Trevor Noah said, when I was on the program, and he used the word able bodied, and I said, I don't use that word. I use non disabled. And I said, because you know, you'll have a disability in the course of your life. And he said, Are you threatening me? And I said, I guess so.

Qudsiya Naqui:

Oh, that's great. I love it.

Judy Heumann:

So thank you so much for asking me to be on this program.

Qudsiya Naqui:

Thank you for doing it. I'm really happy to know you. I'm really glad I got to talk to you it's really an honor.

[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!