



ADA Live! Episode 107: Breaking Barriers for Disability Rights: Historical Reflections with Judy Heumann

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Guest: Judy Heumann, Disability Advocate

Host: Peter Blanck, Ph.D., J.D., Chairman, Burton Blatt Institute at Syracuse University

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Judy Heumann: Hello everybody. My name is Judy Heumann, and now you are listening to ADA Live!.

4 Wheel City: Yo. Hi, let's roll (singing)

Barry Whaley:

Hi everybody.

Peter Blanck:

Good day, everybody. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and the ADA National Network, welcome to ADA Live!. My name's Peter Blanck. I'm a university professor and chairman of the Burton Blatt Institute at Syracuse University. And to our listening audience, please feel free to submit questions about the ADA, at any time, to adalive.org.

Barry Whaley:

I'm Barry Whaley. I'm the director of the Southeast ADA center. We continue our celebration by welcoming our guest Judy Heumann. Judy is an internationally recognized disability advocate who has served in the Clinton and Obama administrations, was a senior fellow at the Ford Foundation. Judy's story, of course, was featured prominently in the documentary Crip Camp, A Disability Revolution, an award-winning documentary produced by the Obama Higher Ground Productions. In 2020, she published her memoir, Being Heumann: An Unrepentant Memoir of a Disability Rights Activist, which I recommend very highly. She has a new book out called Rolling Warrior that we hear is excellent as well. Judy is now the producer of the Heumann Perspective, a podcast and YouTube channel that aims to share the beauty of the disability community. As always, Judy, we're honored to have you as our guest. Our host for the series is Dr. Peter Blanck. Peter, I'm going to turn it over to you.

Peter Blanck:

Well, Judy, here we are once again, and it always is an amazing honor and privilege to be with you.

Judy Heumann:

Mutual. Mutual, Peter. It's great to be here. Thank you for asking me.

Peter Blanck:

Well, it's hard to believe 50 years have passed since you were holed up in various places, protesting that they hadn't put out the 504 regulations, with an amazing group of individuals who really changed the course of history, and for our community, in ways that have had lasting impacts and twists and turns that you and I would never have anticipated. So today we're going to talk a little bit about some of those issues, Judy. And some of the things that perhaps went unsaid about the passage of the Rehabilitation Act and some of the twists and turns it has taken. What was your state of mind, that 50 years

ago, in terms of your sense of the disability community and what you were hoping to achieve? And the follow up will be, has it turned out the way you envisioned?

Judy Heumann:

So honestly we're discussing 1972 and I was young. We were, we meaning me and other younger friends with disabilities, were really working on creating a stronger disability rights movement that was more intergenerational, but, I guess at that point, really cross disability. We had started a group in New York City called Disabled in Action. There were a number of small groups that were being set up around the country, not in any coordinated way, but programs on college campuses and community based groups of younger, disabled people who, as you see in the film Crip Camp, I think we were moving away from discussing only problems and looking towards solutions. We really, we, at this point my friends in DIA, we didn't really know what the Rehabilitation Act was. We didn't know anything about Title V because really Title V, at that point, was included as a sleeper. There were no hearings on it as opposed to ADA, and the years and years and years of public discussion and debate. That did not happen with Title V.

Judy Heumann:

Some of the people who were more involved with national organizations, and had lobbyists in Washington, were aware of what was in Title V. And we in Disabled in Action, another group called Pride, and another group was parents and doctors from Willowbrook on Staten island. So to understand the context of where we were Willowbrook State School for the, quote unquote, mentally retarded, the scandal had broken. Geraldo Rivera had been given a set of keys to come in unannounced, and done all this photography of the conditions that people with significant disabilities were living under in that state institution. And they had started a small group, and DIA, Disabled in Action, had sent a woman by the name of Bobby Lynn who has cerebral palsy and could walk. None of us could really get to Staten Island, but Bobby was able to get there. We started working with them and they were a progressive group of parents and healthcare providers.

Judy Heumann:

So it was DIA, Pride, and the Willowbrook group, and that's who really organized this demonstration. We'd never really organized a demonstration before, but we pulled all of our thinking together and decided we would go to Manhattan and we would have a demonstration outside a federal building. When we got there, Peter, it's kind of funny because I think we found the only place in all of New York City, where there was basically no traffic. There was a federal building, there was nothing else around it. We get up there, we're like ready for blood. And it is quiet. They send somebody out from the building. What did we want? Nothing was happening. So we went, we sat on the street, where there were virtually no cars, but the police had come. And so the guy in charge of the unit said to me, "What do you want?" And I said, "Where is Nixon headquarters?" And he called in and said, "Where is Nixon headquarters?"

Judy Heumann:

And that's how we decided to go and protest on Madison Avenue. And we got up to Madison Avenue, there are about 50 of us, and you can see it in the film, Crip Camp, and we shut down the traffic. But the reason I go into detail about this is, there were many, many organizations that were working on civil rights demonstrations, anti-war demonstrations, women's demonstrations. We had not really been involved with any of that, in many ways because of accessibility. And so we had images of things that had gone on, but nobody in our group had ever really organized anything like this. Although we had these great flyers. We had to get them reprinted a couple of times because once we got to Madison Avenue and we stopped traffic. People were reading the flyers.

Judy Heumann:

People were engaging, which I, for me, I remember vividly sitting on Madison Avenue thinking, "This is really interesting. People are holding these flyers." So that was like a little dingdong that this is an issue that really impacted people in a way that they were not necessarily aware. The story goes from there where we wound up then having many years of, well, another year of trying to get Nixon to finally sign the law, because he vetoed it again. There was a demonstration in Washington, DC that was, at that point, working as a disability head in Mayor Lindsey's office, had come from Chicago. A blind

activist woman and United Cerebral Palsy, and a number of other groups, what was then called President's Committee on Employment of the Handicapped. This is before they changed their name. And there was a big meeting once a year, there were like a thousand or more people who came, and we organized this demonstration to go from the Hilton on Connecticut Avenue up to the Capitol.

Judy Heumann:

Ultimately Nixon did sign the Rehab Act in 1973. So it took like six months or more before he was finally willing to sign. And our expectations, I think it's fair to say that there were probably different expectations from different people. I need to underscore that the group that I was with was mainly younger disabled people who had never been involved in politics in Washington, DC. We had some interesting stories to tell when DIA started. We heard about the President's Committee and we thought, "Oh, we should go to this. We're not just going to go down to do nothing. We need to have a discussion." You know they had all these panels. So we applied to do a panel and they wrote back and said, "We had missed the deadline." And so I'm like, with my friends, "No, no, no, this is not acceptable."

Judy Heumann:

So we looked at who the congressional delegation was, and we reached out to one of the Congress members, and he reached out to the President's Committee and said, "You will give them a room." So that was really, I think, when we all started to realize that if we were strategic, really did allow us to see, again, don't accept no all the time. And so we were learning as we were going. We were learning about what were regulations? We'd never even heard of The Federal Register, the comment period. And none of that was anything that we really knew. Our expectations began to increase, as we began to understand more clearly what this law could mean, what these regulations could mean. And looking at our own personal lives, and the experiences that we had had... For me personally, I had been denied a job by the Department of Education in New York City.

Judy Heumann:

Clearly this was before 504 was signed into law. But had 504 been in law when I had been denied my license... So if 504 would've even been an inkling in their eyes, they never would've refused me teaching because I couldn't walk. Anybody, a limited knowledge of what the law would mean would say, you can't say that's why you don't want her teaching. But there was no law. I was able to go to court with some attorneys and we, I got my teaching license. And then to teach. But that was glaring for me as an example of the kinds of discrimination that people were experiencing in employment.

Peter Blanck:

What was your relationship early on with the civil rights efforts of blacks or women? Or other groups later on? LGBTQ? Did that influence the way you thought about things? Did those groups join you? Who were some of the leaders in those groups that stick out in your mind early on, relevant to what you were doing?

Judy Heumann:

Yeah, I mean, I would say absolutely. When you look at Crip Camp, and read my book and other books, what you see is that many of us talked about how we were learning from other political movements. For many of us, we were learning about what was happening on television, reading the newspaper, listening to the radio, and learning from people about what they were doing. And at the same time, very much noticing things like the Civil Rights Act of 64 did not mention disability. And we really didn't see disabled people in prominent positions unless they were older and sitting in a wheelchair. And I think much of this was because, at that point, it was still very much a medical model going on in the area of disability, a cure model, a research model. Kids were not going to school. Job discrimination was prevalent. The one other group that really, I think we were aligning with were disabled veterans.

Judy Heumann:

We were definitely learning from anything and everything that was going on. Very much were impacted by the growth of the civil rights movement, and the history of it, and the use of litigation, and research, and how things were being done very methodically, and

how we had all these voids. You were seeing leaders in the Black community who were lawyers. My judge for my court case was Constance Baker Motley. Our case got settled out of court because Judge Motley basically said, to the school district, "I encourage you to review this case." And so they did give me another medical interview. So it was like really very fortunate that we had Judge Motley as our judge, because of her experience, both as a black woman, the first black woman federal judge, but also because she'd been involved in litigation in the area of civil rights and working on discrimination issues in the area of education and other areas. So absolutely very influenced and learning.

Peter Blanck:

What was in your mind, did you have a glimmer of an ADA in the future or how did you begin those relationships?

Judy Heumann:

I mean, I think if you look at the seventies, which is 504 and other Title V provisions, we were looking immediately at getting regulations, getting people educated, beginning to use it. And we were very clear that Title V provisions, in 504 in particular, were not comparable to the Civil Rights Act of 64. And it was very clear to us that the lack of a movement that was strong, like the civil rights movement, meant that we were going to not be able to engage and get things as quickly as we wanted.

Judy Heumann:

What was the importance of the Centers for Independent Living and why should language be included in the next reauthorization of the Rehab Act that would fund 10 centers nationally. Things like Centers for Independent Living, which would be disabled run organizations, was really turning things on their head because there was growing resistance from the disability community to organizations that were working on behalf of disabled people, but did not have disabled people on their staffs or on their boards.

Judy Heumann:

So really in the seventies, there was this growing strengthening of a disability rights movement. Now, as far as you were asking me a question about working with members, I think for me, it was just something that was gradually happening. Certainly with the 504 demonstrations, and of the work that we were doing in Washington, we were calling on staffers and members who I had worked with. But certainly again, because we've been working with people in many of these offices, a lot of what was happening was also within the offices themselves, where the staffers there really understood the issues and were working for the issues. But I firmly believe that the demonstrations that we held in DC, and in San Francisco, and around the country really gave a push to them not making changes to the regulations.

Peter Blanck:

Looking back now, would you have done something differently? Obviously you were learning as you were going. That's clear. You were making connections and building a coalition. That's clear. Could you have foreseen the move towards, the such extreme and political environment we move towards, since passage of the ADA? Or maybe it has nothing to do with the disability rights movement, maybe it has everything to do with the movement of difference and civil rights. But how did we get here? And where is the disability movement at in the here, now?

Judy Heumann:

Interesting discussion. We are in such a different place than we were 50 years ago. In part, because there are so many categories of disabled people, who previously were just looking at themselves in a medical category, who now are really seeing themselves as needing to be a part of the disability rights movement. And the movement itself, in addition to expanding in the area of disability, is also engaging much more the whole issue of diversity. So racial diversity, sexual orientation diversity, religious diversity, it's kind of like an explosion that's going on. And you've got all these different groups around, and how to help people come together, look at our issues and the common ground that we have. And of course all these new issues, global warming, and the environment, and famine, and all these additional causes of disability around the world. I personally, if I'm

understanding a question correctly, never dreamed that we would be living in a country where there is such division.

Judy Heumann:

I really did, naively speaking, feel that at the end of the day, the tensions that exist have always existed. And that's, I think healthy in a democracy. Not everybody should have the same perspective and they don't. And we should allow people, not even allowing, but one needs to be able to express one's views, have healthy debates, and look at how to move forward. I think social media clearly has played a very strong role, both positively and negatively, in how information is shared, constructed, helping people look at how do you determine fact from fiction.

Judy Heumann:

All these changes happening so rapidly are really causing great turmoil that does concern me a lot. But I am consistently inspired by the younger group of disabled people. My view is that we need to be not only a stronger cross disability movement, but we need to be a stronger intergenerational movement. Because the numbers in the area of disability increase as people get older. But we're still dealing so much with stigma, discrimination, of people being afraid to identify, or not wanting to be seen as having a disability because they believe they'll be perceived of as lesser than.

Judy Heumann:

I mean, my mother, I mean, God knows my mother was an amazing advocate. When my mother got cancer, she wouldn't go outside in a wheelchair. She didn't want to be seen in a wheelchair. And only a few of my friends could go and see her and say, "Elsa, we're going out." And so if you have people, like my mom, who were such strong advocates for me and for others, feeling that they are not perceived of the same way as they were before, and not wanting to engage, I think these are fundamental issues that we have to be discussing much more deeply.

Peter Blanck:

Yeah. And certainly true my own experience in the mental health arena as well, which many people, my own family and others, you never think of yourself as a person with a disability. You think of yourself with bipolar or depression or, but not as an identity in some sense. I wanted to ask you,

Judy Heumann:

But I want to say-

Peter Blanck:

Yeah.

Judy Heumann:

But I want to say that's changing. I think that's one thing that's very important, that people with mental health disabilities, never everybody. But I would say again since the seventies, our experience in Berkeley, was that people with mental health disabilities, as a result of people like Judy Chamberlain and others, who were seeing themselves as a part of the disability community, that was very important. CIOs that are including people with mental health disabilities, serving people with mental health disabilities, and looking at the fact that our disabilities may impact how we do things. And I may need a ramp and some with depression may not. But at the end of the day, if we are being denied, if we're being discriminated against, it's important that we can speak for each other. And I think that's really one of the important aspects. If you look at groups like the American Association of People with Disabilities, and the breadth of the people who are involved, and their internship programs, where they have people with all types of disabilities, all racial backgrounds, I think that's really the model that we're moving towards.

Judy Heumann:

And I feel that it's the right direction. And now what we have to be able to really, Peter, is keep being positive that some of the very tragic things that are happening right now are things that we have to combat. And we, regardless of our age or disability, need to really be a part of the voices that are rational. That really do want to live in a world where all

people are treated fairly, and equally, and where rights and justice are something that we believe in and fight for. But I want to say, on the issue of voting, why I feel it's so very important that we continue to fight against the same group of people that are fighting to take rights away from people, significantly poor and minority and disabled individuals. We need to be able to take back our country in a way that really, that respects each individual person's rights, and right to vote, and right to participate.

Judy Heumann:

I think one of the important parts of ADA Centers is how work that you're doing is really there to help people not only learn about their rights, but to learn about what to do if their rights are abrogated. And voting is certainly a critical issue. It's a nonpartisan issue. We need, as a society, to recognize that if we truly want to be a democracy, and one that other countries can look to and say, "This is what democracies look like and can achieve. And how democracies can struggle and over time ensure that the population across the board is being able to participate equally within the country."

Peter Blanck:

Thank you, Judy. It really is an unbelievable honor and pleasure to speak with you. I could sit here all day for our listening audience. This is not scripted, what Judy and I have been talking about. And I would really suggest strongly that you take a look at her book. You take a look at her documentary, *The Crip Camp*. We will post information about that for you. We reach thousands of people across the country.

Peter Blanck:

So Judy, I want to thank you very much for being Judy really. I don't know how else to say it. I want to thank our listeners also, because we all will be enriched by this episode. For questions and comments on this podcast, please submit them anytime to adalive.org. You can access all ADA Live! episodes on our website at adalive.org. Every episode is archived, stream, video, transcriptions, resources, and we're definitely going to get, Judy, your book and videos posted. And you can listen to it on SoundCloud, soundcloud.com,

ADA Live! channel, or download it to your podcast. Thank you, Judy. And God speed to you.

Peter Blanck:

ADA Live! is a program of the Southeast ADA Center. Our producer is Celestia Ohrazda with Beth Harrison, Mary Morder, Marsha Schwank, and Barry Whaley, our fearless leader. Our music is from 4 Wheel City, the movement for improvement. Thank you all and have a great day.

4 Wheel City: (rapping)

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