



## **ADA Live!**

### **Episode 82: History and the Future of Disability Rights: A Conversation with Judy Heumann**

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**Speaker:** Judy Heumann

**Host:** Peter Blanck, Burton Blatt Institute at Syracuse University

**Judy Heumann:** Hello everybody, my name is Judy Heumann and now you are listening to ADA live.

**4 Wheel City:** (rapping)

**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 anytime to [adalive.org](http://adalive.org).

**Peter Blanck:** Our guest today is an extraordinary American and really world citizen, Judy Heumann, who I have known for 30 plus years and who is perhaps among the most influential figures in the area of disability rights in the United States. She's been a lifelong advocate for the rights of people with disabilities, an international leader, on the cover of Time Magazine in the 1970s, worked in the State Department, began the Independent-Living Movement, Co-Founded with Ed Roberts and others, the World Institute on Disability, and I could go on and on. Served in the Clinton Administration as an Assistant

Secretary in Education, served as the World Bank's First Adviser on disability and development, served in the Ford Foundation as an advisor on disability rights. And so Judy, it's a terrific honor to be with you particularly at this time. Welcome.

**Judy Heumann:** Thank you very much, it's great to be with you. Let me just make a little correction. So this year, 2020, Time Magazine highlighted 100 women from 1920 to 2020, and I was listed as the woman of the year in 1977, which was the year of the demonstrations at the Health Education and Welfare Building in San Francisco. So it didn't take place in '77, the highlighting took place in 2020.

**Peter Blanck:** Judy Heumann, who's been recognized globally is truly a leader and a great American. I've had the privilege of knowing Judy for many years. It's interesting to speak with you, Judy, particularly at this time from New York city, the day after my first grandchild was born, in an environment where people with disabilities are perhaps in the most dire circumstances that we have ever seen in our lifetime. And I was wondering if... I will ask you about all the amazing things you've done and accolades, but at this 30th anniversary of the ADA in particular, what is your view of how as a community, we can come together, both people with and without disabilities, and address the terrific challenges that we face today as a country and as a world.

**Judy Heumann:** That's a great question. I got involved with the Disability Rights Movement many, many years ago, and it was really because of the discrimination that I was facing and other disabled people are facing, and recognition that in order to address problems of discrimination that I was experiencing, we needed to work together and I think that really reflects where we still are today. While over the last 40, 50 years, there's been important progress that has been made, I think when we look at the current situation in the United States and around the world with COVID-19 and the overall pandemic, we can see positive and negative. The positive I would say is the terrible things that are happening, the higher rate of death amongst disabled individuals in particular, those living in segregated living environments and nursing homes, and those individuals who are poorer and have poorer health outcomes because of inadequate healthcare, et cetera.

We at least have a stronger disability community today that can be litigating against states that are trying to flip through policies that would put the lives of disabled people at risk based on disability, that the community has been able to get HHS to put a policy out that stipulates that it is the responsibility of healthcare entities to ensure that disabled people are not being discriminated against under the ADA or section 504. Those are all very important things that I think that's, in part, the result is that we're seeing of an increasing disability rights community in the United States who is able and more effectively armed to act rapidly.

**Peter Blanck:** Thank you, Judy. Also at this time, it's certainly important to reimagine, as you say, how this community moves forward. I had the great privilege, of course, of reading, your book about Being Human, of course have watched the documentary about Crip Camp, that we can talk about your time at Camp Jened when you think about that long history and what you've accomplished, and I do want to talk about it, what are your feelings about this next generation of people with disabilities and the leadership who are going to be the next Judy Heumann's over the next 30 years of the Americans with Disabilities Act, and how are those folks emerging and being supported to emerge?

**Judy Heumann:** Well, I'm very proud of the amazing group of young, disabled people who are really moving forward and advancing the movement, taking the reigns and are doing work in many different arenas. And I think it's also really, for me, very important that many of the people in leadership positions are in fact disabled women, and disabled women who are being recognized for the work that they've been doing. I think if people like Maria Town, who is the Executive Director of the American Association of People with Disabilities, who is about 32 years old, has been doing incredible work, first in the White House under the Obama Administration, then as the Head of the Houston Mayor's Office on disability, and now as the Executive Director of the American Association of People with Disabilities.

I think of people like, [Sarah min Carro 00:07:27], who is a disabled Muslim woman in Boston, who is leading an organization called, EIT, is graduated from Harvard and from MIT, was recognized as one of 30 women under the age of 30 for their entrepreneurship

work. I think of people like Katherine Perez, who's leading the Coelho Institute at Loyola University in California, and the class that they've just graduated of young, disabled individuals with incredible diverse backgrounds, who are moving forward into the field of law or public policy. I think of people like Conchita Hernandez, who is a disabled blind woman who originally is from Mexico and now is living in DC, getting her PhD in Special Education, the Director of the Office for Services for Blind Students in Maryland and heading up an organization, working with families, teachers, and disabled individuals in Mexico who are blind.

And so many other people who really are moving forward, people like Rebecca Cokley, who is now working for the Center on American Progress. And Rebecca, I think, has an amazing history. She started out working at Victoria's Secret, she's a little person herself, and then moves forward into the Disability Rights Movement. Her last position before she went to the Center for American Progress was as the Executive Director for the National Council on Disability. What I think is very important about the position that Rebecca Cokley now has at CAP is the fact that CAP, which is a very progressive organization, has integrated disability into their overall work. And I think that's very, very important, that we are looking at the strengthening of the Disability Rights community, both through the work of the disabled people's organizations, but also working within organizations like CAP that are very influential in many ways. And now that they have this section on disability, it's responsibility also is to work across the organization to get disability integrated beyond just things that are disability specific, and I can go on naming many other people.

We've got organizations like the Disability Rights, Education and Defense fund, which was one of the key groups working on the ADA. And then if we look at the international level, we have organizations like the International Disability Alliance, which is led by Vladimir Cuk, and they are the preeminent international group right now with 13 international DPOs, groups like the World Blind Union, the World Federation of the Deaf Inclusion International, on and on, and their organization is really leading efforts at the United Nations on implementation of the convention on the rights of persons with disabilities. We have people like Catalina Divine [inaudible 00:11:03] special on disability

based in Geneva from Costa Rica. And because the convention on the rights of persons with disabilities has been very strongly influenced by the ADA, I think it's really important for us to recognize that while the ADA has direct benefit in the United States, it really has been an important instrument in driving civil rights and human rights for disabled people around the world.

**Peter Blanck:** That's an amazing answer, Judy, and clearly your legacy is cemented by this next generation of fantastic individuals who are picking up the torch. But going back in time and there's so many different achievements we could about, but when you were first starting out Heumann versus The Board of Education of City of New York, which was of course a seminal effort, of course, the protests in 1977 with regard to the enforcement of the section 504 regulations, who were your mentors? Who did you look to in this beginning civil rights movement that helped you see your course?

**Judy Heumann:** I think it was very much, for me, both my parents, in some way, Mrs. Roosevelt, but also very strongly the Civil Rights Movement, people like Dr. King and other leaders in the movement at that time. And people like Rosa Parks, who refused to get off a bus, and really ultimately resulted in black people being able to ride on the bus wherever they chose. Now, what was important for me about that movement was that it enabled me to learn a number of things, the importance of believing that we had a mission that was right, believing that we could use the word discrimination, that we didn't have to continue to say things like, "Oh, they didn't mean it. They didn't understand," or, "Oh," whatever the, "Oh," would be. It was very much looking at the ability for the Civil Rights Movement to organize people, to have a broad agenda, to be looking at integration in the most in depth way, and also to be looking at the ability to change society.

To recognize that the color of one's skin, from our perspective, the ability to see and hear and walk and think in a traditional way, but to be able to do things differently didn't mean that we were lesser people. And that still today is a message that I live by and I think is a very important issue, because in the United States today, according to the CDC, we have 56 million disabled people in the United States. Many, many of, those of us who have disabilities, are still not yet identifying, either to ourselves or openly.

I think it is imperative that we own disability as a part of who we are, and that in owning it that we can speak up and out it so that we're not alone. So that we're able, when working, to discuss the need for accommodations. That we don't have to feel embarrassed about needing an accommodation and we feel like we have a right to be able to ask for it and work with the employer to get it. That we have a right to an education. That IDEA and 504 and ADA laws really require that disabled children receive education in the least restrictive environment. People need to understand if their child may have a disability, they need to understand how their child can get services.

And it's very important for the parents to be able to believe that their child has a future and that part of that future is by becoming a part of the parent movement, the Disability Rights movement, to also ingrain within your children the fact that disability is a part of who they are, and it is an important part of who they are. So I think we are moving forward, but again, we have so much more that we need to be doing. And I think Camp Jened, which is discussed in my book, *Being Human*, and in *Crip Camp*, you can see in both the book and the film the importance of us as disabled people coming together, learning and supporting each other, recognizing that discrimination was limiting our opportunities to advance, and that we were the ones that had to take responsibility for addressing these issues.

**Peter Blanck:** Thank you, Judy. A couple more questions just because it's such a thrill and pleasure at this time, particularly for me, to talk with you. So obviously we live in a very politicized litigious time, would you say that it's really different climate than what you grew up in terms of your advocacy? And if so, are there different ways of doing civil rights business today than there have been in the past?

**Judy Heumann:** Today is different than what I've experienced in my life. I mean, obviously the pandemic has really thrown life in the United States and around the world into a very different place. And we are meeting while trying to get our balance, so to speak, in whenever the new normal is going to be, have to really make sure that we maintain our ultimate belief in our rights as disabled people. And we need to, even in a more virtual world, which I think we're doing pretty well, look at ways of bringing stories

forward, look at ways of continuing to organize. I think the elections in 2020 are going to be pivotal because I personally believe we need leadership that understands the needs of disabled people and understands the rights of disabled people, and that there is a responsibility of the U.S. government to make sure that we don't stomp on the rights of disabled people or people of color or people from different sexual orientations or religions or on and on, respect for our society overall.

I do believe that the work that we've been doing over the last four to five decades, which really has been working more collaboratively with other movements and other movements with us, particularly now, people are seeing that disability is something that can occur at any time. Certainly for some of the people who are being infected by the virus, they will have longer term disabilities, and I hope that this is really, I don't like using the word, hope, but I want to really believe that people will begin to look more carefully at issues that we have been fighting for.

The need for more money for home and community-based services, the need for people to be able to live in their home, their own home, and not to have to be placed in segregated nursing homes or congregate living programs. People need to understand that the data that we're seeing, which is showing higher incidence rates of people dying because they're living in these segregated environments, that we as a society have an ability to make these things change. And we have to recognize that we are all equal within our country and we should not be prioritizing one life over another because we believe that someone with a disability's life is not equally valued.

**Peter Blanck:** If you look at the recent jobs numbers in April, Judy, as you know better than I, there is a disproportionately high number of people with disabilities who are now out of work, 30 million people unemployed in the United States. What can we do as a community to begin to address some of those issues?

**Judy Heumann:** Well, we have to be a part of the whole, I mean, that's one of the points that I'm making. Right now a lot of times we've been kind of at the end, right, the last tire, the first buyer. We're looking at how jobs are going to be changing, what training people are going to need for new jobs, how are we going to be really reinventing our workforce?

We have to make sure that disabled people are not the ones that are thought about last. You have to look at the people who've been in the workforce and people who want to move into the workforce and make sure that we are at the table, that we are not somewhere way up on the side not invited to the table, that I think is a really, really critical issue. As I said earlier, I believe we have stronger voices now. We're not as strong as I would like us to be, but I do believe that we have more knowledge, we have more people in the Congress and state and local governments understand disability in a way they didn't in the past.

I'm not saying I'm not trying to paint a rosy picture at all, but I think they at least know broadly. So we at the city, county, state, federal levels, as well as within the public and private sector on the issue of employment. We as disabled people need to be really demanding and pushing that we're at the table to be ensuring that we are included. I think we need to look to mayor's offices on disability with people like Victor Calise in the mayor's office in New York, that they need to be given the authority to be able to have meaningful participation in what's going to be going on within a large city, like New York, likewise in LA and San Francisco and Chicago and Houston and other cities.

The centers for independent living are definitely a critical voice in all of this, the protection advocacy centers on and on. I would like that we don't have to see litigation as our first tool, but I definitely feel like our ability to use litigation when needed is critically important. And I hope that some of the good work that's been done over the last number of decades will be recognized, and that employers will really see that disabled employees have been a benefit for their companies, not in a trivial way, but in a meaningful way, and that our country is becoming more and more diverse. And that disability is a part of that diversity, and disability is part of black disabled people, LatinX disabled people, Asian disabled people, gay and lesbian disabled people, on and on

**Peter Blanck:** My psychological makeup Judy is, as you know, I'm sitting here in New York city, looking at my new granddaughter with terrific joy, but wearing a face mask and watching social distancing in this city. What's your message, what's your final message

for hope and optimism? You've said so many positive things, which reflect that at this 30th anniversary of the ADA, how do you tell us to March on?

**Judy Heumann:** We tell each other. We tell each other that we know that our messages are correct, that the ADA was a pivotal piece of legislation, it needs to be implemented. We need more legislation for things like more money for home and community-based services that enabled disabled people to live in the community, to work in the community, live in the community regardless of their age, and regardless of their disability. That we need to speak out as disabled people. We need to look at whether we've been a part of this dialogue, and if not, we need to begin to become a part of it, at the dining room table, within the religious communities, on your block.

As things open up, really be proud of the fact that you may have a disability visible or invisible. Reach out to local organizations to become acquainted with and friends with other disabled individuals and parents with parents. And we can, as we move through this really difficult time, I do believe if we're vigilant and forceful and I want to really underscore courseful and vigilance, that we will come through this, and as a movement, we will be stronger.

**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. So Judy, I want to thank you very much for being Judy, really. I don't know how else to say it. And 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](http://adalive.org). You can access all ADA live episodes on our website at [adalive.org](http://adalive.org). Every episode is archived, stream video, transcriptions, resources, and we'll definitely going to get, Judy, your book and videos posted, and you can listen to it on SoundCloud, [soundcloud.com](http://soundcloud.com), ADA live channel, or download it to your podcast.

We were given one assignment and that was to reflect upon perhaps some of our most meaningful memories during the period of the ADA, during the past 30 years. For me, Peter Blank, the most memorable elements of the ADA, or years of the ADA, has been looking into the eyes of the children like [Jayon 00:26:56], who was trying to be sent to a segregated learning environment. Or Sarah Kay, who was living in an institution, and then lived at home with her parents successfully. And all the thousands of children, we and others have worked with, to show them and help them achieve a better world, a more inclusive world, that was welcoming and a sense of belonging. You will be hearing from the seminal person with regard to the ADA and other areas. For closing words, I thank you all for listening and it's most appropriate that we close with the words of Judy Heumann, Judy.

**Judy Heumann:** So I want to first say that what's been incredibly important for me is to be a part of an ever-growing Disability Rights movement. That to me is really one of the most seminal moments, seeing younger, disabled people saying that they're part of the ADA generation and recognizing that they have the law, but it isn't going to get implemented effectively without all of our voices. And also to be able to look at other legislation that needs to be developed, like home and community-based services.

One of the other seminal moments for me was when Michael Winter, who unfortunately has passed away, who was one of the directors of the Berkeley Center for Independent Living and then work at the Department of Transportation, told me that as a result of the ADA, all of the buses in the United States have become accessible. That to me as a wheelchair rider was incredibly momentous, and I want to thank Adapt and all the other centers for independent living that had fought so hard to make that true. Thank you all very much. And seminal moment will be when 56 million disabled people acknowledge that we have disabilities and that we're proud of who we are and that we can really make the impact in our country and around the world that we deserve to make.

**Peter Blanck:** Thank you, Judy and Godspeed to you. ADA Live is a program of the Southeast ADA center. Our producer is Celestia Ohrazda with Beth Harrison, Mary Mortar, Emily Rueber, Marsha Schwanke, and Barry Whaley, our fearless leader. Our

music is from Four Wheel City, the Movement for Improvement. And we very much look forward to seeing you and being with you on our next episode with our special guest who Judy mentioned, the honorable Tony Coelho, who was crucial in the passage of the Americans with Disabilities Act, I should say the honorable Tony Coelho, in our celebration of this 30th anniversary of the Americans with Disabilities Act. Be well and safe and hopeful in this time. And we must stick together, as Judy said. Thank you all and have a great day.

**Barry Whaley:** To celebrate the 30th anniversary of the Americans with Disabilities Act, the ADA, we ask you to share your #thankstotheADA moment. The ADA National Network is asking everyone to share a moment in their lives when they were thankful for the ADA. On a social media platform of your choosing use #thankstotheADA and share what the ADA means to you. (lyrics)

**4 Wheel City:** (rapping)

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