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Woman's Voice: From DisArt, it's DisTopia

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Jill: Hello, this is Jill Vyn.

Chris: Hey Chris Smit. Welcome back to DisTopia where we look at disability from the inside out and Happy New Year.

Jill: Yes, we're glad to have it be January 2019 and to kick off this year with our first podcast with Judy Heumann.

Chris: Have you written 2019 yet?

Jill: I have. I've stopped myself from writing 2018

Chris: Yeah, me too.

Jill: ... and made it 19.

Chris: It's very odd but it's going to be a good year. It's maybe time to reflect on our last year. We've had a really busy busy fall and it's been good. It's been really good.

Jill: Yeah, with the exhibition Process and Presence: Contemporary Disability Sculpture that took place in Grand Rapids, Michigan. While that has sadly come down. It is no longer at the gallery, we can still take a peek at all of the art that was there on our website at DisArtnow.org.

Chris: Yeah, that's right. There's a virtual tour there and a bunch of other supportive material that I think people should take advantage of. You can get to know the artists more. There's audio description there of all the pieces. We just encourage everybody to get out and take a look at that, DisArtnow dot o-r-g (DisArtNow.org). And not only just the exhibition, but it's been a season of a lot of engagements with audiences. You and I have done a lot of public speaking about disability and philosophy and education and we've just been with a lot of people. 2018 was a good year for us, I think.

Jill: Yeah, we had our fashion show too. Which people are saying, "When are you doing the next DisArt Fashion Show?" We had one in 2018 and there's a replay on our website as well. We are not sure when we are doing our next one but stay tuned. We think maybe we'll have a call this coming fall for the following year.

Chris: Well, and it's important for people to know that these are events that we just...we don't just throw them together. The Process and Presence Fashion Show was a year long production. It's been fun to get to know that community of people and our models are amazing and we want you to meet them too. Get to the website, take a look and, then, if you're so inclined take a look at the book, Chrysalis. Chrysalis is available on the website. It is a collection of portraits of our fashion models by Jeen Na. It's a spectacular book. So take a look at that. So, Judy Heumann...

Jill: I'm going to admit I just listened to Judy Heumann's podcast.

Chris: Well, we've had it in the can for awhile.

Jill: I did for the first time. Chris was the one who interviewed her. I can't stop thinking about it. It's really really good and what I especially love is how she takes us back in time a bit to some of the Disability history and the activism that took place in the 60s and 70s, is that right?

Chris: Absolutely.

Jill: And how necessary that was to make the gains that people have made particularly in education and other areas of access.

Chris: It's a very moving thing to talk to heroes. I remember when we talked to Mike Ervin I felt that way and with Judy it's even more that way because, as you pointed out the other day, Judy even predates some of that Chicago activism that Mike was such a big part of. This is the first interview I had to go through an FBI security office for. (laughs) At the time she was working for the Obama administration in the state department and it was a really, yeah, just a really dynamic meeting with her and we're thrilled to be able to share it.

Jill: Great. Let's take a listen.

[Music plays]

Judy: So, my name is Judy Heumann and I'm the special advisor for International Disability Rights here at the United States Department of State. I started, I believe, June 10th, 2010 so it's 6 years and one and a half months.

Chris: It's an honor for me to be with you. Again, thank you for letting me talk to you.

Judy Thank you for asking to meet.

Chris: It's fantastic. I wonder if we might just start a little bit thinking about your childhood. This time in your life where your mom was a big advocate to get you into school.

Judy: I had polio. I was born in 1947 and I had polio in 1949, in August of 1949. So I was 18 months old and spent a lot of time in and out of the hospital because I was in an iron lung for 3 months. I would say that my mother was a very strong advocate. It's not how she started out and my father was very supportive. I think my dad worked full time plus he and his brother had this same butcher shop. It was me and my mother was pregnant with my brother. I had polio in August, my brother was born in September. They were also immigrants. We're Jewish and my parents were from Germany and so they had each come over at different point of their life. My mom was 12 when she came over and they both lost their parents and grandparents and other relatives. I would say, really, the course my parents were on when they met in 1945 and got married in 1946 was kind of like finally settling down and raising a family. My father was in the Marines and just kind of being an average American middle class family. But that very much changed and I think what my parents really had to address the way they, in bits and spurts, told me. I was 36 years old and I was talking with my dad one day in our house in Brooklyn and my mom was upstairs. He told me that when I was 2 years old a doctor had recommended to my parents that they put me in an institution. And I said, "Dad, that can't be possible." And he said, "Your mother said never tell me. Never tell Judy." So I said, "I don't believe it." So he goes running upstairs saying, "Ilsa, Ilsa, isn't it true?" and my mother said, "Yes." So I think for them when that happened, they made really a decision that they didn't want to treat me differently than, at that point, my other brother. Maybe more than like parents today. At least today in 2016 there are all of these laws, rights that are on the books. The laws may not always be implemented as they're intended to but, at least, there are laws like the Individuals Disabilities Education Act, the [Americans with Disabilities Act](#) (ADA). In 1949 and in the 50s and 60s and nothing until the mid-70s, there were no laws that protected the rights of Disabled children or adults so really they were learning while they were doing it. So my mom took me to school expecting no support and the principal denied me entrance into the school 'cause I was using the wheelchair.

Chris: And there was a fire hazard, was that right. Something like that? Ridiculous...

Judy: I'm sure that was one of the issues. But it was more that people didn't see the need to have an equivalent education. Because basically what the principal said to my mother was, "the board of ed will send a teacher to the house." And they did and it was for a total of 2 ½ hours a week and then once or twice a month they sent like an occupational therapist and that was the total amount of time I was going to have in school. At that time my parents started looking for other schools and the special ed classes that they showed my mother were like real babysitting programs and that wasn't what they were looking for.

Chris: So in 1953-54 around that?

Judy: Yeah. But some other things had happened at that point because my parents thought, "Okay. So maybe they'll send me to a Jewish day school." They had always been interested in public schools but they thought maybe that would work. So we went and visited a school and I was going to be going into the 1st grade and the principal of the school told my mother that I

didn't know enough Hebrew. If I learned Hebrew, I could go to the school. So my mother really believed him. So, I had a physical therapist at that point whose wife was from Israel. So I got taken to their house almost everyday for Hebrew lessons. So, I knew certainly enough Hebrew for any other kid from Brooklyn, New York. I knew the alphabet. I knew some words blah blah blah. So she called and the principal, I think, never thought that she would do it and so the answer was "no". I couldn't go there. Then there was another Jewish day school and there the principal was really eager for me to come but it was a new school and so they were adding a new year each year and it would have meant that I had to repeat the 1st grade when I was going to the 2nd but actually learning a lot more and doing a lot of reading so was more advanced than that. So, then, finally in the middle of the 4th grade my parents got a call for me to come and this is very important because at that point you had to be screened to be able to get into a program and what that meant was my mother took me to school five days. She had to stay there the whole time and I had all these evaluations. Then they had a screening committee to decide whether I could go to this particular classes. It was in a regular school and there were like five or six special ed classes. So, I think telling these stories is really important for people also to see the changes that have gone on. Then when I did get to school, it was kind of a joke. I was the first kid in the special ed classes who had polio. The other children all had cerebral palsy. And then sometime that year or the year after my friend Friday T came in and she was the first kid with Muscular Dystrophy. So, we use to joke, all of us, that how we were integrating the program.

Chris: Integrating. You did the work. Yeah. Yeah.

Judy: But I want to say one other thing about programs in Brooklyn at that time and I'm sure it's true in other areas. While the education system where we were was pretty segregated racially, the special ed classes and the camps that we went to were all racially integrated which, I think, is a very important also piece of information because some of the issues that like my brothers and other people in our neighborhood were experiencing schools that were completely white, etc... That wasn't the experience for Disabled kids in New York City at least.

Chris: It was a more multicultural...

Judy: It was a totally multicultural program. We went outside of our classes to the rest of the school and it was basically white kids but that wasn't true in our classes. We had African American kids, Latino kids and our camps were all racially integrated both staffing wise and services, I mean, and campers.

[Music plays]

Chris: You know it's interesting Mike mentioned that too, Mike Irvin, that his school was racially diverse in Chicago that he and his sister went to and Riva Lehrer brought that up to in her discussion of growing up and going to some of these schools. By the time I....

Judy: How old are you?

Chris: I'm 42.

Judy: Hmm....I'm 68.

Chris: So by the time I was in high school, I was completely mainstreamed and I was with other Disabled kids in gym class and therapy.

Judy: Were you walking at that point?

Chris: No, I never walked, no, so I had a very different experience of disability. In fact, it's not until my 30s that I really begin to identify as a Disabled person and it's an odd thing for some people to understand, but I grew up privileged. I grew up quite frankly in the shadow of the work that you guys did which allowed me to achieve what I've been able to do. You know when you were mentioning 4th grade so you're 9 years old. Are you grasping any of this at that time as a sort of oppression or as a sort of, that something's wrong?

Judy: Certainly 9 year olds don't define things as oppression.

Chris: Sure, sure. (laughs)

Judy: I also think that I had a friend in Sweden who was a social worker, sociologist, and later on I met her in my 20s and 30s and she had done research on the issue of when do Disabled children start recognizing that they have differences. Her research was showing like 7, 8, and 9 years old which is exactly the time that I remember. So, we lived in a neighborhood in Brooklyn with a lot of houses, not big houses, small houses. I was friends with the kids in the neighborhood so while I didn't go to the schools that they went to, when they came home we all played together. I had a wheelchair. I wore braces. I couldn't really walk very much so I was basically always in my chair. As we got older we could leave the block and go around the corner to the candy store and things like that. On the street that I grew up in, I never felt different from the other kids even though, like in my brownie troop, we naturally modified games so no one needed to tell us. But one day we were going to the store and this kid from another block, so another neighborhood, came over and said, "What's wrong with you?" And I remember for the first time, or I think what he said was, "Are you sick?" Which of course is a common thing that, you know, one hears and that was really the first time that I ever really realized that I was different. When I remember when he said that to me feeling like I wanted to cry because I...and my friends, I don't think whether they heard it or not, they didn't think anything about it. And I said, "No, I'm not sick." I was 8 or 9 when that happened.

Chris: You know people have these pictures of disability that they get from movies or that they get from wherever that sort of indicate these realities for them and then when we grow around and bump into them it can be chaos, right?

Judy: I never minded anyone asking me what happened to me. I have friends who go apoplectic if somebody asks them a question. I was in an elevator with a my friend once and somebody asked her a question and I thought she was going to cut off his head. For me, I've always been the kind of person where I'm actually happy when someone asks me something that, I know if they don't ask me, they want to ask me. And they don't then they have all these visions of what they think happened. That kind of can't get to talk with me. In the 70s, you know, society was different. At that point I moved from Brooklyn to California and I was involved with the sexual attitude restructuring program which was being done at the University of San Francisco Medical School. It had a component on disability and I would give, I mean, with LGBT and gender and disability and on and on. And when we did our disability discussions we would be pretty open and direct about who we were, about our disabilities, blah, blah, blah. Then we also would do frequently get asked to do presentations at community colleges and universities. One day I had a friend of mine from Sweden who went to one of these classes and he had polio, he was a quad. I knew that in these kinds of discussions if someone did not ask the question about sex that it wasn't a good session 'cause they knew that, because it was the 70s and that's what we were there in part to talk about. So I would have pretty explicit conversations with people just because they looked at me and others as if we couldn't be sexual. So I had no problem doing that and he thought, "How can you do this? How can you be so explicit?" It was really because I thought, "I don't want to tell someone they can't ask me the question." I don't want people to ask me questions and say, "It's none of your business." So I answer it. I answered them frequently. When I was teaching in New York another...

Chris: ...that was another adventure. As far as I've read that you had to kick some ass and to do that too, right?

Judy: Yeah. Let me just say in relation to this discussion of answering peoples' questions. I was teaching second grade and the kids were all sitting on the floor. I was reading a book about Harriet Tubman and everybody was really quiet and listening. I'm like, "Oh, this is great." This was a big class. And this little boy was raising his hand so I could have ignored him, but I asked what he wanted to ask. And he asked, "How do you go to the bathroom?" He was 7. I'm like, "Well....do I answer the question? Or do I say I'll answer it another time?" But, of course, if I say that they they'll all be now thinking about how does she goes to the bathroom and forget the book anyway. So I explicitly explained; I turn to the side, my friends help, I don't sit on the toilet, blah, blah, blah. That was the end of the question. Everything went smooth right after that because I answered the question. Then one day for a holiday party around Christmas, December time, this kid came up to me and said, "My mother said to say happy holidays to my sick teacher." And I said, "Tell your mom thank you very much. Also please tell your mom I'm not sick." But those moments have been so important to me. Not that I wanted them to be said, but I really feel, for me, that it's important for at least some of us to be willing to talk to people because I think people have an inability in many ways just to even ask what our name is because one common question people say is "What do I call you?" And when people have said that to me. The first time that happened to me. I thought they...'cause my name is Judith but

most people call me Judy. So when this happened he said, "What should I call you?" I said, "Oh, you can call me Judy or Judith." And this was after I had given a presentation on work I was doing at the World Bank in Vietnam. The group of people I had never met. This young guy said, "What should I call you?" And I said, "Judy or Judith." He said, "No. Should I call you handicapped or disabled or the abled disabled?" And I was like, "You can call me Judy and I use Disabled person, Disabled people but I hope you listened to what I was talking about because that was the most important part. What can you in this room do to help advance inclusion of Disabled people in Vietnam." (laughs)

[Music plays]

Chris: I'm curious about the transition to California and what brought you out of Berkeley and...

Judy: Well, first when we set up Disabled In Action (DIA, <http://www.disabledinaction.org/>) which is an organization that still exists and the Arc (<https://www.thearc.org/>) which I'm actually very really proud of because it's never really had any money. It's a complete grass roots advocacy organization and it was set up by a group of us when I had been denied my teaching credential in New York. I was getting a lot of people writing to me, calling me, stopping me on the street and I would take people's information and while the issue was discrimination in a job people were talking about all kinds of areas of discrimination of strangers as well as, of course, those of us who were friends and had been elementary school or high school or whatever together college. So we sent out a letter to all these people and no social media at that time.

Chris: And no email, right.

Judy: Right. And asked other people to ask people and 80 people came to my undergraduate school Long Island University in Brooklyn. 80 people at that time was a huge number because there was no public accessible transportation. There was really very little cross-disability work going on and so that and the fact that it was a cross-disability organization that was purely advocacy based was really important and we did a lot of really great work.

Chris: What were some of the initiative that you guys were working on during that time?

Judy: So, we had somebody on our board, Jimmy Lynch, who had Muscular Dystrophy. And so he and a number of people led a hunger strike outside the MDA (Muscular Dystrophy Association) telethon.

Chris: Fantastic. This is before Jerry's Orphans. This is way before.

Judy: Jerry Lewis was in charge then. We had work going against [sheltered workshops](#). We were fighting for accessible transportation and accessibility standards and we were doing so many different things and a number of us were working and so it was all in addition to what we were doing. We had a bunch of committees. Some of the major activities that we were involved

with; a group of us were approached by PBS of that time. I did a film called America 73 which you can find. It's hard to find. I don't know, but it's hard to find but I think it was Lehrer who did the piece and it was a number of things but including a kind of advocacy group that used to get together once or so a month of Disabled individuals. That was part of what was going on, but DIA was...there used to be something called the President's Committee ([PCPID](#)) on employment of people with disabilities and that committee met every year and it was a real gathering place for the business community and Disabled people. It was done away with in the Clinton administration I think for legitimate reasons but there was something that was very unique about that gathering. And so we used it as an opportunity to...we, DIA. So we wanted to do a workshop at DIA and the President's Committee had said, "No." They wouldn't grant us to do the workshop so we wrote one of the congressmen in New York and he wrote to them and they gave us a room. We were kind of like figuring out what to do every step of the way. So we came to D.C. We had a number of demonstrations at the President's Committee including a demonstration out which was organized by a bunch of different organizations which was when Nixon had vetoed the [Rehabilitation Act](#). This was in D.C. and so a group of 100 or so people, we marched to the Capitol, we had a demonstration outside the Lincoln Memorial because at that time it was not wheelchair accessible. That was a really momentous event. We also had a number of demonstrations in Manhattan when the bill was vetoed, the Rehab Act was vetoed, including taking over Nixon headquarters. It's a little funny story. The Thursday before the election we, DIA, plus a group called Pride organized a demonstration in the city and we, again, no accessibility. So we said, "Oh, let's go to a federal building" so it was this federal building so we were able to get some of the private companies to agree to drive us to the city. They didn't charge us anything for it. So we came with flyers, great fliers of tombstone and we actually had a coffin with us.

Chris: Fantastic.

Judy: And when we got there, there was nothing there. It was probably the only place in Manhattan where there was virtually no traffic and so we're like, "Oh my God, this is terrible." And the police didn't want us there. Then we went and we sat on the street where there was basically no cars coming. And the police said, "We really want you to go. What can we do to get you to go?" And we said, "Hmm, where's Nixon's headquarters?" So they got us the address and it was on Madison Avenue. It was about 50 of us that went and there was a sit down on Madison Avenue. We cordoned off four streets so the traffic couldn't go at all. We did, however, get scared by the trucks and then moved only to cut off traffic on one street. But basically shut down traffic in Manhattan. There was something at that time called WOR...the Whirlybird...the Whirlybird or something, a helicopter that would do the look at traffic and we did go in...they sent somebody out from Nixon headquarters to ask what we wanted. We said we wanted to debate with Nixon on t.v. Of course they walked away saying their crazy and then we got into the building; we got on the floor. They called in a bomb threat and we thought, "Nobody's leaving, probably no bomb threat." So we were doing a lot of activist stuff. A lot. We had a demonstration outside of the New York Times because of the coverage that they were not giving and when

they did coverage it was always on the socialite page or the medical page, never on the political page or activist sections.

[Music Plays]

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Judy: I went to California because Ed Roberts called me one day. I didn't know who he was. None of us did. He told me about this group that were working on setting up the [Center for Independent Living \(CIL\) at Berkeley](#). I was teaching at that time. So in New York, at that time, you had to have a masters in 5 years so I decided to go to school. Teach for the 3 years, go to school full time because I couldn't do both because of the problem with transportation. I had been accepted into Columbia in the school of social work in the area of organizing like community organizing. And then Ed called and he said, "Oh, I've been talking to people around the country looking for a few activists who could come out and study at Berkeley. We have two departments that are interested in recruiting more Disabled students or some Disabled students. Would I be interested in applying?" So I did and I eventually went to the school of public health. So it was completely not in my plan. But I was very intrigued by what CIL was beginning to do and I liked Ed, you know, when we were speaking. We had a lot of the same visions of what we wanted to see happen. So that's why I went.

Chris: And then co-founded, right? The Center...

Judy: Right. I came like the second year so I think I feel comfortable saying I was one of the founders.

Chris: For my generation of Disabled activists, that time in Berkeley is elevated to mecca. That was a moment not only in the movement but the culture. Did you feel that way too? When you were there were you able to sense the importance of it?

Judy: Sure, I mean I was able to sense the importance of it because we were making it important and, you know, if you look at Chicago, Boston, New York City, much much bigger areas geographically. The university that I went to: Long Island University (LIU) we had anti-war demonstrations and students strikes and all kind of things like that. But we were a small university and so universities like Columbia and Berkeley they overshadowed things that we were doing, for example, at LIU. I was happy to get into Berkeley to go to graduate school and it was very, um, an important time for me because Berkeley was so small that with a motorized wheelchair you could kind of get anywhere even without accessible transportation and the university was not accessible. But, nonetheless, what I really liked was a small community of Disabled people and I kind of viewed being at Berkeley as and CIL like being in a candy store because there were and are so many issues that need to be addressed that it was kind of the dynamics of the people working there that we said, "Ok, well..." It wasn't totally disjointed but it really was. "So what does the group feel we need to be working on?" So things like personal

assistance there were things that were going on that you could build on, you could get. I, mean, in New York I couldn't get any personal assistance services, but I could get personal assistance services money when I was in California. I did have support in New York and in California for rehab so I was really very... my age group, for whatever the reason, we had a lot of opportunities to be able to go to school to get our tuitions paid. But the center, it was such an amazing dynamic place where we felt that all things were possible and doable. And the center itself was always buzzing with people. When I got there it was mainly dealing with adults who are physical disabilities and who are older. So blind, low vision, people with physical disabilities. So the center itself started as a coalition cross-disability but Berkley over a number years, before there was any legislation, began to become an intergenerational organization and an organization that also was working with people of all types of disabilities. When I went on to Berkeley then a number of people from New York started coming out to Berkeley and were working in the center. People who'd been active in Disabled and Action or the Pride Organization or other things. See Ed had his disability when he was 14 so he really didn't relate to children's issues because he didn't experience them and people like [Hale Zukas](#) who did have, has cerebral palsy but he, I believe, had gone to regular schools. But those of us from New York hadn't. Even if we were in regular schools, we'd been in special classes and so this whole drive for inclusive education standards where children with disabilities were expected to be taught and learn the same standards. Those were things that the center wasn't working on at all. The Center really wasn't really involved with parents. The Center, at that point, wasn't involved in the area of deafness or psycho-social disabilities or intellectual disabilities. So it was really the East coast crowd that started pushing that. And that, in part, was when... So as things were, you know, you had Disabled in Action as I was discussing, one of the things that came out of the Rehabilitation Act once Nixon signed it was Title V. In Title V one of the provisions is section 504. Section 504 CIL and others began to really work on getting regulations developed and people like [Mary Lou Breslin](#) and others from Berkeley were very involved with that, [Kitty Cone](#). But, at the same time, there was this national organization set up called the [American Coalition of Citizens with Disabilities](#). It was in 1975. I was the secretary and there were a number of presidents. It's a short-lived organization, about 7 years. Here we have this cross-disability group and when I was at CIL we began looking at expanding the organization to also bring Deaf people onto the board. We set up services for Deaf people. Then we began when the IDEA ([Individuals with Disabilities Education Act](#)) was passed we also applied for money and set up. You know the [Disabilities Rights Education](#) (and Defense Fund). So prior to DREDF there was at CIL a legal clinic. It was what really spawned DREDF.

Chris; Okay. That makes sense. Yeah. Sure.

Judy: So, we hired. We applied for money from different places and got a grant to start working on helping parents learn about what their rights were under the, at that point, the [Education for All Handicapped Children's Act](#). We were working on fighting for accessible transportation with the state and county of California. Working with legal aide. It was just, it was like an exploding time. CIL had very little money. I mean, at that point, I was living on benefits getting \$200 a month salary. And it certainly wasn't just me. That was true across the board for many of us, but

it was a really critical time 'cause there were few other centers being set up around the country and there was more focus over the years from the international community. So I would say it was definitely an explosion of the disability rights movement in the U.S. but also Finland had set up an organization that was virtually the same as the Berkley center and we knew nothing. So, really very amazing things that were happening. But I think, you know what, that period of time in the late 60s and 70s resulted in or a moving away from kind of going in the candy store and picking things up that we wanted to develop to really having to become much more expert. Because it's one thing to fight for accessible transportation, but then, what would it look like, how would it be run? It's one thing to fight for inclusive education, but what would it mean and how would it be done and how would you work with parents? Deinstitutionalization or whatever the issue was. We had to really buckle down to go beyond just talking about this is what we want to figure out, yeah, this is what we want but how do we get it?

Chris: Becoming strategic. Yeah, yeah thinking about...

Judy: And identifying people who were interested in and becoming experts in things like social security disability, social security benefits, personal assistance services, how to work with the city governments, the county governments, the state governments to demand funding from multiple funding sources. So, it was a real explosive period with, I think, very very positive results and it was very significantly the result of Disabled people who finally came to a place where, you know, we didn't want other people speaking on our behalf. But then creating the mechanisms and tools to let that happen. How do you reach the media? How do you get your message out? All of this had been done from the telethon perspective and they have all the connections and we were called Communists and, oh my God, I remember, you know, people that would just not grateful because the system had allowed us to get to where we were and, in part, that was true. And the system had afforded us education which then allowed us to learn about other movements and to recognize well, "Why are these other movements out there fighting for rights and why are we on the sideline complaining and not taking our rightful place?"

Chris: You know 25 years ago the ADA gets signed. What did that feel like for you?

Judy: I lived in California so I came back and forth. I think there was a core group of people and I wasn't in the inner circle, but I did certainly speak on a regular basis with those people. I testified at the hearings. I was back and forth a lot and did work on the phone. Definitely was very involved in the ADA and I think what's very important is the ADA advanced Section 504. Were there not a 504, the development and implementation of the ADA would've been much more difficult because people like [John Wodatch](#) and the Department of Justice and people around the country from the Disability community who were not only pushing the Department of Justice to develop regulations, people like [Jim Cherry](#) who filed the first, I believe, major lawsuit against the government for failing to implement Section 504. The regulations that came out for Section 504 were critically important and were, in many ways, the framework for parts of the ADA.

[Music plays]

Judy: I think the Disability movement now is coming of age and one of the, there's so many issues still.. You know you said you didn't identify as being a person with disability until you were 30. I don't know if that's a good or bad thing. I think from a movement perspective obviously it's a bad thing. But, on the other, 30 years down the road, 40 years down the road regardless of if you're in the [LGBTI](#) (Lesbian, Gay, Bisexual, Transgender, and Intersex) community, the Disability community, the women's community, African Americans, Asians, Native Americans, whichever. In creating a better society we really want all forms of barriers of discrimination to be removed so that we can be who we are. I don't know 30-40 years, maybe that's too optimistic when you still look at where we are, I mean, in any of those areas. Certainly, huge progress when you look at the LGBTI community as an example. Something that one we really never thought could happen in some ways so quickly and in some ways so slowly. But Disability, I think, is different in as much as most of us don't acquire our disabilities when we're young. And so, when you're more integrated the stigma of disability, I think, can be such for some people where thinking of oneself as having a disability. See, I see disability as a political issue. I don't see having a disability as a negative thing. But...

Chris: It's hard to break that, you know...

Judy: I never had it.

Chris: Right, yeah yeah yeah... No, I mean, it's hard for other people to break that. I mean, the work that DisArt does and the work that we're trying to do with DisTopia. You know, we're trying to say there is one definition of disability that is filled with mystery and fear and anger and all that stuff but there also is Disabled identity, capital D, a cultural identity that quite frankly can give as much joy as it will give frustration or, you know, all the other things.

Judy: That's empowerment. I mean it's the ability to come together even though we may be coming together in lots of different areas like as a Jewish woman I come together but my disability is always a prominent part of my life because, like, looking at religious life what are some of the big things we're looking at? Issues of inclusion. How do we as, whatever your religious background may be or not, what are the barriers that we experience?

Chris: The one thing that I really wanted to ask you too and maybe we can wrap up on this is, as a Disabled person, when I do my work, advocacy work and Disability Arts and things like that. I'm out there talking about Disability capital D and when I come home sometimes from that work, I'm exhausted because my small d disability, this intimate personal part of me, is also part of my everyday work. In other words, I sometimes feel a struggle or a tension between what's private and what's public. You know, I'll be in a meeting where I'm arguing about Disability Culture and I know that in my mind, I know that I can trump any argument that's made against me if I were to give them a real story about my own body, my own life, my own struggles. You know? I don't often.

Judy: Give me an example.

Chris: For example, if I'm talking about accessibility at a theater and they say, "Well, we can add 2 or 3 seats, you know, that are set aside but not 5 because that would be too many." Then I can tell them a story about, you know, when I was at a theater in which I had bought a ticket, they didn't have a space for me and I can give them my story as proof of the discrimination that's happening. This is with any identity politics, I'm sure. But how do I...? Sometimes that tension for me between my private disability experience and what my...

Judy: Yeah, I don't believe that there's a private disability experience.

Chris: Talk about that. That's very interesting.

Judy: I very much believe that stories are important and I believe that, you know, [Justin Dart](#) had both the vision and the financial ability to go around the country and get people to tell their stories and I always talk about people telling their stories because, for me, my ability and your ability and the millions of others who have disabilities to be able to talk about the stories as a part of our life experience. Good and bad stories are important, I think, for us, for me in some way to also go through a healing process. So, you know, for me I (laughs) frequently feel like I'm on the verge of crying like I am right now. I'm like, "Why is this?" Partly because I feel like I'm maybe very angry about what has happened and I don't always get behind it in a strong enough way maybe to express anger. Although I certainly do in many different ways. I don't want to be exploding being angry. I want it to be learning experiences for me and others so, I feel like when I can share a story. I can tell lots of movie theater stories. Those are things that I want to talk about. I don't see them as personal. I don't see them as private. They're personal, but I don't see them as private. There's very little in me that I see as private. Something between my husband and myself, that's private. But something which is disability specific...you know, for example, when the 504 regs came out and we were asked to do trainings, I always talked about bathrooms. Nobody would talk about bathrooms, but I live my life around bathrooms.

Chris: Of course, that's my whole day.

Judy: Exactly. Is there an accessible bathroom? That was a big part of the discussion because there weren't. Now, in the United States, it's infrequent that you can't find an accessible bathroom. In people's houses, that's different. But in buildings, in shopping centers, etc... you can find them. But now the questions is, "Okay. I found them, but I need personal assistance to use them." And if I don't have enough support, then that changes my whole day. Nobody wants to talk about pooping and peeing.

Chris: Right, right, but that's the essential...

Judy: If we took bathrooms out. If, in my world, if I could do what I wanted to do there would be no bathrooms on airplanes. There would be no bathrooms in places that I couldn't access. Now, it may go beyond just having a physically accessible bathroom, but the whole issue of issue of personal assistance. You know, if you look at the 504 and ADA regs, there is an explicit provision in the ADA regulations which says that an accommodation...you do not have to provide assistance going to the bathroom, eating, getting one's coat on and off.

Chris: That's in there.

Judy: It's in the law.

Chris: No shit.

Judy: And it's in the law. It is in the law because people believe that if they kept it as something that it had to be done that entities would fight against it. So what has that meant? That has meant, in the Federal Government as an example, that people who have personal assistance service needs you find very few people or people are not getting the support they need as a part of their job. They can get assistance to do their work. Right. Technology....

Chris: But not to go to the bathroom that allows you to do the work that you're being hired to do.

Judy: The EEOC, the [Equal Employees Opportunity Commission](#) has in their new draft for the Section 501 regulations language which would state that the Federal Government should, as a model employer, should provide these supports to people who need them in order to do their work. The reason I mention it, it is something that everybody does. There is nobody that doesn't do it one way or the other; have to pee or poop.

Chris: Or put their coat on or whatever....

Judy: But people don't want to discuss it. They, in my view, think lower of people who provide those kind of support services and they medicalize it. It's like, back to the medical world. No, you can't just hire someone. You have to get all kinds of medical things around it. I think we have a lot further to go. Stories, I believe, are pivotal, especially as we become a more included society. So when I went to camp and I went to school until I went to college, even when I was in college, I had a stronger group of friends who had disabilities. I saw them everyday. I went to camp for three weeks to eight weeks with all Disabled kids. And so we got to dream and create dreams and look at what we wanted to do and to talk about the barriers. For kids who have invisible and visible disabilities who are being included in school which is great because they have different opportunities. But they also don't get to, on a regular basis, speak with peers. You know, we talk about the importance of transition school to work. I'm completely behind that and doing all kinds of work for that to happen, but I really believe that we have to do a lot more work to begin to work with people at the point of them acquiring the disability and I think we have to recognize that we have to do a better job of directly and indirectly preparing the general society

for the fact that they, too, may one day acquire a disability and that they shouldn't see it as a tragedy. They should be able to reach out and we as Disabled people should be able to reach out to them which is why I think a much stronger alliance between an intergenerational movement so that people who acquire disabilities along the age continuum don't see that what they want to do is go to a senior development. Why do people go to a senior development? They go to the senior developments because they feel like they are, they feel that they are more protected, that their families won't have responsibility for them, they don't want to be a burden...

Chris: Guilt, guilt.

Judy: Yeah. In reality, the place that they're living in may not be accessible. They can't get the services that they need. So, again, it's this systemic problem.

Chris: Do you think art can do activism?

Judy: I think art is, in many ways, a form of activism. I think all art forms can express activism but not 100% of each art form all the time. So, yes, I think it's important that there is Disabled art. I also think it's very important that Disabled artists, just like Disabled people, shouldn't have to do everything around disability but we're not there yet. But population of Disabled people in the United States and around the world is more diverse than just the kinds of disabilities we have. And I think in many we have a lot more to do to truly diversify our art, our daily living, our schools, our work sites, etc... We've done a lot in a relatively short period of time. We have to do a lot more to really allow, I think, people with disabilities to own that. What it means to them. Whether they're wearing a sign that says, "I had polio. I use a wheelchair" like I would do and like you do now to. Or I have a psycho-social disability or whatever. Helping people move away from shame and helping people... This is where, I think, the art part comes in. Helping people be able to feel proud of who they are. I think that's really and using different ways of expressing that and engaging leadership not from the Disability community to really demand that they get a better understanding of what the hell it is we're talking about because I think whereas there are more people who see and understand some of the changes that have been going on and deep and fundamental issues like jobs that people get or don't get. I gave a talk once at my synagogue which started out by saying, "So if your daughter or your son came home with someone who had a disability and said they were getting married, what would your first reaction be?" and "they were Jewish". Because they're Jewish, Jewish, that's okay.

Chris: Well, thank you for talking to me and for all the work you do. It's really an honor. Thank you so much.

Judy: Yeah. I hope we can talk again.

[Music plays]

Jill: That was Judy Heumann. Great interview. I have not met her in person but she does sound dynamite.

Chris: Well, she is dynamite and she is probably one of the silent heroes of the Disability Rights Movement. She's very behind the scenes, you know, and that's the way she wants it. But as you can tell she's a wealth of knowledge, but she's also very down to earth about these issues and I think that that is so important for everybody listening to realize that these issues of Disability rights and Disability activism they can seem grand and sort of idealistic, but when you hear people like Judy Heumann talking you realize these are human issues.

Jill: So get a little personal here we were just having a conversation before we started recording today is about pooping and peeing to tell you the truth. And how, if you don't have the right care at the right time, that is can really disrupt your day. So when she talks about that, if you haven't experienced it or you don't know anyone who has, it's a real deal.

[Background music begins to play]

Chris: It is. Yeah. And it is the kind of thing that most folks keep private, but Disabled people we have to make it public because, like you said, it's so connected to your everyday equilibrium, right, and being able to do what you're asked to do and so our thanks to Judy Heumann really for spending time with us and our thanks to you, too. Please give us a review on iTunes. Let us know what you think about what we're doing and you can always reach out to us and listen to other episodes at DisArtnow.org under the podcast link but until next time...

Jill: Yeah. This is Jill Vyn.

Chris: and Chris Smit. Thanks for listening everybody. Bye Bye.

[Music plays louder]

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