



A conversation with Judy Heumann

Voice Over:

(Hip-Hop music plays)

Barry Whaley::

Hi, everybody. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and the ADA National Network, I want to welcome you to “Section 504 at 50.” I’m Barry Whaley, I’m the project director of the Southeast ADA Center. “Section 504 at 50” is a special interview series created in recognition of the 50th anniversary of the Landmark Rehabilitation Act of 1973. In this series, Dr. Peter Blanck speaks with leaders of the Disability Rights Movement who’ve advanced the cause of equal rights through their tireless work. We continue our celebration of Section 504 at 50 by welcoming our guest, Judy Heumann. Judy is an internationally recognized disability advocate who has served in the Clinton and Obama Administrations and 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.

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:

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.

When we learned about the fact that President Nixon had vetoed the Rehabilitation Act in 1972, 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 5, because really Title 5 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 5.



I mentioned this in the book, we learn about the veto, some of the people who were more involved with national organizations and had lobbyists in Washington were aware of what was in Title 5, and we in Disabled in Action, and another group called Pride, and another group was parents and doctors from Willowbrook on Staten Island.

To understand the context of where we were, Willowbrook State School for the "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. 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.

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. We had great paraphernalia. Someone made a coffin; we had great flyers that had a coffin and around the coffin it basically had phrases about what was going to be lost.

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 ready for blood, and it is quiet. They send somebody out from the building, what did we want? Nothing was happening, so 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?" And that's how we decided to go and protest on Madison Avenue.

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, people were engaging, which, for me, I remember vividly sitting on Madison Avenue thinking, "this is really interesting. People are holding these flyers." That was 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 Eunice Fiorito, who was at that point working as a disability head in Mayor Lindsay'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. There was a big meeting once a year, there were like 1,000 or more people who came, and we organized this demonstration to go from the Hilton on Connecticut Avenue up to the Capitol.

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, we should go to this. We're not just going to go down to do nothing. We need to have a discussion. 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."

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. What is it that you need to do to try to turn a no into a yes?

This was before the bill had been vetoed. It might have been in 1971. And that was the first time that we, I don't know how many of us, there were six or seven, had gone down to this meeting where there were so many people, not many disabled people, mainly non-disabled people, and we really started thinking about the importance of getting the voices of younger disabled people out there to really talk about this as a civil rights issue. At that point, human rights justice, those words



were not really being used in any of the communities, but I think what we were definitely looking for them, and still are, is development and implementation of laws that remove barriers that enable people with disabilities and others to live quality lives without prejudice towards disability or gender or race or religion, whatever.

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, none of that was anything that we really knew. And so again, we were linking up with some of the bigger groups.

I had moved from Brooklyn to Berkeley, and I was getting my master's in public health, and I was elected to be on the board of the Berkeley CIL, and I had to do a placement as a part of my graduate school, and Senator Williams, who was the chairperson of the Labor and Public Welfare Committee in the US Senate, there was a committee on the "handicapped" also. So I moved to Washington, I worked for him for a year and a half on the committee staff, and that's when I really started learning how laws were made, how regulations were developed, started working with other national groups, but still connected to what was going on at Berkeley, because I stayed on the board.

I think because the 504 regulations were also under the jurisdiction of Senator Williams, it gave me an opportunity to meet people like John Wodatch, who you know very well, some in the audience will know. But John at that point was working for Health, Education, and Welfare and he was in charge of the development of the 504 regulations, which he worked on for many years with a number of colleagues in justice.

They were going around the country and talking to people about what kinds of discrimination were people experiencing. Looking at 504 and what was the definition of disability and what kinds of discrimination were people experiencing and what could be done to end discrimination when there was such a history in the built environment of things that weren't accessible. It wasn't going to be possible to put regulations in place that required everything to be made accessible in a short period of time.

We were learning a lot. We were beginning to comment on regulations when they came out in the Federal Register. There was another organization that was started, a national group, called the American Coalition of Citizens with Disabilities. And Eunice Fiorito was one of the founders, as was Fred Fay, myself, people in the deaf



community, blind community. It was the first national cross-disability rights organization that later on hired a gentleman named Frank Bowe, who was deaf, as their executive director.

ACCD really was a critical organization at that point in time, because it was run by disabled people. The bylaws required that the organizational members had to be controlled by disabled people. One of the reasons for setting up ACCD was to be able to have a voice in Washington that could be lobbying, could be educating, could be really reinforcing the work that was going on with 504, and of course the other provisions in Title IV.

We were gradually learning, and I think what was very important is ACCD really allowed local organizations to also meet other local organizations around the country, as well as the national groups. And it was at this time that the Centers for Independent Living were beginning to develop. Ed Roberts had been appointed as the head of the Department of Rehabilitation by then Governor Brown.

And Ed, the visionary that he was, because he was one of the founders of the Berkeley CIL, used his authority, although Washington was challenging it, to use something called innovation and Expansion money that state rehab agencies had to set up 10 Centers for Independent Living above the Berkeley Center, so there'd be 11. And so California had 11 Centers for Independent Living before the federal government even put a penny into creating the 10 Centers for Independent Living in, I believe, 1978.

You can see Michigan and Massachusetts, the two state directors there were friends with Ed and they also started one or more CILs in their states. This approach of consumer directed, consumer controlled, most importantly people who really understood the day-to-day barriers that people were facing and really were working very aggressively at multiple levels. I think what you saw in Michigan and Massachusetts and California were local organizations and state groups that were working on many different issues.

The CILs were very important working in numbers of areas like home- and community-based services, but also working on legislation that was being passed at state levels. I mean, I could just go on and on, but I think what's very important is that really we were learning as we were going, we had limited opportunities or expectations about what we could study in school, even for those of us who went to college. I was encouraged by my friends who were older than me and had disabilities in high school, "Don't tell the Department of Rehabilitation you want to



be a teacher because they'll only support you..." Whether this was true or not, I believed them. They said, "If you tell them you want to be a teacher, they're going to say, show us a teacher who has a disability and is teaching from a wheelchair, and as soon as you say you don't know anybody, they're going to say no, they're not going to support you. So tell them you want to be a speech therapist."

So I did. I said I wanted to be a speech therapist, and I minored in education. So we were still building in our community knowledge and capacity about how laws were made, how to implement them. When we were working on the 504 regs, really wanting to make sure that they could be as strong as possible, and that ultimately, once those regulations were signed, which took until 1977. The law was passed in 1973, it took all those years to get the regulations signed. There were more and more people that were participating in that process that were commenting on the draft regulations, but even there, we were needing to really look at them, come up with our thoughts, our comments, so that we wouldn't just be rubber stamping what was coming out, but we could be more analytical in what we felt were the strengths and weaknesses.

Of course, one other thing that we were really learning about was lobbyists. We didn't know from lobbyists. But you had a law now that said if you got money from the federal government, you couldn't discriminate against disabled people, and that certainly was making hospital associations, institutions of higher education, on and on, look at what obligations they were going to have to adhere to. It was in their best interest to do everything they could to get these regulations not signed and to be as weak as possible.

For historians, there's a gentleman by the name of Jim Cherry, and Jim Cherry was a disabled lawyer and he litigated under 504 before there were regulations. His position, correctly stated, was that this is a law and that the law needs to be implemented once it's signed, whether or not there are regulations. And so Jim was, I think, an important figure as this was moving forward. He was not really involved, to my recollection, with the Disability Movement per se, a lot, so you had many different things going on at the same time.

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. 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 with 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 I got my teaching license and then did teach, but that was glaring for me as an example of the kinds of discrimination that people were experiencing in employment, and then, of course, in public education, in higher education, both in services and in education that we were or weren't receiving. Transportation--the one penny federal money contaminated everything, meaning for us, that wasn't contamination, that was like gold. One penny ignited the possibility of being able not only to articulate discrimination, but also to look at being able to get someone to seriously look at the discrimination, was it discrimination, and then what would the entity be required to do. So we were learning a lot and, I think, drinking by the water hose.

I think many of us were really seeing, both at the federal level and more at the local level also, how we were able to begin to move things forward. So in some way, I kind of talk about this period as going into a candy store, because there's 50 kinds of candies, and when you think about disability, there were so few laws in place, like what's your priority? People had different priorities, so even being able to decide what we were going to work on also depended on what the issue was, whether there was a state law, local law, things that we could do even before the federal laws came into being. So we were learning.

Peter Blanck:

You, of course, anticipated so many of my questions. We had to do John Lancaster in two sessions, because in the first session we barely made it out of the 1970s. John, of course, came at it from a very different perspective and assignment than you did. 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. Some people, like Kitty Cohn in California, had been more actively involved in other political movements. When she started



working at CIL in Berkeley, she, through the organization she had worked on, had direct context with people in some other groups.

But 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.

Likewise, the Women's Movement didn't really include disabled people. 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. And so when we had our demonstration in New York on Madison Avenue, we realized that we got very limited press and thought one of the issues was we didn't have any disabled veterans. So we called McGovern's office. We had planned, this is a Thursday, I believe, and we had planned to have another demonstration the day before the next presidential election, and I randomly called and said, I'm with this group, we have no disabled veterans, were there any disabled veterans that they could identify that would be willing to join us for the demonstrations that Monday?

And Nancy was her name, and Nancy got us two disabled vets. One is a guy by the name of Bobby Mueller, who was a very big anti-war demonstrator and a paraplegic, and Bobby and I were friends for years. And so John Lancaster, also a disabled veteran, when I was in Washington working for the senator, senator's office worked with all disability groups, including disabled veterans. So that was the first time outside of Bobby that I was really meeting people from Paralyzed Veterans Association. I knew people from Eastern Paralyzed Veterans Association in New York, but I hadn't met any of the people at the national level.

I would say that each group offered different things, but disabled veterans and disabled civilians, we were learning a lot from each other, certainly the civilians from the vets, because the benefits that vets get, which they well deserve, are not the same benefits that civilians get, which is not the way it should be.

I remember, Peter, at one point, I think I said to Jim May, "Find me a disabled vet that I can marry. It can be a marriage of convenience, but it would give me all these kinds of things, like benefits through personal assistance services and making your



first home accessible, and a vehicle that would be accessible." I never had heard of any of those things before. My dad was a veteran, but not at that level of disability. So we were definitely learning from anything and everything that was going on. Very much we 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 from 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. Now, had it been a different person who didn't personally understand discrimination, things could have been quite different. So it was 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.

I mean, again, this theme of, the people that I was mostly involved with at that point, we didn't know these people, we weren't involved with groups like the Leadership Conference on Civil Rights. Those were all things that started happening a number of years down the road. But yes, I think many of the approaches that we used were ones that we were seeing from leaders in other movements.

Peter Blanck:

Senator Weicker was very early on, maybe even before Ted Kennedy. When did you start getting to that level of engagement with the Weickers and the Kennedys? 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 70s, 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 5 provisions, and 504, in particular, were not comparable to the Civil Rights Act of 64. 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 to.



I think Senator Humphrey, I don't know if it was in... My year might be off, but '67, I was looking at an amendment to the Civil Rights Act, which would've included disability, but of course there was legitimate opposition to that happening because people were concerned that if they opened up the Civil Rights Act, that there would be amendments that would put on that would weaken it.

So we didn't get in in the beginning and we couldn't get in in the middle. So absolutely there was discussion and thought about the need to be able to continue to evolve legislation so that it wasn't just protecting people in programs that got money from the federal government. I think while that was definitely something that we were thinking about, our first goal was to really get the 504 regulations done, the trainings done, to begin to allow people to see how a law like this could benefit them and to have spokespersons around the country. I mean, there were thousands of disabled people that were trained as a result of the 504 contracts or grants that had been awarded. And then that's when I think people were... That success of getting reasonable regulations, getting money for training, really one of the impetus is to begin to say, okay, our next step needs to be.

Then people like Justin Dart, who, during the 504 period, really was not on the scene, he didn't really begin to get involved nationally until later in the '70s. He started in Texas first and then at the national level. So I think that's also when more people were realizing... If you remember in the film, the reason that Ford refused to sign the 504 regulations, which he could have signed, and the statement that Califano made during the demonstrations in DC, they were both looking at, and why Nixon had vetoed the bill two times before, expectations that couldn't be met. That would be the kindest way to put it, but I think the more clear way to put it would be that discrimination against disabled people was acceptable and they did not feel the pressure that they felt from Civil Rights Movements, the women's community, because we were not really in positions of authority or responsibility at that point.

I began meeting staff and members on the Senate side when I worked for Senator Williams, because Senator Randolph at that point, Senator Cranston at that point, were big people, and also Stafford, he was a Republican. It was a much more bipartisan group of people on the House and Senate side, Democrats and Republicans, and I was engaging with them on a day-to-day basis. I was a legislative assistant, and I was working under a woman named Lisa Walker and Nick Eddies, who were the Chief Council for the Senator, and it was really a wonderful



opportunity for me, both to be learning and also to be giving meaningful impact, because there weren't any other disabled people on their staff.

I think that was, particularly when looking at laws like IDEA that were being developed at that point, I was very much able to engage in supporting work that they were doing and look at some of the language that eventually got developed.

When I left DC and went back to Berkeley to go on payroll at CIL, we were looking at the evolution of the Independent Living Movement in California, and Jack Duncan, who recently passed away, was working for a member Congress named Brademas, and Brademas was one of the leaders on the House side at that point in the area of disability, and so Jack and a Republican member on the House side from Ohio came to CIL at Berkeley, and we organized a hearing. It was an all-day hearing, and that was something that I had learned about when I was working in DC. What was a hearing and how did you set them up and how did you want to select people? And so that was another really great opportunity.

We had like four panels that included both people working at the CILs, but also elected members of city council and county and employers who were able to talk about 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.

So really in the 70s it was this growing, strengthening of a Disability Rights Movement, legislation beginning to move forward more, and disabled people coming more prominent.

Peter Blanck:

The bipartisan sense, which you mentioned, which is so foreign today, -- you have Justin, who's talking to a new vice president who gets it, George Bush, who's head of Reagan's regulatory reforms, and you have that baked in bipartisanship. Were you guys cognizant of what a unique time it was? I mean, it's unique in the sense what we see today, but were you cognizant of the fact that this was truly a bipartisan effort?

Judy Heumann:



Well, let me say that I would modify that a little bit, because what happened when Reagan was elected, they were specifically going after a number of things. One was they were trying to deregulate IDEA. And Justin was not, I believe, at that point, really involved yet on the national level, because this is in '81. And the Disability Rights Education and Defense Fund had been created splitting off from CIL when it was a paralegal program, and people like Pat Wright, Mary Lou Breslin, and others who had been very involved in the 504 demonstrations and were meeting elected representatives and staff that we were all becoming friendly with, they retracted the changes they wanted to make under the IDEA specifically because of the huge letter writing campaign and demonstrations that were going on. So I would say there really was not a friendly, amenable, bipartisan approach when he first came in.

Peter Blanck:

So that was a myth that we all think about today, this bipartisan-

Judy Heumann:

I wouldn't be so strong to say it's a myth, because you did have members on the House and Senate side who were working together, Democrats and Republicans, but I definitely think that when Reagan came in on disability, in the areas that I'm aware of what he engaged with, he was definitely looking at going for the jugular, weakening laws like IDEA that were very new and where there was a lot of opposition.

When Reagan came in, remember not every state had yet signed on to the IDEA. So 504, every state was obligated, once the law was signed, the regulations then were there to tell them what to do. It wasn't until December of '75, when IDEA was passed, that there was actual money that states could get to increase the educational dollar for services. The last state that signed, I believe, was in 1982, and it was New Mexico. When the states were finally realizing that they were going to be obligated to do, under 504, pretty much what IDEA required them to do, but under civil rights legislation, they weren't going to get money for it. Lots of variables that were going on.

I think for sure the issue of bipartisanship continued in the 80s and early 90s, but you began to see a decline much more rapid after 94, because I was working in the Clinton administration when we started out as a Democratic president, House, and Senate, and then in '94 lost the House and Senate, and so that definitely had some



traumatic changes. But even then, there was still more bipartisan work than is going on now.

Peter Blanck:

So, ADA, it's not a myth. The bipartisan. You have Thornburgh, you have Bush, you have Justin, Evan Kemp, you have a whole crew there.

Judy Heumann:

Yes, absolutely. All I'm saying is in the very beginning... I think you are correct in what you said about Bush 1, that he was friends with disabled individuals, he was influenced by them in a very positive way, and definitely as the ADA was moving forward, that bipartisan approach was very, very important. Boyd and Gray and the work that they were doing with him, all very important. Likely we would not have gotten the ADA had that level of bipartisan work not been occurring, and certainly Dick Thornburgh and his role as Attorney General, having a son with a disability, and Jenny Thornburgh, who is, as you know, this amazing advocate, was critical.

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 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'd 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 and people would get pulled in and out to... I remember when we met with Senator Cranston in '77 during the 504 demonstrations, they were being told on the Senate side and House side, that we were overreacting, and that changes that we were discussing were, in fact, not being proposed.

But that was really fraudulent. I think it might be true that Califano, in the end, might have done the right thing, 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 in the end. So the 32, or however many areas they were looking at making modifications to weaken the regulations, they ultimately didn't do any of it.

Peter Blanck:



Within the bounds of reason, Judy, 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. In retrospect, are there things that you might have approached differently?

Judy Heumann:

People ask this question. We could only approach it in the environment that we knew, and so I think we really went beyond a lot of what had ever happened before. We really did work, like in the Bay Area, Phil Burton, George Miller, the Congressional delegation for the Bay Area was very supportive. The hearings that we held were a result of the two members saying they wanted to come and listen. And actually the reason why the demonstrations lasted as long as they did in the federal building was because George Miller, Congressman Miller, happened to drop by the federal building, and Pat Wright and I were on the phone with a guy named Peter Albushies, who was the attorney at that point that had been designated to work with us, and he was going over point by point of the changes that they were looking at making.

When George came in, we quietly directed him to a phone to pick up the phone to listen to the discussion. And at the end of the discussion... For the audience, George is a very big, burly guy with a very big, deep voice, and he said, "Hello, Peter, this is Congressman Miller," and he basically gave him an earful about, "How can you be telling us that nothing is being considered when obviously these are the issues that you're looking at?" And when he got off the phone, he said to the people, about 150 people who were in the building said, "Stay here until this is resolved."

I don't know. We couldn't have planned that. We didn't know he was coming. You can fantasize what you would do differently, but I can only think about it in the environment that we were in.

Peter Blanck:

I think that's fair, Judy. Even though I think you're a prophet, none of us are prophets. Could you have foreseen the move towards the such extreme and political environment we moved towards since passage of the ADA? 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, racial diversity, sexual orientation diversity, religious diversity, it's kind of like an explosion that's going on.

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

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:

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, but not as an identity in some sense.

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 70s, that 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.

CILs 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 someone 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.

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, and I feel that it's the right direction.

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 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. I mean, the US is just behind. We're ahead in many areas. We're behind in other areas.

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. Judy, I want to thank you very much for being Judy, really, I don't know how else to say it.

Barry Whaley:

Listeners, you can access this interview, and more interviews, at the Section 504 at 50 website. That web address is section504at50.org. The 504 at 50 series is produced by the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and is a collaboration with the Disability-Inclusive Employment Policy Rehabilitation Research and Training Center.

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