

Regional Oral History Office  
The Bancroft Library

University of California  
Berkeley, California

Disability Rights and Independent Living Movement Oral History Project

Judith Heumann

On the 504 Demonstrations in San Francisco and Washington DC

Interview conducted by  
Ann Lage  
in 2007

Copyright © 2012 by The Regents of the University of California

Since 1954 the Regional Oral History Office has been interviewing leading participants in or well-placed witnesses to major events in the development of Northern California, the West, and the nation. Oral History is a method of collecting historical information through tape-recorded interviews between a narrator with firsthand knowledge of historically significant events and a well-informed interviewer, with the goal of preserving substantive additions to the historical record. The tape recording is transcribed, lightly edited for continuity and clarity, and reviewed by the interviewee. The corrected manuscript is bound with photographs and illustrative materials and placed in The Bancroft Library at the University of California, Berkeley, and in other research collections for scholarly use. Because it is primary material, oral history is not intended to present the final, verified, or complete narrative of events. It is a spoken account, offered by the interviewee in response to questioning, and as such it is reflective, partisan, deeply involved, and irreplaceable.

\*\*\*\*\*

All uses of this manuscript are covered by a legal agreement between The Regents of the University of California and Judith Heumann, dated November 11, 2007. The manuscript is thereby made available for research purposes. All literary rights in the manuscript, including the right to publish, are reserved to The Bancroft Library of the University of California, Berkeley. Excerpts up to 1000 words from this interview may be quoted for publication without seeking permission as long as the use is non-commercial and properly cited.

Requests for permission to quote for publication should be addressed to The Bancroft Library, Head of Public Services, Mail Code 6000, University of California, Berkeley, 94720-6000, and should follow instructions available online at <http://bancroft.berkeley.edu/ROHO/collections/cite.html>

It is recommended that this oral history be cited as follows:

Judith Heumann, "On the 504 Demonstrations in San Francisco and Washington DC" conducted by Ann Lage in 2007, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2012.



Judith Heumann, circa 2007

## ACKNOWLEDGMENTS

This phase of the Bancroft Library's Disability Rights and Independent Living Movement Project was funded by DBTAC-Pacific ADA, as part of a study of "Antecedents, Implementation, and Impact of the Americans with Disabilities Act." Additional funds came from a generous donation from Professor Raymond Lifchez in 2006 in honor of Susan O'Hara.

Thanks are due to other donors to this project over the years: Dr. Henry Bruyn, June A. Cheit, Claire Louise Englander, Judith Stronach, the Prytanean Society, and the Sol Waxman and Tina P. Waxman Family Foundation. The Bancroft Library's disability history program was launched with field-initiated research grants in 1996 and 2000 from the National Institute on Disability and Rehabilitation Research [NIDRR], Office of Special Education and Rehabilitative Services, U.S. Department of Education. Any of the views expressed in the oral history interviews or accompanying materials are not endorsed by the sponsoring agencies.

## Table of Contents—Judith Heumann

Interview History vii

Narrator Bio ix

Interview date: October 12, 2007

Audio file 1 1

Thoughts about earlier disability groups of 1940s and 1950s: Paralyzed Veterans, United Cerebral Palsy—Growth of disabled student programs, centers for networking—Judy’s experiences in college, influence of Ted Childs on her civil rights perspective—Disabled in Action [DIA] and other local groups—Importance of growth of networking and better communication, role of the telephone—Ed Roberts urging Judy to enroll in UC Berkeley graduate program—Growing national networks, getting to know others through President’s Committee on Employment of People with Disabilities, roots of the American Coalition of Citizens with Disabilities [ACCD]—Growth of cross-disability concept, Judy’s experiences at Camp Jened—Setting up deaf services at Berkeley’s Center for Independent Living [CIL], adding programs for other groups, controversy over parent involvement—Differences in life expectations based on age of onset of one’s disability—The KIDS project at CIL—Importance of parents in DIA and then at CIL—Difficulties of adequate funding for ACCD and like groups—Compares DIA and CIL, New York and Berkeley—Role of independent living centers in creating a cross-disability consciousness—Importance of funding—504 regulations as driving force in formation of ACCD—Decision to issue ultimatum and to hold demonstrations for 504 regulations, not controversial—Differences in perspective between Washington groups and people outside Washington—Involvement with lawyers in DC who worked on 504, characterizes John Wodatch—Judy’s perspective on rights.

Audio file 2 22

Importance of Judy’s time in Washington on staff of Senator Harrison Williams, 1974-1975, other staffers open to disability issues, making connections—Asked to wear shoes in the senate office—Later, setting up hearings in Berkeley re funding independent living centers nationally—Inside-the-beltway mentality of ACCD and “doing our own thing” on the West Coast, to save 504—Developing relationships with Congressmen Miller and Burton, pipelines to Washington during the 504 demonstration in San Francisco, Peter Libassi, Ann Rosewater—Key role of Congressman George Miller, urging San Francisco demonstrators to stay the course—The vision and planning for the 504 demonstration in San Francisco, Kitty Cone as organizer, others—Previous relationships with Black Panthers, Delancy Street, Glide Church, California Rural Legal Assistance, and other non-disabled Bay Area groups—The benefits of Berkeley being a small community—Wanting to educate the average citizen about the issues, support

from city councils throughout the state—Kitty Cone’s leadership skills—Thinking about the spontaneity of the sit-in—Educating the press—Effects of the 504 demonstrations on the disability movement and leadership—Going to Washington, the demonstration at Califano’s house, differences in approach with ACCD leadership in DC—Meeting with Stuart Eizenstat, singing civil rights songs in the White House—Thoughts on public speaking, on being prepared and being resolute—Recalling a demonstration in a movie theater.

Audio file 3

44

Judy’s testimony in the Burton hearings in the San Francisco federal building, anger, fatigue, tears—Confronting power—Life inside the building, like a village, sexual relationships, getting the group’s input—Pat Wright’s early involvement in the movement—How decisions were made inside the federal building, mass meetings, sharing information--A life altering experience for participants—Sense of disability community in the Bay Area, contrasts with DC—Lasting impacts of 504 demonstrations, on the regulations, on embedding disability rights in the community, on Judy—CIL and Berkeley as change agents—Importance of the 504 trainings—Discussion of the international disability movement and its connections to the US and Berkeley—Important leaders in disability issues globally.

## Interview History—Judith Heumann

This oral history interview with Judith E. Heumann is a supplement to her lengthy biographical oral history recorded from 1998 to 2001, comprised of seventeen interview sessions conducted by three different interviewers (available online at <http://bancroft.berkeley.edu/collections/drilm/collection/items/heumann.html>). Although it was very complete in most respects—discussing her early life, education, and involvement with the disability movement in New York, Berkeley, and nationally—a major omission was the topic of the 504 demonstrations in Washington and San Francisco in 1977. Ms. Heumann was a key strategist and leader of these historic demonstrations, so we began plans for a supplementary interview to cover this crucial topic soon after her oral history was published.

This interview was conducted on October 12, 2007, at Ms. Heumann's hotel in Berkeley, during a visit to California. The planned topics included her role in the growth of a national network of disability leaders and organizations, leading to the founding of the American Coalition of Citizens with Disabilities in 1975, and the planning for the nationwide demonstrations in support of implementation of Section 504 of the Rehabilitation Act of 1973. A primary focus was the four-week long 504 sit-in at the Federal Building in San Francisco, a groundbreaking civil rights action that had lasting impact not only on disability law but on the political and social outlook of the disability community. Ms. Heumann was also part of the delegation from the San Francisco group to Washington DC, and she discusses the numerous actions there, which culminated in the issuing of the implementing regulations by HEW secretary Joseph Califano.

The interview was transcribed, audited by students in the Undergraduate Research Apprentice Program, and sent to Ms. Heumann for her review. She made a few corrections to names, and only minor alterations of wording. At the time of the interview, Ms. Heumann was the director of the Department on Disability Services for the District of Columbia. In June of 2010, she was appointed Special Advisor for International Disability Rights at the U.S. Department of State.

This oral history with Judy Heumann joins others in the Disability Rights and Independent Living Movement series. The transcript and selected videoclips from this interview and others in the series are on line at <http://bancroft.berkeley.edu/collections/drilm/>. Interview transcripts are also available in the Bancroft Library and in the UCLA Department of Special Collections. Complete videotapes of the Heumann interview session are available for listening in the Bancroft Library, which also holds a collection of Heumann's personal papers.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Bancroft Library's materials on the history of California and the West. The collection of the Regional Oral History Office can be accessed at <http://bancroft.berkeley.edu/ROHO>.

Ann Lage, Interviewer  
November, 2011





<http://www.state.gov/r/pa/ei/biog/144458.htm>

**Judith E. Heumann**

Special Advisor, INTERNATIONAL DISABILITY RIGHTS

Term of Appointment: 06/07/2010 to present

Judith Heumann is an internationally recognized leader in the disability community and a lifelong civil rights advocate for disadvantaged people. She has been appointed Special Advisor for International Disability Rights at the U.S. Department of State. She previously served as the Director for the Department on Disability Services for the District of Columbia, where she was responsible for the Developmental Disability Administration and the Rehabilitation Services Administration.

From June 2002- 2006, Judith E. Heumann served as the World Bank's first Adviser on Disability and Development. In this position, Heumann led the World Bank's disability work to expand the Bank's knowledge and capability to work with governments and civil society on including disability in the Bank discussions with client countries; its country-based analytical work; and support for improving policies, programs, and projects that allow disabled people around the world to live and work in the economic and social mainstream of their communities. She was Lead Consultant to the Global Partnership for Disability and Development.

From 1993 to 2001, Heumann served in the Clinton Administration as the Assistant Secretary for the Office of Special Education and Rehabilitative Services in the Department of Education. Heumann was responsible for the implementation of legislation at the national level for programs in special education, disability research, vocational rehabilitation and independent living, serving more than 8 million youth and adults with disabilities.

For more than 30 years, Heumann has been involved on the international front working with disabled people's organizations and governments around the world to advance the human rights of disabled people. She represented Education Secretary, Richard Riley, at the 1995 International Congress on Disability in Mexico City. She was a US delegate to the Fourth United Nations World Conference on Women in Beijing, China. She has been active with Disabled Peoples' International, Rehabilitation International and numerous Independent Living Centers throughout the world. She co-founded the Center for Independent Living in Berkeley California and the World Institute on Disability in Oakland California.

Heumann graduated from Long Island University in 1969 and received her Masters in Public Health from the University of California at Berkeley in 1975. She has received numerous awards including being the first recipient of the Henry B. Betts Award in recognition of efforts to significantly improve the quality of life for people with disabilities. She has received an Honorary Doctorate of Humane Letters from Long Island University in Brooklyn, an Honorary Doctorate of Public Administration from the University of Illinois, Champaign, and an Honorary Doctorate of Public Service from the University of Toledo, Ohio. In 2010 she was a recipient of the JFGH S. Robert Cohen Award, and the Medtronic National Courage Award honoring

outstanding individuals who have made a significant contribution to the health, welfare, rehabilitation or awareness of people with disabilities. New Mobility magazine named her their 2010 person of the year.

Interview #1: 10/12/2007

Begin Audio File 1 10-12-2007.wav

01-00:00:00

Lage: Okay, Judy. Let me start with a brief introduction. Today is October 12, 2007. I'm Ann Lage for the Oral History office at Berkeley, recording an interview with Judy Heumann.

01-00:00:21

Heumann: Nice to see you.

01-00:00:22

Lage: This is a follow-up interview, Judy. Today we're going to focus on ACCD, the formation of—

01-00:00:30

Heumann: The American Coalition of Citizens with Disabilities.

01-00:00:33

Lage: Right, and 504. Two things that were skimmed over in your—

01-00:00:38

Heumann: Oral history.

01-00:00:39

Lage: Right, so this is a supplement. I want to start even before ACCD, talking about the growth of national networks in the movement. Maybe *pre-movement*, really.

01-00:00:52

Heumann: You know, for me it's always interesting to discuss a pre-movement, because I think we've grown to define the movement based on our own personal experiences, when in reality, if you look at history, like from Paul Longmore and others, there clearly were disability movement activities that maybe would have grown into being more recognized as part of the political movements if they were being developed at the time when television and radio were more in use. So that being said, the movement in my lifetime—what I believe we see is many different groups that were continuing to emerge. And one of the big changes that began to occur over the last thirty years really, has been the work as a cross-disability movement.

So we see, in the fifties from what I know, but I'm sure it must have been true also after the First World War, disabled veterans coming home who—previously died in war, who were now surviving, because of things like the advent of penicillin. And when those veterans came home, they had more significant disabilities. They also had greater stature in the community. So if you look at much of the work that was beginning in the forties and the fifties in the area of architectural barriers, that was really being pushed by many of the disabled veterans groups. And I know in New York State, for example, there was a group called the Eastern Paralyzed Veterans Association. And

they were very, very active at the state level, the city level; involved in passage of legislation and the development of regulations addressing the issue of new construction. And the Eastern Paralyzed Veterans organization in New York was also bringing in non-veterans. And so some of us began, for myself, I—

01-00:03:18

Lage: Yes, let's focus on your own role.

01-00:03:19

Heumann: I participated in some of the meetings that were being organized by EPVA in New York City.

01-00:03:28

Lage: Was this before you founded Disabled in Action?

01-00:03:31

Heumann: Yeah, this was in the sixties. I think when myself and others—we were trying to find organizations that we could participate in, and the organizations then were really more focused on disability groupings. So you had groups like United Cerebral Palsy and the Muscular Dystrophy Association, and the March of Dimes. But they—

01-00:04:00

Lage: They weren't consumer-controlled as we've come to call them—

01-00:04:02

Heumann: Well, you know, that's an interesting issue too, because United Cerebral Palsy was really, I think, one of the few organizations that was dominated by parents. If you looked at groups like the March of Dimes, they were really much more a fund-raising arm. They were dealing with issues of cure around polio and then moved on to others, but they were absolutely not political in any way. I mean, my mom had gone to the March of Dimes when I was having difficulty getting into school, and the March of Dimes was very clear they didn't get involved in any kind of activities like that.

But UCP was different. United Cerebral Palsy, the parents there were the ones that *did* get some schools opened; they were the ones that were, and some cases still today are supporting sheltered workshops. But at that time, in the forties and fifties, when kids with cerebral palsy for example weren't going to school--although they were segregated programs, I think in some way they were setting up these programs to demonstrate that kids could go to school. So for the time period that they were in, they were doing advocacy work.

And then they've changed over the years, too. But the *disability*-run organizations— you had the blind groups which were always run by the blind, and the deaf organizations, you had a number of them, like National Association of the Deaf, and they were also run by deaf people. But the

organizations of physically disabled people, I think those—there's never really been, for example, a *national* organization of physically disabled people.

01-00:05:57

Lage: But PVA, what about PVA?

01-00:05:59

Heumann: But they're a veterans group. So Paralyzed Veterans of America—yeah, they definitely are focused on physically disabled veterans, but they don't serve people who aren't veterans. So you could be served if you were a veteran and became disabled while you were a veteran, or if you were a veteran and became disabled later on. They served that whole grouping. But if I came in for services, as a non-service-connected person—

01-00:06:29

Lage: So they were mainly male also.

01-00:06:30

Heumann: Right. And the number of females has increased obviously over the years as women have gotten more involved in the military. But certainly after the Second World War, Korean War, and even the Vietnam War, it was mainly men.

What we started to see in, I believe, the nineteen-forties, more fifties, sixties, et cetera, were the development of different kinds of groups. The disabled student programs for example, that started I think in Columbia, Missouri and in Champaign, Illinois. I think—actually the Columbia program started before the one in Champaign. Now, they were not disabled student programs run by disabled people—I know the one in Illinois, the head was a non-disabled man—but they were an opportunity for disabled people to go to a university. And since a reasonable number of people lived on campus, it also was a time for people to get together and talk with each other.

01-00:07:45

Lage: Network.

01-00:07:46

Heumann: Networking, exactly. And for myself, in the sixties, when I started going to the university, many of the universities in New York did not have disabled student programs. The school that I went to, Long Island University in Brooklyn, didn't have a disabled students program. But we were able to organize and to get the university to set up a disabled student programs office, which was headed by a non-disabled man named Ted Childs. He was a great man; he was a veteran, he was an African American, he'd been very, very active in the civil rights movement. He was from the South. And—no, he wasn't from the south. Sorry, don't know where he was from. Eventually he went south. But he was a very dynamic person. He was a physical therapist, by training.

01-00:08:48

Lage:

Did he bring any civil rights orientation to your thinking or—?

01-00:08:52

Heumann:

I think what he brought to my thinking was a subtle—well, not subtle—I don't recall ever sitting down and having lengthy discussions on the civil rights movement per se. But the way he conducted his work and the way we worked together, it had a very strong civil rights orientation.

So I recall, once, when a teacher didn't want to accept a disabled student in their class; the student needed to use a tape recorder. And I remember him very clearly saying that this teacher was paid by the university and they had two choices: to accept that student in the class or to leave their job. And he was a very—you wouldn't ever say that Dr. Childs was an in-your-face kind of person, but it was just a part of his being. He had very clear morals and ethics of what he believed.

And for me, when I was trying to become a teacher, he was very supportive: he went down to the Board of Ed when I was having my interviews. And it was that kind of persistent actions, and being very supportive of what I and other people were trying to do, that really allowed us to look at our work that we were doing as part of the civil rights movement.

At that time the school itself had significant numbers of white people; there weren't many minorities. But one of the things that he was able to bring to the university over the years was bringing in more minority disabled students, and he eventually got his doctorate in special education from Columbia. So he really played a very strong role of integrating the university with minorities and minorities with disabilities.

So, we talked about some of the civil rights activities that he had been involved with; it was just a part of who he was. And I think it was a very important influence for me, because he never questioned anything that I was doing, where other people might question—when I was going to sue the Board of Education, was this something I should do—there was never any question of that.

01-00:11:44

Lage:

He had a strong sense of rights, it seems.

01-00:11:46

Heumann:

Exactly, and he lived it and he worked it, and he pushed it at the university. He pushed for a stronger disabled students program, he pushed for better staffing, and he saw—he saw the needs that had to be addressed in removing barriers within the school, both physical and attitudinal. He was a strong role model.

01-00:12:11

Lage:

I think we should, because our time is limited, I think we should really move into the—

01-00:12:17

Heumann:

Let me just say one other thing: we saw the disabled student programs really starting to emerge. In addition to that, then groups like Disabled in Action in New York started. And then, I think there were also more and more small, locally driven disability organizations that began to crop up across the country, before the independent living centers started.

That in part was being fueled by a little better communication, articles that might be in the newspaper, things that people might share with each other. People were finding out each other's telephone numbers and calling and finding out what people were doing. I think that was one of the ways that we also started moving away from the organizations that were dominated either by the "cure" groups, or the parent groups, or the veterans groups.

01-00:13:18

Lage:

And also it seems from local to a more national—I've always been struck by the story, if it's true, that Ed Roberts called you up and urged you to come out to Berkeley. What's behind that? How did he—

01-00:13:33

Heumann:

Well, what happened was Ed, Fred Collignon, and Henrik Blum—the late Henrik Blum—were interested in bringing disabled students into [the departments of] City and Regional Planning and Public Health. And Ed was involved with that in some way.

01-00:13:52

Lage:

But how did he know about you?

01-00:13:53

Heumann:

What they were doing was recruiting. So Ed started calling different people around the United States saying we have a few slots at the university; he was trying to get names of people. So he got my name from a lot of different people around the country and called me and said, "I've heard about you from a lot of other people. Are you interested in coming to Berkeley?" So that's the telephone—

01-00:14:21

Lage:

It's just sort of indicative of this beginning.

01-00:14:24

Heumann:

Growing movement, exactly. Well, the telephone really was very, very important, because it really did open up a whole new world.

01-00:14:34

Lage:

Yes, and people didn't do long-distance telephoning too much before that. It was a big move.

01-00:14:37

Heumann: Yeah, it was unusual at that time.

01-00:14:41

Lage: Yeah, right. Well, I guess I want to lead up to how ACCD was founded. Did you know Fred Fay and Lex Frieden, of course you knew them before, but—

01-00:14:56

Heumann: I knew all of them. I knew all of them. I'm trying to think . . . I definitely knew Fred, because I was working in Washington. Fred was living in Washington at that time, but I had known of Fred—maybe we had spoken before—when he was involved with the Boston Center for Independent Living. And we actually probably had met at one of the meetings. There was a national conference on independent living that Sue Stoddard and CIL [Center for Independent Living, Berkeley] had put together —

01-00:15:44

Lage: And there were those President's Committee on Employment meetings? [President's Committee on Employment of People with Disabilities]

01-00:15:45

Heumann: The president's committee meetings were going, yeah that's true. And Disabled in Action was active at the president's committee meetings, probably starting in '71. Okay, when did they... I graduated in '69, the lawsuit was in '70. Actually, I think we went to the president's committee meeting in '70, because it was after we had started Disabled in Action and we had heard about the president's committee. We tried to get a meeting room, couldn't get one, wrote to Herman Badillo, who was a congressman in New York, and he wrote to the president's committee, told them to give us a meeting room. That's how we got there.

01-00:16:38

Lage: So you were making it your business to make this a national thing.

01-00:16:42

Heumann: Oh yeah, because I think we were recognizing very early that we were looking for opportunities of being able to get together with other people. Either to be critical of what was going on and to try to influence people to do things differently, and/or to also identify other people who were of like mind. And I think, because it was difficult for some of us to get around, being able to go to venues where there are a lot of people with one location, like a hotel, it made it easier to be able to network.

And there were other—actually, there was a National Spinal Cord Injury Association. Fred Fay was very active involved in that. Lex . . . I'm trying to remember when—I knew Lex in the seventies, I think I knew him before the ACCD meeting. I'm pretty sure I had met him before that. And I knew Al Pimentel and I knew Fred Schreiber, who Al Pimentel believed was—no,



Terry [Terrence James] O'Rourke. Who was the first president of ACCD?  
Was it—

01-00:10:11

Lage:

Was it Eunice [Fiorito]? That's who I have: Eunice is the first president and Frieden is the first secretary, and don't ask me where I got that info [laughing]. From one of the interviews, I think. Who came up with the idea, do you remember that? Of this type of organization?

01-00:18:31

Heumann:

I think we were all recognizing that there was a need to bring a group like this together. And there was a national meeting—I believe the first meeting took place at the National Spinal Cord Injury meeting. My recollection of it was that it was a bringing together of people, many of whom were from different organizations, talking about the need to get a coalition together because of what had happened, first with the vetoing of the rehab act [Rehabilitation Act] under Nixon, and then once the Title 5 provisions had become law, the regulations not happening.

So people were recognizing that we needed to be able to become a force, and it would be better if we were one that wasn't un-united; that we really need to make a united front. And so as the group—we were looking to bring this diverse group of people together. I guess Eunice, maybe Fred Fay, I don't know. I'm trying to remember how people got invited to that meeting, but it was a cross-section meeting. And it was the first time really that the deaf were involved in a meaningful way. And—there definitely was a deaf president at one point. Okay, we really should find out.

01-00:20:26

Lage:

We should find out. And where are the records of that organization, do we know?

01-00:20:30

Heumann:

I don't know. And now that Frank Bowe has died, Eunice died, Phyllis Rubinfeld died, I wonder if the archives went anywhere.

01-00:20:43

Lage:

We should try to figure that out. We could talk about that after.

01-00:20:47

Heumann:

Al Pimentel would be somebody we should try to track down. He's alive.

01-00:20:51

Lage:

And interview.

01-00:20:52

Heumann:

Yes. He's in Connecticut or New York. But the way you can find Al Pimentel is to go through Gallaudet [University]. They'll know how to reach him.

01-00:21:09

Lage:

Okay. Was this cross-disability a new word? Do you remember a discussion about cross-disability? The term or the concept? Did it just—

01-00:21:20

Heumann:

The concept, yes. The word, no. The concept, for myself, I went to a camp called Camp Jened. And I went to a camp called Camp Oakhurst. Oakhurst was a camp just for physically disabled kids. But Jened for some reason was mainly for physically disabled kids, and some physically disabled kids who had intellectual disabilities. Jened had some blind campers and deaf campers. And so for myself, one of the years I was at the camp, there were about three deaf women. We were in the same cabin, and I started learning sign language. That influenced my thinking as I began to become more involved. It wasn't planned, so my getting involved in doing what later is discussed as the political movement just kind of evolved.

01-00:22:38

Lage:

And that's important, I think. Because looking back, we ascribe different kinds of meaning.

01-00:22:44

Heumann:

Things just—for me, you know, deafness, and I guess because when I went to school there were kids in my class who had what was called mental retardation, and because I had some exposure to blindness—it always felt to me that we needed to be working together. Because the problems were the same.

01-00:23:12

Lage:

You seemed to get it instinctively somehow.

01-00:23:15

Heumann:

I did right away.

01-00:23:16

Lage:

As this movement moved on into the seventies, say, did you have to argue that point with others, or could you remember any significant discussions?

01-00:23:28

Heumann:

Oh, I believe, CIL naturally started out as a group of physically disabled and blind people. But as we evolved, for example when the deaf got involved, that definitely wasn't planned. And the involvement of deaf people began in a more meaningful way because of a man named Dale Dahl, who was deaf from birth, and then became a triplegic. And couldn't get services from DCARA [Deaf Counseling, Advocacy, and Referral Agency] because—I'm not sure if their building wasn't accessible or they just didn't know how to serve people who had multiple disabilities. And I think the Deaf community had in some way really seen itself as—and in some parts still does, you know—we're deaf, we're not disabled, and we're only deaf. So then, when you come along with a learning disability or wheelchair or something else, it kind of throws things off a little bit.

But there were a group of deaf people who came to CIL and asked if we would provide services. And actually, what we did at that time was, we didn't want to get into confrontational situation with DCARA. So we put together a working committee that was made up of all deaf people and one parent who had a deaf kid. And we asked them to look at what we were doing and what other groups were doing, to make the case for why it would be a good idea for CIL to, or not to, get involved in deaf services. And they came back with a recommendation that the board accepted. So that was—

01-00:25:25

Lage: That you do get involved.

01-00:25:26

Heumann: Yes. So that's when we set up deaf services. But then as we moved into working with people's psychiatric disabilities, I would say that that was more of a contentious issue. Not like vehemently, but I believe that as the organization got older, there was more of a look at —well, do we have the competencies? In the beginning I feel like it was less an issue of competencies because we just felt we were competent in everything. And if we weren't, you filled it—

01-00:25:58

Lage: Right, it seems in the beginning you just added programs.

01-00:26:03

Heumann: Yeah. You figured out what to do. And I think that was what was very exciting about CIL in the beginning: we were definitely change agents. We believed that a problem could be solved. And we were able to create many different ways of solving problems.

So I think the evolution of CIL becoming a cross-disability organization was probably hindered in some way by not having enough exposure across the disability groups, so that people could feel comfortable in doing that even as equals. You know, when we brought parents into CIL, that was a big issue. Because Mary Lou [Breslin] at that time was *vehemently* opposed to bringing parents in, and I was very supportive of bringing parents in. And I don't know if she's talked about it, I was saying to Kitty [Cone] yesterday: I really wish there'd be some way of getting some of us together, just here in Berkeley, having some different group discussions. Because not only—

01-00:27:20

Lage: For the historical record? I think that'd be great.

01-00:27:22

Heumann: Yes, oh yes. I really think so, because there are things that we each can't exactly remember. And even our views of why certain things happened, I think historically would be very important. But in this case here, on the issue of cross-disability —it wasn't just cross-disability, it was age. Because there

are many different divisions, and by this I don't mean based on political philosophies, but divisions of when one acquired one's disability.

01-00:28:01

Lage:

Is that what you meant by age? Not how old you are at the time.

01-00:28:03

Heumann:

Yes, right. So there are a group of us who acquired our disabilities at birth or very early on. I would say the five-and-younger group, or eight-and-younger group. And we were affected by, even looking at the young group, we were affected by, A, having a disability when we were younger. Not yet having created identities which were formed more about being in the majority —

01-00:28:41

Lage:

Kind of an entitled identity would you say? Is that it?

01-00:28:44

Heumann:

Well, you know, if you didn't have a disability, you were part of the entitled group. So if you had a disability it affected not just you, but your family. And depending on where you lived, it affected everything from movement in the community to the ability to go to school, where you went to school, what you learned in school.

If you became disabled like Ed [Roberts] at the age of fourteen, or many of the other men and women who were spinal-cord injured when they were eighteen and older, they really had a lot of their personality formed. Because at that point, we weren't really involved in the poorer communities, so the non-disabled people that became disabled later on, they'd been through regular public schools. Primary schools, secondary schools. Their families had a view of what they wanted them to do that wasn't affected by them having a disability. And even when they acquired a disability, if their family views changed because they thought disability was a tragedy, they themselves could eventually evolve to recognize that they were able to do things that others thought they couldn't. And they had the benefit of having an education which supported them to be able to do that.

But for people like myself and others who hadn't been able to go to regular schools, we really were at a disadvantage because we believed very much that we would be able to do what others could do, but if you didn't have—it was both the academic, but I also want to say, very much, you know, growing up as a second-class citizen. So this issue of how to create a vision for what you wanted to do, and how you could go about pursuing it, and what to do if you hit barriers —those were different issues for the younger and older group. And for me, when I look at CIL, you had Jan McEwen [Brown] and Hale Zukas, who had their disabilities when they were young. But as a rule—I guess Dick Santos, maybe Larry Biscamp, had them when they were younger. But a lot of the leaders: Ed, John Hessler, the Rolling Quads, Phil Draper, they all had

their disabilities when they were older. And they didn't *think* about issues affecting kids.

So when I got involved with CIL and a number of my friends from New York moved out here, people like Ann Capolo and Nancy DiAngelo and Jan Boulter—they're both dead now. And a woman named Nancy Rosenbloom, she died also. But they came out here. And that's when we started looking more at kids' issues. The kids' issues never would have been addressed at that period of time.

01-00:31:56

Lage: And then that brought parents in.

01-00:31:59

Heumann: Then—I went to Berkeley, I was on the board of CIL. Then I went to Washington DC and I worked for Senator Williams.

01-00:32:09

Lage: I want to talk about that more too, as a background.

01-00:32:12

Heumann: Well, and it's part of the ACCD thing also.

So we were working on the Individuals with Disabilities Education Act. When I came back here, because of the IDEA, that's really when we started looking at getting money to do more work on kids' issues. So first we got this grant called the KIDS Project, which was intended to work in the schools in Berkeley with disabled people and parents, working on training teachers and separately working on training non-disabled kids, about bringing disabled children into the school. Then we had set up the paralegal program, which was the precursor for DREDF, and that was done through a CETA grant.

And then we got this—God, what was the money?—anyway, we got money I guess, I think again from the federal government, to do training of parents. And Julie Landau—I'm trying to think if Julie was here already. But at any rate, we had positions for advocates, and that's when the issue came up of whether or not we would hire parents. And I felt it was really important that we look at doing that. I guess to me at that point, it started to seem like if we could get parents knowledgeable earlier on with their kids to become advocates, which many of our parents had been, but in a more organized way—

01-00:33:55

Lage: And more political maybe, instead of—my individual child.

01-00:33:59

Heumann: I think because—yes. Well actually, the only reason I'm hesitating on that is, my mother organized with other mothers. So they pulled other mothers together, they just didn't put it under a named organization. If you look at

what happened in New York City with the Board of Ed agreeing to make some of the high schools accessible so that physically disabled people could go the high schools—because what was happening when I was in grade school is if you were in a wheelchair, you went back on home instruction. So it was the parents that organized with the Board of Ed—or against the Board of Ed—to get them to agree to make some schools accessible. So they were political. And I think that parents, the UCP parents, they were political. UCP parents probably more than many others, because the head of ABC had a kid with cerebral palsy.

So some of the parents in UCP traveled in different circles. So they became, some political in the true sense, and others used, like for the telethon, they used their connections to get things going. But I think you were seeing different ways of people coming together and beginning to realize that coming together gave them a strength to correct a problem. I think one of the issues like with my parents and others is, there was an issue and an issue and an issue. They weren't coming together for kind of a lifelong engagement. The kids, like myself, were the ones who were doing that. And the parents played a supportive role, because we were already in college and out. So my mother was always involved, as were my friends' moms, in Disabled in Action. They were the note-takers, the typers for the newsletter, the mailers of the things. They drove people around. They were very supportive and let us. They weren't looking for any limelight.

01-00:36:16

Lage:

That's interesting, because I don't know that that's been brought up too much.

01-00:36:20

Heumann:

I don't think so. I think we need to talk more to parents. But anyway, with CIL, what was going on at that point, I can't speak obviously about all the centers. But there were definitely a growing number of us who recognized the need to look at how we worked, focusing on the needs that were cross-disability, sometimes disability specific, but also this issue of age. And I think when the parents, what I found very interesting about the parents that we hired through the first project that we had at CIL doing advocacy work was that they were all parents who had children with very significant disabilities. So they weren't parents who had kids with disabilities like myself or Mary Lou or Kitty or any of us. They were parents, all of whom had kids with significant intellectual disabilities and significant physical disabilities. And in some way, it really intrigued me that these parents would look at us as role models. But I think it was very powerful, because they then spawned a whole other group of parents who really had much higher expectations for children that many completely felt were incapable—okay, they belonged in school. Sit them in a classroom. Who cared.

01-00:38:01

Lage:

It seemed like they almost got the connection, the cross-disability connection, before some of your own age group did.

01-00:38:09

Heumann:

Oh, absolutely. But again, it was this, I think you know learning from what other people had done. And in some way, my presumption is, they're feeling that, well, you push as hard as you can push and see where you can go, because everybody was learning as we were going. And I think ACCD is another example of that. The disability movement today is still woefully underfunded. At that point, and I'm jumping ahead a little but it's relevant, there was never money to be able to really get an ACCD organization meaningfully off the ground. There's a group in DC called the Consortium for Citizens with Disabilities. It's been around for a long time. It just recently became incorporated, like in the last couple of years. It's made up, primarily, like ninety-some-percent or more, of the national organizations: the UCP, the Epilepsy [Foundation], Easter Seals, which are not disability-run organizations. But they're the lobbyists in DC on disability-related issues.

01-00:39:29

Lage:

And they have more money.

01-00:39:31

Heumann:

Well, they don't have a lot of money either.

01-00:39:33

Lage:

Don't you think groups like Epilepsy Foundation are well funded?

01-00:39:38

Heumann:

Well, I don't know what they're doing and whether it's well funded enough for them. But the issue I think for a consortium of groups, getting funding for those groups has been hard. I think the difference between a CCD— Consortium of Citizens with Disabilities, CCD—and an ACCD, to your point, is the disability groups really didn't have a lot of money. So if you wanted to look at creating a group like the ACCD and being able to sustain it with funds from the disability groups, it was very hard because we were struggling here at CIL. We didn't have an appropriate amount of money to give to an ACCD.

And at the same time, the National Council on Independent Living was just being created. So this issue of national coalition was very complicated, because you had emerging disability groups, some not. NAD, for example, National Association for the Deaf, which was more than one hundred years old. And groups like National Federation of the Blind and American Council of the Blind. But everybody was also, there hadn't been an opportunity to create trust, and to really spend time together in some way, I think like we were able to do in the CILs around the country. At the grassroots level, what we were able to do by becoming friends and working together was to begin to see, A, that we needed to have a respect for each other. We needed to learn about each other's differences, and the way we addressed those differences. We needed to be able to become conversant enough so that we could move away from "my need is more important than your need." When they're both equally important, and at the end of the day, you as an individual person want

something to improve your life, so how do you compromise on, you know, something for someone who's blind versus someone who's deaf versus someone, whatever it may be. And I think that's what the ILs allowed us to do. And at the national level, with ACCD, it was a short-lived organization. Seven years, seven or eight years.

01-00:42:07

Lage: Eight years, '75-to-'83.

01-00:42:09

Heumann: Yeah. And really, the last couple of years was not very functional.

01-00:42:14

Lage: And was that because of kind of the divisions that you describe or lack of understanding, or were there—

01-00:42:21

Heumann: I think a lot had to do with money. Quite frankly, I think the leadership of ACCD was much more at the level of accepting and agreeing about our diverse needs and being supportive of each other. I don't think that was really an issue for that group. Most of us knew each other when we came together, and respected each other. But what the issue was, we needed to set up an office. We needed to raise money to set up an office and to keep things going. How to get the money. There were very limited ways of getting the money. And I remember one of the issues that had come up is that Frank had applied for money in the area of independent living. People were not happy, because that was money that needed to go to the independent living programs. You could understand why he maybe did it, but it didn't build harmony. But I think really, you know, it might be a little bit easier now to get some funding for national organizations. But it's still very difficult. The movement itself, as much as we've grown, we still have not made it into the circles of money.

01-00:43:54

Lage: That's interesting that you bring that up, because often it's overlooked. It's not philosophical or ideological.

01-00:44:02

Heumann: Money is very important because you need—all activities don't have to be driven by money. You can have local committees that—Disabled in Action [DIA], as an example, it doesn't really have any money. And it has succeeded as a grassroots local organization that does various work in New York City. But as one of the founders of Disabled in Action in New York, for me, what was very clear when I came from New York and came here to be involved with CIL was the big difference in being able to have an organization where people's jobs were to do X, Y, and Z. Where people were being held accountable for setting up an organization like a CIL, working with disabled people to look at what our needs were, learning how to define them, to be able to get money from the city and the county and state and private sources, to be able to make the case of what would happen if we could do these things that



we couldn't do individually or as volunteers. We could use volunteers. But volunteers couldn't make the difference. It made it much easier to be able to do things that we had incredibly difficulty doing in New York.

In New York and Berkeley, there are lots of variables, including size—not having buses in Berkeley was very different than not having buses in New York, because you could walk almost anywhere in Berkeley. You didn't have curb cuts but you went in the street, but you could still get around. In New York, obviously, as such a big city, the lack of accessibility had a much deeper and more profound effect on people. I think it also made people in New York in some way stronger fighters. But on the other hand, you still came up against these barriers that really did limit what you could do at—

01-00:46:12

Lage:

Your organizing ability.

01-00:46:14

Heumann:

It took longer to be able, but when you made a change there, it would have a bigger impact.

But I think cross-disability has always been something that I've believed in. When I was a part of Disabled in Action, there was a little article in one of the newspapers. There was an organizing meeting at Willowbrook State School for the Mentally Retarded, which Geraldo Rivera and some doctors in the hospital, a man named Bill Bronston, Michael somebody or other, had brought Geraldo in. So this was only dealing with people who had a primary disability of what we now call intellectual or developmental disability. And we sent somebody from DIA to that meeting. So when we had our demonstrations in New York against the vetoing of the rehabilitation act, the group from Willowbrook came to our demonstrations.

So I would say in 1972, it probably was the first time probably ever that these demonstrations were much more cross-disability, particularly in bringing in people who had intellectual disabilities. Now, a lot, there were parents there, and advocates, a few people who had developmental or intellectual disabilities themselves. But you saw, like from this sixties on forward, this movement on the part of some of us to really expand. And ADA, obviously, I guess was the next really big—because we weren't really players in the passage of Title 5.

01-00:48:07

Lage:

Right, the 504 Section [Section 504 of the 1973 Rehabilitation Act].

01-00:48:09

Heumann:

504 and other section. We had nothing to do with writing of the language. ACCD came together many ways immediately to try to address the 504 problem.

01-00:48:23

Lage:

Now what brought that to your attention? You didn't have—

01-00:48:25

Heumann:

We knew about the fact that the regs [regulations to implement section 504 of the Rehabilitation Act] were being worked on. That was something that groups were involved with pretty quickly. So there was a committee, or the government itself was beginning to work on the 504 regulations. The senator that I was working for was involved with that. So I was somewhat involved with that, working with the staff in his office. Groups like The Arc and UCP and others were getting involved in that.

01-00:48:58

Lage:

Did you immediately see how important this 504 was? It's just interesting that you say there was no feed in to it.

01-00:49:06

Heumann:

We had no input into the writing of it, but we got it immediately when we saw it. Because it was the same as the civil rights language from the sixties. So getting the importance of that was not an issue. That wasn't the problem. The problem was we lacked, as a disability community, the political know-how, organization to really be able to influence this. But we—

01-00:49:33

Lage:

Was that one of the reasons ACCD actually was formed?

01-00:49:36

Heumann:

Absolutely, absolutely. I would say that one of the main reasons—I would say that if there weren't an issue around the 504 regs, there wouldn't have been an ACCD at that time. Because I think that was really the driving force. If you look at what ACCD's biggest success was, it was moving forward, getting the regulations promulgated, getting the regulations implemented. That was probably the strongest benefit that ACCD had. And not a minor benefit at all, quite significant.

I also believe that the work that happened in the Bay Area around the 504 demonstrations really made the 504 issue rise to a much higher level than it would have. Who knows what would have happened, but my projection would have been, if the organizing in the Bay Area had only risen to the level of organization around the rest of the country, and everything would have dissipated in one or two days, the regulations would not have come out the way they did. They would've been watered down. And I'm sure ACCD would've claimed a victory, because you always claim a victory. But it wouldn't have been anywhere on the magnitude of what we were able to claim. And I think there was always a division about what was going on in the West and what was going on in the East. There wasn't—

01-00:51:23

Lage:

I really want to take this bit by bit, because I think these things you're saying are really important, and if we can kind of go back to how, let's take the decision for ACCD to do two things: issue that ultimatum, and decide to do

sit-ins. Can we talk about that for instance? Do you remember the actual decision to—

01-00:51:51

Heumann:

I do, I remember. I remember what I remember, which may not be what happened. But you're never sure. What I remember was, we had a board meeting in '77. At that board meeting, people were very frustrated, because Frank and Eunice, they were committee meetings, Mary Lou had been going to meetings, I was going to meetings. Kitty, I think, was involved in some of those meetings in Washington. There were all kinds of activities going on in relationship to the development of the regulations. But still, they hadn't happened. And Carter had been elected. And many of us had worked on his campaign. People were concerned about what was going to happen. I was saying to Kitty yesterday, "I believe I was the one that made the recommendation at the meeting that we set a date specific and we have demonstrations."

01-00:52:57

Lage:

They went hand-in-hand like that.

01-00:52:59

Heumann:

Right. There would be a day, if the regulations weren't promulgated by that day, there would be demonstrations on that day around the country. And we looked at the nine regions, federal regions. That's what we looked at.

01-00:53:19

Lage:

Did people accept this right away, or was it some—

01-00:53:21

Heumann:

Yeah, no, I think there was a motion that was passed.

01-00:53:24

Lage:

So that wasn't controversial, to issue that ultimatum, because that's a big deal when [HEW Secretary Joseph] Califano is saying, "We need to study this."

01-00:53:31

Heumann:

Well, we didn't even exactly know what was going on at that point, I think. They were saying that, but remember everything was very new at that point. We had the demonstrations, when were they, April?

01-00:53:41

Lage:

April 5.

01-00:53:43

Heumann:

Started April 5, so I believe the board meeting was in February.

01-00:53:48

Lage:

That seems to be what I've read.

01-00:53:51

Heumann: Right, I think the meeting was in February and we planned the date for April. And Frank and Eunice and the people back east were going to keep doing the work that they were doing, and of course—

01-00:54:03

Lage: And were they working with—

01-00:54:05

Heumann: Members of Congress and different, and with people in HEW [Department of Health, Education, and Welfare], et cetera. You know, one of the issues at that point was, I think, what still goes on today, how Washington handles things, and how people outside of Washington handle things. So in Washington, and I really know this being there, there is no real movement in Washington.

01-00:54:37

Lage: You mean political movement?

01-00:54:38

Heumann: There are gazillions of national organizations based in DC, like ACCD. But the worker bees, like you have around the country, it's just different. And even where you have worker bees, they're not connected to the national in many cases. And for us here in Berkeley and the Bay Area, really in California, as the IL movement evolved, we recognized very early that influencing our city council and our county boards was completely insufficient. We had to make—we understood the political process. You had to be making changes in federal laws and in state laws. That would impact what was going on at the local level. And where the local level could make its own laws and things on certain things, a lot of what drove and drives its work is influenced by state and federal legislation.

So we had people in California, for example, who were the most knowledgeable people, bar none, on things like Social Security benefits. People like Greg Sanders, Hale Zukas, Doug Martin, a couple of those, I don't think anybody would ever dispute that they were more knowledgeable, including people in Washington. They knew the law. They knew the regulations better. In part, they needed it for themselves. So they learned these rules. They were all brilliant. They learned these rules as much to benefit—well, they learned these rules for themselves. That's the reason.

01-00:56:25

Lage: Their lives depended on it.

01-00:56:27

Heumann: And then there were also people that went beyond just working for themselves. You know, that was a very special part of what was happening then. This was true with 504 and other issues. We recognized from the beginning the importance of 504. We recognized very early that it was a 26-word law that was going to have to get interpreted. And I think we recognized

very early as we were beginning to work with John Wodatch and others, that we had to be able to get in there and make the case for specificity.

01-00:57:08

Lage: How much did you work with John Wodatch and other people, lawyers who weren't disabled who were working in the office—

01-00:57:16

Heumann: Well, when I was working in the Senate side, I was involved, because we, Lisa Walker, Nick Edes and myself, we would meet with them and get briefings on what was going on.

01-00:57:30

Lage: Did you have an opportunity to put forth kind of a philosophical view that they might not have been exposed to?

01-00:57:36

Heumann: I think we all did. I think as we got involved—has anybody interviewed John Wodatch?

01-00:57:44

Lage: Mary Lou's program did a brief interview with him.

01-00:57:48

Heumann: I think John would be really an important person, because he's been doing this now for thirty-some years.

01-00:57:56

Lage: I'm just interested in who or what made him see the world in a different way regarding disability.

01-00:58:03

Heumann: I don't know. You know, I could say that he was a good listener, and he was not a "no" person. So he could be persuaded by talking with people who made sense. And at that point in time in the government, I think he had some decent latitude; that I don't know as a fact. But everybody was learning as they were doing. So there definitely were "no"s that were coming down on the part of—I think what happened, not think, what happened is this law [section 504] came out. The recipients of federal financial assistance were totally caught off guard. And they started organizing. If they didn't know about it, and they stayed out of this, none of this would have been a problem. But it was their desire to minimize the impact, and to leave the regulations as brief as possible, because that would leave it more up to interpretation in the courts. And I'm sure that was their rationale.

01-00:59:15

Lage: The universities, the hospitals.

01-00:59:18

Heumann: The transportation [sector], whomever. They knew nothing about this. As they saw these regulations evolve, I think obviously money and who are these people, and we don't want to deal, blah, blah, blah, federal intrusion, et cetera, et cetera. And we saw this as a logical way to get them involved, a logical progression—

01-00:59:47

Lage: To get them involved in making change.

01-00:59:48

Heumann: In making change. Since they were getting federal money, and this is for me where Dr. Childs was very influential, you know, his example of this teacher not wanting to serve the student, well, you have two choices: you serve the student or you leave the school. So my perspective personally was, you're getting federal money. If you don't want the federal money, you don't have to do this. Get rid of the money. But if you want the federal money, there isn't an issue of discussion. You're obligated to do it, because I pay money into the federal system and you have to serve me like everybody else. So I think for me, and I can't speak about that issue except for myself. But it very much was driven, I think also by the fact that we knew these things could be done.

01-01:00:41

Lage: I'm going to stop you right there, because this, the tape is running—

[End Audio File 1]

Begin Audio File 2 10-12-2007.wav

02-00:00:00

Lage: Tape two, with Judy Heumann, on October 12. Okay, Judy—

02-00:00:06

Heumann: 10:30 at what used to be called Gramma's, now called the Rose Garden [Inn].

02-00:00:12

Lage: Right, we didn't put that on the first tape. While we were off the tape, I asked you if you could recall during that period when you were in Washington, was it '74 and '75, when you were on the staff of Senator Harrison.

02-00:00:32

Heumann: Harrison Williams.

02-00:00:33

Lage: Harrison Williams. Can you recall any ways that you might have helped educate this group of staffers?

02-00:00:40

Heumann: Well, there was a gentleman who worked for Senator Cranston named Michael Burns. He was a vet. So Michael was one of this small group of

people who were involved in writing Section 504 and Title 5. So Michael definitely had been involved in helping, just by being there to change people's views.

02-00:01:04

Lage: Now, was he a vet with a disability?

02-00:01:06

Heumann: Yeah, he was a wheelchair rider. I would say that the people who I most immediately worked with had pretty decent attitudes or I wouldn't have gotten hired. I think that's kind of a foregone conclusion that if they didn't already have a commitment to the issue, they wouldn't have hired me. And people like Lisa Walker and Nick Edes had been involved for a number of years on working on the individuals with disabilities—or was then called the Education for All Act. They'd been the ones, Lisa and Nick and Mike and Jonathan Steinberg and, oh God, Bob from Senator Stafford's office, they were the ones who were the core group on putting this together. So they were an open-minded group of people.

But, you know, one incident that I remember, at that time, was what '74, I didn't wear shoes a lot. I had stopped wearing my braces in about 1968, after my spinal fusion. And in the summer, when it was hot, I just didn't wear my shoes, because it wasn't easy for me to find shoes. So I would go to work without my shoes. And one day, the senator's head person, like the office manager, called me into her office and she said, "Dear, I have to ask you, could you please start covering your feet when you come to work?" It's relevant to this because I think it was really difficult for this woman or anybody to ask me to start wearing shoes or socks or something on my feet. And I laughed, you know, think her name was Marilyn. But it was a big deal.

02-00:03:06

Lage: Did it offend you?

02-00:03:07

Heumann: No, I kind of laughed about it. No, nobody else in the Senate was walking around with—but in some way, I didn't even see it. It was like not even an issue for me.

02-00:03:19

Lage: Well I'm thinking Berkeley hippie [laughing].

02-00:03:21

Heumann: Right, but you know, I'm from New York. I just didn't think anything about it. But I laughed because I thought, this had to be a big deal for her to do this. Because people did have this level of discomfort. Now, I'd been there for a couple months. In reality, if any other staffer would have come to work for five minutes without shoes or socks, and just entered the door of the building and walked around all day without shoes or socks, it wouldn't have taken any

time for somebody to say, “You have to wear shoes.” From the guard at the front door to somebody else.

So I think over time also I had an influence on people, after I left, because when there was legislation that was moving forward to fund the Centers for Independent Living, I was able to get people on the House side, staffers, and we had two congressmen who came out to Berkeley and held hearings in the, at that point, the garage of the CIL. We had a day of hearings on what was going on in California with CIL and the other independent living centers because Ed was the director of Department of Rehabilitation. At that point, I think there were ten centers that Ed had funded around the state. So in '77, we had some very good work going on in many parts of the state. So we never would have been able to get those hearings if I hadn't, over the time I was there, developed relationships with quite a number of the staffers.

02-00:05:10

Lage:

And were these East-Coast congressmen, or east—

02-00:05:15

Heumann:

Somebody from Ohio, a congressman from Ohio came. And Brademas was a staff person. Brademas was from Indiana. I don't think we had any California members at that time. But we had a day of hearings. And in those hearings, we had representatives from the city and the county government. And I don't remember if Tom spoke. Tom Bates might have spoken. What we were trying to do that day was to set up a series of panels that would allow the Congress to see why they should be funding independent living and what its benefit was. So we had people with all different types of disabilities, very well organized. So I had learned about how to set up a hearing.

02-00:06:04

Lage:

Right, you learned in Washington and brought that back as well as educating people there.

02-00:06:09

Heumann:

Exactly, yeah, so—

02-00:06:11

Lage:

Sounds like that was very important.

02-00:06:13

Heumann:

Yeah, it was kind of a combination of—and I wasn't treated as an intern. I was treated as a regular staffer, because I was in the Master's program. So I was a legislative assistant. But I think people learned to trust what I was saying, not necessarily across the board, because I was considered fringe and out there. But they would listen to more of what I was saying than not. So for me, I think that one of the most important outcomes, separate from the 504, was the role that we played in the national legislation on the formation of money for independent living centers.



02-00:07:02

Lage:

Let's go back to that, [attitudes] inside the beltway in ACCD. You mentioned it, but did it come out as you were planning how to handle the sit-ins?

02-00:07:13

Heumann:

My recollection was on the West Coast, we just decided that we were going to do our thing.

02-00:07:20

Lage:

You planned your own—

02-00:07:21

Heumann:

We did. We planned it around, and we were not disrespectful. But we decided that we—and it's not that we were being told not to. But we decided to lead with our strengths. And we decided that what we wanted to do was to set up this committee to save 504, which was organized by a broader group than you saw going on on the East Coast. But that's the way it would've been, because they were working with staffers in [the Department of] Health, Education and Welfare. And they were working with congressional offices. And they were doing the Washington thing. And we were trying to figure out what could we do both to keep our linkages in the Washington scene, because as I was saying earlier, we did develop that. And because I was working, had worked there, other people had been involved over the years in doing activities nationally, we kept those connections going. So we had very good relationships with Congressman Miller's office and Congressman Burton's office. And of course we used those, and Miller's office.

02-00:08:40

Lage:

And how did you develop those relationships?

02-00:08:42

Heumann:

Ann Rosewater.

02-00:08:43

Lage:

Tell me about Ann—Kitty said for me to ask you about Ann Rosewater.

02-00:08:49

Heumann:

Well, Ann Rosewater used to work at the Children's Defense Fund. So I got to know Ann Rosewater I think through Lisa Walker, when she was at the Children's Defense Fund. And then she started to work for George Miller. So she, we had a very good—we, the disability community, and she—had a very good relationship. And, of course, George Miller had worked for Congressman Phil Burton. And Phil, you know, was such a progressive, and knew Hale and Ed and all these different people. So trust was always something that was there. And I think, you know, for the congressmen, they know their constituency differently than the senators. So George really did know people in a much deeper way. And Ann played a very important role. Then of course Pat Wright, who was then emerging at that time, and Ann became very good friends. And Lisa and Pat, they were all very good friends.

And Lisa was working for Harrison Williams still. So we were able to get information. And I think—

02-00:09:54

Lage: Now, tell me what information is this. What was going on in the—

02-00:09:57

Heumann: Yeah, but I think it was easier for us to be able to speak to Ann and Lisa and talk with them about what they were hearing. They were talking to John Wodatch. We were trying to pull together the different sources of information.

02-00:10:20

Lage: Of what was going on in this task force on the regulations, is that—

02-00:10:25

Heumann: Yeah, but we were, I'm trying to remember. Until Carter was elected, there had been a number of meetings that were being held on different subject matters, that as I said earlier, like Mary Lou, Kitty, and myself participated in. Hale [Zukas] might have been involved with some of those too. So we were in and out of Washington, participating. I don't remember if after the election in November, there were any other meetings like that. I would tend to think there weren't because, because the party's leaving and new people coming in. So I think in February, when we started, Frank [Bowe] and Eunice [Fiorito] were hearing I guess from John [Wodatch] and others, I don't know that for a fact, about the re-looking, the reviewing for—but I don't—

02-00:11:28

Lage: Well, they have the task force on the regulations, which had nobody with disabilities on it.

02-00:11:33

Heumann: Well, it was a staff task, internal task force. I think part of what was going on was a breakdown in communication. Because there were these new people who came in who hadn't been involved in the previous process. They didn't know any of us. Califano [Carter administration's secretary for Health, Education, and Welfare] didn't know any of us. And Califano was, of course, influenced by the lobbyists and not by the disability lobbyists. So I think that, for me, my recollection of the communications really started coming down when the demonstrations were happening, when we decided to stay in the building in San Francisco, our ability to have really good communication with George Miller's office and to some degree Cranston's office, but I think George's office in particular. And then the ability to talk to John Wodatch, and also Peter Libassi. Now Peter was John—

02-00:12:31

Lage: He was, came in with Califano. He was a new—

02-00:12:36

Heumann: Peter came in, oh my God, Peter came in with, my goodness, I can't believe I'm forgetting his name. I'll remember it. David, oh my God, I'll remember it.

David was the head of OCR [Office of Civil Rights] and Libassi worked for David. David was a blind man. He's now a judge. When we were in the building is when we were getting lots of different information, because we were able to get Peter to talk with us on the phone on a regular basis. And I think Peter and Ann [Rosewater] were speaking on a regular basis. Ann was, Ann should be spoken to, but Ann was completely—she was a very strong advocate. She came from the Children's Defense Fund. She understood the civil rights issues. She completely understood the disability issues. She was working for George Miller. So there were no barriers there.

So she was really a very important link in being able to identify what concerns were coming out from the task force. And ultimately I think, it became very clear that this just "correcting and simplifying English" wasn't true. And as we were able, through various ways, to get communication going, we were hearing about the kinds of changes they were looking at making. Does that make any sense?

02-00:14:20

Lage:

It does. It does. From what I've read, Peter Libassi wasn't such a sympathetic character. Was he, in your experience?

02-00:14:33

Heumann:

I think no, I mean, I think Peter Libassi, I would not say was a John Wodatch at all. I mean Peter was new to everything. And he was there doing a job. I would certainly say that he wasn't a bad person, because he was willing to talk with us. And he gave us, I mean the sit-in in San Francisco stayed on as long as it did because Pat, he, and I were having this long discussion, listing—I mean he listed for us all the issues that they were reviewing.

02-00:15:14

Lage:

So he was very open about it.

02-00:15:16

Heumann:

Very open about it. So I mean I don't know what his personal views were, but I would tend to say that he was—want to shut off a minute.

02-00:15:31

Lage:

I think, oh, okay. [pause in recording]

02-00:15:33

Heumann:

I would tend to say that he was more favorable than unfavorable. Because if he was unfavorable, he was stupid. You know what I'm saying? If you really don't want anything to happen, you don't sit down and list the eleven or fourteen issues that were up for negotiation. So George comes in unannounced. We put him on the phone unannounced. He listens to what Peter is saying. And at the end of Peter's list, he says, "Peter, this is George Miller. And I thought, da, da, da." And he gets off the phone with Peter and he announces to everybody in the room that we should stay in the building until the regulations were signed the way we wanted them. That's the reason I

think ultimately that the demonstrations went on so long. Because as a congressman, he—we had been telling the Congress, people like Alan Cranston’s office that, “No, what they are telling you is bullshit. This is not what's going on. This is what they are telling us.”

So I have a sense that we were learning things that the staffers didn't know, which wouldn't be illogical, because they were doing so many other things, and it was Democrat to Democrat. They would have tended to say, “Oh, these people out there, they're from Berkeley and San Francisco. Even the people in Washington DC, they don't understand it. We have to compromise.” I can hear all the discussions. But at the end of the day, George happening to come that day, when we happened to be on the phone with Peter, telling us to stay, is what not only let things continue but not to fall apart and to grow.

02-00:17:34

Lage:

And how far into the demonstration, do you happen to remember?

02-00:17:39

Heumann:

It was a Sunday. And there were a number of weeks left. Well, let’s see. Do you know when the hearings were?

02-00:17:52

Lage:

They were two weeks into it, I believe, the hearings with Phil Burton.

02-00:17:57

Heumann:

I think, okay, I may be very wrong in this. We went into the building, I think George came that Sunday. Did we go into the building on a Tuesday?

02-00:18:10

Lage:

Whatever April 5 was.

02-00:18:12

Heumann:

Okay, we went into the building on whatever day April 5 was. I think George came on that Sunday. And for some reason, I think the hearings were like nine days later.

02-00:18:25

Lage:

That sounds about right.

02-00:18:27

Heumann:

Yeah, so then we left for Washington after the hearings. And then we were in Washington for more than a week. Right, we were in Washington for almost two weeks.

02-00:18:39

Lage:

Because the whole thing was, what, twenty-eight days.

02-00:18:41

Heumann:

Right. So yeah, I would say when looking at Washington and the organizing out here, there was some contentiousness. It was maybe an inability for people

to accept that we all had different roles to play and they were all of equal value. I think we were definitely seen as, you know, out there kind of rabble rousers.

02-00:19:22

Lage: Within your own group, you're talking about?

02-00:19:24

Heumann: No.

02-00:19:25

Lage: Within the ACCD? That's what I meant.

02-00:19:26

Heumann: Within the ACCD, yeah, yeah. But not by people like Fred or Lex or, because they also came from the IL [independent living] movement. So no, I don't think there was any of that. Maybe a little bit from Frank and Eunice. But overall, when we went back on their territory, and that was a whole other thing too, because in reality, we came back completely able to do our own thing.

02-00:19:53

Lage: Yeah. I think we should stop right here, because we have a break coming up. And then we'll come back to that. Is that all right?

02-00:20:00

Heumann: Yeah. [pause in recording]

02-00:20:01

Lage: Okay, now we're back on after a break. We are talking about San Francisco and the 504 demonstrations there. I want to back up and talk a little bit about planning and conceiving the demonstration. You mentioned that there's a reason San Francisco's went on longer, and it was partly your vision. Can you talk about how that happened?

02-00:20:24

Heumann: Well, we had a great group of people, both at CIL Berkeley and in San Francisco. And we decided that we wouldn't, that this committee to save 504 wasn't an incorporated group and wasn't part of CIL per se, because we were a little bit concerned that what it would be doing could be risky as I recall around our 501(c)3 non-profit standing.

02-00:20:55

Lage: You were all funded by the federal government too.

02-00:20:57

Heumann: Federal government. Well, actually we had a fair amount of city and county and state money. CIL didn't take independent living money until the nineties. So there wasn't any money actually at that point for IL. We did have different

federal grants. We had a mixture of government sources. But nonetheless, Kitty Cone was a great organizer.

02-00:21:24

Lage: And how did she get chosen to do it?

02-00:21:25

Heumann: I think it was just a natural. There wasn't any competition [laughing]. I mean CIL was not like huge organization where you had twenty people who would be vying for something like this.

02-00:21:37

Lage: Did you have organizing experience in the way that Kitty did, coming out of the anti-war movement?

02-00:21:42

Heumann: No, I mean Kitty came in having experience with the Socialist Worker's Party, and not really having done much in disability. She'd done some, when she was at University of Illinois. But her organizing experience had nothing to do with disability. And then Dorothy [Dillon], who was at the—

02-00:22:04

Lage: Dorothy?

02-00:22:05

Heumann: Dorothy, at the moment I can't remember her last name. But Dorothy was a good friend of Kitty's. And Dorothy at that point was Joni Breves's lover. They were partners. And Joni was involved also in the planning.

02-00:22:29

Lage: And did they have experience in—

02-00:22:30

Heumann: Well, Dorothy came from the SWP also. So then I think Lorrie Slonsky was involved with Kitty and they were good friends. Then there was a whole committee, Ray Uzeta and Kathy, can't remember her last name, from San Francisco. And they were of course some of those tugs as the committee was coming together. But we had our own committee. So Mary Lou [Breslin] was involved. A man named Jim Peachum was involved. And he was with Swords-to-Plowshares. He came out of the anti-war movement. And he, I guess at that point he and I were having a relationship [laughing]. And Pat Wright was involved. But Kitty was, of course, the leader. And so you know, my recollection, we'd have meetings and talk about issues. Kitty and I would talk about things, where there were questions. I went to some of the meetings. But she and the others, I think Karen Parker was involved at that time also.

02-00:23:38

Lage: Who decided, or how did it come about, to make such a outreach effort to non-disabled—

02-00:23:47

Heumann: We always did that. We had a history before those demonstrations of doing that.

02-00:23:52

Lage: Did you have relationships with Black Panthers and Delancey Street and—

02-00:23:57

Heumann: Yes, we did. We had some, none of that was cold. And the Black Panthers came about because one of the members of the Black Panthers party had MS. So he actually was getting services at CIL I think. So, and Delancey Street, we were involved with some way. And Kitty—

02-00:24:16

Lage: And the drug and alcohol issue in 504 was a big issue, apparently, one of the controversies was would it extend to people with drug and alcohol—

02-00:24:26

Heumann: Substance abuse, yeah. Now, that issue from I believe our perspective was the same as every other disability group. We just saw it as an obvious group of people who had disabilities. And it was one of those groups that people felt uncomfortable with, because they just did. You know, it's something you do to yourself, and therefore it shouldn't be considered a disability.

02-00:24:54

Lage: For some it's a moral issue.

02-00:24:55

Heumann: Exactly. But we never had any debate about that at all, that I remember. For me it was, we always agreed it was the right thing to do.

02-00:25:05

Lage: So did that bring you in closer to Delancey Street, do you think or?

02-00:25:10

Heumann: Well, Delancey Street I think we got involved with probably because of fundraising. I'm trying to remember if Lynn Kidder and—yeah, Lynn Kidder was involved. And another man that we had, Larry somebody or other, I think his name was, who were doing fundraising. I think we were involved with Delancey Street in some way, learning from them, Glide Church, because we had stuff—so none, we had never worked with the Black Panthers like we did. But we didn't go out as I recall, searching to find somebody for the Panthers. It was just that—

02-00:25:54

Lage: It was there.

02-00:25:55

Heumann: It was there because this man, Brad, I think his name was, had MS. And there was another man that worked with him who was with him all the time. We were just colleagues. And so Kitty, of course, would be able to milk all these

different relationships. But you know, remember before the 504 demonstrations here, we'd had litigation, where we'd worked with the Legal Aid Society on transportation. We'd had various activities with the county where we were a part of broader coalitions to work on issues where the county was trying to cut back funding. We'd been involved in transportation demonstrations where, and other various types of demonstrations, where we'd invited the unions in and the religious community. So in some way, when this started to happen, I think things were able to move along at a rapider click—clip, because we weren't making all these new relationships.

02-00:27:05

Lage: Yeah, that's important, probably hasn't been noted quite enough.

02-00:27:07

Heumann: I think that's true. I venture to say if you ask Kitty that question directly, she would say that we knew many of those people. And Cecil Williams, we'd done stuff with them.

02-00:27:20

Lage: How about California Rural Legal Assistance? Ralph Abascal.

02-00:27:28

Heumann: Yeah, because Ralph was involved from the very beginning with CIL and before. I mean Ralph was involved before CIL. Ralph was involved, I believe, with Ed and Hale and them on litigation against the state when they were trying to cut Social Security, the state share for Social Security. So there were long relationships that had been going on. It's a small community.

02-00:27:52

Lage: Of activists? How would you describe that small community?

02-00:27:55

Heumann: Well, you know Berkeley is a small community, period. And many of the people certainly at that time were activists. And you lived on the same block with somebody, or a couple of blocks away. Ed lived on the same block as Loni Hancock [then a member of Berkeley City Council]. So when I moved into Ed's place for a while, while I was looking for a place, you know, I met her. And that's just the way it is. It's a town [laughing].

02-00:28:26

Lage: Yes, it is—

02-00:28:28

Heumann: Brooklyn, New York, you know, Brooklyn, like four million people in Brooklyn. So in a couple of blocks, you have the whole city of Berkeley [laughing]. But I think it does go to show that the more intimate relationships you can develop with people where they can begin to trust you and learn about your issues, trust you to say that the directions that you're moving in are the right directions. And then people can use their skills to support what we were trying to do. And we did that over and over and over and over again. And the



504 demonstrations became this big thing because it wasn't just going on in the Bay Area. You know, it was being organized out of Washington DC. And in some way I think we looked at this as wanting to make the issue of the failure to promulgate the regulations one that the average citizen could understand.

And for me, that's always been the way I've been involved in organizing. The demonstrations that we had against Nixon in '72 in New York, with Disabled in Action and some of the other local groups was really intended to educate the average person. So when we shut down traffic on Madison Avenue four days before the Nixon election—or the election where Nixon was elected—we had very simple fliers. We had a tombstone and we had some short but clippie heading on the flier, with the services that people were being denied. And we gave out thousands and thousands. Because people took them, which was very interesting, you know. A group of disabled people sitting in the street shutting down traffic. Small people and large people on the sidewalk giving out fliers, in the middle of New York City in the middle of rush hour. I remember we had to go back and get more and more of these fliers redone.

And that was what I think was going on here. I believe that people were—people had been growing to accept this disability movement that was happening. And this group, the Center for Independent Living, and these other independent living groups. So there wasn't this, like, distrust or lack of knowledge. I mean, many people didn't know much of anything about us. But there was a core group. And when [California Assemblyman Frank] Lanterman came out, and when [San Francisco Mayor George] Moscone came out, when we were able to get the media, when [journalist] Evan White was doing regular publicity, and then it became an international issue. I mean, there was national press coming. And I remember TASS came. The Russian. TASS came into the building to do interviews.

02-00:31:48

Lage: Oh, interesting, the Russian news agency.

02-00:31:52

Heumann: I think there was a French paper that came. So it was—

02-00:31:56

Lage: It built itself. That wasn't all managed by—

02-00:32:00

Heumann: Oh no. But we had press. We had people doing press work. We had people like Cici Weeks and Mary Jane Owen and all these other people. So Kitty was like the expert. But many of us had lots of expertise that we'd been getting in different ways. She was the leader, and people respected her leadership. And one of the reasons why she was such a great leader is because she listens to people's views, and you know she'll make everybody feel like they're listened to. She'll take what she thinks was right, go ahead and do it, and everybody

was right. But the fact that we were able to have demonstrations on a regular basis outside of the building, that was definitely Kitty and Dorothy that did a lot of that work.

02-00:32:48

Lage: A lot of organizing behind the scenes.

02-00:32:50

Heumann: Yeah, but the main people in the city. That's why I'm saying, you know, Moscone and Cecil Williams and Lanterman and Brown, all these people. And city councils passing resolutions in different parts of the state, from the local disability organizations, pushing them, in support of the demon—I mean here we are having taken over a federal building. And all we're getting is accolades for what we're doing. I mean [laughing] you know it's—

02-00:33:18

Lage: Might be a little anti-federal sentiment there too.

02-00:33:20

Heumann: Yeah, I mean who knows what it was, but—

02-00:33:23

Lage: What about Moscone? Had you had ties with him before?

02-00:33:25

Heumann: Yeah, we knew him before.

02-00:33:28

Lage: He was part of the Burton group.

02-00:33:29

Heumann: Yeah, but also there was the Independent Living Center in San Francisco. So Ray Uzeta and Kathy and that crowd, they knew them, because again, San Francisco's bigger, but still not huge. So all of the centers in the beginning had connection to the local politicians. And none of them were so new, even if they were a year or two old, they were old enough that they had made connections with their elected representatives. And Ed [Roberts] was the director of the Department of Rehabilitation. So he was a [Jerry] Brown appointee. And Lanterman and Ed obviously knew each other well. I mean, we were getting, the state was sending down mattresses. Moscone is like trying on the phone to get us showers. I remember when I heard that I'm like, "What?"

02-00:34:20

Lage: So was perhaps more than you expected in terms of support?

02-00:34:25

Heumann: I think so. But I do think that there was, you know, the first couple days we were there, there was this same scenario that had happened in New York when we had taken over Nixon headquarters. There was a bomb threat that was

called in when we were in New York. I don't remember if it was the first time or second time we took over Nixon headquarters. So for me, you know, when the bomb threat was called in in New York, or when the police told us there was a bomb threat, you know, your first thought is, we better get out of this building. But then there was just something about what was going on, where, well, there's a real bomb threat, these police look pretty calm. I know at the end of the day, they don't want to get blown up any more than I do, so I'm going to trust the fact that if they really felt there was a bomb there, they'd want their butts out of the building. So we just ignored it.

And then what happened when there was the bomb threat in the HEW building in San Francisco, we did the same thing. We said, well, we would move to another part of the floor while they did what they had to do. As I recall, I think there actually was something found. There was. But obviously whatever it was, they dealt with it. But I think for us, again, and it is something that I had said earlier, which is being able to get into the building, which really wasn't a group decision, and when we went for those demonstrations, there were just a few of us, I think Kitty and I had had some discussions the night before about, well, should we think about staying in the building? What would we be looking for? And I remember packing something in my bag, toothbrush, pair of underpants. You know, I thought, well, we'll be there at night or something. Nobody—

02-00:36:15

Lage:

So you hadn't planned this, I mean I know you hadn't planned such a lengthy takeover. But had you not planned a sit-in at all?

02-00:36:27

Heumann:

I would say we had done great planning. But the majority of the planning was for that day. It was to get a lot of people, a lot of press, cross-disability, union, religious community, et cetera. But, and we had this community that had gone in to work out relationships in the building, so they would let us into the building. But I don't believe, for me, I would say no, we absolutely did not plan for a long sit-in in the building. It was a few of us thinking about it late. But I think, Kitty may have thought about it more and not really articulated it. I don't know. But the infrastructure was there to be able to do it. But I mean, Safeway bringing us food? Definitely not. We had not been on the telephone with Safeway for food.

02-00:37:22

Lage:

Or Black Panthers.

02-00:37:23

Heumann:

Right. Panthers would have been an easier thing, you know. But I don't even remember how Safeway got into this. But we had Safeway and the Black Panthers dealing with food for the twenty-eight days we were there. We had, you know, a medical unit that was there the whole time. We had all, it was a little town that just emerged and collapsed overnight. And it was a very

diverse group. We had everything from parents with children to adults and older people and all types of disabled people. I think, you know, there were many things that were going on there. But one of them was our educating the press.

I remember we had a meeting specifically where we called the press into a meeting to tell them that we didn't like the way they were reporting the issue. That we wanted them to look at this as a civil rights issue and not focus it on the living styles of disabled people while in the building. We wanted them to look at the substance. And I think that that did have an effect on the coverage. And I do believe that because CIL and the other organizations had a good relationship with the media, and then we found these people, you know, like Evan and others, who—

02-00:38:53

Lage:

He seemed very key, Evan.

02-00:38:55

Heumann:

Oh, Evan White was great. I mean, he was a renegade, you know.

02-00:38:57

Lage:

Did you—there were a lot of interviews that took place, of people in the building. Were those people kind of prepared to do interviews beforehand?

02-00:39:10

Heumann:

We were selective, yeah, yeah. I mean I think we, Kitty, myself, and others would be involved, Cici Weeks would be involved in deciding who we felt would be the spokesperson. So everybody wasn't, it's not that anybody was told they couldn't speak to the press, obviously. But on substantive issues, there was a select group, Mary Lou and Kat—

02-00:39:31

Lage:

You had a message you wanted to get across.

02-00:39:33

Heumann:

Yeah, we would obviously talk about it in advance. So we had written information that would go around to people. We'd have regular briefing meetings, like once or twice a day, to bring people up-to-date on what was going on, so people felt a part of it. We tried to make sure people had things that they could be doing, so you know the different committees were set up. So I mean, I think Cici Weeks must've been involved in doing organizing work too, before she became disabled. And you know it was this enclave of people—I think everything that's gone on here, there are a group of idealists who have a philosophy for their own life, and what they believe communities should be like. And this disability movement, because we have our own disabilities, it's just kind of an addition into the vision of what we believe society should look like. And because I think all of, how can I say, I think there are some people who have a disability but don't really see it as a part of them. So they can be involved in organizing all kinds of other things and not

include disability, because it's not them. But that was the complete opposite of who we are. So bigger vision of what we believe society should look like, including us. And the—

02-00:41:05

Lage: That's an important point.

02-00:41:06

Heumann: Yeah, and I think the 504 regulations and everything surrounding it was a real opportunity for us to begin to be thinking amongst ourselves about what we wanted the regulations to look like. What was too much. What was too little. How to negotiate. I think negotiation skills was something that, you know, we obviously all, the people who were involved, had good negotiation skills. But it really pushed us. And the demonstrations themselves really pushed us to be able to put forth the strongest argument, so that we could try to rebut what other lobbyists from health, et cetera, really had difficulty rebutting. They had to fall back—and if the people that we were working with, like John and Peter and David and the others, felt that we were putting forth uninformed arguments, or arguments that were really impossible to make reality, I don't think we would've gotten as far as we had.

You know, there definitely are provisions in the 504 regs that aren't as strong as we would like, clearly. But that was one of the reasons I think why we fought so hard for those regulations. Because we believed that we'd been spending years negotiating and had given things that we didn't want to give up. So for us there was, that was the bottom line. And we were not going to go below that bottom line. And we didn't really have lots of discussions about what would we have to give up, because, you know, for myself, I think we completely believed that we had to go for this. We had to go for broke on this.

02-00:43:01

Lage: And when you say we, are you talking about the national group?

02-00:43:04

Heumann: Yes, but—definitely yes on the national group, but I guess when I'm saying we, I really mean here in the Bay Area. Because we didn't have—we were having discussions with Eunice and Fred about what was going on. But they were doing their own thing. No one ever thought that this group in the Bay Area would do what we did here. And definitely no one ever thought that we would go back there. So that was, when we called them and told them that we had gotten the money and we were coming back, quite frankly, I don't know that it was thought about as, wow, this was great.

02-00:43:54

Lage: How do you think it was thought about?

02-00:44:00

Heumann: Not based on fact, but speculation, I think people were probably concerned about whether or not we would tread inappropriately and kind of shake up the balance and be the result of things turning back.

02-00:44:17

Lage: I see. Maybe too radical or outspoken.

02-00:44:19

Heumann: Exactly. Too radical, too outspoken. Not seen necessarily as team players. But on the other hand, we brought, there were other people who came in from other parts of the country for the demonstration in DC. I mean, we came in, and what happened? We stayed at church. We're there. The first day we're there, we have, you know, a demonstration outside of Califano's house.

02-00:44:49

Lage: And who decided on that?

02-00:44:51

Heumann: You know, Kitty and I were talking about this. I think it was Phil—

02-00:45:00

Lage: Phil Neumark.

02-00:45:01

Heumann: Yeah, Phil Neumark, who was good friends with Kitty. And you know, it's really hard to say how things happen, because here were all these people from the Bay Area. Plus there were some people from Philadelphia, New York, some other places who had come down. We were having a meeting, and we were discussing. And my recollection was that we were talking about how we couldn't just come and not start acting immediately. So we were trying to figure out something that we could do immediately. Because we had no support from—like Frank, I don't believe, was at our meeting where we were—I don't believe so. Maybe Kitty would remember. I don't believe he was at that meeting. But anyway, I think it was Phil.

And we decided to go to Califano's house. And I remember something like, Phil said, "Doesn't Kitty have family that live on the same block as Califano?" [laughs] Okay, so we organized this demonstration. We had fliers made up. And we did a sunrise mass—not mass, but sunrise service. Yeah, and so there was a minister who did the service. And then as the kids started going to school, we were giving out fliers to the kids in the neighborhood. And I remember going up to kids and saying, "You know, Secretary Califano lives in this house. He's just, we need him to support some very important, you know, rules for us as disabled people. Maybe you could talk to his children." [laughter] You know, but we went back there twice. Did you see the chapter in the book, in Califano's autobiography—

02-00:46:56

Lage: No, no, I've seen it quoted.

02-00:47:00

Heumann: It's very funny, because when we went back that Tuesday, he, Califano, was at, I think, a joint session of the House and Senate. We got back over there to do another demonstration. And when he found out that we were coming, they didn't come in the regular driveway; they went in through the back. And so Phil went, I don't remember if he knocked on the front door. Then Phil and I decided that we were going to go to the back. So he knocked on the back door. And the chapter in the book talks about he had a fantasy that the next day in the *Washington Post*, the headline would be, "Califano Bites Crippled Woman."

02-00:47:51

Lage: [laughing] That's wonderful.

02-00:47:53

Heumann: That was me.

02-00:47:55

Lage: You did throw fear into a lot of these people.

02-00:48:00

Heumann: Well, you know, it's the issue of the shoes. I really think so. It's not a thing of fear, like a terrorist. It's having to deal with a disabled person whom you've not treated as an equal. Because you've seen yourself as taking care of us. And us being thankful for what we get. And here you had all these people, and increasing numbers of people, who were basically saying, you know, as the slogan goes, "Piss on Pity. We want our rights. We want to be treated like a civil rights movement. We want you to see our issues as being the same. We want you to acknowledge discrimination. We want you to acknowledge the role that you are playing in discrimination. And you've got the authority and responsibility to address those issues." He never, I mean even at the end, Senator Cranston called him and asked him to have a meeting with people who were in town. I'm sure Frank and Eunice, but the ACCD group. He refused. That, to me, was amazing because you would not—you could have differences with the unions and with the other civil rights groups, but at the end of the day, the Democrats certainly would never say they wouldn't meet. But he would not meet. Would not meet. Never met, wouldn't meet. So I think he—

02-00:49:33

Lage: And then you objected to his getting an award from ACCD a couple of years later. Do you remember that?

02-00:49:40

Heumann: No, well, probably. I mean I thought it was hypocritical. You know, because I wouldn't—

02-00:49:48

Lage: They wanted to smooth the waters by giving him an award. You spoke strongly against it, apparently.

02-00:49:55

Heumann: You know, my feeling, it was hypocritical. Because what they did to the DC group, if you look at the difference between how the political leadership in Washington dealt with the disabled people in the HEW building and what happened to us in San Francisco, it was like night and day. To me, the relationship that we had developed in California at the city, counties, and state level, clearly showed an understanding. The fact that they wouldn't do things like let someone get their medicine in, Fred Schreiber, who needed heart medicine, that to me was inexcusable. You know, you could see, okay, we don't want to set a precedent, da, da. But the way they did it. They could have met. They could've negotiated much better. And unfortunately, the DC people left. That was another thing that I was just, why are you leaving? This is like the opportune time. Make them drag you out. Don't just get up and go. I mean it was like—

02-00:51:10

Lage: Did you have that conversation?

02-00:51:12

Heumann: They were gone already. We couldn't have. We did, inside. I remember you know when I was talking to the press and others, and just saying, "We have no intention of leaving here because of what happened in Washington. We're not going to let them starve us out." And I know that had the same scenario unfolded, we never would have walked out of the building, ever. I mean, to this day, I don't get it. I really don't. You know, it's like, and maybe I don't know what—

02-00:51:53

Lage: So when you went back to Washington, you must have had this in your mind, they'd left the demo and, now we're here.

02-00:52:02

Heumann: Yeah, and I mean we just did, we had the demonstrations outside Carter's church. We had the meeting in the White House, Eunice and Frank.

02-00:52:11

Lage: With Stuart Eizenstat [Carter's chief domestic policy advisor]?

02-00:52:12

Heumann: Yeah, we went singing through the halls of the White House, civil rights songs. It was a great place to sing songs, because the echoing was amazing.

02-00:52:21

Lage: Now, was that planned? Were you invited in, or—

02-00:52:25

Heumann: We asked for a meeting, and I don't—I think our group definitely was involved in, I think George and Ann and all those people were involved in helping to set up that meeting. It was HolLyn Fuller. I don't remember all the people who went in. Small group, I guess six-to-ten people.



02-00:52:43

Lage: And how did it go? Did you speak?

02-00:52:45

Heumann: How did it go? Oh yeah, yeah, sure we all spoke. We basically told him that, I mean I can't remember. I remember being in the room. I remember going down the hall singing. I remember, because I studied voice, I remember thinking, oh my God, this is like a great echo chamber. We were singing really well. And doors are opening. And people are looking out, what's going on? What's going on?

02-00:53:12

Lage: And what were you singing?

02-00:53:13

Heumann: Civil rights songs. "We Shall Overcome," different pieces like that. And we had to go a long distance to get into his office. And it was a decent meeting. I think we were very clear on our points. We'd had a bad meeting with Cranston's people, because Cranston still at that point was feeling that, I mean it wasn't a disrespectful meeting, but he clearly, well, John Steinberg, his staffer, clearly was not keeping him informed the way we felt he should. But I think at the end of the meeting, Cranston got it too. But the meeting with Eizenstat was a good meeting. We were clear about our issues of concern.

I think even in DC, I don't know what happened internally, but obviously what happened was we prevailed over what some of the people were trying to do. Because what they were trying to do, they clearly didn't have enough people inside defending their position. And I'm sure John [Wodatch] and his people were doing, I know that they were doing what they could to present our position. Because as I said, everybody had been working on this for years. It's not like Carter came into office in November and people first sat down starting to work on these rules. Years.

02-00:54:40

Lage: It'd been all lined up before he came.

02-00:54:42

Heumann: Exactly, and the only reason they hadn't been signed was because the Ford administration wouldn't do it. But so—

02-00:54:52

Lage: Well, did they eventually get signed without change?

02-00:54:54

Heumann: Yes. They were signed without change.

02-00:54:57

Lage: So they were signed in the way that the Ford administration had finally written them up.

02-00:55:02

Heumann: Yes, they were signed without change.

02-00:55:04

Lage: So you didn't have to compromise.

02-00:55:06

Heumann: We didn't compromise at all.

02-00:55:07

Lage: Tell me some about your feelings and your role, partly as a public speaker but also when you confront people. How do you do it? Where do you get the strength?

02-00:55:25

Heumann: I love to do it. As long as I feel—what?

02-00:55:30

Lage: Did Kitty mention to you that she wanted me to ask you this, how you were able to really put it to [regional director of HEW Joseph] Maldonado and the others that you spoke with.

02-00:55:42

Heumann: I guess because I've always had this view that officials have a responsibility, and now being an official and having been an official, you know, under the Clinton administration and now in the [Mayor Adrian] Fenty administration, it's my responsibility to do the right job. And for Maldonado, I felt really bad for him, because clearly they were not being informed. But he also clearly didn't get informed.

02-00:56:10

Lage: This was the San Francisco HEW person.

02-00:56:12

Heumann: This was the day we took over the demonstrations. And I always felt that it was important too that the people that we were with, disabled people we were with, needed to see how to do it. So I always felt that I'd try to be respectful of the person that I'm speaking with. And I guess, this is going off topic a little bit, I was at a meeting once with Jerry Brown. I can't remember. Might have been with Ed. I can't remember who else it was. But we were up there on some issue that we were discussing. It was the first time I'd ever met him. And I was really nervous. And I thought, you cannot lose it at this meeting. He shits just like you do. And you have to deal with him just like you would deal with anybody else. That's true. That's always been in my mind. He or she is no different than you. They're in that position today and gone tomorrow. At the end of the day, they're holding a position of responsibility where they have to act, we have the right to present our position as strongly as possible, and it's not just my responsibility but all the people that we selected. It's all of our collective responsibility to be able to be firm and not to be giving away something that we would otherwise not have to.

And that's what I have really learned over the years, is if you can really hold strong, it's not that you're always going to get everything that you want, but you lose less than you would if you gave up too soon. And I think what we saw in those 504 demonstrations is we had worked so hard, we knew the issues so well. Again, what I've said before, that people who came in unarmed and unprepared could not fend off what we were saying. They couldn't present logical opposing views. They couldn't use a cost argument because we had an answer to it. They couldn't use—there was timelines, all these things in place, everything had been thought about. So—

02-00:58:28

Lage:

Plus you had the basic kind of civil rights aura.

02-00:58:32

Heumann:

We had the civil rights aura, but we had the facts. I mean I think the civil rights aura without the facts actually doesn't get you where you need to be. But the facts without the civil rights perspective, doesn't necessarily get you there either. So I think there has to be a true resolve that what we are doing is reflective of what a larger group of people agree needs to happen. And then you have to be resolute. I mean, that's what all of us have always been here. It's always been, in my view, for myself, you never walk away from something. The littlest thing, I mean "never" is maybe too strong a word, but pretty much never. You know, I will not give up on something that I think is wrong, even if it's something [happening] just to me. Because my thought is, if it's happening to me, it's happening to other people. And somebody's got to take a position at some point in time and deal with it.

You know, there was this great thing that happened here, movie theatres, there was a particular movie theatre in Oakland that was telling people they had to get out of their wheelchairs. And Mary Lou had gone, had a problem. And so we decided very quickly one night, Kitty and I and a couple of friends went to this movie theatre. They didn't want to sell us the tickets. We got them to sell us the tickets. We went into the theatre. They didn't want us to go in. We went in anyway. They told us we had to get out of our chairs. We said we wouldn't. They said they'd call the fire department. We told them to do it. We had brought these other people with us, because we figured if the fire department came, we would disrupt the movie by having the other people not in wheelchairs going, "Shh, shh, shh," which is exactly what happened. The fire department came. They asked us to come out to talk with them. We told them we wouldn't. We gave them our CIL cards and we said, they could call us. We'd have a meeting. And they left. And those types of things were very well organized, but—

02-01:00:46

Lage:

And this was when?

02-01:00:48

Heumann:

This was, I don't know, before or after the 504 demonstration.

02-01:00:51  
Lage: But early in the seventies sometime.

02-01:00:52  
Heumann: It was in the seventies.

02-01:00:53  
Lage: I'm going to stop this. It's end of the tape.

[End Audio File 2]

Begin Audio File 3 10-12-2007.wav

03-00:00:00  
Lage: Tape three. October 12—

03-00:00:03  
Heumann: Judy Heumann, October 12, Berkeley, California.

03-00:00:08  
Lage: Okay, where were we? We talked about being resolute, which I think is a very important point, and not really being afraid to confront people and make them uncomfortable.

03-00:00:16  
Heumann: I think resolute because we believed we were right. So I think, you know, that was very important. We believed our positions were correct.

03-00:00:23  
Lage: Yeah. Tell me about the Burton hearing, which sounded like a wonderful piece of theatre in part. Did you plan—

03-00:00:37  
Heumann: To cry?

03-00:00:39  
Lage: Your testimony and crying?

03-00:00:41  
Heumann: Actually, you know, okay, so there were hearings in the building that were held by Congressman Burton and Congressman Miller.

03-00:00:51  
Lage: We're back to San Francisco.

03-00:00:53  
Heumann: We're back to San Francisco. And Phil Neumark played a very important role in that. And we had organized the hearings.

03-00:01:02  
Lage: With Burton's staff, you organized it?

03-00:01:05

Heumann:

Ann Rosewater was very involved. I don't remember all the, but we basically had put together various people speaking who would be able to represent different positions of authority in government and people knowledgeable about the law, who'd been involved in the demonstrations. Many of the people had written their testimony, like Kitty. Kitty never ever goes anywhere where she's speaking where she hasn't written her testimony. I, on the other hand, will frequently go having spent a lot of time thinking about things. I don't always write my testimony down.

So I definitely had not written my whole testimony down, because if I had, I would've been reading it. That's one of the reasons why I'm frequently not sure whether I should write my speech or give it. Because if I spend all the time really writing it, I wind up getting nailed to it. I do a lot of work on note-cards where I write my ideas down many different times. If I don't have the right podium, which is usually I don't, I hate not having eye contact, I'm really putting my things to memory. So for that hearing, there were many things going on. We were really tired. I was really tired.

03-00:02:35

Lage:

You were two weeks into it.

03-00:02:37

Heumann:

Yeah, I was really tired. We were on the other hand, [laughing] see here I go again, we were on the other hand really happy, because I guess it was because we knew that what we were doing, again, this theme of, we were right. We were able to convince Phil and George to come and hold hearings in the building. So our resoluteness, all of the work that we'd been doing was paying off. So it was this tension about knowing that we still hadn't won anything, that these were our congressmen who were definitely left of center, and what did that have to do with what was going to go on in Washington, although we did know that they were influential with the Carter administration. But then I was a speaker towards the end. And this poor man, who was sitting there, Eizenstat? No, Eisenberg—

03-00:03:45

Lage:

Was he the HEW representative?

03-00:03:50

Heumann:

I think Burton had told him they had to send a representative out. They didn't send a high-level person. They sent this poor man [Eugene Eidenberg], who I think didn't want to be there. Why would you want to be [laughing] at this hearing where the two congressmen are here in the building that's been taken over? What's your role, right? So what I was told is that he was in an office, and Burton went down and kicked at the door and told him he had to come down to the hearing. So on the one hand, he's sitting there shaking his head. So you could say that it meant he was completely bored and he was just like

nodding his head, uh huh, uh huh. Or he agreed with me and he was saying uh huh, uh huh. Whatever it was, it just completely undid me.

03-00:04:33

Lage: This is as you're—

03-00:04:34

Heumann: This is as I was speaking and not reading a paper. So I'm like watching this man's head bob up and down in agreement. And I thought, he clearly can't get what the hell's going on here or we wouldn't be in this building. That's why I went off and I said what I said.

03-00:04:51

Lage: So can you give—

03-00:04:53

Heumann: My emotions basically were when I get, I think when I get angry, I have difficulty being angry and yelling. And I tend to cry when I'm angry. And I do that a lot. It's not that I'm always crying because I'm angry. Sometimes I'm sad. But in that situation, I think it was a combination of tired and really angry. And if I could've, I would've, you know, but then it also felt disrespectful to really be yelling at this man, because I didn't really know him. But it was just I think however many days we'd been in the building, it was kind of enough. And we wanted this thing to be over with. We didn't want any longer to be having to continually make persuasive cases that in our view were logical and was getting caught up in politics.

03-00:05:46

Lage: So how did you confront him?

03-00:05:48

Heumann: Just that I think, you know, in the video, you know, what it says is, I confront him on saying, stop nodding your head. Because if you understood what I was saying, this wouldn't be going on. That's in essence what I was saying to him. And, but I know people—I think people find that part of the hearing honest, genuine. Although I've been ridiculed by some lobbyists—

03-00:06:22

Lage: Oh really?

03-00:06:23

Heumann: Oh yeah, in Washington, when I was the assistant secretary [Department of Education, Clinton administration], and I would be speaking to these whatever, you know, lawyers on the other side for the school boards. And I was furious about things that they would be doing. And there were a couple times when I was speaking where I would get like emotional in my voice because I was so angry. And you know, people don't do that. It's like you get up, you give your speech. And I'm very connected personally. So when I'm speaking to these people and I see, it's not just a difference of—with some of

these people, it's not a difference of opinion. It's they're going to win. I mean you know, it's—

03-00:07:03

Lage: It's power.

03-00:07:04

Heumann: It's power. And it's not based on having negotiation skills or believing that there's a way of coming to a compromise. It's pure power. And I've got more money than you do, and I've got more whatever. And I'm going to win. And I, of course, come from the absolute opposite side of, if you're wrong, even when I was the assistant secretary, I'm not going to support you. And we're going to deal with what I can do to fight you. That makes my job more interesting.

03-00:07:38

Lage: Okay. We haven't talked at all about life inside the building in San Francisco. Do you want to tell some of the things you remember?

03-00:07:50

Heumann: Well, from when I was younger, starting out probably with president's committee meetings, whenever you would get into this situation where you'd be in one building, it was always an opportunity for people to bed hop [laughing] in those days, when people were not thinking about things like sexually transmitted diseases and AIDS. And in the building, there were people who had relationships. Some of them were made in the building and some of them came from outside the building into the building. But I was seeing this one man, Jim. And he was one of the members of the committee that had been dealing with organizing and monitoring what was going on. And of course at night, you had to go to bed, so we would find different places where we could sleep.

One night we were sleeping, I guess it was like in an elevator shaft. And what they would do is they would take, they would have the cleaning crews come by in the middle of the night. Those really loud carts, waking everybody up, so you didn't get a good night's sleep and everything. Oh yeah, there was definitely stuff going on all over the building. It was a little village that was living its life, 24, really 24-hours a day, having to be together. So we were trying to live our live inside the building like we would've lived it outside. And you know, sexual relationships was part of that. Yeah, that was definitely—

03-00:09:26

Lage: Maybe this contributed to cross-disability alliances.

03-00:09:29

Heumann: That's right. Jim did have a substance-abuse problem, so [laughing] I'm sure that's partly true. But yeah, but I think yeah, it was an important part. I think one of the reasons why the building was so important, not just because of the

outcome, but you know, when you see the video on 504 and you hear people speak, it was very much empowerment for everybody that was there, regardless of the role they played. We all left feeling that we had made a difference. I wasn't there—do I think what?

03-00:10:13

Lage: Go ahead.

03-00:10:15

Heumann: I wasn't there because—

03-00:10:17

Lage: When you left the building, when they left the building.

03-00:10:20

Heumann: Right, I wasn't in San Francisco when they left the building. Everybody went back. But I stayed because there was a meeting. And I know Kitty wanted me to talk about the signing. I have no recollection of going to the signing. I don't know. I don't think I did go to the signing. But I have to ask Pat. I have to find out, I'll let you know. I could've sworn I didn't go, but now as I'm sitting here.

03-00:11:00

Lage: You might've. You mentioned Pat. Now Pat—

03-00:11:03

Heumann: Pat Wright.

03-00:11:04

Lage: We have not had an oral history. Tell me about her role.

03-00:11:08

Heumann: Did you do Pat's oral history?

03-00:11:10

Lage: Mary Lou recorded an oral history with her [and Arlene Mayerson], sort of a joint oral history. But it's completely embargoed, and I don't know if it'll ever see the light of day. But tell me about her role in all of this.

03-00:11:25

Heumann: Well, Pat was a very critical part of what was going on. She was a great strategist. She was a very hard worker.

03-00:11:34

Lage: Was she working at CIL at the time? Something about the Antioch program?

03-00:11:39

Heumann: Yeah, she was working with the Antioch program.

03-00:11:43

Lage: Out of CIL.



- 03-00:11:44  
Heumann: Yeah, I don't believe she had an office there. But she was working with woman named Lori. And they were working on setting up this Antioch program.
- 03-00:11:53  
Lage: Which was a university?
- 03-00:11:55  
Heumann: Yeah, Antioch in Ohio had a program out here, which lasted a while and then closed. And then Pat was also traveling with me as my personal assistant. And so, you know, we would go to a lot of meetings together. She wasn't involved in the disability movement at that point. She was just getting involved. Yeah, she—
- 03-00:12:20  
Lage: What was her background? She's always described as such a great strategist, even in these relatively early days. What did she come out of, in terms of experience?
- 03-00:12:31  
Heumann: I don't really know. From that perspective, Pat's a bit of a mystery. So I think Pat had said she'd been a doctor, but I don't know. Just like working with Pat, she has very good ideas and she's very smart, thinks on her feet very well, moves into action very quickly, is very observant, played a very important role in the ADA, the Americans with Disabilities Act legislation, because she is such a knowledgeable, strategic person.
- 03-00:13:11  
Lage: But at the time of the 504, did she have the connections in Washington or—
- 03-00:13:16  
Heumann: No, she was just beginning to build them at that time, as I said, in part because we were traveling together. So she was meeting Ann, Lisa, and all these other people. And I don't exactly know how she got involved in the Antioch project. I don't know, or don't remember.
- 03-00:13:35  
Lage: Was she part of the group that went to Washington then? And then, as your assistant or—
- 03-00:13:40  
Heumann: Oh yeah, my God, I don't, I should say I remember. I don't remember. Because, then she stayed back with me. Yeah, I don't think she went back. I think maybe she was. I don't know. I need to call her and ask her. Funny those things you don't remember. I have so many people—
- 03-00:14:04  
Lage: It was a while ago.

03-00:14:06

Heumann: And I have so many people who travel with me, that it's really hard. But Pat would definitely remember—I've got to call her. I'll find out.

03-00:14:15

Lage: Okay, that would be good. Encourage her to do her oral history [laughing]. That would be a great benefit. Anything else to say about what went on? I know people have the sense that they were involved in decisions within the building. You had mass meetings. And you ran them.

03-00:14:36

Heumann: At least once a day. I ran some of them. Kitty ran some of them.

03-00:14:39

Lage: And how much, how did you involve people? How much were the 150 or so people involved in making the key decisions, how much did they know about what was going on?

03-00:14:52

Heumann: I think we kept people fairly informed. I mean once we were inside, there were some things maybe that we didn't always talk about, but the reality is we talked about most everything.

03-00:15:05

Lage: Were there any moments where there were—

03-00:15:07

Heumann: Oh sure, there was always issues going on about whether we were open enough, whether we were involving people enough. Definitely that was a part of what happened. But for the two weeks or so that we were there, two-and-a-half, three weeks, I think we tried to be very open in sharing information and getting information. Because it wasn't just that we were giving—there was a media committee that would be monitoring what was going on. And they would give input and the other committees would report in on what they were doing. And you know, people participating in the discussions. I mean I think obviously people felt included enough that they didn't leave. People felt that they were in the middle of something that they didn't want to walk away from. And I think that was, because it was very difficult. For a lot of the people there, it was difficult. It wasn't easy.

03-00:16:07

Lage: It wasn't your ordinary sit-in.

03-00:16:09

Heumann: No, and it wasn't, yeah, because the people that were there, it was difficult for many of the people. You know, they actually put their health at risk by being in the building. But I believe that those demonstrations for the people who were there were life-altering, because they allowed people to see what a difference they as an individual working in a bigger group could make. I think that was true for a lot of what went on here, is people saw this role that you

played as an individual as a part of a bigger group. And pretty much people, so many of the people with disabilities who live in the East Bay are from outside of the East Bay, from other states. So in many ways, they were change agents. They wanted to come someplace where they had greater opportunities.

03-00:17:09

Lage: Self-selected in a way.

03-00:17:11

Heumann: Exactly. And so you can see over the years, like Thursday night on the 11<sup>th</sup> of October was the 35<sup>th</sup> anniversary party for CIL. And there, you know, I was like crying, again, with Mary Lou. Because now that I'm working in Washington DC, and there is nothing like it.

03-00:17:34

Lage: Community do you mean?

03-00:17:36

Heumann: There isn't a disability activist community at all there. You'd find it in New York. You'd find it in Chicago. You'd find it in many places. But DC, it's not there. And it really has an impact on what doesn't happen.

03-00:17:58

Lage: In terms of personal life you mean, what doesn't happen?

03-00:18:02

Heumann: Because there hasn't been—you live in Washington DC. Many of us, like when I came there, I came to live in Washington DC, but to work for the federal government. So I really wasn't involved in DC politics. I mean I wasn't involved in DC politics. And so you've got a group of people who are working who have disabilities, who work for the federal government, and don't see the city government like we here saw the city government in Berkeley, or the county government. You don't have an organized—I really don't want to represent this as there aren't organizations: there are. And they're doing a lot of work.

But you know, you walk up Telegraph Avenue, you go to Rasputin's, and you see this history of the disability movement, and the owner of the store proudly displaying history of the disability rights movement on a building. You see, I go into a restaurant yesterday and there are two young disabled people coming in from Berkeley sitting down and having lunch together. The waiter's moving the chairs out, and I'm like, oh, I guess two people in chairs are coming. And these things are natural now, because there is such a large number of people here that the community itself has become more accepting. It's normal. But in DC, there isn't this level of normality of disabled people being a part of the city life. It's just not there yet.

03-00:19:51

Lage: Do they have a CIL in DC?

- 03-00:19:53  
Heumann: They do, but it's nothing like here.
- 03-00:19:57  
Lage: And here you are now working for the DC government.
- 03-00:20:00  
Heumann: And the CIL is under my responsibility.
- 03-00:20:02  
Lage: Oh, it is [laughing], goodness.
- 03-00:20:05  
Heumann: They get their money from us, or some of their money from us, so.
- 03-00:20:09  
Lage: You have your work cut out for you. You know, I read and I was surprised, I think in the Richard Scotch book, *From Good Will to Civil Rights* (2001) that some people feel that the demonstrations didn't have an effect, that everything would've happened as it did without them. Have you heard that, or?
- 03-00:20:31  
Heumann: I mean, I saw Richard's book years ago. What do you say to that?
- 03-00:20:35  
Lage: You hear that about the antiwar movement and everything else. But you've expressed very strongly that you think—
- 03-00:20:43  
Heumann: I think it's a ridiculous argument. And I think it's an academic making an argument.
- 03-00:20:47  
Lage: Or Califano, you know, the insiders themselves.
- 03-00:20:51  
Heumann: I never heard them say that. I don't believe for a second that they believe that. Richard didn't get that from them, no. I mean I think, why wouldn't they have made changes if nobody was opposing it? Any new administration that comes in wants to make a change, for right or for wrong. You come in, you believe, especially if it's a different party, that what they did before wasn't, there were many things wrong. I mean I did. You know, I know they did. You know, when I left and they came in, they tried to undo things that I did in a hair second. You know, they were, some of the changes that I tried to get in when I was assistant secretary, like allowing disabled-run organizations to get as a part of their budget in grants that they would get money for personal assistant services. That was gone a half-second after I walked out the door. And some other things like that, which they didn't support.
- So anybody new coming into a job wants to do things differently. And I don't believe for a minute that the lobbyists for the industries would have not been

able to get some changes put forward if we hadn't done what we did. But also the other thing is that, even if you want to hypothesize that that was true, the reality is, it changed the way so many disabled people around the world—I mean when 1980 was the international year, or 1981 was the international year of disabled people, the film crews from England, Canada, and Japan didn't go to Kansas City. Right, they all came to Berkeley. They went to Washington. Couple of other places. But they spent a lot of time in Berkeley, because—

03-00:22:51

Lage: And did they draw on the lore of the '77 demon—

03-00:22:55

Heumann: Oh, that's why they were here, absolutely. And other things, but certainly the demonstrations. I mean that was all over the world, in some way. Not in every household obviously, I'm not trying to misrepresent this. But people in the media and others had heard that something had happened. And that Berkeley as a whole was a more accessible community, and that there were a lot of disabled people here. And so people always and still do come to Berkeley, before they go to other areas where quite frankly I think they may have stronger centers. But Berkeley as a whole is a more accessible community in the broadest sense, because things have continued to expand and gotten deeper, because things are becoming a part of life.

03-00:23:47

Lage: It's embedded.

03-00:23:48

Heumann: It's embedded in the soul of the city.

03-00:23:50

Lage: Yeah, let me ask you, I think you've given a good vision of what the meaning of those demonstrations were, and the victory. What is the meaning in the trajectory of your life?

03-00:24:03

Heumann: Well, for me, it reinforced my belief in working collaboratively, working cross-disability, keeping broad groups of people informed, believing that the more people you inform—not just disabled people, but others—the more you can move an agenda forward. And that hard work for long periods of time pays off. It also, once the regulations were signed and we then had to move into training and enforcement, I think that was another great cycle, you know, where Mary Lou ran the trainings for the regions that CIL was involved with, and did a great job of taking that same approach.

Our approach in trainings on 504 was very focused on impeccable knowledge. You select people who are committed and hard-working. You put them through a rigorous program. You expect them to learn a lot substantively, to learn good negotiating skills, and to be able to go back to wherever they're

coming from with a commitment to repeat that. So I think I feel that the model that we have is a good model. It's a replicable model anyplace around the world. And we try to share that, have people come from around the world. And for me, when people come, I always spend a lot of time with people, when I was here, and where I am now, because I think it's very important to share—

03-00:25:52

Lage:

And now the international movement in some ways seems to be having maybe even broader visions.

03-00:25:59

Heumann:

Oh, of course. Well, I think one, a decent percentage of people involved in the international movement also spent time in the States and in Berkeley. If you see what's gone on in Asia, that's very influenced by what happened here. And in Germany and other places. And then of course people create their vision based on their life experiences. And so the core is empowerment. And belief that you can create a new vision and that working together, you can make it a reality. That's a motto that goes everywhere. It's not an exact duplicate of a CIL. But it is a duplicate of empowerment, making people believe in themselves. Your ideas are valued. You know what you need. Work together. Create a vision. Work on it. Don't give it over to somebody else. Take responsibility yourself for being part of a group.

And that's what you see over and over again from little villages in tsunami-affected areas in Thailand to areas in Pakistan affected by the earthquake, to places in Africa and Latin America. All over the world. It's natural, and if you also, when Berkeley CIL started, it was really at the same time that the exact same model was being created in Finland, and nobody knew each other. Kalle Konkkolla, who started a group in Helsinki called Threshold, is a disabled man who started exactly what we call CIL Berkeley. And they have a number of centers in Finland—

03-00:27:51

Lage:

Same philosophy, self determination—

03-00:27:55

Heumann:

Totally, totally, it is a carbon copy.

03-00:27:58

Lage:

When did you—

03-00:27:59

Heumann:

I actually met him before I came here. And he hadn't started it yet. They were just, I met him in Norway, at an international youth Red Cross camp. And it was a group of disabled and non-disabled people who came together for ten days. But we've been very good friends ever since. And he's been to the States. He came over in the seventies on a USAID grant.

03-00:28:27

Lage: And what is his name?

03-00:28:29

Heumann: Kalle Konkkolla. I'll give you his information. He's actually going to be in the States in two weeks. He is great, and his center is amazing. They have—he was the head of the center. Been involved in the center from the beginning, but he's also been a member of parliament in the Green Party. Member of the city council in Helsinki, and still is. President of Disabled Peoples' International for two terms. Very active in the, chairperson of the Global Partnership on Disability and Development. He is a sage. He's a wise—he uses a ventilator. He has a tracheostomy. Travels all over the world.

03-00:29:24

Lage: Wow, amazing.

03-00:29:25

Heumann: He is a brilliant man. And was friends with Ed. It's all kind of a very inner circle, you know, and he's revered. But his center, I mean, you know, they do their things a little bit differently, but a big focus on personal assistance. Big focus on peer support. They actually had people like Lillian Pastina, myself, come over to do training over there. Now they've got this great legal program that they've started, only training disabled people. He is totally into selecting and training disabled people.

03-00:30:10

Lage: Now, did the visions—this is kind of off our topic [laughing] but it's of interest. Did the visions grow up separately or were they interwoven from the beginning, with the back and forth and he knew you?

03-00:30:23

Heumann: We didn't know each other.

03-00:30:25

Lage: But over time, you knew each other.

03-00:30:27

Heumann: Well, over time, of course we've influenced each other. There's another man in Sweden named Adolf Ratzka who was a German who got polio. And in the late fifties realized he was going nowhere in Germany, because of the discrimination, and got the government to pay for him to go to UCLA. And he did all his college work, including his PhD. And then he had to do his dissertation, finish it. He decided he wanted to go to Stockholm. So he went to Stockholm. But he was in California for years. Knew Ed, came up here to visit the center. They've set up a whole model on independent living in Sweden that was very much influenced by this issue of self direction, personal autonomy. And then in Germany, the leadership there of the independent living centers, many of them spent anywhere from a year or more here in the States to others just coming for weeks or a couple of months. But many of—

03-00:31:27

Lage:

This is a whole other project for us, which we've actually thought we should do something internationally, but it seems overwhelming.

03-00:31:35

Heumann:

Well, then Latin America and Asia, it'd be great, I think it would be very good, really as I said earlier, to try to get some time with a few, a group of people having some discussions together, to get more away from just our own personal reflections to really delving more deeply into some of these issues. And obviously you need more money to do that. But, and I'd bring some more people in. There's a great, the Independent Living center in Chicago is a great program. I think they're doing really wonderful work.

03-00:32:19

Lage:

Mary Lou interviewed Marca Bristo. We just sent it off to her to review, so we have done that.

03-00:32:25

Heumann:

She's done great work. And I think Andy Imparato at AAPD is also doing some really, really good work. John Kemp, that crowd. But internationally, I really believe it would be valuable to be able at least to talk to people like Venus Ilagan, who's the just going out Chairperson I-L-A-G-A-N, she's from the Philippines. First name is Venus.

03-00:33:05

Lage:

This is all recorded, so I can—

03-00:33:08

Heumann:

Yeah, Teresia Degener, who obviously spent a lot of time here, at DREDF and up at Boalt [School of Law, Berkeley], is doing a lot of work on the UN convention, active with the European Union.

03-00:33:24

Lage:

It's global, like everything else today.

03-00:33:26

Heumann:

Very much global. It's definitely, it's becoming a locally-driven, like local, international, national—local, national, international, kind of all the balls up in the air. But it is amazing, you know, when I was working at the World Bank and I visited a man named Tapong, who unfortunately died this year, a driven leader in Thailand, ex-military, was injured. And so had a lot of connections into the military. And set up the CIL, which was influenced by the work of the Japanese, which was directly influenced by the work at Berkeley. And they had a project where they were working in rural-affected tsunami areas.

And I visited one of the projects that they were doing. And in this very small community, they had done a door-to-door campaign to identify disabled people. They had brought this group of disabled people who had basically never met each other. Some people didn't have wheelchairs that they got wheelchairs to be able to come to this event. And it was like a four-day peer



support kind of meeting. And they were doing this all over. And he's gotten women much more involved, set up numbers of IL programs in Pakistan, they've got this great, the Japanese have set up a program, it started in 1981, by a man named Duskin, who owns a doughnut company. I'm forgetting the name of it for a second. At any rate, he decided that his commitment to the decade on disability was going to be sending ten disabled people a year for one year to the US to study about the disability rights movement, in addition to the fact that they were putting money into having busloads of disabled people coming and touring and not spending as much time here and in Canada and in Europe. So there were at least 100 people that were really trained. One of those people was in Berkeley for a couple years. She's now working for another organization in Japan.

Duskin is now funding a program to bring people from the Asia region to Japan. They bring six-to-ten disabled people in a very highly-competitive, selective process, where Masako gets applications, then goes into the communities, some of them in very rural areas, selects people who come and live in Japan for a year. They spend three months all learning Japanese. So the common language is Japanese. Because they come from Manila, Pakistan, India, you know, Bangladesh. They're all over. They don't have a common language. So Japanese becomes their common language. And then they can select an area they want to work in. So some of them work on independent living, some of them, whatever. And they had two people who trained in Japan who went back to Pakistan, in Islamabad. And they set up an independent living center, which is being supported by the Japanese, and now the World Bank is giving them some help. But after the earthquake, there's men and women involved in the group, but I think it was the men that got in their trucks and went and drove out into the earthquake areas, trying to find disabled people. And weren't finding people.

The long and the short of it is, they had a good relationship with the then director of the World Bank office in Pakistan who has a disabled kid. And his wife had a background in disability. And they were able to help get money also from the Japanese. And now they have ten independent living centers being set up in Pakistan, that are very much driven by our model, the Japanese model, but it's the, you know, self-help, disabled run, cross-disability, when I visited their office, they had deaf people and blind people and people with different kinds of physical disabilities in Islamabad. And when I went back the next time and visited some of the earthquake victims, they had basically fought with the hospital to get a disabled person as a peer counselor in the hospital, to be able to be working with the disabled people and the medical staff.

03-00:38:37

Lage:

It's really amazing. You must've seen a lot in the World Bank.

03-00:38:41  
Heumann: Yeah, so anyway, it's an international movement because it's logical. I think once you can—

03-00:38:50  
Lage: Yeah, of course, but it's not necessary that it would follow this model. That has—

03-00:38:53  
Heumann: Some of it kind of is, from my perspective, if you look at the women's movement, there are very similar things that happened, right. It's women getting together and talking to each other—it's the same thing.

03-00:39:04  
Lage: But they're all filtered through the culture.

03-00:39:06  
Heumann: Yeah, but so these are too. But in all of them, it still is women, indigenous populations, disabled people, coming together to discuss similar issues, come up with solutions, empower each other. Some of them set up businesses, build schools, get kids into school, various things like that. In disability, a common issue becomes, what are the barriers to being able to get into school. And so you're dealing with in some cases very basic, I mean in Pakistan, very basic things. Helping people learn how to transfer from a bed to a wheelchair. Helping people learn how to catheterize. Do bowel and bladder things, because they couldn't do them themselves. They weren't learning it when they were first injured. So it's very hands on. And that in part was some of what happened here.

03-00:39:58  
Lage: In the very early days.

03-00:40:00  
Heumann: Yeah, I mean people would get bladder infections or pressure sores, and they would talk to each other about what was happening. And share ideas of things that worked. And actually, Sue Stoddard, who did the first study on IL here, I remember her telling me there was a little piece of information that they hadn't been able to go deep enough into, but it looked like the peer contact was having an effect on reduction of pressure sores and bladder infections, which are two of the biggest causes of death for disabled people, so—

03-00:40:39  
Lage: Hey.

03-00:40:40  
Heumann: Hold on. [calling out] Wait a minute! Oh, okay, come on in. [Visitor enters.]

03-00:40:45  
Lage: We probably should close up.

03-00:40:47

Heumann: Yeah, yeah.

03-00:40:48

Lage: So we're going to finish now.

[End of Interview]