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ORAL HISTORY INTERVIEW WITH CHRISTINE DAHLBERG NOVEMBER 16, 2009 INTERVIEWER: PHIL STAFFORD VIDEOGRAPHER: PEGGY HOLTZ

RECORD ID: 113-DO

**PS:** PHIL STAFFORD

**CD:** CHRISTINE DAHLBERG

[TITLE CREDITS]

[00:00:10]

CD: Hi. I'm Christine Dahlberg and I'm the Deputy Director of the Governor's Council for People with Disabilities here in Indiana. I've been with the Council since 1984. And so, we've been around for quite a while. And the Council represents people with disabilities. That's our primary constituency. And we try to advocate for independence, inclusion and community integration and work on trying to convince policy leaders and legislators and train people with disabilities and family members about their rights and about how to be advocates, how to be good advocates and work with policymakers to get what's best for people with disabilities embedded in state and local policy.

**PS:** What was the legislative history of the Governor's Planning Council? Does it go back beyond 1994 or?

[00:01:10]

CD: Yes. Actually, we are established under the Developmental Disabilities Assistance and Bill of Rights Act and so are two other agencies in our state, the Institute. And I know you're familiar with that because you work there, and the Protection and Advocacy organization. So our money is federal money. And I believe that the Council itself was established in the early '70s as an advisory body to the Department of Mental Health at that time. And since with-- continuing reauthorizations of the DD Act, it's gotten a stronger and stronger presence. And now we are an independent state agency and we're broadly representative of people with disabilities, not just developmental disabilities, because that's what we found over the years. Advocating for disability issues is a broad topic. And when you advocate, you don't advocate for people with a particular type of disability, your advocacy affects everybody with a disability.

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Center on Aging and Community, Indiana Institute on Disability and Community 1905 North Range Road, Bloomington, IN 47408 indianadisabilityhistory@gmail.com | indianadisabilityhistory.org And so that's why we have gotten that broadened definition and including some responsibilities in our state legislation as well as in past governors' orders for the ADA and spreading the word about that and getting good implementation done as far as recommendations of policies and issues that need to be looked at in regard to the ADA. So that's kind of how we got the ADA focus or one of our focuses.

[00:02:47]

**PS:** What drew you into the disability field and this particular position that you're in?

CD: Well, my boss, Suellen Jackson-Boner who's been the executive director of the Council for many, many years, longer than I've been with the Council. And she and I used to be daycare advocates together back in the day. And we advocated for childcare, especially daycare childcare and early childhood regulations at the state level as advocates for children, and wasn't children with disabilities, but as a daycare center director, there were a lot of kids with disabilities that came to our center and, you know, were part of the regular mix of children. At the time, I never really even thought about it, but when Suellen had an opening and invited me to be on her staff, I quickly became very excited about the issues around disability. And it's just-- I'm just really passionate about it. It's been so much fun. And there's so much exciting-- so many things that are happening that are so exciting now and in the past when the ADA was being passed, it's just really been an exciting time of my life being involved with the Council and people with disabilities and their families. I just love it.

**PS:** So you were working in the field of disabilities several years before the ADA Act had been passed in 1990. So, what can you tell me about the early days, the years leading up to the ADA? When did the idea of a federal piece of legislation emerge or--

[00:04:26]

CD: Well, there was a book that came out. I think it's called "Toward Independence". And that was a National Council on Disability had the first draft of the ADA. There were findings about people with disabilities and what their status was in life and their independence which was pretty nil. And in the back of the book is an addendum, there was a first draft of the ADA. And that's where the very beginning of the ADA started was with the National Council on Disability. And this is my recollection if there's somebody that has a stronger recollection, I may need to be corrected on some of the details. But that's when we first got involved, when we got copies of that information. And then we were asked by our-- because we were a Developmental Disabilities Council and there's one in every state, the agent-the organization that represents all Councils with disabilities was asked to find people, point people in all the states to help spread the word about the ADA and get people activated. And we were lucky enough to be chosen.

For Sue-- I was lucky enough because Suellen agreed that I could spend most of my time at that point in working on the ADA issues because that was a huge job back then. And we were the-- we were one of the point people in Indiana, the Council was, to get out the word about the ADA as it was passing, the weakening amendments, what was going on at the national level, who to talk to, you know, what to talk to them about, talking points and I worked with P & A, Jay Steinhardt at the time. He's no longer here.

And we developed, you know, some materials that we would send out to people. It was really a very exciting time.

[00:06:11]

**PS:** So what year are we talking about?

CD: Late '80s. I'm not really sure exactly when. But it was about the same time that Justin Dart was touring the country and coming. And, you know, as a Council, we helped with that as far as finding a venue for him and getting it organized and getting people invited as he came out with Major-- I can't remember, Major from New York. Do you remember who I'm talking about? He was the chair of the committee that was hearing the ADA. And I cannot remember the gentleman's last name.

**PS:** Is he a congressman here or?

**CD:** Yeah.

PS: OK.

**CD:** And so Justin brought him and then we had these crowds invited to talk about the ADA and their issues and discrimination. And it was just-- it was a fun, fun time to organize and get people out. It really got people excited about becoming involved in really changing government. It was neat.

**PS:** Now was that -- Now, was Justin Dart working as a volunteer advocate at that point or was he employed by--

CD: He--

**PS:** -- the committees or how did that work?

CD: He was the chair of the President's Committee on Employment. And so he was a volunteer advocate. He wasn't paid but he was appointed by the president to be the chair of the president's committee. And in that regard, he helped organize around the nation in regard to the ADA. And then later, he didn't-- he no longer was the chair but he still worked with the congressman and the senators and everyone else that was involved to help promote the ADA as an advocate.

**PS:** And tell me a little bit about his coming to Indiana, how he called you, what was your responsibility?

CD: Well, the--

[80:80:00]

**PS:** -- what kind of rallies were held--

[00:08:09]

CD: OK. Well, I don't know if you remember Costa Miller who is the executive director of INARF [Indiana Association of Rehabilitation Facilities] well he was the board of the President's Committee on Employment and he was the chair of the Council at the time. And so, through that connection with Justin Dart, who was the chair of the President's Committee and Costa was on the board, we were the primary agency that organized the rallies when Justin Dart came into town under Costa's encouragement since he was the chair. So that was kind of the jet-- the main connection. So our job was to find a venue and get it all set up and make sure all the advocates were invited and that there was sufficient room for them, and then even to try and get media coverage of the rallies and the information that was being presented and given, so.

**PS:** OK. Well, tell me, tell me what was the venue, how did you select the venue, how did you connect with the media, what media were involved or people that went and listen and--

CD: Well, we-

**PS:** Go ahead and go into details.

CD: OK. Well, you know, this has been a while ago. We're talking 20-- over 20 years really because this was all done before the ADA actually passed. But we looked around to find of course an accessible venue and where Justin could be comfortable and, you know, made sure that we had every-- that we had interpreters, that we had braille, that we had materials, so made the venue really accessible. And then we invited all of the major disability organizations to send folks. And it really turned out very well. I mean there was a good crowd. He was very pleased with the people that came out to hear the committee talk and they were pleased to hear from the folks in Indiana who had issues related to disability access and inclusion and what we wanted, what we thought was important in regard to the ADA. So he-- I think he went to every state at least three times. And so it kind of fuzzes in my mind as to which time he came and at what point the ADA was in the process of each of those times.

But because we were connected with Costa as a board member and Justin as the chair of the board of the President's Committee on Employment of People with Disabilities, you know, we were really heavily involved in everything that happened.

**PS:** So where were those rallies held?

**CD:** They were held in downtown Indianapolis. And I think we had one outside of the Indianapolis area. I just can't really remember--

**PS:** In hotels?

[00:10:48]

CD: In hotels. And I think one was held at the ISTA [Indiana State Teacher's Association] building where our current office is, it wasn't at that time, where we-- they have a fairly large conference room and it's centrally located on a bus line. So we had at least one that I can remember at that building.

[00:11:07]

**PS:** Was this -- people from all over Indiana that came?

CD: Yes.

**PS:** So you were connecting with disability organizations. Had anything like that ever happened in Indiana before?

CD: Not like that. No. Most of the time, if there's any kind of government agency that's looking for testimony, you have to go to Chicago. That's where it all-- they do it regionally. They have a hearing in Chicago. Sometimes people don't even show up except the recorder to record the testimony. Nobody on the committee shows up. In the case of the ADA because I think of Justin Dart's involvement, we actually had real committee men come and listen, not just a secretary recording people's comments. So it was very powerful.

**PS:** Was he a charismatic figure himself?

**CD:** Absolutely.

**PS:** Can you talk a little bit about him?

CD: Yeah. Justin Dart was really something else. He was so humble and so-- he gave every-- he gave away the credit for everything. He was known for his cowboy hat and he uses a wheelchair, of course. And he was actually from a pretty wealthy family. And after his disability occurred, it kind of gave him a change of heart as far as just kind of a hard drinking playboy type guy, and then when he acquired his disability, he really changed his life and got him into the advocacy scene that became the core of the rest of his lifework. And so he had his trademark hat. And one of the things he used to do before he came to any state or any venue at all, he will say, OK, tell me the people who have been the disability advocates, who's then the ones that I should mention? And we say, oh Justin, you know, you don't have to mention me, you don't have to mention-- no, no, no, I want to mention every single person that you can think of that's been important to this effort.

[00:13:03]

And so, every time he would talk, he would start out by thanking dozens of people that are, you know, from the local and statewide that had been involved in disability advocacy. And he did that. That was kind of a trademark of his. And even in the written documentation, I don't know if you've seen some of the covers and the addendums to some of the things that were published during the passage of the ADA, there's a book with President Bush signing the ADA. And in the back, you can see state by state all of the advocates, those are the ones that Justin-- and plus more that Justin used to go-- used to thank at every venue that he went within a state, he would thank all those people plus anybody else that somebody gave him a list of. And that was one thing that I thought it was just so charming that he did that and he didn't want any credit for himself, he wanted to give away the credit.

[00:14:02]

**PS:** Do you-- there were three rallies that you said?

**CD:** I believe there were three, yeah.

**PS:** What kinds of numbers of people came?

CD: I-- you know, it's hard to really remember. You know, one person you really need to talk to is Nancy Griffin because she was also very heavily involved in all of this. And she may have a clear recollection of the numbers. But I remember one that had at least a 150 to 200 people. I think some-- one of them was a little smaller than that. I just can't really remember the size of those crowds.

**PS:** Do you think the activity surrounding those events helped build the disability community in Indiana?

CD: Absolutely, because we know-- at once the rallies were over, we know-- we knew who came. I mean, we had a list of everybody who came. And then when the work began on trying to rally the disability community in Indiana in order to get the legislation actually passed and making sure that no weakening amendments happened which were happening-- I mean, there were a million of them introduced. We had a list, which our speaker this morning was talking about. That's where you start, you start with your list in organizing, then you know the people that are interested in the topic and then you get the word out to them and they in turn contact their congressman and their senators. And that's what we did. That's what we used in order to get the information out. And, you know, that was way before the internet. We didn't have the internet back then. So there was no email, we could not send the stuff out on email, which is so convenient today. We had to use telephone calls, mailings and usually there wasn't time for that.

So we used fax machines to get the information out. We used to have these broadcast faxes that we'd put in, you know, with 50 or 60 names and then put another one out with 50 or 60 more names to get the information out on what the provisions of the ADA were and what the best thoughts of the national folks were on what were weakening and what were to be supported. And people were really encouraged to then respond and write and talk to their own legislators about what they felt were the good issues or the points that they felt that they wanted to support or not.

**PS:** Were there any other national figures who came to Indiana at that time?

**CD:** You know, I can't remember anybody except a senator from New York. And I just cannot remember his name, but it was Major-- I just can't recall. I bet you'll get the name from somebody, probably Nancy.

[00:16:55]

PS: Now, where were you when the ADA was actually signed? What was your--

[00:16:58]

CD: I was at home. I was at home wishing that I was on the lawn of the White House. And I just remember being so excited that finally, we had the law and finally, it passed. We did-- the chair of our Council at that time that law passed was Greg Fehribach who's a lawyer here in town. And he did actually go to the signing ceremony. He was there during that period for the signing ceremony and actually witnessed that. I did get a redline copy of the ADA though, which I-- is some kind of limited edition copy of the ADA that the National Association on Development Disability sent me for our work on passing the ADA. So that was kind of neat. And I got an invitation. I just didn't get to go. [Laughing] I wish I could have gone, that would have been wonderful.

**PS:** Now, once the legislation was passed--

**CD:** Oh then the real work started.

**PS:** -- and what was your [inaudible] at that point?

CD: OK. Well, then-- OK. After the-- everybody knows. Once you pass legislation, that's the first step, but it's not-- unfortunately, that's only the very first step. Regulations are very critical. Because of the upthe groundswell of support for the ADA and because we have people in good-- in positions in federal government that really believed in the ADA including President Bush at the time, the regulations were put on a fast track. Really a fast track, considering how long it takes some regulations, could be years after the passage of a law before regulations even are proposed. And this was on a fast track, so we spent the next couple years working on regulations for each title of the ADA and, you know, figuring out what the steps should be and when should buses be accessible and what should be the progression, at what point will all buses be accessible and at what point will all employers have accommodations in place and policies in place.

And so, that was all part of getting the ADA regulations in place. And that, again, was again the subject of a lot of grassroots, advocacy efforts. Again, using the fax to get the information out and what the proposed regulations were and what the national organizations like DREDF, the Disability Rights Education Foundation felt were good or bad about those regulations. So people had some kind of a framework for kind of deciding for themselves whether they agreed or disagreed with the national organizations. And if you have a chance, I don't know if Liz Savage is going to be available after her speech tomorrow, but if she is-- and I don't know when she's coming in tonight, but boy, she would be great to have on this because at that time, she was working with the states in the coalitions getting out the information from DREDF on those regulations and helping us get our grassroots organizations activated in regard to the regulations.

**PS:** So, regulations, are you talking about net regulations at the national level or are you talking about state implementation at the local and state level?

[00:20:25]

CD: No, I'm talking about the regulations at the national level to implement the ADA.

[00:20:29]

PS: -- people in Indiana to try to influence what was still what was happening with the--

**CD:** Right, right.

PS: -- national or--

**CD:** At the Department of Justice and the EEOC in regard to employment and Department of Justice in regard to state and local government and public accommodations.

**PS:** Now was the Governor's Planning Council been involved in training around the ADA?

CD: Yes. After the regulations passed, there was a big infusion of federal dollars to train people, mainly people with disabilities and other advocates on their rights, their new rights under the ADA. And that too was pretty unprecedented. And I don't think that's ever happened in any other civil rights legislation. And I'm not sure what good, you know, what good star was shining on the ADA, but they really put a lot of money into it. And the Disability Rights Education Foundation got a big grant to do training all around the nation on the ADA and it was focused on people with disabilities and advocates that could then take that information and use it to train and educate others. So, we were heavily involved in that training happening here in Indiana and helped support that by providing some assistance to make sure consumers, people with disabilities and-- could get there and could have the opportunity to participate in some of those trainings.

So we were-- I was there myself at one of them. And Liz Savage was one of the presenters at another one, which I did not get to go to. And so, we've-- I think there were maybe two or three-week or two-week long sessions where people would come in from out-of-state and do really intensive training on the ADA and how to look at it and what it meant in regard to each of the acts of the ADA, analyzing a situation to see if it's even covered under the ADA, and how it's covered. They had a really excellent curriculum that really [cough] helped you focus on how to analyze a particular situation and find that is it or is it not covered by the ADA, is it discriminatory and then what are the next steps.

**PS:** What kind of people attended that training?

[00:22:44]

CD: It was mostly people with disabilities and the heads of-- or staff of advocacy organizations, independent living centers for example, a lot of them came and brought folks, and a lot of folks-- the Arc Community came, parents came to some extent, but the main focus was on making sure that people with disabilities themselves knew about their rights under the ADA, so the focus tended to be either on them themselves or on organizations that where then going to take that information and use it to train people with disabilities. And after that happened, we had a contract with our local independent living center and, again, Nancy Griffin was the head of it at that time to do statewide training on the ADA, which we held-- I think they had that for three or four years. And their goal then was to take that information and get it out around the state to more and more people and educate them about the ADA.

[00:23:47]

**PS:** I know you have to leave, so I'll just ask one more question, which is, what work remains to be done do you think around the ADA?

CD: Well, we have new generation of advocates. I mean 1990 was a long time ago and there are people that don't really understand the ADA very well. So I think there's a real need for additional education on the ADA. There's also-- because we've had so many bad Supreme Court decisions, there's the ADA Restoration Act, many people don't understand what that really is or what it does. And it's mainly focused on employment and broadening that definition, so more people are included under the ADA. People that were always meant to be included, just the Supreme Court because there's some bad decisions had narrowed it down to the point where pretty much, if you had a significant disability, they thought, well, you're not-- you can't do the essential functions of the job so you're not covered. And if you have any other kind of disability, then it isn't bad enough to be covered. So it wound up, if you looked at all the decisions taken as a whole, very few people were actually covered under the ADA regarding employment.

And the Restoration Act then restored that so that it really is now broad like it was meant to be when the ADA was passed. And I think that's something that most people don't understand, what that does and it's something we really need to educate people about. So I'd really like to see a little more training and education. And there's still a lot of work to be done. I mean, a lot of work at the local level trying to get communities more accessible, which is the focus of what we're doing this year in getting ready for the 20th anniversary. That's going to be a fun year, I think. And I'm hoping we'll have some real impact on the state as we get near the 20th anniversary of the ADA, really make another push to really get some people educated and get some stuff done.

[00:25:43]

**PS:** OK. That was excellent. That's really good.

[End of interview]