

## CLAWS AND WINGS:

### AN ORAL HISTORY EXPLORATION OF DISABILITY IN DELAWARE 1917-2017

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Interviewer: Kim Burdick, MA, MPA (Referred to hereafter as KB)

Interviewee: Daniese McMullin-Powell (Referred to hereafter as DM-P),  
Disability Rights Activist

Topics included: Polio, Activism, *Olmstead* Act, ADAPT

Run time: 1:07:48

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DM-P: My name is Daniese McMullin-Powell, hyphenated, because I was married in the '80s. [Laughs] That's what you did then. Now I wouldn't even add the "Powell." It would just be my birth name, but, that said...

KB: Well, I find myself telling everybody your ballet story. Talk about when you were a little girl and what you wanted to be when you grew up and when you went to Walter Reed and all that.

DM-P: When I was a kid there were a few good parts, and a lot of bad parts, too. I wanted to be a ballet dancer and so my mother was a seamstress for the family and, and she made me a little tutu and everything. Why not? I mean we don't all grow up to be ballet dancers but probably 70% of us aspire to it! And it was green and made out of that netting thing that she made it for me. And so I used crutches and braces at the time. I didn't have to use the braces all the time but sometimes I did. And so I thought, "Yeah, I can do this. I can really be a ballet dancer," because I could use the crutches, lift up, and be on my toes. So I thought, I have privilege. So, easier to be a ballet dancer. And nobody told me that I couldn't! So that was one of the funny kind of things that I did.

Of course, we lived in Germany for, for a while, a long time. I had polio when I was three. And we moved to Germany when I was four right out of Walter Reed Hospital and so when we there, it was shortly after the war... Let's see, when was it? 1949 or '50 when we went to Germany. And everybody had a maid because there was such unemployment and the, the people there. So everybody in the army had maid's quarters and they paid people in cartons of cigarettes and, and cans of coffee and maybe a couple of dollars.

And so, my little tutu was up in the closet and I wanted to get it down and the maid was there and my mom wasn't. And she wouldn't get it down, so I climbed up on a chair to get it out of the closet and I fell and broke my leg. I think that was the first of 4 or 5 times that I, I did something like that as a kid. You know, what did I know? And she kept saying, "No, you can't have that. It's your Sunday dress!" And I'm "No, it's not for Sunday. It's mine. That's for my ballet lessons." [Laughs] So I got it down.

KB: So that spirit has always been with you! [Laughs] So, talk about going to school in Germany.

DM-P: School was school. There wasn't any special school. There wasn't any orthopedic school or I don't know what they would sometimes call the schools that kids with disabilities would go to back then. But it was Germany. My dad was in the army. I went

from being in the hospital for a year to straight overseas with my mom. My dad was already there. So I went to school with everybody else. I was sort of accidentally mainstreamed when it wasn't happening anywhere else.

How did I get there? On the bus. I had crutches at the time. Sometimes the bus would break down. So they used these big old army trucks because the school was off the army base in Hanau, Germany, and the kinds with the canvas over the top and the benches going down both sides. And so what they would do is pick up the kids, throw them in the truck. So I just was picked up with the rest of the kids and thrown in the back of the truck and off to school we would go. We learned how to speak German as almost a first language, and I could speak German without any accent by the time we left Germany four years later 'cause I was a little kid and they're easy to, to learn things. I can't remember any of it except the bad words now. Those I remember very well!

KB: So, how old were you when you came back home?

DM-P: I was 8, 8-years-old. [KB: And then where did you go to school? Still (unclear)?] I went... Well, we lived with my grandmother who was in Maryland for a while. And I went for one year to a parochial school, to Father Andrew White was a Catholic school in Maryland and we lived with my grandmother while my father was sent, they had called it TDY, Tour of Duty Something or Another. In California. And so I went to Catholic school where I spent most of the time standing out in the hallway.

KB: 'Cause you were naughty?

DM-P: Yeah. [Laughs] I guess I wasn't a very good Catholic.

KB: So, when you were in high school, where did you go to high school and then what happened?

DM-P: I went to high school in New Jersey, 'cause eventually my father was stationed in New Jersey, Long Branch, New Jersey, and shortly after I started high school there he was transferred to Delaware, at the Army Reserve Center that's on the Kirkwood Highway. I think it's still there, I'm not sure. [Murmured assent] It is? And so I went to John Dickinson High School. [KB: Oh.] It was, it was different. I didn't have any friends at first. I didn't make a lot of friends, mostly because in the '60s people were very cliquish, I guess, and people with disabilities weren't usually seen out in public or going to high school. They were somewhere else in, I don't know, John G. Leach, maybe? [Editor: Leach School serves primarily students with disabilities who need more services than other public schools provide.] Or someplace like that, or at home, or, or not even educated a lot of times.

And so people were a little leery, I made a few friends. And,...

KB: And a boyfriend? [DM-P: Yeah, and a boyfriend.] So what about your son?

DM-P: My son? I have two of them. I got pregnant in high school and since in the '60s it was quite contagious, you know, so you couldn't go to school. They threw me out of high school so that I couldn't graduate, along with six other girls that got pregnant in there because you didn't have a right to an education. And you were just bad news and other people would go by your example and think it was okay to get pregnant and have babies then, too.

So, yeah, I was, I was thrown out of school and I had my son Thomas. But before that, my parents weren't always the nicest people. My mother was complacent. She didn't save me a lot. My father was quite abusive through my entire life. He, I guess he didn't like it too much that I had a disability. But I think his number one reason was that I was female and first born, so. You know, that was bad news. He, he liked to force-feed me if I didn't like something and he didn't like it if my crutches would scratch up anything or if I leaned them against the sink and was doing something, if it fell down. So I was pretty much a pain in his butt, I guess.

When I went to church I couldn't kneel and I'd make a lot of noise and doing all of that, so when we came home from church every Sunday he would put on his "Spanking Pants," which was those khakis. And so I got my Sunday spanking. It's kind of why I'm not so religious any more, I guess. [Laughs] I don't know. But, that's the way it was. Nothing happened to my two brothers. I guess they... You know I'm not very close to them even now because they were like a separate family because they were treated different than, than I was.

KB: Were they much younger?

DM-P: The one was about 5 years younger and the other one was 8 years younger. So... And they were born, both born in Germany. So now, when I got pregnant, my father decided that I was... He called me a few names that you call girls that get pregnant or even if they don't because of what they do, and tried to take me to... This was in the '60s, before Roe v. Wade, and tried to take me to a...they called them "backstreet butchers" in, in Wilmington. But his friends – now here's where the religion came into play and worked! 'Cause they're Catholic. So they didn't believe in that and they took me to his friends' house who were also Catholic and they kind of stood up for me and saved me from getting any forced abortion.

So I got married to the father and lived in Delaware for a while and then, then New Jersey and my son Thomas was born. He's, my gosh, gonna be 53. And then my son Martin was born. And after 14 years of being married to someone who also turned out to be quite abusive, mostly because of disability. I, I guess people take advantage of that at times and don't see any worth in people with disabilities and some people express that, that hatred and that disdain more than others. And I guess if you're close with someone they feel a privilege to that more than if you're not that close to people.

So I got out of that marriage with a lot of, lot of help from some friends, and I'd started to work. I worked when I was in high school, too, in, in Delaware at Almart. It used to be Almart. I think it's HH Gregg or something now, it's been through a few things, as a telephone operator. Was kind of like the one where you have the cords all over the place and the headset. I just came across a picture they had in the paper. It was one of those "One ringy-dingy. Two ringy-dingies," you know. And that was my first job.

KB: Emily Litella, huh? [Editor: A Saturday Night Live character played by Gilda Radner.]

DM-P: And that was...yeah. But it was unusual that I would actually be hired 'cause I was 17...17 and they hired me! [KB: I was 18, too.] Yeah. And had a disability and that was... It, it was strange though because that was considered to be, this is going to be your

career for the rest of your life, one, because you're female, so there isn't too much you can do there. And the other was because you have a disability, so what could you possibly do? Probably won't get married 'cause men don't want to bother with you. So you gotta have a career. I don't know how long you'll live at home. Maybe you'll go to an institution and have to live there. So, okay, you're gonna be a telephone operator.

And then they said, "Well, you could work your way up to secretary." Except that I got a "D" in typing class! [Laughs] I'm not so sure it wasn't on purpose, 'cause I just didn't feel like I wanted to be a secretary. I didn't know what I wanted to do. The ballet thing was past. I was old enough now to get over the... [Laughs] But I didn't want to be a secretary and so I just never learned to type. Now because of the computer I can type as fast as anyone else can, but...

KB: Did you get a GED?

DM-P: I did when, later on, when I was married and when I wanted to go... Well, I worked over (at) the Ronson Company for a while, that closed down. It was in Newark [Delaware] and we made the little RONII lighters. And, they closed down because of foreign imports. And so this Trade Readjustment Act of 1974 kicked in, which meant that you lost your job because of foreign imports and so, the company you worked for and the federal government would reeducate you into another profession.

So I took advantage of it and I went to college. It was Del Tech and they said... And I went down to the Department of Labor, they give you all these tests to put little round things on the spindles and other types of, you know, intelligence testing, and interest testing, and they said, "You did really well on all of them. What do you want to do?" And I said, "I don't know. Whadya got?" So they said, "You can go to college and you can take courses and we'll pay for it and we'll even pay for the books and everything." I said, "Great."

Now I was divorced then, just divorced, so I said, "Okay." And they said, "You'll also get 70% of your, of your wages while you're gone." And I said, "That's great," because I had these two kids now, two sons, I think they were like 14 and a couple of years younger, 11, I think. And I lived in an apartment in Newark, and so I went. And I decided to take chemistry because it looked interesting and some of the other ones required some physical ability, like an X-ray technician, and I figured I couldn't be carrying the X-rays and taking them out, because they're large and they're heavy. And so, I didn't even know what H<sub>2</sub>O was and I decided, eh... chemistry sounds fun.

KB: And that's what you got your degree in?

DM-P: That's what I got my degree in, applied chemical technology with a 3.5 average.

KB: [Laughs] And then what did you do?

DM-P: I went to work, almost immediately for Hercules, which is now Ashland, which is going away little by little, I guess. But, when I started working there, or when I was in college, I met my husband, that we just celebrated our 35<sup>th</sup> wedding anniversary. And we... I had had my tubes tied because during my other marriage without permission (which I got in an awful lot of trouble for that) because I didn't want to have any more children with an abusive man and I was trying my best to take care of the two that I had.

And so now that I'm remarried it was like, we had a lot of time and we're making an okay living, and we want another kid. So we decided we were going to go the adoption route. So we went looking for Shirley Temple whose parents had been killed in a car accident [laughs] that was newborn. Which didn't exist. Because in Delaware, the average person up for adoption is 17-year-old male African-American who has no family. And so, they wouldn't allow us to adopt African-American kids, which was fine with us. They wouldn't allow it because of culture, that they always wanted to place adoptable kids with the same culture and race as the parents were.

They wouldn't allow that and then we came across three sisters that were Hispanic and we tried and they said, "No, they're gonna have to wait," to see if they can find a Hispanic family. So that wouldn't work out.

So then we came across a girl who had been adopted previously. And she's 11 years old. And she was being abused by her adoptive parents. And she had been abused in every possible way you can imagine by her original parents. Well, not original parents. She had been born to a 15-year-old girl and the 15-year-old gave her away to her sister and her sister's boyfriend and the sister's boyfriend was textbook abuser. Until they found out when she was about 6 through her guidance counselor in school. And, so they removed her from them and she was in foster care and then she was adopted by a family, who adopted another child that was 3 years old and when they adopted the 3-year-old, they figured they didn't want the 11-year-old anymore, as if you could trade a kid in like a used car.

She had been in Terry Psychiatric Center for a while also, so she has a disability. But it turns out right now, today, she's on a business trip in Texas because she's in, in management with one of the banking companies. And my grandson, her son, is at my house with my husband, going fishing right now. So her life turned around and she's a successful businesswoman.

KB: That's so cool.

DM-P: Couple things going on every once in a while that try to impede her, but she gets past them. I raised her. What else can you do? [Laughs] [KB: Certainly learned from you.] Right. You know, put the past in the past like, like I did. She knew, she knew my story, too, she knew that... I call it "Lima Bean Theory." Lima beans is one of those things that my father used to hold my mouth open and shove them down my throat. And so I never ate lima beans after I was away from home and all of that. And I hated them 'cause of that. That was the main food. I couldn't remember the other ones or I'd hate them, too.

So, so when I was in my 30s, I just up one day and decided, "How dare somebody have importance to the way I run my life when I'm an adult? Why can I let that happen? Why can I let somebody else take charge of me when I'm not even there anymore?" So I just decided I'm in charge of my life and I decide what I like and what I don't and not because somebody else did this or did that. And not even because of the husband that I was married to before, who was quite abusive, would I have any thoughts about any other men or women or anybody else at all. Why should I allow other people to impede my life and to make me into anything other than who I am inside? And so from that time on is when I became a whole person.

KB: And did you eat lima beans? [DM-P: Pardon?] And did you eat the lima bean?

DM-P: Oh, I ate lima beans. They're fine. Especially in succotash with a little corn. But, that's why I call it my "Lima Bean Theory." And that's what I taught my daughter. Over and over again, that she can't allow, she can't allow her abusers to be in control of her life when they aren't there any more. And her abuser is still in jail, still in jail. I think he got 80 years.

KB: So, how did you get involved in activism?

DM-P: Long af... well, sort of after I became in control of my own life, and I could see, I could see other people then and I could recognize injustices instead of being enclosed in survival mode to where I was, "I need to survive this. I need to survive that. I need to get away from this person. I need to be close to that person," and all. When I became my own person, then I can see what was going on with other people that were like me and think, "WTF? This is injustice. Why shouldn't this happen? Why shouldn't we be able to go into this building or that building?" when before that, it was like, "Oh! That's the way it is."

I didn't think it was wrong. I didn't think it was right. I just thought, this is the way it is. I can't go in there unless I can get up a couple steps, which I could at the time with crutches, and then more and more using a wheelchair to get around. And when I became using a wheelchair more, it was more of a, "I can't go there anymore? Why not? And what is this thing called an Americans with Disabilities Act?" This is in the '80s. I asked my brother, who worked for, he worked for Biden at the time, and I said, "There's a thing. It's a resolution." He says, "Oh, it's just a resolution. It doesn't mean anything." And we were talking about the Americans with Disabilities Act of 1990, which is today. Today is July the 26<sup>th</sup> and it's the 27<sup>th</sup> anniversary of the ADA is today.

And, to realize the difference there and to know that I became a part of it. Because when they put it in place, it still wasn't – it was like, dealt with as a big favor to people. "Oh, yes, well, we'll get around to that. Well, it's... Well, we just put in a ramp just for people just like you. Isn't that special?" So... [Unclear, laughs] Actually, it's the law. And so I became a part of it.

And then I discovered there's a whole lot more. That accessibility is a lot more than a ramp. It's a lot more than putting in an elevator. It's a lot more than removing barriers. It's, it's, it's healthcare. It's attitude. It's even adoptability. I mean, it was after that, it was like '94 when we adopted my daughter because before that I wouldn't have been able to adopt because I have a disability. Even though my daughter has a disability. You just couldn't do it.

You couldn't get into places. I couldn't get car insurance, couldn't get car insurance. I remember it wasn't mandatory at the time either, but my husband could get car insurance, but I couldn't because I had a disability. So it was assumed I couldn't drive right. I couldn't get life insurance. I was turned down by Equitable Life Insurance Company for life insurance. And I'm not dead yet. [KB: Those things have changed now?] Those things have changed. They have to sell me life insurance the same as anyone else. Especially since my disability isn't even fatal, but they can assume and do whatever, whatever they wanted to.

And healthcare, it was always pre-existing condition. So I couldn't get insurance unless I worked someplace and then, then I would have the same insurance but I couldn't get disability insurance like other people could. You know, I had to pay for it, along with everybody else. It would be in the policy and everything, but it wouldn't follow through because I already had a disability. Even though I acquired more disability later, and, and it would apply to it. Which did happen, after the ADA. Because when I worked I, I worked for Hercules for 8 years and I became more disabled and I couldn't do the 8-hour-a-day thing. And the shifts, we had 8-hour shifts, you know, midnight to 8, and 8... And then we had 12-hour shifts, like noon to midnight, midnight to noon, and it's changing back and forth and around a lot of chemicals and asbestos and things like that that you had to be very careful with. And then I couldn't work anymore. That long a time. And so I collected disability from Hercules because I was, at the... [KB: (Unclear) ADA?] It was right about then. Well, it was 1989. But it was, was when, with the policy there, that Hercules did, particularly. They didn't cut me off from that. And the Americans with Disabilities Act wasn't even there for another year after that.

And so, I was retired for 20-some years. And that's when I became involved in activism. After my daughter was fully adopted, because I've kind of been arrested 30 times since I got highly involved in the activism, and I would, might not have been able to adopt with all that on my record, so I had to wait till that's taken care.

KB: How old was she when the first time...? [DM-P: 1996.] What were you protesting then?

DM-P: Well, I kept reading about this group called ADAPT. It was "American Disabled for Accessible Public Transportation." And in the '70s they started in Denver, Colorado, as the Gang of 19. There's plaque on a corner now because they noticed... It was a Center for Independent Living just like the place that we're filming in here. It was called Atlantis and it was the second Center for Independent Living in the whole United States. It was put together by a man named Wade Blank who worked as an orderly in a, in a nursing home. And he started getting people out because he didn't feel like they belonged there. And then he started up a community of activism and ADAPT and set up this Center for Independent Living to educate people and to recognize their freedom and their abilities and, and a sense of justice. Not a sense of pity. Not like a, I don't know, an organization that "helps people." [Laughs] Not with a [helpless gesture] but a "Come on! Let's go and get 'em." That kind of an attitude.

So they couldn't get on the buses and they couldn't get anywhere in Denver, Colorado. We're talking in the '70s, in 1978. So the 19 of them went down to the corner, Colfax and I can't remember the other street, and they got in front of the bus when it stopped and "You gotta get out of the way!" And they said, "No. No. If we can't get on the bus, nobody's going anywhere." And they laid down in the street [in front] of the bus. For a couple days. And the press came out. And it... It's on my Facebook page, it's bringing it up again. And they finally agreed to have lifts put on the buses. Then – in 1978. So Denver, Colorado was the first one to have lifts put on the buses so that everybody could get on that bus. I mean, we couldn't even get on and sit in the back of the bus. We couldn't get on the bus at all! So, now we can, most of the time. [Laughs]

But that's what they did and then they went on to other things and getting people out of nursing homes. They found out that Medicaid laws would, would pay for you if you qualified for Medicaid to go into a nursing home to get your services, but you couldn't qualify or you couldn't get Medicaid to pay for services in your own home. You had to go into the nursing home to get any services, to get any help. And it wasn't nursing and it wasn't a home. It wasn't like a hospital. You just had palliative care. You had somebody there that would fix your food and wipe your butt and maybe help you with a bath twice a week, maybe. And that goes on now, too. You know they don't get a shower every day. They get twice a week. It's about it. And it's still that way.

And I said, "People don't belong here." They just don't belong there. So they started pounding on desks and sitting in doorways and this has gotta happen. We have to have the same freedom and the same privileges of living; not privilege, RIGHT, the same right to live in our own homes as everybody else does. And so they started getting people out and they'd put 'em to work in the Center for Independent Living getting other people out. I still go there every January for our meetings with ADAPT, 'cause when I went to Atlanta in 1996 they had already been in business of being a large group since 1983. That's when they went to Washington, DC and decided to pound on Congress and, and their government, did some fundraising and all.

They never did advertising. They never did things with government money and all. They got it so that they wouldn't be obligated to anyone. And if they got donations, it was always on the premise that "we don't do what you say." You're funding our cause and we do what we do and that's it. And it's still that way.

So, every, twice a year, every year since then, we go on what we call an "Action." We went to Tennessee a couple of years ago. We went to Columbus, Ohio, and in Columbus, Ohio was one of the arrests, too. And I'm banned from Columbus, Ohio for the rest of my life because their warrants never expire. [Laughs] I never showed up for court. The first one, we were arrested when we were near the Medicaid building, and so we were, had to go to court, we were...we had a "Keep Away" order. We couldn't come within 10 feet of any, any government building for the rest of the week. And so, we went 10 feet exactly, measured out with a tape measure from the Medicaid building now, for the second time. And we had a coffin, a wooden coffin and we had the names of all the people that we knew that died in a nursing home. We set it out in front, by the front door, and we had a procession to where we went by the coffin and dropped in the names into the, into the coffin as a street theater.

Then we decided, "Oh, the hell with this," and we just went over to the building, got stuck in the doorways and got all arrested again. But we made a point and people took notice. And so they were working and working to try and get *Olmstead*. Two people in Georgia. Lois Curtis and Elaine Wilson were the two women in Georgia. And they sued the state of Georgia because they were in the Georgia Hospital, which was a nursing home, and they wanted to get out. They wanted to live in their own home, their own place, instead of having to get their services in there and they couldn't. So they sued the state of Georgia because the Americans with Disabilities Act was in place, and Title II, which goes into the things I'm really involved in, said that "A person has a right to live in the most integrated setting according to the needs of the individual with a disability." And that's in the ADA.

And they just, like, “Oh, whatever. It’s too expensive and all that. You can’t do it.” Well, it’s in civil rights law. It’s federal law that you have a right to live in a community. So they took that to court. And they won in the... And *Olmstead*... They shouldn’t even call it “*Olmstead*,” because Olmstead was the commissioner there who was the Commissioner of Health and Social Services, the one that wanted to keep them in. His name was Tommy Olmstead. And so they sued him and the state to get out. They should call it “*Lois and Elaine*.” [KB: Laughs] So, *Olmstead*, the state of Georgia took it to the appellate court and they lost again. Lois and Elaine won that. Then they took it clear to the Supreme Court.

So in 1999, in April, is when they heard the case. Meanwhile, while they were working up to hearing the case, the state of Delaware signed onto an amicus brief in favor of *Olmstead*, in favor of keeping people in nursing homes. That’s what the state of Delaware did. Jane Brady was the Attorney General then. So some friends of mine and I, we went down to Jane Brady’s office and we pounded on the door and we all piled in and we got a boom box out and we were singing some songs and doing some chants like, “Our homes, not nursing homes. Our homes, not nursing homes. Support *Olmstead*.” And she wasn’t in the office and they said, “Oh, she’s up north.” We said, “We’ll wait.” So we stayed there and stayed there and stayed there for hours. And then she called up from up here and she said she would meet with us in the Supreme Court Building, which is sort of catty-corner across the street from the office, on such-and-such a day.

And that was about two or three days from then, and we all went over there. And we sat down at the table. We brought in our signs and we put them all over the Supreme Court because we were there first. And Jane Brady faxed the Attorney General in Florida, who was in charge of gathering up all the *Olmstead*, the amicus briefs of the states that were in support of the state of Georgia, and took us off of that brief. Took the state of Delaware off of that brief so that we would be for Lois and Elaine and for getting people out of nursing facilities.

KB: What year is that? [DM-P: Pardon?] What year?

DM-P: It was probably ’98 when they were working up to it. It was already set to be heard in the Supreme Court but people were signing onto one side or the other as to, you know, what they would do. There was a case before that called *DiDario Nursing Home vs. Helen L.* [Editor: proper citation, *Helen v. DiDario*, United States Court of Appeals, Third Circuit] that happened in Pennsylvania. A friend of mine, Steve Gold, who’s a disabilities rights lawyer there, handled that case, and that was a case where Helen L. won her way out of a nursing home also to be served in the community under the Americans with Disabilities Act, the Title II. Well it’s also in Title II is transportation.

So, a lot of people don’t realize where all this stuff is. Like (Title) I is for labor and employment and (Title) II is transportation and state things going on, like state services. It kind of mirrored the Rehab Act. And then Title III is stores and banks and all those retail places and public accommodations is in Title III.

So what’s ADAPT do? We go after all three of them. But mostly, mostly, getting people out into the community is where we’re at and we’re dedicated to that. And that’s why we get arrested most of the times. So we got Delaware. It was ADAPT and the small group of us that, by the way, was right here in this building. It was IRI that we put it together.

[KB: What's IRI?] Independent Resources Incorporated, this. That was when I was chair of the Board of Directors here. They don't do that anymore, It's un, unfortunate that they think they can't, so now they just do...whatever they do. [Laughs]

KB: What was going on in 2003?

DM-P: 2003 was the March. Some people called it the "Death March." [KB: And why? What was the protest, because...]Mi CASA. [...that's when Vince was on a starvation diet, too. What was going on that year?] We gathered in and I was – by then I was in the leadership of ADAPT, too, I wasn't just an observer. After all, I got arrested twice on the first trip in 1996. I had no intention of doing it then but I was. And so, we decided for our action that year we would march from Philadelphia, the Liberty Bell in Philadelphia, to the steps of the Capitol Building in Washington, DC. And by "march" I meant we would wheel and walk in the street, no transportation, and it would take us two weeks 'cause we could only do seven or eight miles a day.

So Nancy Salandra, she's at Liberty Resources up in Philly, and I, and I wasn't with IRI anymore, but I was with Freedom Center, the other Center for Independent Living in Middletown, got together and did the route and worked months and months getting donations for the first night we spent in Philadelphia, outside of Philadelphia. And then we ended up at the Goodwill Center, close to here, for the night. We got with them and they allowed us to put up our tents overnight there and supplied us with some food and left the bathroom open all night for us. We had outhouses that we were hauling along. Never saw so many accessible outhouses in all your life, 10 of them lined up there, every place we went.

And we met in Rodney Square the next morning, this is Day 3. And Joe Biden came out and talked to us. We were working on legislation called "Mi CASA," the "Community Attendant Services Act," "Medical – Medicaid Community Attendant Services Act." And that would make it the law that community services would be the number one choice of Medicaid because, still today, nursing homes are an entitlement. If you are, qualify for Medicaid. Home and community-based services are not. They're set up by the states choosing to fund waivers, where you're waiving your right to go into a nursing home to get your services in the community. Delaware has some waivers. Most states do. So that's the way it was and we wanted it to be in federal law to have a right to live in the community.

We've been doing it every year. It started in Atlanta when we got Newt Gingrich, back then, and we got in his office and he, he signed onto it while we were in Atlanta. I didn't even know what it was 'cause I was brand new to this, on a napkin in his office. And we've worked on it and worked on public hearings and everything. Didn't get it through, didn't get it through. On and on and every year it changed. It went from "CASA," Community Attendant Services Act, to "Mi CASA" which Spanish is, "My, my home." Or "My castle." And so it changed to – it's introduced again now, too, to make it a right, to live in the community.

So, year after year we've been after getting that done, and so, Joe Biden, who was Senator then, came out and talked to us in Rodney Square and said it may not be that year, but it would probably be the next year. And we've tried and tried and it still hasn't... Work on it all the time. But we got through it. We got rained on. We got

lightning. The chairs went down because they were getting wet. They had to be taken to a fire station to dry out. My chair went, I had a scooter at the time, and one of the fellows with us took my scooter to, to a hair dressing salon, while I had a manual chair, and I used a hair dryer on it and it got it running again.

It was something. It was 150 of us. There are pictures available online, too, that marching down Route 13, all the way down past... We did a little bit of protest outside of the Holloway Campus, 'cause Delaware Psychiatric Center is in there, with the "Free our people" chanting and, and all. We hesitated and then we went on. We got Bob Evans to give us breakfast one morning. We stayed in Victory Fellowship Church parking lot in the back then left early in the morning. We stayed at the, that night, at the Troop 2, Troop 2 Police Station. 150 of us set up tents and everything and my family put together a pig roast in the police parking lot. [Laughs] It was kind of...ironic.

So, and we let them have the leftovers after we were all... And they enjoyed 'em. It was a whole pig that we had that time. Sides and everything. We got food donated all the way. We went on into Maryland. We stayed at a campground, Methodist campground just over the Maryland line near the Hatem Bridge, and with cabins in there. It was like "Dirty Dancing." It was like – that's what it looked like. And they fixed us dinner for seven bucks apiece, a nice fried chicken dinner. Before we left in the morning...after we got a shower that night because they had indoor showers. We went two weeks without... [KB: Pew!] I got one of those big bug sprayers that, except it was brand new, full of water and I made five bucks apiece by washing people's hair with it. [Laughs] We had people that, whose chairs reclined like this do, and so the one woman who could walk some, she got out of it and stood...you know. Get in that chair and lean, lean it all the way back and she and I would wash people's hair out in the grass somewhere and made a little bit of money to buy a little bit of food and did it that way. We... When we were there, a Freedom Center people, other Center for Independent Living, gave us breakfast that morning before we left and came out there and brought us bagels and things like that. So that was cool.

We went on to Washington, DC, and ended up at the steps of the Capitol Building. We had a whole lot of other people join us and everybody was [unclear] around. Like 300 people there pretending that they marched 144 miles when it was really 150 of us really did.

KB: So did you go... You went through towns and villages, not the main route.

DM-P: Yeah. We went down Route 1 through Baltimore and all that, which was under construction which was very, very scary. When we were in Delaware we'd already arranged with the Department of Transportation. They were great. They don't provide great transportation, but I mean [laughs]... They got an attenuator truck to follow us. An attenuator truck is a great big truck with big bumpers on it that if it was hit doesn't move. You could run an 18-wheeler into the thing and it won't move. And they got behind us all the way from the Pennsylvania line to the Maryland line. And, they went ahead, and we were in the street, we didn't do sidewalks. You can't do that. It's impossible. So we'd no stopping for red lights or anything else. And they went ahead of us and changed every single light in the state to green, from the time we got up and went down the street until the time we got to, to the state line.

KB: Was that when Anne Canby was secretary, or Knight?

DM-P: Was it, 2003? We didn't talk to her 'cause we did...

KB: She might have been gone by then. Maybe Nathan Hayward?

DM-P: Yeah, I don't think so. [KB: I don't know. Certainly wasn't Kermit (Justice). He was long gone. Wonder who it was?] Yeah. I don't know. I can't even remember who Secretary was. It was really the Emergency Management Department that, that we met at, and talked to people at. It wasn't the Department of Transportation but they're the ones that supplied the truck and everything, so that was pretty nice.

KB: That real [unclear]

DM-P: Oh, Anne Canby. We had an action that, one of the few that happened right here in Delaware. We had, we had a training, here, at Independent Resources. We hosted a 3-day training for community organizing. And we did some role-playing as to how to do an action and what happens and how to keep calm and how to support each other because in the ADAPT group are multitude of disabilities. And some have multiple disabilities and some people have mental illness. And some have developmental disabilities and physical disabilities and sensory disabilities and it's just, we're all together and we don't silo anybody and we support each other. And sometimes if you have a mental illness and you can go on the action, and you have that will to do it, it might be a little harrowing and bothersome or get a little anxious. And so we can recognize that and know ahead of time. And then they'll, like, "Ooh. There's Jane over there. Looks like she's having a little problem," and just go over and sit with Jane. "You know, you know everything's gonna be cool, right? We're all of us in together." And, "Yup, yup, okay." [Sigh] "Got it."

So that we are all together. And we always support each other that way and we never leave anybody behind. And we never have anybody that's too disabled to do this or to do that. Everybody has a job to do. And sometimes it's not very democratic, either, because when we want to get it done, you're gonna do what the leadership [laugh] is telling you to do. If we tell you "Get over there and take that door!," you don't say, "What door and why?" [Laughs] You just say, "Yes!"

Or, "Where are we?" Often we can't tell you where we are because people like to brag and they like to say, "I know we're going to the White House." You know, and there's a cop there, who buys an ADAPT shirt and puts it on, and thinks we don't recognize him! [Laughs] Like we don't know who's with us or anything. And we always do. And now they know us. Now they're like, "Hi!" [KB: Laughs] "How ya doing?" They say, "Where ya going?" Uhhhh, "Next intersection we're gonna take a left." "Okay." And they, you know, help with the traffic, but they don't, they don't need to know the end now or anything.

So they're become helpful and they know that we're non-violent. Always non-violent. And almost everything that has been accomplished and done for people with disabilities has been done through action. Has been done through civil disobedience. Through the way that Gandhi accomplished things. The way that Dr. King accomplished things. No violence whatsoever. And we even pick up the trash before we leave wherever we are because we never want to say, "Look what they did. They, you know, they made a mess

here and all” and we get it done. It’s why the buses have lifts on them. It is why *Olmstead* happened, because people did that.

When the Supreme Court decision came along when they were holding the case, 50 of us went to Washington, DC and slept on the sidewalk like they’re doing right now. In front of the Supreme Court. And the police came and they said we couldn’t sit on the steps that are there. So we were on the sidewalk with sleeping bags and air mattresses and bullhorns and Justin Dart came down, who was the father of the Americans with Disabilities Act, he came down with box full of food and his wife, Yoshiko Dart, and his family and wished us well.

And in the morning, at 6:00, we got in line to go into the courthouse because 50 people from the public can sit through the whole thing. Otherwise they have a three-minute tour. You can go and come in the back door and stand there for three minutes and then you’re ushered out again while the Supreme Court is hearing cases. And the 50 of us got in to hear the entire *Olmstead* Supreme Court hearing. So we sat there. When we went in, you couldn’t even take a pencil or a piece of paper. You couldn’t take notes. You weren’t permitted to smile or cry or anything or they had the court guy walking through there looking at you like, “Is there any emotion? Is there anything going on here?” You know. So we had to sit there in the back, because it’s not accessible in the other chairs. And the people that could walk could sit in the seats and listen to the whole case. The whole thing. Afterwards, we partied with Lois and Elaine and the lawyers and had coffee out there and had dinner over in the Methodist church which is sort of catty-corner across from it. They even let us hook up a coffee pot all night with a cord coming out from under the door while we were there.

And I’ve met... Elaine passed away in 2004 but Lois is still out since they, of course, won the case and the Supreme Court upheld that Title II of the Americans with Disabilities Act and said, “Yes, indeed. You do have a right to live in the community and get your services there. You don’t have to go into a nursing home and from now on, what the community has to do, is supply the services that you need, that is not hospitalization, in the community, the same that they have them in the nursing home.”

KB: And it’s true that it’s cheaper to live on your own than in a home? [DM-P: Absolutely.] Talk about that a little bit.

DM-P: But you still have people going around saying, “Well, we have to look at that. We have to study that.” And then they say, “Oh, it costs more for the services in your home.” And we’re like, “Historically, it doesn’t. Let’s look at...” “No, we have to do our own report.” And so what we did then was we came up with, it was ADAPT again, we came up with a program called “Money Follows the Person.” And it wasn’t some old guy sittin’ up on the hill and a couple of women that came up with a stupid name like “Money Follows the Person.” It was us. It was us.

And we fought for it and fought for it and we went and we chained ourselves to the White House fence, while Clinton was in office. And, oh, the good old days. Al Gore came out and talked to us. So, he said, “What are, what are you here for? What do you want?” you know. And we said what we wanted and what we wanted to do. And he said, “Why don’t we have some meetings and get together and talk about this?” And Al Gore got 1.75 billion dollars put aside for that program, Money Follows the Person, because we were

chained to the White House fence and because we had the intelligence, meaning, I don't mean "the brains for it," but I mean the information together and we knew what we were talking about. And we don't go, we don't protest and say, "Give us services! Give us services!" We go, "You need to give us the services and this is how you're gonna do it." [KB: How they understand...] Yeah, we have the solution along with the problem along with it.

And so that's what happened and we got 1.75 billion dollars. And so, then, I was one of the about 12 people that would meet with the CMS Director, McClellan [Centers for Medicare and Medicaid Services former director Mark McClellan] was his name, at the time, almost every month for a year or more in DC to come up with the criteria. And that needs to surely be integrated, that no, you can't be moving into, people out of nursing homes into group homes unless there's... We conceded on four or fewer but not 6- and 10-person group homes, just the... no assisted living and no, what do they call them, like congregate, segregated farms or farmettes or, or gated communities for people with particular disabilities and all that – none of that, 'cause that's all segregated. Must move into the community and get your services there. Medicaid can, with this program, pay for moving you from the institution to the community, which they can't usually do. You can't use Medicaid funds to move somebody and, and set up a few supplies and maybe pots and pans and put some blinds on the wall and moving expenses. You can't do that. But with this program it's an exception and you can. And it's sunseting this year.

And we got that program put into the Affordable Care Act. So since it was sunseting we worked some more, with, recently, with Obama, which we had meetings with his staff, to get the Community First Choice option, which was Community First Choice Act, which we couldn't get through which was sort of the child of "Mi CASA" and "CASA" and on down. So we worked with Senator Harkin in Washington to get that in the Affordable Care Act.

These are the things that they're working in DC, today, to get rid of, to throw out, so that the people in the community right now that are living with the Community First Choice option won't have it because they are going to get rid of the Affordable Care Act. And when they do, that program will not be there and people will go back into the institution or refuse to and die. And they don't even know it exists. All they think of is insurance, and your premiums are high, and that's about it. And they don't even know what the Community First Choice option is.

KB: Were there people from Delaware that were down there, recently?

DM-P: Delaware is, I hate to say it, but, 'cause I live here, so I must not be that great an organizer with ADAPT. I'm the only one. Because we were going to DC six or eight, sometimes 12 of us, on these actions and being highly involved, when I first started up Independent Resources. Because Independent Resources used to be the Center for Independent Living was with Easter Seals, and they, they couldn't do that because Independent Living Centers or Centers for Independent Living had to be autonomous and had to be at least 51% run by and employ people with disabilities. And Easter Seals wasn't that. They couldn't do it. And so we broke off and became autonomous, I was part of that. It was CIL, Inc. and then Larry Henderson, who passed away last December, and I and some other people came up with the name Independent Resources and had got a

Board of Directors together and I was the Chair of the Board of Directors. I don't think they even know that. [Gestures to outer offices.]

KB: Probably not. They'd be so old. [Laughs]

DM-P: And so that's the way Independent Resources came and then we formed, I went off and formed another Center for Independent Living, Freedom Center for Independent Living in Middletown, because of demographics and all we needed across the state. So that was the second one that I was also part of putting together.

KB: So... Talk about the Princeton 14. We're sort of skipping backwards a little bit, but what was that? [DM-P: What was what?] Princeton 14.

DM-P: Oh, the Princeton 14. It's another issue that I guess I haven't touched on yet. And I'm involved with another group also that's connected with ADAPT and it's called "Not Dead Yet." And we're anti-, adamantly anti-physician-assisted suicide, euthanasia, and the degrading and mistreatment of people with disabilities.

There's a professor at Princeton University that they hired in 1999 called Peter Singer. He's a bio-ethics professor and he writes books. And his philosophy is that if you're useless and you don't have the intellect to know where you are and your place as to what you should be doing, then it would be okay to euthanize you, especially babies that are born. We're not talking abortion, they're two separate things, two separate things here.

But he was professing that after a child is born, and the child is born with a disability, say an intellectual disability, maybe even profound physical disability, that the parents and the doctor should be able to get together and decide if this kid is gonna make you happy or not. If this kid is gonna take up too much time and you would rather get rid of it and make room for another one that was whole and unbroken, then you should be able to remove the kid's personhood and then declare that kid no longer a person. Then it would be okay to euthanize him. If it was okay with you. If the kid was gonna make you happy and you were fine to, to raise it, then you could go ahead. And so that's what he's professing.

He was also a friend of Dr. Kervorkian. Kervorkian, most of the people that he, he actively participated in the drip in killing people. And about, oh, 60% of the people that he, that he murdered, with their permission, were not even terminal. They were people with cerebral palsy and just wanted to die and that sort of thing. Peter Singer thought also that if you were elderly and had Alzheimer's or something like that, and that it would (be) okay to remove your... You weren't a person any longer. So you could remove the personhood and kill you. Even without your permission.

So, we went to Princeton to go protest his hiring and they said, "Well, it's"... What is it? Universities can, freedom of teaching and spreading the word about whatever they want to? And we said, no, you wouldn't allow a Hitler proponent to come in and say, "Well, you need to kill all, all people that are Jewish." Or you need to kill all people that have disabilities, and like that. So it shouldn't be that you have someone there with that type of philosophy.

So we went there to demonstrate, and spent the night, and got up early in the morning and we went to the main administration building because they had gotten wind of it and

closed off the streets and everything to get to the building where he was teaching at the time. So I kinda chained myself to a(n) administration door and so did seven, seven of us did. And the police came eventually. That was after the campus... The people, the students there, brought us pizza and stuff for lunch. And I'm sitting there, in the rain, and my service dog and all, and arrested us. And when they pulled the seven of us off the door, seven more moved in and attached themselves to the door. And then they pulled them off.

So we had to go to court and we were declared *persona non grata* for the rest of our lives for... So, I can't set foot or wheel on Princeton property for the rest of my entire life. [KB: Laughs] Because I think it's quite ironic that I am "person not recognized" for demonstrating against somebody who likes to take away personhood from somebody that he doesn't think is valuable enough, so that you can kill them.

KB: So, if you were gonna... If somebody was gonna write your biography or something, what do you want the future to know about you, in your own words?

DM-P: I would hope – nothing. I would hope that everything would be common. That people would be equal and they wouldn't bother with knowing anybody that made any of that happen. You know, I would hope that my name would be lost, along with everybody else as a freedom fighter because everyone is free and because everyone is equal.

And I can't point to one thing anyway because it's not like an epiphany. It's more like an evolution. I mean, I was the person in my first marriage who was very apologetic, and "Oh, I'm so sorry. I'm, I'm, I'm just a cripple and I should be thoroughly grateful," 'cause I was told this, that somebody would even bother to marry me at all. "And so I shouldn't complain, so go ahead and beat me or do whatever you want to," to "Are you kidding me?" You know? "You're gonna get your butt kicked [KB: Laughs] if you try anything from me or anybody else that I know of." So, it's, it's things like that.

And I, I wish, I wish Delaware was more involved than writing letters or bitchin' and moaning behind closed doors. Like "Oh, I don't like this. And I don't like that. I wish we could do this and that and the other."

KB: So everyone should be an activist like you?

DM-P: Yes. [KB: Yes.] I need help. [KB: Being an activist!] Yes. It doesn't pay well. [Laughs]