



Oral History and Folklife Research, Inc.

AN INTERVIEW WITH AVERY OLMSTEAD
INTERVIEW CONDUCTED BY

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KJL Let me start with a little bit of housekeeping. We are in Old Town, and we're interviewing Avery Olmstead about the Americans With Disabilities Act and his experience as a person with a disability, and it is Monday, July 7, 2014, is that right?

AO Yeah.

KJL Okay, (laughs). Alright, Avery, do you mind if I ask what year you were born?

AO 1971.

KJL Okay. I'm going to do a little bit of checking, here. Okay, you were born in 1971.

AO Uh huh (affirmative)

KJL Okay, so you came of age during the late '70's and '80's?

AO I did.

KJL What was that like?

AO I was born in '71, so I was born at a time when, basically when I was born, it was advocated that I go into an institution. Because that was--basically, that was the norm at that time and my parents were completely against it, even though everybody--all the medical professional around them were saying that that would be the best thing, and they were young, and could have more kids, because I was the first. My parents were absolutely against it and wouldn't listen to any talk of institutionalization, for which I'm really grateful, because if they had agreed to institutionalization, my life would have been completely different. I don't even know if I would be here right now.

Growing up, I would say that for the first few years, I really didn't notice anything. I really didn't notice anything was different. I didn't have a wheelchair until I was five, but if I wanted to get around, I crawled, or my parents carried me, or something and I just thought that was my normal, so I didn't think anything of it, and I didn't really notice that I was different from other kids until I started school.

When I started school, my dad was in the military, so we were stationed--my dad was stationed in Landstuhl, Germany. My parents must have said basically--I don't know who they talked to, but they told the powers that be,

I have fuzzy memories about that time, but my impression of what I remember and what I've been told is that once I was in the school, you know, and people realized that I wasn't an alien and I didn't have three heads, and I moved differently than everybody else did, but--I had a wheelchair, I had my first wheelchair at the time, so I might look physically different and move physically different, but I was still a six-year-old boy. I had a lot of the same wants and needs

and desires as the other kids. I think once people realized that in a lot of ways I was like my peers, I think people started to relax. And I will say that the teachers that I had never treated me any differently. I did well in school, I had a short attention span, which I still do.

I remember the reading corner was in my--my desk was in the corner of the room where the reading corner was, so when I was supposed to be doing math problems or science or something, I'd be looking over and seeing what the kids were reading. So I got in trouble (laughs). A lot. And the really cool thing was because my mom needed to go to school with me every day, she became really good friends with my teachers and stuff. They would, like, meet socially, and stuff like that. And I do remember when we went on field trips they really did their best to accommodate me. I think there was a mountain hike, or something that I went on. I don't remember much about it, honestly. I'm kind of afraid of heights, so I kind of wanted to blank it out, and that's kind of when my fear of heights started.

When we moved back to the States--my dad got stationed in Brunswick when I was in the second grade. This is 1979, the fall of '79. Before we moved to Brunswick, we lived for a couple of months in Bangor, and I started school in the Bangor school system. One thing I thought that was really cool that my new teachers did was they came to Bangor to meet me and they kind of interviewed me about what kinds of things I like to do, what my hobbies were, you know, what toys did I like, you know, stuff like that, and they took a lot of pictures. (inaudible) What they did was they got everybody in the second grade together before I started, and they had, like, a little assembly where they introduced me. Because, at that point--when I was in Germany, I was the first person with a disability to go to that school, and when I went to Brunswick, I was the first person with a disability to go to that school. So the teachers got all the kids together, and they said, you know, "This is Avery, and he's going to be in the second grade with you," you know, "and he has something called cerebral palsy," and they explained that. They showed them pictures of me in the chair. And they also reiterated things that I like to do, and stuff like that. I think they did that so kids would be comfortable and get to know me a little bit before I showed up and so it wouldn't be so much of a shock. And it worked really well. I remember the first day of school, for some reason I didn't go out to recess, as I remember. Kids were pressed up against the windows at recess, like, looking at me and stuff. I kind of felt like a zoo exhibit, but again, once everybody realized that I have a lot of similarities to them, I think people chilled out.

I've always been really lucky, I've always had really good teachers that I think saw potential in me, even when I didn't see it myself. Once things chilled out, it was a really cool experience. I will say, having a disability in elementary school is very different than having a disability later in life, because when you're in elementary school, it's kind of cool, because kids would fight over who got to push me at recess, and I would get out of class to go to physical therapy, which I actually kind of liked, because, you know, who doesn't like a school break. So, I was involved in Special Olympics at the time. I got a lot of attention for it. I got a lot of attention for having a disability, and most of it was positive. I was the Easter Seal Poster Child for 1980 and '81, so I got to do some traveling and got a lot of attention and stuff. I will say I feel differently about the poster child thing as an adult than I did then, which I'll probably talk about a little later. I just

bring that up to reiterate that at the time, that was a really positive experience too, because I got to do things that I normally wouldn't have done.

So elementary school, for the most part was really positive. Even--in the fifth grade, they had basketball leagues. I knew that I couldn't play basketball, but I wanted to do something, so I became the statistician. I think I was the most myself then because I was just me. I wasn't shy, I was really talkative, so people would gravitate to me. Elementary school was really positive. When I got to junior high and high school, that really started to change. "A," you've got puberty, which is never easy for anybody; and "B," my dad passed away really suddenly.

So we ended up moving around a little bit. I went to three different schools within a year when I was in the seventh grade. Having to go through that adjustment was really tough anyway, and I think around junior high, high school is when people start to, like, go off into groups and really find your identity, and I really didn't know what mine was. It stopped being cool to have a disability, and the older I got, the more I realized, "Okay, this is--it's gonna be work. It's not fun. I'm not going to get the positive attention that I got when I was younger, that's probably not going to happen."

So I went through a lot of adjustments and I didn't really deal with them too well. I withdrew a lot. I became much more shy; much more reticent to speak up. I basically kept to myself for years. When I was younger, I liked school, and I was good at it, and I also got a lot of attention for that, because I did well. In junior high and high school, school was something I survived. School was something I felt like everybody had to do, but I didn't really like it. Basically, I would go to school, do what I had to do, come home, and that was basically my life for junior high and high school.

I look back on it now, and there's a lot of things that I regret. I wish that I'd been more involved in putting myself out there more. I started getting glimpses into a reality--the fact that I was different from everybody else; from most everybody else for other people was going to be a problem. There was a lot of really ignorant and prejudicial stuff that happened. It wasn't even so much that it was blatant, it was just like it got to be so commonplace that I kind of got used to it. Things people would say out in public, or places that I couldn't go because it had stairs and I couldn't walk up them. There was just stuff like that. Having a disability, I started really resenting and by proxy, resenting myself, didn't have a great self image and it was a really rough period.

And when I was a senior, that's when I started seriously thinking about college and what I was going to do next, and... In school I was mainstreamed. I don't think they call it that anymore, but that's what they called it back in the day, so in school I was mainstreamed and I would go--my only interaction with special education services was I'd go there instead of study hall, and I would get, like, extra tutoring and stuff. One of the drawbacks for me of being in special education was there's a real focus--and I don't know if it's changed now. I have a feeling that it's still kind of stuck in the old--still kind of stuck in the '80's, but--although it's getting better. But

when I was in high school, there's a focus where you, when you're in special ed services, or getting whatever services of a year to year focus. And so I got used to that. I never thought past the next year. It didn't cross my mind, and so when I was a senior, and I realized, "Oh, I'm graduating," I was like, "Okay, what am I going to do?" As I said, I hated school at that point, I really--I didn't do horribly, I did okay. The things that I liked I did well in; the things that I didn't, I didn't do well. As a result, I graduated average, and I started thinking about--my mom hadn't gone to college and that's one thing she really pushed for the three of us, and I was the oldest, so I remember we would have really big arguments about how she wanted me to go to school, and I didn't. I didn't really know what I wanted to do, I just--I was basically lazy, well, "A," I was lazy, and really didn't want to put in the work, and, "B," I couldn't--when I was growing up, I didn't see people, I didn't see adults that looked like me that were in the community community, having jobs or whatever. I didn't see that, so I didn't--part of it was, I didn't see a future for myself, really. I don't think that I ever actually articulated that, but I think that's kind of how I felt.

So we would have these huge fights about going to college, and one day I sat down with a piece of paper, and I was like, "Okay, skills that I have right now." I wrote that down, "skills that I have right now." And I realized, well I can talk a lot. I can talk, I can carry on a conversation. I'm pretty good at people listening to me, talking to me and stuff. And I sat there, and I sat there, and I sat there. And I really couldn't think of a second thing, so I thought, "Okay, maybe she has a point."

So I went to school. I went to the University of Maine at Farmington. The main reason that I went there--don't get me wrong, it's a great school, I'm glad I went. Wouldn't trade it, but the main reason that I went was that my friends, my peers that were in college, that I knew; that's where they went, because it was the most accessible campus at the time. So there were schools and other programs that I wanted to do more, I went to Farmington because it was the most accessible at the time.

Going away to school is really, really scary because--and I had great teachers that I'm not faulting. I think because I had such low self esteem when I was in school, the fact that I had people pushing me and in my corner was really good. But one of the drawbacks for me also, being in the special education system is that I was surrounded by people who were very good at their jobs. They were so good, that if there were problems, half the time I didn't even know about it because they identified the problems and took care of it, so I never knew about. So I didn't have to deal with it.

But when you go away to school, it's kind of just you. As I mentioned earlier, I was not a social butterfly. From, like twelve to eighteen, I basically was a hermit. So I lived on campus, because I wanted to have the full experience. I thought it was really important for me to have that. Well, if you're going to live on campus, you've gotta learn how to talk to people and deal with the problems, and do it very quickly. I was always really friendly. I was never, like, standoffish, or rude, or anything. Well, everybody has their moments, but I mean in general, that wasn't me. But

I wouldn't say, "Boo!" to a ghost. So I had to learn really quickly how to put myself out there and interact with people and it was really tough and really scary and really hard. I tend to describe my college experience as--there's a line in *A Talk of Two Cities*, which, I'll be honest, I haven't read, but I think there's a line in the book that says, "It was the best of times, it was the worst of times..." I think it's from that book.

KJL It's the opening sentence of the book, yeah.

AO Okay, I picked that up somewhere. It was really true. I learned so much about myself, but it was also the most painful journey that I think I've ever done. But again, I wouldn't trade it. It's funny, I remember I talked earlier about needing to advocate for myself. And I went to college in September of 1990, so the Americans With Disabilities Act, if I'm not mistaken, had just been signed in July of that year, and was slated to go into effect two years after that, which I didn't know at the time, because I was nineteen, and I thought everything was instantaneous.

My first semester I had a class on one side of campus, and a class on the other side of campus; one right after the other. (inaudible) I had had up to that point until--from the time I was six until the time I was eighteen, all I'd had was manual wheelchairs. Actually, that's not true. My first wheelchair that I got in 1977--don't ask me why; I have no idea; it was through the military. It was an adult-sized wheelchair; an adult sized electric wheelchair. And I was six, so I swam in it. I remember it had a tendency to short out and go haywire and do really weird stuff, so I have memories of going along and it would short out and it would spin around in circles and stuff. I had the electrical chair for a short period, and then I got a manual wheelchair, which basically is a chair that you push--a non-motorized chair that you push.

When I was younger, up until, like, high school I had--they were really big and kind of clunky--I still swam in them (laughs), even though they were made for kids. They were so big and clunky and stuff. Then I got into high school, I started getting the more modern chairs, smaller, more lightweight, compact and stuff. So when I went away to college, I got an electrical chair. I got an electric wheelchair through the Shriner's Hospital. I got the electrical chair--say my first day of college was like, on a Wednesday. I got the electrical chair that Monday.

For those of you who don't know, learning how to use an electrical chair is kind of like learning how to drive a car. If you're learning how to drive a car, most people don't have their first lesson on a Monday, then have to functionally use it two days later, but I did (laughs). Because I didn't know what I was doing yet--honestly it took about a month for me to feel comfortable in it. Because I didn't know what I was doing yet, I went to the professor who taught the class I was going to. Class "A" was on one side of the campus, and then class "B" was on the other side of the campus. It was, like, a ten-minute break. And I knew that I wasn't going to do it in ten minutes. Like I said, it took about a month for me to get really comfortable, realize that I wasn't going to tip this thing over, or whatever.

So I went to the guy that ran class “B,” and I explained the situation, and I said, “Would it be possible to move the class closer to where class ‘A’ is, or some other alternate arrangement?” He was really resistant, to the point of kind of being rude about it. I was a rehabilitation services major (inaudible). And we were going to my advisor and explain the situation to her, and she went with me for a second meeting, we tried to work something out and it didn’t work out, so I just didn’t take that class. It was an introductory, freshman level class that I could just take next semester, so that’s what I decided to do. Because I basically thought this guy was a jerk and figured the less (inaudible), the better off for both of us. It’s funny, because when I tell that story to people, like, “You didn’t get what you want, so how is that a positive thing?” and don’t get me wrong, it sucked having somebody be that rude, when I thought that I was being reasonable. But at least I identified the problem; I tried to take care of it. Didn’t work the first time, I tried a second tack, that didn’t work, so I thought up a new plan. So at least, even though it didn’t work, I think that was the first time that I really took care of something on my own and actually kind of felt good about it.

KJL Now this was during the period--you were just starting college when the ADA was a bout to go into effect, is that right?

AO Well, it got signed into law by President Bush in July. I started in September, so two months later. I think most of the provisions of it, if I’m not mistaken, went into effect in 1992, so there was kind of a limbo period. I could be wrong. That was a really long-winded answer to your first question, but, yeah.

KJL That’s all right. So you were born with cerebral palsy?

AO I am, yeah. Do you want me to talk a little bit about what CP is?

KJL Sure, yeah,

AO Okay. Hopefully, there’s no medical scholar listening, because I’ll probably screw something up. Most people who get CP get it because sometime during the delivery process, something goes wrong and there’s oxygen deprivation. The majority of people get CP that way. Some people might have oxygen deprivation because they have an accident as they get older, and they might get CP from that. I know one person that that happened to. When he was like, three or four, he had oxygen deprivation because he fell in a pool and he’s getting CP, but most people, something happens during the delivery process, which basically is what happened to me.

For whatever reason, my mom went into labor at seven months. Her water broke one morning and they went to the hospital, and it was a really rough delivery and I had some oxygen deprivation. I got diagnosed when I was a year. I think there are three different kinds of CP. Don’t quote me. I had to learn it for a test one time in college, and I probably forgot the answer to that after I took the test. I believe there’s three different kinds, and depending on where you have the damage is the type of CP you’d have; how it’s going to manifest itself. I have spastic

cerebral palsy, which basically means I can have a lot of muscle spasms, and if I get really angry or upset or excited, or fill-in-the-blank, my body can go into contractions, and I have muscle spasms and stuff. Now, they're better as I'm older and I'm able to control them more, but it also affects me that I use a wheelchair for mobility. CP's a really interesting condition, because, like I said, there's a few different kinds, depending on where the damage is to your brain. I know people that have CP that it just looks like they just sprained their ankle. And I know people who have CP where their arms and their legs are severely affected, and they might not be able to speak. I know people that can walk, but they might have a speech impediment. It really runs the gamut. As far as disability, it's actually really--I find it kind of interesting, the different manifestations of it. It's not progressive. It does not get worse as you get older. Barring family genetics, and all that stuff, people with CP can live a normal life span. That's my CP 101 primer.

KJL So the second half of your college career, the ADA would have been in effect, is that right?

AO My assumption is my junior and senior year, they would have been in effect, that's right.

KJL Did you notice any difference?

AO Yeah. For me--I'm only going to speak for myself--I found Farmington physically a very easy campus to navigate. And it's a smaller campus, so that's a plus. I like smaller environments, anyway. I tend to thrive more in smaller environments. That's one of the reasons I'm very grateful that I went there, because I personally think I would have gotten lost in a bigger school. Because it was a smaller school, I found it pretty easy to navigate. When I went back for my junior year--this was the fall of '92--I believe this is when a lot of the provisions of the ADA started going into effect. The town decided to redo the sidewalks. The school and the town kind of run into each other, so I don't know if there's a school jurisdiction, or a town jurisdiction, but the sidewalks at school were being redone. And I was excited about it, because even though I thought it was a relatively easy campus to get around, you know, there can always be improvements, and you know, even now there's a tendency, especially in bad weather, for there to be holes in sidewalks and some of them don't tend to be plowed very well. So I'm just saying that in life in general now, that's still a problem.

So, as I said, I was excited. I thought, "Okay, this is great." But it became really clear to me really quickly that I don't believe they talked to anybody that actually had a disability--any kind of disability. I think they just went by a book, or something. I have no idea. Because I'm not quite exactly sure how to explain this. The angles of the sidewalks were so steep that I couldn't-- Oh, I take that back. They did the renovations to the sidewalks in the fall of 1993, so my senior year. My junior year was just like the other two. So the fall of my senior year, they (inaudible) The angles of the sidewalks were so steep, that while there were a lot places where I could go alone before, I couldn't go alone now, because if I had gone by myself, I would have tipped my chair over and hurt myself. I remember being really incredulous, like, whoever designed this, they absolutely didn't do their homework. They didn't get input from elderly people, from people

in chairs, from people who were blind, or whatever. It was obvious to me very, very quickly, like day one, after they finished, that they felt like if they went by certain (inaudible) that they'd be okay, and I actually want to see the book they used, because I've seen some of the ADA regulation stuff, and it wasn't that. It wasn't what I got, or it wasn't what we got. It wasn't just (inaudible).

KJL What about outside the campus?

AO Outside the campus was better. Actually, outside the campus was better than within the campus. I mean, was it perfect? No. If I went somewhere in town, I could go, and not worry about my chair tipping over. I remember feeling, like, really incredulous. But I also didn't know what to do. I didn't think that I had any options, because there was--I was, like, well, they just spent all this money to do this thing, and it's crappy, but I really honestly didn't know what to do. And so I just (inaudible) "It's a year; I'm graduating in a year, and so I can put up with this." If I knew then what I know now, you know, there are resources that I'd try to take advantage of, but I didn't know that stuff then.

KJL Why is that?

AO I think part of it is--I don't know if you know who Geri Jewell is. She has cerebral palsy. In the early '80's she was on *The Facts of Life*. She was the first person with a disability to be on--to be a series regular on national television, and she could walk. And I'm of that age where--that show was popular when I was younger, so I started to watch it. I saw an interview with her recently, because she wrote a book She wrote a fantastic book called. *I'm Walking As Straight As I Can.* " and I recommend it to anybody. It's a fantastic autobiography.

Because she wrote this book, I started looking up other stuff about her, and she did an interview where she said something that really clicked with me. She said that when you're born with a disability, especially in the era that we were, there's an unspoken assumption by society that you're a burden; that your existence is going to cause other people stress. The reason I bring that up is I think that's kind of what I--I didn't want to make any more waves than I had to. I did feel like I was a burden to myself, the people around me, my family. Even though my family was great, and is great. And I still struggle, although much less, now with, so forth, and who I am as a person and is who I am okay. I'm much better than I used to be.

When I look back on where I was and where I am now, I don't even recognize myself. I do feel like a different person. Part of it's being 20, 21, 22. At that age, nobody knows who they are, and I think if they say they do, they're being naive. But the fact that I was still trying to figure out who I was, plus all this stuff on top of it, I just wanted--I used to say that I used to try to blend into the woodwork, which is really hard to do if you're in a wheelchair. But I really did try. I wanted to be invisible; I didn't want attention brought to me, because I didn't want negative attention.

When I was a junior, there was a dance company where I went to college. I think they were called the UMF Dancers. It was a modern dance company. I always liked theatre and music and arts and that, and I had friends that were in the company, so I would go to all their performances and stuff like that, so the woman who ran the company--her name was Margaret Wescott, whose son actually is Seth Wescott, the Olympic gold medalist. Her name is Margaret Wescott, and she came up to me really early in the fall of my junior year, and she said, "I've seen you for two years; you go all the performances. You're obviously into it, so why don't you take my intro class--my Intro to Modern Dance class?" And I really thought she was insane, because I was used to a world where there were things that I could do and things that I couldn't do, and a lot of that was a lot of people telling me that I couldn't do stuff. And I believed it, because it was easier to believe it than to go against them and try, because, again, I didn't what to make waves. So I was used to a world where there were things that I could do and things that I couldn't do, so it totally threw me off my game when this woman asked me to take her dance class. That was something that never even entered my consciousness that, "Oh, that's something I could do."

So, again, I thought she was crazy. I'm sorry that's a bad word. I thought she was not of sound mind (laughs) and so I tried to avoid her. The truth is, Farmington is a very small campus, so you're going to run in to everybody, and if anybody knows Margaret Wescott, she is not one to be ignored, so every single time that I saw her, which was a lot, because, again, it's a small campus--she would ask me to take her class. So I finally agreed to it, around November, just so she would shut up and leave me alone.

And it was funny, once I got into the class--I'd had a friend in a wheelchair that took the class before I did, but I still, for whatever reason, I didn't feel like I could do it. I didn't feel like I would fit in well. I mean, I was nervous the first time in class. I was like, "Are people going to accept me? Are they going to think it's really weird?" Blah blah blah blah. And it was actually a really cool experience. So much so, that the next semester, which was the fall semester, my senior year, I took the class again. And then the spring semester I took two other classes from her. They weren't dance classes. One was like a phys ed for the elementary school class, and the other was a--It wasn't a dance class, but it was like a body works, Reiki kind of class.

So I took a bunch of other classes from her, and it was really, really neat, because that was the first time that I felt--I got used to thinking of myself as a thing. I didn't think of myself as a person. I got used to thinking of myself as an object. I had and I have a supportive family and I had and I have supportive people in my life, but the majority of feedback that I got from the general public was that my existence was a pain in the ass. I got used to thinking of myself--I started feeling like I wasn't a person, I started feeling like I was an object, and I was a thing, so she was the first person in all that time that made me feel like a person, and that was really cool. I remember telling her the whole, I-just-wanted-to-blend-in thing. I remember she looked at me and she said, "I don't think that's ever going to happen." At first I was really insulted, and it took me years to figure out that she was paying me a compliment. I don't know if she'll hear this, but... (inaudible) some of the performances. I was never in the company, because I couldn't fit it into my schedule, but I was still in a lot of the performances. I was in, like, three. I was part of

the company, but I was never actually in the company. When they had a reunion in 2005, I got (inaudible) for that. I got (inaudible) performances.

[Break]

KJL Let me get this out of your way.

AO I almost went to broadcasting school, actually. I was going to go to Orono to broadcasting school. I was going to go to Farmington and go into social work. I chose to go to Farmington, but, yeah, I almost went to broadcasting school.

KJL That's a good segue to another question. How, if at all, has the ADA changed opportunities for you?

AO That's a really interesting question to answer. I am very grateful that the ADA exists, and I'm grateful beyond words for the people that came before me that fought--and they really did fight for this. And I'm so grateful that they did. I'm so, so, grateful that they did that and I'm very appreciative that it exists. That being said, I think there's a misconception in the non-disabled community--and I'm being general (inaudible), and I'm not saying everybody--but I think there's a misconception in the non-disabled community that because the ADA exists for us, everything is great, and it's not. Even though there's laws on the books, that doesn't mean people follow them, which is obviously true because we have an exploding prison situation in the country, which I think has a lot more to do with race and class disparities, but that's another story for another time. There's still a lot of physical access issues. the employment rate for people with disabilities is, I think, four times lower than that of people without disabilities.

I think I said before that I really didn't like school, but when I got to college, I started realizing that knowledge is power, and power (inaudible) control, and I'm kind of a control freak, so I was happy. I have a master's degree. Now, granted, I have a master's degree in this economy, so there's that. I have a master's degree, but throughout my life, I've been unemployed or underemployed more often than I've been employed. And even when I've been employed, a lot of it's short term, and, you know, it's what I can get. So, you know, that's really tough. I and a lot of us, we have a lot of the same goals. We want to have a satisfying career, whether it be in the home or out of the home, and we want to have a thriving social life, with friends, you know, we want to have places to live that are our own, that we pay for.

And for a lot of us with disabilities, that--it's not that it's not happening, but it's happening a lot slower--it's happening slower than I would like, especially since it's been twenty five years since the passage. I don't know why it's like that, and I don't want to lay blame, because it's vast. There are a thousand reasons, I'm sure. Has it changed my life? Yes and no. Yes, in that there's an awareness that we exist; and there's an awareness that we count, or should count, and there's an awareness that we should matter. I think that's what passage of the ADA started for us. But there's a reason that I said, *should* count and *should* matter, because I think there's still a struggle

for a lot of us with disabilities to get the respect and recognition and dignity that we are here, and we do deserve the same opportunities. If you work really hard, and you're willing to try to achieve whatever goal, then we should be able to get it, or we should be able to at least have an opportunity to do that. And I think for a lot of us, we're still struggling, in general to be seen as people. I'm glad it exists, but I think there's still a lot we need to do. And I think that the people that drafted it would agree. I think that the people that were in this fight would agree with that. I think--I would hope that they would say that they were and they are proud of the work they did, and they were and they are proud of the changes that have been made. But to achieve true equality and true respect and true--really feel like a person, "I can just do what I want to do."

KJL So did you participate in some of the activities around the disability rights movement, even after the ADA?

AO Sure I did. I'm very active in disability rights. Well, I like to think (inaudible) I'm very involved in disability activism. I got to that point because there was a point in my--I'm 43, so--there was a point in my '30's somewhere; my early '30's or something, where I was really depressed, for a myriad of things; it wasn't just one thing. I was dealing with clinical depression, and it got to the point where, if I didn't start talking--didn't start opening my mouth and saying--If I didn't start to work for something that was better, I was going to die. I was at a point where I was really suicidal, and didn't want to--wasn't sure I wanted to live. So I basically started talking. I basically started speaking up because I didn't want to die. So I've been really active in disability activism on a personal and a professional level. It's funny because on one level I love it, and one level I really--I can't say I hate it, because I don't hate it.

KJL The activism?

AO Yeah. Hating it isn't the right word. On one level I love it, and on one level, I'm really frustrated by it. The level that I love it is I love, like, connecting people when...I found myself the last few years speaking to a lot of college and graduate school local classes on disability issues--which some of them, I really love to do, and if anybody out there is listening, I would really love to do it again. Call me. Get in touch with Keith. So on one level I love it, because I love--this isn't easy for me to do this, but I actually really like doing it. I love it when I tell my story and know that I'm heard; I know that people hear me. I'm not saying they have to agree, but they understand where I'm coming from. And that's really powerful for me. What frustrates me about it is that sometimes I feel like as a movement, as a people, we're still talking about the same things that we were talking about 25 years ago, in terms of respect, and access and equality and personhood. Personhood's not the right term, but respect and access and equality and dignity. It seems like we're still talking about the same things. Even the people I think should know better. God know I'm not perfect, we all have our faults, but that's frustrating to me. That's hard. And sometimes I do get kind of burned out and, I'm like, I don't know if I can continue doing this activism, but I feel like I have to, because I feel like I'd rather do something than do nothing. (inaudible)

KJL I noticed the plaque on the wall, there. Tell me about that.

AO The Center for Community Inclusion and Disability Studies is an organization at the University of Maine. They are one of a group of centers call the UCEDD's, which is University Center for Excellence in Developmental Disabilities. They're research and dissemination organizations. They're usually on college campuses, and they're in every state. There's at least one in every state, and ours is the Center for Community Inclusion and Disability Studies on the Orono campus. And they had their twentieth anniversary celebration in the fall of 2012, and I got nominated for the--I don't know if it was social activism or (inaudible) change award, or something. I got nominated for that. I remember I gave a speech, where I said

[Break]

I have a YouTube video of the speech I gave, if I could e-mail to you, it'd be cool.

KJL Sure. I went off and left my cards, bit I'll write down my e-mail.

AO (Inaudible) I'll e-mail you, then. I'll e-mail you the speech.

KJL Okay. What do you remember as the biggest victory in disability rights that you can remember?

AO Well, I think the fact that we got the ADA passed was pretty incredible. And I'll be honest, I look back on it now, and I wish that I'd been a part of that movement more, because I've seen a lot of things, and read a lot of things that just--the fact that there were, like, thousands of people in wheelchairs, crawling up the steps to the capitol is incredible. Would I have wanted to do that? No, because I probably would have broken something (laughs). But the fact that they did that, it blows me away. I think the fact that we got the ADA passed is amazing and incredible; and as I said before, I think the ADA is great, but I think there's a lot more that we can do to build on that. I think the ADA is a great foundation. But you can't just leave something as a foundation, you've got to build on top of that. And I think that's what we as a movement need to do, build more.

KJL Were there any moments at the state or regional level that made you say, "Wow!"

AO If I think of something later, could I--because I'm blanking on it.

KJL Okay, that's fine. I didn't mean to put you on the spot.

AO That's fine, I'm just blanking on it.

KJL So you were active at the state level as well.

AO I am, yeah.

KJL And still are.

AO Yeah.

KJL Okay. What do you think is the biggest priority?

AO I'm not sure I understand the question.

KJL At the state level, in your work at the state level, what is it that you would most like to see happen?

AO A couple things. I would love to see people be able to get the services they need to live and to thrive, and not have to decide between that and a job, because I think the two--for a lot of people, still, with disabilities, the two are mutually exclusive. You can either work and make a living, or you can get services and benefits that you need to thrive. It is changing, I know there are people that I like and respect a lot that are going to hear this and disagree with this, but in my opinion for a lot of people--it is changing for the good, but for a lot of people it's still--it's either one or the other, and it shouldn't be. I think you should be able to get the services that you need to live, and be able to work, and be a full participant in society. That's a big one. That's something that I've struggled with throughout my life, because, like I said, I've been unemployed or underemployed most of my life.

KJL You have an M.A in what field?

AO I don't have an M.A. I have a bachelor's degree in rehab services. I have a graduate certificate in psycho-social rehab, and I have a master's in library and information science.

KJL And you work at the library on the Orono campus?

AO I don't. Basically, what I do; what I've done for the last couple of years is I've worked on a grant with the Department of Disability and Human Development at the University of Illinois-Chicago on a grant that's basically researching what research is out there on the ADA; what areas are covered well, what areas are not, what needs more focus, stuff like that. I'm what they call an independent librarian for consulting, which is a very fancy word for I spend my work day--which I really like (laughs)--I spend my work day looking for obscure articles in databases and seeing if they fit our project. But I love it. I love it. It's on a grant, so the grant is actually--my portion of the grant is ending September 30th. So I'm back in the job market after September 30th, so...anybody out there? And I'm on radio, so this is being taped So, yeah, this is what I do now. When I first got out of library school, I did work at the Center For Community Inclusion for about a year. I worked on a grant there.

Like I said, I've struggled throughout my life, my professional life, wanting to work, but also needing services and stuff to survive. A lot of my life, those two haven't really gelled well, so I had to make a lot of sacrifices in terms of--I took jobs for a lot less money because I needed the health insurance, whereas, I think if I was an average Joe Schmo, off the street, with the qualifications that I have, I could have made a lot more money and...anyway. Does that make sense?

KJL Yeah, yeah it does. One thing I want to go back to, you said fairly early on--this was kind of interesting--you talked about your experience as a poster child. It seems like you had kind of a love/hate relationship with that.

AO Well, I was nine, and I like attention, and I did like the attention. It's funny, though, when I look back on it and I read some of the flyers and stuff. One of the flyers was, "With your help, Avery will walk some day," and similar stuff in that vein. And this is going to sound really weird. I think for the average person this might sound kind of strange, but when I was younger, I knew that I couldn't walk, and it bothered me, but I wasn't focused on walking, because I knew that I couldn't. And I knew that this was my body. So I wasn't focused on walking, and I wasn't--I mean I was focused on getting good grades, I was focused on getting people--I was focused on hanging out with my friends, I was focused on getting a toy that I wanted, or something. I wasn't focused on walking and the focus on these campaigns was basically, look, these kids are broken--they didn't come right out and say this, but they're like, "These kids are broken, with your help they'll be fixed."

That bothers me, because as an adult, I tend to subscribe to the social model of disability, as opposed to the medical model, which--the social model of disability is, look some people are born with disability is like some people are born female, or with blond hair, or with blue eyes. It isn't a negative. It just is what it is, and so how do we make it so that all people can play; whatever ability or disability they have. I tend to subscribe to that model of disability as opposed to the medical model, which says that we're broken and we need to be fixed.

Now, don't get me wrong. I'm not opposed to the idea of cure for some disabilities and conditions where that's possible. I'm not opposed to that at all. I think if there is a cure for things, and people don't have to be born with a disability, rock on! That's awesome. Because it is tough. I'm not going to sit here and say that it's easy. It's not. Sometimes it's really frustrating and I get depressed and I cry. For me, like most of the time, I'm just me. I have my life; I have my friends; I have my job. I have relationships. I have a life. For me, having a disability is part of my life, it's not all that I am. It's not my whole identity. It's a part of who I am. It's a very important part of who I am. It's a very important part--It's been a very important part of my growth experience, and it'll continue to be. But it's not all that I am.

And so, I'm not opposed to the idea of cure. But I think that, "Look, we're here; we exist. We deserve dignity, respect, and opportunities and choices as we are." If scientists want to work on a

cure, that's awesome. But in the meantime, let's work on physical access. Let's work on attitudinal access. Let's work on employment access. Let's work on fill-in-the-blank. And I think in the medical model, that gets overlooked. I don't see myself as broken. This is my body, for what it is. I don't think it's broken. Is it atypical? Sure. But I don't think that I'm broken.

KJL Okay. You've been very generous with your time. Is there anything you want to point out to me that I'm overlooking?

AO I'm kind of numb, sometimes. (laughs)

KJL I hope I haven't worn you out.

AO No, this actually helped. I haven't been in a really good space (inaudible), so it actually helped me out. I do want to e-mail you that speech, because I do think that's important. There is one thing that I did want to bring up, can we...

[Break]

It's funny when I graduated from college, I wanted to--as I said before, I had a lot of the same ambitions and goals as my peers, and one of those was to earn a degree and get a job. It was funny, because when I started going on interviews, some people were really nice. Some people were really progressive and cool. And some people, like, I would go into the interview, and it was pretty clear to me that I don't think they'd had a lot of experience with people with disabilities, because they would get a look on their face that I in my nicer moments would call the "Oh crap what do I do now?" look. Like I said, some people were really cool when I went into interviews and, like, saw me and they might have had questions like how would I accomplish certain things. The fact that I had a disability was secondary to my personality and my qualifications. I could tell people that were really comfortable and people that weren't pretty quickly, like the first two minutes. And it was funny, because I started getting the "Oh, crap what do I do now?" look more and more. This was like, before I opened my mouth. This was, like, going in to the interview it was like a deer-in-the-headlights look. It would be like, "Oh, God!"

And I think that's part of the problem with (inaudible). I think we need to see more people with disabilities in life, just being themselves. I mean, we are more visible than we used to be, obviously, but it's funny how--to be visible and to be heard; that's still a struggle. So, yeah, that's all I'm going to say.

KJL When you say you got the "Oh, crap, what do I do now?" look more and more, were you saying it was because of the ADA?

AO No, it didn't have to do with the ADA specifically, but I thought--naively, I thought--remember I had just graduated from high school when the ADA [was passed]. So being nineteen, I automatically thought, "Oh, the ADA's here, now everything's going to be great," right? This is

1994. I'm going on interviews, and before I even open my mouth, people are looking at me with fear. I can tell in their eyes they're afraid. Because they don't know what to say. I think people are afraid of saying the wrong thing. I think they think that we're going to sue them, which, I'm not going to, so I'd rather people ask--quote, unquote--an ignorant question and be able to talk about it than be afraid to and carry that fear, or that shame, or that whatever. I think it's still a struggle to be seen as full people. And I'm not even just saying work, I mean socially (inaudible). There are social events that I haven't been able to go to because I physically can't get in there. I accept that as a part of life, but I shouldn't have to. and it does hurt, because--I'm paraphrasing something that a friend said recently, but If I have something that I want to go to that I can't, because I can't get into it, or if there's a job interview that I can't go to because there's stairs and all there, I know it's not meant to be personal, but it does feel that way. I can't help but feel that way a lot. In a way you're rejecting me. You're rejecting my participation. You're rejecting my ability to break bread with you and be able to communicate and get to know each other. It's stuff like that.

[End of interview.]