

CLAWS AND WINGS:

AN ORAL HISTORY EXPLORATION OF DISABILITY IN DELAWARE 1917-2017

Transcription of video recorded July 28, 2017

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

Interviewee: Tim Brooks (Referred to hereafter as TB), Parent and Advocate for Persons with Disabilities

Topics included: University of Delaware, Delaware Transition Project, Respite Care

Run time: 27:02

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TB: Name is Tim Brooks. My jobs were all in higher education. I have a doctorate in higher ed administration from Oregon State. I ended up in Delaware. I came here from a position at the University of Maine and started here in '79. Was the Associate Dean of Students at the University, then the Dean of Students for many years. I retired from that around 2002. And... 'Cause I frankly got a little burned out of dealing with student problems day and night. And, but then the University of Delaware has a great Center for Disabilities Studies. And I had been on one of their committees for a number of years as Dean of Students. They were looking for somebody to work about 20, 25 hours a week on a variety of projects because they get so many grants, both state and federal. And I applied for that position and got it.

That was a great eight years that I worked with them. Meanwhile, I also taught. I had kept my faculty appointment so I was teaching in higher ed administration but then I got to teach the Capstone course in the disability minor, which was also terrific.

So I look back on my time at the University of Delaware as really two different eras. Really loved being a Dean of Students but it was a very, very difficult job. It was 24-7, 7 days a week, for many years. The other job gave me a totally different look at the University. There weren't a lot of the political pressures that I'd had before and I could really zero in on disability issues. And I'd been a volunteer in the disability world for almost 40 years by that time. So it all seemed to mesh together and it was, for me, a great experience at the University, a total of 31 years.

KB: And where did you grow up?

TB: I grew up just outside of Boston in Milton, Massachusetts.

KB: And how did you get interested in this kind of a field?

TB: I, I wasn't. We, I have one cousin who's a person with a pretty severe intellectual disability. That was my only involvement with disability, was her. So it was never a focus. It became a focus when we adopted Ross. Well, really, when we got him as a foster child and then adopted him later. And, and it served, as Martha said in her interview, he's always kept us grounded. Well, he did even more than that for me. He made me an advocate for people with disabilities. And I really tried to do a great deal of advocacy when we got to Delaware. I had a very supportive boss at the University of Delaware and he would allow me time off to literally come to Dover and serve on the Governor's Advisory Council on Developmental Disabilities and other things, he was

great. So that's how I got into the volunteering thing in Delaware. And I, I am kinda proud of my service in that way.

KB: Was it under President Trabant?

TB: I started under President Trabant. He was terrific. He was a gentleman with a tremendous amount of empathy. He wasn't my direct boss, there was a person in between, but they were both great so, yeah, he was wonderful.

KB: That's almost the same time that there was turmoil in the race relations as well, right?

TB: A lot of turmoil in race and some turmoil in the disability world. I have told this story before, I'll leave names out, but when I got there it was clear I was gonna be an advocate as the Associate Dean. I had Disability Services underneath me and I made that very clear in my first few months and a few of the higher-up administrators made it very clear to me that they could care less about disability and didn't want to have to deal with it. However, they did eventually put me on a Section 504 committee. From the 1973 Rehabilitation Act was one that, that essentially said public entities had to be accessible. And when I got to the University I could find one building out of 300+ that was accessible. So I got on that committee and I think that kinda started the ball rolling for me.

KB: So when did you meet Jamie Wolfe?

TB: Jamie came, I'm chuckling because I've just been emailing back and forth with Jamie. I met Jamie when she first came to the University, which mid-80s somewhere. And she was terrific because, this was before ADA, which was 1990 so we had 504 which we used, but Jamie presented the University of Delaware some really dramatic accessibility issues and she wanted to live on campus which made it even more dramatic. So, between the two of us, I think we were able to move UD much quicker than I ever thought would happen in, in the movement towards full accessibility. Frankly we're still not there. I mean we're still making the move but we're so much better off today. And I look at Jamie as really the pioneer who, who did that for the University of Delaware. And she also worked in my office, she was a very public figure while she was on campus, and that really helped the movement. We had a student organization which also supported disability issues. So she was terrific.

KB: So tell me about the Center for Disability Studies.

TB: I only saw the Center from my position, so it'd be much better to have one of the directors of the Center come and talk about it. But for me, looking at it, it had some dramatic pluses and some minuses that... I'll start with a minus that I saw that bothered me.

Everything's grant funded and as I said before some of the grants are state, in fact Martha, my wife, granted money through her office to the Center. And a lot of the grants were federal. And the first one I became involved in was an amazing learning experience for me. It was, and I worked on it for three years, it was a family support federal grant. Perfect for me. Because of our family situation, I was able to relate to any other family that's dealing with a person with a disability, at least to some extent. It was based on the

East side of Wilmington, a predominately African-American area. Also, you know, here I am: middle aged white guy and I'm in that area. That was a good learning experience for me. And I got to meet with a lot of families, explain to them what the services were that were available in the state at the time we were doing this.

Well, that was the plus. The minus was, and one of the family members said it to me, said, "Tim, you understand you're on a grant, you're gonna be gone in a couple years. We're still gonna be here. What kinda support are we gonna have then?" I had not worked with grant funding before, so that comment was a terrific eye opener for me and that's the downside of grant funding. That person was exactly right. When the three years were up, my work wasn't done. I knew a lot of families that still needed help. We needed to get a lot more information about, out about DDDS, the state's office that deals with developmental disability. We were nowhere near really informing people on the East side of Wilmington as to what their services are in the state. So, that's the downside.

The upside, in general, is that they do a lot of terrific work at that Center. And it goes all the way from dealing with issues of autism to developing a higher education program for people who have intellectual disabilities who wouldn't normally get to go into a college or university environment, did a great job on that, to supporting a minor. The minor in disabilities at Delaware is the biggest minor, there are about 500 students in it at any given time. So the Center does a lot of terrific stuff. It's, I just wish they had a more permanent funding mechanism that would make life simpler for them and that they could dedicate more time to some of these areas that really deserve it.

KB: Did you have anything to do with ADA and IDEA?

TB: At the beginning?

KB: Yeah.

TB: No, not at all. As far as implementation of ADA, I got very involved at that, in that issue at the University of Delaware. Because in 1990 when that passed, UD was still way behind on both basic, physical accessibility and what the law called program accessibility. And, so, at that time my office was controlling services for students with disabilities. So I was constantly trying to educate faculty members on what ADA meant and, and educate staff as well. We had to do things like move 400 people from one classroom to another because the first classroom wasn't accessible. And you've got a couple students in that 400 group who needed the accessibility. Well, it, it was kind of interesting as we went through that transitional period, probably from 1990 to 1995. That, there was some pushback from faculty and staff on the whole issue. You know, "Why should I have to move 396 people just for 4 people who might have disabilities?" Well yes, you have to because we have to have program accessibility to meet the guidelines of the law. So that's the part I played in ADA, nothing in its development at all.

KB: So how has it changed the lives of those kids do you think?

TB: Of the people I dealt with at the University?

KB: Or of the students.

TB: I think everyone's attitude towards disability has changed to some extent since the ADA was passed. We recently had the 25-year anniversary, two years ago. The

knowledge that people have today about disability and differences in disability is so much greater than what we saw before 1990. I mean, every bus you see is accessible now, you know. That wasn't true. Every time you see a curb cut it reminds you of why you've got that curb cut. It's so that somebody with an ambulatory disability's gonna be able to get up there, if they're using a wheelchair or whatever. Every time you open a door and its pull is more than 8 pounds that's a violation of the ADA. That's one I see all the time still. But I think it was a clarion call for all Americans to understand the whole arena of disability.

For a place like the University of Delaware, who, quite frankly, had ignored the issue for a long, long time, it was a wakeup call and it was terrific. If you walk around the campus today, it's very accessible. Rarely do we have to do what, what I mentioned before about program accessibility. Don't have to worry about that, the buildings are accessible. We've made some mistakes along the line and Jamie Wolfe will tell you about one of them. We built these outside elevators because some of our older buildings have all these steps. And I remember the one at Mitchell Hall. One of the problems was they rusted. So Jamie would maneuver her wheelchair into one of these things and it wouldn't move, it'd break down all the time. And, so that was a good lesson we learned. We didn't build any more. And she taught us that lesson.

So it's always a learning process when you're trying to create full accessibility. And we're probably never actually ever gonna be there but, certainly, places like the University of Delaware have done a great job. So I, I am proud of this country. That was a bi-partisan bill that passed in, in 1990 and I think today there are many, many people who are much better off because of that law. As a parent, it's terrific, because we see how that law supports our son. So, yeah, a real game changer. When I look back over my life there are few laws that I think have had an incredible impact. Some of them came out of 1964, Civil Rights Act, Title VII, Title IX in 1972, for women. Fantastic law. People tend to focus on athletes but that law covers everything in higher education. And ADA, which I think is a fantastic law. When I look back those are the ones that grab me and say to me that this country is very, very different today because of those laws, and much better.

KB: What do you think about mainstreaming?

TB: Mainstreaming?

KB: Of kids.

TB: That's an interesting one, because when we first got our son that was not a term, I think, we heard much at all, if ever. I am a believer in mainstreaming as much as possible. I think we learned from segregation that separation is never equal and that's the problem we have, you know. We still have institutions in this country that separate people with disabilities and put them in place X that doesn't mix with other individuals. I think that's unfortunate. I know from talking to, and again, I've never been a teacher at that level. I know from talking to some teachers that mainstreaming can be very difficult, especially if you've got children with behavioral issues. And our son has pretty severe behavioral issues, so we know how that goes. But the bottom line is, with the right supports, the right services, anyone can be mainstreamed.

And I think we, Martha and I have had this discussion many times, I think it's also true of supported employment. Now our son came along after, well, before supported employment became a major issue in the disability world. Because of that he's always been in a sheltered workshop. If he were coming along today, instead of being 52 years old, if he was 10 years old, we believe that with the right supports he could have gotten into a situation which would have allowed him to work in the community. Frankly, I think it's too late now, but that's the same thing as mainstreaming in my mind. Giving the person the right supports and getting them out there and putting them with everybody else.

There's a movement, I'm getting a little bit off your question here, but there's a movement right now to reestablish institutional-type environments. I'm disgusted by that movement. Because we grew up in the era of institutions we know it was like. I was on the committee that reduced the population in Stockley here, our institution, by 95% over a number of years. That was a great thing for the State of Delaware to do. Reinstitutionalization would be terrible. It would lead to exactly the reverse of mainstreaming. It, it would be putting people away.

I think one of the great things about ADA is that opened the world of able-bodied people, whatever you want to call 'em to seeing people with disabilities. I think that's incredibly important. If you see a person, if you get to know a person with a disability, you can get to understand the issues much better. So this new movement of reinstitutionalizing and villages. And these villages are supposed to have their own residences and their own stores and all that kind of stuff. I think that's exactly the wrong way to go. We need to keep the American people educated on disability issues. Sorry for the harangue, but it's one of my favorite topics.

KB: We should make you talk more. What's the Transition Project in 1994?

TB: That's Martha's and I, I don't even want to attempt that because she's watching me right now [KB: We'll bring her back up in a minute.] and I'll botch that one completely.

KB: So, what do you think about waiting lists?

TB: Well, you're asking about waiting lists and that is a state-by-state issue. A lot of it is based on finances. A lot of it's based on Medicaid. And I think waiting lists are horrible but most states have 'em. Delaware has been very lucky to avoid major waiting list issues. We still have had some issues, but in my involvement with the Governor's Council for Developmental Disabilities it's pretty clear that we can handle, without waiting lists, people who need residential and people who are exiting the public school system and need a day program or day service of some sort. We've been pretty good at filling those needs without developing a waiting list at any point.

There are waiting lists in other areas and they're always problematic. Because what is a person gonna do if they, if they can't get, through the State, someone to help them get up in the morning, go to bed at night, get dressed, whatever it might be? If they can't get that kind of assistance, what's gonna happen? They're gonna end up sitting at home doing nothing. And there have been waiting lists for those kind of personal-assistant situations. That's unfortunate because it's deleterious to that individual, no question about it.

When I look at other states, right around us, we're very much better off than Maryland, Pennsylvania, and New Jersey, because they have waiting lists in virtually every category for people with disabilities. Now, they're a lot bigger than we are and they're facing more difficult issues perhaps. But, one of the reasons I'm very worried about the current debate over healthcare is that within some of the plans that have been ushered forward there is an enormous cut on Medicaid. And Medicaid is the insurance program that supports people with disabilities. So it would be incredibly bad to have those cuts and, to your waiting list question, it would add enormous numbers to the waiting lists across the country. So it would be a terrible way to go in my judgment.

KB: So if you had a magic wand what would you do?

TB: If I had a magic wand, and my wife and I talk about this kind of thing all the time, I would change our healthcare system. I would join with those people who believe a single-payer system is the way to go. We're lucky, we're retired, we travel a lot, we travel abroad a lot. In the last two years we've traveled to Iceland, to Norway, to Sweden, and to Denmark. All four of those countries have single-payer systems. All four of those countries have much better healthcare for half the cost than we do.

I get very angry when I look at this country, and we saw it very recently in the *New York Times*. They ran an article, I should remember the author, maybe Kristof. But it was on a health fair in southwestern Virginia that just occurred a few days ago. And the author of the article went to the health fair, met with the Governor, Terry McAuliffe of Virginia, and they toured together this fair. Well this fair had thousands of people show up for basic healthcare because they don't have any. And the lead paragraph in the article was about a gentleman who had to have 18 teeth pulled – because they also provide dental care in these things – 18 teeth pulled, because for 20 years he hasn't had healthcare and he hasn't been able to pay for a dentist. He's a construction worker.

You know, in this day and age, in the richest country in the world, in the most developed country in the world, we have a backward healthcare system. So if I could change anything with a wand it would be that. Because that would impact not only people with disabilities but it would impact every citizen in the country.

KB: So if somebody was going to write your biography, or your epitaph I should say, what would you want it to say about you?

TB: Oh, brother. That is a very hard one. When I look back on my life, as, as Martha said in her interview, you always zero in on family and, and that's absolutely the first thing I would zero in on. I think adopting Ross was, without question, one of the best things we did as a couple. Having two of our own children after that, fantastic. I don't know many families, in fact I know of none, who've adopted a person with a disability first and then had their own children, if you will, after that. So I would look back on that and say that certainly was super.

Now, we're very lucky to have four grandchildren and, because of Ross, our sons, their wives, and our grandchildren, know probably more about disability than any average family around. I think that's terrific. There are other things I've done in my life that I think would be worth mentioning in, in a biography. I am a Vietnam veteran. That was a very difficult situation, my wife helped me recover from that. In fact, Ross was a part of

that recovery. And I also think my career went pretty darn well. Not quite as well as I would have hoped, but I loved what I did, I liked the University of Delaware. And so there are those components. So, and now that we're retired, except for my foot injury that I'm currently nursing, our travels have been fantastic. We have the same travel interests and we've been going around the globe and going to every state in the country and most of Canada. Life's been very good, can't complain.