

CLAWS AND WINGS:

AN ORAL HISTORY EXPLORATION OF DISABILITY IN DELAWARE 1917-2017

Transcription of video recorded May 11, 2017

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

Interviewee: Jamie Wolfe (Referred to hereafter as JW), Advocate

Topics included: Transportation, IDEA, Arthrogryposis

Run time: 48:28

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KB: Our next speaker is, is Jamie Wolfe, and, Jamie, tell us about what position you hold at the current time.

JW: Right now I have my own consulting firm called Wolfe Consulting and I do disability training, research, and evaluation.

KB: And tell me a bit more what you do with the kids. I saw your brochure online, I think.

JW: I have a contract right now with the Developmental Disability Council to run Junior Partners in Policymaking, which is a week-long course for people 15 to 22 that have disabilities and that are from Delaware. And what we do is, we teach, I see it as two different but equally important pieces. The first piece is self-determination, having them decide what do they want out of life? Where do they want to live? Or are they living now in a place they like? Do they want to move out? Do they want to stay? Do, do they have a social network? Have they chosen their social network? A lot of times parents do it. Are there any things that they want to change in terms of what their parents have chosen for them? What type of job do they want? Do they want to go on to further education? And anything that, you know, helps them to decide how they see their future, not their parents, not the family, not the caseworkers, but how the, how the person him or herself wants their future.

And also the second part of that, which self-determination leads into, is self-advocacy. If there is an issue personally or with an agency that they're dealing with or in the school or with their parents or with friends, how do we, how do you advocate for yourself? How do you do that, how do you negotiate? How do you get, how do you get the things you need in order to, you know, to make yourself where, to get yourself where you are? And we also do exercises in advocacy for legislators. The last day, we go to Legislative Hall and we have, it's kind of like, I think the TV show that's called "The Voice"? Where the people sing and the performers give feedback? Well, we have usually two legislators, or a legislative aide and a legislator, listen to their testimony and each person does give testimony on whatever they want. And then the two legislators or aides or both, they give feedback and say, "This was really good in points A, B, and C. You might have helped if you said this in point D."

KB: Oh, that's good. So you're getting it from the policy makers' perspective [JW: Right.] which strengthens your work. [JW: Right.] That's cool. That's great.

JW: And sometimes the director of the Developmental Disability jumps in, and so do I sometimes.

KB: And how many years have you been doing this?

JW: This is my second year. Junior, Junior Partners in Policymaking runs every other year, runs the odd years. And they have an Adult Partners that runs the even years.

KB: And you just do the Junior?

JW: For now, yes.

KB: 'Cause you are the senior? [Laughs] It's such a great thing that you do. So what was your defining moment in the history of the field, but also in terms of working with these young people?

JW: Well, well in terms of the young people, I think the first class I did we, we got it at the very last minute, and we turned it, we turned it out to be very good. It turned out to be excellent. It was a little...Every year it gets a little hairy 'cause you get down to the wire and you're like, "Oh my god, did we do everything?" But apparently I guess we did everything right the first time, so hopefully we'll do it this time like that.

KB: And what else does Wolfe Consulting do?

JW: We would do training on disability sensitivity, training on the different policies and laws. We also do evaluations for [unclear] program, that they want an outsider to look at to see if it's effective. We can do that. And also, research. If someone wanted to do a grant on Medicaid or wants to do something about looking at transportation issues. These are just examples. But I can do that type of research to lead them in whatever way they feel they need to be led to.

KB: Especially transportation. They need you! [JW: Yes. Yes.] Yes. So what have you done that you think has the most impact?

JW: I think, a) just being out in the community and being successful. I'll put that in quotes, "successful," [KB: You are. You are.] by being able to utilize the, the programs that Delaware offers, such as the Attendants Service program, such as DART, such as Medicaid and Vocational Rehab. I was able to use those programs, and I still use, most of them, so I can live the way I choose. I think specifically some of the things I've done... We have, in Delaware, there's a... It's Medicaid buy-in program, it's called Medicaid for Workers with Disabilities. 'Cause under Medicaid, there's an income/resource limit. With Medicaid for Workers with Disabilities, MWD, people can work, make a little bit over that income limit, and depending how much you make, you can actually pay like a sliding scale, almost like you pay an insurance premium, but it's according to your income.

KB: There's one fellow that we interviewed who works for DNREC. He had to move back home with his parents 'cause he makes too much. [JW: Right.] So, he could use you.

JW: The state doesn't tell a lot of people that.

KB: No. So, this question is: how do you define an institution and did you ever live or work in an institution?

JW: Never lived and I never worked, purposely. An institution is a place where you go where you think you're getting good services but they... An institution is a congregate,

it's big setting. And, you have no privacy. You have no choice. You... When they say it's time to eat breakfast, you go eat breakfast. When it's time to get up and get dressed, you get up and get dressed when they tell you to. You're giving away a lot of your own privileges. That I like, I would have in my own apartment. And, a lot of times, you wouldn't be doing anything during a day. You just kind of hang out and sit there, from what I've seen. And one thing you, one real, basic thing people (don't) understand, you have to sign in and out. So if you want to go to the mall, a), you have to get permission, b), you have to sign in or sign out, say how you're getting there, who you're going with. And when you come back, you have to sign back in saying that, "I'm here."

KB: It's like when I was in college 50 years ago, right? [Laughs]

JW: At least college you had a choice. [KB: Sort of.] Yeah. Well, I mean, at least you could choose what you wanted to eat, when you wanted to go to bed, what you wanted to do that night. And in institutions, you don't get that.

KB: So limited choice is probably the hardest thing, huh? It would be for you and me. [Laughs]

JW: Right. People go to institutions they think for services. They're not going there for the bricks or mortar. Maybe you don't like where you live, you can move to a different house. Same thing with me. If I don't like where I live, I would move somewhere but make sure I had the same support in my other place, wherever that would be.

KB: So, were you involved in the passing of ADA or IDEA and, if so, how?

JW: Well, not really either, because when the... When IDEA was passed, I was 10 years old. But, I was the first student in the segregated school to go into a regular school system once it passed. [KB: Which was good.] Yeah. And the ADA, I helped a little bit with letters, but I was in college, so I was busy with, you know, college stuff.

KB: What did you major in?

JW: I, I, here at the University (of Delaware), I majored in sociology. I went to Del State and got my Master's in social work.

KB: Oh, that's cool. So, how have you seen, or how do you feel people's lives have changed since before and after ADA?

JW: Well, people have a lot more choices now, especially in terms of living where they want to live because the state can't say, because it's cheaper, quote/unquote, which it really isn't, but, the state can't say, "Because it's cheaper, we're gonna put you in an institution." That's going... That's violating that person's rights under the *Olmstead* decision.

So, they have a lot more choices in living. They have equal access to public facilities, like, you know, they can go anywhere they want to go. Where you would go, I could go. And there are some restrictions in some places, but very few.

KB: And, one thing, what was his name? Dick [Editor: Correction – "Tim"] Brooks, is that his name? At the University? [JW: Yeah.] He said, he said it's because of you that the University changed all their approach to handicap. Was, Trabant was president when

you were in school? [JW: Mmm. I think so, yes.] Tell me, tell me why Tim would say such a thing as that, 'cause that's pretty important and he was really impressed.

JW: I thought it was important because students couldn't... Students, particularly with physical disabilities, couldn't get around campus easily. A lot... In Memorial Hall. Now that's where the College of Arts and Sciences is. That's where my college was. I couldn't get into that building. I'd have somebody meet me in another, in another office. Because they had this elevator. And I couldn't length-wise, 'cause the way my wheelchair was, I couldn't fit into the elevator. And there was always an argument, because, "Oh, we have an elevator." We had to show someone above Tim's rank how hard it was for me to use that elevator. And they finally built a ramp. A lot of the doors didn't have door openers. So, like today, if there's no door opener I'd be sitting out in the rain waiting for somebody to open the door for me.

And I just think it gave him a sense of what it's like for a student with a disability to actually go to college. I don't think they ever had students with my level of need on campus.

KB: And your level of brain. Combination was irresistible.

JW: Well, I think need was a big part of it!

KB: But, the fact that you can advocate and explain what you need, that makes all the difference for everybody. When did you graduate? [JW: '91.] '91. I was trying to think when I was at Urban Affairs, '91. [JW: Okay!] So we probably must have passed and didn't know it. [JW: Right.] And what, what more do you think, in terms of all of these things, at UD and elsewhere, what other things need to change to physically make better, more accessible places around?

JW: Well in terms of buildings and everything? I think there should be some type of door opening mechanism on all doors. All classrooms should have the same, an ADA-doorway that a chair like mine can get through. I went at Todd. I worked in the Center, actually, for, like, a little after, almost, you know, it was a little bit more than 10 years. And we, I taught a class. And one of the classrooms we had one semester, the doors were beautifully wide, but you opened it, and there was a bar down the middle. [KB: Oh, for heaven's sake!] So I could get everything but this side, the left side, in the building – in the classroom.

So, and, I think that the ramp should be where everybody else goes into a building. A lot of buildings here [Editor: at UD] and a lot of different public places have the ramps around the back, where, you know, I should be able to go in the same door that everybody else goes in. And, one last thing, I think universities and colleges, especially universities like the University of Delaware, of this size, should have some type of attendant program or some type of list that people that want to come to this school but can't just because they have an, they don't have an attendant. They may be out-of-state and if they're out-of-state, Delaware Medicaid won't cover them. And whatever state they're in, that Medicaid may not cover them either 'cause it doesn't go the same in each state.

KB: Is that something, who was that guy, Alvin Somebody and his son who have a program? It's actually a maintenance program, for kids to come and learn how to do

stuff, but it might be some kind of a, a program where kids could be trained or do that as work-study, do you think?

JW: Yeah. I mean, I think you'd want somebody committed to doing it, because if the person isn't committed, I don't think it's gonna work, but if they don't feel a certain dedication to it, then, you know, they're not gonna come the next morning, get the person out of bed. So work-study is a good idea but I think it needs to be somebody a little bit more...

KB: 'Cause I wasn't thinking about getting them out of bed. I was just thinking about handling them around the school. [JW: No, I'm talking about...] It's a deeper, bigger picture.

JW: Right. Because, you know, I went to one school that had an attendant service program, or they called it "an attendant service program." It was a really, really small town in North Carolina, smaller than Dover. And, what they... You still had... It was like living in a nursing home. You had to be in bed by midnight, otherwise you were in the chair all night.

KB: It was like a dorm situation?

JW: Yeah, but it was a dorm inside the infirmary. [KB: Oh, weird.] You know, I don't want to live in an infirmary.

KB: No, I don't think so. You're not... Huh! That's strange.

JW: And how many students in college want to be in bed by 11:30 on Saturday night?

KB: I remember getting in trouble because I forgot what time it was and called my father at 11:30. [JW: Yeah.] Scared him out of his wits.

JW: Yeah. Exactly.

KB: So, how was that funded? How did they do that?

JW: Usually the state Medicaid programs fund it, things like that. But, like I said, Medicaid doesn't travel across states.

KB: That's really stupid isn't it? [JW: Yeah.] I mean, especially as close as we are to Pennsylvania and Maryland. [JW: Right.] That's really awful.

JW: Sometimes, "Okay, sure, yeah, (Vocational) Rehab will cover it." Just depends on if they, if it's a program spec.

KB: So, it needs to be changed at a federal level? [JW: Right.] But would the states complain if you did that?

JW: It depends how you do it. If you are, if - 'cause Medicaid has what they call "menus." One menu is a menu of required services they have to provide. The states have to provide. The good thing is, the federal government will give you the match up front. And then there's another menu: optional services.

KB: And that would be what?

JW: That would be, if the states wanted, like, all the community-based services that help people like me and Emmanuel live in the community. Those are considered optional.

They don't have to have them. If the state wants it, they have to put up the match and the Feds cover it. But if the Feds say, "You have to have it," the Feds put up the main match and the states have to match it. So it's like, the money... If you're doing an optional service, the money has to come out of the state budget first. And instead of like, "You already know what's required," like any other department they have to use federal money for, they know what, what they have to provide. They take that out of the budget right away.

KB: So who at JFC [Editor: Joint Finance Committee] would be the first person to approach?

JW: I don't know. It changes every... We have new people this year. I think Deb Heffernan, Representative Heffernan, and maybe Senator McDowell.

KB: Oh, he's been there a long time. [JW: Yeah.] Is Margaret Rose still on that committee? [JW: No.] No? She's off? She was, she was... I was her first staff person.

JW: Okay. Yeah. She's a sweet lady.

KB: Yeah, she is a good egg. So tell me about your childhood. Did you grow up in Delaware and where and were you an only child and all that kind of stuff?

JW: Oh, I grew up in Dover, unfortunately. (No, I didn't say that!) And, I had two sisters. We lived with our parents. And, I mean, my parents tried to make it as normal as possible. You know, we had, we had... I had semi-normal childhood. So did my other two sisters. We were far apart in age but we still... 'Cause my older sister and I are like 6½ years apart. My younger sister and I were five years apart. So we were... [KB: So you were three only children?] Yeah. [KB: That's what my dad used to say about us.] Yeah, but I was a tomboy. You know, did, used to crawl around in the mud and all that kind of stuff.

KB: That is good. So, were you in a chair back then when you were...? [JW: Yeah, since birth.] Even there?

JW: Yeah, I walked a little bit but I got my first power chair when I was 10.

KB: Oh, wow. I bet that made you the coolest kid on the block, right?

JW: Yeah, and my parents didn't like it so much 'cause I'd run away too much. [Laughs]

KB: [Unclear] escape! So, what, what, what... So what did you do besides play in the mud? What was fun?

JW: Well, I think one of the greatest things I liked to do was music, listen to music, just still today. I mean I had, we had a stereo all rigged up that I could do myself, 'cause back then it was a turntable and albums and then slid into the CD era, slid into tapes, which were much easier to handle 'cause they were smaller.

KB: Do you know, I went someplace the other day and they were selling those big vinyl records? I couldn't believe they're coming back.

JW: They're all over the place. Yeah. I see them all over the place.

KB: So who are your favorite musicians?

JW: Now, or back then? [KB: Then.] Billy Joel, which I still love, probably Styx, I liked Meatloaf. A lot of rock.

KB: And, what else? So where did you go to school and what was it like?

JW: Well I went to, I started out at the segregated school in Kent County. Then when I turned about 10, which is when IDEA came out, I went to William Henry Middle School. Started there in fifth grade. [KB: Where is that? I don't know it.] It's in Dover, it's right... It is... You go down, kinda toward Route 8.

KB: So, you're going south?

JW: Mmm hmm. Then I went to Dover High and it was difficult because I was the first one with an obvious disability in it, you know, a visible disability. So a lot of the kids didn't know how to handle it. So I got teased a lot and...

KB: So you used your mouth a lot and fought back? Yeah?

JW: Well not so much as I do now. At 10 years old you don't know how to fight back yet. I know for some people, but you know... But, yeah, there was a lot of teasing and a lot... Academically I did fine.

KB: Uh huh. I'll bet. So, so how did you get around these kids?

JW: I simply ignored them. I had, you know, a few teachers watching out for me and they would take care of it if I couldn't.

KB: Well, and sometimes it's not even a disability. I was painfully shy and I, I know that feeling. [JW: Yeah.] In an odd sort of a way, it's similar. [JW: Right.] Did you have everything that you needed to get around in a school in those days?

JW: Yeah, when I got the power chair I did. And I had, you know, good friends that helped me.

KB: And you didn't have a school with two floors or anything?

JW: No, it was all one floor. Both schools were, one floor.

KB: Oh that was really lucky. And did they make you take gym class?

JW: No, I was... I could take theater instead.

KB: That's good!

JW; Today it might be a little bit more difficult, but back, way back then...

KB: Yeah, in New York State where I grew up it was required. I hated that stuff. The theater, that would be good. [JW: Yeah.] And did you have any roles in the plays?

JW: I had a couple plays. [KB: Yeah?] Yeah, one. One play was done by Jules Feiffer. It was just a bunch of comic strips from his works, so I had a of couple roles in that. And I was in one, I think it was "Whose Life is it Anyway?" They needed a lot of female roles, you know, female actresses, so I was in that, I was a, you know, you know, one of those little people in the corner.

KB: So, what did you want to be when you grew up?

JW: You want the whole list or a condensed list? [KB: Everything you think is appropriate!] Well, okay. We'll leave out the inappropriate! [KB: Yeah, that too!] Well, for the longest time, I was gonna be a special education teacher. Then, I was thinking about doing something in social work. Then I wanted to do, like, rehab counseling in a, like a rehab hospital. People who had new, newly-acquired, you know, disabilities, spinal cord injuries, brain injuries. You know, work with them. Then, I wanted to be journalist. Then I was gonna be an actress.

KB: And you were all of the above.

JW: Yeah. So, but I, I went the social work way and my first job in social work I figured out that I really don't like this. That's when I went into the advocacy because social work you have to deal with the policies that are already in place and the policies didn't work for a lot of the people that I worked with. So I decided, okay, let's change this around, do community organization, which is a part of social work, and change the policies so they do work for everybody.

KB: So you never went to the College of Urban Affairs? You would have fit right in there.

JW: I tried, but no.

KB: There's still lots of people around, but that's what I did my, masters thesis on, lobbying, so. [JW: Okay.] So, did you take political science courses in your new major? [JW: Mmm hmm, yeah.] So it's all the same stuff then, huh? Who did you have?

JW: I don't remember from poly sci. I took a couple courses, but...

KB: When you were a young adult, did you date people and what was that like?

JW: Well I really didn't date that much.

KB: What else? As an adult, tell me about your life now. Where do you live and do you have a roommate and what else? "Do you wish you could live somewhere else?" it says.

JW: Okay, one at a time. Right now I live in Dover and I live on my own. I have attendants that come in to help me with my personal needs but I do have my own apartment. I tried roommates for a few years, and I hated it. Just, it was just a lot... I like having my own space, my own... I'm a control-freak. I can't help it. And, but I have thought about, maybe like in a bigger city at first and I really, I didn't go, fact most of my family was in Dover. And when my... 'Cause my mother and my sister passed, so when my sister passed, my older sister wanted me to move to New York. [KB: Oh. Is that where she is?] Yeah, she lives in Manhattan. [KB: Oh, man.] So we'd be closer together in case I needed something. And I told her I didn't want to move to that big of a city. And the only city that I would make money and be able to live by myself, live on my own, would be DC, 'cause of the lobbying and the advocacy. And she agreed with me, and I said, "Let's try it this way." You know, there's been the ups and downs, believe me, but it's, for the most part, I've got a really good circle of support.

KB: It always helps, I think, maybe, to be in the community where you grew up so there's still people that know, know you as a person. [JW: Right.] Yeah. Did you ever live in DC?

JW: No, I've been there a lot, but I've never lived there.

KB: I can remember Jerome Lewis in Urban Affairs. He said, "I'm worried about that Kim. She has Potomac Fever!" I love DC! So, but you do all kinds of advocacy stuff, so you must spend time there, huh?

JW: Well, I used... I don't spend as much time now as I did.

KB: And how did you get there?

JW: Usually train.

KB: Oh, yeah? There was a train from Dover or you had to come to Wilmington?

JW: We had to go to Wilmington. [KB: Yeah?] But we would... 'Cause I have a van with a lift on it. [KB: So you can get to, to the train station?] Right. [KB: Did you see Joe Biden a lot on your train?] Mmm hmm, I did. In fact, one time an attendant and I were waiting for paratransit, I didn't have my dr..., I didn't have my van at the, at the parking lot, and Senator, Senator Biden at the time, was walking off the train and getting ready to walk out. And he knew, at least he knew my name, 'cause I did chair the DD Council for about 10 years. So, and I saw him walk by and I said, "Hello, Senator Biden." He said, "Hi! How are you?" I'm like, "I'm fine. I'm Jamie Wolfe, the chair of the Delaware Disability Council." "Oh, yeah! I remember your name."

KB: What kind of protests and messes did you get into?

JW: A lot of it was with ADAPT, [KB: Yeah.] about closing nursing homes and having attendant services. Those are national. In the state I've done a lot of protests for transportation.

KB: I mean, what's ADAPT? What does that mean?

JW: ADAPT, it stands for "Americans with Disabilities for Attendant Programs Today." It used to be for accessible transportation, but after the ADA, when it was mandated, they went toward nursing homes, closing the nursing homes down. Closing the nursing homes down and making sure they had enough ... Getting the money for attendant services. And, 'cause earlier I mentioned that Medicaid has those two programs, the menus, the option and required, nursing.... To live in a nursing home is a person's right, to live in the community is a person's privilege.

KB: Huh, it should be both rights, which is what we want.

JW: Right, or should we turn, leave the nursing home as a last resort if they even need that level of care. So we did a lot of those marches. In Delaware a lot of it was paratransit. One specific policy they had years ago was if you didn't, if you called, if you made a reservation and you didn't meet, meet the bus, they called it a "Do Not, Did Not Show," "DNS." If you got three or more DNSs from, in one month, they would cancel your, you know, they would suspend your service for a whole month. So what about the people that work or need dialysis or need medical attention?

KB: Yeah, or in the hospital when you call.

JW: Right. They said that doesn't matter, they're, they're suspended for a month. So we got that changed. A lot of it was, some that were spontaneous. One driver, while I was

going up north. The buses, they stop at the county lines, so if you're in Kent County and want to go to New Castle County, you have to transfer a bus in Smyrna.

KB: At the Smyrna rest stop?

JW: Right.

KB: So, the regular DART bus doesn't do that. I take the 301 and it goes all the way. That's crazy. Why do they do that?

KB: Terminology. [KB: That's nuts.] They're not saying it's a fixed route bus anymore it's a "commuter shuttle." If they call it a "fixed route," they would have to do it.

KB: But that seems insane. I mean, that's just...would make sense to take you all the way.

JW: I know, and, but I had one... The driver was like an hour late and I said, "I'm not paying for this ride." And they were pulling out and they, they called dispatch and said, "She has to pay for the ride, otherwise she's not gonna ride the bus." So she turned around and back inside the parking lot, and I got the bus, made the bus stop. Then I got a lift. There's a way, but it's my secret. I don't want everybody know how to do it. But the bus couldn't drive. And I said, "I'm going to Newark and I am not paying for this ride. So you may want to call your supervisor."

KB: You probably already knew the supervisor, too, right?

JW: Right. And another friend saw me go back. He got his driver to turn around and see what's going on. And we were calling for the Delaware coordinator for ADAPT to come and get newspapers. And they were there. I got the ride.

KB: I'll bet you did! 'Cause you don't back down. So you're talking about these marches. Is that like that thing Daniese did from Philadelphia to DC?

JW: No, I, I wanted to do that. [KB: Yeah.] But I was sick at the time.

KB: So what kind of marches were you involved in?

JW: Not many marches, just... Well, in DC with the attendant services, you know, getting attendant services as a right, we would march.

KB: And how did you do it? [JW: What do you mean?] I mean, how, were there, like, just a back-up bus or did you just wheel your chair down the main street? How'd you do it?

JW: People just wheeled their chairs down the street and chanted.

KB: Uh huh. And blocked the traffic?

JW: Mmm hmm.

KB: So that worked, right? Blocking the traffic in DC.

JW: Yeah. You know, we were peaceful in the road, anyway. We were always peaceful.

KB: And then what, what happened in terms of the, the police and the traffic and getting through and doing stuff?

JW: The traffic didn't like us. [KB: No.] But the police helped us get across.

KB: Oh, so that was good. And how many went?

JW: Oh, there were usually, when I went, there were like five to six hundred people from all over this country.

KB: That's a lot, whoa. And so, where, where did you stay and how did it all, how was it organized?

JW: Well, I usually... When I went to DC, actually, we stayed, usually, at like a Holiday Inn-type hotel. And there were day leaders who organized everything, where we were gonna march, where we were going to block off, and they would let the Color... I, they would, they wouldn't tell anybody but the Color Leaders and the way, the way it worked, they would have Color Teams. There was a red group, there was a green group, there was a black group, a white group, you know? Just to keep it organized like that. And they would tell the Color Leaders what was going on the next day, but they wouldn't tell everybody else. And I was always the Color Leader so I could... [KB: So you knew.] Yeah.

KB: So you're the leader of the red group [JW: Yeah.] and so you could direct the...

JW: Right. You just kinda be there to make sure that everybody's, you know, doing what they're supposed to. Make sure there's not [unclear] 'cause any crisis intervention needed.

KB: And where, were you, right on the Capitol lawn?

JW: We were all over the place.

KB: You were everywhere. Yeah.

JW: One day we had a protest in Newt Gingrich's yard.

KB: Cool. In his house? [Jamie: Mmm hmm.] So there!

JW: Of course it wasn't accessible, so. But we did get in, but...

KB: And what are they protesting about now, besides DART?

JW: That's a state issue. The federal issue still is the nursing home issue. People still are going into nursing homes where they shouldn't.

KB: Is it true that it's three times cheaper to be on your own? [JW: Yes.] And they have, the statistical studies have shown that? [JW: Mmm hmm.] That's crazy then, isn't it? And, what else? So, what do you do all day? You never rest, we know that, but...

JW: Well, I am either going to meetings. I chair the state Council for Persons, for Persons with Disabilities. So, I'm there a lot. I, you know, work from home 'cause I have two programs with the Developmental Disability Council, Junior Partners and another mentoring program for groups like People First, to help them get organized.

KB: Talk about that.

JW: Well, what I do is I go in and help them figure out how, what can happen to make the group more effective? And it's been a struggle in Delaware 'cause they're relatively new. And there's some issues there that I think I came in a little bit too late. So we're working on some of their issues, like in terms of leadership. Who is leading the group?

Who shouldn't be leading the group? And just figuring out tasks and who should be doing what.

KB: And how old is that group? People First?

JW: I, I want to say like five or six years old.

KB: But it's a chapter of a national thing, or?

JW: Supposed to be.

KB: Yeah. Well, it's Delaware. We do our own thing.

JW: Right. Exactly.

KB: So, let's see.

JW: I have music on in the apartment a lot.

KB: You have music? [JW: Yeah.] Yeah. So, as a grown-up, is there anything you find challenging to do due to your disability? [JW: Yeah.] Everything!

JW: Getting into places that don't have a door opener and nobody's around to help me, so that's one thing. I think some of the bigger issues are finding, I guess, "good," for lack of a better word, support staff, that are really willing to do the work and realize it's a job. 'Cause I'm the supervisor. So many people that do this type of work for someone with a physical disability are used to being employed by a home health agency. So they don't see me as the employer, they see the fiscal manager as the employer. It's like, "Thank you, listen to me."

Last night I had friends over. One person that I did hire as an attendant, we had, she made dinner for us. [KB: Well, that was nice.] But... And I'm thinking, "I hired this person?" She took dinner out, left it on the counter, took some for her son and her, and then left. And I already told my attendant to come later 'cause I said, "Mary's here and she's gonna help." I didn't eat dinner 'til 10:30 last night.

KB: 'Cause you couldn't reach it.

JW: No. I can't feed myself either. I can some things, but...

KB: So you really need somebody just to put it in your mouth?

JW: Right.

KB: That's pretty tough.

JW: Right. And like, there is no list of support workers for people with physical disabilities. So when you're... Like one of my attendants quit a couple weeks ago and I'm still trying to find somebody to permanently fill her space.

KB: How do you, how could we make that happen, to get a list, or something?

JW: I don't know. Begging. Because it was... [KB: I'm...] I'm sorry. [KB: What... Are there agencies that, that handle those things? I wouldn't assume, like, it would be so hard.] There are agencies that do home health but not the attendant part. So I, I've used home health and home health tells me what I'm going to be doing in my own apartment. [KB: I don't think so.] Yeah, exactly. That's why I'm in the attendant service program.

Actually, I was one of the ones that helped pass the law for it. It says, the person who the people are supporting is the employer. And most of my attendants understand that. But sometimes, you know, they, some have problems understanding that at first.

KB: Yeah. Some people have trouble with any new boss. Me, too!

JW: Right, yeah, but, I mean, you know, if you want... I mean, I try to be as nice as possible. And I understand, I get impatient sometime, a lot of times, I get frustrated a lot of times. But, you know, I get frustrated when my attendants can't get a day off because there's no back-up plan. You are responsible for your own back-up. And if you... When my sister and mother were here, when they were alive, there was no, there was no issue. I would... My sister would either come over to me and stay the night or I'd go over to my mother's. I'd have to stay in the chair 'cause she had a two-story house that I think was purposefully. She had a two-story house because she didn't want me staying over. [KB: Laughs] But, that's something different. [KB: But that's a teasing.]

But, my sister would give me all kinds of pillows and stuff and they would let me stay over there so I wouldn't be alone if I needed something. But when they left, I mean, I have really close friends that'll help, but a lot of them live up here.

KB: So it's all... It's harder and harder.

JW: One of the biggest challenges a person who wants that type of control, to be on their own, and have the proper support people. And be willing not to be walked over.

KB: I keep going back to making a list of those things. That, that seems like it would be doable. What kind of a grant do you need to, to just pull it together?

JW: They're doing... I don't know if a grant, 'cause there is money there. [KB: Yeah?] It's Medicaid money. You probably get grants from, like, some of the national healthcare that give grants, but are you gonna ask for that? But the big thing is people. There's such a small pool of people that are... I mean, I've been a realist. The woman that quit quit about four or five weeks ago, right? And, she... I thought I found this one person. And I, she was doing an application, and it's almost done but, she's a friend. And I learned the hard way, you make – if you want to be friends, you hire the stranger first. They're like any other type of employment, the friendship hopefully will blossom, but there is some of that objectivity.

KB: That's really an interesting thing. [JW: Right.] It's probably true of lots of stuff, though. But it's tough. So, do you think you're treated equally or the same as other people our age?

JW: Most people, most of the time, yeah. I mean there's still times when I'll be in a restaurant or be in a supermarket or wherever, doctor's office, and they'll ask my attendant, "Does she have this, this, this?" Like in a doctor's office, "Does she have diabetes? Does she have this?" She's like, "I don't know. Ask her."

KB: Great answer, right? Ask her. Why not? That's the brain, right there.

JW: "Does she want more soda?" "I don't know."

KB: [Laughs] That is kinda awful, isn't it? [JW: Yeah.] Yeah. Insulting. You sleeping? So, you feel like you're in charge of your own life, probably more than most people, huh?

JW: Yeah, for the most part.

KB: And do you feel like your voice is heard? [JW: Yeah.] Yeah, I think so. I hear... At least 25 people we've been interviewing, you'd be amazed how many people mentioned Jamie Wolfe. So you're a famous, lady. If you had a magic wand and you could change anything about your life, before now, after, what would it be and how would you change it? So we know transportation and door things, but what else?

JW: Attendant services, support people. To see everyone with a disability as having a disability, not as an intellectual disability and a mental health disability. Not physical, but a disability so services could be equally provided.

KB: Are they provided better for some things than others?

JW: I think personally and, you know, some people will disagree with me, but people with intellectual disabilities get pretty good support. In fact, they just had a bill that didn't go through, but direct support workers who worked with people with intellectual disabilities, and probably some of the Division of Substance Abuse and Mental Health, their group homes, people that worked in places like that would get a raise. [KB: Oh, that's weird.] Well, that was the bill. People with physical disabilities were left out of it.

KB: Huh! But the bill didn't pass.

JW: No, because they don't have the money to do it. [KB: Oh, well.] Well, believe me, I was like, "Yeah, you're forgetting a group here." They're probably the most vulnerable. Magic wand would be for everybody to live where they want, how they want, with the supports they want.

KB: And that's fair across the board. So, what else? If you could tell people one thing about yourself and your own lifetime, what would it be? What message do you want history to talk about you? If they were gonna write about you in a textbook for sociology or something, what would it say about you?

JW: I guess, don't be afraid to live the way you want and have your voice heard. You know, if you want to live in a four-story mansion, go find ways to do it. You may have to get a job first. [KB: Or a rich husband!] Yeah. But don't be afraid to live the way you choose.

KB: Yeah. Well, that's a pretty powerful statement, actually, and that's what you're passing down to the kids who come to your program.

JW: Right, right.

KB: What else? Oh, and ADA. How has it impacted your life and, I don't know, what, what case studies or whatever do you know about it, and...?

JW: Well you know it impacted my life, because for... When I was sick back in '03, I had to go to a physical rehab and they were saying, the social workers, I remember them saying I needed to go to a nursing home. 'Cause see, Delaware doesn't have overnight support which I need 'cause I have breathing issues when I sleep. And I said, "Well, they better get it." And luckily my friends know the ADA, probably even a little better than I do, and they would say, "No. That's an *Olmstead* violation. Delaware's gotta suit Jamie."

And, in fact, we had a meeting, 'cause I went two months back in '03, I guess, without any formal support. My family was helping me, either monetarily or physical, you know, physically. My friends were helping me physically. There were nights when I was in the chair. And we had this meeting with the Division, from the state Divisions, and I said, "Isn't there a pool of either people or money that we could work with until we get this straightened out?" And the state people, they were sitting on my couch, I remember. There were like four of them. They all in sync said, "*Olm*" – said, "Nursing home."

KB: Oh, isn't that weird?

JW: And my friends were like, "Don't. That's an *Olmstead* violation." So it kept me out of a nursing home. And it continues to keep me out of a nursing home.

KB: So you could or could not go into a nursing home? I mean, you didn't want to.

JW: No. It's even right in my living will that I will not be. Even for rehab, I do not want to be in a long-term care setting.

KB: So there was nothing for you to be on your own?

JW: Uh uh. They finally got it set up with a lot of legislators' help. I mean, I went knocking on their doors saying, "I need help. I don't know where else to turn."

KB: So what else do you want to let people know about? For the good of the cause.

JW: Well, friends come in all different ways. You don't have to be, unless you choose that, you know, all your friends don't have to have disabilities.

KB: No, no, and they shouldn't.

JW: Right. A lot of, a lot of people think they have to be grouped in with people with disabilities only. And you don't have to.

KB: That's such a crazy idea, though. But it's coming from the general community?

JW: Yeah, from the general community. When a person with a disability is born, I learned this from, his name is Guy Caruso, he's from Temple University. He's part of their University Center. He said, that when kids with disabilities are born, there's two roads they can go down: either a client road, where they go to a segregated school, if they're 21, and then go into a sheltered workshop and stay there until they can't work anymore or until they die. And they make a dollar an hour. Or you can go down the citizen road, which is you to, as soon as possible, you get into a diploma program. You may have to be in special ed for 21 years, but you may not. Look at the potential of what's there. And you, you can go onto post-secondary or you get a job that you want. You vote. You live in the community. And that's what, kind of what I want people to go into.