

CLAWS AND WINGS:

AN ORAL HISTORY EXPLORATION OF DISABILITY IN DELAWARE 1917-2017

Transcription of video recorded July 18, 2017

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

Interviewee: Stephane Merritt (Referred to hereafter as SM), Advocate

Topics included: Quadriplegia, Division of Fish & Wildlife, Medicaid,
Outdoor Life

Run time: 32:01

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SM: My name is Stephane A. Merritt. I work for the Division of Fish and Wildlife. I've been there since January of 1990. I was seasonal for about 6 years and in December of 2096 became a full-time employee to the present time. [Editor's note: should be "1996"]

KB: So, Stephane. Tell me about your childhood and you didn't have your accident until you were a bigger kid, right?

SM: I didn't have my accident until I was 16. I was born in France in '59. My father was an airman and my mom was a French native, and we came to the United States in 1961, something like that. I was about a year and a half old and then we went to Massachusetts, Andrews Air Force Base, where my dad was stationed. Then after he went to Viet Nam for a year he transferred to Delaware, which was in December of '66, and we've been here ever since.

KB: So, tell me about your accident.

SM: It was actually September the 8th in 1976, I was 16 years old. And it was the very last day of summer. The next day was starting my junior year in high school. And a friend of mine and I decided to celebrate the summer or that day by swimming at a spillway at McGinnis's Pond. And while I was, we were there for about an hour or so, I get this wonderful idea of running down the embankment and taking a shallow dive. But, instead of taking a shallow dive, I stumbled and went vertically instead of horizontally, and next thing I remember waking up looking straight down at the sand. No big deal, it was shallow enough to do a push up. Well, I couldn't do a push up. All I could do was just splash. I kept on splashing and then my friend that was with me, Brian Irwin, he came over, straddled me, picked me up by the armpits and said "Stephane, quit playing." See, before my accident, I loved to tease. And, thinking about this years later, Brian and I had never went swimming together before, and he didn't know that I took being around water serious.

A little bit of a flashback. Earlier that summer my mother and I went over to France to visit my grandparents and in the town that they lived in, Lunéville, the Village of the Moon, they had an Olympic-sized swimming pool. And I was able to dive into the pool. I could hold my breath for almost 2½ minutes. And they also had different types of high dives. You know the 10 meter platform dive that you see in the Olympics, I was jumping off that. Diving and stuff. I loved to swim and I love to dive.

Now, back to September of '76. I said, I was splashing and Brian pulled me up. I didn't have enough time to yell to Brian to let him know what happened. I was able to take a

deep breath. He dropped me back in the water. [KB: Whoops.] So, he walked away and all I could do was keep splashing. Then he came back over. He rolled me over, and I told Brian, I said, "Brian, I broke my neck." I knew exactly what I did. He drug me over to the shore and he more or less abandoned me. He, he panicked. We were both 16. I was begging him to, you know, call the ambulance for me, which he didn't do. And then a few minutes later, this young lady in a brown bikini and her little daughter were coming down to where we were. They were going to swim in the spillway also. And, I told her, I said "Ma'am, would you mind calling 911 for me?"

So she disappeared and then a few minutes later an older lady, I believe it was her mom, asked if there was somebody that I would like to contact. I said, "Well, you better call my mom." My mom was the director and a teacher at the local Christian school. And she disappeared and then a little while later the ambulance came and picked me up, so that was a big change in my life.

KB: Pretty scary stuff. So, then what did you do about school? Obviously, you didn't go. Took a long time to get back?

SM: I went to Milford Memorial Hospital where they put me on a Stryker frame and took the pressure off my neck. I transferred to A.I. du Pont two weeks after my accident and when I were there, when I was there, they had a school.

So mom contacted Lake Forest High School where I was attending school, and, she talked to Mrs. Phelps, the principal at the time, and her, Mrs. Phelps' comment was, "Oh, why do you want to do that? Stephane has a brain injury." Mom says, "Stephane doesn't have a brain injury. He broke his neck!" Well, they contacted A.I. du Pont and I continued my junior year there at A.I. du Pont. And I get out, I was discharged from A.I. du Pont April of 2077. [Editor's note: "1977"] And I continued my education with two tutors who came to the house. One was an English teacher and the other one was...I forget what Mr. [inaudible] did. I don't remember what that class was.

But then in September of '77 I went back to high school. I went with my, a senior in high school, and I was able to graduate with my class in 1978. [KB: Oh, so that was good.] But at first they didn't want me to attend high school, but apparently they changed their mind and allowed me to, to attend the school again.

KB: In those days they didn't have accessible entrances and stuff like that?

SM: Well, fortunately Lake Forest High School is all flat, all one-story building at the time. Now if it was Dover or CR and such, may not have been easily accessible, but fortunately Lake Forest was at the time.

KB: That's good. What else? So, what about being married and all that stuff?

SM: I got married in March of 1997. My ex-wife was an LPN. She worked as a nurse at Westminster Nursing Home there in Dover. Unfortunately she wasn't able to be a caregiver and a wife and we got divorced in 2000.

KB: And do you have kids?

SM: No, she had two sons from a previous marriage.

KB: So, now you're with Fish and Wildlife. Tell me how that all came about.

SM: Ooh. That's an interesting story. I, after high school, I went to Del Tech and got an Associate's Degree in computer programming, this is on the big mainframes, not the little PCs that we have now. And I looked for a, tried to be hired here in Dover. I did not want to commute to Salisbury or up to New Castle with it, the big computers are. And not having any luck with that, I went back to college and got second Associate's Degree in accounting. And, I applied for several accounting positions or openings with the state and I wanted to work for the state. And did several interviews and was turned down. And then in January of 1990, I had this interview with the Division of Fish and Wildlife and what's really strange is the secretary was also a member of the church that I attend in Milford. And I was talking with Bobbie and she said that they already knew who they were going to hire, it was just a formality of going through the hoops.

So, I wasn't going to take the interview. What's the sense of doing it? So what, I'll just do it for the experience. So it was a three panel interview and at the end of the interview they asked me if I would be interested in working as a seasonal, entering hunting and fishing licenses into the computer, from like 4-6, Monday through Friday. So that was my intro into working for the state, and I took the position for one reason only: to prove to them that I was reliable and that I could do the job.

And I did it for about 8 months and then they transferred me to start doing accounting work. And I was, in the morning I did accounting and in the afternoon I did licenses. And for about a year I just did accounting work. And, like I said, the seasonal went to December of 1996. So, I've been doing accounting work since then.

KB: And now you're full-time.

SM: Yes. And I plan on retiring at the end of this year.

KB: Then what will you do?

SM: Ah, I don't have to get up early in the morning. I have several different hobbies that I enjoy. I like doing ancestry, finding out where my heritage came from. I love to fish. I love to travel. I drive. I love driving everywhere. I love people-watching, going to the movies. So I have quite a few things that I'm interested in doing, so.

KB: So, are there, are things that are especially frustrating about having had this accident and the way your life has turned out, or...? What do you think was the result of it?

SM: Actually for the better. Which is unusual, because, I was an introvert. I wanted to be an electrician before I had my accident, where I went to the high school, Lake Forest, in the morning, and in the afternoon I went over to Kent Vo Tech which is now Polytech now. Since I had my accident I couldn't build my body up anymore so I had to use my mind and use what I have available to use.

Before my accident I was more of a follower and such. And, if I wasn't, if I didn't have my accident I'd probably be dead, in jail, or not doing very well.

KB: [Laughs] Why do you think that?

SM: Just the way I was heading at the time. Said I, I was not a very strong person at the time. And after my accident I had to learn to be a strong person.

KB: So that's pretty, pretty neat, actually, in a way. So, do you think you're treated equally in your wheelchair, to other people who aren't?

SM: No, no. It's...well it depends upon the circumstance. There's some people that are willing to go out of their way to help you and there's other people that, you know, almost are afraid that they may get your disease that you have, you know, not knowing about you. But, other than that. I take that back, I really don't see that much of a difference anymore. I did back when I was younger, and such, but now, it doesn't bother me one way or the other.

KB: So, you kind of, you're definitely in charge of your own life. Talk about [SM: Pretty much.] what your schedule's like and how do you cope?

SM: What's my schedule like? On a daily basis?

KB: How do you cope with working and getting around and all that stuff?

SM: Well, I think everybody has their, their moments. Some people let it frustrate them. I'll sit there and get frustrated but then after a few minutes, half an hour to an hour, it, I just let it go. I don't let it bother me too much any more. It doesn't frustrate me like it used to. So.

KB: Do you have a helper that has to get you in and out of bed?

SM: I have some aides through... I have Ticket to Work that I pay on a monthly basis for secondary health insurance. And they, they...it's through Generations. They have a wonderful aide, her name is Darlene, that comes in and gets me up in the morning. She comes in at 6. She gets me dressed and such and up in the wheelchair. And after she does that, I am pretty much, I wash my face, shave, brush my teeth. Now, she washes my hair for me and such, then she'll get out my shirt.

I live with my parents. I mean, I work for the state, where it's a good job but you don't make a whole lot of money, not enough to live on your own, And, with working I actually hurt myself by going to work, because I don't qualify for a lot of the benefits that handicapped people are entitled to if they don't work. So, that's why I (had to) go live with my parents.

During the day I'm pretty good on my own. I don't really need much assistance. In the evening I have some other aides that come in through the Easter Seals through a program called Personal Assistance Program, or something like that. Again, it's through the Easter Seals and I have several aides that come in the evening. They help me transfer into bed, disrobing and such. My parents are, my dad's 80 years old. He has a bad back. He had hip surgery and he has, he had some heart surgery a couple years ago. Mom's 79 and she has a bad back and arthritis, so they could do that occasionally, but not on a regular basis, so that's why I have the aides that come in to help me with that.

KB: So, if you, as an advocate for other people with disabilities, how would you make sure your voice is heard?

SM: Through the program, through Easter Seals a few years ago I was asked to speak before the state legislators and spoke to them a little bit about what the program was. That was one way to do that. And then, back in the early 2000s, there was a big tobacco

settlement and they had the, legislators were having different open meetings throughout the state to see how to spend the money. And I spoke before them about, you know, seeing that, where I would like to see the funding go, to help, you know, people disabled like myself. To be able to have more benefits for people like myself that want to work, but they're afraid to 'cause they'll lose, you know, what they have. 'Cause I know several other quadriplegics that would like to work but they don't want to lose what they have, which, you know, I can understand.

KB: So what was the outcome of that lobbying?

SM: To be honest with you, I don't know. But there was an article in the News Journal and my name was in on it, so that was pretty cool.

KB: That is pretty cool. If you had a magic wand and you could change anything about your life, what would you do?

SM: What would it be? [KB: Yeah.] Let's see. Let me think hard on that. Go back to September the 8th 1976 and not go swimming that day. [KB: Laughs] I was supposed to stay home and cut the grass. [KB: Oops!] See, I'm an only child and...definitely go back to that day.

KB: Start over, huh?

SM: BUT, it has to be with what I know now. So, that, that has to be kept to it.

KB: Yeah. So if, if you were gonna have somebody write an autobiography about you or feature you in Times or something, what would you want people to remember about you?

SM: Caring, persistent, and didn't give up.

KB: All good things, right? Yeah. And what about ADA? Did that come before or after your accident?

SM: Oh, that was well after.

KB: Yeah, and so, did it make a difference?

SM: To accessibility, different buildings and such. Case in point: back in the early '80s, when Kmart was here in Dover, there wasn't a ramp to get into the store. I had, we had this Ford Econoline that we had purchased and Voc Rehab paid for the conversion for me so I could attend school, or college. And, that was, the only way for me to get into the store was to park along the sidewalk and put the ramp out in order to get into the building. Otherwise, I wouldn't have been able to go into the store. That was one of the biggest notices that I found.

KB: Wow, that's really something. So, what more is needed to make life more accessible?

SM: As I mentioned earlier, for, you know the governor has a committee to hire handicapped people. But there needs to be more, like I said, programs that won't restrict or take away benefits that the people have available. Don't make it where it's monetary restrictions. When I was working as a seasonal, I had SSI, and I was able to keep Medicaid. When I went full-time, I went \$100 or \$150 over the threshold. Now this threshold, it's the [Editor: Healthcare] Blue Book 1619(B), and every state has different

monetary amount for the threshold. And every year it's supposed to go up, so technically you're not supposed to ever catch that threshold. Well, the year that I got hired full-time, they never increased the threshold. So I lost my, the SSI and I lost Medicaid. By doing that, I hurt myself.

KB: So, the result was you had to move back home with your parents?

SM: I lived, I lived at home with my parents anyway at the time, so. Except for when I was married, so.

KB: So, what do you think you've done in your life that's had the most impact? Not on you, but on the world.

SM: Actually, the strange thing is, I had a conversation with my mom just the other day about this. And she said that she was amazed on how many people saw life differently upon meeting me. And, she said, you know, I could have easily died that day, and drowned, you know, and nobody would have known who I was. But, she said, you've had a big impact on several people. You know, friends, colleagues, people that don't know me but watch from afar, so.

KB: And they see you're really a guy, not a chair, right?

SM: That's the biggest thing, is... One of the questions on there was talking about dating. It's really hard to find a girl that sees the person and not the wheelchair. And that's the biggest battle that you really have to deal with. You know, they just see the wheelchair and they just assume one thing and they don't see the person.

KB: So what can we do to...

SM: ...open up that window? [KB: Yeah.] That's a good question. I don't know.

KB: And maybe nobody does, right? Were you involved in the work towards getting ADA passed?

SM: No.

KB: No?

SM: Now I was on a committee at the beginning for Ticket to Work.

KB: And what, when was that and what did you do?

SM: They had a meeting once a month up in New Castle at Wood Voc Rehab and we met... We had a lot of discussions and then once this one person came on the committee, I didn't care for this person, the way they handled themselves and the way they did things, so I distanced myself from it.

KB: That's too bad. So, what else needs to change, besides the piece about working full-time. What other things would open doors?

SM: Nothing I really could think of at this moment.

KB: And...ah yes, this is kind of an odd question 'cause you're in Fish and Wildlife, but what, what have you done in your career that's had the most impact on your profession, on your colleagues?

SM: I think working with a person that's a disabled person. Everybody has a disability in one form or another but they're not obvious. [KB: Yeah.] Well, mine's quite obvious. And, just working with someone that's disabled, I think so.

KB: Just so they see it's a person. [SM: Right] Yeah.

SM: Yeah, my, my colleagues they, they treat me just like they treat everybody else, but they know my limitations. They don't "Oh, can I help you do this? Can I help you do that?" They've learned not to do that. They know they wait till I ask for them to do it. Okay, it takes me five minutes to pick up a piece of paper. I cheat. I have a [KB: A grabber?]. I don't have the dexterity for a grabber, so I use a paperclip and I'll have an extension that has a magnet on it. So, I'll sit there and put the paper over top of the paperclip. I use my magnet and I pick it up.

KB: [Laughs] That's pretty creative! You should patent it.

SM: You have that extension with a magnet and a paper clip.

KB: So, what, what else do you want to say? What else would you think make an interesting show?

SM: With my situation, with the ADA, I really didn't notice that much at the time, like I mentioned earlier with the situation with Kmart. That was basically the only thing that I was exposed to, was the accessibility to buildings and such.

Emmanuel Jenkins (hereafter EJ): So, so once, so once the help became the only, the only thing that really impacted your, your world at that moment, when the ADA came into play, the day the world changed, the day the school changed, did you see a difference once the ADA was in play?

SM: If it's pertaining to school, remember I graduated in '78 and the ADA in the schools, I have no idea. It didn't impact me at all.

KB: How old were you when [unclear]...?

SM: I think they just celebrated their 25th year. [EJ: Yes.] So, remember I've been in a wheelchair almost 41 years, so that's been over 16 years, so I was done with high school and I was done with college, both times. And, I was already working for the state.

KB: So, we're interested in your experiences as a fisherman and also how you were a kind of guinea pig to see if these ramps and things would work. [SM: Accessible more?] Tell us more. Yeah.

SM: Working through Fish and Wildlife, I have been asked on a few occasions to go out to different locations that have fishing piers or not just fishing piers, but docks and such, to be able to fish from, being in a wheelchair. And then also with the, the state parks, they have a nice fishing pier down in Lewes that they just revamped, to make it accessible for people in wheelchairs to fish. There's also, you know, several other different places throughout the state that they have access to, being in a wheelchair And there's one place in particular, down in Kitts Hummock, which is just east of the Air Force base, there's a pond that has a floating pier to it that's just for disabled people to fish from.

KB: So, I guess if you bring your grandson or somebody with you he's allowed to fish?

SM: Technically, no. I've been fishing there with my dad and he's not even allowed to fish.

KB: That's weird.

SM: So, it's, like I said, it's just strictly for, for disabled people. They actually have some day camps that bring school buses with them, children, who go over there and fish. I remember seeing them there a few times. It's a nice little facility. The only bad thing is during the summertime, the greenhead flies are really bad.

KB: Well, that's Delaware! [Laughs]

SM: That's Delaware!

KB: So, how long have they had that system?

SM: How long as they've had that pond or...?

KB: Well, in general, whatever?

SM: Probably since the ADA was established and tried to make, you know, to give some more opportunities for people that are disabled, so.

KB: And but you're, you go out and test them, sort of?

SM: I get a chance to do that, yes, but as a private citizen I've fished throughout the state, all the way from Indian River down at the inlet, I mean, that's a state park. I fished over at Seaford, the Nanticoke. I've fished over at Milton, where there's a nice pier there and a pond. Down at the spillway, there's a nice boating pier. I fished all the way up the C&D Canal, at the fishing piers there. Down at Lewes, in Lewes, there's a variety of different places to be able to fish from.

KB: Does Augustine Beach have any?

SM: No, not at this time, that I'm aware of. That doesn't mean that there's nothing, something that may not be in the plans, but not that I'm aware of at this time.