

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: Karen Gallagher (Referred to hereafter as KG), Advocate

Topics included: Cerebral Palsy, Mary Campbell Center

Run time: 1:13:06

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KB: Our next interviewee is Miss Karen Gallagher. And Miss Gallagher, we'd like to ask you, tell us a little bit about your childhood. Where did you live and did you have brothers and sisters and whatever?

KG: I lived with my parents for 44 years. I have one brother and one sister. They are, umm, my brother lives in Wilmington, North Wilmington. He's a lawyer, has his own law practice with another guy. He just branched out. I'm the youngest of the three of us. My sister [unclear] three years older than I am. My birthday is [unclear] October 29th, 1952 and we moved... I was born at St. Francis. I was nine weeks early. Like, should've been, I was October rather than January. Second, as far as childhood, we tried to make it as normal as possible as far as... Well, let me back up a little bit. We moved from Elsmere from a split-level because at the time I had to be carried up the steps because that's where bath... Up and down steps because that where everything was.

And I moved when I was like nine. We went from one house, one school day to another house that was all one floor. My father and mother helped design it. They actually had to, when they built it, they had to turn the house around so that everything was, every doorway or everything else was 90 degrees, so that the doorways were wide enough for the chair. We had a pretty normal life. My mother and father tried to include me in everything as much as they could. They encouraged my brother and sister to bring their friends in there so I could get to know everybody as, on my level rather than being segregated into a facility, segregated and be just around people with disabilities. Which I think now is the goal of both of the committees that I'm on, which I forgot to bring a list you a list of those.

When my sister and brother got to go to college and got to go on with their lives, they, I used to tell my mother I felt like the only chicken was left in the chicken coop. They understood but they were frustrated at the same time because they knew that I couldn't go. I never got a degree or any form of something. I went to Leach School for, from age, actually it was 3 to 21. And I had one teacher tell my mother that when I got [unclear] became a... They were going to change the curriculum, if you could call it that, to home ec kind of thing. They weren't going to educate, do any education or do any reading support.

When this teacher, who I liked at the time, was talking to my mother (at) one of the parent-teacher conferences, the teacher said that, "Why was it important for Karen to read? She had talking books, she had radio, she had TV." But it got to the point where my parents had to read my own mail and that was a little bit frustrating because, because of the fact that I couldn't read or still can't. Some of it is due to eye problem, some of it is

due to I take things orally, I mean auditorily, better than visually. I am, when I talk to people I sound like a [unclear]. When I moved to Mary Campbell. After I graduated, got my Certificate of Participation my last year at Leach, I went from there directly to Elwyn of Delaware, I think it was on Orange Street at the time, if you're familiar with the area.

I went into, they had adult basic ed, which I tried to participate in but there again, I had this orally and auditorily. I could not read, read by myself without... What happens is when I try to read an entire sentence or if it's too much on a page, by the time I read the paragraph, I lose, I'm so busy concentrating on the words that I forget the content of the information. Whereas if somebody reads it to me I can understand it better and maybe dictate better than I read.

Then I moved to Mary Campbell and I, when – I was almost 25 when I moved. But I moved in July, my birthday being in October, it was... After... In the beginning it felt [unclear]. At one point I, I was never too good at testing [unclear] or in any other capacity. Surprisingly enough, when I took the GED test, I missed it by two questions. So I did do pretty well at that time but I never really got to get a diploma, get my GED proficiency test finished. But it's...

I had many eye problems get worse which I just found out, it was what it was. And the specialist we went to said that I would be, if it would... It would only be cosmetic and not beneficial to my reading ability. Because my eyes are separating so I look at, in one eye one way and out of the other eye the next. That's the way I understand it.

Anyway, when... Mary Campbell got to be too restrictive. You had to do their program. In order to live there you had to go to dinner at certain times. You had to go to therapy at certain times. Mine was maintenance therapy. And there's problems in the institution but there are also problems as far as being out in the community whereby you don't have as many things that you may have had in the facility. I almost said "institution," but I (mean) "facility."

And I'm under the umbrella of a system whereby I have to check with nurses on certain medications. I'm not allowed to do over-the-counter medications. I do, I may buy a couple over-the-counter things and eye medicine, cough syrup, or what have you. But, I have to, if it's a controlled substance, which is most of my problem, it's...like I take my medication every day. When we moved, when I first moved, we discovered that I was anti-medicine, it was partly because everything I take, to my mind, has a drowsy effect, and when I do things like this and I meet with Emmanuel or something, I tend to fall asleep. So my days get mixed up. I'm not a very good morning person. And I don't want to wake up that way. So I was a little bit late but I'm glad we have enough time to do everything.

KB: Tell me, what was a typical day like at Mary Campbell?

KG: A typical day was: you had to go to classes. You had to, there was adult basic ed, and those that had the higher level visual, visual functions could apply for [unclear]. And somebody had told them onsite when I went to Elwyn it was adult basic ed. Unfortunately... Oh! The first book I got through was "Charlotte's Web." [KB: Ah. That's a nice book.] But it takes somebody actually sitting with me and helping me through it rather than me doing it by myself.

KB: But you always remember, “Some pig!” right? I love that book, too. So, at, at Mary Campbell you had to get up at a certain time and eat. How did that work?

KG: We had to get up at a certain time and all my life I’ve been a, I’ve not been a morning person. Though one day, days when, even now, people will tell you that I don’t want to get up when I’m in bed. It takes me a while for me to relax. And if I’m just running late or things I’m doing that, which sometimes there are, it can be a problem. After I got out, I used to sit with my mother. When I was home, she used to make most of my clothes and make my dresses so that they were easy to get on because point about CP is I’m spastic and I have what is called a very active cerebral reflex. Both, I think about other people have different opinions, but when you don’t know what that person goes...

I don’t think you know what that person goes through unless you’re in that position or in some kind of adapted position where you have to be restricted for a certain amount of time just to see what it might feel like to be in a wheelchair, to be blind, or to be disabled.

There are a lot of things that were at Mary Campbell that aren’t at my beck and call now. I don’t have to call if I need to go to the bathroom. Although I have a very good staff and get my needs met, sometimes I get a little bit impatient, mostly with myself because I can’t do the things I like to do on my own, although I try to do them because everybody says if you don’t use it you lose it. But my feeling about that is that you have to accept, at a certain point you have to accept your disability or ability, if you will, or lack of ability and just not worry about what other people think or might think or... You just have to deal with, work with the cards you are dealt [unclear].

I, one thing I do regret about moving is that I don’t, I can’t find a therapist on the...that was at Mary Campbell that I can afford with Medicaid or Medicare without a doctor’s order. Feels like (if) you breathe you need a doctor’s order! But, there’s a lot of the therapy that I did with the therapist at Mary Campbell that I can’t show a person coming in because they need to see it rather than me taking time to talk about it or try to explain it and everybody seems to be going with the lifts now and I haven’t walked, I mean, I never walked, but I used to be able to stand in a position where I would be supported or be able to hold onto something or someone while pants were being pulled up.

But as far as falling goes, and I hope I’m not giving out secrets too much, they, when I was home, everybody did a little bit of everything. My mother and sister would help me in the bathroom and help me get dressed if I needed to, even when I was at church. When I found out that, I had this condition that I would have to go to the bathroom in the middle of church, so you can’t really worry about your inhibitions. You have no... As long as a female went in with a male it was okay with me, because I had to block out the fact that other people might think it was sexual or anything to be...do that kind of stuff. I mean, let’s face it, males are stronger than females and it was easier for me, especially if you’re not familiar with the disability, how they bend or how they don’t bend, in my case. They don’t understand and a lot of times in the beginning, they’re so timid that I get afraid and somebody has to teach them not to be so timid because if they’re too timid, I get afraid. I get scared that I’m gonna fall or do something like that.

But after a while it got... I thought I knew enough to describe to people, when I wanted to leave Mary Campbell, that I was able to teach people how to take care of me and I found out later that I didn’t even know how to tell them to plug in my chair. Because they

took it to one room and I was in my bedroom on the other side of the building and I didn't appreciate what they were doing. And certain places change where I still need help to call somebody and get my chair fixed. I'm on a portion-controlled meal. Before that I was... I like to eat and I, it took a while to get myself adjusted to this portion control and getting [unclear] some "slave driver," because she has been willing enough to put up with my mess and agitation, if you will, in getting me o the point I am that I look like I looked when I was home because I could get to the refrigerator and was only, my mother would feed me what she thought I would be eating.

And before all that, I went to a program up in Philadelphia that was called a physical therapy program, where they tried to put me through my paces, crawl, or being able to get up on my knees myself and crawl or creep or... And along with that, that was a...thing called in a physical therapy program. I don't know whether you're familiar with that but they had different resources on diets. And you had to do, wear sunglasses that had one eye covered and you had to use the undominant eye or undominant arm.

KB: So what made you decide to leave Mary Campbell and go live on your own?

KG: Because of the re... It got to be restrictive. Umm, because after I took Partners in Policymaking, I took all these, working on all these committees like the Developmental Disabilities Council and subcommittees. They, I was out when I was there and I just got, I just felt like I was losing something, when I was gaining. There's a lot of things I've learned now, that they keep saying that it's cheaper living in an institution, but regrettably, I don't feel that way because I, you know, you have to account for everything. Your stamps, your food, whatever you may need, mentally or physically. People write out checks for me. I make a mark like I did for you [Editor: on the video release form]. I sign my checks that way.

And, because I can't read, I have to, I have certain words like "ice cream" that I use for identifying myself, either by email or over the phone if I need to call the bank. But I, right now, I can't use the voice-activated stuff because of my oral, my speech isn't distinct and clear. I don't know whether it's because I'm working so hard to get it right so I, with voice-activated equipment right now, I, my voice changes and it affects what goes on the paper. I have tried it twice. I have a voice-activated TV remote that I can't use myself, but I can't use myself, because the same reason. My voice changes whether I try to or don't try hard enough. But the harder I try the more difficult it is for me to relax.

KB: Tell me how old you were when you left Mary Campbell.

KG: I was there 25 years and I left, I've been in the apartment 15 or so years. During the transition they were trying to say I couldn't do it myself and I needed a roommate. And I was lucky enough at the time to go get a lawyer from community legal aid because I had shared a room with my sister all my life. And I had shared a room with one person, then at the... Then after my father got sick, after 30 years of working at GM, I got very emotional about it, so they decided to put me in a private room. And when I got used to it, they needed it for somebody else and they put me in with two other people. It was private mostly, but I could hear everything that was going on. And, that's one of the reasons I moved also.

But, they said I could stay there as long as I didn't... If I decided to move because I was, I'm done there and I don't know distances. I don't drive, so I don't pay attention where I'm going. So I try my best to get directions for every place that I go. And when I was, I just don't know distances, and when I was moving I said, I started inviting everybody to my house. And they sent a lot of volunteers to do stuff, write letters, do email if I needed it and figure out dictation or whatever. And when I found that I could not get the volunteers that knew how to do email or wanted to take the time to do letters, my staff does the email for me. But the other things that they have to do, I understand it, but the other things that I have to do that I can only ask for or like, sometimes I don't get to the computer because I'm out doing other things so that I don't get to read the follow-ups or sometimes they don't come through right or...

I can't do much physically but run my mouth at anybody. [KB: Laughs] But run my mouth too much, it tends to get me in trouble. [KB: True of all of us!] But the difference between you and me, I have to work with somebody I feel like. I push the envelope sometime but I can't always get mad. I do my, I try my darndest not to get mad but I've had a couple people leave because of that, because in the emotions I got a little bit loud and screaming at people or doing something like that. And one person that (I) particularly liked said to me one day, "If you can't get counseling or don't want to get counseling, I'm going to have to leave." And I did it. I got counseling. But I think the reason that, one of the other reasons that I started acting out at the time – and there were a lot of reasons – was that one of the former case managers at DDDS got a hold of my number under false pretenses and my previous person, I was talking to getting a roommate, 'cause that was what we all were lying to her about, the reasons she was there. I got upset and we all got upset.

But that's... But when I started to get myself calmed down, I mean there were times when I wanted to throw the doctor, go out the window. I wasn't. And one time when he wanted me to go out the window. And now we have one of the best relationships I have. And when he gave up my, the contract with DDDS I just stayed with him and just, for a while, paid for it myself really carefully until I get some money so he, we agreed to. He'd decide to fight with. for me to continue with him because it's difficult (for) me to start over with other people.

KB: So, let me just look here. So, mostly you're just at home and what do you do?

KG: Well, I'm not "mostly at home." I do things like this. I do, I go for Council, besides going to, besides that I go for counseling, either one day, one time a week or every two weeks, depending upon the need, how frustrated I get with people because for something's going on that I can't fix and that was what I do. I do advocacy with a lot of different groups. That's why I say I'd send you the resume that I have. And I've thought about it. I would gotten other people, I would've printed it out last night, but when I got home from [unclear] meeting, I noticed that the computer was on but it was acting up so I need to call my tech that I am working with this morning when I get back or this afternoon.

So that's basically it. I made some mistakes. I'm regretting moving, at times, from Mary Campbell. But my parents, my mother... My father died in '90 and due to complications of pneumonia somewhat due to deceptions of breathing or whatever. I don't know what

went on. But, I'm busy despite the fact that I don't go to work. I don't go to day programs. I've got a calendar with a lot on it. I can show it to you when I get done here.

KB: And what things make you happiest?

KG: Being with people. Going out different places. But right now I had a list of places I wanted to go but for some reason or another because I'm losing track of years here. I don't know whether I'll be 25 or 24, I think I'm 24 now although I did [unclear]. So, I'm not sure.

KB: What kind of places did you want to go?

KG: On my list is, on my list when I first made it, was the cemetery where my father and mother are both buried. My mother passed away from, she died at the age of 93. It was just three years ago in February and... But luckily my niece had been trying for a while. They had twin boys, though not, fraternal rather than identical. But she got to see them before she died. They were due in March 18th, I think. Again, they came 9 weeks early and were in the hospital for a while. And my mom, mom was the glue that held everybody together, I think, both after Dad died and before she got sick. The only thing was down steps was the basement and that was the only place at the time that they could put the washer and dryer. And the house was constructed before we sold it. The kitchen wasn't conducive to putting a dryer upstairs, anywhere upstairs. So she began to forget things and fall a lot so we tried (I say "we"), my brother and sister had to put up with me because I couldn't do anything but give my input as far as caring for her, because I can't take care of myself. And I visited as much as I could, no matter where she was, no matter what transportation I had.

For a long time, like 7 years, I don't know whether [unclear] 6 years, I had been there I bought my own vehicle because going downstate by DART is like [KB: It's hard!] transfers and you've got buses being late and if, because it's door to door, if you make two reservations for the same day and one gets cancelled, they cancel both, because it's not protocol. Ask me why, I can't tell you. You know, it's a pain but I have to ride once in a while, which I haven't done yet to avoid being, having to go for the recertification, so...

KB: And that's coming up? So, in your, in your life, if you had a magic wand and you could change anything, where would you start? What would you do?

KG: Having enough money to...although let me preface it by saying, on the whole I think I have a pretty good staff. They all have their strengths. They all have their differences of opinion as to what should be done on day shift and what should be done on night shift.

KB: So, tell me about ADA. Was that...was passed when we were kids, right?

KG: Yeah. Unfortunately, all the Medicaid and Medicare, all you hear about is this hospital is for kids, and this, we're raising money for St. Jude's for Children. And I think they forget that we grow up and still have the same problems we did when we were kids but they don't want to give us the money we need to support ourselves. And between you and me and the camera over there, and everybody in this room, I did not vote for Trump, because he imitated that gentleman, like on TV, because he involuntarily shook while he was talking and a lot of times I do that. It may be misanthropy at that time but the more

that that's said, the more upset I get, and the more upset I get, the more difficulty in calming myself down.

So, but I keep busy and I do most of the phone calling to my friends because most of them either can't get to my house because they can't drive or I can't get to their house because of those stupid steps or the house isn't big enough to get wheelchair in, whether it's got steps or anything else.

KB: So thank goodness for telephones. So, if you wanted to have history remember you in any particular way, what would you want them to say about you?

KG: I did want to say that I forgot something: I have never dated. I have never even considered dating because I don't want anybody... That is my choice. It works for different people but this is my choice.

There's all kinds of different kinds of love, if you will. There's a romantic love and then there's people love. I am a people-person and I figure, what am I going to do if someone that I'm supposed to be taking care, I can't take care of them, so I just never considered it. I know when my sister went away – I'll get back to your question in a minute – but when my sister went to college, my mother talked to a priest about having me have a hysterectomy because I could not take care of myself and she couldn't handle the monthly issues that go with our bodies, so she felt like it was too much of an invasion of my privacy because it was only be my father and mother. So, and she didn't feel, before I did, that I couldn't take care of people, as far as marriage goes, having babies or...

I always like to be remembered as somebody with a lot of sense of humor. I need that because those, that's the only way I can relax a little bit and it's good to have a sense of humor because if you can't laugh at yourself or laugh at your situation you're going to kill yourself. I mean, I'm not declaring on videotape that I'm going to kill myself, but it's... That's the only way I can deal with the cards that I have been dealt. Sometimes it works. Sometimes people are more serious than other people or aren't used to my humor or aren't used to my behavior, but I'm going to tell you I don't care about those people. But if I sit there and worry about everything I'd be worrying myself to the point of going crazy.