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Judy Walker Cunningham interview for the Lest We Forget Collection of Oral Histories

Judy Walker Cunningham

Jeff Moyer

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WRIGHT STATE UNIVERSITY
Lest We Forget Interview Project

Interview date: July 14, 2003

Interviewer: Jeff Moyer

Interviewee: Judy Walker Cunningham

JM: -wanting to do our best.

Judy Walker Cunningham: Mmhmm.

JM: You know a little bit of dynamic tension is a good thing.

JWC: Yeah.

JM: Ready?

Judy Leasure: I'm ready.

JM: Um...this is Tuesday...uh Monday actually...July 14th, 2003. We're in Akron, and talking to Judy Alexander.

JWC: Walker.

JM: Walker.

JWC: Judy Walker.

JL: Everybody's Alexander

JWC: Uh-hun.

JM: Judy Walker.

JWC: Cunningham. Judy Walker Cunningham.

JM: Ok, Judy Walker Cunningham. I don't think I heard that at all ever.

JWC: I know, probably not.

JM: Well nice to meet you.

JWC: Nice to meet you.

JM: Uh...will you tell us what your background is with state institutions for starters?

JWC: Ok. Um...back in--first of all, I have a son who's 36 and he's autistic. And uh...I was um...I was introduced to all of that when we had some problems with Tommy. Um...aged 3 and then the University of Cincinnati guided us into uh...the University's uh psychiatric center and uh...that's where Tommy went until he was seven years old. And then after that, um...experience, they told us uh...when he was seven and he started to speak and...and because they were like finished with his age group, they uh recommended that Tommy go to an institution because he needed structure. And...that was very devastating.

JM: What year was this?

JWC: Uh...I believe that was in '60...'69/ '70. No that was like '72. '72/'73. Because he's 36. That was like in '72/'73. So I started to go around and visit the places where it was recommended that he go in the State of Ohio, and that was devastating. I mean I went to Apple Creek. I went to a couple places in the Cleveland Area that...I don't know the names of them now, but...

JM: (unintelligible)

JWC: Yes. And uh it was pretty scary to me and the fact that I have three sons, and Tommy was the middle son, and um...having a few problems with him and being recommended that he needs structure, and without the structure that he might not ever get along in life, it was pretty scary. It was pretty scary to think that I would have to let my seven year old son go anywhere...outside of our family. You know I--I really felt very responsible...for them saying that to me. You know, I felt like why do you want...my son to leave me? But that wasn't the issue at all. You know I've learned a lot of things since then.

JM: Those were doctors?

JWC: And those were doctors and that was the...the group that...that was the recommendation, at that time.

JM: What were the developmental centers like that you saw? The institutions?

JWC: Just exactly what Wayne said.

JM: Well this is--we're gonna use your words so--

JWC: Ok.

JM: --you give a first impression and take it.

JWC: Uh...it was just really scary. They showed me around uh what they wanted me to see...but the fact that all the doors were locked and it was very...it was very institutionalized, you know. I mean, I just--it wasn't any place I wanted...my son to be. And so anyway, what we did was, we investigated outside..outside the state. And uh that took us to the Devereux Foundation in Philadelphia. And um...they had--it was a beautiful setting, it was a beautiful place, but it was very very expensive. It was like uh I think it was \$6700 a month. Now how you gonna pay for that? My husband was a university basketball coach and I didn't work. How you gonna pay for that? So, we went to the county and...Hamilton County, and they provided, with our insurance and everything, they provided for Tommy to go there. Everything was provided for him to go there, and we paid on a sliding scale...with the hospitalization. But that was a fight too...for about a whole year with Blue Cross/Blue Shield at the time. But, it was a hospital setting, and they had doctors, and that's what they needed to get the hospital...type there to go. Anyway, it was very far away and how you gonna let a 7 year old go to Philadelphia when you're in Cincinnati? It was...it was not a fun time, and I can imagine how scary it was for Tom. The same as I can imagine John was in the same situation, and just sitting here listening to you know, him saying how scared he was, I'm sure my son then Tom, was just as afraid. But, what was really nice about that whole thing is just like John says, how he talked about how he had friends there and he liked this person or that person or a staff. Staff...in those situations and at those hospitals, did treat the individuals nicely. I mean, my son has very fond memories of the Devereux experience.

And uh so then we came to another county. From Cincinnati we came to another county and Tommy was still there, and we came to uh Summit County. And I came to Summit County and we--my husband became the head coach at Akron University uh basketball. And you wouldn't think that because we didn't leave the state, that there would be any problem. We didn't feel that you know, so that just carries over. You get another Blue Cross/Blue Shield. Well, that's...that's not true, you know. I mean the insurance fight became, you know a big thing again. And uh...at that time um...I met--I wanted to bring him home anyway, so uh I mean the whole time that he was gone of course I wanted to bring him home because I'm a mother. And uh I met uh some people here in the county and...but the county just never heard of putting money together to send somebody out of state to a...a different place other than any other developmental centers...in this state. I mean why would they send him out of state? Well, the reason they would send him out of state is because they didn't have anything. A lot of people never even heard of autism, you know. And where you send someone with those kinds of problems. So...Summit County ended up paying for a couple of years, but I could not really handle the fact that you know, I mean he was gone. And he came back when he--I mean he handled it for three years and two years. So a total of five. Three in Hamilton County and two in uh Summit County. But, we brought him home, and at that time it--the reason that I did that is because when the new law came into effect that everybody was entitled to an education. What was? I don't even know.

JM: 9412763

JWC: Yeah, yeah no yeah. And uh so I just went with that...in my mind, and made sure that all those provisions were--they started a program over at Kent State University, at that time. Kent State University with uh Kent-Roosevelt Schools. So living in Stowe, all we had to do was take him to that area every day. So...that's where Tommy went until he was 21. And then through

case workers, and different people, you know they said do you want us to sign him up for living in a group home? Well, you know, no I didn't want to sign up for living in a group home. I did visit some of the group homes and group homes are fine. There are some very fine group homes and there's some that need a little help, but uh...I just thought well gee, you know I could do this. I could do the same thing. So...I had raised three sons. I had a big house, and that's where my uh...I felt my experience and my expertise came in. Everybody used to compliment me on Tommy's manners, but I do say that a lot of his discipline and things that happened for him and the way that he is, has a lot to do with the fact that he did have that structure at the Deveraux Foundation. You know. And he...you know...he is very disciplined.

JM: Did you--would you visit frequently?

JWC: Uh...they did not allow us to visit frequently. It was...uh...they didn't want us to do that because...especially in the first year, because that--they felt that would be more harmful to Tom. But, we called all the time. You know, we called and we talked on the telephone and...every holiday we visited and we brought him home every holiday. But, you know as far as visiting...they didn't want us to be there every month or anything like that. They wanted us--the holidays were what they wanted, you know. So that was...I don't even know how he I through that, but I did. I did. It was a very hard experience.

JM: So, you brought Tom back...

JWC: So we brought Tom back and um...and he thrived on you know, being at home and...and he's in Special Olympics too, and uh I went through different agencies and started to do respite work and uh then I just wanted to be a foster parent and so, I saw an ad in the paper one day, and that's how John came to live with--in my home. And so since then I have--I've had several people that have been with...you know, in our home. But uh I think now we have, what we call our final...our final family. (laughs) Um...I have another foster guy that uh is 56 and he gets along really great with John and Tom and...and it just really works out great. They're--they're all very very compatible. So now I'm looking ahead to what's next. You know, for them. In my case it's you know when I'm gone. So...I'm looking ahead. I've just started to uh think about what we're gonna do for the future. I know what I'll be doing but you know, we don't know how long I'll be doing it. I'm getting old. But, I mean I want to do this until I'm not here anymore. But, you just never know when people aren't going to be around. So...I want to think of the future and maybe have our house for John and David and Tom.

JM: Mhmm.

JWC: You know I'm thinking in that area. So I'm just gonna...

JM: Judy was just explaining the uh chain mail to me. Uh the uh...tell me what the doctors told you for--the point of the best thing for the family and the best thing for Tom in his situation. Looking back.

JWC: Um...back in the University of Cincinnati and that uh...hospital situation that we--that I was going to...my husband went to uh therapists...it was a family thing. I went to a therapist, he

went to a therapist, Tommy went to...you know went to the school every day. Uh...at the end of the three--that--he started that when he was three and he wasn't speaking. And we'd had all these tests. And uh at age seven when he was saying everything, all at once Tommy just started to talk and said every single word there was. Uh...he just uh...they came to us and the end of that year and said, uh what we feel is that Tom needs a structure. He needs more of a structured uh where he gets up every day and he's like in a hospital, really is what they said. Institutionalized. That's what they told us. And they said there are some programs in Ohio that have it and this, this, and this. This is where you should go and check it out. I went out and could not believe that anybody would want me to do that. I mean how could that be...how could that be better than living with me? You know, I just could not believe that. Was it because I had said the wrong things in all those therapy sessions? I don't know. I never ever made them think that I...you know, I was very truthful but I just never...I think I was good. I think I was good at what I do...being a parent. So...

JL: They made you doubt that?

JWC: Yeah. I really doubted that. I really doubted that. It was a...

JM: Can I--

JWC: Except, then you know I have two other sons.

JM: Because we're not going to use the questions...

JWC: Yeah.

JM: If you could just make the statement that the doctor's exchange with me made me doubt I was a good parent. Or something like that. Make it a full statement.

JWC: Yeah. Um...by the time Tom was seven and he had seen many many doctors and yes uh...you know we really didn't...I didn't know too much about autism at the time, and I really...I really felt that there was you know...I didn't know what really was goin' on. So, the doctors are...the doctors were really...I mean they acted...they knew what they were saying, and knew what...you know, I mean I had to go by what the doctor said. You know, we were seeing the doctors for that period of time. I just don't know what you want me to say, you know.

JM: Judy--what Judy had in your exchange, you said you really doubted your skills as a parent.

JWC: Yeah. Yes, I did.

JM: I'd just like you to say...

JL: The doctors made me doubt...if that's what...

JWC: Yeah.

JM: However--however you'd like to say it.

JWC: Ok. The doctors made me doubt that I was a good parent. Uh...

JL: You made a wonderful statement about um...when they recommended him--Tommy going to the institution.

JWC: Mmhmm.

JL: How could that be better than living with me?

JWC: Yeah, really. That's right.

JL: But the doctors made...

JWC: But the doctors made those statements and the doctor is always--in my-- you know I was always...you know, I always listened to the doctor. I mean who doesn't listen to the doctor? You always--that's why you go and you get professional help. You know, uh...if a doctor or people...I mean we had a group. We--we had psychiatrists and psychologists and all kinds of people working with us for that whole three years. And we--sometimes we saw them twice a week. Uh...it was a family thing, that they were just starting in that area and um...they wanted to you know, they really--they were very helpful. I thought they were very helpful to me when I would go in and we would talk about different things. Um...but at the end of that, it was the biggest shock of my life when they s--they called my husband and I in and they said, our recommendation to you is to put Tom into a structured setting. And a structured setting would be to institutionalize him. I--I just couldn't believe--I just really couldn't believe it.

JL: Can you identify just real quickly, in one or two key points when you went to look at the institutions, what made you make the decision that they would--that he would not be going there? What's--I mean what really got to you as a mother that said he will not go to Apple Creek or one of those institutions?

JWC: Well, even though at the University of Cincinnati and the hospital that we were associated with, Children's Hospital in Cincinnati, we were associated with, everybody was very nice but the doors were locked, it was a hospital setting, I meant you went in--it wasn't like uh nursery school or anything like that. It was a hospital. And then...you had windows where you were watching the children and you know, everybody could see in, the kids couldn't see out. And what you see, you've seen stuff like that on television and things. But, uh...when they told us to go to these other places, my first thought was I went to two of 'em and I thought, have they ever been here? Have these people who sent me here, ever been here? You know, they're telling me to send my seven year old son, here? You know, I mean maybe I'll just have to stay home with him forever because that was my choice. At that time there was no bill, 9412763 (laughs). Whatever. There was no bill saying that...you know, he was to have the education that should have been provided to him. So, my choice was stay home with him? Well, I guess I--guess I'll do that. But I was told that that was not the right thing to do, was not the right choice to take. You know, I went back for several counseling things after they had told me that. I had to go

back and you know, they told me like two months before he was out of that school. And I had to go back and I had to tell them what I was discovering and I just couldn't...they just told me that I was wrong. They were right, and I was wrong. And so, that's why the decision to go ok, if I'm not--if I'm not happy here, maybe I could be happy with some other setting. And so that's when I found Deveraux. And Deveraux was a beautiful, beautiful setting. But it was very very expensive.

JL: And Apple Creek you chose not to--

JWC: Oh...

JL: Because it was...

JWC: Because it was real scary. It was real scary. It was everything that I'd ever heard of. As I--as I was growing up, you know to hear so and so had a nervous breakdown and so they're...they had to go to a hospital and the doors were locked and you know, it was just very scary. And I could just not even imagine sending my seven year old there. So no...I...

JM: Judy, we have just a few more minutes. We're on a timeline because the building needs to be locked up, to be out before then.

JWC: Mmhmm.

JM: The trend--what capsule of--of time that you're bracketing here...

JWC: Mmhmm.

JM: Is uh...it--we're talking about assumptions...and pressing people into the institutional--institutionalizing their children. And then adults being integrated into the community and living successfully together--

JWC: Right.

JM: as common--

JWC: Right.

JM: --community members. If you had to make one closing statement, to people who didn't--who don't understand and who are resistant to inclusion, people with disabilities in the community. And--and you had one opportunity to change their attitude, what would you say?

JWC: One thing I can say is that I can understand come of family members and parents. I mean I can understand them in one way, because not everybody can do what we as providers do. I mean a lot of people even...I know I'm getting off what you had even said, but a lot of people have even said to me, my very, very good friends, how can you do this? How can you do what you do? You know, what makes you think that you want to do this. It's very very natural to me.

It's very natural to me. But I think it's only because there are some people who can do it, and there's some people that just aren't cut out to do that. And I mean even family members. You know, that...don't get a lot of respect. I think a lot of people--a lot of family members...just try not to recognize it, you know. I mean I don't think it's--I think there's a, you know, just a lot of problems in that...in the family member...thing. I know I've been very critical to a lot of people. It's like I can't...I can't believe that some family members might not call for...a whole year. But, that's just because I think that some people do this and some people don't do this. You know as far as taking care of, and are caregivers.

JM: Thank you very much. What you said is uh--