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**ORAL HISTORY VIDEO INTERVIEW WITH
BETTY WILLIAMS
OCTOBER 1, 2016
INTERVIEWER: JENNIE TODD
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 047-DO**

BW: BETTY WILLIAMS

JT: JENNIE TODD

PH: PEGGY HOLTZ

[00:00:10]

JT: Are we ready to go?

BW: Yes

JT: Alright. So, like I said, you have come a long way, Betty. Congratulations!

BW: Thank you.

[00:00:19]

JT: You had a recent award called the National Association of Council on Disability as the Champion of Equal Opportunity Self-Advocate Award from U.S. Senator Joe Donnelly. Can you tell us about that award?

BW: Well, the award is about leadership. And it's about, it's called the CEO Award, Self-Advocate of Equal Opportunity, Champion of Equal Opportunity. And to me, I think what it means is that as a leader, I champion, the opportunity to help others get opportunity to do the things that they want to do and the things that help self-advocates become involved in their community.

[00:01:22]

JT: Good. So, how did it come about that you got this award? And you can tell me about some of those reasons you were nominated.

[00:01:32]

BW: Well I really don't actually know why I was nominated other than, I guess it was through the history of what I've done and the things that I've done. From the stuff that I've done in my own community to the stuff that I've done with Self-Advocates of Indiana and then through, you know, all the things I've done with The Arc of Indiana. And through all of the different things that I've done over the years.

[00:02:14]

JT: Can you elaborate on some of the things that you've actually done, because I know there's a lot of them.

BW: Oh, god.

JT: Some of the training and education programs that maybe you've been involved with? I know you've been involved with voting--

BW: You know, at one time I taught voting, I taught people the importance of voting and why they should vote and what's important about voting. And then, you know, this is a good time to talk about that because we have an election right around the corner. And the most thing I tell people about voting is that it's important to vote because that's the way we get our voice heard and get, that's the way we get things done, you know? Is to stay involved with local and then state, and national, and vote. You know? And get our voice heard about what's important. And another thing I tell them is that to vote for people that champion your issue.

The ones that care about your issue. So, that means that everybody's going to vote whatever their heart tells them to vote or what's important to them and not hopefully what's important to their friends. But what are you, what are you championing? What's important to you, you know? And I hope that's how they vote.

[00:04:01]

JT: Okay, and I know you've done some trainings?

BW: Mm-hm.

[00:04:04]

JT: On other topics, and you've done some work around teaching people to be advocates?

BW: Yeah.

JT: You want to talk about some of those?

[00:04:10]

BW: Well, some of the stuff I've done, right here at IU with the Building Leadership Training I did that for a few years, where I taught people that were just coming into advocacy. Some of them were just coming into it and I talked to them about the importance, you know, I co-trained and taught them about the importance of advocacy and what advocacy is and why they should be involved.

[00:04:46]

JT: And didn't you guys have some, I don't what you'd call it, was in your groups where you have different topics that people give speeches or presentations on?

BW: Yeah, um--

JT: Did you ever have that?

BW: Well, we're just getting ready to start that over. So it's the Speaker's Bureau, and then we're getting ready to start a new, we're getting ready to do that all over again. And we're going to have topics from self-advocacy and, self-advocacy and supported decision-making, and some things that are really, that we think are really important to people with disabilities. And the main thing we want them to do is to go out there and talk to people about what's important to them and what, you know, the topics that people want. And then hopefully we have the topics they want.

And we'll just have people pay to go out and speak about the importance, mainly about the importance of self-advocacy, supported decision-making, and any topic there is we have that helps people grow.

[00:06:21]

JT: Good. And you've been on lots of committees for all kinds of things. How do you? Well, let me take that back, I'll ask you that in just a little bit. So you got this award in Washington, DC.

BW: Mm-hm.

[00:06:37]

JT: Tell me about the experience of getting the award and what it was like to meet with the president, you know, because you could talk about that committee as well?

[00:06:47]

BW: Well, I haven't met with the president yet, I haven't been that lucky but maybe one day. If I don't meet with this president, maybe I'll meet with the next one. So, to me, what I went to get that award for, to me the award, it was a surprise. It was really a surprise, especially since I had been so sick. So it was actually a reason for me to get up and start moving again, you know? It reminded me of all the things that I had done that I wanted to continue to do. And so when I went and got the award, one of the things that I talked to them about was the fact that I was at that time, still in a nursing home, I left the nursing home for a couple of days to come and get that award.

And I talked to them about the fact that I had been so sick lately, you know, and that I had a couple other sicknesses. But even while all that was devolving, I kept going and kept doing stuff. And then so it's important to let people know that even though you have something going on, you can keep moving. And so what I didn't understand and what I didn't know at the time was I was talking about my illnesses and talking my heart, the fact that I had a heart problem. And I was talking about my latest illnesses, and then there was some self-advocates in the audience in Washington that took all this to heart. And they came and talked to me about what they were going through and then some of them came to me and was talking about, "How did you do what you do? How can I do that?" you know?

So then, I was all like, no matter what you say, it's important. You know? How you say it and what you say to people, even in the middle of whatever you're going through, all your adversity, there are people out there who need your message, who are listening. And so I got a few conversations with people that were either just wanting to know how to keep going in advocacy and some wanted to talk to me about their own illnesses. And so, through that I just learned how important it was to share your story, even if it's about an illness that you went through, that you just went through. You know, no matter what you're going through, there may be something that you have to say that will help somebody else.

So you just got to keep moving, it's important.

[00:10:13]

JT: That's really good, Betty. Okay, so now I'm going to ask you specifically about the President Obama's committee for people with intellectual, developmental disabilities leadership. Because you're on that committee.

[00:10:26]

BW: Mm-hm.

[00:10:26]

JT: So what is that committee and what's your role?

[00:10:30]

BW: Well, my role, and I'm a self-advocate and so I, you know, I talk about whatever it is I think that's going to help people with disabilities and other self-advocates. And what we do on that committee is that we, we are commissioned to write a report to figure out what that report is going to be between the committee members. And then we write a report on it. We gather the information we need in order to do that. That is the main goal of that committee. Is to get and write a report of what we think is important to families and people with disabilities to help their lives. And we usually do that within a year, a year's time.

[00:11:38]

JT: How far have you gotten on the report?

BW: Well, we're starting on a new one and we have started to toss around what those issues might be but we haven't gotten any further than that.

[00:11:52]

JT: Is this your second year in the committee, then?

BW: This is, yeah, this is my third year.

JT: Okay, so let's...

[00:11:59]

PH: What's the committee that you're on just until you want to be, or? Every year?

BW: No, it's either every year or every two years. It doesn't, I think I'm on it for another two but I'm not sure. You know, you're either on it for a year or two and you know, people are different in different ways, so.

[00:12:28]

JT: Well let's back up and somewhere I need you to say that you're on President Obama's Committee for People, because it could be any committee. I forgot to have you do that.

PH: Well I could always just maybe add that as a title.

[00:12:40]

JT: Oh, okay. Okay. So since you've been on this for several years now, what kind of issues have your reports focused on?

[00:12:51]

BW: I think the last one was, it had quite a few on the last one. And I can't remember what they are but I can tell you where you can get those reports. They're on the AIDD website, the Administration on Intellectual and Developmental Disabilities website. Now, they're pretty important reports and they're written by professionals, family members, and self-advocates. And then we have some federal partners on there, too. So it's a pretty important committee and the report we do is pretty, as important because we also do recommendations for policy and then different things like that that are written in that report.

[00:14:04]

JT: Okay, great. Good answer. Alright, so let's talk about what you're currently doing. So what's up with Betty Williams-- after accepting the award, and--

BW: What am I currently doing? Well, one thing like I said, I'm, we're really starting to work hard right now on the Speaker's Bureau and besides doing our different meetings and things that we do all the time, we're doing, you know, our Speaker's Bureau is the next thing that we're going to bring up, and so we're working pretty hard on that right now.

[00:14:44]

JT: Now the R-word, do you?

BW: The R-word?

JT: Getting rid of that.

BW: Well, you know, getting rid of it in Indiana, I don't know that, I know that we're still kind of working on the statutes for it, but getting rid of it in the, when we were on the DD commission, and that's why it ended up being a DD commission, because it was the 202 and the MRDD commission. And we got rid of the MRDD commission. And the funny story around how we got rid of the MRDD commission name, and the way that we got rid of the MR on it, is that Indiana had the 2008 self-advocates-- the SABE Self-Advocate conference and the way we got rid of it is that the self-advocates, the legislators came and we did a session with the legislators.

It was legislators from all over the country. And it was, and the people that did the, the people who work with them or did a lot of work with them they invited their legislator to come and talk and so we invited Sheila Klinker to come and talk, who was at that time one of the heads of the MRDD commission. And when she got up and she introduced herself and shared a bit about MRDD commission, she got booed real loud by the self-advocates. And she didn't understand what it was about at first, but then we explained it to her, they explained it to her as when she got done, they explained it to her, you know, as we were talking, it got explained to her why everybody booed her.

[00:17:18]

...But, it only took the next meeting of the MRDD commission to change that name from MRDD to DD commission. You know, she may be a part of that name change. She got up and she said, "Betty said that the recommendation to change the name of the MRDD commission," and I was like, "Yeah," so she was like, "What do you think of that?" I'm like, "Yes!" And so we made the, you know, we did a, I can't find the words that I need.

PH: It's fine, just go with what you have.

BW: You know, not to make it the, you know, we did the vote and everything so we changed the name of the MRDD commission that fast, that day. And within five minutes the name of the MRDD commission was changed. And, like, she got up and said it was all due to the fact that the self-advocates let her know that they did not like the MRDD words and that they wanted the MR taken off. They didn't mind the DD, but they wanted the MR taken off. So, that's a funny story about how that happened, you know, it happened because at that time there was a lot of discussion and a lot of stuff going on around the MRDD, around the MR word and changing the MR word.

JT: That was a good story.

PH: Good story. And I need to go back and look at that footage because we videotaped some of those meetings to see if that was on.

BW: Yeah, it's on, you probably do, somewhere!

JT: She was probably thinking, "Betty, why didn't you give me a head's up!" [Laughing]

BW: And then you could edit it out.

[00:19:4]

JT: Now Betty, going back to the early days when Darcus started Self-Advocates and you got involved, did you ever--

BW: Did I ever think that we'd go this far and that things would happen like they have? No. No idea, and you know, I never thought beyond, you know, that moment and what it could be like other than I knew at one time we were just meeting at Noble and that's all we were doing, and then I realized that we needed some other kind of place where we could do other work and we could do like the important stuff that we needed to do. So I knew we needed a board of directors. And so beyond that, I really couldn't see, but I knew that we needed that board of directors so that we could get more work done. And so that was some of the hard work that we did to starting the board of directors and at one time getting us a 301, a what is it?

[00:21:02]

JT: 503C?

BW: Yeah a, well whatever it is, you know what it is. I'll redo all this but --

PH: You're doing great, you're doing great. I edit and if there's something that I can't work--

BW: 501c3 that's what it is, it's a 501c3. And we did all that and that was a lot of hard work. And those are the kinds of things we did, you know, besides going around and going around the state and training people on what self-advocacy was and the importance of it and just really getting organization started. And that was, in the middle of doing it, it was a lot of fun, but it was a lot of hard work. Because you had to do a lot of preparing in order to do those, you know? So, we really worked hard with all the stuff. So, and I miss her so much, every day, you know?

JT: Say that again.

BW: And I miss her so much every day because she was like my friend, my mentor, my trainer. Just, just everything, you know? And that, you know, she was important to the start of self-advocacy. And then the start of our working on the state of Indiana and all the, you know, self-advocates and people with disabilities and showing them and just let knowing them know they had a right to hope and dream about anything they wanted for their life. And still today there's a lot of work to be done because there's still people out there that don't really understand that they have a right to hope and dream, you know? And to do what it is they want to do with their lives.

[00:23:18]

You know, I work with that every day and it's really hard sometimes to keep on track and to really do the things that you want to do. And I keep getting sick in the middle of everything that I want to do. But, you know, hopefully something happens and all my hopes and dreams come back. And I was beginning to lose hopes and dreams, when I was in the nursing home this last time, I really didn't have any. I was like just climbing the walls trying to figure out when I was getting out, you know?

When everything was going to heal and when I was getting out because it took me a long time this time to you know, being in a nursing home for 8 to 9 months and being in the hospital for a month and a half was a really hard thing this time.

And so I'm hoping that I can stay well and I can keep moving and I can keep helping people understand, and supporting people to understand that they have a right to hope and dream for their life. And you know, when you've been through an illness like this, everything becomes more and more clear and I want people to be able to live the life that they want and to be happy.

[00:24:52]

PH: So what, I was just wondering, going back to when you got into self-advocacy, was there something that triggered you to say that you wanted to get involved, or how did you get in?

BW: I'm just nosy, if you want to know the truth. I've seen this sign up on the wall and it says, "There's a meeting at such and such," and it just said what time and where the meeting was at and said, "And if you want to know more, come to the meeting." It didn't really say, it was like a mystery of some kind. That's the way they wanted it. And it was actually a self-advocacy meeting. And actually, I-- it was on the wall for like three or four months. And every month, I seemed to get some kind of cold or some other reason I couldn't go. I seemed to not be in the building on that day, for whatever reason. And it went on for about four months. And finally, on this like fifth month or so, I went into these meetings and then that's how I got started.

Going into the meetings and trying to figure everything out. And one of the first things they wanted to know when I got in there is, "Can you write?" They needed and wanted a secretary. And I was like, "I don't know, yeah I can write," but I wasn't too eager, you know. And that was the beginning, you know? I got involved with my local group and we started doing a lot of interesting things and started talking about a lot of interesting stuff. And from then on I started going to the statewide meetings and went to one national conference and by the time I went to that one national conference, I was really hooked. So I really wanted to be involved and then I really wanted to just keep going and hope that one day, you know, it would be, you know, I couldn't see really what it would be.

But I just knew it was something that I wanted to be a part of. And that I actually want to be a part of now until I retire. And I am going to retire like normal people. You know, I am. I have that plan. But, you know, even then I might do something around self-advocacy, who knows.

[00:27:53]

JT: What year did you get involved, do you remember?

BW: 1990, 1991. Probably. I know it started in 1990 and I'm thinking I got involved, really involved, in the late 1990's or early '91, you know, because one of the first things that I did as I was becoming involved with self-advocacy was I got involved with Partners in Policy. And I graduated from the first class of Partners in Policy. And, you know, that was one of my first, you know, looking into and being involved with the Council and today I still get excited about the Council, so. You know, I get excited about IU, I'm probably more excited about IU, I'm really excited about IU and some of the things that IU's getting ready, that you guys are getting ready to get into, so.

JT: Well I have a quick, I have two long questions for you.

BW: Mm-hm.

[00:29:12]

JT: So if Darcus could tell you what she's thinking of what's going on with self-advocates, you know, and what do you think she thinks, you know? Do you think she's surprised, too, at how far the group has come?

BW: I think she would be surprised, I think she would really be happy with the fact that we have an administrator who is helping us to be able to do the things we're doing and that person gets paid for it. I think it would be a surprise. I think she would really be happy if we could get like 10 or 12 or 15 self-advocates that could be paid on a regular basis to be involved and work for self-advocates. That's my next dream, you know?

[00:30:07]

JT: That's my next question, because you've been doing this now for like 25 years?

BW: Yeah, 20, 25, something.

[00:30:13]

JT: Yeah, you've been doing it for a long time and a lot has changed. Like you said, you were really surprised at how far the group has come. So what do you see for the next 5 or 10 years for the group?

BW: I'm hoping for the next 10 years, somehow or another, we can really get some funding to, because you can really, you can do stuff without funding. But, I think if we could get funding, all over the nation for all the self-advocate organizations in the nation, that would be my biggest dream and my biggest hope for our growth as a nation of self-advocates. And I just, I have, all kinds of hopes of dreams about that and it may be starting, I think it is, but I don't know for sure. But I'm just, that would be my biggest hope and dream.

[00:31:21]

JT: If the groups get funding, how would they use that funding?

BW: Well, to help them continue to do the work that they do and then be able to, you know, maybe hire some more support to be able to do what we do because one thing about it is, you know, one person or two people can't be all over the state. But if we had more people that we could pay to support people to do what we do, then it would be important. But then, you know, we could use some money on projects, too. You know, to get projects started and keep them going and stuff like that, you know.

[00:32:16]

PH: Do you have a feel for what the trends are in self-advocacy, what are self-advocates talking about, what do they want to see?

[00:32:23]

BW: What do they want to see? I think most self-advocates just want, I really can't tell. You know, in employment, I think people, our hopes and dreams are still that people get a decent pay. And people can go out into the community and get, you know, get decent pay and be able to do the work and do the jobs that are important to them in our communities. Around housing and all that, and just to have affordable housing and to be able to buy your own house, if that's what you want. It's just, I think it's all about being happy and growing and there's all kinds of issues out there so I don't know which one to really talk about.

[00:33:20]

PH: You made me think of something. You talked about your health, I was wondering if you have any stories related to the healthcare or how you felt your services were, or.

BW: While I was getting... You know, I think about that and-- I can't really say, because I was so sick that I wasn't really into what, how I felt even. I was just, you know, sometimes I was just laying there. And I really didn't know about how I felt and how I wanted my services to be and all that. And I kept getting, I got in a lot of trouble about, I was at the point where I wouldn't eat and didn't really care about eating this last time. And so I got in a lot of trouble about the fact that I didn't want to eat. And my doctors kept telling me, and one in particular kept telling me, how I needed to eat and how I wasn't going to get stronger if I didn't eat.

And so as far as, you know, the healthcare services, I just mainly wished that doctors would figure out how to talk to people with disabilities. And just remember that it's important to be able to talk to people about what's going on and how their health is now and, you know, what you want their health to be like, you know. And I think that's important conversation for doctors to have with their patients. You know, and for you know, sometimes for the nurses to be able to freely talk about what you may be going through because I know that I was laying there and, you know, I think people really didn't understand what I was going through and I didn't understand, but I had, I won't tell you the story of one young man that I had that was a, him and his sister both, well, he had a sister that was, they were students.

And as students they worked in a different areas. Like his sister worked in admittance. So she remembered me coming through there and she remembered that at the time when I came through there I wasn't talking and she could tell that I was really sick. And I didn't know, you know, I got into the ambulance, I didn't realize how sick I was. I actually passed out and didn't know anything by the time I got to the hospital. And so I was very sick and didn't know already.

So, I was admitted to, they put me in ICU. And there was a young man that worked in ICU and then he would come and take my blood. And every time he'd come, I'd have something, I'd like make a face or have something to say, and he would like, he finally told me one time, he said, "I know you don't like seeing me," he said, "But I got to do this job," you know?

[00:37:05]

Come to find out he was a student in training to be a nurse. So, he actually became a nurse and him and his sister both became a nurse this last May. And so I thought that was a great outcome, that I didn't realize that until after I left the hospital. And I went to the nursing home and they came through the nursing home as part of their training, too. And I said, "You remember me?" and he said, "Yeah," he said, "Do you remember me?" I said, "Yeah." He said, "You were a sick person," he said, "You were very sick." I said, "I know." I said, "You worked in ICU, didn't you?" And he said, "Yes." And so, I mean, that was important, that's an important story because it was, I think it's something about how important it is when you don't know that those relationships are pretty important and that you may see them somewhere else at some time.

And then, you know, they became two of my favorite people because they really had to work hard to take care of me. And I understood that and I now understand how important doctors and nurses are. And I probably didn't understand it until this last illness, so, it's really important. And I'm glad to know that hopefully you guys are going back into this area.

[End of interview]