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Betty Williams

10/19/2007

10:30 AM – 2:30PM

Indianapolis, IN

Caldwell: Would you mind sharing how old you are right now?

Williams: I am 48.

Caldwell: So, where were you born?

Williams: I was born in Richmond, Indiana.

Caldwell: And you grew up in Richmond?

Williams: I grew up there. I was born and raised in Richmond, Indiana. I went to school there and had all my first bad experiences in school there.

Caldwell: Why do you say that? What kind of experiences did you have?

Williams: Well, school was like really hard for me. When I was at school, kids would tease me and call me names sometimes. And make me feel bad because I was different, or I was different from them and they knew that. If I wasn't dressed they could see my braces, so they knew I had a disability. So kids were always picking on me. Even the kids in special education picked on me. Everybody picked on me. A lot of times they had me to the point where I didn't want to go back to school the next day. For me growing up, things were hard for me. One of the things I did notice before they sent me to the special education class was that I was slower than a lot of the other kids in the class. Usually they were waiting for me to get something done before they went to something else, and that kind of made me feel bad all the time. It made me feel like I didn't know anything, or something. In elementary it was really hard. I knew I was different. I knew I had a disability, but I didn't know anything about any of that.

By the time I got to junior high school, I felt a little bit better about it but then I decided to take my braces off. So I quit wearing them and people didn't know I had cerebral palsy. They didn't see my braces. But people who knew me in elementary knew that. I think part of the reason I stopped wearing my braces was because I wanted people to stop teasing me all the time and stop messing with me. I don't know. I think it helped some, but then it didn't make me feel better because my legs would always hurt then. A lot of it might have been that a lot of them didn't know other people with disabilities, or something. They just thought I was an easy target maybe, like they think all people with disabilities are an easy target. If they get to know us, we are just like they are. We want the same things. All I wanted in school was fiends, and I didn't have too many of them. I had people that I said "hi" and "bye" to all the time, but I didn't have very many friends. I had one friend in particular all the way through school.

Caldwell: Who was that?

Williams: Her name was Charlene. Now she lives in Ohio. When her mom died she moved to Ohio to live with one of her sisters.

Caldwell: Was she in your class?

Williams: Yeah, for most of the time she was. We went to high school at different times, but for the most part we were always in the same class.

Caldwell: Did she have disabilities, Charlene?

Williams: Yeah.

Caldwell: Do you think that is why you became friends?

Williams: Well, I don't know that we knew that at the time. She didn't have the same disability as I had. She was kind of slow like I was, but I don't think that was what tied us together. One day she was just there in my class and I was just there. We didn't start out at the same time; by the time I was in second grade she was right there. She moved here from another state. I think she was born in the other state and they moved here when she was young. So by the time we saw each other in school we were friends. We are still friends, but we are not the kind, either one of us, to pick up the phone and say, "How are you?" So, whenever I know she is in town I go and check her out, and she will do the same with me. That is the only time we see each other now because we don't bother to keep in touch. I want to, but I move around so much, it is hard to do. Yeah, that was the one friendship through school that I truly had. We started out in elementary school but when we got to junior high school her mom would take us to school. She would take both of us to school. We just had this good relationship through school and kept it until she moved. Today we can still talk, just like we haven't missed a beat. So that is the good part about it. We talk to each other just like we haven't really missed anything. So we probably are still as tight as we ever were, we just don't see each other.

Caldwell: When you were in school, were you in a class with all people with disabilities or were you in an integrated school? How was that?

Williams: I was in special education, but I did take some classes outside the class. When we got to junior high I took some classes. I took math classes and a little bit of English and stuff outside of there. They were always letting me take something outside of there, but it was like for the most part of the day that is where I spent my day. When you are in that class, to me it was like, even when you were in junior high school, it seemed like you were learning the same stuff you learned in elementary school. To me the stuff wasn't hard. It was like they were teaching you the same stuff over and over and over. Sometimes I felt like I didn't learn anything new. That, to me, was the bad part about being in special education because I felt like I

didn't learn a whole lot of new stuff until I was outside of the class, and I had math classes and algebra class.

But the thing about going to school and being in that class was that most of the time that class was somewhere way away from all the rest of the classes. You had to go down to somewhere we call the boonies to get to your class. It was like the last class on the end of a hallway or something. I remember in junior high it was up on the top floor but way back away from something else. In high school it was way back in the boonies. It was dark back there. The only other thing back there was the high school band. That is where the band and stuff were. Everybody said we better go back in the dungeon. That is what we called it. We had to walk a long way to there and it seemed like it was dark back there all the time. So some people called it the dungeon because it was just so dark.

I had quite a few friends in that class. One girl in particular, she was one of my good friends too. I had about two. I only had about two. But this one was a little younger so we didn't have a lot of classes together, but when we got to high school we were in the same special education classes in junior high and high school. One thing I remember, we were talking about being back there in the dungeon. We ran into each in a reading class after we were adults, and she is like, "You are taking reading too?" I am like, "Yeah, I am taking reading too." She said, "You know, why didn't they teach us this stuff in school?" Now, we know we could have learned, but they just didn't take the time with us when we were in school. They didn't have or they didn't want to take the time to teach us in school, and some of us could have learned and had a better life. Education is so important even for people with disabilities. Some of us can learn, but they don't take the time to really teach us. So that is the really bad part. We want to learn, but sometimes people say we can't learn or they don't take the time to help us do that.

So, we would feel bad when we were in school. I didn't really start feeling good about myself until I was an adult and saw that it wasn't so bad to have a disability. You could feel better about yourself even though you had a disability. When I was younger, even though I really didn't pay attention to the fact, people didn't say, "oh, you have a disability," I knew it was there. I knew I was different in some way, but I didn't like thinking about it. The first time I really thought about having a disability I was about nine years old. I was sitting there thinking, "Why am I so different?" Nobody wants me to play ball with them nobody wants me to do anything. I am the last one to be picked for anything. I was just really feeling bad that day I think. I was watching everyone play ball and I couldn't play. They wouldn't let me know or I was the last one picked, which always made me feel bad, and then after that I didn't want to play. So a lot of

times I just found myself on the sidelines watching everyone else play, even though I knew I wanted to. I knew I wasn't that good at it, but.

Caldwell: So, you were talking about when you were about nine and you started to think about having a disability. You said you used to feel bad about yourself and your disability. How did that change?

Williams: Well, I didn't start to change until maybe I got to high school, and different things started happening in high school. Like I would hang out with my cousin sometimes and go to games and stuff, and I just started feeling a little good about myself as I got older. I felt like having a disability and being different wasn't so bad, as long as people accepted you sometimes. I think just being able to hang around with different people as I got older helped me do that. I guess when I really started feeling good about myself and better was when I went into services and got services through the local Arc. I could see some of the skills that I had and learn new skills, but I stayed there a little too long. I went back and forth, back and forth. I spent like 20 years there, or more. Like last year I just left for what I think... But I think that is when I started to feeling better about myself. I was an adult by the time I really started feeling better.

Caldwell: And what kind of services?

Williams: Like the workshop and vocational stuff, and that is how I started getting involved in self advocacy too. Being the type of person I was, I saw this big sign up on the wall the one day. It said if you want to find out more, come to this meeting. It told you what time to be there. I seen that on the wall like three or four times though, cause every time I got sick. It seemed like I was always getting sick and hardly getting better. Then finally I made it to one, and as soon as I got there they said, "Can you read and write?" I said, "Yeah, I can read and write a little bit." They said, "Okay, well you are going to be the secretary for a little while." I was like thrown into it from that point on. But that was an experience. I think then is when I really started to learn about what skills I had and what I really wanted to do with my life. But I never thought I would be doing the things I am doing now.

Caldwell: What was that first meeting like, when you went to your first meeting?

Williams: Well, it was like I went in there and they were talking about all the different stuff that we wanted to do. They were trying to set up some different goals. They said, "What do you want to do?" I remember one of the first things we wanted to do was to teach people outside where we were that we were no different from they were, and that we wanted the same things they did. So, one of the first things we did was talk about what we wanted to do. I just remember sitting up there with all the different ones who started this and we were talking about the different goals, like educating

the community. We always talked about how we were going to raise money –like have a dance to raise money and do something like that. A lot of times when we first started out we wanted to do things to help our agency. So we would do things, like one time we did an open house. We arranged the whole thing by ourselves and did the whole thing by ourselves, and some people came. It wasn't many but it was a start. We did stuff like that. That first meeting, I just remember having an agenda and going down through there and trying to learn how important those kind of things were. I just remember walking in there and they were like, "Can you read and write?" And I am like, "Yeah, but just a little bit." But it was enough to get us started.

Caldwell: Were they just starting as a group?

Williams: Yeah.

Caldwell: Had you ever heard of self advocacy before that?

Williams: No. Not before we started in Indiana, I had never heard of anything about it. I didn't even go... They had like three trainings in Indiana, and I didn't even go to any of them. Our agency sent some people, sent like two or three people to this meeting and they came back and started the group. One day I just seen that thing up on the wall and wanted to know what they was talking about. So I went to one of the meetings, but it was like three or four months after they had started.

Caldwell: And this was still in Richmond?

Williams: Yeah, I was still in Richmond. I was getting services there and everything. I think I kind of went into it because of some of the concerns about some of the stuff that was going on in our agency. I wanted our voices to be heard, but never knew there was a vehicle like self advocacy to do that. When I went to that meeting that is when I first started learning about it. I think I really learned a whole lot when I went to the first national meeting. That is when I learned the most about what I was trying to do. I knew a little bit before I went there, but I think I learned more and more when I went to that first national meeting.

Caldwell: Where was that meeting at?

Williams: In Nashville. That was the first time I went to one and it was in like 1991, something like that. I remember seeing people like Tia and Nancy there, but I didn't know them at the time.

Caldwell: What else do you remember about that national meeting? You said that is when you first started to understand more about the movement?

Williams: I just remember seeing all those people with disabilities and seeing that there were other people around just like I was or just like the different people from Indiana that I already knew. That was one of my first national experiences. Just going to that meeting, and I just remember going to a few sessions, and going to this one meeting where there was a whole bunch of people in it –just seeing all these people with disabilities. I guess that was one of the first times I realized that there are a lot of people in this world with disabilities and a lot of us have the same stuff in common. We all want to do more with our lives. I don't remember a whole lot about it now, but I just know I got more and more excited about self advocacy and wanting to be involved.

Caldwell: What are some of the things that you realized that you had in common? Do you remember?

Williams: We all wanted to have a job. We all wanted the same things that other people wanted. We wanted to have our house, to have our own apartment. I think we just wanted our own life and we didn't want people telling us what to do all the time, or living with our parents all the time and telling us what is what all the time. I realize that, but it took me a long time to get there, or just being able to get around in our own community, because I didn't even do that for a long time.

I had to negotiate with my mom in order to be able to do anything. The first time I took a bus ride by myself I rode from Richmond to Indianapolis, and that was like killing my mom. She was like, "Well, you better call me every night. You call me. You make sure you call home as soon as you get there." She really wasn't wanting me to do it, but she knew she couldn't hold me back forever, but we negotiated and she decided to let me take this class called Partners in Policymaking, that was one of the first times that I really ever went away from her and stayed away for a weekend or so. Then we did some training across the state and that was another chance for me to get away and do something that I wanted to do. So now, I travel all over the United States by myself and we still have the same rule, "You call me when you get there. Don't be in those hallways at those hotels. You get what you want and get back in your hotel room." Stuff like that. After all these years though I think she can see where I really want to do stuff and I really want to grow, so now it is like, "Okay, just call me." And now she might not even know that I am going to go do something until an hour or two before I am going to do it because I have that kind of leeway now. All I have to do is let her know where I am going and how I am going to get there. All she wants to know is that I know what I am doing and I am going to be safe, because I have done some stuff where she didn't know that I was going to be safe, and I didn't know.

One time my friend we were talking to some people from the university center and the lady convinced us that we needed to go to this rally. So we went to this rally in Washington and it was ADAPT, or somebody like that doing this rally. All we knew is we went to this rally. We didn't know where we was going. We had these tickets at the airport waiting for us. We didn't know where we were going or what we were doing, and we didn't really know the actual hotel we were supposed to be staying at. They had all this stuff arranged, but we didn't know where we was supposed to be. So it was like we get on the plan and we go to Washington DC and we get there we think that somebody is on the other end waiting for us and nobody is there waiting for us, right. Nobody is there waiting for us. So it is like we sit there and we wait for a couple hours, and then we wait, and like three hours went passed, and we are still sitting there. I am like, "You know Darcus, I think they are not coming. I am pretty sure they are not coming. It has been at least three hours." So then we start getting on the phone, trying to call all these hotels to see if they have our name. Well, we don't get through all the hotels. You know, there are too many hotels so we don't get through all of them. We think we know the hotel, we think we know the chain, right. We start calling all these chains and we still don't call the right one. And so I told her, "You know, I have a little bit of credit on my credit card, so let's just go downtown and find ourselves a hotel" So we do that, we go downtown and find us a hotel.

We go to sleep and the next morning we wake up and we call this number that we have, because we had been calling the number and nobody answered. We call this number that we have and we asked them where they were last night. We said, "Why didn't you pick us up." They said, "Oh, we went out partying." We were like, "What? You have us waiting at the hotel. You have us waiting at the airport, and you are somewhere partying." They said, "Oh well. There will be people with disabilities all over the place. Just follow the people them to the train." It is like, what? Just follow them? And you know how big DC is? They told us to just to get on that train thing and follow the people with disabilities. So we follow them and we do get to the rally. Oh, we had such a good time though. We forgot we went through all this stuff to get to the rally. We get to the rally and we are having a good time and, you know, the rally is over and we go back to the airport cause we wanted our tickets.

When we were at the airport we wanted our tickets so we could go back home and they said we couldn't go back because we couldn't get them until the next day. So the rally is over. We had a good time. We met a lot of people. And we go back to the airport, and we get lost from each other and we get nervous. She still talks about that today, how nervous she got because the plane was getting ready to leave and she couldn't find me. I was in one place and she was in another place, and we got lost

from each other somehow, and I am running around trying to figure out where I am supposed to be. We found each other finally, but that was an experience. If we hadn't had self-advocacy skills we wouldn't have survived that trip. We tell people that all the time. It is like if we wouldn't have been self advocates we wouldn't have survived that trip. That was one trip where we should have been sitting there bawling trying to figure out where we are going, but neither one of us had time for that. We was trying to figure out where we were going and who was going to be there and how we were going to get back. It was like two people with hardly any money and a little bit of credit and we survived it, but that was a trip to remember. We always talk about the fact if we did not already have self-advocacy skills there would have been no way we would have ever survived that trip. We were scared in some ways, but we never stopped to cry. We didn't have time. Our skills were taking over, our survival skills that self advocacy taught us.

Caldwell: And you had each other?

Williams: Yeah, we had each other, but we still talk about that we would never do something like that again –not have information. I always make sure I got my information because you never want to not know where you are going or what hotel you are staying at. I tell you, that was a trip to remember.

Caldwell: You mentioned your mom. Do you still live at home with your mom in Richmond?

Williams: Yeah, I still live at home, but I also have my own apartment in Indy when I am working. That kind of gives me a little bit of both worlds.

Caldwell: You said you come here like three days a week and then you go back to Richmond.

Williams: Yeah, or however long they need me to work. Because what we found was with what the expenses of how the hotels are here, it was almost cheaper to have an apartment. So we just have this apartment and then any time I am in Indy I can use it.

Caldwell: You work for the Indiana Arc?

Williams: The Arc of Indiana, yeah.

Caldwell: And what do you do?

Williams: I am the coordinator of consumer education and training, and I do a little bit of everything. Right now my main project is to get information about the waivers and we also are in the process of getting people with developmental disabilities out of nursing homes. We are also in the

process of setting up self-advocacy groups. We are going to set up ten a year. That is about it. Those three things.

Caldwell: How long have you been working with the Arc?

Williams: I have been working with the Arc since April of last year.

Caldwell: What did you do before that?

Williams: I was actually working at my work, actually the workshop. I had been out before doing different jobs, but things happened and I ended up back in the workshop. This opportunity came up with the Arc and so I took it, and it has been the best experience of my life. I have had other jobs, but this has been the best job I have ever had because it is kind of like working in the line of work I wanted to do.

Caldwell: You are getting paid for what you like to do?

Williams: Yeah, I am getting paid to do what I like to do and I get to meet new consumers. Our project is actually called the Arc Network, and now what I do is I kind of like manage a project this year. I just started that. We have ten self advocates and ten family members out there in the field kind of putting that information out there about those different projects, about trying to get people out of nursing homes and trying to start up the self-advocacy groups. Just putting information out there and doing what we need to do.

Caldwell: Is it a permanent job or just a grant?

Williams: Right now it is a two year project. We will be out there for two years doing it.

Caldwell: It seems like, with other people I have talked to, there are not enough jobs for people like you to do your advocacy and get paid for it. Would you say that is an issue for a lot of self advocates?

Williams: Yeah. That is an issue for a lot of self advocates, and you just need to be out there letting people know that we are serious about having jobs, like with our state and with who ever. We need to be out there helping to do some of the work that needs to be done. For the future, we need to figure out how to fund self advocacy so the self advocates are out there doing a lot of this work and influencing policies and we are out there doing whatever needs to be done. So, I think one of the future things that needs to be done is that we need to figure out how to get self advocates out there doing the things that they want to do. A lot of us want to be out there working side-by-side with the Arcs with the UCEDDs and with everybody else doing the work that needs to be done. We don't want

people out there doing the work for us all the time. We want to be out there as partners with people doing some of this work.

Caldwell: Does People First of Indiana, do you get any money from the state or the Arc.

Williams: Right now we are getting our money from the DD Council. Like right now all we are getting is money to set up. Actually, all we are getting is like money to have meetings and to do things like that so we are getting money to set up our organization and getting things rolling. Some of us in the organization are helping to find money so that we can help set up the national conference next year. So that is what a lot of us in Indiana are doing right now. We are working really hard making sure the conference is good.

Caldwell: At the national level, where does SABE get their money right now?

Williams: We don't have a lot of money, right now. We get money from grants and stuff like that but we don't have permanent money coming in all the time. Mostly, our money comes from grants right now, and what we want is permanent money. Money that we don't have to try to figure out where the money is coming from all the time, and that the money is going to be there. So that is our biggest worry right now is trying to figure out how to get the money.

Caldwell: What would the money help you do?

Williams: The money would help us like make sure that we are setting up self-advocacy organizations, making sure they are out there, and help us to educate families and the community and help us educate anybody who needs it. Hopefully, we can get the money to do that stuff. Right now we don't have it. We are barely staying afloat, really. We don't have a whole lot of money.

Caldwell: In some states they don't even have a state organization unit? Isn't that right?

Williams: I think so, in some states. In some states they do have organizations, but it is hard to do anything when you don't have a lot of money. Like our state organization, we don't have a whole lot of money. We just mostly have what is coming in from the DD Council. Our P & A will give us money too, but that is for transportation. We just don't have a whole lot of money coming in.

Caldwell: Do you think that the states that have the strongest self-advocacy movement or organizations have money or funding? What do you think the strongest states are that have the strongest movement?

Williams: Well, one state I know is the state of New York. I think Pennsylvania might have some, but I know New York does and probably California, probably some of these bigger states.

Caldwell: Let's go back to your family and growing up. What was it like growing up with your family? What are some of your memories growing up?

Williams: My family was so different. My mom was my only parent. It was me, my mom, and my grandfather or my uncles. That is the family I knew.

Caldwell: Do you have any brothers or sisters?

Williams: No. I am an only child.

Caldwell: And so it was just you, your mom, and your grandfather?

Williams: Yeah, it was just the three of us most of the time, and off and on my uncles would come in –mainly two of them. Until I was about eight or nine it was mostly just me and my mom and grandfather and whichever one of his sons would pop in. I guess it was just like any other family though. I spent most of my time between cousins or aunts and uncles or stuff because my mom worked all the time. So I was either with an aunt or a cousin or uncle or somebody all the time. Then when she was not working she was in school, so I just moved around a lot. I always knew my mom was there, always there surviving, and there on those special times anyway –whenever there was a birthday. I remember one time she packed me and my cousins up in this little car and we went to the fair and that was fun. I was a little older and my cousins were a little younger than I was. I just remember her doing this special thing and just packing us all up in the car and taking us to the fair, letting us have a day of fun with her. I don't know. I mean, she was there in the mornings mostly when I was growing up and getting me off to school. Later on she went from nights to days, and she was at the same place for years, 29 years. You know how when people first go into somewhere they usually put them on the second shift. As she got time in there she went to the first shift so I got to see her more then.

I guess it was good growing up. When I spent time with my cousins I didn't feel different. They never really made the difference in me. I just did whatever they did. That is the one time I didn't feel different, when I was around my family, because they always made me feel good. My uncle, he tells the story of when I was first brought home and I was little. He says my mom and the family were sitting around worried about me because I was just a little bittie baby, you know, that they brought home. He said, "They sat around and worried about you, but I don't know why they worried about you because the doctor said you would eat when you were ready. They was always worried about the fact that you wouldn't eat

and when you got ready to eat, you ate.” I asked him, “What was I like when I was a baby?” He said, “I don’t know. You were like any other baby. The only thing about you was you crawled. Instead of walking, you crawled.” But the story he tells me is I crawled until I got bored. That is how he tells me. He said, “You didn’t worry about whether you could walk or not getting around here playing with all the rest of the kids, because you crawled to cause trouble.” I said, “I did?” He said, “Yeah, you caused trouble.” Because I would be doing something and know that I wasn’t supposed to be doing it. He said, “Then you would crawl to get away from people. You became the queen of crawlers. Then when you finally got bored you started walking.” That is how he tells me. He just tries to make it more interesting by telling me like that. I didn’t walk until I was two so that is why they remember that so well. One of my cousins, he is an only child too and we were more like sisters and brothers growing up, when he was around, because by grandmother would have us both. He said that I would cause trouble with him and then crawl away from him and have him on his feet trying to catch me. I said, “I don’t believe that.” He said, “Yep. You caused trouble.” Both of us caused trouble with each other. Every once in a while when I caused trouble, he said I would just crawl away from it like I hadn’t even done nothing. It was funny hearing those stories because when you are little you don’t remember anything about how you were as a kid. So, I think at home I had the environment where I wasn’t treated any different from anybody else, to hear everybody tell the stories that they tell about me.

One time they told the story about when I was little and I was in a play pen and I guess I took an apple and threw it out of the play pen. My grandmother and somebody else was sitting there and I called my grandmother by her name. I said, “Anna Lee, pick that apple up.” She said, “You need to get up out of there and walk the way you are talking to me.” Just hearing them tell the stories of her. I remember her and she had a really special way with me. So I can remember that and to hear them tell the stories about her. I can remember her talking to me in that way and just treating me like anybody else. In that way, I think I had a pretty good growing up environment, even though my grandmother left me too early. I was only seven, but I still have a few memories of her. I guess I can say, some of the stories my uncle tells me and some of the stories my mom tells me, I had a really good upbringing.

My home environment, they treated me like any other kid. They didn’t make any differences. They didn’t treat me like, “You can’t do this because you are special.” I remember my mom bought me bikes. Every so often she would buy me a new bike. I didn’t know how to ride the bikes. I wanted the bikes but I didn’t know how to ride them. So every year I would practice riding my bike. I remember falling off the bike a hundred times. I remember one summer I must have fallen off that bike

three or four times. I was fifteen years old and couldn't ride a bike. One day my friend told me, now this is the same one I ran into at the reading class because she used to live across the street from me. I remember he telling me, she said, "I am getting really bored sitting here waiting for you to learn how to ride a bike. You need to get up and learn how to ride that bike." So that summer, a few days after she said that to me, because she was really tired of sitting there waiting for me, I learned how to ride a bike. I knew if I didn't learn how to ride a bike I would be sitting there and she would be gone. So, a few days later I learned how to ride that bike, and I don't know how I did it to this day. I know a couple people were holding me up trying to help me figure out how to balance the bike. I finally learned how and I was surprised I did, because I don't know how to skate today but I always tried that too. I just figure out that there were going to be something I could learn to do and some things I couldn't. There was going to be a limit on what I could do. I think I had a pretty good family upbringing just by the things I am remembering now, I did.

Caldwell: So after you graduated from high school what did you do right after you graduated?

Williams: Right after I graduated, I sat at home. I sat at home for nine years. But I mostly sat at home doing something. I mean I was at first I kind of just sat at home, and then a little bit after that there became a purpose. I didn't have a job and nobody would hire me. You know how they used to put on the application if you had a disability; and I was sort of out and I told the truth, and nobody would hire me. I mean, nobody even gave me a chance. So I would just sit at home and it got to the point where my mom needed someone to watch my grandfather and be with my grandfather all the time. That is what I did for almost nine years, and then after he died that is when I went and got services. I went to a local Arc and got services. I was supposed to only be there for a little while. I remember seeing the original paper that said I was only supposed to be there for eight or nine months and I was there for twenty years. They saw a potential and they were going to have me in and out of there in eight months. That is what the original papers said as long as they wanted me to stay. They were going to give me some job skills and send me on my way, but eight months turned into twenty years or so.

Caldwell: What was the workshop like?

Williams: When I first got there, I am going to tell you how it was. I was the person who sat or stood in the back of the corner and didn't talk to people when I first go there. I had friends there too, and I didn't talk to them. They were probably the only people I would say anything to at all because I already knew them. But when I first got there I wouldn't talk to anybody because I didn't want to be there. I wanted to be anywhere but there. What I

wanted was a job out in the community, but nobody would hire me, so I had to do the next best thing and go to the agency and go to the workshop.

The workshop, for me, was probably the best thing that could happen to me, because I was the person who liked to say, "No. I can't do that. I can't." That was just my favorite word. I got one supervisor who was that person who was really going to get to know me, and she really did. The one thing she taught me was, "Don't come in here saying I can't today." She always said that to me. I would say, "Oh, I can't do this job." And she would look at me and say, "You know, can't never did anything, now did it." She would talk to me about the choo choo train and I would say, "Don't talk to me about the choo choo train." She said, "You need to stop saying no. I do not like that word and you know better than to say that to me." I know I went through this with her for over five or six years. I had been there for a while and I was still doing it. She got to the point where she said, "Why do you still tell me you can't when every job I put you on almost, you have been able to do?" Finally I got out of it but it took me a while.

I think the workshop was the best thing that ever could have happened to me, as far as that time in my life, because I really didn't have any skills. I really didn't have any beliefs in me or who I was or anything, and I think the workshop helped that. Not only did it give me some work skills, but it taught me how to come to work every day. When I didn't, and didn't have a good reason, there were consequences. It taught me how to come to work every day, even though I didn't want to be there most of the time. I figured out, you know, I can either start liking this or else, but things are not going to change until I change my attitude. Finally, when people started getting tired of me just standing back there in the corner, they would pull me out and say, "You are going to talk today." I would literally be in the corner during break time because I wouldn't talk to anybody.

I had this one girl who was really nice when I first went in there. Her and her husband was probably the first married couple I met who had a disability that showed me we could do what we want to do. I think she had something to do with my attitude changing too because she was one of the first people that I tried to really talk to all the time. After a while I noticed she was frustrated around there. She used to tell me things like, she told me one day, "You are too much like me." I said, "Why you say that?" She said, "They are kicking me in my butt around here and you are going to be the same way. I am out of here after next week." She got frustrated and tired of the place, so she kept telling me that. I kept thinking she was just talking. There is no such thing as being tired of being there. Sometimes it really does get to the point where you get tired of being there, because if you learn all the stuff they have to teach you, you

get bored. If you are not learning anything new or if you are on the same job day in and day out or if they tell you they are going to let you do something and then they don't let you do it, you get tired of being there. That was where my friend was after a while, and she told me I was going to get to the same place.

I liked it, but then I got to the point I didn't like it. When you got good at stuff then they expected too much of you. I had this one job one time where I was like the third in line to do the job. Because there were two girls there that always did the job before me, I never really got a chance to do the job. I knew how to do it, but I never really got a chance to do it because I wasn't fast enough. I would get mad on the days when neither one of them were there because they would expect me to do same job, and then I would get mad because I never get to do it when they were there. I remember having a conversation with our main workshop boss. I said, "Why is it I only get to do this job when they are not here?" He says, "Because you are the third one. Each one of them do it faster than you and neither one of them are here today, so you have to do it." I was like, "No, not if you don't ever let me do it any other times, but then you are going to make it when they are not here." He was like, "Well, you said you like the job, don't you?" I said, "I like the other end of it because that is the one I do all the time." He said, "I thought you liked this part." I said, "No, cause I don't ever get to do it." He said, "I can't help you. You have to do this part today even though you don't like it." So I got mad and I was throwing the stuff in there one day. Every time he would come around I would look at him and throw another one in there. So finally he can back around one time and he said, "You know what, you can keep doing that all you want, looking at me and throwing those things around in there like that, but you are doing more than you ever did before while you are being made at me." So, then I was like I may as well stop being mad and do the job because he says I am doing better than I have ever done.

Sometimes my experiences there were good, and sometimes I made them bad, like that day because I was bound and determined I wasn't going to do it that day because they weren't there. He was really mad at me and I was really mad at him because I was always the third. And I never get mad when they were there, but because they weren't there and nobody else was there to do the job ad he expected me to do it, it was like. I even said to him, "Why don't you teach somebody else how to do it today." He is like, "No, you know how to do it and I don't have time to train today. So you have to go do something you are able to do." So, every once in a while I had those days were I didn't want to do something because I was always the third string.

Caldwell: Did you like the work or did you want to be doing something else?

- Williams: Most of the time I liked the work, until I found other stuff to do, until I found self-advocacy stuff to do, I liked the work. I guess I liked the work because I knew nothing besides what was in those four walls. All my dreams had to do with what was in those four walls. My first dream was to be a workshop trainer. I wanted to train other to do the jobs that I already knew how to do and just teach them how to do new things. My second dream which was within those four walls was to actually become a supervisor, which by the time I got to that point, that supervisor told me he would never hire me. By then I had learned how to advocate and tell him when things were not right, and he did not always like that. Sometimes learning how to advocate in those kinds of places was not the best thing for you. By that time, it was like, you can't do that.
- Caldwell: When you look back, do you think they helped you enough to try to get a community job of a job outside of the workshop?
- Williams: Yeah, but the thing about getting a job outside of the workshop, I never really found one that I really wanted. I found some but it was never really what I wanted. When I thought about it, I was always the type of person who would own their own business. When I thought about my dreams and stuff, I always thought about owning a record shop. That is what I thought about when I was a kid. I wanted to own a record shop, mostly just a record shop, or somewhere where they have books. Even though I didn't read very well, I always loved books. So I wanted to own something with those two things in it, and I still think about that. One day owning my own business, a bookstore with internet access is what I say now –like a coffee shop or something, where people could come and relax and read books if they want to. I don't know. It is a dream.
- Caldwell: So you were at home for nine years after school and then you went to the workshop and you stayed there for 20 years until just last year when you got the job with the Arc?
- Williams: Yeah, and see I had all kinds of jobs within that organization. I even had a staff job there, but it didn't work out and I went back to the workshop. I kept that job for over three years too, but it just wasn't what I wanted, and so I ended up going back to the workshop. When I had the opportunity to get this job, it was like, "Yes!" It was the kind of job I always wanted, but never saw myself working at the Arc. My dream job had all the components of that were at the Arc, but I never saw the Arc in my dreams. I always wanted to do something where I could influence policy.
- Caldwell: To go back to the self-advocacy movement. So you first went to your first meeting when you were at the workshop? Had you been there for a while?

Williams: Yeah. I had been there over five or six years. I went there in 1985 and I think when I seen the sign was like 1990 or something like that, so it was like five or six years.

Caldwell: And that group was just starting?

Williams: Yeah. They had just started. There were like three or four of them that started it. I went in after three or four months after them starting. The poster on the wall just intrigued me.

Caldwell: And you started as the treasurer or the secretary?

Williams: I started as the secretary and then I was the treasurer and then I became the president.

Caldwell: So that group was part of the workshop?

Williams: Yeah. Well, like they say it was never part of their agency. It was just like another program on the side. It wasn't really theirs it was ours; at least that is what they tell me. That is how they thought of it. It wasn't really one of their programs at the agency, but it was one they helped us start.

Caldwell: And what kind of things did that group do?

Williams: We did all kind of things. We advocated for our consumers. We even protested and led a march out the door one day.

Caldwell: What was that over? What did you protest?

Williams: I can't remember what it was over. It was something to do with the workshop, I remember that. It was something that we were mad about. I think it was kind of encouraged. I think it was just about some of the different changes they made around there that we didn't agree with. That is mostly what it was about, because they had made quite a few changes and we weren't too happy with them. Then when we went to talk to somebody about them, they wouldn't let us talk to them. The supervisors and everybody at the agency was behind us, but they couldn't do anything to help us because they said they might lose their jobs. They weren't ready to give up their jobs, so they just encouraged us but did not let it be open. We know that they were encouraging us to protest. I think those were the good days when we had all that communication going on, and people were believing in us and believing in what we were doing. Then when all of a sudden when people aren't doing the right thing and you have to start advocating against what they are doing, then they are not your friends anymore. They become your enemies because they don't like the way you did things. As we always say, they taught us and tell us what to do, but if we take what they taught us and use it against them then they are not our friends anymore. And I have been through something like

that before, and it is not the easiest thing to go through. All of a sudden the people who were believing in you all of a sudden don't believe you anymore. And they don't talk to you anymore because you have learned to use your own mind instead of them telling you everything to think and then they don't like when you take what you have learned and use it. That is some of the stuff I have run into. As far as what we do and what we have done, we did a lot of things. At first we were just doing social stuff, like most people do when they first start out. Then some of learned how to go to the state house and learn how to talk to legislators. We did some local stuff like with our mayor.

Caldwell: How often did you guys meet?

Williams: Once a month. It was usually on a certain day every month, usually the same week every month.

Caldwell: How did you get involved with People First of Indiana?

Williams: We just started going to the meetings. When we first started not everyone was going, just I was going at first. Our Executive Director would take me over there and drop me off and come back and get me.

Caldwell: Where was that at?

Williams: Indianapolis.

Caldwell: So, were people coming from across the state?

Williams: Yeah, from across the state. When we first started, we would meet from like ten to eleven, or something like that, the officers would. Then we would go to lunch and come back at one in the afternoon and start having our state meeting. We still do that now. Our state meeting is from one to three. We don't have officers meetings in the mornings. We have then at other times. When we first met we met in these little rooms cause there wasn't very many of us who were supposed to come to these meetings, then it got to the point where more people were coming. We had to find a bigger room. I guess that was a good problem to have. After all these years, after good 17 years we are still meeting at the same agency but now we are having to meet in the gym or the lunch room because we had grown so much that they didn't have anywhere else to put us, nowhere else that was big enough. That is a good problem to have, but I still think we have room for improvement.

Caldwell: Let's go back. Can you say more about the work you do?

Williams: It is not good to keep going through life feeling bad about who you are and what you do, cause sometimes you have to come to the point and realize this is the hand you were dealt and you got to live with it and figure out

how to make your life better and all those people around you. Change people's attitudes and maybe you can't change their attitude, but you can sure try, at least you can change your own.

I used to think our number one enemy was our parents. The reason I used to think that was because most of the parents I know and knew are overprotecting, my mother included. Just protecting us all the time and you can't go through life doing that. You got to let people lead their lives. What I want people to understand is that parents have a big role they can play in our lives. Instead of protecting us, instead of making plans for our lives after you are gone, why not make plans for our life right now. If somebody wants to get an apartment with somebody, let them get that apartment. Or if they want to hang out with this friend or that friend or a group of friends, let them hang out with the people that they like. Because you know what, we only truly live this life once that we know about. So we have to spend time with the friends that we care about and love. That is the way I see it, anyway.

So, I used to think parents were our number one enemy, but you know now I don't think that. Because all it is, is the parent may come from it from a different angle than I come from it, but the only reason they are trying to protect their kid is because they love them so much. I don't want them to be protected because I love them so much and because I want them to have a life. So we kind of really come from different angles but we want the same thing. In the end, parents really do want their child to be happy, but they don't want them to be hurt or anything like that so they over protect them. Or they don't think they know how to make decision the right way so they over protect them. Most of them don't think that we know how to think for ourselves. That is not the truth when you go to talk to people with disabilities. I don't care what kind of disability they have. They can have cerebral palsy, Down syndrome, whatever disability, but it does not mean they don't know how to think for their self or think about what things they want to do with their lives. Sometimes, I think I have learned how to embrace that fact that parents want to protect people, and I talk to them from that point. I say, 'You know, I know you want to protect your kids, but she grown. Let her live a little bit, you know.' It is hard to tell parents that because they don't want to hear it because they want to protect you.

I used to think about this one friend. She used to go home to her mother. She has an apartment and everything now and she shares it with like two or three other people. It used to be when we were in the workshop. She would go home and see her mother and she would come back to the workshop the next day, or come back to the residential services, and she would be crying. I am like, "Why you crying for today?" She said, "Oh she told me I can't do this and I can't do that, and that I am only a little kid, and

I can't think." And this girl's mother was telling her all this. I was like, "You are not a little kid. You are a grown woman and you can think." She was like, "Well my mother said..." And I said, "Well your mother is not here right now so you need to start thinking like you are a grown person." So every time I felt like I had to fix her. But there was really no fixing to be done. Her mother had said what she has said, and I was only trying to help her feel better about herself. It really wasn't fixing anything; it was just trying to help her feel better about who she was. Every time she would run to me with that, and I am like, "You know, I don't know what to say to your mom." To this day, the girl's mom won't speak to me because she probably went and told her what I said. I was just trying to help her and that is what I did, try to help my friends anytime they needed something.

When she would come back to the workshop, she would feel bad on Monday, and it was just the things her mother would say to her. She was so bad about who she was and her disability. She says, "I can't do anything." The good thing about it is that the girl has what I would say a two or three hour job away, one or two days a week. She is working a little bit away from the workshop and then she ends up going back to the workshop. So that is progress a little bit for her mother I think. You know, sometimes just doing this stuff is so hard. You want your friends to have the kind of life that they want, but then you have to work around the fact that their parents are telling them one thing. You are wanting them to feel good, but then they are still remembering what their parents told them. She was the kind that she would still be remembering it two or three weeks later. She would still be remembering what her mother told her. One time we took her to a conference and she come back, and she was sitting there the next couple days, and she was crying. And I was like, "What are you crying for?" She is like, "Cause I just want stuff and my mother says I can't have it." She just wanted her life and her mother said she can't have it. I think she might be feeling a little better now, but last year or the year before last, she wasn't feeling so great. Those are the kind of things you run into all the time I guess, some people do.

Caldwell: Would you say you feel a bond or a connection with other people with disabilities?

Williams: Yes. I feel a bond or a connection because a lot of times they have been through, and go through, the same things that you go through. Like yesterday, I was with some people who were in their fifties. I was with some people who were in their twenties, some in their thirties, and I know there was some probably in their thirties and forties. It was a mixture of people and the one bond that I know, the one thing I know that we all felt in there was when we got to talking about being in school and people bullying us and feeling bad about ourselves. Every one of us connected to

that story that somebody was telling about people bullying us all the time. I could feel his pain when he told his story about how people were bullying him or how he thought he had to protect his friends who were also growing up with disabilities. Here he is. I don't really know him from Adam. I just met him a couple days ago, but yet there is that connection. I could feel his pain. Yeah, there is a connection. I think so.

Caldwell: Do you think is it for all people with disabilities or do you think there are differences between people that have different kinds of disabilities?

Williams: Well, when you talk about certain things. When you talk about how it was when you grew up in school and how people were bullying you, I think those kind of connections are the same no matter what kind of disability you have, but yeah, sometimes you feel a connection to certain people who have the same kind of disability as you have. Sometimes there is that disconnect because you don't really know about that other person's disability, but you know what research says about your disability and what that other person might be going through and what you have been through or are going through. I think there is a connection between all people with disabilities. But then when you have a certain kind of disability, I think sometimes you feel even more of a connection to that other person with the same type of disability.

Caldwell: Do you think there are differences between the self-advocacy movement and the independent living movement?

Williams: I think there are differences. One of the things I think, and I am not saying this is a bad thing, but with the self-advocacy movement, we don't always think as fast as other people. I think that is the main difference between people with physical disabilities and people who have cognitive disabilities. I think there is a difference, but I also think we could help each other. And I think that is what should be going on that is not going on. The two movements could be helping each other and I don't think that always goes on.

Caldwell: Why don't you think it goes on?

Williams: Well, for one thing, take Indiana for example. I had an incident where me and my friend were on the phone talking to each other like we always do. She mentioned to me, she said, "Oh, by the way, you know that one dark haired girl in the wheelchair." I said, "Yeah, so who you talking about?" So she told me the name and she said, "She called me." And I said, "Oh no! The other one called me." So she said, "They are up to something." And they were. They were up to something. The one called her and one called me. What they wanted was. There was a time when people were feeling that the self-advocacy movement was really moving up and people needed to be involved in it, and I think they were trying to get involved in

it. We are pretty sure that once they got in there they were going to take over and they were going to do everything. It was like, "You know, what does she want, you know?" I said, "I don't know cause the other one never did tell me what they wanted." What we did know was that they wanted to know when we met and how much it cost and all this stuff, because they were going to come to our meeting. They kept saying they needed to talk to us about something, and my friend said, "You know, this sounds like of fishy." We were comparing notes and we were like, "No, they can't come in yet, because we need to figure out what we are doing first." That just shows you that they thought that we weren't going to catch on to what they were doing, and those were two people with physical disabilities. They were both in the wheelchair and both had just physical disabilities. But they just though, "Oh we will trick them and we will just get right in there." And it was like, "What did they think? Did they think they were just going to move right in?" We were like, "Yeah they can join, but they can't come in and take over. They can join but they can't have any votes." I was like, "Well, if they join and they can't have any votes, then they ain't going to want to be involved." That was just one incident. These two, I know they were more involved in the independent living movement, but they were trying to get everywhere. They were trying to get involved in everything. And I don't know whether that was. I don't think what we. They were trying to get in, and it did not move any further than our conversations really because they did not make a move to come in.

From that experience, I think that the two movements really do need to work together and help each other. Because I think we all want the same thing, but sometimes people take us for granted. Act like we don't know what we are doing or treat us like we don't know what we are doing. What I say is that the two movements need to work together, but they need to have respect for each other too. I would love to see a time when we are all working together all the time, but I know that doesn't happen every day. We might work on an issue together, and then we go back and do our own thing. I think the self-advocacy movement and the independent living movement both have some things they do, and they probably both should be doing them together to make things happen for people with disabilities. But the only thing is I think both should have respect for the other, and I don't see that always happening all the time. But it is happening more and more, because I have a friend who is both involved in the self-advocacy movement and involved in the independent living movement. She just became an officer with the independent living center so things are changing. That is the good part. Only thing is, I am not at home anymore so I am not involved in my independent living center as much, but they put my mother on the board.

Caldwell: They put your mother on their board?

Williams: Yeah. So, it is pretty cool. She goes to the meeting all the time now. And she is always telling me, “Oh, I don’t have anything to add or have anything to say.” And I say, “Well, you wait until you do because you have experience. I mean, you raised a child with disabilities. You also have nieces and nephews with mental illness. So you know a lot. You just don’t know you do. You don’t know that you have something to contribute.” Yeah, my mother is involved. She is 77 years old and that is the first board she has ever been on. So, I think that is pretty neat.

Caldwell: What boards have you been on?

Williams: I started on with my local Arc board. Their board was maybe one of the first I was ever on. I have also been on the Mayor’s Council for People with Disabilities in my home state, on the national AAPD board, and also SABE. I was on the national Arc board, but I came off because I took a job with the state Arc. Then I went over to AAPD’s board. So, I stay pretty active right now.

Caldwell: Let me ask you some questions about leadership, because we haven’t touched on these yet. When you were growing up and getting involved in the movement, did you have certain role models or mentors that you looked up to?

Williams: The only person that probably I had in my life that I looked up to was one of the social workers I had at the local Arc. She was probably the first person that I looked up to. Probably because she was close to my age, that looked up to her so much. That is the one person. Because I did not know too many people with disabilities, so I did not have too many people with disabilities that I looked up to –until I met a lady who was blind. She was probably the first person that I ever looked up to with a disability that I looked up to. We became very, very close friends and then she dies. She probably was one of the best friends I had with a disability but it was a short friendship. She was another mentor. She was becoming a very good mentor. The thing about her and me was, when we first met she didn’t think that I had anything to offer her, didn’t think that I had anything that she even wanted to know about. She said that she could tell that I talked real slow and that I had a developmental disabilities and she didn’t really want anything to do with me because she didn’t know anyone. Even though she had a sister growing up, her intelligence was normal, but she had cerebral palsy. But I think it was different from knowing anybody somebody like me because I obviously talk slow to her. And she told me herself, after a while and our friendship had built up, but she told me herself. And that was kind of sobering because she told me she had all those thoughts at first but as she started working with me they went away because they were proven wrong. All her bad thoughts about people with developmental disabilities began to change. Especially I guess after that

one weekend I had to take care of her. Her husband got sick on her. We were at a conference and I had to go pick her up, make sure she had her food, and tell her where everything was at. So after I did that her attitude about me changed, after I had to take care of her for a whole weekend. It was shortly after that that she told me. In between that and right before she died she told me that. It was kind of weird to hear that because I was like, "What! You felt like that." I didn't know what to think of it, but now when I think about it that was the best thing she could have done for me.

Caldwell: Why was she your role model? What did you look up to about her?

Williams: One of the things was the fact that she could, after spending so much time with me, change her mind about how she felt about somebody. Because what she did was she built up her stereotype and after she realized that her stereotype was wrong she embraced our friendship totally. But she realized that the way she felt about people with developmental disabilities was wrong and she changed her whole attitude. So that is kind of why I looked up to her. Then she was the kind of person that was a go getter. We were at some kind of meeting or conference and we went into this one that was on independent living and we looked at each other and said, "Let's do it!" We were just at a regular meeting because they came to talk to us and she looked at me and I looked at her and we said, "Let's go for it. Let's try to start one." The right in the middle us staring, she died and I just lost all interest because this friend had died.

Caldwell: When was that? When did you first meet her?

Williams: God, I don't remember.

Caldwell: Was it during workshop?

Williams: It was during the workshop time.

Caldwell: Did you meet her at the workshop?

Williams: No. I had started venturing out to what I call CCDA meetings which was the mayor's council. She was a part of that. That is where we met and we sort of formed a bond shortly after that, but it was after all that stuff where she didn't believe I was going to be able to do anything for her or with her. She had made up her mind she didn't want to work with me.

Caldwell: But you saw her as a good leader or role model?

Williams: Yeah, because she was a real go getter. If she believed in something she was going to go get it. That is why I saw her like that. She wasn't going to let her blindness stop her from anything.

Caldwell: Who would you call a great leader?

Williams: Living or dead?

Caldwell: Either way. Who comes to mind when you think of great leaders?

Williams: I think of people like Martin Luther King and I even think about people like President Kennedy when I think about great leaders.

Caldwell: Why do those people come to mind?

Williams: Because I went back and read about some of the stuff the civil rights movement did. I just think that some of the stuff Martin Luther king went through and all the people in the movement. People losing their lives for something they believe in. Even the people, the ones that we didn't know, and there were so many of them in this movement that we didn't know. When I think about people like that dying for a cause and having a reason for it I just think those are some of the greatest leaders we can probably have.

Caldwell: Do you think your experiences being a person with a disability have helped you be a leader?

Williams: I think so. Because sometimes when you are a person with a disability people tell you that you can't do something. And you have to figure out how you can do it and go for it. Sometimes you have to figure out how you can get other people to help you do it. And I think those are the kinds of things that make you become a leader. You know, people not believing in you and then you having to figure out how you are going to go want it is you want to do and take action on it and do it anyway. So that is some of what I think makes a good leader. And just having those skills to listen and care about other people and what they are going through and how you can help each other.

Caldwell: That is really good.

Williams: That is what I think.

Caldwell: What would you say leadership means?

Williams: Leadership means being able to take action on something when something needs to be done. Being able to lead people and make them believe in the same things that you believe in. I think that is part of leadership. And just leading people to do what I hope is the right thing.

Caldwell: Do you think you have a certain leadership style?

Williams: No. I don't think I have a certain style.

Caldwell: Do you think you are a leader?

Williams: I do.

Caldwell: Why do you say that?

Williams: I know how to take action on things when I need to and hopefully know how to back off when I need to too. So I hope that makes a person a leader. Knows how to take action and what we need all the time, and if I don't know the answer I know how to go ask my colleagues for help. Me and Darcus do that all the time. We bounce stuff off each other all the time.

Caldwell: It seems like in the self-advocacy movement that happens a lot. People support one another in their leadership. Would you say that is true?

Williams: Yeah. I think that is what helps us be a leader. When we know we can go talk to our vice president or our secretary or whoever. Talk to them and know how to bounce stuff off of them and talk to them about whatever it is we need to do. Get their opinion on it too. I don't like to do stuff all on my own all the time. I like to go get other people's opinions on stuff. One of the things I am trying to learn how to do more is not take so much on myself but delegate to other people. Sometimes that is hard for me but I am trying to learn how to do that more. Instead of me doing everything I might call this one or that one. I think the conference is going to make me learn how to do that more often.

Caldwell: Yeah, too much for one person to do?

Williams: Yeah. There is a lot to do. Too much for one person, for two people, you know. I am just depending on our board to come through and work on stuff with me. But the more I think about it why not go to our statewide meeting and say, "Hey, what does anybody want to do to help?" So not only the board of directors has a say in what we do, but why not the whole membership statewide. So I am in the midst of opening it up to other people in our statewide leadership now

Caldwell: When you look back on your life, what do you think are the things that helped you develop your skills as a leader?

Williams: Well, when I look back at my schooling, the fact that I was always the kind of person who was intrigued with stuff. I had to learn to go ask my teachers for help when I wanted to do something different. I always wanted to do something different. I always wanted to do something different. I was always different. I don't think there were many people in special education who looked in the window and wanted to take a photography class. Just because I had this little 35 millimeter at my house, I wanted to take a photography class. And that was unheard of. So I went to my teacher for help and she told me, "You can't do that." And I said, "Well, why not?" And she said, "Well, you can't do that because it

is too technical.” I said, “Too technical? I have a camera.” And she says, “You probably don’t even know how to run your camera.” I was like, “Yeah I do.” She said, “I can go ask him, but I don’t think he is going to let you do it.” So he asked to talk to me, the teacher who was teaching that class. I said, “I come by your room all the time and I look in the windows at those pictures that people take. I want to learn how to use my camera.” He said, “Okay, I am going to give you a chance.” So, I got into this class and I was sitting in the class and holding my head down like I didn’t want him to call on me. He said, “Wait a minute. You are not going to sit in this class and hold your head down like you are not think you are going to speak. Now that you are in here you got to learn how to read the book and answer the questions like everybody else.” And that was probably only the second or third time that I ever felt good about myself in school. Because he let me know from day one, “You are not going to ask to come into this class and then act like you don’t know nothing. You do, we just got to get it out of you.” He was probably the best thing in the world for me.

Caldwell: So having a good teacher helped you develop your skills that you use now as a leader. Is there anything else you can think of that really helped you?

Williams: I think just learning how to advocate for myself before I knew there was a word for it or before I knew there was even going to be a movement somewhere down the road later on in my life. I think of the kind of things – just learning things and trying to figure out who I needed to talk to about it helped me to develop those leadership skills. Those kinds of skills that it would take years later to speak up for what I wanted even for myself.

Caldwell: Let me ask you about the self-advocacy movement. We talked a little bit about this, but what do you think are the biggest challenges facing the future of the self-advocacy movement?

Williams: Well, number one for state and local I think is transportation. Funding. Mainly just bringing people in who believe. Figuring how to work with providers to believe that you have something valuable to add to what they are doing. Working with service providers to advocate on a state level, local level, or even a national level to help people get the services they need to help their life be better. That is one of the things our people tell us when they come to our statewide meetings, one of the biggest things we can do is learn how to advocate with lawmakers and policymakers because those are the biggest things that will affect our lives. Just getting involved, because I sometimes think that state organizations or local organizations are as involved in government as we could be.

Caldwell: What supports do you think are needed for the movement to grow and expand?

Williams: Well, I think the support that is needed on all three levels is people who believe in us. People who want to see us take self advocacy higher. People who will support us, but not take over. Teach us something but not take over for us. There is a difference between standing here and helping us and teaching us how to do something versus somebody who takes over and does it for us, because that way we are not learning how to do the work.

Caldwell: You mean among the advisors or support people?

Williams: Advisors, support people, all of them. Because sometimes support people can sometimes will just not believe we can do something and want to do it for us rather than let us struggle and do it for ourselves. So, those kinds of things are needed. When people don't just take over for us, they teach us how to do the things. They support us to do all the things we think we want to do in our organization. I don't know. Just having the community and all the people who are around us and important to us in our lives supporting believing in what we are doing because it is only going to help us all to have people with disabilities knowing how to take care of themselves.

Caldwell: You are saying people who value the self-advocacy movement?

Williams: People that value us for the people we are because within all of us we are all great leaders. We just need that push and that shove to get it out sometimes. Or that love and support that some advisor or some support person can give us to become all we can become.

Caldwell: You have some experience on the national level so you kind of know what is going on across the country. What is your vision for the self-advocacy movement? Where would you want to see the movement go in the next ten years or so?

Williams: I want to see us have all the funding we need. Ours statewide groups getting the funding they need and our national group getting the funding they need; and also local getting it from someplace. I don't know from where but maybe that is where they get it from too. But I would like to see us have funding over the next ten years so that we can go around and do the things that we need to do. We can go around doing the trainings that we need to do and talk to the people that we need to talk to all the time. Just doing what we need to do to make our lives better, to make everybody's life better. Because if we are happy and if we are productive then that community out there should be productive too. Because every one of us, people with disabilities and people without disabilities, has some kind of gift to offer. We need to be doing it. If every person with a disability is just sitting at home and not contributing, then there is something the community is missing. We are just missing something

when we are not out there contributing. I wonder. I just thing we all need to be out there contributing. Hopefully, the movement can grow and help people become the happy productive people they want to be. As long as we can hopefully get that funding that we need.

Caldwell: Let me ask you about younger self advocates. First of all do you see many young people coming into the self advocacy movement? Have you seen young people coming out of high school and getting involved in self advocacy or even in high school?

Williams: I haven't seen a whole lot of it yet. But I know one of my friends in the southern part of the state is getting ready to go into the high schools. Hopefully through what she is doing there will be some high school students coming out and wanting to get involved. Because somehow this movement, after we are done there has to be somebody has got to wanting to come in here and keep it running and keep it going. Otherwise, why are we doing all this? We got to find a way to keep it running and keep it going.

Yesterday I saw some of the most energetic young people I have ever seen, so I would love to see some of them come into this organization and start contributing to it and be able to run with it one day. Keep it going. Knowing eighteen, nineteen, and twenty year olds –they got their whole life ahead of them. So I would just love for younger people to start coming in, because I have seen some of the best young people in the last two or three years in the state of Indiana. Some of them just keep you wondering, keep you smiling, and keep you going because they have so much energy. It is like, “Was I like that when I was young, you know?” This one young lady at the last policy seminar from Indiana, she just kept me in awe the whole time I was with her. She was a young lady with Down syndrome, but she was like no other person I had even known. Maybe it was because she was younger and she had a different way of thinking, but I enjoyed her the whole time. I was really nice to get to know her, but see I haven't seen her since. So I need to find out where she is at because I need to get her involved with the conference stuff. I hope that we have some young people coming from everywhere. They think differently too. A lot of them want to do more things than we ever thought about doing with our lives. And some of them are going to end up doing it. So, I would just love for some of them to come in and show us how to do and think like they think. Just spending the two days with some of the kids I spend the day with yesterday was like way different.

Caldwell: What do you think is different? You said there was something different?

Williams: I think they just think differently. I think this comes from being young –they don't really set limits for themselves. I met one who all he talked about was a hobby. He wants to be a musician more than anything and that is

all he ever talks about. And I think that because of that he will become a musician and do the things he wants to do, because that is all he ever talks about. I was hearing him sing a little bit and I am like, "Wow, he can sing too." It is not just like, "I want to be a musician," he even has talent for it. So, it is just like he needs the find the one or two people, or however many people it is going to take, to help him get to where he wants to get because he is definitely going to need help to get there.

Caldwell: Do you think it is because times have changed and maybe there are better teacher now, parents are better, or better expectations?

Williams: I think there is a little bit of all of it. I hope. Maybe it is the environment he is from. I don't know, but his way of thinking about what he wants to do was surely different than what I have ever heard. I never knew anybody with a disability that was that sure of their self that that is what they wanted to do. Everything he talked about was music. Then there was another one. They even have instruments and they know how to play them.

Caldwell: So, you seem pretty optimistic and pretty positive about the young people?

Williams: Hopefully. I hope they are able to do what they want to with their lives because some of us sure weren't able to. Not like they were, because we come from a different era –an era where people were telling us what we couldn't do, rather than what we could do. So hopefully when they were coming up, people were telling them, "Yeah, you can do this. You can do whatever you want to do." Because that is what it takes –people making you believe in yourself.

Caldwell: Do you still think they experience some of the same discrimination?

Williams: Yeah, I still think they do because you can hear it in their voices when they talk and you can hear it in their stories when they tell their stories. Just like one young man I was talking about who told how people were bullying him every day or bullying is friends. He stood up there and told the story and you could feel the pain through the story that he was telling. Yeah, I still think they experience some of the same discrimination, especially from kids with and without disabilities. Well, hopefully mostly people without, but I think it is a little bit of both probably. I know growing up for me it was. Even kids with disabilities who didn't think they had disabilities were making fun of people.

Caldwell: Do you think it is going to be important for them to know about the history of the movement and the struggles that you had?

Williams: Yeah, I think so. Going back to the independent living movement, I think that both movements could probably learn a lot from each other. That is

why I am hoping that one day we can all get together and forget about whatever differences we think there might be or we know there are and just work together for the good of all people with disabilities.

Caldwell: Do you think that young people will see you as a mentor or look up to other people in your generation?

Williams: I hope so. I hope they understand that we paved the way for them. Just like we understand that if weren't for people like Martin Luther King paving the way for us. We wouldn't have anything to measure it by if it wasn't for the independent living movement and the civil rights movement. We learn from the civil rights movement all the time. I know that is important. So, yeah, I hope that people learn from us too.

Caldwell: What do you want people to learn from the self advocacy movement?

Williams: That no matter what people told us or no matter what people believed about us, we believed enough in ourselves enough to keep moving and keep doing self advocacy. Keep going, and believing that one day we are going to get there. Wherever we end we have helped people become as independent as they want. That is what I am hoping.

Caldwell: I wanted to go back to Self Advocates of Indiana. You were involved when that was first starting?

Williams: Shortly after it got started. In April it will be 18 years and I think I have been involved maybe 17.

Caldwell: Do you know much about the history of how it got started? Funding to get started?

Williams: No, we don't have any funding. Well, they had funding to try to get some groups going at first. We went around and tried to do that. We went around and tried to get ten groups up and going. I was involved in that time when they started picking people to go around doing the training because I was one of the people that they picked. But if you really want to know a lot about the history of Self Advocates of Indiana you really need to go talk to our favorite storyteller: that is Darcus, because she really knows a lot about the history.

Caldwell: Was that when you first met Darcus?

Williams: Yes. She came to our agency one time. She had seen me maybe once or twice. I had been in state meetings with her. She came to our agency to interview me for one of the jobs. As she tells this story about this one guy who was really, really smart and told you all the right answers and you knew he was smart. There was no doubt about that. But she says, "When I walked in there and I started talking to Betty, we just clicked. I

knew I had to have her on my team.” She said the lady that was supporting us wanted the other guy because he was so smart. But she says, “I had to go with you because me and you just clicked.” I said, “What, I wasn’t smart?” She said, “You wasn’t smart like that I guess but that didn’t matter. You clicked with me as soon as you started talking.” And today we are still really good friends. That is why I am telling you, you need to interview her. I can tell the story but she was there and she tells the story like no one else can.

Caldwell: So, did you serve as an officer of Self Advocates of Indiana?

Williams: I am president now. I was vice president and at one time I was secretary and I think I was even treasurer at one point.

Caldwell: How long is your term as president?

Williams: This is my second year of my first term. You get a second term if you are elected?

Caldwell: When did you first start with SABE?

Williams: I got involved with SABE during the 2000 conference. I got involved in the one in Rhode Island. That was the first one I went to and I have been involved ever since. That wasn’t the first one because I went to the Nashville before, before they were really started as a national organization.

Caldwell: When did you get elected to the board?

Williams: 2000. So I go out at the conference.

Caldwell: You are vice president now? But your term will be up?

Williams: Yeah. Then I come home and rest.

Caldwell: What has it been like working with SABE?

Williams: It has been a learning experience. It has helped me believe in my leadership skills a lot more. Just getting to know all those different people from all over the United States has been wonderful. That is the one thing I am going to miss is seeing some of those people. I just know I am going to have to learn to pick up the phone and call them. I learned a whole lot from the areas of the bylaws to the areas of finance and how important all of them are important to each other. I think being on SABE has helped me learn how to ask questions that I probably would not have asked. Being involved with other organizations has helped me to be able to ask a lot more questions than I usually ask.

Caldwell: What is your personal goal for the future? You mentioned the record store and the coffee shop, anything else?

Williams: I am also a big Starbucks fan. So there is always hopefully a chance for a new Starbucks store. I don't know. My personal goals are just to figure out what I am doing in the next two years, just stay active after SABE and stay active caring about what I care about. Doing the things that I do to help other people become what they want. Help them achieve their dream. I know I am supposed to have more personal goals than that, but I guess my personal goal is to grow more as a leader. Because I still think even though you consider yourself a leader there is always more you need to learn or can learn. I know that just from being involved with groups like AAPD. I know there is still a lot more I need to learn about leadership and doing the things that need to be done. I also want to figure out how can people with developmental disabilities, how can we fit in to organizations that have other people with disabilities and feel comfortable with other organizations. And not feel like we are not being heard or nobody is paying attention to what we are saying. And that we are equal at the same table with everybody else. I think that is one of the things that is very important: that we are equal and at the same table with everybody else.

That is something that we teach or talk about with Self Advocates of Indiana all the time. We talk about wanting to become equal partners at whatever table we are invited to come to because if we are not we are not going to feel comfortable being there if somebody has already made the decisions before we get there. The decisions have already been made and we don't have to do nothing. I don't think we want to do that anymore. I don't think any self-advocacy organization should have to do that. We should want to be equal partners at the beginning. And if we can't get there at the beginning then when we are asked in the process when should be treated as equals as soon as we get there –because that does not always happen. Sometimes I think people just ask us because they want us to lend our name to something. We have had incidents at SABE where people would put our name on stuff before they ever even asked us. What we decided to do when people do that is we say, "No way!" Even if we know it is something good and even if we decide we want to do it, we have to think about it. If they put our name on there before they ask us, that is not good with us anymore.

Caldwell: So just to come back to a couple questions that we didn't talk about. Do you have certain beliefs that guide your life?

Williams: Well, I don't know that I do. The one thing I do believe is that there is a God and if you ask him for help he will help you, if it is what he desires for you to have. That is the one thing that I do believe. Nothing that you go

to do, you do alone. You do it with the help of God. He helps you do the things that you do. When people start to think that they are doing things on their own, that is not good. People can believe what they want to believe. I cannot tell people what to believe, but I know what guides my life. Knowing that there is a God and he helps you do the things you do if you ask him. If you don't ask him a lot of time you will get yourself into a lot of trouble that I don't think you would have to get into otherwise.

Caldwell: Are there any lessons that you think you have learned in life? Throughout your life, some lessons you have learned?

Williams: I guess the one lesson that I have learned is you have to believe in yourself because if you don't believe in yourself no one else is going to believe in you. So you have to be the first person that believes in you. If you believe then you can always hopefully make other people believe. Also, there is a lesson that I have learned lately. No matter what you do there is always going to be some people who don't believe in you, or your leadership, or anything else. So, you have to just go with what you believe and who you are and what you know and what you think is the best thing to do. Do what you think is best. Hopefully people will come around, but if they don't, don't you worry about it because there are always going to be some naysayers who don't believe in you. Especially if you have been brought to a certain place in your life and people don't believe you should be there. There are always going to be those kinds of people, so you have to believe in who you are and what you do.

Caldwell: Just to talk about the people you are closest to. Who would you say are the people you are closest with in your life?

Williams: Right now, I would say the number one and closest person to me in my life will always be my mom. There are my three uncles and then there are all the people over here that help me. I would say all the people at the Arc. I can talk to them. Like I said, I have several friends now that I can talk to. Mostly I would say the people I work with and my family.

Caldwell: I saw the pictures you have on the wall. Who are those people?

Williams: That is Frankie from Bloomington. That is Mr. David who hired me to do the job I do from the state of Indiana. That is Nanette and her daughter, Suzette. Nanette is my counterpart. She does the family part and I do the self advocate part. That over there is one of my best friends in Indianapolis. Her name is Melanie and she is also the friend I was talking about that is also involved in the independent living movement. That is her husband with her. He just got a book written about his life.

Caldwell: Those are great pictures.

Williams: Yeah. I am hoping to get some more put up. He asked me what I wanted on my wall and I thought about it and said you can put some picture of me and my friends from around the state. I knew he had some. Frankie is one of the self advocates from Bloomington area. Then Melanie he knew was one of my best friends. Then he just loved that picture of me and David so he put that up. Suzette and Nanette is part of the reason we do what we all do. She was in one of the institutions that closed down. And her mother was one of the ones who was screaming and yelled the loudest when they closed the institution down, because she didn't think her kid could live in the community. Now she is on the other side telling people how wonderful it is to have her kids live in the same city as her. She lives within five to ten minutes from her house and she can go see her anytime she wants. So that is the story of the people on my wall.

Caldwell: I think we covered everything. The last question is just if there is anything that you can think of that we didn't talk about? Anything you want to bring up and talk about?

Williams: No, I don't know. If I think of something I will let you know when I see you.