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Julie Petty

2/14/2008

10:30 AM – 12:30 PM

2:30 PM – 3:30PM

Fayetteville, AR

Caldwell: The first part is to really go back and talk about growing up, your childhood and your memories from school, what school was like for you. So that is where we will get started. The first thing is would you mind sharing how out you are now?

Petty: I am 36. I will be 37 in April.

Caldwell: I think you might be the second youngest person I have talked to. So you might have a slightly different perspective because you are from another generation. So were you born in Fayetteville?

Petty: No. I was born in Newport Beach, California. My mom and dad moved to California from Arkansas. My father was a coach in the college level so we moved around quite a bit when we were growing up. I have two older sisters. They were born in Arkansas. Then like I said, we moved to California. I got all the good supports in California. We lived there until I was about two, maybe three. Then after California we moved to Springfield, Missouri. That is when I started going to United Cerebral Palsy. I got really good supports there too. I got physical therapy. I had to wear braces on my legs. I had speech therapy. My older sisters really took care of me a lot when I was young. They said, "I was a sweet little girl." They don't know what happened to me. I started school... After Missouri, we moved to Kansas and I started school there. I don't think I went to kindergarten. I just remember going to the first grade in Kansas. In the first grade I would go all day in the special ed classroom. Then in the second grade, I would go half a day special ed and half a day to the regular ed class. That was the first time I really got to be around other kids who didn't have disabilities, besides my siblings. It was okay too. I will never forget it was in the second grade when my little brother was born. There was a telephone in the special ed classroom. My father called me in the morning and told me I had a little brother. I was so happy. I will never forget when they called.

In the second grade was when I started using a typewriter to do my work. Because I could write pretty good, but I wrote so big and it took me longer so using the typewriter helped get my work done quicker. In the third grade is when I started going all day in the regular ed. I didn't go back to the special ed. I remember my teacher in the third grade. Her name was Mrs. Cell. I really liked her. She was a good teacher. She would write down my math problems on bigger paper. It was like big paper with lines on it and I would use big fat pencils. They were easier to write with. I was using a typewriter. It was a little embarrassing because I used one of

those electric typewriters in the classroom. So you could hear it –tap, tap, tap. But my dad was always my advocate. He made sure I had all the accommodations that I needed. In the classroom no one really ever argued with him. He was always pretty well known in our community because he was the head basketball coach at the college wherever we lived. In the fourth grade, that is when it really got harder and kids started making fun of me a lot. That is really when it all went downhill. I will never forget one of my best friends in the fifth grade imitating me, the way I wrote. I would put down my arm like this to hold down the paper and I would write like this. She used to mock me. And she was supposed to be my friend. In a way, that really hurt. I would go home crying. My father would tell me to be tough and not pay attention to those kids. I used to play sick a lot, so I wouldn't have to go to school –because it was really tough. Then junior high got tougher too. Kids can be really mean, you know. They thought it was funny to make fun of somebody else. They thought it was cool, I guess.

In high school we lived in Texas. My sisters, you know, they used to drive me to school and pick me up because they are older. My sisters are like older, four and five years older. One time it was in the ninth grade and I was waiting for my sister at school. And I don't know why, in Texas it was the black kids that would make fun of me all the time. And now that I know what I know about the Civil Rights Movement I don't know why they would do that. But anyway I was waiting for my sister Mary and I was crying because the kids were making fun of me, imitating me and mocking me, and calling me the "R" word. So my sister picked me up and took me home. Then she went back to the school and had a little talk with that kid. She scared the crap out of him. My sister is a pretty tough woman, you know. She is very athletic. That was funny. She never told me that until like I was an adult, you know. They used to stick up for me all the time. They got sick of it too, I am sure.

Caldwell: When you look back on that, almost everyone I talked to brings up similar experiences about being called names or being bullied, do you think, looking back now, is there anything that can be done to teach kids about disability or make it so that does not happen as much?

Petty: Yeah, I really do think. I have done some work myself in Arkansas with the Independent Living Council on training for junior high kids called *Creating Acceptance*. You go in and you tell kids about disability and about the history and about how people get disabilities. Then you do like different activities. Like, one activity we do is we put duct tape around all

their figures. Then they can't move their figures and we ask them to write. Another activity that the kids really like is we give them three big marshmallows and we ask them to put them all in the mouths. Then their partners try to interview them. It is hard to with three marshmallows, so they get to see what somebody like me, you know with the with speech. They slobber and stuff with the marshmallows. They have to understand that I don't have any control over a lot of my slobber and stuff like that. Yeah, I think kids can be educated. I think you are still going to have those kids who have the personalities, or the environment they grew up in, where they do bully other kids. I don't think we can ever get away and have no bullies. That would be nice, but...

Caldwell: When you were in school did you have other friends with disabilities or people you could talk to about, you know, those sorts of things?

Petty: No, I never really hung out with kids with disabilities. The only time I started hanging out with another girl with a disability was when we lived in Texas. She had Multiple Dystrophy. Me and her became really good pals. We had a lot of classes together. We were involved in journalism. We liked to write. She was a really good friend. But it was funny because the high school I went to in Texas was so big. I mean it was huge. So we got to leave class five minutes early because if we didn't we would just get trampled in the hallway, especially she, with her wheelchair she couldn't get around. So we would always go get lunch early. We would take our lunch to the school newspaper office. We would hang out there. We didn't even eat lunch with the other high school kids. I mean, we had our friends who would also come do that in the newspaper office. So, I guess we had like a little Lunch Club. Sort of like the Breakfast Club, but the Lunch Club. It was fun. We used to mess around on the computer and play games. I really hated leaving that school. Even though I didn't like that school because it was so big, I really liked my friends: Shannon; there were two guys named David –David and David. They were part of the Lunch Club. I hated leaving them.

We moved the summer of my sophomore year. My dad decided, "Okay, we are selling everything and moving to Hawaii." So we did. We sold everything and moved to Maui. I think my dad was having a middle age crisis or something, I don't know. I loved the islands. I loved Maui. My older sister, Jamie, was with us. It was me, Jamie, and Billy, my brother. My sister Mary was living on her own, doing her own thing. So, it was nice to have Jamie in Hawaii because school was even worse. School was the worst experience I ever had, because the Hawaiians are real prejudice

against white people. White people are called “howlies.” Anyway, not only was I a “howlie,” but I had a disability. Not even the white chicks, the white girls, wouldn’t even talk to me because they grew up in Maui and they were considered locals. In Maui I started going to the resource room –the special ed room. Just a nice name I guess. It was cool because I would go to the resource room and I would do a lot of my homework, so I wouldn’t have a lot of homework to take home. A lot of the classes over there were a lot easier. I was learning more stuff as a sophomore in Texas then I did as a junior in Hawaii. My math teacher, he was a white guy from California, and he was just amazed how quickly I did the math. I am like, “Well, I have already done this, you know.” I mean it was junior level math, but anyway.

So, I would eat lunch by myself and it was just terrible stuff. I really relied on my sister, Jamie, to hang out with me. And we had a pretty good church, so I liked going to church back then. Then Jamie didn’t want to hang out with me a lot, because she was 22, you know, and she wanted to go out and party. I was only 16 so my dad wouldn’t let me go with her anyway. But we had a couple good times where we snuck out of the house, you know. It was fun. But we only lived there seven months and then we moved back to Arkansas. Dad knew I wasn’t doing very good at school. He could see it was hard. So we moved back to Arkansas. My mom and dad are originally from Arkansas. My dad is from Little Rock and my mom is from the Fayetteville area. Her family farm is about 30 miles East of Fayetteville. Is it East? Towards Oklahoma. Her sister still lives on the family farm so we go out there ever now and then to hang out. It is nice.

Caldwell: So you moved back here to finish high school. You moved back to Fayetteville?

Petty: No, a little town called Lincoln. Like I said, it is about 30 miles from Fayetteville. And it was really cool because I knew some of the kids from going to vacation Bible school in the summer when I stayed at my grandma’s. People really embraced me, you know. It was great. It was awesome to finish my high school years on a positive note. The only issue I had at Lincoln was that guys still didn’t want to date me. I guess they thought they were going to catch my disability or something. I really had a big crush on this guy I really wanted to go out with. I never dated in high school. One time I did have a couple guy friends who used to give me a ride home from the basketball game or whatever, but still they never wanted to date me. I went to the junior prom with a bunch of girls. The

senior prom, I am so embarrassed, but I asked a freshman to go with me. If I had to do it again I would have gone by myself with the girls because he was sort of a dork. He just wanted to go to the prom; he didn't want to really go with me. But my other friend she also went with a freshman, so we rode together. But still, that guy did not want to go with me; he just wanted to say he went to the prom. Anyway, that sucked.

My mom went to the same high school I did. She graduated thirty years earlier. My mom was voted Most Friendliest in her class and so was I. I was also voted Best All Around. Now that I look back it, I think it is nice that people did that, you know, but there were other girls there who grew up in Lincoln all their lives. I just wonder if they did it. I mean I try not to overanalyze it, but I wonder if they did it because they felt sorry for me or, I don't know. I understand the Friendliest.

Caldwell: What was the other one?

Petty: The Best All Around. Yeah, we had different categories at our high school. For the Friendliest, it would be one girl and one guy. So it was me and a guy named David Bush. Have you heard of Bush's Baked Beans? Yeah, part of that family. It might be, I don't know. So, that is my school story. Well, I still have college.

Caldwell: Did you go straight to college from high school?

Petty: Yeah, and if I had that to do again. I went to a small Christian college about 30 miles north of here. I think north. My grandmother went there, my mom's mom. So I thought it was kind of cool to go to the same school as grandma. I thought as a private Christian college I might get the support I needed. Man, no types of supports for students with disabilities –none what so ever. This was in 1989 so this was before the ADA and even after the ADA it wouldn't matter because they are private and don't fall into the category. I don't think, but I don't know. Anyway, I went there. I didn't study much. At every school, Christian or state school, there is a party crowd –and I found it. So I had a lot of fun in college. I made a lot of good friends. Me and one of my friends I met at that college, we are still friends. She lives in Oregon now so I see her when I go to Oregon. So basically, I failed out of college. I had a GPA below like 2.0. It was awful, so my father said I needed to decide what to do.

Caldwell: I know you were partying, but did you get the accommodations you needed?

Petty: For the accommodations at this college I had to approach the professor myself. Being 18 and 19, just away from home, that is a little scary. I would go to the professor and tell him. I would find students to make copies of their notes but for like tests I needed to use my typewriter. Oh, I forgot to tell you, in high school I got one of those portable typewriters that run on batteries. The brand of it was called Brother. It was so quiet. It was so nice. So, anyway I still have my portable typewriter. I tried to take notes but it was too hard. So, I had to approach the professor about tests. Because, like in English, I needed to do my tests on my typewriter. Because you had to do essays, you know. So, it was hard. The professors were nice, but they were uneducated. I was probably one of the first students with disabilities they probably ever had.

So, my dad told me I needed to decide. In the mean time, mom and dad had moved out of Arkansas to Missouri. Columbia, Missouri, it is a really cool town. In Arkansas they have what they call Hot Springs Rehabilitation Center. It is run by the Arkansas Rehab Services. Hot Springs is the name of a town in central Arkansas. Actually, Bill Clinton grew up there. Anyway, so what you do is you go, and this is a huge place. It used to be the old army hospital, right, so the building is huge. So, people with disabilities –people with dd, people with learning disabilities, people with acquired disabilities, like have been in a car wreck –they go there and they get physical therapy and they can also learn a vocation. So, I said, “I think I want to learn a vocation.” You get a certificate. And they have anything from learning to be a mechanic, to data processing, to file clerk.

This is the closest I have ever been to an institution because you have to live on the grounds of the rehab center. And I was scared to death. Because I stayed in that room, and the beds were like hospital beds, and it was just scary. I had a roommate I didn’t even know. It was just awful! So you go there and you go through this evaluation to see what you would be good at. You do all these test for a whole week. And they decided after my evaluation that I should be a file clerk –filing papers at businesses or whatever. I am like, “You got to be kidding me! With my motor skills?” At the vocational school you go through the program at your own pace, so I really zipped through the program and got my certificate really quickly. Well, they had a community college in the town of Hot Springs and some of the people who lived at the Rehab got to go out to the college and take classes. So, I told my counselor. Everybody had a counselor. So, I told my counselor that is what I wanted to do. I wanted to go back to college

and retake some of the courses I failed. And I had the support I needed to do that. So, I got to be friends with the other people who went to college who lived at the Rehab. We supported one another. I was totally successful. It was the only good thing that came out of the Rehab. I was on the Dean's list every semester. I got my GPA up to like a 3.5, you know. So that was in 1995.

Caldwell: How long were you there, at the Rehab Center?

Petty: I was there for two years.

Caldwell: And you lived there at the Center?

Petty: Yeah. It was terrible. Eventually, I moved up to here I had my own room. I didn't have to have a roommate, so my life was a little better. If you were a college student, you had different rules than the other people. Like if you were going to the vocational program, you could not be in your room from 8:00 AM to 5:00 PM. You had to be at your vocation thing, training. But as a college student you could come and go. See they had a girls' dorm and then the guys' dorm was in the main building. And I will never forget it. When I got sick with a cold or something, I just wanted to stay in my room and sleep. They wouldn't let me. I had to go this place called Second Medical. It was on the second floor of the main building, the medical place. And I just got hysterical because that was even scarier. I got hysterical. I made them call my parents. I was like, "I am not staying the night on that medical floor!"

And if you didn't show up for your vocational class, if you didn't go to class, you got written up. We had a curfew. We had to be in by 10 o'clock every night. I got in trouble for that a lot. And if you got in trouble like that you didn't get to... You had to get a weekend pass from your counselor to go out on the weekends. You had to tell them where you were going and stuff. If you broke curfew or whatever, they wouldn't give you a weekend pass. It really sucked, man! Because my family lives in Little Rock –my dad's family, my cousins and stuff –so I would go to Little Rock on the weekends to hang out with my cousin Emily. Well, I don't think they ever denied me a pass. My mom and my aunt were the ones who took me to that place. My aunt said, "Julie, one of these days you got to write a book about the places you have been."

So, then I transferred back to the University of Arkansas because my mom and dad had moved back to Fayetteville at that time. So I came back to Fayetteville and I got an apartment with my cousin and I have been here

ever since. That was in 1995. I did start going to the University of Arkansas part time, because I didn't want to fail again. I really wanted to get my degree. I spent all this money and time. I really wanted to have a college degree. I also thought it would help me get a job. But what I do now, well it is sort of related to by degree, but not really. But the University of Arkansas was so great. They have a center for students with disabilities. They would hire my note takers. They would give me a room to take my tests in. I had to take college algebra again, so they would give me a scribe to write for me in class. They were just really, really accommodating. I wish I would have gone there in the beginning, but you know, you live and learn. I have a lot of great friends because of all the different experiences I have had. I finally graduated college. My degree was in 2004, cause I only went part-time. In 1998 is when I got a paying job with Arkansas People First, the statewide self-advocacy organization.

Caldwell: How did you get connected to them?

Petty: My sister was working for a local provider and that local provider actually got a grant from the DD Council to start a statewide self-advocacy organization. They were looking for a person with a developmental disability to work part-time on the development of this organization.

Caldwell: And where was that?

Petty: In Fayetteville.

Caldwell: Was that the first time you were connected to the self-advocacy movement.

Petty: Yeah, but after I learned what it was about, what self advocacy was about, I learned that I have been sort of a self advocate on some level. But I never... It was so awesome because I got to meet other people who knew how I felt when I was growing up. So, it was really cool to be connected to all the self advocates across the nation. Even in the state, when I started groups around the state, I could identify with people who had been labeled and told they couldn't do much. When I was born, they told my mom and dad they didn't know what I would become. They didn't even know if I would be able to walk. I didn't walk until I was three. But after becoming involved in the self-advocacy movement it really did change my life and changed my perspectives about a lot of things. I didn't even know what an institution was because I had never been around people who lived there. In Arkansas we have too many institutions. I told my mom, she doesn't understand it but, "I could be one of those people. I

could easily have been in the institution.” She says, “No, Julie.” I said “That is because how you think, but if I was born.” Anyway, I just think institutions are terrible places. They need to be closed. People die. People are being abused right now.

Caldwell: So you started working in 1998 for People First of Arkansas?

Petty: Yeah. It was really hard because a lot of the people around Arkansas have the mentality that people with developmental disabilities should be put in institutions or need to be taken care of. They are very heavily stereotyped or labeled. I think that is because this is the south because if you look at other places. Like on the east coast, I think they are more progressive. I guess it just depends because Maryland just shut down Rosewood, their biggest institution, and it is 2008. But it was a struggle to get people to embrace self advocacy in Arkansas. We still have that struggle. We have a strong VOR presence here. Yes, very strong.

Caldwell: So, can you talk more about when you first got involved in the self-advocacy movement and what that was like? You said it was really good and you could identify with other people?

Petty: It was really cool to be able to travel around the state to meet other people. I am very much a people person, so I love to talk and meet other people and hear what they are going through and help them understand that they have rights like everybody else and that we don't need to be discriminated against. I mean I was still going to college when I got involved with People First and it helped me believe in myself. It helped my self esteem. The grant money that started People First in Arkansas was going through a provider agency and that came to be a little conflict of interest because if people have issues or situations with their support, their provider, I didn't know how comfortable they felt coming to talk to me because my office was right there in the middle of it all, you know, at the agency.

In 1999, the provider agency told me they were not going to go for more grant funding for people first. So, I had a friend. Actually, my friend I was telling you about earlier from Illinois, the old advisor. Her name is Kim. She worked for the University of Arkansas, the Rehabilitation and Continuing Education Center. They have them all over the US at different Universities. So I told Kim what was going on. Kim talked to her boss, the Director. They said they would help me write the grant again to the DD Council, but we were going to do it differently. So, in 2000 Arkansas

People First sort of got revised. Kim became a great mentor to me. Before 2000, I really had no support or direction. The provider agency had good intentions, but I don't think they realized it was a movement and not a program. Self advocacy is not a program it is a way of life, it is a way of being. I think they realized it was taking more time then they wanted to put in so. It was a great move to get the support of the University. We started it off by having a self-determination day in 2000 and Tia Nelis came over and did some of the *My Voice My Choice* curriculum. Ever since 2000, People First and self advocacy has grown in Arkansas.

I believe in 2000 was the first national conference I got to go to. It was in Rhode Island. That really changed my life a lot because I got to meet a lot more people. I already knew Nancy Ward, and Tia, and James, but I didn't really know a lot of the other people. It was so amazing to see all these people with disabilities together. I met people from all over the nation who knew how I felt. My mom got to go to that conference with me, so it was really nice for her to be able to meet people too. So, at that conference I got elected alternate to Self Advocates Becoming Empowered (SABE). Then the board member ended up having to quit in 2001 so I was the replacement. That was the first time I got on the board of SABE, in 2001.

That was awesome. It was in Rhode Island and my favorite part was going to the beach. We got to go over to Newport Rhode Island and me and my mom went to the beach. It was a good time. I am really a mama's girl. My mom carried me around on her hip until I was three or three and a half, because I could not walk. She used to do everything. She used to cook supper and do the laundry. I can't imagine how she did it. She got to go to Rhode Island with me. In Buffalo, I ran again for my Regional representative, but I didn't get it in Buffalo. That was good timing. That was in 2002. Brian asked me to marry him in 2002 and we got married in 2003. I was still going to school off and on, still working on that degree.

Let's see, I met Brian in college. He had a degree in Geology, but then he went on hiatus to play music in a rock and roll band. So when he got serious again about getting a job, he didn't really want a job in Geology so he went back to school to get a Broadcast Journalism degree. And I have a Print Journalism degree. We met in class. When I met Brian and when I saw him he was walking with a cane. So I was thinking, "What is up with this guy? Does he have a disability or what?" He sat right in front of me in class. Later on, he told me that the first day of class he sat in the front

to scope out all the girls and the second day he sat in front of me. So we became friends and we studied together and stuff.

He learned all about People First and he thought it was a really great movement. He learned a lot about it. And I always wanted to learn how to drive. That was one thing my dad would never teach me. My dad would say, "Julie, if you were going get in the car and only hurt yourself that would be okay, but you might hurt other people." So he never really taught me how to drive. So, Brian said he would teach me how to drive. But his truck was a standard and I didn't want to learn so we asked my mom if we could borrow her car. She said, "Okay, if Brian is going to ride with you. I am not doing it. Brian can." So, Brian taught me how to drive. In 2002, we took a road trip to Colorado, to Denver to see some of my friends. We took mom's car, so I got to practice driving on the highway. I totally recommend before you marry somebody –take a road trip. If you still come back liking the person, then that might be a good match. I still liked him after that long road trip. We had a really good time. Brian taught me how to drive. I got my driver's license when I was 28. You know what? I got my years mixed up. We got married in 2001, so we must have took the road trip in 1999. Anyway it does not matter.

When we got back from Denver, I didn't want to get married. I was anti-marriage. I was scared the person would leave me. I didn't want to believe in divorce. I never want to get divorced. My mom and dad got divorced in 1996, after 32 years of marriage. It really shook me up, man. I don't know what would be harder, if I was five or 35. It was just really hard because everything I believed in and everything I based my values on were my mom and dad. They taught me everything. My dad was such a great advocate. Then they just got divorced and it was all gone. It was really hard. At the time Brian and I were friends and knew each other, and a year later his parents got divorced after 30 years of marriage. So, it was kind of nice to be able to help one another. But he didn't seem to have as hard a time as I did with my parents.

So, I was anti-marriage. I never wanted to get married. I never wanted to have kids. So me and Brian started living together. We lived in sin. We got an apartment first and then we finally got a house. Then he asked me to marry him. It was Thanksgiving of 2000. He asked me in front of my whole family. We were moving from a house to an apartment because it was a little cheaper and we were renting. We were getting ready to go get another load. His brother and his brother's wife were here helping us and he was like, "Julie, I am going to drop you at your mom's so you can visit

with your family. You don't have to help us." I am like, "No. I want to help!" I was getting really mad, you know, because he was telling me what to do. So he pulled out of my mom's driveway and everybody got out. I am like, "What is going on?" He asked me in front of my whole family. When he pulled out the ring, he wasn't on one knee. So my sister was like, "Get down on your knee!" It was funny.

When we got married I was really worried. I am not your typical wife. I don't like to cook. It is harder for me to do some things, but some things I do really good. Anyway, one of the reasons we lived together was I wanted him to know what he was getting into. I didn't want him to settle. I didn't want him to think I wasn't good enough because I have a disability. Sometimes I feel like, I still feel guilty because I can't do as much as some other women might be able to. But he says he knew what he was getting into and he married the woman he wanted to. He is a very nice guy. He is very supportive of my advocacy and self advocacy. After we got married, we had a long talk about kids. Like I said earlier, I never wanted kids. I wanted to have a good time: go out and listen to music; be carefree. Working in the self-advocacy movement, it is not like I am in a job, because it is something I am passionate about. I love it. I don't know what I would ever do if I don't work in the self-advocacy movement. So, we decided we wanted to have kids. We tried and tried for a long time. I was getting a little concerned. It took so long. I will never forget when I got pregnant with my first son. When I told Brian, it was a very happy time: We are pregnant! It was scary too. People don't think if you have a disability, you should have kids.

Caldwell: Did you get any of that from people?

Petty: Well, Brian notices it more than I do. I guess I am so oblivious to it all. People stare at me all the time. Every day, they just stare. I think they stare because they don't know. I just smile. But when I was pregnant with a belly they would stare even more. And Brian is so embarrassing. When people are staring, he will say something to them. He will say, "Isn't my wife beautiful?" or, "Don't I have a beautiful wife?" I am like, "Be quiet." Then we came up with a little thing we used to do. We haven't done it in a while. Brian will say to me, "Professor, I see another human exhibiting Type A behavior." And I say, "Okay, I will put it in the book."

But now, with my kids... Logan is four and a half and he is starting, he is starting to notice. Me and Logan were in the store, just me and him the other day, and he was like, "Mom, people are staring at you." I said very

loudly, "Now Logan, what do we do when people stare?" We say, "Hello, how are you today?" Or, we say, "Hi, how are you?" I said, "Okay?" He said, "Okay." I worry about him and his brother. They are going to have to deal with people discriminating against their mother. Logan will probably knock somebody out if they say anything mean about his mom. Brian says we just need to educate them and let them know. I think they already know that I have a disability. One time when I was out of town, Logan said to Brian, "Mama's got a big ouch." Brian said, "What do you mean?" He said, "Mama's got a big ouch." I don't know, that is a good way to put it that way. I have a big ouch, but you learn to work around the ouches. I do worry about my kids. So that is why I am trying to do all I can to educate others so that they won't have to deal with the stuff that I had to deal with when I was growing up.

Caldwell: I wanted to ask you a little bit about disability identity. Have you heard that term before?

Petty: I have heard about like when people might need to disclose they have a disability. Is that different?

Caldwell: More like disability pride or disability culture.

Petty: I have heard about disability pride.

Caldwell: How do you think being a person with a disability has influenced who you are and how you feel about yourself? It is a tough question.

Petty: Well, first of all, I don't know any different. This is Julie. This is who I am. I don't identify myself as "disability girl" or whatever. I think I am a good person. I am funny. I like being with my friends. But I think when I was younger it was harder to love myself. I believe you got to be able to love yourself, before you can love other people. So, that was hard. Like in junior high and high school I do remember sometimes... This is hard to talk about. Sometimes I didn't want to stay around. There were a couple times where I tried to kill myself. I was younger. Me and my sister were actually talking about that a few weeks ago when I went to see her in Missouri. I don't think I really wanted to die, I just think I wanted to be accepted by society. I don't think I really wanted to die, but I wanted to be accepted by society and not just my family. I wanted to be accepted by everybody. I tried it more than once you know. From the time I was thirteen to eighteen I tried to kill myself a couple times, because I was sick of it. Not being able to do something. Not being able to do the simplest things that people take for granted every day. Not being able to button my

shirts for myself. I just got so sick of it at that age. I just didn't want to be around.

Caldwell: So what helped you get through that? Were there things that helped you, when you look back on it now, about how you felt about yourself or how you felt about being a person with a disability?

Petty: Well, my family. They really did help me. Now I feel bad about what I put my mom through because she was there every time. My dad traveled a lot. My mom had to put up with a lot through the kids. I don't know. We were taught to have faith in God. I have faith in a higher power. I am not sure what the higher power is. I have an idea. I just had to believe. I had to believe that there was some reason that I was born with CP. I was meant to do something. I have a purpose. I think it got easier the older I got and the more people I met with disabilities. I just believed in myself and had faith in a higher power that I had a purpose. That is how I got over it. I mean, it didn't happen overnight. I still to this day, I still get frustrated not being able to do stuff for my sons or for my husband –but it is just something you just live with. You have to think about all the other stuff you can do. I am very blessed. I am very blessed.

Caldwell: Do you think the self-advocacy movement helped with that? When you got connected to the self-advocacy movement, or met more people with disabilities, or learned about the disability rights movement?

Petty: Definitely! Definitely self advocacy really changed my life. Even though I had to believe in myself, it really taught me. I believed in myself, but I didn't think I loved myself. In the self-advocacy movement I was part of this training called *Reaching My Own Greatness*. That training really helped change my life. It was like five or six year ago when I first went through this training. The training talks about who you are and what you need and want out of life. Sometimes it is easier to tell people what you like about them instead of what you like about yourself. So, I really had to do some self-reflecting. You even have to look in the mirror in the training. It is really hard. Because the first time I looked in the mirror all I saw was my disability, my involuntary movements. But through self-advocacy and *Reaching My Own Greatness*, I learned that I am great.

I also have to say, Kim. Kim helped me learn. I always used to be afraid to say stuff because I didn't want to sound stupid. So I was always afraid to ask questions. I was always afraid to ask for support. I used to say I am sorry all the time. Before I would ask somebody if they would help me

I would say, "I am sorry, but could you move that over." Gosh, it really gave me a new way to think about myself. I love myself. I am not saying I am perfect. Nobody is perfect. I really like the person I see in the mirror. I hope to convey that to other self-advocates. They can be great too. I mean, gosh, if you would have told me six or seven year ago that I would be married with two kids, driving my own car. I never would have dreamed I could reach all of these goals. Like the other day I was laughing at myself, because I had the Administration on DD calling my home number and then I had the director of NASDDD calling me. How many people can say that? I thought it was cool. It really did change my life.

Caldwell: With SABE you were the regional representative until two years ago and then you became chair?

Petty: Well, I ran for my regional representative seat in California in 2004. So, I won my regional representative seat and you had to win your regional representative seat to run for the board. I really wanted to run for chair, but I knew I had tough competition. So I ran for vice president and I got it in California in 2004. Then in Atlanta, in 2006, I talked to Brian. We had a long talk because I knew it was going to be busy, but I didn't know how busy. I really didn't. So I talked to Brian before I ran in Atlanta and asked him if I had his support and I did. So, I ran for chair and I ran against one of my friends and somebody I really admire, Tia Nelis. I got elected to chair. The last two years has been a rollercoaster. I have been to DC many times. It has been fun. It was really one of my goals as a self advocate, to be the leader of SABE. Like I said, a lot of people I admire like Tia, Nancy and Chester have been in that leadership role. I think I have done a lot for SABE. I am so happy with everything we have accomplished together in the last three years. Some people say that they used to be a little scared of SABE because SABE doesn't really take any crap. We tell it how it is! But you can also tell it how it is and still have friends and allies. So that was something I... We have a lot of great allies.

Caldwell: Just to stick on that and talk about the future of the self-advocacy movement for a little bit. What is your vision for the future of the self-advocacy movement?

Petty: That we won't need it. That everything will be inclusive. That everybody will be inclusive. I don't know how realistic that is. But I worry about the self-advocacy movement and where it is going to go because with the

youth with disabilities it is a totally different situation, totally different issues than what some of us older people had to go through. But yeah, it would be nice if we didn't need the self-advocacy movement. If everybody was created –well, not created –but treated equally. But I don't see that happening before I die.

Caldwell: Well, when you say you are concerned about, you know, where it is going to go with the young people what do you mean by that?

Petty: Right now the young people have their own youth leadership organization. We don't have... We have a few young people involved with self advocacy, but not many. So, one of my goals is to embrace some of the youth and help that transition in the leadership of SABE. I don't think youth are worried about sheltered workshops or worried about institutions. I think their issues. To be frank, I don't even really know what their issues are, so I need to educate myself. I think maybe some of their issues are just going to college. Just like everybody else, how am I going to get what I need to be successful at college? How am I going to get what I need to be able to go to work after high school, have my own apartment, get away from my parents? A lot of the self advocates I know, some of them didn't even go to school. Some of them just went to a day program. I don't think the younger generations are looking at day programs as the answer. I think that is a good thing. I think that people with disabilities are living longer than they used to, like people with Down syndrome. There has to be alternatives for people.

Caldwell: So you talked a little bit about some of the difference you see between your generation, well your generation is younger, but the older generation of self advocates and the younger generation of self advocates. You talked about some of the differences, about sheltered workshops and that, but what are some of the similar things, where maybe they could benefit from the self-advocacy movement?

Petty: I think some of the similar things are labels. Like we were talking about earlier, there are always some people out there who are going to bully you and label you and make fun of you. So, I think that is similar. We could have a good discussion around how to deal with stereotypes and labels. What else? I think we all just want to have a life, you know. We want relationships. I think everybody's life revolves around the relationships they have and they make. I think we all want healthy relationships. We want someone to spend our time with. That is what I hear from self advocates all over the nation. They want a life. They want relationships.

They want that social capital that everyone else has. I think we could all have a good time together. I love our national conferences because it brings everybody together. No matter what your age is, no matter what your disability is, we all come together as one. It was so awesome in Atlanta when we got to have a march from the Martin Luther King Center to the capitol. We were all together.

Caldwell: Did you have any role models or mentors that we like in the self-advocacy movement or people with disabilities?

Petty: I have to say Nancy Ward is one of my great role models. I just really admire her. I met Nancy first. I have known Nancy since 1998, so ten years now. She is in Oklahoma, which isn't very far away from us, so I invited her over to the conferences. She really taught me a lot. I didn't know much about the self-advocacy movement when I first got involved, so Nancy was a great role model. Teresa Moore and Tia Nelis –Tia can be a little bratty, but that is okay I still love her. One good thing about the self-advocacy movement is that we don't always agree, but we can all respect one another's perspectives. I wish I would have had the opportunity to meet Roland Johnson. I read the book that Karl Williams wrote about Roland and his speeches in the back are just so powerful. I mean just so amazing. Everything he went through I wish I could have talked to him. It is so amazing. It is awesome. I really wish I could have met him. I think another one of my role models, people without disabilities, I had a teacher in high school in Arkansas that really knew me and helped me through a lot of stuff. She was not in the self-advocacy movement, but.

Caldwell: Was she your high school teacher?

Petty: Yeah. I talked to her over the holidays. I found her on the internet. She was happy to hear from me. I wanted to tell her thank you for taking time with me and believing in me. She was a good teacher.

Caldwell: What are some of the biggest challenges that you think the self-advocacy movement faces in the future, or now?

Petty: Some of the biggest challenges right now, that is easier to speak to because we are in the middle of it right now. It is sad to say, but a lot of the self-advocacy organizations around the nation are not being run or directed by self advocates. They have people who have the money over them influencing them on what they do, where they go, what they say. It is really sad. I have come up with some core indicators, along with some

of my co-workers, about what makes up a good, a successful, self-advocacy organization. Me and Teresa Moore have been working on those. The support is just. If you don't have good support people, if they have ulterior motives, if they have a hidden agenda, that is one of the big issue we struggle with right now. It is a local level, a state level, and it can be at the national level. Do you know what I mean? Advisors and support people who don't really believe in the movement. They are there –I don't even know why they are there. It is very frustrating. I see that issue continuing in the future if we don't stand up and do something about it.

I also see some issues in the future, like I said earlier, with the membership. Maybe we created a movement that some youth don't want to be a part of because they don't want a label. A lot of people involved in the movement are labeled with the "R" word. So maybe some youth or younger people don't want to be associated with the "R" word, which is sad, but I think it is a reality to think about that.

Another struggle that we have is money. The self-advocacy movement does not have any solid money behind it. We are hoping to change that with the reauthorization of the DD Act, but that is not a guarantee. I look at all we do around the nation in the self-advocacy movement and it is remarkable. I just think about how much more we could do if we had more resources. It is unfortunate. You got to have resources. I wonder how Martin Luther King did it. But I think he was supported by the church and by his followers.

Caldwell: Yeah, you got to have some funding for at least a structure?

Petty: Yeah. I mean we don't even have like an executive officer or people who work for us. It is a working board. I mean being the SABE president is like having another job. It really is. I am not complaining. I love it. I love it and I wish I could run again, but I need to spend time with my family. I want to be a soccer mom. I will not drive a minivan though!

Caldwell: That is what you say now.

Petty: No. Mini vans are not cool. I know, I said I didn't want to have kids too, so we will see.

Caldwell: It is true. I remember going to meetings and sometimes the only people there who are not paid to be there are like self advocates or people from the self-advocacy organization. Like you said, being the chair of SABE is a full-time job. It really is.

Petty: When people want me to come to meetings in DC, I have to ask for help to get there. I just hope they understand the situation that we are in.

Caldwell: Do you think most people understand?

Petty: No, I don't. Because they are used to having their own money and they just assume we have money, you know. I don't think they really understand that we don't have money. Our budget is less than \$50,000 a year. No matter what you do, you always have to pay some out of your pockets. I feel bad that we can't even pay for our board members to come to a meeting. I see all these other organizations having great lunches and going to Florida, anyway. It is very frustrating.

Caldwell: Why do you think that the self-advocacy movement hasn't been funded the way that the independent living movement has or other organizations have?

Petty: That is a good question. I don't know for sure. I wonder sometimes, if it is because we do have the label of the "R" word so maybe people think we cannot handle our money. And, you know, some DD Councils around the nation have been very supportive of self advocacy, but a lot of them have strings attached. We will give you this money, but you can't say this, this, and this. So, I don't know a definite answer. You look at the family movement too. They have a lot of money under the Arc, so I don't know. If you find out let me know.

Caldwell: Well, there is no right answer. It is just interesting to think about why it is really the only part of the DD movement or the disability rights movement that hasn't really got any funding or any real support to get it going.

Petty: Hopefully it will change.

Caldwell: Have you worked much with the independent living movement at all?

Petty: Some, not a lot. Those trainings I told you about that I was part of in the junior high schools those were part of the Independent Living Council here in Arkansas. I sit on the board of our local independent center, but I have not been a board member for very long, maybe a year. They seem to have meetings when I am out of town. I wonder if they do that on purpose. I speak up a lot because I don't understand a lot of what they say. So I have to ask questions.

Caldwell: Just sticking with young people and young leaders. Is there any advice you would give to young leaders –any advice to people who were just new

to the self-advocacy movement or young people who wanted to be a leader?

Petty: Don't be afraid to speak up and say how you feel. Because if you say how you feel, you can never say anything wrong. I was always scared I might say something wrong. As a leader, I don't think about myself alone. I have to think about other people around the nation, because I represent other people. So I have to think about if this will be good for everybody around the nation. Or how will it hurt anybody, when you are making decisions.

Caldwell: So, let's go back and talk about leadership. First, when you think back on your life, what are some of the things that helped you build your leadership skills?

Petty: I think my leadership skills really started to build after I got involved in the self-advocacy movement. I did a lot of different trainings, like I said *Reaching My Own Greatness*. I did a training called, *The 7 Habits of Highly Effective People*. Essie Pederson and Tia Nelis developed a version of *7 Habits* for people with disabilities. It is really awesome because one again you have to look at yourself first. The first three Habits are about independence and the fourth one and the rest are about interdependence. That really helped a lot. I like to read and I like to listen to different books. The latest book I read was called *The Four Agreements*. Have you heard of that book? It is a really good book. I will have to show you. One of the agreements is: don't take anything personal. I used to be so sensitive. I used to take things personal. As a leader you have to believe that you have good judgments and that you are making the best decision for the organization. That is how I got my leadership. I have to tell you, I also read a couple of marriage handbooks. That really helped too because I believe in a marriage you are both equal so you have to be able to communicate and compromise. So I think that being married helped too.

Caldwell: That is actually a good point –the whole communication thing.

Petty: Yeah. You can't expect people to read your mind.

Caldwell: So, the other area is on the meaning of leadership. Probably from your reading, you know that leadership means a whole bunch of different things to different people. I think what I am really trying to understand is really how you look at leadership and how self advocates look at leadership –

whether that might be different from how other people look at it. So first, what would you say leadership means?

Petty: I think I look at leadership as like going down a path, you know. There is something you want to get to and there are different steps along the way. Trying to figure out what is the best way to go on the path. Leadership to me is not about being in charge. It is about helping others in the organization, or the movement that you are involved in, reach their goals and get what they want. Leadership can be challenging. It can be very hard. I think as a leader you are supposed to model the way for others in the organization. Leadership is about communication, like we talked about. I think really a good leader is a good listener. Leadership is also not being afraid to stand up for what you believe in knowing that you might get pushed down. Other people might not feel the same way.

Caldwell: That is really good. Are there certain qualities or skills you think are important for leaders to have?

Petty: Like I said, you got to be a good listener. I wasn't always a good listener. Sometimes I am not a good listener. There are different types of listeners. You could be sitting there nodding your head and agreeing but thinking about the next question you are going to ask and not really hearing what they are saying. Thinking about something else and not hearing the person. Other qualities of a good leader? I think you got to have a good sense of humor. You can't be so serious all the time. Life is too short. There is a time to laugh –because the self-advocacy movement can be pretty heavy. It can have pretty heavy situations and subjects. I mean we are fighting for civil rights. So you got to have a sense of humor. You got to be able to communicate the message to people. I think you got to be tactful. I don't think all self advocates would agree with that. They just say what they feel and they don't care who they piss off. But I believe we you got to be careful with what you say.

Caldwell: This is a tough question, but I want to see what you say. Do you think your experiences as a person with a disability have helped you become a good leader?

Petty: Yes and no. I don't think everyone with a disability is going to become a good leader. I think my leadership has to do with my personality and my ambition, but because I have a disability I have something to fight for. So that is where I think it has helped me become a good leader, because I

am passionate. Like I said, not all people with disabilities want to be a national leader.

Caldwell: Do you think you have a certain leadership style or way you approach leadership that is different. What is your style?

Petty: I like to think I am pretty hip. My leadership style, I am very open to other opinions and other input and feedback. But like I said earlier, when it comes down to it I will make the best decision for everyone, for everyone around the nation.

Caldwell: When you think of great leaders, who comes to mind? Who would you call a great leader?

Petty: Martin Luther King. I am sure you get that a lot.

Caldwell: Yeah, almost everybody says that. Why do you think?

Petty: He is such a great role model because of everything he went through. I think people with disabilities can relate to Martin Luther King because he died for what he believed in. I would die for any of my brothers and sisters. I hope at this day and time it wouldn't come down to that, but there are people in the institutions who are dying. I just think people can totally relate to Martin Luther King. Who else is a great leader? I really think Oprah Winfrey is a great leader. I think Jackie Onassis in her own way was a leader of her family, you know.

Caldwell: Why does Oprah come to mind? What sort of qualities or things do you think she has that makes her a good leader?

Petty: Well first of all she started out as a journalist. I always wanted to be in broadcast journalism, but of course with my disability. I like being in front of the camera. I like to cut it up. Oprah is a journalist. She worked her way up. I don't know if you have seen any of the old videos in Chicago as an anchorwoman. She worked her way up and made who she is today. She has helped people. She hasn't responded to us, but. We did contact you Oprah, many times.

Caldwell: The self-advocacy movement? What did you guys want her to do?

Petty: Give us some money! Show me the money. I thought she would relate to the self-advocacy movement. She is a black woman. She has had to struggle. She was abused when she was younger and many self advocates are taken advantage of an abused. I thought she could relate,

but I am sure she gets requests all the time. I think she is a great leader. I like Jackie O because she was great. It would be hard to be First Lady, especially if your husband was as promiscuous as JFK was. That would be hard.

Caldwell: You talked a lot about this, but when you think about the people who have been the most supportive throughout your life or the closest to you throughout your life, who would you say?

Petty: My family, my mom and my sisters; not so much my brother because he is in a different generation –he is seven years younger than me. So, my sisters.

Caldwell: Some questions about spirituality or beliefs, not like religious beliefs. Are there certain beliefs that guide your life? Certain sayings or beliefs?

Petty: Yes. Number one is that I try to treat people how I want to be treated. That is really important. I try to teach that to my sons. I think that is number one: treat people how you want to be treated.

Caldwell: How do you think you developed that belief?

Petty: Well, first of all, my mom and dad. And second of all because of my experiences; because if I want people to look at me as a person first I have to treat them that way too.

Caldwell: Are there any lessons or things you learned in life that stick out and you remember?

Petty: Lessons? No, not really. I will say at one time I was pretty naïve.

Caldwell: What are your future goals for yourself? Where do you want to go?

Petty: I want to retire.

Caldwell: To retire?

Petty: I really have achieved a lot of my personal goals. We recently moved into this new house and this is where I want to raise the boys. Personally, I think that is my number one job to raise my sons and have them become great people. Second of all, I will continue my work in the self-advocacy movement but not on the national level. I will probably step back from the national level and concentrate more on Arkansas and other states where I am working right now. In Arkansas I am really excited about the youth. I think the youth is our future. So in Arkansas I am working with youths with

disabilities. Creating a youth center and helping kids transition from high school to wherever they want to go. I mean the possibilities are endless – just letting them know that. I wish someone would have talked to me more before I was out of high school and said, “You don’t have to do this. These are all your choices.” But it wasn’t there. With the internet there are so many possibilities.

Caldwell: So, is there anything else you can think of that we didn’t talk about or cover? Any stories you wanted to tell?

Petty: I don’t think so. I think we covered it. I just hope society’s views of people with disabilities will change and that we can be treated equally. And free out people! Get them out of institutions!