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Joe Meadours

9/7/2007

12:30 PM – 1:30 PM

9/8/2007

10:30 AM – 12:30 PM

Sacramento, CA

Caldwell: Let's start at the beginning and talk a little bit about your childhood and your family life growing up. So, first of all, do you mind saying how old you are? Were you were born?

Meadours: I was born in the late 60s in Selma, Alabama, in the heart of the Civil Rights Movement in Alabama.

Caldwell: Really. I didn't know that.

Meadours: And some of the things I guess I saw living in the south most of my childhood –and I guess in the south most of my childhood right during the civil rights movement in late 60s and seeing that –really got me where I am at today. Because I think they were fighting for the same things as we are fighting today: for their rights. So, it was African Americans fight for their rights, what they should have in their life and should be available to them as citizens of this country. So, growing up from Alabama to Louisiana to Texas and Oklahoma, I finished high school seeing that. I remember as a child looking out of my bedroom window one night and seeing a group called the KKK. People warned us about them. And they were always very bad to black people, but if you had a son or daughter with a disability they come and get you. They hated a lot of people and I remember that day. That is the group that I didn't want to be around with.

Caldwell: Yeah. Did they come to your house then or you saw them go to another house?

Meadours: No, I probably saw it from a distance, probably from less than 200 or 300 feet away. I was just looking down from my bedroom window, wondering what was going on. I thought I heard a lot of yelling back and forth and my dad just came into the room and told me, "Don't. That is one group we don't socialize with. Just close the window and don't see it," and as we spoke they were burning down the cross.

Caldwell: On your yard?

Meadours: I saw it 200 or 300 feet away, not in our yard.

Caldwell: Yeah, but your family was afraid they might say something because you had a disability?

Meadours: Yes, because they hate anybody, anything, especially black people, but even if you have a family member with a disability. The KKK group hated anybody and everybody, so if they knew you are living with a disability, they'd probably come to get you or your kids, make their lives miserable.

Caldwell: For how long did you live in Alabama?

Meadours: I was just a young kid, probably the first few years –a year, probably less than a year –but I just remember my mother talking about it and seeing it as a person as I was growing up and moving on.

Caldwell: Did you go to school in Alabama?

Meadours: I went to school in Louisiana, Texas, and Oklahoma. From kindergarten to sixth grade – from kindergarten to fifth, I went to Louisiana. From sixth to eighth, I went to Texas; and ninth to twelfth, I went to high school in Oklahoma. So, there was some good coming from each of the schools and there was some bad, especially in the early 70s, because when you were going to the Individuals with Disabilities Education Act. It was right in the middle of a debate –should they pass it or not? I just remember my mother going to the school board fighting for my rights as a student, “My kid should get education like anybody else, not just because he has a disability. He needs to have an education like anybody else.”

Caldwell: Do you remember? Were you included in school or were you in a special class or special education?

Meadours: For a while, I was in special ed. But as I got older, and my mother saw that I had a lot of gifts to give back, she wanted me included into regular classes. By about the time I was in the fifth or sixth grade, most of my classes were regular classes. And so I had my ups and downs like anybody else, but again I was included and they took time and really studied. And by the time I graduated from high school, six out of my seven classes were regular classes. So I worked my way up and trusted my abilities and know that I can do it. And I guess I made the B honor roll by the time I made the 11th grade. So that was a real surprise to me. So, I was very happy. I knew that my hard work over those years did pay off eventually, and then I graduated with my class, not with a special class.

Caldwell: Overall, would you say your school experience was positive or negative?

Meadours: At first it was negative, because I was growing up in the era of the IDEA, Individual with Disabilities Education Act. But as I got older and knew my abilities, slowly but surely, it came out being positive, because I knew I was included with the regular kids. Inclusion helped with trying to make a difference, because I knew I need to do something without going back into special ed. Because with special ed you don't learn much in special ed. All I did was twiddle my thumbs. Or they pick on you. I had a good friend who was African American, we did everything together. He got left behind I think because he was African American, not because he has a disability. They kept picking on him because he had a problem. I was the one that always hung out with him. We did

things together. We talked about different things, sports. We ate lunch together, talked over phone, talked about girls, whatever we want to talk about. We were buddies together.

Caldwell: Was he your best friend you think?

Meadours: We were best friends and we did a lot of things together. I mean from the first to the fifth grade, we did almost everything together –from talking on the phone to meeting somewhere, to chatting what's on our mind. I think we were good friends.

Caldwell: You mentioned your mom a couple of times. Could you talk some more about your mom?

Meadours: Mother was a big role model in my life as I grew up. She was determined for me to learn, whatever it takes. She had summer school in her own home, to be sure that when I go into the next grade that I had education, I had the tools to go forward. She sat us down and taught us the basics so when we went to the next grade in the fall, we'd know what's going on. She took the time and studied with us, whatever it took to help us to get the right tools to be successful in school. And so that's what's missing today. Two parents are working and there is not enough time to spend time with your loved ones. I was speaking to a parent the other day. Both are working; they are home at probably sometimes at five, and sometimes they are home at 11, 12 o'clock at night. There is not enough time to really spend with their loved ones. So, we need to have families to understand or help places of employment get back to the basics when it is time to spend time with their loved ones.

Caldwell: Are you older than your brother or is he older than you?

Meadours: James is older than me. James is ten months older than me.

Caldwell: And it's just the two of you or do you have any other brothers in your family?

Meadours: I've got two brothers and one sister.

Caldwell: So, you have three brothers and sisters.

Meadours: The one I have a good relationship with is James, who lives in Texas. We have a good relationship because I think we both can just feel or know that it is almost like a call, a choice. When you make this call it is part of your life. We talk about choices. I hope my other brothers and sisters respect what I decided to do for a living. Is it something I am going to do for the rest of my life? Probably so. But again, that door is always open. If I believe that I can better myself I will go for it. But right now, this is the call. When I was a kid, I remember my dream or goal

was to become a professional ball player, but look what happened. I am an advocate for people with disabilities. Politicians probably wish I would have become a ball player. But again, this was a call, and it has been the right call so far. Has it been an easy road from playing ball to this? No. There were some rough times during my childhood, but we all have those times when growing up as a young adult. You know: which direction to go? I am glad I made this decision because it's got me the opportunity to meet people that I never thought I would be able to meet.

Caldwell: Right. When would you say you first decided to go down that road? You said you wanted to be a ball player. When did you change your mind and get into advocacy?

Meadours: Too many surgeries for one. Then, it was before the Americans with Disabilities Act was passed and I saw too many people getting discriminated against. I was still a young kid, or a young adult, didn't know which way to go, but did know that I wanted to learn. How can I give back to my community somehow? And so, I had three or four different jobs. They were alright, but again, I don't think I was giving back to my community. I always wanted to find ways to give back to my community, the community that has helped me get me to where I am today. How can I give back to my community? And we all should give back to our community. Whether if you have a disability or not, it is important to give back to your community and there are a variety of things you could do.

Caldwell: Can you talk some more about your brother and your relationship with him?

Meadours: Me and James have, I guess, a business relationship and a brother relationship. It is amazing. We both work together and we talk almost every night for about a minute or two, just checking in and see what's happening. We have a good, positive relationship. I guess it came from him living in a group home and me living in my own place. And seeing how he has grown over the years and now living on his own and just doing things as brothers. As we were growing up as kids, I thought that would never have been possible. I was going my way, he was going his way, and probably that was the end of it. But slowly but surely, we grew into our relationship before we even joined the People First group. Slowly but surely we were growing into a relationship, knowing that we probably had to depend on each other for support or having somebody to talk to because we didn't have a good relationship with my dad and my other brothers and sisters.

Caldwell: Did all your brothers and sisters live together?

Meadours: Yes, we all lived together. Course they were younger, so they were somewhere between, I should say, 10 to 15 years younger than me. So, I am the middle child. James is the oldest. So, me and James, probably the closest between us two; we are 10 months apart. We did a lot of things together as kids. I guess a little as teenagers, but again he has his own agenda and I had my agenda. And we didn't really connect as we got later in teen years and after he moved out to the group home and I moved into my own apartment. And I couldn't figure out, since I was the middle child why am I moving into my own apartment, and he's living in a group, and he is the oldest. So, I couldn't understand that for a while –and I still don't understand it. When he moved into the group home, we started talking. He was down the street from where I was working, at the day program. I used to try to go visit him at least once or twice a week or visit him at the group home to let him know I am there –even before we joined the advocacy group.

Caldwell: Yeah. It seems like that was a big issue. With him going to live in a group home, you weren't happy about that or you didn't think that was right?

Meadours: I couldn't understand why he was going to live in a group home. It was hard for me to understand, because I was just an 18 or 19 year-old kid still, and didn't know. I had been around people with disabilities as a kid, but when he moved into a group home, and seeing a big set up, I couldn't understand that.

Caldwell: Was he happy there, do you think?

Meadours: I think he was happy at first, but as he got older and seen me got my independence, and seen what I'm able to do, and do what I want to do, and come and go when I want, I think basically he wanted to do it too. And when you are in group home, you can't. A lot of the times you need to get permission to do this and that, and a lot of times, you can't do it, unless you go as a group.

Caldwell: And so did you help him to eventually get out on his own?

Meadours: He asked my opinion about it one time. I said, "It will happen when you least expect it, but let's do some homework on it. Let's think about what kind of place you want to live in and let's look at the options. I will support whatever decision you make." And this is before I knew about choices in life or People First or anything. I think he made a wise choice in moving out of the group home.

Caldwell: And that was all in Oklahoma?

Meadours: All in Oklahoma, yes.

Caldwell: Yeah. So, when did you move out on your own, was it right after school or did you stay at home?

Meadours: It was July 4th weekend in 1987, July 4th weekend. So, my dad got married to my stepmother and she couldn't... I guess she's never been around people with disabilities before. I guess she thought it was time for me to move on. For about three or four months, I survived on crackers and water and peanut butter and jelly sandwiches. I was working at the day, I call it a day-wasting program. Then I was working down the street at McDonald's making biscuits and I was going to try to do it somehow. I had good support around me to make that happen. It came from my family. It came from my friends who I met in the community. That's when I first realized you need to your community – people get to know who you are, and not who your disability is. So, it was important for me to know my community and that's why I like to give back to my community because they have given me so many tools to get where I am at today in being successful. That is why I think it is important to give back to your community.

Caldwell: Who were some of the other people in your community that helped support you?

Meadours: My good friend Bob and Linda Lance because they have always accepted who I am. They didn't look at my disability. Yeah, I had a disability, but again they helped me in different events. They helped me to prepare as a young successful man out there, knowing that if you don't take care of yourself you won't be successful. And so I went to the choir on Sundays, on weekends, spent the weekend with them. They fed me and helped me deal with problems, because I didn't have a good relationship with my dad now and so it was hard. But they were helping me to be successful, Bob and Linda Lance. They deserve a lot of credit and my aunt in Colorado –she was my mother's sister – because, again, she always looked at my abilities and gifts. She always tells me I am welcome over the holidays with her family. So, in the last, I guess, 20 years now, I've been going over there for the holidays over the Christmas and New Year's break. I guess I call it my quiet time, and know that I'm around some family who appreciates my abilities not my disabilities. She looks at my gifts and helps me on some basic stuff.

Caldwell: And Bob and Linda were just –they were like neighbors or friends of your family?

Meadours: They were very good friends. I guess I met them when I was in the ninth or tenth grade and they were moving down the street. I just went down and started chatting with them like birds, and the next minute we became friends and I became friends to his whole family, and so they kind of adopted me into their family, especially for Thanksgiving. I'm

supposed to go home next week but something came up. They were going to have a big bash for my 40th birthday next week. But again something came up, so we had rescheduled it to the spring. They treat me like almost like one of their sons in many ways. He has helped me in many ways, from helping him to do yard work to whatever. Got me where I am at today to be, I guess, a successful businessperson. I've gotten clothes that I thought I would never need to wear.

Caldwell: I want to go back to two things. One, you talked about the day wasting center, the workshop, was that what you did right after high school?

Meadours: I went to the day program, I guess, right after my mother's death. I needed some job skills. They did give me some job skills, but as I got older, I wanted a real job, a real paying job. I knew that one day I may want to retire. I may want to settle down. I want my own place, so to afford it, so I could live independent and do things I like to do, and buy things I want to buy. So, the day programs had some good parts about it and some bad parts about it. I guess the bad part was how they treat people. They don't look at people's abilities or gifts. If you have a disability, they put you here and let you almost waste away. It gets me sometimes upset when I see people doing that. That means that all people could do a job somehow.

Caldwell: How long were you there?

Meadours: I'd say two and a half years. Not long. By the time I got to be a senior in high school I just told me that I don't want go to a day program. I wanted go to a trade school, learn a trade. I just want to learn a trade, learn something new so I could give back –so I could think of my career. So I took trade school as a masonry, as a bricklayer. I didn't become successful. I just wanted something away from the day program, and it was not getting me where I am at today. I just wanted something to –and I remember this at the time –just look good. And so I went back into the day program for three months. Before ADA was passed, Americans with Disabilities Act was passed, a lady named Judith Goodwin, she took me on and supported me trying to find me a job out in the community. I was working at McDonalds. That was for about four months. The hard part about it was, I guess, that I was working every day. I was getting up early in the morning and then going home around noon. That was fine, but it meant that I had to go to bed early, and I am not an early bed person sometimes. So that was the hard part; and know how to look with my appearance... I was an 18, 19-year-old kid; you don't care how you look. You just want to pull up your pants, whatever fits, and go. That can't help me get where I am today. If you are going to be successful, you have to look professional.

Caldwell: Do you think that even that early work and experience in McDonalds helped you to get where you're at?

Meadours: I think so, yes. I think so, because McDonalds had it required that you have to look nice, look nice and groomed. So, it helped me, get me thinking about it. I was a 19, 20 year-old kid, a kid without a care. I didn't, so I just quit. Then I started working in a grocery store that had strict guidelines on how I need to look. Slowly but surely, I was looking at that. I cared a little bit more because I didn't have to go in as early and I got off later. I guess I was working nine to five, nine to six, so that was helpful. I was still having my struggles, my ups and downs, I mean like any young 20 year-old kid would.

Caldwell: Then where did you go after that, after the grocery store?

Meadours: I went to work in retail at Wal-Mart. I was there for almost six or seven years.

Caldwell: At Wal-Mart?

Meadours: Yeah. I guess that's when I really saw the light, right there. I had a job with full benefits –because I was again 23, 24 years old –full benefits. I knew that I needed to make it because I can't go from job to job. So, I knew I had to make it somehow. Yeah, I was having my times there. But slowly but surely, I was getting nice clothes, looking nice. When you work in clothing you have to look nice. The hard part about it was wearing shirts and ties almost every day.

Caldwell: I have seen you in a tie.

Meadours: I don't mind wearing ties, but again I like to bring my own agenda. They put me on overnights. That was fine for a while, but again, I was working from 9:30 PM to almost 7:00 to 8:00 AM. So overnights, I could wear whatever I wanted and they didn't care. So, at that time, I was just wearing my warm-up suits or my shorts as long as it is comfortable to me. So, that helped me, but the hard part was while my friends were out playing I was working overnight. So, that was hard and going back on days. I was still having my days. But again, slowly but surely I was realizing that I needed to make a choice in my career. I had a good store manager who believed in me. He taught me. He looked at my abilities, sat it down. At the time, I was I guess rebelling. I was having a rough time right then. You know I was right at that place. I was still playing sports, but I didn't know what I wanted in life because I was having a rough time in life, still rebelling. I guess I was having a little problem with the alcohol, drinking almost every night. Remember going to work a couple nights with a good old buzz. But I knew that I can't keep doing it. So, one night I found out that I was laying in a meadow and nobody was around. So, I knew that I needed to take care of it somehow and my brother whom I am more close to was getting worried that I was going to die or get sick or whatever and something will happen. I kept saying nothing will happen and slowly but

surely something did happen. I hit my head and got a very serious concussion and I ended up in a hospital. I knew that I need to wake up and if I wanted to become a professional, the time is now –not laying in the hospital with a concussion. So, I think that is part of the reason I am thankful for the People First movement and the Arc movement, because I think if it wasn't for the Arc or the People First movement – who has given me the tools and looking at my abilities –I probably would not be sitting here today. They have given me the opportunity like choices. They have given me plenty of job opportunities. I have sat on different boards with them and they look at my gifts –what I can do and not what I can't do.

Caldwell: Let's move to that. When did you first become connected with the Arc or with the self-advocacy movement?

Meadours: I think I got involved in the early 90's because my brother was in the group. He asked me why don't I start a local group in my community. At first, I had mixed emotions because I was working overnights and meetings would be during the days. So, I told him I was working overnights and it was time consuming. He told me, "That's okay, just fine, from 7:00 to 9:00, that's okay." I had to be at work at 9:30, so it was just fine. So, slowly but surely, I got involved with the local group and then he asked me, "Why don't you get involved with the state group?" I said, "This is only temporary, this is six months. You won't see me in this group anymore. He said, "Well, just try and see what happens." I said, "Well, it will only be six months." He said, "Okay, six months, I'll give you six months." And almost fifteen years later, I'm still in it.

So, I mean... And it is very rewarding. I got involved and seen more and more people speaking up, people like myself, and people like others who are making a difference in the community and giving back to the community –giving them the tools they need to be successful and look at their gifts. So it is interesting. From a local chapter, as an officer; I started as a secretary, and then the vice president and president both stepped down, so that moved me up to the president on top. So I was president of my local chapter for a while, and then I decided to try on and state. At the top, I ran for the state vice president as well. Okay, we will see. Because he was running for president and we knew that we both wouldn't be presidents. So we both agreed and he went for president, and I went for vice, and we both won. And so we achieved together. We traveled around the state of Oklahoma to help start up new local chapters. We didn't know much about People First, but we had a good advisor who supported us through that and knew how it worked. So, we agreed that he takes half of the chapters now and I will take the other half of the state, and then we would visit all the local chapters and start new chapters throughout the state. And so it

got me thinking, well, someone who's been in the group for six months, now it's almost four, five years later, and so I mean it is just amazing. The connections I made and the people I met in that little short time, for somebody who was only going to be in it for six months.

Caldwell: You say you moved to being vice president within six months?

Meadours: I was vice president and James was president. Then at the next state conference James, I guess, was going to step down because he was going to take a job at People First of Oklahoma. That put me as president about two and a half years later, and so got me in a powerful leadership position. I had never been president of any organization.

Caldwell: So you became president of People First of Oklahoma?

Meadours: So, I was his boss, and so I guess, that was the hard part.

Caldwell: What was he doing? He was the executive director?

Meadours: He got a grant from the AmeriCorps project to strengthen the self-advocacy movement and the People First movement. And Department of Human Service in Oklahoma gave us a grant to do leadership across the state of Oklahoma. One of the things I made a commitment to was to visit my peers in the local chapters, because that is where it all starts –in your local group, not at the state level. I helped them grow as a local chapter and give them the tools they need to be stronger and bring back to their local chapters.

Caldwell: Can you go back to when you first went to that local group and you said you weren't going to stick with it, what made you stick with it? What was it like when you first went to those first groups?

Meadours: I think what I saw within the six months was seeing how this group might benefit me; they wanted me. Yes, we all had the disability, but again we all were in there together. We all have something in common and how can we overcome that?

Caldwell: So, how it might benefit you? How?

Meadours: I guess knowing that I'm not the only one fighting for the same rights. I could get more people on my side as a team which would be beneficial and help policy makers realize, yes, they do have a group, they do have a organizing group, and are making a difference in the community.

Caldwell: So, would you say that was one of the first times you really saw that other people have similar issues or are in a similar situation?

Meadours: Similar issues, similar problems, similar diverse issues, and it all came back to almost about the same thing as I went through. You know, if it is

all me they probably won't listen to it, but when we come as a group could be beneficial to all of us.

Caldwell: You think it helped your self-esteem or how you feel as a person with those groups?

Meadours: As I got into the group, it helped me get the tools to mould my self-esteem –knowing that I have support behind me and people are depending on me and my leadership abilities. And I guess I was the only person in the whole group who has lived independent. The rest of them were living in the group homes. My brother is living in a group home too, I couldn't figure out why. That is why we see people –it is not them coming in late –it is the staff dragging their feet coming in late. Granted, there are some great staff out there trying to get people there on time, but when there are certain things going on, it just... I saw things I didn't like. Slowly but surely, my job was not done. I need to be sure that all of my peers here are there at 7:30, not at quarter to 8:00. So, what do I need to do to help staff or help the individual to be here on time? Do I need to change the time to work together with them? So, I guess, that's one part of leadership I learned: What does it take to work together, work with staff or work with the individual. If he's working till 7'o clock, what do we need to do with this time? I don't want to shut him out because he is working; I believe that work comes first before you come to a meeting or anything. So on the time schedule, or whatever, let's work together –slowly but surely, working together as a team.

Caldwell: It sounds like that moment you got connected to the self-advocacy movement really changed your life and the direction of your life really. So you became the president of People First of Oklahoma and then how long did you serve as president?

Meadours: I was president for two and a half years. One of my commitments after the second year was to kind of fade away and help the vice president become the leader as president –because I knew my third year I am not going to run again, because it's time for me to move on. I said to myself, it is job related, mostly in that state or whatever, it was time for me to move on. So, I made a commitment to my vice president at the end of my second year, between my second and third year. I said, "I want you to take on the role. I will be there in the background to support you as an advisor or whatever. You take on more of a role so if you decide to run for president you have some of the leadership tools to do so." So, I was helping her take the role in that.

Caldwell: I think that is real key about the way you approach leadership. You were helping other people to become leaders, would you say that's true?

Meadours: That is very much true, yes, for her to be successful –if she takes it seriously, fine. If she doesn't, at least I have given somebody the tools to become a leader hopefully one day. And she did become president afterwards, so I will give myself some credit. It is up to her to be who she wants to be and for the members to trust her like they trust me.

Caldwell: Why do you think the members trusted you when you were president?

Meadours: I think I was committed and one of my promises to them when I became president was, "To come visit each of you in every local chapter, no matter what it takes, whether it is me or my advisor or just by myself, on the weeknights or whatever I'll come visit." There were I was in four cities in five days in Oklahoma. It was very helpful. And I made a commitment, quite a bit at the capitol –and I was just a volunteer. If I was at the capitol every day, well not every day, but making an appearance, saying, "Hey, I am here. Can you listen?" Or just meeting with the parents, meeting the director of human services, just making and appearance at these meetings, letting them know I am here, I am visible. So, made some commitments to my members, knowing I could be at the ball game instead. A lot of times on Saturday afternoons, I was hosting a meeting, knowing that I could be at the ball game, chowing down on a hot dog.

Caldwell: I think that this important and a lot of people might not understand that you didn't get paid to be president of People First of Oklahoma, so all this was on your own time right? So, you were still working?

Meadours: I was still working at Wal-Mart full time and so I was juggling with my full-time job at the same time volunteering as President of Oklahoma People First, visiting different local chapters –giving up a lot of my weekends. Instead I could have gone out with my friends to a ball game, but I knew my members selected me to do a job. I need to go visit them or host a meeting to give them the tools so that they can be successful.

Caldwell: And then I guess we will stick on that... Where did you move after you stepped down as president?

Meadours: Alabama People First. They offered me a job. They found out that we did a similar project here in Oklahoma and they wanted to do a similar project in Alabama. So, they asked me back in July and I said let me think about it –this was back in the early 90s, It was about community living, why community living is better than inside an institution. So, we did a number of leaders in Alabama. So, Alabama People First found out we did a similar thing so they called and asked me for an interview and, of course, I talked to some people first. That fall was very hard because I had to tell my best friends at the that I might be moving –that was Bob and Linda Lance who has helped me get where I am today,

being successful, known. They knew it was time, but again, I was talking to some people to be sure it's okay. So, I took the job. It was only for ten months, but I said, "I am going to try it. Nothing will happen." It was a learning experience. Did I get homesick? Yes, but again I was down there in Alabama meeting some people that I never thought I would meet in a short time. In those ten months, I met some neat, neat self advocates, and I met a lot of nice professionals, who helped me adjust. It was the first time I moved out of the state –from Oklahoma to Alabama –as an adult. Who is going to accept me? What's going to happen? In the first few months, I did get homesick. I missed my friends; called them almost every night, "When can I come home?" Their schedule with my schedule, it was hard. When I went home, I was thankful. People First at Alabama let me go home for about a week to spend to get adjusted again at the beginning, to let me know it is all right.

Caldwell: And so you were getting paid at this job. Was this the first time you got paid for doing advocacy?

Meadours: Alabama People First paid me to go around the state and do several interviews around the state –interviewing self advocates, interviewing professionals, and interviewing parents about why we believe we should put our money into the community instead of institutions. So, it helped me grow more as a professional, and more in my personal life. I know that they have a story to tell that I can't tell because they are the ones who have lived in an institution and I haven't.

Caldwell: Was that the first time you were in an institution –or went to go visit one?

Meadours: First time I visited one, it was in Oklahoma. When I walked out, it was first time I cried at what is going on. Why? There is something wrong with that picture? When I got home that night, back to my hotel, I couldn't focus and I couldn't sleep thinking of the people who I had talked to –their abilities were no different than my abilities, but they were in an institution. I couldn't understand what was going on. My advisor explained it to me, but I still couldn't focus –thinking about them. From that day on, I think my heart was in it; we need to find money for community living. Nobody... Our prisoners are getting treated better than people that are living in institutions, I mean, everyday as we move forward.

Caldwell: Why do you think it is that the institutions still exist and there are still people in the institutions?

Meadours: There are some parents that believe that their loved ones are not able to live in a community, are afraid that the community will hurt them. They think that people would abuse them, but again, you can get

abused in an institution. That is why part of building community integration is get to know your neighbors, get to know your community, who you are, so they can accept who you are, not what your disability is.

Caldwell: So, you were in Alabama for the ten months and then what?

Meadours: Then I went off to Tennessee.

Caldwell: To Tennessee, I didn't know you went to Tennessee.

Meadours: People First of Tennessee got a grant to do AmeriCorps, to do outreach. Tennessee was fine, but again, it was not for me. I just needed a job to survive. I was just going through a little rough time there. I was recovering from hand surgery, broke my hand in two from playing ball. Tennessee was fine, but again, was not for me. I refused to move back to Oklahoma, because I did my time in Oklahoma and I couldn't do it anymore. Cool project. Tennessee People First got a grant to do, I guess, outreach in developmental centers and other state institutions –almost like being an advocate, but not quite an advocate – to help people get the services they need to have a life they need in a community. And that was okay but again there was not... I guess it was just a struggle there, back and forth, with Tennessee People First with AmeriCorps. It didn't work out. So, it was just good for one year; I just needed a job to get me by, to survive on. I refused to go back to Oklahoma because I did so much for Oklahoma and I hate to go backwards. I was taking steps to keep working forward for the process of my career. I wanted to help, but again I know that it was struggle. I know some good things come out of it, but again overall it was a struggle for the one year I was there.

Caldwell: So, you were there for one year.

Meadours: One year.

Caldwell: And then where did you go?

Meadours: Then went off to Chicago.

Caldwell: To Chicago?

Meadours: So, in Chicago, the independent living center I was working at, they got a grant from the Kennedy Foundation to do outreach for people with cognitive and developmental disability. So, I was there for three years to start peer support groups and it was very good. It got me thinking more, this is how it should be. I mean, it was going good, I mean things were going great, smoothly. I was on two boards, the Illinois Council on Developmental Disabilities and the Arc of Illinois. So, I was very active with both of my boards. I felt like I was contributing back to my

community. I got to the point of my career that I knew this was the right choice, so I was making smart decisions in my career now. At first I was wondering if I made the wrong move again, but now I think I made the right move to Chicago. Again I was on the Council and on the Arc board; that helped me grow as a person and as a professional in this field to see the other side of the story, to see what a service system is like and how there is a lot of speed bumps throughout.

Caldwell: You mean to see other states and their systems and their services?

Meadours: I guess it helped me to understand how Illinois state system works and what we needed to do as self advocates to work with the state system. It woke me up a little bit more to understand how Illinois works and how other states go through the same thing every day. It helped me understand if this is going to be something of a career move or is this just something I am going to be around for a while and gone again. But I was there for three years and I made an impact in those three years because I reached a lot of self advocates, a lot of professionals, and lot of providers out there and there was lot of good communication back and forth.

Caldwell: Working at the independent living center, was that your first experience to the independent living movement or the independent living centers?

Meadours: It was the first time I moved into the independent living center, never worked at an independent living center before. But again, I believe that we need to work together because numbers can make an impact when you go to visit up at the capital. It makes a difference. So, it was a learning experience in a lot of different ways and for me coming from the outside, I guess an out-of-towner, they didn't understand what I was saying. It was hard. They believe in protesting and this and that; don't get me wrong, I believe protests, but again there is a way to do it in a professional way with the respect of my peers –I would like to get their permission before I do anything crazy. Again, they are going to be around; I probably won't be around so it is better to be safe than sorry. It will come down on them, before it will probably come down on me. So, it was difficult. The difficult part was it was just that they had their own agenda and I had my own agenda; and it was, I guess, hard for me to understand their agenda for a while. And I thought I caught on... Sometimes I joined them and sometimes I just kind of stayed to myself.

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

Meadours: I think there is a big difference in the independent and the self-advocacy movement. And the big difference is, I guess, we both have two different agendas. I just wish we could both somehow come together and I would like to see that. I see it coming to get it slowly but

surely but again it is taking a lot of education on both sides –on my side and their side, to be at the table. I think we both want the same kind of mission: that our brothers and sisters should be free in the community and should have the choice who they want to live with and do whatever they want. Again, until we come up with some of that dialog there is still a lot hate, of who should get the pot of money. The self-advocacy movement thinks they should get the money; the independent living thinks they should get the money. I think we should split it in half and let them duke it out. If the independent living shows the answers to what they are doing, give it to them. If the self-advocates show answers for what they do, give it to them. Hold them accountable for their actions.

Caldwell: I think... Were you one of the first people from the self-advocacy movement to work in an independent living center?

Meadours: Yes. I was probably one of the few or one of first ones that worked inside an independent living center. And so, I guess, I hold that title as an honor, but again, it was a struggle. I had some good friends who worked there. Outside of work, they had warned me and told me stories about it; and I saw some of it, but again, I believe we need to work together and diverse. Let's find a common mission and find something that we could work on together. The fight between us, it does not look good when we go to the Capital. Why aren't you working with the rest of the disability groups across the state? So, I believe if we come together and come as diverse, it will be very helpful.

Caldwell: What do you think some of the differences are? You said there is a difference in that they have their agenda and the self-advocacy movement has a different agenda. What are some of the differences in your mind?

Meadours: In the self-advocacy movement, I guess, we were a little upset because we don't get much attention as much as like ADAPT, and stuff like that –what they do and how they take care of themselves. So, some of us are going over to the independent living center to get that attention. I think that's wrong. But again, let's work on our agenda and hopefully we can come together and work together on the same issues. I guess ADAPT thinks that everything has been handed down to the self advocates. There are a lot of words that have been back and forth –I have been hearing across the country. And I have to tell them that I have worked at both sides, so I'm kind of right in the middle. What side do I go on –the self advocacy side or the independent living center? There are times I have caught myself on a hard rock position because both are great advocate groups. I wish both of them continue to be successful. But again, I am right in the middle and what side do I go on? I mean, I have seen some of them from the independent living movement go protest at the White House and get arrested. I don't

believe in getting arrested. I believe in protesting, but again, let's do it the professional way so people won't label us. Why give the community another reason to label us? As if we don't already have enough labels already? If we are going to educate the community who we are, we can do it. If we get arrested that will make us look bad as we are educating the community who we are. In the self-advocate movement, I guess it's hard because... There are a lot of great self advocate leaders and they wanted to do this and that. For me, I like to take measurements to cover my tracks. So, I kind of know what I am doing. Well, they say, "Nobody is doing this or that." But again, I like to be accountable for what I do and do my homework before I go do something. Before I go to a meeting, I do my homework and study it. If it is something I want to do, then I do, and that is fine. But again, I want to make sure I am accountable, do my homework on it, because if it is something that gets me in trouble, or getting in a situation that somewhat comes me... I want to know my facts before I tell the story.

Caldwell: This might be jumping ahead, but one of the things that I think is interesting is paid positions for self advocates. You had a lot of paid positions in Tennessee and then you went to the independent living center in Chicago. You know, it seems like the independent living centers would be a good place for self advocates to get a job doing advocacy, but it doesn't seem to happen too much?

Meadours: It doesn't. I have lost contact a little bit with the independent living, since I left Chicago. I guess I put the blame a little bit on me, but then I put a little blame on them, because before I left I told them I would like to continue the relationship, working with them or whatever. But again, we both have fallen by the wayside. I just wish we could again come to some common laws and we could find ways to work together –even just picking up the phone and saying, "What is your stand on this or where do self advocates stand on this? What can you do to help us?" I have seen some of the self advocates jumping on the independent living, I guess helping them, but again it is far and few between. I went to the meeting the other day with the independent living center and it was all people with physical disabilities. Nothing against that, but again I think it needs to be a diverse group. It has been hard. I guess that is why the self-advocacy movement or the DD population has mixed emotions about the independent living centers –because they think they will control everything. And so, again I believe in working together but a lot of people thinks they are controlled in this and that. You can have a control over a lot of things, but again that is when as a self advocate you need to speak up or you need to find a way to work together.

Caldwell: So, you were at Access Living for three years. Is there anything else you want to talk about during that time when you were there?

Meadours: I just appreciate the opportunity to work in an independent living center. Someone who came from the outside and didn't know much about independent living center, I got another look. I can say that I have worked in an independent living center and have worked from the outside now in both ways.

Caldwell: Did you know much about the history of the independent living movement before you worked there?

Meadours: I knew a little bit, but not much about it. I just knew couple of people who was in it. I never really did my homework on it, just continued with it, until I got the job and knew what they were really about. I just knew I have seen them at conferences; a couple of people that I've met and have tried to tell me to get involved. Again, that's when I put the blame on myself a little bit, because I didn't know much about the independent living and they didn't know much about me. But again, we stayed in contact every so often when we see each other at the conferences or somewhere. They kept reminding about this and that and I never thought of it, then I got the job at the independent living center. I look back and I wish I did get involved because I would have had a little wisdom of what was happening and know what their agenda is about.

Caldwell: And now in California, where you're at, the independent living centers started here.

Meadours: I am planning to go visit the first one here. Probably in the next six months to a year, I will probably go visit.

Caldwell: I think you are in a great position with your experience coming from both.

Meadours: I tell people I have worked as a state employee to independent... It is just amazing. I guess I am not trying to brag about myself, but I mean not a lot of self advocates can say that today. So, people keep teasing me; they say, "How can you keep continuing doing this?" I say, "It is almost like a call, it's my call of duty." When you're in the service, people go on their call to service. My call is this.

Caldwell: Okay. So then after Chicago you went to Alabama?

Meadours: Back to Alabama, and I worked for the State Department of Mental Health and MR for five years, and that is the longest I have worked anywhere. Everything was going good. I had met some main contact people. It was a wonderful experience. I just got to know a lot of the self advocates. I met a lot of parents; we was working together to understand how the state really works. I got a picture how Illinois works over, but now I'm on the inside, as a state employee –one of those politicians, I guess you would call it. And so, understanding how the services and how long it takes for people to get services...

Understanding that it takes steps... Everybody wants services just like that, and I agree with them, but now it takes measurements to get those services that he or she needs. You have to go through this person, and this person, and this person –a longer road than I thought it was. Because at first I thought it was easy. Why didn't he get service right away? He has been waiting. I thought he was just going to have to wait for a month or two. But after seeing this now I have a better picture of understanding how long it takes for a person sometimes to get the services he or she needs in the community. And that helped me, I guess, understand how state government works better. It gave me a better picture –how before I joined the state, what other state employees were going through and to know that there is a lot of great state employees out there trying to make a difference to my peers and trying to get the services they need. So I try not to bump off any state employees anymore, because I think their hands are tied. It is not coming from them; it's coming from people at the capital. If you don't educate your politicians, you won't get the service you need. It's not the state employee's fault that you cannot get services, mostly it is coming from the capitol, the legislatures are holding up the budget or the bills to get the services you need. I guess the department has a small pot of money, and if that runs out, you have to wait until next year. So, that helped me understand a little bit how the money works back and forth.

Caldwell: And what was your title at Alabama?

Meadours: I was the Director of Consumer Empowerment. We got a grant from the somewhere. I forgot where it was. I guess from Medicare and Medicaid to strengthen the self advocate movement, for the first year and a half. They wanted me to strengthen the self-advocacy movement and go around and speak to self advocacy groups and host different trainings throughout the state to strengthen the self-advocacy movement. So, I did that for about the first year and a half –get to know the self advocates again and strengthen the movement and see what happens.

Caldwell: Is that People First of Alabama? Is that the name of the self-advocacy group?

Meadours: Yes. But People First of Alabama didn't get the grant, the Department did. It was from a Real Choice grant. And so the Department got the grant and they wanted us to strengthen the self-advocacy movement within the Department. With me new within the Department it was hard to adjust for a while because you don't know what to say, what to do, what button to push. I thought it would be easy but it wasn't easy because I was new at this and didn't know much about it. So, we strengthened the self-advocacy movement. It was great. I thought it was very successful. When the grant ran out, they put me on the state

funding budget so I had the state position job. Before that it was a state job too. It was always a state job but the commissioner at that time made sure that there was money after the grant was over so that the process could continue going. And so we continued doing the process to strengthen the self-advocacy movement –help them in any way we can with some points. Then I guess I also was working real closely with families, helping them understand or helping with their loved ones decisions, sitting down and talking with them about what services do they need. I reported back to my commissioner saying, “Here is what he or she is saying that he or she needs to have quality of life.”

Caldwell: Do you know how many other states have done something like that where they hired a self advocate or a person with a disability to that, to go around the state?

Meadours: I think about three or four, not many.

Caldwell: Not many?

Meadours: Not many. I think it was Chester from New York, myself, Michael Long, he was from here. And others worked with other agencies but I think there were only about three or four of us. But if you don't support somebody, the project won't be successful. So, that was a big problem with some other states; they hired a self advocate but didn't budget in money for a support staff. I had money in my budget so that I could hire support staff. Well, I don't drive, so I needed somebody to take me to a meeting or to a conference in the area or in a state somewhere. So, there was money in the budget to hire my support staff to make that happen.

Caldwell: It seems like that's an issue for a lot of self advocates that are trying to become leaders or professional advocates, there is not many paid positions either at the state, or at the independent living centers, or the universities. It seems like it is really hard to find those paid positions?

Meadours: They are wrong. And I don't know what... That is why I think it is important for the independent living movement and the self-advocacy movement to work together on ways to do that. And I don't... At one point I thought I saw it coming but with state budget problems and federal budget problems with all the different projects... Unless you have been in it for a while... If you are coming in new, it's going to be harder to get in a position. You always have to have, now, some experience, and it's sad. How else would you get experience, if you don't get the experience, if you can't get hired as a state employee or a similar independent employee?

Caldwell: But if you look at the independent living centers, because they get funding and they have executive directors, leaders, and a lot of the

leaders that come up are paid workers at independent living centers. It seems like that's a big difference with self-advocacy movement, it is really hard to get a paid position?

Meadours: Yeah, and I am not sure how we are going to go about doing that. I think it will happen but I am not sure when. I guess some of us are determined to make it happen, like myself. Others want it to fall in their lap and if you wait for it to fall in your lap, you will have to wait for a while. Myself, I want to make it happen for me to go to Washington, DC and meet those contact people and build a relationship with those people. Maybe with my contacts and their contacts, that could make it happen.

Caldwell: What do you want to see in terms of self-advocacy movement?

Meadours: Well, I would like to see self advocates given more opportunities, for self-advocates to have a voice at the table. I mean, and more, you got myself, you got other leaders across the country. But I am worried about the self advocates that are sitting at home doing nothing. We don't take the time to help them to become leaders of tomorrow. And sometimes it is their choice to stay at home, but again we don't help them produce a product. A lot of times we depend on the people who have been around for a while and that is fine, but again if we don't come with new leaders or young leaders we are going to be facing a lot of problems. I don't want to see that happen. So, one of my personal goals is to help the youth movement, somehow. We can't let it die right now. We've got to. If we don't, we will be facing problems that we faced 10-15 years ago –from day programs to sheltered places to group homes and possibly open up state institutions again and nursing homes. And we don't want that. We have worked too hard to get where we are at today, and if we don't help the youth population or the generation after me, we'll be facing problems. If you think the budget was real bad this year, just wait for the next couple of years. It will be real bad if we don't work together or find ways to help the next generation that is coming up.

Caldwell: Do you see that –you may or may not be able to answer this, but just on the national level –do you see the self-advocacy movement growing, or is it staying still, or shrinking?

Meadours: I see it as diverse on a national level. Everybody has great ideas, but nobody wants to come together on this. There is a lot of diverse people out there who are scatter-brained and don't know what to do. One of the things I think we you need to do is at one of our national conventions –and I am hoping it is next year, but I doubt it –all of us come together and find out what are the three or two missions that we could all come together and work on, like when we first started. Again, we all worked together one time on closing institutions. Okay, that was

fine, but I haven't heard really one or two things that we all could work together on. I mean, all I have heard is closing institutions. That is fine. I believe in closing institutions, but again, let's go on to the next step, find something that is going to be an ongoing thing. The money the state's got with the budget problems... So, let's find something that we can all work together again and find a common mission together. Each state is working on different things and that is fine, but again, if we could all come to an agreement that each state will work on this one project to make a difference, I think that will help strengthen self advocacy. But again, we've got everybody scatter-brained; they don't know what's going on.

Caldwell: What support do you think the self-advocacy movement needs to keep to continue growing and becoming stronger?

Meadours: I think we need new leaders in the movement, new ideas. Help the new population that's coming up –people who are just getting into the movement, help them to become leaders of tomorrow. So when I am old and gray, they are there behind me. I hope to be doing this my whole life, but help us to understand what they want and listen to what they have to say. It's going to be their movement soon. I mean you got people slowly but surely straying away from the self-advocacy movement and doing other things. So you have to help the new leaders that are coming up. Train them or find out what they need and find out what they want to work on, because I think it's going to be their project soon, in the next five to ten years.

Caldwell: Do you think that what they want to work on, or what they will want to work on, is different from what you've been working on?

Meadours: I think so. I think they have a different purpose.

Caldwell: Why do you say that? Because times have changed or?

Meadours: I think they want to take different challenges and take that risk. We took that risk too, and we had the support and everything. But they will take the risk because we learn from our past, what we did, and they will take that risk, too. They probably will be more successful because they will learn from our mistakes –what you should or shouldn't do. So, I think they will be more successful at it, whatever they take on, because they will learn from us, from the struggles and the challenges that we went through every day.

Caldwell: Do you see yourself playing a role like a mentor for the next generation, or the people that are your age?

Meadours: I am hoping people ask my advice –maybe to be on an advisory board. Bring on the old timers somehow –five, or six or ten of us who has been around almost since day one of the self-advocacy movement. Use us

as an advisory board. Just call and say, “Hey, let’s have a cup of coffee. Let’s talking about this.” So, almost like being a mentor or peer to peer. Should we support them or not, or whatever? Talk it out. And that’s why I don’t think they will make the same mistakes as we did, because they will have somebody to talk to and know how to deal with things.

Caldwell: What else do you think the next generation needs that could be done to help support leadership in the self-advocacy movement? We talked a little bit about money and funding for the self advocacy movement, could you talk some more about that, about what you would like to see happen there?

Meadours: I would like to see more states try to find a way to fund self advocacy. Not just to go to conferences and everything, but to have an office, like we do here in California. In California we have an executive position. It all starts at the state and local level, then go to DC. But if you have a local state level office where people can call and ask for advice; that might help.

Caldwell: We skipped over but you went from Alabama to here in California and you are the first executive director, I think, with the developmental disability in the self-advocacy movement. So again you are kind of the first, but I think it is a good model for other states, maybe?

Meadours: I am hoping other states can learn from us. As they say, we are on the frontier for the next generation. So, when their state comes, they could call us, and they could learn from our mistakes, so they won’t repeat the same problems like California did at first. I am not sure of all the problems California went through, but learn from our mistakes and take it to another state and learn from it so it will be better.

Caldwell: Do you think California was able to do this because they got money from the DD Council?

Meadours: Got money from the DD Council and some key, I guess, leaders in California to push it through to make it happen –the president, Michael Cook, who worked very hard on his commitment before he left office. He is still president, but one of his commitments was to establish an office for People First of California. So he met one of his goals. Both of our next goal is to look for continuous funds, what we need to do. So the next year, year and a half, we will hope to find ways to continue, because we can’t let the ball drop now. It would be ridiculous. We are doing all this work now and a year, year and a half from now, everything stops. Let’s find ways to continue. We see people making progress in their life and making a difference in their community.

Caldwell: Why is it important to have that funding for the self-advocacy movement?

Meadours: We fund everything else. The most important thing is that we are making a difference in our community, local community and state, in different ways and we have people who understand. As we are continually making a progress, we can't let it die. I mean California is a perfect example how to take measurements and see the progress making. We've seen people making a difference on their boards in their community or on board they sit on across the state. We all don't sit on People First boards; we sit on different boards to make a difference. The peers that we support are the peers that we depend on. So, if we let the ball drop, I got the feeling that once we will go backwards and let people just walk over us –almost be seen as a token. Tokenism is still going a little bit, but not as much as it used to be. Part of it is that now we got a higher state position here. That will help us understand and be more included at the table. People will have to take us more seriously. They know that they got a paid position and he or she has to answer to a board now. So, that will help. Before, people could just walk over you and not care. It still goes on a little bit, but not as badly. And again, it is up to the self advocates. I tell them, "If you think you are going to be a token, stop them. Don't be afraid. Just pick up the phone and call me and we can talk about it. Don't sell out. Yeah, you may be upset at them, but there is a professional way and a right way to do this. So don't mess it up. Don't give them a reason to label you and say you are a bad board member. Be sure you understand what is going on. If you don't, it's fine. Let's find ways for you to understand. Boards are not for everybody, so that board may not be for you. So, let's find a board that fits you, and if you don't want to join a board, that is fine too."

Caldwell: Let's go back and see what we haven't talked about yet, and go back to the key people in your life that helped you get to where you are at today. And you talked about some of the people... But who else do you think really helped you along the way?

Meadours: I think my circle of support of my friends –the friends I have met in my community. It's from outside of my circle. They saw my troubles; they saw my success –my friends outside my circle who knew me as me and not as my disability. They knew my struggles and were understanding and knew it would be alright. I guess they almost gave me a pep talk; they told me, "It is okay. Don't worry about it. Let's find ways for you to be successful."

Caldwell: Who were some of those people when you look back?

Meadours: I guess the different store managers I had at the different places I worked, a couple or more of my friends, a couple of my friends from the

police department, I guess one of my landlords and my neighbors. And that's why community integration is important so it can help you if worse comes to worse. So people like that, and my neighbors, helped me see the other side of the fence. My circle of support, but again, I have gone beyond it and got to know my neighbors. They know who I am, knew that I have my days, and knew that if something is wrong they could read me like a book. So, they helped me understand it's all right to struggle.

Caldwell: Was there anybody that you would say was your role model or role models that you had, looking up to that you wanted to be like?

Meadours: Probably like there are two that came to my mind –probably John F. Kennedy and Martin Luther King. Both of them liked to work with people, no matter what color, race, disability, or religion whatever. Now both fit in my description as how we should treat our people and both of them treated people very respectful. I look at them as role models in how they treated other people, and that's how I like to see myself how I treat other people in my work, what their disability, what their color, religion, whatever, help them understand I am a friend, not some professional. It's like when I was with the State of Alabama. I tell my peers, yes I am a state employee but I am here for you to understand to get the services your need. So if I don't hear from you, I'd think everything is fine, but if I do hear from you, I may come over to them and go back and talk to someone to make it happen. So, I think how John F. Kennedy and Martin Luther King talked to people. I think those are my two role models.

Caldwell: Those are good role models and good leaders. Do you remember when you first became aware of them or first learned about them?

Meadours: I guess I first learned about John F. Kennedy a little bit in school and I learned about Martin Luther King in self advocacy movement. Because John F. Kennedy I guess, I read a lot of books about him and did a lot of study on him, trying to figure out who this man was, what he was like. Someone told me that he had a sister with a disability. I didn't look at that at first. I just thought he was a regular man who was President and tried to make a difference in the country how people should be treated. And Martin Luther King, I guess people told me about how he was active in the civil rights movement in the late 60s, how he wanted to make a difference in people's lives too. We didn't really talk much about that in school. When I mentioned I guess Martin Luther King, people hushed me up on that; called him this or that and used the "N" word a lot on him. Of course, at the time, I didn't know much about what that mean, but after I caught on, I knew what that meant when they were using the "N" word. That is when I lost respect for a lot of people because I saw he was with all people. No matter what color they are, he was a difference to what he believed should be right.

- Caldwell: When you got involved in the self-advocacy movement, was there anybody in the self-advocacy movement that you saw that kind of influenced you in the movement?
- Meadours: Not really. I just wanted to be myself and I knew so people could look at me and influenced in my life and not put that label on me. So, my gut feeling was that I just wanted to be myself and go on and let people accept me who I am.
- Caldwell: Do you think people look up to you as a role model now, people in the self-advocacy movement?
- Meadours: I think it is important for us to educate the youth for them to look up to us as role models. So, that's why my gut feeling is that I need to go back to the youth movement from high school to 22, 23, help them and say, "We need you on this." So, when they get to 30, 35, are saying, "Look, Joe was my role model, and this is how I go where I am at today." So, I think there are some role models out there like myself in the youth movement, but it is up to them if I can be their role model or not. Because they probably won't know who Martin Luther King is or who John F. Kennedy was unless they read it in the books or someone tell them about it.
- Caldwell: It seems like there is more... The self-advocacy movement is getting into schools more and trying to connect with younger people at an earlier age. And why is it important connect with people when they are in the schools?
- Meadours: Because they won't be in school forever. If you start with them young, finds to service their needs, finds the stuff they want to do, of course, it's their agenda... So what is the number one or two things you all want to work together on? Find a common mission. I think that is what has to happen with the older bunch. We have so many agendas out there and nobody has one, common mission. So find it and help them to be successful at a young age because our youth faces a lot of problems today. So, help them and let them know that they have a friend out there who has been through this and know that if you don't start now, it is almost a struggle when you get to high school. Help them to get to that next step as a leader or just a member of the community.
- Caldwell: And going back to the people that supported you, are there people that we haven't talked about, other people that come to mind who supported you along the way?
- Meadours: I guess my good friends in Oklahoma. There is too many to name, but there is a lot of good friends in Oklahoma who struggled through the bad, the ugly, and the good. I guess, from my involvement in the self-

advocacy movement today to back then, who supported me, talked to me, and sat me down. So, I could call some of my friends and ask for support and nine out of ten times I could get it. I could call someone back home and get some advice and support on this if I don't understand.

Caldwell: I wanted to ask you, and this might be a touchy subject, but your mother passed away when you were younger? About how old were you?

Meadours: Yes. I had just turned 16.

Caldwell: Sixteen when your mom passed away?

Meadours: Yes, two weeks before Christmas.

Caldwell: So, that's similar to Roy's story too. His dad passed away when he was very young.

Meadours: Another thing. I dedicate a lot of the stuff I do today to her. As I look back on my childhood, this is what she told me this, and this is why she told me this and that. I think it shows today how I carry myself in the workplace. She always told me, "Come early or be on time. Don't be late." I guess she was a little bit like a role model to me as a kid. She accepted me and she educated the school system about how her kids deserved the right to an education and deserved a quality of life in the school like everybody else.

Caldwell: She sounded like a strong advocate.

Meadours: She was very strong.

Caldwell: She connected it all with the Arc?

Meadours: She was not. She didn't know much. That is another thing we need to do: We need to help the youth parents understand what the Arc does. We don't do enough education about the different providers out there. A perfect example is, I was in Atlanta Airport, eating breakfast, going to Washington DC on a trip, and I was eating my breakfast minding my own business. A pretty lady came to me and said, "You must be an artist." I said, "What do you mean an artist?" She said, "Because you draw pictures for the Arc." I said, "No." She goes, "What do you do?" I said, "Well, I am an advocate for people with cognitive development disabilities." Then she goes, "Well, there is hope for my son with Down syndrome." So, she didn't know what the Arc's about. So, somehow we need to outreach to doctors or medical centers saying the Arc's available for your loved ones. Because if I didn't have my Arc shirt that day, she would never know what the Arc is. We exchanged business cards, and we were talking little by little about her son – who is now six

–having a rough time in school. So, I’m trying to get her connected with a local Arc in Atlanta. I mean, if it weren’t for my Arc t-shirt, she wouldn’t know what the Arc was about. But again, we need to continue educating our community, our people, we need to educate like the doctors’ office, dentists, whoever –help them understand that we are out there as a resource to help you to understand.

Caldwell: When did you first become aware of the Arc?

Meadours: It was right after I joined People First. My advisor was working for the Arc at the time. The grant for People First of Oklahoma was through there; the Department of Human Services was giving a grant to the local Arc in Oklahoma. So, they paid somebody as an advisor to do People First work. At the time I was a volunteer, and slowly but surely I got to know what Arc does. My brother was on the local board, because he was involved before I was; he talked me into getting involved.

Caldwell: And now you are on the national Arc board?

Meadours: Yes, on the national Arc board –have been there for a year now. I am also on the national Disability Policy committee and that is within the Arc too –going on about four years for that.

Caldwell: What other boards have you been on?

Meadours: I am very involved with the environment health issues.

Caldwell: Environmental health, is that with AAIDD?

Meadours: Yes. I have been on the Council, the MRDD councils. I’ve been on different sub-committee groups, because at the time I didn’t feel like I should be on the board. People asked me to be on boards but I said, “No, I like to sit on sub-committees so I get to know the board.” So, I sat on a lot of different sub-communities from local support employment boards to my local president of People First boards and to state boards.

Caldwell: Do you think those helped you build leadership skills?

Meadours: I think when I was vice president and president, People First of Oklahoma, they helped me really understand to be, I guess, more cautious, more awareness of what is going. They helped me with my leadership today. It gave me the tools to be able to speak in front of public, to make friends, and meet some key contacts that helped me get to where I am at today. So, community contacts was a big benefit. It helped me with public speaking, because when you president or vice president, that phone just rings off the hook. They want somebody to speak; a lot of times when you are the president of an organization, you

get the call to speak. They did have an executive director but she didn't have a disability; so a lot of times I would get the call to speak.

Caldwell: So, you learned a lot of those skills on the job when you were vice president, president, and in different positions?

Meadours: And I wasn't paid for it. I was paid sometimes when I go to speak, but again a lot of times I went to just try to get my name out there, anyway I can. So, the tools I learned was within the People First movement.

Caldwell: What else would you say about how you developed your leadership skills?

Meadours: I think it is just friends I have met in this field and the key people I have met in this field have helped me get to where I am. If I am listening to them and they are listening to me, and I have a diverse crowd in my circle of support... It is now always just one person it is diverse and listen to everybody's side. You may not always agree with them, but again, is that bad? No. Is that good? No. But again coming together and listening to everybody's side of the story...

Caldwell: Where did you learn to do that do you think?

Meadours: I did it within the People First movement. I think just listening and being diverse.

Caldwell: Why do you say it is within the People First movement?

Meadours: Because I was very active in the People First movement and I took my role very seriously as my peers let me in this position. They know that if I would have been a horse's high end I wouldn't have been a good role model for my group or for them. So, just really listen to everybody's side of the story and being diverse. I may agree or disagree with it but again, working together, making them more aware and understand what's happening.

Caldwell: Another thing, just in terms of leadership, it seems like with the self-advocacy movement, there is more decisions that kind of are made together or as a group. Would you say that is true?

Meadours: Yes. I guess some people are confused and they just want to vote to go on. And that is wrong, if you are there just to vote and go on. Be sure you understand what is going on, don't hesitate. That is one thing I learned from all the boards I am on, to be very vocal about what you think is right.

Caldwell: Let me ask you a couple of questions about disability identity? And do you know what I mean by that or what I am trying to get at?

Meadours: What is my disability?

Caldwell: More how your disability you think has influenced who you are and how do you feel about your disability?

Meadours: I don't blame nobody for my disability. I mean everybody has a disability, but I don't blame nobody for my disability. At one time it got me down and out: why am I this way? But again, I've grown out of it and become more of a professional about it. So, it does bother me anymore like it did before, because people who I know accept me for who I am not my disability. My real friends and true people who believe in me, they accept me for who I am and because I have a "disability."

Caldwell: How did you come to that... Not feeling negative about your disability?

Meadours: I guess I saw other people talking about their disability, and seeing people at different conferences, knowing that it is okay.

Caldwell: So, at People First conferences, would you say?

Meadours: People First conferences or conferences that I've traveled to across the country. I look at the person, not the disability, and so that helped me get a better picture. I saw other people who were having a more rough time, than I have with their disability. So I guess I can be thankful I am not that way. That helped give me the confidence too –that it is okay.

Caldwell: So seeing other people talking to other people about disabilities?

Meadours: Yeah. Just walking and talking to people like we are talking today, just talk away.

Caldwell: But, you know, some people with disabilities might feel very negative about their disability and you said in the past you have felt that, but then you...

Meadours: I saw other people speaking up and other people making a difference. Then I thought well I am not as bad as the person who is in a wheelchair, who cannot walk. And so I am able to walk and give back. She is in a wheelchair, but she gives back in a different way. So, I'm looking at being diverse and have a better understanding of people.

Caldwell: How do you think being in the self-advocacy movement has influenced who you are? You said yesterday that you wouldn't even be here if it wasn't for the self-advocacy movement...

Meadours: Yeah, I think that if I didn't find the self-advocacy movement, I probably wouldn't be here. I still believe that to this day. I tell people I would be in two places... I was going through a rough time. I was in my early 20s and like any other 20 year-old kid I guess I was kind of rebelling. I didn't have my mother; she had been dead for almost four years at the time. I just moved on my own and was having a rough time trying to

find what life is about. If I didn't find it, like I tell people I would be in two places: dead or in jail. But again, I have friends who were so supportive from outside the system and inside my circle to give me confidence and give me the wisdom and the tips that if you are going to live this way, you will have a rough time as you get older. So, from the circle of friends, from inside and outside, I am thankful to them for giving me the wisdom and the confidence and look at my talents and gifts and not my disability.

Caldwell: I don't know if we talked about this but when you first became aware of the self-advocacy movement, what was that like to you – you've said it saved you?

Meadours: Yes, it was strange. Like I said I told my brother it was only going to be for six months. I look at it now and it is more than six months later. So, I guess I was not used to being around people like my peers. I was feeling, I guess, different. I didn't know what to expect and seeing people coming to the meeting now having more difficult time than that I have. Why is he that way or why is she that way? I need to understand how people are feeling? Now, I look at people as people. No matter if they are in a wheelchair, using a walker, or having seizure, or whatever, I look at them as people now –not because he or she has a disability. And I look at their gifts, what they can give back. Yes, he or she has seizures, but what gifts does he or she have? I just thought at the time that he or she has seizures and no gifts. Now, I look at the picture that he or she does have gifts –what can we do to make that happen? Granted, he may be slow, but again, we all are slow. So what gifts can I give him or what gifts can he give me back? So, we share each other's passion and story together.

Caldwell: Have you ever heard people use the word or term disability pride?

Meadours: I have.

Caldwell: Do you think that that is something that happens in the self-advocacy movement?

Meadours: I am not sure. I don't blame my parents for my disability and so again it's natural. And so I am not sure.

Caldwell: Yeah. Do you think the self-advocacy movement helps people to be proud of who they are?

Meadours: Some of us, some of us. And help us to look our abilities and gifts so we can share it with others. Some of them are not so proud of their disability and they get upset or depressed. One thing leads to another, so help people understand that.

Caldwell: Do you think the self-advocacy is going to help some people with that? When they feel like depressed?

Meadours: Sometimes and sometimes not. I might have a good support around me to help me, but if you go down the street, he or she may not have that same thing.

Caldwell: And do you feel a connection with other people with disabilities?

Meadours: Yes.

Caldwell: With all types of disabilities?

Meadours: All types. I don't look at nobody different. We are all different, but I look at them what they can you give back to me or what tools do they have that I don't have. We can piggyback on each other because we all have gifts, ways that we don't know. And so help each other to learn to diverse. And it's okay that you make that mistake, we all make mistakes, but again, learn from each other.

Caldwell: Let's see what we haven't covered. We have skipped around a lot. Let's go back to some of the leadership stuff. What do you think are some of the qualities or skills that good leaders should have?

Meadours: I guess three things: good ears to listen, good eyes to see what's going on, and when you talk you know when to be quiet and what to say at the right time.

Caldwell: And would you say you have a certain leadership style?

Meadours: I guess one of the three things –good ears, good eyes and good mouth. So that is one of the things I learned about how to be a good leader. Good ears to listen, eyes to see what's going on, and mouth to know what to say at the right time. That helped me to become a good leader. Know those three basics and when to use it at the proper time.

Caldwell: Another question I wanted to ask is... Looking around the leaders you see in the self-advocacy movement –and something you seem real interested in is diversity and people, African-Americans or women being leaders –do you see that in the self-advocacy movement?

Meadours: I do see it. Our leaders are diverse. At the conferences I go to, the people I just meet on the streets, how diverse this is coming together as leaders in the self-advocacy movement.

Caldwell: Do you think there is any barriers to women or minorities being leaders within the movement?

Meadours: Some, because people will put that label on you and then they don't look at their gifts or their abilities. I guess in the south or whatever

people like to label people, especially black leaders. It just irks me that we don't look at the abilities or the gifts they can give to us and give back so we can learn from them. I think that holds a lot of them back because they are afraid someone might point fingers at them or say this and that to them. I see it somewhere but I don't see it as much as when we first began because we have great leaders now, a majority who are African American. People accept who they are and have a better understanding.

Caldwell: In independent living movement, a lot of people have raised concerns about that movement being mainly white men and not enough diversity in independent living movement. It seems like the self-advocacy movement has a little more diversity in the leadership.

Meadours: Right.

Caldwell: Is there... Do you think there is any thing about the self-advocacy movement that is different that way?

Meadours: I am not sure. In my self-advocacy group we accept everybody, anyone because that one voice may be that one voice we need to turn the corner. She may have the idea that will help us to get where we need to go. So, if I shut her out, she may go to some other group and I lost a gift. Because she is making a difference in that group and that group give her a chance to have a voice. If I shut her out, that make me look bad and that come back and bite me.

Caldwell: Yeah. It seems like another thing that I heard you say... Throughout your career, you've always looked for chances or opportunities for other people to take leadership and for you to give up the leadership and let somebody else to take over. Is that something that is important to you and why?

Meadours: I like to share the power because I knew as a young kid that I won't be around forever to have that power. If I could share with others and give him or her the tools for them to be successful, hopefully he or she would hand it down to others; so, we all come together and work together, and have some common mission together, and have a better understanding of what's happening.

Caldwell: Do you think your experience as a person with disability has influenced how you are a leader or how you practice leadership?

Meadours: What helped me to be a good leader, I guess, is seeing others out there being good leaders –knowing that when I think things are bad, things are not bad. What other people are going though as leaders, so that helped me a little bit.

Caldwell: Talk a little bit about kind of your beliefs that guide you in life. Are there certain beliefs or things that kind of guide your life or the way you approach life?

Meadours: I believe people should be treated equal, not different because they're "slower" than others. So, my belief is that you help people to be successful, not set up people to be failures. So, help people to be more successful in life. Don't... If you put that label on people, it is going to be with them. Until you take that label away from them, it's going to be with them. So, help people to be successful in life whatever it takes. I believe that people can be successful if you give them the right tools and the right quality support, inside the circle of support or outside the circle of support. Help people to be successful. Some might say, "Well, he is disabled." One of my things is that, nobody is disabled. He or she has something to give back to their community or to give back to someone. So when you help people in day programs, find their gifts and what they can give back to the community. Don't let them sit there 10, 15, 20 years doing the same thing that we were doing the first day, they got there. Find their gifts to give back to the community or to give back to somewhere.

Caldwell: Would you say there are any lessons you've learned in life? Things that you wish you would have done better or differently?

Meadours: I think in my early days, the things I did in my early 20s. I grew from it. Know that if I did it today again I will be dead or in jail. So I learned from my mistake and I still learn from my mistake. One of the things I think I learned the most is how to accept people more and more into my life, instead of shutting them out don't listen to them. Accept them for who they are and look at their gifts and what they can give back to me. Share each other's friendship or business relationship, or whatever, share information together.

Caldwell: And some questions about the future. We talked a little bit about it, but what's your vision for the self-advocacy movement in the future?

Meadours: My vision for the self-advocacy movement is: I would hope each state will have a state office somewhere, preferably at the capitol –have a state office in each state at the capitol and have an executive director with a disability running the show. And when we come to our annual conference, or every two years conference, come together and have a conference with all the executive directors across the states. Find out what we learned from in our states, so we can learn from other states and piggyback on each other. So, almost like what the Arc has. The arc is very big and has been going for something like 50 years –have something like that in the People First movement. Have a conference that we can call our conference. And we do have one, but have a conference where you have 50 executive directors across the states

coming together. Then build on that and make it international. Right now we don't have many states who has a position like I have here in California as executive director. We do have people in the state governments but that's a little different. In People First movement, it is run by people with disabilities, so have a position like that in each state; have a board of directors that they need to answer to them. And advisors or helpers are fine, but again, have a state position like mine here in California who is a self advocate who works everyday and knows what is going on.

Caldwell: What's your vision for the younger leaders? What would you like to see happen to help support younger leaders?

Meadours: For the young leaders, to help... The old bunch needs to step back and let the young leaders take over –not completely take over but take over and see what is on their plate. And see what we need to do to work together with them and to make that happen. And share the will power, whatever it takes. Listen to what the young leaders are saying. What's on their plate? We are not listening. We are listening to us, but we are not really listen to young leaders without saying how can we make it happen. Listen to their concerns and what they have to offer back to us. I think they have something to offer, but I am not sure what. Each person is different with what they have to offer. So let's find a way that they could offer back to us as well as we can offer back to them.

Caldwell: And is there any advice you would give to younger people or new people to self-advocacy movement?

Meadours: Don't give up. Just don't give up. When you see those dark days, and there are a lot of dark days, but just don't give up. I mean, as we struggle together, just don't give up what you believe is right in your life or your vision –because if you give up the battle is over. I mean, just don't give up. That is all I can say.

Caldwell: What about your personal goals? What do you want to do? Where do you want to go next and what do you want to do?

Meadours: When I interviewed for this job in California one of the things I told the president of this group is I said, "California, is not going to be my home. I am going to be truthful." He said, "Is California going to be your home?" I said, "No." That door is always open and if I can better myself here in California or wherever, I'm going to take that opportunity and better myself. When I do make a commitment and honor where I am going to respect where I work at. You can expect 100% respect and attention on this project until something better comes. If I leave I will respect where I came from and talk good and nothing against it unless it is something crazy or stupid. My priority is probably to live and work in Washington DC on Capitol Hill as a policy maker for people with

disabilities; and I could see it happen probably next within the next few years. And if it happens, fine; if it doesn't, whatever state I am living in at the time, I will make sure that happens in the state. Because I know Washington, DC is not for everybody. And it is meant to be, I will be there. If not, I will be in whatever state I am living at the time, ensuring that I make a difference in my local and state policies.

Caldwell: Do you think there should be more opportunities for people, for self-advocates to go to DC and to learn about policy –like internships, fellowships?

Meadours: I wish we could find ways to support self advocates to more understand how policies are shaped. As we get with the youth, I think they have a big key on this. So, as we are moving forward on policy help us to make it available in DC. If it is internships or whatever, from grants, help us to get to DC. We're sure that's how we can get to tools we need. Again, is Washington DC for everybody? No, but help us to get to us get the tools –the people who want to go to DC –to understand federal policy and that.

Caldwell: When did you start learning about policy? Like, when did you first hear about the ADA or any disability policy, do you remember?

Meadours: I think when I first got involved in the self-advocacy movement –about two or four years after that. Getting to know policies or talking to my friends about it and going to meetings at the capitol... Going to meetings in my community about transportation –how policy could shape up and what we need to do to make it happen... I think transportation was my first project we were really working on as a local president of my local chapter. Understanding how it worked and getting the support I needed to understand it better...

Caldwell: What would you say your biggest accomplishment in your life has been? The thing that you are most proud of?

Meadours: I guess the biggest thing I think I'm very proud is: I have lived in five states where I have met some nice wonderful people and I met some key contacts. I know that I could pick up the phone today, and in any of those days, have a friend –not just a friends but a colleague there –who I can say to, "Can you help me with this issue? Can you Go back and forth and help me clear that up a little bit and understand it. I have been in five states and have a better understanding of how the state system works in five different states. Knowing I have a key contact person I have met and knowing that I can call them and we can, not just chat, but talk about business too on top of it.

Caldwell: What would you like to see in terms of policy or services for people with disabilities? What is your vision for the future in that someday?

Meadours: I haven't really thought of that.

Caldwell: I mean like institutions, sheltered workshops...

Meadours: I would like to see more of supported employment –find ways that people can have meaningful jobs in the community. More housing available and not warehouse people as we are closing the institutions down –don't close it down and in about six months later reopen it. Move people into the community of their choice. When I talk about community –have people renew their community relationship with them. Get to know your neighbors, get to know your community and who you are. Have more communities of outing of people with disabilities. And find housing that people will like. Don't move people into group homes. Move them into a two/three bedroom home. Two or three people is big, but as we know budgets are tight these days. So, I accept three people, but when you have four, five, six people, you may as well keep them in the institution. That is unprofessional I think. People get lost and you have to go as a group. Help people get the tools so that they can live in their own home or be successful in the community. So find ways to be successful and to have a proper community job doing something they like to do. Everybody is able to do something, maybe slow, but let's find the tools they need to be successful in the community.

Caldwell: And when you get to DC you can make all that happen. So, I think we've covered almost everything that I was thinking of. I think we covered the most of big topics. Just going back to the purpose... I wanted to learn about your life story, how you became a leader in the self-advocacy movement? I think we covered a lot of that. What leadership means to you? What would you say leadership means to you? What is the meaning of leadership to you?

Meadours: Leadership means giving back to other people so they could be leaders. Share relationships skills with others so that they can be a leader one day. Given that you only have so long. Show others that you are there for them as a leader too. Support them.

Caldwell: And then we talked a little bit about the future of the self-advocacy movement and your vision for that. Is there anything else in that area that you can think of for the future of the self-advocacy movement? What the self-advocacy movement needs? We talked a little bit about the funding and you would like to see funding at the federal level for the self-advocacy movement?

Meadours: Right. Have a national office like all other organizations have in DC. It doesn't have to be in DC, but it would be nice to be in Washington DC because since that's where a lot of the national offices are at now. So, have a national office that's run by people with disabilities in the self-

advocacy movement. So when there is a bill that comes up we'll have a national office representing there. It will help us to get that way. Do I see it coming? I do see it coming slowly, but again, it's going to be a lot of hard work with the old self-advocacy bunch and the youth self-advocate bunch working together to make that happen. It's going to be a struggle for a while, but I think I see this happen probably in the next five to ten years. Is that too soon? No, we need to have it sooner, but again, we need to take steps to make it happen. I think it could happen with the old self advocates and with the youth self advocates coming together and working together to make it happen.

Caldwell: It seems like the time has come for that to happen? The movement was started in...

Meadours: In early 70s and now to almost 40 something years later and we still don't have an office. I would like to see it again happen. We have other national offices in DC or in the Washington DC area. We are probably the only group I know of that doesn't have a national office in the DC area. I think we could find ways to make that happen, and I think it would be a good project for organizations to piggyback on or a representative or a senator to take it on, because most of them are only in office four to six years. One of them could piggyback on as a fellowship position and grow into a full-time job.

Caldwell: So anything else that you can think of that we didn't talk about or touch upon that might be important to talk about? Anything related to leadership or self-advocacy movement?

Meadours: No, not really.

Caldwell: Yeah, I think we've covered quite a bit.

Meadours: I don't know if this makes sense or not: But today's leaders are tomorrow's leaders?

Caldwell: What do you mean by that?

Meadours: Today's leaders are leading the pack as we are educating tomorrow's leaders to go on to lead on. I was trying to think about how to say that, but I was thinking about that last night.

Caldwell: I think that goes along with what you said the meaning of leadership was –had to do with tomorrow's leaders and helping other people. Is that what you mean?

Meadours: Yeah, right.