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Marvin Moss

10/20/2007

10:30 AM – 1:00 PM

Cincinnati, OH
Caldwell: The first thing is to talk about your childhood and growing up when you were young. How old are you?

Moss: I am 61.

Caldwell: And where were you born?

Moss: Here in Cincinnati, Ohio.

Caldwell: Have you always lived in Cincinnati?

Moss: Yes, all my life.

Caldwell: So what do you remember about your childhood?

Moss: Okay, let's go back. My mom and dad met here. On my dad's side every other generation kids were born with a little bit of handicap, on my dad's side. My mom's side was normal. My brother was born in 1941, here, and they didn't have much. They told my parents to put him away in an institution. He is mentally retarded with maybe a year old mentality or two year old. He was in a state institution when he was fifteen until about eight years ago. I moved in back here to Cincinnati.

Caldwell: So he went to the institution?

Moss: When he was fifteen years old. He is five years older than me. That was something you don't want to see. You never been there. It was Columbus State. You never been there. The first time we left him there my parents said “bye bye,” looking at my brother through the window with bars on it, like he was in jail. Some of the rooms were as big as this room, with a day room and another room, one helper to 60 people in a unit. You brought clothes up to him and they could be one day on him and another day on somebody else. To give them baths, they took the fire hose and give them bathes that way. Drip dry. Yeah, that's the kind of institution. My mom started the Hamilton County, Cincinnati Arc, the State Arc, and the U.S. Arc, the National Arc.

Caldwell: What was your mom's name?

Moss: Dorothy H. Moss. She wrote the Three R's, a book on how to teach "mentally retarded," how to teach people like us. The first book to teach. When my mom started with the schools here in Cincinnati, the teachers didn't know how to teach us.

Caldwell: And she wrote a book?

Moss: Yes, what the teachers need to learn to teach us. I don't think I have a copy of it. The Arc has a copy in the library. I think it is in the library in Washington? They put it in there.
Caldwell: So do you remember going to see your brother?
Moss: Yes, I used to go up all my life, once a month.
Caldwell: What was that like?
Moss: It messes up your life: take the two hour drive, four hours roundtrip. You know what I mean?
Caldwell: How did you feel about it?
Moss: I didn’t like it but what are you going to do. When my mom died in the 80s, I promised her I would keep seeing my brother four times a year and I kept my word. Yes, I saw him four times a year. For many years I wanted to bring him here but the group home in Springfield, Ohio did not want people like us to have him. They fight it with me. They took me to court four times. The second time I got APSI, Patty, you remember Patty. We argued. One time I was up there with my buddy Tom, who you met today, and Patty and I asked him a question, “Do you want to move down to Cincinnati?” He said yes, so I got the Hamilton County Board to help me to pull some strings to move him back here. The home in Dayton lied. They call the social security office and said he was dead. He was alive! It is about the money, you know, the social security checks. The group home in Dayton tried to stop the money because they did not want to give him the money. Before my mom died she bought funeral arrangements for him to be buried by her; they came up with ideas to start another fund so that he could be buried up in Dayton. I fought that in court and I won. They thought I was trying to get his money. Yes, I could use it, but I didn't want the money. I just wanted him to be happy. When he was here in Cincinnati we took him to a school, a Catholic school in Winton Woods, fifth and sixth graders. We asked how many kids there wanted to help support him. We started counting, one, two, three, more. We took my brother with the kids up to Columbus to talk to the Senators during budget time.

Caldwell: You took your brother up there to talk to the Senators?
Moss: Yes. On the way back, the kids were using their ear phones, juke boxes. They put the earphones on him. You know what I mean, treated him like a normal person. He was thrilled! All the kids was happy.
Caldwell: Do you think he was happier after he moved back here?
Moss: Yes, you is happier. He went out. We took him to meetings, took him around to meet people, took him to talk to the kids about “mentally retarded.” The kids loved it. We teach them "mentally retarded" from the wheelchair person to me. He is on the lower level. I am on the higher level. You know what I'm trying to say.
Caldwell: How did the kids react?
Moss: They liked it. They started asking more questions. Like what happened to his teeth? The State of Ohio took all his teeth out because they did not want to brush his teeth. Yes, that happened at the institution. They did a lot of crazy stuff like that, the State of Ohio. When my brother died a couple months ago there were over 50 people at his funeral from all over the Cincinnati area and Columbus.

Caldwell: Could you talk more about, you became the guardian?
Moss: Co-guardian. APSI and me work together as a team. And I had to go to court four times. The group home didn't want a handicapped person taking care of another handicapped person, but we won with APSI's help.

Caldwell: What was it like going to court?
Moss: Horrible! Horrible! Scary! The judge asked all kinds of crazy questions, like, “Can you read the paper?” I said I don't want the money all I want is his body. We can't handle money, but we didn't want the money we wanted his body. The fourth time after seeing me that judge said he got tired of seeing me. That case is thrown out. No more; me and APSI are his guardian.

Caldwell: Is that when you decided to move him?
Moss: Yes. The group home got mad. There was no rule that money follow the person. I took money out of their pocket. They lost money. I did not make any!

Caldwell: I think it is funny that they were worried about you taking the money, but they were taking his money?
Moss: Yes. If they would have been his guardian, they would have got more money. There is a way they would have got more money from the state of Ohio. Not me.

Caldwell: Could you talk more about your relationship with your brother growing up?
Moss: Sometimes, when we were growing up, before he went to Columbus, when I was born he brought all his baby toys into the baby bed. He was thrilled to have a little brother. When I went to school, after first grade the teacher saw my brother and said I am the same as my brother. We are both "mentally retarded." There was not classes when I went to school. It is better today than when I went to school. We was in one room all day. Today they teach school from class to class. You know that. You see that.

Caldwell: So, there were all kids with disabilities in one room?
Moss: Yes, in one room.

Caldwell: What was it like?

Moss: You have the same teacher all day. Hard! What they teach us, when I went to junior high and high school, they told us we will be on welfare, in an institution, or in the state pen.

Caldwell: They told you that?

Moss: Yes! Only two of us made it out of there. A couple years ago when I was at an APSI meeting I saw the teacher there. And I took a piece of paper wrapped it up in a ball and said, "There, eat that!" Eat her words. I am the only one who made it out of her class to get a car and driver's license. I am working and on half a dozen boards across the state and the country.

Caldwell: What happened to the other people in the class?

Moss: State pen, institutions, or they died. I am the only one. It is crazy.

Caldwell: Why do you think you were able to do all those things?

Moss: With good parents.

Caldwell: What was your mom like?

Moss: Good. She said, "You can do it!" My dad said sometimes yes sometimes no. My mom said I was able to do it. She pushed me to do it. Like when I got a driver's license, her told me to do it. After I got it, my dad was thrilled. When I was taking the test and trying to do it, my dad said, "You can't do it." After I got that he was proud of me, like a proud dad.

Caldwell: But your mom wanted you to do it. What other things did she push you to do?

Moss: Going to work. Do volunteer work. The city where we grew up was Golf Manner, Ohio. If you know of Cincinnati, Golf Manner is by the Cincinnati Gardens. You know where that is. I grew up in of Golf Manner. My mom and dad was on the recreation, men's club and women's club. So when they had dances for the teenagers, I was there passing out pop and candy—doing volunteer work. Then when I was old enough I got on the men's club with my parents. We all went to the same meetings in one car. In some of the meetings, my mom and dad voted one way and I voted the other. Or if they take that as one way I'd take it as another way. We got into arguments. At home, not at the meeting, but at home my dad would say, "I voted yes for something and you voted no for something." He didn't like it. We have a lot of arguments.

Then, for many years I was an Ohio Jaycees member. Locally, in Cincinnati. I was a Cincinnati officer and a state officer. That group
helped me learn more about volunteering. They gave me information about volunteering projects. The Jaycees Haunted House for Saint Rita’s School for the Deaf. We put that on for ten years. Every year we made $180,000. At Alt Park, we put the Cincinnati soap box derby on –go out to Akron and make race cars. Worked at carnivals all over the city. Put conferences on –that was part of my job with the Jaycees. It helped me learn how to do all the Jaycees projects and be an officer. But today they do not have the Jaycees.

Caldwell: They don't have the Jaycees today?

Moss: It is gone! That was the group from 18 to 35. When I was in it there were two groups, a men's group and a women's group, then somebody took us to court and said we want one group.

Caldwell: So were you in it from age 18 to 35?

Moss: No. I was in my twenties. It helped me learn more about their annual carnivals and what to do, the haunted house, conferences and what we need to do. I learned a lot from volunteering. When my parents died, I was working in jobs through the years. I was working downtown Cincinnati driving an elevator.

Caldwell: Driving an elevator?

Moss: The old fashioned elevators. I would work the leavers and in the old fashioned elevators. That was before they had elevators with buttons on them. There used to be people when we were kids that worked the elevators. Ask your mom that question. There were elevator guys who worked the elevators. I did that. Then I went through Ohio BVR, Ohio vocational rehabilitation service. When I was growing up I helped the Arc with their projects to raise money then my mom stepped out of it and I did too. So in the 80s, when my mom died, I got back into working. I was making $2.95 per hour. There was a BRV meeting. The big shots from Columbus come down every year. You know, the government comes down to get information about what they're doing wrong and what they're doing good. So, I went to that group and ask one question, "Can you live on $2.95 an hour? Why are you making us do it?" After the meeting was over with, they contacted me and asked me to be on the board –on their board at the local level and then I was also on the state level of BVR.

When I was on the board, they brought the paper in about the meeting with the Arc. They have a conference on the weekend about how to get a job. So I called up the Arc. The woman I spoke to said it that was all booked up. I say, "How dare! My mom started this agency. Without my mom you would not have a job." So we hanged up. Five minutes later her called the back and said, "You can go." Her went into the big boss and said, "I have a person on the phone and he said his mom started the Arc.
He wants to come to the conference." He said, "Oh, I remember that guy. Yes, he better come! His mom started the Arc." I went to the conference and met her. About two to three weeks later, she called me up and said they had some other training programs to learn how to do certain jobs and to be on boards. So I said, "Okay, I will take that course." And I met Essie through it, Essie Pederson. Essie and Marcy were teaching the course about how to get on boards. So I said, "Okay, I will do it." I met Tom Gannon. He was working at Children’s Hospital with Essie. I went into there and started talking to doctors, student doctors, about what we need. Teaching doctors how to be doctors.

Caldwell: What did you teach the doctors?

Moss: If we brought the helper in, don't talk to the helper talk to me. We are the same. You know what I mean? Some of the student doctors say, "What is mentally retarded?" All kinds of crazy questions. I started to work my way up on how to be on boards. I was on the Arc board in Cincinnati, local Arc and then I got on the state Arc. Every time I go out to the state Arc meeting, Tom and I stop over to see my brother on the way up. We would go from Cincinnati to Dayton, Ohio to Springfield to Columbus.

Caldwell: You would stop by Springfield and see your brother?

Moss: Yeah. That is why we moved him back here. A couple times we had a conference with that Jaycees up in the city, Springfield, so I took my car over to see him for about five minutes. I was wearing my costume. What we usually were to our meetings. You know: crazy hats with buttons. One meeting at the Jaycees there was a talk about "mentally retarded" people –so, I went to that Jaycees meeting. My mom knows the guy who did the talking –that was before I knew the Chicago group. He was talking so I kept asking him questions. I had a whole bunch of questions to ask him so I asked him those questions. After we were done and I walked up to him and told him who I was. He said, "Why did you ask all those crazy questions?" I said, "You don't know me, but my mom taught you." He was one of the 30 students to teach people around the state. My mom knew the guy. I said by mom was Dorothy Moss. He thought for a minute who that was and said "Oh no!" and he bowed to me. I have a degree that you were the teachers that we learned from in the fifties and sixties. We were the teachers! My mom was a teacher. So I work up on many committees.

I did work at motels. I left my elevator job many years ago. I did a dishwasher job at a nursing home. Houseman at many motels–houseboy at motels. Making thermometers –you know, what you take your temperature with, at a factory. I was bug man –you know, kill bugs –an exterminator. Mixed chemicals together, what they don't have no more because the EPA told them to put it away –the bad chemicals.

Caldwell: Did you get all those jobs on your own?
Moss: Some yes and some no. I had some help from the BVR. Three times I went to the workshops to work at Jewish Vocational.

Caldwell: Did you like the workshop?

Moss: No. You only made $25 per week at workshops. I don't think they are worth a dime today. Then about five years ago, after my brother moved here, the Arc offered me a job to work at the Arc. So I took it as a self advocacy leader and helper. I help my supervisor, my boss. I'd teach classes on self advocacy. I work in the office. I do a lot of office work. I go to more meetings all over the city all over Columbus by myself. I go to Chicago. I have been to Oklahoma. I'd talked to the kids whose parents were killed in Oklahoma after the Oklahoma City bombings. I talked to some of the kids. There was a People First conference there and some of the kids asked questions to us. Some of the kids' parents died in the Oklahoma City bombings, and they asked questions about handicapped people.

Let me go back. When my mom died I ask the Jewish Family Service in Cincinnati for help. I had too much money. I had $50,000. I ask for somebody to help me; they got me an attorney. My attorney took the money. I took her license away. No more, but I had to prove in court. Like the paper I signed today—you gave me today. That is why I ask for copies. And I took her license away and I got my money back.

Caldwell: So, you were talking about how important the Jaycees were?

Moss: I was the only handicapped person in my chapter. Other chapters in the state had handicapped people and sometimes and we would be at conferences and we would start talking about how we could make it better. We have a couple people in wheelchairs. Jaycees was a good group. It was from 18 to 35, men and ladies. Mostly they are college people. But today we do not have the Jaycees. Now I was talking about the groups with Marcy and Essie that was 99% handicapped people.

Caldwell: When did you first meet Essie? Do you remember what year?

Moss: In the 80s. One of her jobs was helping people to get on boards and committees. One committee board was the Community Chest where all agencies met like Arc, boy scouts, girl scouts, all the agencies met to work with handicapped people, Goodwill. We all met. There was a committee and I was on that with Essie. I was on the board of Arc before I started working my way back into the field of the "mentally retarded." I was out of it for many, many years, out of the "mentally retarded" field for many years.

Caldwell: And when you met Essie you got back into the field?
Moss: Yeah. Yeah, then Essie one year brought me up to Chicago. I met Alan, Tamar, and Tia. The first People First conference I went to was in Illinois—that was the first time. I went back up to see my family at the same time—my mom’s half-sisters. I hadn’t seen them for about four or five years. We broke off because of what I did with my money and some of my ex-roommates. You remember Three’s a Crowd on TV, two girls and a guy used to live together on TV. I don’t remember what it was called. The three people lived together in one apartment. That is similar to what I did. My family didn’t like that. I did; there is a lot of things I did after my mom died. Now I am sorry I did some of that stuff.

Caldwell: So, when you went to the People First of Illinois conference, was that your first self-advocacy conference?

Moss: Yeah. It was neat. I learned a lot of stuff. That was their first conference, People First of Illinois. I went to all kinds of stuff: meetings; met people; talking; trying to work together in the state. Some of the staff people seemed like the kind—taking over. They didn’t like the people to be in charge of it. Some of the staff people didn’t like going to the meetings and sit back and let us handle it. They were not used to it. There were big arguments about that. A lot of the staff people said they are supposed to be in there, like the secretary said, “I am the secretary. I am supposed to be taking notes.” And her staff person said, “I am supposed to be sitting with you to help you take notes. That is part of my job.” And her say, “No, you are going to another room.” A lot of the staff people did not like going that way. Now, today, a lot of staff people know how to behave.

Caldwell: Did that meeting give you ideas to come back to Ohio and start something?

Moss: Yes. It took many, many years before we do it.

Caldwell: And what did you guys do?

Moss: We started a state chapter. A lot of the state people think that they were first. We were the first chapter, in Cincinnati, in the State of Ohio. We stared in the mid-80s. They started in the 90s.

Caldwell: So, were you involved in helping to start the state chapter?

Moss: Not the state, but the Cincinnati one. Two of us are left that started it. We got together with Essie. We decided what we wanted to be the rules, the by-laws. We started asking questions and making the rules. We said, “Yes, we need an advisor, but the advisor must let us handle it.” If we are making a mistake and they see it, come tell us what our mistakes are. All the advisor is supposed to do with our rules is to sit down in the back and make sure are going by the rules. If we need help raising money or making arrangements for a party, her is supposed to help do it; or if we need equipment, movie camera, stuff like that, her is supposed to help get
the equipment. If we are going to go out of town for a meeting, her is supposed to help make the arrangements before we get up there and back. Help us raise the money.

Caldwell: Do you remember how many people came to the first meetings?

Moss: About twenty of us. Today’s chapter, the meeting we had a couple weeks ago, about five of us.

Caldwell: So it has gone down?

Moss: No, in Cincinnati we got thirty members that come to our meetings. Not everyone comes to every meeting. Then we got 150 that we can say are members, but they don’t come to meetings. Then we got 900 mailing list for Cincinnati. We meet once a month at our office at the Arc. Right now our advisor in Cincinnati will sit and listen what is going on. Her is there to help. We are saving up. We just ordered calendars to sell to go to Indianapolis to the big conference. In March of this coming year we are trying to get the money to raise to go to a conference center about 30 miles outside of Cincinnati in Middletown, a conference for People First of Ohio. Two years ago Cincinnati put that on. We were in charge of it. This year the state took over. They have that every two years. We are trying to save money to go to both of them. Now, every other year we have a Solidarity conference. That is run by the DD Council; that is a conference run by all the groups in the State of Ohio.

Caldwell: What are some of the other groups?

Moss: DD Councils, BVR, Down syndrome, Protections and Advocacy. All kinds of agencies have a booth there. A couple years ago we had the guy in the wheelchair, Superman. Christopher Reeves. It cost the State of Ohio to have him there with security. He had a special airplane to come to Columbus. He wanted an ambulance from the airport to the hotel with special equipment so he could breathe. Oh man, that was a mess to have him here. One year we had the girl who plays on one of the programs who is Deaf to speak. That is every other year and the People First conference is every other year. Then this year we are trying to go to the big SABE meeting, the national group, in Indianapolis. It is only about two hours. We talked to one of our bus companies in Cincinnati. We are taking six people up in wheelchairs and about 20 people and then we have to have some helpers for people with wheelchairs. Sometimes the helper companies don’t want to go, so right now we are arguing to find helper companies to go – helpers to help the people in the wheelchairs or helpers to help us. That is some of the problems I am working on with People First of Indiana.

Caldwell: Are you trying to get people to volunteer or get paid?
Moss: The county will pay them to go. We got a couple helpers for the guy who has seizures problem. He is in the wheelchair.

Caldwell: Does People First of Cincinnati get help?

Moss: From the Arc.

Caldwell: Do they give you money, or an office?

Moss: Both. I am the officer. I am the one doing all the office work and we have an advisor who is my supervisor. Our office space is my desk at the Arc. They will give us money, and the county board, if we go to them and tell them what the problems are. Right now there is a problem that has come up and we are talking. We work with the country boards. We work with the county as one.

Caldwell: So you are the president of People First of Cincinnati?

Moss: The treasurer. I was the president. I have been everything.

Caldwell: Does the group vote?

Moss: Yes. We go by Robert Rules of Order. The Jaycees taught me years ago how to run meetings and what an officer is. I took that information, what I learned, and give it to the People First group. I teached them; together with Essie and Marcy we sat down and wrote the rules. We use Robert Rules of Order. You asked the question where do we get our money. People First of Cincinnati —we get it from the Arc, Hamilton County Board, DD Council —a little bit —or we send letters out to companies; some churches will give it to us. Right now we are selling 2008 calendars. Or we have spaghetti dinners or dances. Once a month we have a movie night. We charge $2.30 per movie. We have pizza and movies. We make on average $30 every month from the movies. Some people come to us and say we don’t have the money and we say come on in anyways.

Caldwell: I wanted to go back to when you met Essie and got involved in the self-advocacy movement. Was that good to get back into the field, because you said you had been out for a long time?

Moss: Because my mom didn’t want to be in it. Her stepped out because the paid people took over, the staff. They didn’t want volunteers.

Caldwell: So what was it like when you came back into the field?

Moss: I did good. I liked it.

Caldwell: Was it good to come back and work with other people with disabilities?

Moss: Yes, there was a lot of improvement through the years. I learned more. Today we are learning more. You know what I mean. My problem is that I
would like to see more younger people take over. There are not enough young people in the field.

Caldwell: That are coming into the self-advocacy movement you mean? Young people with disabilities?

Moss: Yes.

Caldwell: What do you think they need?

Moss: They don't have today. Some of the parents never teach the younger people the “volunteer bug,” what we used to call it in the Jaycees. We need that back. All they want is give, give, what they can use. A lot of agencies I work with, groups, don't have volunteers or younger people taking over. I can see it in all kinds of groups. In Hamilton County and statewide. Younger people want to stay by themselves. I can see it when I go to conferences all over the state, with the paid people, their conferences and I give a talk to staff. You see the younger people stay to one side and the older staff members. They don't have it. You see a lot of older people working.

Caldwell: Why do you think that is?

Moss: They don't have it in them: their parents never teached them to volunteer. In some of the schools today the kids got to go do so many volunteer hours. A lot of companies don't make their employees volunteer. Some companies do, like Cincinnati Proctor & Gamble, some of them ask to volunteer as their job. Some companies don't ask them. You see it in the world. In this field, all the agencies worry about themselves because they don't want to work together.

Caldwell: Do you think young people know about the self-advocacy movement?

Moss: They have heard about it. There is not enough information out there. They need more information, or they don't care. Some of the girls do but the boys don't. Like last night I went to the Saint Xavier girls volleyball team with a couple other clients I work with. When other people saw us they wanted to keep away from us. They just kept a distance. They didn't want to say hi to us.

Caldwell: You mean other people with disabilities?

Moss: Normal people, younger people. I was at a Saint Xavier volleyball contest in Dayton, Ohio.

Caldwell: Do you they still have, younger people, bad attitudes about people with disabilities?

Moss: Yes. A couple years ago there were two high schools and this year there were over 80. Just like that for girls. Yes, the girls are learning. Where
are the boys? The mothers and dads were there but the brothers don’t want to be there. You can see some of the girls are learning. I am talking about the older teenagers. I will be, this coming year, going to some of the high schools in Cincinnati to talk to some of the students.

Caldwell: Are you talking to students with disabilities?

Moss: Yes.

Caldwell: What are you telling them?

Moss: My life history, work, teaching them their rights. I say, “Come on volunteer. That be good on your job reference, on your letter.”

Caldwell: What else are you telling them?

Moss: I teach them their rights, like you can vote. Some of the parents don’t want them to vote. They think they will give up their social security, because if they vote. I see a lot of parents today don’t want to let their child. A lot of teachers and parents want to keep their kids in workshops and don’t give them a chance to go out and work in the world.

Caldwell: What do the young people say to you? Do they have questions?

Moss: Crazy questions. Can we have sex? Can we get married? Can we end up with each other? You know what I mean. I say, “Yes.” You know what I mean. But the moms of the teenagers want them to live at home and have the parents take care of them. And I ask the parents a question. At the sib conference in Ohio with Tom Fish there was a sister, her mom is 90 and her brother lives at home and he is in his sixties. I say, “What is going to happen to him?” You know what I mean. We are seeing more and more older parents. Then the county has to take over in five minutes with APSI. A lot of people are not ready because you don’t think like that.

Caldwell: Let me ask you about the people who have been the closest to you in your life. Who would you say has been the closest to you in your life?

Moss: My mom and dad and family members. When I was growing up my parents and family or some of the people I was going to school with. Today I make my own friends. Ninety percent of people I know today are people working in this field, like the two guys you met today, both Toms: Tom Eamoe is my boss, my good friend, and Tom Gannon. I asked Tom Gannon this week about the money I get from social security. I need somebody for the money to go to because I cannot get the money for myself. With social security there are rules. I need a guardian. I don’t have that right now, so I am asking Tom right now to be in charge of my money. Tom Eamoe is my guardian over my body. He helps me a little bit. A couple years ago I went into the hospital. My sugar level was over 800; you know what that means if you study medicine. So he was with me
on both sides. Tom Gannon, starting this coming year, will help me with my money. Not my money, but my money from social security.

Caldwell: So he will be like our payee?

Moss: Yeah. Yes. Now that will be the first time I done that, but I am trying to do it. I got the county board to back me. Talk about the county board. When my mom died, I was too good to get help from the county board, because I have my own car and I was working. About five years ago, I tried about four or five times with the county board. You know what the county board is, don’t you? I pulled some strings to get services from the county board.

Caldwell: What kind of services?

Moss: Just help, period. Today they are helping me with 15 hours a week in services, plus they pay my salary from the Arc. I am on contract. You know the contracts.

Caldwell: So who else is closest to you in your life?

Moss: Essie; the two Toms; my supervisor; people you work with; my family up in Chicago. My family here in Cincinnati –in this library, I am here –if I walk out, I don’t know what they look like today. That is crazy to say that. I don’t know them. I am the black sheep of the family on my dad’s side.

Caldwell: So these are like cousins? Do you have any other brothers or sisters?

Moss: This is it. If you are a family, you are supposed to be helping each other. I don’t see my family on my dad’s side helping me.

Caldwell: So who else has supported you in your life? What about Essie, what kind of support from her?

Moss: Friendship –Essie is a good person. I am doing a lot of projects with Essie. I am working on the exercise book with Essie. The RRTC out of Chicago have an exercise program; me and Essie is running it here in Cincinnati.

Caldwell: So what supports do you think contributed the most to your leadership? How you developed to be a leader?

Moss: A couple things: my mom’s training; the Jaycees; Essie Pederson and Marcy; and my own self doing it. I go to a lot of board meeting all over the country and Cincinnati. Some of the questions I ask at the board meetings. I ask myself, “Where did I get those questions?” Like a couple weeks ago I was at a board meeting with the county on MUIs –if you get hurt, investigations. I was the one that mostly asked all the questions. There was two of us there with handicaps.

Caldwell: Have you always been like that or did you learn?
Moss: Sometimes when I go to meetings I feel someone in back of me, pushing me—teaching me to ask questions. You know what I mean? When I go to RRTC meetings up in Chicago, you know who is asking the more questions? I mean at the Chicago meetings how many clients are there? I am the one who is asking the most questions.

Caldwell: Have you always been like that?

Moss: I am getting more confidence.

Caldwell: Where do you think you got that?

Moss: Essie teaching us how to behave in meetings; learning the Roberts Rules of Order. A lot of groups today don’t use that, go by the rules. I am working on, with the county, I am teaching the articles to be in the paper. We come up with about ten questions to ask if it is good for the handicapped person. Can a handicapped person understand it? Are they using the right words? Like today, you met the one girl I was talking about, the college girl. I got the papers with me today. I am going to teach her. Next week I am going to talk to her and teach her about what we need to know. Her is taking. What is that? Her learning how to work with newspapers—how to write the articles.

Caldwell: Journalism? She is studying journalism?

Moss: Yes. Her is on a ten week, what you call it, in our office learning how to do it.

Caldwell: Can you talk more about what you did with Essie around leadership and boards?

Moss: There are some books that the Chicago people used to make: choice making; how to be on boards. There were some books about how to be on a board and serve on a board. We used those books.

Caldwell: Did you go around the state or the country?

Moss: Around the state.

Caldwell: What are some groups you talked to?

Moss: Down syndrome; Arc board. We helped people get on boards. Doctor’s offices and UC Medical School—how to teach doctors. I don’t think the books are being used much today. Are they?

Caldwell: I think they are still being used. Maybe not as much because I think a lot of people have gotten on boards, more and more, don’t you think?

Moss: Yes. One of the problems I see on some of the boards, the staffs are not helping the board members, the clients. We are trying in the State of
Ohio, working with the senators, to change the rules so that two handicapped people to be on their board. Now there are seven. We want to make it nine on the county boards; there are seven voters right now. We want two handicapped people on the boards.

Caldwell: Right now, are there any?

Moss: None. In the state of Ohio, there are 88 counties.

Caldwell: So all 88 counties, you want to have two people with disabilities on each board? And you are trying to get a law passed?

Moss: Yes, through the Senate. I got to go back up to Columbus this month, next month, to start passing the law. A couple months I went to senate house on a speaker stereo to talk to the senators about a bill. When I was talking to the senators, the speaker system came on and somebody said, “This is God.” I was talking to the senators about a certain bill.

Caldwell: So you were talking to all the senators about it?

Moss: Yes. You know when the senate has a bill going you have to go through so many houses. You know what I mean, go to meetings.

Caldwell: You testified, to a committee?

Moss: Yes, a couple times. I will be going back up. Yes, if it goes though it will help me. I am going to be running for it. I want to get the seat then I will be on their board and be the first handicapped person on the board of the county. But, my mom helped start the county board. That is a little bit funny to say I am on the county board and my mom helped start that agency. Like some people ask me today, “How many years have you been working for the Arc?” My mom started the Arc 51 years ago. Not many people can say that today.

Caldwell: Yes, you have a unique story. What does self advocacy mean to you?

Moss: Speaking up for myself and asking for help if I need it. Like today we went into a restaurant and the waiter didn’t understand me. You know speaking up for yourself, standing up. You got to.

Caldwell: When did you first become aware of discrimination against people with disabilities?

Moss: In the sixties. I seen it in the Martin Luther King era.

Caldwell: Against people with disabilities?

Moss: Yeah.

Caldwell: Was it when you were in school?
Moss: Yes.

Caldwell: What were some of your experiences in school?

Moss: Other classmates called us dummies, the stupid people. Make fun. They didn’t want to be around us. We went into the gym classes because you got to. They didn’t want to be around us. If we got picked on a baseball team, we was in last place being picked. You know how the classes pick.

Caldwell: Did it make you feel bad about yourself or did it hurt?

Moss: Yeah, it hurt. Or if we asked to be on certain committees they didn’t want us on the committees. If the school was wasting money, they didn’t want to tell us.

Caldwell: Do you have any good memories from school?

Moss: Yes, some of the dances; some of the good teachers.

Caldwell: Do you think you got a good education?

Moss: No! But that was the best they knew how to do for us in the sixties. Today you can go to college with a little help, but when I went there was not college. Today, everybody can go to college; you can go.

Caldwell: How do you think being a person with a disability has influenced how you feel about yourself?

Moss: I have to prove myself. I can do the thing. Like driving a car, a lot of people said, “You can’t drive a car.” Like People First and some of the groups I belong to, out of twenty people maybe two of us have cars. Eighteen of us don’t. Yes, I see people working in the workshops and I think they can be out of there working with regular people. Or somebody today, doing the walk. He was the last person, but he did it. He did it.

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

Moss: Yes. Yeah, I don’t get that close. I see a bond.

Caldwell: What do you think the connection is?

Moss: Because we all got handicaps: brothers and sisters.

Caldwell: You are all brothers and sisters.

Moss: In the groups, yes.

Caldwell: You have all experienced similar things?

Moss: Yeah.
Caldwell: How do you think being in the self-advocacy movement has helped influence who you are and how you feel about yourself?

Moss: Let me answer it this way. I was working, doing my volunteer work and working in the hotels as a houseman. Then this job came up working for the Arc. I took it; one, I can go out and work in the office; two, I learned how to work the computers; three, how to be an aid in an office. What to wear and what not to. I had been working in factories. I never worked in an office. But self-advocacy people taught me, yes you can do it. And I am doing it. Yes, with the help. Let’s take you as an example: you never worked in a factory or been a dishwasher. If I teach you how to do it, you are not going to like it. You are going to want to work in the office.

Caldwell: So the self-advocacy movement helped teach you things and give you more opportunities?

Moss: Yes. More opportunities so I can be where I am at today.

Caldwell: How did that help how you feel about yourself?

Moss: Make me feel better; helped me get more friends. Right now my name means something. My name means something in the State of Ohio. If I go to meetings or places in the state, I am known. My name is known or my face. You know what I mean.

Caldwell: You are known as a leader?

Moss: Yes. Is it going to help me? Yes, maybe the next year or two, not this minute.

Caldwell: Do you think the self-advocacy movement helps people feel better about their disability?

Moss: Yes, a lot of the things that I got. The self-advocacy program get’s them out of their houses away from the “idiot box” or TV. Get them away from it and make them go out in the world. Like in that exercise class, we had somebody come up with the question. Her want to keep doing it, keep doing it. That gets her out of the house; that is the only thing her does. You know what I mean. Get them out of the house.

Caldwell: Do you think it is important to be around other people with disabilities?

Moss: Yeah. I like to be eighty or ninety percent around people like that. I love to be around normal people but… Like there was a question come up in one of the classes I teach on dating, how to date girls and guys. A lot of people say you work in certain offices you can meet certain girls. Like my job I cannot meet single girls because I do not work with them, or date. I am not in the right place. The clients I work with want to meet girls, but
there is no. A lot of the guys I work with in the field want to meet normal girls and they don’t want to date with us.

Caldwell: Let me ask you about leadership. Did you have any role models or mentors? People you looked up to and wanted to be like?

Moss: No.

Caldwell: I sort of asked this a different way. But what events or opportunities you think helped you develop your skills to be a leader?

Moss: The training that I had through the years.

Caldwell: What training?

Moss: The programs with Essie and the Jaycees and all the other trainings.

Caldwell: Any other opportunities?

Moss: On boards. The training I am getting today working. My question is this: without the training I got today, I would never be where I am at today? If I was not working at the Arc, I would probably be working in a motel. Cincinnati is not the best. In the winter months it is dead. In the summer months it is going like a dog. Now I am working year round.

Caldwell: Do you consider yourself a leader?

Moss: A little bit, not much.

Caldwell: Why do you say that?

Moss: Because I am doing it. Some of the programs I got to do with the county board, I got to get up and talk to people. They are pushing me as a leader.

Caldwell: What qualities do you think a leader should have?

Moss: Responsibility. Can do the work. God in your background. Some things that you’ve been through, you can help the other people not to go through it.

Caldwell: So the experience you had. Do you think your experiences as a person with a disability has helped you be a good leader?

Moss: Yes.

Caldwell: How so? What do you mean?
Moss: Both ways, everything. There was some of the stuff I done when I was younger. I try to say to people who are younger, like your son, don't do what I did. When I was growing up there was no help like there is today.

Caldwell: Who would you call a great leader?

Moss: Kennedy.

Caldwell: Kennedy, why?

Moss: He did good for our field.

Caldwell: For the field of disabilities?

Moss: Yes. Some of the things he did. They didn't want his sister. Now they are making up for it, the Kennedy family. They give grants. I see that similar to my story with my brother and my mom. Some of the family didn't want her around, the sister who was handicapped. I can see a similar case.

Caldwell: Do you think that made Kennedy a better leader? Having a sister with a disability?

Moss: Yes.

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

Moss: I can do it. You know what I mean.

Caldwell: I want to ask you about the self-advocacy movement and the future of the movement?

Moss: I would like to see younger people in it to take over from us. There are not enough younger people in it. I would like to see that: younger people take over. We have mostly people in our chapter over forty. Or people who are in it don't want to volunteer to do it, to be officers. They don't want to do it.

Caldwell: Do you think younger people might look up to you as a role model?

Moss: Yeah. I go out and speak. I do it. Sometimes I go to meetings at the county and I am the only handicapped person there with all staff people. I stand up and start asking questions, but I act like a normal person. You got to look the part. You got to ask the questions at their level.

Caldwell: How do you think the younger people can be supported?

Moss: With more staff people to help. With money. Go out and meet people. A lot of them want to stay home and watch TV or the staff person or parents never teach them.
Caldwell: So, how would you go about helping younger people become leaders?

Moss: Teaching them.

Caldwell: What would you teach them?

Moss: The stuff that Essie taught me.

Caldwell: So, the training that you and Essie helped develop? Going out and teaching young people?

Moss: Yeah.

Caldwell: So they need skills?

Moss: How to behave. How to dress. Not going in wearing t-shirts. Look the part. If you want the help you got to be the help.

Caldwell: What advice would you give young leaders?

Moss: Do it! You can do it! With the right help you can do it.

Caldwell: When you think about the self-advocacy movement, not just in Cincinnati but nationally, where would you like to see the movement go in the next five or ten years?

Moss: See more of it. More jobs that are coming out right now.

Caldwell: Do you mean jobs in advocacy like you are doing?

Moss: Yes. There are more jobs. Working in a bank doing bank work. Get the people out of the workshop into regular paid jobs.

Caldwell: What are your personal goals for the future?

Moss: Keep working. Get my social security. Get more money. Do good. One of these days, maybe meet a girl.

Caldwell: Do you think you will ever retire?

Moss: Maybe. I got to be 67 years. I got six more years of work, then I might retire but keep my volunteer going.

Caldwell: You really like your job now?

Moss: Yes. Just keep going, doing good.

Caldwell: Are you glad you got back into the field?
Moss: Yes. I don’t think I would have been a good houseman all my life – working in the motels.

Caldwell: So to go back, could you talk more about your family?

Moss: My dad didn’t like when my brother was born. In the Jewish tradition the first born boy will carry the name on. My brother was not and never will. He was upset about that. Make him gray hair. When I was born he thought… When my dad saw my brother in the institution he was crying on the way back from Columbus to Cincinnati. He was not happy. I just feel with my dad, when I asked him if I could drive a car he said, “People like you can’t.” When I did, he was so proud. Some of the things I did he was not happy. We fight like cats and dogs. When he was dying from cancer… My mom was the person who pushed me to do it. If I wanted to do something, “Do it!” My driver’s license, you can do it. There are ways to do it. Her push me. When I become a Jaycees member, her was thrilled, her was the proudest mom in the world. Then I was working at Golf Manor recreation, we went to meetings; her was thrilled. My dad was thrilled. But you know you could see it. You know what I mean. When I was going to school there was a dance I wanted to go to. In those days the parents had to meet the girl’s parents. My dad said he didn’t want to do it. My mom said yes, we are doing it. You know what I mean. Today you don’t have to do that – boy’s parents meet the girl’s parents – but when I was in school in those days you did. You did stuff like that. When I started doing the Jaycees work, her was thrilled. Her could see the difference in me if I go to a meeting.

Caldwell: Now after you graduated from high school, did you live at home?

Moss: Yes until my mom died. When my mom was alive and I was growing up teaching me how to behave, like the laundry, I did not listen to her. I am sorry I did not do a lot of the training. Today I could use it. I thought I was too important. Today I could use it.

Caldwell: So you lived with your mom and then your mom passed away?

Moss: Then I was on my own.

Caldwell: How old were you?

Moss: I was in my late twenties.

Caldwell: So, what happened then?

Moss: I go to the house and got some roommates. And I got into trouble because I got the wrong type of roommates. I didn’t know. Today I do. Like a couple months ago the county asked me if I wanted a roommate. I said no, because I don’t want no problems. With roommates if they don’t
pay the bill that is your mistake. I don’t need problems. The county told me we have people to live with you in your apartment. I said, “No thanks.” Because they saw my name and knew who I was and I would be good as a roommate. I don’t need problems today.

Caldwell: When you look back at your life, what beliefs do you think have guided your life?

Moss: My mom. God. The good people I know today.

Caldwell: What beliefs do you think you got from your mom?

Moss: Do the good thing. Be a good person.

Caldwell: Did you look up to your mom and want to be like her? She was sort of a role model?

Moss: Yes, a role model.

Caldwell: Do you think you are carrying on her work today?

Moss: Yes. Yes, many of times. That’s why when we was talking earlier when I go to sibling conference I get to see the Arc, what they got on my mom. I got to do it. I got to see that pictures.

Caldwell: So you have never seen that.

Moss: No, I got to go. I know a couple people who work there, but I have never been to their office. I been to the local office and state office but I want to see the national office.

Caldwell: So your mom helped create the national Arc?

Moss: Yeah. My mom started the local, the state, the USA, and international – out of her kitchen.

Caldwell: Do you know what the Arc was like when it first started in Hamilton County?

Moss: Nothing. There was nobody, no office. It was out of our house.

Caldwell: It was out of your house?

Moss: Yes.

Caldwell: And what did she do?

Moss: People phone called her up at all times of the night and day. In the 40s there were three mothers. All three of them had kids. There was nothing.
In the 40s, if you had a mentally retarded boy, daughter, or kids you send them to the institution. But my mom didn’t want that. So her helped start the county board for mentally retarded, the county boards — got that bill. Her wrote the *Three R’s*, the book helped start all the teaching, helped hire some of the teachers to help teach the program to the teachers — what they need to teach us. The teachers didn’t know, nobody know. She got it going where it is today.

Caldwell: That is amazing. What us do you remember?

Moss: Going to all the meetings with her; sitting back and listening.

Caldwell: Do you remember any of those meeting?

Moss: There was too many of them. I go to too many of them today. I don’t remember what the meeting I had Friday night.

Caldwell: Are there any lesson you think you learned in life?

Moss: Yes. Do it. Treat people good. What my mom told me. Be nice to people. Help people. Do a good deed per day. And I have tried to do it.