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Tia Nelis

11/25/2007

4:00 PM – 8:00 PM

Chicago, IL

Caldwell: The first question is really where were you born and where did you grow up? First, how old are you now and when were you born?

Nelis: I was born in Chicago; and I was born in 1963.

Caldwell: Have you always lived in Chicago?

Nelis: All my life.

Caldwell: Okay. And where did you grow up?

Nelis: I actually grew up on this south side of Chicago in the Bridgeport area, Mayor Daley's area. So we went to school with all the mayor's stuff. Mayor Daley senior was always at our school talking and interacting. So it wasn't a big deal to see the mayor. He was always there.

Caldwell: What are some of your memories growing up –in your family or in school?

Nelis: Um, let's see, in school... In the city you are always with kids who are like more into, and in later on, the gang issue situation. So it was more like you had to know how to protect yourself and who to interact with in school, grade school –well, mostly high school. And in grade school I was in only two different classes and the rest were regular classes, which was math and reading. And then in fifth grade was a separation of when we went out for math and reading. There was more of a segregation because we sat by the teacher's desk so you wouldn't interrupt the rest of the class when you left. So more in fifth grade, we were separated when we outside of the room for math and reading. They were doing all the other subjects, so when we came back from school they did math and reading so we were separated again. They told us to do homework or work on art stuff. So we never really worked on school work during that time. And then we figured it out and got tired of doing artwork and stuff like that we just left the room, math and reading room. We took off and went to the store and came back almost after school was done.

Caldwell: What were some of your teachers like? Did you have any favorite teachers, or good teachers?

Nelis: In high school I did, but grade school wasn't that many teachers. Chicago schools... There was more advanced after we moved. The school kids out here learned more things than in the city. Chicago schools were sort of poor and kind of didn't have a whole lot of stuff in the neighborhoods we went to school in –big difference between the city and the suburbs.

Caldwell: Do you think it was like that for all students or just for students with disabilities? Was there any difference?

Nelis: No. Well, I think you knew it more in high school, that it was more advanced in high school, when you went somewhere else. Like when we moved from Chicago to Naperville you could tell. Like in my old school they have manual typewriters and not all the kids had books to use for typing. And then you came to the suburbs and they were on the other side of the book and they had electric typewriters and we didn't even know what they were. And in the suburbs they had all those exams, the final exams and everything; and in Chicago, we didn't hardly have any of that. So we didn't even know what that was. My sisters and my brothers were young when they move to the suburbs, so they got a good, better education to choose from.

Caldwell: When was it when you moved from the city to the suburbs, Naperville?

Nelis: When I was 16. Yep, we had to leave. Our neighborhood was getting bad. There was gangs and guns, shootings and drugs, and things like that.

Caldwell: And did you have a lot of friends when you were in the Chicago schools? Did you have friends there?

Nelis: In the high school we made friends with people who were a lot older than you. I went to an all girls' school. In high school I went to an all girls' school while I was still in Chicago. And they had things like, you know, where you have someone they call your "big sister" to help you and show you around the school. You're supposed to pick somebody older. And some of my friends picked each other, and they didn't pick people who were older. And so when they had initiation time, those were the girls who usually got in trouble. I would pick seniors and juniors, who would punch the teacher in the face with no problem, to be the person to show me around the school. And there was a lot of drugs. Downstairs in the basement was like drugs, smoking marijuana and everything; the next floor was like cigarettes. So you really had to get to know people who would be a guard out too. Finding people who would help protect you against that. So during the initiation, two weeks of initiation, I never got anything done to me because I picked seniors and juniors who had a reputation of hitting teachers and fighting teachers and getting suspended.

Caldwell: And you said there were a lot of gangs. So how was that, did you have to be careful who you made friends with?

Nelis: Yeah. You always had to be prepared of who you were friends with. I was a friend with someone who was part of the Latin Souls, a gang in Chicago.

Caldwell: Did anyone ever tried to get you to join a gang?

Nelis: No, I was pretty lucky because I had mostly the seniors and juniors who hung out together. That is who I basically stuck with. And then we had all guys on our block. So, all the guys would make sure there was protection. So when my step-dad passed away, when I was 16, they all came to my dad's funeral, my step-dad's funeral, and basically said, "You have no problem for as long as you live here. We will watch out for your house." They told my mom they would protect.

Caldwell: So to go back to your family, how many brothers and sisters do you have?

Nelis: I have two sisters and a brother. And they are all younger than me.

Caldwell: So growing up it was your two sisters and brother and mom and dad?

Nelis: Yes, until I was 16. Oh, my real dad, they got divorced when I was five.

Caldwell: Did you ever have a relationship with him?

Nelis: Not until much later. He contacted me and we sort of talk on the phone. Now he lives in Wisconsin.

Caldwell: So it was mainly your step-dad?

Nelis: I did have a relationship with him. He was mostly what I consider my dad growing up.

Caldwell: So he passed away when you were 16 and then that is when you guys moved to Naperville?

Nelis: Yeah, because the rest of our family was here; my aunts and my uncles and my grandparents were here in Naperville.

Caldwell: So what was your mom like? What was it like growing up? How would you describe her?

Nelis: My mom didn't work that much she was more stay-at-home. And then my dad did most of cooking and stuff. I mean she did some cooking too but mostly my mom was like the stay-at-home mom. She was there when we got home. She didn't work until she had to, much later. When my step-dad passed away she had to find some kind of work to get by, to help us.

Caldwell: So what was it like growing up in your home?

Nelis: I mean it was all right. As far as my sisters and my brothers, we never considered each other as not having the same name, because they had by step-dad's name and I had my real dad's. We never said that's your real dad or that's your step-dad –because family is just family.

Caldwell: What are some of your other memories at school?

Nelis: School was mostly... There was like some special ed stuff I did in high school in Naperville. Tests. We would go in for tests, which was easier because you know they can read the stuff. I wish I was in Naperville schools more at the beginning cause I would have got more stuff out of it from the beginning years.

Caldwell: From special ed or just from overall?

Nelis: Overall. And in my school we had individual plans in special ed, but I didn't even know what that was until after I came to UIC. Someone asked if I wanted to talk about my individual plans in school, and I said, "What's that?" They go, "You know the goals are supposed to work on in special ed. Everybody has one." And I am like, "We did?" I didn't know what it was. So kids now days are really lucky because if they are in those kind of classes someone is there to help them. You know, figure out their goals, what they want to do. Someone is there to talk to them. They can have those people in their meetings, and stuff like that. So I didn't get to have that. Basically my rehabilitation counselor in high school told me I should sit at home and watch TV and collect Social Security disability.

Caldwell: She told you that?

Nelis: Yeah, because I told her my parents didn't have a lot of money to send me to college –because college was a lot of money. I didn't know anything about scholarships or anything like that. What that was all about or to help figure out things like that, I never had anybody to help with that. Basically, I just did the stuff on my own. So, she said if you don't want to go to college or work in a sheltered workshop you can do these things. That is basically what she told me. And the first time I went and spoke, my first presentation was in front of 150 rehabilitation counselors to talk about my experience with that.

Caldwell: So when you graduated from high school what did you do right after that? Did you graduate when you were 18?

Nelis: I did graduate when I was 18 because I wanted to get out of there. I got a regular diploma. I did babysitting for a while. I worked in a nursing home, which I didn't like too much. But then I interviewed and saw a job at the YMCA. So I worked at the YMCA until now I work a UIC.

Caldwell: What did you do at the YMCA?

Nelis: Their baby sitting room in the morning and then afternoon their second and third graders after school program.

Caldwell: So how long did you do that?

Nelis: Five years, almost six.

Caldwell: Did you like the job?

Nelis: Yeah, but it didn't pay a lot of money though. I also did a day camp in the summer. That was through special rec –for 10 years. So I did special rec in the summer, counselor-in-training and then worked my way up to a regular counselor. So it was two years a volunteer without any pay and then work your way up to getting paid. I did that all the way up until I started working at UIC full-time. It was about 10 years.

Caldwell: Did you ever get any assistance from the disability service system? Was that your voc rehab counselor? But she didn't help you get the job at the YMCA?

Nelis: No, I did that myself. I just looked in the newspaper and did it myself.

Caldwell: So they didn't help you with transportation or anything?

Nelis: No. I did in-school jobs before that, where you went around and did in-school jobs during school; so you got a little bit of money that way.

Caldwell: To go back to school, and some of the experiences you had as a person with a disability, you talked a little bit about the rehab counselor?

Nelis: Definitely school wasn't... I mean we had some issues with high school in the suburbs too, with the kids. When you are separated from people, that is when they distinguish you are different from them. So, usually you got the "retard" room. "Stupid" people ride the buses. I never rode the buses because we lived real close, but that is basically what you got from the other kids. I think anytime you separate anybody, where it is different from anybody else, people notice and it makes it harder for people to accept other people, other kids.

Caldwell: Can you remember some other experiences?

Nelis: We used to go at lunch time. My friend Liz and I used to go eat in our classroom so we didn't have to deal with the other people starting stuff.

Caldwell: What would they do?

Nelis: Oh, they would basically call us names. In grade school they would trip you down the stairs and things like that.

Caldwell: Would you say your closest friends were other students in the special ed classes?

Nelis: I had some friends outside. Well, I mean in Naperville. I only went to two different rooms in the Chicago system.

Caldwell: So, how did you first get involved with the self-advocacy movement?

Nelis: Our teacher in high school was still friends with a lot of us who had graduated and she met Leigh Ann Rusche, who was from Nebraska. She had come down to the Illinois and talk about why wasn't there a self-advocacy movement in Illinois. She asked us to come to UIC and meet People First of Canada and talk about the self-advocacy movement there and meet Leigh Ann. And so we went to Chicago to meet her. But actually when I first met her I didn't want to talk to her because she was another authority figure and I didn't want her telling me what to do with my life. I was like, "Another person going to tell me what to do with my life." I am not gonna say too much to her. So basically I just answered "yes" and "no" questions. She thought I didn't know how to speak. But we went and heard about self advocacy, my teacher finally said, "Why don't you talk about the job that you got discriminated against?" I went through all these interviews to do a teacher assistant job. And then the last interview all the teachers liked me but they found out that I was part of special ed and they didn't hire me. And so I said I would talk about that. She kept interrupting my sentences and my words. So, I was basically mad because she kept interrupting me while I was telling the story. So, I basically told her to shut up. And that was the first time I ever disrespected an authority figure. I wasn't a person who would speak out because when you're small you taught to respect authority: they basically know what they're talking about, you shouldn't disrespect respect them. They just freak you out. So, I basically told her to shut up at this meeting. Then she told us that she didn't know if we should be part of the self-advocacy movement if we were gonna go around telling people to shut up. Leigh Ann explained that when you're part of the self-advocacy movement and are going around, and are learning how to speak up and express your feelings, that it's gonna come out differently because you don't know how to express your feelings or what to say.

Caldwell: So you told your former teacher, the person invited you, to shut up. And she invited you because she wanted you to tell that story?

Nelis: Yeah. She invited us because she wanted us to be part of a group to learn about self advocacy and what it's about.

Caldwell: How many people were invited to come to that?

Nelis: Five. Five of us were invited. We were friends and stayed friends after school was over with. And she invited five of us to come and be a part of that. Then Leigh Ann worked with us to be able to do things more, to be able to speak out more and disagree –it's okay to disagree with stuff. I have never disagreed with that.

Caldwell: So when you heard Leigh Ann and the people from Canada that came that was really the first time you heard of the self-advocacy movement?

Nelis: Yeah and even then we didn't know what it was. We just knew they had great stuff we wanted: t-shirts, jackets, and that kind of stuff. They had t-shirts and jackets on and the guys had baseball hats –advocacy t-shirts that said People First. We wanted their stuff so we wanted to join. It was nothing to do with anything else. Just give us your stuff. That is why we joined. It was something to belong to that had cool stuff.

Caldwell: So how did they help you? They came just once?

Nelis: They did a little bit and then Leigh Ann brought in Nancy and this other girl, Mary Lou, from Nebraska. So we mostly got a lot of other stuff from Nebraska. Leigh Ann lived in Nebraska and worked for Shirley Dean who was another person who was involved in advocacy movement. In Nebraska people were treated a lot different in the disability movement. So Leigh Ann was surprised when she moved here about how different it was in how people were treated. Here it was like a whole new world. People with disabilities were more respected there.

Caldwell: Yeah, Illinois has always been behind.

Nelis: Also by professionals too.

Caldwell: So when was this, do you remember what year?

Nelis: About 1990 or 91.

Caldwell: So how long had People First of Nebraska been around?

Nelis: A long time already. We always thought that groups would never catch up to be that kind of organization –a big kind of thing.

Caldwell: So after that first meeting, she brought in Nancy, and Leigh Ann kept working with you?

Nelis: Leigh Ann kept working with us. Not so much on advocacy so much, because when you first start out I think it is always important to get to know the people and do things together where we would get to know each other and work with each other a little bit –learning to work as a team. So we used to meet in restaurants and stuff like that.

Caldwell: So it was just five of you guys?

Nelis: Yeah, we were the only people then.

Caldwell: So what was that like? What would you talk about?

Nelis: Just about labels. How it was like to be called different names. Labeling and stuff like that. Our first set of goals, our wish list... This kind of funny when we looked at it now, later on... Like our first ones are like notebooks and pencils. There are so many more things you could want, I mean. But that was kind of our first beginning stuff. And just hanging out together and learning to know what speaking out meant. Our first projects were like... Leigh Ann would ask questions and Leigh Ann would be part of our presentations then until we were able to learn to do it on our own.

Caldwell: Were you ever quiet and shy when you were in school or back then? It is hard for me to imagine you been shy? Were you like that?

Nelis: Yeah. It took a long time for Leigh Ann to teach me how to argue back with her just because of the whole authority figure thing; and she is only, not even a year older than me, a couple months older than me. I mean she is the same age but I still saw her as an authority figure. I didn't really speak up for a lot of stuff because I didn't really have anybody to say you can speak out. There wasn't many people around like that.

Caldwell: When the rehab counselor told you to just sit in home, did say anything to her?

Nelis: If I didn't have a whole bunch of people saying, "No, you shouldn't do that," I probably would have tried the sheltered workshop routine or something.

Caldwell: So what happened next with the group? You were meeting at restaurants and then what happened?

Nelis: We started forming a group and meeting a couple times a week at different places; then we started forming our organization afterwards. So there were a couple more people and we started forming chapters.

Caldwell: So did you have any kind of support? It was really Leigh Ann who was providing support? Did she move to Illinois at that time?

Nelis: Yes. And then Dr. Braddock asked her to come work at the University of Illinois. And she said she wouldn't work without someone who had a disability with her because she didn't believe in taking that kind of job without a person with a disability. If you're showing how to make a movement in Illinois, or how to make a movement wherever you are, and showing the relationship between people with and without disabilities, you should set the example of how you are going to do that at the place you're starting. So we started a self-advocacy support project. That is what it was called at the University of Illinois at Chicago. And that is what Dr. Braddock basically agreed to commit to develop the self-advocacy movement there, along with Cathy Ficker-Terrell, who was at that time part of the DD Council putting some money into forming the group in Illinois.

Caldwell: So the DD Council provided a grant to help you guys getting started. And it went through UIC? Was that the first time you met Dr. Braddock?

Nelis: Yeah. Well Leigh Ann got to first. She didn't know if she was going to take the job and then she talked to a whole bunch of people. And they said, "Do you know who he is? That would be good!" And then they said, "You want to work there," but it took a long time to get on the payroll at UIC. If Leigh Ann wasn't able to give me money until I could get on the payroll, I would have been in trouble because of the switching over from the YMCA and it was only part-time. The university bureaucracy... I had to take the test to be part of that, but Leigh Ann could go in and help me meet the words.

Caldwell: So Leigh Ann approached you?

Nelis: Yeah, she asked me if I wanted to work at the university with her on starting the self-advocacy movement there. So then I worked there part-time at the beginning. So I still work of the YMCA, part-time at the Y and part-time at the university.

Caldwell: So what were some of the things that you guys did to get the group going in Illinois?

Nelis: We went out and give presentations at some of the provider agencies to talk about what People First was, trying to get people interested in starting

a new chapter in their area, and about what they needed to get started; and supported them until they were starting to work on their own.

Caldwell: Was Naperville the first chapter?

Nelis: Yeah.

Caldwell: And then it spread to the Chicago area?

Nelis: Yeah, a little bit everywhere.

Caldwell: So how long did you guys do that for? Go around the state?

Nelis: It was a couple years before we got people organized enough to do things.

Caldwell: And you got money from the DD Council to do this?

Nelis: Some money from the DD Council and some money from the university. So it was kind of supporting between the both.

Caldwell: So when did People First of Illinois officially become sort of incorporated or an organization?

Nelis: It took a couple years after starting at the university. Probably about six or seven years and then we started learning about incorporating.

Caldwell: So how did that develop? It was mainly Leigh Ann and you? Were there other people involved at the start? Like the other five people?

Nelis: No, they were sort of involved in the local stuff. Then people were asking to come together and talk about forming a state organization. So we met a long time with them to learn about incorporation, what it would take to incorporate and all the stuff that went along with that. So we had to do stuff like sell t-shirts to raise money. And one of the things that Leigh Ann did where she wanted to make sure we learn all the steps instead of doing it for us. You know, some group's support people just fill out all the forms and send it in, but she wanted to make sure people understood what it was and so it was really our group. Anything that was written in that language... We would always put on the flip charts and then people would be able to understand it and then they would just transfer it over to the incorporation papers that were more a legal document. But everything we did to form new organization was all done by people and not by support people, except for the transferring over of the stuff. But it was all explained and flip charts used for people to understand what was happening.

Caldwell: And then when you became incorporated, is that when you formed the board? Do you remember what your that was?

Nelis: Maybe like five or six years afterwards.

Caldwell: So it was like 1995 or 96?

Nelis: Yeah, something like that.

Caldwell: And how many people were involved statewide at this point or how many chapters?

Nelis: There was only a couple chapters then; and then people helped form stuff.

Caldwell: And then you were elected the first president of People First of Illinois?

Nelis: No, the local chapter. I went from local to national; I never did state until afterwards.

Caldwell: So who was the first president of People First of Illinois?

Nelis: Nancy Boright. But it wasn't that long before I became the state president. But I went from local to national. We recommend that people do local, state, national –but I had a little more experience and the timing was right for me to do the national.

Caldwell: That was really when the national level was all happening?

Nelis: It was happening all of the same time.

Caldwell: So how did you get connected to the national level?

Nelis: We went to the national meeting in Estes Park, Colorado. We went to Canada afterwards but Estes Park was the first one.

Caldwell: What was that meeting like in Estes Park? Did you know you were going to form a national organization?

Nelis: People were working on forming a national organization, but there was a lot of fighting and arguing. Not so much people, but support people. They were arguing and fighting more than the people with disabilities of how it was gonna be formed and what was gonna happen. Actually Nancy and I thought they weren't really paying attention to what we were giving them information about. We were really upset about that. We thought they were paying attention. But that if the two main important ideas and started

to form the stuff. We were pretty happy about that but I mean it was kind of scary because people were fighting and arguing, and advisers pulling their people one way. Support people actually got in the way, actually sometimes –until we got to Chicago.

Caldwell: So what were the arguing about? What was the main argument, do you remember?

Nelis: How it was going to be supported? Who was going to help? Things like that: how it should look; how the board should be structured. And then they came to Chicago and we were in charge of helping them do more of the structure in planning when they came to Chicago. And that was the first time that the national organization kicked support people out of the room and told them they needed to leave because they weren't helping. So, all the support people were kicked out of the room. And then they came back in about two hours and we were all done with a bunch of stuff. We had a bunch of stuff done. We had a name, we had a mission statement, we had everything, we had goals to work on, belief statement.

Caldwell: Is that when the name Self Advocates Becoming Empowered was decided?

Nelis: Well it was sort of and then we made it more formal at the next national conference. It was sort of decided because we didn't want to call it People First because there are so many self-advocacy groups with different names so we didn't want to fight about which name they choose. So that is why we did Self Advocates Becoming Empowered, so it would be a generic name so everyone would not fight about the name, because not everybody's called People First. We knew that would start the whole another argument about which group to call it.

Caldwell: What were some of the other decisions you had to come up with around the national group?

Nelis: Money. How people were going to meet. We did conference calls for a long time which did not work. It is just too many people from all different places. And getting 20 people on a conference call plus support people does not happen in a way it should happen. Because basically people want to spend the first... Because you don't see each other, they want to spend the first 15 - 20 minutes on personal stuff instead of what you're supposed to be talking about –so those first set of phone calls were pretty expensive!

Caldwell: You know this is something I don't know... With SABE when people get on the board did they have to come up with their own money to get to the meetings?

Nelis: Yes. You have to try to come up with your own money to get there. We will help people who can't, but it is encouraged that you try to raise your own money to get there.

Caldwell: And so when SABE finally did get incorporated you were the first co-chair with Nancy?

Nelis: Yes.

Caldwell: So you had support from UIC?

Nelis: And Leigh Ann was in there with me.

Caldwell: So what was that like, the beginning of SABE? What was it like when it first started?

Nelis: People were just learning how to work with each other because people are from all different places. Things happen in different ways in different groups. But it is an interesting issue, because people are from so many different places and things work differently in different places. I think people were just trying to find their own voice and what it's like at the national level. Learning about national was a lot different than your state. Some issues are the same but some are totally different. And that was learning all the issues in DC and the national level and how people interact.

Caldwell: So to go back to the funding issue, how did the national SABE get funding to get started?

Nelis: Minnesota pitched in and helped out with some money, well not only money but technical issues, and Syracuse had a grant. And so basically people did some work on some projects and that is basically how SABE has worked the whole time. It is amazing how the national organization was able to survive on what we had to survive on. There's always a time when people are like okay are we gonna have enough money to have a national meeting? But it always happens somehow. Or we have just been lucky! Because we don't have any set funding from anywhere. And that is why it is so important now that we are working on to get that set funding.

Caldwell: I guess we could jump to that and talk about that now. Is that something that people have thought about for a while?

Nelis: Actually, when we were working with Laurie Powers' leadership stuff, the self determination and leadership stuff, we had started to talk about that.

And Chester was a part of that. Nancy, Chester, and I had been working on trying to get, when Sue Swenson was commissioner, funding for self-advocacy, just like the independent living centers have –for a long time, and it didn't really go anywhere with Sue Swenson in office.

Caldwell: Why do you think there hasn't been funding for the self-advocacy movement?

Nelis: I think they are different. People are faster at learning how to write things and make things happen in the of independent physical disability movement. It is a lot faster. It goes faster. I think in the self-advocacy movement –you know people with developmental disability, learning disability, stuff like that –things take a little more time because you have to explain everything. If it is truly from the people than it needs to be slowed down a lot more so that people can understand it. And it takes a little bit longer for people to be ready for it to happen. I mean I don't know if people were ready for people to handle their own money like that as an organization. On a national level, it took time for people to be able to... I mean SABLE can do their own money now it doesn't have to run through somebody, but before people had to learn how to do all that and it takes a little more time, if they are truly running the organization. You know they don't have a hard time writing grants or anything; so you don't have to sit there and explain it in great detail like you would to a People First group, and that kind of stuff, if they're really writing the grant. Or if somebody's writing it for them it is a different story. So I think if they are really writing it and it is their ownership it is going to take a while to make it happen. And I think people have more experience now, I mean more than when things first started. The physical disability movement has been happening for a long time. The self-advocacy movement hasn't –for people with cognitive disabilities, developmental disabilities –that long.

Caldwell: Can you talk a little bit more about that? We have talked before about maybe some of the differences and similarities between the independent living movement and the self-advocacy movement? Do you see them as two different movements?

Nelis: Well, I think they are two different movements. I think their issue is more access, getting into things, they don't have the stigma that people with developmental disabilities have. They don't have you know the "retarded" word and that kind of stuff pounded on them and told they are not worth anything. It takes a lot more for people with that kind of disability to speak out about it, and how it makes you feel. And even in the physical disability movement, people with physical disabilities don't want to be referred to as having "mental retardation." And that is why some people don't want to interact with people who have that label because of the stigma towards people who have that kind of disability. You know, "You want to be seen

as that?" And I think also that people who have a disability, even if they have it, don't want to try to admit that they have it, or get labeled because of the stuff that goes along with it. And I also think that they are able to think of things faster, and do things faster, and make decisions faster than People First groups or self-advocacy groups like that.

Caldwell: So what does the self-advocacy movement do that's different for people with that label?

Nelis: It is slowed down. It is more detailed. It is simple language, pictures. Not so much words all the time. For people to truly be able to understand it you have to break it up into easier concepts so that people can understand how it relates to their lives. Some of the things you work on in the self-advocacy movement, especially at the national level, are huge. You know, looking at bills and looking at different things. Getting people interested in why they should work on that if it doesn't relate to them. You know, how does it affect your life? How does it affect your friend's life? Just that whole understanding of what it means, takes time for people. And then money... Most people in the People First groups don't have a lot of money. They work in sheltered workshops or work in the institution. They don't have many jobs. Now they do, but before not a lot of people had jobs. It is just starting to happen where people are starting to get jobs. And it is just starting to happen where people are starting to get jobs at the Arc, the universities, the Protection and Advocacy organizations. That didn't happen until just recently.

Caldwell: Like jobs doing advocacy work?

Nelis: Yeah, real work for real pay and benefits.

Caldwell: Do you think that is happening more?

Nelis: It is starting to catch on. Hopefully it will be even more. But the people who are just starting there are going to need a lot of supports and leadership skills. It is a whole different ballgame when you work at a university compared to working at a self-advocacy group. It is a whole different ballgame.

Caldwell: You were probably one of the first people from the self-advocacy movement to work at a university? I am sure, maybe a couple other people, and maybe still one of the few?

Nelis: Yeah, at the university. A lot of people work at the Arc. Protection and Advocacy is still kind of new too. What is coming out too is the departments of mental health, working for the state. Not a lot thought.

Caldwell: But you think it is increasing?

Nelis: More and more people are trying to make it happen, but more people are going to need to be educated about how to help people work in those kind of jobs. I mean there are a lot more supports that people need when they choose to do that kind of a job. Or even move to another state. Because when you get out there more other states start to see you. You do work in other states and they want to bring you in and keep you in their state. That is another decision you have to make: if you are going to move to another state. They always want you, and somewhere else. But you have to make sure that you are prepared to do that and that you'll have supports when you get there –because people don't think about that because they offer you nice things. They offer you more money, travel; they will offer your whole bunch of things. But they won't think about: What kind of supports I am going to have when I move there? What am I going to do after my job is done? What happens after nine to five? Is someone going to introduce me to my community? Am I going to get involved with that? Are they still going to use the other people they have in their state to do some advocacy stuff and not just the person they brought in so that they don't get mad at the person they brought in? They have done that too. I mean people have been upset, depressed, all that stuff moving to another place because they don't think about all those things before they go there. And some of the employers don't think about those things. You know, they don't think about how people with disabilities don't have credit cards, don't have all those things to support them, you know, paying for their trips ahead of time. Who is paying for all that stuff? Figuring that out... It sure ain't gonna be the universities or the Arcs right away because they have to figure that system now.

Caldwell: And I know this is an area that you are interested in doing a leadership institute. What are the some of the issues you want to get at?

Nelis: It is huge because right now people are working in these kind of jobs. They are getting these kind of jobs and the need to be prepared for how to work and what is happening and how to be involved in that. Thinking about when you're done, when you have done the local and state. What is the next thing after national, the next thing to move on to? And sometimes people don't think about how the talk to people about that issue. They talk about, "Oh my god! You are done with the national! What are you going to do with your life now?" Well, if you don't have anything in your life before when you say that to somebody they freak out. You got to think about how you can say things. You could get people saying, "You could go back and help your local chapters. You could maybe not do anything in advocacy at all. You could get in to other things like helping your church or community to be more accessible. You can become a support person to a group. You could be the support person, the advisor to the

group.” That kind of stuff. And then be if you do get offered a job out of state, what kind of things to look for? Many people have already gotten jobs out of state and they haven't worked. And they are just moving, moving, moving. And they are not thinking about what is going to happen after the leave one place to another. It is always best to have more than one support –different people doing different things in your life to support you on different things. And that is the best way to try to make connections.

Caldwell: Really your generation... You were really the first generation of leaders at the national level. So what role do you think you will play in the next generation of leaders or next generation of people coming up? People like you or other people who have been at the national level?

Nelis: Well, we have the history of the movement. It is really important for the younger generation to know about. Because they really don't know what has happened to make this happen –the history. And that is important for people to know about, you know, you wouldn't have all these things that are happening now if we didn't go through those things that we went through. Also, there are support things that people can help with: starting a group or how to organize, what happens during some of those conflicts in there. You can be supports to other people, helping them. But they can also be supports to you. Because they are doing more advanced of than when we first started.

Caldwell: Other people have said it is amazing that some of the younger people, some of the skills and passion they have, or some of the expectations people have for them are a little different today?

Nelis: Yeah, basically they did not have high hopes for dreams for a lot of people earlier. Now it is like, “You can do all of these things.”

Caldwell: But it is also interesting that some young people do not even know what an institution is or what a sheltered workshop is?

Nelis: They have no clue about what anything in the past is; and it is important for people to know that so that they can know where their movement came from –what helped get them there and guide them there. They can use those experiences from people who have gone through those things to help them. I think it is both. We can pass on what we know to them; and they can help you with the new, more advanced things that are out there. I think it is both. It is a good way to bring these two groups together. We are working with the national youth leadership organization, NYLN. We talk about our experiences and they talk about their stuff and what is happening with them. So that has been pretty good.

Caldwell: Who organizes that?

Nelis: Betsy and Laurie Powers help them in Portland. It is a really good youth group. They just got funded again. Again, that is another funding issue, to get funding for the national youth groups to get together. They work on issues and a lot of those people have already been part of the stuff in Congress and testifying. They did all those sorts of things. They have a conference every year and work on labeling issues. One of the other things is how to include, again, people who have cognitive and developmental disabilities –because a lot of that is learning disabilities and things like that, some physical disability. Some of our stuff... We have been helping them on how to include people with cognitive disabilities, talking about labeling, and do some fund raising things. It is a pretty good national youth group.

Caldwell: Do you see many young people coming up and getting involved in the self-advocacy movement?

Nelis: We are hoping it will be an easy transformation if they get involved in the national youth group and SABLE has been involved with NYLN for a little while hopefully to transfer after they age out of the youth group. It is only for so long. They can go straight into the self-advocacy movement. It can be an easier transfer than if you are just trying to figure it out without any connection.

Caldwell: On the national level, do you see a lot of young people getting involved in the self-advocacy movement right now? Or is it something you are worried about?

Nelis: I think it is the mixture. A little bit of both. They are interested, but they are still trying to figure out how to make that connection. They are working on their things and we are working on our things. They got to get involved in coming to each other's stuff I think. Like, we have invited them to come to the national conference, so that will be a connection for them. They will be able to see how a national conference is done and put on. It is one thousand people with disabilities making it happen, being a part of that. The next one is pretty close. It is in Indiana so it is not that expensive I think for a lot of places to come from. Indiana is not that expensive of a place.

Caldwell: I always wondered... In the self-advocacy movement conferences are really important. Why are they important? What happens at a conference when people come for the first time?

Nelis: I think a lot of things happen. It is a time when people learn about becoming independent. It is a time when people get to go to a hotel who

sometimes might be at the nursing home or an institution –a whole weekend and a whole environment to get to talk to people who have the same issues and have gone through the same things that you have gone through. And the workshops... I think people have a whole bunch of time to go to a new workshop and learn different things. Also, it is time to have fun. Sometimes people see conferences as it is a big party and people get together. They don't talk about the workshops. In the workshops they learn skills and leadership, skills on how to start a new chapter, how to speak out. There are all kind of different workshops that people go to: sexuality, legislation, leadership. Yeah, it is fun too! But I think there is the combination there that people don't know about. Elections... It is the whole voting process. After a while it gets to be real competitive – especially at the national level. When we first started, you just had an easy get in. It wasn't too hard to get in. Now there is campaigning, buttons made, posters, really thought out speeches. It is a whole different concept. You have to fight to really win your region and then be on the board. It is a whole big issue. It is not just some little thing now. It is happening. And it is always surprising. You can't assume now who is going to get elected. You can't assume now that you are gonna win your region. If you are up for your region you have to really start campaigning after the last conference is done. You got to really start being out there. It is a really big issue. People are taking it serious; before, they will just elect you.

Caldwell: Let's stick on the self-advocacy movement and then we'll go back to some other stuff. What do you think are some of the biggest challenges that the self-advocacy movement faces right now, the future of the movement?

Nelis: Funding. Transportation. Everywhere you go in the world transportation is a big issue. It is a big barrier. People need to get to where they need to go. And money. Because they need to do the things we need to do. I mean, there is not a lot of money out there that people are willing to give to a group to get their structure together, startup even, even a chance to have any funding. There are still people out there who believe in labels, still disrespect people with disabilities and how they think that people with disabilities can do things. It is an issue. Even some of the famous people out there... It surprised even Nancy and me: Justin Dart didn't think people with cognitive disabilities could do a good meeting and be successful at organizing until he came to the national group and solve the self-advocacy movement. It was pretty interesting. This is someone who believed in people with disabilities and was idolized as the father of the ADA. Yeah, he told Nancy that, and it blew us away. He came to the national meeting and he said he had been to many, many meetings, even with people who worked in the White House and the President's cabinet, and he said he had never seen a meeting more organized than when he came to the national self-advocacy meeting.

Caldwell: But you are saying that is still a big issue?

Nelis: It is an issue: the stigmatism –people believing in people with disabilities running an organization, making decisions, controlling money. It is an issue still! And how to support people to make that happen... And another issue, huge issue, is people giving you the money that have their own agenda. And that is a huge issue because you can lose your money as soon as you disagree with what they want you to work on or don't want you to work on. That has happened a lot. A lot! Everything is fine and dandy and okay until you don't want to work on an issue or you disagree with what they are working on or you don't want to be a part of something. They want you to do it all. And as soon as that happens the disagreement comes in and sometimes they take the money away.

Caldwell: How do you think that is going to work if you got the federal funding?

Nelis: It is going to be given to the people. I think there will still be some, but it is a base for the group to get started and have some support and then find their own funding from other things.

Caldwell: So how do you see that working? If the self-advocacy movement was able to get federal funding, what would that provide?

Nelis: I think a lot of it would be the structure and staff. That kind of stuff so people could work on the stuff they wanted to work on. There would be projects but a lot of it would be helping to get organized, just like the independent living centers get the basic structure money. And that is what people need –an office and support people! Some of the money would help pay staff because that is a problem. People do it for free. You are asking people to volunteer their time and they're not getting paid for it unless you are able to find funding to pay your support people or unless they work for an Arc and then that is where you get into all this stuff with conflicts. It also would support people if they work for an agency and their agency is giving them time and that group decides they want to advocate something against what that agency is doing. You know, then it is another issue, how is the support and work? What is going to happen then? They could lose their job. That is why we try to find independent support people, trying not to find someone who works for the same group. But there are some people who work for some places that have really good supports and would go beyond for the cause of the people they are supporting. But there is little of that; a lot more of the other. They need their job. They have families to support.

Caldwell: Do you think it is getting harder to find good support people?

- Nelis: I think it is probably about the same now. When people are also thinking about doing, what People First of Illinois used to do is we had a support person retreat where support people can get together for a weekend and bring in speakers or just talk amongst themselves. That way they can network with each other, which brought the groups closer in working with each other. Of course, we have a big state so we had regions and we found some money for each of the chapters in the region to get together and have small conferences. That way the chapters in each region can have their own little conference and bring in speakers in their own area besides the big conference.
- Caldwell: So what is your vision for the self-advocacy movement? In the next 10 years what would you like the self-advocacy movement to look like? What would it be like?
- Nelis: Hopefully, we have federal funding. Internships –we have been trying to push for internships to give people more experience working at the national level and many other places. Leadership –the academy I am trying to start and stuff like that out there for people who are just beginning so that they know how to interact. And it is not just for the people with disabilities. We are thinking of having a panel of employers from the disability side and from the not disability side to talk about what they look for in hiring people with disabilities. Talk about that so that people can learn interview skills. Like the MAPS for their career and personal stuff so that people have an idea of what they want to do. What are the jobs that they are thinking of that they want to do? And then practice their advocacy skills. And then a place for an advanced leadership group for people who have been through all these things on the national level and now they're saying the youth are coming up and the next generation are taking over. So what are people going to be part of? You can't just say, "Okay, now you're done. See you." Something where people are going to need you; and then hopefully they will teach the other people when they come in. And I hope it will be better for young people with disabilities to be accepted more. That there won't be so many hoops you have to jump through. It will be a little easier in society as a whole. People will not think of people as separate.
- Caldwell: What do you think are some of the biggest issues that the self-advocacy movement needs to take on? What are some of the priorities of SABE now and what you think they will be in the future?
- Nelis: I still think transportation is an issue. Money is always an issue. People are working on trying to figure out legislation like Medicaid and bills. There is always supports –what to look for in a support person and how to find a support person. Employment –now that people are starting to get more jobs, not only do people with disabilities need to learn but employers

need to be taught how to interact with somebody at the job, how to help support them, how to let them know what their job responsibilities are going to be. You know it is a lot different in a university setting than it is somewhere else. Plus, all the bureaucracy that goes along with the job at the state level or federal level –how to survive that. Teaching people how to get around the money issue, the credit cards, figuring out how they're going to pay for lunch. That is a huge issue for people with developmental disabilities who have no credit cards; they can't get the credit card, especially if you want to travel.

Caldwell: I want to go back and ask you some questions about leadership. I know you have done a lot in the area of leadership. When you think about your life, what were some of the most important leadership experiences that you had? How did you develop your leadership skills?

Nelis: One of the things is that people think that support people are going to be there forever. One of the things that support people did for our group that I think was really good was that they said I am preparing you for when I'm not gonna be there anymore. I'm not gonna be there forever. Things happen in your life. One of the things you can do for your group is to help them build their own leadership skills and step back and let them make mistakes and try to do what they are trying to do. They have to learn it on their own because you're not going to be there forever. People have to make mistakes and fall on their face and get up again. I think that is a huge thing that she helped people do.

It is okay to make the mistake and it is okay to ask for support. That is another thing that has taught me how to be a leader: it is okay to ask for support. Because you are seen as a role model. In your mind you are saying, "Independence." You're the role model you're not supposed to ask for support. You're supposed to be strong. You're supposed to lead the group –blah, blah, blah. But they forget that everybody needs support in their lives. It is really hard to ask for support. Then if you don't ask for it until you are drowning, or it is a big mess, then it is worse; and you should have asked for it at the beginning. That is another issue: you have so much pressure. I think leadership has a lot of pressure too. Not that we can't take it but it has a lot of pressure. You are supposed to be the one who is always able to handle it and be the person giving support more than getting support. And what will they think of you if you ask for support? So I think that support is a hard issue for people who are in leadership roles. It is hard to ask and say, "I really can't do this." The other thing is if you did ask before and you had a horrible experience from somebody who you asked for support from, you are more hesitant to ask for support again. Or if you just came into those big responsibilities at some of those other places and you think that they might not ask you to come again if you tell them that you need support. So it takes a lot to ask.

Caldwell: That really is an important issue. One of the things I want to get at is if leaders in the self-advocacy movement think about leadership differently than other people think about leadership. And maybe the support thing would be a key issue?

Nelis: Support and trusting people. I think that trust is a big issue with leadership. Where you have trusted somebody, I think it is emotional. You talk about your life and you talk about issues that you don't actually want to spread around or talk to other people about, are private. And how people react to what you say after you have said it. It is a huge issue with how people feel about trusting somebody again. If you were burned by somebody –told other people about people's lives. When they trusted somebody and then they went off and did something that truly hurt the person. It is real hard to build that relationship and trust again. It is not going to happen again.

Caldwell: You think that is an issue especially for people with disabilities? The trust issue?

Nelis: I think it is a huge issue because people form relationships and then they say different things to make you think that they are a part of it and then they do something else. I think that is a huge issue that people go through. Especially, the trust of somebody to say they're gonna go somewhere in the neighborhood and go into an institution and they lock 'em up. "We are going on an outing," and all of a sudden you are in a nursing home or off in an institution.

Caldwell: So you are talking about the trust between the person with a disability and a professional?

Nelis: Or your parents. It is in all different issues and relationships, even friendship. Trust is a huge issue to be able to trust somebody again to say that they need support, or they are for it, or they need help with something. They have to build their relationship. I think that other people go through it too, but it is a little bit more harder for people with disabilities. They have been hurt a little more than other people –unless they have an issue, not really a disability, but like drugs or somebody who is gay. They distrust someone a little bit more just like people with disabilities because of the stigma behind it.

Caldwell: But it seems like that is one of the things the self-advocacy movement does is help people to build trust in other people, like people with disabilities?

Nelis: I think that people get help learning about trust but that people still have hesitation with trust depending on who they want to trust and talk about things to. I think that where people have a hard time with it is when the person that the trusted does something or messes up things. But I think also that if you have gone through that experience where you have had trust broken and it is in the disability movement, I think that you learn to become stronger. You learn from it! It makes us a stronger person after it has happened. It has happened to a lot of groups who have trusted people and have had their trust broken, but it has made the group stronger because they had to pull together and they had to work together and they had to figure it out. I think that that is something that is by far gross and bad when you go through it, but after it is done it make sure a stronger person. It makes you a lot stronger person and you learn a lot from it, but it really is bad when you go through it.

Caldwell: Just so I understand, you're really talking about the trust with somebody who doesn't have a disability breaking that trust? Is that what you are talking about?

Nelis: Yeah, people without disabilities breaking a trust; and that is why it is hard for people with disabilities to trust people. But it is also about risk and people with disabilities learning how to take that risk. And it is easier to take that risk with people and learning about that with your friends.

Caldwell: What is an example, without mentioning names, an instance where somebody betrayed the trust of a group?

Nelis: Where support people or professionals have their own agenda and they convinced the group that they were for them and supported them all the way and then when off and did other things that the group didn't find out about until later. Or they also said that they wanted to be a part of things and help and then got other jobs and talked about people to other people, some personal things that shouldn't have been mentioned. People have done that kind of stuff. I think groups have gone through some of that where they also had to fire support people. That is a big issue. They had to tell a support person that they didn't want them to be part of their group anymore. That is an issue, getting the courage to say that. Hiring and firing your staff is another.

Caldwell: I want to go to something else because it is sort of related to this and then we'll come back to leadership. Around the issue of disability identity... First, you have heard that term before? What does it mean to you? Would you think about it?

Nelis: You mean, "Oh I am proud to have a disability" kind of thing? I think it is really hard for people who have a label of developmental disabilities to say

I am proud to be whenever their label is because of all the bad stuff that goes on with it. It is a lot easier to say I have a physical disability and say, "I'm proud." An access thing compared to a mental disability. Because of all the things you get called all the things that people relate to you as when they see you as that. So it is really hard for somebody to stand up and say, "I am retarded and I am proud" because of all the stuff that goes on with it. Society labels us something different. And the stuff you have gone through, put in institutions, kids not liking you, hit, called names, spit at, beat up because of the label. Not a lot of friendships. I know that is a huge independent living center movement thing, "You should be proud of your disability!" But they don't get all the stuff that goes on with it. Yeah, I am sure they got some labeling and they got called some things but not seen as you're worth nothing, you're stupid.

Caldwell: Can you say more?

Nelis: And I think discrimination is an issue because if you have and disabilities sometimes they won't hire you and a job. You can't get a job. People treat you different when you say you have a disability; it and its harder for people to relate to that. That is why sometimes people do not want to admit that they have one. Because as soon as that happens people don't think you can make choices on your own, they don't think you can think for yourself, they don't think you can make your own decisions.

One of the things that happened... This is a cool, but not a really good story. Somebody from the planning council got into a car accident. She was in charge of our grant for People First of Illinois and she became disabled. She was in a car accident and because she became disabled people started making decisions for her and talking about her life, in the room and front of her, and not talking to her. One of the things that she learned about the disability movement is how important independence is and how people see you differently when you become disabled. People First taught her how to speak up and how she can make choices. She truly understood now what it felt like to have a disability and how people took over. Her whole family and friends started doing the same thing that they were doing to people with disabilities after all these years. Lessons she learned in attitudes and how to treat people with disabilities, just being part of our organization and then experiencing that first hand. It is a bad story that she was in a car accident and had to experience that but what a difference in outlook of life. In reality, because everyone is going to become disabled someday, it is going to happen.

Caldwell: I am trying to get more at the similarities and, like you said, the differences between the independent living movement and the self-advocacy movement around that issue of disability identity or disability pride.

Nelis: I think that people with developmental disabilities are proud of who they are, but I think it is a little more different than standing up there and preaching about the disability of who you are. I think they are proud that they have accomplished so many things despite they have a disability. I think they have learned so many things. I think most people say that they wouldn't trade it, not having it with having it, because of the experiences they went through and how their life is meaningful. Especially people who have just become disabled at an older age; I think that is much harder for people to accept then being disabled their whole life. That is another in-between group of people. And the people who are on the borderlines of disability, that is a whole other issue. If you are on the borderline you don't get services. You fall in that crack, you are not disabled enough.

Caldwell: Do you think the self-advocacy movement helps people feel proud of who they are?

Nelis: I think people are proud of who they are. They don't want to change; I mean they are not saying, "Oh, I want you to cure me." They have accepted disability but they don't go around and push. They don't go out and show it as much as the independent living would go out and say their label and that they are proud of that because of all the stigma that goes along with it. And I think they have done it, where they say they're glad that they have this and that and then they've gotten rejected when they said they have a disability. Things have happened to them, bad things. I also think that people in the independent living movement have more control over running their meetings and they think faster and they're faster at making decisions. It is a little slower in the self-advocacy movement. Self-advocacy groups are a little slower. People have to take time and explain things. Sometimes people are not able to make decisions right away and you have to say things in different ways. Sometimes you have to draw pictures. It might take the group longer. And we don't have the money to go fly off to do a direct action because people who belong to the movement don't have that kind of money. It takes a little bit more time for people to understand that unless you have supports. And how to help people get to those things... People who are in self-advocacy groups need lots of supports at times. They may need support learning about what is involved in the meeting, how to make their presentation. It takes a lot of time for people to prepare. Somebody else it might take 10 or 15 minutes. Depending on the person you're supporting it might take anywhere from a few minutes to hours or to a couple weeks to prepare for something. I think that is a big issue that they don't get: how much time it takes to support someone who has more disability to understand things. The more severity of the disability the longer it is going to take.

Caldwell: To go back to the disability identity thing. Sometimes a lot of people with disabilities I think feel ashamed of having a disability or ashamed of who

they are. Having a lot of issues like not having self esteem or feeling bad about themselves... Do you think that the self-advocacy movement helps people to feel more proud of who they are?

Nelis: I think one of the things that the self-advocacy movement does is to be accepted for who you are. It doesn't look into disability. It looks at the person. You are not called "consumer" and you are not called "client." You are called by your name. And you get at the level you are at. And I think that is really cool thing about the self-advocacy movement, people accept you for who you are and they support each other in learning how to work with all kinds of people. Not a lot of people have worked with someone who uses the ventilator or does something differently, but they are willing to support that person to be part of the group and figure it out. That is one of the cool things about it: they try to figure out how to support the person where they are at. I think that is a huge difference. And a lot of people will say, "Well, how many people with this kind of disability do you have in your organization?" Well, we don't know because we don't look at your disability. We look at the person. And I could tell you some of my friends, but I could not tell you all the people in the self-advocacy movement, because we do not ask. We don't ask you what your disability is. Some of them are obvious but people do not ask.

Caldwell: Do you have to have a disability to be in the self-advocacy movement?

Nelis: Just like any other group, there are some people. I don't think there are a lot of people without. People go to meetings; they are usually open except when they're explaining an issue where people have a personal thing to work on during that time. People may not be welcome to come during that time. I think people work with people who don't have a disability. They come to meetings sometimes. Some groups don't want people without disabilities to be a part of things because of again what has happened before, the trust issue. What are they going to go out there and say after they leave the meeting? Because it has been broken... I think they are scared to accept that. Or are they going to come in and tried to control the meeting?

Caldwell: And it seems like that story you just told about the lady who became disabled and said I finally get it. Somebody without a disability probably doesn't get it, right?

Nelis: Right. There is a shared experience. And people talk about that! They talk about the things that have happened to them. And it is hard to talk about that in front of the stranger who might not understand, or who might think it is stupid, or might say something in the middle of somebody's story. And it is embarrassing at times too for people who get out and share an emotional story. So people have a hard time with that and the

more trust that is in the room the more people share what they feel, the more secure they feel and sometimes things come out that aren't even related to the topic. Like someone who has been abused. Things that are happening that are bad.

Caldwell: But when I listen to you talk about it, it sounds similar. You know, Carol Gill has done a lot of research on disability identity and it sounds very similar to what she has the except for you have a real issue around the last stage, kind of coming out and saying I am disabled am proud. It sounds like that is really where the issue is?

Nelis: I think people can say they are disabled and probably they can say the label that they are proud of, but I think that is the issue. I don't think too many people would have a problem saying I have a disability and I am proud –except if you do not admit that you have a disability. It is the label that is the disability, the label that people identify as. So I think people would have an issue saying, "I am a behavior and I am and proud' or "I am mentally retarded and I am proud." The stigma of that label is what people would have an issue with. I don't think they would have an issue with saying I have a disability and I'm proud. Some people... Some people who do not admit that they have a disability would have a hard time saying "I have a disability and I'm proud." I think in the self-advocacy movement you have people who would be willing to stand up and say "I have a disability and I'm proud." I just think the label, the stigma behind the label, is the issue. I think they would have a problem with saying what their label was. That is where it gets into the... Because that is how people are viewed.

Caldwell: I think you are right. I think you are really on to something because there is the difference with the label. And the label itself is really the disability?

Nelis: Right. And how people accept you after you have said it. If you say I have a disability and I'm proud, it is not going to get you a lot of bad stuff. But if you set it the other way, what new label is and you're proud, that is where all the stigmatism comes in. I also think that many groups are working to get rid of the label. And it is happening in more and more states now. Another big thing that people are working on is getting their department of mental health to change the name from mental retardation. Many different states are now changing the name and it is because People First groups are working on that in making it happen. Connecticut just got their name changed. There is no longer a MR word in their name. A lot of self-advocacy groups are trying to get rid of the MR word in organizations and in their departments of mental health. And it is working! It is a huge issue that people are working on.

Caldwell: So how do people realize then that they might have a disability or might have an impairment and separate that from the label, which is something else?

Nelis: I think one of the best things you can do to give people self esteem, is telling they are a very good person, no matter what –teaching them about that. And it starts when you're really small. It is really hopeful that you tell your kids that they are a very good person, that they are great looking, and it doesn't matter –because you love them and care about them the same way no matter what. It starts very young. And if a person at that young age has enough self esteem it helps them through the rest of their life. I am not saying it is going to be perfect and they're not going to be upset about something, but that self esteem is a huge issue.

Caldwell: How does the self-advocacy movement help people in terms of self esteem or pride?

Nelis: I think it is about celebrating people for people. People are always telling people after stuff is done what a great job they did –pointing out people's best things about them. It is always good when people say the things that are nice. We work on the *Seven Habits* and there is a thing called an emotional bank account. It is now actually talked about as an emotional relationship account. What can you do to tell someone something good about them? They go home and it is like a check. What are you going to do for someone? You have to make sure it is really for the person – something to make them happy and not to make you happy. And it could be anything from telling them that they have this wonderful great smile or have done something. And I think it is really cool. People need to complement each other and support each other. It is the strongest support that you can have. It is the bonding of friendships that you make –giving people the courage to speak out. People helping people and supporting each other is what really makes it strong. That gives people the courage because if they see people with the same kinds of disabilities –it makes it easier for you to try to on your own, to try it, or to take a risk. Another thing we do is something called “open mic.” It gives people a chance to get out in front of everybody and say anything they want. And by the time “open mic” happens, by the end, people are up there doing anything from saying their name, which may not be a lot to some people but if they have never had the courage to get up and speak before and they just said the name that is a huge issue! That gave them the courage to do something on their own! Anywhere from that to poetry, to music, to jokes –it is an opportunity for people to say anything they want and they see their friends doing it and they want to do. Practice in giving people opportunities to go see things and to be a part of things.

- Caldwell: So just to go back to this... The last stage of disability identity in the independent living movement is when people come out and say I am disabled and proud, what do you think the last stage is for people in the self-advocacy? What do they say or what do they reach?
- Nelis: Leadership. People are learning something all the time and there's always something different coming out. I think being a leader at the national movement, being on the national board, is a really big thing for people to be proud of because that is a really big thing. You have done local stuff and the state staff and now you are at the national level, I think that is what people in the self-advocacy movement build up to.
- Caldwell: What does that mean at the national level?
- Nelis: That is sort of like everybody in the movement has supported you to be on the national organization. They trust you enough to be part of the national organization to make things happen for people with disabilities at the national level. I also think it is a new area and experience for people. You can be a leader that a smaller level but as your leadership skills build it is more responsibility. Not everybody wants to go to the national level, they want to do things in their own area and you can have leadership skills and that. But there are some people who want to go national and even international, all of it at the same time. But I think being part of the national organization, people see that as sort of like you have made it.
- Caldwell: Let me ask a couple more questions and then I want to get back to leadership. How do you think being a person with a disability has influenced who you are today? How it has formed to you are as a person?
- Nelis: Well, I think you learn a lot of skills. I think it helps you grow to grow and learn about speaking out. I think there is a lot of prejudice in the world that you wouldn't know about until you have actually been through it. And learning about working with people in accepting all kinds of people has helped people grow. For me, I think you look at things differently from trying to help support somebody or who people are than some of society – for accepting people where they are at. It is a different way of looking than if you didn't have that prejudiced against you.
- Caldwell: Right. That is exactly what I was asking, some of the positive experiences of being a person with a disability and what it teaches you.
- Nelis: I think that that is a huge experience. And the experience of having been to many places and learning and you thought it was really bad, but how lucky you really are. I mean seeing different countries in different places. And you thought where you were was bad. Growing as a person and just having the experience of all different nationalities and people. In the

professional way, I think that people have learned that we can learn from each other. People helping people –not so much as them saying, “We can let them do some of these things but not all of these things.” Many people are getting involved in things, are changing the world, and it is not only in disability, it is in the culture altogether.

Caldwell: How do you think being in the self-advocacy movement has influenced who you are?

Nelis: I think it has. I talked a lot about people learning about trust and relationships and speaking out. As I told you earlier, I didn't do a lot of speaking out and didn't trust a lot of people –seeing people as authority figures. And expressing what you want and what your dreams are. I think the self-advocacy movement helps you being part of that. It helps you when things are not good, things that happen. There are people you can talk to, people out there who believe in what you are doing. It gives you a lot of role models. Young kids today are going to have a lot more role models than we did. When we were first starting the movement, there wasn't too many role models to look after.

Caldwell: Well, that was the one of my questions. Did you have any role models when you were becoming who you are? People you looked up to?

Nelis: I don't think a lot and the self-advocacy movement. I think Leigh Ann and Cathy Terrell –how they interacted with people and how they treated people. I think a lot of people, when we were starting, looked up to role models who were people in that kind of way, rather than other self-advocacy. I don't think there were many other self advocates. They were just learning themselves and doing things.

Caldwell: And what you saw in them was how they helped other people?

Nelis: I think how they respected people with disabilities, how they talked to people, how they interacted with people. All they shared and supported and did all kinds of things and it wasn't just during the support group it was outside. It was more than just supporting somebody in the group: learning that you support them as much as they support you. How that works in partnerships and relationships –the things that they teach you. Helping you grow and opportunities that other people didn't give you. Like the opportunity to be on the planning council; to be part of the planning council not just the committees that are formed, but the committees that made big decisions. Being the Illinois representative, going with the chair of the planning council, going to the national planning council meeting –those kinds of opportunities that help build your leadership skills. Support you when you are doing those kinds of things. Those are the kinds of people we had it that time. And I would also say Nancy when she came, but she

was living in Nebraska. Because she helped to start our group so we've looked up to her. For me it was Leigh Ann and Cathy. They gave me skills in a way that wasn't disrespectful, teaching you things if you messed up.

Caldwell: And now probably a lot of people look up to you as a role model? Younger self-advocates?

Nelis: Yeah! It is huge pressure. It is really cool when you hear it but then you are like oh my god. People are like okay you are the leader now. And the other part is that people don't expect that you need supports anymore because you are supposed to be the leader. And it is really hard to say, "Wait, don't forget me, I am drowning."

Caldwell: And are there people there you have really mentored? Or brought along?

Nelis: I think there are some and it is really cool to her that they you've done something to make a difference. That is what makes the job that I have the most awesome job that you can have because you are able to pass on your skills, your leadership stuff to somebody else. The first time you hear that people have done something for the first time and you have something to do with that it is a really awesome feeling. You helped that person speak out and stand up to somebody, done something that they wouldn't have done before. That is really cool. It is a really good feeling. It is a little embarrassing in a way to sit there and talk about all this stuff. When you are a leader you are always thinking about, "Did I do a good enough job?" You are always questioning if you did a good enough job. Do people think you are a great leader? Or just because you are a leader now doesn't mean you don't need supports. That is always the hard thing to pass along to people. People think because you have all these great skills things come easy for you. But they don't understand where you came from. How you had to work so hard to get those skills; how you had to do all those things before those things happened for you. How you still may need support even though you can do many more things. That is how having the leadership academy can help people in an advanced leadership role. Because you have been through all those things in now you are going on to new other experiences and how are you going to cope with that now?

Caldwell: People use the word leadership in a lot of different ways and it means different things to different people. What would you say leadership means to you?

Nelis: I think leadership means somebody that you can trust. The person you can look up to. It is a role model for other people. I think a leader knows how to run a group. Include other people in the conversation and

hopefully not be so stuck on themselves. A lot of times that happens when you're a leader because you get all these opportunities. People can drag you into things and you forget where you came from. One of the things you need to learn about being a leader is that you need to step down and let somebody else take on that experience. And that is a really hard thing to do, especially if you didn't have many opportunities in your life before. It is a hard thing to give off because then you think they won't ask you again to do things and you think you will be forgotten about. I think that is what people are afraid of. They don't want to be forgotten about and they don't want to be a "somebody else." So that is really hard.

Caldwell: In other big question I want to get out is how self advocates approach leadership and think about leadership and whether that might be different than how other people think about leadership. A couple things you said about needing supports, that it is okay to need supports, and the other thing you just said about passing on leadership to other people. I think those are two key things. Would you agree?

Nelis: I think they are the two key things that are really hard. I also think when you become a leader to not be so stuck on yourself let it go to your head. I think that is one of the things that I also admire Leigh Ann about. She does it so well, not letting you get a big head –slapping you down in a nice way. I think that is important to learn that kind of stuff. I mean everybody still gets that way sometimes.

Caldwell: But do you think that is especially important in the self advocacy movement?

Nelis: I think it is because those opportunities don't come often for people with disabilities, to have those kind of big leadership experiences all the time. So it can get to you because you don't have those things all the time. If you have never been asked to do things and people start listening to you, it is hard to give up. It is hard to say, "Okay, let's give someone else a chance," because you haven't had that before. So it is hard. People have not had those opportunities before. It is not as though you are giving it up. You are moving on to new things, but it is hard if you don't have new things to move on to. So, there has to be something out there. One of the other things is to ask, "If the self-advocacy movement were to go away tomorrow, what would you do with your life? Tell people to think about your life beyond the self-advocacy movement. That is a really important thing to do because some people base on that: "It is my whole life." What if it did go away what would you do? So you have to have things beyond the self-advocacy movement, not just the self-advocacy movement in your life. So, people need more experiences beyond disability things.

Caldwell: Do you think there are any other differences between how self advocates might view leadership and what other people have said about leadership?

Nelis: I think there are some things that are similar. People are learning how to build a career and the struggles they go through. It is the same with anybody else I think. I just think it is a little more difficult because you already have a strike against you and you feel like you have to prove yourself more than if you didn't have a disability in so many things you are asked to do. People with disabilities are looked at and observed more when they are asked to do projects that are big, or on a review team that is reviewing things. People will get you more. It is more pressure than if you didn't have a disability, I think. They are always watching what you do, especially if you are the first group of people who are a part of something. You always feel that pressure, that you have to do better, and if you don't do better will they ask people with disabilities to be a part of that again. Or did you mess it up for the rest of the people? That is huge pressure. They are always looking at you and you have to do four steps ahead. That is a lot of pressure on you. You have to do more than somebody else because they are looking for you to fail. There are some projects where they come right out and say, "We don't think you can do this."

Caldwell: Is there anything else you want to add on that?

Nelis: I don't know if there's anything more differently. It is how people view different leadership skills differently in a person with and without a disability. I think you have to work hard in proving that you can be a leader and proving that you can do some of the things they're asking you to do before people start realizing that you are a good leader and ask you to be a part of things.

Caldwell: So when you look back about how you developed your leadership skills, you mentioned some things like the opportunities you had on the DD Council and your work at the YMCA and all that. What are some of the other things that helped you pick up your leadership skills?

Nelis: I think presentations, learning about speaking and making presentations. You know, developing those kind of skills.

Caldwell: And where did you get that from?

Nelis: The self-advocacy movement. We went out and did presentations. That is basically the first year. We did all kinds of presentations everywhere. So, the opportunity to give a presentation; where it went from interacting with Leigh Ann, where she would sit with us, and just doing a 15 minute presentation was a big issue for us. Fifteen minutes seemed like a lifetime

of talking. Compared to now when we can do two to three hours of presentations, workshops, getting up there and giving keynotes for other people don't show up.

Caldwell: What about all the stuff you did with Essie on boards and committees, developing those skills?

Nelis: Yeah, learning about the boards, learning how to be part of a board. Getting opportunities to be on boards and committees and then teaching other people how to form their groups and be on boards: how to develop an agenda; things to look for; things that could happen.

Caldwell: And the Covey stuff that you did. What drew you to the Covey stuff? What is it about that that you think really works?

Nelis: I think that the *Seven Habits* teaches you leadership skills and also about relationships and how to organize things around relationships instead of the clock. A lot of people are always saying they're working and they don't have time. It makes you have time for the things that are important in your life. It makes you think about that. And the eighth habit is sort of on self advocacy almost. Now he has come out with the habit and it sort of talks about advocacy in a way. So, I think that that is really good. And it actually helped a self advocacy group get their funding after they went through the *Seven Habits* and talked about it, they told a director that he had a paradigm shift. And he was surprised that they even knew that word and used it in an appropriate way. A lot of people have gone through their mission and their dreams. It helps you build a mission statement for your life, what you want to do in your life. And hopefully if we get to do a leadership institute we are going to do a career. People are not only going to have a mission in their personal life but a career mission to go a long that. So by the time they will leave they will have a mission statement, but career mission, leadership skills. And what do you do if you get a new job in state and out of state, what are some of the skills that you will need in how to build a resume and do interviews. And you talk about some of that hard leadership stuff that people go through, and what it is like to work at a university or a Protection and Advocacy, and how different it is from working somewhere else.

Caldwell: So with that leadership institute that would be for people who are already advanced leaders? What about for younger people? What kinds of things would you like to see for them to develop skills?

Nelis: I think some of the same things: employment; support; self esteem; learning the advocacy movement can be a part of that; the history of everything. The reason I am doing an advanced leadership institute is because now more and more people are on a national level and some are

getting those kind of jobs out there. That is who people are hiring now. I have seen too many of my friends not think about some of those things before they take a job in really become miserable after they take a job.

Caldwell: So your leadership institute would really be for people who are leaders in the field now a preparing them to take jobs and do other things?

Nelis: Well, they are already in jobs, some of them. Some people might be thinking about taking a job out of state. What do you need to be prepared up if you are thinking of that? People don't even think about: Oh, I might not have the same kind of supports I have learned was or what is it going to look like after work. What's it going to look like after work? If I totally get up and move away what is it going to be like? Do I have to start all over again? Are there going to be supports in place? Are you going to help me get to know my community? Things that people don't even think about until they get there and then it is too late and then they'd get depressed, some people even suicidal. I have already seen this now with people who are great leaders but went somewhere else without having the supports in place.

Caldwell: For younger leaders what sort of things would you like to see? Before you had mentioned internships? What sort of things could help them build skills just to get to that first level of leadership?

Nelis: I think opportunities. Including them on boards and committees that are making choices about people's lives. I also think other people could help by teaching them how to make an agenda and run a meeting. People with and without disabilities can learn from those kind of things.

Caldwell: I want to go back to a couple other things about relationships. You already talked about some of the people, but when you look back, who do you think was the best support to you throughout your life?

Nelis: I think friends. Just having relationships. In the self-advocacy movement, definitely Leigh Ann! All the things that she had taught us, the respect and relationships. Even when there were people who worked for us that turned out not to, she was always there for us –always supportive and teaching us things we needed to learn how to do on our own. And telling us when you know, you got a big head to knock you down and think about things in a respectful way. For me, I think that was an important person. Also, teaching you that you support them as much as they support you. Her saying that you have a responsibility and that you support as much as I support you. Being out there for us all the time and not expecting us to worship her. She was always there for us. Things that she has done, she has never said, "I did all this for them." She is not like that. She has really been there for people. And Cathy, Cathy has always been a part of things

for the group and I think that really helped the group believe in the self-advocacy movement. But for me, I think Leanne has always supported me and been there.

Caldwell: These are a couple very broad general questions. So you can answer them however you want. What beliefs do you think guide your life? Are there certain beliefs that you have, or sayings, things that guide your life?

Nelis: I always say, "If it is not fun we won't do it." I just think you need to have fun. You need to have friends in people in your life, relationships. It shouldn't be all work. There is a time for work and there's a time for play and you need both. And if I am working with the self-advocacy group for other people with disabilities in a supporting role I will say, "If you are going to hire me to support a group or start a self advocacy groups there may be a time when people do some things that you don't like, but I am going to tell you now before you have the sign the contract that I am going to be on the side of people with disabilities and support them! So think about if you want to hire me before we get into this!"

Caldwell: So you have sort of learned?

Nelis: I have learned ahead of time that I am going to be on the side of the people. If I'm going to support people then I'm there to support the people! If that is what you are hiring me to do actually, then that is what I'm going to do.

Caldwell: Are there any lessons do you think you have learned in life when you look back? Are there any lessons that you want to pass on to other people?

Nelis: The self advocacy movement is great! The self advocacy movement can sometimes suck! It also can be fun! It also can be emotional! But it is an experience that you will want a trade for anything! At times it can be a lot of happiness and at times it can be a lot of sadness, scary. But once it is a part of your life you never want to give it away.

Caldwell: That's good! Just in terms of your personal goals for the future, I know you really want to do your leadership Institute. Are there any other goals you have? Where do you want to be in the next five to ten years?

Nelis: I would like to do something new in the advocacy movement. My leadership institute is totally new, which would be an awesome thing. It would be a challenge to keep getting funding for, but it would also be something totally new to take responsibility for. An internship at some place like ADD, the Administration on Developmental Disabilities. Something like that to get that kind of experience. There are also a couple places I would think about moving to, so that would be a whole new

experience for me to move to another state. But I would like to move to another state because I think I need a change. Fifteen years at one place, not that they haven't been great years, but I need a new challenge. Hopefully it is going to be Georgia. It would be working for a Protection and Advocacy which would be to whole new atmosphere in the things that they do –some the same, but some different. Yeah, there are certain places that I would consider.

Caldwell: It is in line with what you were talking about making sure supports are there.

Nelis: It is a really big issue. Supports need to be there and set up ahead of time. Who is going to help you with all that stuff and who's going to help you after the job is done at night? Do you know more than one person in that area in that state?

Caldwell: I think we covered most everything that we want to cover right now. Is there anything else you wanted to bring up or talk about in terms of developing leadership skills, and the meaning of self advocacy, the meaning of leadership, anything that we really didn't get into?

Nelis: I think that the more opportunities that you have in learning the more stronger you build your leadership skills. The more chances you take the stronger you become so I think those are important things to do and hopefully you find opportunities to go to presentations to hear people speak in the movement. If you have an opportunity to travel, go to other places. You always learn something new in different places you go to.

Caldwell: We didn't even get to talk about all the countries you have been to and places you have gone to and helped with the self-advocacy movement and the movement internationally. You have been to a lot of countries.

Nelis: Yeah, those are great opportunities. Not everybody gets those opportunities. I have just been lucky to be able to travel and do some of those things. There are so many groups out there in other countries that are just starting that you can be a part of. I know Chester is helping a group from Africa. Of course they have money to help the group from Africa.

Caldwell: And you guys helped the group from Kosovo? What was that like going there and working with them?

Nelis: Yeah, we helped the group from Kosovo. It was a brand new group and they had parents and people with disabilities together and some professionals working on helping them get started. They are brand new and some of their wishes are having their sons and daughters come to

America. Get the opportunity in America because there is not a lot of opportunity there. The institution –just seeing people that could be living in the community and don't even need to be in the place... And seeing the work that they do there, making beautiful blankets and sweaters and knitting, and beautiful things, and then someone coming over in taking it apart and doing it over again just kills me. Beautiful things that could be sitting on a shelf. People could be buying those things! I talked to the director and said, “Are you sending anybody to our presentation, mine and Chester's?” He said, “Well, my staff are coming.” And I said, “What about the new friends we made? Are any of them coming?” “Oh,” he said he could send some people. But they didn't come right away. The people there were like, “What should we do?” He didn't send anybody from the institution. They didn't know what to do. I said, “Get him on the phone!” He said he was sending my new friends! She called him and said, “Can I quote you?” And I said, “Yeah!” I said, “You told me you were sending somebody!” They came in the afternoon and that was really cool. They got to spend a whole afternoon out of the institution. It was really awesome! They probably would've never had that opportunity if we didn't call them and bug them. If I didn't make a call and fought them they probably would have not sent anybody. But for that afternoon, somebody got out. It is a long way to go, but for an afternoon people got out and hopefully their staff started to learn how to treat people with disabilities – about treating people with respect more. And I'm sure it is just as hard for them because they're in a country that does not have a lot of money, in helping people get what they want and what they need. So yeah we gave them money. I gave them money –from me. I didn't have as much as the self-advocacy movement from New York had, but I did give them some money to help them start their group because that is what they need. They got supports; they need money. Ne per Ne. Speaking Up for Ourselves –that is what their group is called in English.