Oral History Usage Guidelines

Oral history is a method of collecting historical information through recorded interviews between a narrator with firsthand knowledge of historically significant events and a well-informed interviewer, with the goal of preserving substantive additions to the historical record. Because it is primary material, oral history is not intended to present the final, verified, or complete narrative of events. It is a spoken account. It reflects personal opinion offered by the interviewee in response to questioning, and as such it is partisan, deeply involved, and irreplaceable.

Acknowledgement

Development of this oral history was supported through the Mary E. Switzer Research Fellowship program, under a grant from the Department of Education, NIDRR grant number HF133F070013. Contents do not represent the policy of the Department of Education or endorsement by the Federal Government.

Permission to Quote Requests

All literary rights in the manuscript, including the right to publish, are reserved by the interviewer and interviewee. Quotation from this oral history interview transcript is allowed without explicit permission if it falls within standards established for fair use of copyright materials. Permission to quote must be applied for in writing.

Requests for permission to publish should be addressed in writing to:

Joe Caldwell
Adjunct Research Assistant Professor
Department of Disability and Human Development (MC 626)
University of Illinois at Chicago
Jcaldw3@uic.edu
selfadvocacyhistory@gmail.com

List material to be published and how the material is to be used, including:

a. Type of publication
b. Proposed title
c. Publisher’s name
d. Expected date of publication
e. Nature of publication, e.g., scholarly, commercial
Nancy Ward

2/13/2008
10:00 AM – 1:00 PM
Oklahoma City, OK

2/14/2008
9:30AM – 10:30AM
Fayetteville, AR
Caldwell: So, the first set of questions are really to go back and talk about your early childhood and early school, some of your memories of that. The first thing is do you mind sharing how old you are now?

Ward: No, I don’t mind. I am 57.

Caldwell: And where were you born?

Ward: Lincoln, Nebraska. So I am a diehard Cornhusker!

Caldwell: Did you grow up in Nebraska?

Ward: The first 46 years and then the last ten have been here.

Caldwell: What memories do you have of your childhood?

Ward: Well, one of the very first memories I have is, because I was the oldest, I always thought I was supposed to teach my brothers and sisters how to tell time, how to read, how to ride a bike, how to tie their shoes, all that kind of stuff – and they taught me, except for my youngest brother who is twelve years younger than me. And that was hard for me to deal with because that was not my idea of how the role should go. Then when I became old enough to go to school, we were in a regular classroom because they did not have special ed when I went to school, they taught us phonics. I think phone and pharmacy should start with an “F!” But it did help me learn how to enunciate my words and to speak better, but the thing I didn’t like about it was that it segregated me. The kids knew that I was doing something different, and I didn’t like that. Then when we would do sports, people did not want to pick me because they didn’t think I could do them. Then one of the people who was in my class, we would play kickball every night, then he could see I could do stuff. Then they started slowly, slowly letting me play and be on the team, but that took a lot of time. Finally, I was able to do it all the time.

Then one day some people made fun of me, and that really hurt, and so I got mad. When you are a kid you don’t know that you are supposed to educate people about that – because our biggest barrier is the fact that people do not understand people with disabilities, so the ignorance and fear. But when you are a kid, you don’t understand that, so I got mad. And what does that say to them? That I do have a disability because I am acting out.
When I was in sixth grade somebody from the principal’s office came to my class and told me that I was going to have to go see the principal. And all the way down there I am trying to figure out, “What did I do?” Because if you are going to the Principal, you obviously had to have done something wrong. So I am trying to figure this out all the way down the stairs and to her office. I never did. So I am sitting there waiting for her to talk to me, and she asked me if I knew what special ed was when I got in there. I told her, no, I didn’t. So she explained it to me. She told me that that was what I was going to do when I was in junior and senior high. This really hurt me, because I thought that was something that should have come from my parents. But talking to my parents about my disability is really hard for them, because they blame themselves, even though I don’t. I have told them numerous times, and they have seen it, it is my disability that has given me the opportunities that I have had. I wouldn’t be doing this, for example, if it wasn’t for the fact that I have a disability. I wouldn’t have gotten a lot of the awards that I got unless I had a disability. So, I think it is very cool that I have learned how to deal with the fact of having a disability and that is just part of my life. I wish my parents would be able to do that, so that they didn’t have to feel guilty –because that really bothers me that they have to feel guilty.

So, then in junior high everything went well. I had a teacher who believed in me and he helped me get into some regular classes. So I did some special ed and some regular classes. That went really good. But the thing that was hard was that being in special ed, even though it is in the same school building, it still is in its own wing, so people know. So we went from being called “retarded” to being called “dumb.” People that talk about “sticks and stones may break your bones, but words will never hurt you,” don’t know what they are talking about! Because words do hurt. They hurt a lot! In fact, sometimes I think they can hurt worse. So, it really bothered me a lot that we were segregated and I didn’t understand why. Then when I was in senior high is where I started having problems. We had a grading system of one through seven, and three was average. The highest we could get was a four! Where does four come to seven? Below it. So what does that tell us?

Caldwell: That is the highest that kids in special ed could get?

Ward: No, three is the average. So, we couldn’t even be average because we were in special ed. So, yea we could get a seven because that is unsatisfactory. So, one, two, three was good and four and under was bad.
That really made me mad. Because no matter how hard we tried we could not change that. My counselor, the head of the Special Ed Department, my friend had her planning period the same time I had study hall, so I asked her if I could come in and write a report I needed to get done. She also had the only set on encyclopedias. So I am sitting there writing my report and this kid comes in. He brought a film for my teacher’s next class. He goes, “Well, you have a small class.” And my teacher goes, “Well, it is not small if you would understand what I teach.” The kid goes, “What’s that?” My teacher goes, “Well, mentally retarded kids.” That is the first time anybody ever told me that people saw me as being “mentally retarded.”

So, ever since I have been a little kid I have loved being with people and interacting with people. So, I went and took an exam to pass a nursing test because that is what I thought I wanted to do. I don’t know if you have ever taken a test and not studied for it, but that gives you an idea of how I did. Then you put on top of that that I didn’t know calculus; I didn’t know algebra; I didn’t know chemistry. I didn’t know have the stuff that was on the test, because they put us in this little box! Even if we could go beyond that little box, they wouldn’t let us. Because we weren’t supposed to know what was good for us. So what I did was I went and talked to the counselor about what I needed to do to get my grades up. So that took me five years to take the classes I needed to take the entrance exam again. So I took the entrance exam again. You had to have a 40 to get in and I got a 39. I about died. I went back to the counselor and asked him what I needed to do to get my grades up.

I had told them from the beginning of this that I graduated from special ed. What they told me was that since I graduated from special ed, I was going to have to get my GED even after graduating high school because what they gave us wasn’t a diploma. I called the school board and asked them if they were still doing that with kids because I didn’t think that was fair. I didn’t think we should be treated any differently. If we can do the work then why should we not get the diploma? The thing that I liked about getting the GED was that you also had to have a 40 for that. The lowest I got was a 49 and the highest I got was a 62. I must have studied because it was in my worst subject, which was science, to get the 62. So that gave me an average of like 60.5; it was above normal. This is an example of advocacy, but it is an example of bad advocacy —so you shouldn’t do this—but I took my GED diploma and I went back to all the people who had
told me “no,” that I wouldn’t be able to do this. I pushed it in their face and said, “Yes, I can!”

I got a job working at Goodwill. To understand this story you have to understand that the shop I worked at is separate from the main building downtown. My boss became ill and she would go to the doctors; when she was gone I would supervise the contract we did. What we did was the mailings for the Cushman golf carts. So eventually it got so bad that she had to quit. No matter how hard staff tried to convince me that I could be the supervisor, I didn’t see it! Even though I was doing it, I didn’t believe it, because when you are in a segregated setting, people don’t tend to believe in you. So, you need to be in places where you can show people all the different things that you can do. Eventually people convinced me that I should at least go down to the main building to fill out an application, because what would that hurt? So I did. I went down to the main building to fill out an application and they wouldn’t even let me fill out the application because I was a sheltered workshop employee.

Well, this made me very angry, but I went back to work. A couple weeks later, staff and I were standing around talking and there was a new staff. It turned out to be the new supervisor. A little while later the new supervisor and I were talking. Then a little while later the other staff people came back and one of the staff explained to me that I was going to train the new supervisor. Now you explain to me: If I can train the supervisor then why couldn’t I be the supervisor in the first place. So this made me very angry! So, I quit and I got my own job! That is an example of how advocacy can work for you.

Caldwell: Where did you get your next job?

Ward: I worked for Region Five. Nebraska is divided into six different regions for the services of people. So, I worked for Region Five. What I was supposed to do was teach people how to advocate for themselves. So, I am trying to get people to speak up and they won’t speak up because the two people that were teaching them were the boss of the region and the assistant director of the region. Now, would you tell your boss, honestly, what you felt about the service system. So, they figured out that they should hire me to help them learn how to advocate for themselves. I loved having that power because what I wanted to do was to help them shut down the workshops. I thought that would be a good thing to do, given my previous experience. So, I am trying to get them to speak out for
themselves. Nothing. Trying to get them to speak out for themselves. Still nothing. So I am asking them to speak out for themselves again. Finally, this guy, let's say his name is John, raises his hand and says, “You know Nancy, staff can have their coffee break at anytime and we have to have a set time for our coffee break.” So the staff could take their coffee break all day, but the people they worked with had a fifteen minute coffee break. He wanted to know why. I go, “Well, gee John, that is a good question. I don’t know the answer to that, but I will find out for you.” Then a little while later he raises his hand again and he goes, “You know what else Nancy? Staff can also take their coffee out on the work floor. And I don’t see how that is fair either, because we cannot take our coffee out on the work floor. So why should staff?” So I said, “Gee John, that is a good question too. So I will ask for you and I will find out the answer.”

So what I did was I went and I asked the director. She told me to see if it was an issue for any of the other people. So I do. Region Five serves sixteen counties. They have seven different areas in those sixteen counties. It was an issue for four of the seven. So I asked them, “Okay, you guys, you are upset about it, what do you want to do about it?” They said, “Well, we want to talk to staff about it.” So I went to each of the four places it was an issue and helped them talk to staff. You know, in all of the four places, they said they didn’t even realize they were treating people differently –because that is just what happens when you are in a segregated setting. So now if you look at Region Five policy and procedure manual it will say that staff will have a set time and place for their coffee break. So they got it put in the procedure manual. That is another example of how advocating for yourself can work.

The next story is about one of my friends, let's say her name is Jane. She lives next door to Ann. I work for Jane on the weekends. So Jane, Ann, and I do a lot of stuff because we are friends. So Jane and I go knock on the door and there is no answer. So we start pounding on the door and there still is no answer. So I start pounding on the door really loud and there is still no answer. We went and we called 911 and they came. Them breaking down the door didn’t even revive Ann’s attendant. I don’t have a problem with people going out on a Friday night and having fun. That is everybody’s right to do that, but you also have to be responsible. Ann got left in bed for fourteen hours. So you know what her bed looked like and what she looked like after fourteen hours. In Nebraska you can hire and fire your own attendants and that is true here too. So she fired
her attendant and I went with her. She got a service dog so now she has somebody who can give her unconditional love and does not talk back to her. Spy will take her shoes and socks off. He can push the elevator buttons. The apartment complex already lowered the stove and stuff, but they even lowered it more. So Spy helps her cook. Like I said, she now has a friend that will give her unconditional love and not talk back.

Caldwell: Was that part of your position or job in Nebraska or was that just your friend you were helping out?

Ward: That was just my friend.

Caldwell: Let’s go back and just to talk about your early experiences in childhood. Can you talk a little more about your family? You mentioned you had a bunch of brothers and sisters who are younger than you. You also talked a little about your parents, but could you talk more about your family when you were growing up?

Ward: When I was growing up, it would get to me because my brothers and sisters did not want to do things with me. I would want to do stuff that wasn’t necessarily age appropriate. I love sports, so that is what I did every day, when I could get invited in. When I could not get invited in, I would read. I belonged to the Scholastic Book Club, then finally my parents told me I had to go to the library because I had so many books. Even in high school, with the grading system I couldn’t get the grades that my brothers and sister got. That always bugged me because they got praise for that. When my sister and I were old enough that always used to bug me –because I am seven years older than my sister –that she could stay out later than I could. I had to be home by midnight. That bothered me a lot. It bothered me a lot that my brother who is closest would always make fun of me. That bothered me a lot. When I started advocating for myself...

One of the things that is really important to me –for any advocacy organization or person for that matter –I think it is really important that they accept the fact that they have a disability. Because until you accept the fact that you have a disability, you are not going to be able to get the confidence to advocate for yourself. You are always going to see yourself as this “poor disabled person.” In order to get the confidence in myself, it took me five years to do that. People First of Nebraska started in 1975 and we had our first conference in 1980. I didn’t have any role models so
it took me five years to learn how to speak out for myself. I think it is real important and what I want to do anyway is to not help people not have to have it take that five years so we can have more self advocates and have more people advocating for themselves and getting what they need and want. Family may think that they know what we need and want but they have not walked in our shoes so they can’t really because they don’t know what it is like for us. In some cases, family can be the cause of being kept down. So, I would like to see where people would be able to gain the confidence in themselves to be able to advocate for themselves a lot faster.

Caldwell: I really want to come back to something you have said a couple times, accepting the fact that you have a disability and making that part of your identity. To do that, you said, it took you five years. That is one thing in this project I really want to get into and it seems like you are there and you have some experience there you want to talk about and share. Some people are not that open about that. Maybe they don’t want to accept that they have a disability. Could you talk more about that process? You said it took you five years, what is that process like?

Ward: For me, it was like a light bulb going on, sort to speak. Once I figured out that, “Yeah, I do have a disability,” but I am still a person, I am still Nancy. So, that part is not different, but the part that is different is the fact that I have a disability. I now know that in order to help people understand that, you have to do that. Like for example, handicapped parking spaces, people with disabilities would like them to call them accessible parking spaces. Because “handicap,” if you look it up in the dictionary it means cap in hand, so standing on the street corner begging. Do we want people to see us that way? So that is one example. Another example, when you are talking with people with disabilities… I was working with a group of people and we came back from People First doing testimony. So I talked to the seven people I worked with from the service system and I asked them if they wanted to ask their senators –Nebraska is the only state in the country that has a unicameral –about how they felt about their services, what they would like changes, what they think is good. They said they would like to do that. But now if I went in there and asked them if they wanted to talk to the appropriations committee? See, it is a subtle difference. You don’t have to talk baby talk to us but you need to talk in words we are going to understand.
Caldwell: Another thing, sort of about accepting that you have a disability, but you mentioned this about your parents—that they have a negative attitude about disability, versus a positive attitude. So, how did you form your positive disability identity? Do you know what I am saying? Because you seem to be very proud of having a disability and that it is part of who you are, but there are some people who don't feel that way and feel ashamed.

Ward: Because they have been made to feel that way.

Caldwell: Well, could you talk about what sort of things helped you to form a positive image of disability?

Ward: The biggest thing is People First. There was a whole bunch of people who had experiences like me and we supported each other to work though those experiences. That is one of the things that I think is very important about People First. More than likely you are going to have somebody who has had the same experience that you have had. So, you are always going to support you do whatever it is you want to do. You are never going to do it by yourself. That is important to know, for a variety of reasons. I think that is part of it. The other part of it is, you know the saying, “You get more with honey than with anger?” I think by educating people about how people with disabilities want to be treated helps that. Gaining the confidence in myself is what has helped me do that. Because I wouldn’t even have be able to talk to people about having a disability before I saw myself as a person and I was okay with it. So, the people you are talking about have not reached that yet.

And even though people with cognitive disabilities are on the bottom of the disability pile, in the bottom of the disability community, at least we are there. My dream is that we will have everybody with a disability—and that would be like 57 million people—voting on candidates and then we would have a majority and we would have people doing that would do stuff for people with disabilities. Gee, wouldn’t that be neat? It just makes me frustrated. How can we expect people to accept us, when we cannot even accept ourselves. That really bothers me. One of the things that I really think is important on the confidence part. It is just as important for somebody to say their name at a self advocacy meeting as it is for me to be doing this video. It takes just as much confidence.

Caldwell: That is a really good point. Do you see differences between the independent living movement, people with physical disabilities, and the
self-advocacy movement and the process people have to go through to feel proud of their disability?

Ward: You are not going to put who says this, right?

Caldwell: Well, if you don’t want me to. It is a tough issue.

Ward: I will answer. Here is why I say that. I think that in the disability community, I think that people with a cognitive disability are on the bottom of the pecking order. I think that is because people don’t want to catch “mental retardation” because that is the “worst disability.” And I am not saying that, that is not changing. We are starting to have a change because we have been asked to work with different groups. So that is what my previous point was, until people with disabilities can learn to work together then we cannot expect society to see us as a group. That really bothers me because that is where I think we need to be. If you look at the solidarity that the civil right movement had, it was all different kinds of people.

Caldwell: When you talked about forming a positive disability identity, you said how important People First was. So, when did you first get committed to sort of the self-advocacy movement in Nebraska or the national level?

Ward: Why I think it is important to have that experience? I will give you an example. We had a woman who lived in one of the towns in Nebraska. When we first did the conference we talked about rights. We always talked about how people with disabilities should always have rights. Well, she went back to the group home and whenever staff would ask her to set the table or do her laundry or to clean her room, she said, “No, because I have the right to tell you that.” She did have the right, but she was not getting the consequence part. Well, it got so bad that she finally got kicked out of the group home. Then that made her parents mad. Her parents wrote to their senator and wanted the funding for People First taken away. Well, People First is not state funded so that would not happen, but the thing that did happen was that it definitely taught us that we need to talk about our responsibilities along with rights. Because I think that it is real important for people with disabilities—as long as they understand what they are doing—to have the same consequences that anybody else would have.

One of the people who was president of the VOR in Nebraska—they don’t call it VOR in Nebraska but it is the same thing—her son lived in a state
institution and she was glad he lived there. Because when he hit the police officer he would not get in trouble for it. Well, now he is going to keep doing that and keep doing that because he is not getting any consequences. Why would you want to live in that kind of setting? That just made no sense to me.

We had this conference; it was called “Sharing Your Best.” Okay, so you had people coming from all over the world to share their best and guess where they had it? The institution—which was the only place big enough to house people. This organization asked us to present with them and we said that would be no problem, the president and I, as long as people from the institution came to the presentation. Okay, fine. Then it came time to do the presentation and there were no people from the institution. So, I told the people “We are not going to do the presentation because there are no people there.” And they go, “Well, it is a long walk back to Lincoln.” And that freaked Tom out because he didn’t think he was going to have a ride and at that point he was developing his skills. There were a whole bunch of people from Lincoln. We could have got a ride if we would have asked. So what we did was we ended up doing the presentation, but it made for an interesting ride home. So that is why I think it is important to have the confidence in yourself so that you can advocate for yourself.

Caldwell: Where do you think that you got the confidence that you have? When you were in school did you have the confidence?

Ward: No.

Caldwell: So, where do you think it started coming from?

Ward: I think it came from people like—I don’t know if you have heard of her or not—Bonnie Shoutz, originally from Nebraska. David Powell and Rucker. Shirley Dean. I think it came from all of them.

Caldwell: And they were all advisors of People First of Nebraska or were they in other positions?

Ward: Well David and Lynn weren’t. Lynn was my boss and David was the director of the Arc.

Caldwell: Were you working for the state or for the Arc?

Ward: The state.
Caldwell: So those were people that were working with you on advocacy sort of stuff?

Ward: As I developed they kept pushing me so that I would develop more and more. I will give you another example. People First, a long time ago, had “moron,” “idiot,” and “imbecile” in our state statutes. We wanted to get rid of that. We testified but we didn’t know how to write a bill. So we went and asked David and he said we were going to have to ask one of our senators. We are going, “We are going to have to do what?” People see legislators up here. So finally he got us convinced that we should go do that. And the thing I mean about pushing me is that he could have done it for us, but if he didn’t push me then I wouldn’t us everybody else. I wouldn’t have had the same effect if he did it for us. It felt good that we did it. So, we went and talked to the senator and we had to do a compromise, but it is in our state statutes now. It is in Nebraska’s state statutes—“people with mental retardation.” Still hate it, but it is better than “moron,” “idiot,” and “imbecile.” And I don’t know if they have worked on it since I have been there or not.

Caldwell: So, at that point, was People First of Nebraska an organization? Were you involved in starting People First of Nebraska or was that already in place at the time?

Ward: Well, yes and no. People First of Nebraska, the first chapter was in Omaha. It was started by a gentleman named Raymond Loomis. If you look on the wall, there you will see the poster. He wanted to have a support group. It was called Project Two, because the Arc was Project One. That was for the parents and Project Two was for us. So they supported each other and that is how it got started. Then I got involved about three years after they started, right when they started planning the first conference.

Caldwell: So, they were really just starting, within three years. Do you remember the first time you went to a self-advocacy conference or a meeting?

Ward: A self-advocacy conference, I wouldn’t have felt any different, but in a meeting I have.

Caldwell: What was that like?

Ward: I didn’t have the confidence of the professionals. I said some stuff, but it took me a while to get to the point where I would really talk about stuff.
One time I spoke to 500 people from VOR, and that was scary. A lot of
them didn’t like what I had to say. But that was okay, because some of
them did listen. That was good because you were able to change some of
their opinions. I can remember the first award I got. It was from the Arc.
Because of David, I always used to go to the Arc conventions. They were
talking about how to include kids and having a playground. They were
going over, “Well we need to have all these specification so it will be safe.”
And I told them what I thought about that. I said, “Gee, what a concept to
ask you kids about what they want.”

Caldwell: So, can you talk more about some of the key people or relationships you
had in your life when you were young and first started getting involved in
self advocacy. You talked about Bonnie and David. Could you talk some
more about some of the supports you had?

Ward: I worked doing a bunch of different nursing jobs. That is okay, but I didn’t
really like it.

Caldwell: You didn’t like it. I thought that was what you wanted to do?

Ward: Well, I did cleaning. That is what a person with a disability is supposed to
do. Okay, I am being sarcastic. So David encouraged me and
encouraged Lynn to talk about working for her. So then I worked for her
for a while. I volunteered doing the People First stuff for about ten years
and then they finally hired me. So, I did it for seventeen years total and
then ten years here.

Caldwell: So you did it mostly as a volunteer for ten years, and then when they hired
you what position did you take?

Ward: I was the Self Advocacy Coordinator, so I was the first staff person and
the first staff person with a disability.

Caldwell: And that money was from the state?

Ward: Well, when Sue Swenson was DD Commissioner, I went and told her how
our DD Council did not believe in the self advocates. Sue got pissed and
made our DD Council give us money. But hey, you got to advocate for
yourself sometimes.

Caldwell: So you got a grant from your DD Council. That is a whole other thing I
want to come back to –the funding of the self advocacy movement, some
of the issues and things you are working on now. But to go back, what does self advocacy mean to you?

Ward: What self advocacy means to me? My advocacy skills are very important to me because they are what have given me my job. You know the saying, “You can’t have your cake and eat it too.” Well, that is basically what I have because I get paid for doing what I love. What I mean by this is, for example, one of my friends wanted to be secretary for her local People First chapter. Well, she didn’t have the confidence at first but she came and talked to me and said, “Nancy, how do I learn how to speak up? How do I tell people how I feel?” I asked her, “Well, how do you think you do that?” So she talked to me about saying what she was feeling, but it is hard to tell people that if you are all emotional and you don’t know how they are going to respond to it. I go, “Okay, that is true. There is that possibility. So what are you going to do about it?” She said, “Well, would it make sense to explain to people that just because I got secretary it doesn’t mean that there aren’t going to be times that I am going to need help doing something. So maybe you could help me write the notes. I can play the tape recorder and you can write the notes. We can do it together.” So that was the way they worked out their issues.

Other issues aren’t necessarily that easy. One of our members wanted to move out on his own. He had very protective parents. So, instead of having his parents help him and bringing his parents along –say his name was Joe –would just go and do things. Well, that would get him in trouble because he does not necessarily know the concept of money. So he would be signing these things but not having any idea what he was signing. So, then his parents got a guardianship. What we helped them see was that maybe what they should do is get a conservatorship so that you would be able to help them with his money. So after taking him through step-by-step-by-step... You have to educate the person with the disability as well as what the barrier is, which in this case was his parents. Did that make sense?

Caldwell: Yeah. So a lot of it is supporting one another? So, when did you first get involved with the self-advocacy movement in Nebraska?

Ward: 1979

Caldwell: Wow. Then you were involved for seventeen years with them. Were you elected to different offices?
Ward: Yeah, I was all the officers. The chip on my shoulder that I have is that the person who is the staff person of People First of Nebraska is the same person it was ten years ago. It was supposed to be a person with a disability and that has never happened. So there was supposed to be a partnership between the person and a person with a disability and that never happened?

Caldwell: I though you said you were hired as a staff person?

Ward: It was for People First, but when I moved here they hired a person for my job—instead of having it be a person with a disability and having someone support them to be able to do that job. Because I thought I figured out ingenious ways. For example, the person who was president at the time taught me how to go to the newspaper. Because the *World Herald* goes all across the state and I could get rides to all the different chapters. Now I had to deliver newspapers, but I got a ride for nothing.

Caldwell: So then how did you get involved with SABE?

Ward: Well SABE was one of my dreams.

Caldwell: This was when you were at People First of Nebraska?

Ward: Yeah. There was United We Stand. Well, through the Kennedy Foundation there was a group of people who had tried this before.

Caldwell: To start a national organization?

Ward: Yeah, and it didn’t work. So, of course, people were telling us that we couldn’t do it; and that was part of the reason why we were going to do it. We had a dream where we were going to start a national organization so that the right hand would know what the left hand is doing. And we wouldn’t have to reinvent the wheel with all the trainings and presentations that we do. We could just share ideas. So that is what the national organization was started on. We met in Atlanta and then they had a meeting at Estes Park. They didn’t put aside time for us to meet, so we just held our meeting at night and crashed it. That is how the idea for doing a steering committee came about. Each person on the steering committee was given a responsibility. My responsibility was on how to divide the country. People had the responsibility of figuring out how we would do a newsletter, figuring out who we could go to for money, different things. We all had different kinds of jobs. Well, the advisors started taking
over. We got pissed, so we told them they had to leave. That was the first time we ever kicked the advisors out. When they came back in, they were amazed at how much we had got done. Then we became incorporated around 1992-94. That is when we formed the national organization. So we have been a board ever since and it is still going strong. I would like to talk a little bit about the first agenda since we are talking about confidence.

Caldwell: Yeah, go ahead.

Ward: Speaking for Ourselves flew me to Philadelphia, because Mark and Pat were two of the advisors. So, we were sitting at Roland’s apartment trying to figure out how we are going to put this agenda together. So Mark and Pat are asking me all these different kind of questions, and I am like "I don't know! I don't know!" Then I would think about it and, "Well, I want this. And I think it would be a good idea to have a mission statement and what we believe in. I want that to have that be on the agenda." So, once again it took people to push me to get me to do what I knew that I knew how to do. If that makes sense?

Caldwell: Yeah. Say more. You just needed them to push you to give you the confidence to do it?

Ward: Yeah, I knew how to do it. I really did. I just didn’t have the confidence in myself because, you know, a national agenda had never been done before. Then one time we had our meeting at Wingspread, which is where the older Bush had his last meeting. The guy who was there told us that our meetings were better run than the President of the United States because we were able to come together. Even though we disagreed with each other at one point, we were able to all agree at the end because everybody got something. What we were talking about was our campaign called Close the Doors.

Caldwell: What are some of the other stories you have from those days, when you were first starting the national organization.

Ward: Well, one of the most valuable lessons I ever learned was when we had our first meeting. There was this one gentleman who wanted to have money. You have to have money to have an organization. Well, to me you have to have the foundation and you have to have the structure before you even worry about the money. So he was making me frustrated because I couldn’t get him to shut up and I didn’t know how to do this. So,
we had just talked about money. We had just done the treasurer’s report. So I took all the officers and advisors out of the room. When we came back in everybody was all upset because what they thought what was going to happen was I was going to change the decision they had made about the money. There wasn’t the trust there yet. That is an important piece of a self-advocacy organization. It was fine, but until that trust is built. It happens every two years because we change our board every two years. So, what I learned is that it is okay to talk to my advisors and officers if I need to do that, but I don’t need to go outside of the room to do that.

Caldwell: Just to stick on the self-advocacy movement. I guess to get into some of the questions about the future of the movement. Where would you like to see the movement go at the national level or state level?

Ward: I would like to see SABE have its own funding source so we didn’t have to sit around begging for money –and to have an office and staff. Just like I was the first chair, I would like to be the first executive director, because part of what my dream is, is to work in DC.

Caldwell: I think that is important. So maybe it has just taken a while, like you said, you have to get the structure first and then get the funding. So maybe the time has come now for the funding, is what you are saying?

Ward: Yeah. I think I was the right chair to do the structure. I think that Tia did more with advocacy. I think that is what Chester did too. Now, we are definitely doing more because of all the different organizations we are involved with.

Caldwell: I think the funding piece is a key piece. A lot of people don’t understand the lack of funding, that the self-advocacy movement really doesn’t have much money at all.

Ward: Yeah, they are amazed that we are able to do all of this for $50,000.

Caldwell: And where do you get that from now? Is it all from grants?

Ward: Yeah.

Caldwell: So it is soft money too?
Ward: Yeah, that is why we would like to get it to where we knew we were going to have the funding. We have a way we want to do that but we don’t want to make it public yet.

Caldwell: So, some of the things that funding would provide would be, like you said, a national office and an executive director in DC.

Ward: Yeah. Because I think this would be a good organization to get my feet wet to do other things in DC.

Caldwell: Are there other challenges or things you see the self-advocacy movement faces? What are some of the biggest challenges you see that the self-advocacy movement faces?

Ward: Until people with disabilities can accept people with disabilities, nothing is going to change. We cannot ask society to accept us if we cannot accept ourselves. I do think it is changing but I think it is a long way from being there. I don’t think they think about people with cognitive disabilities being on boards and stuff like that because they don’t know how to support us, because you can see how to open a door for somebody who has a physical disability. You know that they have a disability and you will support them that way then, but you can’t tell that I have a disability.

Caldwell: So, are you talking about the larger disability community accepting people with cognitive disabilities or intellectual disabilities?

Ward: Yes, and us accepting the fact that they haven’t accepted us. It goes both ways.

Caldwell: What do you think it is going to take to bring more acceptance?

Ward: Well, ADA was a perfect example where everybody worked together. I don’t know how we could do legislation like that again –unless it would be to get the meat for ADA.

Caldwell: So, you are saying that sometimes something like legislation can bring the whole community together?

Ward: Yes, because that is true with self advocacy. I think there are things I think you need to have. One is that the members have to want it. So, unless they are interested in stuff they are not going to want to do it. The second thing is that the advisor be independent –that they don’t work at a workshop, for example, or group home. We had 60 people, People First
of Nebraska did, in this one town that signed up, so everybody in the agency signed up to come to our conference, but nobody got to come. That was because I got them to talk about how they didn’t like the workshop. And so there way to keep them quiet was. Until we can become a unit we are not going to be strong enough to educate the rest of society.

Caldwell: What else would you say your vision is for the future of the self-advocacy movement? The funding and coming together and being more accepted in the disability community?

Ward: That is part of it, but you know my favorite show is Star Trek. The reason why I like Star Trek is because look at all the differences that are on the Enterprise. They probably have like fifty different groups of people. Well, why can’t we have that? So that is what my dream is: there won’t be any disability. Everybody will be accepted for who they are and then we won’t have to deal with all the other stuff.

Caldwell: You know, on that, other people I have talked to mentioned that the self-advocacy movement sort of accepts everybody, regardless of disability or category. Is it more accepting?

Ward: That is my point, because in the physical disability community, “mental retardation” is at the bottom of the pile. So why would you want to go down? I can understand that. I mean that is self survival. But, okay, so you don’t want to go down, then bring us up! Not that anyone goes down, that we come up to be equals with them.

Caldwell: Do you think there is something different about the self-advocacy movement that is more like that, more accepting of differences?

Ward: Well, the reason why I think that is true is because nobody knows how to deal with us. So, we really do understand prejudice. Because you can ask somebody to support you, like you did with Tia, for example. The person I had support me, I went with one of my other friends to the ticket counter. Got her ready to get on the plane because she uses a wheelchair, so she would have had to pay somebody to help her, but I left my coat on the desk of the ticket counter. So the person who was supporting me rings the emergency call button and has the attendant come back and asked to have the pilot call to get my coat sent to Oklahoma City. Now how do you think that made me feel? Everybody on that plan saw us push the emergency call button and everybody heard her
question. Thank you very much, I already have one mother. I don’t need another one, but there are things I need support with. She had to have her name on everything I did. I had the chance to be the editor for a big magazine, but because I was going to be paid $200 to do it and she wasn’t, she wouldn’t help me.

Caldwell: That seems like a big issue too—the issues that come up with support people. Do you think it would be better if support people were paid? If the movement had money to pay support people and hire support people, would that be better?

Ward: I think that does happen now, some people are paid, but what I would like to see is people just in relationships where they support each other. So you have a person with a cognitive disability and a person with a physical disability. The person with the physical disability helps the person with the cognitive disability understand stuff and then the person with the cognitive disability helps the person with the physical disability with physical stuff. Then everybody gets something out of it. I don’t see why something like that wouldn’t work. And I would feel much better asking a peer than I would, you know, somebody who didn’t understand about disability issues.

Caldwell: It seems like that is also a lot of what the self-advocacy movement is about—peer support. Am I right?

Ward: Yeah. A lot of doing self advocacy is juggling different things. You have people up here. You have people down here. Well, people down here need to be able to participate too. So how do you get the person up here to support the person down here so both can enjoy it?

Caldwell: I will some back to the self-advocacy movement, but I wanted to go back to disability identity and ask you a few more questions on that. How do you think being a person with a disability has influenced who you are as a person? How you feel about yourself?

Ward: I don’t think I would be the same person if I didn’t have a disability. I think I am more compassionate. I think I understand how to support people. And that wouldn’t have happened. My one brother has dyslexia, but that is the only other person in my family that has a disability. I just can’t imagine my life because it would be totally different. I think about that sometimes. Yeah, my disability is frustrating. It gets in my way. But I really do believe that it is my disability that has given me all the opportunities that I have gotten. To do all the speaking that I do has been
about the fact that I have a disability. To be on the different committees to
go to DC to meet the President was all because I have a disability. So, I
don’t want my life any different—even though it is frustrating to me
sometimes because I don’t understand stuff. That is frustrating. But I like
it and it is the only thing I know. People who acquire a disability, I think
have it a lot worse because, they had a life before that. My friend Henry
talks about that because he has an acquired disability. He was really a
jerk, he said, before he was a person with a disability.

Caldwell: I think the stuff you are saying about this is really interesting. I think you
have somewhat of a different take than I hear from other people—in a
good way. Not as many people are as open as you are about talking
about some of the good things about being a person with a disability. Like
you said, you are more compassionate, you understand how to support
people more—so I think it is a real important area. How do you think you
got… Have you always felt this way or was this more of a process that
you have come to think more about it this way?

Ward: It was a process.

Caldwell: What was that like? I know it is hard, you say when you were younger,
before you got involved in self advocacy, do you remember how you used
to think about your disability? Were you ashamed about it or upset about
it?

Ward: People always wanted to play monster. That always used to hurt. I never
had kids my age that I could play with. All the kids that I played with or did
stuff with were younger than me. I always knew that I was different, but I
didn’t connect it with having a disability before I became involved with
People First.

Caldwell: And how did that help change how you think about disability? How does
being involved in People First or in the self-advocacy movement change
how people think about having a disability?

Ward: Because I saw other people like me. They were able to do the things I
wanted to do. People like Bonnie and David and people like that all
encouraged me, but none of them have a disability. So none of them
really understood where I was coming from.

Caldwell: Did you have any role models or mentors with a disability that you really
looked up to?
Ward: Well, there became some. Roland I would say.

Caldwell: What was it about Roland?

Ward: Well, one thing about Roland was, you know, he had horrible life and now he had a life he was really good. He was really pound of his house and he had a cat. He loved his cat. He had all different kinds of things and it didn’t matter. It mattered, but it was all behind him now. He didn’t have to think about that. Because school was terrible for me. He was able to take that terrible part of his life and not think about it. It was there and he would talk about it at time when something was relevant for the conversation. So that is one thing. Tia is another person. Then the biggest one would be Justin Dart.

Caldwell: Now what was it about Justin Dart? Almost everybody I talk to brings him up.

Ward: Here is what it was. When we would do stuff with Justin –he came to the SABE meeting and then the national conference. When we talked to him after the national conference, he said it just blew him away. He didn’t think that people with a cognitive disability would be able to do that. And he admitted that!

We had this one institution here, called Hisson. My friend David was the court monitor for it at first, so he brought me down here to teach the plaintiffs how to advocate. There was this one doctor. His name was Dr. Adler. He told the judge –because he was the judge’s expert –that these people would never be able to live out in the community. So, David brought him to Nebraska and brought him to a People First meeting and saw how we had people who use wheelchairs and we had people who we blind and we had people who were on ventilators. We had people that he said couldn’t live in the community. He went back and he told the judge that he was wrong; and that made the judge change his mind. Now, Dr. Adler didn’t have a disability, but that always amazed me because I have never since then seen a doctor admit that he was wrong.

Caldwell: That is a good point! So, the thing with Justin that really seems to connect with people was that he admitted that he was wrong and he saw how capable the movement was. Because almost everybody I talk to at the national level brings up Justin as a role model.
Ward: The other thing is that he didn’t flaunt all the money that he had. That didn’t matter. Because owning Walgreens, you know he had a lot of money. The other thing was that when we first thought he was going to die, Tia and I went to go see him. He couldn’t believe that we came to see him just because we wanted to be friends. Most people that came to see him wanted something. We had just come because he was our friend. Then I go to talking about how the movies in DC cost a lot and he gave us thirty-five bucks. That wasn’t my point in saying that, but. Yeah, Justin means a lot to me. I don’t know if you got a chance to see my wall or not, but he is up there.

Caldwell: I wanted to ask you a couple more questions about disability identity. Have you heard people talk about disability pride or disability culture? What do you think about those sorts of things, when people say “I am disabled and proud?”

Ward: Well, people that I have heard say that, have you noticed what disability they have? It is a physical disability. They are accepted. People with a cognitive disability are not accepted.

Caldwell: Why do you think that is?

Ward: Because of the horrors of how people with mental health issues are depicted. So they don’t know the difference between the two. Society thinks that there needs to be a difference. I don’t think that there does.

Caldwell: You don’t think there needs to be a difference between the physical disability?

Ward: No, between people with mental health issues and a cognitive disability?

Caldwell: So, you don’t think there needs to be a difference between mental health and a cognitive disability?

Ward: I think. Well there are differences. There are similarities because both disabilities affect the brain.

Caldwell: I want to go back to the whole disability pride thing. And these are tough questions and there are no right answers, but you have seemed to have thought about things. You are right, because you brought it up, that in the physical disability community that is where a lot of people are saying “I am disabled and proud” and talking about disability pride, do you think those
things have a place in the self-advocacy movement or people with cognitive disabilities.

Ward: Yeah, because having a disability is part of me. So, yeah, I think that need to be there too. But you don’t see people calling people who use crutches, “crippled.” You don’t see people using a wheelchair, “wheelchair bound.” On and on and on, but you do hear people being called “mentally retarded” still.

Caldwell: So, it seems like one difference is around that label, or the words and how hurtful they can be?

Ward: Yeah. It is like I said earlier that, “Sticks and stones can break your bones but words can never hurt you,” that is not true. I do think that words can hurt worse sometimes. I think we need to have, with a new president, a platform where you did disability issues.

Caldwell: Let me ask you some questions about leadership. How do you think you developed your leadership skills? When you look back over the years what kind of experiences or things helped you build your leadership skills?

Ward: Well, the example I shared with you about trust. That was an example related to leadership. Also, I think you need to give people what they want or they are not going to follow you. Like when ADAPT does the different rallies that they do, for example, their call of “Free our people! Free our people,” that everybody there is going to want that to happen. So that is another way of leading is to have people around you that want the same thing. But when you have people around you that don’t want the same thing, then what do you do? Well, I think the example that I gave where you can have a situation that is win-win is a good way to get something that both ways can win. So, that way nobody loses and so everybody is at least happy. So, like when I was talking about the legislation we did – getting “moron,” “idiot,” and “imbecile” changed to “people with mental retardation” –that would be another example.

Caldwell: Where do you think you picked up your skills as a leader? Was it through the self-advocacy movement or did you get any skills from school or other places or other experiences you had?

Ward: Well, I think being a leader means having confidence in yourself, being willing to share the lime light, and having something people are willing to work on. People that have shown me that are people like Bonnie and
David. How to be a good negotiator is one of the things. I understand but it is really hard to accept the war, for example. I don’t understand how people can go on killing each other. I don’t see why we can’t sit down and talk about it and have some agreements on both sides. So that would be a sign of a great leader.

Caldwell: Let me ask you a tougher question. One of the things I am trying to get at is if people with disabilities might view leadership differently because of some of the experiences being a person with a disability. Do you think you look at leadership differently or people with disabilities look at leadership differently?

Ward: I think when I first learned how to be a leader and advocate for myself I think I looked at it differently, because it was that it was my right and I should have it. But now, it is like, okay, what if we would do this would we be able to have this? So, it is like negotiating what you want. So going in and asking for like $750 when you would really be satisfied with $500, but then that gives them a chance to come back with $500. So I think those are strategies that leaders use.

Caldwell: Do you think people with disabilities view leadership any different? About what a leader is or what leadership means?

Ward: Absolutely.

Caldwell: How so?

Ward: I have been told I don’t know how many times that, “My son or daughter couldn’t do what you do.” And it is like a slap in the face—because people don’t understand where I have come from. They don’t know the struggles I have had to go through to get to where I am at. I am not this big polished person—when I first started. I had to work and work and work to be able to get the polished results that I have now. So don’t say that your child can’t do it.

Caldwell: Do you think having to go through all that, does it make you a better leader? Do you think that teaches you about leadership?

Ward: I think it makes us a better leader because we understand how to lead by supporting people, taking the time. It shouldn’t matter that a person doesn’t speak by words. We need to figure out how they are communicating with us and then learn to listen to what it is that they are
saying. And because of being a leader in the disability community, that makes a huge difference. A lot of people do not have the patience. A lot of people say the message on my phone is too long, for example. But there is a reason why it is so long: so my friends can understand and get it. I mean isn’t that who is supposed to be calling you?

Caldwell: So, you mentioned a little bit about this but, what skills or qualities do you think it is important for leaders to have?

Ward: I think they need to have confidence in themselves to be able to give other people confidence. I think that you have to trust the person or people. I think that knowing what a person is trying to say, then repeating what they say, and then ask, “Did I get it right?” Like I said before, I think it is just as important for somebody to get up in some meeting and say their name as it is for me to be doing this. So you have to make sure that everybody feels like they are that leader. A big thing about it, and I feel bad about this, some of the leadership that started the People First movement let it go to their heads. So you need to have what I call “bubble bursters” every once in a while come up and burst your bubble so you don’t get that big ego.

Caldwell: That is something I heard from other people too, that and knowing when to let other people take over –those sorts of things.

Ward: We are having an issue with the person who wants to run for SABE has been involved for like fifteen years and he wants to run for chair again. I understand why he is saying that, but is that what it is really about? And granted, I have been chair before too, but not as long as he has and I think just as powerful as they are. So, it will be interesting to see because both of us have been involved for a period of time. I would like to see somebody with me or Julie as mentor.

Caldwell: Do you think you feel that role sort of now –as a mentor to younger self advocates or people that are newer to the movement? People like you who have had a lot of experience being a mentor to younger people?

Ward: Yeah, I do. While I think that is very important, it is when do you get time for yourself? If you don’t have new leaders, your movement is going to die. But on the other hand, you don’t want the mentors to either.

Caldwell: I will come back to the next generation of leaders, but just to stick on the meaning of leadership. Who would you call a great leader and why?
Ward: Living?

Caldwell: Either way, living or someone from the past.

Ward: Lincoln, Gandhi, Martin Luther King, and Justin.

Caldwell: And why do some of those people come to mind as being great leaders?

Ward: Because every one of those people were for the people. They cared about people. I think part of the difference between being a person with a disability and being a leader and being a leader in just a business is the compassion. A person that is a leader in a business would say that would get in the way. I don’t think that is true in the self-advocacy movement. I think you have to have that in order to be able to understand where somebody is coming from. I think there is a big difference between sympathy and empathy. Did that answer what you were asking?

Caldwell: Yeah, I think so. And how do you think your experiences as a person with a disability has helped you become a leader?

Ward: Because of having to advocate for myself, and others. One of my friends lived in a nursing home and I couldn’t figure out why she needed to be in a nursing home because she was 28 years old. So, I took her out in the community and we did stuff. Sally had cerebral palsy and because of the cerebral palsy she had the spasticity that went along with it. Just because somebody doesn’t speak with words doesn’t mean that they don’t have anything to say. I think we need to take the time to understand that and to figure out what it is they are trying to say. She could yell, but she couldn’t speak with words. So whenever people would stare at her she would start yelling. Well, then they would stare more. So, I taught her social skills; and what she taught me was that if she looked at me she could tell me that she was becoming frustrated and that I needed to explain to somebody that she had cerebral palsy and because of her cerebral palsy this is what happens. That would not occur to a person who didn’t have a disability, for example.

Caldwell: Do you think you have a certain leadership style? Or how you approach leadership?

Ward: I think each one of chair’s leadership style is different. I think each one of the leaders at the time they were chair was there for the right reason. Their style of leadership was what we needed at that time.
Caldwell: That makes sense. That is interesting. So what do you think your style was when you were chair, or your style today?

Ward: What is it that people want? And then when we figure out what it is that people want, how are we going to go about doing it? So it is all about being part of a team, giving people the chance to learn to work together and to develop that trust. I think that is what I brought to SABE – to help people work with each other.

Caldwell: You said it has been different for different people. What are some of the other styles or how they have approached it differently?

Ward: I think like with Chester, for example, it is advocacy. Because the “just do it” statement for example. I think that was something that SABE needed to do. I think maybe SABE could have been more at the table sooner, but we worked it out. Julie’s? I think hers is big picture. Mine is big picture too.

Caldwell: Thinking back to how you developed your leadership skills. It seems like a lot of it you got from just being in the self-advocacy movement and having people around you, support people, giving you confidence. It seems like a lot of it you learned as you went along and had to deal with things. Are there other things, outside of the self-advocacy movement, that helped you build your skills as a leader?

Ward: Meetings. I have learned that it is okay to interrupt and say that I don’t understand something. That is an outside place but that is a self-advocacy skill. Also, time. Time needs to be flexible. So what if we don’t finish the agenda? Everybody in the room understood what was going on and had a concept of it. Now we can take that and use it to our benefit and probably finish the agenda not in a meeting. So if everybody is on the same page, that is a self-advocacy skill, but I use it all the time in everything.

Caldwell: What about young people, right now that are in school or maybe not connected to the self-advocacy movement yet, what sort of things do you think would be helpful for them to build leadership skills?

Ward: NYLN is one thing. The National Youth Leadership Network.

Caldwell: Have you worked with them a lot?

Ward: Yeah.
Caldwell: What are some things you have seen there with younger people?

Ward: They look to you to see if they are doing something right rather than looking to the person who is supporting them who doesn’t have a disability. So that is one thing. So it is a mentoring chance then. They want it to happen. They are more willing to have another person with a disability jump in. I think we have ways to teach each other, because we have been through a lot of stuff that they haven’t had to deal with.

Caldwell: Like what do you mean?

Ward: There have been several generations of people who have gone through school, for example. A lot of states have closed institutions or have mandates that you can’t put more people in them. If you talk about the institutions now, some people will not even deal with you. There is no way their kid is going to be put in an institution. So, I think it can go both ways.

Caldwell: It can go both ways. They need to learn about the history from your generation, you are saying?

Ward: Yeah, but we also need to understand what it is like now. In a way they have like an institution in a different way—they have 911; they have the Oklahoma City bombing; they have Columbine. So they have different things that weren’t around when we were growing up that are around for them. We need to learn from them about their history too.

Caldwell: What do you think are some of the issue that young people with disabilities face? Do you have a sense of what some of their issues are right now that might be different from your generation? Or are they the same?

Ward: No. I don’t think they are the same. I think their generation has to deal with more violence. We have the horror of what was done to people with disabilities in institutions.

Caldwell: Do you see a lot of young people coming to the self-advocacy movement and getting involved? Seeing the benefits of getting involved?

Ward: There are a bunch of states that have what is called Student First. So, yeah.

Caldwell: Trying to start chapters in the schools, is that what they are doing?

Ward: Yeah, transitioning students.
Caldwell: Is that something that you think needs to be done more?

Ward: Yeah. I do think it needs to be done more. I also think it needs to be done sooner than transition.

Caldwell: When do you think is the right age to start introducing people to maybe self advocacy or the movement?

Ward: Parents are going to think I am crazy, but I don't think there is not a right age, because you can shut up a baby, so I think you always need to teach your kid about rights and responsibilities.

Caldwell: What are some of the things that you think are different about the younger generation? You mentioned some. I guess, what are some of the differences and what are some of the same things?

Ward: They have all the new stuff. What is happening now gets rid of what has happened. I think to understand what it going on now you need to have the history, because it repeats itself. It has. I mean you look at Hitler and you look at the terrorists now.

Caldwell: Yeah. I think that is important. There are a lot of young people who don't know the history of institutions and in some states even sheltered workshops.

Ward: So all that kind of stuff is important. Our history definitely has to do with the fact that we have a disability. There history doesn't: like terrorist nature, I don't even know what to call that. Having several generations going through school now, people with disabilities are being seen. So, I think what I talked about before is beginning to happen. I think people with disabilities are starting to be accepted for who they are, but we still have a long ways to go.

Caldwell: One of the things that we did talk about is how people feel about their disabilities; is it important for young people to get connected to the self-advocacy movement and things they can learn from and benefit from?

Ward: That is the one area where I definitely think we are the same. Our surroundings aren't to a certain extent, but definitely the fact of having a disability is.

Caldwell: What advice would you give to young leaders?
Ward: One would be: don’t let anybody tell you that you cannot dream. Dreams are important. If we didn’t have the dream of having the national organization, then that never wouldn’t have happened. If Martin Luther King never had the dream that people would be treated equal –not that that has completely happened –but we are not segregated like we were. Another thing would be: do not let people put you in a box. If you know that you are capable of doing something then show that person that you are capable of doing that. If it is your parents then have them go to school with you. A lot of times that is what happens. That is why we have the P & As.

Caldwell: Was there anything more you wanted to add about you childhood and growing up that we didn’t get to talk about, like your school?

Ward: When I was in junior high I had a teacher that believed in me. She helped me get into some regular classes, so junior high was really good for me. The only thing I didn’t like about it was that we were in a separate wing, so it was segregated. I didn’t like that because kids knew there was something different because we were put apart from them. We went from being called “retarded” to being called “dummies.”

Caldwell: By the other kids?

Ward: By the other kids in school.

Caldwell: Do you think that was the first time you experienced discrimination being a person with a disability.

Ward: No. I didn’t have any friends that were my age or wanted to play with me. So, I have known what discrimination was ever since I was a kid.

Caldwell: When you were growing up, other kids didn’t want to play with you?

Ward: No, and I was always the last one picked for a team. I didn’t have the confidence in myself to do it. I wasn’t able to do it at school, but at home people believed in me so I was able to do it. So I think it is real important to make sure you believe in people and encourage them. They are not going to think that they are good or that they are a person themselves, unless they are told that.

Caldwell: How were your parents when you were growing up? Did they support you in things you wanted to do?
Ward: I didn’t get the same kind of grades that my brothers and sisters got. I was asked one time where my homework was. We had study hall and I always did my homework in study hall. So I never had any to bring home, but my brothers and sisters always had all kinds of homework. So that was another way I was made to feel different. I couldn’t get the grades that they got and then also the study habits that we had were different. When I was in senior high, is when I started having problems in school.

We had a grading system from one to seven and average was three. The highest we could get, no matter how hard we tried, was a four. Well, where does three come to four? So if the highest we could get was below average, what does that tell us? When you are in high school you are supposed to take history. Well, we had my fifth grade social studies book. Again, what is that supposed to tell us? The way I knew that was because I was in regular classes in grade school. My teacher, my friend, and my counselor, she was also the head of the special ed department. She had her planning period the same time I had study hall. So I asked her if I could write my report because she wasn’t going to have class the same time I had study hall. So I am sitting there writing my report and this kid came in with a film for her next class. They go, “Well, you have a small class.” And my teacher goes, “Well, it is not small if you consider what I teach.” And the kid goes, “Well, what is that?” She goes, “Mentally retarded kids.” That is the first time a teacher had called me that. That really hurt!

Caldwell: You talked a little bit about after school. Was the first job you had at Goodwill? Did you go directly there?

Ward: No. I worked in a deli. You have the four “f’s” for people with disabilities.

Caldwell: The four “f’s”?

Ward: Yes. You have food, filth, filing –those are the only kind of jobs we are supposed to know how to do. So I worked in a deli. I worked in the deli for like ten years. Then I decided that I had had enough of that, so then I worked at some nursing homes. I liked that because I was around people. I didn’t like the fact that I only did cleaning.

Caldwell: Did you have any other friends with disabilities when you were that age?

Ward: No. I am a real emotional person. I get upset real easy and I care about people a lot. I showed my emotions real easy and that embarrassed the
other kids. So even though there were other kids in special ed none of them were really what I could say were friends. Except for one –Linda and I hung out together all the time.

Caldwell: When you look back to your whole life, who would you say have been the closest people in your life?

Ward: My grandmother. Then I have had people who believed in me a lot, people I have talked about like Bonnie, Shirley, Patty, Lynn, and David – they all believed in me.

Caldwell: When did you first meet Bonnie?

Ward: I met Bonnie when she first did her book, when she wrote her book and when we did the first conference.

Caldwell: That was the first conference for People First of Nebraska?

Ward: Yeah, Bonnie and another self advocate, his name was David, had an opportunity to go to Australia. Well, Bonnie had planned the conference for us. We hadn't done it ourselves. So I finally figured it out, “Well, we are not having any conference this year because Bonnie is not here.” So, it made me mad. I got some other self advocates together and we started planning our own conference. I kid when she got back that we didn’t need her anymore, because we could do it ourselves. That is not true. She would always be my friend and she would always be there for me when I needed help. She just frustrated me because she had all these people depending on her and it was an awaking moment for me, “Oh, we are not going to have a conference.”

Caldwell: Was Bonnie working for the state or the Arc?

Ward: She was one of the advisors.

Caldwell: Was it just a volunteer position?

Ward: Yeah.

Caldwell: And who were some of the other people you mentioned?

Ward: Lynn gave me my self-advocacy job. She took a risk in hiring me to be the self-advocacy coordinator for Region Five. She was encouraged to do that by David.
Caldwell: And who was David?

Ward: David was the director of the Arc. People First of Nebraska had this language that was “moron,” “idiot,” and “imbecile” — you know all the language that self advocates like. We knew how to testify but we didn’t know how to write our own bill. We went to talk to David about what we needed to do. Nebraska is one of the only states that has a unicameral. So, he told us we were going to have to go talk to one of our senators. We were like, “What!” Because you know people see legislators up here. So we were afraid to go talk to them, but we did because one of the People First members had a father who was a senator. We asked him to sponsor the bill and he did. When they have what they call the introduction of the bill, the sponsor introduces it, he let me introduce the bill. That was cool that I got to read that. The People First had to do a compromise. It was that we had in there that it was “people with mental retardation.” So we didn’t get rid of the labels but it was better than it was.

Caldwell: So you said you were with People First of Nebraska for seven years and then you got a paid position?

Ward: Yeah. I was the self advocacy coordinator for People First of Nebraska. Part of my job was to support the chapters and also to start new chapters. Well, the person who was president found out that you could go to the newspaper and get rides with them. It was called the Omaha World Herald. They took the paper all over the state. That is how I got to the chapters. I would ride with them and I had to deliver the newspapers, but I got to the chapters that way. So that is my story of being resourceful.

Caldwell: That is a great story. So that is how you got to the chapters?

Ward: Yeah. I also used to do it with the mail truck too, but because of 911.

Caldwell: Is there anything else about the history of People First of Nebraska you would like to talk about?

Ward: Well, one thing like I said, I didn’t have any role models to help me gain the confidence in myself, so I had to do that myself. That is why it is important to me to help young self advocates or other people to learn how to advocate for themselves, to speak up for themselves, so that it doesn’t take them the five years it took me.
Caldwell: So you were saying you didn’t have any role models and it took you five years to speak up.

Ward: It took me five years to learn how to gain the confidence in myself. That is why I do what I do now. I want other people to learn how to speak out for themselves. I don’t want it to take the five years it took me to learn how to be a leader.

Caldwell: What were the things that helped you in the five years? Was it going to the People First meetings? Meeting other people in the self-advocacy movement?

Ward: That was part of it. I met other people in the self-advocacy movement and I learned from them. I will share with you a story about one of my experiences. Life Goes On and Chris Burke. He comes to a lot of self-advocacy conferences or different advocacy conferences. He was at The Arc conference. This was just after Life Goes On quit, and I was on the board of The Arc of the US at the time. It was called the Association for Retarded Citizens. I was on the board and Chris is like twenty years younger than I am. He really liked me and he asked me if I wanted to get married. He told me and then I told him that I said, “I am twenty years older than you are and you are like twenty. What are your parents going to say to this? Don’t you think you should love the person you are going to marry?” So we had this discussion about all of that, but I just thought it was funny that this big TV actor asked me to get married.

Being on The Arc board is one of the examples I wanted to share with people. I don’t think you should just have one self advocate on the board. You have all these boards and they are made up of professional people and then you have one self advocate. So how is the self advocate supposed to have confidence in themselves to say the things they want to say. So I got mad at a board meeting and I told them that. I told them that I didn’t think it was right to only have one self advocate on the board and have all these parents and professionals. It is not fair because they talk over us. Then they started having more than one person on the board.

Caldwell: I am sure you have been on a lot of boards and committees. What other boards have you been on?

Ward: Right now it is TASH because of my job. Right now it is just TASH.
Caldwell: Do you think being on those boards helped you with your leadership skills?

Ward: I definitely do. Because I think you learn from any experience. The TASH board is the only board I am on but I am also the secretary for our DD Council. I think it took a long time to admit to myself, “Okay, how am I going to sit here and not understand what is going on and make informed decisions?” Or am I going to tell people that I don’t understand and have them stop the meeting, which would be embarrassing, but at least I would be able to make an informed decision. So that is what I did, but it took me a long time and a bunch of different boards to be able to do that – to gain the confidence in myself to think that it was okay. What people taught me is that if I don’t understand, I am probably not the only one who doesn’t understand. I am the only one though who is willing to ask. I think part of being a good leader is you have to know the people you are leading, what they want. So you have to be able to read people, know what it is that they want. One of my friends taught me a very valuable lesson. When I was working with what was called SAC for Region Six, he would just sit there during the meeting. I didn’t think he understood what was happening. I realize I already said this.

Caldwell: Okay. We can go on to something else. Is there anything more about leadership you wanted to talk about? How you think you gained your leadership skills?

Ward: I think there are different types of leaders. Right now I think SABE would be ready to help younger people learn their self advocacy skills and I think that it is time to do that. I think we are at a place where I would rather have one of my peers tell me something rather than someone who doesn’t understand the history tell me. So I think that would be an important thing to do, to help people understand that. Part of it is hard because people now have gone through whole generations of special ed, so people are being accepted; they don’t want to admit that they have a disability. They don’t want to admit that they are different, but I think that that is part of their history and they need to understand that, you know, there are things that are different about them. There are different things that you can do to help with the accommodation you need and you should not be afraid to ask for those accommodation, which a lot of people are because they don’t want to admit that they have something different about them.
Caldwell: That does seem like that might be a different issue for kids today who have always been mainstreamed and integrated and might not have connections or relationships with other people with disabilities?

Ward: Yeah, because you are going to go to your neighborhood school. While there are probably other people with disabilities in your school, just like anybody else you are going to know the people who are around you. I think people with disabilities can learn from other people with disabilities how to be more disabled, but they can also learn from people who don’t have a disability how to be part of society.

Caldwell: What do you mean by people can learn from other people with disabilities how to be more disabled? What do you mean?

Ward: Say for example, you are in a classroom and you are with a bunch of kids who are non-verbal, but yet you can speak. Well, if you are around people who don’t speak all day, are you going to learn how to talk? Are you going to learn how to express yourself better? You can learn how to get by in not using words or get by having temper tantrums, because people have behavior problems, for example.

Caldwell: Another thing we didn’t get to talk about. So you decided to move from Nebraska to Oklahoma. How did that come about? Can you talk a little bit about what you do now?

Ward: Well, I was 46 when I left Nebraska. I was older and I have always lived in Nebraska. I have always lived in Lincoln. Even though for six months of the year my parents go to California for the winter we still lived in the same town the other six months. It was hard for my parents to deal with that. I have a condo in Lincoln and I have a trust fund. Well my parents told me I wasn’t going to be able to use the money from my trust to move and I wasn’t going to be able to rent my condo out right away because they thought I was going to come home. Nebraska is always going to be home to me but it is not where I live now. So it took six months for them to let me live in Oklahoma before they decided I am not going to come home. I was hired to work from Oklahoma People First and be the self advocacy coordinator. I was recruited from my job. That meant a lot to me because that means people really believed in me and thought I could do the job. That was really cool. I had done contract work with Oklahoma before with the closure of Hissom.

Caldwell: So you moved about 10 years ago?
Ward: Yeah, it was 11 years last month.

Caldwell: Did that work out good for you, going to People First of Oklahoma?

Ward: Well, at first I did because Michelle was there. Then she quit and she went to work for the health authority, so for the state. I had other people hired to work with me but nobody wanted to do the traveling that was required. Just like in Nebraska, part of my job was to support and start new chapters. I don’t drive so that was an issue. They don’t have where you can do the newspaper in Oklahoma. I checked that out. The other thing that made it hard was that I don’t look like I have a disability. So, it is hard to describe the supports that I need — other than to say to somebody that I will tell when I am at a meeting. They need to come to meetings with me so they can do notes and they can tell me what stuff means when I don’t understand something so that I don’t interrupt the meeting. It is not like a person with a physical disability where you can tell, you know, that they need a door open. One of my favorite saying is: accessibility doesn’t always mean a ramp. What I mean by that is that there are other ways of having something be accessible. Like people don’t always know how to read. So you could have something be accessible by having it recorded so it can be read to them or you could use pictures for different things. One of the things I think is cool about People First is that they have icons for the agenda. One of my favorite icons is a spider web. That is for old business. They will have like the dollar sign for money. So they have different ways to describe what is on the agenda.

Caldwell: So then after People First of Oklahoma you went to the P & A to work?

Ward: Yes. When I was still at Tulsa Arc I was hired to do a self-determination grant. This was a very cool grant. People First members developed a way to ask for proposals. They gave out grants to all different kinds of organizations to promote advocacy. It was for $5,000. The person who was chair, her name was Michelle, looked at me when she figured out how much money we were going to have. Over the course of the grant they had $100,000. That is a lot of money for self advocates. It is a lot of money for anybody. So it was really scary for them at first to go through the process and learn how to deal with that.

The self-determination grant led to working on the Medicaid Reference Desk. That has been an eye opener for me. Because you take this stack of paper and I couldn’t figure out how you take this stack of paper and put
it on the computer. Now we are done with all fifty states. So we have done each of the state’s Medicaid system and made it accessible by using pictures and having people read the medical definitions. For example, you take occupational therapy and for Medicaid it was 57 words long and 24 of those words had three syllables of more. How are people supposed to understand that? So we got it done to 17 words with three syllables or more. So that is what I do for The Desk. The other thing that we have done that I am real proud of—it is starting to be used across the country—is a bunch of self advocates and us have developed a plan that people can use for their IEP or IP. It talks about people being allowed to dream. It talks about people being allowed to have sex. It talks about all kinds of things that are important to self advocates but that maybe parents are afraid to talk about. So that is what I do now.

Caldwell: What are your personal goals for the future?

Ward: Well, one of my dreams is that I want to work in DC. One of the ways that I think would be a good way to do that is to be the director of SABE. So the first director of SABE, I would like to be that.

Caldwell: The first executive director?

Ward: Yeah. I think that would be very cool. That would be a stepping stone to something like the commissioner for ADD, the Administration on Developmental Disabilities. Now, I will admit that cerebral palsy is a developmental disability. They have had two commissioners who have had that, but they have not had a commissioner who has a cognitive disability. So that is one of my dreams, to be the commissioner of ADD. I think they should put their money where their mouth is.

Caldwell: You would be a good commissioner. Is there anything else that we didn’t get to talk about? You said you had a story you wanted to tell?

Ward: One of my friends was 28 years old. I couldn’t figure out why somebody who was 28 years old needed to be in a nursing home. I was hired to help her eat. Because when you try to help somebody with cerebral palsy eat, it is hard for them to swallow so it takes a long time for her to do that. So they hired somebody to do that. I took her out into the community with me. To understand this story you also have to understand the labels that go along with this, and I hate labels. Sally had cerebral palsy and because of her cerebral palsy she had a lot of spasticity. She didn’t use words to communicate, but just because someone doesn’t use words to
communicate doesn't mean that they don't have something to say. So I think we need to figure out how to communicate with people and figure out what they are trying to say. So I took her out in the community with me. Because people would start staring at her she would start yelling. And, of course, because she would start having spasticity and yelling, that would make people start staring even more. So what I did was I taught her social skills and she taught me. She would look at me and that meant that she wanted me to explain to people and to not have people stare at her.

So Sally and I became great friends. We did everything together. We went to movies. We went to the store. We went shopping. We went to church. We just did things that friends do. Then I quit being her staff. She got all freaked out because she had only had somebody paid in her life to be her friend. She didn't know what it was to have somebody be her friend. So, I don't think you can be somebody's friend and be paid for it. That is not friendship. So, I quit working with Sally. It is easier for me to tell people stuff by writing it down, so I did. I wrote her this poem that explained to her that she was my friend. Because she was my friend I would not be leaving anytime soon. So Sally and I still did everything together. Eventually, I asked her if she wanted to move into a group home. That was real hard too because the only home she ever knew was the institution of her parents' home. So, what I did was I took her around and showed her the different group homes. She got to pick out the group home that she wanted to live in. She got to pick out the room that she was going to have –well that was pretty staged –but she got to say whether she liked it or not. Sally's favorite color is red so she decided that she was going to have everything in her room red. I showed her what that would look like and then she decided, okay, maybe she would not have everything in red. She got to pick out the stuff for your room. She got to pick out the pictures and hang the pictures on the wall.

Everything was going great. She was part of a family. You can be part of a family and not have it be your natural family. She was being accepted for who she was and was being seen as a person that was very capable. One day I went to go see her –and I will never know how this was able to happen –but I wasn't allowed to see her. Sally's mom is her guardian and she wasn't allowed to see her. For two weeks we tried to get in and finally I asked my friend Lynn, who was the director of Region Five, to go with me. It would be real difficult to tell your boss that she could not come into one
of her group homes. So that is how I got in. I used my friendship with Lynn. We go into Sally's room. To give you an idea, Sally is the same height as me; but, I admit I weigh a lot more than 88 pounds. When we go into her bedroom, Sally is down to 44 pounds. She was as stiff as a board. They wrote in the log book that they did her exercises, but they obviously didn't because she wouldn't have been so stiff if they had. She had bed sores because she had been left in bed those whole two weeks. The reason why she was down to 44 pounds was because they tried to feed her in bed. So I told Lynn that we needed to get her out of there, and I used a lot stronger word. Lynn asked me how. Because of Sally's spasticity she is going to hit you so you need two people to lift her, so she stayed in the group home for two weeks.

On the day that I was supposed to go see her, they told me that she had turned blue, “Sally had turned blue and quit breathing.” That is how they told me, like they didn't even care. I go to the house and Sally did four more times. You can’t convince me that somebody who does it five times isn't trying to revive themselves. Because of all the bureaucracy, she ended up going back to the nursing home. That is why I hate bureaucracy. In order to get her out of the group home she had to go back to the nursing home. She had to have a gastronomy tube put in. That is where they put a tube in your stomach and they just pour the food in. Well, you take away the one thing that meant more than anything to Sally, because people had to spend time with her. Now, they are not going to have to spend any time with her. She looks at me with her big brown eyes like, “Why did you let this happen to me? You told me that living in the community was going to be a good thing for me.” She said the same thing to her mom and we didn’t have an answer for her. It tore us up.

The one thing that was good about her moving back into another nursing home, and an institution, was that The Arc was having its national conference at the time in Omaha, which is 60 miles away from where I live. I wanted Sally to with me to the conference. The first thing the nursing home threw in my face was that she would lose her spot because she gets Medicaid. If you take her out of the place where she gets Medicaid then she would lose it. That is how they said it, like Sally is this inanimate object. Well, Sally, is not an inanimate object, she is my friends. They just kept throwing, and kept throwing, and kept throwing different things in my face. It took me a whole year to get her able to go
with me, but she finally was able to go with me. She was being treated as a person again by people. She was being accepted for who she was. Do you think she had any what I call “institutional” outbursts while she was there? She had one because she was telling me she didn't want to go to my session. She had heard me enough times. She wanted to go do something else. So, how can I get mad at her for doing what I taught her? At night they had a banquet and at the banquet I got the Citizen of the Year Award. And I think it was because of Sally. Sally taught me more about life than any of my other friends could have taught me.

Body language doesn't lie. She had to be totally honest. Yes, she got mad at me because part of by disability is forgetting stuff. So when I would lock myself out of my apartment or my office she would get frustrated. Her mom got to spend time with Sally without her hooked up to all the tubes. I want to people to understand this—and if this is the only thing you get out of this presentation—I think there is a huge different between quality and quantity of life. Sally wanted to be fed. As long as the person understands what that means to them, because having food after having a gastronomy tube, she could choke. She knew that. To her, being able to eat again was worth it. I think people need to listen to that. Because people with disabilities say that a lot and we just ignore it because we think quantity of life is better than quality. We need to start listening to people. So, we fed her. You should have seen the look on her face. There is no price you can put on that, because she was enjoying life again. After the banquet they had a dance. One of the guys who was the director of the Arc of Louisiana at the time took Sally out of her wheelchair and was dancing with her. I have that picture up on my wall. It is a very cool picture and I like it a whole lot.

Sally moved into what was like a medical unit. It was a house staffed by nurses, so she was getting the medical help that she needed. She was starting to be part of the family again and having people accept her for who she was. One night staff went in to check on her and she was doing fine. The next time staff went in he wasn’t doing fine and they called 911. By the time the ambulance got there she was dead. One of the things that another one and my friends did was that we did this camp where we taught kids how to interact with people with disabilities. They did friendship bracelets for us. Sally was buried with my friendship bracelet on.
So the story doesn’t end on a sad note. One of the things that Sally used to have was she would have this big board up on the wall. One of the things that was on it was if you had two different outfits, she would look at the outfit she wanted to wear. Well, when the aids came in to get her dressed they would just put anything on her. She would fight them because they were taking away even that little bit of dignity she had. So, of course, then she gets another label of “behavior problem.” One of the things we were trying to do before she died was we were trying to get her a communication device. One of the things I thought that she should have on her communication device was “F off,” so she could tell that to staff whenever she got frustrated with them. That would be a way for her to deal with her frustration. Anyway, thank you for letting me share that story with you.