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**ORAL HISTORY VIDEO INTERVIEW WITH
DONNA ROBERTS
JANUARY 10, 2013
INTERVIEWER: JENNIE TODD
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 005-DO**

DR: DONNA ROBERTS

JT: JENNIE TODD

PH: PEGGY HOLTZ

[00:00:10]

JT: So you can just start by saying "My name is."

DR: My name is Donna Roberts. I'm originally from New Hampshire. I've lived in Indiana for almost 30 years now. And for 23 of those years I've been Executive Director of United Cerebral Palsy Association of Greater Indiana.

JT: Okay. How and when did you get into this line of work?

DR: Forty-seven years ago I gave birth to a child who was born with multiple disabilities. This was back in New Hampshire. It was before there were any laws about education or anything. And I found problems getting services for her. They wouldn't let her in school, but they would send the truant officer to my home once a month to find out why she wasn't in school. And there were no services. Even before that, my grandparents both worked at what they called a "state school" in Massachusetts. And I remember as a child, on Easter and Christmas -- my grandfather was the organ musician there -- going to the services, and we would have to sit up in the balcony and look down at the people. And I remember my grandparents talking about "those poor souls" that they worked with. And then when my daughter was born, my grandparents never admitted that she was one of those poor souls.

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So I got involved first in New Hampshire just because I didn't -- I was angry that they wouldn't take her in school; I was angry that there were no services; and I was too young and too stupid to know what I was getting into, frankly; and started a school for children with disabilities in New Hampshire, which --

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and that was forty years ago -- which the building still exists. It still carries her name. And it is now a community center for everyone in the community.

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JT: Fantastic. So that must have been really kind of just amazing to think about your grandparents and your grandparents' perspective of things. And then now they have a grandchild or a great grandchild and --

DR: It was difficult when she was born. But I started questioning my grandparents' opinion, even years before that because one Christmas my sisters and I each received from my grandparents these beautifully hand-carved doll cradles. And they had our names on them and they were just gorgeous. And they were made -- my grandfather said -- by one of the inmates of Wrentham State School, the institution he worked for. And so I remember even then thinking "How could a poor soul create something so beautiful?" So I started questioning it long before my daughter, Kimi, was born. And it did sadden me that my grandparents would not look at the positive things about my daughter. But quite honestly, I understood their generation and the general society's lack of acceptance of people with disabilities.

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JT: So luckily we've come a long way.

DR: A long way.

JT: Okay. Can you tell me briefly about the Indiana UCP organization, how and when it started?

DR: Right. The Indiana affiliate of United Cerebral Palsy was started in 1953, again, by a bunch of parents. That's how many nonprofit organizations started. Initially it was just for information and that kind of stuff. Twenty-three years ago when I came on board, we started -- the board was looking at "What else can we do?" We had received a large bequest from someone, and the bequest included a caveat that we use the money to purchase durable medical equipment. And so that's one of the things we focused on. And over the years we focused on our role, not just for people with cerebral palsy because we want to be the home for people with cerebral palsy in Indiana who need information or assistance or that, but also as part of the bigger family within the disability community.

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And so there are other things we do. We give three scholarships a year to high school seniors with cerebral palsy. Again, we provide information when a parent calls and says their child has been just diagnosed. I think it's reassuring to them for me to say, "I remember that day when my daughter was diagnosed." And then they know that they're talking to somebody who's walked the same path as they have. And then for the last seventeen years we've been very involved with the Governor's Council in trying to create a community where there are positive attitudes about people with disabilities and by people with disabilities about themselves. And so every year since then we've sponsored an essay contest called "The Attitude Essay Contest," where kids submit essays and think about their attitudes;

interview family members; read books; that kind of stuff. So those are pretty much the three most significant things that we do.

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And we spend about \$150,000 a year on durable medical equipment because insurance companies -- public and private -- are just getting tougher and tougher to get money out of for that stuff. So those are the three things we focus on. And when I say "we," basically I'm the only employee now. So we've had to -- like a lot of nonprofits -- we've had to cut down and cut back. So.

DR: I just lucked out to find the organization that has given me so much over the 23 years. And I tell people "One of the blessings in my life is for 47 years I've never had a question about why I'm here." First, I'm here to have been Kimi's mother, and second I'm here to have been Executive Director of UCP for all these years, so.

JT: Well, in the time that you spent at UCP, can you talk about some of the biggest changes, challenges, and successes during your tenure here?

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DR: Sure. I think some of the changes have more to do with our national affiliate and the fact that they have pretty much expanded to include all disabilities. Our board meets -- has a retreat every year. Every year the question is raised: Do we just want to continue serving people with cerebral palsy or people with other disabilities? And the answer is always the same: We want to stick to our name; we want to make sure that if we buy a wheelchair for somebody, it's somebody with cerebral palsy. If we bought a wheelchair for somebody with another disability this week, we might have to say no to somebody with cerebral palsy next week. I think that's one of the big changes is that, unlike other affiliates, we have stayed true to the name of just serving people with cerebral palsy. If somebody with another disability calls with a question that I can answer, I'll give them the answer, but that's about as far as it goes. I think another issue is that, unlike some other organizations, we have decided not to provide direct services.

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We have decided not to -- for example, there are a number of affiliates that have branched out and developed residential programs, employment programs, that kind of stuff. We would rather be on the side of the client, making sure that those programs and services do what they're supposed to do instead of trying to deal with all the other stuff. So that we really haven't grown; in fact, we've shrunk over the 23 years I've been there. And then, finally, I think is getting more involved -- changing so that we're more involved and partnering more with other disability organizations in the state so that we're not just this isolated little thing. We have a great relationship with The Arc of Indiana for instance. And we have a lot of clients in common. So that's a real advantage I think not only to us, but to our clients. I think one of the things I'm proudest of doing over the 27 years is -- it got to a point where I realized some of the same questions are going to be asked by everybody.

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And instead of having to look up the answers or research the documents, about twenty years ago I started putting together these information memoranda. And so we now have about 250 of those, which list all the doctors who specialize in treating adults with cerebral palsy, for example, and ways to get home healthcare, all that kind of stuff, so that I guess the positive thing for me is if I get run over by a bus tomorrow, somebody else can come in and do my job and have the resources that they need. And that gives me some peace. And it makes things easier for our clients, too, because I can send them the information easily.

JT: Do you guys act as an advocacy organization as well or?

DR: Not directly. We provide information, and advice, and resources. For instance, we can refer people -- we have a list of attorneys who deal with disability issues. We have written information about Indiana protection and advocacy services. But you know, I'm not a lawyer, I don't play one on TV. But we can give people resources where they can get advocacy that they need.

JT: Okay. All right. And you talked some about your daughter. And so did your daughter help focus the work that you did or, you know, to keep you motivated? Do you feel like that was some of your driving force, and if so how?

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DR: I think the gifts that my daughter gave me -- it's kind of hard to explain. My daughter had cerebral palsy; epilepsy; profound mental retardation; heart and respiratory problems. This was after a year of the doctor telling me there was nothing wrong with her. And what she taught me were two things. Number one, just persistence. If she would fall, she would get right back up again. She was determined to do things. And the other thing she taught me was to rejoice -- not just to appreciate, but rejoice in the small positive things. A day when she didn't have a seizure; or a day when she didn't get a bloody nose; or a day where I'd been running around the house and I'd just looked at her and she would say, "Hi" -- hi was the only word she had -- but she would say it in this high-pitched voice. I can still close my eyes and hear her little voice say that. And I think those things helped me professionally, too, that I don't get stuck on the little snags in life.

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And I've learned to appreciate the positive things. And I've also learned the determination that if somebody says "No, you can't," it's like, "Okay, watch me." And I think that I learned from her a lot about disabilities, certainly, and that's helped me. I learned -- not because I was always a good mother -- but I learned some of the parenting skills that, you know, parents need to just let go of that child that you thought you were going to have and embrace the child that you have. I think that's a helpful thing. When I talk to a lot of parents, they've expressed gratitude to me for pointing those kinds of things out. And you know, I don't know what my life would have been without her. I don't know what I would have done with my life professionally or any of that kind of stuff. I've had 46 years of just a career that I can't imagine anybody having a better career, a better life anywhere.

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I've loved what I do. I never want to stop what I do until I can't, you know, function anymore or breathe.

JT: That's great. That's great. I want to go back to the attitude dinner. And what I'd like to know about it is, you know, you did mention that you have the attitude dinner and it has essays and that sort of thing.

DR: We don't do the dinner anymore though. [Multiple speakers] The essay attitude contest. Yeah.

JT: Okay. So if you could talk about who applies, you know, what's the process, and maybe if you have a story or two to share about someone.

DR: The attitude essay contest -- I don't even know how it came up. It went from 28 essays the first year, now we get between 600 and a thousand. I joke with everybody that I take a day, I sit at home with a two-liter bottle of Diet Pepsi and a huge box of tissues and I read all the essays. And then we have judges, people with disabilities, teachers, whatever who narrow it down to the top six. We send notices -- and this is in partnership with the Governor's Planning Council -- to every elementary and middle school in the state -- public, private. Last year we had, I think, about fifty essays from Amish children in Amish schools. So the message is getting out to that community as well. It's for children as I say sixth -- I'm sorry -- third to eighth grade. We figure by third grade they've got some decent writing skills.

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By sixth, seventh, eighth grade they've pretty much formed their opinion. And it is to get them to think. We send a reading list, for example, of books about disabilities and that kind of stuff. Last year we had the author of a book come and speak to a couple of schools and at a dinner we had. And she wrote a book called "Out of My Mind", which is about a child, a girl with severe cerebral palsy who can't speak who gets a communication device, and then talks about how different her attitude is about herself and the attitudes of others are different about her because now she can communicate. As I say, we get hundreds of essays every year. I've got copies. We print copies of the top thirty essays every year. And so I have a notebook this thick of all of them.

There was one essay written by a little girl. And it was not an essay, it was a poem. And it was about how she had begun joining her friends in making fun of a girl who had disabilities and then started talking to the girl and realized that she was more like her than unlike her, and that they became friends all through school. Those are the kinds of essays that I just love to read. There was one little girl who wrote she called her grandmother in Florida, and her grandmother had post-polio syndrome. And she interviewed her grandmother about how having a disability was difficult and that kind of stuff. The grandmother called me to thank me for the best conversation she had ever had with her granddaughter. And I still get choked up about some of these stories because I think the impact is far beyond just the essays that we get.

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JT: So kids with and without disabilities write the essays.

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DR: Right. It's children with disabilities writing about their own attitude or writing about the attitude of others. It's children without disabilities interviewing a relative, reading a book, and talking about how attitude affected the person in the book, or just writing about their own attitude.

JT: So what would the question be? What is the topic of the essay that gets them thinking? What do you present to the group?

DR: The title of the contest is "Attitude: The last barrier for people with disabilities." And when I go and speak at school -- I talk at schools -- and sometimes I go, sometimes I bring other people with me. What I talk about is the fact that my attitude, your attitude can either be a barrier or a bridge to people with disabilities. And how does that work out in your life or in the life of a friend you have or that kind of stuff. Kids pick up on it. And the really encouraging thing for me -- and it's part of my general optimism; I believe that children are not born with bad attitudes about anybody -- is that these essays are proof of that, that children will write about "My friend Becky who really likes Taylor Swift, and her favorite color is purple and my favorite color it purple, and I like Taylor Swift, and oh yeah, she's in a wheelchair." But that's not the first thing they focus on.

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I firmly believe -- and the essays prove -- kids want to focus on what is the same, what is similar, what do they have in common with somebody, not what is something that's going to put up a barrier to them. And our hope is that there will be a generation of children who grow up understanding that people with disabilities are more like us than unlike us, so that the kinds of experiences that many of us have had in the past aren't going to happen again. When my daughter was -- well, she was maybe four or five years old, I was in a supermarket. And I had her brother who was three and her sister who was about three months at a time with me. And I'm grocery shopping. And this old woman -- probably somebody my age now -- came up to me and she said, "My dear, why don't you put her with her own kind?" And my first instinct was to ram my grocery cart into the woman, but I had my kids and all that. And instead I looked at her and said, "You know, she is with her own kind.

This is her brother, this is her sister, I'm her mother, and this is where she belongs." Our hope is that the children in this generation that either read or write these essays will never turn into that kind of woman that believes that people with disabilities are not our own kind.

JT: So what time of year does this contest start, and does it go to every school in Indiana?

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DR: We send out the notices -- the Governor's Council sends out notices -- the first of December. The cut-off date for essays is February 1st. And then in March, which is Disability Awareness Month, it is when we give the awards because we get some late essays in. We have a list of every public and private elementary and middle school in the state. And as I say, we get them from Amish students last year, which was really very interesting.

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JT: Do you remember any stories of essay winners that you could share? Just the gist of what they wrote about?

DR: Yeah. There was one little girl that wrote a poem called "Butterfly." And she had a friend who had cerebral palsy, was in a wheelchair. And the poem was about her imagining this friend of hers growing wings and being able to fly to anywhere she wanted and do anything she wanted. But then at the end of the poem she got back to what was important to her about this friend: That she was a good friend, that she was happy and could make people laugh, and that kind of stuff. Those are the kinds of essays that really have an impact. A lot of kids will write about Helen Keller or, you know, other famous people. A lot of kids, again, will interview their parents. It's surprising how many more children of people with disabilities there are now than there were back in, you know, the '50s and '60s.

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And so they write about how their mothers and fathers are their heroes because they don't let anything get them down and they just, you know, go ahead and do things. There's one mom, and the quote from her daughter was that she's "finer than frog's hair," which I don't understand what that means, but I'm assuming that it's a real positive thing. And I think that's the general tenor of all the essays is that they're very positive. Even if they tell a sad story about somebody being bullied, there's a lesson clearly that they've learned at the end of it and a message that they're trying to get out. Often it's just the golden rule, which is a pretty simple, easy rule that just about covers everything.

JT: And what do the winner -- what happens? What do they receive?

DR: The top two prizewinners in each of three age categories -- we lump the third and fourth grade together, fifth and sixth, seventh and eighth. First prize is \$150, and we have these bears that have T-shirts that say "Attitude" on them. And we give those. Second prize is \$75, and we give those. We've awarded more than ten thousand dollars in prizes over the years. And then we also print the top thirty essays in a booklet. And we provide a copy of the booklet to every school that participates, to every student whose essay is in the booklet, and then to anybody else who wants a copy of it. So.

JT: That's fantastic.

[Multiple speakers]

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DR: The inspiration -- if I could -- the inspiration for the book, we have a gal who was a client many, many years ago. And she lived in Fort Wayne. And she wrote a letter to the Fort Wayne newspaper asking for one day at school where the kids wouldn't make fun of her. And the City of Fort Wayne just did a wonderful thing. They turned around and the mayor established an Amy Hagadorn Day. Amy Hagadorn is the girl's name. They had a parade, they put her on a float. They made a big deal of what a wonderful girl she was. And in fact, there's a Chicken Soup for Kids book that has Amy's story in that, too. And

Amy was the inspiration. And most years Amy's been able to be with us when we give the awards to the kids, too. And she's just a fine young woman now. And that's kind of an inspiration for the kids, too.

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JT: That's fantastic. Do you have a robotics program?

DR: We are involved with Riley Hospital and have worked with them and, in fact, contributed funding for some of the equipment to develop the very first robotic therapy center for children with cerebral palsy in the country. And basically, they use robotic equipment to move a child, even a child who can't walk. There's a robotic piece of equipment that they get into and it walks for them. The theory behind it is that we all have stem cells that haven't decided what they want to be when they grow up floating in our brain. And if we can get the attention of those stem cells, we can get them to function for cells that have died. And if the movement is consistent, if a therapist -- if I moved your arm like this, the angle would be different, the speed would be different. If a robot does it, it's exactly the same.

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And the theory is that if that movement is the same, it will call attention to those stem cells. And here's how I simplify it so I can understand it, is they all gather around and say, "Oh my gosh, I can do that." And then they link, again, between the brain and the muscles. It's worked very successfully with veterans coming back from Afghanistan with traumatic brain injury. It is working now for the children. The center's been open for about a year and a half. It's working. I saw a little girl who used a walker but just didn't have the stamina to walk very far. I saw her walk the equivalent of ten football fields until finally we had to say, "Anna, we need to stop now. We need to give the robot a rest." And so it's working. The research that's going on as part of this project is to see if the change lasts over time. And it's just very exciting. I tell everybody, "This is the most excited I've been about treatment for people with significant disabilities like cerebral palsy in my whole life because it is starting to work and it's not just" -- you know, there's all kinds of wonderful equipment out there that can help people deal with a disability; this is a way to just overcome the disability and get on with it.

And it's just very, very exciting. It's very expensive. We had great cooperation from the State of Indiana. Medicaid has approved this treatment on a preliminary basis, which was a huge benefit for us. Margaret Goldsmith, the wife of the former mayor of Indianapolis, probably had more to do with that than anything else. Margaret has just been an amazing ally in getting the robotic center funded and started. The equipment is probably -- we've probably got over \$2 million worth just in equipment. Our organization kicked in \$75,000 toward that, and then has worked to raise the rest. But it's a very exciting, very exciting project.

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JT: That's fantastic. Okay. So this is -- this question is: "In looking at your tenure in the field of disability human services, what are some of the most noteworthy changes in the State of Indiana, and what brought about those changes?"

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DR: I think Indiana really started to change when there was an investigative report about the New Castle Developmental Center. I think that most Indiana residents, Illinois residents, whatever -- even ten, fifteen years ago -- weren't that aware of people with disabilities. I mean, they knew they were around and that kind of stuff. But they still assumed that there was a place where they could go and live and that kind of stuff. And I really think that investigative piece that just sort of ballooned into newspaper articles and TV series and that kind of stuff, I think that more than anything changed the perception of the average Hoosier about "Who is a person with a disability?" It's not what we thought: "Oh my God, there's a person with a disability that, you know, competes in the Olympics, the guy with the artificial limbs.

Oh my God, there's a person with a disability that, you know, writes books and is a lawyer," and all the other things that we who've been in the business have known about for years. But I think the general community is more understanding that people with disabilities are the same differences, the same ups and downs, the same pluses and minuses, the same heroes, and the same jerks as the rest of us are. And I think that's the other thing I think that has changed both in Indiana and across the country is when I was in school you didn't see a person with a disability. Children with disabilities, like my daughter, were not allowed in school. I went to my 25th high school reunion and found out that one of my best friends in school -- and I was in class of 35 kids -- one of my best friends in school had a sister with Down syndrome, and I never knew it until our 25th graduation anniversary.

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I think one of the big changes now is that you see people with disabilities everywhere. And children with disabilities are in school and their friends see them, and I think that's probably the biggest change. It raises some concerns. I have some concerns based on 47 years of watching things change historically. But I don't believe that things will ever go back to a place where people with disabilities are those "poor souls" that you hide in institutions like my grandparents thought.

JT: In what year was the New Castle blow up? Do you remember?

DR: I think it started in 1998. I've got some information in a thing I can check.

JT: Okay. Yeah. All right. Yeah. Okay. And let's see. In thinking about noteworthy changes and changes coming about, there's been a lot of movement with self-advocacy, a lot of grass root movements, a lot of changes. Have you noticed a lot of that and have some personal experiences with advocacy from people with cerebral palsy and them advocating for themselves?

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DR: I think one of the things that we all need to bear in mind is that if I haven't walked in your shoes, I really can't tell you what's the best way for you to walk in your shoes. I think the advantage I have in talking to parents is that I've been a parent. But I've never had, you know, cerebral palsy. And so I think the rise in self-advocates and the rise in the visibility of self-advocates has made a huge difference. I think that sometimes good things or good intentions lead to bad results. And I think part of the reason for that is

we never really asked the people that were going to be affected by the good intentions. When the State of New Hampshire funded Laconia State School, the League of Women Voters talked about, you know, a class of harmful people. If they'd ever asked some of the people that lived at Laconia State School, they would have seen these people don't need to be walled away from society; they need to be supported in their own community.

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And I think that's one of the things that -- one of the important roles that self-advocates have now is: "Don't you tell me what I need. I will tell you what I need, and then we'll make sure that your good intentions lead to a positive road instead of the road to elsewhere." So.

JT: Okay, good. All right. So in looking forward, what do you see in terms of support services for people with disabilities? You know, what do you see down the road? What are your hopes?

DR: When I look down the road, I'm scared. And I'm scared because I think that it's very easy to slip. Economically we are dealing with senior citizens like myself who have needs, we're dealing with the healthcare system that is just extraordinarily expensive. We're dealing with nonprofit organizations that are struggling to stay alive. And my fear is that we'll forget the past, that we'll forget those "poor souls" at New Castle or Wrentham State School. And by that I mean I look now at the need to instead of a person with a disability living in their own apartment, it's like, Okay, now we'll put -- they have to be two or they have to be three people. What concerns me is that how much of a leap is it from three people to four hundred people?

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How much of a leap is it to say, "Well, you know, they all have the same disability and so we'll put them all together." There are programs like that existing right now. There are programs like that being built right now that are basically isolated communities where people with disabilities live and they have their stores and all that kind of stuff. That's not much different from New Castle Development Center or Laconia State School. And my fear is that we will forget that any kind of congregate living, any kind of putting a bunch of anybody together over the long-term in a living situation -- at some point, somebody is going to forget the individual human beings involved there. One of the sad things about institutions is that the staff were not bad people.

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But because everybody was, like, sort of living in a lump they forgot the individuals there. When I was involved in the closing the Laconia State School, I was asked by the court to go back and monitor the closing of the institution. And I remember going down a hallway, and by a door there was this huge box of boots and shoes and stuff. And I remember saying, "What is that?" "Well, that's their boots." "Well, I don't see any names on them. How do they know?" "Well, they don't really have their own. It's just, you know they take a pair and put it on. And if it fits, that's fine. They walk out the door and the last person out gets the last pair of shoes." I don't ever want our general community, our government even to forget that these are individual people and that we can't treat them as if they were cattle or a group - that we need to remember they're individual people. It's costly and it's going to be costly.

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But if we value people, we've got to make sure that the living arrangements, the working arrangements, the social arrangements take into consideration they're individual human beings and we don't ever want to go back to opening a New Castle or a Laconia.

JT: And do you -- excuse me -- do you see us going back instead of going forward, and promoting meaningful lives of quality and dignity? Do you see us going back from, like you're saying now, it's too expensive to be in an apartment by yourself. So now you have two, or three, or four roommates. And then you see that being a group home, and then a larger home, a small ICF/MR all because of finances, or do you think it's mentality or attitude, and why are you scared that we're going to go backwards?

DR: I'm scared but I'm also an optimist. And let me take it from the optimist side of me. The optimist says if we can build communities and get the sense of community that existed when I was a child, when, you know, if there was somebody sick next door, your mom made a thing of soup and brought it over to them. If we can develop that sense of community where we really do believe we're our brother's keeper, where we really do care about the neighbors next door and the people that live around us, the people that work in our supermarkets, the people that go to our schools, I think that that kind of sense of community is going to be what stops us from sliding all the way backwards. I think if we don't build that sense of community, then I'm scared that the economic situation is going to take priority. We can't let money take priority over community. If we do, in my opinion, we're doomed as a society.

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I don't want to be around in that kind of community. And I think that's one of the things that gives me a more positive optimistic feeling, is that I do see that sense of community. And it's funny because I see people with disabilities teaching other people in their community how to be a good neighbor. When we brought people out of Laconia State School, for example, there was this big -- and this was in 1991, so -- there was this big flap in the newspaper about the neighbors did not want. We had two women moving into a house. Neighbors didn't want them to move in. We won -- thank God -- and moved in. And one of the first things we did was have a neighborhood picnic. Nobody in that neighborhood knew each other. They just didn't know each other. When they came to the picnic, one of the people, one of the men who had been one of the strongest voices in opposition to it came up to me and he said, "Shelly and Sharon are the best neighbors I've ever had because they're accepting and they're teaching."

And I think we need more opportunities for people with disabilities to teach everyone else how to be a good neighbor and a good member of community.

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JT: That's good. So when you look at the future again, what do you see as foreseeable trends? What's the direction of service, and what sort of training are young professionals going to need? What sort of skills are young professionals coming into the field going to need to have? What are they going to need to know to work with people with disabilities in this century?

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DR: I think one of the things that people who are going to work in this field need to do is to learn how to listen and to learn how to pay attention to people like self-advocates and people who have been around for a while and know where we've come from because it's the young people that are going to be able to see where we need to go. They're going to have to build that road to where we need to go. But I think it's important that they listen to the self-advocates. I think it's important that they look -- it sounds so cliché -- but look outside the box. If somebody doesn't have a good living situation, look at other options. I think one of the advantages is we've got a lot of senior citizens who are needing support services and stuff. And I think we can learn from those people, too, in terms of what kinds of support we senior citizens want because it's not going to be any different for us than it is for people with disabilities.

And I think that's one of the things. I think probably social services, being able to support somebody in supporting themselves, letting go of people and making sure that they have the skills they need but not building, you know, a life around that. Let them build their own life. That's one of the things. And I really think that being good neighbors and being a good member of your community is probably one of the best things you can do. And again, teaching children, making sure that generations know that people with disabilities are not poor souls.

[00:41:44]

And this is very interesting because I went through the school of social work and I'm a social worker by trade, and I can't imagine that the school is that different now. And these are things we talk about at work, too. You know, what makes a good staff person? What skills do you need to have to be a good person who works with someone with a disability? And the very things you were talking about, I'm wondering how they're going to learn these things. Like you we're saying, you know, learn to listen to people that have disabilities; learn to listen to self-advocates; learn to think outside the box; learn to be a good community member. These are not things you're going to learn at a university unless the university starts teaching in a different way or starts talking about things in a different way, and maybe some of them are.

PH: We need more service levels?

JT: Yeah. And so that's my question to you is: Given the things that you are recommending or suggesting that people coming into the field need to have, whether they're in the school of social work or any other field but they're going to be supporting people with disabilities, how are they going to get this information? How are they going to learn these skills? I mean, a lot of us learned it through life lessons, you know, people with disabilities taught us.

[00:43:03]

DR: Yeah.

[00:43:04]

JT: So is there a way? You know, do we start asking people with disabilities to start teaching classes? To start co-training? So that's my question to you: How would you take what you were talking about further, and how do we start providing these good creative ideas that people need? How do we get them these skills?

DR: Well, one of the advantages I've had over the years is that every once in a while the School of Medicine - IU School of Medicine -- will send me an intern or two that they evidently have to pick a nonprofit organization and go meet with them. And so one of the things I make sure that every single one of those interns hears from me is: You maybe know everything there is to know about medicine but that parent of that child that you're examining, they know their child better than you can ever hope to know. And if you don't make that parent a respected and equal member of the medical team, then you're not doing your job as a doctor. The same is true of social workers. If you don't make that person that you're trying to help or their family or whatever, if you don't make them an equal and respected member of the team that's trying to work things out, then you're not going to do your job well.

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And I think it's going to be important that people with disabilities become the teachers, or at least have an opportunity to address a class or speak to individuals that are looking to get into social work or medicine or whatever. I mean, I think that's one of the most difficult things. And I mean, I've had case workers -- I mean, professional case workers -- call and say, "Well, you know, I've just got this client and he has cerebral palsy. And I'm wondering, you know, about what options there are for him for employment." And I'll say to that person, "Well, have you asked him what he wants to do?" And it just floors me that that is not the very first thing on their mind: "What do you like to do? Where do you like to live? Who do you like as your best friends?" All those kinds of questions, that ought to be the very first thing that is taught to social workers, to medical professionals, and to everybody else that's out there to help because if you don't learn to ask those questions and listen to the answer, you're not going to be very good in what you do.

JT: Our center has done a lot of work over the last 20 years. That's what we've done is really try to, you know, work around community building; community membership; person-centered planning; and supporting people with disabilities to have a voice. And so it is very interesting. And we now have a woman that we helped learn how to be a trainer who goes to the IU dental school every year, every semester, and she talks to future dentists, and talks to them about what it's like to be in the chair and to, you know, not be respected or to them not ask her questions. Not to be afraid of her and that sort of thing. So there's a little bit of that. But I think that's the direction. You know, and you can --

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DR: And that person-centered planning, you know, it's much easier to do things the right way the first time around than to correct them. And if you focus on the person, it's really hard to mess up, you know, that first time around because there's a friend of mine that used to say, "Any road will get you there if you don't know where you're going." And if where you're going is not where that person wants to go, it's

not going to work no matter what you do. And so it's real important to have a clear vision from that person where they want to go so that you're not putting them on a, you know, on a bus to go to China because that's not going to work. [Laugh]

[00:47:13]

JT: That's right. That's right. Well, are there any career highlights that you'd like to talk about or anything that you're particularly proud of?

DR: I think there are three. One is that the center, the school that I started in New Hampshire that was named after my daughter when my daughter died when she was seven. And they named the school after her -- The Kimi Nichols Center. One of the proudest things that I can talk about is the Kimi Nichols Center now is a community center that's used by churches for bingo games and Girl Scouts for meetings. It is part of the community. And although my daughter was only on this planet for seven years, when I stop and think of the people whose lives she impacted directly or indirectly through me, and now indirectly through the center, I just can't tell you what that means to me. One of the best days of my life was in 1991 when I was invited by the Director of Mental Health in New Hampshire and handed a plane ticket to go back to Laconia State School and visit the grounds of the former institution for people with disabilities.

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And I visited with people who had lived there and other advocates that had helped to close the institution. One of the best moments was walking into one of the wards and seeing it completely empty. And this one gal that we had helped move out into the community looked at me and she said, "This means I'll never have to come back here again, right?" And I said, "Right, you'll never have to come back here again." That was one of the best days I ever experienced. And then I think the third thing is just the overall involvement that I've had in Indiana, in making United Cerebral Palsy -- helping to make it something that's going to be around long past me, something that is going to remain home for people with cerebral palsy in Indiana and is going to be part of a disability community that's going to make Indiana one of the best places to live if you have a disability.

JT: Well, that's a question that I didn't ask you. Do you feel like Indiana is ahead or behind in terms of a disability community, a community for all people?

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DR: I think Indiana is probably on a par with -- it's not a first in anything. I think it's on a par with most of the positive states and positive communities in terms of looking at person-centered planning and looking at trying to develop a service system. I'd like to think that it's a positive that so many children have participated in the essay contest, and that's sort of a guarantee of future generations. I think that it would be a mistake for Indiana or any other state in the union to think we're here, to think, "Oh, okay." One of the things I talk about is I don't drive my car by looking in the rearview mirror. And I would hope that whoever drives the service system for people with disabilities is not going to do that, that they're going to look down the road at where they're going instead of in the rearview mirror at where we've been and say, "Oh, yeah."

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But it's so much better than when we had New Castle." Yeah, but it's still not equal. You know, I want it to be equal for people of color, I want it to be equal for people, you know, of different sexual preferences. I want it to be different for people with disabilities. I want all of us to just be part of the community. And I think if we don't look down the road at that as the goal and instead look in the rearview mirror, then there's a good chance we're going to run into a pole and just stop dead. So that scares me a little bit, but I'm optimistic. I'm a believer. Go Indiana.

JT: All right. Can you think of anything else?

PH: Maybe -- and I'm trying to remember because we've gone through a lot about UCP and how maybe funding for it has changed over years and the role of the board.

JT: So talk a little bit more about UCP?

[00:52:00]

DR: UCP of Greater Indiana is going through what a lot of nonprofits are going through right now, and it's -- we're pretty much depended on fundraising and private donations. We get no government funding. We don't operate any services that we get fees for. We're down to one staff person. I've offered to take a cut in pay. One of the things that they say is, "If we cut your pay and you get run over by a truck, we couldn't hire anybody else to replace you, so no." That's the only reason they're paying me what they're paying me. But I haven't had a raise in seven years. One of the things we've decided to do is take a proactive stance and say -- so we developed something called the "SOS Committee." And SOS doesn't stand for "oh my God," it stands for "save our services." We want to make sure that we preserve the services that people rely on more than we care about preserving United Cerebral Palsy. So if there's a way for somebody else to do something that we're doing as well or better than we're doing it, then we want to make sure that we make that move.

IU is one of those -- I've talked with David Mank, and David Mank has agreed to include our resource memoranda in the Institute's electronic database and also has agreed to assign a student every year to update the top thirty or forty of those resource things so that that then the information will be there still for people. We've worked on the essay contest with the Governor's Planning Council, and they're committed to it. We're also working with another foundation, the Maley Foundation. And that was founded by the mother of a young man with cerebral palsy who died. His mom started this foundation, and they bought this puppet show called "Kids on the Block," which is puppets -- almost life-size marionettes -- with disabilities that go into schools and talk about disabilities.

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We're talking to Vivian Maley, the head of that foundation. If we can no longer do the essay contest, would she be willing -- her foundation be willing -- to take over the essay contest and work with the Governor's Planning Council to keep it going forever? And then the third thing that we do, which is buying durable medical equipment or doing the co-pay, that is money that came from a bequest that started at a million dollars. We spend about \$150,000 a year. While the market was doing well, we did

well. And so we still have a \$1.4 million in that account. That's the one thing that probably -- until, you know, that money runs out, we're going to focus on making sure that that's the one service that keeps going on whatever. It can be done -- I can do it from my home using my computer, that kind of stuff. The bank is cooperating with us, that kind of stuff. So that's the one service that we're focusing on now.

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And what we're going to focus our fundraising effort on to make sure that the one thing that we do that nobody else does, the one thing that we do that nobody else can do as well, remains. And if it remains under the name of UCP, that's fine; if it doesn't, that's fine, too. We're also working with The Arc of Indiana because we have a lot of clients in common. And so their case worker and I share information, although there is a rut between our two offices because we share information, and referrals, and that kind of stuff. So I'm pretty comfortable that number one, the SOS committee has focused on what's really important; and number two, focused on planning for those two services that if we can't do them anymore, somebody else can do them; and number three is focusing all our other efforts on making sure that we can do that one service that nobody else does. That helps me sleep at night.

JT: Good. Well, thank you. Is there anything else you want to say?

DR: I'm very pleased that you guys are doing something like this. I think this is one of the ways to help and make sure that fifty years from now when all of us are pretty much not on the planet, we're not going to make the same mistakes -- that somebody will remember, or read something, or see something and make sure that we don't make the mistakes. So I appreciate what you're doing about this. So thanks.

[00:56:41]

JT: Well, thank you for coming in. That's good. We'll talk a little bit about the parent perspective.

DR: Right.

JT: And if you could go back and kind of tell us the same story where you were talking about how for a long time you didn't know and you carried the guilt and --

DR: All right. I think the biggest issue for parents, especially moms of people with disabilities, is this guilt that we carry. It's like, I had one job and that is to safely carry this child for nine months and deliver him or her perfectly into the world. And I think that sometimes the service system -- oops -- [Mic falls off] is that okay?

PH: Yep.

[00:57:24]

DR: I think sometimes the service system does a disservice to those parents, too, because the overprotective parents I see are the ones that feel so guilty that something happened that they're going to wrap their children in cotton padding and make sure nothing else happens. When my daughter was born, I had a friend who had a child the same age -- I think there was two weeks separating them -- and I would

watch her child, Sandy, on the floor doing things and I would watch my child doing nothing. And I would go to my doctor I would say, "I think there's something wrong." And he would say, "Oh, you're just being a nervous new parent and all children develop at their own rate." Well, eleven months later there was a day she had fifty grand mal seizures in one day. And an associate in that doctor's office said, "Maybe we ought to look into this," put her in a hospital. And then I sat with another doctor who looked me in the eye and said, "Okay, your child has cerebral palsy; epilepsy; chronic heart and respiratory problems; profound mental retardation; and she probably won't live to be ten."

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Just bingo, like that. What that did was just cement the guilt I felt forever. It's like, "I had a healthy pregnancy." You know, they did everything but shine a flashlight in my eye and say, "Well, did you try to have an abortion? Did you want this child? Did you do drugs?" I did nothing. It was the best, the healthiest I've ever been. But they added to that guilt with the questions and that kind of stuff. The irony is that I had a friend that I was talking with one day, and I had written an article called "Original Guilt," which is about that original guilt that parents of children with disabilities feel. And he said to me, "If you could have Kimi back today, what would you want to have be different?" And I said, "Nothing." I mean, she wouldn't be Kimi if there were anything different about her. I wish there were days she didn't have to suffer with seizures and shots and stuff, but I wouldn't want her to be any different.

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And he said, "If you wouldn't want her to be different, if she's had such an impact on your life and other lives, how can you feel guilty about that?" And I tell everybody it was sort of like I'd been sitting in this dark room and there was some writing on the floor. And I knew it was there, and I knew it was important, but I couldn't read it. And this friend came in and just shown a flashlight on it. And the flashlight was: Kimi was perfect exactly the way she was, so how can I possibly feel guilty about this perfect Kimi? And I tell other parents that story, too, to try and help them let go of that guilt because it will tear parents apart, it will prevent them from dealing with some things that they need to deal with. One of the things that concerns me is a lot of parents who are in their 50s and 60s haven't made plans for what happens to their child after they're gone, and they don't want to feel guilty about "Oh my God, I'm not going to be here and nobody's going to treat my child."

They need to make those plans. They need to let go of the guilt of the past and make plans for the future so that their last thought on earth isn't "I wonder what's going to happen to Lucy," but "I'm so glad Lucy is going to be taken care of after I'm gone." And I think the guilt factor influences that. I think the guilt factor influences parents being willing to let their sons or daughters take a chance, to fail, to succeed, to be whatever they want to be. And that's why I work so hard to talk to other parents about guilt and to tell them that story about that day that I realized I have nothing to feel guilty about. I had a perfect child, a perfect Kimi. And these other parents, their child is perfect, too.

[01:01:38]

JT: That's a really nice story.

[01:01:40]

DR: Thanks. You're going to get me all choked up.

JT: You're a wonderful storyteller, good speaker.

[01:01:47]

DR: Thank you, thank you. Thanks.

[END OF INTERVIEW]