John Dickerson, December 4, 2013, interview 020-mi, transcript, Indiana Disability History Project, Center on Aging and Community, Indiana Institute on Disability and Community, Bloomington IN, https://indianadisabilityhistory.org

ORAL HISTORY INTERVIEW WITH
JOHN DICKERSON
DECEMBER 4, 2013
INTERVIEWER: JENNIE TODD
RECORD ID: 020-DO

JD: JOHN DICKERSON
JT: JENNIE TODD
PH: PEGGY HOLTZ
JHS: JANE HARLAN-SIMMONS

[00:00:10]

JD: Well, I'm John Dickerson and I'm the Executive Director of the Arc of Indiana. And we're a statewide advocacy group formed in 1956 by families when there were no services. I got into this really quite by accident. I went to college to play football, little tiny school in South Dakota, and I was going to teach History and coach high school football when I got out of school. Well, in 1973, there were a ton of Social Studies teachers and History teachers. And so I didn't find a job. And one of the coaches -- and I think back now and this is kind of interesting because the Arc had only been around, at that time in '73, for about 20 years. And South Dakota isn't a big state. But one of my professors in college was the first Special Ed professor at Huron College. And he said, "Why don't you go talk to these people at The Arc of South Dakota, they're looking for somebody". And that's how I got into The Arc, not by any family connection, not by any professional drive, but couldn't find a job.

And worked in the Arc for a year in South Dakota, then came to Indiana. Got a chance to work five years at the National Headquarters where I pretty much traveled the country and saw that we had family based organizations all across the country, Alaska, Hawaii, Vermont, Texas, everywhere. And then came back to Indiana in 1983 as the Executive Director.

JT: So, basically, your whole career has been The Arc.

[00:01:47]

JD: It has, it has. I often think my dad, who was in manual labor, would wonder when I'm ever going to get a real job, you know, because all I do is go to meetings and talk to people. So he would find that really strange.

[00:02:01]

JT: Well, talk to me about the early days of The Arc because, originally, I guess I have thought it was parent-lead as you were saying, it was organized and kind of put together in a variety of different states and communities by parents. So talk about how it began and how it evolved.

JD: Well, it's really an interesting history. In the late '40s, after World War II and I think it's triggered a lot by the whole phenomena that changed our country in World War II where women went to work. And all of a sudden, they realized they could do stuff. So, up until that time, doctors, educators, their predominant advice was, put your child away, forget you ever had them, get on with the rest of your life. And we had a group of mothers in the end, late '40s, early '50s that got together and said there's got to be something else. They had learned they could go to work in the factories, they could support their family and, tragically, many of them had lost their husbands in the war. And so they were now looking at a whole different way of thinking, and started in various places. We have this great argument in our movement of where it started first. New York claims it, Washington claims it. But however it happened, in late '40s, came together and, in 1951, we had the first national gathering of folks in Minneapolis.

[00:03:24]

And, out of that, it truly was an organization that started at the bottom and came together. We first formed a national organization, then we started forming state organizations. But, again, it's a very loose confederation, it's not a top-down model. But it was those first early moms and dads that wanted to get something together. In Indiana, we had, again, the same kind of argument, Marion County says they're first, South Bend, Lake County, Evansville, everybody claims they were the first. There was about 7 that formed right in the early '50s. And, in Indianapolis, they pulled -- we actually have it in the office, a little 1 inch ad, went in the "Indianapolis Star" and, of course, the language was we would consider very, you know, awkward today. But it asked for, and it just said, "Parents of retarded children, there will be a meeting at the Indiana War Memorial Sunday afternoon, 1:00".

And these two moms that put it together, they just had this idea, they'd maybe get 10 or 15 people, 300 people came. And they just sat and talked. So there was this huge undercurrent of people looking for this. And there was no internet to spread the word, no way of, you know, there was just this little 1 inch ad. So they got organized, got started and it was a couple years' later, they actually then formed the Marion County Arc, which then became Noble. And then those 7 first organizations formed the State Association in 1956.

JT: Well, it seems like some counties still have small moms and pops sort of Arcs, Brown County for instance.

[00:05:14]

JD: Right.

[00:05:14]

JT: Many years ago, I remember hearing about The Arc and it still appeared to be family-lead. Now some had moved to DSI in different counties, but they still considered themselves the Arc of Brown County.

JD: Right.

JT: And in Morgan County, where I worked, it was a long time at Arc and it had originated with family and then it became the School of Hope. So, is that typical, too, that many of the organizations started as maybe preschools and then developed into more of a service organization?

JD: The history of our movement is really interesting that, when those families got together, they first looked at we couldn't go to school. We -- the idea of work was really kind of foreign. And it was just this blank canvas. So folks got together and started the first schools. So, many times in, literally, in church basements. And some of the first teachers were people that were accredited teachers for something else because there were no Special Ed degrees at the time. And so they just found somebody that really cared and started the first schools. And the history of our advocacy movement, Wolf Wolfensberger wrote a really interesting book in the '60s, late '70s. And he traced this, that we first came together as advocates and started things. And one of two things happened, they either spun them off as they got bigger and to a professional service organization, or The Arc kept it and morphed into a service providing organization itself.

[00:06:53]

And, in Indiana, we developed both. So we, today, have 45 chapters of The Arc in Indiana, there are around 800 nationally. And about 25 of them still run services, some very large, 20 million dollars a year. About 20 of our chapters spun their services off and they're advocacy only. And this is a pattern that other states have done. So, in Minnesota, they're all advocacy organizations. In New York State, they're all service providing organizations. And we're kind of this hybrid along the way of -- we've seen the transformation of various different models that are out there. It's one of those interesting challenges that we face as an organization, too, because those families that we need. And the other really exciting development is The Arc was very instrumental in was the self-advocacy movement.

[00:07:54]

So, while you're running services, if you're a service chapter, then you also had to have this family base that, like in Logan up in South Bend, they created the first Guardianship Board. So here's a service provider that added a Guardianship Board that has actually sued themselves because they've, you know, they're advocates at one hand and they're also service providers at the other. And it's kind of a difficult balance to achieve sometimes. But I think it's what separates out some folks, if they do it right, they keep that family connection where the board is largely driven by folks that have a consumer interest first and a provider interest second. And they also have developed a strong self-advocacy component to hear from people about what's important to them.

[00:08:44]

JT: And we're going to talk about self-advocacy in a little bit. I'll drill you more about that.

JD: That's okay.

JT: So, now what I'd like to talk about is your name because, originally, it was ARC, Association for Retarded Citizens. Now it's pretty much The Arc. And I know that, because it was so branded, it would have been very difficult to change that, but you want to talk about the thinking behind that?

JD: Sure. Well, The Arc name is an interesting story in itself. And having been around for a lot of the changes. We actually, when it came together in the '50s, there were groups that were called Parents and Friends of Retarded Children. And, again, at the time, there weren't a lot of adults, because most of our adults had been placed away in institutions. So it was that core group of families that started us who had younger children that were rejecting that model. And so when we came together in Minneapolis, the very first name was Association for Retarded Children. And it was very common, at that time, that people thought of their adult kids, too, as they got older as children. So, in the '70s, we went through our first change and I came into the movement right at the time that debate was going on. And the move was from Association for Retarded Children to Retarded Citizens.

[00:10:15]

And the whole effort around the word, "mental retardation" was just starting to begin in the '70s, where people were realizing how negative and hurtful that was. But it hadn't reached that level. And so there was a movement at that time to just begin to get rid of the "R" word. And, but it didn't catch on. Because we had the, a lot of old time folks that had grown up with it and said it's not a bad word, it's a medical term. And it's just how people are using it. And it's also probably interesting to note that the self-advocacy movement in the '70s was just starting out. We had started out with citizen advocacy which was Wolfensberger's third stage of advocacy of teaching people to speak for themselves. But the idea that, in the '70s, we still weren't listening, which is interesting because the whole civil rights movement was emerging at that time, and the Voting Rights Act of '65 and all these things that happened.

[00:11:31]

But we had pushed the rights of people through the system, but we hadn't extended it down to them within our own organization. And so it was in the '70s that some leaders started coming forward and it was also interesting in the '70s because we had the very first youth ARC. And now it’s funny because, being on a college campus in 1972, I remember seeing a organizing poster for youth, NARC which is was our National Organization, National Association for Retarded Citizens. So I remember walking into the dorm and seeing Youth NARC, wonder what this is all about. Wasn't real popular. But it was that youth movement in high schools and colleges that started reaching out to young adults with disabilities and just hanging out with them and doing stuff that other teenagers and young adults do that really, I think, spawned our self-advocacy movement.

[00:12:33]

And they were saying to the adults, the parents, you know, you need to be listening to what your son's telling you. And it was really that, they became that bridge. Now the youth movement ended in the '80s and it's kind of interesting. And I think, as kids became more interested in themselves as opposed to others, in the '80s it was kind of a curious time. And it's kind of like now we've got through Best Buddies and Special Olympics a whole lot more interesting things going on with high school and college kids. But that whole name change, then, in the early '80s, we went to citizens and then we just went to Arc, where Arc doesn't stand for anything. It's not an acronym anymore. It's just a name. And that was a compromise because there were folks that wanted to go to something totally different and to not have any remembrance of mental retardation anywhere.

[00:13:35]

And it's just been an interesting evolution. But what came about in the final compromise, and most things are compromises in a large organization, is The Arc isn't particularly well known in the general public. But we're remarkably well known within policymakers and legislators. When we did -- it was interesting -- when we did the National Council of State Legislators in Indianapolis, and we had the first booth for The Arc about 15 years ago. And this is legislators from all across the country. And it was an interesting experience because we had legislators coming up to us and stopping us, "Oh, do you know so-and-so in New Hampshire?" or "Do you know so-and-so in Missouri?" And the policymakers knew who The Arc was. But if you went down the street in New Hampshire and Missouri, they probably -- average people on the street didn't know who we were because, over the years, so much of our work has been focused on policy and advocacy on the system's level and then working directly with families.

So the name has been an interesting evolution. And, over the years, we've seen, you know, the Down syndrome organizations were once part of The Arc. And they broke off in the '60s because Down syndrome was different. And now we have two different Down syndrome groups. And the whole rise of Autism. And we have multiple Autism groups now. I was thinking, after hearing a presentation the other day, it just struck me, I wonder what The Arc would look like if we were being formed today in the internet age. Because anybody can start a group in moment and, all of a sudden, have a thousand followers on Facebook and, all of a sudden, you have a group. Whereas these women that got together at the War Memorial, they had to have minutes, they had to have old fashioned communication. And you couldn't have splinter groups start as easily as you can now. So I think it's an interesting phenomenon that we didn't have to deal with at that time.

[00:15:39]

JT: You touched a little bit on this, but maybe, very concisely, if you could tell me what the role of The Arc is in the state of Indiana. You know, what you see the primary role of the organization.

[00:15:52]

JD: Well, the role of The Arc is a really good question. And it's evolved over a period of time to where, I think, today we really have three primary missions. One is we continue to have that family and self-advocacy base that, if you ask me the one most important thing we do is we fight on behalf of parents of individuals with disabilities to make the systems responsive. That includes funding them, making sure the administration works, making sure, when we pass a law, it actually does what it's supposed to do. The second is that sort of systems advocacy back with families to make sure they know what's out there. It still stuns me, when I run into someone, and I was speaking at a conference. We did -- cosponsored a conference for fathers put on by the Fatherhood Leadership Center, it's actually an African American group here in central Indianapolis. And the leader happens to have a son with Autism.

And so he wanted to branch out and train fathers how to cope with what he was dealing with. And one of the guys working at the hotel, Ivy Tech's Conference Center, happens to have an 18 year old daughter with Down syndrome and, if the high school has told him, he didn't hear it, which is possible, or he wasn't ready to hear it or they didn't tell him. He knew nothing about Medicaid, knew nothing about waivers, knew nothing about voc rehab. And she was going to get a certificate of completion this May. Now all of those things are there, they shouldn't be hidden back behind a curtain, so part of our job is the policy side fighting for to put things in place. But then, secondly, making sure families and individuals know what their options are, and many don't. We now have a mailing list. We do a newsletter 4 times a year, and it goes to 20,000 households in Indiana now. But we probably have 180,000 people with developmental disabilities in Indiana.

[00:17:59]

So we have all these folks. So, I gave him my card, and we hope will connect him with the right people so things don't fall. So, the policy advocacy, the system's advocacy with family and then, third, is the area of innovations that we've always been about change. And so, now we're trying, with our blueprint, to think creatively about whole new ways of doing things. Because we don't have enough money, we don't have enough staff, potential staff, to sustain the system exactly as it is. So, we've got to think of new ideas and new ways of doing things that are what people are asking us for as opposed to what the system is really good at doing. You know, systems are really good at doing the same thing they've always done. And so, we're about innovations, and so we try to gather from folks the new ideas and then say, "How do we pick from those and do some different things?"

[00:19:00]

So, now we're working on -- our Board just approved, we're going to get 5, 10,000 dollar start-up awards to people that want to start their own business. And we're going to link them with a business school so that, if it's somebody from Bloomington, we're going to approach the Kelley School and say, this is, it's going to be a competitive process so that they want to start a business, and be self-supporting. Then how do we hook them up with a business school and get them the kind of support they need? Because starting your own business is really hard, half fail in the first year. But we have a young guy that has his own cookie store in a mall in Evansville. And he's been doing it for 12 years, and he loves selling his cookies. We have a young guy who has a coffee shop, happens to have cerebral palsy in Connersville.

The idea that people can be dreaming, and that's the nice thing about our conference here, Dare to Dream, that it's not just what's offered in front of you, but what do you really love? So, policy, systems advocacy and innovation are our 3 biggest roles.

[00:20:05]

PH: I think we lost – mic fall down.

JD: Oh, did. [Laughter] Don't tell me I have to do that all over again.

PH: No, we got it so that when I tapped her.

JD: Oh, okay. [Laughter]

JT: You're doing an excellent job [inaudible].

JD: Well, you said concise, I'm never concise.

[00:20:23]

JT: No, you are doing an excellent job.

PH: You need more water?

JD: That might be a good drink right now.

JT: Did you get everything out you wanted to say in that piece?

JD: Mmm-Hmm.

JT: Okay. Let's see, are you ready? Okay, so The Arc Trust is something that I've heard about for years and years and years. Can you talk a little about The Arc Trust and what that is?

JD: It's part of our innovations model. We -- 25 years ago, a group of family members got together and said, "You know, it's really hard, if you have a son or daughter with a disability and you want to leave them some money." You had to have a lot of money, because, if you went to a bank 25 years ago, you had to have, at least, 150,000 dollars. Most Hoosiers didn't have that. And so we had some really smart parents come together and say, "Well, you know, there's this way we could pool this, put in small amounts of money" and so they formed, helped us create The Arc Master Trust. So we're now 25 years old. The idea that we were able to use existing legislation that allowed what's called a qualified special needs trust. So families could leave money to benefit their son or daughter with a disability. It can be intellectual or a mental health disability or a physical disability as long as it meets the Social Security definitions.

[00:21:53]

And it doesn't count against their, as an asset for either Social Security or Medicaid. So, we used to call it the five TV rule. Somebody'd get a back payment from Social Security of 10,000 dollars, or Aunt Nelly put them in their will and, all of a sudden, they had to go spend 10,000 dollars before the end of the month. And it was crazy. So, this allows families to plan and say, just like they would do for the rest of their family, I want to leave 30,000 dollars for Joe. And what we have is a pool that is a very low-cost option that we give them all the legal paperwork to give to their attorney, usually it's put in their will, and this is a irrevocable trust that then goes for the sole benefit of their son or daughter. They leave us what's called the Letter of Intent that they can change right up until the last day and says, well, I'd like him to go visit his sister in Florida once a year. I want to make sure he has new winter clothes, I want him to go this, I want him to do this, I want him to live in our family house.

[00:22:59]

Here's the trust that'll help support that. We are given, then, a set of instructions. The important thing there for families to understand is, while they can give us those instructions, we're not bound by them. That has to be part of the trust relationship that the government requires. Ninety-nine percent of the time, we follow what they ask us to do in the Letter of Intent. But we approach it, we have a -- governed by our Board, which is parents, and we look at it, we would make decisions based on what you would do if you were still here. So, if Joe comes in and says, "I want to take my whole 30,000 dollars and buy a used red corvette," we'd say, "No." You know, let's think about some other things you can do for fun. But, and most cases it works very well that way. But the trust was a tool that was designed to help families plan for the future and still take advantage of those important benefits, because most people don't have enough money to cover all the services that their son or daughter would need.

[00:24:05]

And if you happen the wrong way to get too much money, you lost all your benefits and then you lost your services. So, we have two trusts. One is the original Master Trust one which is for families to leave for their son or daughter. The second is [coughing] excuse me, we have two trusts. The first is the Master Trust designed for families to leave for their son or daughter. The second is when people come into money themselves, back payment from Social Security, an inheritance, and that is called Trust Two. And that has a little bit different set of rules because the government used to just take that money. And now, they give us a different way of doing it. [Coughing] Now I need more water.

PH: We'll just leave the pitcher here.

JD: Good morning.

JHS: Good morning, how are you?

JD: I still remember a picture of you from the self-advocacy picnic. Do you remember the one where you made an Indian headband out of tickets?

JHS: [Laughing]I will be forever trying to [inaudible] that headband.

JD: It was great.

[00:25:16]

JHS: I guess you have to be remembered for something.

[00:25:19]

JD: Being a good sport. I don't know if my coughing took too much out of that one or if you want to do it again.

JT: Think you got that?

PH: I got most of it.

JD: Okay.

JT: Well, and this is maybe off camera, and I don't know if this would be clear or we would need to know this. The money that -- say I put money in or I give you 50,000 dollars -- .

JD: -- Yes.

JT: To take care of my daughter down the road. Does that money sit there and say, I, say, all right I want her to stay in my house, this is going to help. Does that 50,000 dollars help find support for her to stay in the house? So, you do a lot of legwork to make these wishes come true.

[00:26:01]

JD: Right, right.

JT: And that has to cost some money.

JD: Well, one of the nice things about this is the Board made a commitment that, one, we'd be low cost so it's less than 700 dollars to enroll in the trust. And that gives you all your legal documents, all the planning and set-up, that's a one-time fee. Go to a lawyer, and say you want him to write a trust, they'll spend several thousand dollars. And they'll do a good job, most times. But what we then did is, the Board subsidizes it and it now brings in enough fees that it pays for our staff, including now the staff of 4 and we're just going to add 1 and a half more people. In fact, we're asking the Board on Saturday to approve hiring our first social worker because we have a small number of people that have really intense needs. And they have money, but they need somebody kind of blocking and tackling for them every day because they just get in unfortunate situations. So, what we've been able to do is build a fee structure because our Board was saying, "We've got to, if we're going to say this, we're going to take that 50,000 dollars and be there for the life of your daughter, we've got to be able to deliver on that".

[00:27:11]

And we are not fundraising to make this work, it's got to be self-sustaining. We now have 50 million dollars on deposit in the trust. That's a big number. More importantly is last year, in 2012, we gave out over 6 million dollars to beneficiaries to buy things for them. Again, everything from trips to cable TV bills, things that there that mom or dad would help with. Now, if somebody's living in their own house, and what we try to sit down and we plan on the front end, and we'll meet with families as many times as they want to meet. And say, "Okay, we need to be realistic. If you've only got 15,000 dollars, we invest that, but we don't promise great returns. But that'll buy so much. But if you have 150,000 dollars, you can buy more. But you need to think about what is it you want to accomplish and what other services are going to be there for you. And this is an extra in life."

[00:28:12]

So, we've also found one of the interesting things about half the people in our trust now are people with mental illness. And one of the real challenging things for a number of folks with intellectual disabilities, as well as people with mental illness, is they don't have much of a circle of friends. And so we have a number of people that don't use their trust because life is chugging along in the group home or in the waiver setting, and nobody thinks to ask for the extras. And so, we're working with this -- the idea of the social worker that would help them develop some -- we're targeting some folks that don't spend their money. We're not saying go willy-nilly spend your money. But, you know, when somebody dies and they've had this money and it's been available to them, we give it to other family members or other people the families have said, if it's Trust One. If it's Trust Two, the deal the state made with us, the federal government is, we won't take that money the way we have.

[00:29:13]

But, when they die, if there's a Medicaid lien, half goes back to the state of Indiana to pay their Medicaid bill. We can retain half for people whose trust run out. So, we don't use it for The Arc operations, what we do use it for is people whose trust ran out and they're still alive. So, we have several people now that their trusts were exhausted. We can't promise that we'll, with your daughter, keep going once that 50,000 is out but, right now, we believe that, until things change, we'll be able to keep helping people on that end of it. So, it's designed that -- I often tell my colleagues in other states, don't go into this think you're going to make a lot of money doing that. But go into it because it's a great service back for families. I had a mom, Kate, share with me, and it took her a long time, took her 20 years to think about finally doing the trust. And what pushed her to the edge of doing it is she discovered she had a very serious form of cancer.

[00:30:18]

And she sent me a note and she said, "John, it just took me a long time to get to this point, but now that I've signed it and I've done it, I can rest a little more easy at night knowing that my son's going to be -- have this as an option for him. And it doesn't burden my husband to be thinking about it." So, it's been something. It's just funny, yesterday, I was in the office and our trust staff happened to be all out helping other people. And one of our beneficiaries, and he's a real nice guy, and he comes in every month and he's making it on his own pretty much. But we help out with some of his bills. And he said, "John, I just need help with my cable bill this month. And I'm sure I'll handle it my own next month." And he was almost apologetic. I said, "You know," I'll change his name, "Sam, you know, we'll -- I'm sure we can take care of this and I'll get this done". He said, "You know, I just I'll do better next month". You know, and he's really doing quite well. He has a job and this way, the trust helps pick up a lot of those other things with his rent and electric things that we can help take care of.

[00:31:20]

And he's fairly independent.

JT: That was a great explanation. So, how is The Arc funded? Where, what sustains you all?

JD: Well, we're really fortunate. Our 45 chapters provide about 20 percent of our funding. Then we do a lot of fundraising to make money for The Arc. Then we, we're now at the point where the trust sustains itself, so that carries its own weight. And we've been just very fortunate that a lot of folks contribute and give money to us. We do a number of grants with the state and that's been a really good thing to get us to follow some of the things in our mission. You don't make a lot of money doing grants, but it's been real helpful. And we've been really fortunate. We've had some great partners here in Indiana. I think that Indiana's this interesting state as I travel around the country, that we've got some wonderful relationships here that aren't always there or everywhere else. The relationship we have with the Institute is just tremendous, the Governor's Planning Council, IPAS, INARF, the Autism Society.

I think there's, you know, we're not known as being the great innovators here in Indiana, but I think we get along pretty good, and figure out how to do things. And so, we may not capture the attention of a lot of folks, but I think that one of the things we've been fortunate is people have found a way to work together in some interesting ways.

[00:32:50]

JT: Good. Well, the next question that I want you to talk about has to do a little bit what you were just saying, how does Indiana stack up? How does our Arc stack up against other states in terms of innovation, self-advocacy, leadership, those sorts of things. You know, where are we ahead? Where, maybe, are we a little behind, if anywhere? Just trying to compare Indiana to fellow states.

JD: Well, it's interesting. If you were to look at how Indiana compares with other states, again, we don't get a lot of the publicity. And maybe that's because we're Hoosiers, we're too busy doing stuff instead of telling people what we're doing. But I thought it was interesting, there was a period of time and, I believe it was back in the early 2000s, 2005, 2008, somewhere in there, but it was interesting that we had the past President of CEC was from Indiana. David Mank was President of the UCEDD group. We had the President of The Arc Professional Group was from Indiana. We had a President of the Professional INARF Group was from Indiana. And, you know, it's interesting. So, we must doing something right along the way. But we're never looked at as one of the great innovators that are out there. In terms of where The Arc stands, probably that would be easier for somebody else to talk about. We're the second largest Arc in the country, New York's bigger than we are.

[00:34:21]

They have more members, they have more chapters and, but I think that, where I would go back and look at it is, when we always do our annual evaluation of how well we're doing on our strategic plan, we don't so much -- we have to look at the budget, are we making money or losing money? And I'm really good at, my Board will tell you, I'm really good at spending money, not so much at building up big reserves. But we try to look at what's the difference for people with disabilities. And I think we're just quietly making a lot of changes. You know, we were the 13th state in the nation to close all our institutions. At the time, we are the largest to do it. Now that's changed, Michigan's done it. We've never been out there, I think, tooting our own horn, but I think there's a lot of really good things. You know, we have a lot of folks working in jobs in Indiana. We have a lot of innovation going on in programs around employment. So, I think Indiana's come a very long way, and we're not often recognized for that.

[00:35:24]

But we've got some really world-class leaders here that people look to. If you want to talk about employment, there's no one better than David Mank and Teresa Grossi in the whole country and, perhaps, the world. Now, they would not like me saying that, but I think it's true. You start talking about Autism and Cathy Pratt, again, one of those national leaders, was President of the Autism Society of America was right here in Indiana. And I think there's just this kind of can-do attitude we do, and we just kind of do it, and don't spend enough time, probably, telling everybody all the great things we're doing so.

JT: That's a very good answer. All right, so legislation. So, you talked earlier about that that was one of your roles, or one of the roles of the Arc. So what we'd be curious to learn about is how's that work in Indiana? And are there some stand-out politicians that you've worked with, people that have really supported disability issues and people with disabilities, that sort of thing? Let's see what else I was going to ask you about that. Some benchmark pieces of legislation that has passed? So, if you want to elaborate on.

[00:36:37]

JD: Well, yeah, here, it's interesting, when you talk about our role in public policy, and The Arc has a rich history in that. I was fortunate. When I started in '73, we were just on the cusp of mandatory special education. So, the very first meeting I went to was writing the first draft rules for mandatory special education in South Dakota. So, imagine you're in this room, we had no rules. And we had educators and parents and The Arc was there, and people were saying, "Well, how are we going to do this?" Because we knew it was coming and the states were charged with starting to plan for it. And it's interesting, Congressman John Brademas from Indiana, from South Bend, people don't often go back and look at that, he was one of the prime sponsors of the original special education mandate. And he is quoted on the Floor of the House of Representatives, it was interesting, he was debating, I believe it was a colleague from Texas, who got up and said, "Well," and it's hard for us to accept today, this colleague from Texas was saying something, I'll paraphrase here.

[00:37:47]

Some of these kids, they can't even be taught to put their pants on. And Congressman Brademas stood up and he said, "I don't know about you, Congressman, but it's important for me to know how to put my pants on every morning to keep my job here." So I think that we've had champions like that. They've been on both sides of the aisle. Senator John Chafee, from Rhode Island, who looked at the first idea of how do we transform Medicaid. Ronald Reagan did the first Medicaid waivers over Katie Beckett, a young lady he met in Iowa who couldn't leave the hospital because Medicaid would only pay for her to stay in the hospital to get a machine that she needed, instead of putting it in her home. So, we've had some great champions over the years that just have kind of set the stage for us. Our current Speaker of the House, Brian Bosma, his dad, Charlie, went on the first trip to Minnesota when group homes were not even thought of in Indiana, Charlie said, "Well, let's go take a look".

[00:38:55]

So, he loaded up a van with legislators and we drove to Minnesota to go visit group homes. So, we have people, if I get into our current day ones, I know I'll offend too many because I'll forget some. But we have some tremendous folks, and it doesn't matter whether they're Republicans or Democrats, that, once they've gotten it, they continue to understand. Some have family members, most don't. But they've just been touched by someone and that's the real spirit of what is different about our movement is, it's not what Kim Dodson, our Associate Executive Director, and I say with them. It's when families touch them, and individuals with self-advocates coming to them and talking about what's important to them, that they start getting it. And I remember, he's now retired, but Senator Thompson, not the current Jeff Thompson, his dad, was -- came up to me one time and he was kind of, he was a very fiscally conservative Senator from over in Hendricks County.

[00:40:07]

And he said, "Dickerson, I finally get it". He said, "Our bank hired a guy and I'm on the Board of Directors of the bank and we hired this fellow with a disability. I don't even know what his disability is, but he's one of our best damn employees." And, all of a sudden, it clicked for him that, you know, it wasn't just this chart. Or it wasn't something there, it was good business. And I think that's what's worked. And, you know, we just recently honored the House Republican Caucus because they supported us on the idea we're building the training institute and hotel in Muncie to take advantage of the hospitality industries in one of the fastest growing areas. It's an area where you can get a career and you can advance without necessarily a full college degree. But we can tie post-secondary education into working in a hotel and developing a career path for people with disabilities. And we're excited about that. And they gave us 5 million dollars to start towards. We just now have to raise another 20 million dollars to do this.

But it's never been done before. And 20 percent of the people in the hotel, from management down to every associate, will be individuals with disabilities of all different kinds. The hotel is being designed from the ground up so that anybody can work in any station and be trained, whether it's the front desk, back office, management, housekeeping, the restaurant and find a career path to move forward.

JT: Is that something that is done other places, or is Indiana the first?

[00:41:42]

JD: This has never been done before. We're, hopefully, going to be able to make our announcement of the franchise will be -- you'll recognize right away the franchise we've got. But we're still going through all of the I’s and T’s being crossed and dotted. But they're very excited about this because nothing's been done like this before. And they're starting to get interest from throughout their chain because every day, in hotels just like this one, there are jobs that go wanting. Because they can't find the right folks to do that job. And they -- if we can help them understand that there's a good workforce here that really does want to work. Suzanne Clifford did a great demonstration project with RSA and, of course, it went through sequestration, it got cut, funding was removed. But their target population, and this is what steered us toward the hospitality side was people with mental illness and an intellectual disability and being homeless.

[00:42:50]

So pretty tough series of things to tackle. They had 63 people they recruited; they found all of them jobs. Their average training time was 8 to 12 weeks.

JT: Wow.

JD: Now these were folks that were living in shelters and one of them got a job working the Super Bowl at Lucas Oil. And for the previous five years, he'd been homeless. Now he still has a problem, he can't get VR, he can't get Social Security because he has no address, he's living in a shelter. So, it wasn't magical, I mean, but he's on a path now where he's got a full time job with benefits. And, if we can get him a credit history, and get him going, it was remarkably successful. And they started with the first idea is the first thing we've got to do, Jeff, is you've got to take a shower every day. You know, if you're going to go to work, you've got to take a shower. Now he still has all these challenges, but he's got a job. And even though the funding quit, they've kind of kept meeting and keeping going. And so, it really showed us that we have a lot of people that want to work. We have a lot of folks that we have to still break down a lot of stereotypes. There's a gentleman in this very hotel who's worked here in the Westin for 14 years. He got his job through Noble. He doesn't like being talked about as a person with a disability.

[00:44:07]

He's just worked at the Westin for 14 years. And he'd probably get a little peeved if we pointed him out to people. You know, he just likes working.

JT: Okay. Well, I think that pretty much covers it within the role of legislators doing good work. You've pretty much given us some good information. Well, this'll be fun. This is where we talk about self-advocacy some more. In Indiana, who do you see as leaders in the self-advocacy movement, and why? And, also, the skills that they have to be leaders, how did they get those skills? Where did they develop them? And kind of what are key skills to be a leader?

[00:44:53]

JD: Well, we are blessed here to -- one of the things that well, I'm very thankful for is the role of Indiana Institute on Disability and Community. Because they really gave the first kick start to self-advocacy, and supported getting the first grants, helped the Board get going when we didn't have much of a movement at all. But we had a few sparks out there, the people that wanted to start speaking up. And so our first generation of leaders were folks like Darcus Nims and Betty Williams that had the courage to step up and say, "Well, I want to talk about this". And it was hard. And they came together, started figuring out their role and then they -- we've always had what we called "helpers" for them. And then they started pushing back against their helpers a little bit that some of the -- it was just the natural growth of it.

[00:46:00]

What we, we on the advocate side, have witnessed is people now being taken more and more seriously. I always try to have Betty, Melody Cooper are always going with me to meetings. We're bringing in the next generation now of folks speaking up for themselves. We're seeing some interesting evolutions, too, on the Autism spectrum where it's really quite fascinating. Because we, on the Autism side, we haven't had the years of people with Autism being their own leaders. And so now we're seeing a emerging statewide and national movement of persons on the spectrum speaking up. And that's really good because they have a different view of the world. Next Saturday, I'm meeting with a group that's been meeting at the Calvin Fletcher Coffee Shop here in Indianapolis.

It's young adults and they just get together and talk about stuff. And we're not trying to get them into developing more of a training role. Now they're interested in being with folks that are more like them than with people with intellectual disabilities. But so there's just some forming going on right now, but I think that's all good, if we find that we have the patience to listen to folks.

[00:47:31]

JT: Well, what makes someone a good leader? What makes Betty Williams or Melody a good leader? What makes up and coming people a good leader? You know, what skills would they -- what skills would you hope they have, and how would they get those skills?

JD: It's a really interesting question of what makes a good self-advocacy leader. And I think it's the same set of criteria that makes anyone a good leader. I think being understanding of your role, not taking yourself too seriously, but taking the work very seriously, listening to your constituents. But I think that we are looking for folks that understand that, as a leader, you have a responsibility not just to always be right, or not to always be speaking, but to be there representing folks.

[00:48:24]

And sometimes that's representing folks that you don't always agree with, but if the group feels, here's where we've got to raise an issue. And there's an old Methodist phrase in the hymn book that the, I think is interesting, because it talks about advocacy. And it's a little 4 line, little phrase, not a hymn. But it said, "Our mission in life is to bring comfort to the discomforted and make the comfortable, uncomfortable". And I think, with self-advocacy and our overall advocacy, that kind of sums up what we're doing. We've got to find the right ways to do it. We don't always have to be pounding on the chairs with our shoes. Sometimes we have to be a little bit forceful. But we're also Hoosiers, you know, we're a little bit different than people in New York or California. But I think that one of our goals on leadership is we are now talking with Best Buddies, with Special Olympics, with Kiwanis Action Clubs and with Self-Advocacy of Indiana, they're all doing leadership training and it's all great.

[00:49:30]

We've got to be sharing all that. We did the first brochure for self-advocates saying, here are all the Action Clubs in your area. Here's all the Special Olympics Ambassadors Programs. And they have now their Academy Program which is great. Here are the Best Buddies Groups. And we're saying, let's -- there's room for everybody in this tent to do things. And it's not all being done one way, and I think that's pretty cool. But when we have a young man going out and speaking about going to Greece for the International Special Olympics, and it's not just about the fact he ran a race or lifted a weight, but he was representing his country. Very cool. So I think, as we look at this, we're also seeing how they give back to their own communities, and I think that's a nice touch.

JT: Yeah, that is good. All right, so, you know, we all agree there's many notable leaders in the state. Many of them aren't with us any longer. And one person that I would like you, if you're comfortable doing this, to talk about is Elbert Johns.

JD: Oh, yes.

JT: Because I know you and Elbert worked together and you were friends and comrades and that sort of thing. So, would it be okay if I -- ?

JD: -- Sure.

[00:50:48]

JT: Asked a couple questions about Elbert? All right. So, what I'd like you to do is just maybe describe Elbert and Elbert's work, what people would remember about Elbert, maybe a story or 2 about Elbert, and then I'll ask you a couple other things.

JD: Sure. Well, one of the leaders that I recall was a great friend is, even though he was a Duke University basketball fan, but was Elbert Johns, who came to Indiana from Albemarle, North Carolina, where he was the local Executive Director of The Arc, and came to Stone Belt Arc in Bloomington. And, you know he followed a one of those early trailblazing leaders in Joan Burton that, you know, we still have the only Arc program -- it was a school on a major college university in the country is at Indiana University. And, like in one of those founding chapters that was one of the first 7 that came together. And Elbert kind of represented this interesting part of our history because there was a time when we attracted a lot of executive directors who came from either the church or a background with a Divinity degree which is what Elbert had.

[00:52:06]

And they came with kind of this mission. We don't get that so much anymore. It's more professionals that have been through university training, they've got a degree in something else. But these degrees didn't exist back then. So, when he came in, it was this kind of learned skill and brought with this his empathy. And we had a lot of former pastors or divinity students leading what was -- which makes sense when you think about we started in church basements. So, it has a lot of sense. Elbert was always one of these critical thinkers that was always thinking ahead of how do we, how do we do things? And he was always one that I could call and say, "What do you think about this?" Or he'd be calling me with this idea. Here's this crazy idea we want to try to do something different. He was a true believer in self-advocacy. And when we were starting support in employment in Indiana, and I was looking around for somebody to be a champion for that, he was one of the first ones.

[00:53:07]

And his idea is we can get anybody a job. We've just got to be more clever about finding the right job, how we do that. And the thing that I guess I think about with Elbert, there's many times we'd walk through some place and he'd see somebody and he would always be stopped by someone. And it just -- he had that connection with people that was so powerful. And I remember when he passed and we had a chance to talk. I was driving back from southern Indiana and was coming through Bloomington and it was late and it was late afternoon and I still had an hour and a half to get home. And I thought, well, I'm just going to call Elbert because he had not been feeling well, but he hadn't had gotten the diagnosis yet.

And I said, "I'm just going to give him a call". And it was that afternoon, he had just come back from the hospital, from the doctor. And they had found out it was pancreatic cancer. And I said, "Well, you want some company?" And he said, "Yeah, I'm home alone right now and that'd be nice". And Chris hadn't gotten home yet. That's not something you want to call your spouse up over the phone and tell them. So we sat and talked. And probably he had the most wonderful attitude about everything, that here was now faced with this incredible diagnosis, one of the more tough ones. But he was all about, okay, what am I going to do about it? You know, how am I going to get through this and whatever happens, happens. But I'm going to make the most of it, and here's what we're going to keep doing together as we work on this.

[00:54:43]

JD: He was one of those, when anybody ever needed help, he'd drop what he was doing and go do it. I know when Chris and Elbert bought that house out in Ellisville and turned out that Bobby Knight lived down the street. And he was going through all the troubles, and he said, "Do you think Coach Knight would ever want any -- anybody just to talk to?" And I said, "Probably not".

But he was -- he wasn't doing it for the star power, he was just thinking, boy, if you ever needed somebody just to talk to, you know, I'd be glad to. He was that kind of a guy. And he had friends in The Arc movement all across the country. And when he passed, there were so many self-advocates that wanted to be -- from completely different agencies, they just knew him, that wanted to be there just to say goodbye.

[00:55:35]

JT: So, speaking of self-advocates and other people that knew Elbert, what would they say about Elbert? If they were here, and you were just saying, "What do you remember about Elbert Johns?" Or "Tell me about Elbert". What do you think they would say?

[00:55:48]

JD: He was a good friend. You know, that he was this trusted friend that if I needed help, needed advice, needed an idea, he was a good friend. And I think there isn't a much better epitaph that you can get than that. And when we did SABE, you know, Betty came to me. And we were actually at a conference and Elbert was at this conference. And Betty went to Elbert first. She went to Elbert first, instead of me. And they came to me and they said, "We've got an idea for you. We want to bring SABE to Indianapolis". And something had fallen through with something and so we only had a year to pull it together.

JT: Oh my gosh.

JD: And I thought that -- I hadn't thought about it in this way till you asked that question, what would people think about Elbert? Betty went to Elbert and he immediately knew this was a brilliant idea. And, yes, a lot of work. Yes, it would take us away from everything else. Yes, we had to raise a lot of money. But it was a brilliant idea. And, you know, with anytime you have someone that sees that gem and looks at the positives, instead -- there was a million reasons why we shouldn't have done it, you know. Everybody gave up time and money and energy we didn't have. But Elbert saw the possibility. And, you know, he really embodied, you know, there was a lot recently about the loss of President Kennedy 50 years ago. And his favorite phrase of, "Ask not what your country can do for you, but what you can do for your country". And that was Elbert's way of living.

[00:57:29]

You know, he wasn't about what he was going to get out of this, what he was going to build his agency or leave his legacy, it was all what he was doing for other people.

JT: And he was a very kind hearted.

JD: Yes.

JT: Simple soul. I really liked him. Okay, then, I guess the last thing that I'm going to ask you before I let you just talk is, in looking forward in terms of the field, what do you see as future trends, future movement? Where are we going next? And what sort of education, training are people going to need to have to support people with disabilities to do really good work on their behalf? You know, what do you see as kind of the future?

[00:58:19]

JD: Well, really interesting question. And I'm fortunate. If we ask the question, "Where do we go from here?" I've got some great help because we, 2 years ago with David's help, brought in 20 of the smartest people in the country to kind of help us answer that question. We've got to rethink everything we do from school all the way up to work. We've got, we've got to get much better at employment, and really building career paths. There are folks that we are looking to bring into the service system, they really don't need a lot of services. What they need is help getting a job and becoming more independent. We then have to work on greater resourcefulness for families. We're now telling people, a lot of times, here's what we can do for you, instead of saying, "What do you need?" It's interesting. We're bringing in about 2,000 people into services a year and a lot of traditional agencies are saying, "Well, we're not seeing them". And I did an [inaudible] survey of families and it -- who had recently gotten services.

[00:59:21]

And they said, "Well, there's two things. They are given this pick list and they start calling people". Said, "First thing, people got to call you back". Said, "Eight out of 10 people don't call you back or you can't work your way through their phone maze to get to somebody". Second thing is, when you do get somebody on the phone, you get two different responses. One is, here's what we can offer you. The second one is, tell me about your son or daughter. Which one are you going to pick? You pick the person that asks you. And that's got to be a whole mindset different, because we have some of the fastest growing agencies are not traditional agencies that have served people with disabilities. And there are folks that are listening to families, responding to them, being more nimble to what they want to do. So, I think there's -- we've got to be much more responsive to what people want. We've got to be less bureaucratic in our own thinking of what we can do. And we've got to keep changing the system because we still, we're really good at doing what we did last year, but we're not real good about thinking about what we should do next year.

[01:00:28]

And I think that's a mindset. A good example is I was speaking to a group of professionals and telling this story about this -- beautiful story -- this woman got an award. And I'm sitting up and she's getting an award at this annual dinner. I said, "Joyce", not her real name, I said, "Joyce, what are you getting the award for?" And she kind of looked down and she said, "Well, I moved myself out of the group home". I said, "Cool". I said, "Where did you live?" And she told me. I said, "I've been to that group home, it's a nice house. What is it you didn't like there?" "The other 7 women." I said, "Okay, so how did this happen? “ Well, turned out she was really unhappy and, every day riding the city bus back, she was crying when she got to the group home. And the city bus driver was elderly lady and was worried about her. And, finally, after a week of this, knocked on the door of the group home and "What's going on here? She's crying." So, came down that they decided they're friends and they got together and the lady said, "You know, my husband died a few years ago.

[01:01:29]

I have this big, old house. I'm kind of lonely, we kind of get along. Why don't you come live with me?" And she said, "Well, I don't have money to pay rent". Said, "I don't want any rent. I'm lonely, you don't like where you're living. Maybe we'd like living together." And I told this story to a bunch of staff and case managers. And this one nice, young woman with an MSW raised her hand and said, "Well, that's a beautiful story, Mr Dickerson, but it would never happen here because." I said, "Why not?" She said, "Well, we don't have any bus drivers to meet". We've taught people to be so literal and we've taught them to follow these plans that we quit listening to people. We quit thinking about what are some natural things we could do. So, the third thing's we've got to get more into looking at what makes people happy? What is naturally what they do? One of the things with self-advocates' unemployment is, I'll look at you and say, "Jennie, we've got a job for you over here at the McDonald's". Never asking you, "Do you really want to work at McDonald's?"

[01:02:27]

JT: Right.

JD: And I want to work with my friends over here. I want to work with nice people. And was talking with our self-advocates about this and there was an NPR thing, it just -- one of those odd little things. I was driving to their meeting, and they were talking about 100 people who self-identified as they love their job. And you know what the number one thing is? They worked with nice people. And we never ask people, "Are you nice?" before we're going to place people for jobs. And why do most jobs fail? Not because we can't do the job, it's the social thing. So, it's like, duh. I mean, what's wrong with us on some of this stuff?

JT: Okay, so, knowing this.

JT: Yeah.

JT: How do you bring in new people that get this? And how do you see influencing current people there to think outside their old traditional way of thinking?

[01:03:21]

JD: I think really three things. I want to see us start -- we've proposed this, we haven't gotten it done yet. I want to see us start paying people with disabilities to be job coaches for other people with disabilities. I think, why not get somebody that's already cracked this code to, as opposed to some person that's never had to do this, be the job coach for folks. And be that leader for them to be able to do that. I think, secondly, we've got to put into parents' minds, a whole new mindset about what the future looks like. We have a lot of folks out there that are still struggling, don't know what help is out there. But this is an investment that what you're doing for the future. So, yeah, maybe you'll only get the family support waiver, but that's 16,000 dollars a year. That's an investment for your son. And what do you want that investment to pay off in 10 years? You're going to get Medicaid, that's worth another 10 grand a year. And you may get Social Security for a while, until his earnings are up there.

[01:04:22]

So, you've got about 40,000 dollars a year to invest in your son. And it's not just taking what everybody offers you, but what do you really demand for your son. And, when he gets old enough, how do you listen to him about what he wants to do? So, I think that we've got to train that. And then, on the professional side with our organizations like INARF and our universities and our colleges, we've got to infiltrate them with people to think differently, take risks. And it's not about just doing the system, what we know how to do, where we know how to do it the way we did it last time. But how are we going to do it to make a difference for people and what they want. And you know what's interesting? We talk a lot about our DSPs and we need to pay them more, and we really do. But, you know, we have a lot of people, young people working in our field that are lost as well. They don't know where they're going with their life.

[01:05:17]

JT: Right.

JD: And we tried a project, it was really cool here, we've got to figure out how to fund it, continuing it. But we started pairing up one person with a disability with a DSP to really get to know each other. And the idea is, you know, the best person centered plan is one that never has to be written down, because I know you so well, I know what you want to do with your life. And, conversely, you know me and you know that I want to sing in a bar one day, you know. I want to break the courage barrier and get up there and perform in front of people. So, your job, as my friend, is supporting me. So, I think we've got to just keep that ball rolling and thinking differently. There's no one thing we're going to do. It's going to be this tidal wave that just keeps moving and, if providers and professionals don't grasp that and ride it, then they'll get washed away with it. If they do, they're going to transform themselves and be the next generation of new leaders.

JT: That's a really good answer. When we did the project in Morgan County, back in the late '80s, community membership project, and that's all we did. And we supported 20 people, kind of like the Make A Difference.

JD: Right, right.

[01:06:30]

JT: The best work happened because staff did spend time really pairing people up and all the good changes that came from people came because of people they met in the community like the bus driver.

JD: Yeah.

JT: And people got moved out of the group home. People started taking classes in the community because you said, "Hey, I see that you like to move a lot, you want to come to aerobics with me?"

JD: Exactly.

JT: Things like that. And it's because they got to know them.

JD: Yeah.

JT: And it wasn't [inaudible] away.

[01:06:55]

JD: You know we've -- I've asked our self-advocates to write a play of what a team meeting looks like from the self-advocate's side, with no rules. I don't tell them what it's going to be. And I keep telling professionals that. And they kind of laugh, but it's kind of this sad laugh because, you know what, our team meetings aren't about the person anymore. It's about the paperwork and the budgets.

[01:07:28]

JT: I've done a lot of training with people with disabilities around the leadership aspect. And one of the things that the scenarios that I do in this -- very short, but I talk about a chocolate chip cookie. And maybe they told you.

JD: Yeah.

JT: But we talk about all the ingredients of the cookie and, would it be a cookie without the vanilla and would it be a chocolate chip cookie without the nuts? Would it be a chocolate chip cookie without the chocolate chips? Well, of course not. So then I talk about what a good plan looks like. And they tell me all the ingredients about the plan. And I said, "But you're the chocolate chip of your plan". And that really resonates, you know.

JD: Right.

JT: It's your plan. I don't care what they call it. I don't care what kind of meeting it is but, if it's about you, it has to be about you. And he knows it's your responsibility to say, "I want this". It's not the same person with a different name. And that seems to help too.

[01:08:02]

JD: Yeah.

JT: It's just really empowering people to say "This is what I want".

JD: Well and, you know, when you talk about what makes a good leader is a self-advocate. The work that you've done with the leadership program at IIDC is really exemplary. And I think that -- when folks hear that there's this opening for them to speak up, it's so empowering. It's like when they saw Corky on "Life Goes On". And, all of a sudden, well, if he can be on TV, what about me? And it's just very, very cool when people see others speaking up and being in leadership roles. And it gives them that chance to say, "Maybe I can do it too". You know, I remember I got in trouble one time because I was sitting with one of my good friends. And we had a self-advocacy meeting here in Noble, this was quite a few years ago, and Brian, he said, "You know, nobody listens to me.

[01:09:07]

Nobody listens to me in the meetings." And I just happened to have a little plastic notebook folder thing to him. And I said, "Now, Brian, take this to the next meeting and, when the meeting starts, I want you to open it up and just write some things in it". He says, "John, I don't know how to write". Said, "Doesn't matter". I just said, "Make some scribbles and close it". And then, when they ask to see it, say, "No, it's private". And he said, "I don't know if I can do that". And I said, "Just try it, it'll be fun. Just watch what people do." And Erv Picha was the Executive Director then and, about a month later, he calls me and says, "What in the hell did you do with Brian? We didn't even know he could write and now you have him taking notes on staff and he won't show them to us." And I said, "Everybody else has a file, they don't show him their file, what they're writing about him". But I mean that's that whole dynamic of when you ask me the question about how things got to change.

[01:10:07]

We really have to make sure -- we use the term "consumer". And sometimes it's thrown away pretty loosely. But they're the boss. We should be satisfying them, not the system. And too often, the case manager and the providers go down to the end of the table with their calculators, come back to mom and dad and Brian, and say, "Here's what we can do". And nobody says, "What do you want to do?" That's got to change. And that's part of the role that we've got to do is keep holding up that mirror to the system and saying, "This is what you look like". You know, it's interesting, I was talking to a behaviorist the other day. It was a really interesting experience. I was out doing a photography project with a young man with severe Autism. He's a runner. And he wouldn't sit still. And I have a digital camera and he would hit the crash bar in that door, run outside, come back. Run outside, come back. Probably did it 100 times. And I finally got a quick picture of him of his face, and showed it to him.

[01:11:08]

And it just changed. And I said, "I want to take more of you, will you come sit?" And he kind of looked at me. And I said, "And I'll show them to you". And I called this behaviorist friend of mine and says, "Anybody ever done some work with videotaping of people when they're having these behavioral outbursts?" And his was pretty mild. He just like the crash door. But she said, and she's a psychologist, she said, "You know, I've never really read anything about that". And I just thought, well, somebody needs to do some research on that because maybe people don't know. And it's interesting, my little grandson that lives with me, he was throwing a little temper tantrum. He's 18 months old. I had my daughter film him on the iPhone and then show it to him. He stopped crying. And now, every time he starts crying, we show him what he looks like. And it stops. So, we're -- behavior is communication and so we've got to figure out some different ways of doing that.

So, just a -- I'm rambling again.

JT: No, I mean it's all good. And I think that those are things that should happen at the university level as well. I think, if you're going to go to school and you're going to come out and be someone that is paid to support people with disabilities, you ought to have some different experiences in your college career.

JD: Right, right, right, so.

JT: And that's where I think people are sold short.

JD: Right.

PH: But, anyways, there's something I thought of that we didn't touch on is the Arc's role, or their involvement, with the closing of the institutions.

[01:12:48]

JD: Ah, yeah.

[01:12:48]

PH: We didn't really touch on that.

JD: You know, one of the probably landmark things in Indiana is we looked at in -- you know, we -- some of our early leaders did place their son or daughters in institution because they were very severely disabled. There were no services at home. And so it's always been an interesting issue for me, that a time we had over 3,000 people living in institutions in Indiana, approaching 3500 at probably at our top. And it was in 1998, we were doing a 317 Plan. We had a terrible situation out in Newcastle State Hospital, Kathy Davis was the Secretary and we went over and there's hidden video taken by a brave, young woman who, interestingly, got fired, lost her job, found difficulty working in the field again. But she had shown people being beaten, duct taped to chairs, horrible situations. And Governor O'Bannon called me up and called Kathy Davis and said, "John, I don't think we can fix it, can we get this closed?"

And I said, "Yes, we can do it if we do it the right way and we do it in a person centered way, but we just don't move them to another institution". And we closed Newcastle, I'd given people incredible choices. People hated us, just hated us. I still remember this 70 year old man, he called me out in the parking lot. He said, "I'm going to kick your ass". I said, "Hey, I ain't going out in the parking lot". He's about 5 feet tall. He would have, you know. He was an ex-marine. I wasn't going out there with him. He later got his son, Robert, moved to within 5 minutes of them in Lafayette. And he became one of our best champions. But they had been told, "No" so many times.

[01:14:35]

JT: They weren't trusting.

JD: Yeah. They couldn't trust at all. We now, then, you know, after that, closed Silver Crest, then Muscatatuck and Fort Wayne and then, finally, we now don't have a public DD institution. We still have a few people with very severe and they're people with more serious mental illnesses, but they also have intellectual disability, about 50 that remain in state hospitals and about 25 that have been moved to a private facility. But it's, it was a landmark. We were the largest state at the time to close all our institutions. I think New Hampshire was the first state to do it. But it's -- I'm glad when I see the land's been used for something else. I think what we, in the community side, have to be careful is that the community programs don't become the next institution, that an institution does not have to be big. It just has to be closed.

And you can be as isolated in a waiver home as you were in an institution. If you don't have those kind of community connections, if somebody's not looking to do things with friends, it's all about building those connections.

JT: Very good. Now, now's your chance to just talk.

[01:15:53]

JD: Ah.

[01:15:54]

JT: You probably need a break.

JD: You talk now. Well, you know, probably the biggest thing that I still see in this information age. And we're trying things with every way we can to reach people, but families out there, you know, there's this incredible pressure on families that, not only may they have a child with a disability, but they have aging parents to take care of. They have other kids that aren't finding jobs that are moving back home with them. This is an incredibly trying time for folks. We have more single family -- single parent families out there. And the economy's not just very helpful. And we have this incredible need to get information to people, but getting it to them in a way that they can help them. And, if you're a single mom working two jobs, asking you to come to a meeting, ain't going to happen. You know, they're barely surviving by the skin of their teeth. And we've got to find ways to get back to doing outreach. We've got to find ways to help people and let them know they're not alone.

[01:16:55]

Because it's a very tough world out there right now. And we've got to find a way to get back to some new ways of supporting folks. The interesting work that, again, coming out of the Institute about how do we use technology to do time banks? And how do we help one another in different and unique ways that don't cost a thing? And that, I think, is part of our challenge for the future that we've got an awful lot of people that need help. And their answer isn't just a waiver, their answer is community.

JT: Good.

[01:17:30]

JD: All right.

[END OF INTERVIEW]