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**ORAL HISTORY VIDEO INTERVIEW WITH
KIM DAVIS**

JANUARY 17, 2013

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VIDEOGRAPHER: PEGGY HOLTZ

RECORD ID: 009-DO

KD: KIM DAVIS

JT: JENNIE TODD

PH: PEGGY HOLTZ

[00:00:10]

KD: Okay. Hi [chuckle]. I'm Kim Davis and I live in Bloomington, Indiana and I just recently retired from the Indiana Institute on Disability and Community. Specifically working at the Indiana Resource Center for Autism, here in Bloomington.

JT: Great. Well I know that you spend a lot of time here. So how and when did you get into this line of work?

[00:00:32]

KD: [Chuckle] It was totally by accident. I -- to give a back end to the story. In my student teaching and in my first few years of teaching I had experiences with kids with disabilities by -- one was for a class and the other was by accident, and I thought that would be really fascinating. So I came over here to Indiana in June of '77 to get my Master's in Adapted Physical Education and part of that work was doing a -- I guess it was a practicum or an intern -- it was more a practicum. Here -- at that time we were called the Developmental Training Center. And at that point in time which was the '70's so '77 we had kids who lived here at the Developmental Training Center and they were at that point too challenging to be in their local schools. So I worked with the kids -- with one specific kid in adapted physical education. I participated in the IEP process. I participated in meeting with parents and developing the lesson plans for this girl in adapted PE so I did that for a semester and then I thought well, I want to finish the year for Pete's sakes so I asked to do an independent study second semester and I worked with the little girl as well.

Indiana Disability History Project

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[00:01:49]

This little girl was -- had "autistic like" tendencies they said that point -- and we can get into that in a little bit. But so I worked the whole year here and I was thinking about what am I going to do now that I have my degree because it was like basically a year and a half program. And that August -- August of '78 my supervisor here called and said, "Hey I just got a job coaching basketball would you like this job?" And I went, well why not? You know. And she said. "It would only be a year appointment because of the equal opportunity they'd have to post it, but since they're in a bind and the kids are coming would you like it. If you want it it's yours." And I said, "Sure!" And I thought well, if I like it and I do a good job they'll keep me and if I don't like it it's going to look good on my resume either way if I leave. So that's how I got here. It was really -- it was really an accident totally. But it was a good accident. It was a really good accident.

JT: You said it was called the Developmental Training Center.

KD: Right.

JT: Some kids lived here.

KD: Exactly.

JT: So was it like a mini Institute? And what I'd like you to talk about is what was life like for the kids?

[00:03:00]

KD: Okay.

JT: Talk a little bit about why they were here.

KD: Right.

JT: Could you go into detail about why they were here? How long they stayed. What their day looked like.

PH: What was the age range?

JT: You know just...

KD: The age range?

JT: The age range and family involvement. Did the parents come visit them?

KD: Okay.

[00:03:14]

JT: Did they just drop them off and run?

[00:03:15]

KD: Okay. All right. Well the students were here when I started and thinking back to the program we had -- at the Institute here, we had three different cottages. They're basically where the offices are now at the Institute we had three different cottages that would have -- each have three bedrooms on the top floor. And each of those rooms was filled probably with two kids at least. So we had students and -- ranging in age. I think the youngest I think we had was five who lived here and then went up to age -- at one point age 21. So -- but it varied year, to year, to year. The children were -- came in from all over the state. We had one that came down from Hobart, which is all the way up Chicago. We had another one who came up from Salem. We had kids from Indianapolis area, from Evansville area. And the reason these students were all here was because their local schools said that their behaviors were so involved, so challenging that the local schools didn't know how to support them.

They said we don't have the services, we don't have the knowledge or the skill base to serve these guys. Remember this was back in the '70's when kids with disabilities weren't necessarily as visible, or as involved as they are now. So the schools approached -- as far as I can tell -- the schools I think approached the DTC and said we have this candidate, we'd like him to come. And I'm not sure what the selection process was but there were kids who had language -- but -- or some who had minimal language, some who had no language. They all had significant challenging behaviors. Some were self-injurious, some were very aggressive toward everyone else. So it was -- they were kids who were challenging. The deal was that when they would come here, they -- the school system and the parents would both work and meet with the staff here from the DTC so we could help them develop home programs for the families and then school programs to ultimately get the kids back to their home and to their home school.

[00:05:36]

So families were as involved as they could be. Like on Sundays there was always something when they brought the kids back, you know, for the families to do. They were meetings or whatever and then on Fridays when they picked them up there was something going on too for the families. We also offered family support activities for them during the year where they would come down and do things with the staff. The day for the kids was pretty packed. It was pretty structured. We [chuckle] -- there were a lot of staff. I mean where they lived in the cottages or our offices so they had to have a house manager, and then they had all sorts of assistants who would help the kids learn their adaptive living skills. You know? So the kids would learn how to get dressed, how to take a bath or shower. Brush their teeth, all that. Making a meal. So that was their morning so they started very, very early learning and being engaged and then they would march their little selves up to the school building and there was staff that would accompany them of course.

[00:06:42]

And when they came into school they had either small group or one to one. They had speech and language; they had adaptive PE with me. They had lunch in the room for a while and then I think at some point during some of those years some of the kids went down to the elementary school cafeteria, which is where they were. After school, they had a recreation program that I helped with sometimes

and they would take the kids out into the community, do activities in this very room that used to be the recreation room. And then in the evenings it was kind of just like winding down, helping fix dinner, taking a bath of they did that again, getting their jammies on and so the day for the kids was really packed, really packed.

[00:07:23]

JT: So what was the time frame of kids being here?

KD: Oh gosh. Okay, the years?

JT: Yeah would a kid -- would the expectation be they're here one year?

KD: Oh.

JT: Two years? Indefinitely?

[00:07:35]

KD: Okay. The goal -- I think the optimum goal was for a kid to be here a year. You know, we want to kid to be here, get the program, get the parents involved and bye. I don't know if that happened for very many kids. I think most of the kids -- most the kids that I remember were here at least two. And so the hard part was when school was out, you know, at the end of the year. What I recall is that for a number of summer's we had a small or a short like summer Institute kind of time or a program for the kids so they could come back and get their services, but at the same time teachers from around the state would come and that would be part of their continued learning and they would actually learn how to support the kids and work with the kids too. But that wasn't the whole summer long so a lot of these guys went home for most the summer and it was funny after the kids had been here a year the parents were saying the kids couldn't wait to get back to the structure, and the safety, and the activities, that we were doing here at the DTC.

JT: Okay, this is just a question.

KD: Yeah.

JT: [Inaudible] interview. So rather than -- parents think about sending their child here, versus a state hospital? Was that something that they even considered? Or did -- was this something so entirely different because it was short term where many people who go to the state hospital there is not plan to return. [Inaudible].

[00:09:05]

KD: I think -- for a lot of the kids I think the difference in being sent to a state hospital and being sent to the DTC at that time was that this was looked at as short term and this was also -- I think because a lot of the families had young kids. They were still incredibly hopeful that their child would evolve. And I don't know if any of them were hoping for a cure for their kids, but I think they were still parents that were hopeful. Interestingly enough when we had parents of kids who were older there was definitely a shift in kind of their perception of what was going on. It was almost they were resigned to the fact that my

kid has a disability, he's not going to get any better. If you guys can do something for him -- yippee. If not it's okay too. So I think in the beginning when I was here a lot of the folks were younger and so I think the option of going to an institution or a state hospital was not what these families wanted.

[00:10:04]

They really wanted that education piece. They thought we're going to make this work. So I think that -- and the schools basically said, "If they don't come down here they're going to a hospital." So the families I think were very much the ones who pushed coming to the in -- to the DTC.

JT: So the schools often kind of made the referrals to this here.

KD: Yeah, the school's made the referrals and said here's an option. What do you think?

JT: And who paid for it?

KD: I think the local schools paid for it. I think it was -- and I'm not sure. I don't remember. I don't think there was cost to families. Because I think it was due to the fact that the schools didn't feel they could provide for the students. That the schools footed the bill for the kids to come down here.

[00:10:50]

JT: Okay. Do you have a story of a child that maybe you remember from here and you watched them, you know, come and then leave and then maybe you heard about how they did in public school?

KD: Wow.

JT: Maybe you do. Maybe you don't.

KD: Yeah they -- there's a lot. A lot of the kids -- they're all old now [chuckle]. There's a lot of them that I think about and I wonder about. There's one young woman -- I can tell you a couple stories -- there's one young woman who came here, and she was incredible self-injurious. And [chuckle] I -- she was here the first year I was here and I got to walk her up to school the first day. Not only was she incredibly self-injurious but she just moves like a turtle. I mean there's nothing about her that's fast. Her language is fast, she moves -- excuse me, slow and she moves slowly. So we ambled our way up to school and she was moaning the whole way up [moaning]. Just moaning. So again -- I thought this is not [inaudible] she's not hurting herself or doing anything. So we get to school and I'm waiting to open the door to go into the school and she was standing right by the wall and she bum, bum, bum; hit her head three times against the wall.

[00:12:05]

Cracked it open and I thought first day on the job I'm done. I'm toast. You know, with this. But we got her in. She didn't really have -- hadn't really cut herself a lot. But I watched her change over time. Initially she used all her self-injurious behaviors to get out of any activities. Well, we figured her out, we got her involved in activities that she liked, we figured out ways that she couldn't hurt herself and her language started coming. She seemed more relaxed, she got more invested. And I know that she's still in town now. And I know she has lived with someone in an alternative family. Her parents were both

elderly and are both passed on and she does have a sister elsewhere in the state. But -- and she also has a job, a supportive employment job. This is a few years ago I heard this, but she has a supportive employment job and it's putting pizza boxes together for one of the local pizza places and she works with other folks, and the other folks are not people with disabilities so it's not an enclave. She works with college students.

[00:13:06]

And remember I told you that she speaks very slowly. Well they say that this person has a very wicked sense of humor when she tells a joke but it just takes forever to get to the punch line. So they really enjoy her and, you know, when I hear that and I see her out in the community -- which isn't very often but I do see her -- it just makes my heart feel good when I think about her. That's just one story. I've got tons more that I could tell you.

[Multiple Speakers]

KD: Oh sure.

[00:13:34]

KD: There's another one and this one I really like. A young man came to us and he was 10 when he came to live here, and he was from southern Indiana and he was 10-years-old and he had lived in an institution for a great deal of his young life. He had very little language and was scared. You could just tell this guy was scared about everything that was going on. And when he came he had a shoestring that was like his safety net and he'd flick his little shoestring and sometimes he's flick us with his shoestring and -- but he was not happy doing activities if he didn't have his shoestring. Matter of fact somebody yanked the shoestring out of his hand and he attacked that person and it took three people to pull him off. I remember at that point there were a number of the staff who said, "This guy is too dangerous for us to have here. We can't have him here." And the supervisor at the time said, "Look, he's here. It's our job to learn how to support this guy regardless."

[00:14:37]

So with great reluctance some of the folks were like all right. I guess we'll do it. So we worked on figuring out, you know, what does this guy like? Because that's what you have to do is get them involved in things they like. And we called the institution and, you know, there wasn't a lot going on at the institution at that time for him. They said, "Oh, he does kind of like Bert and Ernie." We're like okay. Oh yeah, he likes bananas too. We're like okay. So we found everything Bert and Ernie we could find. I had posters in my gym that were Bert and Ernie. I had Nerf balls with Bert and Ernie faces on them. We had placemats, shoestrings, plates, coloring books, color forms. Anything that had Bert and Ern- -- puzzles of Bert and Ernie to get his attention. So I'll never forget this. The one day that we brought him in and we had a Bert and Ernie puzzle here; just had a face of Bert and Ernie and a little bite of banana up here and another Bert and Ernie and a bite of banana and then we had a little circle on the table where his string was supposed to go. So we -- we're like, hey look this is what we're going to do. And he's like Bert and Ernie.

[00:15:38]

Cool. So we demonstrated for him about, you know, put your string down, put Bert, put Ernie in and get your banana and you can have your string back. So we kind of modeled that for him and then we said, "It's your turn," and he was kind of interested so he moved over. So one of the staff took her hand and said, "String down," and just kind of held it there and with his other hand guided him to put Bert and Ernie in and pop, you know, the banana in his mouth and then gave him the string back. It was like yeah, way to be! And from that time on we could see that we could help this guy learn by using what was interesting to him and keeping things short and successful, you know, for kids. And so over the years his language developed a whole lot more. His skills developed a whole lot more. I mean he's not like a Forrest Gump or [laughter] anything like that -- and that's a movie we know. But what happened with this guy is he lived in a group home for a while and his behaviors were still pretty significant at times.

But I think they figured out a measurement through medication to some degree but he also lives with a guy -- and he's lived with this guy for years. To the point where this guy -- his home provider has gotten married and now has kids. And I see this young man who we struggled with here and who some people said he's not worth the time, he's too dangerous, get him out of here. I see him now at the YMCA at soccer games watching his what would be adopted brothers, you know, playing soccer and people relating to him, just like they'd relate to you and me. And I think about that and it's pretty powerful to think that you know when he was 10-years-old he was this scared human being and now he's out in the community and people talk to him and appreciate him and he's really included in what's going on. That's a pretty cool story.

[00:17:38]

JT: [Inaudible] really good.

KD: Yeah.

JT: I'm trying to decide.

KD: Okay.

JT: Let's talk about autism a little bit.

KD: Oh, okay.

JT: You work -- you did work around the spectrum...

KD: Yes.

JT: ...a lot of your life.

[00:17:51]

KD: Around the spectrum, yes [Laughter].

[00:17:54]

JT: So I guess there's two things I want to talk to you about. When you first -- you said that early it was called autistic like.

KD: Mm-hm.

JT: Which was a label that I used to write in social [inaudible].

KD: Yeah, yeah, everybody did.

JT: So can you talk to me about [inaudible] how that's kind of a new diagnosis? How it has moved from autistic like to now there's a lot of labels within the autism spectrum.

KD: Sure.

JT: And why there is -- why there are so many more people who are diagnosed.

[00:18:29]

KD: Okay, okay. Well when we talk about autism -- I mentioned before that when I started in '77 I was also on an assessment team here, and people would come down here. They were referred by schools to get an assessment because they wanted to know if these kids had autism. Which was really interesting. So we would do an assessment and many times we would tell them "definitely yes, he has autism." But there were other times when [inaudible] well, your child has autistic like tendencies. And I always -- you know I -- when I talk about that in some of my presentations I say that's like telling a woman you have pregnant like tendencies. You know, it either is or it isn't, you know happening. And I think back in the '70's because autism is a relatively new diagnosis -- I mean was it the '40's that Kanner coined the term autism? I think it was 1942 or something like that. I'm not -- you can check the date on that. Excuse me. But so I think people were kind of unsure about naming it, so specifically, because it seemed like autism was the oh my God you have autism.

Forget it, there's nothing that can happen. So we had a lot of that autistic like tendencies that weren't really helpful. I mean if you think about it they're not -- they weren't helpful for parents to get that. What I think happened over time is that as we started having programs like we had here where we were working in vey concentrated measure with kids with autism, supporting the kids and down in North Carolina at the TEACH Program they were working really hard with kids with autism down there. But I think over the years as people worked more and more with folks with autism and we figured out more and more about -- okay, what are kind of some specific behaviors that we can see? What are those characteristics that really mark these people? And yeah, we have some folks who seem to have no verbal skills but they still have other skills that they're able to do. What's that about? Or we'd have some kids who are really verbal but boy, they still have a lot of the social issues. So what's going on? And I think -- excuse me -- over time -- drink time. Excuse me. Is this what you want?

[00:20:46]

JT: [Inaudible]. You're doing a great job.

[00:20:49]

KD: Okay. I don't know what that is. But I think over time what happened is we were able to kind of pinpoint those -- the specific characteristics we were looking at. The social issues and what all that means. It's not just looking at someone but its how we are able to follow a conversation. How we're able to take turns that we learn as little kids. It's all of the -- it's not just based on academics because you have those kids with high-functioning who do really well but then you get them in social situations and they fall apart. I had one kid who was over in another school, an elementary school and it was about 4th grade and the teacher's called and said, "This kid just beats people up and the playground all the time." What about the rest of the time? No, he's fine in the classroom. Really has a hard time in school or on the playground. So I said, "Okay."

So I went and watched and in the classroom he did really well. He answered questions. He was quiet but he answered questions and did the work and was really on it. So at playground I went out and watched and he went over and I could see him by a group of kids and all of a sudden he, you know, popped a kid and the teacher said, "See I told you. Every day this happens at recess." I'm thinking okay. So they brought him in and they took him in and said, "Come on with me mister. You're going to the office." So they march this kid to the office and he sat in there. So at the end of the day after I observed all day, and of course I'm thinking -- okay recess, there's got to be something with recess. It's pretty logical and stuff so I asked does this happen every day? Every day at recess. And I asked them, I said, "Have you asked this kid?" Well no, why would we ask him? He wouldn't tell us the truth. Which is something that folks with autism always tell you, is the truth. So I asked him, I asked this kid who was bright and kind of autistic like or whatever and he said, "Well, can I say a bad word?"

[00:22:48]

And I said well sure what the heck. He said, "Well recess is my personal hell." And I said, "Well what do you mean?" And he said, "Well, every day I go out and I try to get people to play with me but they don't want to play with me and they kind of -- they don't talk to me, and so he said "I just hit them because when the teacher's get mad at me they bring me in here so I can talk to the people in the office and they'll always be nice to me." So you had, you know, these kids who seemed to fit in but didn't fit in and teachers and administrators who weren't sure -- what is going on with these guys? So I think that what happened over the years is people became much more clear about what -- what is autism? You know, how does it impact individuals? What are we looking at when we're looking at this broad spectrum basically, is what they call it of kids, who all seem to share the core characteristics of social deficits and channels of in communication and some folks have big sensory issues too.

[00:23:49]

So I think what gradually happened is people realized we needed to really name this, you know, as a spectrum. And then, you know, you had Hans Asperger who came up coined the term Asperger's syndrome who are the people like this young kid. Very bright, very articulate but socially they just don't fit in. You have the kind of classic Dustin Hoffman from "Rain Man" Autism and then you have -- you had -- you used to have this PDD; Pervasive Developmental Disability not otherwise specified. Which were kids who maybe had communication issues or maybe had some social issues but didn't really fit

completely -- they were like the autistic like if you will. But I think that's all going to be changing with the new DSM 5 -- but I'm not sure how that's going to impact everybody. But so I think what happened is -- getting back to the -- why are there more people. I do think there are more people on the spectrum. I really do. I think part of it is that we are better at assessing and calling a spade and spade and saying you know we have this spectrum, we have a kid with Asperger's, you have a kid with PDD, you have a kid with autism.

[00:25:00]

But I really believe that there are more people who are somehow impacted with these common core characteristics and I, you know, where are my beli- -- I'll just tell you why I think that's [chuckle] true. I'll just go on into this. When I think back to when I was a kid and when I was in school I don't remember first of all seeing any kids with disabilities. I didn't even know there was -- disabilities existed until literally I was in high school and I had a friend invite me over to her house and we -- I went upstairs and this was this person in this playpen and it wasn't a baby but it wasn't a full grown -- and I wasn't sure -- I wanted to stare but my mother taught me not to stare so it's [chuckle] and it's really weird and my friend Lois said, "That's just my brother Timmy" you know he has a disability or he's handicapped is probably what she said, "And he stays at home with mom". I don't know what his disability was but, but I don't remember seeing kids with disabilities.

[00:26:04]

And then in -- years and years, high school, college; I don't remember so many kids with allergies or asthma, or, you know, compromised immune systems kinds of things. And so when I look at these kids and, you know, there's a lot of stomach or gut issues or intestinal that go along with kids with autism. There's all the sensory kinds of things that go on with folks with autism. And then I think about all the things that are happening in our environment and I'm not going to be like a, you know, cheerleader for the environment but I believe in the environment; but I think about the chemicals that are in -- that are used to produce our food that mothers can ingest or fathers can ingest. In the milk, in the air we breathe, the water we drink. And I do think that that somehow has a -- can be a trigger. I think kids are born with kind of an imbalance -- I don't know what they would call it -- if it would be a chromosomal imbalance kind of thing and what happens is I think they get -- they eat, they drink, they get injected, whatever and that triggers it.

I don't think that -- I know there's research that says the vaccinations do not cause autism. So -- and I've never believed that because if that was the case we would have millions of more kids with autism. What I think is that kids are born with kind of a genetic weak link and that something environmentally triggers that, and then all the symptoms occur. So -- and I think they're looking more at that genetic kind of thing and what's going on genetically with that.

[00:27:36]

JT: Okay, well that was good. I was going to ask you, you know, in the '70's it was 5 or 10,000.

[00:27:41]

KD: Yeah.

JT: And now it's like 1 in 100.

KD: It's 1 in 88 in the public school in Indiana. Yeah.

JT: So -- and so [inaudible] pretty much did say you feel it's -- there's a trigger in the environment.

KD: Mm-hm.

JT: Well -- and this is kind of off subject too but...

KD: That's okay.

JT: ...we spoke to Cathy Pratt...

[00:27:57]

KD: Did you?

JT: ...one day. Well, years ago.

KD: What did she say?

JT: We were asking her about autism.

KD: Yeah.

JT: Why is there such -- and one of the things she said was environment. But she also said that sometimes it could be a proclivity if a parent had a mental illness.

KD: Mm-hm.

JT: Is that something that research has [inaudible].

KD: You know what, I can't...

JT: [Inaudible].

KD: ...I can't answer that. But I think that in some families we definitely have seen that. That one of the parents -- there's something going on [chuckle] with one of the parents. But I don't know of any research on that. I couldn't be a good person to talk about that.

[00:28:37]

JT: Because I had never heard that and I thought well, you know, that does make some sense.

[00:28:40]

KD: Sure, sure. I think Cathy would be better able to address that. But... That doesn't surprise me at all.

JT: Well let's go back to the Institute a little bit.

KD: Back to the Institute.

JT: You spent about 37 years here.

KD: 34 by God.

JT: 34.

KD: 35 if you count the year as a grad student.

JT: So what are some of the major influences that the Institute has brought to the state or what would you say have been some of the most significant pieces of work that the Institute has contributed...

KD: Wow.

JT: ...to the state that basically is, improving lives of people with disabilities?

[00:29:15]

KD: Well I think first of all just the fact that we exist is pretty cool.

JT: Okay, you got to put my question in there.

KD: Oh, okay. What has the Institute contributed [chuckle]? What has the Institute contributed to the state and how has it impacted? That's a big question. I think the fact that we exist is huge. Now when I started here we were associated with Indiana University, and at that point Riley Hospital was also associated with the -- what were they -- we called; the UAF's at that point. University Affiliated Facilities of something like that. I don't remember. So we worked in tandem with Riley a great deal at that time. And at that point too the only program here was the program for kids with autism. There wasn't an early childhood program, a program for folks who were aging, or anything else, and so a lot of the families would work with Riley, get a diagnosis and then shoot down here to get some educational programming and stuff. So I think that initially we were really supportive of families. I think that the Institute over time has really become a place where families could come and get information and I think that's a huge thing.

[00:30:29]

Because I feel like families many times are being given here's your diagnosis now run with it and they don't have -- they don't know the first place to go to get information. So in thinking -- I've worked here at the Institute in the autism program and also in the early childhood program for a number of years and I know in the early childhood program I think what we did was really help families and early care providers connect to help make a bridge between those two so there wasn't a disconnect among them. So they would see each other as collaborators and not adversaries. And I think what we've tried to do

with that from the early childhood program -- I know that those of us who were consultants back then really tried to nurture that all along the way so that when they would move from the early, early intervention into public schools where there's a big change they wouldn't see those people as adversaries either. So I think what we've tried to do at the Institute, one of the big things is foster that collaboration between family and school and help them understand that each comes with their own set of values and their own set of concerns and they may not always, you know, mesh nicely but it's important to listen to one another.

[00:31:48]

I think the fact that, you know -- and again, just speaking from the Autism center and that's the best place I can speak of -- I think the fact that over the years the parents were helped from here, and that Indiana now has a legislative Commission on Autism, I think that's a huge thing that I know the Institute kind of in a back handed way may have had something to do with it. They may be right -- had been right at the forefront. I don't know. I kind of stayed out of all that kind of stuff. But the parents certainly gelled around that in helping that to be created, and that really has been a powerful force in our state for folks with autism and families with autism. To work with the legislature and also thinking about the insurance. You know a lot of therapies and services were not covered by insurances if kids had autism, people had autism and through the legislative commission those kinds of laws have been, you know, amended and changed.

[00:32:51]

So -- what else have we done? I know we've certainly supported schools over the years in my program. You know the Institute is filled with so many other programs now but I know that -- gosh I -- the teachers that I've seen over the years, and the families that I've seen, and the kids that I've supported over the years, I just think that being out there -- and many times you know what I felt like I was doing? I was being a cheerleader. I was being a cheerleader for the teachers who just needed to know you're doing the right thing. Or here's a little tweak that you can do because I don't think I met -- I met a couple of teachers who I wondered if they wanted to be doing what they were doing, but by and large I met so many teachers who wanted to do what they were doing and just needed that reassurance, or just needed that little bit of guidance to help them along. So if all of us here who are consultants are doing that I think we're doing a great job and I think that's one of the big things that the Institute can do is to be that leader, and we have been that leader to, help families and schools better support the folks with autism.

I really believe that while I was in the early childhood program and also working in IRCA [Indiana Resource Center for Autism] that those people that I know I worked with, we were doing a good job and I totally believe that everyone else here at the Institute has that at their -- that's their passion. That's their passion and it comes out in providing great services for everybody.

[00:34:17]

JT: [Inaudible]. Are you okay?

[00:34:19]

KD: I'm great.

JT: All right. Okay, so I know the book "Movement Differences and Diversity in Individuals with MR and Autism" had a huge impact...

KD: Yeah.

JT: ...on your approach here.

KD: Yeah.

JT: Can you talk about that impact?

[00:34:34]

KD: Yes. The impact of "Movement Difference and Diversity," the book by Ann Donnellan and Martha Leary that was written in 1996 and really impacted me greatly. I got to hear Ann and Martha in 1996 or 1997 at a facilitated communication conference, and facilitated communication which is now called "assisted typing" -- same thing different name -- was pretty controversial and I think remains controversial for the mechanism that is used to support someone to communicate. But when Ann and Martha started exploring this book and realized through their research and finding like 151 references and other journals that people with autism who are most of the people using facilitated communication had movement challenges that were similar to people with Parkinson's disease, similar to people with Tourette's and similar to people with catatonia.

For me that put a whole different spin on how I'm providing support. Because I remember when in working with kids I'd say, "Come on it's time to come to the gym," and people would just sit there. And, you know, we look at those kids and we're saying ah, they're being willful or they're being avoidant. Come to the gym, come to the gym and they're still sit there. We'd be like you need to come right now or you're going to time out which was ridiculous. But when I read that book and when Ann and Martha talked about how people with autism share characteristics of people with Parkinson's and if you think about people with Parkinson's who can't necessarily all the time get up when they want to get up, or respond when they want to respond, or find an answer or a memory or a thought immediately; we don't send them to time out [chuckle] because they can't do it. We provide support. And so I think when I read this book and I heard Ann and Martha and I thought back to so many of the kids that I had seen before 1996 -- because I started in '77 you know or '78 -- I thought oh my God, how many of those kids did I say lying on the floor, willful behavior this is the -- you know this is what you do.

[00:36:47]

Not in a punishing way but not in a way that truly understood the impact of their disability. So after I read the book and I heard Ann and Martha talk a few times I thought I have to share this information. If nothing else to get people not to jump to the conclusion that these people are doing things willfully. It's not that they are -- they're unable. It's not that they won't. They can't necessarily provide the responses we want -- whether they're bodily or orally -- without some support. So over the years I put

together a presentation on movement difference and I called a "Challenge to Reframe Our Thinking" because that's what I had to do. I had to go back and think wow, what I was doing was fine for the time. You know I was doing the best I could with the tools I had. But now I have this new information. What am I going to do with it?

[00:37:47]

So when a kid is lying on the ground or not getting out of their chair am I going to immediately to they're being willful? No. I have to come back and think what can I do to provide support to this person so they're better able to respond. So, you know, that -- that can give you pause because I -- okay, did I screw up the -- that can give you pause because I had -- you know, my reputation -- not that it's good, bad or whatever -- was based on what I had been saying and now I needed to change my tune. That's hard for a lot of people. I remember hearing Ann Donlin at one point after she had written the book and was giving talks about this stand up in front of a whole room of people -- she was giving a keynote and the slide up behind her was saying you know, sometimes as professionals it's okay for us to say I don't know and the whole slide behind her was just filled with I don't know, I don't know, I don't know.

[00:38:48]

And she had us say that all; three times. And it was so refreshing and for me then what I realized I needed to do was not invent knowledge. You know, taking a little bit here and a little bit here, put it together, give you an answer because I'm the professional. I realized I could say I don't know but I also realized that we weren't seeing the full scope when it comes to how autism impacts people. And so for me my biggest hope was when I would do that presentation or share that information I would give people enough information that they may just pause and reconsider their next move before they kind of jumped to conclusions and I think I did that. I mean, I've had some pretty decent impact on that but it -- for me that whole book and that whole concept really spoke to the humanness of all these people with disabilities.

People with autism. I think sometimes we forget about the impact that disability has on the human being and we want them to respond in the way we want them to respond. But we forget they have a disability and it impacts them in many different ways and it's up to us, the people without the disability to figure that out and provide that support.

JT: So [clear throat] -- excuse me. So when you would say come to the gym...

KD: Mm-hm.

JT: ...and originally you would think when they're sitting there that's willful behavior.

KD: Mm-hm.

[00:40:22]

JT: They're being obstinate. You read the book. You realized, hmm, they might want to come to the gym but they just can't snap to it.

[00:40:31]

KD: Right.

JT: So, now that you have the new information you say come to the gym; everybody's different, everybody's going to respond differently. What would be some examples that you would say wait 30 seconds, wait 45 seconds, ask again. Go over and -- you know, what would be some examples that you would throw out? Because I know one example's not going to fit everybody.

KD: Right, right.

JT: But when people would say, so how long do we wait Kim? How...

KD: Right, right.

JT: ...do we know if it's really movement difference or they're just being obstinate?

[00:41:04]

KD: Right. Exactly. I get the questions all the time. Because when I get called out -- excuse me -- or when I got called out I was called out because there were challenging behaviors. I never got called out when things were happy. You know, which is a real drag part of the job [chuckle]. So, you know -- and so I talk about movement differences and then people say how do you know if it's a movement difference? Or how do you know when it's behavior? And it's not easy. I can't go into any situation and say, "That's a movement difference by God. Oh that's -- he's being willful. You better deal with this a different way." There's a long answer. I'll try to give you the short long answer. The short long answer. Number one they have to know the individual. You can't just read the folder on the kid and think that that's going to be all the information you need. You really need to get to know the individual and so I talk to -- every group I talk to I said, "You need to know the kids strengths, interests and preferences. You know, whether the strength is they can talk or they can work for 20 minutes on their own, they can go to the bathroom. All those are strengths. Interests might be the Bert and Ernie or Pokemon, or John Deere tractors.

[00:42:08]

The preference might be wearing shorts instead of long pants and sandals instead of shoes, or cotton clothes, or milk instead of water." And -- but then there's another list that I don't think people look about and that's the things that are what are fearful or frustrating for that kid. Because those are the things that will trigger behaviors. Okay? So do we give them enough time to process? Do we give them a visual support? What are we doing? So those are things that I say we all need to do. Get to know that kid more readily. So we get a kid who's lying on the ground and he's not getting up or he's not coming to the gym. What do I do? Well, I think as a consultant what I had to do is look and see what kind of warning did that person have? Is there a schedule for the kid? Do they know what's coming next? You know, and if they're -- that's not there, that could be an initial reaction of like I'm not going here. You didn't give me any warning. I don't know what's coming next. Why am I going? Where am I going? Or

if the kids, you know, just sitting there and, you know, the schedule is there and everything's there for the kid and just kind of is sitting.

[00:43:13]

Then I might think maybe they need a little more support. Maybe they need a tap on their arm to get their body to wake up. I have a young man who graduated from Warren Central High School; used facilitated communication. Didn't get FC until he was in 5th grade and the first thing he types out was tell my mom I'm not retarded. Which was pretty cool. So they moved him from special ed into gen ed and he graduated with honors from Warren High School but what he would say is his body would go to sleep. His brain was fully engaged in class and then when it was time to move when class was over he couldn't because his brain had been engaged in whatever was going on and he needed someone to tap him on the arm, or his shoulder to wake his body up so he could move. So what I might do then is go over and you know provide the kid with that support to get them up. And by and large when I would provide that -- after I read the book and I went into situations and I did provide that kind of stuff, it worked! It was amazing [chuckle]! It worked! So I mean and there's so many -- like so many instances because every person is an individual and they're movement difference, or even people with Parkinson's, their Parkinson's will impact them differently.

[00:44:25]

It's so sad because there are -- I know of two unpublished dissertations where people have interviewed folks with autism and these people are adults and they talk about the movement difference and how it impacts them in so many different ways. There's a woman, Sue Rubin who CNN interviewed and they did a video documentary called "Autism is a World" and Sue talks about movement difference and how it impacts her, and it really impacts a lot of the sensory issues for her. You know, hearing is -- you know, she may bang her ears, you know, and stuff because things are too loud and that can get into some of the sensory issues and -- that get into processing that is movement difference too. So I mean movement differences; it sounds so Parkinson's, catatonia and Tourette's but there are so many other areas that are involved in that. But it just -- it's important for people to understand it's there.

It's not a new diagnosis. It's just another way of kind of really looking at someone and getting to know that individual and I think it's really important information.

JT: Very good. Okay, so here's another topic.

[Clears throat] [Multiple Speakers].

JT: Yeah, you need to take a little break?

KD: I need a little drink -- a little. I'm getting phlegm [chuckle].

[00:45:53]

JT: Any pictures I mean of any of the kids you've talked about? Well we probably couldn't use those.

[00:45:57]

PH: Yeah, couldn't use those.

JT: We're thinking also when people tell stories what we could use an [inaudible]. So that's something [inaudible] in the back of your mind [inaudible].

KD: I have some -- well Sue Rubin might be able to put in. I don't know. She's kind of a public figure. But I have some of the pictures that were used in the video for me that they did. There's a couple of them where I'm far away with a kid or you can't see the kids face.

PH: [Inaudible].

KD: Yeah, or you can't see -- you can't tell the kids face. Yeah, I can give you some of those. I can bring -- I'll just bring you the little packet over and you can pick through. There's only a few but...

PH: That would be wonderful.

[00:46:38]

KD: I don't know about -- well Ann Donnellan is all over the internet and Martha Leary -- you can find pictures of them.

JT: Well we can certainly -- I can get that [inaudible] book.

KD: Mm-hmm.

JT: You know things like that [clicking].

KD: It's a 100 pages that changed my life. It's the best -- I tell people it's the best book on autism I ever read. Because it's not the same -- it's not autism is a social communication blah, blah. It doesn't -- it goes -- it just goes off in a whole different direction and looking at autism is very, very differently. That was refreshing and it also truly was more educational than any of the stuff I had read before. Gave me more meat, more information to really gnaw on and use.

JT: Some good strategies to support people and think about...

KD: Oh God yeah.

JT: Well I know that we both have a love for Herb Lovett and loved his way of talking about behavior as communication.

KD: Yeah.

[00:47:37]

JT: And I know that you were involved in writing a book about that. So would you talk about what that means? Like when people say behavior is communication.

[00:47:48]

KD: Right, right. Yeah Herb Lovett was a wonderful human being who had -- he was another person who had a huge, huge impact on me. I remember the first time I heard Herb speak was in Philadelphia at a behavior conference, and I had heard about Herb but I didn't -- hadn't really heard him and he just blew me away. He really talked about people with -- hi David [chuckle]. He really talked about how all people deserve respect and all people deserve dignity. And he also talked about how he would go in institutions and work and support people who didn't have language and help their quality of life improve. So his message just really struck me and I think in my work as a young person -- I was 27 when I started working here, and what did I know. But I always felt like with some of the folks who I supported who didn't have language -- and I know other people have said I know there's something going in on there-- because you can look at the eyes sometimes, or I felt I could look in somebody's eyes and know.

There's words and messages in there that there's no way for this person to let me know right now. And the only way they can let me know is when they get pissed at me [chuckle] and they fall down, or they attack me, or they bite me, or they giggle uncontrollably. So we know that there's stuff going on. So over time before I even heard Herb I kept thinking that there's something else going on. So I think when I heard Herb it was like yeah, behavior is communication. These guys do -- it's all they have is their behavior to communicate. And so I had been talking to people in my presentations and in consultations that you need to listen. There's a reason that this guy is doing this and this is all he has to tell you. So Sue Dixon and I had been doing presentations for years called "The Behavior Communication Link". Excuse me.

[00:49:55]

The behavior communication link, which really is our belief that all behaviors do communicate. Whether we're nodding at someone, whether we're giving someone eye contact, whether we're looking towards something or turning away. Whether we're screaming. Whether we're shaking our fists at someone. Everything is communication and when we're supporting someone with a disability, even someone who has a disability where they can still speak but at times they may be so mad they can't find their words -- just like you and I might be -- we again as the support people, need to realize that we need to learn to listen which is what Herb used to say. Learning to listen differently to people who have a diagnosis. It's up to us again who supposedly don't have a diagnosis or may have one. Who knows. But it's up to us to listen differently and I think again that's another message I want to get across to people that behaviors communicate and we need to listen differently.

Hang on [chuckle]. Am I answering the question that you want?

JT: Yes you are.

KD: Okay.

[00:51:05]

JT: Basically I just want people to understand what it means.

[00:51:08]

KD: Mm-hmm [Clinking]

JT: [inaudible].

KD: Okay. Okay, I think I'm good [laughter].

JT: Okay. Is there anything else you want to say about behavior is communication and if not can you give me some examples?

KD: Let's see. Do you want examples of kids communicating?

JT: Any time that you saw behavior being a communication and what that behavior communicated.

[00:51:31]

KD: Okay. Well it's -- when behaviors do communicate most the time sadly I think of the refusals that I'd see or the avoidance. You know? The kid who just would throw themselves on the ground when they were given a direction even if they're given the visual schedule and everything, and they throw themselves on the ground and you think -- you know the next activity is going to eat in the cafeteria. It's just like wow, why would they be throwing themselves on the ground? Then you have to think about what does going to the cafeteria involve. Well, it can be noisy, it can be smelly, there can be too many kids shoving and pushing. So it's looking at that one. Let's see, what else have I seen? I've seen kids who have come up to someone and just stood very, very close to someone. You know, it's not a negative behavior but just standing very, very close to someone, or they'll stand in front of the refrigerator. You know? There's a behavior right there that says I'm thinking I'm interested in the refrigerator or you. Or giving people something. I had one kid -- I remember I had gone to his house to talk to his parents and at one point he came and just gave me my keys [chuckle].

Bye-bye [chuckle] he says like -- okay. That's a big clue. You know, get out of my life. So those are just some of the things and I, you know, when I leave here I'm sure I'll think of a bazillion others. But those are just some.

JT: That's good.

PH: That's a good one with the keys.

KD: Yeah. I was like oh God [laughter].

JT: My little grandson [inaudible] follow him around. When he wants to sneak or do something he'll [inaudible] [laughter]. I got it. I got it.

KD: All right. Bye-bye. See you later.

[00:53:07]

JT: Okay, so let's talk about how things have changed for kids with disabilities in the school system during your tenure.

[00:53:18]

KD: Wow.

JT: Attitudes, opportunities...

KD: Things certainly have changed over the years for kids with disabilities. Maybe not as fast as we'd like things to change. When I think of starting here we had the segregate -- I mean the kids had the segregated program through Monroe County Schools here and there weren't necessarily opportunities for kids to be necessarily, mainstreamed is what they called it and so everybody was separate. But over the years, and thinking about kids in public school. More visibility, just having those classrooms in the schools was good because at least kids would see those kids. The sad thing was they were always in a clump. You know? And no one approaches a clump of anybody who's different. I mean I don't approach a clump of Harley bikers because they scare me. You know? But I got to know one Harley biker and I was like; really? You're a Harley biker? So now I'm not like as intimidated. And I think that kind of analogy is happening in the schools -- or has been over the years.

[00:54:23]

You have the kids with disabilities who are in the school and the typically developing kids see them and they're not as scary as I think they once were. So I think that's a really good thing. I think more and more kids are being supported to be included in general education with their typically developing peers and I think that typically developing peers are the ones who are more apt to jump in and support the kid in natural ways, more so than the teachers. I think teachers or adults get so roped into the should be's, and the must do's, and this is the protocol that we use that they get tongue tied and arm tied and they don't know what to do. And I think that sometimes we follow the lead of the kids peers; they know what to do and they do it in a very natural way. So I think it's -- things have changed. Kids are more included -- they could be included more. I think that there are still some areas, you know, like some of the -- in schools like some of the after school activities where I think more kids with disabilities -- it would be great for them to be involved more somehow in the after school kinds of -- in the sports, or in the theater, or in the choirs, that are going on and not necessarily have to be relegated to the special -- like the special Olympics all the time or whatever.

KD: But get involved in what's typically going on.

JT: What's it going to take to get to that next step?

[00:55:56]

KD: Boy, that's a good question. How do we get to the next step of getting -- making that happen? You know, I think it's going to have to come from the kids. The kids -- not just the kids with disabilities, but the peers. I think what's going to have to happen is those typically developing peers who have been around the kids with disabilities for so long, it's just a natural thing for them to come on. It's just natural for them to go. And I think -- again sometimes I think, we as adults who know the rules and the protocol need to step out of the way, and let what is going to naturally happen happen. Because you know I worked with a circle of support for a young man up in Munster, Indiana and we started when he was in

preschool because his mom wanted him to fit in, to be included and heard about a circle of support. So one was started and all through school -- he's graduated now -- but all through school he had this -- we had these circle meetings and his typically developing peers were always there.

[00:57:01]

It was just always a party for this kid first and we'd ask him what's good about school? What stinks and what would make it better? And the kids always had something to say. And then the parents all met -- or the school staff all met to kind of talk about what did the kids say and what are the next steps that we might want to do? And it was -- the circle was about life. It wasn't just about school. But as these kids grew and they went into middle school and they still were having the circle and -- but as they got into middle school and high school the kids kind of took charge, and the kids went to -- when they got to high school the kids went to the football coach and said "This guy needs to be the manager on our team. He's always been our manager, he needs to be the manager," and the coach was like okay. So he was the manager of their football and basketball team for the four years he was there. The kid graduated with honors and he still has his friends and it's in -- the friends still come to his house and so it happened with the adults starting it, but then the adults getting out of the way and the kids still want to be involved because they've grown to appreciate this young man and love this young man as their friend. So -- yeah.

JT: I just wrote that down to ask you about that. Because you do see all these videos, and you read wonderful stories about circles of support.

[00:58:17]

KD: Mm-hm.

JT: Maps, PATH [inaudible].

KD: Mm-hm.

JT: And you see how it does work just like your story.

KD: Right.

JT: Why -- what would it take to make that more of an everyday thing? Not just one story you hear about from one circle.

KD: Wow.

JT: Or do you -- maybe you could talk about maybe why it's a challenge to have it happen.

KD: Yeah.

[00:58:39]

JT: I mean it just seems like it should be happening [inaudible].

[00:58:41]

KD: Yeah. I mean, have a circle of support for this young man that was so successful. I mean boy oh boy, if I had have saved all my papers we could have a great story and done a video tapes. My goodness. I mean, he's such a success story. But it took dedication from the parents. It took dedication from the family. It's not something that -- you know, it's -- being in a circle of support is voluntary. No one is paid to be in a circle. There are hours above and beyond what a teacher's day would be. But this circle was interesting. The preschool teacher stayed involved forever. You know just because she loved this kid and she wanted to and because the circle was making a difference in his life. So circles of support are wonderful and they really do make a difference, but it's dedication from -- there's got to be that cheerleader and generally it falls to someone in the family. And I think -- I don't think it's a good thing for everybody. Because I think what would happen if people were required to do a circle of support it would turn into just another meeting, another IEP, or another thing that I have to get through.

So for a circle of support or a circle of friends to be truly successful I think it has to come from a place of I want to change this person's life. I want this guy to have a life that's meaningful and wonderful. And it can't come from a place of I got to do this. So it takes dedication, commitment and I think the ability to envision a bigger life. To envision something bigger and grander than, what happens for people with disabilities. You know, I think initially everybody's like oh my God, this is all he can do. This is they'll be able to do. And what I think a circle of support can do or using the tools of MAP and PATH which are really looking at the future; I think what that does is it helps people to dream and I think for families with disabilities it's hard to have that dream. You know? And with this young man they had another son who was going to college and stuff and said, "Well, you dream for him. Why not for him?" They hadn't even thought about it. They were so focused right here today that the circles of support, MATH and PATH allow them to expand what they're doing.

[01:00:57]

And that took, you know, guts and courage on their part and I don't think every family is cut out for it. I really don't.

JT: And for a family to do that -- so maybe we don't know any stories in Monroe County.

KD: I don't know either.

JT: Is that -- to get that started would a family member have to have heard someone talk about this? Would they have had to have witnessed something like this to even have that idea, or would it be a teacher who says to the family members, you know, I've seen this work. What would you think about this?

KD: MM-hm.

[01:01:32]

JT: Is that how it comes about?

[01:01:34]

KD: I think circles of support or using a PATH plan or a MAP plan are initially things that I think teachers have heard about. I don't think enough families have heard about it. That's the way this one started. Someone heard a presentation on futures planning, personal futures planning and about circles of support. Told his mom this would be a good thing. And so I don't think it's common language. I don't even think when we talk about disabilities -- and I've talked about disabilities for years -- I don't think that person centered planning or personal future -- and when I started certainly wasn't -- weren't terms. I don't know exactly -- you might know when the terms actually -- when Marsha Forest and Jack Pearpoint actually started circle of support or MAP and PATH. But I think certainly in the last 20 some odd years I've heard those terms, and know that they can make a significant impact on people but I don't think families know about them as much as they should and it's sad. And the families that do -- I've had -- I've worked with a number of other families who have wanted to start a circle of support and it just -- I don't know what it was but it just didn't get going and I think one of them they didn't get kids involved enough so it ended up being the adults talking and it turned into almost like another case conference.

You know? Which was why are we doing this? We ate M&M's and everything but it -- they needed to get the kids. The idea is to make the life meaningful for that individual with the disability. It's not for all the rest of the people who get together and -- you got one more meeting. So that was a special group. But I don't think that there are -- I do think there are other people who could do it. I think they just need to have the information. And this mom is willing to talk to anybody about the whole process. But it's such a wonderful process for a person.

[01:03:28]

JT: Good. Okay, so this is something that you may have already talked about but I'm going to just ask you anyway.

KD: Okey doke.

JT: So, how do you think you have personally changed and grown through the years?

KD: Wow. How have I changed and grown over the years? Wow. That's a good question.

JT: Well I know that -- you know, I listed to your DVD the other day and you did talk about that there had been a lot of changes and a lot of growth and if you don't want to answer that...

[01:04:00]

KD: No, that's fine. I just need to think about it a minute [Laughter]. It's like -- I think certainly I'm much wiser than I was. I think when I started working here I thought -- I was one of those people who kind of had the category -- categorized people with disabilities and people without disabilities. And now it's just like we're all people. You know, I could become disabled in a heartbeat. You know, it doesn't matter. So I think I've grown from categorizing people to just realizing we're all people. I certainly have grown in my ability to listen differently. To all people, specifically people with disabilities. I think I've grown in my

ability to have some empathy for families. Not that I didn't before but I think in some times when I was younger I might have been well just do it. You know? Just do it. And now it's -- I can understand. I can - I think I'm better able to look at things through different lenses and not be so quick to make -- pass a judgment.

[01:05:09]

To say well, if only they'd do this. To realize that that every situation is challenging in its own way and every person comes at things from their own perspective. And that I feel like part of my job was being a mediator [chuckle]. Not that I was every trained to be a mediator. But I feel like I was able to do a better job at providing people avenues to see things differently. And I don't think I could have done that. I think this job has made me a better person. I really do. I think this job has allowed me such growth in all the things I just said but just growth as a human being who really values every other person, regardless of ability and skills. I -- yeah, that's just kind of a vague general but it really has impacted me.

And I like everybody who I've met over the years really too. It's allowed me to meet a lot of different people and hear a lot of different views and take a lot of different things in, and meet some incredible people like Herb and Ann. A lot -- George and his mom. I mean, just pretty amazing folks. I'm blessed. I'm blessed.

[01:06:34]

JT: That's very nice. So what do you see in -- looking forward in terms of services and support -- what do you see as future trends in where we're going down the road, in terms of, making life better and more meaningful for people with disabilities?

KD: The future and making life meaningful for people with disabilities. I -- you know, I feel hopeful. And I feel hopeful because of what I said earlier about kids -- starting young. You know? You know for people who are our age, my age and a little younger -- I mean, things may be set in stone for those people get -- this is the way things are supposed to be. But when I look at kids and I go into schools and I see kids with disabilities just being kind of included. Little wheelchairs being pushed across the playgrounds, and kids of course incorporating those kids, and teachers being better educated now about disabilities so much more than I ever was. I mean I got one textbook that covered every disability and it was very generic. But I see the opportunities for teachers now being better educated about things. Information is out there. The internet as much as I'm not a technology person. But the internet allows so many people so many avenues to learn.

[01:07:54]

Even what -- YouTube. I mean you can download -- and so many videos that are out there for people to learn. So I think that the information is powerful, and I think visual information is a powerful tool, too. So I see a lot of hope for folks with disabilities. I see them being more incorporated into everyday situations whether it's, you know school, employment, recreation, just the community in general. I think that people are just going to wake up and realize you know let's just help each other out. Let's just

make life livable for everyone. And maybe I'm naïve but I like to envision that. I feel like if I can envision it it's going to happen by God.

[01:08:40]

JT: Good. That's really good. So people coming into this field, newbies coming into work.

KD: Mm-hm.

JT: Wanting to have a career or maybe just falling into it like you did. What kind of training do they need? What kind of education do they need to help them be creative, be supportive? Think outside the box, so to speak. Instead of just what you get in college to be an adaptive PE teacher or a social worker.

KD: Right, right.

JT: What do they need?

KD: What would have helped me in my job, instead of, my typical run of the mill classes? What would I need?

[01:09:18]

JT: And the current -- you know the current kids coming out of the Department of Special Ed -- School of Special Ed.

KD: Wow.

JT: What do they -- what would improve it to make them [inaudible].

KD: How could services be better? How could people be better prepared? Well I think -- and I think back to when I was going to school. I think being out amongst the kids you're going to serve, especially in schools, needs to happen sooner rather than later. I think somehow the universities and teacher preparation partnering with places like -- you know, like LifeDesigns here in town or whatever. To getting folks involved with folks with special needs much sooner rather than their senior year student teaching. Whatever they're doing. Social workers, getting people more involved with the individuals who they're going to support. Not necessarily listening to lectures all the time. I think there needs to be much more hands on. That's one thing. I think having -- being -- having more mentorships set up, I think would be a really important. I know that in public schools they try to set up mentors for new teachers. But many times those mentors are so busy that all they do is go in and check down saying how you doing today?

[01:10:33]

And if the teach says, "Okay it's like, good I'll check back with you," and they may never get back. So I think more specific mentoring I think needs to go on. And I think -- I don't know. I mean where's Herb? You need Herb [chuckle].

[01:10:50]

JT: What about [inaudible] you teach some classes.

KD: I have yeah.

JT: Do people with disabilities every teach the class? Do people with disabilities act as mentors?

KD: I have -- when I taught my class on Intro to Disabilities -- which I don't teach anymore because they put it online and I said "I wouldn't teach it online. Call me old fashioned I want to be in front of the people [chuckle]." Yeah. Damn them. But -- you can leave that in. I don't care [chuckle]. Many -- what I did with that class is I did some of the talking but I made sure that somehow -- I had the young man with autism that using FC [facilitated communication] came down and talked to my class and it was really interesting because a textbook that I generally like said that FC -- assisted typing for some -- was voodoo basically. And he was just like duh. You know, come on. And so they -- the kids got into the -- the young adults got into the interaction with that young man, you know right away. One of the things that I had my students do when I taught class was they had to observe and interview a special education teacher. So they had to get out into the schools to see what was going on and then they also had to go meet a family and meet the individual with disability.

[01:12:02]

So they had that experience. And when I got my evaluations back those three things that I thought were like oh, going to be really hard; they said that was the most invaluable part of the class for them. Was actually seeing people, talking to people, having that face to face time, and so I tried to get people with disabilities into my class or get them exposed to people with disabilities as much as I could because sadly, for the students in my class; that was the only class they were going to have on disabilities. And I had a lot of music education majors and then graduate students who are in education in some form or another. So it was -- it's powerful I think for people to be involved and on a face to face basis, instead of just reading about it in textbooks. You need to have that heartbeat behind it.

JT: I would go in and talk to Sharon's class.

KD: Yeah.

JT: Each time. And she told me that that class that she taught, which was something along the lines of Introduction to Disability.

KD: Right.

JT: But was the only class that these kids got the whole time that they were in school.

[01:13:08]

KD: Oh my God.

[01:13:09]

JT: And these were kids that were going to be general educators and they were high school -- you know high school educators.

KD: Oh gosh. Yeah, that's right. That's right.

JT: It's the only one. And I asked them how many of them thought they would see someone with a disability and it was interesting; not everyone raised their hand.

KD: Really?

JT: So I'm thinking, you know...

KD: Yeah.

JT: ...you guys are seniors...

KD: Yeah.

[01:13:29]

JT: ...and you're already of the mindset that [clinking] you're going to be working in a public school and you think you're going to have no involvement with kids with disabilities just because you're not a special ed teacher.

KD: Exactly.

JT: Which was so disappointing.

KD: It is disappointing. I remember -- yeah, you're right. You know that makes me remember when I talked to Sharon's class too. I did the behavior communication link or when actions speak louder than words, and I didn't ask them that question but I said, "I come from the Autism center." And I said, "And I will guarantee you probably half of you in this classroom will see -- I will guarantee you you will have someone in your classroom that has autism, at least Asperger's, and you won't know what to do. So if you think that you're not going to get -- your kidding yourself [chuckle]. You're totally kidding yourself."

JT: I told them all of them would because they would have someone in homeroom and...

KD: There you go.

JT :Band, whatever.

KD: You're on it. Yeah.

[01:14:20]

JT: And but I just couldn't believe that not everyone raised their hand. And I also asked you know how many know someone with a disability?

[01:14:27]

KD: Right.

JT: Probably half raised their hand.

KD: Mm-hm.

JT: But the others didn't.

KD: Right. You know, and I think that that's part of -- they may think they don't know someone with a disability but then you have people with epilepsy or learning disabilities, or ADD. You know those invisible disabilities. And even folks with high functioning autism can blend in. You know the Asperger; they can blend in and so they may think they don't know some -- it's like how many of you think you know someone who's gay?

JT: Right.

[01:14:55]

KD: Well, yeah, yeah, yeah, yeah. , You may know someone. It's that -- it's the same -- you know, it's that same thing about thinking it's not going to happen to me. I don't know anyone. When in fact yeah.

JT: But I mean I guess I was just [inaudible] because it did surprise me that its 2012 when I asked that question.

KD: Yeah.

JT: This is IU. This is the School of Ed.

KD: Right.

JT: And, you know, they didn't get any of that.

[01:15:18]

KD: Right. Right. It's -- you know, when I've talked to classes -- it's so fascinating. When I talk to social work classes I get much more involvement, much more activity, much more wow, this is so interesting than I do from a lot of the education classes that I get. And I don't know what -- I don't know what that was about but it's been an interesting phenomenon, to have that interest in other areas, and not in the education area. That part's a little concerning. But then there's always those -- I find -- what I have found is that the early childhood folks are much more engaged and much more like thinking I'm going to get these little kids, these little goobers and they're -- you know, all this kind of stuff. And when you get into the high school it's almost as if it's reflecting what happens when you get into high school. Because when you get teachers in the elementary school they're involved, they're engaged, they're there and then you get into middle school they start kind of disengaging because I'm teaching Science.

[01:16:18]

And you get into high school and it's I'm the Science teacher. These kids -- just their faces. You know, they're not -- they're not these little guys that I -- and that's the sad thing about education I think. That's a whole scenario we can go into, and I...

JT: No, and I told Sharon, I said, "I don't know how you do this because I feel like I'm a pretty engaging speaker."

KD: I would think you would be.

JT: And I talk and I tell stories [removing lid and closing lid]...

KD: Mm-hm.

JT: I did so much talking. I mean I get more talking when I talk to people with disabilities and get more participation from them.

KD: Yeah.

[01:16:48]

JT: Okay, so we'll talk a little bit about the D&E assessments. Who was involved, what it looked like.

KD: Okay.

JT: What the team...

KD: Okay. Okay. Okay. The assessments when I -- back in the early days when I -- we did assessments here, and we -- I don't remember when we stopped doing them, but we didn't do them -- maybe we did them for about five years when I was here. I was -- did the gross motor on that team. We had a psychologist who did the psychological. Obviously we had an educational specialist who did education. We had a speech and language clinician who did that part then we had a social worker who kind of did parent interviews with them and sometimes we had the nurse get involved if there were medical issues. And the way we -- when people came here to get assessments -- and these weren't the kids that were involved in the classrooms. They were -- those kids were here already. This was a separate program. Schools would say we need further assessment or the parents aren't agreeing on the assessment that we came up with. So they would come down here and most the time they would come down here and so the psychologist would take the kid off.

[01:17:57]

Everybody would take the kid off and do their own little assessment and then we'd come back as a team -- the family would go away -- we'd come back as a team and kind of talk, and then bring the family back in and say what we you know had discovered and that's when autistic like was used a great bit of the time. So that was one way we did it. Another way we did it when we worked with like, little kids -- I was on a different assessment team with Program for Prepare, which was for little kids and it -- of course it was easier to do with little kids. We did what we called "an arena assessment." I guess they used it at

that time where all of us consultants were around. The education, the OT, PT, speech; there was a lot more involved. We would be sitting in a room and we may use the parent to help facilitate things. Like the OT might say -- or the PT might say see if you can get them to sit up, you know, on their own and they have them reach out to get a ball, or reach out to get something, and then while they were doing that the speech and language clinician could say well see if they'll reach up to get the ball or they'll look over here if you say something.

[01:19:01]

So we were all seeing the same thing with our disciplined eyes. Which was really cool with little kids and sometimes, you know, a PT would go in and work with the kid too. But sometimes it was getting the moms involved first to make the kid comfortable. So I like that much better than the separate and then coming back together. And the funny thing was that I would do the gross motor assessments which was like basically play for kids and many times I got -- the kids would make noises or say things or do things or weren't obstinate, willful in my setting and so the other people would come and watch because they would hear the language and they would -- if you think about it -- years later I thought about it and I thought well who would want to be taken away by a stranger, put in a little room and given toys to play with that they're not even interested in and do that three times in a row before you get to go play. You know? Just like I got the best deal out of the whole thing. So assessments back then were -- I think we were -- it was an evolving kind of thing.

[01:20:04]

I'm not sure how they -- what they do now in schools. If they even have multi-disciplinary assessments, of if it's just the psychologist because I feel like very removed from that. So that's how we did it.

JT: [Inaudible] You want to talk about some career highlights?

KD: Ah! Career highlights. The first thing that comes to my mind is meeting Herb Lovett who was an incredible human being who impacted my life. And then meeting Ann Donnellan and reading her book. Huge. I think -- move -- I think my move from autism to early childhood -- that early childhood was a great highlight for me. That was an incredible group of women who I worked with there. We were like - it was family and we kicked butt when we were there. I mean we had modules and videos and things that we just -- we produced and we had a big impact on the state. Then I think another highlight for me was moving back over to the Autism center and kind of finding my voice in the field of autism, and it was due to Herb and Ann Donnellan, and the whole movement difference. Then really getting my feet solid on how behavior is communication. I think those things were really important for me.

[01:21:29]

I think -- and this is funny -- I think that the first time that I went out to a national conference was in Anaheim at the -- what was it? The National Association for the Education of Young Children conference. And as an old PE teacher -- now old not meaning age but [chuckle] former teacher I'm used to using a big voice. Right? So I had this big room full of people and I was talking and it was packed and I was like, wow! And they said use the microphone and I didn't really want to use the microphone. I thought I could boom my voice out and they said use the mic. I was like, okay. So it was one of those

wireless mics and I got the mic and I picked it up and I was like -- I started to talk and I went oh my God, this makes me want to sing [laughter]. So I said [singing], "Do be do be do [laughter]," and people said, "Put the microphone down [laughter]." I'll never forget that. I'm thinking oh my God Kim, what just happened to you [chuckle].

[01:22:30]

You know? And, you know, I think, you know, that's a fun thing and then I think more -- there are more fun highlights, you know, that happened. You know, being ABBA here at the Institute for our Christmas party was just fun. And I think, you know, a good thing about this place is there's a lot of people who come and go. The sad thing about this place is there's a lot of people who come and go. But I think that has actually been a real highlight. I try to look at that as a highlight because there's been so many people who come through this Institute who I have been able to meet and learn from, over the years, and there's been a lot of different contributions in this little brain of mine that people have given me. These little kernels of things that I remember from different individuals who have been here. And also, from the families too. So specific highlights -- retiring was a specific highlight [chuckle]. Most recent that I can remember that was -- someone said is it bitter sweet?

And I said, "No it's not bitter at all [chuckle]. It's very sweet." It's -- I feel satisfied with my career. I feel like I did a good job, that I impacted some lives in a positive way but I'm ready to rest. As my friend George said, "My brain needs a rest [chuckle]."

[01:24:00]

JT: That's good. You don't have a rocking chair attached to your rear end.

KD: No.

JT: You're not ready.

KD: No, not ready for that yet [laughter]. Not ready for that yet. Anything else?

PH: Not unless you have any...

JT: Do you have anything that you want to talk about?

KD: No I think you've talked about everything.

PH: Family stories?

KD: Meeting my sweetie was a highlight wasn't it [laughter]? A family story, a funny story.

[01:24:29]

JT: Or just anything.

[01:24:31]

KD: A interesting kid. We had a real interesting kid -- one of the first years I was here. A high functioning kid with autism and -- I don't know if you'll use this but it's an interesting story. He had a -- well a couple things about him. He had this self-stem that he would do. He would take his arm and he would just kind of do this with it [thumping]. And he'd look at it and watch his arm and he could talk and I thought I'm going to ask him what the heck [chuckle]. So I said, "Why do you do that?" You know he's doing it at certain times. I go why do you do that? And he said, "Oh, oh, oh. Well, when I'm upset it calms me down." And I said, "Well, how does that calm you down?" "Well when I took the train ride to Chicago with my mom I'd put my head against the window and that's what I saw when I did and things would go f-a-s-t, and then they'd go s-l-o-w." And so he was really -- kind of recreating that for him which I thought well that's fascinating for him to do that. This same young man had -- you know, they talk about kids now who may have dual diagnosis with maybe bi-polar or, you know, another mental illness going on.

They even talked about autism being childhood schizophrenia. And this young man, I remember one day hearing him -- over hearing him and there was his voice and there was this other voice that was much higher and it was like telling him you should do this. You should do this. And his voice saying, no I can't do this. And so it was like he was having conversations with it. But as he was doing it he was drawing a cartoon that had this alter ego and he gave it a name -- and I'm not going to say it because that will give it away -- you know thing, and then him. And this thing was always this little voice that would get him into trouble and it -- so he was -- he made comic strips that would show different episodes of his school day in which he got in trouble and he would say -- his drawings actually were a clue as to what was going on with him. I often -- I wonder about him so much. He was fascinating. Bright, could talk, memorized things like crazy.

[01:26:46]

He came to the gym one day and was talking about the solar system. Mercury is the closest planet to the sun. It is this many. Next to Mercury is our sister planet Venus. Blah, blah, blah. And so I'm listening to this going -- whoa, this sounds familiar. You know? So he went on talk -- so I said, "Hey, can you tell me -- I can't remember the order of the planets. What's the next one?" He just looked at me and goes like -- woo! And I was -- okay, so I said "I really want to know." And he finally -- the third time I said, "Well can't you tell me? You sound like your not..." -- [scream noise]. And he just left the gym and I felt really bad about it. And I thought well I really want to tell him sorry so after school I marched myself down to the cottage and I walked in and I could hear something in the background and as I listened to it, it was, you know, Mercury is the closest planet to the sun. And then we have Venus our sister planet. And I went, oh I know that voice. And it wasn't him, but it was -- Walt Disney used to have that one guy who narrated all the nature films and science films and he had that intonation and that this is dah, dah, dah.

[01:27:51]

Well this young student had memorized that whole tape and when he was up there talking it. That's why it sounded familiar to me and got my brain going. So it was fun for him to remember it but it wasn't functional because he couldn't interrupt himself and give any information back. And, you know, that happens a lot of times with kids, you know -- I'm sure kids with autism but it may be other kids where they can memorize something and sound like they've got it down, but then if you interrupt them of you try to make a tangent to that, it can't happen and he got really upset because I was interrupting him and stuff. But he was a fascinating young man. Fascinating young man. I have no idea what happened to him or where he is. It would be interesting to know.

[END OF INTERVIEW]