David Mank, March 19, 2015, interview 026-MI, transcript, Indiana Disability History Project, Center on Aging and Community, Indiana Institute on Disability and Community, Bloomington, IN, https://indianadisabilityhistory.org

ORAL HISTORY VIDEO INTERVIEW WITH
DAVID MANK

MARCH 19, 2015
INTERVIEWER: JENNIE TODD
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 026-DO

DM: DAVID MANK
JT: JENNIE TODD
PH: PEGGY HOLTZ

[00:00:11]

DM: Hi, I'm David Mank. I live in Bloomington, Indiana. And I am the director of the Indiana Institute on Disability and Community at Indiana University.

JT: OK. Can you tell me how and when you got into this work? What brought you to do this line of work?

DM: Working with people with intellectual and developmental disabilities began for me almost directly out of college. And it wasn't a planned career. I've graduated from college with a degree in Psychology and English. And moved to Oregon mostly on a whim and found a job working in a small residential institution for people with intellectual and developmental disabilities. And it just seemed like as a society, as a community, we needed to do a better job about how people lived.

JT: OK, great. So, what is the role of universities in serving people with disabilities? And why is it important to have university centers of excellence?

[00:01:20]

DM: University Centers on Disability issues, has an interesting history which I'll tell in a minute. But I think the purpose of the center on disability issues is research, training and development. Researching best practices, implementation practices, curriculum and instruction, new ways for people to get employed, better ways to support families that have children with disabilities. There's a whole research side of how do we support quality of life for people with developmental disabilities and their families. So, the research side is important. I think, the development of new ideas, new projects and new demonstrations are better ways to support people is an important role. And then, there's a dissemination role of telling practitioners and families and people with developmental disabilities, here's the news, here are ideas that are working, and-- to get the information to as many people as possible and as many ways as possible.

[00:02:26]

And it's a combination of what we typically think of university work as research and working with practitioners to put research and good ideas into practice in schools, in typical community settings. So, in a way, we're not typical academicians or university folks, nor are we practitioners. I often use the phrase, "We don't run schools. We help schools run better." And I think take out schools, put it in employment agencies, take out employment agencies, put it in early intervention services, the same notion applies.

JT: OK, very good. OK. So, I was going to ask you, does the Indiana, you see differ from any of its counterparts nationally or how does it compare to its counterparts?

DM: Well, let me start with the history of the University Centers for Excellence. There are 67 centers or institutes in the country and in or US territories that have the designation as the University Center for Excellence on Developmental Disabilities. And that designation comes with a grant from the Administration of Community Living and the Administration on Intellectual and Developmental Disabilities in the US Department of Health and Human Services. Every state has one. And a number of territories have one, a few states, California, New York Georgia, some of the largest-- Florida, some of the larger states have two or even three. Most states like Indiana have one. Now, the history of why there's the University Center for Excellence is-- at any state, is somewhat unique. And it actually comes from the John Kennedy administration. As you know, many people know, John Kennedy had a sister, Rosemary, who had a developmental disability.

[00:04:23]

And he and the Kennedy family were keen to draw attention to the issue of quality of life or lack of services, the situation, if you will, of people with developmental disabilities in this country. Of course, in those days, in the '60s, the phrase was mental retardation, a phrase we haven't used for over a decade or more. Now, instead say intellectual or developmental disabilities. Well in 19-- I believe it was in 1962, Kennedy was preparing for the State of the Union address. And for the first time ever, the quality of life conditions for people with developmental disabilities he wanted to bring to the attention of the nation in the State of the Union address. And while he was doing this preparation, he realized he couldn't really find any information from anyone about the national status of people with developmental disabilities in the United States.

[00:05:24]

And he was quite shocked by that, by report. And so, he called his sister, Eunice-- now, let me take a little sidetrack on the story before I move on. Now, because Eunice and the Kennedy family had a friend by the name of Bob Cooke. And Bob Cooke was a pediatrician who happened to live in Florida, I believe. And his specialty was, as a pediatrician was children with developmental disabilities, so very unusual sort of specialty in those days. Well, on the day when John Kennedy called Eunice, Eunice was playing tennis with Bob Cooke. And they got on the phone and the president said he couldn't believe he couldn't find any information, what should we do about this? And Eunice and Bob at that point started to sit down and crafted this notion that, well, there should be centers in major universities around the country that would have information and data about the status of people with developmental disabilities and they're state here in the country.

[00:06:36]

And that notion grew as a piece of legislation called the Developmental Disabilities Act. There's a longer title, I'm not remembering-- of I guess it would have been 1964 when it was eventually-- no, 1963. So it included university centers. It also included the idea of the Governor's Planning Council for Developmental Disabilities that would be a policy unit in every state and a Protection and Advocacy system which would be an equal rights protecting the rights of people with developmental disabilities. So those three ideas, the university center, a Governor's Council and the Protection and Advocacy system were all defined in the Developmental Disabilities Act in 1963. And it's passed by Congress and we believe it was the last piece of legislation that Kennedy signed before he died. I don't know if you guys knew that story?

JT: Not-- No. I knew a little bit of it but not-- it was a great story.

DM: And I, you know, you hear a story like that, you think well that's a really charming story, is it true? And I have two things to say about is it true or not. Number one, I heard it directly from Bob Cooke. He came to our national association, the Association of University Centers on Disabilities, gave him a lifetime achievement award some years ago and he told the story. And number two, if you look on the website, you can-- if you do an internet search on Bob Cooke and Developmental Disabilities Act, you'll find a recount of pretty much that story of how that happened. So that was 1963. It takes a while to fund 67 centers or develop those around the country. They essentially began in the '70s to start funding university centers. And Indiana University where we sit now at 1905 North Range Road was constructed.

[00:08:42]

Was built with funds from-- that started with that legislation in-- and we believe about 1970, but it would have been-- I could be wrong exactly on the date. We'll correct that later if we need to. The last university center, Wyoming was funded in 1996. So, it took 25 or so years to go from initially starting university centers to having one actually in every state of the country.

JT: OK.

DM: Indiana's University Center is similar in many ways, unique in many ways as well. We all carry a mission of research, dissemination and preparation of students, primarily graduate students for careers related to working with people with developmental disabilities. So there are those general similarities, but then, there is a uniqueness to each one based on their opportunities, how the staff developed over time, the issues they were invited to be a part of. Some university centers have a healthcare orientation primarily and are located in medical schools. Some are more purposed to community services and education as we are here at the Indiana Institute on Disability and Community, and are involved in early intervention services, pre-schools, schools, employment programs, residential supports, aging supports, autism supports and the like.

[00:10:29]

Indiana's center is bigger than some, larger than some. It's probably in the larger side generally speaking, but there are some especially those associated with medical schools that tend to be actually quite big. And often provide actual healthcare and medical services to people with developmental disabilities.

[00:10:49]

JT: OK. Very good. Do you need a drink or anything?

DM: Nope.

PH: We have water over there if you want.

JT: OK. Everything still working Peggy?

DM: Is this is what you've got in mind?

JT: Yeah. I'm going to get back to the IPAS GPC connection a little later too.

DM: Sure.

JT: So that was a good prelude to what I'm going to ask you. That is a focus of the Institute. How it has involved over the years and if the evolution had to do with the name change, so if you could just talk about how you-- since the '70s when we became an institute, how that has evolved for the last 40 years and then the name changes?

[00:11:29]

DM: Well, I can talk about the history of the Institute as far as I know it. And I'm sure others can add interesting and charming pieces to the history. And what initially built the buildings of the Indiana Institute, it was built as a small institution for people with intellectual and developmental disabilities. And 50 or 60 people would live here. And so, you know, I'm sure we'll talk about closing institutions later and it's somewhat interesting that with federal funds, our buildings were constructed to be a place where people with developmental disabilities lived. In those days, it was initially called the Developmental Training Center. And people would learn things here presumably, live here for a long time or short time. There would be live-in staff in the buildings. And so, you would see a place that had primarily bedrooms, living rooms, dining rooms, and kitchens.

Over the years, as the notion of institutionalizing, people with developmental disabilities we discovered, is not a very good way for people to live separated from the rest of us in community. And starting to close institution-- it had to be. It was before my time that I felt quite a transformation for the Developmental Training Center to move people out of the buildings and then what would be the purpose. What evolved initially was focused on two particular issues. Then later, three and more. First two were early childhood services and special education, education services. In the early '70s not long after this was built, the first piece of legislation guaranteeing a free and appropriate education for students with disabilities was actually passed in the early '70s. You know, this was revolutionary. And the Institute picked up the issue of special education as an important topic and began doing research and training projects in conjunction with the state of Indiana on education issues.

[00:13:46]

Somewhere in there, funding was found and staff were hired that were knowledgeable about early intervention and early childhood issues for little ones with disabilities and their family. So-- as I understand it, the first two community support areas were early childhood and special education services. Now, a little bit later, a unique focus emerged on the part of the Indiana Institute and that was on autism issues. I'm not exactly sure how that emerged, but it had to have come from families and interested legislators that wanted to create a center specific to issues for people with autism. And when the Indiana Resource Center for Autism was created, we'll have to look up exact dates for that, I'm thinking it was some time in the '80s when the Indiana Resource Center on Autism emerged with support from the Indiana legislature.

[00:14:57]

And even to the point of creating a legislative commission on autism that would have multiple meetings a year and was specific to autism issues. Now, what's interesting about that is a couple of things. Number one, that there would be a legislative commission related to a specific disability. They're along the same time, a legislative commission on developmental disabilities was created. But that's an additional commission separate from-- it had some overlap with-- it's largely separate from the Autism Commission. But it was important enough to constituents, of people with autism and families that had children with autism to create a specific focus for fear of being overlooked in other areas. Now, at the time, the diagnosis of people with autism was maybe 1 in three or 4000 that we knew of.

Today, 2015, arguably, the diagnosis is one in 60 or 70 children born. You know, the definitions have changed somewhat, but I think it was also pretty clear that there has been an increase in the diagnosis of autism well beyond any definitional issues. And then based on opportunities, the Institute grew in a number of directions. So now, having at seven centers, early childhood, education and lifelong learning, community living and careers, Indiana Resource Center on Autism, Center on Aging and Community, Center on Planning and Policy Studies and the Center on Disability Information and Referral, which is dissemination, and our library as well. So these are, you know, all important issues in the lives of families of people with developmental disabilities and we, you know, we seek those opportunities and we, frankly, we capitalize on the unique talents and interest of staff members that, you know, come to us in one way or another.

[00:17:11]

And that oftentimes bring us into new areas that are still relative to our mission of support, welcoming and valuing the meaningful participation of people of all ages and abilities.

JT: Do you think it's noteworthy to talk about how we went from DTC to ISDD to now IIDC just so that there's some continuity?

DM: You know, the naming of centers is an interesting, interesting thing. Developmental Training Center, when you're building a facility where people will live. Training center was a common phrasing. Sometime in the late '80s or early '90s it would have been. The question came up what should be the name of this place? And by way of report, the way I hear it, a small group of leadership made a decision at the Developmental Training Center to rename the place and re-brand the place as the Institute for the Study of Developmental Disabilities. Now, in the late '80s and early '90s, the notion of disability studies was emerging in universities and special education programs in universities around the country. And in fact, a number of universities created majors-- primarily, graduate programs in developmental-- in disability studies.

[00:18:40]

So, the phrasing of disability studies was-- it was emerging in today. It's not common but it's not uncommon either. And the notion of studying disabilities certainly an area worthy of research, et cetera, and the name was agreed upon the Institute for the Study of Developmental Disabilities. Not long after I arrived in Bloomington in the Institute in 1996, you know, I began hearing discussions from self-advocates of people with developmental disabilities as well as advocacy organization and families that would comment on the word study. And on more than one occasion, remembering people asking, why do you study us? And I can see there's-- It's almost a-- well, often delivered with a smile, there was also a notion of discomfort in this.

[00:19:42]

It's like you're an institute that studies us. What does that mean? And we took that seriously. And while honoring, you know, the origins and the name, we began in what would have been about 1998 or '99 I think, a community process both the Institute community and our broader constituents, our advocacy community. I think we helped focus groups with various groups around the state and asked the question about what matters in the name. And we spent the better part of a year as I recall. And in that conversation, a couple of things emerged. One, while our origins had been and our history is very much tied up in intellectual and developmental disabilities, there's a much far work that touches disability issues more broadly than that.

And while wanting to certainly honor our history and certainly where we are today and so much of our work being about developmental disabilities, we didn't necessarily want that to be constraining to our work. So, we came to consensus that disability would probably be in our name rather than developmental disability. Along the same line, the notion of community as opposed to a special place for people with disabilities was extremely important and that people with disabilities are-- it should be people in community, the way people with brown eyes, people of community or people of other identifiable labels. But it's not about the label. The fact is, community is a place for everybody. So, we liked the word institute. It had been part of that-- the label for a decade or more. And slowly we came to, you know, there would be these words in the name, institute community and disability.

[00:21:50]

And then we wonder how shall we name it? We knew that in New Hampshire, there was the Institute on Disability. No label ahead of-- it's the IOD, the Institute on Disability in other places, the center on the Institute on et cetera, et cetera. And gradually, kind of the obvious, I think dawned on us. And that, you know, the Institute on Disability isn't the only institute on disability. However, we were-- for all intents and purposes, the only Indiana Institute on Disability and Community. And we adopted that phrasing, tested it out, kind of among ourselves and among our constituents, kind of familiarized ourselves. We're trying to say it after having said the Institute for the Study of Developmental Disabilities for a decade or more. And finally, adopted and did a re-branding effort to become the Indiana Institute on Disability and Community.

JT: Perfect.

DM: Does that fit? You guys-- have been here longer than I have you-- so, that's my memory of how that--

[00:22:58]

JT: That's pretty much how I remember it as well. So, Dr. Schroeder handed the reigns of the Institute over to you when you came about 20 years ago. Did he impart any words of wisdom to you as he walked off and welcomes you to the new role of institute director?

[00:23:17]

DM: Dr. Henry Schroeder was director of the Institute for 25 years, almost its entire history before 1996. I think there were others that had been named director. I know a former faculty member name Sam Guskin who was involved in creating the Developmental Training Center initially. But for all intents and purposes the first permanent and long standing director was Henry Schroeder. And he just did an incredible job of putting together just a wonderful group of professionals and family members doing work about quality of life for people with developmental disabilities. You know, I remember the day, you know, Henry, he handed me the master key. And, you know, it's if the-- it's that-- this single item I have carried with me every day since, you know, August of 1996, you know, this single key that opens up every door in the place.

And I became a student of how Henry had set this place up and how he ran it both organizationally and financially. You know, he'd say things like-- again he's had a great sense of humor and he had great-- incredible insights. He'd say things like, "Remember, everybody wants something." And to-- and to know that. And not-- in a kind way is, everybody needs something. And they're talking to you because they think the Institute can help. And that seemed like a special responsibility. It's like people talking to you because they want something, they need something and they see maybe the Institute isn't [inaudible] for something better for themselves, their family members, their school, their employment agency, their community, their neighborhood. What else did Henry tell me?

[00:25:18]

He told me what the Institute does for Indiana is really important. And he said-- He made it his business to make sure all of the centers that are part of the Institute understood that Indiana is important and we needed to serve Indiana. And I think we honor that in our naming of the Indiana Institute on Disability and Community. But the-- and the other things he imparted that we didn't necessarily talk about all that much was a financial structure for trying to run, you know, a small business like an institute that's part of a major university. And a lot the fund, the financial structures that he set up, we maintain today because they worked. And they work well. And I saw no reason to adopt-- we've had evolved and grow and changed with the times of course and the technology changes in the world.

But some of the basic assumptions and structures in financial operations is remarkably the same. And I credit-- Henry, Harriet Figg who is the business office manager for so many years for constructing a structure that works.

PH: I was just wondering if now would be a good time if you want to talk about the advisory council just what their role is--

DM: OK.

JT: OK.

PH: -- since we're talking about the beginnings and--

JT: Right.

[00:26:45]

PH: -- when it started, do you?

[00:26:47]

DM: Yeah. Yeah. The Institute like every other university center in the country has like a consumer advisory council and actually the notion of a consumer advisory council is in the legislation now. And so, it's expected to be largely people with intellectual and developmental disabilities or family members with other interested constituencies. We, of course, include our partners in the Developmental Disabilities Act, the director of the Protection and Advocacy System and the director of the Governor's Planning Council. Our council meets twice a year and as we tell them, your role is advisory and to help us think ahead. The truth of the matter is, in any kind of organization like this, you know, what happens in the next six months is already in the books. The plan has been made, the finances have been set up, the grants were written, the promises were made, and we're fulfilling our responsibility and our promises for the next six months, a year, or even two years in large part.

What happens after that is an open question. And what issues, what ideas, what quality of life concerns from people with intellectual and developmental disabilities should we be thinking about or knowing about and in thinking, two years, four years, five years ahead. And that's what we ask our Consumer Advisory Council is to think ahead and help us be prepared to be the Institute we need to be two years from now, five years from now. We also make sure that the council is informed about the work that we do. And we welcome comments about that, the value of it, what direction it might go in the future. But it's not about operations, it's about good advice in being a better Institute in the years ahead.

[00:28:53]

JT: So when you're thinking about the Institute as a whole, what would you say were some of the most significant contributions to research, practice, quality of life to people with disabilities?

DM: Well, when you start to name important contributions of an institute, then you become guilty of the sin of omission of what's not named. But, I will name several that I know of that is especially important over time. One is the focus on special education and moving toward integrated and inclusive practices. The Institute was well-regarded in inclusive practices before I came here. I knew about the Institute's investment in inclusive education and special education before I arrived. And as a part of the working group, at that time on special education, education issues have developed a manual called "Adapting Curriculum." And the notion was taking the regular curriculum and making adaptations so that it would be accessible to students with disabilities.

[00:30:10]

And the main point was that students with disabilities should have access to the regular curriculum, and that adaptations could be made in any one of a number of ways. That would mean that students with developmental disabilities could have access to it and learn it, whereas before it wasn't available to them. Well those documents, these adapted curriculum manuals and materials were wildly popular on a national basis and states would call up and buy these manuals for every school on their state. You know, I've heard tell, you know, some state calling and say, "We want 25,000 of those." You know, it's quite remarkable, you know, when you think about the word of something spreading in just that way. It would be interesting to see if there were any records about having tens of thousands of those were actually sold over the years. You know, things were all electronic now. And so, you know, that sort of thing really doesn't happen but, you know, that notion of adapting curriculum, you know, extended then into early childhood and the early childhood group did an adaptive curriculum series.

[00:31:21]

I actually think the aging-- the Center on Aging and Community, there was a point where they had some adapted curriculum kinds of material. So I think that just that notion is really important. I'm going to stop and scratch my eyes because something-- it's really itchy.

JT: I'm going to squeak my chair.

DM: So, the education focus in the adaptive curriculum materials as representative, if you will, of something that works. You know quite important, sometime in those earlier years in what I think would probably been the early '80s, there was a governor-sponsored conference. The governor was in some fashion -- partial sponsor of it, the-- Herman Wells, the President of Indiana University at that time endorsed the notion of this conference about inclusive practices in education. In fact, in my office which has always been the director's office, I still have the poster.

You know, other major contributions of the Institute in the mid 1980's, Indiana at the leadership of the Institute became one of the first states in the country to have a federally-funded systems change grant from the United States Department of Education to invest in support employment for people with developmental disabilities. And the early pioneers in Indiana were well-known on a national basis even then for the leadership in supported employment certainly has been an area. Another area of clear leadership has been the Indiana Resource Center on Autism for decades now. You know, we get calls from other university centers saying, "Tell us about the Indiana Resource Center on Autism." "What it does?" "How it's setup?" "How it's maintained?" "What is its work?" And is admired and its Director Cathy Pratt, long time director of the Indiana Resource Center in Autism very well-respected on a national and international basis.

[00:33:27]

That has been a major contributions. The Institute was also one of the first in the country to create an emphasis on aging and disability issues and that began as well in the late '80s or early '90s. And is a focus that is maintained to this day in 2015. The Early Childhood Center was one of the first areas and-- of interest and work of the Institute. And to this day probably has more data and information about the practice of early intervention services in Indiana. More so, has more data than probably any other such group in the country about not only the nature of the services delivered for early intervention to individuals and families, of quality and outcomes for that as well. And I hope I'll be forgiven for the magical things that I'm not mentioning--

JT: That's fine.

DM: -- that happened at this institution.

[00:34:32]

JT: Right. Well, that's great. So, we talked earlier about or you talked earlier about the collaboration between the Governor's Planning Council and IPAS and the Institute. Can you elaborate a little bit more on some of the collaborative projects and why it's important for the three to, you know, to work together? I mean, you explained how they were set up and they had the mission to, you know, to partner. So, elaborate a little bit on some of the projects that you are-- you have done and are currently doing with them.

[00:35:03]

DM: Yeah. The Institute partners with our Developmental Disabilities Act named partners, the Governor's Planning Council and the Indiana Protection Advocacy System in a number of ways. Two of them that are especially important at this point in time is self-advocacy and the notion of accessible communities or communities for a lifetime. Self-advocacy, the-- Indiana is really fortunate, we've got a strong self-advocacy organization called Self-Advocates of Indiana that is its own nonprofit, is incorporated. Runs itself and is run by people with intellectual and developmental disabilities. And it's extremely important to all three of our organizations to support that effort and in going wherever it chooses to go in self-advocacy for themselves and their families. And all of us support self-advocates in a number of ways. In partial funding either in kind or with financial support to Self-Advocates of Indiana, but also training in leadership.

The Institute runs a series called the Building Leadership Series, which builds self-advocacy and leadership skills in the part of people with intellectual and developmental disabilities. We've had supported funding for that from both the Council and the Protection and Advocacy System over the years. And that's one area that's quite important to us. All of us are supporters and sponsors of the conferences that Self-Advocates of Indiana have as well. And we are also make sure that we were in the public policy discussions in the State House in Indiana with Indiana government that we were always asking, where are Self-Advocates of Indiana and supporting their voice in the public policy process. The second area that's been more recent is an effort we've been working on particularly with the Governor's Council, they just more recently-- as in the Indiana Protection and Advocacy System has been quite intrigued by this notion of communities for a lifetime.

[00:37:18]

Because what that really is, is the notion that a community should be for everyone whether that's about young or old, middle aged, little kids, people with disabilities, people of different cultures, backgrounds, et cetera. And that we all belong together and that we can make a place, our towns, our cities, our communities that work for everyone that are accessible, that have things like shopping for your needs nearby that have stores and services that welcome people of all ages and abilities and know something about how to welcome people all ages and abilities. And in another language system, it's about universal design. You know, how-- what's the design of a place and a space and service that's-- that works universally for everyone.

So, Phil Stafford, the Director of our Center on Aging and Community likes to use the phrase, you know, a community where you can grow up and grow old. You know, the notion that, you know, babies can live here and older people can live here too. And then what does it mean to be in a place where you're welcome where the physical environments welcome you and the services, the recreation, the neighborhood association, the stores are easy to get to and everybody could get in and out.

JT: Perfect. That fits with our name too, community. OK. This next question is kind of long. So I'm going to read it to you and you can think about it and then we might break it up.

[00:39:06]

DM: OK.

[00:39:06]

JT: Because what I want you to talk about are the changes that you've seen in Indiana in terms of, one, attitude towards people with disabilities about their families, about service organizations and by them themselves. Opportunities for people with disabilities and then services and support, you know, changes that you've witnessed and that sort of thing. So, you can answer it all at once or you can answer it--

DM: You know, I think over the last, you know-- especially 20 years, probably the longer time period than that, you know, that attitudes of community members as well as people with disabilities and families has changed pretty dramatically. From a community standpoint, you know, people with disabilities and people with developmental disabilities are seen in our community now. In employment, in stores, in the same places that everybody else shows up, you know, whether is that a movie or the grocery store or the classroom. And so, unlike 30, 35 years ago. It's common to see someone with an identifiable disability in the community. And community members have come to realize, "Oh, there are those among us that have disabilities. And I think there's much more of a matter of fact sort of attitude on the-- of community members.

[00:40:31]

Now, there are still issues of attitude of people I think. You know, students with disabilities would be easy targets for bullying or jokes and things like that. And those things certainly do still happen. But I think by and large, from the community standpoint, disability has become discussable at a constructive way. What's interesting about it, you know, attitudes and how we use languages, you know, to reflect on a phrase in the Americans with Disabilities Act which was passed in 1990. So now, it's 25 years old. So 25 years ago, using the phrase, disability is part of the human experience. Then frankly saying that, you know, either by virtue of an accident, birth or aging disability will touch everyone. And it's a natural part of human experience is actually the phrase.

The disability is a natural part of the human experience. And I think the community much more reflects that than it has in the past. The part of attitudes with people with disabilities and family members, I think the most important shift has been the shift to we're community members, and we belong like everybody else, whereas earlier versions of attitudes and I think people and families were somewhat forced into was an attitude of gratefulness and gratitude. It's like be grateful for whatever you're getting. And the notion of gratitude is like, well, yeah the community services may not be available to everybody and some of them may be a little bit questionable, but you should be grateful. I actually learned that lesson about, you know, people moving from a gratitude attitude to something beyond member to a full membership from a woman by the name of Lucy Gwin who herself is a woman that's had brain injury as an adult.

[00:42:47]

And Lucy, a self-advocate from New York, I believe it was. Not sure about where she was from. She started a newsletter in the early 1990s. And the first title of the newsletter was "This Brain has a Mouth." And later on, the newsletter evolved, to simply “Mouth.” And Lucy was a brilliant writer and satirist. And she had-- and I don't think she's doing “Mouth” anymore. I should look that up on the web and see what's happened to “Mouth” because it was largely her and a couple other people. It was a fabulous newsletter, exposes about institutions and a lot of self-advocacy things, a lot of satire and disability jokes that people with disabilities could tell. You know, like the classic cartoon of someone in a wheelchair, student in a wheelchair outside of school and it had snowed.

[00:43:54]

And there's snow on the steps and snow on the ramp. And the guy with the snow shovel turns to the child in the wheelchair and says, "I'll get to the ramp after I shovel the stairs." And, you know, the humor being, if you just shovel the ramp, then everybody can get out. So, you know, just, you know, hard-hitting, but pretty, there's humor in those things. So “Mouth” is fabulous. And Lucy like me because I ended up like being one of the first 15 people that actually paid for the newsletter. And so she actually remembered my name because I was one of the first paying members. And she did an entire edition of “Mouth” and it was called, "The Gratitude Issue". And it just laid wide open this notion of how, you know, people with disabilities were taught to be, you be grateful. And then that was, you know, completely uncalled for. And so-- and I think we’re well past that now.

Another thing that I think we're moving past is, I hope we are, is people needing to demand their rights. There are still inequities. There's no question. And then people's rights do get run over. But I think far less so, than in years past and things like the Americans with Disabilities Act helped in that regard. And, you know, when you're always demanding your rights, it's hard to be the regular participant at the meeting of the Commission of Parks and Recreation. You know, when the point is, participant in the community issue. And when you've got to demand your rights, it's harder to be that full member and participant. And I think we're in a time now of moving through the attitude being, I have to demand my rights or my rights won't be respected. And I hope, you know, we're moving toward the attitude of, you know, community needs all of us. And it needs the contributions of all of us.

[00:46:00]

And the attitude of people with disabilities should be-- and their families should be, "What do you need from us?" And we'll tell you what we need from you.

JT: What about how people with disabilities see themselves? You touched on that a little bit, but do you think that that attitude and some of these are-- the answers are obvious, but do you think that attitude has changed as well?

DM: I will always first refer to speaking with people with disabilities speaking for themselves about their attitudes. And we'll follow as they speak. What I've heard and what I've come to believe is that people's attitudes are moving the same direction of realizing it's like, "Wait a minute, it's not about being grateful, it's about being a member."

JT: OK.

[00:46:54]

DM: And I think we're seeing increasingly people with disabilities getting involved in more of the community issues. Although, I think it's extremely important that particularly people with intellectual and developmental disabilities be a continued and increasing strong voice in developmental disability issues of the day. And be in the rooms where decisions get made about funding services and issues for people with developmental disabilities, way too long. Decisions were getting made by policymakers, even people like us being asked for help. And there is no one with that intellectual developmental disability in the room. It's like, "Wait a minute, what's that about?" Now, there is-- you know, we're seeing some change in self-advocacy organizations. And I credit Indiana for funding-- providing funding to Self-Advocates of Indiana so that there actually are paid staff with developmental disabilities. Because one of the things that has made me uncomfortable, even as people with disabilities and family members were-- began to be invited to policy meetings or commission meetings or hearings or committee meetings that the government would have, I would look around the room and I would be uncomfortable even when people with disabilities were in the room and uncomfortable for this reason.

[00:48:15]

Everybody in the room is getting paid to be in the room, but not the family member, not the person with the disability. Family member had to take a day, [inaudible] a day off work. Likewise, the person with the disability, if they had a job. But everybody else getting paid to be in the room and contribute and they're not. It's like that. It's made me uncomfortable. And I think, you know, the notion of-- that Indiana now has, you know, funded-- Self-Advocates of Indiana is a move in the right direction. And I-- you know, again, I'll-- I will listen to the voice of the people with disabilities. And, you know, some of the most, I think important cutting-- and instructive comments for people with disabilities are actually now posters. Things that say like, “to boldly go where everyone else has gone before” is kind an ouch phrase originated for people with disabilities.

[00:49:17]

And it's like, you know, the people that don't have disabilities or community members that don't think about disabilities like-- take notion of that that the notion that people with disabilities are asking for something. What they're asking for is resources, relationships and meaning, which is what everybody else is asking for. You know, another phrase that's been around from self-advocates for quite some time that I think is especially important and says a lot about attitude is nothing about us without us, which kind of speaks to that notion of who's in the room, with a new funding rate gets set for a Medicaid waiver structure. And do we realize how important it is that in the decisions we made about people lives, we sort of expect them to be part of the conversation.

JT: Like you said, Indiana should be proud of the advocacy because a lot of these changes have come about because of their voices.

DM: There was a remarkable event that transpired. And no one knew it was going to happen and no one knew how in the hell it would happen. We all know the name mental retardation was common for decades. And the Legislative Commission in Indiana for decades, was called the legislative-- the MRDD Commission, the Mental Retardation Developmental Disabilities Commission. And that was common phrasing. Well, of course there was a time when Indiana was moving to change all of its legislation to take MR out of legislation and answer intellectual disability. And this was happening roughly 10 years ago or so. And I think it was in about 2005 or 2006, the national self-advocacy organization called Self-Advocates Becoming Empowered had their national conference, six, seven, 800 people in Indianapolis.

[00:51:29]

It was a remarkable event. And the Chair of Indiana's Commission was invited to speak. Now this was at a time when the country was eliminating-- beginning to eliminate the R word and use intellectual disability. And I've heard Sheila Klinker who's the Legislator from Tippecanoe County, I believe, and was Chair of the Commission was invited to speak. And she was delighted to be asked by self-advocates because, you know, the commission was important to her. She was personally friends with Self-

Advocates of Indiana, very passionate about services and supports for people with developmental disabilities. Well, she takes the stage and is standing in front of, you know, six or 700 people, how many there is in the room and proudly says that she is the Chair of Indiana's MRDD Commission.

[00:52:32]

And the crowd boos her. And then there's a stunned silence. And you think, "I didn't see this one coming." That a legislator elected official proud to be in association with and helping work for people with developmental disabilities, has just been booed by a room full of people with disabilities. She paused and then realized the issue. And I know-- and I think she apologized. She immediately made it right. And not only did she make it right in the room in saying intellectual disabilities in recognizing that's a phrase I should not be using, but I think it was little within like three months the commission was renamed and just simply called the Developmental Disabilities Commission. But it was kind of a stunning intersection of the past and the future as well as the intersection of legislators and people with intellectual and developmental disabilities.

PH: I'm glad you included that story but she's someone that we've talked about wanting to interview.

DM: Yeah. Yeah.

[00:53:54]

JT: And I remember seeing her or seeing-- we looked for her at a couple of conferences and we saw a lot of the buttons. And I think we have photographs of getting rid of the R word.

[00:54:03]

[Multiple voices] Yes.

JT: I see that a bunch of them had those-- so those will be--

DM: So, if you talk to her, you might ask her about the story that strike this if I've got that go in a way that's hurtful-- not helpful.

JT: OK. That's great. So, I know one of your--

DM: But I also-- it seems, I actually have some memory of her actually having told the story too. And proudly that, you know--

JT: Right.

DM: -- she used it as a way to change something.

JT: Right. And that's a great way to do it instead of just being ashamed or embarrassed or--

DM: Right.

JT: -- run away.

DM: Or run away, yeah. Or feel, be offended. You know--

[00:54:38]

PH: Right.

[00:54:39]

DM: You know, I took time out of my busy schedule to talk to you folks and now you're unhappy about it.

JT: Right. It's like, "Oh you're right." I did make a mistake.

DM: Yeah.

JT: And I'm sorry. OK. So, I know one of your personal focus areas is employment. So, can you talk about how Indiana stacks up against other states in terms of job placement, retention advancement and pay? So, you know, you have a long history with that.

DM: Well, employment of people with disabilities broadly speaking and certainly employment of people with developmental disabilities have been an important part of my career for a really long time. And, you know, coming to Indiana, I was, you know, really pleased to know before I got here about Indiana's early leadership in supported employment and to this day, as well as to have known a number of people from the Institute, later before I came here and know of their work. And I think Indiana is, you know, that-- doing better than the national average. Still a long way to go as in every state. But I think in particular, you know, our wages, we make little use of sub-minimum wage, I mean in supported employment, and that's good. And so people are making above minimum wage by and large in supported employment and community jobs. And the number of hours that people work exceeds 20. Now, you know, closer to 30 or 40 would be better, but a lot of states hours have been creeping down, especially since the great recession of nearly 10 years ago now.

[00:56:10]

And it's not creeping up. Indiana has maintained the hours in supported employment at well over 20. You know, I think that's to the credit of a lot of people. And a lot of that has been the leadership with the Institute. Now the Institute’s had a great job in having partnership with the provider agencies of Indiana to try to support and improve employment outcomes. And that now, it's always had some focus on transition I think the last six or eight years, the-- maybe [inaudible] longer, actually probably closer to 20 years. The Institute's focus on transition from school to work is quite strong. And I think substantially stronger that it is as a state than it is in a lot of states. Then, we've got things going now with, you know, entire school districts to try to do a better job of students going directly to work as opposed to segregated setting before they get a chance to work. And I think that's to Indiana's credit as well.

And I see no reason to not continue to expect the Institute to be a leader in the decade ahead on employment and transition issues. And that's about in large part to the Center on Community Living and Careers and a lot of the leadership of that group.

JT: OK. Can you think of anything else around employment that would tie in to other tapes you recently listened to?

PH: We don't-- So far, we don't have a lot about employment.

[00:57:45]

JT: So, we've got some people to talk to them, will talk--

[00:57:50]

PH: Right, right.

JT: Is there anything you can think of that would move Indiana ahead faster or more quickly or keep us on track besides the leadership? We know there are things that funding streams or things like that you want to talk about?

DM: Well definitely, our recent developments out of the federal government, that could be helpful in moving Indiana forward, frankly the nation forward in the interest of full inclusion, full integration of people with intellectual and developmental disabilities. A couple of things I'll mention. First of all, it was called the Center for Medicaid-- and Medicaid Services, company called CMS. Medicaid is the main funding structure for services and supports for people with developmental disabilities in the country. It's the majority funding, it's where all of the big money is. Nothing-- what Medicaid waivers paid for, that's what's going to happen by and large. Now, it's possible to do supported living, supported employment with Medicaid waiver dollars, but an awful lot of the money, in the recent past and historically has funded segregated sorts of services.

[00:59:09]

That may be changing. In the last year, CMS has issued language that is indicating not only a preference for, but an expectation of individualized and personalized lives. Right down to indications that a person picked their own weekly schedule, that they choose what their meals are, that they have access to their money, that they have full access to every room in their house, that they have control of their own front door, that they had a choice of who they would live with, that they had a choice of where they would work, that they had a choice among community jobs. And the language of CMS is suggesting that they're expecting that that's what funding will be purchasing. Now-- and they've asked every state who are-- to provide a five-year plan. And here in the middle of 2015, states are being expected to deliver those plans on how is it you're going to move in this direction.

And if we find more creative funding and new funding schemes and mechanisms, that has indicated a preference for personalized, that people choose, that are fully integrated. And they use language like, you know, common to any other typical community member. Anyone else in the community that had scheduled, a job, an experience, should be like any typical community member. And in the places where typical community members are, not in places specialized for people with developmental disabilities. That could help Indiana a great deal. I think the leadership in Indiana, in developmental disabilities, is noticed that language and is asking the question, "How do we move in that direction?" And I think that state of leadership will be extremely important. And I noticed the Institute already has a role in that conversation about trying to answer the question how, not if, we move in the direction of more inclusive employment communities but how do we do that in Indiana.

[01:01:17]

And I think that's just, you know, an opportunity to do that where, you know, maybe an opportunity for every state, but I think Indiana is ready for it. The leadership is ready for it. We understand it and we've got community partners that would want to go with the same-- to the same place very quickly.

[01:01:32]

JT: Well, that kind of leads into the next question. Do you need a drink before we go into the next question? OK. We'll come back to this question in a minute, but given what you just said, what do you see as present and foreseeable trends in the field of disability and people coming out of school, what sorts of skills, education and training do you think they'll need to have to be successful in supporting people with disabilities?

DM: Particularly on transition from school to work. I think we've collectively realized that that's-- it may be one of the most important transitions because that's the bridge between childhood and adult life. And getting started into adult life, well, we know that's how important that is for any young person. Well, we also know-- and the data is extremely clear that if you have multiple job experiences while you're still in school, you have a disability, you're far, far more likely to have a job when you're 25. And the single most important thing we can do while any-- frankly, I think this ought to be true for kids without disabilities as well as students with disabilities, is three or four or five job experiences before the age of 21. And even starting hopefully, you know, at the age of 16. In getting multiple job experiences, not only to find out what you can do and want to do, but to find out what you're not very good at and don't want to do.

[01:03:06]

So I think that's become extremely clear now in anybody that is associated with high school in particular and certainly the transition years. And on a national basis, it's almost like an "aha" moment if you look at where the Department of Education is going, the Department of Labor, Social Security Administration and others. And I think if-- if you think about it, you know, if I've been at the Institute close to 20 years. If we had collectively done a better job with every young person with a disability coming out of school. And if we had said, "We're not going to do anything to make sure 80% of the young people with disabilities coming out of school have a job at 21," we'd be having a different conversation today. Because then, there would be the expectation that almost every kid coming out of school would either be in postsecondary education or in a job. And the trajectory would be really clear.

I think we know that this time, that if we do a great job at transition, then in 30 years, problem solved. Now we also need to be asking people in sheltered workshops in day settings, "What do you want to do?" And when we had a doctoral student here a few years ago, Alberto Migliore, he interviewed 200 people that went to a sheltered workshop every day. Two thirds or more when asked said they like to try a job in the community. You know, we need to continue to ask that question and then try to figure out, when two thirds say they like a job in the community, what do we need to do to try to offer that up?

JT: Peggy and I interviewed a bunch of older people, do you remember? And asked them what they'd like to do when they retired.

DM: Yeah.

JT: And they were already at retirement age many of them and they would say, like a job in the community.

[01:04:56]

DM: I'd like a job in my retirement. Yeah. You know, a lot of people in retirement say that. Just a second here.

[01:05:01]

JT: OK. So, you see one trend being transitioned from, you know, like you were saying, having X number of jobs before you're 21. And did you also include in there the transition that more kids are going on to postsecondary education?

DM: I do. I've mentioned it. We talked--

JT: Is that another trend and are there other trends that you see coming that you feel like you'd like to talk about?

DM: The transition to your employment is an appropriate one for maybe most of young people with significant developmental disabilities coming out of school that-- and the last-- just in the last 10 years, the notion of people with intellectual and developmental disabilities going to postsecondary education is becoming a possibility. There are easily several hundred projects now around the country, postsecondary education environments where young people with intellectual and developmental disabilities are on college campuses, taking classes, joining social clubs, getting job experiences, et cetera. A lot of those classes that students are taking are integrated with other students. So, increasingly, postsecondary education is becoming a possibility. I think it's probably only a fraction, a small fraction for whom it's truly available in this country. Indiana's fortunate at this time, in just the last five years, six or seven campuses now include people with intellectual and developmental disabilities and two of those either have or soon will have students with developmental disabilities living on campus in addition to taking classes.

[01:06:35]

And postsecondary education for any of the families, young people is about getting an education, learning something, it's about getting some kind of work experience so that you feel like, "I've got the resume lines to get a good job when I leave." And it's about social participation. It's like being a member of the college community and however you define that. And I think we'd rather make sure, we do all three. Learn something, get into classes, and get work experiences to build a resume and look at the social context and show up and recreate, contribute where you want to which is what college is about. It's finding out, you know, where is it social, you want to show up and will have a good time or contribute in some way. I expect that to continue. You know, I think the hardest part about postsecondary education program is to make sure they include the vocational component. And I think it's absolutely critical. Postsecondary education can't be a place you'd go before you start looking for work.

[01:07:39]

It's got to be a place that builds resumes. And that's-- when you think about it, college is a time when any young person is building a resume that gets them that first more permanent, more full time job. And that's the language we need to start using. It's not about, you know, if a person with a disability has a part time job, we call it good. It's like, "Wait a minute, standards and expectations is [inaudible] same standards and expectations as anybody else." So, you know, saying it's OK for someone to work $10 a week. It's like, "Well, who said that's OK because somebody has a disability?" It's like, "Wait a minute. You're going to pay your own bills? Then you probably ought to be working."

[01:08:20]

JT: I can't live on $10 a week. OK. All right, I think there's like one or two more. I'm trying to figure out. If this is redundant, don't answer it. I know you talked about the Institute's proudest accomplishments. But since this is the Indiana disability history, do you think we've talked enough about Indiana's proudest accomplishment?

DM: Yeah. You know, there were probably others that are going to give you more of that. And in fact, you need to talk to Suellen.

JT: We asked a lot of people except the same questions.

DM: Have you talked to Suellen?

JT: Not yet.

DM: OK.

PH: The one thing I know that we're missing was about the 317 plan?

JT: Yeah we had that down here. And you want to talk about it, you know, the big minds sort of 317 or--

[01:09:08]

DM: Yeah, sure.

JT: -- some of those things that you've been involved with.

DM: In the late '90s, one of those times when tragedy turns to good instead of to more tragedy. And the tragedy in about 1997 or '98, '97 I suppose, was an employee at New Castle State School, whatever the name of it was at New Castle, an institution for people with developmental disabilities. And an employee that worked there, extremely unhappy and offended with what was going on in the institution for people with developmental disabilities, snuck in a video camera in a purse or a bag and provided videotape to a TV station of people with developmental disabilities being made to sit in chairs, hit over the head with clipboards, spoken to rudely and cursed at, and all of the things that you can believe when you're told, happen in institutions when you don't want to think about it or believe it.

But then you see it. That appeared on 6 o'clock news one night and the disability community, the advocacy community and the community at large was offended that this is happening to Indiana citizens with developmental disabilities probably daily only never witnessed by anyone outside. And that led to the Governor, Governor Frank O'Bannon at that time deciding that there needed to be a commission that would rethink services for people with developmental disabilities. That came on the heels of that. And the-- a piece of legislation was developed and sponsored. And it was called Senate Bill 317. And so, the commission got named as a result, it was called 317 Commission. Now, the mildly humorous story of someone being asked, "Why was it called the 317 Commission?"

[01:11:20]

And someone said, "Well, because that's the area code for Indianapolis?" It's simply a coincidence. It's the 317 Commission named after -- the numbering of the legislation. So that commission of people with disabilities, family members, professionals, practitioners and government people were charted to put together a new path. And that path essentially started us down the path of person-centered planning.

Or at least more person-centered practices and down the path of saying maybe Indiana doesn't need its state intuitions anymore. And while that may have happened or it may have started anyhow. It was the tragedy of the videotape on the evening news that prompted the gears to start moving that resulted in the 317 Commission that started the conversation about what do we want in the future that's 10 and 20 and 25 years out.

[01:12:33]

And I think a lot of the things around more person-centered services, certainly the closing of the institutions, the expansion of community-based services for people across Indiana, you could pretty much mark that as the beginning of that chapter. And it started with that 317 Commission. I was pleased to be a part of that 317 Commission in the late '90s. And I think that was a really important moment in Indiana's history.

PH: That was excellent.

JT: Is there anything you want to talk about, anything that we haven't asked you that you think would be important for the project?

[01:13:13]

DM: I mean, you asked the questions that I would want to speak to.

[END OF INTERVIEW]