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**ORAL HISTORY INTERVIEW WITH  
VICKI PAPPAS  
APRIL 5, 2013  
INTERVIEWER: JENNIE TODD  
VIDEOGRAPHER: PEGGY HOLTZ  
RECORD ID: 019-DO**

**VP: VICKI PAPPAS  
JT: JENNIE TODD  
PH: PEGGY HOLTZ**

[00:00:10]

**VP:** Hi, I'm Vicki Pappas and I live in Bloomington, Indiana. And I just recently -- about a year ago -- retired from working at the Indiana Institute on Disability and Community.

**JT:** Okay. Can you tell me how and when you got into that line of work?

**VP:** Yeah. It started when I was here getting ready to come to graduate school and, of course, looking for an assistantship. And I was enrolled in the interdisciplinary doctoral program in young children. And Myrtle Scott, who was the director of that program, sent me over here because Mike Tracy was interested in graduate assistants. So I came over and talked to Mike and decided it was interesting, although it was way out of my field but to work with him on the Deinstitutionalization Project. And that's what started it. And even though I got my -- eventually got my -- degree in educational psychology with an emphasis in child development and children's policy, most of my education came here in the disability field, and the adult disability field, and continued on, and continues onto this day.

**JT:** Okay. Good. Can you talk about your work with Mike Tracy?

[00:01:37]

**VP:** Yeah. It was really probably the most influential work I'd ever done, and certainly influenced the rest of my career because what we were doing in those days, we were a team of graduate assistants working with a team of faculty, and that in and of itself was a wonderful educational experience. But what we were trying to do is to look at different ways of treating people with disabilities and especially looking at people who were institutionalized and having the conviction that they needed to live lives just as we do

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-- lives in communities, hopefully with their families, having more control over their lives. You know, just the opposite of all the things that would happen in an institution. And Mike had just been funded to do this project and therefore had money to hire, I think, eight of us. There were eight graduate assistants who worked with him on the project.

[00:02:42]

So that really was how I got into the disability field. And as I said, that just sort of stayed with me all my life.

**JT:** Can you back up just a little bit and say -- in the beginning can you make one sentence about when I ask you, "Can you talk about your work with Mike Tracy?" can you say something about, "When I worked with Mike Tracy blah-blah-blah."

**VP:** Oh, yeah.

**JT:** And then if you could tell me the name of the project because you talk about the project.

[00:03:06]

**VP:** Sure, yeah. When I started here as a graduate assistant my work started here with Mike Tracy -- Dr. Mike Tracy -- who was a faculty member in the School of Education, but also was one of the co -- not co-directors but associate directors of what was then known as the Developmental Training Center. And he had been funded to work on a project called the "Deinstitutionalization Project."

**JT:** Perfect. Okay. So what did the work look like that was moving people towards community inclusion?

**VP:** Yeah. It -- wow, it was an attempt to believe that if we gave people who had lived in an institution -- it was Muscatatuck -- the opportunity to live in settings that were more natural and to allow them to explore those settings, and live in those settings, and do all kinds of things in those settings, that somehow that that would make a better life for them. And what we realized is -- and probably realized later -- that the project was way ahead of its time in terms of what the community was like. But we were really attempting to -- I guess in a nutshell -- to bring people from Muscatatuck here to the Developmental Training Center and have them here for three days in what we call the "halfway house."

[00:04:48]

But it was actually one of the cottages at the DTC. And we made those cottages as home-like as possible so that they could try out living in a more family-like setting, and most importantly, to explore activities in the community -- recreational activities, social activities, some work activities. And so we -- each of us graduate assistants -- had one of the persons as our -- we were the advocate for that one person. And the sort of, I guess, revolutionary thing for me was the value systems that Mike incorporated into the project was to say that you don't train people to get ready to go out in the community; you take a risk and let them go into the community and see where their strengths are and see where they needed support and offer it then.

[00:05:49]

So even though we called it a halfway house, it was really jumping them into group living in a group home-type of a setting, which the halfway house really was, and then doing things in the community and seeing how far they could go without putting a lot of constraints, although helping them to understand there were consequences. So it was a very -- you know, for us very exciting, very fearsome - - for those of us who were graduate assistants because I had never done anything like this. I was a first grade teacher coming into graduate school. And even to this day, I remember those people that we worked with. I remember things. I mean, it made such an impression on us. And of course, for us as graduate students, grappling with the issues of: How do you take people that some had been institutionalized almost all their lives and find places for them to be in control of their lives, to live natural lives, to do things that they were good at and wanted to do?

[00:06:58]

So it was very broad-based but it had those kinds of values involved. And we often sat on the other side, you know, here were all these ideal dreams and things that we wanted to help with to achieve the project goals, but on the other hand coming face-to-face with reality and ethical issues of what was our role, and were we trying to make things happen for people that maybe weren't supposed to happen? And again, because Indiana was in such a very -- I mean, I don't even think they thought of the things that we were thinking of. I think at the time there were only nine group homes. I remember six in southern Indiana. There were no community services, no idea of work experience for people. You know, the general trend was you were born with a child with a disability, it's better to institutionalize that child to protect your family and to allow you as a family to live a better life.

So the whole way of thinking -- and not only in Indiana, in many places at the time -- was very different from what we were trying to do. So it was a very -- project that had not much impact in terms of actually finding places for the people we worked with but huge impact on us as growing new professionals in the field. And, you know, kind of as I said, it affected me for the rest of my work and even in retirement. Still does.

**JT:** Okay. Well, this isn't necessarily a question that you have to answer, but this is just a comment. You were saying that people came here three days a week as kind of a halfway house. And we interviewed someone else who described it as a place that people came for a year, this was [multiple speakers].

**PH:** She talked about them, the family.

**JT:** Was invited to come here.

[00:09:03]

**PH:** Is that a different?

[00:09:04]

**VP:** That's a different project. That was the -- that was -- actually, that project was the beginning of the autism work that the Institute did.

**JT:** Because I thought she said that project was when the DTC was just developed and they invited X number of families because her son had been at Muscatatuck, and she and her family lived here for a year. And there were families that they kind of evaluated.

**VP:** Yeah, yeah.

**JT:** She was really glad that they chose --

**VP:** That was Kathy Byers, and I think Nancy Dalrymple was involved in that eventually.

**JT:** So that would have been after?

**VP:** No, that was before and maybe overlapping. I think before.

**JT:** Okay. Do we need to talk about any of that so that it ties -- it isn't confusing with that other project?

[00:09:47]

**PH:** Well, I mean we'd have to see exactly --

**VP:** Did they have young children? They had a project --

**PH:** He must have been older.

**JT:** They were not adults. I thought he was school age or --

**PH:** Yeah, he was school age.

**JT:** Everyone that came here was school age. So I was just wondering if we need any sort of --

**VP:** Well, I could talk a little bit about -- yeah.

**JT:** Okay. Maybe just talk about, you know, this project.

**VP:** Where the Institute was when this project started. Yeah.

**JT:** Maybe it followed up with a project that had been here before.

[00:10:20]

**VP:** Well, it didn't I don't think it -- I can tell you a little bit what I think the connection might have been. The Institute -- before I got to the Institute, I got here in '74 -- in August, actually, of '74. And a little before that, with younger children and with another project, the Institute was involved in bringing families and children together to live in these cottages and to have the children assessed and to look at better ways of educating them. And I think some of the children came from institutions and maybe others came

from family homes. But they actually worked here with an early childhood or school age, I think, team to look at the issues that those children and those families were having. I think the connection -- what I can remember -- is just before the Deinstitutionalization Project started Mike, and Fred Kladder, and some other people helped out and did -- were very interested in family assessments of, you know, developing some assessment tools to look at how the families interacted with their children and what were the consequences.

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And I think from that Mike drew into the Deinstitutionalization Project the idea of a different kind of an assessment where, you know, most testing looked at what are kids doing right now, and where are the gaps, and where do they have to go? Which leads into what he felt was a training approach where he looked at -- and we did this in the Deinstitutionalization Project -- looked at assessing the person in a particular environment, looking to see if we could find out what were their strengths. And I think today it's the same thing as asset building. But looking at their strengths, looking at their interests, and then using that to build an individual plan with no pretraining needed. And I think for most of us because most of the students were ed psych students as I was. And we were sort of engrained in that idea of you test and then you work from there and improve. Whereas with Mike it was look at -- and Sam Guskin was part of this team, too, and some other faculty from the University of Michigan -- but to look at how does a person operate in a setting, an ecological setting, and recognizing that it's not just the person you fix, it's the setting, too, and then going from there, identifying their strengths and interests, and building on that.

[00:13:01]

So I think that notion of assessment Mike tried out first in this family grouping that the -- I think it was called the Early Childhood Program -- no, the School Age Program I think it was. And I believe Kathy Byers was involved with that and at some point Nancy Dalrymple. And eventually that evolved into the work that the Developmental Training Center did in autism and with school age and young children. So Mike was sort of connected to it, but his Deinstitutionalization Project was really focused on adults and looking at this whole process. He called deinstitutionalization "a process that meant changing systems, not changing the person." And so we got involved, and that led to my work and planning beyond -- once the project ended -- looking at how do you change provider perspectives and provider procedures?

How do you change the state to build community services, to look at different ways of delivering services? And that's where he was heading. And with mostly a focus on adult, but of course, some of the issues affected kids and families, too.

[00:14:17]

**JT:** With all this work around inclusion that you and Mike Tracy were doing, where did the push -- what motivated Mike to do this? Was it from people with disabilities? Was it from families? Was it from academia?

[00:14:32]

**VP:** Well, at the time -- see this, right -- remember in the '70s, early '70s, all the national and some state legislation was popping up. I mean, we had the public law 94-142 for mainstreaming and special education services for kids. We had the DD Act, which was starting. We had the Rehab Act. And all of it was beginning to look at different ways of providing services for and with people with disabilities. So that was one. I mean, it was just a hotbed of all sorts of legislative policy activities happening. And then Mike came from the University of Michigan, and that's where many of the faculty that he brought into collaborate with us came from the program that Dr. William Rhodes did. And I think all of them were just so influenced by the values of that system that they brought it here.

And it was also the time of Wolfensberger and normalization. So everybody was talking about these big philosophical, ethical, values-based issues related to how you, you know, provide services or not so much -- the consumer advocacy idea, I think, came a little later, but there was still this idea of people having a voice and what happened with them, people's doing what they wanted, not being routinized and institutionalized. So there was that influence in it. The idea of consumer advocacy was just beginning. And even I was looking back at some of the case conference and case meetings we had on the project, even the insistent that the person with the disability had to be at the table. So those things were starting. I don't know that -- they were all part of the impetus of everything that was happening.

[00:16:40]

**JT:** But it sounds like it was academia.

**VP:** Yeah, I would say. And -- yeah, you know, I think Dr. Rhodes had a powerful influence on a whole bunch of his graduate students, Mike being one. And all these other people, Ron Neufeld [phonetic], Spencer Gibbins, they all were in that graduate program. And in many ways the graduate program that Mike created here, I think, the same thing happened with us as we left, carried that on. But I think you can trace it back to the University of Michigan special ed program.

**JT:** Okay. That was good. Okay. So now we're going to go on to thinking about, in thinking about the Institute broadly as a UCEDD, what were some major influences the Institute brought to the state, and were some of the most significant pieces of work that the Institute [inaudible]?

[00:17:37]

**VP:** Well, I think the -- boy, there's so much. When you think about the history and, you know, I think it -- starting with Dr. Schroeder, Henry Schroeder's almost insistence but strong sense that the DTC and all of our names since then had to provide service to the state. And that was one thread that went through all of the programs. And the other thread was a real concern for families and helping families, and in turn then helping their kids and their adult progeny. I would say you have a whole strand -- and you might want to be talking to other people about this -- a whole strand of groundbreaking things, again, all in the '70s -- with early childhood and the idea of having a preschool.

And when I was involved here as a graduate assistant at the same time we had Project PREPARE going that was really taking a look at similar ways of assessing and programming for kids in preschools when

there were no preschools in the state. And so I think that program had a big emphasis, which then eventually grew into our early childhood program, which, you know, even to this day pushes the window as to what early childhood education should be. I think with us, with the Deinstitutionalization Project, that led into a lot of work -- very close work -- with the state in planning and using data for planning. And we moved into assisting the state in developing their developmental disabilities plan and bringing together a collaboration of people from different state agencies to take a look at the issues.

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We worked with the Department of Health and Social Services at the time, I think it was called, and Education. So I think being the impetus for that and bringing together people from all those state agencies to begin to address the issues of "What's disability policy in the state?" So I think that was a major contribution. Clearly in the field of autism, you know, as I said it started, I believe, with that family assessment program, at least the seeds of it. The autism program and the attention to autism in the state has been a contribution of the Institute. And now it's, you know, almost no matter what you think of the Institute and its people are right there doing training; doing research; writing materials; writing books to talk about best practices all the way up, I mean, from preschool to aging.

[00:20:49]

**JT:** Okay, good. So what areas in thinking about Indiana -- and let's see, UCEDD -- do you think we are ahead or behind other states?

**VP:** Well, I don't know. That's a hard question to answer. You know, in some ways -- boy, I don't know. I know -- I don't even know how to. It's just hard to answer, to compare. Because the UCEDDs are so different. And we weren't -- in the past -- other than Mike and me and maybe a couple of other graduate assistants going and getting involved with the interdisciplinary training, I think we had some leadership roles there, again, in the '70s and '80s. Up until recently, a lot of our programs weren't well-known in the network. And I'd say in the past ten years now more of our people go -- David Mank was a president of the association -- and people are more aware of our work, especially our work, I think, in autism.

But they see our products. And again, the national association has done a much better job of publicizing what the network is doing. So, again, that helped, too. It was a little bit different in those earlier days. So it's really kind of hard because we have such a broad scope to compare us to other -- you know, we always like to say we're among the leadership groups. And I think in many areas we are. But it's just a hard -- you can't even ask that question, I guess, of people in the network.

[00:22:48]

**JT:** Well, can I ask you that question in terms of the work the Institute does nationally? You know, how the work that is happening in the State of Indiana compares to work that happening across the nation, you know, not looking at it as a UCEDD but just looking at it --

[00:23:07]

**VP:** Indiana -- that's even hard, too.

**JT:** Okay. Well, you don't have to answer.

**VP:** Yeah, it's just hard because we're --

**JT:** What we're trying to look at is: Where are we ahead, where are we behind in these areas? So.

**VP:** Well, I think clearly with that Deinstitutionalization Project, I think we were way ahead -- we were way ahead of Indiana; we were way ahead of Bloomington in Monroe County; and we were way ahead in the country because people were just -- in fact, I think at the time there was even a backlash because the mental health arena had tried deinstitutionalization and, you know, all the criticisms of dumping people with serious mental illness onto the streets with no supports. And they pulled back on it and then all of a sudden here the disability community comes out with it. So we also had to fight that. But there was nothing. There was just nothing for people, other than if their families could cope and keep them or put them in an institution. And as I said in '74, '75, '76, there were six group homes. That's it.

[00:24:23]

And the state was just starting to begin. And of course then, you know, into the '80s those group homes really grew because that was the model. I think that where we've made significant impact since then, I think, is in the least restrictive environment issues dealing with the schools. And that probably was really when Barbara Wilcox came here to the Institute. She really provided an impetus to that. And also the whole idea of supported employment. So I would think that in the state -- and probably nationally -- we were very early leaders in both of those arenas. And again, those were ideas -- I like to think -- those were ideas that came out of the people who were thinking about deinstitutionalization in the early '70s.

I think in early childhood we've also made very steady, very good progress in terms of looking at early childhood services. And likewise, now I think we're right at the forefront of looking at assessments and teacher competencies in the education field. So.

**JT:** So what was your role with ADA Indiana? Can you talk about that?

**VP:** Yeah. That started coming about in the --

**JT:** You say "The ADA."

**VP:** Oh. ADA, oh.

[00:26:08]

**JT:** Because they're not going to hear my question to you.



[00:26:10]

**VP:** That's right. ADA Indiana, and what was my role and the Institute's role in that? The Governor's Planning Council, I believe, in the late '80s sort of teamed up with Justin Dart and his people. And there was a lot of talk about the up-and-coming legislation. And I know the Governor's Planning Council at the time called that brought Justin to a big meeting. I don't even know if I recognize -- I remember being at the meeting but, you know, I'm not sure everybody like me recognized the significance of him coming until later. I think people with disabilities did, but not all of us did. But we knew what was starting to happen. And then the law passed. And I can recall David Braddock from the University of Illinois calling me and asking for a letter of support for a project he was trying to get funded, which later became ADA Indiana -- or the Great Lakes ADA Center -- and we said yes.

We did it and got some other letters for him to show that Indiana was on board with that because he had told us he wanted to develop a center that involved the six states around us. And he got funded. And even though he had approached us, he connected with Costa Miller, I think, and Amy Cook Lurvey from COVOH and Nancy Griffin. And somehow the leadership of Indiana's portion of that grant fell to them. And that was in 1990 and 1991. And they did some gathering of people to talk about what we would do in Indiana. But it didn't really get going, a lot of it because I think COVOH was involved in some other advocacy things and it wasn't quite a priority. And then David asked us -- me, I think, or us -- to be like the staff contact person, to receive the money because he had to funnel it into us, I guess, to receive the money to provide technical support to ADA Indiana, which I think at the time it was called the "ADA Steering Committee for the Implementation of the Americans with Disabilities Act."

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Real long title. So that's how I got involved, as I was the project director of that and had enough funding to hire at least half time a graduate assistant to serve as staff to that committee. And that's how we started. And I was also a member of the committee. So I wore two hats: I was Project Director of the Technical Assistance Fund but I also was a member of the committee. And, you know, we went from there. That's how we started.

**JT:** Well, I know there was some big global, you know, projects and work you did, but some of the local things I know you were involved with the voting accessibility [inaudible] because you used some local people and they helped to assess the polling places. Could you talk a little bit about [multiple speakers]?

[00:29:42]

**VP:** Yeah. That was another project that I was involved in that probably -- aside from the Deinstitutionalization Project -- probably was, at least the people in my center who worked on it, was one of our best projects. And we called it "People Power." And we were funded by the Governor's Council for People with Disabilities to help people understand and exercise their rights in voting. And we did -- part of it was that we did maybe five or six workshops all across the state, talking to people about registering to vote, and voting, and what kinds of questions you might ask legislators, things like that. And then we focused on Bloomington a little bit and did a workshop here and did a disability rights workshop.

But then we got the idea to have a candidate's forum. And so we helped to organize a candidate's forum with a group of people with disabilities here and invited everybody that we could think of. And I remember the room was packed with people with disabilities. And we had a question panel, and then we had all the candidates. We had probably five or six of them come and asked them questions. And I remember one of the questions that -- we had developed the questions -- was asking the candidates what they were doing in their campaign to make their campaign accessible in terms of materials, in terms of presentations. And everybody fumbled on that question; they had never thought of that. And I remember at the time Mark Kruzan was running for mayor, and he was about the most straightforward.

[00:31:53]

He just said, "I don't know," he said, "but I will certainly go back and look at it." And people just cheered at that. So that was a very powerful meeting. And then the group homes in town -- Stone Belt especially -- it was, I believe, a presidential election year so they began educating their people, using some of our materials about what are the candidate's positions on issues, and writing letters, and getting registered to vote, and all of that stuff. And then the fun thing we worked on is we worked with the bus company to see if we could get free buses in Bloomington to take people to the polls -- any people, not just people with disabilities. And Lou May, who's the Director of the Bloomington Transit, agreed to do it if we could give him I believe it was \$900 because that's what it cost him per day to run the buses. And so we started a big fundraising thing and went to different people all over town, and by golly, we raised the \$900.

[00:32:58]

And that happened. And we had signs on the buses and all of that. I'm not sure how many people took advantage of it. But that was sort of a highlight of that activity. And then out of that, we weren't really the -- I don't think we were the impetus. I think mostly Suellen Jackson-Boner developed the idea of access to polling places. And she started a Count Us In project that drew upon the things that we had done in People Power. And that was -- even though People Power was funded by her, too, this was, like, the next iteration of it. And a big, big stress of that project was to train people all over the state in how to assess polling places. They developed a modified checklist based on the ADA to do that. And then we helped some of the people in Bloomington to do the assessments of the polling places in Bloomington.

And then all that information was fed up to Suellen. And they did their advocacy work about the importance of doing that. Again, that was something that was in its early stages in terms of looking at ADA accessibility, in terms of voting. And of course now, you know, it's a very, very big thing.

[00:34:27]

**JT:** Well, I was going to ask you if you have a story or an example of this works' outcome. And I know Angie loves being at the polls. And she talks about how she surveyed and made some recommendations. And now she has different politicians that she supports and promotes and that sort of thing. But I didn't know if you had a story that you wanted to share.

[00:34:50]

**VP:** About someone with a disability?

**JT:** And what their work -- how their work changed things. If a polling place made their site more accessible because someone had a recommendation or any follow up to [inaudible] or anyone else who you [multiple speakers].

**VP:** Well, yeah. I think, you know, one of the things I remember that I learned from Mike early on -- because it was a hard lesson for me to learn -- is that the role of the Institute is to start a project. And the best thing that can happen to a project is if someone takes it and goes with it and then we drop back and do other things. And that was -- you know, giving up that professional ownership was a big learning for me because it was like, you know, you're in charge of a project and you don't ever want it to end because it's going well and you're building it and all that. And I think that's what explains some of the projects that the Institute did as, again, like People Power. You know, People Power was the start of something: We developed training materials; we trained people in other cities; we did a lot in Bloomington; and that stimulated other people to take that up. So when our project was not funded and when Count Us In was stopped, the process still goes on.

[00:36:17]

And I think that's probably back to an earlier question you asked me -- that's probably why it's so hard to say, you know, what lasting influences did the Institute have? Because we started things, you know, in the early childhood area, in the school area -- everywhere we started things -- and many times the success was that people took them over. And I think the -- you know, now the polling place accessibility is a state policy. You know, it's a national policy. And we don't have to push it anymore because individually each the counties are taking care of it. Sometimes they'll contact us for materials, or to consult with them, or to do some training. But essentially, we don't have to worry anymore about pushing to have it implemented because other people have taken up that banner and are pushing it. So I think that's probably a hallmark starting way back, you know, as people like Mike and Henry, and now continuing with David, you know, that we don't want to be in the driver's seat; we're good at developing things, and providing initial training, and technical assistance and supports.

But eventually our real goal is to have communities pick up what we're doing, schools pick up what we're doing, state policymakers pick up what we're doing, and start implementing it themselves.

**JT:** That was a really good answer.

**PH:** That answers four in a way.

**JT:** Uh-huh. So we don't even need to really answer past this one. [Laughter]

**VP:** That was a good cop out. [Laughter]

[00:37:51]

**JT:** No, that's very good.

[00:37:53]

**VP:** Well, it just came to me because I remember -- I remember a project in particular where I was -- Mike had given me the development lead on it and we did it for two years. And we were all set, already planning what we were going to do the third year. And he said, "No, it's done." And I remember walking out in that field there just being so upset as, "How could you just stop it?" You know, it's done. You know, but it isn't done; there's still more to do. And so it was a big topic of discussion among the graduate students.

**JT:** [Inaudible]

**VP:** Yeah. It's like, "Others will finish it."

**JT:** Now we're going to talk a little bit about --

**PH:** Does she want some water?

**JT:** Yeah, do you want a drink?

**VP:** I'm okay.

[00:38:33]

**JT:** Okay. So we're going to talk about Dr. Schroeder and so, you know, basically his legacy and his impact on the field. So the things that I'll ask you -- and you can figure out how you want to talk about them and I can come back -- but I'm going to ask you to describe him; how people would remember him; some of the projects that he would probably feel most proud of; and the impact that he left. So you can think about all that, and then I'll ask you more probes as we go through this.

**VP:** Okay, okay.

**JT:** You can organize your thoughts as to how you want to go through it.

[00:39:08]

**VP:** You want me to start? Oh. Well, you know, of course Dr. Schroeder was my first big boss, being the director of the DTC when I came here as a graduate student. And, you know, we didn't see a lot of him, but what we did -- I mean, he wasn't an unapproachable person. He was around and, you know, his graduate students were a little afraid to talk to him sometimes as normal. But he -- I think as we got to know what he did -- he started out as, I think, he got his degree in speech and language. And through that, though, he always had a commitment to families. And I think that was something that was central to him, is: How do we support families, how do we help families? And families in trouble need to get -- you know, somehow we have to work something out so they get out of trouble.

If they have, you know, whatever issues they're dealing with, they need to be supported in getting those resolved. And so, you know, that sort of -- we just knew that about him. The other is he was a very down-to-earth guy. And he was like buddies, you know, with a lot of the state people. He really

developed especially close relations with Gill Bliton who was head of the Special Ed Department and through that was able, then, to get some changes, and start getting the changes made, and least restrictive environment. And when he brought Barbara here, I mean, that was a big thing. I think he was very, very -- that was probably very, very close to his heart in those years. And brought Madeleine Will here to talk to educators.

[00:41:16]

She was at the time -- or she became -- federal head of the Department of Education. And again, I think that was coming from his concern for families. So that's probably where -- his interest was probably in the education arena. And this forming of strong relationships with the leaders in the state, the state government leaders, enabled him to get a lot done. And I think he was always respected. And the Institute was always respected as a resource that state people could trust and could turn to. And Henry cultivated those relationships. I think the other -- when I look back over his years of being director of the Institute, I think he brought in good people and he let those people do their thing. You know, he wasn't a dictatorial director or anybody interested in hierarchy.

But he wanted good programs, and he saw an opportunity to develop programs by bringing a person in. And he did that. And he was very supportive to graduate students. I mean, you know, Mike hired me as a graduate assistant. And then when I got my PhD -- I had been -- at that point I was still a graduate assistant, but I was also working on training things, training and evaluation. And when it looked like I wasn't going to get a job, he offered me -- Henry offered me -- to look at evaluation of training and to set up an Office of Training and Evaluation. And I just saw that as, you know, very good. He could have just said, "Well, Vicki, your assistantship's up." And he did that with a lot of students. He was very caring of students and nurturing all the students. And we had a lot of students in those years. Because he -- when I came -- he brought in maybe six or seven faculty members, mostly from the School of Ed, one from speech.

[00:43:28]

No, it was interdisciplinary because Darcy Sing came from social work; a woman from speech and hearing; people from special ed; people from special education. And they had offices in the main building. And they were, like, consultants to the programs, which was back to your question about the UCEDDS. That was what we were supposed to be doing. And so when I came in as a graduate student, I was assigned to one of those faculty members and, you know, periodically sat down and talked to them about what I was doing -- besides Mike. I mean, this was somebody different. So he really looked at this place as bringing in students and developing an interdisciplinary training program. And I think our training program was very different from the kinds of training programs -- and it still is today -- from the kinds of training programs that go on in other UCEDDs in that we don't have classes per se for our students, but they're learning through their work in the various program areas of the Institute.

[00:44:35]

And I think Henry -- that's sort of how Henry operated in terms of, you know, allowing a lot of students to come here and work and relishing that vibrancy that students bring and problems that students bring. And then being very supportive of students.

**JT:** What would you say his legacy would entail or some of the pieces of work that he was involved with that he would be most proud of?

**VP:** I think the education stuff. Because even though he didn't work directly in it -- you know, bringing in Barbara Wilcox, you know, that was him. He wanted her, and he talked to her, and he worked to bring her here. And because she was here -- I mean, he kept very close to her program -- because she was here, we began the push towards least restrictive environment and also to supported employment. And Henry was very close to those programs. Even though he supported the early childhood programs that were going on and supported, you know, the planning that we were doing as an outcome of the Deinst Project, those were probably the programs where he was -- I don't want to say he neglected the other programs but that's what he was really seeing as, "Wow, this is something important to push, and look what we're doing, and change is happening, and this is great."

And I think he'd be, you know, very pleased to see where Indiana is now in terms of school and supported employment and even now that we're working or even beginning to address the issue of why sheltered workshops. I mean, Henry was talking that way early. And so those are the things I think he'd be very, very proud to see now, that his, you know, his establishment -- the DTC and the -- what was it called? ISDD, Institute for the Study of Developmental Disabilities, that where that has evolved to. I think he'd really like that.

[00:46:49]

**JT:** Can you think of any ways or anything people would say as a tribute or memory of him? And if you can't -- this is a hard question.

**VP:** Yeah, because he has so many other things. [Laughter]

**JT:** Yeah. How would you say people remember him? And maybe you answered that, but I just wondered if there we're any other comments or things that [multiple speakers].

[00:47:09]

**VP:** I think people will remember him for creating a wonderful resource for the state in the Institute. You know, he was -- I don't think he was the very first director once it was built; there was another man who I think got the initial funding from the Developmental Disabilities Act to build this place. And of course, the idea was that it was an assessment center for kids. That's why the cottages, you know? And they sort of floundered in the beginning, but did it a little -- families came here to have their kids assessed. The main building was set up like doctors' offices. And the reception desk and the big room that we used to call the "lizard lounge" for the graduate assistants -- and projects lived there, too -- was really

the infirmary. So the whole place was set up to do that. And then Henry took it over and it didn't become that.

[00:48:13]

And he probably -- let's see, I got here in '74 -- I think he took it over maybe in '71. It was built in '69. And when he took it over, he changed the face of that. And of course, in the beginning we actually had residential people here, living here. The autism program was going; Stone Belt used two of these cottages for their group homes; we had the Deinstitutionalization Project. But when Henry saw the field starting to move to communization, which is what we used to call it, he was the one that said, "This doesn't fit that we're housing people here," and made the move to encourage the project directors that -- and talked to Stone Belt -- that we did not want to be a place that was housing people in institutional-like settings, that our role was to help people live in communities, to go to school in their neighborhood schools, all of that.

So in a way, you know, he created the Institute for what we are now, in terms of our outlook. And as I said earlier, his model was always, "No matter what we do, it's service to the state first. Yes, we can get federal grants and do all these other things, but it's always service to the state." And I think that served him well because in times of budget cuts, you know, the Institute had a good base that we didn't suffer as much as we could have, had we been focused outside or too inward into academic things. We were always the bridge from academia to the community and pushing what we knew to the community.

[00:50:04]

**JT:** That was good. So I have one more question and then I'm just going to let you talk.

**VP:** Oh, wow.

**JT:** If you want. [Inaudible].

**PH:** Hold on, you pulled the microphone.

**VP:** Oh, right.

[ Pause ]

**VP:** How much of me do you -- are you just getting me from the waist up?

**PH:** Yeah.

**VP:** Because I'm sitting cross legged and all that.

[00:50:31]

**PH:** No, no. We're just getting from about [inaudible].

[00:50:32]

**VP:** Okay, that's good.

**JT:** Okay. So how have you personally changed through the years in terms of your own value system, beliefs, and attitudes?

**VP:** How have I changed because of my association with the Institute and working in the State of Indiana? Hmm, I came from a pretty ordinary background, you know, regular schools. I wasn't in special ed at all. I was a first grade teacher in Buffalo, New York. I worked at the Lab School at State University of Buffalo, SUNY -- State Teachers College it was called at the time -- and came here with, you know, not much background at all in disabilities except I had been to an institution in Buffalo, visiting, and was just totally turned off with what I saw. And also was friends with a family who had a -- actually, the daughter was in my first grade classroom and her sister never had any preschools, you know, and was considered severely handicapped and they should put her away someplace, but the family kept her.

[00:52:01]

So that was my only experience. And then I came here. And as I said, I met Mike and talked with Fred Kladder. And I remember Fred saying -- because I was thinking, "How could I help out in an adult deinstitutionalization project?" And I remember Fred Kladder saying, "Mike will never ask you to do anything that he doesn't think you can do." And just in talking with the different people and sensing the excitement of this project, I decided to come on board. And as I said, that really changed me. You know, the conversations we had, the ethical issues. You know, I remember for the woman that I was the advocate for, she had only been placed in the institution because the public health nurse was worried that as she was thirteen, fourteen years old -- she was lovely girl and she would walk down to the little square in this little town in southern Indiana -- and that she might get in trouble with boys.

And because she was unable to speak and they thought she was deaf that it was best to institutionalize her, and the family did. I forgot where I was going with that. My surprise -- oh, dear. I forgot.

**JT:** That's okay.

**VP:** Well, anyhow, what I learned is -- oh, the values. This was an example of some of the values we confronted and how that changed our thinking. I remember going down to meet the sister of this woman to see if there was any possibility of them having her live with them again. And this was part of the Deinstitutionalization Project, where we had to go into a community and look for empty niches because really our research base was Barker's ecological research. And the idea was you find some empty niches in the community that would more likely accept a person that might not -- you know, that might be different from the others because that person then could make a contribution. And so we -- another graduate assistant and I -- went down to this town and assessed it for that reason.

[00:53:04]

And one of the things to assess was the willingness of the family to take her back. And so I met the family. We went down there several times -- and actually, just to close her story, the family had a trailer



in the back. And they thought, "Well, you know, that's where she could live." And she also had a placement. They had a disability program, an ARC down there. So she got a job in a sheltered workshop. She had a boyfriend there. We didn't succeed in getting her a regular job, although we found some other jobs in the town she could have had. But anyhow, in the interaction with this family and after meeting the sister a couple of times, she -- I remember her saying to me once, "Can I ask you a question?" She said, "I noticed scars on her sister's pelvis. And could she have been sterilized?"

[00:55:30]

And so Valerie Smead and I were the two going down there and, you know, we come back and we thought, "How could this happen that the sister who was her guardian didn't know?" And bringing it back for this huge, complicated discussion here of, first of all, it was wrong, you know, that nobody gave consent for this. And what are institutions doing that they're doing this stuff to women? And coupled with "What's our role in finding this out?" You know, are we to be the whistleblower and call them on this when the state is funding us to do this project? Very, very complicated role. And so those kinds of discussions led to, you know, these -- bringing out and learning about these values of the worth of people with disabilities and the need to empower people with disabilities and empower families, giving them information was probably the greatest learning of that time.

And everything we did on the Deinstitutionalization Project, you know, was always geared to that. And it was just opened up for us because we confronted, you know, realities. For instance, you know, my -- I think we called my protégé; I was the advocate, she was the protégé. We struggled, I remember, to find a name for the person we were advocating for. And Mike had said, "We ought to let them go to the mall." And we're saying, "Let them go to the mall? Do we have to take that risk? What are we going to do?" He said, "Well, you can follow them from behind, but you have to take them. You know, let them do that." Well, we couldn't quite let them walk to the mall. So we took them to the mall and then there were about six of them, and they just went. And remembering my person, my protégé, couldn't talk. We didn't think she could hear. And all of a sudden she comes back with this lovely blue dress.

[00:54:27]

And we're thinking, "How did she do that? You know, where did she get the money?" We were just waiting to be called or waiting -- you know, "How is this going to work?" just like Mike said. And it sort of validated this notion that these people that have been living in such a structured environment because they had to be protected had abilities that we never would have dreamt of. You know? This woman could have been in Muscatatuck for the rest of her life. She was the one in the project that -- I don't know what's happened to her now -- but because she had a family willing to accept her she actually was deinstitutionalized. Nowadays we wouldn't like it so much that she worked in a sheltered workshop and stuff like that. But at the time that was a good thing. But it was the constant -- I think, the growth that affected me the most was constantly looking at what we hoped and what we valued about people with disability and their own self-determination versus the realities of a very harsh environment that lots of times didn't involve that.

[00:58:53]

And so then what it became is looking, you know, in different projects as I progressed in my career here, looking at different ways to work around the system, or beat the system, or try to figure out ways. You know, I'll give you another example, one we probably all remember. Another excursion was the people wanted to go to Nick's. And of course, they met Ruthie at the door -- people who remember Ruthie -- and they had no IDs. They couldn't get in. And so we sat and we pondered, we thought, "Well, what are we going to do?" I remember we went into the Xerox room and we made ID cards and put their name, birth date, everything, and gave it to them. And they went to Nick's. And you know, nothing happened. And we were quite proud of ourselves. We thought, "Wow, we fixed Ruthie. She wanted an ID, we gave her an ID." [Laughter] But it was that, you know, never letting the system stop you, the figuring out there must be a way that this could be done and not always succeeding.

But so that was just sort of a modus operandi I think I gained from that. But, of course, the biggest thing is just the whole values that started with the Deinstitutionalization Project and went on through all of our projects about consumer advocacy; self-determination; empowerment to people with disabilities; language use about -- you know, because, again, in the '80s was the change of how you -- I was reading some of the old deinstitutionalization papers that we had done, and it was "the retarded people," and "the clients," and "the disabled people," you know, all those words that now we just never use, we don't even think about using. So I think that was the biggest thing, is just the growth of looking at a totally different way -- just totally different values -- about people with disabilities.

[01:01:07]

**JT:** That was really good. Lots of good stories. Can you think of anything else? I mean, you covered so many things.

**VP:** I know. I have lots of deinstitutionalization stories. [Laughter] I was reading -- Tessa [Durham] wrote -- there's some academic-type papers in the book, too. But Tessa wrote, and another woman wrote, and I thought, "Boy, they really smoothed over a lot of the things." [Laughter]

**JT:** Well, is there anything that you can think of that would be important to talk about that I haven't asked you?

[ Pause ]

**VP:** No, I think we probably -- I mean, I could go in-depth about each one of them, but you probably don't want all that.

**JT:** No. And Peggy's going to have to cut them down.

**VP:** Yeah, that's what I'm thinking.

[01:02:01]

**PH:** Any of your other work later on or -- I mean, you covered some of it.

[01:02:07]

**VP:** Yeah.

**JT:** Going to celebrate your birthday?

**VP:** Yeah. [Laughter] No, I'm just kind of thinking, "Well, we did the Deinstitutionalization Project. Then that went into the planning and the simulation games. We did that all over the country."

**PH:** Do you want to talk any about the lab?

**VP:** Yeah. Actually, that came out of the project, too, in a way. And that's -- you know, yeah. We could do that. I don't know where it will go, but. [Laughter] One of the next projects after the Deinstitutionalization Project was getting involved in planning activities and supporting interagency planning with the leaders in the state agencies, particularly around community services. And there were several -- lots of years of being funded by the state, mostly by the Governor's Council for People with Disabilities, to help develop the state plans for disabilities.

And it was a combination of helping the state agencies to put together data. And at the time using computers for the first time to look at data, to collect data and display data but then combining that with "What are your values?" So the planning process always became the combination of data, and information, and values. And so we would work with a group over the course of a year of state agency leaders and look at, "All right, what's the data saying? How many people are we serving? You know, how much is it costing?" All sorts of questions. And we went to each state agency and tried to collect information, and then Mike entered them into the computer.

[01:04:36]

And then he wrote a program -- and I remember for the people who know computers he had an Osborne at the time -- and we would project it onto a screen to show people what the data were. And then we would ask them, "Where do you want to be in a particular program?" And then we would look at the gap and, of course, then the outcome of those planning sessions were then, "What are the goals that we want to set to get to this vision of where we wanted to be?" And that turned into the state plan. And that -- we did that for a lot of years. And then Mike, and Leonard Burrello, and another guy from Arizona, and another faculty member from speech and communications began to look at this notion of putting data together on a computer, and projecting it, and helping a group analyze that data and come up with ideas, brainstorm about it.

[01:05:43]

And this man from -- boy, I can't remember his name -- from Arizona happened to have connections with a team there in computer science that was developing what we now know as the Collaborative Work Lab software -- the software that we use, Group Systems. And we became a beta test site for that and ran some planning meetings using the technology where people could -- they all had computers at the time, we had them set up on desks -- and they could enter in their ideas, and then it would be projected on a big screen, and then they could vote on it. And we started doing that with the state plan

data that we had been connecting for that project. And then that grew. And actually, in '82 -- in the beginning it was always located in one of the cottages. And it was mostly business school people who were there, running a few sessions; they didn't have a lot.

[01:06:50]

I remember one big session was -- we always called it the "shrimp tray session" because they brought in executives from IBM to use the software and to have a planning session. And of course, it was a business school so we had a shrimp tray for a break. But Henry -- this is another thing that Henry did -- he was looking at this and seeing it as really fascinating technology and saying, "But people in the human services field could never afford this. And I want to make it affordable and available to people with human services." So he asked me to be director of that. And that's what became the Center for Planning and Policy Studies at the Institute. And one of our big things was the Collaborative Work Lab, although in the beginning it was always called the "Decision Support Lab" because that's what the business school -- it was a decision support system was the type of software. So they called it the Decision Support Lab. And my charge from Henry was to make this available.

And so we subsidized a lot of the cost and began to bring in a whole variety of people from the state. And I think the first thing we did here in Bloomington was when the United Way did the big COMPASS survey and they had small groups analyzing the data -- some for education; some for healthcare; some for transportation -- and we offered free for them to use it. And I think about three or four of the groups volunteered to do that. And of course, they loved it because they got their work done quickly and they could all have input into what was going on, they could see everything on the big screen. And that was the start of making the use of the Collaborative Work Lab available to people in Bloomington. And then we did the same with state people and did a lot of things. And of course, the software developed and changed. But we still -- for a long while -- we were the only place in the country that had a focus on human service.

[01:08:57]

And still there aren't a lot of human service people using this type of software because it's very expensive. Businesses pay, like, \$5,000, \$6,000, \$7,000 a day to use it. And then we were the only place that had a focus on disabilities because we dealt with -- we did service some businesses, we serviced human service groups in general, but then we also had specific planning sessions around disability issues with disability groups. Now that's changed a little. You know, we set up -- or The Arc with us in Indianapolis -- set up another lab up in Indianapolis. So there are at least two of us in the state. And then there are a few more in the country and internationally that deal with human services than there were. But we were really probably a -- definitely a leader in that area, but people just didn't know that we were because it was new technology and so specialized. But really it was Henry's thought to say to these other faculty members, "hey, you know, we've got to do something to make this available to the people in our field because it's great." So, that is how I got started in the lab and we moved it forward from them. So that most of the sessions that we did do were for human service or disability groups, few businesses but that was no longer our focus.

[END OF INTERVIEW]