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ORAL HISTORY INTERVIEW WITH
DIXIE PATTERSON
FEBRUARY 5, 2013
INTERVIEWER: JENNIE TODD
RECORD ID: 012-DO

DP: DIXIE PATTERSON
JT: JENNIE TODD
PH: PEGGY HOLTZ

[00:00:10]

DP: I'm Dixie Patterson, and I live in Bloomington, Indiana and I'm retired from the Institute on Disability and Community.

JT: Okay, and how and when did you get into this line of work, the line of work of Human Services?

DP: Right. Let's see. I believe in about -- the late '80s, I got into working in the disability field.

JT: And what did you do in the '80s?

DP: I worked on a transition grant. It was actually subcontracted with IN*SOURCE, the parent training center out of South Bend, and I worked as a Family Support Specialist. We worked on supports and resources for families who had children with disabilities on transitioning from high school to adult life.

JT: And tell us a little about IN*SOURCE, or how it was useful to parents and what parents would contact that organization for.

[00:01:10]

DP: IN*SOURCE is the state parent training and information center for parents who have children with disabilities, and they did a lot -- they do a lot of workshops and also did a lot of workshops at that time on helping parents and families understand the special ed laws, what their rights were, how they could work better with the schools to get better education for their children.

[00:01:39]

JT: Is it still in effect?

DP: Yes. IN*SOURCE is still in effect and I think has expanded. I think they now do workshops on transition and many things, but they have regional parent representatives and have -- at that time they just had parents who were volunteers and over the years they decided that they needed like a leader in different regions of the state and so there are regional staff and then still the volunteers.

JT: So IN*SOURCE was probably a pretty helpful organization for new parents, young parents, anyone just getting involved with services for their children.

DP: I think IN*SOURCE has served as a very helpful organization to parents who are new to special ed, whenever their children start receiving special ed or even if they are questioning whether or not they should receive special ed services.

JT: Okay, good, so what brought you to the Institute and what was your work experience at the Institute?

[00:02:54]

DP: Well what brought me to the Institute first was they had received a grant, and I believe it was their first grant where they had put in the grant that they would hire parents to do a parent piece of that grant. And Nowana Nicholson, I had known through some volunteer work, and she called and asked if I was interested in a -- it was a very part time job, and so that's how I got started at the Institute. And after I did about three years of that, then I did something else for a while and learned of another transition grant and had missed that work and came back then.

JT: So how important do you think it is to have a parent or to have several parents on projects that are involved, you know, around children and families with disabilities as opposed to you know not having anyone?

DP: Well I think that projects really benefit from having parents of children with disabilities work with them because it's just a little bit more in depth experience when you've had the experience of having a child with a disability. And even though professionals are very good and a lot of times very empathetic, it's still not the same as having lived it 24 hours a day. And I think sometimes we can bring the realistic side if you will. Even though it's really nice to push forward and be proactive in doing things, I think it's we're the ones who live it and kind of can ground it if you will.

[00:04:42]

JT: That was good. Okay, and so you have a daughter with a disability and have spent a lot of time thinking not only about what's important to her and her rights and what makes her life good, but you've also spent time thinking about other people, too, besides just Jennifer. Can you talk about how your experience of being a mom of Jennifer has focused your work and influenced the sort of jobs that you took or the projects and things of that nature?

[00:05:16]

DP: Well the -- I believe that you know having a daughter with a disability I had to learn a lot of things and so I kind of had a passion for helping others that had children with disabilities or helping other -- as she got older, helping other adults with disabilities and I think it made me passionate about my work, and I always felt like it was very good on both sides because I felt like I did a good job because I was so passionate about making things better for people with disabilities, and at the same time my work enabled me to keep up with everything and to learn what was going on and it benefited us and Jennifer.

JT: Well this question is just a kind of a side note, but I know just from knowing you and knowing other parents they talk about how much there is to keep up with, and how hard it is to always know what to do, and being in the field and being someone that is surrounded by other professionals, it's still a challenge. So how do parents not in your situation keep up with things that are going on and that would benefit their sons and daughters in Indiana?

[00:06:30]

DP: Well I think it's really hard if you're not working in the field to keep up with everything because there is so much going on all the time and things change and of course now I think more than ever -- I mean there are so many resources I think a lot of parents today use the Internet. If they live in a community like Bloomington, there are lots and lots of groups and resources who can -- there's lots of groups you can join. I know the Down Syndrome Foundation is very active in this town. There's now a visually impaired preschool group. There are lots of ways, but I think it's really a -- always challenging for parents because, you know, they have the job of taking care of their child and just, you know, if they have other children I think parents are busier than ever. A lot of them still, you know, both parents work full time and I know it is a challenge, but I think that you know if they really need resources there are many ways to find them you know through the newspaper, through the Internet, contacting -- I'm not sure if there's really a support group other than for autism for parents in this community, but I think it will always be a challenge for people.

JT: Do you think Indiana does a pretty good job making information current and available to families?

DP: Well I can only speak you know for myself, and of course now Jennifer is an adult. Do you want to start over on that one?

PH: Fine if you want.

DP: Okay because I didn't answer the question completely.

[00:08:10]

JT: That's alright. You're [inaudible].

[00:08:11]

DP: [Chuckles] Okay. As far as Indiana keeping -- doing a good job in keeping people informed, I think the Governor's Planning Council does a good job, The Arc. I think our local agencies do pretty good, too. I know there are a lot of times forums or informational meetings for parents and yet I think a lot of parents feel like they don't know what to do or where to go and I've spoken to some parents who have moved here from out of state and they said, "We just didn't know where to begin," but again I think that the Internet is a real resource and there are lots of things that are updated. I know as legislation comes along you know there's always information about that.

JT: Okay, and weren't you and Terry some original board members on Options Board?

DP: Terry and I were among the parents who started an organization. At that time it was called Better Living for Special People, and it's gone through several name changes including one that most people know as Options and since Options has joined Christole, it is now LIFEDesigns and we were a part of the original group that started that organization.

JT: Can you talk about why it was started and how it began?

[00:09:38]

DP: Well we started Better Living for Special People, which is now LIFEDesigns, because there really weren't a whole lot of services at that time and we felt like that we needed more. I always thought Options was a wonderful name because that's what we really wanted was more options and more family involvement and several parents I think saw the need for that and felt like they wanted to be more involved, and felt like we, you know, knew what we needed. And we actually started out with respite services and then a few group homes, and then of course evolved into it – semi-independent living and when the Medicaid waivers came along of course people started living in their own apartments. Of course now due to the budget cuts we're back to combining. You know more people have roommates than they did, and of course some people still live alone.

JT: Okay, so that was a pretty good explanation of how the services and supports evolved. Do they provide any sort of services other than residential and respite? Don't they do some day services now?

DP: LIFEDesigns currently does what's called the CEO Program, which is classes out in -- they usually meet at a church or someplace out in the community. Our daughter is involved at this time in one at the Y. She's also done a cooking class and they also provide employment services, so she works a little bit part time actually at LIFEDesigns in the office and they are helping her seek more employment.

JT: So you and Terry and Jennifer have been involved with LIFEDesigns for what, 30 years, 25 years?

DP: I believe LIFEDesigns is celebrating their 30th anniversary, and we have been involved since the beginning.

[00:11:38]

JT: Congratulations [chuckles].

[00:11:41]

PH: [Chuckles] You should get a plaque.

JT: Good. Okay, you're doing a good job.

DP: Oh good. I'm a little nervous, so I keep thinking, "Does that answer sound right or not [chuckles]?"

JT: No, you're doing a good job.

PH: I had one question about the very early days. How did you connect with these other parents to start the...

DP: Do you want me to go back and talk about when kind of -- okay.

JT: Yeah, so in starting Options, you said that you started it because you really.

[00:12:10]

DP: But even before that, okay when Jennifer was very young, it was kind of a slow diagnosis because she was born with a cleft palate which we were told would not cause very many problems and then we kind of realized that her developmental stages were very delayed and so we kept seeking, you know, through doctors, and a neurologist was kind of like well. That time they used the term mentally retarded fluently and said, "Jennifer's mentally retarded and just you know, take her home and keep her happy you know," and that did not make me happy, so we came home and after crying for several days [chuckles] I kept looking for opportunities. And she was just two, so there weren't very many really early childhood things going on, but there was an article in the paper about a little preschool.

It was called Preschool for Handicapped Children. It was down at the Presbyterian Church and there was a nice article about what they were doing with the children, and they were just beginning to take two-year-olds, and by that time Jennifer was about two and a half. So I called them and we got her into that little preschool program, and we were just very, very fortunate because the lady was very ahead of her time I would say, who was the director, and she involved the parents and the kids went to visit a preschool that wasn't for handicapped children every two weeks or something. And so I just kind of got off the ground with thinking a lot about Jennifer being integrated, and she had a younger brother. We had neighbor kids that were close to her age that she played with. That little preschool closed. Then she went to a segregated preschool, and I felt that was not necessary and even though Jennifer has a pretty moderate disability I felt like she should be with other kids at that age and all day, but that didn't happen of course because there wasn't anything available.

[00:14:24]

So then she went to a -- they decided -- let's see. That was after the law came about, special ed law IDEA, so they started moving kids from this segregated facility into schools. And Jennifer was at Templeton School, but I have to say it was very, very segregated at that time. They did play and have recess at the same time, and they were in the lunchroom at the same time, but they were in a pretty isolated classroom and then -- but let me back up just a minute because at the preschool that gave me a set of parents that I knew who I could, you know, we could talk about the problems we were having with kids with disabilities. And there were only about I would say 11 children in that little preschool class, but to this day I think we -- some of us have stayed in touch to some degree and, you know, we kind of formed a support group for each other.

[00:15:27]

So that's how I got involved with other parents.

JT: That's wonderful.

DP: And I felt like that was just really crucial to our survival, [chuckle] and so then Jennifer stayed at Templeton. They did not have a middle school program for kids that had more significant disabilities at that time. Then she went to Bloomington North, and that was very -- still very away from the other children or students. By that time I should say they're not children I guess in high school, and then they decided that everybody should be in their home school, so she went to Bloomington South and that's where she got her certificate of completion from was Bloomington South.

JT: That's good. Okay. So I was trying to figure out if you asking the question as how she got together [inaudible].

DP: I know and I think I strayed from…

[00:16:22]

PH: No that helped tie in the parents that she got to know them through the preschool. That's what I [inaudible].

JT: Okay so …

DP: Let's stop for just a second

JT: Yes, do we want to talk about how she got together with the parents that helped formed Options as well?

[00:16:39]

DP: When Jennifer was about five, the preschool that she had gone to closed and there was a preschool program at Stone Belt and Stone Belt was the agency that served school age children at that time. The law, IDEA, had come about and so the kids who had more significant disabilities, moderate and significant disabilities, went to Stone Belt. However, parents started, you know, wanting their kids in the public schools, and I believe the first class to move out of Stone Belt was at North High School and then gradually they moved classes out. So Jennifer was at Stone Belt until she was about 10-years-old and then she went to Templeton, which was not actually her home school. Her brother went to Grandview, but that's where they had the program for kids with moderate and significant disabilities and as I said, there is no middle school program at that time.

[00:17:42]

She stayed at Templeton until she was about 13 I believe. Then they had a class at Bloomington North High School, and since Jennifer stayed in school until she was 21, she could receive services until she was 21. She did her last three years at what would -- what was her home school, which was Bloomington South and from there she got a Certificate of Completion, went through the graduation ceremony which was rather exciting and that was, you know, her formal schooling.

JT: Okay good.

PH: That worked.

JT: That's fine. That's really good. Okay and so back to -- well I've got two questions for you. Since you're still in the field and you still are involved with parents that have kids with disabilities, how do you think it's changed for them now than your experience with Jennifer in public schools?

DP: Well again I speak from living in Bloomington as far as how things have changed for kids with disabilities who are in school. I think that probably there's a lot more -- I know there is a lot more integration, particularly for kids that have milder disabilities that might have been put in with the kids with moderate and severe, but I also know that parents really struggle. I don't have a lot of a contact with younger parents right now, but I do know that a few that I have talked to, they're still concerned about the supports the teachers get when their kids are in regular classrooms and just really knowing how to work with the schools so that their kids are getting the most of out of school and being integrated as much as possible.

[00:19:35]

JT: Okay. That's good. So if I didn't know what IDEA was, could you explain it in layman terms what IDEA was and what it meant for students and families?

DP: The special ed law that came about, I believe, in 1975, the Individual -- IDEA stands for Individuals with Disabilities Education Act, and that meant that all kids with disabilities had the right to be in public school and their education would be paid for. Their transportation would be paid for and so before that, a lot of kids weren't going to school or they were in a very segregated daycare type facility, so it meant that you know, they were with other kids and had the right to be there and had the right to an education.

[00:20:34]

JT: Okay. Now we're going to switch over and talk about parent perspective and said we're going to spend a lot of time talking about Jennifer. And some of this you've already shared you know with that last bit, but I'm going to kind of go through this and just see you know if there's other things, you know, if want to add. So tell me a little bit about Jennifer, what she does, where she lives, and what sort of things she dreams about for her future.

[00:21:05]

DP: Well Jennifer is now 41 years old and she lives in an apartment. She is on a Medicaid waiver. She shares that apartment with one other lady. Jennifer had lived by herself for nine years until about two years ago, and because of the budget cuts to Medicaid she was pretty much forced to have a roommate. She works in the daytime three days a week at LIFEDesigns and she does, oh, simple office tasks and she cleans their kitchen and does kind of a variety of things. She goes to the Y, to a Y program on Mondays and Thursdays. And she's been participating a little bit in some bowling and some outside activities and she's very happy. Actually, she would like to have more work than she has and I believe, you know, due partly to the economy it's just hard to find more work, and I think -- I actually think people with disabilities are not being hired as much as they were even.

And every other weekend she comes to our house, and it's kind of a respite for her, and that eases her budget some and as long as my husband and I are able to do that we probably will have Jennifer every other weekend. She seems to still enjoy it. I was trying to think what else she does.

JT: That's quite a bit.

DP: Yeah. Well should I talk about her contact with Chris?

JT: Sure.

[00:22:40]

DP: Okay. Jennifer has one brother, and he and his wife and two boys live in Wisconsin. Jennifer keeps pretty close contact with them. Her brother actually is one of the owners of the Night Owl Support System, which is a response system that she and her roommate use at night so they don't have to have overnight staff, and she's very happy with that. That's gone very, very well and she loves talking to her nephews. She has a cell phone, so she calls them a lot and they keep in touch or we visit with him a few times a year and Jennifer's always a part of that.

JT: And she was doing things at the Latest Glaze and doing some?

PH: That closed.

JT: Oh did it [chuckles]?

DP: [Chuckles] We can’t go to the Latest Glaze, Jennie. She had a boyfriend, but that's no longer, so. Can't talk about that [chuckles].

[00:23:36]

JT: Okay. Well alright.

[00:23:38]

DP: Well I could talk about that, you know, Jennifer does really have to rely on her staff to help her plan, you know, her social activities because she has a real communication problem. And she can't just call someone and make them understand what she wants to do and she needs help with, you know, getting where she wants to go. So, you know, she does rely heavily on her staff or us to help her with that.

JT: Well and you mentioned she lived nine years by herself and the roommate came about because of the budget cuts. Tell me about Jennifer getting a new roommate and...

PH: Her feelings on it.

JT: And Jennifer, did she pick the roommate? You know, how the roommate came about and how Jennifer felt about all that.

[00:24:26]

DP: Well when Jennifer's budget was cut in half we knew that we only had so long to find a roommate, that that was the only option. And she was not real thrilled about it because she'd always been very proud of living by herself and had lived in the same apartment for some time and we really thought if Jennifer ever had to have a roommate that it would be best for her to move so that she wouldn't feel like it was her place, just her place. So we -- they were not finding a roommate that even fit with Jennifer as far as she had already started to use the Night Owl Support System and that was a big problem because we didn't want her to stop using it because that would've given, you know taken away some of her independence, so we were getting a little panicky because the state was only giving us so long to do this and one of -- well her team manager came to us and she had a half-sister who was wanting to move from her living situation, and she said, "I just, you know, thought about this and thought they might be good roommates."

That's how we found a roommate, and of course we no longer have that team manager because she couldn't be their team manager, which was kind of sad, but it all worked out. And the lady is about 10 years older than Jennifer and things have gone actually pretty well. I think they, you know, enjoy each other. It was an adjustment for both of them in many ways, but it you know we all worked on it, and fortunately Jennifer's staff and Linda and Jennifer all, you know, had to work out some things, but the staff was -- they were very helpful which was great.

[00:26:11]

JT: Good. Good, so I know that through the years you and Terry have been Jennifer's biggest fan and have done a lot of advocacy. Can you talk about how you stayed motivated to keep advocating and what sort of advocacy you've had to do because I know you've had to do it through school, through work, through her own apartment? Talk about what that's like being a parent.

[00:26:41]

DP: Well we've always of course been big advocates for what Jennifer needed, and I guess just because I -- I came from a family that always supported each other no matter what, you know, and so I guess I grew up thinking that's what families are [chuckles] supposed to do and certainly when you have a child with a disability. We used to say you know we're always the case managers and to some degree that's true. Jennifer's become more independent over the years and, you know, we don't do all the things that we used to do and have kind of worked with the organization so they know what our values are, you know what we expect and that sort of thing, but there are always things coming up and, you know, serving people in residential -- with residential services is very complex and there's a staff turnover.

Jennifer's been very fortunate that it hasn't been as much staff turnover as I know some people have, but it's a lot, you know, for the new people, for the agency to carry over with what is expected so it seems like Terry and I are always, you know -- we kind of keep a watch on things and we're always intervening if it's needed, you know. We try to be good about not being too picky and prioritizing you know, but there are always things. Sometimes things just don't get handed down, information or -- you know, what Jennifer really needs some help -- a little bit of help with that maybe makes a big difference. And that was true, you know, I think we've been her advocate since day one, in fact probably being her advocates is part of what started Options, because we wanted, you know -- we wanted more options in Bloomington and a choice and I think that makes things better.

JT: That was good.

[00:28:50]

PH: Why don't you put your paper down?

DP: Oh, is it rattling?

PH: A little bit

DP: A little bit and I'm not looking at it anyway.

PH: That's what I thought.

JT: Okay. Well you talked about Jennifer getting a roommate and the adjustments that that, you know, brought into her life. Let's talk about when Jennifer decided she wanted her own apartment because she had been living with you all prior to that hadn't she?

[00:29:12]

DP: Jennifer lived with us until she was 29-years-old and we have a very small family and our son is in another state and so I felt like that it would be really good if Jennifer moved out. It wasn't that we, you know, wanted to get rid of her but I also was hoping it would be her choice. And we had a Medicaid case manager at that time who said, "You really should sign up -- sign Jennifer up for Section 8 because it's really hard to get and there have been waiting lists, and it probably won't happen for a long, long time," so at that time Jennifer had a helper that she was just very good about taking Jennifer out in the community and doing things, so we started thinking about, "Well she's going to move out. We need to find out where there are places to move and, you know, where she would like to live." So this lady took her -- I knew some people who had apartments already, so we asked them if we -- if Jennifer and this lady could come and visit and so they went around and looked at apartments, took some pictures outside of the apartment complexes so Jennifer could remember what was where, and suddenly -- I mean Jennifer started getting an interest in moving out and she said she did want to move and the Section 8 housing voucher came up quicker than we thought and so that's kind of how it evolved and I remember.

[00:30:40]

My husband had said for years, "Oh well Dixie really doesn't want to move Jennifer out, but we really should," and so when the time came we didn't have a lot of time to use the voucher if I remember right. We either had to use it or had to go back to the bottom of the wait list and it was something like 60 days, which seemed like a big rush at that time and Jennifer really wanted to move so she kind of pushed it you know and we did it and she was very excited. And I think it was a bigger transition for me and Terry than it was Jennifer in a way, so she found an apartment. It was where she chose to live and we did it, and at that time they had just really started getting a lot more Medicaid waivers. She'd had one for about a year and a half, so they were moving a lot of people out and I felt like we were kind of a guinea pig again in a way because she -- well it -- we had -- I know the first couple months it was really hard.

[00:31:44]

There were a lot of helpers in and out. We stayed a couple of nights to see what it was like with her, and it was I think a big move for everybody and I think it was kind of new to the agencies to have so many people moving out into apartments.

JT: What was it like for you? I mean were you nervous, scared, excited?

PH: All. [chuckle]

JT: You know, what did it feel like for you and Terry to have Jennifer move?

DP: Well like I said, Jennifer really -- I think she adjusted better than we did when she moved, but we were nervous and, you know, we were nervous about -- I mean we lived out in the country and Jennifer was moving to town, so, you know, and in an apartment complex in a college town [chuckles] so we were sort of wondering how that would go and, you know, if she would sleep well and you know what the neighbors would be like and everything, but I think you know you have those concerns with a child without disabilities, too. And I think in a way Jennifer was more protected by having her helpers than, you know, our son when he moved out you know, but it -- we were anxious about it.

[00:32:55]

JT: Okay good, so she's been in her apartment now for 11 years roughly?

[00:33:02]

DP: I think Jennifer moved out I think it will be 12 years this summer. I think she moved out 12 years ago.

JT: And things seem pretty good, and things are?

DP: I always hate to brag, but -- because things can always go wrong. She's had some times in the apartment complex she's in now where there were neighbors that were noisy and not particularly nice, and she weathered through that and, you know, again it's just kind of like everybody else where you can move into a house and not like your neighbors [chuckles], you know.

JT: So when you look down the road 10, 15 years from now.

DP: Can I add to that?

PH: Sure.

DP: Okay. Can I stop you just a second and add to that?

JT: Sure.

[00:33:47]

DP: The nice thing about Jennifer being in an apartment is she's very social and after bad neighbors moved away she became friends with another -- well a couple other ladies and there was one summer where they would sit out on their little patio and do their nails and they had coffee together and she just really enjoyed it, so she likes, you know, the socialization of neighbors when things are good [chuckles].

JT: Good. Okay. I didn't hear what you said. Do you want to answer the question about Jennifer's life down the road?

DP: I don't know much to say. Yeah I will.

JT: Okay.

DP: Sure. Sure.

JT: So when you look down the road, what does Jennifer say about, you know, what's next for her, what she'd like down the road and what do you see, you know Terry see for her?

[00:34:36]

DP: As far as what Jennifer sees about her future I don't know that Jennifer thinks a whole lot ahead. I mean I think she -- you know if she's happy now, she's happy [chuckles] but I think she would like to have more work. I know she would like to have more work, and I think, you know, she just wants to stay active in the community and for -- as far as Terry and I, I think -- I mean I was thinking about this the other day, and we just talked about being advocates. I hope that, you know -- well she always has an advocate if we're not here. I know that our son would always make sure that things were going well, but you know, being in another state's a little different and Jennifer has made it very clear that she does not want to leave Bloomington, that she has her friends here and, you know, this is her home and so you know we probably would not have her move to the state he lives in or vice versa, but -- so I hope she always has someone if we're not here to be an advocate and make sure things are going well for her.

[00:35:43]

JT: And that kind of ties into the next piece is that I know Jennifer's had some really good person centered planning throughout her life, and she's had a Circle of Support and she's had people in and out of her life, which has to make you know you feel good that there are people that know her and care about her and they're there for her. Can you talk about how it came about that Jennifer got a Circle of Support around her because not everyone does and had some really good person centered planning?

DP: Well I guess from working here at the Institute I learned a lot about person center planning and circles of support and so, you know, I guess that's kind of how it -- we instituted the person centered planning and she did have a Circle of Support for a while. It wasn't a long, long time but there were friends and I think at that time Chris maybe was still here, our son, and we would get together and talk about, you know, Jennifer's future, what she wanted and do some illustrations on a piece of paper on the wall and leave it up you know so she could look at it and then you know assign who would follow through with her on it. And so that got some things off the ground. In fact now I'm remembering back, that was also how we got started talking about her moving away from home and getting her own apartment and some other things that, you know, with some different jobs and getting together with friends and things like that.

[00:37:21]

JT: So it wasn't as long term as maybe I'm thinking?

DP: No

JT: Okay. Okay.

DP: So you may not want to use that. I don't know.

JT: Pardon me?

DP: You may not want to use that [chuckles]. I don't know.

JT: Well no, I mean I think it's still.

DP: And that's okay if you don't you know.

JT: Still good. If it did something, if it got some things moving, you know I mean that's better than nothing.

[00:37:42]

DP: Yeah.

[00:37:44]

JT: Okay, so I guess we've kind of talked about this, but I guess parents -- what my next question was but I think we've already talked about this. Parents today have available that parents of your generation didn't, is there anything that wasn't said?

DP: That I can think of, not really. I can't think of anything. Let me look at my notes a second. I don't think that I wrote down anything on that.

[Silence]

DP: Well -- oh, I could say a couple of things.

JT: Okay.

DP: Okay. I do think a couple things that parents have today that we didn't have are a lot more early intervention programs. I think a lot of schools have better transition programs. I know Monroe County has a transition program that is strictly out in the community that you don't even go to the school building but they're learning you know how to get along in the community and what resources they need to access. And I think some schools at least, and I'm not positive about this, have transition coordinators so they really, you know, work specifically on transition from school to adult life which is a real plus. And we did have a transition coordinator here in Bloomington, but I know when Jennifer was in high school not all schools did, not near as many I don't believe.

[00:39:16]

JT: Could Jennifer experience transition in high school?

DP: Jennifer did experience transition in high school. It wasn't all out in the community, but they had what they call you know community based programs where they would go out and do shopping. They would go look for jobs. They would have job placements. They were not paid. Those were just experiences at the time, but she did have -- she got a lot I think out of the transition program here in Monroe County, and she left high school with a job in place.

JT: Well I was going to ask you because I couldn't remember, but was it [inaudible] job a transition? Did she do that?

DP: Yes. Yes.

[00:39:55]

JT: Do you want to talk about that as an example?

[00:39:57]

DP: Okay. Well when Jennifer was in high school and we're working on a transition plan and she had several job experiences and it was pretty clear you know that one of her choices would be in an office setting and the semester was almost over and we had not placed her. The school had not placed her anyplace because the idea was for them to have a job in place before she left high school, and we did advocate pretty hard for that [chuckles] and so it ended up a couple months before she left high school she did get a job at one of the departments at IU, and she worked there for many years in fact until the department no longer existed.

JT: That was good. Yeah because I remember she had worked there for many, many years.

DP: She worked there until you know they moved over to Eigenmann [Hall] and they meshed with -- oh what's the department that Russ? What's his name?

PH: Skiba?

DP: Skiba, and then it just dissolved their part of it, so.

JT: That was a long term job.

DP: Oh yeah. She was there about 15 years.

[00:41:08]

JT: You want to say that on tape, you know?

DP: Oh, I don't know if it was exactly 15 years. Okay.

JT: But that's.

DP: Okay, Jennifer worked in her job that she left high school with for many years, and it was a very good job for her. It was a very small part time job, but everybody was very supportive. She got a lot of natural supports there, and she worked there for I'm thinking almost 15 years, and the department she was in was put into another area and eventually just kind of -- the jobs dissolved.

JT: That was good. Okay and then from your notes Dixie, is there anything -- because I kind of skipped around here -- is there anything you wanted to say?

DP: Let me see [chuckles]. Just a minute – I guess the other thing that I could say, and I should've said this a while ago and I forgot [chuckles]. I can't remember [chuckles]. I forget everything. This is what you're dealing with when you're with older parents.

JT: That's why we can edit.

[00:42:13]

DP: Well I was going to say not only.

[00:42:15]

JT: Wait until you're ready to say it. You ready to say it?

DP: Not only have we been advocates for Jennifer but I found over the years that many, many people in a different way that were advocates, but that friends, acquaintances, you know people through church advocate for Jennifer. We just recently had a change in our church services, and since we have Jennifer every other weekend this has become quite [chuckles] a problem for us because [chuckles] I am in the church choir and so I want to continue in the church choir and they switched from the traditional service being 11 o'clock to 8:45, so on the Sundays that Jennifer's at her apartment -- she called the first of the year when this happened and said, "Do you care if I go to the 11 o'clock service?" and I said, "No," because she and her roommate have attended our church some, not always. Well Jennifer likes 11 o'clock service and the contemporary service [chuckles] and she's not an early bird and neither am I [chuckles] so when she comes home she really [chuckles] doesn't want to go to the 8:45 service, but I found out later, too, that when they went to the 11 o'clock service -- her helper and her roommate and Jennifer, the lady who's the church secretary always sits behind us or behind them and she said it was Communion Sunday, so Jennifer got up to go to Communion and the other two people that were with her didn't and so Jennifer hesitated just a little bit and Rita said, "Oh come on, Jennifer, let's go."

So she feels very comfortable in a lot of situations and there are a lot of people that have really, you know I just feel like they kind of watch out for Jennifer.

[00:43:59]

JT: Have you noticed a lot of attitude changes in the community through the years? I mean do you feel?

DP: I have noticed a lot of attitude changes in the community, and I think that one of the biggest differences that I can think of in the 40 years that we've had a daughter with a disability is when Jennifer was little you didn't see a lot of people out in wheelchairs or who had significant disabilities. They just didn't go out that much and it's not uncommon at all, you know to see someone with a disability out now and I think people are more accepting. I think even in smaller communities, small towns they're more accepting and I think it's been good for everybody. You know I always took Jennifer out and sort of thought you know people should accept her [chuckles] and -- but I know that when she -- and there's still times that you know people stare because she has quite a speech impediment you know, and that's the biggest -- probably to Jennifer her biggest disability and it makes it difficult for her but she still finds a way to interact with people and most people are pretty accepting.

JT: Good. Okay well Citizen Advocacy is something that I was going to talk to you about because I know you were involved with that. Can you talk about what Citizen Advocacy is and how it's gone here in Indiana? [chuckle]

DP: It hasn’t gone too well. [laughing]

[00:45:31]

PH: Not everything can be a success.

[[00:45:34]

DP: I became involved with Citizen Advocacy of South Central Indiana and -- about 10 years ago I think and we got a grant -- actually it was a workgroup here in Bloomington from Stone Belt and Options and Self Advocates of Monroe Country and SICIL, the Southern Independent Center for Independent Living and I think there was one more group and I can't think what it was, but anyway, they determined that there was a need for citizen advocates. And the difference -- a lot of people say, "Well you know aren't there volunteers and you know don't the organizations you know serve in that capacity for people?" But the difference is they try to match community members who volunteer their time in a little bit longer term situation. Now in Bloomington it's been very hard to do because there's a lot of people come and go and there was lots of commitments to other things, so over the years we've kind of given in to making it at least a year's commitment but they base their matches on interest so in other words if someone was my advocate and they wanted to do gardening I would not be happy so [chuckles].

JT: So citizen advocate [Inaudible].

DP: So we wouldn't match someone.

JT: Is the person and a person with a disability?

[00:47:02]

DP: Oh I didn't explain that very well did I? Okay. The matches are made between people with disabilities who want an advocate and someone in the community who willingly gives their time to be their advocate, and they're matched on their interests so that, you know -- because we found that most people really just want their advocate more as a friend than anything, but that way, you know, a lot of employees of the agencies in many ways are advocates but sometimes when there's a problem they also want their job and so you know they're torn between the person and their job. So this is a difference you know and why it's needed I believe and so we -- it's a very time consuming thing to match people, and it's kind of hard to do and it grows very slowly. I think we have about 12 matches maybe, but they're still going some of them and you know like I said that most of them want to go out and do something or have someone to talk to and I think there is a need for it and I think the more budget cuts we see, the more there is a need for it.

And I spoke earlier of hoping Jennifer always has an advocate and, you know, that's one of the reasons I became involved with it.

JT: Do you have a story or two that you can share about a match [inaudible] and an advocate is doing well or doing anything?

DP: I don't.

[00:48:43]

JT: If you don't, that's all right.

[00:48:44]

DP: Yeah I don't know. I know, you know, there was a nice story, but then that match ended. They kind of somehow didn't get along over something and [chuckles] that ended so.

JT: Well and that's fine.

DP: Yeah I don't really.

JT: Okay, well the last question I was going to ask you is some of your proudest moments as a parent. Want to say anything about that?

DP: Okay, well I guess some of our proudest moments with Jennifer would be -- it was really exciting when Jennifer was little I don't think I ever dreamed that she would go to a prom or actually walk up on stage and get a Certificate of Completion with the other kids who were getting their diplomas and those still stand out in my mind as really you know being the highlights, you know. The other time I think was when she moved into her own apartment. I mean she was just so proud and you know that big step of independence and let me tell you getting your own apartment does make you more independent. She's become more independent than I ever thought she would become. I mean I think those are really the highlights that I -- at least first think about.

[00:50:01]

JT: Would Terry say anything different if he were here?

DP: I think a lot of our work here eventually involved, you know, how important it is to build relationships and network with people and that's always been something maybe without even thinking that I'm intentionally doing that. That has really helped with Jennifer and, you know, knowing the resources and knowing, you know, the difference between, you know, what you can expect in high school and adult life. And that's a big transition for parents and people with disabilities to go from high school to adult life. And it's just so important to understand that and understand that, you know, you -- I think you have a lot more leverage when your children are in school and, you know, the bus is going to come and take them. And I think there's a big gap in transportation still, and I think the biggest concern right now is budget cuts to Medicaid and Medicaid waivers. And another concern I have is, you know, they really want people to get a lot -- get a lot of people off of the Medicaid waiver waiting list, which of course is very important especially as parents age.

[00:51:20]

And there are more and more older parents and a lot of them still do have their sons and daughters at home, but at the same time I look at the agencies and with what they can pay staff and just the fact that it's a different kind of a job to work with people. They're not getting people through the door to work with people, so I keep thinking, "How are we going to get enough help to support all the people that are coming of Medicaid waivers?"

[00:51:50]

JT: All right. That's a good point because you get them off the list and someone has to support them.

DP: Yeah, so I mean they're very short staffed the agencies are and I believe it's across the board not just LIFEDesigns or, and people don't stay sometimes for $8 or $9 an hour and yet, you know the budgets don't permit them to really pay more.

JT: Right. Well, thank you.

[00:52:20]

DP: You're welcomed.

[END OF INTERVIEW]