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**ORAL HISTORY VIDEO INTERVIEW WITH**

**CONNIE FERRELL**

**APRIL 28, 2015**

**INTERVIEWER: JENNIE TODD**

**VIDEOGRAPHER: PEGGY HOLTZ**

**RECORD ID: 027-DO**

**CF: CONNIE FERRELL**

**JT: JENNIE TODD**

**PH: PEGGY HOLTZ**

[00:00:10]

**CF:** Okay. Well, I'm Connie Ferrell, and I live in kind of partly in Brown County and partly in Morgan County, Indiana. I have about 200 acres out that way. And currently I work part-time with Virginia Commonwealth University. And I'm the coordinator of training for training new benefits specialists, work incentive counselors to help people with disabilities to know how employment will affect their benefits, particularly Social Security benefits, but other federal benefits as well. And so I travel a lot with that. And I also do email and phone technical assistance with individuals that have been certified as benefit specialists. So I do that. And I also have a little consulting business of my own, Integrated Services. And I do training around supported employment and person centered work and some around team building and some around benefits counseling.

**JT:** Okay. Well, how did you get into this line of work, and what brought you to Indiana?

[00:01:17]

**CF:** You know, I got into this line of work many, many years ago in the mid 70s. As I was raising my little bitty children we moved next door to a family who had a daughter who had an intellectual disability. She was 11 at the time. And I wanted to be a stay at home mom, and her mom wanted to work. And we were both new to the area and knew no one. So I volunteered to be a caregiver during her mother's working hours for Julie [assumed spelling]. And Julie became like part of our family, and I feel like she's one of my grandchildren nearly and helped me raise my children. It turned out that she was so capable and so interested in kids that I felt guilty to take any money because she was like a mother's helper to me. And so that was kind of my beginning in having some sort of a relationship, this long term with someone with an intellectual disability.

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[00:02:18]

And I got very interested in learning more about what type of lives do people have who have different types of significant disabilities. And I had done a couple of years of my college experience at that time in psychology. But when I finished my degree in psychology, I decided to get my masters in clinical social work and began to offer some counseling for families and individuals who had disabilities, particularly intellectual disabilities. Because at that particular time there wasn't much there for people, particularly people with intellectual disabilities that were looking to have some mental health counseling. Most of the clinicians and most of the counselors pretty much had the attitude that people with intellectual disabilities can't benefit from counseling which I didn't find to be true at all. And so I took that as a specialty area. But my true love became working with people around going to work.

And so I had my first introduction into that area in 1981. And that was through having gotten acquainted with an agency in Norfolk, Virginia called Hope House Foundation. And it was a little tiny agency that was running a couple of group homes, which at that particular time was pretty innovative. And had a small little pre-vocational activity center with about 25 people there. Individuals who couldn't get into the local shelter workshop. So I went to work there as the pre-vocational trainer and watched the Marc Gold film about "Try Another Way". And went out and got my bicycle brakes and my circuit board parts. And began working with setting up bench work, simulated bench work. And it wasn't probably two months until I thought this is ridiculous. And I probably would have just gotten out of the work altogether except that I just had an opportunity with the executive director of that program to drive 90 miles up the road to Richmond, Virginia where I met Dr. Paul Wehman.

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And this was in 1981. And I got to go and shadow one of their original job coaches, Vicki Brook [phonetic], on a job site as she was providing job coaching to an individual and telling me a little bit about how what's now called supported employment works. And I got the bug immediately. And on the ride back to Norfolk I asked the director can I do that? I don't want to do the simulated stuff. Can we do that? And he said, "well, as long as you take three people with you every time you leave the building. If you can find employment for people go for it." And so I began setting up, I didn't know this was what it was called, but enclaves. I set up a few enclaves in the Norfolk area, one with the Cousteau Society. Jacques and boys were in town in between tours. And they all spoke French. And we did a whole lot of signing to try to figure out what we had to figure out what we had to say to one another. But it was just a click for me seeing people really grab the opportunity to learn how to use the bus and to get out in a more natural environment and learn how to do the work that they needed to do.

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And about three months after I started doing that a job offer came up with Virginia Commonwealth University to replicate the job coach model down in the Norfolk area. So I began working with them late in 1981. And my job was to start a supported employment program in an agency and work there as a lead job coach for a year. And that agency would match my position with two others. And after a year I would move on and they would replace me, and then I would set another one up. So over the next four years I set

up four supported employment programs, two with school systems with transition age youth, Norfolk Public Schools and Virginia Beach Public Schools. At that time classrooms were self-contained. Whole schools were self-contained. So I was working with the school systems that at that point the labels of students that were there was severe and profound handicaps. And the other two programs were with local shelter workshops, one in Norfolk and one in Virginia Beach that could kind of receive students as they came out of the school system employed.

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And that was our focus. We weren't doing community based work experiences in the school. We were getting kids, young adults, into jobs.

**JT:** That's great.

**CF:** Yeah.

**JT:** And then you – what brought you to Indiana?

[00:07:00]

**CF:** Well, I had worked, again, with VCU and then hopped off onto working with our state's supported employment systems change grant. Back in the 80s supported employment got written into law at the federal level. And then for a period of time different states were applying for some federal money to take five years to change the system in that state away from segregated, congregated employment to integrated supported employed. And I had worked on that in the State of Virginia for about five years. And as part of that work I went to do a presentation at a conference in St. Louis. And met the first person I ever knew of in this field in Indiana, and that was Jim McClish who was the executive director for Community Incentives at the time. And he was on a speaking -- we were both on a speaking panel.

And he was talking about what that agency was doing and what the staff were doing. They were really trying to push to community inclusion for individuals both employed and in other ways actively involved. And I was so impressed and so excited and so I wanted to know more about that. And I had an opportunity to come out a couple months later and do some in-service training with some of the staff at Community Incentives. And got reacquainted with Steve Hall who was with the Governor's Planning Council at the time. I had known him at VCU but hadn't seen him in some time. I got back from doing that in-service training and got a call about a month later from Steve Hall saying Indiana is finally applying to get a systems change grant. And if we got it would you come and work here? And before I could even answer him I got struck by lightning over the telephone, but I came anyway. [laughing]

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So some months later I hadn't even thought about it again. I did get a call, and Indiana had gotten a systems change grant, and it had gotten a little delay getting started because they were one of the last states to apply for one. And then when they finally got it, state voc rehab had gotten it, and they were like, nah, we don't really want it. You take the money back. And the feds went, no, you need to do it. So they

were in a hiring freeze. So they subcontracted it out to IIDC [Indiana Institute on Disability and Community]. It had a different name at that time. But I had meanwhile moved to Indiana just because I wanted to move to Indiana. And so I began working on that systems change grant when it started up in fall of 1992. And so the next few years I worked for Indiana University on that systems change grant which was a three year project. And worked mostly in the southern third of the state. Did some trainings all over the state. But most of my technical assistance was with agencies in the southern part of the state.

[00:10:07]

**JT:** That's good [inaudible].

**PH:** [Inaudible] story.

**JT:** That funny because Suzie Rinne and I went to Virginia Beach in the like the 80s, 85, 86 and we heard all about the supported employment. [Inaudible] Jim had just gotten that big VR grant, we bought our building, bought our equipment. [Inaudible].

**CF:** Oh, forget about it.

**JT:** He's like no, no, and then you kind of came into the picture.

**CF:** That's so funny.

[00:10:28]

**JT:** Yeah [inaudible].

**CF:** Yeah, I don't do that. [laughing]

**JT:** And I remember thinking, oh good [inaudible].

**CF:** Yeah, get rid of this stuff.

**JT:** Okay, so first we're going to talk about person centered planning and employment. Person centered planning, person centered thinking was a focus of your work for a long time. Can you talk about the original concept of it and how it was innovative? Just talk about person centered planning. Maybe who else has an important role implementing it in Indiana. How is Indiana still following the principles in its thinking and that sort of thing.

[00:11:07]

**CF:** Okay. Person centered planning is a concept that is really integral with supported employment and a lot of other things as well. Because at the very heart and soul of supported employment forget about the federal definition, it's one person, one job that makes sense for that person. And you just cannot do that in a way that works for people unless you start with just getting to know the person. In my mind person centered planning is all about throwing out all the programs, throwing out all the systems in your mind and having

system amnesia, and just sitting with an individual and really getting to know the person. The heart and the soul of the person and where they're trying to go with their lives. And to try to figure out how can I support this person along their walk, and how can I support that individual to bring along the people who love them and care about them in the direction that they want to go? I'm a firm believer that parents are not the enemy, and they're not the block.

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That for the most part they care, love and care for their children. And unless we help the individual to have a voice to help their families to know what it is that's important to them, and then help the family know how we can work together to make sure that an individual's not at high risk by having something more in their lives. I just don't think people can move along. They need their families. So I really believe that person centered planning is at the heart of supported employment. And that when we do sit with people and when we ask the right questions and we take the time to listen and we get out and spend time with an individual, I think that's every bit as much a part of person centered planning. It's not as much what happens in a room as what happens by being with people. So getting out, spending some time in the community, watching people light up when things are working for them. For an individual who's looking bored and tired and you get into an environment or into an activity or around certain people, and all of a sudden the energy comes it tells us what we need to know.

[00:13:17]

And so I think we have to listen with our eyes and we have to listen with our ears and we have to listen with our heart. And then if we are creative about, well, how do you get more of what you want and need in your life and how does employment mix in with that, I think that's the key really to getting supported employment off to a good start with individuals. And then providing the supports that work for the person. So I think the other part of person centered planning is listening to what works and what doesn't. Because a lot of individuals have had a lot of well intended support in their lives that didn't work well for them, and they didn't feel respected. And I think that's an important part of person centered planning as well.

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**JT:** So in thinking about person centered thinking, planning around the whole person where do you see Indiana? I mean how good of a job is Indiana doing in really looking through those kinds of lens at a person?

[00:14:14]

**CF:** You know, some of the influences, first of all, for me in terms of personal centered planning, some of the big time influences for me were Beth Mount, and John O'Brien. Those are people that I've learned so much about person centered planning from over time. And I know both of those individuals have been in Indiana countless times to come bring the message of person centered planning. And at one point in time John O'Brien had about a two year contract with IIDC to do some technical assistance with a handful of agencies around community building and community inclusion using a person centered approach. In the State of Indiana, I think that IIDC has been a big leader in getting the word out and getting training out. And

hopefully lighting the fire with agencies and hopefully families and schools that person centered planning is the way to go in terms of doing planning. I've been a little out of touch with where we are in Indiana for the past 15 years.

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It seemed before I stopped working at IU that we were making some inroads. It seemed like particularly when I'd go to the transitioning conferences there was a lot of buzz about using a person centered planning approach. And I know that some of the school systems were using a lot of the pieces of person centered planning in their transition planning as were some of the agencies. How much that's still true I'm not quite as versed on.

**JT:** All right, so another big focus is employment. Can you talk about Indiana employment services for people with disabilities and give some history what preceded supported employment? You did a little bit of that in the beginning, the movement of supported employment through the years. How Indiana kind of compares to other states. And maybe some important legislation that has moved it along. And I'll help you if I've said too much [inaudible].

[00:16:11]

**CF:** Well, you know, supported employment has kind of been a long time in the making. And as I've mentioned before my first introduction to supported employment was in 1981 which about three and half, four years before supported employment was actually written into federal law. So we were kind of inventing it if you will at that particular point in time. I know there were places across the country prior to that that had dabbled with job coaching. But the concept of providing individual supports on the job site, not requiring people to be job ready before going to work. And then the real unique feature being ongoing support is really unique to supported employment. So I think nationwide it's been in its incubator stage in the 80s, and then in its implementation stage across the 90s.

And where it is now in my opinion is stuck. I haven't really seen progression in supported employment since the 90s. And it's really fairly dismal in my mind that things seem to have plateaued, it's become another program in a lot of areas. People kind of take it for granted. But that push to be creative and try to figure out how to reach for those individuals who still aren't accessing it just doesn't seem to be happening in any sort of way except for an example here and there. Again, I've not worked as closely with agencies in Indiana in the past 15 years. But I have continued to be part of the employment specialist training that teaches job coaches and certifies them in the State of Indiana. And in the past 15 years when I've not been working with agencies as closely, I've been disappointed with what I hear from people when they come through the job coach training in terms of what their agencies are doing, the push or the lack of push for working with people with the more significant disabilities.

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**JT:** Why do you think that it's stagnant?

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**CF:** I wish I knew exactly why supported employment seems to have hit a plateau. Some of my theories are that as we've gotten out of the 90s there's not seed money that's going towards kind of demonstrate -- you know, here's some block money to just try it out. And agencies are working more with dealing with trying to have a program within existing funding systems. One of the things that happened around the year 2000, I can't remember exactly when it happened is, for instance, in Indiana we moved to results based funding. And before that time agencies that were sending a staff person to work with people, either through the planning stages or in the initial stages of employment or long term, billed and were paid based on the time that they devoted to that individual's support plan. That changed, and instead agencies were paid for an outcome.

So in order to get paid they had to have a person in employment for a certain length of time. There were a lot of reasons that they switched to that, some of which were valid reasons. But the results I'm afraid has been what I had thought it probably would be, and that's that agencies have pulled back away from people with the most intense support needs because they're afraid. They're afraid they're going to lose money. So agencies that are really committed and are really values driven around having people in the community have continued on. But the pace is slower. Some other agencies that maybe certain people in the agency were values driven, but other people are driven by show me the money, have backed way away from serving people with the most significant disabilities. So what I see is probably more people now being in day activity programs. I haven't seen growth in sheltered employment, but I've certainly seen growth in day activity programs.

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And I think some of that is because Medicaid has weighed in with some of their dollars for some of those kinds of services. And it's really disappointing I think and scary to me that the growth doesn't seem to be there anymore. I'm hoping it will pick back up.

**JT:** So do you think there's a chance it's going to go back instead of outcome based go back to just support hours reimbursement?

[00:21:07]

**CF:** As far as whether the current billing system for supported employment will stay in place or whether it will revert back to an hourly billing or something new will come out of that I guess time will tell. However, I was just in New York two weeks ago, and they're reverting back to an hourly billing system for supported employment. And I've heard rumors that that could be the case in the next few months in a couple of other states. So my hope would be maybe that they come up with something that's some sort of a blended system. Because I understand why they went to results based funding in the sense that in some instances agencies were basically billing and billing and billing, and fading wasn't happening, and natural supports wasn't happening. And I even had job coaches occasionally to come into training that would say, "well, my agency says I have to stay out there for 100 hours whether I'm needed or not." So I think what happened was with our state funding system they were overly reactive around those kinds of situations.

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And instead of dealing with those isolated examples they just changed the whole billing system. So my hope would be that we come up with something that's kind of a blend, but I don't know that we will.

**JT:** So in looking at the nation, would it be a fair assumption based on what you just said to feel like all the states are somewhat stagnant, not just Indiana in terms of the 90s versus where we are now and supporting people with more significant disabilities to have employment?

**CF:** I see stagnation in supported employment all over the country. Although I'm doing less work directly with supported employment agencies, I'm a member of APSE, and I do still try to keep my ear to the rail so to speak as to what's going on nationally. And I see stagnation everywhere. I think one of the things that's so disappointing to me about Indiana's plateau or stagnation is that 90s was an incredible decade for Indiana. We were way ahead. We got into the game late and surpassed many other states and agencies in terms of movement in the direction of community inclusion and supported employment. And I think the fact that we showed we could makes it that much more disappointing that we're choosing not to at this point for a myriad of reasons.

**JT:** Do you want to elaborate on any of the reasons? Besides the funding is there anything else you want to talk about?

[00:23:45]

**CF:** Well, I think some of the reasons why supported employment, the growth has slowed, from the perspective of finances with agencies I think it's risky business. And so unless you are values driven and you're trying to figure out how we're going to make this happen -- I heard somebody once say when I saw what could be done, I stopped thinking about reasons we can't. And all of a sudden I came up with a million reasons why we had to. And I think unless that happens supported employment looks like a risky business. Because we don't control the economy, we don't control businesses. We went through a bad financial time here five years ago, five to seven years ago, and that slowed things down. But if agencies aren't truly committed, and I know that some aren't in our state and in other places, that it's basically, well, if the money's there and that seems to be the flavor of the month we'll go do that.

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But when things like an economic downturn come if you're not really committed that becomes the reason not to do it anymore or to slow it down. I think the other reason is that the pressure away from congregating people kind of stopped -- it's push from a federal level. Now, it's picked back up some more recently. Now they're saying, you know, you need to have people in their least restrictive environment, and you're breaking the law if you don't which has become the impetus in a couple of states for all of a sudden now they're doing transformation. But in Indiana I'm not really seeing anybody paying real close attention to that federal law in terms of saying, well, if they know about it, but in terms of saying, gosh, we need to get on the stick and do this before we have a class action suit that says we have to. And I think that's right around the corner. And if we're not going to move without it I'm glad it's right around the corner. And I'd be happy to be part of it.



[00:25:50]

**JT:** Good.

**PH:** Want to move the wire maybe over on the other side of your leg if your arms are moving. [Inaudible]

**JT:** Well, very good. You're doing great.

**PH:** Yeah.

**JT:** All right. So the next thing that we're going to talk about is the benefit pieces of employment which is a lot of what you're doing now. And what I'd like you to think about when you talk about that is there anything that is missing that would make it easier for people with disabilities to keep their benefits and work? And have there been changes to public policy that have helped people keep their benefits once they started working? So probably in your overview with what you're saying you're going to cover all that anyway.

**CF:** More recently as I've mentioned before I'm doing a lot of work in the area of work incentives. So looking at the different federal benefit systems and what incentives are in those systems to support people to try to go to work. Most of those systems, Social Security, SSI, Medicaid, TANF, food stamps all are really kind of punishing of going to work at any significant level, have been and have a reputation for being more punishing than they actually are. But there are a lot of work incentives in each one of the systems. And so my latest mission is to be part of trying to get the word out to people that the urban myth that if you go to work and earn over about \$700 or \$1,000 you're going to lose your Social Security, or you have stay under \$85 if you're on SSI, or if you go to work you're going to lose your Medicaid and Medicare, I'm trying to bust those myths because they're not true. If an individual is on SSI and they go to work they would have to earn in excess, in this state in excess of \$37,000 a year to lose their Medicaid.

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And even then they probably wouldn't lose it if they're a high end user of Medicaid because they can do an individual threshold. I know somebody in Indiana right now that earns about \$60,000 a year, her individual threshold is \$85,000. Unless she starts working earning over \$85,000 she's got no worries with her Medicaid. With Medicare you can keep your Medicare in place unchanged for at least eight and a half years after you go to work. And that's if you're ragingly successful all that time and work your way off cash benefits. So there's lots of health insurance pieces that are very helpful. The new Affordable Care Act doing the expanded Medicaid and having the healthcare exchanges made a huge difference for people who do get to a point where they don't have health insurance through the government or don't want it. So there are a lot of options there to help people with healthcare coverage. There's a pilot underway right now for people on Social Security Disability Insurance.

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It's being piloted that if they get to a certain level which typically causes your check to stop, then instead of it stopping it would be decrease \$1 for every \$2. And so that pilot is in its completing stages. It's just got

another year or so to go. And there's a really good chance that Congress is going to change the law and put that into place ongoing which would make a huge difference for people on Social Security Disability.

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**JT:** Is there a dollar figure attached to Social Security now that you're seeing changes?

**CF:** In the regular Social Security system with Social Security Disability Insurance the amount a person gets is based off of what they worked before. But right now it's an all or nothing deal. And you keep getting your check unless your earnings go over a certain plateau. This year that plateau is \$1,090. However, if you're having to pay out of pocket expenses for special transportation or medications or anything, that \$1,090 could be much higher. I've seen people earning \$2,500 a month that were still getting their Title II check. But that threshold goes up every year. And as I mentioned before if this law changes sometime in the next few years, when you hit that threshold instead of your check stopping it would just start going down \$1 for every \$2 of earnings over that threshold amount which would be huge. There's also proposed legislation that would say if a person was on Social Security Disability and they worked their way off the cash benefit, that right now after three years they would have their case file closed.

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But if this proposed legislation goes through your case file wouldn't be closed. You would just be a non-check status or in that reduced check status ongoingly. And the only thing really that would close your case would be if you medically recovered. Which if you weren't working and you medically recovered your case would be closed. In the SSI system people who are living on SSI are living at two thirds of the poverty level. In my trainings I always say you have to be really, really poor to get SSI, and once you get it you've moved up to really poor. You haven't even made it to poor. You're at two thirds of the poverty standard. And so that system has work incentives in it all over the place. And so a personal SSI unless work literally makes them sick, work is always a good thing. And the only way they're going to get above two thirds the poverty level is to either work or hide income from Social Security which is illegal. So they've got nowhere to go but up. There's a new law that's just gotten passed called the Able Act that we don't even have the regulations yet.

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They're being promulgated. But it's wonderful for people who have disabilities who are poor because instead of there being like a \$2,000 cap on how much money you can save if you're on SSI or Medicaid or food stamps or whatever, it will allow an individual or their family to set up an account that's kind of like the 529 accounts for saving money for kids for college. And you can put money into that account to use for stuff, to buy a home, to pay for medical costs, pay for assistive technology, transportation costs. The list just goes on and on. And it's super, super easy to set up. And I can't remember the caps on how much you can put in but it's significant. And this is going to change the landscape tremendously I think in the next year as that gets implemented. So that people who do go to work that are on benefits are ready. You can make more money and have more money by working, but once the Able Act is in place you can actually

save it, and you can actually build financial stability and have assets like a home and an education and a bank account and those things for a rainy day that we all need to have.

[00:32:45]

**JT:** That's really good. Can you think of anything else [cough] need more clarification? Okay. And this you probably kind of talked about, and I don't know if you have anything else to say about this. But basically one of the things that we're asking people, too, is how does Indiana compare to other states in the disability arena in terms of quality of services, meaningful lives for people, leadership, those sorts of things? In your experience in traveling and talking to other people how do you see us? Top half, bottom half, middle of the road?

**CF:** In my travels and talking with other people and going to some agencies in different states in trying to think about how do we compare here in Indiana with the services that we have available to people with disabilities, more importantly the lifestyles that we're able to live, my just off the cuff guess would be that we're running about middle of the road in our state. As I've mentioned before that makes me very disappointed because we have the ability to do a lot better than that. We showed earlier that we could. And so middle of the road is not okay. One of the things that seems to be kind of a prevalent attitude in this state, this is totally my opinion, I've lived in five different states, is that we seem to be fine with being middle of the road. And I don't think that's okay. I think we need to be doing everything we can to move community inclusion ahead and employment ahead. And so being middle of the road's just not okay.

[00:34:22]

**JT:** And what would it take? A change in leadership? I mean I have some ideas in my head, but what would you see besides funding? I mean what would be some things that would get us moved forward?

**CF:** I think in Indiana change in leadership would go a long ways towards making some differences here. We've had some periods of time when leadership at a state level has changed out fairly frequently, and I think that's devastating. And then you have different people that come in while they're getting briefed and up to par, you know, things kind of slide back again. We have a few agencies in our state that have executive director level leadership that is superb. And if at a state level they were looking at what do we learn from those agencies, how do we showcase them, and how do we also insulate them so that they're not kind of slammed by funding cuts that happen? Because we need to grow those kinds of efforts, not let them suffer when changes come in Medicaid funding, Medicaid waiver funding, etc. And right now I think they're the ones that get hit the hardest, the earliest, which reinforces that, okay, well if you keep people kind of congregated, segregated you can kind of control for those changes. So I think leadership -- change in attitude in leadership would make a huge difference. And if that doesn't work class action suits I really believe are going to be the thing that's going to make the change.

[00:36:04]

**JT:** Any rumblings of something like that taking place? Do people know how to file a class action suit?

[00:36:13]

**CF:** I haven't heard rumblings in Indiana of a class action suit. But the wave is coming across the country. And our advocacy groups and people who really care about people being out in the community I'm sure are listening and paying attention, and at some level saying how did that come about? So I'm not aware of it on an overt level, but I think it's just a matter of time.

**JT:** In our lifetime?

**CF:** I hope. [laughing]

**JT:** Okay. In looking at your tenure in the field of disability and human service, are there any noteworthy changes in Indiana that you want to talk about? And then basically in looking forward -- well, we'll do that one first and then I'll ask you that. And maybe you've already talked about this.

**CF:** I've got to think about it for a minute.

**JT:** Noteworthy changes. You kind of talked about the 90s being terrific and then we're kind of at a lull.

[00:37:16]

**CF:** One thing in Indiana that we have been a leader in in the past decade has been that our state vocational rehabilitation agency has funded a network of benefits information specialists. So at a federal level Social Security funds work incentive specialists and their training and their certification. But it's a tiny little pot of money, and there aren't anywhere near enough of those work incentive specialists to help people to understand how their particular benefits would change and to make informed choices around being employed at a substantial level. And in Indiana we've been kind of a leader in setting up a network that supplements that program that Social Security has. And State Voc Rehab has actually been fairly generous in their funding model for funding the support and training and the ongoing services provided by those benefits information specialists.

Now, I have heard that's been a little bit on the decline in the past couple of years, but I don't know that for a fact. But that's something that I applaud Indiana for doing in the past ten to fifteen years.

**JT:** Okay, great. You want a drink or you need a break?

**CF:** Yeah, I'll take a little drink right quick.

**JT:** We don't have too many more questions so hopefully --

**PH:** You're just whipping right through them.

**JT:** I know, you're really good at this.

[00:38:46]

**CF:** Well, it's totally off the cuff so I hope it's not too raw.

[00:38:49]

**JT:** No, no, it's very good.

**CF:** There, control my cough here.

**JT:** Okay. Do you need to move around?

**CF:** I'm good.

**JT:** Okay. So in looking forward what do you hope for in terms of supports and services to promote meaningful lives for people with disabilities?

**CF:** My hope for the future in Indiana and across the nation would be that we see an end to congregate and segregate service systems. And that we take all of the resources that are tied up into those programs and convert those into providing people supports to be in their communities in inclusive sorts of lifestyles whether that be employed or not employed. I think the money's there. You know, we keep saying there's just not enough money. I think the money's there. I just think it's tied up in brick and mortar and in high executive salary, executive director salaries and in a lot of other activities that really aren't producing anything for people. So my hope would be that we just get off the stick and do it because I think we can.

[00:40:03]

**JT:** All right. And then [inaudible]. Okay, so in looking towards the foreseeable future in those areas and in things that you're thinking about, what kind of training do you think people coming into the field need? What's going to help people be more creative and think outside the box? What sort of knowledge, experience, education, training do future people that want support people with disabilities need to have? And where are going to be the new trends?

**CF:** In terms of who do we need and how to train them and give them the resources that they need in order to do the kind of work that I'm talking about that we need to be doing, I'm not really sure where to think about recruitment. One of the things that I've learned in the school of hard knocks is that certain degrees don't seem to coordinate or correlate at all with who is really good at this type of work. It's more of a type of personality and belief system I think are more important that we're looking for in terms of people who are respectful of other people, that are invested in being pathfinders and introducers. I think if we are in a job because it's the only thing we could come up with we're going to have a hard time finding innovative jobs for people with disabilities. So that's the other thing is a person in this job because this is all they could find?

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If so, then they're probably not going to bring the type of resources and connections to the individual that the individual is going to need in order to find their place in the community. So folks who connect with others well, that are people people, that seem to have a knack for how to network folks and how to put pieces together of a puzzle that's kind of hard to solve and love to do that. So I think we need people who

are less about what's the job description and just tell me what I need to do and I'll do it, and more about what needs to get done and do I have a little room to be creative to get it done. Tell me what my parameters are but let me go for it. So I think we need innovators.

[00:42:23]

**JT:** Good. Okay, so I think we're about finished. I'd like you to talk about some of your, I guess the most fulfilling career highlights. Things that you either are most proud of or found the most personal satisfaction along the way. And you've been doing this for a long time. So what sort of things do you really feel good about in terms of the lines of your work?

**CF:** Some of the highlights for me in my career, and I didn't even mention it earlier, there was a short period of time, like a year, that I worked in a group home for people with intellectual disabilities. Which looking back on it I can see better ways to support people. But at the time in the late 70s these were individuals that had spent their entire life in a state hospital and were moved into this group home. And it was so early in the process of moving people into places like that that Medicaid hadn't got its regulations together or whatever. And we were flying by the seat of our pants. And we didn't know what we were doing. But we thought what we needed to do was to help people to have a life. And so we took people out. We took the ladies out for ladies' night out, and we'd go to the Commodore's concert. And when it snowed we'd get TV trays and slide down the sides of the interstate. All types of things that now you would get in all kind of trouble for doing.

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But when I look back on it these individuals were having so much fun and doing things that most of us just take for granted that they had never had never had an opportunity to do. We never lost anyone. Nobody ever really got hurt. And it was really -- it was just really I think a wonderful opportunity for people to experience life without some of the safety guards around them. We didn't have a dietician plan in the meals. We sat down in the living room on Wednesday nights and came up with a menu. And everybody had input and everybody took turns helping to cook. And so I look back on that and I thought, you know, when we were so grass roots that we really didn't even know what we were doing, there was a lot of what we would love to be able to help people find in life today if we could just get out of their way. And kind of stand back and support them without overregulating what's happening. So that was great fun. And I look back on it and got a lot of lessons from that. A second, I've got to tell you that my most favorite job ever, ever, ever was being a job coach.

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Because, again, I got into it before federal regs were ever even written. Paul Wehman told me when I was new to that job that there was only one criteria for an individual to be able to go to work in the community, and that is that they pass the mirror test. And I said, "what is the mirror test?" He said, "If you hold a mirror up in front of the person does it fog up? It if does they're alive. And that's the only criteria we have. And so you can't guarantee you can help somebody get a job. But your job is to do everything in your power to help people to get into jobs that they're successful and satisfied in." And so we had a little bit of

parameters there. But for the most part our expectation was get out there and make it work. Figure out some way to make it work. And it was the best job I ever had. And we were part of a research project. So we had to keep all of this data and take pictures of the person every month to see if they were like losing weight or looking more normal.

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We even did the pinch an inch with the diamometer [phonetic] to see if their total fat content was going down as a result of work. And we laughed about all this stuff. Because when you were a job coach and you saw the changes in a person you didn't need data to tell you that this was the way to go. And it was literally the best job I ever had. But I can tell you when I moved here to Indiana and there were three different agencies that I worked with while I was on that systems change project here in Indiana that got it. And you could see when they got it. It was like a major conversion in their thought processes. And they began moving in the direction of transformation. Now every one of them still has some semblance of a congregate program, but they're small. And to be part of that and to watch the leadership and those agencies catch fire, and at the time they were doing it it was like heresy. And they had parents up against them and everybody else up against them. And yet they were on fire.

They couldn't not do it at that point. And so that was a big time, wonderful part of my career was to be part of that.

[00:47:14]

**JT:** Very good. Now, is there anything that we haven't talked about that you think would be important to have on record or just talk about or say in terms of things that you know about? Any stories that would be --

**CF:** I can't really think of anything else.

**JT:** Anything that you've forgotten that you want to add to what we've talked about?

**CF:** I don't think so. I can't think of anything else.

**PH:** We don't have a lot on person centered planning, so I'm wondering if we could talk a little bit more about it.

[00:47:57]

**JT:** What do we want to talk about specifically?

[00:48:03]

**CF:** Well, I could tell a story. And this wasn't formal person centered planning, but it was coming from listening to who knows the person well if you want me to do that.

**JT:** And do we also want to ask her anything about Steve? You know, what we've done with some folks, and I don't know, you said you wanted to be home fairly soon, so I don't want to keep you. But what we've done in some cases where people have passed on we have talked to the people who knew them. And the questions would be [inaudible] but basically how would Steve be remembered? Or what were some of Steve's biggest contributions to the field, that sort of thing. What time do you need to leave, Connie?

**CF:** Probably in about 15 minutes.

**JT:** Okay.

**PH:** I think she can handle those two.

**JT:** Okay. Are you comfortable talking about Steve?

**CF:** Yeah, yeah.

**JT:** Okay.

[00:48:58]

**CF:** I'll start with the story. A story I like to share is remember I told you that my beginning in being interested in this field was moving next door to a family that had a daughter with an intellectual disability who became like an extension of our family. And at a later time when I'd moved away from Virginia I went back to visit. And I went to look Julie up. And she was in a sheltered workshop. And when I went in, of course, she saw me and she came running over and gave me a big old hug. So I was talking with one of the staff, and I'm like why is Julie in here? Why isn't she in a job in the community. And they went we tried that, it didn't work. I said what? And they said, well, she worked at McDonald's and it just didn't work out. She was always trying to talk to everybody, and she wouldn't say focused on doing the fries and all that sort of thing. And so I began telling the story about how she had been like a mother's helper with my children, that she absolutely loved young children. And when she had gotten a little older and I had gone to work, I helped her to get networked with a childcare center.

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And even though they didn't have a paid position at the time, she went there and volunteered after school every day and helped the children get cookies and get their books together, coats and everything when they got ready to go home. And the people absolutely loved her. And then she ended up for a short period of time doing that for pay. And it was a whole side of her they had never discovered, didn't know anything about. Her mother had passed away at that point, so her primary person who had been the historian in her life was missing. And they didn't see her that way at all. They just saw her as somebody who was a slow producer with bench work kind of work, intended to get off task a lot versus looking at that she's a people



person and she loves people. And if she's in a role where your outgoing personality can really shine she'd be highly valued. And the fact that she absolutely loved little children. She ended up going to work again some months later working in a situation in which there were younger children around, and she was able to help with those children.

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But what we now call person centered planning at that point was exactly what was missing. They were seeing the client Julie, they weren't seeing Julie the individual that I knew and that her mother had known. And she wasn't able to express to them by herself. So that was really a meaningful opportunity to see person centered planning at work.

**JT:** Very good.

**CF:** And now, what to say about Steve. I remember the day that I first started working at IIDC. And it was in fall of 1992. And I had taken a job working on the systems change project. Susan Rinne was my supervisor. And I was a little unsure whether I wanted to do it because I had my little consulting business. I was working out of my home, and I wasn't sure I wanted to do the commute. So I was a little tentative about it. And on my first day I drove up in front of the center and I went in, and I found that they had also hired another individual to do the same job, and his name was Steve Savage. And he and I were to share an office. And so that's how I met Steve Savage. And he and I shared an office for about three years and became good friends. And I learned so much from Steve about Indiana for one thing because he had worked in programs in Indiana and just seemed to know everyone.

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But he just always was such a leader in the field for many reasons, one of which if he thought it he said it. He didn't worry about being politically correct. He was driven by his beliefs. And he just spoke what he believed. But he was always willing to help anyone move ahead in the direction of inclusion and employment. So he wasn't somebody who just talked it, he walked it. And one of the other things that I really appreciated about Steve was he would take a break every so many years. Because he really felt like particularly if you worked in an educational role or a technical assistance role that you needed to kind of step back every so often, get a breath of air, restabilize, recommit to what's important to you, and work again in the field so that you come back fresh and really centered on what the challenges are in a community. And Steve was somebody who did that. So he made a big difference when he worked for Gateway for a period of time.

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He was making a big difference already at The ARC he was working in when he passed away. But he's someone I will always remember as being totally driven by his value system, outspoken about it, a real leader in the field. And somebody that I rarely remember ever having something bad to say about anyone. He led by optimistic, hopeful sort of a demeanor that most people I believe really appreciated even when he was outspoken.

[00:54:08]

**JT:** Thank you. Very nice.

**CF:** You're welcome.

[END OF INTERVIEW]