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**ORAL HISTORY VIDEO INTERVIEW WITH  
PAUL SHANKLAND  
JANUARY 11, 2013  
INTERVIEWER: JENNIE TODD  
VIDEOGRAPHER: PEGGY HOLTZ  
RECORD ID: 006-DO**

**PS:** PAUL SHANKLAND

**JT:** JENNIE TODD

**PH:** PEGGY HOLTZ

[00:00:10]

**JT:** Okay. So we're going to start off with you telling me your name, where you're from and from where you retired.

**PS:** Okay. I'm Paul Shankland presently from Indianapolis and have been for some 30 some years and I've retired from the Governor's Council for People with Disabilities.

**JT:** Okay. And how and when did you get into this line of work?

[00:00:36]

**PS:** 1964. I was working in a shoe store. Hated it. Had a very aggressive manager and I was getting more return customers than he was and he didn't like that because I wasn't as aggressive as he was -- anyway. Somebody said well there's these kids over at the state school that need somebody -- they're looking for somebody to help them learn how to play. So learn how to play, are you crazy? That sounds a lot better than this. So I went over and applied and had a short interview with Don Bueller and went away feeling like I was supposed to come in Friday for some kind of a -- of a initial signing up, you know, and then start work maybe. Well I got a call on Ash Wednesday and you know what this means for the shoe industry. We want you here -- we want you here Friday, you start work Monday.

[00:01:37]

That was so good. [laughter]Anyway, I wound up spending from '64 to about '71 working full time and part time as a AT -- as a recreation aid or activity therapy aid and working mostly with the younger children. And that's -- from there I went to a local agency for a year and then to the state.

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[00:02:08]

**JT:** Okay. And I thought you had worked at Fort Wayne State Hospital --

**PS:** Yep.

**JT:** -- is that -- Okay. What can you tell me about that experience? What was it like for you? What was it like for the people that lived there?

**PS:** Well I started out when I said state school, it was Fort Wayne State Hospital and the experience is a lot different in retrospect than it was when it was being lived. When it was being lived it just was what it was and I didn't know a lot that I know now. And I can say that while at the time I had a lot of fun and the young -- the kids that I was working with and then eventual adults that I was working with, mostly had a lot of fun when we were together. Maybe mostly. But in fact over all it was pretty miserable for the folks that lived there and today it's one of the things that I try not to think about too much because it makes me too sad to think about the things that I was part of and saw there. The mistreatment, people encouraged to mistreat each other.

[00:03:26]

**JT:** Can you elaborate?

**PS:** In some ways I'm afraid to. It --

**JT:** I should take that paper too because I'm about ready -- [laughter]

**PS:** [laughter] So to go into much detail is a little scary because of some of it was just too hard to do but the head of security was an abusive person and I watched him abuse people and I remember a guy, great big guy, who was physically and mostly pretty good shape. And his name was Paul and he liked me because my name was Paul and he was always hey big Paul. [laughter] And -- but then I watched that security guard or the head of the security for the institution would be in a canteen or something and he'd come up to him and supposedly being friendly and whatnot would start punching him and there was nothing I could do about that -- at the time even at that time in that milieu when most people didn't think much of that, it upset me a lot but there was nothing I could do about it.

[00:04:51]

They segregated the people with Down syndrome for no reason that I can understand. At the same time they had -- I have -- I actually have video if you're interested from the camp, the summer camp of groups of people up there. And there were a lot of events that at the time everybody thought oh gee Isn't this nice. That these folks can do this. And we had dances and I remember I pulled a surprise on my now late wife by showing up for one of the dances in a tux [laughter] and there were -- there were a lot of really -- at the same time in terms of staff there were a lot of really wonderful people. Really good, sweet people participating in an absolutely horrible milieu and it only takes later advances to be able to look back and see how bad it was.

[00:06:04]

**JT:** Well you know one of the reasons we're doing this is so that down the road people that don't know about life in institutions --

**PS:** Um-hmm.

**JT:** -- don't get the bright idea to create institutions.

**PS:** Yes.

**JT:** So we are trying to capture some stories and capture some reasons why they were bad places even though the intention in that time was good and to talk about lessons learned and why we never want to go back there and people have talked about abuse and the part that you're talking about in that it was common place.

**PS:** Oh yes.

[00:06:42]

**JT:** And that it was, you know, basically no one did anything about it.

**PS:** No.

**JT:** That's really hard to understand and imagine a person who is brand new and has never even thought about that how they could believe it so if you could kind of maybe set the scene a little bit more --

**PS:** Yeah.

**JT:** -- so that --

**PS:** Some of the -- some of the -- its interesting I was talking to friends about this just night before last and the abusive nature of it was not unlike, in many ways, not unlike prisons today. And I think, looking back on it, without thinking about it and without describing it or -- can't find quite the right word -- articulating. Without articulating it, people were operating under the assumption that there was a separation in terms of quality of humanity or even humanity, between the people who were incarcerated and the staff. Essentially everybody operated on the assumption that the people that lived there were subhuman. If you had challenged them on that, they would have denied -- they would have been upset, but if you looked at how they interacted with people, then it was -- it was continuous.

[00:08:18]

There's a building that should have been preserved there, it was called Cedar Cottage and that one had cells in the basement with chains in the walls and things carved in the walls from people that had been incarcerated there over the years. While some activities in the institution were done in a fairly open free kind of way, I mean we had football games and baseball games and that sort of thing. We had summer camp, but much of it -- much of the daily living stuff outside of that, the getting up and going to bed and eating and bathing and all of that was handled very much the same way as it's done in prisons

today. It was very regimented and it really depended on the emotion of the staff person at the moment on how individuals and groups of individuals were treated.

[00:09:26]

It's that old story of, you know, if mama has a bad day, everybody has a bad day, well if the attendant had a bad day whoever came next to that attendant had a bad day. And all of the staff were referred to by clients as Mr. or Mrs., rarely by name. And all the clients, the residents, the whatever label you want to apply to folks were generally called by name frequently last name. So it set up that dichotomy of the keepers and the kept and that caused me once to write a piece to -- to author the line that, "I'm not my brother's keeper, I'm not called to hold the keys. I am my brother's brother." And that sense of brotherhood just wasn't there in the institution.

And if you think about the difference between what I've been describing and how the people within your family relate to each other, provided you don't have a really horrendous family, I think that probably explains it about as well as I can, but it's clear that any time -- and really if you want to find out what the -- Fort Wayne State Hospital was like, spend some time inside one of our worst prisons. In fact, we had something similar operating -- the infamous Angola Prison. We had people operate -- working the farm. It wasn't in operation during the time that I worked there but at that time the farm in Muscatatuck was. People were working this farm for no wages and the produce was being sold or at least some of it. Much of it was being consumed by the institution but some of it was being sold.

[00:11:33]

**JT:** Well that was -- excuse me -- one of the questions I was going to ask you and you did answer, you said people have names. You know, did -- and you said they were referred to by last name.

**PS:** Last name and frequently nicknames that had been given them.

**JT:** So it was not a very friendly --

**PS:** No.

**JT:** And I guess it would be anything else I could ask you about that is, you said they were treated as if they were in the worst prison in Indiana, you know --

**PS:** Um-hmm.

**JT:** -- or worse than a prison. What was the mentality, I mean was it just that the attitude of the staff, some of the staff was that people with disabilities were less than human? Where did that attitude come from? Did it come from just wanting to control? Do you have any thoughts on --

[00:12:25]

**PS:** I think it was something that needed to be trained against and wasn't because it's a kind of attitude that you see prevalent in society in general and -- but not, you know, not by everybody, but it's the kind of thing, well, isn't that sweet when somebody does something and if it was an adult doing it or a person who's not labeled with some kind of a disability, it would be oh, well, you know, it's that attitude of

some kind of difference between us and them that makes them less than. And as long as less than is considered attractive and pleasant and a good thing, that generally doesn't do much harm, but the problem that the less than attitude is there at all when things get all uncomfortable when isn't that sweet, when the one that's done something that isn't that sweet does something demanding, then it's not too far from there to a slap because they're not us.

[00:13:47]

**JT:** That was good. So you had experience with several state hospitals in Indiana. Muscatatuck and Fort Wayne, right?

**PS:** I was not -- I did not work at Muscatatuck. I knew about it. In fact my first wife had worked there and she -- it's also interesting that there was considerable difference, I think, between what went on in different institutions. One thing that I don't think ever happened at Fort Wayne that did happen in Muscatatuck, some of the staff sort of semi-adopted some of the residents and would take them to their family events. Take them out for Christmas and take them home with them on various times and they became a little bit more like us to -- at least to those individual staff that did that. I don't know of anybody doing that in Fort Wayne.

**PH:** We had heard stories of that too.

[00:14:44]

**PS:** Yeah.

**JT:** Well that was one of the questions I was going to ask you, if you could talk about maybe you don't know the answer to this, the differences between the state hospitals around the state and how it was decided who went to which state hospital. Was it geographic, was it -- if you had a seizure or epilepsy, you went to New Castle. You know, how was it decided?

[00:15:10]

**PS:** Determinations of who went to which state institution varied over the years. Early on, I'm not sure when New Castle was established but New Castle -- the minute it was established people -- when people had seizures, they were sent there. And I don't know if the woman is still alive or if you can find her, Christine Dahlberg might know. There was a woman that I -- that used to ride the bus with me when I went to work occasionally, I would see her on the bus and if you got in conversation with her, she would tell you how she spent 35 or 40 years in New Castle because she once had a seizure in the second grade and she got -- they put her in New Castle, she never had another seizure and she couldn't get out. And by the time she got out, she was marked. I mean, you could see her walking down the street and you'd know there was something weird about this person and mostly it was a combination of behaviors learned in the institution and behaviors that she didn't have because she had no opportunity to learn them.

[00:16:23]

But at some point, the others -- the other institutions as I recall depended upon some combination of geography and diagnosis. People with multiple diagnoses often went to, as I recall to Logansport or Richmond and there were -- there was a children's hospital in Evansville, I believe.

[00:16:56]

**JT:** Silvercrest?

**PS:** Silvercrest came along a good deal later. That was supposed to focus on I believe on autism. My memory of that's not very good.

**JT:** Okay. Well, is there anything else you can think of about the institutions you want to talk about before we move to --

**PS:** Not especially, although if Bob Spalding is still alive and you can find him. The last I knew he lived somewhere near Suellen in that neighborhood in North Central, somewhere around 14th or 15th and Central Avenue here in Indianapolis. Bob was the director of the Division on Mental Retardation for many years and he would know a lot of what you're asking me about, how things happened. I don't know that he had any inside experience on the institution as I did but he was involved in a lot of those policy kinds of things.

**JT:** Okay. Well the next thing I want to talk to you about is the Governor's Planning Council. So what I'd like you to do is, first just kind of talk about what it is.

[00:18:17]

**PS:** Um-hmm.

**JT:** And basically what's the role of the Council and then possibly some big grants that you were involved with and what changes they brought to Indiana and then I'll ask you a few more questions about that. [Coughing] We all have coughs -- alright, so we'll --

**PS:** After I left the -- after I left Fort Wayne State Hospital, I worked for a year at a local agency and then in 1972, I hired on in the Division on -- well let's see, the name's changed so much over the years. Then it was called Division on Mental Retardation and Department of Mental Health. Under the Developmental Disabilities Federal Act, there were three consultants and one program manager and I think I'm the only consultant left alive [laughter] out of that bunch. It's tough on consultants in that program. [laughter] And at that time, we started out the role of the program under the federal agency was -- was to -- gosh, how do I put that? It was to be part of -- they didn't call it change agency then.

[00:19:44]

That term hadn't been coined yet. But that's essentially what it was. Our job was to bring new ideas into the disabilities field in Indiana -- at that time it was primarily mental retardation and they brought in epilepsy gradually and then just kept expanding the definition of what disabilities, the program was going to cover over time, but to begin with, we traveled all around the state, working with mom and pop

operations in cities and towns everywhere and -- but we didn't mess with institutions much initially. And we had -- it's one of those things that started out great and then had some unanticipated consequences. We brought modern management techniques and program management techniques to agencies that were made up primarily of volunteers.

[00:20:48]

We began to introduce professionalism to small -- small operations and those operations grew and there were a lot of great consequences of that. Agencies became more stable, they became better able to support themselves, they became more competent at doing what they were doing. They became more competent at fundraising. That was the upside. Some of the unanticipated consequences of professionalism were the business side of the picture in that they developed administrative models that were more like local business and then they developed administratively top heavy models that were like local -- larger local businesses, banks and insurance companies and whatnot and then the top level salaries began to eat badly into what should have been going into the lives of people they were serving. And they were -- there reached a point where executive directors of agencies of any size at all were -- and sometimes a couple of levels beyond that -- were, in my personal opinion, rewarded far beyond the kind of job they were doing and kind of lost track of the notion of being a servant.

We also -- I'm not sure what order I'm in. My notes might help a little bit.

**JT:** You want this?

[00:22:32]

**PS:** Yeah. Yeah. We introduced -- we were probably the prime mover in the development of group homes and -- around the state and this was in the '70s and coming up to 1980, we piloted a lot of group homes in the state and initially, that seemed like a really good idea and the -- later on as the for profit folks got involved it became much less so. Mostly I can share anecdotes. I remember as we were developed -- we developed -- our division developed the regulations for group home operation and I remember as we were developing those we were had -- I met with -- I remember Jim Taze [phonetic] and John Hess and myself and some other folks met in Elkhart and we were sorting out what to put in the regulations and trying to get as much what was then labeled normalization into them as we possibly could and I think it was Jim Taze that prophesied that it looked -- he was afraid that the institutional model would be exported into the group homes by -- and a lot of that proved true -- and it was again people with good intentions, or at least they thought they had good intentions.

[00:24:20]

Although there was one that I'm a little concerned about. We were working -- the fire marshal's office was insisting that we put in these sprinkler systems -- and restaurant type fire extinguisher in the kitchens and a variety of -- external fire escapes on every home. And I had an interview with a woman who at that time was second in command at the state fire marshal and tried to explain what we were trying to do and she responded, "We believe that the retarded should be institutionalized for their own good and we're going to see to it that they are." And that's a quote. That -- we did succeed in modifying

and getting the fire marshal to ease off on some things but it took a lot of advocacy by a lot of people and a couple of other things did a great cause -- did a great deal of damage to that whole effort.

[00:25:28]

Again, some of it was unintended consequences. It was demonstrated that community living could be done less expensively overall than institutional living and then the powers that be, some combination of legislators and legislators hand picked bureaucrats declared that community living can be cheaper than institutions, therefore every community living setting has to be cheaper than an institution. And they also insisted that if institutions were going to close, then the state had to hire staff from those institutions in other places so we wound up with people and not always the most ideal people who had been working in institutions coming to work in group homes. So you can see what started out to be a really great idea to help people with disabilities to become integrated into the community and have lives like the rest of us and become us instead of them, there'd be a little thing here, an opening there, a little something else just begins to narrow down and tear it down and the -- a story that you probably know, this was by -- this may have been somewhere in the late '80s or into the '90s.

[00:26:58]

Probably into the '90s when as progress towards community employment and community living moved forward Johnson County ARC was a bit of a leader in that effort and they had virtually closed their sheltered workshop. They got everybody jobs in the community and they had, I think maybe three people left that did not have a job in the community. And there were several group homes in the county and they were taken over by a private for profit operation. And immediately after the for profit operation took it over all of the adults in those group homes who had jobs in the community suddenly decided on the same day that they wanted to go back to the sheltered workshop. You know, for those who don't know, I'll explain, the cause of that was that when you operate a facility with six or seven or eight people in it and each of them have jobs in different places and their schedules are different, it means your staffing and your transportation costs run a little higher and it puts pressure on your profit margin, but when everybody goes at the same time of the day to the sheltered workshop and comes home the same time you don't have to staff all day and your transportation is narrowed down quite a lot.

And that kind of thing has -- has really wreaked havoc with the whole concept of group homes in the community.

**JT:** I'm thinking Steve Savage told us a story about that in Johnson County.

**PS:** Yeah. Yeah. Yeah. That happened during the time that we were running that transportation shop.

**JT:** So if I knew nothing about the Governor's Planning Council and I didn't really know about their role, is there anything else you could think of that you would say --

[00:28:30]

**PS:** Oh my, yeah.



[00:28:37]

**JT:** -- some particular projects or big grants they had?

**PS:** Well, this isn't any kind of chronological order.

**JT:** Just an overview.

**PS:** I think we did -- we moved more and more into change agency as opposed to just a project to start up, just startups. All the startups did accomplish change agency in the communities where they happened up to a point and then things -- it reached a point where okay, we've got group homes, we've -- we funded -- supported employment projects that got people out into regular jobs or something close to a regular job. We supported the supported living, which is not the same thing as group homes. It's having the support you need to have your own home. The single most important project, I think we ever funded and one of the biggest ones and one of the longest running was Partners in Policymaking where we brought people with disabilities and family members with dis-- family members of people with disabilities in for eight fully funded weekends a year over the course of a year to learn about the field, to learn about their own disability because many of them had a lot to learn about that, to learn about the system and how to operate within the system and how to relate to the system so that you could get what you really needed.

[00:30:33]

And it was -- it had as far as I know still has great support. We had legislators who came in and talked to people about how to communicate with a legislator, taught people how to write to legislators. We had people from all the state agencies involved in any way with disabilities come in and describe their programs and help people identify, you know, what they might really need in those programs. That little vignette in the early years of that program, we farmed out the administration of it for quite a number of years before bringing it back in house and we put out an RFP for the management of the program and it wasn't going anywhere and we couldn't find out -- couldn't figure out what was the problem. And we got called over to the statehouse to meet with the state budget director.

[00:31:37]

They didn't want allow the project to continue and we said, "I don't understand, it's 100% federal funded. It does not impact state funds." And finally the budget director said, "Well we can't have you going out and telling people about all of these state programs and benefits when we may not be funded well enough to provide them." There was this silence and finally I said, "So are you telling me that -- all these things we're talking about it's public information and you want us to somehow keep it secret?" [Laughter] And that kind of ended that conversation. [Laughter] Some of the -- one of the projects -- in the supported living area, the people in Fort Wayne got this great notion there had been all of this preparation, preparation, preparation, pre this, pre that training for this, training for that.

[00:32:41]

Training for how to get around in the community, training for how to run your kitchen, training for how to dress, training for how to clean your bedroom and yet people were still in the institution and the pre wasn't going that far and so finally the folks in Fort Wayne got this great notion. Why don't we experiment with taking people just straight out of the institution into their own home with supports and see what happens. And several of us went, "Whoa, that's an interesting concept. Why didn't anybody think of that before?" [Laughter] And so we funded it. And it was fabulous and it's one of my favorite stories that I've probably told -- I know I've told many people this story. There was a man that I knew when I worked at Fort Wayne State Hospital back in the '60s who had spasmodic -- spasm kinds of issues so he was flexing his muscles all the time and he as a consequence built quite a physique and preferred the nickname of Mr. Muscles.

Somebody put that on him and he liked it. Well at the time, I was working in the institution, Johnny Appleseed Agency in Fort Wayne was wanting to bring some young -- some adults out on a day program to the sheltered workshop and I was amongst the people at the state hospital that said, "This'll never work. These people can't do that kind of thing. That's ridiculous." And then -- and that was somewhere in the '60s and then somewhere in the midst of that project, I was at a conference in Atlanta and up comes Mr. Muscles with the support staff that lives with him and invited me for a beer and wanted to tell me about his home that he was sharing with a partner. They were buying a house together. And that just -- that's what it's all about. That was really cool.

[00:34:37]

**JT:** That's really good.

**PS:** And that's the kind of thing -- another one of the major projects that we supported. It only lasted a few years but it did a lot -- and that was the community transportation initiative and we basically copied the model off of Partners and Policymaking and what we did there was invite communities to put together a team and send in people who were leadership and service agencies, somebody from city and county government, local financiers if we could get them. I don't know if we ever succeeded at that. And people with disabilities from the community to create a team to come and work out a plan for transportation development in their communities. And we hired Peter Shower as the trainer for that. And it was -- it made changes to local transportation all over the state.

The single most successful one that we did was when we managed to get both city and county government members in the training session along with the rest of them. So there were -- and it was -- it really brought a lot more transportation to a lot of people and a lot less cost than anybody thought would be possible.

**JT:** You mentioned request for proposals.

[00:36:07]

**PS:** Um-hmm.

[00:36:08]

**JT:** And what I'd like you to talk a little bit about is request for proposals, the unsolicited projects where people would apply for money, how the council dispensed of some money and what -- how projects came about.

**PS:** Oh dear.

**JT:** And maybe that's not -- you know, just whatever you can think of but I know that there was two avenues to get funding from you all and there would be the RFP process --

**PS:** Um-hmm.

**JT:** -- and you do a broad base announcement and people would apply. And then there was also an avenue of the unsolicited --

**PS:** Um-hmm.

[00:36:42]

**JT:** -- proposals where you would just submit an idea.

**PS:** Right.

**JT:** So I don't know if there's anything you want to say about either of those that would be noteworthy or not.

**PS:** Well, the whole granting process over the years improved greatly and I'm rather proud of a lot of what was done there. I remember when the program first started out, the folks running the epilepsy clinic at the med center basically bypassed all existing processes and sort of pirated the entirety of the funds for the first year or two and that took -- that was an interesting battle. I don't remember the details anymore but it was something. There were -- as in all fields there were some folks that because of certain credentials they carried figured that gave them some sort of incontestable power. [Laughter] But we did develop a really good solid professional grants management system whereby we determined our priorities and the kinds of things we wanted to accomplish and then we put out requests for proposals to address those.

[00:38:00]

We had those proposals reviewed. We had a blind review process that provided very professional reviewing process and we got -- and as a consequence, we generally got high quality projects. We also had a process where people could submit unsolicited proposals for limited amounts of money. We did not have a wide open budget so we didn't have wide open opportunities in that area, but these also met with a professional review process and one of them resulted in one of our better projects that I haven't mentioned yet and that's the Fifth Freedom Project, which is a -- it came in initially as an unsolicited proposal and we looked at it.

[00:39:01]

We got excited about it. I believe we involved the Institute. We got a bunch of people -- you know, people got excited and we expanded on the initial concept and that's developed a -- that's developing a grassroots self-advocacy. There's a self-advocacy movement of one kind that involves a great deal of sponsorship by different supporting groups and that has -- is also one of our better projects where people with disabilities have their own organization and there's quite a range of how strong these groups are depending -- in my opinion it depends on who the sponsor is. If it's a local service agency they often become just a social club, but if it's somebody who if the sponsor is somebody like the Institute or somebody that, in some cases a local service agency that's got a different attitude, they become a part of the local, social, and political system and have some real clout in developing changes in their community that make life for dis-- people with disabilities more like life for the rest of us.

But the Fifth Freedom Project is by -- completely by and for people with disabilities and it's modeled after, at least part of it is modeled after the work of Saul Alinsky and people with disabilities form their own -- basically their own advocacy group in the community and create their own agenda and push that agenda in the community. It's a project that I think for it to be truly successful it needs more longer term support than the Council's ever going to be able to give it and that's unfortunate. The way it is now it's a pretty mixed bag. There are some communities that are very successful and some that are not at all and I have no idea -- I've been away from it for long enough now that it could have gone in any direction and I wouldn't know what its current a status is.

[00:41:24]

**JT:** Okay. One of the things that I know that Indiana's Council differs from in other states and I don't know if it's all states is that you all have expanded your focus. It used to be people primarily with intellectual --

**PS:** Um-hmm.

**JT:** -- or developmental disabilities and now the scope is people with mental illness, traumatic brain injury --

**PS:** Um-hmm.

**JT:** -- that sort of thing. So I'm curious as to what brought that change about and do you feel -- since I think most of your funding comes from ADD, if there's risk in terms of funding or anything along those lines.

[00:42:06]

**PS:** Well I think in terms of expanding the definition, I mean when it started out, it was mental retardation, epilepsy and autism I believe and then we expanded -- the definition was expanded to include mental illness and basically the whole field of dis-- the whole range of disabilities. Not entirely but a great range of people with disabilities and frankly, I credit Suellen Jackson with most of that change. I think she saw appropriately that to develop the support base within the state, because the Council -- okay, it has funding from the Feds and it has support in state and law regulation. But you can have that and still not be very successful. You can have that and just shrivel up if you don't have other kinds of support. And to rely on the community of people with cognitive disabilities alone, or people with cognitive disabilities

and people with epilepsy and autism, those three groups alone were not a broad enough base to accomplish the kind of change in the community that we wanted to do.

[00:43:29]

In order -- because change -- the change has to happen at the local level and Suellen could see that. That in order for -- where we want changes in neighborhoods or where we want changes in Muncie and Lafayette and Roanoke and, you know, Angola, in order to do that, if it -- in Angola, how many people with cognitive disability and/or epilepsy and autism are there? Well you don't have enough to get very far, but if you enable that group to ally and bring in people who are blind, we have cognitive -- visual impairments, people who have auditory impairments, people with mental illness, you begin to get a large enough body to actually have an impact on the community. So that's how that happened. I hesitate to speculate about ADD because it changes a little bit with every change in federal administration and -- but what happens every time the administration -- almost every time the administration changes, there's the effort to create an image of change and so everything -- everybody and everything gets threatened and scared for a while.

And then it calms down. There is some moderate changes and usually not for the worse and things go on, whether that's good or bad.

[00:45:10]

**JT:** But you didn't see any risk or you don't see any risk in broadening the scope?

**PS:** I don't. Some other people might but to me it seems -- it's going to depend on what the -- whether the Feds want to see success or not. And it's current staff at the federal level. If they want to see your program succeed, then there's no risk. But if they didn't want it to succeed, if they -- you know, if -- being able to demonstrate success allows -- increases flexibility.

**JT:** So what have been some of the biggest changes in the field that you've seen in your tenure in the field?

**PS:** Oh my. Closing the state hospitals. You know, that's probably the biggest and --

**JT:** Wait a minute. They're not going to hear my questions.

[00:46:11]

**PS:** Oh. I'm sorry. In terms of changes that I've seen it's been -- I've been in the field since '64 and it's now 2013. That's a lot longer than I care to remember [laughter], but the biggest change, the biggest visual, visible change is the closing of institutions and they're -- that process as I've indicated in other parts of the discussion was either intentionally or accidentally sabotaged by the way the funding was handled and failure to provide the level of community support especially for people with multiple diagnoses, but that's brought other changes. What I'm seeing that's a really big change is you can see it mostly in anecdotal kinds of things.

[00:47:14]

I don't know that anybody's done the research on it yet, but community attitudes are changing and if you look at community attitudes as the whole community, what is their attitude, I don't think that yields you much because communities are made up of individuals and I see lots and lots and lots of individual attitudes changing drastically. The way people relate to folks with disabilities they really are becoming us and that's the most important change.

**JT:** Can you give me an example?

**PS:** People with identifiable disabilities are working in visible places in the community and nobody's paying any attention.

**JT:** Good.

**PS:** Nobody's noticing good, bad or otherwise. They're just another employee; they're just another person on the street. That's the easiest one to see. I see it on the Internet. I see it in Facebook where something about somebody with a disability will come up and where in times past, you could readily expect a raft of patronizing kinds of remarks or hostile kinds of negative kinds of remarks. Now if something patronizing or hostile shows up, everybody else is all over it. And that's a sign of change in community attitude.

[00:48:46]

**JT:** Good. [cough] well I know that you shared with me before that your wife had a disability.

**PS:** Um-hmm.

**JT:** And I guess one question that I would have is did your personal experience with disabilities help drive your agenda or help keep you motivated or how did that affect the work that you did?

**PS:** Um.

**JT:** And maybe it didn't.

**PS:** Well, it -- my personal -- my late wife was a person with multiple disabilities. She was -- she had a birth anomaly in her right hand and quite a bit of distortion in her left. She was also a diabetic from the time she was 9 and had heart disease and she died at age 71. We lived with her disability for 30 -- 39 years together and it was very good. And I don't know. I don't know what to say about how it affected my commitment to the work. I think I was -- whatever change it made in me I didn't notice particularly. I can't identify it. I do know there were some great stories. She had a myoelectric artificial hand, was shopping at Marsh one day and the battery went dead while she was pushing the grocery cart.

[00:50:25]

[Laughter] She had to take it up to the manager, take her arm out of it and said, "Could you watch this while I go home and get another battery?" [Laughter] And she worked for the VA for a while in recreation and it involved taking guys to the bowling alley on the weekend and driving a bus and they

wouldn't let her drive the bus. So she went out and got her chauffeur's license. They still wouldn't let her drive the bus. She thought it was because of her disability. So she went out and demonstrated she could drive the bus. No. It was because she was a woman. She became the first woman bus driver in the Veterans Administration. [Laughter]

[00:51:08]

**JT:** Good for her.

**PS:** It was the same year that we had the first woman driver in the 500. [Laughter] Whenever that was. But she always encouraged me so in that sense, but not because of her disability, but because of who she was.

**JT:** It was just a random question. So in general, did things differ from one administration to the other across your tenure in terms of policies, funding --

**PS:** Oh my, yes.

**JT:** -- programs and if so, how?

[00:51:50]

**PS:** When I started with the -- the whole funding process and the policy process changed a lot over the 35 years I was with the State, 37, I guess. When I started out, the whole program was in the Department of Mental Health in the Division of Mental Retardation and they had full use of -- pretty much full use of the funds. And over time, initially that was fine because we did a lot of innovation. We did a lot of startups. We started up lots of children's programs. We even supported some Doman-Delacato projects and that was an interesting and overall unfortunate experience, but it was controlled by the Department of Mental Health and by that Division, but over time, the Division as it supported community agencies began to use more and more of the funds for ongoing support of community agencies, which basically was in violation of the federal requirements and Suellen came on as the director for the Council and the Council, the state agency was one thing and the Council, well sort of captive the state agency was its own thing and developed its own administrative staff.

[00:53:19]

It got an administrator and associate and that was Suellen Jackson. Well she succeeded in splitting the Council entirely from the Department of Mental Health and taking the money with it. And that was quite an accomplishment. Prior to that, the funding that the -- the overall funding gradually increased a little bit, a little bit, a little bit like federal funds tend to do but it gradually -- it was gradually losing its ability to do -- to accomplish change in the state and to accomplish innovation because it was being more and more soaked up in ongoing support. But once Suellen managed to get the Council free of the Department, it became innovative once again and at the same time, because of its innovation and because of its advocacy, different state administrations were -- had different -- had a different approach to it.

[00:54:25]

Some of them were threatened by it and attempted to either shut down or limit -- severely limit the Council's ability to accomplish things. There were efforts to grab the funds one way or another from time to time. Almost every administration there would come a new effort to pull the funds away from the Council's purpose and use them -- pull them into other parts of the state budget if at all possible and I have to credit Suellen for being able to successfully negotiate all of those situations and to keep the Council going. There were -- most of the stories I know about aren't repeatable in public. [Laughter]

**JT:** Well in looking down the road, what do you see in terms of future services, supports, trends for providing meaningful lives for people with disabilities? What's that going to look like in the future?

**PS:** Right now, I quite frankly have not addressed my brain to this since 2009. [Laughter]

**JT:** Okay.

**PS:** But as I -- as I do think about it and as I -- since I got invited to be involved in this, I have thought about it quite a bit. It's a little scary that the upside, the good side is that I'm seeing more and more people getting involved with their neighbors. And that is as other things go along is going to become more and more important, I think. The personal -- the personal involvement by people with other individuals with disabilities. Right now, in terms of state and federally supported efforts to enable or to support people with disabilities, to be part of us, looks a little -- looks pretty scary to me right now. The whole business of money is not looking good.

[00:56:50]

There was something that just escaped me that I wanted to mention and I can't think of what it is. Maybe it will come back.

**JT:** Okay. Well if you had the power to provide training and/or education to people that were new to this field and they were going to enter in a variety of capacities, what would be some things that they should know to do a good job supporting people?

**PS:** Well the absolutely most important thing to know is that every person that you meet is your brother or sister and if you don't care to be a servant to your brother and sister, get out. [Laughter] That's -- don't do this if you're not ready to be a servant and that's at any level because you'll -- you can only do harm to yourself and others if you can't be a servant. That would be the most important thing to learn. Beyond that, as much as I hate to think about it Wolfensberger was a prophet. [Laughter] The man -- the man's pretty strange but the things that he emphasized and the things that he prophesied have definitely come about are continuing to come about and so I would read Wolfensberger.

[00:58:25]

I think it would be really cool if every person who was going to have direct contact in terms of serving people with disabilities would participate in Partners in Policymaking because they're with direct contact with the people with disabilities and with all the aspects of the system. I think that would be one of the best training experiences they could get. I was thinking -- it came back to me when I was talking about



the future. One of the things that's grown out of all of this effort, I have a friend who is -- a lead administrator with the Veterans Administration here in town and she told me last night they had a program for a while, of foster or transitional homes for veterans with mental illness and basically they were single women of middle age and above who took in two or three veterans with mental illness and it was highly successful in terms of transitioning into the community.

[00:59:41]

Well most of those women died and there wasn't the support, you know, it kind of just died off. So they got in a proposal yesterday from some people for veterans' foster care. Again, families taking -- families who would be willing to take in up to three veterans, they call it medical foster care so -- and that's exciting that that's happening and I think if that kind of thing can catch on in some other areas particularly people's concern about the closing of and lack of support for people with mental illness that could have a great positive impact.

**JT:** We heard of that program. It's pretty interesting.

**PS:** Yeah.

**JT:** Well, are there things that you wanted to talk about because you've pretty much gone through my list.

**PS:** Let me look and see if I had anything else on my list.

**JT:** Anything --

**PS:** That pretty well covers the territory.

[01:00:52]

**JT:** Okay. [inaudible]

**PS:** Well the Mr. Muscles story was one of the major highlights of my career. The Community Transportation Initiative was another one. That went very well. Most of the others -- most of them are just personal stories and my own -- no, I don't think I have any further things in that area to share.

**JT:** Okay.

**PS:** In general.

**JT:** You did a great job.

**PS:** Thank you.

**JT:** And I knew you would. [Laughter]

[01:01:34]

**PS:** Well what I didn't include in this is that I had my own disability to deal with in all of it. I was on -- one of the dynamics that affected my work and in some ways kept me at it, was my own struggle. I dealt with

depression and anxiety throughout my career. And fortunately medication enabled me to survive in the career, but it was always a struggle and that's -- that was part of the issue. I've always felt that if it hadn't been for that, I could have been a lot more effective and accomplished a great deal more. But that's water over the dam and under the bridge.

[01:02:29]

**JT:** Well you were very effective at the Planning Council.

**PS:** [laughter]

**JT:** I remember you from the early days and I've told Peg this, I said you know, in the early days you could call people, I could call Paul and say --

**PS:** Um-hmm.

**JT:** -- are there any grants coming out --

**PS:** Yeah.

**JT:** -- this and this and this or you would say hey, you know, I remember talking to you about this. We're going to be putting out an RFP --

**PS:** Um-hmm.

**JT:** -- get your ducks in a row or --

[01:02:48]

**PS:** Um-hmm.

**JT:** -- and I could say I don't understand this part. And you would say well, here's what you need to look up or come to a meeting or this or that. It was so much easier. [Laughter]

**PS:** Yeah.

**JT:** I mean it truly was --

**PS:** I'll be darned.

**JT:** -- in terms of just being able to get information and have someone you could call and they could give you an answer.

[01:03:11]

**PS:** Well I'm glad to hear stuff like that because often, I had no idea there were so many -- the last at least the last ten years when things changed, the early part when I was traveling a lot and taking out new ideas and introducing new stuff and start-ups and training projects, it was fun. That was really enjoyable but as it moved more into bean counting and making sure they don't steal anything and yada-yada-yada it just -- and then as the state -- different elements in the state -- we became a thorn in the side of the

state because you could not question that what we were doing was right, but it cost money and when right comes up against cost money, it's always a conflict and there's always an effort to do away with whoever's advocating what's right.

[01:04:10]

[Laughter] And the pressure on us was just be getting worse and worse and worse to where we had to -- you know, when I started there was so such thing as a time sheet. Everybody knew you were doing everything you possibly could and it was more than anybody could do and then we -- we had people assigned to sabotage us. And then we had time sheets and we had more time sheets and then you had to fill out every 15 minutes what you were doing, what goal and objective it related to, and on and on and on and it got to where I didn't even want to come to work anymore. It was just -- you know, I had enough trouble with depression and anxiety [Laughter] it just made it worse. So yeah, but it is good to hear that some of those things really helped people out because --

**JT:** It was great. That was in the '80s and early '90s and I can remember calling you. I didn't know Suellen and Christine near as well as I knew you --

**PS:** Um-hmm.

**JT:** -- but I could call you and ask you a question or like I said I could call you and say hey, when's this RFP coming or do you have anything --

**PS:** The funny thing is, the funny thing is many times when you or somebody would call me and I'd say I'll get back to you I'd go talk to Christine and then I'd call you back. [Laughter]

**JT:** [Inaudible] Now you have an idea.

[01:05:31]

**PS:** Christine was our walking encyclopedia. That woman just never ceased to amaze me in what she managed to in mass in her head and have it immediately available.

[END OF INTERVIEW]