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**ORAL HISTORY VIDEO INTERVIEW WITH
RANDY KRIEBLE
OCTOBER 18, 2012
INTERVIEWER: JENNIE TODD
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 001-DO**

RK: RANDY KRIEBLE

JT: JENNIE TODD

PH: PEGGY HOLTZ

[TITLE CREDITS WITH MUSIC]

[00:00:10]

RK: Okay. My name is Randy Kriebel, and I worked in the field for 41 years, all that with the State of Indiana in state government in a variety of positions -- hands-on to administrative positions. And my last position was in what was called Family and Social Service Administration, Division of Disability -- what used to be Aging and Rehabilitative Services -- rehabilitative services. And I was one of the assistant directors.

[00:00:49]

JT: Okay, what... [Inaudible] just a little... Now, you said 41 years. Okay, so do you want to tell me when and how you got started in this line of work?

RK: Sure. Well, I went to Indiana State University, and I lived -- grew up in Terre Haute, went to Indiana State University. And this was in -- I graduated in 1970 -- January of 1970. And I think I came to be in this field more by being chosen than by choice, but I -- because, at that time, you know, there really wasn't a whole lot to choose in terms of working with people with disabilities. I mean, there really weren't a lot of programs back then. It was mostly institutional programs. And that's pretty much what was -- what was taught in school. But I was really -- really appreciated the opportunity to have two professors in particular that kind of -- kind of guided some of us in this direction.

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[00:02:08]

...Tom Songster, who later became the international director for the Kennedy Foundation Special Olympics, and Gerald O'Morrow, who wrote several books about programming for people with disabilities and what was called activity therapy at that time. And so, they had us involved with a lot of hands-on things at school. And so, you know, through that, we kind of developed an interest and a little bit of background, understanding, field trips. We worked at the first Special Olympic games that were held at Terre Haute -- the first Special Olympic games were held in Indianapolis, but I think after a year, they went to Terre Haute and been there ever since. So you got -- you know, some awareness that way. So, it was -- today, they say people graduating are going to have five or six different professions -- not jobs, but professions.

So, it's kind of unusual, I think, today that people [chuckles], you know, would want to stay in any job for any period of time. And it occurs to me that a lot of people who get into this business, is because that's where -- that's where the job is. You know, maybe there's a institution in their town, or there's an agency in their town. And so, they do what mom and dad did, or their uncles did or whatever. But we were, I would guess, the fair way to say, we're guided by, you know, some leaders -- early leaders in the field. And, you know, you just took the opportunities that were available to, you know, to work in the field.

[00:04:07]

JT: Okay, so this -- one of the things that I wanted to ask you, because you mentioned loyalty and loyalty to a job. And that's one thing that I've noticed many people that I know in the field have always been in the field, or have been in the field 20, 30, 40 years. Nowadays, younger people that I meet in the field, it's kind of a stepping stone or a -- just a job. Do you see that, and -- I mean, we don't have to answer this -- if you see that, would you speak to that as to why you think people were more invested when you started in the field than they are now?

RK: Well, I think there are some really dedicated young professionals coming up. And those that I've had an opportunity to kind of do a little arm-twisting with, I've really encouraged them to stay, you know, in the field. But I think it's not so much what we are doing or doing wrong. It's more how, I think, society thinks today about immediate gratification, and people see a job that they'd like to have, and so they move more frequently just because that's part of our nature today. But I -- but I think that there's a group of people, like us, that are about the same age that kind of grew up with the system. And I think they feel some loyalty, some responsibility to continue to make things -- continue to improve things.

And people coming into the business today, I mean, just quite honestly, aren't -- I can't imagine them -- I'm going to say it this way. I can't imagine them seeing the advancement and the progress that we saw. So, maybe it's not as gratifying to a young person. But certainly, any young person starting today, if they stayed in the field, they would have the numerous benefits and gratification of working with people and -- you know, the wonderful people that we've worked on behalf of. You know, they would experience, you know, that same thing. But I can't -- to say it differently, I can't imagine that there would be as many different approaches to serving individuals in the future as we've seen in the last 40 or so years.

JT: I was going to say, your collar has somehow -- I [inaudible] it out, and now it snuck back in there.

RK: Okay.

[00:07:21]

JT: And I was wondering if I should let myself [inaudible] show that it was different.

PH: But... Well, the pieces are going to be [inaudible].

JT: Okay.

PH: Do we want to talk about training now, as long as he's...

JT: Okay, instead of...

PH: You know, since he's kind of on that. I don't know. I mean, that's -- just keep [inaudible].

[00:07:39]

JT: Yeah. Let's keep on this [inaudible]. Okay, so here's the question. What was the field of disabilities or human services like when you started, how has it changed, and in terms of how it's changed, what were some of the most noteworthy and biggest changes in Indiana?

RK: Yeah, I've truly been fortunate and blessed to be part of the changes. And it...

JT: We need to start over. I forgot to tell you, Peggy is not going to hear anything I'm saying. So, when I ask you a question...

RK: Okay.

JT: ...they're not going to know what the question is.

RK: Okay. So, I kind of need to repeat it, then.

JT: So, you need to -- yes, repeat back my question, basically saying, "You know, when I started, services were like this."

RK: Yeah, okay.

JT: "Some of the biggest changes in Indiana have been this."

RK: Okay.

JT: Because they won't hear the question.

RK: Okay.

JT: I'm sorry. I should have told you that at the beginning.

[00:08:33]

RK: No, that's all right. I thought about trying to do that. Okay. The dramatic changes that have been made over the years that I have experienced and seen personally are numerous. And they would probably be categorized in a variety of different ways -- administration, how services are funded, the philosophy, nomenclature, the actual services themselves. But in terms of, in 1970, when I started in the business, everybody was served in large, congregate facilities. I mean, there was a few pilot projects here and there, but virtually everybody was served in large, congregate facilities. When I went to work, my first job was actually in corrections, because I wanted to finish my master's, and so I stayed close to Indiana State and worked at the Rockville Training Center, which interestingly enough, had individuals who were probably on the borderline scale or socially or culturally deprived, and probably many had some obsessive-compulsive behaviors or learning disabilities of some kind.

[00:10:07]

And so, it was interesting, in 1970, there was a lot fewer people in institutions, or in prisons, than today. And a lot of the people who've gone to prison have been people with developmental disabilities. And so, -- that was a good -- that was a good experience. Then I went to Beatty Memorial Hospital, and when I looked for a job, I did look for kind of a community job, but there really -- you know, they were few and far between, and so I ended up at Beatty Memorial Hospital, which is in Westville, Indiana, and that, interestingly, became a prison. It's now the supermax facility for corrections. But there were over 1,200 patients there. That's what they were called there. And they were a variety of disabilities, from being physically involved, mentally retarded, at that time, to being just, you know, very schizophrenic, just unable to function -- catatonic.

And people who were criminally insane -- that's what they were referred to at that time. So, the system was set up at that time based on funding institutions. I mean, institutions like Beatty Hospital or Muscatatuck or Fort Wayne had their own budget through the state budget. They had a separate line item, and the money went directly to them, and then, you know, they paid their employees. And then, later, it became more of a centralized administration and funding program. And I think another, maybe, interesting thing is, not only the size, but what those facilities were called. I mean, people with intellectual and developmental disabilities lived in settings that were called "hospitals," or even before that, you know, "colonies for feeble-minded youth" or whatever.

But when I started, they were called state hospitals, whether it was for people with mental illness or people who were intellectually and developmentally disabled or physically disabled or just somebody who didn't fit in society that often got placed there. And there were a lot of people in the facilities at that time that really, really didn't need to be there, I mean, for their own safety or the safety of others. And how that has changed, obviously, today, the administration is through family and social service administration. It's all in one kind of umbrella of social service agency, and the distribution of funds flows through, you know, various accounts within the different departments of that social service agency.

[00:13:37]

Early on, some of the, what was called, family care programs -- that was some of the first residential programs in the community -- they were operated completely through the state hospitals. And there were social workers that made visits and established and hired and trained caregivers, householders, kind of like adult foster care model. But that was -- that was the first movement to the community. And then, Title XX actually, which was -- block funding -- paid for some of the early group homes that were just kind of piloted around the state. And I'm not sure how the first, kind of, residential program here in Bloomington was funded, but I think it was either a grant or it might have been a Title XX-funded -- at least partially. And a lot of that was totally state line item funded -- later on, the next payment, kind of, mechanism was state line item funded for all DD services.

[00:14:52]

And then, in -- well, in the late '70s, it was in '78, the DD facilities -- Muscatatuck, Fort Wayne, Newcastle and [inaudible] -- began their Medicaid certification program to follow the Medicaid standards that were established in the '70s and revised in 1988. And they're pretty much the same standards today. But that was a big, big, big effort in terms of trying to get that federal funding, is really -- was the state's motivation to cut the cost. Because the cost of running facilities was going up, and also, it was a very positive thing for the -- you know, the residents, too. But administratively, you know, from being local, kind of, autonomy to more of a centralized control, if you will -- oversight administration was kind of a big change.

And size-wise, again, I can remember visiting facilities that were 1,200 or more. The largest population in Indiana was in -- I believe in 1969 of all the -- of all the facilities. And since then, obviously, it's gone down, and Indiana is the second-largest state not to have any state developmental centers at all. And I understand that the last few people who are DD at the MI hospitals are going to be transitioned to the community. It's going to be in a large ICF/MR, but it's -- that's the -- so, there will not be anybody who is primarily diagnosed as developmentally disabled or intellectual and developmental -- developmentally disabled in any of the state hospitals, which once had ICF/MR units, like Evansville and Madison -- Logansport and Central, when it was open.

[00:17:12]

But so, you know, big to smaller, and today, you know, people are living by themselves, or with one or two other people in supported living, or in group homes of four to eight. So, you know, a dramatic difference in size. In terms of, like, nomenclature and philosophy, I mean -- and it was about custody. It was about control. It was about keeping people there, because a lot of people did run away from the facilities. And you know, today, it's more about choice, more about person-centered planning. It's more about offering people opportunities in the community, protect their rights and health and safety and dignity. So, I mean, there's been a tremendous shift in philosophy and a lot of reasons for how that's happened over the whole nation.

[00:18:26]

But in Indiana, there -- you know, I think we had some really good administrators in FSSA and in -- when the facilities used to be supervised by the Department of Mental Health, until 1990, when FSSA was started, we had some great administrators that really pushed for more community-based services with the right philosophy. But, you know, service-wise -- well, another thing about nomenclature that I think is kind of interesting is, people used to, when somebody would leave a facility, they would talk about being released [chuckles], as opposed to transitioned. You know, people were called -- referred to based on what they could do or couldn't do, such as a "wheelchair person," or a "feeder," because they had to be fed as opposed to being able to feed themselves.

I mean, we really, really tried to get away from that. But it's been interesting to see how people are thought of and referred to today versus, you know, the way it was then.

JT: Oh, yeah. I really liked where you talked about the language about what agencies were called -- the control versus, now, the freedom. That was -- it was really good [inaudible].

PH: So, do we want to, maybe along with that, get a little bit of what people did during the day, what type of programming there was?

JT: Yeah, that was what I was wondering [inaudible] go into that. So, okay, so talk about what a day looked like.

RK: Okay.

[00:20:16]

JT: A day in the life along -- you know, when you were early in the field to now and how the role of advocacy has played.

RK: Okay.

JT: Okay, so, a day in the life.

RK: Okay.

JT: What services looked like, what their life was like.

RK: Okay.

[00:20:32]

JT: Versus now.

[00:20:34]

RK: A day in the life of a person in 1970, when I first started, versus today is dramatically different. The array of services, the quality of services, the individualization of services, is entirely different. But a typical day at a - - when people lived in institutions, they would all get up at the same time, a ward of, you know, maybe 30 or 35 people. And they would have slept in dormitories with maybe 30 beds in a big room. That was very common. They had gang showers, so if you were to go in to, you know, bathe in the morning or whatever, there'd be gang showers. The toilets were commodes that didn't have toilet seats.

They have formed porcelain rings that were seats. And so, it was very de-personalizing, I think may be a way of describing it. And so, most of the kitchens were -- for breakfast, they had to walk to the kitchen. They'd walk over in groups, and they'd get their metal trays and sit at picnic table kind of arrangements. But they were all fixed to the floor so they couldn't be turned over or whatever. And there were a lot of really good staff at the facility, very caring, dedicated staff. And so, you know, they may have some therapy sessions, or they may have maybe, you know, bowling or an exercise class or a weightlifting class, or there were libraries at the facilities.

And the vast, vast, vast majority of people stayed right there on grounds. And then, you know, lunch would be the same. They'd get their medication by -- you know, everybody'd get their medication at the same time. They'd line up to get their medication. They'd have their name called out. I mean, it was really kind of very [chuckles], you know, very demoralizing, I would think, to an individual. I mean, a lot of -- a lot of -- I remember at Beatty, the attendants will wore white uniforms, so it was very, kind of, stigmatizing type of environment. And, I mean, they had a lot of activities, but again, they were kind of self-contained. There was a movement to try to do more community-based things, everything from Special Olympics to going bowling in the community, go to some movies in the community, go to the YMCA in the community, to help them think about what their life might be when they would hopefully leave.

And then, probably the -- another kind of vision, if you will, another picture of the facility, Beatty was the facility that I first -- first mental health facility I worked at, and it had five miles of tunnels. And a lot of times, people were restricted to -- you know, either health-wise or what, but these tunnels were kind of dark and dingy, concrete walls, pipes with asbestos covering them, and people would carry open trays -- other patients would carry open trays, like if they went to breakfast, they'd bring a tray back for Johnny, who was back on the unit. It wouldn't be covered. It was a metal tray, glasses of milk or juice, and they'd be carrying it through this kind of tunnel.

And my point in saying that is, the -- a lot of the health regulations were different then, you know, today. And that would probably be a good example of, you know, -- what was considered acceptable at that time. There were -- oh.

[00:25:29]

JT: What about the sort of activities they did during the day and their rights, and -- basically, they probably didn't have any, but if you...

[00:25:38]

RK: Their activities during the day, and their rights, were -- they virtually -- I mean, I don't want to say no rights, but if they had been civilly committed, they couldn't leave. And the vast majority of the people were civilly committed, not voluntarily committed. And that meant that the court actually -- they had to go to -- a judge somewhere committed them to a facility. And at that time, they would commit them to different facilities specifically. And so, they had to be reviewed periodically to determine if that was, you know, in their best interest. But so, they didn't get to vote, and, I mean, they did have some phone access, and that got to be more and more accessible, and voting became more and more accessible.

But one of the things that they did a lot during the day, the people who were, quote, more capable worked at the facilities. I mean, even taking care -- excuse me for using that term -- but taking care of the other patients many times. And so, they -- and the people who worked really enjoyed that, even though they didn't get paid, because it was -- you know, if you think about the true meaning of work and what you get out of work, I mean, they got -- they got a good feeling for working and accomplishing things. And there was some status to some jobs that people would have. And then, the Anti-Peonage Law came along, which was a very good thing. And that occurred in the -- in the, I believe, the early '80s, if I'm not mistaken -- the late '70s. And that required the state to pay wages to people who worked at facilities.

So, if a patient at a facility had a job, they had to get some payment for working. And that limited some of the jobs that people were able to do. And interestingly enough, a lot of the patients felt like they had done something wrong. And so, you took my job away. You know, what'd I do wrong? Because they may have had that job for 10 or 20 years, you know, carrying mail or working in the kitchen, something that was kind of prestigious within that social environment. And again, I'm not saying we shouldn't have paid them, but it was interesting that how people reacted. So, the day was pretty -- could be active, but a lot of people honestly stayed on the unit, or spent a lot of time on the unit.

And I can still smell [chuckles] the units where they allowed smoking, and patients were given what was called Hoosier tobacco. That was grown by the prisons, and they came in these little white pouches with papers, and they'd roll their own cigarettes. And many of the people had nicotine-stained hands that you just can't imagine. But there was a Lake County -- they had two Lake County units, because Lake County was a large populated area, and the -- it was set up on a geographic system. So, everybody from Lake County were on these two buildings. But the smoke was so thick, I mean it was thicker than [chuckles] anyplace you've ever been at. And they had these automatic lighters on the wall that people could go over and punch, and it would kind of light up and -- not a flame, but it would -- kind of like an old cigarette lighter in a car kind of thing. But, so, that was kind of the life of a person, you know, during the day and some of the activities that they were involved in.

[00:30:07]

JT: Okay. We have a couple questions from what you were saying. One, I'm curious if people had personal possessions.

RK: Well, thank you.

[00:33:14]

JT: And then, the other one was, you said that many people were placed there by the court system. But also, didn't families bring people there because they were recommended by their doctor that that was the best place for them back in the [inaudible]...

RK: Right.

JT: ...if you could talk about those two things.

[00:30:31]

RK: Well, if I -- can I just offer -- I think I kind of got stuck on Beatty, because that's -- I'm thinking that's where, you know, my first vision. But, so, I'm hearing you say, maybe I ought to talk more about the DD facilities. No?

JT: Yeah. I mean, in general.

PH: Yeah, [inaudible].

RK: Okay, okay.

JT: Everything has been good.

RK: Yeah, okay.

JT: So, just in general, because we're talking about Indiana.

RK: Okay.

[00:31:01]

JT: But I know a lot of people didn't have many things in institutions.

[00:31:04]

RK: Right. In terms of personal possessions and personal choice, as I mentioned, there were big day rooms and big dormitories is typically where people lived. And so, you know, they may have a little nightstand or something, but they really didn't have a lot of personal possessions. Even wore some institutional clothing -- not that that was required, but they'd have elastic pants and, you know, pullover shirts, the kind that would resemble, maybe, the scrubs that you see doctors and nurses wear. And so, the institutions provided clothing for individuals, but they didn't provide personal possessions like watches or rings or books or things of their preference -- hobby kind of things, things that they would collect, and, you know, kind of set around.

[00:32:15]

...And that's one of the things that we'd really try to promote when we transitioned folks from the state developmental centers, was give them an opportunity to have personal possessions. And many of the people who moved from Fort Wayne and Muscatatuck had very, very nice bedrooms, sometimes private -- most of the time, private bedrooms. And their personal possessions were there, and they were safe. At the facilities, it wouldn't -- it wasn't uncommon for people to carry a lot of their stuff with them, because it would get stolen or used by, you know, somebody -- example, if they bought some cookies at the commissary, you know, they couldn't leave them laying around. They'd -- somebody would, you know, take off with them. And we did have some lockers that people could put some -- you know, some things in. But a lot of the -- a lot of the units were locked, and people had to be buzzed in or out of the unit.

[00:33:23]

And so, they didn't have free access to move to or from the units. Not all the units were locked. But in 1977, when I started at Muscatatuck State Developmental Center, I worked on the behavior mod unit, and that's what it was called. And it had two floors of about 30 people on each floor, big day rooms, locked units, locked time-out rooms. Time-out rooms that were not only locked but just checked every 15 minutes or so. There may be a mat in the time-out room, and that, you know, really was it. The day rooms were plastic Dixon chairs -- they were, like, a plastic molded chair that was very durable -- not very attractive, but very durable.

And maybe a picnic table, you know, so it couldn't get dumped over or used as a weapon. And so, pretty -- you know, pretty stark environment. Again, the toilets didn't have toilet seats. They had, you know, kind of a thick rim around them. The bathrooms and the showers were locked, and so people were kind of escorted in and out, so there wasn't freedom to do those things. But, so, it was -- the environments and the choice of options for folks back at that time, you know, really wasn't great. The Muscatatuck, in the late '70s, before they became ICF/MR certified, did a lot of renovation.

None of the -- none of the units were air-conditioned, as an example. And I can remember some really, really hot days doing rounds -- I mean, just fans blowing hot air across rooms of people in cribs or beds that were really severely involved. But, you know, again, the environments have changed, and people's rights and choice and personal possessions, but even in the late '70s at Muscatatuck, people didn't, you know, have a lot things -- a lot of institutional clothing. They could buy some things. Parents could give them things. They could wear, you know, any type of clothing, but there wasn't a lot of preference. We tried to have a clothing room where people could go and pick out clothes, but it was a pretty small [chuckles] selection of clothes. People who needed special adaptive equipment -- you know, if Mom or Dad wanted that, or if a person needed, we would have to take them to Vincennes to get special-made shoes, corrective shoes.

[00:36:47]

Adaptive equipment, in those days, was pretty non-existent -- I mean, pretty crude kind of -- kind of things, whereas today, you've got, you know, fancy power chairs. And we had a great OT at Muscatatuck that made -- you know, actually invented some things there that offered, you know, a better quality of life for people who laid down their whole life were able to sit up. One gentleman, they developed a standing, kind of, board for him, where he was -- had a board that he'd lean on, and his arms were, you know, supported. But before, he pretty much laid down. So, this enabled him to be able to stand up and see the world from - - you know, from -- now, is that a rights issue? No, but it certainly is a quality of life issue.

[00:37:48]

JT: I was going to ask you to talk about -- and I think this is -- this is really good, because I think we know a lot about what today is, so I think this is great you're telling us what it was like in the '70s. So, how did people come to be at Muscatatuck?

RK: Okay.

JT: And then, if you could -- and you've done some of this throughout this talk, but maybe if we could kind of [inaudible]...

RK: Okay, sure.

[00:38:10]

JT: If it was in the 1970s, late 1970s, and you walked into Muscatatuck, what it would look like and smell. Because, I remember being there in the '80s, and even in the '90s, and seeing people sit in the hallways with sheets over their heads and things of that nature. And that might have been even in 2000. But just some visuals and why, maybe, it was like that, if you're comfortable.

RK: Yeah.

[00:38:37]

JT: [Inaudible] about that. Because those lead -- the point of that is, is that it leads to why we're not doing things like that now. And what can happen even with good, well-meaning people.

RK: Right. Okay. A life in a day at a developmental training center, and the one that I worked at in 1977 to 1980, was Muscatatuck State Developmental Center in southern Indiana. And it was actually a farm colony of Fort Wayne State Developmental Center. And people from Fort Wayne came there, and actually helped build that facility. They quarried stone and actually helped plant the orchards and different things. And of course, early on, the facilities were self-sustaining. You know, they had -- they raised their own cows, pigs, milk, virtually everything. But when I came, there was a movement away, you know, from that. We still had, you know, some -- they had an orchard and different things. But the buildings were built in the WPA time, and so they were all big, yellow brick buildings.

[00:40:04]

...Typically, a basement, a first floor and a second floor with two sets of units, one on each -- one on each wing. A lady that had been there for over 50 years would tell us stories about, she was called a "working girl," and she actually took care of other patients -- other residents. And a building that had, again, a basement, a first floor and a second floor, essentially six units, a unit on each wing, each floor, she told us about how many people would be on one of the larger buildings like that. And it was just unbelievable that they would be that many people crammed into those buildings. And if I remember correctly, I think she said there were, like, 200 people in one of those buildings, if I'm not mistaken.

And so, you know, there wasn't a whole lot of space for, you know, any kind of activity or whatever. But in 1970, those basements were used for the dining rooms and the kind of finishing kitchen. At that time, food was prepared, like the meat and things, and then -- and then trucked to the units, and then they had these finishing kitchens where they kind of prepare the food. And so, the environment was better than, you know, 100 or 200 people in a building, but the -- again, there were no elevators. There were no -- there wasn't any air-conditioning. And staff were allowed to smoke. Residents were allowed to smoke. The personal possessions were very limited.

A lot of things kind of got bartered or [chuckles] stolen. And we had some people at that time that were really, really high-functioning and, you know, probably shouldn't -- wouldn't have ever gone there if it hadn't been that they had gotten maybe in a little bit of trouble with the law or maybe had some, you know, behavior issues, and so, you know, people of that persuasion ended up at the facility. But the -- you know, there was an effort by the staff, and really good, conscientious, talented staff, and they made the most of what they had. But there was -- it was pretty, you know, limited in terms of options for people. I mean, I can remember people talking to me about -- "well, Randy, can I go somewhere? Can I move somewhere?"

Well, the options were staying there, going home, and Mom and Dad were the ones that typically put people there, because doctors advised people -- we had a nursery building, as an example, and it was -- it had a unique design in that it had two floors, and they had these rooms that had glass -- big, glass windows all down this building that was probably, you know, I don't know, a couple hundred feet long. And all these rooms, on both sides of the hall, I can remember there'd be crib after crib after crib after crib in every one of those rooms. And that was because there really wasn't any early intervention programs, and doctors at that time did advise their -- you know, the parents, the new -- of the newborn, you know, they're never going to be able to be functional, live a normal life, so, you know, you know, place them there.

And unfortunately, a lot of times, parents didn't visit very much and didn't, you know, help support their child with personal items or clothing. You know, some were fantastic -- visited every week -- I mean, for 30 years. But a lot -- a lot of the -- that's how a lot of the people, you know, lived their life there. I mean, they were placed there as infants, and stayed there, you know, their entire life, or as teenagers, because they got -- they were incorrigible and they were placed there. And so, if a -- if a child was, you know, under the age of 18, you know, parents could place them there and not be civilly committed. But when they became an adult, then typically, all of the people at Muscatatuck and Fort Wayne and Newcastle were civilly committed -- a regular -- what we call a regular commitment.

[00:45:31]

And that was through the -- you know, through the courts, which had to be reviewed periodically. So, you know, you know, parents were in a tough spot. And, you know, do I keep them at home or at Muscatatuck was basically the -- you know, the only options. Nursing homes started taking a lot of referrals from the facilities, which was thought to be a good idea. But really, a lot of people who went to nursing homes shouldn't have gone to nursing homes. They were higher-functioning, they really didn't have severe medical needs like is required today through the OBRA process.

JT: And so, that's one change from then and now is that people -- what...

PH: No, I'm just clearing my throat.

[00:46:17]

JT: Oh [chuckles], okay, is that people that were committed then as babies, or like you were saying, trouble with the law. So, there were reasons that people were put in institutions that wouldn't happen nowadays, correct?

RK: Right. I mean, the difference between -- in the early or late '70s to today, in terms of choice, is that there really weren't any choices in those days. Parents either dealt with their -- and I don't mean that in a negative way, but they were the sole provider back then. I mean, remember, in the community at that time, there weren't early intervention programs. There weren't a lot of day programs. A lot of schools didn't serve people with disabilities at that time. And so, you know, it was pretty much keep them home virtually all day or place them in an institution or a nursing home, if -- which there, you know, were a couple of children's nursing homes that still serve people with -- who are severely and profoundly involved and physically involved.

[00:47:42]

So, today, a parent, you know, has the option of utilizing an early-intervention program, which has been fantastic. And then, later on, you know, go to school in their own community. Plus, the support service waiver is available for a lot of individuals to get -- to help support the family with, you know, respite. And virtually all of the services are on the waiver except for the -- you know, the supervision that one would get if they were living in a supported living setting.

JT: That was good. Now, we're going to ask you some more specific questions about Muscatatuck later, but I want to go back -- unless there's something you want to...

PH: No.

[00:48:29]

JT: Okay. So, you talked about -- a little while back about administration. And you were saying that Indiana was very fortunate in that they had a lot of good administrators prior to coming to FSSA, and you know, you just -- it sounded like things were going really well, and they provided a lot of leadership. So, this question is basically, in general, how did things differ from one administration to the other? And it sounds like they were all pretty good. But were there any changes that you noticed that were brought on by maybe politics, advocacy movement, media scandal, families or the economy? Was there anything that motivated a change other than, it was the right thing to do?

[00:49:21]

RK: From when I started in the field in 1970, to today, there's been numerous enhancements, and I really want to credit a lot of the great leaders that we've had in the field -- leaders in the legislature, people who were commissioners, people who were -- you know, even superintendents that did some innovative things in the early days. The advocacy organizations, COVOH, INARF, the ARC -- people were fortunate in Indiana to have had knowledgeable, willing partners. There hasn't been a lot of, you know, real litigious fighting, legal issues. We seem to be able to work through most of those issues without getting to -- you know, to that degree.

And we -- Indiana and the citizens of Indiana have really been fortunate to have people that were willing to work together and try to solve problems and make things better for -- you know, for individuals. Was it always perfect? Did we always agree? No [chuckles]. But you know, we had some -- you know, some great, great leaders. There were some champions in the legislature that promoted some programs -- you know, it's hard to name names, but, you know, Denny Jones did, you know, some really good things when he was the DMH commissioner. You know, Jerry Thaden did some, you know, innovative things. Even though it was at a facility, he brought in the community to his facility. He had early intervention programs, Head Start programs, a lot of people there on grounds.

[00:51:25]

And Marci Bryan, who really developed the first residential -- community-based residential programs in Indiana, and actually took the administration of the family care program to the community, and agencies like Stone Belt here in Bloomington, and other agencies became the providers and administrators of those programs. I would have to put Kathy Davis at -- very high, if not at the top on the list. She was the FSSA secretary, and during her time, she not only advocated for the -- what we call the 317 plan to very definitely define what our principles, values, would be in serving individuals, but she actually chaired the monthly meeting with a group of volunteers every month to bring that position paper together.

I mean, that was a tremendous change in how it solidified everybody was to work together to follow that 317 plan. And that coincided with the downsizing and closure of Newcastle State Hospital. So, virtually everybody who left Newcastle State Developmental Center followed those new principles and values. And, you know, there's a lot of other community administrators -- John Dickerson has been at the ARC for a long time; Costa Miller, who was in INARF for a long time; Jim Hammond, who's there now. They've all -- you know, the things that individuals have today and professionals have today, tools to work with, was really built on these -- the shoulders of these people that -- you know, that I -- that I mentioned.

[00:53:47]

...And there's a lot of other people that have done some heroic things through -- you know, through the years just to stay with the movement [chuckles] and keep things moving. And you know, it may not have been fast always. We had a lot of ups and downs. We had a lot of cuts in funding. But I think the -- you know, we have been blessed in Indiana to be supported, for our program to be supported. Was it always enough? No. But thanks to the good partnership, I think, you know, we've really been blessed. You know, if I -- if I said there -- I was never disappointed, I'd be [chuckles] not telling you the truth. And there were some cuts that I think were wrong-headed, short-sighted. You know, bigger -- typically, what happened, bigger issues got in the way of what our small program was in comparison to the big issues across the state.

You know, people who could vote, people who had an influence, typically got -- I mean, there was a lot of competition for funding through the years. And our voice wasn't always heard. And a lot of the changes that actually occurred were not because it was a well-planned -- this was the right thing to do. Anybody would tell you that. The 317 plan that I mentioned was one of those plans. But really, what precipitated the closure of Newcastle was an expose -- a lady had a hidden camera who was an attendant there. That's what they were called at that time. And it made the press. And that caused, you know, some changes. The reason that Central State was closed -- Central State was the seventh-oldest state hospital in the United States at the time of its closure.

[00:56:08]

And the reason that it -- the decision to close it was not because people needed to live in the community and because the mental health centers, you know, wanted to bring those people into the community. It was because of a horrible incident that occurred there. And so, it was a reaction, you know, to that. You know, I think Muscatatuck and Fort Wayne, the decision to close them was based, honestly, more on the Department of Justice looking over our shoulder. And as you may remember, at Muscatatuck State Developmental Center, there was a lawsuit that delayed the closure of Muscatatuck. There were parents, and they were actually -- that sued the state not to close the facility. So, you know, everybody wasn't in favor of the downsizings.

[00:57:12]

And oftentimes, they were -- they were done without a lot of total agreement. But there were some real champions in the legislature that promoted some positive mental health issues. The starting of the residential program that I mentioned was one of those that -- that was a big change, to have group homes, to have the adult foster care and what we called semi-independent living, which was kind of a precursor to what we call waiver-funded services today. But I would have to say that the 317 plan was the most monumental effort that I saw under Kathy Davis to make both philosophical changes and programmatic changes in the system that supports people intellectual and developmental disabilities.

[00:58:20]

JT: Okay, well, I think you kind of answered part of this next question. But here's a couple things, and maybe you've addressed these. First of all, I want to know where Indiana is in relationship to other states in closing down the institutions. Are we ahead or behind the times? And you kind of talked about that Indiana did craft a plan for the closures through people getting together, but if there's anything that wasn't said, because that was a question -- how did Indiana craft the plan for closure? Were people with disabilities and families involved? Was there an internal working group? That sort of thing. And then, what research was conducted to ensure that the new housing arrangements would meet the needs and be a good match? So, some of that was indirectly touched on.

RK: Okay.

JT: That's a lot of information.

RK: Okay.

PH: Do you want to take a break?

RK: No, I'm fine. I'm fine.

JT: Because I was thinking, after this, you definitely should take a break.

RK: Okay.

JT: Because we've got a few more...

RK: Okay.

JT: ...long questions.

RK: Indiana, in relationship to other states, in terms of how many people live in large, congregate facilities, I think is really up at the top. We're the second-largest state, population-wise, without any developmental -- state developmental centers specifically to serve people with intellectual and developmental disabilities. There have been some people with intellectual and developmental disabilities at our state hospitals, because they had ICF/MR units. But since Muscatatuck and Fort Wayne were closed, people have transitioned from those facilities into the community, and real soon, there won't be anybody with a primary diagnosis of developmental disability at a state hospital. They will be in the community. I think it may be helpful to say that a special large ICF/MR is being developed to serve some of the most challenging people who may be dual-diagnosed or have some pretty severe behavior problems and may not totally assimilate into the -- into the community.

Help me with the next question.

[01:00:45]

JT: Okay, so, is Indiana ahead of the times or behind in terms of closing them? And I got the numbers, but are -- there are lots of other states with institutions still open.

[01:00:56]

RK: Okay, I got you. Indiana met the target of closing all the state developmental centers in 2005, when Fort Wayne closed. And at that time, there were, I believe, either seven or eight other states that didn't have any state developmental centers at that time. So, we were, like, the ninth or the 10th state not to have any state developmental centers.

JT: Good. Okay, do you want to take a little break?

RK: No, I'm okay. I'm okay.

JT: Okay, so now we're going to talk -- I actually couldn't think of anything else -- do we need any more of that? It seems like we got most of it, except...

PH: [Inaudible].

JT: Well, I was going to ask him that...

PH: [Inaudible] okay.

JT: About Muscatatuck.

PH: Okay.

[01:01:54]

JT: What I'd really like to know is, you know, I know you lived on the grounds for a while. So, can you talk about what it was like living at Muscatatuck during the process of moving people out? And I'll ask you some more questions, but overall, this is kind of what we're going to get -- you know, what it was like for you to live there, personally. And then, what it was like dealing with the staff that didn't want it to close or that were stressed out about no jobs. Families that didn't want it to close. People that were excited that it was closing. You know, just the mixed reaction -- mixed reactions that you think were going on in the community. So, that's kind of the flavor of this.

RK: Okay.

[01:02:36]

JT: Your life, and then what it was like dealing with all those fires and people's uncertainty about what was going to be next. And then, there's another little series that we'll do after you talk about that.

[01:02:50]

RK: Okay. Muscatatuck State Developmental Center was originally called the Colony for Feeble-Minded Youth at Southern Indiana -- something like that. And then it became Muscatatuck State Hospital, and then it became Muscatatuck State Hospital and Training Center, then it became Muscatatuck -- the Muscatatuck State Developmental Center. And actually, about 30 years ago, there was an attempt to close Muscatatuck. And the community -- I mean, truly, got up in arms. And there was a political movement. So, the governor at that time decided not to close Muscatatuck. But it had been kind of on the chopping block, if you will, for some time. And some would say that Muscatatuck was kind of the stepchild of the system, because it was in southern Indiana, it didn't, maybe, get all the resources that, maybe, Central State or Larue Carter did, because it was in Indianapolis, or Fort Wayne, because it was a much newer facility.

They had just built a facility. Fort Wayne originally had a campus closer to downtown Fort Wayne, and they built a new campus out away from the city. And it was -- that was concluded, I think, around 1970. So, it was -- it was a, you know, relatively new facility. But I mean, there was a lot of upkeep to, you know, running a facility. And when I started at Muscatatuck in 1977, the buildings needed, honestly, considerable renovation. And when we started the ICF/MR certification, a lot of those building renovations occurred -- air-conditioning, there was a new dining room built, elevators in the buildings, new windows, built some -- transitioned some of the units to smaller rooms.

But the -- but Muscatatuck was going to close -- well, let me say this. In 1997 is when the Newcastle expose came about. The Department of Justice heard about that and asked if they could come and look at Newcastle, Muscatatuck and Fort Wayne. And that was in October of 1998. They wrote a report and filed a lawsuit in federal court that Indiana was violating the CRIPA, which the Civil Rights of Institutionalized Persons. And in 2000, an agreement was reached, and Indiana submitted a plan to make corrections.

[01:06:34]

And it was called the SDC plan. So, at that same time, there was a state freeze in Indiana, and Muscatatuck couldn't hire any staff. And at that time, in the Jennings County area, there was a growth in some industry in that area, so people had choices of jobs. At one time, Muscatatuck was the largest employer in that area. So, many people either didn't come to work at Muscatatuck or chose to take other jobs. And so, Muscatatuck was decertified and lost their ICF/MR certification that they'd had for about 20 years. And that was considerable revenue loss. And so, a decision was made through some -- a lot of discussion to -- that Muscatatuck would be closed.

And I remember going down to Muscatatuck to meet with the staff in the chapel, which was a building that was built with voluntary -- by volunteers with donated money. And that was kind of where the people assembled for meetings and -- as well as church service and little concerts and things. And that chapel was full [chuckles]. And people were not happy. But Steve Cook and I were there, and we allowed people to talk and ask questions and say things. Steve Cook still teases me today about a individual who was very young -- I think she might have been a summer student or something, but she got up and started talking about a whole lot of things, and that Steve and I came down here, and we didn't know what it was like to work in a facility, and you know -- and of course, I -- both of us had worked in a facility.

[01:08:49]

...And so, finally, I just literally yanked the microphone away from her, which probably wasn't the smart thing to do [laughs]. But you know, enough was enough. I mean, that was the tenor of the meeting. But it was -- it was a tough time for the community and the staff. I mean, it was interesting that a lot of the community leaders came to meetings with various people who would come and, you know, have open discussions with people. And I mean, it kind of hurts me to say, this, because I knew some of the people, but their interest was about money, not about the individuals. Bankers would say, "well, these people have mortgages with us, you know, what's going to happen?"

I mean, there was a lot of uncertainty. And we had a contract -- a management contract with Liberty Incorporated -- Liberty Health Services, and they provided a superintendent and some other key staff that we didn't have. Because, remember, at that time, we were working to achieve the Department of Justice state SDC plan, which required additional staff to be hired, which required services to be enhanced, therapy services to be provided -- you know, a whole host of things -- enriched the staff. Because that was really the reason that Muscatatuck was decertified by the state Department of Mental Health surveyors was lack of staff.

[01:10:54]

When we had our final hearing with the state Department of Health, we indicated all these things that we were doing. This was just local state resources. This was before we brought in anybody to help. And they listened and listened and listened. They asked one question. Do you have -- how many new staff did you hire? And of course, the answer was zero, because there was a state freeze. And that was it. I mean, then we were decertified. So, to meet the Department of Justice SDC plan that came along, again, we hired some outside contractors to help kind of, you know, bolster up the services there. So, there was a big, big effort to get -- to get recertified. And sequentially, that occurred, and then the closure announcement. So, we were working to get recertified, and then people were told we're going -- we're going to close.

And so, the interest and the motivation to work to get recertified was certainly dampened. And so, there was a lot of social dynamics going on. The contract staff, which we had to hire more and more contract staff, because other people were leaving, had to meet the SDC plan, we had to keep hiring more of these other contract people to -- you know, to keep -- you know, because we had to meet the SDC plan. And there -- we could have been fined, like Tennessee was fined, if we didn't do, you know, certain things. And so, again, there was a lot of social dynamics issues going on. A contract person may be working right alongside another direct support professional and make more money than the state employee. I mean, things like that that really didn't set well with people.

[01:13:04]

...But, so, I was asked -- when the Newcastle issue occurred, I was responsible for all the community programs in the Bureau of Developmental Disability Services. And I just kind of inherited [chuckles] the kind of job of working with the Department of Justice. And I was with them, I think, on all their visits except for one that they made to Newcastle. And so, I was asked to go down and help at Muscatatuck. And so, I was technically the assistant superintendent at Muscatatuck for a year and a half. And again, put that in perspective, it was from the time of decertification, trying to get recertified -- the closure announcement and until we were at a point where the Department of Justice SDC plan was being achieved, and a lot of people had been -- had been transitioned to the community.

So, I would go down there on Monday and stay until Friday. I would live in one of the state houses there. I ate my meals at the kitchen there. Pretty much stayed on grounds. There were many weeks I never left the grounds from Monday to Friday. And you know, there was a lot of discussions with staff and working on transition plans. A lot of staff meetings to keep people working on -- there were -- I think there were, like, 150 parts to the SDC plan, so we had to monitor the achievement of all those goals. It was 150 goals. And then, in the evening, I would do rounds and talk to staff, and you know, try to keep people motivated and thinking about the consumers. But, during that time, we also started the -- what was called the outreach program, and that was to help ensure people who left the facility had services in the community, like OT, PT.

[01:15:34]

A lot of the people who left had adaptive equipment needs, and so we helped support and train the providers to meet the needs of people. We provided training on a variety of topics. We had psychiatric services, because that was a -- kind of a weakness in the community. If people wanted to call and say, you know, Johnny's doing this, what's going on, it was -- it was really a helpful piece to transitioning people successfully. So, we had a structure for how the closure occurred. There were a variety of committees. There was communication that went to families and consumers. There was communication that went to providers and to central office to let people know how we were doing.

So, that was one -- that was one focus. There was a piece about transitioning. There was a piece about finances, because we had to, you know, balance all the finances. And again, we were still trying to get all of the units recertified. They were recertified in four pieces, if you will. Let's see. There was the maintenance of the facility. We had to -- because there was a lot of issues with getting -- I mean, do you put money [chuckles] into fixing the facility that you're going to close just to get recertified? I mean, there were all kinds of fiscal issues -- facility issues, fiscal issues, transition issues, communication issues. But the committee met regularly, and it -- and it really worked pretty well in terms of the closure. But the Department of Justice added a piece to our SDC plan that very specifically delineated components that had to be in place for our transition effort, for every person who left, which was a tremendous upgrade from years past.

[01:17:52]

...I mean, when people left Beatty, when it closed -- it was the first state hospital to close -- they virtually just went to another facility. Their chart went with them. Their possessions went with them. And there wasn't a whole lot of -- you know, any real plan to that. When Central closed, we used the waiver to serve a lot of people in the community. Some did go to group homes, but we did use the waiver, because it was brand new to the state at that time. The waiver started in Indiana in 1992. Central closed in '94. So, we used a lot of the waiver funding to serve people from Central State. And at that same time, also, trying to package kind of a -- the transition piece here. The first large privatized ICF/MR, St. Vincent New Hope, closed about that same time also.

And so, they were some of the first people to get waiver-funded services of those individuals who transitioned. And, you know, we would meet at Central State every week with the providers, talk about things that people needed. We had budgets, you know, for the individuals. But it -- I mean, it was pretty primitive compared to what we did for the people at Muscatatuck, and even Fort Wayne. And I have to give Liberty credit. They did some very innovative things, too, to help kind of package the needs of an individual in a -- in a, you know, real condensed way. And we had to train the new staff, and then no one could leave unless the staff were trained, people had visited the facility, everything was in place. They had all the -- all the service. If they need a psychiatrist, that person was identified. They needed a neurologist, OT, PT, speech -- all of those services had to be in place before anybody, you know, could leave.

[01:20:00]

JT: Well, that kind of goes with this last little cluster about Muscatatuck. And I was going to ask you how you thought the closure went. Did Indiana do a good job? Was it a model for other states? Were there lessons learned, things that you would do differently? And how folks are doing in general now they've come out of Muscatatuck.

RK: Okay.

RK: So, that might be too much, but just...

RK: Okay.

JT: ...if you could summarize those points.

[01:20:24]

RK: Okay. The transition effort, specifically at Muscatatuck, it was, in my opinion, a tremendous success. I want to share with you that one of the most gratifying things that I did in my career was to visit people who left both Fort Wayne and Muscatatuck after they had moved to the community. And, you know, there were some issues. I mean, there's -- there were. But for the vast majority of the people, they are living a much more enriched, healthier, safer life. They have more personal possessions. They get to see their families more. They get choices of -- you know, if they want to go to church, where they want to go to church, who their roommates are going to be, where their live, who their case managers are going to be, if they want to go to a day program, if they want to get their own job.

[01:21:24]

...You know, whatever, it's dramatically, dramatically different. And if I told you some of the things that we observed, you would think you're -- Randy, you're making this up [chuckles]. But truthfully, we saw people at the institution that did not walk that walked in the community. Now, the little background is that, you know, they were using a wheelchair because they were -- maybe had issues ambulating, and the wheelchair might have been used for kind of convenience to help get them long-distance across grounds or something. But that's a true story. The behavior of people -- a lady at Muscatatuck took IM Valium injections every day. Every day. Because she would get, you know, so upset. For the first six months in the community, she didn't have one IM injection. Not one.

There were people who were very self-injurious. In the community, once they got in a more relaxed environment -- I can think of one gentleman who was dual-sensory impaired, so he was very tactile defensive, you know, being bumped around in a large group of people in a facility. When he was in the community, I mean, he really just settled down. His self-abuse was, you know, pretty much non-existent. A lot of real positive stories about how individuals grew and exceeded in the community. Again, the transition process -- you know, we made it hopefully better [chuckles] over the years, but no one left Muscatatuck unless they had all their services in place -- day services, therapy services, dining plans, adaptive equipment.

Everything had to be in place before they could leave. And they were not assigned a case manager or picked a case manager who, you know, helped arrange all of those services including their -- you know, their budget and their allocation for -- their waiver allocation.

JT: That's great. I think that kind of captures everything we were going to ask for that question.

[01:23:55]

JT : What I'd like you to do is talk about training in general that people should have and how they get it. Is it up to the agency like it was a long time ago? Where agencies had to provide their own training in-house or co-mingle with other agencies to split the cost of bringing someone in. How is that handled in -- what do you think is essential for people coming into the field to know?

RK: Okay.

RK: The training of staff to work with individuals with developmental disabilities is really a very vital component to ensuring that not just services are provided but they are provided in a way that's meaningful and that there's real quality in the services. Years past, the agencies were pretty much responsible for providing that training. The training that was actually provided to what was, the people who were attendants at the state hospitals was really pretty thorough, pretty intensive training program. And as people moved to the community, ICF/MR standards required, you know, certain training. And then with the Supported Living Waiver funded services, there was a core training program that was required and it was pretty much based off of what we call core A and core B which was the Direct Support Professionals requirements if they work in a group home.

[01:25:48]

...First aid, CPR, med-administration, a variety of things, you know like that. But for a professional staff and for the people who serve individuals with developmental disabilities in the community, that's kind of a whole different realm of training, so it'd probably helpful if we maybe separated the provider training versus the, maybe the doctor, or nurse, OT, PT, you know, kind of training. I see those as two separate components. But over the years, the Indiana Institute on Disability and Communities is really been a great partner in helping to provide the whole host of training. And still-- still does, for example the training on supported of employment. I believe IIDC still trains people in that area.

IIDC was instrumental in developing the curriculum for our direct support professional trainee and it's actually still being used by you know, you know, by Ivy Tech and the core curriculum is still available for agencies to use if they-- if they so desire. But on the provider agency side, there are minimal requirements the direct support professional are trained and then, in those core areas that there in the regulations for supported living, including CPR, first aid, some training around behavior management, those kind of things. But it's pretty general.

[01:27:53]

The ideal would be to have competencies that people would need to meet in a variety of areas, the core areas like health, behavior, medication administration, community life, because after all, people are living in the community and, you know, you can be in the community and then you can live in the community and there have been situations where people are in the community, in their home but they don't really interact in the community too much. And there's a variety of reasons for that, not get too long winded on that, but there were some people that left that were transitioned appropriately to the community but were deathly afraid of living their home hardly wouldn't leave their bedroom. I mean-- and so a lot of desensitization was occurring to help move some, you know, some people help them feel more comfortable, access the services in the community.

But providers do, you know, a good job but providers may do it differently. So the idea was, wouldn't it be nice if all the providers had these areas of competency that they would testify that people were competent in and then theoretically, a surveyor or state agency or the Bureau of Quality Improvement Services would know that everybody would have had these levels of competencies in these areas. So we're still improving but there's-- ideally if we could have training that would require meeting these competencies, now people could get that level of competency in a variety of ways which is what was developed with the DSP program, the Direct Support Professional training program, one could get this training through Ivy Tech, through the college direct support or through an apprenticeship program.

[01:30:22]

...It really doesn't matter. Its how-- it's whether, it's believed they have those competencies or not. And a real easy example would be, did you pass CPR? And, you know, there are, you know, American Health Association has that, Red Cross has it. So, you know, if you met and passed those tests and have a certificate then would, you know, that's then you would have that level of competency. So I think we could be a little more demanding if you, that's okay to say it that way. That people meet different levels of competency. But it's one of those things that in life where people have not always agree. I think we've had great partnership in Indiana. But some of the decisions, some major decisions, people didn't always agree. I mean unanimously across the state, and I think training is a costly thing and so people are little afraid to kind of rock the boat so to speak.

[01:31:20]

But, you know, if the DSP, direct support professional leaves an agency, study show that it takes 3,000 dollars to fill that position by recruiting, training, filling in with overtime, a variety of things. And another interesting point about training I think is interesting is the-- and these are my statistics. This come, you know, from Department of Labor statistics that in a next few years, direct support professionals will be for people who are aging, people who are physically involved; people with both mental illness, that's going to be the most needed job in the country. Think about that. The most needed job in the country. So to the extent that we can get ahead and train people and have a training program that people would be required to go through, to meet competencies, it seems like it would be an advantage to Indiana.

[01:32:22]

Some states have adapted like the College Direct Support, all their agencies have to do this online training which is a nice program. But we offer options of variety to pass to get to those areas, levels of competency which seemed to be more palatable to, you know, to the providers. Now, you know, the issue of-- the more your training, the more marketable you are and people [laughs] find other job because they are more marketable. Plus a lot of our DSPs really deserve more money than what they earn now. But again, that's a financial issue which may be holding down on the advancement and the training for, you know, for DSPs. For other people who work in the agencies, the agencies do provide a host of training through INARF and other areas on, you know, helping what used to be called QMRPs, Qualified Mental Retardation Professionals, who or case managers, you know, for the behavior folks that worked-- professionals who work in Indiana, they have their professional organization and there are, you know, certain requirements for becoming a different level of behaviorist, according to the waiver, you know, certain educational requirements.

But overall, there's a lot better quality of staff than, you know, than years ago, tougher requirements.

[01:34:08]

JT: Here's my question. So there's core things that, you know, we can all agree on the DSP needs to know. We just have to basically be competent in the job and take good care of people. But I guess, that I'm also thinking about is professionals that come into this field, college graduates, those who were something to other people that fell into middle management. Do you think, there should be-- and this is just a general question. Do you think there should be some training around values and philosophy and dignity of risk and relation, you know relationships, things to really, do our jobs well. I mean these things are important

RK: Right.

JT: But, what about-- how do you learn those things?

RK: The way people acquire a philosophy or get trained in one of the, you know, basic principles, do's and don'ts and working with our population is not standardized. And ideally, anybody in a provider agency should go through or be certified as competent just like a direct support professional is. And part of that training, does speak to the right philosophy, the right attitude, protecting people's rights and dignity, so ideally it would be wonderful if even the CEO of an agency was certified at all of the competency levels that all of their [laugh] direct supports professionals, their hands on people are required to have.

Ideally that would be in my opinion, the best way to ensure that everybody is on the same page, you know, philosophically about how people should be treated. I don't mean that in medical treatment but that should be how we should engage people in service.

[01:36:29]

JT: Would you speak to maybe young professionals coming into this list that would be ideal if they could-- where they might get this. If they would have specific trainings, and what it would take to maybe get that 'cause that kind of goes into the future but--

PH: And maybe you don't have any answer.

RK: Yeah.

JT: And that's fine too. I made that question up.

RK: For young professionals coming into, to the field, it's paramount that they have their own set of values and principles and a philosophy to work by. Without that, you're guided by, you know, other people's opinion or the agency's opinion which may or may not always be a hundred percent appropriate. And so, but how one would get that ideally should occur as part of their education and more at the IU med school, doctors are have a one hour, it's not a lot but they have one hour program that they have to take, a class that they have to take on working with people with disabilities. Now is that enough but that's-- that's the kind of-- and part of that should be "Okay, what's going to be your philosophy about working with people with disabilities?"

[01:38:03]

...Are you going to serve them on your practice?" And if so, you know, here are things that you need to be thinking about, that they're going to require some time to get information ahead of time, to do work out prior to them coming in. It may take more time because of, you know, ambulation issues or other, you know, just physical issues to actually examine and treat someone. And then what's the follow up going to be? It's paramount that people who may not have total control over their life, you know, that the staff are going to be knowledgeable as to how to carry out the doctor's orders to ensure them, you know, the health of the person, you know, improves or whatever the issue was that they were at the doctor for is addressed on an ongoing base. So ideally there's, you know, that should occur in the college curriculums.

And again I just want to say this again, everybody should have their own set of values, principles and a philosophy for how they're going to work in this field and that has changed remarkably, over in the last 40 years. I mean people, you know, the attitude about people is so much different. People think-- used to be, you know, out of sight, out of mind, put them in institution. But today, you know, people are in the community and they are seeing, you know, regular physicians like you and I would see a physician or regular dentist like you and I would go to a dentist. So, you know, there's a big need to train those people who are in field today, as well as, new people coming in to the field

[01:40:03]

JT: Okay. What practical and significant changes do you think have come about due to the self advocate movement, you know, maybe where has self advocacy made the biggest impact in Indiana?

RK: Self advocacy is a very vital program to not just protect the rights of individuals, but for them to take ownership in protecting their rights and health and safety and dignity. The self-advocate movement in Indiana has-- is probably ahead of a lot of states and again, it's because of The Arc and IIDC and other entities that help support that effort. But given-- given the opportunity with some mentoring and guidance, it's remarkable what the self advocates do and the ideas that they come up with to help all people who are disabled. You know, very creative ideas, I mean let's face it. They live that life. [laughs] That is their life. And, yeah, they do need some help in organizing their effort.

But I believe that that mentoring idea is a good approach for a lot of disability groups. I mean for us to think you know, outside of our field, for us to think that, that okay, somebody just going off unemployment, you know they would say it, maybe lose their food stamps, they're going to be able to make that move to total self-sufficiency without some ongoing help and guidance. I mean that's part of the problem why people don't get out of poverty is because they don't have a mentor, somebody to help them solve some of the little problems along the way. That's my personal opinion. But IDC, during a couple of initiatives, provided that guidance and mentoring to, to individuals and to the providers, which help them grow and excel and implement programs that were innovative, but without that, they wouldn't have individually been able to do that themselves.

[01:42:38]

...So I really believe that the self-advocate movement with the mentoring, I mean it's a cost saving as well. I mean, you know, they may not be totally independent but they can do a lot of things that, with just a little bit of help, to manage their future that is positive in terms of service provision. It's positive in terms of their own morale and self-feeling of self-worth and again its cost efficient to help them be as independent and productive as possible.

[01:43:25]

JT: Okay good. Now this is the hard question. [laughter] Okay, so were there times in your career, where you kind of wondered if what you were doing with the right thing. Maybe you had job obligations that somewhat went against your own philosophy, for your own personal values. For instance, when I worked for Jim McClish, he asked me when we were gung-ho with support employment to start an enclave at Harman Motive. And I just said, "I can't." I mean that was, so something like that. Were there times where you wondered if what you were doing was going to make an impact and basically internal conflicts, personal beliefs versus expectation, maybe there weren't any. But it if there were an example and how you'd handle that, because I'm sure everybody, not everybody, I'm sure many people having dealt with that or had been faced with that.

[01:44:33]

RK: In the 41-plus years that I worked in the field, I was truly blessed to be in that moment in time and that moment in history were things continued to improve, excel. And so, while it was hard, while you may not have always agreed with some of the things that were being said or to the extremes that things were being pushed, everybody was moving forward in-- in some-- in some ways. So you felt like you are part of improving, not just the system but the quality of lives of people. And that was, you know, was always something that I could go back on and-- and say, "All right, today was tough.

[laughs] May not have hundred percent agreed with maybe the way we got there but, you know, we are making-- are making progress. I think in the last, you know, few years of my career it was difficult to see some of the services stopped or, I mean it always, I'd have to admit that that was very difficult for, you know, to see things not that I personally but things that were benefiting individuals that we couldn't no longer afford. I mean I'd-- that was a tough-- a tough thing. But, you know, I was also always blessed with a boss that I could say, you know. "Do you think, you know, we could it this way" or I was given the latitude to be able to, you know, do things in a way.

[01:46:43]

The hardest time was during the down economic times where you didn't have any flexibility to move any kind of money, you maybe had a few extra dollars in this pot and you needed to move it over to this pot, and that was most frustrating probably time is, you know, is just that inability to utilize all the resources to their best advantage, because it was about saving money and-- but I mean, some things you just can't-- you just can't change and. But, you know, we could always bring a proposal back to say, "Well maybe we could do it this way."

[01:47:33]

JT: It's good. It's good. Okay, and then the last question is, in looking forward, what do you have for in terms of supports and services to promote meaningful lives people with disabilities?

[01:47:21]

RK: The future in our field supporting individuals with developmental disabilities is going to be, I believe some more of a rocky road with the Medicaid expected cuts over the next nine years that we have promised to cut is definitely going to have an effect on our long term residential services. I mean, the states are going to-- the states are going to have that push to them to deal with that short fall. It would be my hope and desire that states will understand that our population is-- has some of the most vulnerable citizens in our state and they're going to maybe not have to take as drastic a cut as maybe roads or something else.

[01:48:58]

But I mean we're-- this is going to have to be a time of strong advocacy, strong partnership to be able to come up with plans that are as cost effective as possible and not reduce the services that are needed and especially the extreme services or the services to meet people with the most extreme needs. It can't be, okay, one size fits all. Everybody gets X number of dollars because people, I mean we've worked away from that model for such a long time to be more individualized, and to give people budgets if you will based on what their needs are. And I understand the new waiver is supposed to help achieve that. But you know if a person has extreme need for psychiatrist or whatever, you know, we got to make sure that happens.

[01:50:05]

Or in the other hand, if mom and dad just need a little bit of help at home, they would save a ton of money if they were moved out of the home, we need to make sure that happens. But the, you know, the best advice that-- well, let me say it this way. What I would hope would occur is that we would provide more training and education so that all professionals and all disciplines would understand how to work with our population and we could develop some specialty services to meet those challen-- those real extreme challenging needs of people through, you know, through IU Health or community network that would be willing to, you know, provide neurological services or psychiatric services. But we're going to have to make sure that it's, you know, fiscally possible for people to do that.

Right now, it's all on a flat rate basis, you get X number of amount for Medicaid. You know, for a 15 minute visit, a person gets a maximum of 600 dollars for dental needs which means they get a lot of teeth pulled instead of teeth repaired. You know, we need to fix those things so that our population gets this-- gets the best health care possible in a preventive way so that we're saving money in the long run so. And also, the system needs to be streamlined because right now states have to, and I'm talking about the big, big system from the federal government. States have to apply still, I mean this is the same as in 1982 when the first waiver was written, states have to apply to a federal government to get a waiver and that waiver as you know is to waive use of, institutional funding to be used in the community.

[01:52:24]

...We still have just wrote a waiver as an example in Indiana to revise our waiver which is good, that's not saying that we shouldn't try to improve, but why should we in states be having [laughs] to write all waivers to the federal government when the vast, vast, vast majority of people today live in the community and not in institutions. We spend tons of money managing a waiver that I know could be than in a less expensive way if services-- if we didn't have to work through that channel.

JT: That was really good. Can you think of anything else?

PH: No, just maybe you might want to [inaudible] final comments.

[01:53:04]

RK: Well, in terms of differences --the way it was [cough] [Pause for water]

RK: The difference today as opposed to the way it was is dramatic and we have a lot of people to thank for that, our consumers, individuals with intellectual and developmental disabilities have dealt with a lot of changes but hopefully they've been for the better and a person today is living a better quality of life and a lifestyle of their choice. But it-- you know, reflecting back, we've talked about a lot of things but specifically with like dining services. Forty years ago people, you know, ate pureed food or, I mean they-- their assessments for swallowing difficulties, you know, the environment that they ate in.

[01:54:20]

The utensils that they used were just very, very basic. Today, you know, people eat in their own house or a restaurant if they choose to go into a restaurant. If somebody needs a pureed diet they take portable blenders with them to McDonald's and puree the food right there. So there are special diets for people, you know, whether it'd be chopped or pureed, the thickened liquid. They have the right thickening of their drinks so it's easier for them to swallow so they don't aspirate. I mean, that in itself has probably saved lives, improved the quality of lives and the health of people tremendous-- tremendously, behavior management. I mean people, you know, forty years ago were locked in isolated areas, what we called time out rooms.

[01:55:26]

We used everything from roller boards to four-way restraints to-- restraint chairs and we're in the middle of open area where other people were around them. So not only were they were restrained but they you know, it was undignified to be out there maybe even unsafe if, you know, another resident would attack them or something. Chemical restraints, you know, was prevalent. Medication authorized for other than as a psychiatric diagnoses. And, you know, we burned all of the restraints at Muscatatuck. People never-- I mean, they thought, "You're nuts. You'll never be able to do that." But we did. You know, we virtually use no mechanical restraints, maybe in certain health situations where somebody if it's ordered they may get, you know, some restraint.

[01:56:33]

...But I mean we went to the opposite end of where what I just tried to describe, where even if you prevented somebody from any kind of movement that was a restraint and it had-- you had have an approved plan to do any of that. And we even had to have any plan authorized before it was done and an evaluation after it was done. In the realm of like working with people with epilepsy. I mean, they were segregated at New Castle State Developmental Center. That was the place that people with epilepsy went. Now at that time it was thought just, you know have a specific service, trained people to, you know, how to work with that, unique disability but, you know, today with the medication and, you know, people aren't having to be stigmatized by wearing a helmet, you know, it's-- it's so much-- it's so much better.

[01:57:43]

You know, do people still have seizures? Certainly, and for whole variety of reasons. But, you know, we still have some gaps in the system that we, you know, need to work on because there are low instant populations like people who are traumatically brain injured and if that's before, you know, age 21 they're going to be determined intellectual and developmentally disabled. If they, you know, have functioning levels in certain ranges but-- but, that's a big area that we still don't know a lot about. And, you know, people with personality disorders that are also developmentally disabled, that's-- that's a tough combination to deal with. I mean-- so, you know, I'm not saying we fixed everything. But, you know, what about-- we talked about the living arrangements but, you know, think about the effect that has on the individual and the family and the guilt that they no longer have to have.

[01:58:59]

I mean, there's so many other biosocial aspects of this medical as well that, you know, people are able to live a better quality of life, a healthier life, a life that's hopefully more and richer with their rights protected, and hopefully their dignity protect it. Again, it's not perfect but in terms of, you know, behavior, medical, you know, the dining as I try to mention, the way people are transitioned today. You know, person center planning versus-- that's a big area. I mean, before program plans really not existent, you may have had a one page, you know, medical plan and then we had maybe some-- some group, you know, like for Ward A, you know, they were of this persuasion and so they got kind of this approach.

[02:00:09]

I remember a unit at Beatty Hospital years ago where they had a reality therapy. That was a reality therapy unit and it was, it was kind of innovative idea but everybody was involved in that. And it wasn't the people who were thought to be who could benefit from what the most. You know, and today we've got all kinds of different versions of person centered planning and everybody who left New Castle, Fort Wayne and Muscatatuck at a person center and plan and a lot of choice was given, and a lot of involvement trying to engage families in that, friends, people who knew them well. I mean it was really-- really neat thing. That reminds me at New Castle, the summary of the closure of New Castle was entitled, "I Got My Yellow Kitchen" and a lady wanted a yellow kitchen. I don't know why but she got it.

[02:01:17]

JT: I had a yellow kitchen. [laughter] So, a couple things that aren't really on here that I wondered about them and in which I was curious about sterilization if that happened at Muscatatuck during the '70s. And then the other thing that struck me when we were going to Muscatatuck during our audio tapes is the cemetery. The cemetery, that was really interestingly, such a contrast because here there were-- there're two cemeteries--

RK: Public.

JT: Right, the public and the private and walking around that cemetery, the fact that it would just say, boy or male and, you know, no name or nothing. And I don't know if that's worth even talking about, but those were just a couple things that I personally was curious about. Do you have any [inaudible]?

RK: Yeah, sure.

JT: Is it worth?

PH: If he's willing to talk about. I think a few more minutes.

RK: Sure. The burial arrangements is another contrast from the way it was to the way it is today, and unfortunately, dying is part of life and I think people today, I mean as resilient as this population is and I've heard pro-- you know, learned professionals, a nurse as an example, she said, "You know, these people are very resilient. They're tough." You know, if they can tolerate, you know, some of the things, you know, they-- they've got to be just, you know, have stamina and-- but you know, people have died for just aged out kind of dying to, you know, accidents to other unfortunate circumstances.

But how people-- unless the person had an involved family, most of the people were buried at the facility, and Muscatatuck as an example has a cemetery that's right next to the community cemetery and it's still-- it's still there and people actually I think are still being buried there if that had been their, you know, their wishes. But they're-- the-- I guess human aspect of burial, I mean as hard as it is, I mean, they would have a funeral at the facility and sometimes parents would come, sometimes they wouldn't. And, you know, they would be buried in the cemetery. Their tombstones were not very attractive I would say.

I mean, they're very basic not very descriptive of who the person is or maybe even their name. But there is a register, as ugly as it sound, there is a register of all of those graves and I think pretty much who is there and that was turned over to FSSA, so, it's still there, it's still managed. But today if, you know, someone dies and unfortunately, I've been to some funerals of people who've died in the community but they, you know, it's a typical funeral of their choice or their family's choice.

JT: Okay, good.

[End of interview]