ORAL HISTORY NARRATIVES MUSCATATUCK STATE DEVELOPMENTAL CENTER WITH PATTY COOK
OCTOBER 22, 2004
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RECORD ID: 139-DO

PC: PATTY COOK
JT: JENNIE TODD
SS: STEVE SAVAGE

[TITLE]

[00:00:12]

SS: Why don't you talk a little bit about when you first got here, what it was like, what year was it, what brought you to Muscatatuck.

PC: It was 1971 and I tell people that I came here by accident. I got pregnant. Actually I got pregnant at the wrong time. Our twins were born during the school year so I couldn't go back into teaching that year. The only job that was open when I was ready to go back to teaching was at Muscatatuck. I thought well I'll go there until another job opens up. I didn't even have a clue what it was like. I had a degree in music education. The job was in music therapy so I basically learned about therapy on the job. I really, really liked the work much better than working in the school system. The programs here at Muscatatuck at that time, first of all there was about 1,500 people that lived here.

SS: How big was the staff?

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PC: I don't know how many staff here. I know that the music therapy department I had 5 working under me. We had all kinds of programs that went on. The biggest thing, and that was one of the first experiences here, was the Easter Cantata. We had approximately 55-60 residents that were in the children's choir and then we had other residents that was in the adult choir and we had staff members that were in the staff choir and we had a narrator. A lot of the music that we sang was sung by the residents and then some of the harder parts the staff would take part in. I was never involved in the musicals but I was told before I came that they actually did musicals here at Muscatatuck that the clients and the staff participated in. Jack Griffin, who was the director of music therapy before me and also the

director of the school program, had said that one time they were doing "The Sound of Music" and the lead trumpet player was a client and the lead violin player was a staff person that got sick. And of course the violins got the main part, the melody all the way through it. So for that particular performance the trumpet sat in and picked up the lead and played by ear that entire performance. So it gives you a little bit of idea of the level of functioning that some of the folks had here at Muscatatuck at that time. So we did two cantatas at Christmas and Easter and then we did lots of recitals. I had children that I worked with and we found that helping them to develop some musical skills actually gave them self-confidence and helped them in school, it helped them in their work assignments. I had one fellow that he was a teenager, well adolescent really and he wanted to play the guitar and he wasn't very good. Of course I couldn't speak because I'm not a very good guitar player either but I taught him to play two chords in one key. When we had the recital I would play the piano, played the melody on the piano and I would nod to him and he would play the key of G, he'd strum the guitar. And I'd nod to him when it was time to change to D7 and he would change the chord and we'd go back and forth. But he played the guitar and I mean it just really boosted his ego. I could tell you stories all day about the folks, the kids that we worked with and the things that happened with them. One of the therapists that work for me had what she called Melody 10 and it was like a swing choir. They traveled all over the state and did performances. They actually made a record, one of the long playing records of the music and sold copies of that. The money that they made from selling the record and the money that they made when they would go out and sing and people would pay them was applied towards the chapel because the chapel here was all built with volunteer money. There's no state funding in the chapel at all. So evidently they would go out to these different churches and they would sing and they would pass the hat and bring the money back and put into the church. So we had a lot of other activities that went on at that time. They did skating in the gym. We had programs on the stage in the gym. They had movies. The projection booth was behind the school and they had a big movie screen on the back of the school. So the residents would all sit out in the grass every Saturday night and they would project movies up there, just like an outdoor drive-in except there were no cars. They would have parades. When it came time for Memorial Day we would have a line of residents that walked all the way out to the cemetery. Those that were in wheelchairs the other clients would push them and we'd have a memorial service out there. They didn't have the marching band when I was here but they did have prior to the time that I was here. They had a lot of dances, street dances. I can remember when I worked out on 8, 9, 10, 11, those buildings, we would have street dances down there often. We'd have watermelon and everybody would take a slice of watermelon and we'd have balloon fights, water balloon and things like that. At the time that I came here they weren't actually using the greenhouse or the dairy barn like they had in years past but there was still a lot of growing stuff in gardens and we would use that then for the folks to eat and they could grow whatever they wanted to and then have that. We had one guy that would go out in the summertime and I don't know where he went but he always came back with a bucket full of blackberries and he'd sell them to the staff and then he'd go out and get some more the next day. There was a lot of activity; a lot more things going on on a regular basis than what we now, even with all of our staff today and all the special programs that we have. There were still an awful lot more activities back then than what we see now.

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SS: So what do you attribute the changes to?

[00:06:23]

PC: A lot of it is due to the different functioning levels and the majority of the people that live here now are profoundly retarded and a lot of them are multiply handicapped and can't participate in some of the programs. There was a lot of working patients back then. Sometimes the only way you could tell the difference whether they were a working patient or a staff person was the color of the uniforms because the staff wore white and clients wore pink.

JT: Can you talk more about that, what working clients did and how you got to be in that level?

PC: I'm not real sure how they decided who got hired for those positions because I really wasn't familiar with the voc. rehab program but it was obviously functioning folks that they could trust to be in these different situations. And they did a lot of different things. They worked in dietary, they helped to deliver the food, helped to prepare the food, they worked in housekeeping, they cleaned, they mopped, they made beds, they helped in the laundry. We also had people, actually clients that were helping other clients. I know over on building 7 they had high functioning individuals living upstairs on 7B and lower functioning ladies, well it was actually girls at that time, downstairs. The ones from upstairs would come down and get them up in the morning, get them dressed, see that they got their teeth brushed, get them off to school and those kinds of things. Years ago we had a nursery over on building 21. It's a house back here. And they had the babies, actual babies there, and some of the working patients took care of them.

JT: Now were the working patients paid?

[00:08:08]

PC: Not for a long, long time and actually when the law went into effect that said you can't work if you're not paid they had to do away with the program and a lot of people lost their jobs.

JT: I thought that's what I heard before and then I thought you said something about they were working.

PC: No, they did that without pay and they were very upset because they hadn't been getting paid but the job meant a lot to them and they couldn't understand why they were losing their jobs.

Then they also put this patient payroll program that we've got in effect now, they were able to replace it with that but it took a while to get that done, not as many people were able to participate and it just never really quite took the place of that.

JT: Well the nursery that you were talking about, where did the babies come from?

[00:08:59]

PC: Some of them come directly from the hospital. Some of them the mom's never took them home. Our society as a whole told parents at that time, they're retarded, you don't want them at home, stick them in an institution, forget that they were born. We would have people that maybe mom never even saw the baby. The doctor wouldn't let mom see the baby and they would stay in the hospital until time to come here or maybe they took them home but they were only home for a very short period of time. We

would get, I can remember admitting a little girl that was 18 months old. The only problem she had was she was Down syndrome. Well she did have a heart condition, which we found out later but at the time the only obvious problem was that she was Down syndrome and they said her hair when she was 18 months; I remember her very well because she was a little bit younger than my oldest daughter, who was only 17 months old when the twins were born, so they were all right together and she was in between them. We had lots and lots of frilly dresses and little pink pretty things so I would bring clothes out here for her and she was young enough, smaller than my girls so as they grew older she could wear the clothes that they had. She didn't have anything.

[00:10:19]

JT: Were there any babies ever born here?

PC: Oh, yeah, I'm sure there was. After I came here I'm not aware of a birth but I know that there were some pregnancies and they may have taken them elsewhere. I did not work in nursing service, which basically ran the units at that time. I was over in activity therapy and education. But pregnancies was a problem. I do know that there had been some pregnancies and the assumption that I had was that they had taken them somewhere else. The babies were born and then they were adopted out. I always thought, I didn't like that practice because they would adopt the babies out and not tell the parents where they came from and I thought that if both parents were living here that that's something that the adoptive parents should have been told. I don't have first hand knowledge of that. That's just what I got from the social workers who worked here. They did do sterilizations here.

JT: Up until when?

[00:11:20]

PC: I don't know when they stopped that. The 4th floor of this building was the surgical unit. So that's where they did that and other surgeries too that they performed. But I was told that with some people they were not allowed to go back into the community until they would submit to that surgery.

JT: Would you estimate that would have been even in the 70's or would that have been in the 50's?

PC: I'm not aware that any of the sterilizations happened after I came so I would say it was probably 50's and possibly some 60's. But I know it was going on in the 50's.

JT: So when you were talking originally about what brought you here and some of the things that were done, would you talk a little bit more about some of the work that you've done here and some of the changes that you've seen.

PC: The different jobs that I've been in?

[00:12:16]

JT: Yes.

[00:12:20]

PC: Well, I started here in music therapy and then somewhere along the line they changed the job classification to rehab therapy. I don't know why but it was a group of people, the rec therapists, the music therapist and the dance therapist, art therapist were all together. In the mid 70's we became certified under Title 19 and began receiving Medicaid monies and they asked me to become a case manager. They told me I was a case manager, I didn't know what a case manager was or what they did but now I'm a case manager. And so they basically gave us a draft of an ISP and said here's what you do and these are the people that assigned to you. So I had my caseload of the kids that I worked with and I really, really enjoyed the kids that I worked with because we had dance classes, we had exercise classes. We had a baton twirling class, we had drum class, we had choirs, we had playing the organ, people playing an auto harp and different things like that. But at the same time that I had all these different classes going on I was accepting the responsibility of being the case manager. It soon became real evident to me that we were going toward doing more paperwork and more paperwork as far as what was needed to justify the programs and the monies that was coming in here. I decided if I was going to be doing all that stuff I might as well get paid for it. So I became an assistant director in 1978 and I worked with some pretty high functioning folks for about 5 years and they were realigning some of the staff out there and I transferred to a unit, which was building 15 and Maple at that time. Building 15, everybody that lived on 15 had some kind of mobility challenge. They were different functioning levels, all different functioning levels, but they all had problems with walking. Most were in wheelchairs and a lot of them were actually in carts. So I became aware of those type of problems and continued on being part time case manager because most of the people that worked here also did case management throughout the years. In 19, let's see. What year was it I became a director? '87, no '88. It would have been January of '88 I became a director on the geriatric unit and I was there for a couple of years. Then I left to take a position up north as the executive director at a private facility, worked there for a couple of years, until I got tired of commuting on the weekends and my husband wouldn't move. So I came back to Muscatatuck and worked as evening shift administrator for a while and then was promoted back into the director's position. I stayed in that until it became real apparent that the only way Muscatatuck was going to survive was to downsize because late in the 90's, actually we were seeing this trend in the early 90's which is why they gave me the opportunity to work in transition because I was helping to move folks out into the community. But by 1998 when the Department of Justice came in here, we were short 200 direct care staff. We just couldn't hire them. There was nobody in the community to fill these jobs. The unemployment rate had dropped to less than 3 down to almost 2 in Jennings County. We couldn't hire enough people to fill the factories. My daughter was working for a company that provided staff for the factories and they were begging too. But things were bad enough for the Department of Justice to come in here anyway but to have 200 direct care vacancies, that just killed us.

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JT: Let me just stop you for a second. You said that things were bad enough for them to come in. What in your mind did you see?

[00:16:06]

PC: Active treatment. It was very difficult to keep active treatment going and the areas that I had worked on as director, my professional staff was expected to do active treatment. My professional staff had to sign up to do two meals a day. They had to actually feed clients. They had to participate in the programs; they had to take them to classes. It wasn't good enough for a social worker to sit in their office and do their paperwork. They had x amount of hours every day that they had to work directly with client to try to fill that gap. Of course it wasn't all bad because the more they worked with them the more they knew about. A social worker calls up mom talking about Johnny and said, "Well I know this is the way he acts when his teeth are brushed because I've been doing it and here's how you bathe him." They were real familiar with it. We were also were using restraints at that time. Of course Muscatatuck felt that there was no way that we could survive without restraints and we found out yes we could. There were other ways. But we just hadn't learned those other ways, that had been the approach. When you stop and look back over the history of MR programs, back in the 70's they were talking about behavior modification, you modify somebody's behavior. You don't modify anybody's behavior. You might convince them to change it temporarily but you're not going to modify it. And the techniques that were popular in those days, I'm embarrassed to talk about now. They were the state of the art at that time. But they were adversive, they were restrictive. They didn't work. So consequently we relied on restraints and it was to keep people for getting injured. It was done for the right reason but it wasn't the right approach.

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JT: And the restraints that they primarily used would they be the ones where they were in bed or would they be in the time out rooms?

PC: They had all different kinds. They had the full body restraints that they used in bed. We had chair that had straps on those, we had time out rooms. We had temporary things like basket holds and then we had other things that were a lot less restrictive like if somebody was beating themselves, just holding their hand out. And we've learned since then that of course you and shadow somebody so if they're trying to hit themselves you can stop them from doing it. We had one lady that just figured out a way to hurt herself no matter what you did. They would have a helmet on her and she'd still figure out a way to beat her head or hit her face. So they actually put her in a time out room in a time out chair and then we wondered why she was suffering from post traumatic stress disorder. But she's living in the community today and today she's still having trouble beating herself. So it may be a neurological thing, it may be a cognitive thing, we really don't know. Whatever it is it's very deep seated. It's been that way her entire life and it may be some neurological damage in the brain that causes her to do that. And it's very, very challenging, even with everything we know today. But that was the big problem when the Department of Justice came in was the restraints.

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JT: And that was in the 70's.

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PC: No, when the Department of Justice came in was 1998.

JT: So then what happened after that.

PC: Well after that, of course, we learned that we had to find another way and there was more emphasis put on bringing in professional staff to help train our staff here that would look at other alternatives, people that would look at the proactive approach. If you go into any one of the meetings today where we're dealing with behaviors, and I do this also. I work part time in the community as a behavior consultant. What you look at first is the environment, what's going on in the environment that may be triggering this behavior. And you look at the medical things that might be causing behaviors. It was in the mid 80's when I was working on building 15 and we had a fellow that was profoundly retarded. He was laying in a cart; couldn't sit up in a wheel chair but he would figure out some way to beat his head, either with his hand or on the cart, against the wall, and he just had bruises and he would scar tissue all over his face, his forehead where he had beat himself repeatedly. Well at that time the drug of choice was Mellaril thorazine. 80% of people that got medication in those days it was Mellaril thorazine, that's all you really had. We tracked his behaviors, we tracked the amount of amount of medicine he was given and there was no collaboration. You give him more medicine and he may still be beating his head just as much; you decrease it he may be beating it less, you don't know. And so finally one day I was in the area where he was at and I heard one of the staff members say, "You know the way my head feels today I feel like beating it on the wall too." And I thought I've got a headache today too, what is going on here. Well anybody that lives in this area of the state knows about the Ohio River Valley and the sinus problems, it's just, well you're in Bloomington so you probably know too. If you get up around Indianapolis somewhere like that it's different. I know when I worked up north, when I would go up on the weekdays my head would clear up and when I'd come back down here on the weekends it would get worse again. So that was pretty obvious to me. We got to checking and he had sinus infections and he had allergies and it was really hard to convince the doctors at that time that that might be related to his behavior that they should even check into it. But they did. They got it taken care of and we got his medication for him. Better than that, when he started hitting himself then we actually could give him pain medicine. We had justification to give him pain medicine.

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JT: That sounds like a big change.

PC: The doctors back in those days just didn't see a need for allergy testing. It was something that we had to convince them was important and that it was connected. I can hear the doctor saying, "It's behavior, it's behavior." It was behavior but there was a reason. The behavior was trying to communicate something to them.

[00:22:35]

SS: Obviously this building we're in was the hospital at some point, it was the medical unit. How strongly, because there were a lot of doctors out here in those days I assume.

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PC: For a long period of time we did have four, yeah. We had four Vietnamese doctors here for quite some time. They were pretty stable. Prior to that we would have a doctor come and the most, the longest length of stay would be 2 years because they would have to work 2 years in some type of setting like this in order to get their regular license in Indiana. So they'd come here, work two years and then go on somewhere else. But we were lucky there for a long period of time that we had these four doctors that did stay.

SS: So how influential were they in terms of programs and that sort of thing? It sounds like they had certainly some influence.

PC: They really didn't have much to do with the actual active treatment that was going on. They pretty much stayed separated into the medical field. They're a lot more integrated today than what they ever have been.

SS: You started out as a teacher in regular ed?

PC: Yeah.

SS: Elementary, secondary?

[00:23:36]

PC: I had all. I was a music teacher so the first job I had was junior/senior high school choir and four grade schools. So I had 500 students.

SS: After you came out here how did the other people that you knew that weren't working here react to your working here? Did they think that was a good thing, bad thing? Was there a stigma attached, was there any kind of hierarchy in terms of that?

[00:24:05]

PC: I don't remember anything. Of course I lived in Greensburg and that was a little bit different than living in North Vernon because so many people here had heard all the horror stories and everything. The only thing that I know is later, years later when I was in management, I was having a lot of stress issues and my dad said, "Well, Patty, maybe if you worked with normal people it wouldn't be quite so bad." And I said, "Dad, it's the normal people that are driving me crazy." Working with the clients is a lot easier. I think one of the reasons even today that I like working with the clients, and since I started doing some part time work I can actually work one on one with them which for so many years I've been isolated from the actual therapy, they've got problems and many of them have emotional problems. And I can understand and I can empathize with that. Normal kids are like, "What's your problem? Why are you doing this?" One of the things that I learned working in music therapy, first of all I insisted that they allow me to do some one on one work and that was unheard of because back then the rec department they wanted to see how many hundreds they could get at their movie or how many hundreds they could get because they could put it down and say we had this many people. So I really had to fight against the system to get my one on one. But I felt with those people that it was really, really important or I

wouldn't do that. They found out that I could work with people one on one so they started sending me the worst behavior problems. Back in those days you didn't have to put people in school. The law had not been passed yet and you didn't have to put them in school programs. So they would come from the community, they would be totally out of hand. I had one little black girl that came in to my class. She was quite a character. They told me, they said, "We want you to housebreak her and then she can go to school."

[00:25:59]

JT: Did you have people come from the community here just for music?

PC: No, they were admitted here. They were admitted here into Muscatatuck but then they would actually come to my class and for a while I was considered, I don't know if you guys know Donnie Hern or not in North Vernon? Donnie was the principal of the school here and he listed me as one of his teachers and he gave me a couple of teacher's aides and they helped me. So when the kids were in the school program over in the school building and the teachers took their break for a half-hour the kids would come to my class and we'd just keep rotating throughout the entire day.

JT: And did the kids go to school here on grounds, no one left to go?

PC: Not at the time. Now it got to where they would send some people in town and have the others here. Once the idea of mainstreaming started then they did send people in town, but not the majority of them. The huge majority of them went to school here. Of course we had folks here that couldn't tolerate being in classes longer than maybe an hour at a time because of their behaviors. We had some autistic individuals. Back on those days we didn't understand that when you've got somebody with autism you're not supposed to put them in a room with a bunch of other people that are loud and noisy and when we tried to do that well naturally we found out why you shouldn't. Instead of giving them their own private class, we just sent them back to the unit so the others could stay in.

[00:27:25]

SS: Was the school staff part of Muscatatuck or were they local school staff who just happened to work here?

PC: They were part of Muscatatuck but the teachers were paid on the same pay scale as the county schools. They actually made a lot more because they worked summers. So they got the same pay scale but year round but they were on the staff of the state.

JT: It sounds like you worked all over the place in terms of the different people here. Did you see a hierarchy among the people with disabilities, some people being treated better or hierarchy pecking order?

[00:28:02]

PC: Oh, yeah.

[00:28:04]

JT: Could you talk about that?

PC: The worst thing that you could be called at Muscatatuck even today is a low grade.

JT: What does that mean?

PC: That means profoundly retarded, that means you're, well, they had the high grade and the low grade is what they called it.

JT: And everyone, people with disability and staff?

PC: The clients. The people within their own units, the higher functioning clients here called the ones that were lower functioning or had a lot of ambulation difficulties, they called them low grades. I could tell you that today you could go out on these units and say 'you're a low grade' and it would be fighting words. People that typically were like in Melody 10 or if they were a working patient, that pretty much qualified you to be a high grade. The staff did not use those terms, although the staff in the past have used some terms that I also shudder to think about. If you go back and read the reports from the 70's or before they talk about moron, imbecile, those are the type of terminology that they used then. It's on paper.

[00:29:35]

SS: Those were kind of considered the medical proper terminology at the time.

JT: Did they refer to people as carts or chairs?

PC: They said the cart patients. Yeah, they didn't call them carts or chairs but they would call them the cart patients. Something that I believe that everybody, including staff and I'm probably just as guilty over the years, has assumed that people that have ambulation difficulties may not have higher cognitive skills. And I became very acutely aware of this when I worked on 15. We had a lady over there that had severe cerebral palsy and she had very little movement. We tried to find a way that she could communicate and the only way that we could get her to communicate at all was to get a computer screen that had boxes, big boxes on it with words written in it. We would put a pointer on her head and she would point the light towards the screen. But once we were able to communicate with her and they got to where they actually could assess her intelligence we found out she wasn't retarded. There's been a lot of other people that have never been able to communicate that had to be at least borderline or mildly retarded but people assumed because they couldn't talk to you they weren't comprehending.

[00:30:58]

SS: You just brought back a memory for me because you and I have known each other on and off over the years for a long time. And one of the memories that I heard from another staff was that, and I don't know if this is an urban myth or internally kind of an urban myth or not but the same kind of thing where they talked about someone who was admitted here and they thought that he was retarded and they found out later he was deaf. Does that ring a bell?

[00:31:22]

PC: I don't remember that specific incident but I'm sure that has happened probably more than once because people assume if you can't speak that you've obviously got cognitive problems. There have been people that have lived here that we found out, once we were able to test them, and sometimes the reason we couldn't get a good test is because they were psychotic and when you test them it didn't show their true levels and once that was treated then you could get a good test level. Actually I can remember one teenage boy that was admitted here and his sister was admitted to Ft. Wayne. He was not retarded but his parents were and it was a way to separate them and then he could go out into a foster home or a group home because of the care problems that he was getting.

JT: When you got here and maybe even before, how did people happen to come here?

PC: They were court ordered but there was a long waiting list to get in. I've read case histories which were pretty tragic because the family was having a lot difficulty, they couldn't care for the individual. Maybe that retarded individual was actually hurting the other children in the family. Mom had a nervous breakdown, there wasn't money to get the medicine, there was a long waiting list and they would go through the court process just like they do now and the judge would order them to Muscatatuck. But they had to wait until there was a bed open and the time came.

[00:32:53]

JT: Did you find many people on your doorstep?

PC: I don't know about that. I wasn't involved in the admission process back then. We discouraged that, told them they had to go through the court service. As far as somebody just dropping them off and disappearing I don't know whether that was the case or not. We were talking about the people having trouble communicating. There was a girl that lived on Springdale and I don't know, she must have been 15 or 16 years old, something like that and very involved with cerebral palsy. We got her a device that she could communicate and one of the first things that she said was 'I want a lawyer.' So that pretty well changed the way people think about folks that don't talk back. But we still to this day we've got folks out on the unit that don't speak but understand everything that's said to them and staff will say things that they shouldn't and then wonder why they put their head through a glass window.

SS: What was the term again?

PC: Low grade.

[00:34:05]

SS: I hadn't heard that before until today and Cindy Underwood mentioned that too. I don't think I've heard that before. It's interesting that we hadn't heard it. She talked a little bit about and I don't know if you saw this or whatever but about some of the difference between how staff perceived each other depending on who they were working with too. Is there some kind of pecking order or hierarchy among the staff related to either which unit they worked on or who they worked with? Was there any of that?

[00:34:30]

PC: I didn't notice a hierarchy. What I did notice was people didn't want to be pulled from one to the other. There are people that gravitate towards higher functioning individuals that can work with people that have got challenging behaviors but they're not good at doing direct care and then there are other people that don't mind lifting and bathing and changing diapers but they don't want to try to cope with people that might hit you. I never noticed a hierarchy but she may have been in some situations in some buildings that that was evident. It's possible.

JT: Did you ever get a sense that some people were treated better than others?

PC: I know that when you look at programming, when you look at who gets to go to movies and who gets to go shopping and who gets to go to Olympics and all of those things, it obviously the ones that behave. As a music therapist I took people out into the community at lot of the time that the rec therapist would not. And they'd say, "I don't know how you're brave enough to take them because they act up on us." I said, "Well, I've never had the problem." They're probably more motivated. Either they like the music that we're doing, the singing and the stuff or maybe it's because they have a closer relationship with me, I don't know. And this is one thing that I don't know why it took me 25 years or so to figure out. If you're going to teach somebody something or if you're going to ask them to change their behavior or do anything, the very first thing that you need to do is build a relationship with that person. When I was working on 10 I was the assistant director but I was also case manager for about 30 women there and I was also a behavior clinician for them too. I noticed that we had a goal for mealtime for this one individual and the staff was supposed to document the data at lunch and at supper, well probably breakfast too but at least lunch and supper. When I was reviewing the data in daytime it was all A's. And on the evenings it was B's, C's and my first reaction was the staff are fudging. The ones on days they don't care, they're just putting A, A, A, all the way down. So I talked to the staff. "How do you explain this discrepancy?" And she said, "Oh, she likes me." And that is true across the board. When you've got clients with new staff that they don't trust, they don't now, they don't have this bond with, they're not going to do as well, whether it be learning a skill or whether it's going to be changing their behavior. But everything I've learned here has practically been through experience and it's just like Duh! Why didn't you see that? I think that happens in the classrooms too. Kids that are misbehaving in one class they're going to settle down and really go for the next class if it's the teacher that they can relate to.

JT: In looking back what would be some of your fondest memories?

[00:37:46]

PC: I think some of my proudest work is the one on ones that I did because those classes seem to give people the confidence to go on and to do better and some of the people that I worked with, like I had a teenage boy come into my class that had stabbed in his classroom in Gary, Indiana. And I think they sent him here to keep him from going to boy's school. He wouldn't participate, he wouldn't do anything. He just sat there with his head leaning against the wall. One day after class one of the other clients came up to me and asked me if he could come into my classroom and study drums. I just saw a flicker. I thought, aha, I know what this guy's thinking. I talked to him and I said, "You know, I've got

one class opening here. I thought maybe you might want to learn to play drums. But here's the deal. You have to participate in my class, you have to sing and you have to be a part of it and you have to participate in your regular classroom and if the teacher tells me that you've been participating and not causing trouble in there, then you can come to my class twice a week and you can study drums." He was a horrible drum player. I just turned the tape up and sat back but he beat on those drums and we'd talk. He got transferred to the Ginsburg Center in Ft. Wayne and when he was getting ready to go up, which was a good move for him, it really was because he needed that vocational training. The day before he left he came to me and he said, "I want you to have this." And he handed me a picture of Jesus that he had got in the chapel. I almost cried. But to see an individual that has had so many problems and be able to progress and go on, that has been a real fond memory. Another thing we used to do here was the haunted house. I don't know if anybody's mentioned the haunted houses that we used to do. I started that in the basement of 10. It was just a party was all it was and it just grew. The next year we'd have to find another location. Two years later we'd have to find another location because it just kept growing until finally it was out at building 18, an old dorm out where Purdue is now. We actually one year took in $10,000. That wasn't clear, because we had a lot of expenses. Our biggest expense was liability insurance. It was all done on volunteer time and none of the state money was used for it. The props, everything that we used, the supplies, was bought out of that fund for the haunted house and then we would take what we made and put into it to do the next year. But those were fun times when we could do stuff like that.

[00:40:24]

JT: What changed the fun times?

PC: All of the requirements for active treatment. We, the past several years since 1998 with the Department of Justice came in here, we have been trying to meet all of the guidelines that the Medicaid program requires plus we've been trying to meet all the guidelines of the Department of Justice requires and it's at a different level. We've got fewer staff that are actually available to do those kinds of things because most of us are tied up doing more paperwork and justifications and things like that. I'm not real sure all the reasons why it's changed. It may just be the focus of the administration on passing surveys and surviving the Department of Justice.

JT: So would it be reasonable to say that the last 5 or 10 years have been more stressful?

PC: Oh, yeah.

JT: Can you talk about that part of the change in terms of how staff and people that live here have felt the change?

[00:41:37]

PC: Oh, it's been tremendous. The week that we heard that Muscatatuck was closing was like a funeral. Everybody just walked around in a daze. Of course all of us were naturally concerned for our own futures as well as the people that lived here. But it's kind of like a prolonged agony because every week we have people moving. Of course in our situation in transitions, we hate to see them leave, we know that they've had a good life here, they've lived here for some of them over 50 years and we really hate

to see them go but we have the opportunity to go out and see the homes that they're in and we see how much progress they've made. Most of the staff at Muscatatuck don't see that. All they see is that they're leaving. But then the other thing that's really hard is to see the staff that are leaving and the staff that are grappling with trying to get other jobs. Some of them do, some of them move, some of them don't and some of them have taken other jobs thinking that's a way to stay employed and then finding out that they could be bumped anyway. So it's been a tremendous stress among the staff. For a long time we had so much apprehension and actually we felt that staff members here were trying to sabotage the placements. I don't know what their motives were for sure, whether they thought that if the clients didn't go out Muscatatuck wouldn't close or whether they thought that there just wasn't anything out there that would provide for them and would take care of them safely. Transitions has been the brunt of a lot of comments, a lot of degradation and it got so bad one time we went to Wendy's and ordered salads and they screwed up 3 of 5 and we said, "Well, they must know we work in transitions."

[00:43:24]

SS: Have you had any personal threat or any personal fear?

PC: I've had people scream and yell at me and things like that. We have had, yeah, we had one staff member that would say things like, "Well, did you kill anybody this week?" Because we had had people that went out in the community and had a couple of deaths and it was our fault, we did it. I think the only way that transitions staff have survived is the fact that we're a team and we all support each other and when one person is having a really bad day we try to, and the conversation that you were hearing is one of our best stress relievers, eating lunch together.

JT: What do you think this place closing means?

[00:44:11]

PC: I was very upset when I first heard it, of course I wasn't aware of the possibilities in the community. I wasn't familiar with waiver homes. I didn't even know what the waiver program was. I was probably as skeptical as anybody here but once I became aware of the process and what was available I think for the most part it's a good thing. I think they should have had more beds at the regional center. It doesn't look like any of our folks will go to the regional center at all and maybe they don't need to. I don't know.

JT: Where there some beds designated at the regional center?

PC: There's supposed to be 60 beds that are MRDD but not of our folks, basically what it's turning into is the people from Muscatatuck that are really, really high functioning and have dual diagnosis. So most of our people are not considered candidates for it.

[00:45:09]

SS: And the regional center is where?

[00:45:11]

PC: Madison.

SS: Is it related to the Gold Unit?

PC: That's what it's going to be is the old Gold Unit.

SS: It sounds like that's the same kind of population.

PC: And the folks from here just don't fit into that group.

JT: The way I understood it there would be x number of beds for people that couldn't place from Muscatatuck and x number of beds for dual diagnosis. But that's not what's happening?

PC: It's not happening, they're refusing to even consider our people.

JT: They're not taking anybody from here?

PC: No. Everybody from here is either going to be placed or go to Ft. Wayne and of course Ft. Wayne is phasing out too.

JT: A couple of years ago we were doing regional meetings, the southeast region . . .

END OF SIDE A

[00:46:04]

PC: . . . or how much they intend to pay us. Those are minor details that haven't been worked out yet. At first they said when they hired the facilitators, now we know that the service coordinators are going to be under BDDS because they already have service coordinators so Melinda and Ann will be under that program. But originally they said the facilitators would go to BQIS. But then after we had been working in this job for 6, 8 months, I talked to the director and BQIS and she didn't know anything about that. She said, "No, I think you're in BDDS." Well BDDS didn't know anything about that either and so several months later we figured out who our boss was finally. At that point it was Mike Smith but they created another area, BSOS so we assumed we would be in BSOS. But I talked to Randy the other day and he said, "You know, realistically there's not going to be a BSOS because that's state operated facilities and we're phasing them out." So he said, "You'll either be in BDDS or BQIS." I said, "Well, that's good to know." So I really don't know. I thought about retirement but I like the insurance and I like the state benefits so I'm just going to kind of wait and see. I work for Tina Hegaman doing private behavior consulting and she wants me to pick up more of that. But I'd really like to stay with the state so I hope they come up with something that I can actually contribute to helping the people that are already in the community and when they run into problems out there I'd like to be able to be a part of that process to help the providers in the community to make it work. Because I know they're going to have problems, that's a given. But it's a matter of how you deal with it when those issues come up and how you get through them that's going to make a difference in the long run.

[00:47:56]

JT: Do you have much contact with people that have left and are living in the community?

PC: I have quite a bit and I have a lot of contact with staff. I was at a wedding last week and a staff person said, "I don't think you remember me from Muscatatuck." She had only talked to me on one occasion when I was doing an investigation. And she told me that she was working with two ladies that we had placed. And I said, "Oh, yes, I know them well." She said, "You just would not believe the progress that they have made." So we frequently have an opportunity to see what's going on. Sometimes we do what we call success stories and we'll talk to the families that have been cooperative, real enthusiastic about the process, especially if it was somebody that a year ago was saying 'no way, there ain't no way I'm going to sign that' and then their individual goes out into the community and they do real well. Then we ask them, "Can we quote you? Can we write up your stories?" Have you seen anything that Nanette has done?

JT: Um-huh.

PC: The book that she's got, we keep giving her more referrals of who to add to that book.

JT: So what do you hear from people that have left? Are they happy?

[00:49:12]

PC: For the most yes. Now, the things that seem to be the most difficult in the people that I have placed, and keep in mind that I usually deal with the folks that are medically fragile or have a lot of medical issues, my whole caseload, they have a hard time finding OT services, PT services, speech and when they do the therapist come in and assess them and say that treatment is not needed. Well basically what that means is that therapist is not familiar with this population and doesn't know what to do with them. Speech therapist, obviously they don't need therapy like you would think about with speech but they do need some type of augmentative communication, they may have [unclear], they need swallow studies, those kinds of things. I'm hoping that the regional center can kind of fill a gap there and have those services available if they can't get them in the community. I've also been trying to link up the therapist here with the community providers. One of the providers has hired an OT and a PT to work part time so they can go into the group homes and do therapy. They know those people. But it's those kinds of things. Another thing that has been an issue, not just with my folks but more so with some of the others we've placed, is getting psychiatric treatment in the community. My mother was a health care rep for a lady that just died last week that left here within the last 8 years or so. She had been in the hospital and had surgery for like hemorrhoids, it was very minor, but they took her off her psychiatric medication. She went to a nursing home to convalesce, still didn't have her medications, 2 or 3 weeks later she goes bonkers on them, starting beating on them, starts getting totally out of hand, they send her to a mental health center to get her back on her medications, her condition worsens, they have her in a wheel chair, they try to move her into a different group home, they sedate her, she vomits and aspirates. Somewhere along the line that doctor dropped the ball. She should not have gone with her medications for three weeks. She should not have. And I don't know whether it was the doctor at the hospital, the surgeon, if it was the doctor at the nursing home, but so many times we place people out and we say

"Don't touch the meds, whatever you do, don't. It's taken us 10 years to get them on this regime." And we finally got the providers convinced but then they'll come back and they say, "The doctor wants to do this or the doctor doesn't agree with that diet. How come they have to have chopped meats?" They want to change it but they don't want to do a swallow study, they just want to change it. So we really need to work to try to educate the medical profession.

[00:52:19]

JT: So I've visited the cemetery when I was here and we talked to people about when people die or who are buried there. The people that have moved out to the community but basically spend their whole life here, have any of them come back to be buried here?

PC: I don't think we've had anybody die since they've placed out to come back. We have told them when they moved, back up until we knew Muscatatuck was closing, that they could. So I asked the other day what happens because we had families that. I don't know what they'll do. Basically the land is there and I would think that the army will have to take over maintaining it. If they wanted to use a burial plot they probably would have to have somebody else open the grave. See now the maintenance department here digs the grave. So whether they'll be allowed to use that or not, I hope they can. But I hope somebody will make a decision and have that agreement before it closes.

JT: I hadn't thought about it until you were saying it and I thought that the people that had lived here for ever and had been familiar with the whole sort of seeing their friends being buried here might, I thought that that's what they were going to do as their families.

[00:53:45]

PC: And because of that they may not, the families may not have made plans for another burial plot. Now we have a lot of folks that are leaving here that have a prepaid burial plan, the irrevocable trust.

JT: Here or somewhere else?

PC: Well, actually it's been established, most of them have been at one of the funeral homes in North Vernon but they can be transferred to another funeral home in another city if they want. Some of those didn't have money in there for a plot thinking, others have. Others that the families say we want to make sure there is a plot and there's enough money in there so they go ahead and to that up front.

SS: Just the physical layout of that is interesting, Muscatatuck residents and community residents.

PC: And I always hated it because you can't see the grave stones, the headstones are flat. I would imagine the grass has probably grown. It's been awhile since I've been out there for a burial but you would probably have to go and dig the grass off.

[00:54:51]

JT: The grass wasn't bad the last time I was out there but it was interesting in that some of them the headstone would say 'unknown' or 'baby boy' and they wouldn't all be identified with a name.

[00:55:05]

PC: I bet the baby boys are the ones that were born here. I don't know why it would say 'unknown'. That makes no sense, does it? Of course when you stop and think that this place was started n 1919 and at that time it was called the Colony for Feeble Minded. They may have buried people and didn't do that. Have you guys seen this?

JT: No.

PC: This is a memory booklet.

JT: Who put this out?

PC: Robin Sterns. And they had an aloha recently for family or previous clients and staff to come out here and they had pictures up everywhere, old pictures and stuff like that. It was kind of a sad day but an enjoyable day too to get to meet with people and talk with them. That's got the history of all the buildings.

JT: Do you have copies of this?

[00:56:05]

PC: That's the only one I've got but she's making 100 more.

JT: We'd really like to have one of these.

PC: Let me ask her if I can let you take that one or if she needs another one.

JT: You said Robin and who is Robin?

SS: We did some early research before we started this and there are some good stuff at the library too. There's one document in particular that really struck us. It's almost like it's a term paper from somebody who must have come out here as part of a class. Have you seen that?

PC: No.

SS: It's in their file on Muscatatuck.

PC: At the local library?

[00:56:42]

SS: At the city library, yeah. And it just talks about what it was like at that time and the diet and the farm that was going on, the population that was here, a little bit about the programming and just kind of very matter of fact.

[00:56:57]

PC: The diets used to be a lot different here. The old cafeteria they served home made yeast rolls and pies and they actually cooked on the units. They didn't have it in a central area and take it out. They cooked on every one of the units. That's a big change.

JT: Is there anything that you would like to just talk about that we haven't asked you about?

PC: No. The only thing that I would hope that there's an ongoing group monitoring the success of moving folks into the community and I hope that at some point we will have, I know that it's a positive thing but I hope we have some data. Isn't it a group from IU that's doing a satisfaction surveys here? That's helpful to have that kind of information. I can tell you that I've had several providers, the most recent on was yesterday, who made the comment that taking clients out of Muscatatuck a few years back when we started this process like even as recent as maybe 3 years ago and moving somebody today is a totally different process. The word she used was 'it's awesome' the amount of information that you're sharing with us about that individual. So I hope that we can document the successes and then if they go through this process again maybe at Ft. Wayne or another area that they can duplicate the process because we are doing everything possible to make it successful. I've even been known to have staff that go and stay overnight for a couple of days to stay with the client to help them smooth, help them work into the home. We've done follow-up; we've got outreach. We had one guy that went and he wouldn't sleep in his bedroom. He'd sleep in the chair, the recliner in the living room but they couldn't even get him in his bedroom. And after a couple weeks of this they called us and said, "Help, what are we going to do?" So we sent his bed and once we got his bed there he would go in there and sleep in it. But it was a new bed and he wasn't familiar with that. We have another lady that we moved and I sent the staff with her. I said, "Go and tell them, help her get to bed and help her feel comfortable." What they told the staff was, "She's not going to go to bed for you and go to sleep. Here's what you have to do. Put her in bed and then you sit at the bottom of her bed and you just have to sit there for about 5 minutes and she'll fall right off to sleep." But she might have been up all night if they hadn't known to do that. Those are the things that none of us think about. You can't find that in any of the reports that we did on that lady but that direct care staff was able to make that work.

JT: When do you think they'll actually shut the doors?

[00:59:55]

PC: It's anybody's guess, just guessing and that's all it is is a guess, I'd say March. The reason I say that is the last home is supposed to be open the first week in February because there was a home that was supposed to have been built in Indianapolis and one the people, the brother of one of the ladies that was supposed to go up there did not want her going into that particular company. So when we pulled that one out and put her into one of the homes down here that left the other two we were supposed to have go up there fledgling. So we had to add another home down here which they just approved I think the week before last. They told them it had to be open by the first week in February. We have got 62 right now. They're all in the process at some point, but we've got several homes that have to be built. There's 5 homes that have to be built.

[01:00:54]

JT: How many staff you have for 62 people?

PC: I think there's about 400.

JT: 400 staff still?

PC: Yeah, I think somewhere in that vicinity.

JT: So when they finally shut the doors and turn the lights off and you look back, what are you going to miss the most?

PC: The people, the clients because they all have such unique personalities. When they call me from their hospital bed at home and talk to me and we've had such great relationships and there have been some that I really had a hard time working with, okay, calm yourself down and do this, both the staff and the clients. Yeah, I'll miss them and we already do. It's a continuing thing. I get tired of going to going away dinners, as much as I like to eat.

SS: One of the things we're finding is sometimes we'll go back and review what we've heard and listen to, could we ask a few more questions . . .

[01:02:01]

TAPE STOPS

SS: We're still with Patty Cook, it's still October 22. And interestingly enough it's about 10 days from Halloween, Patty had mentioned something about some of the buildings being haunted so we wanted to ask you again about that.

[01:02:16]

PC: Well I've never experienced the problems on building 5 but I've had so many different staff tell me that the basement of building 5 is somewhere you don't want to be a night time. And the thing that they notice the most is that they'd go down there and turn out the lights and shut the doors and go upstairs and they go back down later, open the door and the light would be back on. And it's happened so much for so many years with so many different staff that there's something going on. I have no idea what but there's a phenomena there that's real interesting. Personal item, though, building 15 has always fascinated me. I worked in that building for probably about 5 or 6 years total. Every time I've been in the basement of that building the hot water has been running in the men's bathroom. I don't usually go into the men's bathroom, okay, but I can hear the water running and I have somebody check it. And of course being the director and trying to conserve energy I didn't like to have the water running all the time. So I'd send somebody in to turn the water off. The next time we go back down there the water would be running in there, turn it off, and I think well maybe we've got some staff that for some reason doesn't want to [takes a phone call] …So one day my brother came out and he was looking at some of the equipment because we were thinking maybe he could build some equipment for us. We were in the

basement, and this was on a Saturday, so nobody had been in the area. We had no housekeepers here; we had no regular staff there. And as we're going down the hall he stops and goes into the bathroom and when he comes out he said, "You know, the strangest thing, the water was running in there." I said, "Yeah, I bet it was the hot water too, wasn't it?" And he said, "How did you know?" And then another time I was in that same basement and we had a snooze room and we had equipment in there that you would go up and you would hit some type of a button, a switch to make it work, and this one thing I kept trying to make it work and it wasn't working so I thought well maybe the battery is dead or something because I couldn't get it going. I turned around and I started out the door and just as I started out the door it turned on.

[01:04:19]

JT: That's great. Thank you.

END OF INTERVIEW