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Steve and Vicki Ward, May 11, 2005, interview 141-SO, transcript, Indiana Disability History Project, Center on Aging and Community, Indiana Institute on Disability and Community, Bloomington, IN, <http://indianadisabilityhistory.org>

**ORAL HISTORY NARRATIVES MUSCATATUCK STATE DEVELOPMENTAL CENTER WITH
STEVE AND VICKIE WARD
MAY 11, 2005
INTERVIEWERS: JENNIE TODD AND STEVE SAVAGE
RECORD ID: 141-DO**

SW: STEVE WARD
VW: VICKIE WARD
JT: JENNIE TODD
SS: STEVE SAVAGE

[TITLE]

[00:00:15]

SS: It's May 11. It's about 3:00 in the afternoon. We're in Batesville, Jennie Todd and Steve Savage, and we're meeting with Steve and Vickie Ward, and they are Steve Ward's parents. We're here to talk to them about Muscatatuck. We'll just ask you a series of questions and after a while you'll ignore the tape. It just takes a couple of minutes. We'll mostly have a conversation around your experiences.

JT: And sometimes people just like to start talking, and if you want to do that, if you have some things you want to talk about first before we ask you questions, you can do that. Well, can you tell me about how you heard about it and how you came connected to Muscatatuck?

[00:01:09]

SW: We basically had Steve at home, he had a brain tumor since he'd been two years old and he had several surgeries, and several operations and so forth, and we've been back and forth to doctors several times, and I kept him at home until he was 14 years of age and the doctors kept telling me that he needed a structured environment, and I couldn't do it at home. A good friend of mine had his son down there in Muscatatuck and he had him down there for a long period of time. He kept telling me about Muscatatuck, that it worked out good for his son, and we finally made a choice, because Steven was destructive at home. He was just totally destructive. He was like a wild bull in a china shop, so we finally give in and put him down in Muscatatuck and through my friend, he's the reason why we took him down there, and it had a more structured environment. It provided something we couldn't provide at home. No matter what we tried, we couldn't do it. That sounds awful as a parent,

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but we just couldn't do it, to take him around the other kids, and I tried to run my house like an army camp, and I couldn't do it. I put locks on my cabinets, I locked my refrigerators up and I couldn't do it. Steven has a very big eating disorder and I just couldn't do it, no way, shape or form I could take him. I went to every extreme I could think to do, and if I had kept him very much longer at home, I'd have killed him out of kindness.

[00:02:37]

VW: The thing I remember the most is as Steven's behavior got out of control, the doctors would refer at University Hospital, they had a psychiatric unit there, and they would try to help his behaviors, but also because of the stress of not having a structured environment and different things, Steven was constantly having horrible headaches and they just kept medicating him, and towards the end, the last time he was at University Hospital, when he came home, he had like a drug store, and he basically was so drugged that all he did was sleep to try to control pretty violent behavior and stuff. And even University Hospital told us that he was going to have to be in a very, very structured environment for his sake as much as ours, because with the stress and stuff, it was just like a downhill spiral with him, and once he was at Muscatatuck, they slowly took him off all of his medication except for the vitamin, cholesterol pill, just normal medicines, and I think he does take Prozac for depression, but other than that, they've got him off everything else.

JT: Now, was he going to school or anything when he was at home?

VW: Yes, he started out here in Batesville in a regular kindergarten and they knew right away that he had some major learning problems, so then he started in the special ed here at Batesville, and he would have been the age about third or fourth grade...

[00:04:27]

SW: Fourth.

VW: And then they had him at the Rod Center at Sunman for the special ed, and then from there, he went to East Central to a special ed program, and then while he was there, that's when he went ahead and got transferred to a special program and then while he was there, that's when he went ahead and got transferred to Muscatatuck and he attended some schools there in North Vernon.

SS: Special ed in North Vernon. Yeah I'm a little bit familiar with Rod too [inaudible]

SW: They did mainline him some through North Vernon, they did mainline him to some classes there, but not a lot. They did mainstream him into a couple of them, but he was basically in special ed the whole time at North Vernon, but he didn't graduate with the class.

SS: What calendar year was it when he went first to Muscatatuck?

VW: Fifteen years ago. He'll be 29, and he was 14. So it's been...

[00:05:35]

SS: So late '70's, '79, '80 around there?

[00:05:38]

SW: Yes.

JT: When you talk about behaviors, you're talking about destructive behaviors?

VW: Steven has an eating disorder and they told us that the part of his brain that gives him any satisfaction from eating is completely destroyed, so the doctor told us it was like if he ate one hamburger or ate 100 hamburgers and actually made himself sick, he felt no more satisfied, so Steven is just like a very bad dope addict and it doesn't matter what it takes, if he knows there's an opportunity, he'll sit and worry, and Steven's smart, and it doesn't matter how long it takes him, he will find opportunities and that's one thing at Muscatatuck where things were so structure, and the food, there was no sense getting upset about it because he knew he couldn't get to it. Without all of that stress, his headaches went away, a lot of his behaviors went away, and a lot of it is all centered around food. He would eat himself to death if he had an opportunity.

SS: Did you guys physically take him there? Did he go with you in the car?

SW: Yes, we took him down.

SS: For a visit, to check it out?

SW: Yes.

[00:07:00]

SS: Tell us a little bit about that, about your first experiences there, what you thought of the place and what your reaction was to it.

SW: When we first took him down, we met the administrator, we met with everybody down there and went through all the paperwork and so forth and so on. We went down to what you call Mod 2, and I knew right away that unit wouldn't work. It was a real rowdy, loud module. It was the more radical kids. I told the administrator right then that if is the only thing he had to offer that this wasn't going to work for Steven, because he needed more of a calm, relaxed atmosphere.

VW: And quiet.

SW: Nothing against the kids. They was thorough kids, but they was just loud kids, so he took and put us up on Mod 4, which is a more laid back, easy-going module, so Steven, he kind of got into that. The very first day of leaving him there, it was just like somebody tore my heart out.

VW: We felt like failures as parents.

[00:08:00]

SW: It was just very hard to leave him there. Of course, we went to see him every week, sometimes twice and two or three times a week when we first put him down there. Of course, when I first put him down there, I tried to take him cupcakes and little things to make up for putting him down there and stuff,

which was totally wrong on my part because it just kept adding to his weight problem, but then it was just like he adapted to it. After a month, he started calling it home, and that hurt me, that bothered me a lot. You know, this is my home, Dad, this is my home. I got used to it. He says he's got two homes. This here is still his home. We bring him out on holidays, including on his birthday and stuff, and we go down and see him every Sunday, or she does.

[00:08:56]

VW: When it finally made Steve quit feeling guilty is every years when the kids were younger we would go on just a little vacation and Steven, when we would go down to see him, he would always be so thrilled about, well, we went and did this, you know, they had so many activities and things, and he was always telling us about them, and this week I get to go here, and Steve, he said, Steven, remember when Dad took you on vacation every year, he named several places, and he said, you know, Dad did things with you, too, and Steven said, but here I'm with my people, meaning he enjoyed it, where when he was with us, things were hard for him. It got to be with the other kids, and even with Steve, because he had to be the one to try to keep Steven in control, and there was so much friction in our household, I'm sure Steven despised us and it made it really hard for us to handle him. When he went to Muscatatuck, all of that just went away, and we could have a lot better relationship with him. We could be really good to him and I guess didn't have to worry about the behavior problems. It was up to them not to let him eat, and at home, we put padlocks on the refrigerator and cabinets and stuff, and then one night we caught him eating out of the trash can, and that just broke Steve's heart, so we just unlocked everything and he said I'd rather him at least good food versus doing that. Steven, he weighed over 400 pounds when he went down there. He was down to about 275, but now he's back up to maybe the highest, 320, but they're kind of keeping it a little more under control now.

[00:11:08]

SS: Where's he living now?

VW: In North Vernon, at Oak Meadow Apartments.

SS: We're certainly hoping he'll come over on Saturday, so make sure he gets an invitation. It would be nice if he would. He is a treat by the way.

SW: He's a pearl.

VW: But it made it to where we could enjoy him and he could enjoy us, and even all the other kids. I guess Steve had to be so strict and stuff, some of the kids were really little, they were all afraid of him because big, bad dad and it just made the whole household calm again and Steven was just like a flower opening up when he went to Muscatatuck. Instead of just laying and sleeping, he would wet the bed every night and do a lot of behaviors and stuff.

[00:12:13]

SW: Poop on the walls.

[00:12:14]

VW: Yes, and they just slowly, it didn't happen all at once, but slowly by slowly they improved and he grew up a lot being there, because we were always so afraid of losing him because the doctors had told us that he would only live to be 10 to 12 because of the tumor he had and everything, and for some reason, he'll be 29, so he's beat the odds so far, but it was really hard to tell him no when you'd seen him in the hospital so much and going through so much.

SS: Did you get to know any of the staff down there?

SW: Oh, yes.

SS: Talk a little bit about some of the staff.

VW: Marietta was the one that Steven first had that he ended up, he still loves her to this day, and she works with Archer which is where Steven's at now.

SS: So a staff member moved to Archer when he left?

VW: Yes.

[00:13:18]

SW: Yes, he took them down. There are several of the staff that come and went over the years that he was down there, and some of them we got on a first-named basis and stuff, we didn't hang out or nothing, but we got on a first-name basis with them and we talked to them quite a bit when we were down there and kind of broke the ice with them a little bit over Steven and stuff, and they kind of kept us what was going on with Steven and everything. Then Marietta, she took and she quit, she retired I guess, and went to work for Archer, which is where Steven's at now, and then she contacted us when she knew Muscatatuck was closing and wanted to know if she could take Steven in one of her houses. I felt good about that, because I know Marietta from Muscatatuck and I trust her, and she's worked out really well. She hasn't led us astray or anything. Archer is not, I mean, they've got their faults, they've got some things they still got to work out yet, but I think over all it's a pretty good deal. They're not as good as Muscatatuck as far as secure, as far as I feel what Muscatatuck. They've got a ways to go.

VW: We did not like Steven to leave, and if we had a choice, we would still rather have him at Muscatatuck.

JT: Talk about that a little bit more, why.

[00:14:44]

VW: Muscatatuck was just like a small little town for the handicapped people, and the workers and everything were trained to take care of them and they were very cheerful around them. They could make them follow the rules and stuff, but they had a way of doing it that was very nice. If one of them was throwing a temper tantrum, they would just say, go to your room until you can calm down. If they wanted to go in there and slam the door and come out a minute later, it was over. There wasn't a lot of punishment, but the whole place had sidewalks everywhere and Steven, he could walk and go get his hair cut. At the beginning, there was a school there, he would go there. They would take them to

church, they had their own hospital which he was in several times. They had a train that would pick them up in the evenings and it was their choice if they wanted to go or not, but it would just travel all over grounds and they would have activities every day, but major activities at least once a week where it would be a gathering where they would have dances, and they would go on picnics, they would have carnivals. They would bring horses in and let them ride them. Everything was geared for the handicapped. It was very safe and us, as parents, I didn't feel we had any worries at all.

[00:16:26]

JT: So you feel, overall, the care he got was worth it?

VW: Very, very good, mentally and physically.

JT: And his day-to-day life, you felt that was good, too, in terms of whatever he did from the time he woke up until he went to bed?

VW: Towards the very end, his programs kept getting cut out. It got to where he was getting a little more dissatisfied, but when Muscatatuck was thriving up until the last, they said they were going to close, it was a very wonderful place. It was a very wonderful place. It was beautiful. They had a campground they took them to. They even had pontoon boats they took them out on.

JT: Do you remember, if you were to think back before they started losing funding, do you know what a day of Steve's life would look like? What would be a typical day?

[00:17:22]

VW: When he was younger, he would get up in the morning and have his breakfast and stuff, and then they had a bus that took him to the regular school and he would go there, but then as he got older and graduated, he was on a very routine, where he would get up and he would go to work, and he would walk to work, and he switched several different jobs. Sometimes he would go to work and then come back and maybe in two or three hours, go someplace else. They had crafts that he would go and paint or do whatever little cement things that later on they would sell. It was very structured. Steven knew every minute of every day what he was going to do, and that just erased all of his stress. But they kept him busy, didn't they, Steve? On weekends, it was a lot more lax. The only complaint of the caregivers was that sometimes they thought maybe they tried to keep them too busy, and the weekends were nice because everybody just kind of got to lounge around or sleep late, but Steven always liked it through the week whenever he was always busy.

[00:18:53]

SW: One of the things with Archer right now they've got to work out, and I'm sure with any of them, they're having a little bit of help problems, and they schedule something and then the help don't show up, so they don't have it. Like the other day, they had a brand new person on for Steven, and Steven took and convinced her that he could get into his money, because we give him money every week to go bowling and do different activities, so he convinced her that he could get into his money in his lock box. Well, he

went and got his money in his lock box and there's a little gas station in front of the apartment house, he convinced her that he could walk up there by himself.

[00:19:29]

VW: And he's a very good risk for fall.

SW: So he went up there by himself and took about five dollars' worth of candy, and shoveled down five dollars' worth of candy. Of course, they fired the girl because she said she didn't know no better. I mean, still, Archer's got some problems with stuff like that that they wouldn't have at Muscatatuck because Muscatatuck would have people that were veterans enough there to know, no, you don't do this. They had a little eat-out machine on what they called 7, and if the kids wanted a pop or wanted something like that, they could walk down on 7 and get a Coke, but they'd know if Steve had enough money to get a Coke or something, one of them would walk him down there and instead of buying candy, he could buy a Coke. So they kept a close eye on him and stuff like that. That's where Archer has a fault.

VW: And mentally, at Muscatatuck, Steven knew everyone and if he would walk to the administration building, the people that worked there would talk to him and make over him, and brag on him, because he had worked there. He had worked at the pharmacy or different places, and it was just like a little town that Steven, he felt very loved and I think a little bit, he feels a lot more isolation because he really doesn't have all of that in place anymore, other than just...

[00:20:54]

SW: There's too many switching hands, there's too much coming and going, too many people going all the time.

VW: Some people had been there for years, and year, and years. Sure, new ones came and went, but there was always the stable people around, and he's lost all of that. Because he had really gotten attached to a lot of them.

SW: And that's a lot for him, because of his state of mind or mentality, for him to take...Steven doesn't forget a name. He can remember names that I can't remember. I've got to stop and think for a minute. He likes to have that longevity of people, and he don't have that with Archer as much as he did...I mean, there's some at Archer that sticks around, that's been around there since he's been there and stuff, but they just seem like they have quite a bit of help problems, and I'm not saying it's just Archer, I'm saying it's probably all of them, because they don't pay that well, it's not that great of a job, and people's just not willing to work.

[00:21:54]

VW: And when it was Muscatatuck and the State, there always seemed to be plenty of money, and now it's just like the last time they brought Steven here, he was worried about where he was going to get his next toothbrush from. Everything is so down to the penny, and a lot of care, well, I've got an insurance thing over there, which I carry insurance on Steven, and at Muscatatuck, they had their doctors, they

had the nurses and they had the physical therapists, all of these people that he needs, a dietician, well, now they're having to take him out into the community, which I don't agree. We have a lot of trouble over the dietician and different things because they didn't know Steven, but it is costing my insurance, I think this month it was \$6,000 just to provide what Muscatatuck provided and to me isn't even as good of care as Muscatatuck did, and once my insurance gets maxed out, which eventually it will, I think it's \$1 million through a lifetime, then Steven's going to have to rely on Medicare and Medicaid, which is going to cut what he's allowed to have even more, which is a big fear, but Muscatatuck just had everything they needed right there, and now they're constantly, they had their own dentist, their own barber, and I know cost-wise, it has to be costing double and triple what it cost keeping Muscatatuck running.

[00:23:45]

JT: So when you go visit Steven's new place and you talk to him, what kind of impression do you get besides worrying about the money?

[00:23:54]

VW: He likes it there, but in the beginning, he really missed Muscatatuck, and with Steven, you've got to be careful because he wants to be a pleaser, and a lot of times when you're talking to him, he'll tell you what he thinks you want him to say. But first I know he missed Muscatatuck a lot. He called out there a lot, and he was real worried about what happened to the people on his unit, because he had been with some of them for years. They were just like family. He had a girlfriend at Muscatatuck, which now lives completely in a different town, but he likes where he's at, but he gets a lot of disappointment and a lot of frustration, because, just like Steve said, well, for instance on mother's day, it had all been set up that they were going to bring him here, his grandmother was here, his aunt and uncle, and I fixed a mother's day dinner, and it was very exciting to Steven. Well, he called me that morning about an hour-and-a-half before he was supposed to be here, and you could tell that he was very, very hurt and he said, well, this girl didn't show up. I can't come unless you can come and get me, which I couldn't because I was in the middle of trying to cook this meal, and I said, well, Steven, all I can do is bring you a plate down the next night, and he said, I know, but you could just hear the hurt and he has, every week, I would say there is something major that he has been disappointed over. I know that's life, but that didn't happen at Muscatatuck. And at Muscatatuck, the jobs they had for him, because he loved the people there so much, it may be working in the pharmacy and he may just be taking a black magic marker marking out the people's names before they threw the bottles away, or shredding paper, or he worked in the administration building, with paychecks. He felt important. Well, the only job they could come up with him right now, which he's on the borderline of getting fired from because of food issues, is doing something where looks at cardboard boxes to see whether they can be re-used or not. He says he likes it, but the thrill's not there, so they can't offer out in the community what they offered at Muscatatuck, as far as him feeling really important, like he walked to the administration building and did payroll. So, that I'm very disappointed in because as hard as they try, there's not as much out there for handicapped people as they lead you to believe, and anything that's out there, there's a whole bunch of people wanting it, just like this job sorting cardboard boxes. They called and said if they couldn't get Steven's

eating under control, there was a whole lot of people that wanted that job, so they would have to fire him.

[00:27:13]

SS: Where is he working, just out of curiosity?

SW: Down there at Austin at the workshop.

VW: Futures, I believe.

SS: Down there by Wal-Mart

SW: All handicapped people.

VW: I know everybody's doing the best they can, but the money issues is making it hard and so many programs aren't there anymore, and sitting and sorting a cardboard box can't be very fun.

SW: I know with being handicapped, I'm sure any job you do, the work is limited. There's not two ways about that. Even out here at New Horizons, kids out there...work's very limited out there. Some days, they don't have no work out there.

VW: Well, at Muscatatuck it was a town filled with handicapped people, so Steven felt really good there, and now he's a handicapped person out in the world with a bunch of normal people that don't understand him, is probably the best way I can put it. Even though people try, they don't understand.

[00:28:29]

SW: He tried working a regular job at [inaudible] and he couldn't do it. He had a habit of stealing their pens.

VW: He's got a hoarding disorder and the eating disorder. So any job he has, you have both things working against him.

SW: I'm not exaggerating, he has probably got 150 pens, because we buy him at least 50 pens every Christmas.

VW: He's probably got 500 or 1,000 pens.

JT: He likes pens?

VW: Well, it could be anything, it doesn't matter, Steven just likes to collect, he's a pack-rat. He even did that as a little kid. If he wants it, he takes it, and it's not like he's really being bad, he just wants to add it to his collection.

[00:29:26]

SW: He had job in North Vernon, and he did real good cleaning offices, and he had just tons pens. They called Muscatatuck up and told them, our pens keep disappearing, and they got to looking at Steven's

collection, and, sure enough, there they was. It ain't that big a deal, but you go get a pen and you don't have it. Steven started stealing the pens.

[00:29:54]

VW: I think the state held Muscatatuck very, very accountable for every little teeny detail, and now they're way out in the big world, and all that accountability, as much as they try, I think their care depends on who happens to be there that day, and the accountability's not there like it used to be. We're lucky with Steven because he can talk, and he can tell us, and I think because of Steven, there has been three or four staff members fired already, that if Steven couldn't talk, I would be terrified because the boy that's in the home with him is blind and he's a lot lower functioning than Steven, and Steven brought it to the attention that while this certain staff member was there, he wasn't feeding this boy. He has his meals pre-made because they have to be pureed and they got to checking without the guy knowing and they would count the boy's dinners and then count them again when his shift was over, he was not feeding this boy.

SW: He would take him and jerk him out of his wheelchair.

VW: If Steven hadn't told that, that's a sad thing.

[00:31:17]

SW: The same issue, Steven told one of them down there, the same kid, let's take him somewhere in a wheelchair and the kid didn't want to do something, and they took him and jerked him out of the wheelchair and slammed him. Stuff like that, that gets to me pretty quick.

VW: If you think about it, the state and Muscatatuck, they had very, very good state insurance, they had a very good state retirement, and the money probably wasn't that great, I think they probably made \$10 an hour or something, but there was that state insurance and retirement they were looking forward to. These people, I think their insurance is really no good, they're making \$8 an hour, they have nothing to look forward to, so the caliber of people that they're getting, a lot of times they're people that maybe got fired from somewhere else and they're just desperate for a job. They're got good people. I can always tell which ones are really good, and which ones are lazy, or they're just there and not interested, and I'm lucky because they all know Steven will tell on them.

[00:32:28]

JT: Well, we were impressed when we talked with Steve just because he was so articulate, and I've done some work and we put together a training, which Steve came and gave us a lot of feedback on the training and potentially still will be a co-presenter to tell his story, because the topic is about choice, and he was talking about how he doesn't choose his own provider, and how about he had some help in figuring out some questions to ask people that would serve him. So you could tell that he was really, you know, on top of his game. He liked the jobs at the pharmacy and with payroll, and he showed both of us his room. His room was just amazing. He's got a huge room all by himself, and I could see there are lots of things he enjoyed because he was very friendly. He had a lot of status there.

[00:33:22]

VW: And he had a lot of freedom.

JT: So, do you think, given time and giving him some time to make some new friends and to get familiar with the community and maybe find a different job, do you have a sense to how he'll react and be pretty happy in his new environment?

VW: Yes and no. I'm really afraid now that the state has these places like Muscatatuck closed that the state will just, because of budget, will keep tightening the screws on the money, because in the beginning, they were supposed to have somebody, there were two people in Steven's house, and there was supposed to be one for Steven and one for this other boy, two shifts a day and then only one at night when they were sleeping, and it was kind of presented to us that this would be kind of like Steven's friend or whatever for the day, and basically whatever Steven wanted to do, they would be there to take him, whether it was the library or whatever, and it wasn't no time, it's down to they only have the double staffing I think six hours a day now, and during that double staffing, they still have things they've got to do within the home, like the showers and all this kind of stuff, so Steven's one-on-one is very minimal, and that, I think, is very unfair and it's not Archer's fault, it's the state's because they won't allow it.

JT: Has he gotten involved in some community activities, like a church or the library?

VW: He was going to church every week, but now I'd say three out of the four Sundays he doesn't go because of staffing issues.

[00:35:18]

JT: So he can't get there?

VW: Right. And then he volunteered at the nursing home, which they're being pretty good about getting him there where one day a week he goes and pushes the people in wheelchairs to their activities for exercise, plus him feeling he's doing something good and then one day a week, he goes and helps them with Bingo, which is Steven's favorite game. So actually I think it was more fulfilling for him to volunteer at the nursing home than Futures because it knocked him out of some of the nursing home because of working now, and I just hate that he's there eight hours looking at cardboard boxes. That just bothers me. I just feel that...

JT: That would be monotonous.

SS: He can't go to the nursing home when he goes to Futures?

VW: He was going to the nursing home three days a week, and I think now he's going one or two, so it's cut it down some.

[00:36:28]

SS: What did you guys like best and least about Muscatatuck?

[00:36:35]

SW: I think the best part I liked about Muscatatuck was the structure and the people, and I guess the least part was sometimes the DSTs was different. Some of them followed the book straight to the tee and other ones took it was lax. There was certain ones that took them that was A to Z 110 percent, this is the way it's going to be, this way it's presented in the book, this is the way it's going to be, there ain't no changing, bam, it's going to be this way right here, strict as it can be. And then you go down there the next week and you've got another set of DSTs, and they'll take and they won't follow the rules...

VW: They'll bend the rules.

SW: They won't bend them enough to where they can hurt anything, but they'll bend them enough to take common sense. It's just common sense things. Okay, you're not allowed to have over two ounces of water. We're going to take and measure two ounces of water, that's all you're going to take to need. Now, if there's a medical need why you can't have two ounces of water, that's fine, but if you're just going to be a butthead and say you're going to have two ounces of water, that's just being a butthead.

VW: But a lot of them at Muscatatuck, I think the reason DST's was like that is they were so afraid of getting fired, because if there was one of those rules that they got caught not following, the Muscatatuck whatever was very unforgiving. We would have preferred them to be a little more lax.

[00:38:06]

SW: Most of them as a rule was. There was just a few of them that was taking, I mean, they took, one of them in particular I can think of, if they gave the clients a 30 minute time period to eat the meal. Some of the clients didn't sit for longer than 30 minutes. That's just an example, I don't know if it's true or not, but that's just an example taken. That's just not cut and dry. If kids want to take more than 30 minutes to eat, let them sit there and eat.

SS: You might be able to do that some days, and other days you feel like going slower.

SW: Stuff like that, they're more stringent towards than they should have been others, and it's just cut and dry towards things. Overall, Muscatatuck had some really, really good people down there. They had some really good DSTs, there was just probably one or two that was taken kind of went off in left field a time or two. Maybe they just didn't like the clients, or they had a reason not to like the client or whatever. I don't know.

JT: They sure had some long-time staff.

[00:39:11]

SW: Yes, they did. Steven never had a problem with any of them. Now, I don't know how, because he hit one of them in the nose, busted one of the girls in the nose when he first went down there, and slammed a door on one of them. He had his temper tantrums when he went down there and stuff, but they never did hold a grudge on him. They told me about it, and I said, oh, my gosh. He actually hit one square in the nose.

[00:39:42]

VW: Steven at Muscatatuck and here has his favorites and ones that he don't like, and even at Muscatatuck, he would spend more time in his room when that person was on the shift, and I think he does the same thing at the apartment. There's several of them that he really, really, really likes, but then if it's one that he doesn't, he just kind of turns into a hermit.

JT: So in hindsight, do you feel like Muscatatuck really did help Steve?

SW: Oh, big time. They made him grow up, because when we first had Steven down there, and say for instance you're going to get a shot or an IV or get anything like that, he would just take like a two-year-old kid, worse than a two-year-old kid, scream, kick, holler, the whole nine yards. And over time, Muscatatuck just got him to taking, if he needs an IV or needs a shot or whatever, he just throws his arm out there and takes it. And I know the last time he was up to IU, they did some work on his head, and the stitching didn't quite take, and the doctor said, we'll just stitch it up and Steven just threw his head down on the table and said, take and do it, doc, and they did a local right there on the spot, a little local shot and they just sewed him right up. Steven didn't flinch a bit. If that had been 14 years ago...

VW: They would about had to put him to sleep to do it.

SS: You say he has brothers and sisters, as well?

[00:41:20]

SW: Yes, his brothers died and he's got three sisters.

SS: Do they visit with him down there?

SW: Well, not a whole lot, but some. They visit with him on the holidays and stuff when I brought him home on holidays and stuff. They don't go down with us to Muscatatuck very often.

VW: When they were younger, they would. Now they're all grown and married.

SW: But they don't go down too much.

SS: Any of them live around North Vernon? How did he end up at North Vernon, just out of curiosity? Did you guys have any input on that, or did they offer any options, or did they just say that's where he would go?

[00:41:59]

SW: We didn't want him around Batesville, because if he's around Batesville he relates to food. So we didn't want him no farther away from home than an hour, so we asked that he can placed someplace around North Vernon or Greensburg or someplace, be far enough away that he still knew he wasn't close enough to home that we couldn't come and get him every day. So we took and asked him to be placed in North Vernon or Greensburg.

[00:42:25]

VW: Well, we wanted North Vernon because of being Muscatatuck for so long, they're out in the community so much, and we figured at least it wasn't one thing that wouldn't change. He knew the community, and to me, North Vernon is very good to the handicapped because they've been years being used to them.

SW: So that's why we kind of picked North Vernon versus Seymour or Scipio or anything like that.

JT: They respected your wishes.

SW: Yes, they did. Marietta worked with us real good on that. She really did.

JT: Do you feel like your transition from Muscatatuck to his apartment went pretty well?

SW: Overall, I think it went pretty well. It was just a little bit drawn out, I think. It was just a little bit drawled out type of thing. I mean it was taking, it was going to happen, it didn't happen, then all of a sudden it happened. It was that type of thing.

JT: It happened pretty quick.

[00:43:28]

SW: Well, they called us up and said, we're going to do this, get through the paperwork, so forth, so on, you take and wait for a while, what's going to happen here.

VW: A lot of it is waiting on approvals, I think.

SW: It just kind of went by the wayside and we thought, well, it's not going to happen, and then all of a sudden, well, it's going to happen, and then it was like, well, you've got to wait for this.

SS: We're back with Steve and with Vicki Ward. It's May 11, 2005, and we're in Batesville. We're continuing conversation with them about their son, Steven.

JT: Do you get down to see Steve pretty often?

VW: I go every Sunday to see him, and then they bring him here. I think he's been here three times, Steve, or twice?

SW: Twice.

VW: They bring him because it's hard for him to get down there, so they bring him and then he visits with us. We see him once a week for sure.

JT: How long of a drive is it from here?

[00:44:44]

VW: It's an hour from here.

[00:44:46]

JT: When you guys visit, do you do anything in particular?

VW: Sit and talk. He likes to play board games. A lot of times he'll want me to play board games with him or we'll just go in his room and he just wants to talk, tell me about his week. And a lot of times I think when he wants to go to his room, it's just private between me and him and he can feel more free, I can see if he's really happy and stuff like that. Every once in a while, I'll take him out, like on his birthday, I'll take him out to eat, but then again, I've got to be really careful with that because he's as good as gold, but when it comes to food, and I guess with us, he's a lot more to ask and want and when you tell him no, you never know when a bad behavior is going to happen.

JT: So you feel like those behaviors are still happening, or are they just something that you're fearful could happen?

VW: Oh, they could happen very easily and do from time to time.

SW: He'll throw a chair across the room.

VW: Like we take him for all holidays, we have big family gatherings, and he takes quite advantage, and if you take it away from him, he'll take the place apart.

[00:46:15]

JT: Now, am I correct in remembering that he had stomach surgery?

VW: Yes. What do they call that?

SW: They took the skin off.

VW: Where's lost from 400 and some pounds to like down to 275, and they took all the excess skin.

SW: The skin fold.

JT: But he didn't have any surgery to reduce the size of his stomach, just the excess skin?

SW: The shunt runs into the stomach, the shunt from the brain, the tubing, now he's had that, but as far as any reduction of the stomach, no.

VW: Even if they reduced his stomach, it wouldn't matter because his brain is telling him to eat. [multiple voices]

SS: He doesn't have the ability to know when he's full?

[00:47:09]

SW: I've seen him, when he first got out of the hospital, back when he was two-and-a-half, he was 19 pounds and, of course, he was skin and bones. Of course, I wanted him to put some meat on him, and I let him eat anything and everything he wanted. And I'll never forget, he ate a bag of chips, two hamburgers and

I think a hot dog, and threw up, and it didn't bother him. He wanted to eat again. Right then, I said, there's a problem.

[00:47:45]

VW: It was hard to realize it was a medical problem and not just a behavioral problem.

SW: I didn't realize then, I thought he just ate too fast, he was just getting out of the hospital, and he just had the surgery, and he kind of looks pretty skimpy, and I thought, well, I'll let him eat some more, so I did, and just over the years, I probably did as much contributing to his weight problem as anybody has, because I'll take and kind of give into him quite a bit.

JT: That's easy to do.

SW: Especially when I saw him eating out of the trash can that night.

VW: That broke his heart.

SW: Immediately, I took every lock I had in the house off. I said I'm not doing this and not living with this. He'll take and drink a whole liter of pop at a time. He'll drink almost a whole gallon of milk at a time.

VW: If it's there, he'll eat or drink it until it's gone.

SW: Whole sticks of butter.

[00:48:41]

JT: So when he comes home, you pretty much have to clean out your refrigerator.

VW: We was cleaning out the refrigerator and putting it in a cooler in the garage. I got up one morning, and he was trying to open canned food, which he's got one bad arm, which he couldn't do, and then I realized, he can't even sleep because that food's there, and all he does all night long is rummage and that's when he ate things out of the refrigerator you wouldn't think, jars of jelly, sticks of butter, and we just don't bring him home overnight anymore. We'll bring him to the holiday, which will be two or three hours, and then we take him back. We just can't keep him overnight at all. And he gets real stressed out and we usually end up having a major behavior problem if we keep him longer than that. Because when he overeats, he gets real kind of mean acting.

JT: I wonder how they deal with it in his apartment.

VW: They had to lock everything up.

SW: They put everything under lock and key.

[00:49:55]

JT: And then you think he [inaudible] at night as to how he can get it like he did here?

[00:50:02]

SW: He knows he can't get it.

VW: He doesn't do as good at the apartment as he did at Muscatatuck, but they've caught him out, the reason he can't be by himself other than he's a fall risk, he was getting in people's cars at the apartment looking for food, and you basically have to keep him in your sight at all times, and he knows the cabinets and refrigerator's locked now, so I think it's took a little bit of the edge off from him, but they did have to lock it all up.

JT: Did you guys get back together, or had feelings about the closure or different issues?

SW: No, different ones sent us letters, we got correspondence from different people and so forth and so on, and I didn't go or correspond because I felt like that once they got involved or take a stance where they did go, you just got sent home.

VW: You can't fight the state.

SW: You're just fighting city hall, and I thought, you can try to get together and gripe all you want to gripe, and you've wasted you time. That was my feeling. Maybe it's wrong, but it's just something to make your blood pressure rise, and I just felt like it was a wasted effort to go back, because I figured once the state took the decision it's going to happen, and the governor says it's going to happen, it's going to happen. There wasn't no two ways about it. I wish it wouldn't. If it had been something we could have boycotted and I felt like it would do some good, I would have been the first one in line.

[00:51:34]

JT: I remember Steve telling me [inaudible] [clock ding in the background]

SW: I'd vote against it. I voiced my opinion very strongly about that but what I seen from the governor, and the news was coming straight from the governor, it's just fighting city hall now. You just can't fight city hall. It's just unbeatable.

VW: Something that throws a red flag up to me, two of the people that got fired in Steven's apartment who were working for Archer, they're now working with DSI, so it's like any bad apples, if they get fired from one, they're going to go to the others, and not just Archer and DSI, I'm sure it's everywhere. You just kind of wonder why there's not maybe a little bit better checks on them and stuff.

JT: Why were you fired?

VW: And why doesn't anyone pick you up?

SW: Well, I'm sure it's a market out there, you're going to hire them if they walk, talk and read, you're going to hire them.

[00:52:41]

VW: Yes, because they have to fill them positions.

[00:52:43]

SW: You got to fill the positions. I know from [inaudible] about a year before I started driving a truck, and you don't do a lot of background check on people if you're in a position to need people to hire. I mean, if they walk, talk and they look presentable, they look like they'd do the job, you give them a chance. I didn't give a lot of kids background checks. If they looked presentable to me, if they looked halfway decent, I took a chance on them. So a lot of people, if you're in that need right now to take and fill the position, you fill it.

JT: Some people don't feel like they have the luxury of time to do the background checks. They need you to start tomorrow.

SW: If you can walk, talk and read, put this uniform on and be here tomorrow.

SS: If you think back to some of the rules that they made, anything that ever, just an experience, something that just struck you, good, bad or indifferent, something just sticks in your mind?

[00:53:37]

SW: One bad one. They had a kid down there, and he was about halfway sane, all the kids down there were sane, don't get me wrong, this kid, he liked to hit you. He's a pretty good sized boy. He was as nice and polite as you want to take him to be. I was talking to him one night, I was joking around with all the kids down there, any of the kids wanted to talk I'd talk to them, and I'd buy them Cokes, I'd do whatever. I was talking to him one night, and was getting ready to leave, and I was telling Steven bye, and I was hugging and kissing him bye, and Sam took and hit me, I had my back to him, and hit me right here on top of my shoulder, and it staggered me about three steps, and if he had took and hit me about another two inches, he would have caught me dead square in my jaw. That's how hard he hit me, and I turned around and naturally it put me on defense, and he was like, ha, ha, ha, I got you, I got you. I felt about this high. I said, Sam, don't you ever hit me with my back turned like that again. If you're going to hit me, hit me when I'm looking at you. He'd take the DST's and they said, I'd ask one of them, if there'd be a big old place on his jaw, what happened, that damned Sam. He'd just haul off and sock them. That was the one bad experience I can remember down there. None of the other kids or people down there ever did do anything bad. They might talk a little trash, but that's the only one that ever got to take to really wanting to pop me that night. And he staggered me. He hit me hard enough to stagger me about three steps. I took them.

JT: Did you feel like the staff was really good to everybody? I know you said they treated Steve really well, but did you get a sense that everybody was treated well or that there was a pecking order for different clients or people that weren't as conversational or couldn't tell on them? Did you ever get a sense they were being treated differently?

[00:55:59]

SW: Not really. I think all of the staff, I think they treated the clients equally. I think each client had a different clique to them, like Bruce, if Bruce was in a good mood, he liked to be picked on. If he was in a bad mood, you'd better stay 10 foot away from him. And the DST's could tell. If Bruce was in one of his

moods, he'd like for nobody else to take him up and just come up, he'd threaten to cut his ears off or do something to take one-on-one attention. If Bruce was in his bad moods, you'd better say 10 foot away from him, because he'd try to ram his head in the mirror, or do something to inflict pain upon himself. Overall, the DST's, they'd take and could tell with all the [inaudible] and stuff, I think they took and could tell with each individual what kind of mood they was in, and they took and kind of deal with teach mood the people was in, not just particularly Steven, but each individual, like eight kids or eight men over on that side, and they had DST's over them, and stuff, one responsible for four, and the other was responsible for the other four. And each one pretty much knew how to handle their people, and I never seen one time that they ever picked or they ever took them or singling out an individual and just picking at them.

[00:57:32]

JT: So in your opinion, everybody was treated pretty evenly?

SW: I think so. I think everybody was treated pretty fairly.

SS: Anything you remember, any incidents or anything like that pops out of your head?

VW: Well, I think they were all pretty well treated fairly, but I do think all the DST's had their favorites, and sometimes it might have been Steven, and other times it may have been Bruce, but even though maybe they had a favorite that they joked with more or whatever, I think they very adequately took care of all of them. But the part I think the most about and -186- is those people on the PRV's, they become a family, and Steven, he likes to help people, and for him to go up to somebody that is completely handicapped that can't move or they're in these little carts because they can't walk or anything, then he would cover them up, or if he was drinking a pop, he would get a glass and give somebody, it may only be this much, but here, you can have some of my pop. They loved each other down there.

[00:58:52]

SW: It was a tight unit. It was like being in the service, it was pretty much a tight bunch of people.

VW: You know, they went to church together, went to parties together, sat and ate together, danced together, but I just thought Muscatatuck was like a little world for handicapped people.

SW: Even the girls, even the girls saw they needed each other. They got back and forth to look at stuff. I mean, nothing sexual, or nothing like that, but they even took them, when they went to dances and stuff, they took and knew each other, and they danced with each other.

[00:59:33]

VW: I guess the world, the way they think now is that it's wrong to have the handicapped people separate, and maybe that's true, I'm the one that's wrong, but it just seemed so nice that they could have their own special little place that nobody bothered them and looked down on them because they were handicapped. It just seemed like a very safe haven for them.

[00:59:59]

SW: They didn't have the staffing problem, because if somebody didn't show up, they just kept a person over, it was mandatory. There wasn't no ands, ifs or buts about it. I mean, it was strictly mandatory that you had two people on all the time, so they had to pull it from somebody else or call somebody in. That's what they knew going into it.

SS: You have a particular memory, Vicki, like Steve had? You get punched? Just something that pops into your head when you think about it.

VW: You know, with me going down there every week, a lot of them got attached to me as much as Steven, being my son, and it got to the point that Steven was getting upset about it because they were taking his time, and it got to where they would have to let us go in the kitchen, just me and him one-on-one, because it was getting to the point they were all wanting my attention, too, and I couldn't leave without five or six out of the eight, I would have to kiss and hug them bye, you know, you just got very attached. So I guess that's the memories I have that I kind of miss, because you get attached to those people.

[01:01:17]

SW: One other memory I have, we first started going down there, and Bruce had been up from his bad mood again, and like I said, he gets off in a bad mood, he gets self-destructive, we had just gotten there and they had just got done sewing his head up, and he had still a little bit of blood on his face and stuff, and we walked in and Steven hadn't been down there probably a month or two, and walk in seeing this person with blood on his face and stitches in his head, and I'm thinking, what kind of place have I gotten my son into here? I'm kind of thinking this. What happened is Bruce had got mad at somebody one of the DST's and had gone back in the bathroom, grabbed a wheelchair and had pulled on the sink until he got it broken, and then he cracked his head into the mirror, and split his head open right here, right before we got there. They had just brought him back from the hospital and brought him back to the unit. We walked in right after all this happened, and everything was cleaned up and everything was hunky dory, but we walked in and his head had been stitched up, and Bruce was still mad as a wet hen, and he was proud of a peacock of what he did. But you walk in and see this guy full of stitches and blood on his face.

VW: We thought one of the staff had clobbered him or something.

SW: I'm thinking one of the staff hit him or something, I'm thinking what happened. I asked Steven, what happened here, and he proceeded to tell me and the staff jumped in and said, oh, no, no, we didn't do that. What kind of place do I have my son at here? He'd only been down there for about a month-and-a-half, and I was pretty paranoid about it.

[01:02:51]

VW: A lot of them down there had a lot of very crazy behaviors and until you got used to it, it was different being there. They had one boy that had something wrong that he would have drank himself to death, so they had to limit what he could drink, but if they didn't keep an eye on him, buddy, he would be grabbing somebody else's drink off the table. Then they had people who would bash their heads. They

had to end up putting helmets on them. It was a crazy place, but I guess you just understood because the people couldn't help it.

[01:03:31]

SW: You got used to it.

JT: What do you think people that didn't know anything about Muscatatuck thought about it?

SW: It scared them.

JT: You think it did scare them?

SW: Oh, yes.

VW: I think the opinion of, even like, I work in a factory and stuff, and you would mention Muscatatuck, I think a lot of people thought it was a really bad place. They didn't understand it and I think they thought even that they were cruel to them there, there were horror stories.

JT: Why do you think that is?

VW: I think just lack of education. I know back years ago, when you were in a certain grade of school, they toured Muscatatuck and all they ever seen, I think, was all the mentally handicapped, and they didn't understand, and it kind of scared, so instead of making these kids understand the handicapped better, it let them grow into adults thinking, oh, that place is horrible, because you had all these people, and if you're not used to them, I think it would give you a really weird perception of it. But I think Muscatatuck was a very misunderstood place.

[01:04:46]

SW: I know it was to Chris. Our youngest daughter went down for a school field trip, and she come back with the opinion that, Dad, that place is crazy. Why are you going to put Steven down there? They'll be cruel to him. I said, Chris, Steven will tell me if they're mean to him. Steven is well enough and old enough, he can still talk and still do whatever, he'll tell me, if they're mean to him, I'll get him out of there. She said, Dad, they're mean to kids down there. And I just told her, I'll just have to see. And I thank my lucky stars a thousand times over that that place was available. All the time Steven was down there, he never complained about being mean to him.

VW: I think if you misunderstand and don't understand something, you're just going to automatically think it's bad, and that's how the everyday person that didn't spend any time down there thought of it, because you'd go down and it would, just like Steve getting slugged, I mean, if he never went back, what would his opinion have been of that place?

[01:05:50]

SS: Anything else you want to share with us?

[01:05:52]

SW: No. Basically that's the history of Muscatatuck. I was pretty upset when they closed, but I knew once the governor took notice he was going to close it, I knew it was a done deal.

JT: Do you have hope for Steve's future?

SW: To tell you the truth, no. They told me, I don't mean this to be morbid and I don't mean this in a bad way, but Steven has outlived his time. The doctors, and I had a team of doctors down in Cincinnati, and he's had several doctors up in Indianapolis, and the doctor in Cincinnati, he's traveled all over the world doing operations, he's a well-known neurosurgeon. I got escorted out of Children's Hospital over Steven, they pulled me into a team of doctors in there and told me he would never see his 12th birthday, and I told them they wasn't God, and I got escorted out of Children's Hospital because I disagreed with that team there. But I know Steven's destiny's route, and sooner or later it's going to kill him.

JT: I guess I didn't mean it quite that way, I meant in his new situation.

[01:07:17]

SW: I think Steven can adapt to what he's doing, just about anything he's got. I think he can adapt to any way as what he's doing, if things are presented to him in the right way, and Archer don't keep following through on his situation and take and make things happen with him. Steven's a very boring person if you don't keep him preoccupied on things. You've got to take and keep him excited. For Steven, say today, Steven we'll get ice cream on Friday. He'll dream for that ice cream, he'll fantasize about the ice cream on Friday. If Archer could take and do things like that for him and follow through, then he'll not have a problem in the world. And that's what Muscatatuck did. Muscatatuck said, okay, Steven, we're going to church on Sunday, so they say this to him on Friday, he'd take and fantasize about this church on Sunday. Or we're going on a bus ride Friday night. They'd tell him on Monday, and he'd take and all week long he'd get himself all worked up about the bus ride. That's what you got to do with Steven, is take and get him something that's going to excite him. With us, we'll call him up and tell him, we'll see you in about a day, and he knows we're going to take him out to eat, and we may call him on a Monday or a Tuesday, and he just goes from being down in the dumps to on top of the world. He'll be totally up about it because he knows come Sunday, he's going to go out to Jim Dandy's or Ponderosa or something to go get something to eat. Them people down there right now, they're falling short a little bit, and I don't know, which I know the help situation is part of the problem. I wish they could get the help situation straightened out, and maybe once they get it straightened out, I think maybe possibly that things will take and open up.

JT: It sounds like they just disappoint him sometimes.

SW: They promise to take him bowling, they promise to take him to church, they promise to bring him here. It's not the fact of coming here that excites him, it's the fact of getting out of the apartment.

[01:09:39]

JT: Doing something different.

[01:09:40]

SW: Doing something different. They told him one time they couldn't bring him because they forgot the gas card to the bus. Then another time they told him they couldn't bring him because they didn't have the gas to bring him on the bus, or they couldn't take him over because they didn't have the staffing, or they couldn't bring him to do this because of this. It's just like Steven's, he'll call up and he's kind of disappointed. Well, he comes here, he doesn't get any more here than he does down there, and it's not that he gets to see anything here or do anything here more than he gets to do there, because once he's here he's bored to death. It's just the fact of taking and he built himself up to come here, and then once he's here, he's done with it, but it's just the fact they took and told him he's coming. Just like on mother's day. He was all pumped up about Mother's Day, and then all of a sudden they just cut it out from under him, and there it went.

[01:10:47]

JT: Well maybe this will help it get better.

SW: I hope so. A lot of promises are made that ain't quite taken follow through, which I don't understand. Part of it's the state, part of it is Archer's problem, too. I don't know which is which.

SS: Thank you very much. We appreciate your time. We appreciate you sharing your thoughts.

SW: I tried to give you the good and the bad.

END OF INTERVIEW