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# ORAL HISTORY NARRATIVES MUSCATATUCK STATE DEVELOPMENTAL CENTER WITH SANDRA BLAIR

**MARCH 8, 2005** 

INTERVIEWERS: JANE HARLAN-SIMMONS AND MARIBETH MOONEY

RECORD ID: 146-DO

**SB:** SANDRA BLAIR

INTERVIEWERS (I): JANE HARLAN-SIMMONS AND MARIBETH MOONEY

[TITLE]

[00:00:12]

- It's March 8, and we're talking to Sandra Blair at her home in Terre Haute. Interviewers are Jane Harlan Simmons and Maribeth Mooney. Maybe you can tell us a little bit about when Brian went to Muscatatuck, how that came about, what was that like?
- Well, when he first went to Muscatatuck, before he went to Muscatatuck, of course, I was a little upset at having to put him in there. He was only seven, but at that time, they did not have the things they have today. There is myself, there are other people that live right here in Terre Haute, that belong to the Mark Association, which are parents and families of patients, and they probably felt the same way I did. You don't want to throw your baby at all. Of course I could go see him at any time, but at the time, it took a longer time to get there than it does now, because you have a better highway now. He was about seven years, and knowing that he was afflicted, that makes you more protective, but the doctor at the time he assured me that it was the best thing to do, and it was hard on us. I felt like I was burying him, but we gradually, after we saw that he said, he won't miss you, you'll miss him, with his mentality. I thought, I'll bet he thinks, where did this woman go.
- **I:** That must have been really hard.

[00:02:16]

SB: It was, however, as time progressed, and we could have taken him home for visits, but we were afraid we'd undo the good that Muscatatuck had done, so we just went to see him. And I didn't get to go as often as I would have wanted to because I had other family and I had to work.

[00:02:40]

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- **I:** You lived here in Terre Haute?
- SB: Yes.
- I: So what kind of a trip was it to get from Terre Haute to North Vernon?
- Well, we went in the car, but sometimes during the holidays, the roads would be slick, and at the time, we didn't have I-65 like it is now. We had all those turns and curves that, if you've ever driven your car down around Spencer and places like that, we were going through there, and on ice and everything, that's not much fun. I often remember, and it was hard driving, but we went down there, of course, we wouldn't have missed seeing him. There were times we couldn't get there and just had to send something. So I always felt like there was a little void there. There was one missing, and then when I got the opportunity to move him up here and have him closer, I'm older myself now and everything, I don't drive as much, so I felt that this was my opportunity to bring him closer to home. My daughter, Brian's sister, owns this house which she rents, and she made the improvements and different things, and that's where Brian is residing now. He's very happy. It's a nice house, and he's been very happy there.
- I: You mentioned a family support group when Brian was seven years old.

[00:02:23]

- **SB:** There is the Mark Association.
- I: The Mark Association and is that a family support group for a certain type of disability?
- SB: It's the Muscatatuck Association for Retarded Children, for other children there. You see, at that time, there wasn't all these facilities, these wonderful things they've got now. There just wasn't. And so I think all they had here in Terre Haute was some little office or something up at Indiana State, and my mother took him up there. I was working at the time, she helped me quite a bit, and she took him there to be checked out. But there just wasn't much here.
- **I:** Would there have been any alternative for you as far as...
- **SB:** Other than keeping him at home, no. And with the other children and everything. We loved him, but he needed things that we couldn't give him. So that led to placing him at Muscatatuck, which was very hard on us, but we did it.

[00:05:54]

**I:** Did he have any medical complications?

[00:05:57]

- **SB:** Not physical. They all had to do with mental retardation. They refer to things nowadays as autistic and you hear all different kinds of terms. But it was all degrees of mental retardation. There are different degrees, I'm sure you've seen people with very different things.
- **I:** The doctor felt it was best for him to go to Muscatatuck?
- **SB:** That would be Gordon McLaughlin. He was the pediatrician here at that time. I don't know if he still practices or not.
- **I:** When was this? What year?
- SB: Let's see, Brian is 48, he had a birthday. When you have six children, it's hard to keep track of the ages. Brian was the second born, so he is 48 now, he was seven when he went to Muscatatuck, so that's been quite a few years ago. He's been here now about a little over two years, almost three years now in Terre Haute. After making the adjustment, he loves it in his house. When they've been gone and they come in, he walks around and sees that he's home, he just smiles from ear to ear, no matter how bad he feels, you still get a smile. It's nice, and they've got it nice and comfortable. He has great caregivers, stack them up to anybody, they do a wonderful job, and the house is always just sparkling clean. They do things with him. He generally goes out to dinner once a week, so it's nice for him. They have a nice patio in the back there off the deck, and they have cookouts in the summer. So it makes it nice.

[00:08:28]

- **I:** Are any of his siblings in the area still?
- **SB:** There are three, two sisters and a brother.
- **I:** Were they able to visit him at all when he was in Muscatatuck?
- Yes, when they went with us they did. And there is a niece that has been down there who took him out for a picnic, since she's been all grown up. She has a little boy that's autistic, so she is very interested in learning everything about Brian and took him [inaudible]. Of course, Jenny has gotten nicer facilities than what I had to choose from, because back at that time, they just simply did not have it.
- **I:** What was your first impression of Muscatatuck when you got there the first time?
- **SB:** That's hard to say. Just a big building, and I wasn't sure what to expect.
- **I:** That was the first time you'd been there?

[00:09:45]

SB: But I thought all in all, it was clean and kids were playing and everything, of course, but they seemed relatively as happy as children can be. With some of them it's hard to tell. Sometimes they'd be unhappy because something wasn't going their way, like all kids. All in all, they took pretty good care of them. There were a few instances and I was a little unhappy, and I won't go into that, but of course I

gave the doctors thunder. I'll be honest, and I gave the staff a little bit of trouble, but after we solved that out, it didn't happen anymore. But I understood they're taking care of a large number of people.

[00:10:45]

- I: How many, do you think? Was Brian in a room with a bunch of other kids?
- SB: Yes. They had different buildings, and then they built some more buildings to where they could condense the number down a little bit. And the new buildings I thought were just great. They had four boys to a room, but they each had their own bed, their own dresser, their own things for their belongings, a little wardrobe, but it was all done, and the room was redecorated, and they all seemed to be happy.
- **I:** Before that, was Brian in a room with more than four other people? Was it kind of like a dorm?
- **SB:** I think it might have been. I never did really just see, I think it was probably more like that. But as you know, they've made improvements, they built new buildings. He's had good care. He was always clean and always nice.
- It was in the '50's when you brought him here? We subtracted 48 from, it was in the '50's?
- **SB:** Well, let's see, Willis and I was married in '58, Brian was a two-year-old. I'd say early '60's.

[00:12:19]

- I: So it was past that farming time, they worked in the farm community at that point?
- **SB:** I don't know about the older ones. They did have older people, but each did little work details, but not everybody, their mentality, was capable of it, because some were more capable than others.
- **I:** Did he have any kind of formal school situation when he was younger?
- Yes, they gave him teaching. He had teaching for what his mentality allowed, which wasn't a lot, but for what he could, yes. Because, as you know, if you're mentally incapable, then it might have been an effort to learn how to brush your teeth if you aren't mentally capable, but for whatever they're able to do, yes, they encourage them and then they taught them. I'd say for what it was and everything, they had nice picnic areas for the families. We had a favorite one that was down, kind of off in the corner property and it ran by a little creek. It was real nice. I had a fireplace in it, and we used to go down there when we went and got Brian. We'd picnic down there. One time, we went out to a restaurant over in North Vernon. We'd do different things. One of his favorite things is eating.
- **I:** How did he feel about your visits down there?

[00:14:08]

SB: Well, by not being around as much as the staff was, he was always glad to see us, but he looks at people who take care of him probably more than he does me, because I'm not the one who's been taking care of him. But he's always glad to see us, and, of course, my daughter rents the house and she's in and out

over there, and she always talks to both of them and they're always glad to see her. Her name's Rita, Rita Johnson. Her and my daughter named Donna Blankenship, that's the oldest one, the most closely related to him. They have a different father. Willis is their foster father. Donna and Brian's father lives in Florida. He lives in Piney Grove, Florida, but he's not had much contact with Brian since Brian was very small.

#### [00:15:22]

- Did you notice any changes in Brian from when you were taking care of him and then when you started visiting him at Muscatatuck, did he seem different to you?
- **SB:** Well, it was hard to tell at first, but I think as he gradually adjusted, he was just, that was where he grew up, you might say.
- **I:** He had a period of adjustment when he first got there?
- SB: Oh, yeah, I imagine. It's just like a kid going anywhere. But all in all, I think that they took very good care of him, and when I couldn't go down, I'd call. I said I can't always get there when I want to, but I remember I still do care.
- I: How often did you get there on average, or did it change over the years?
- **SB:** It did change from time to time because we had illness and different things in the family to where I had times I couldn't go at all. I couldn't go as frequently as I wanted to.

#### [00:16:46]

- **I:** It was probably easier in the summertime.
- **SB:** Yes, if I could go down there in the warm weather, but I had to work, too. It takes a lot of money to raise a family.
- I: How did you feel when people said that Muscatatuck is going to close and that Brian had to move?
- Well, I thought at first it was just a rumor, you know how you hear rumors, so I felt, well, then my niece, Jennifer, she was the first one, oh, it's going to close, and I said, well, I assume if it's really going to close and I need to get Brian out of there, I'll be notified, and I was, but it was quite awhile after that. I don't know as it's officially closed yet or not. I guess it has.
- **I:** Not quite. They still have a few people.

### [00:17:51]

**SB:** For the most part, I thought they had placed most of their people, but I thought, well, when Rita had the house to rent and everything, and she said, well Mom, why don't fit him in my house, and he will have an income, and he can rent it from me.

[00:18:13]

**I:** What kind of work did you do?

SB: Nursing.

If you already said that, pardon me, but I wasn't sure if you had told us.

**SB:** Yes, I was a nursing assistant.

**I:** What kind of hours did you have?

SB: All kinds. Any shift you can name. I've done hospital work as a nursing assistant, I've done nursing home work, I've done home health care. I've sort of ran the gauntlet. I'm not physically able to do it now. If I was, I'd take care of Brian myself.

1: That must have been a challenge with five or six kids in the house.

**SB:** Oh, yes, you did it. So did a lot of other people that did the same thing.

**I:** Did you have family around or anybody to help out with the kids?

**SB:** Yes, my parents helped quite a bit. Willis has always been good. We help each other. I don't know how else to put it. We just lived life, we just did what we had to do.

[00:19:36]

**I:** So Brian is the second oldest in the family.

**SB:** He has three sisters and he has two brothers.

**I:** Were they kind of close together in age?

**SB:** The first ones were and the last ones were a little more varied in their age. The children range in ages from 49 to 31.

I: So the youngest of the siblings probably didn't get to know Brian very much.

SB: Not as well, but actually he lives closest to him right now, because Brian lives on Ridley Avenue, and Jimmy lives on north 8<sup>th</sup> Street. He's a manager at [inaudible], and sometimes when we take the boys out to eat, they'll call Jimmy and make a reservation. He always smiles when he sees Jimmy, so now they've got two of them to take out, so I don't know how that works.

**I:** Do they have different staff come in at night?

**SB:** Oh, yes. It's Community Alternatives ResCare.

[00:21:00]

**I:** Oh, ResCare, okay.

[00:21:02]

- **SB:** Are you familiar with them?
- I: Yes.
- SB: They have pretty good staff, and Rita is a great landlady because she always did say that if she was ever a landlady, she was going to be the right kind, whether it was her brother or anybody else. She makes sure everything is in writing, and there's a staff person that is with him that takes care of all that special stuff. She handles the financial end, she does a lot of things, especially with ResCare. And, of course, I'm free to see the books at any time, I could go over in the middle of the night and demand to see the books and see them.
- **I:** Do you feel like you're in closer touch with Brian's caregiver?
- SB: Yes, it's easier with him here in town, and if anything at all happens, they've got to call me first, they've got to call me and let me know. I mean, short of seeing to the patient.
- I: Do you think that Brian's quality of life is better? How would compare his quality of life at Muscatatuck?

  [00:22:25]
- SB: I think that probably he's, there is a nice fellow by the name of Glenn that used to take him out at Christmastime. He loved to go around and see Christmas lights, and the staff here takes him around. He likes to ride in the car, and they go and see all the lights and drive around, if the weather permits, and they always do that. In the summer, there's a nice park over there, they take him over to the park and sometimes I think usually once or twice a year, I forget now just what it is, something medical, they've got to take him up to Indianapolis. And then they'll do that. Generally they stop and eat, and he gets to ride a long time, and they love that. I don't know what there is about riding in the car, but they love it.
- I: So Glenn was a staff member at Muscatatuck that took an interest in Brian?
- SB: Glenn, he's probably retired by now. He was an older gentleman, and he'd take Brian out and buy him a new coat for Christmas. They'd go out and they went around to looked at all the Christmas lights, and Brian, I think, would have followed him anywhere. He'd just talk away, and he'd say, isn't that right, Brian, what do you think about that? See, Brian was nonverbal, but he knows when he's being noticed and included, and Brian would just be sitting there in his own little world, and he'll say, what do you think about that Brian, do you think that would be all right? He would just include him in the conversation.
- **I:** Were there other staff that he became particularly attached to?

[00:24:30]

SB: There was a young man, his last name happened to be the same as ours, it was Blair, and I can't think of that boy's first name, but he took Brian quite a bit. There were a lot of other staff members, I can't remember all their names, but they were a nice group of people, very understanding.

[00:25:03]

- **I:** Does Brian go to a workshop or anything during the week in the daytime?
- SB: He did at first, and then they didn't think he was getting much out of it. It was over by Union Hospital, where you take a sack lunch and you go and they wanted him to attend. The just didn't think Brian was getting much out of it, so they discontinued. He wasn't mean or anything, but it's just like for no more interest than he took in it, he might as well not even have been there.
- I: Hamilton Center Spectrum Industries?
- SB: Spectrum or something. I think that's actually what they were doing, they were trying to sort of test him out and feel him out to see if they'd be qualified for doing different things, and I know the coordinator said right now, they said, I'll assure you, he's not. Now, they do have him do little things at home, for instance, he will pick up his plate on a verbal prompt, pick up your plate and your spoon, and then he'll walk and carry it to the sink, on a good day. He doesn't have teeth now, but they used to have him brush his teeth. Now he has gum care, and I asked them about doing dentures, and they said that Brian was not a good candidate for dentures because I suppose maybe seizures or something, although he has medicine to control that.

[00:27:00]

- **I:** Oh, so he does have a seizure disorder?
- SB: He does, and he does have what they term as premature aging of the brain, and this caused a lot of it. Right now, he's developed some physical ailments through no fault of theirs, it's just aging. Right now he's got swollen feet and they're really red. I don't know what he's got, but they took him to the doctor today, so I'm kind of waiting to hear. They're very good to call me. They call me if he's got a tiny little scratch, because they have to do that. They say, Mrs. Blair, I hate to bother you, and I say, don't worry about it.
- I: What kind of communication did you have with the staff when he was at Muscatatuck?
- Well, usually I had to call. They would call me if there was an accident and something happened, but otherwise, I was the one who had to initiate the call, but I understand. I'd get Christmas greetings and hear if they got some big thing going, or something like that, and we're always welcome to be down there.
- I: Did you feel like you had a pretty good handle on how he was being cared for, or was it harder being so f or away knowing what was happening?
- **SB:** Well, like any parent, you hope you have a good handle on everything.
- It sounds like you had some communication with them where you called.

[00:28:51]

**SB:** I had some, but like I said, I had to initiate a lot of that myself.

[00:28:57]

- You mentioned that there were a few times when you had to tell them what you felt about his care and how you...
- **SB:** Well, there were a few incidents and, of course, I wasn't there, and I said just because I can't be there doesn't mean I'm not concerned.
- **I:** Is this when he was little or in recent years?
- **SB:** It was coming up at different times, because when someone is like Brian is, and in your heart you always kind of think of him as little, even though they're grown up people.
- I: Now were those the times where you felt that they were not doing what you think they should have been doing for him?
- SB: Yes, there were a few incidents I said, I think you need better communication. I said, somebody's not giving somebody information, like nurses, I said, don't you have nurses have reports when one nurse goes out and another one goes in? I said, and how about your staff, are they communicating? And then they had this deal where the nurses were in one building and they'd just come over certain times a day and administer medications and get a report from staff, which just did the caregiving, and I always thought that was always strange. Why don't they have a nurse for each building, or something?

#### [00:30:29]

- **I:** To have more consistency.
- SB: Maybe have a head nurse, you know what I mean, a head of nursing or whatever that they all reported to. Because anywhere I had always worked, the hospital, the nursing homes, you had the DON, the director of nursing, and she said, oh, we've had [inaudible], but by having so many different buildings. So I kind of like this deal here, because I can run over there, if I get too concerned or too curious, I can go over there, I can run in there whenever I need to.
- **I:** That's really nice to be so close.
- **SB:** The other place, it's all right, but it's institutional care and I don't think that's quite the same as the one-on-one care.
- **l:** Did you have opportunities to make decisions about his care? Did they ask you about those things, or was there any point which you...

## [00:31:40]

Yes, you get a number of documents and -395- and it's all documented, and they give you a complete run-down of what habits they've been trying to instill in Brian and how his care is and I'd have to get in there in the file cabinet and look and look and look, but they do and they send a large manila envelope, and every so often you get one.

[00:32:16]

- I: This is now or back when he was at Muscatatuck?
- SB: Both places. It's all typed up and then they have a little place for you to sign and send the thing back that you received it. So that's pretty much what I can tell you. They just did the best they could. Back then, they didn't have the facilities that they do now. Nowadays, if you have a child like that, there must be 50 different organizations and things you can take them to.
- I: Plus the schools accept children with disabilities now, and they didn't back in the '50's.
- **I:** You must have felt pretty isolated back then.
- SB: You do. You do feel isolated at times, but you don't realize that. I'd known other people that had children like that, because their children were already older. And this one lady in Sullivan, but she took care of her children at home. They're all gone now, all passed away of course, but I remember, but that's what you did. And that made me a little, I wasn't sure whether I wanted to send him or not because I remembered that this lady worked. She worked out, she take care of him at home, her and her husband worked different shifts, they did what they could in order to take proper care of the two that were...they had three children, one normal daughter that was older and married, and then they had [inaudible], so they just took care of them.

[00:34:24]

- I: Thinking back, what do you think were the best parts of having Brian at Muscatatuck over the years? What were the things that were most beneficial for you and for him?
- SB: Well, he got a lot of different care and different therapy that I probably couldn't have seen him have. And it was paid for by the state, and because of that, and doctors were there and everything. That was beneficial, like I said, he needed the kind of care that I couldn't give and Muscatatuck was really my only alternative. If I had had another one, I would have taken it. No offense to Muscatatuck, I would have taken another alternative than sending him away from home.
- **I:** What do you think were the least helpful things about having him there, sort of the other side of the coin for him and for you?
- Well, he was away from his family, his other siblings, and he just didn't have that close family bond like you had if you were around him all the time. And there were times, of course, that it wasn't like he missed us because of his mentality. Like the doctor had told me, he said, I'm going to paint you a very black picture. He said, you'll miss him and you'll remember, but he won't. And with Brian, it's here and now, so in a way, it was harder on the family than it was on him being away. He loves who's there doing whatever.

[00:36:44]

1: Did that make it any easier for you, though, knowing that he was...

[00:36:49]

- **SB:** People say, well how could you stand that? I said, that's the way I could stand it. And people say, how did you do that? I said, sometimes in this life, you do what you have to do.
- **I:** Were there a lot of people that didn't seem to understand your decision or did they support your decision?
- SB: Oh, you always see people like that, but it's like my parents said, we know, the people that love you know and they understand, so it doesn't matter what those people think. And as I've gotten older, I've seen that they're right. You can't make everybody happy. You know what Abraham Lincoln said, you can fool some of the people some of the time, and some of the people all of the time, but you can't fool all of the them all the time.
- **I:** You can't please all the people all the time.
- **SB:** I can't please all of them either, so I said, I just don't try. I said I'll do the best I can and as far as everything, everybody's concerned, and if I can't do everything, so be it. I'll just worry about the important things. The important things are what's important.

[00:38:25]

- Is there anything else that you want to share with people that were interested in what Muscatatuck was like and what was it like for a family of somebody who lived there? Any other thoughts that would be good to discuss?
- SB: No, I think it was just something that they would have had to experience for themselves, and I'd leave many times in tears, not because Brian wasn't being taken care of. And, in fact that he only cried after me one time, and I almost didn't leave until he got interested in something else, and he was crying because he was angry. He wanted to go back outside. It wasn't after me, and that was the only thing, and I thought to myself and I said, if he'd been crying after me, if I'd thought for a minute, I wouldn't have left. They would have absolutely had to have find me a cot somewhere, and that wasn't it. He just wanted to go back outside, and when he got interested in something else, he forgot all about it, and he didn't care whether I was there or not, so that made it possible for me to go out that door. That's the only time. Any other time, he just went right back and went to doing what he was doing, and he didn't really care whether I was there or not. So that made it easier, and he was getting older, and that was his home. As I said before, you do what you have to do in this life, and I believe in the Lord, and I said if I didn't believe in something, I don't really know how people handle anything without believing in something. I don't know what you girls believe in, but I know how I believe, and I said I don't know how anybody handles anything if they don't believe in something. And I believe that Brian was put here and he was like this for a reason. God knows why, I don't question God, but He had a reason for doing it. Whatever that reason was, I just accept it. That's really about all I can tell you.
- **I:** Then I will turn off the machine here.

### **END OF INTERVIEW**