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Brenda Whitney interview for the Lest We Forget Collection of Oral Histories

Brenda Whitney

Jeff Moyer

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WRIGHT STATE UNIVERSITY
Lest We Forget Interview Project

Interview date: May 23, 2003

Interviewer: Jeff Moyer

Interviewee: Brenda Whitney

JM: Did you--were you ever in Orient?

Brenda Whitney: Yes. I didn't work there, but I went there.

JM: And you saw.

BW: Yes.

JM: Ok. First hand?

BW: From the beginning of my career which was in '72 'till when it was closed. We were transitioning people...annually.

JM: Well talk--talk about what you saw, what you know, what you've been told, what you...you know the more direct firsthand the better.

BW: I'm trying to think. Judy kept our notes so I wouldn't lose them. There were two or three things last night, do you know what they were either? I remember, I remember one thing of saying that I try to tell people now when someone's behavior changes and it doesn't have to be a behavior activity. If they're sleeping more or they're not...if anything changes to look at things medically first. I mean kind of what I say to them is we need to rule out any medical issues first. Because when things don't feel right in our bodies we don't act the same. We don't necessarily act out...but you know if someone doesn't want to go to work anymore, it could be something else. (glances at piece of paper)

Judy Leasure: Can you read without your glasses?

BW: Yeah I have my eyeballs in today. (whispers to Judy: My notes don't make any sense.)

JM: What did you say?

BW: I said my notes don't--my notes don't always make sense to me. You know you write something down and go hydrotherapy? I don't know if that was for me.

JL: That, that was Tom was supposed to read because he did that thing about the hydrotherapy--

BW: In the mental health institution.

JM: He did cover that.

BW: Did he? Ok.

JM: Brenda Whitney. And it is the 23rd of May and we're picking up on the Lest We Forget project. You've had a lot of firsthand experience. My questions will not be used in what we're editing so if I ask you a question, the answer would...a complete thought so it doesn't require the question to understand it. What did you see at Orient when you were working there uh preparing to move people back?

BW: My first experiences with Orient were to visit the institution or as it was then called, the Orient State Hospital, and find people who were from Montgomery County and find if they were interested in moving back to this community. So the first time that I went, I went with one of the parents who founded our agency. And I had a background as a registered nurse and I had done some field placements at the state--Dayton State Hospital, here. And so I thought that I was probably prepared for this, but it was probably my first major experience with understanding the true difference between mentally ill and people with mental retardation. So when I went there, I too first smelled the developmental center, or the institution when we were driving in. Um...it smelled like mildew, it smelled like urine. We got out of the car and walked in and everybody came around to us. People were so happy to see us, and that really upset me. That um...it made me feel like no one had been there other than the staff for years. And they clung to us and they told us that they were from our county and they wanted to come home with us that day.

So we talked with some of the social workers and then we interviewed people. But that was very hard to do because there wasn't any space. We had um...a great room I guess you call it. It was just wooden and there were benches and chairs, and then up in the corner was a TV barricaded up on the wall with--with a screen around it and it was just blaring. So we were trying to talk to people and ask them a little bit about themselves and it was very distracting for me. They seemed to be very comfortable with it, just talked over it and they talked if somebody was screaming or carrying on. And usually when that happened, a staff person there came and took that person away. Sometimes not very gently. I think that it was real common there for people to be tied in to chairs or tied to a bench or tied to a bed because I saw that. So it didn't seem to be something they felt should be hidden from us.

Later, I found out from families, is that families who went there to visit their sons or daughters, didn't see those rooms. They didn't go in the great room or the sleeping area. And the sleeping area, as I remember it, was downstairs. And...well let me say first, I heard that we were going to visit cottages. A cottage to me was someplace like at a state park, like Lake Hope where you had a cottage and three or four bedrooms and a kitchen and a great room and a fireplace. So I kinda envisioned this as being sort of a folksy living center. And then I got there and saw these big brick buildings that you know, they didn't have a shutter, they didn't have any color. And when you went in you went into this huge room. And the sleeping rooms were the basement. And the basement windows were higher than me and the pipes were all running through the ceiling. You

know like steam pipes or whatever heating pipes they used and the floors were concrete and they were just rows and rows of beds. Very close, you could probably stand between the beds if you stood sideways. Maybe it's what I thought an army barracks might have looked like. Something like that I--there was nothing personal. I don't remember where anyone had clothing or personal items. There were just beds.

And I found later that there was a laundry room and a clothing room and people went there and got their clothes. I never really determined if those clothes belonged to them. I made the assumption they did not. That they were clothing and you went there and got your clothing. I remember thinking what it would be like to lay down there at night and all these people would be around you and all their sounds, because I grew up having my own bedroom. I was the only girl. Had my own bedroom, I shut my door, I didn't have to listen to my brothers...any of the noises going on. And I remember wondering what it would be like to sleep in a room with...I don't know if I knew the number, but I felt like fifty or eighty people. It was just kinda overwhelming and it was damp. It was very hot. I didn't see any way that there would be windows open. And I asked them that and they said well it's cool at night. So I don't know why the sleeping area bothered me more and stayed with me more or because growing up my bedroom was where I could go in our entire house and it was always my space. I could shut my door or I could read my books, I could play my record player, and I guess I thought about that because I didn't see any way you would have any place to go ever. To have your own little space. And that--that was very significant to me. I felt like there--there was no place that anyone had there anywhere that was their space, other than their bed. I did find out that they had their own bed every day. You know I asked that but that would be the only place if you lived there that you had was yours, was your bed. So if you were...once you were gotten up in the morning you would go upstairs and do whatever your daily chores were.

JM: When you would be visiting people in the uh the day would...did you see people that weren't working, that were just there with no place to go?

BW: I really never saw anyone working. I found out later that people did work there. They farmed there and worked there but I didn't, I didn't see that there were many people on--on the day room. Some were dressed, some were not. Some were tied in chairs. I think I remember some rocking chairs. It seems like I remember people rocking in chairs, but they may have rocked, and my recollection is it was a rocking chair, but it may not have been. Maybe because I had a nursing background and I had been at the Dayton State Hospital, I wasn't as taken back to see people undressed, but I was shocked that people there had no clothes.

I um...that--that seemed significant to me too that it was ok that people would be naked. I assumed that people didn't want to put clothes on and I saw people laying on the ground in urine. And so the first time I was there, when I asked questions about it, it was pretty much told to me that's how they are. That's the way they want to be. And when I questioned it, no one really had an answer for me. They just...it was like kinda like that's what they wanted to do. Well I knew better but I didn't know what you did about it. And I do remember um going to meet with legislators back at that time and giving them this information. Some people were very sympathetic and some people were very interested, but they didn't seem to know what the solution was. My thought was the solution was to help agencies like ours develop residential

alternatives in the community. Um...the--one of the judges, the uh probate judge here in Montgomery County during that time was very adamantly opposed to residential programs or funding for them and he explained it to me that families came to him and wanted their children probated to an institution. And if it wasn't the place, they wouldn't do that. These were fine people that they wanted their children to go there and that people like me were keeping them in the community and that was not a good thing for them. There was nothing for them to do here.

JM: As a nurse did you see anything that uh you have uh categorized as medical abuse or medical neglect?

BW: Yes, I saw people who seemed to have been overmedicated and people who had side effects from medications, like a lot of drooling...um some twitching, nervous movements that I felt were probably drug related. It seemed to me that when I ask about medications, almost everybody took Thorazine. Some people took Dilantin for seizures, and I could almost tell who those people were that had taken years of that because they had very thick gums and their gums were extending down over their teeth. So that's a serious side effect and there--I couldn't tell that anyone ever had any dental care. Although I was told there was a dentist there I didn't know much about that.

JM: In the people you've seen come back to the community, what has been their dental circumstances when they arrived back in?

BW: When people came back into the community from Orient State Institute, they usually had not had routine medical care. Had not seen a doctor or dentist or an ear doctor or anyone like that for their history. I think the medical treatment there was probably emergency related. If someone was very ill, they had medical care at the hospital but I don't know that they had routine medical treatment because we got no records. We got very few records when people came anyway. Sometimes it was almost impossible to get the information when they came. When I first came to resident home, there were not doctors or dentists or eye doctors who would readily see the people that we were serving. There was the woman who was President of the Board when I came here was the head of the social work department at Miami Valley Hospital. And she got resources for us through the clinics there with the residents and interns, which I always found to be a very good resource because in a learning environment people often look for things that other people don't. I did find from doctors and still do find in some situations that the health care needs of people with disabilities is less important. If someone has an unusual disease there seems to be thought and discussion about treatment. If someone may have cancer, should we go ahead and do surgery? Things like that. I still see a little bit of that in some of the older physicians. But I know in the early years, no one saw our people but a father who happened to be a dentist. And he did all their dental work. And to help us raise money he saved fillings and took the amalgam out and he asked all the dentists in Dayton to save the amalgam, save fillings for him and then he extracted the amalgam and we sold it for money. It was one of our fundraisers. So he was the only person that did dental care for any of our--any of the people that we served. And on an occasional basis I still find people who would prefer not to serve our people.

JM: So coming back to the community having had no dental care, did you find people whose teeth were in pretty terrible shape?

BW: Many people when they came back had terrible cavities and they had rotted teeth, and some had no teeth or few teeth. So it certainly limited what they could eat, but it also caused them discomfort. And for some people, once we were able to correct their dental hygiene, and their dental situation, they were a different person. Now they were happier. They were able to eat foods that they had not been able to eat before and they learned how to take care of their teeth. Another area like that, that I saw was foot care. People came back and sometimes they had cracked heels and skin and thickened toenails and untrimmed toenails and ingrown toenails. And I remember thinking that one of the first things to have is some kind of pain in your foot. If you stub your toe or if you have a bruise or a blister, it's extremely painful and the people would come back and I would look at their feet and see these sore areas and ask them does that hurt and they always told me no. I said, this doesn't hurt you, doesn't make your feet feel bad? No.

The pain tolerance that I have seen with people with disabilities has always intrigued me...because many people have all types of disabilities so this can't be something just related to a syndrome. But the people that have lived in our programs for the 30 some years that I've been here, seem to never complain about pain or have a very high tolerance for pain. So it's very important to observe any changes in them if someone may have fallen and injured themselves they're unlikely to tell me that it hurt or even if you ask them does that hurt, they often say no.

JM: When people are (clears throat) in pain who are people who are coming out of Orient who had not had proper care as you said, rotted teeth, cavities and so forth, would you see behavior related to the pain that was attributed to...a diagnose classification or category, an assumption as opposed to a pain basis?

BW: I think that sometimes people acted out and had what people used to call behaviors or yeah...is that door open or?

Mark Lyons: I think so.

BW: Because I closed it but I think one of the guys might have peeped.

JL: Ok I'm ready.

JM: Ready?

ML: Yes.

JM: Alright the question that we were on was, have you seen people who were in pain and their behavior because of the pain was misinterpreted? And the behavior changed once they got proper medical or dental? And then answer that without my question.

BW: I've seen people who have had an illness or an injury and could be, should be in pain and have behavioral changes. They act different, they're grumpy. They may even lash out at

someone. I remember an incident where someone came home from camp and she did not want to put anything away, she was angry, didn't want to talk about her camp experience, and when she was getting ready to go into the bathroom and take a shower that evening, she slapped her roommate for no reason. And I asked her later...

(interruption)

BW: Is somebody coming in? Helped me put that together.

JM: Start again with the woman coming back from camp?

Judy Leasure: I remember a woman...

BW: Ok. I remember when a woman came back from camp one summer and she seemed to not enjoy her camp trip at all. She was grumpy, she didn't want to share any experiences, and she went up to her room. And a little later she was getting ready to go into the bathroom to take a shower and for pretty much an unknown reason, she slapped her roommate. And when we asked her about it she said, I don't want to be bothered, I want her to leave me alone. But her roommate hadn't done anything and then when she was getting in bed and she made some unusual sounds, and a staff person heard her and talked to her for a minute. And it appeared that she had a large bruise on her hip. So the next morning we took her to the doctor and had an x-ray and she had a broken hip. And I asked her when she might have fallen and she said she fell in the shower at camp. She didn't know if it was the first day or the last day. I assumed that it had been fairly recent because of the bruise. The bruise still looked like a fairly new bruise like 2 or 3 or 4 days old. But she didn't tell anyone or if she did they didn't check. I'm assuming she didn't tell. And she told me it really only hurt once and a while. But I think underneath there was a lot of pain and she was masking the pain and lashing out at people. And I have found that to be not uncommon in working with people with disabilities when they get an injury or I see something happen where I would expect them to be in more pain. They show very little pain, but sometimes they--they showed in behaviors. Sometimes they--

JM: Say in one sentence, something like there was a woman who was acting out, actually slapped her roommate and only later did we discover that she had a broken hip, that she had fallen.

BW: Ok.

JM: Just one succinct sentence. Go.

BW: There was a situation. One lady broke her hip..last year.

JM: Start at the beginning.

BW: Yeah. That's right, as soon as I said it.

Mark: And look at Jeff. So we can tell that you're thinking about it.

BW: There was one lady I knew that slapped her roommate very unexpectedly and only later did we find out that she had broken her hip at camp and had not reported it, and it had been several days before it was discovered.

JM: In talking to parents about their experiences, about what they were told, have you--I should say do you have experience with parents who were party to the institutionalization process...learned what it was about and upon the return began to disclose what it was like for them while their children were institutionalized? Do you know what they'd been told about it or what they knew or any of that sort? Do you have that kind of experience?

BW: I'm trying to think, there's something there and I can't bring it back. Most of the families that I worked with had their children at home still that started this organization, but there were some people like Eunice, you know Eunice would be one of my points of reference...uh trying to think who else. You know?

JM: Ok. Ok what about Eunice?

BW: I've heard her stories many times about placing Dan in there, you know he was--had behavior problems, was difficult to manage, so that's where he went. I mean, it kind of is one big comment from people that that what--I don't think that they toured Orient. I think they knew of Orient and people recommended it. They knew that people went there and that's what they did. And they had very little information about what went on inside. And these--most of the people I knew that did that had very low functioning children...so they got no feedback from their son or daughter. Very little. I mean they weren't people like Elgertha and...so I don't have as much information from families. Now when I--when I came to resident home, all of the families seemed to know about places like Orient. They were more familiar and they never wanted their children to go there. Which was why they had started resident home. They were originally a Catholic parent group and so their dream had been to have a Catholic facility community, but they didn't have any money so they just started with one house. But their real dream was to build a campus, which was the trend in the 60s, you know. I know this isn't where I'm supposed to be but I just had this flash of James calling the cottages, colleges.

JM: Right.

BW: And I just--you know we all had our own perception of those cottages but we all thought they were supposed to be small when we got there. Everybody wanted to describe how big those cottages were for whatever reason. I think we all know that cottages makes families think it's homelike.

JM: Mmhmm...anything else that you...listening to any of the other interviews sparked...

BW: No, I mean I thought it was strange for James and them to talk about having their own clothes because I never saw that often. That Elgertha and James both said that...maybe because people took them. You know took them clothes.

JL: That's my understanding.

BW: I do--I do know that I worked with a woman who went there at a very young age and she had no recollection of anything else but that, and her siblings were there. So and I--that's all they had. So, I don't think that they had anything. I'm trying to think. I used to go back and forth...one of the things that I do remember is um the people that came to resident home from Orient in the very early years, were still on the rolls of the institution. They--the superintendent was like their guardian. I can't really remember if that was pur--the legal term, but he was the responsible party so if they needed medical care or anything, dental care by that time, if I didn't have a community resource, which I didn't. I returned--I took them to Orient for those services.

And for several of the gentlemen that I did this with, we first served men, they were very anxious about going there. They did not want to spend the night. They did not want me to leave. They wanted...they didn't care about anything. You know, it was just if I have to do this and they also wanted to do some surgery there. For a couple emergencies I was able to take people to local hospitals, but I had to call the superintendent Dr. Suffrinco or Dr. Moritz at one time. And those, those men, those doctors would give permission for treatment, as the custodian person. So, they still had that link and their medications were managed there and every Friday the drug truck came to our agency from the state and dropped off people's medications. And it was also a courier system. They sent paperwork that I might need or I sent paperwork back that I might need. It was kind of a courier communication system. And the--we called it the drug truck and I think it primarily came for me and basically for Dayton Mental Health Center. But we got to be on the drug truck route.

JM: When people came into the community from Orient, do you see the uh...change in their medication, of course medication management at Orient? Once, was there a recommendation by people who knew uh about the psychotropic medication is that the medications be altered?

BW: When people first came to resident home from Orient, and came with medications, sometimes--often times I questioned it personally because I had a nursing background. And so I would ask the doctor to do a drug evaluation at Miami Valley Hospital in the clinic area we used. Most of the time medications were reduced significantly or totally. So primarily, the medications that people continued on in those early years were seizure control medicines. I would continue those and I used those--used the medications from Orient. If a doctor prescribed it locally, Orient would bring it. It was like a pharmacy. I--It probably was a state pharmacy. It may have been my belief that they came from Orient, but maybe they came from a state pharmacy that Orient ordered. I never saw where the drug truck was there. I just knew that when I talked to people at Orient--the medical staff, they would say well it will come on the drug truck Friday. They didn't seem to have concern that I got other medications. Or that I reduce medications.

JM: You--your memory of the people that are affected and their behavior and the behavior--the functional capacities that you saw in those wards early on...these are the same people that are living in the community successfully now?

BW: People that I saw at Orient lying on floors and tied to chairs and tied to benches, probably are the people we see living in the community pretty quietly and unobtrusively today. One or two gentlemen that came to live with us had histories and reputations of such. But we never saw that at resident home. They came fairly easily, and fairly quickly. And one of the things they did enjoy was going to the day program for the adult workshop. At that time the adult workshop was not as vocationally oriented, it was more uh a day program where they played cards, they did arts and crafts and a small number of people worked. But it was socialization and it was nice. And they had picnics and they had field trips, and they went places. So I think the people really enjoyed that. That every day they got up and went outside of where they lived and rode a bus and have four or five or six hours of some kind of recreation or leisure. And for some people there was work.

There were also people...there were some people who returned from Orient that I found community employment or regular jobs right away. I had a sense from things they told me. Some of the men told me what they did at Orient, and so I found similar work for them in the neighborhood and they never went--were enrolled in the county board of MRDD programs back then. They worked at Kroger's where they could walk and they bagged groceries, they did janitorial work. Another gentleman worked in a um...I can't remember the name of the...another gentleman worked in like a pre-fast food restaurant. A chain restaurant and it was on night shift or an evening shift 3-11 and then he would call and someone would watch for him. It was only a block away and he would walk back home and he kinda worked in the kitchen and a little on the grill. He had worked at the commissary. And when he told me that I knew that was--that the little restaurant up the street was always looking for an evening shift person, and I knew that Bob would go to work every day. He had a very good work ethic. Work was very important to the people who returned to our homes from Orient. Many of those people had--had worked there every day at Orient. A meaningful job. They farmed, they...I think James told us he worked sometimes in the butcher shop area, some worked in the laundry, some watched other children, and they took pride in that. So, for those people, we found jobs within our neighborhood area where they could walk to work. One gentleman worked at a firehouse, and he really enjoyed that.

JM: Anything else?

BW: Nothing dramatic.

JM: We're only looking for drama.

BW: I know. I mean you have so many stories jumping around but yeah--

JM: This is...we have a lot going on.

BW: Yeah.

JM: We have a very very good start.

BW: I remember Tom Reel who--who died last year of cancer, he was not very old um...he--he was not on a list to interview. When I met him he rushed up to me and said, are you from Dayton, Ohio? And I said yes and he said, do you know the Ohio Players? And he said I love their songs, and he had this radio and a headset, so I knew he had to come back. He was not on the list but he came back here and lived until he died of cancer last year.

JM: Were most of the people who came from Orient, did most of them smoke?

BW: I think every man that returned from Orient or young man, some of them adolescents, smoked. Some of the women, but I don't remember that all the women did, but virtually every man did. And over the years many of those men have quit smoking but we still have a few people who smoke. None of the people who live in any of our programs, who did not live in an institution, smoke.

JM: Thanks.

