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Elvia Thomas interview for the Lest We Forget Collection of Oral Histories

Elvia Thomas

Jeff Moyer

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WRIGHT STATE UNIVERSITY

Lest We Forget Interview Project

Interview date: May 22nd, 2003

Interviewer: Jeff Moyer

Interviewee: Elvia Thomas

Jeff Moyer: Elvia you know what we're doing. We're documenting institutionalization experience from various vantage points?

Elvia Thomas: Mmhmm.

JM: Can you describe what you are involved in, in the experience of people who have lived in state institutions?

ET: Well, in 1978 I was employed by The Montgomery County Board of Retardation and Developmental Disabilities. And at that time I was employed in the capacity of residential planner and the whole thrust of my job was to um...help develop placements in the community to bring people back who are returning from institutions. And so I had a lot of involvement with communities. Trying to assist them, prepare and be ready to receive our folks back and I also spent a lot of time at the institutions uh meeting with people there and trying to determine um...the best way in which to return people in the community and to familiarize myself with them and learn some of their needs also. So I had extensive experience uh...and involvement with institutions.

JM: How long were you in that role?

ET: Oh uh from 1978 to about 1983 um...uh I served in that role. And then in 1983 uh I moved on to another uh uh position with the board and also though the state tapped me to open up a special unit which was also a special receiving facility for people returning from institutions. And these were some of the most challenging and difficult people at the institution who had not yet been placed in other community settings because of their um..um... very complex needs and so the special unit um...um...uh it--was quite a project and it was quite a challenge uh but we were up to the task and uh we returned twenty-six people to the community who people otherwise thought could never be returned.

(Off to the side, not really part of the interview) JM: Does that seem ok? If there's a line like that prepared. Yeah I thought about that. Ok, Mark and I are on the same wavelength. Where we're gonna use this, my questions won't be part of the final.

ET: Ok.

JM: So if I ask a question you'd answer it, for example if I said that question, "What period of time did you work in that capacity?"

ET: Mhmm.

JM: The answer should begin with I worked

ET: (interjects) I worked

JM: I worked in. I worked as dot forth so it can be said without my introduction.

ET: Ok. I'll try my best to do that.

JM: So you worked from 1978 until?

ET: Well I worked from 1978 to 1983 in the capacity of residential planner for the county board and uh along that time though the state tapped me to develop a special unit to receive some of the most uh challenging individuals in the system back into the community um...uh those who had initially believed not to be able to be served in the community but we were determined that we would bring um all Montgomery County folks back and so we set this unit up in order to make that happen. It was a challenge but we were successful. We returned twenty-six people very successfully and we're very proud of that accomplishment.

JM: 1978 to 1983 was the full period?

ET: From 1978 to 1983 was when I was really involved more with um...traveling back up and down the highway to Orient State Institute because I was in the residential planner capacity. Again returning, trying to develop uh...community home situations for folks and Orient State Institute was a primary feeder institute for Montgomery County at that point in time and it lies just outside of Columbus, Ohio. And so during that uh period of time I would often travel uh along with other uh key staff to visit a institution, to visit individuals there, to uh learn things about them and to try to um uh figure what would be the most appropriate way to transition these individuals back in the community. Now, Orient was an experience and after several years of work I learned that you can't really just bring people back from an institute and plop them in the community and think that we have people who are out here who are groomed to care for these folks because they hadn't been served in our community before and so staff were having a difficult time understanding how to work with our folks. So, a part of hiring staff was that they would have to travel with me to the institute to actually meet the individuals so that they could become familiar with what we would be um doing once people returned to the community.

Orient was a place of more than 2,000 individuals. Orient um...which is no offense to the people who were there whatsoever, but Orient was a place we smelled before we got there. Orient was um...a place that um...was a nightmare by any stretch of the imagination. We would walk into a dorm or living situation...

(someone interrupts, background noise)

JM: Ok, begin with Orient was a nightmare.

ET: Ok. Orient was a nightmare. Staff and I would walk into a living situation in which would be um almost like a huge dorm room. And there would be maybe fifty people in that particular uh living situation. The beds would be uh, along the wall and you could barely walk between each bed ah they would be generally touching one another. There would be one little attendant for the most part. I never saw more than one attendant in the situation. And she would be running around, usually would be a female with a mop and a bucket. And literally if people would um uh need to have um uh people having bathroom situations she would take care of that with the mop and the bucket. They didn't actually go to the bathroom. Uh, people would converge on us--

JM: (interrupts) Both urinate and defecate?

ET: Yes, right. (nods)

JM: And there was...

ET: There were facilities there for that. And some were able to actually uh have the skills to care for themselves but for others that's how they were cared for. They just went on themselves. And this little attendant with the mop and the bucket would run around behind them. Um, when we would enter into one of these uh cavernous rooms there'd be the huge--well the huge tv up on the--in the corner uh beyond the reach of anybody who could uh turn a station so whatever station it was on was what station you saw. The individuals who lived in the room, and they pretty much lived there, that was their universe. That was their world. They would just converge on us. And it would almost be a frightening experience except for the fact they only wanted human touch. (strokes arms) And so they would come up to us and all they'd wanna do is touch us and talk to us um because there was so little attention. So little of anything else they got in the form of human contact or attention. So um, the shoes that they got each day, who knew what size it would be, whether it would be five sizes too big or three sizes too small. The clothing, same thing, who knew how big it was gonna be or how small it was gonna be. And it was just um it was an overwhelming experience but I also knew that if staff could make it through this experience and stay with us then they were gonna be good people back here in the community and do all they could to serve these folks because there was not one day, not one minute, not one second of their lives that we could give back to them and they had missed so much already because of their institutionalization or incarceration. Um...so to speak. So again,

overwhelming, overpowering, but when we came back we were ready to do what we had to do to make sure that we gave them as much of their lives uh...as much of their lives back to them as we possibly could.

JM: When you would uh be on the site, how long would you spend in the ward?

ET: I would be on the wards of Orient um...for maybe a day at a time. I would go up early in the morning uh again, accompanied by staff and we'd stay till the end of the day. And we might have to go back several times that week in order to make sure that we were um putting together groupings of people that we felt would be the most compatible in terms of living together um...as a family unit because that's what we were about. Trying to make families out of the individuals who were living there.

JM: Did you see uh any discipline while you were there?

ET: I never saw discipline. I've heard things about how people may have been handled and for the most part it's my understanding that discipline generally took the form of uh...medications for the most part. But I never actually saw anyone abuse or assault an individual with MRDD.

JM: When you say you heard, what have you heard?

ET: I was just informed that medication was often used in terms of uh controlling behaviors. And so if you had an individual and uh someone wasn't necessarily pleased, a staff member I would say wasn't necessarily pleased with the way in which this person was uh behaving, that often they would uh be prescribed medications to control the behaviors.

JM: Is that the only thing you uh had heard about them concerning discipline?

ET: No, I have, I have heard that there have been horror stories about how people were disciplined at institutions. In terms of people being uh assaulted, abused, uh neglected. I just never personally witnessed any of that.

JM: The people that you were working with, you established long-term relationships with them? You brought them back to Montgomery County?

ET: I will have lifelong relationships with them. I was in the business of trying to help put families together. Families of people who had different interests, had different needs um didn't really know one another but, it was all about trying to make a family situation and a good life for them and so if you work in residential, it becomes a part of a lifestyle. You take on um...these individuals as a part of your family. It's a 24/7 almost situation in terms of um...I don't go home and I didn't go home and just kind of a um...uh put my keys in the drawer and I was done for the night. I never knew when a call would come and I might need to be out or anything. Birthdays, the individuals we served birthdays were important to me. Holidays were important to me. Their graduations and my family became a part of these families we were trying to create and

they became a part of our family. So no, I'm gonna have lifelong relationships with folks we brought back. Wonderful wonderful people.

JM: When you were observing people in the institution and getting to know them in that, in that environment...

ET: Mhmm

JM: the same people that were transplanted community, returned to the community rather, what-what difference did you see in, in people's emotional states?

ET: People returning from Orient State Institute to the community initially, for the most part, were very confused um...it was a traumatic situation for some of them. They only knew about living in an institution. And now living in a home in a community was somewhat overwhelming. Um...individuals didn't know that um uh necessarily that you could uh go to a grocery store and buy fresh peaches and apples. That they didn't just come in cans that somebody opened. Cooking, bathing, toileting, uh...having their own rooms. Having the ability to choose what they wanted to wear for clothing to the workshop each day. Having a workshop or a school to go to outside of this ward or dormitory room. These were all things that were new experiences to the folks. Going to church, um...making friends, being a part of a community. So, for the most part, for most of them, in the beginning it it it took some getting used to. It wasn't anything that was just easy for them to just step into this strange new world. Uh, but over time we saw dramatic changes happening with people. In terms of them just, just the quality of life in terms of them saying "I'd like to do this, or I'd like to do that." And actually being able to do that. Or for people to go to dances in the community or attend the church of their choosing, or to have their own friends, or to have a job and get paid. So, it was a--it was quite an experience.

JM: While you were working with people at Orient you must have learned a great deal about their interactions with their families. What, can you describe what the, what the range of experience was of people who were institutionalized with their families?

ET: In terms of working with the folks who were at Orient and their families. For the most part um...there was quite a bit of distance. There weren't many families involved with the folks who we came back with. It was the proverbial, the doctor told somebody thirty, forty years ago to put them away and forget about them and so for the most part, for the most part, um...there was little family involvement.

Um...uh it--it just wasn't that much. There were few who still had some attachments and once they got back to the community though, some families did reconnect because uh they didn't have to travel a long distance to Columbus, Ohio to visit folks or whatever. So, we did have some family reconnections once they were returned to the community.

JM: But for those, the majority of people in Orient you believe did not have contact with families?

ET: The majority of folks at Orient had very little involvement with family. Now, in Montgomery County, in the late oh uh maybe it was the early '80s, a Developmental Center was built here, a 104 bed facility and so people from Montgomery County then were placed in that facility versus Orient State Institute in Columbus, and there was significant family involvement with the folks who were placed at Montgomery Developmental Center here in our community.

JM: You talked about the, when people were returning that there was an adjustment period. Did you see people expressing any fear or any concern about uh...anything that would suggest that they, where they had come from...left emotional uh scars?

ET: Can you restate that? I'm not real sure where you're going with this.

JM: Did you see people--did people have fear when they returned? Did you see any expressions of fear?

ET: I did witness uh some fear and anxiety on the part of many of the individuals who returned from institutions. And again it was more because I believe of the unknown. Just not knowing. Uh...and it just being such a new experience. So, certainly there was a bit of--of trepidation on the part of some of the individuals who were returned.

JM: Did the people who you were working with ever talk about what life was like inside Orient?

ET: We have a few--there were a few individuals who did have the capacity to talk about what life was like inside Orient. Um...there was one gentleman who had even probably been wrongly placed at Orient. He had been a window breaker and a troublemaker as a child and in those days uh you could sometimes be admitted for entirely wrong reasons to a state institution. Um...there was another gentleman who was there because he just became an orphan and so he ended up at a--at Orient. Now both of these gentlemen were able to talk about what their experiences were like there, um...and one gentleman would just mainly talk about the food and hoarding um was a big issue for a number of the folks who came back because apparently food was often—it's not that the food was denied--but food was not readily available. You couldn't just go to a refrigerator and open a door or go to a pantry and open the cabinet and pick out what you want so, uh one gentleman used to hoard food all the time and would talk about his experiences in terms of being hungry and he never wanted that to happen again and he always referred to food as "state food" uh...so he would talk mainly about just the hunger element. Um...there was another gentleman who had the capacity to read but never was afforded educational opportunities and he has a thirst for reading. and so uh he's wanted to very much concerned and very much into wanting to read as much as he possibly can because it was an experience that he was denied in the in the institution so uh those kind of stories I have heard. Um many of the individuals we serve are just--don't have the capacity to relate to us um their experiences. Neither gentleman talked much

about um...things like abuse or neglect but they just talked about people treating them uh in a mean fashion, so.

JM: Hunger as abuse?

ET: Yes (nods) Mhmm

JM: The um...the way you describe clothing. Sounds like people did not have control of personal effects?

ET: Not at--Orient people did not have uh access to personal effects. It was more like a state thing in which um, uh and I cannot be completely--I'm not sure I'm completely correct about this but it was more like every morning someone would bring something and if it fit, fine and if it didn't, fine too. So, but they had no personal possessions that I witnessed. Uh, again the wards were just beds uh uh...pretty much uh stacked against one another and uh no pictures um um no personal, no family pictures. No nothing, but the beds and the big TV on the wall.

JM: Did you ever have access to other aspects of the institution? Any areas?

ET: Um, well I was at Orient, I was able to um, to visit people in what was called the um...the rec area. Sometimes we would take uh folks there so we could try to do an assessment and determine what the needs were so we could develop certain service plans. Um...and that's really about it. Between the wards and the rec area. Yeah, those were the only situations where I...had access. On the--

JM: Did you ever see the cafeteria?

ET: (shakes head) I never saw the cafeteria or the kitchen area.

JM: The graveyard or...

ET: Never saw the graveyard. Just heard about the graveyard.

JM: What did you hear about it?

ET: Um...uh my understanding of the graveyard that there were um at--at times um, people passed you didn't even get a headstone. You got a--a number. Uh...and that was pretty much it. Um...so it's--it's just my understanding that uh um even in death there was no dignity. You got a number in a graveyard.

JM: The families are the people that knew each other at Orient did--they came back with those relationships in the community? They--or did--you were putting people together on the basis of personality? I guess let me ask the question again. Were you maintaining relationships from Orient into the community? Moving people as friends for example?

ET: Our efforts in returning people into the community were to try to uh maintain relationships that had been established by the individuals who actually resided in the institute. And some instances and I think in most instances we were pretty successful in terms of doing that. But for the most part the individuals didn't really relate so much to one another. Uh...we had to help them understand what a relationship was all about. And most of that came when they were returned and we established these family home situations.

JM: What did you find the medical and dental experience of people in Orient to be like? What had their medical and dental care been about?

ET: I think medical--I think that the medical and dental care had really been neglected. People came back with their mouths in horrible situations. Um...a lot of the behaviors were just from pain from um uh...the lack of appropriate dental care or medical care. And so one of the first things that we had to do when we brought people out is there were lots of behaviors and we had to get them to doctors right away to try to understand if there might be some condition that had been neglected or not taken care of. And even to this day we still have issues in terms of the dental care is very good right now but just some of the after effects of the many many years of institutionalization and the massive amount of work that has to be done to help people get their uh dental work in order and with the medical stuff though I think we're pretty well on target with making sure that uh...people's needs are adequately attended to.

JM: So you saw, you've seen a lot of uh tooth loss and dental problems as the results of the lack of care, lack of hygiene?

ET: There was a tremendous uh...I was amazed by the amount of uh...or the lack of--almost total neglect of people's bodies through appropriate dental or medical care.

JM: Did you have interaction with the uh professional staff at Orient?

ET: Um the interaction I had with professional staff at Orient was the fact that we were returning people to communities; it was the day of deinstitutionalization. And the professional staff were really good people um...uh and good to work with and they were very helpful in terms of giving information and trying to help us understand uh what people's particular needs were. So, um most of the professional staff I worked with were of the social work, disciplined for the most part, and or psychologists. So there was never an issue in terms of uh working with them and working successfully with them. They were pretty good people.

JM: What do you think happens to a person who is trained as a professional social worker or psychologist that then is working in a setting such as Orient with the conditions that you described? What do you think happens to their point of view that would allow them to be part of that system as opposed to wanting to see a change?

ET: I believe that most of the professional staff who worked at places such as Orient did so because that's just the way things were done at that day and at that time. And I think that as a change came in deinstitutionalization, um...uh began to surface throughout the nation that there was uh...was almost a revelation for these folks, I think so to speak. And that they did want what was best for the people being served that they realize being outside the institution was the way in which people needed to be treated. That people did need to return to their home communities and be served. So um, I think again it was just, it was the time and that's just what you did when you went to work in an institution and that as a change came I think that there probably were a number of staff that may have had some issues in terms of accepting the fact that things were gonna change. But for the most part people seemed to embrace it.

JM: What you describe sounds sort of like waking up in a....waking up in a dream and realizing that you--as other people came and saw what was going on they were....I forget how you phrased it, but it's almost as if...the fact other people were seeing it saying this has to change, they welcomed that and sort of woke up from their lethargy about the circumstances.

ET: I do believe that for the most part professional staff did um..um...have this awakening and that they saw--and whether they just resigned themselves to the fact that there was gonna be change and so they better get on board or whether they really believed that this was the right thing to do and for the most part I think most of them believe this is the right thing to do. Uh...they--they really did a lot to help us in terms of, of um...of trying to see that people who were transitioned from the institution and in the community in a fashion that uh worked really to meet their needs and enhance their quality of life.

JM: When you um were moving people back into the community you mentioned that there was more family interaction. Can you describe how that began and how the experience was for everybody involved?

ET: When people returned to Montgomery County from Orient State Institute, for the most part um...uh families did begin to emerge and did begin to want to be a part of things that were taking place in their sons' and daughters' lives, many of whom were adults at this time by the way, um...and so it became a pleasure and an honor to work with these individuals and to help them plan for Christmases together or brief outings or uh church goings or something else where they would have time to spend together and uh to um reestablish long disconnected relationships.

JM: What about for the individuals themselves who have been separated from their families, what did you see in terms of their...how did that transition work as they were reunited with their families?

ET: Ok, let me figure out how to do this. How did the transition work?

JM: How did--what did you observe in terms of people's reuniting with their families?

ET: In terms of people reuniting with their families there was uh...I think in the beginning there was a little bit of concern, maybe a little bit of anxiety on the part of some of the parents that maybe what they had done was not the right thing because they had placed their son or daughter at an institution and now here they are back in the community so community life must have been ok after all, rather than what they had been told many years ago was the right thing to do. But I think as uh we--we worked through some of their issues and probably a lot of guilt on their part by having our open houses and having parties and events where families could come in and be a part of the new family that had just uh we had--had--had just uh moved into the community um...the sons and daughters had, I think tremendous emotional reconnections. I think it worked both ways. Moms and dads as well as sons and daughters. And I think that uh that probably...I'm sorry I'm just kind of not doing real well here, so I apologize for that.

JM: No you're doing great. Don't even entertain that thought. I'm asking questions that are convoluted. Consider the problem the question, not your answers. And you answered it very clearly.

ET: Well, it's just...it took a little bit of time for the families to make the connections that they did. And it happened at different times for different families. Some immediately made the reconnection and for others there was kind of that guilt factor that caused them to hesitate a bit. But, when we were able to reestablish the connection, it was wonderful what we saw take place. In that...the individuals had their own family but then they had this bigger family out there that they also could go to and it just reconnected relationships that may not have been very close over the years. So it was a wonderful thing to see happen.

JM: How about sibling involvement?

ET: There was some sibling involvement. Um...and lots of the sibling involvement uh...uh...mmm (shakes head)...there were siblings who also got involved with the uh brothers and sisters and what you just saw was a family that probably should have always been. And now they're grown for the most part but they're back together again. And uh so brothers and sisters got just as involved as moms and dads. Maybe not to the extent that moms and dads did but brothers and sisters certainly did come back and become a part of uh their brother's and sister's lives.

JM: You mention medication as form of control in the institution. Did you uh...was there a reduction in medications when people moved into the community? Can you describe that process?

ET: When people returned to the community we saw um general a tremendous drop in the amount of medications that people were taking. People were also experiencing significant side effects from some of the medications. Tremors and um...uh gum problems and um you know, you just name the gambit and so when we began to take people to physicians in the community and they were able to give them um...ample assessment and diagnosis's, we found that the number of medications was reduced tremendously.

JM: Do you feel that functional--or they seemed functional improvement in people's abilities to self-care and be productive and have relationships with the change in medications?...Was there functional improvement?

ET: Ok. Umm...once people were taken to um area physicians and um, had their meds reviewed and in some instances had them discontinued or may have had new meds that were um then prescribed. We were able to see different types of behaviors in people. We were able to see people become more functional. We were able to see people who um were more coherent, less lethargic, um...so there were many ways in which we saw improvements in individuals once medicines were uh looked at and adjustments were made or medications were discontinued.

JM: Going back to Orient, do you remember your first, your first experience of going inside?

ET: I remember my first experience visiting Orient and again it...was like something out of a Norman Bates movie when you--before you saw the institution um there were things that just happened to you and you just braced yourself for it. Uh, and I had heard horror stories about institutions and so I uh a small bit of apprehension about what I would actually be going into. And I do remember again getting out of the car, going up to the door, being taken to a ward. The ward door opening and just all these human beings just converging on me. Just touching and wanting to talk. Um, and again I remember the little lady running around with trying to care for these people. There must have been 50 people and this one little attendant. Um, so Orient has--I have a vivid memory of Orient and the looks, and the smells, and the sounds, and just the pain.

JM: Do you remember the bathroom facilities?

ET: I don't recall the bathroom facilities at Orient. I know that they--that there were bathroom facilities but um I never saw anyone--I never actually entered them and I never saw anyone, any of the residents enter into a bathroom facility.

JM: In the nomenclature of the field of developmental disabilities, what functional level were the people working with you on the--the people you were working with on that ward what was their functional level?

ET: Of the residents?

JM: Yes, the residents who were living on the ward that you described.

ET: The functional level of the um individuals who were living on the ward ran the gambit. For-and I went into a number of wards because there were a number of people who we were bringing back and there were maybe about 50 people to a ward so. And you had your female ward and you had your male ward and that kind of thing. But um many people were of the profound level. Very very needy. Very very involved. Needing total personal care assistance. Uh...and then you had a number of, a smaller number who might be very high functioning individuals, and they often helped out almost like staff in those particular instances and trying to help take care of some of the other ones who were less able to take care of themselves.

JM: So in that circumstance they were acting as caregivers?

ET: Yes, do I need to repeat that? (laughs)

JM: No, I'm just clarifying.

ET: Ok. (laughs)

JM: I'm just stalling (can't hear the rest of the conversation over the laughter)

JM: So, the way you described uh _____ just total lack of medical and dental and personal care. You uh the emotion--you talk about bracing yourself that you saw little inconsistencies, you saw little things. What do you mean by that? That as you were driving up you were bracing yourself. What were you seeing?

ET: Um, when I first traveled to Orient I just wasn't really sure what to expect. I just know that in my schooling and in my past experience I had heard horror tales about uh, institutions. So I just wasn't sure what I was getting myself into. Consequently I braced myself for what I might see, hear and vision. Um, and again, at this point in time, this is 1978 again, and um for the most part the way we served people with mental retardation was a community--was an institution. So they hadn't been a part of our community and I'm ashamed to say that I knew almost nothing about people with mental retardation or developmental disabilities since they had been uh not a part of our community life. So I wasn't real sure what I would be uh seeing or experiencing or what to expect. Consequently I braced and what I saw were just human beings who needed a lot of care. And um, it just made me determine that there was something I could do to help and that these people were gonna get what they needed in the community of Montgomery County.

JM: When people came back into the community you uh talked about their behaviors based on pain and based on dental needs and so forth. Once people had their medical needs met, once their medications were reduced, once they were not in pain, once they understood living in the home, in their new home having their own room, having enough to eat, what--what--what did you see change? How did you see these people evolve once their basic human needs were met?

ET: The transformation of people once they had uh returned to the community, once they had been thoroughly assessed by medical practitioners and dentists. Once they had their physical--basic physical needs met, the transformation was incredulous. Uh, people who had titles I guess at the institution of being this or that, I don't want to particularly call any title now, 'cause I don't want to offend any of the individuals we're serving. But we saw people you could walk down the street and you might not even be able to tell that that had ever been an individual who resided in an institution. We saw people who fit in. We saw people who bloomed. We saw people who wanted to take care of themselves. Who wanted to help others. Who uh...it was just an incredible transformation. I'm not gonna say it was for 100% of the people but I could say for 99% of the folks living in the community made them a part of the community and uh they wanted to be accepted and they have grown and they work and they earn money and they volunteer at social service agencies. And they're just a part of our community. They're our neighbors. They became human beings not like these individuals who were caged on this ward who were constantly um trying to get somebody to touch them or care for them. It's amazing.

JM: Have the people that you've worked with over the years who were at Orient, you mentioned the two gentlemen that apparently did not have any significant level of cognitive disability, has there ever been any...have you learned anything more about people's experience or their perception on what their feelings were about living at Orient?

ET: Have I learned any more about the--

JM: (cuts in) Have they said anything Orient, about where they lived, about Columbus? Their past life?

ET: There is very little reflection by the people we serve on their past life and experiences from their days at Orient. It's very difficult to get anything from most of them and it's just as if it's an experience that they'd just as soon not relive. So I don't have much that I can really say about uh personal experiences at Orient.

JM: So these are people who have the verbal, you're speaking about people who have the verbal ability to speak but they just, it's an area that is too--they just don't want to revisit? Is that what you're saying?

ET: Um...(laughs) that is what I'm saying. I don't know whether I need to repeat that-- (laughs)

JM: My question is, it's not for lack of verbal ability?

ET: Well for most it is. For most it is. But the few--there are a few people who do have the verbal skills and ability who could relate their experiences at Orient but for whatever reason choose not to and again I think it's just too painful an experience for them to relive.

JM: For the families that have been reunited, you talked about the fertile guilt. Have families shared anything with you about the meaning for them of having their loved one reunited?

ET: You know that's an easy answer and that's no, the parents haven't really talked to me about that. (turns to another person off camera) I don't know if they've asked you about that? No. Ok.

JM: Are there experiences that um...are there experiences such as birthdays that uh have become common place in people's lives now that uh you observed it being a new experience for them when they came back? Holidays, birthdays, that kind of thing.

ET: There are many experiences that we are experiencing together with individuals with MRDD in the community now that would not have been a part of their Orient uh uh living situation. For instance, graduations um...are a very important time for us. Proms, concerts, uh dances, uh it runs the gambit of what typical people in the community do that would have been experience denied to folks when they were at Orient. And so now yeah, Christmas and Thanksgiving we gotta make sure that everybody is going to have their Thanksgiving dinner and a big fest family style. Christmas, um we don't care what we have to do, everybody has somebody to go home with at Christmas, if they don't have a family. Vacations, Disneyworld, uh Pigeon Forge, I mean whatever a typical American does, so do individuals with MRDD now. And this was just not a part of their experience at Orient so it's a grand day right now with us and making sure that everybody has their little sense of identity about what's important, and your birthday is important and graduation is important, and prom time is important, and all those other things that Americans celebrate and experience.

JM: Proms and graduations of relatives?

ET: No, many of the people in our system--well proms and graduations of relatives, yeah those are important too--but many of the people in our system who we're serving, also had come out of school and gone on to graduations and parties and that kind of thing.

JM: So you've seen people who have been returned to their education and acquire degrees and uh...and degrees in schooling?

ET: Right, many of the uh, folks who have returned from um Orient have gone on to graduate from high school and to uh experience a prom for the first time or to uh...attend graduation of a sibling so these are a--experiences that are--are new but they're part of the community fabric and they're part of what our folks are experiencing.

JM: Have you, have you seen a um a change in the community since your beginning efforts in 1978?

ET: In 1978, um...the community certainly wasn't ready for what we were doing in terms of establishing group home living situations for our folks. Now in 2003 I'm not sure that they're all that much more ready but right now it's not quite um the problem that we had in the beginning to get homes established. When we first began to establish homes for people with mental

retardation and developmental disabilities, it was an eight bed model. So we were looking for large homes and eight people went in at a time and there were zoning issues in every situation where we tried to develop uh a home. As a matter of fact I jokingly tell people, (laughs) I used to go to zoning hearings and I'd park my car with the nose out because when the hearing was over, I wanted to get the heck out of there before the neighbors came after me. And so they were pretty testy times and some of them were pretty threatening times and um we've had some homes that uh where we had lawsuits that have gone on for years with us trying to get neighbors to accept us. Uh, new laws in Ohio now. We have supportive living. We have four person models that we develop. We don't really have to go in and ask neighbors anymore so we just go in and that's been a wonderful thing that we don't have to ask permission because if we were, we'd encounter the same kind of resistance. People are becoming more accepting but they've got a long way to go. Um, but with our kids now in local community schools, with many uh--with us not being hidden away in some cornfield, you know on the outskirts of some time, uptown. We're here. We're not going anywhere and you can see that we are beginning to see some subtle changes particularly with the kids. The kids are getting it. (laughs) Um, we still have to help mom and dad understand (laughs) but uh yeah community acceptance is, is still a challenge.

JM: When people first came back into the community were able--with individuals who were able to have clothes they could keep track of and personal possessions and so forth. What uh what did you see in that? What happened for those people as they were able to gather possessions of their own?

ET: Um, initially once folks came back to our community and um began to understand, and that's what it was, they had to understand that um you can have these clothes. Nobody's gonna take them away. You can have your cologne. You can have your own hairbrush. You can have uh a shoe, your own shoes, your own coat, your own jacket. Uh...they just weren't real sure what this was all about. (laughs) It's like what does this mean? Um, and as they got used to it, that things--and saw that things were not going to be taken away from them and that they uh...could go to a refrigerator and open the door and get a Coke out if they wanted to and uh that every morning they could get up and go to work and have some place to go outside of the home. They could have friends. It just uh...it was a--it was just new to them and they did begin--and to get it over time but it took time for them to understand. That this is yours and nobody's gonna take it away from you. Not only that if you need more, if you grow out of your shoes or outgrow your jeans or whatever. We're gonna get them replaced. So it was a--it was just a learning experience for them that they had to get used to, stuff was not gonna be taken away and it came over time.

(continued Interview from Tape 2)

JM: Elvia you--you spoke about the transition of--of people in a couple groups. Last being the uh more difficult to place and people with difficult behaviors. And they went into the special unit.

ET: Mhmm.

JM: Can you describe what--what life was like uh on the special unit? What would one observe? What did you see?

ET: In 1983, um...a special unit was developed to help return some of the most, some individuals with some of the most challenging needs that were still left residing at Orient State Institute. These are individuals who had not been placed in community homes because at that point in time it was believed that they couldn't be successful residing in the community. And that they'd always have to be a part of some type of institutional setting. Uh the state of Ohio at that--in 19--at that point in time decided that it was gonna convert Orient into a correctional institute. And so therefore it had to find someplace to--to--to put these individuals. And so they asked me if I would uh develop a special unit program for them. The special unit was located on the grounds of the Mental Health Center here in Montgomery County. We took several floors of a building. At that point in time, this is kind of interesting, um we were trying to go in and um repair and fix the building and spruce it up so that when these individuals returned that they'd have a nice place to reside in while we tried to help them um...overcome some of the issues that they were encountering, generally behaviorally so we could find good community homes for them. At that time while we were trying to spruce it up, we just wanted to find paint. We went to a local paint shop who told us that we had to get a psychiatrist to approve the color of the paint that we were gonna paint the building with, that's just kind of an interesting aside. I don't understand what that's all about. Guess the bottom line is that we did uh do some remodeling and some fixing up of the building. We returned these 28 individuals and it was quite a challenge. Um...again, these were folks who had significant difficulties in terms of behaviors, um mental health issues, uh...and that sort of thing. We brought in individuals we thought, professionals who we thought would really help us and staff in terms of finding ways to serve these people successfully so that we could successfully integrate them into our communities. So we consulted with the psychiatrists and we brought a doctor on staff, and we had a full-time nurse. There was extensive training for staff in terms of behavior management and that type of thing. The staff who we employed--and we almost had to throw this unit together overnight which was, when I look back now, um...was probably about the craziest thing I've ever done in my life, to accept folks who have so many needs and um....I've got green staff who I'm bringing in to work with them. But we literally hired staff off the street. We just put the word out that we were gonna have this unit and we needed people to work, and it turned out really to be a blessing in disguise because these folks came in with no preconceived notions over um...over what they would be expecting or experiencing and I think nobody really expected what the special unit came out to be. In the beginning, our hands were absolutely full because these folks needed almost one-on-one care and attention. And they had many, many issues that were presented. And so we began to

work on them one by one. By the time the project folded some months later, every single individual was able to go into a home into the community. Um...uh...and the staff also we able to transition with them in the homes, so we had some of the most--these were experts, these green folks who came off the street were now experts--uh who could handle almost any situation. Who were committed, who were loyal and who loved these folks. Um...so again it was just the work of bringing in some folks who were--some professionals who I knew were dedicated and who loved the challenge, and bringing, giving staff what they needed in terms of learning some skills and abilities that they could use in order to work effectively with these individuals and then have the providers who were willing to take uh residential providers who were willing to uh...do the community home development for them. Um, we were able to pull this off and get everybody successfully placed and uh most of, if not--well I can't say all--but most of those individuals are still in the community homes we created. I think there were one or two who did end up returning to a more uh...to a developmental center. Um...but it just shows that with the proper training uh, the time, the attention, and the right kind of staff in place, uh...you don't really have to work miracles you just really need to work with people in humane caring ways and wonderful things happen.

JM: The behaviors that you are seeing were fairly difficult I take it? During the--at the special unit. The behaviors were being extinguished or have been extinguished now that they're in the community? Can you describe those?

ET: Yeah, the people who came into the Dayton Special Unit had extremely challenging um behaviors. Uh...many were assaultive. Uh...there were some offending behaviors such as individuals who would um...steal from others. Uh...you name a difficult behavior and it was presented at the Dayton Special Unit. Overtime, the behaviors were able to be distinguished through uh dedicated, well-trained staff who worked with individuals to help them understand more appropriate ways to either get attention or to express themselves. Uh...um or in terms of um...staff role modeling for the folks we were serving. So we were able to see the tremendous turn-arounds in behaviors that had been extremely combative. Um...confrontational, and assaultive, and people were then moved into community home settings where they became a part of the neighborhood. Good neighbors.

JM: Would you say that the uh negative behaviors were a result of the environmental influences that they lived with? Did the institution create the behaviors?

ET: I believe that in some instances, the institution may have been a primary player in terms of um creating some of the behaviors. In other instances though, there were folks with mental health issues, and uh even to this day it's difficult to get proper mental health treatment for individuals with MRDD. Uh...as a matter of fact our agency has just started a dual diagnosis program where we've actually also become um...a mental health center to serve people with dual diagnosis or people who have the double degree of diagnosis of mental retardation and a mental health issue. So, back to the Dayton Special Unit, for the most part, I would say a significant number of the

behaviors were probably caused as a result of institutionalization. But for others it's just typical um...well the same things that typical people in the community have, so do our folks experience and some had mental health issues that needed treatment but they were going untreated.

JM: There's a term uh institutionalized mental illness. Do you think that what we're talking about here are mental health issues that were created by like things in the institution?

ET: I don't know if I can say that. I'm not sure.

JM: Are you familiar with the term institutionalization?

ET: Uhnuh (shakes head)

JM: Any other topics Judy? (answers No from off camera)

ET: I'm released? (laughs)

JM: No, there are more questions. I'm just getting started. (laughs) (too much laughing to hear what else is being said)

JM: I just wanted to say one last question. When you were coming in today you were--you had in mind something of what we were going to be doing. Considering your unique vantage point, that we're not going to be interviewing anyone else that has your life experience, anything else that you think is important that you share that uh the world needs to know and remember?

ET: (laughs) Well, the field of mental retardation is a profession that I would certainly encourage anyone out there um to look into. We need good caring people in this field and it's gonna be a fast expanding field because of the fact that people aren't being institutionalized. They're remaining in the community and um...uh...a number of the services that we provide operates seven days a week, 24 hours a day, so there's lots of professionals that we need. There's lots of good caring um nurturing folks that we need to work as direct care people. So I would certainly encourage anybody out there who hasn't quite made up your mind about what you want your career goals to be, to look into this profession and to um...I also want to say that um...working in this field is probably, you're gonna find if you get into it, is gonna be a labor of love. A lot of people kind of fall into it like I did. I fell into it accidentally. In the 70s our folks were in institutions. They weren't served in the community and you didn't grow up saying I want to work in the field of mental retardation. I fell into it. I can't extricate myself from it now. It's uh...it's important what we do and uh the people who you work with let you know it every day. And that's it.

JM: Well as for me, I mean I think your life has been what matters a great consequence and I've very pleased and honored to have the chance to talk to you about it.

ET: Thank you.