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Connie Mack interview for the Lest We Forget Collection of Oral Histories

Connie Mack

Jeff Moyer

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WRIGHT STATE UNIVERSITY
Lest We Forget Interview Project

Interview date: June 5, 2007

Interviewer: Jeff Moyer

Interviewee: Connie Mack

Jeff Moyer: Alright I'm sorry for that Connie. We'll--let's start again. Uh your name is Connie Mack?

Connie Mack: Yes.

JM: M-A-C-K?

CM: Yes.

JM: And your brother's name is Ronald Benjamin?

CM: Ronnie Benjamin. Yes. (nods)

JM: When was Ronnie born?

CM: Uh January 1st 1951.

JM: Uh huh. And he passed away very recently didn't he?

CM: Yes, uh April 16th of this year.

JM: Mhmm very recently. Well I'm sorry for your loss. How old are you, Connie? When's your birthday?

CM: Um June 30th, 1949. So I'm 53.

JM: So you were a couple years older than Ronnie?

CM: Um yes. (nods)

JM: Do you remember his birth?

CM: Um, no I don't, but my—Ronnie was born in Statham, Georgia and my father's mother was the midwife. And in her uh little black book (shows the dimensions of the book by gesturing vertically and horizontally with hands) that the midwives used when

they uh brought babies into the world. She had Ronnie's birth written in her uh birth record book. And it said that he was normal because if the midwives did not see any fingers or toes missing or any type of um visual—

JM: Visual?

CM: Visual deformity or disability they just considered them normal. So, on his birth record she just put normal.

JM: Ok. What's your first memory of uh life with Ronnie at home?

CM: Um, I remember when we were all younger. I was probably maybe four or five; he might have been three and a half. Um, my parents would take him to the hospital which is now called Children's Medical Center, but then it was called Barney's back in the 50's. They would take him there for um speech therapy and to teach him how to walk because he didn't know how to walk. Um, even at the age of maybe two or three he wasn't able to walk. And I remember him having to wear special shoes. We've got a family photo of all six—there's six kids in our family—and we've got a family photo of him and in that family photo you can tell that he's got special corrective shoes on.

JM: Of the six, what number was Ronnie?

CM: Second.

JM: And you--?

CM: Second. He's the oldest—

JM: Person

CM: I'm the first and he's the second. Yeah, second oldest.

JM: What was life like with Ronnie at home?

CM: Well, I don't think we considered—we didn't really know uh there was any difference um about him among the six of us especially when we were younger. I don't think it was that significant but I remember um my mother since she was—my mother was in her early twenties when she had all six of us. My mother was like 23 years old by the time she had all six children. And I just, I—I believe she had stated that he had become like a handful. You know she wasn't able to adequately uh give him the care that he needed and back in those days my mom would tell me that the doctors were the ones that would make the suggestion that maybe you need to institutionalize your son because he can probably get better care in a setting where there are children um...or people with the same disability that he has and they'll be better able to--to meet his needs. And I believe that encouragement there um was probably what caused my parents to seek a place for him to stay. I think it kind of relieved them too because they didn't feel as

guilty having “a doctor” (uses finger quotes) you know say well it will be better if you institutionalize your child. Um and I think it took some of the guilt away. It took—and it was the relief and then um they could go visit him and then at holidays he could come visit us. And he visited us every long holiday like Thanksgiving and Christmas.

JM: How old was Ronnie when he was institutionalized?

CM: Uh, I’m really not sure. Um...I remember when I started maybe first or second grade, which would probably have been 50’, let’s see 49’, six...maybe 55’. I would say maybe between 55’ and 60’ he might have went. 1955 and 1960 he may have went to Orient. I’m not sure the exact...between sometime—I’d have to ask my mom just to find out for sure when he actually went. But he was a younger age.

JM: Was he able to get schooling in the community before he went?

CM: I don’t believe—the only place that I knew that he went in the community was to Barney’s. And that was for speech therapy and they were to teach him how to walk. But as far as schooling is concerned I don’t believe he went to any schooling at all when he was younger.

JM: What—was he brutalized in the neighborhood? Were there bullies?

CM: No. No, Ronnie’s a very outgoing friendly person...and he’s always been that way so no, there was no—to my knowledge I don’t know of anybody that has ever um...called him names or taken advantage of him or anything like that.

JM: So, in the neighborhood he was—there were no real issues?

CM: No, there were no neighborhood issues. No. (shakes head)

JM: So, when Ronnie was institutionalized what was it like at home? When that happened do you recall?

CM: No, I don’t. I don’t really remember because as I stated before, um...I don’t remember any problems that we had as sisters or brothers. I think the main issue was the fact my mom could not handle the responsibility of um...of taking care of a child with a disability at the time, with five other kids to look after.

JM: Do you remember visits early on?

CM: Our---our visits to Orient were only to take Ronnie back after he’d come home for a home visit...and we would take—we would go back to Orient—but my father would always go get him and bring him home. But our trip to Orient was to take him back when the uh Christmas and New Year vacation was over, the Thanksgiving vacation was over.

JM: Mhmm. You mentioned that your mother went to visit him there, but that he came home for the holidays.

CM: Mhmm.

JM: So your mother went to visit him on a regular basis?

CM: No. No. The only time that we went to Orient was to take Ronnie back after a um home visit. (nods)

JM: When you uh take him back what uh—what was your experience? What was his experience?

CM: Well, when we would take Ronnie back to Orient, I just remember uh my dad and I think he—I don't know if 35 was in existence then. I just remember it was a...country road. It looked like it just ran forever. Going uh, back to Orient. But we were not allowed to go any further than like um...It must have been like a foyer or a visiting room or...or office area. Uh, we were not allowed to go any further than that. And the sad part about it is that Ronnie hated to go back so much that my father would have to take him to the bathroom and leave him in the bathroom so we could sneak out. You know. And you could just kinda hear him um, you know crying a little bit because he knew that when he came out of the bathroom we were going to be gone. We weren't going to be there. 'Cause he hated to go—he just didn't want to go back.

JM: Mhmm. Do you recall anything about—did he talk about what it was like...for him at Orient?

CM: No, Ronnie never...he never talked about his experiences at Orient. And um, the only thing that I can tell you is that when he—my parents finally brought him home in the late 70's for good that um...we probably went to the State Fair a couple of times but after that he did not want to go anywhere near Columbus and he was like that up until the time he passed away. Because I—

JM: His memory—

CM: Yeah.

JM: That trip—

CM: Mhmm. I think it was always a fear that if you take me to Columbus you're going to leave me there. And I think that was just in the back of his mind. You know from the um...times that...when he lived there that we had to take him back and then sneak away from him just so we could come back home.

JM: Was he able to express himself? Communicate verbally?

CM: Uh, pretty much so, yes. Mhmm. But he never...he never talked about um...he never talked about his experiences there. He never talked about that at all.

JM: When Ronnie was—would come home to visit, was—what was his clothing? What was he wearing?

CM: Um...I really don't remember that part. I don't remember. I know that he had like a certain smell about him. Um...like a farm smell, you know? I can remember that part but that's all I can basically remember. As far as his clothing I don't remember uh, what his clothing was like, but I know he was very meticulous about everything when he did come home. His um...shoes were in a certain place. He would put his shoes directly under the bed. He would hang all his clothes up. Everything that belonged to him would be in a—in a space. Where he could go right to it and get it.

JM: Do you recall whether or not he was able to hold on to possessions?

CM: Mhmm...I'm not sure what possessions he had—he had favorite things. He liked cowboy hats and he liked guitars. And, I'm not sure if he maintained those things over the years because every Christmas that's what he got was a guitar, cowboy hat and he liked radios too. Um...Ronnie...um...lot of times he would get angry and he would tear things up. Like he might take his guitar and bust it up against the floor. So if his first possessions were a concern...if anything was missing or destroyed it was probably because he probably did it himself. You know. I think that was his way of um...that might have been his only expression since he didn't talk about things that happened. That could have been the way he expressed himself. You know, with um...destroying his guitar or tearing knobs off his radio and he would pull buttons off his pajamas. You know, things like that. Mhmm.

JM: When you—you said that he uh... your parents brought him home in the late 70s.

CM: Mhmm.

JM: What precipitated that?

CM: I believe there was—if I'm not mistaken. I'd really have to ask my mom to make sure the facts are clear. My father—well I know one of the reasons—my father was getting ready to retire from General Motors so he would be there to help my mom take care of um...Ronnie. And I think that there was going to be—we had heard that the institutions were closing and there may have been another issue with money that parents would have to start maybe paying partial—paying part of the--the hospital—not the hospital bill, but maybe start paying part of their um...residential care. So it could have been all three or maybe just two out of the three, I'm not sure. It's kind of not very clear right now.

JM: Mhmm.

CM: But I know one of the main reasons was that my dad was retiring and they could spend more time with Ronnie. Um...by bringing him home.

JM: Mhmm. Do you remember his homecoming?

CM: Uh...pretty much so. Umm...whenever Ronnie came home, whether it was for holiday visits and even when he came home then he was very quiet for like two days. He would not say a word. He would not talk, period. He was just silent, and then all of a sudden he would just start talking. You know, he would just start, you know opening up. So he was quiet for a while and then my parents um...start making phone calls and then he started going to the workshop program and he was very well received in the neighborhood, because he was our brother. We had grew up in that neighborhood since the late 50's. And he was our brother and he was very friendly with everybody in the neighborhood. He was able to walk up and down the streets in our neighborhood and nobody bothered him or made fun of him. Um...or anything like that. So, the homecoming itself, like I said, it started out real quiet which was his—which was normal and then all of a sudden he just started opening up.

JM: Was there any uh when he was in Orient and when he came back. Do you recall anything about medications—was he taking any drugs?

CM: No, Ronnie didn't take medication. He didn't take any medications. He started taking medications later on. He would take some things. But he didn't take any medication. He didn't come home with any medications. To my knowledge, all the time that he was there, I don't think he was ever on any medication. He just started taking medication—I think the adjustment for him after he left that environment and came home, there was times when he was on like a mild sedative uh...just to calm him down a little bit. But to my knowledge he was not on any medication while he was there.

JM: Mhmm.

CM: And he didn't—wasn't on meds when he came home.

JM: Mhmm. Do you know how he spent his days?

CM: You mean at Orient?

JM: When he was at Orient.

CM: Umm...I think he—I think he worked. I think he said he worked. Um...I'm not really sure. I just remember seeing uh...older guys in the—they had like a big garden up there. Big field. I guess it was a vegetable garden and I remember seeing some guys out there working when we would take him back, but um...I don't think he ever said whether he worked. He probably went to school. Um...but I'm not exactly sure, um how his days were spent there.

JM: After he was home and settled did he ever—you said he just didn't talk about it at all.

CM: No, not really. He just didn't want to go back. You know, he just never wanted—he did not want to go back.

JM: Mhmm. So, it's now late 70's and he's moved back into the community.

CM: Mhmm. Mhmm.

JM: Where was he living? With your parents?

CM: With my parents, yes.

JM: Did he live with your folks, or your mother and father--

CM: Yes.

JM: --until his death?

CM: No, he lived with my parents up until my dad got sick, and that was in the early—'89 or '90. My father was very ill. My father died in 1990. And uh, so, Ronnie went to the emergency shelter here in Dayton out by Stillwater. He went there first, and then he was placed in a group home setting which was first mental retardation.

JM: The group home in the community? In your community? Roughly in the neighborhood?

CM: Yes, in a...actually it was in Jefferson Township which is where he lived up until um...he passed away this year, so he was there for, let's see...the early '90s until—I guess about 13 years he stayed in a group home.

JM: In the same place?

CM: Yes, the same group home, yes. Well he went to the emergency shelter first, and then he moved from the emergency shelter to a group home.

JM: How many people lived in the group home?

CM: Uh, there were four guys there.

JM: Mhmm. Did he like it?

CM: Yes, he did. Yes, he did. He got along real well with the guys that lived there, yes.

JM: Did he ever talk about his life in the community?

CM: Um, he worked at [Coon's PM?]. Work was his life. He—he loved to go to work. Um...as a matter of fact he would come home and stay with me, or stay with my mom during the holidays, especially if they ran over into a Monday, he would get a little anxious because he considered Mondays the beginning of the work week. And he thinks he's supposed to go to work. We'd have to let him know that "you don't work today. You go back on Tuesday." He always planned his home visits and uh....but he did—he loved to work. He liked the people that he worked with. He liked his supervisors. He always talked about working in an enclave. He always wanted to go to high school, graduate, get a uh, driver's license, and work at the post office, and drive a car. Those were his goals.

JM: When he was uh—you mentioned he'd schedule his home visits?

CM: Yes, he always scheduled his home visits. He knew, for instance if he—we were—this would be a weekend that he would be coming home, because of the Memorial Day weekend coming up. When we would take him back to the group home. If I was going to take him back on Monday, late Monday evening, or early Tuesday, he would say, "now, you're going to come back and get me on the Fourth of July." He always knew which holiday was coming up and he always scheduled—he always put his plans in to be with his family on the next holiday. He just automatically knew which the next holiday was coming up. Mhmm.

JM: Mhmm. So, he would then go back and stay at your folks' house?

CM: Either, he would either stay with my parents or stay with me. One of the two. Mhmm. He would rather stay with my mom. That was his preference, but if she wasn't feeling good he would come and stay with me, and then we'd all see each other on the—you know on the main holiday. We'd all get together.

JM: Of the six siblings, uh, did your other four brothers and sisters survive Ronnie? Are they still living?

CM: Yes, yes.

JM: How involved have they been with Ronnie?

CM: Um...probably—well I would say, except for two, quite a bit. There's two of my family members that for personal reasons are not—were not able to be-- as involved with his uh, with his um...with—to be as involved with him, as the—as the four—as the rest of us were. Mhmm.

JM: You talked about him destroying things. Did he do that throughout the rest of his life?

CM: Well, pretty much so. He...like with radios, turning the knobs up and down. Remote controls. You know, pushing buttons, pushing buttons and um, with the um, guitars he would just get mad and bang them and um, so pretty much so. I mean not all the time, but I would say most of the time that he did that. Now, in the group home setting he may not, he may not--it may have slowed down a little bit because you know they have like behavior goals and things that they have to adhere to, but um, I'd say that was probably one of his MOs. Mhmm.

JM: Did you---you said it might have slowed down a bit. Do you think that part of that was that he was in a different setting?

CM: Mhmm.

JM: It wasn't his home.

CM: Well, in a group home setting uh, one of the things that the staff—they try to encourage, um... the people that live there, you know, not to be destructive. But when you're with your family, sometimes you get away with a little bit more than you would you know in that particular setting. So I think with their probably with their behavior plans and positive reinforcement, that those kind of things decreased in the group home setting. So when he would come home, um...he might not have his watch, or he might not have his radio. You might say, "Ronnie what happened to it?" He'll just say, "I broke it." And that would be it. That would be the end of the story.

JM: In a—in the community did he ever have interactions with any adults who had lived at Orient?

CM: Um...I'm not sure. Probably the---I'm sure several of the residents that work in the uh workshop setting lived at Orient but I don't ever remember him stating that he knew any of them personally. You know. I'm not sure—I can't really answer that...that part.

JM: When uh...When you'd be watching and observing him, as uh in the three periods of his life, sort of thinking about who he was, how he interacted, how he engaged the world. What were the differences between Ronnie, let's just take—I guess your memories of him pre-Orient or pre-vague.

CM: Mhmm, yes.

JM: When he was at Orient and after, not immediately but after living in the community for a number of years. Can you describe the differences between uh, how he behaved? How he interacted? How he—to the best of your knowledge—how he felt?

CM: I would say, if I were to sum it up, I would say the main thing was that after Orient, he had more time to relax in the community. More time to get to know us. More time to get to know his extended family, like aunts and uncles. Um...so he was able to be more um...I would say be more flexible with his relationships. Prior—before he came home to

live, that middle period, he was just more cautious about people, because I think—and even with us at times--because I feel like he probably knew, well this is only going to be a short space of time. You know, so I'm going to be here for a short space of time, then I'm going back. But once he came home, and he realized that he was home for good, I believe that's when he was able to kind of um...let his guard down, so to speak, and become more trusting of people and more relaxed and more settled and um...more at ease. Because he knew he wasn't going back. You know, and he was able to form better relationships because they were going to be long-term. They weren't going to be like just temporary.

JM: Did you ever see any uh, him express anything that was fearful? For example when he was home for vacations from Orient he lived in fear of the return, for the trips back?

CM: He really didn't want you touching him—This is coming back—He really didn't want you to touch him or hug him. If you tried to hug him, he would like you know, put you at a distance. It was like he was on guard against anybody coming up to him trying to put their arm around him. So that, that when you asked that question—That triggered um, that particular memory. Um...

JM: So this is on his vacations from Orient?

CM: Yes, yes mmmm.

JM: And was that different behavior than you had seen before? Something that developed while he was there?

CM: Um, I think it was something that might have developed while he was there, because after he came home um, permanently that, that kind of disappeared. He would even hug you um, at some point you know? Um...but prior to that he—he wouldn't. You know, he didn't want you coming near him and—but like I said, after the—after he came home all that changed.

JM: Could he express himself the way that was articulate?

CM: Yes, he—he knew—he could tell you what he wanted. He knew what he wanted to eat. Um...he always dressed himself. Everything was always like in a neat little package. But he knew what he wanted to eat. He knew what he didn't like to eat. Um...there were—there were lots of times when he would overeat. You know, like he would just eat like he had a bottomless pit about him. Like some of us do now,(laughs) so that's not so abnormal. Um...he knew what he wanted. I mean he could talk. Over the years he learned to talk. Um...so yeah he was very expressive.

JM: Over the years, uh before Orient he did not talk much?

CM: No, like I said. When he would come home for like two whole days he wouldn't say anything. He would just be silent and um...then he was—you know, he would start talking.

JM: Mhmm. When uh...let me see...what was something you said that I wanted to pursue? When you---when he was—when he was back in the community and he was beginning to—oh I know what it was—you said—my question about fear. Did he ever express any fear? And you said that he didn't want to be hugged. What about—do you remember what the—what the ride back to Orient was like? What was—how did you interact then?

CM: I would say sad. Mhmm.

JM: Did he say anything?

CM: Uh no, not really.

JM: He knew what the story was though? He knew where he was going?

CM: Once—maybe about the halfway point um...he knew where he was going. That was the sad part.

JM: Mhmm.

CM: Mhmm.

JM: Did he go back with a suitcase?

CM: Yes.

JM: And he had the suitcase when he came home?

CM: Yes. Yes.

JM: So he was able to maintain his possessions?

CM: Yes. Yes. Mhmm.

JM: You never had any experience of any part of Orient other than that the--the drop off area.

CM: Right. That's right.

JM: Did your parents?

CM: I'll have to ask my mom. 'Cause I'm not really sure. I don't—I don't ever remember them going to any meetings or checking on him or—Mom probably called about him. Um...at different times, but I don't ever remember him—my parents going up there—just to go up there to visit. You know, just to see him. 'Cause when we went—when my parents would go up there it was to bring him home. Or to take him back. One of the two.

JM: Mhmm. How long of a drive was it?

CM: Mhmm...it seems like forever but now I know Orient is only like maybe an hour away. But we were little then so I'm not really sure um...I don't even remember the highway my dad took. I just know it was a back way. I don't know if 70 was built then. It could have been 35 or...I'm not sure.

JM: Mhmm. It probably was emotionally, a very long drive.

CM: Mhmm.

JM: So once you dropped him off and were heading home, what was it like in the car then? What was—how did it feel?

CM: Well probably the same way—It was probably the same feeling you know, he had to go back and you know, he's probably really upset. And um...so I think the ride there and the ride back was probably the same sentiments. You know, it was just sad.

JM: Mhmm.

CM: Mhmm.

JM: You mentioned the burr haircut when he was at Orient. He uniformly had hair close cropped?

CM: Um...I don't remember Ronnie's...I don't remember his haircut. I don't remember that.

JM: I'm sorry that was something [not sure what he's saying here. Too much laughing from CM] My apologies. His appearance then...you don't remember anything about that?

CM: Only thing I remember was the smell. He smelt like he lived on a farm. You know, it was a real...just a farm smell. That's the only thing I can kind of remember that part. You know, wasn't dirty or anything like that. You know, wasn't fresh. It was just like a farm. Like if you live on a farm, you know.

JM: You mean sort of like uh...like the smell of a barn?

CM: Uh....

JM: Urine?

CM: Uh, no nothing that severe. It was just like um...I don't know. It's like when you wash your clothes and you don't put fabric softener in them. You know what I mean? Just kind of a...not a fresh air smell. Certainly not that. You know, but it was...it was just an unusual odor.

JM: Mhmm. But that would pass after he'd been home for a couple days?

CM: Yeah, right 'cause after that my mom would you know, put his clothes in the washing machine and she'd probably wash them over and over and so on a so forth. You know.

JM: Do he have any---tell me about Ron's—Ronnie's medical and dental history.

CM: Well, um...when he first came home....I'm trying to think if he had all—no he got...he had all of his teeth when he came home. He didn't wear glasses. He didn't have medical concerns. Ronnie didn't develop medical concerns until later on in his life. Um...

JM: Was he able to maintain his teeth? Like brush, floss, that kind of thing?

CM: Uh, yes. Well, he didn't floss. He brushed his teeth. Yeah he was...he didn't get—he got his teeth pulled um...I think when he lived with my parents.

JM: So he had no teeth at the end?

CM: He had some but he wouldn't wear them. (laughs)

JM: Oh, he had dentures?

CM: Yeah, he had like a partial. He had partials but he didn't like to wear them at all. And um...but he didn't—he didn't have his teeth—he had his teeth pulled after he moved to the group home setting. He was---Ronnie was in pretty good general health when he came home from Orient. I mean physically anyway. You know. Um...he was in pretty good general health.

JM: How many of his teeth did he lose?

CM: I think he had the back ones pulled 'cause he had a partial in the back...and I think he might have had maybe two in the front. Maybe on the bottom...I'm trying to remember....Um...

JM: How many teeth remaining?

CM: No, he had most—no he had the two on the bottom pulled. I think they were bad. The ones down—two in the bottom were bad. And I think he had—had a partial for those but he didn't wear them.

JM: Mhmm.

CM: Mhmm. And he wore glasses. He started wearing glasses after he moved into the group home setting and um...he developed diabetes late last year...and he developed high blood pressure probably about a couple years ago. But I think those were just genetic um...issues that kind of passed on from my family.

JM: Is that what took his life?

CM: Um...they—they may have started—it may have set off um...some things in his body, that his body couldn't fight, perhaps. I'm not sure.

JM: What was the cause of death?

CM: He had uh...a condition called aplastic anemia. Which is a rare uh...blood disease that actually um...is—has previously only been diagnosed in adolescence and since he wasn't adolescent, he was an adult, that's really the mystery of the um...the anemia.

JM: Mhmm.

CM: Mhmm.

JM: He maintained contact with your—your family throughout uh...his--he went back in the late 70s.

CM: Mhmm.

JM: He lived in the community for 25 years.

CM: Mhmm. Yes. Yes. (nods)

JM: His brothers and sisters and there was frequent family contact?

CM: Yes. Mhmm. Yes. (nods)

JM: When you think about what life was like for Ronald. He lived in the institution uh...what do you think the greatest loss of his experience was?

CM: Probably um...not having his family around um, except for holidays. Because sometimes those holidays can be like two or three months in between like Christmas um...Christmas holiday and maybe—there may have been sometime during the summer that he came home, but you're talking about maybe three or four months in between. Uh,

maybe not any phone contact. I would say the greatest loss probably would have been the contact with his family in between home visits.

JM: How about for your family? What was the greatest loss?

CM: I think our life went on. Mhmm. I think our life went on. We went about our daily business. The things that we did on a daily basis. And we probably didn't think very much about it until it was time for him to come home on a home visit.

JM: Did your parents ever talk about it?

CM: To my knowledge, no. No, not, not that I remember. Not to us.

JM: Do you think that they—what they had been told about the place where he could get education and so forth. Do you think they—they believed that that was fulfilling?

CM: Yes.

JM: In--in retrospect, looking back at the uh problems and difficulties and uh...the energy that is put into community living versus institutional living. For society... what uh—how would you compare what the—what it was like...and what happened during the period of institutionalization versus community living?

CM: Well, I think one of the big differences is the fact that an institutional setting like Orient, they were isolated from the community. Because if you've ever been there you'll know that Orient's set way out in the boonies. It's a city—actually it's a city by itself but there's no um...there may be farm houses around but they're so far away I doubt if any of the people that live in those farm houses come over and have any um...um...um...outreach with the people that were in the institutions. As—and then you come to the community you've got people all around you. You've got houses that are close. You've got stores that are close. You've got movie theatres that are close. Everything that you need in a community is right there. So that's a big difference. Isolation—the institutions being isolated versus living in a residential setting or community setting where everything is you know like at hands reach, arms reach. You know. So that's a big difference there, is the contact that you have um...with uh...living in the community as far as an institution. Now, if the institution is someplace that's in the city that's a little bit different. The outreach is probably better but a place like Orient that was out in the country. I mean you even--you'd have to drive pretty far just to get to that place. So I'd say that was you know—unless people came in you know from somewhere else. You know, otherwise it was---it was an isolated setting.

JM: Mhmm. The uh...community setting of course you have the contact, but what about the quality of life? What about the experience? How would you contrast Ronald's experience Ronnie's experience living in the institution versus living in the community?

CM: Well I would say that the uh in the community setting—since we lived in the neighborhood where Ronnie was brought home to, we had been raised in that neighborhood, so he was very well accepted in that neighborhood. He was not ridiculed or made fun of or poked fun at or anything like that. Like I said, he was pretty outgoing once he got used to the fact that he was gonna be there. Um...so—so I would say that probably made him very comfortable, very relaxed, and very at ease, and very relieved to be away from um...the Orient setting where it was isolated and not having a whole lot of contact with outside people other than your staff or the other residents that lived there. You know, your um...relationship base is different you know and even though he may have built relationships with people at Orient while he was there, I still don't think that's the same thing as being home with your family. There's just a—There's just a big difference.

JM: Do you know anything about how many people he lived with? What his--what kind of a setting he lived within at Orient.

CM: I think my Dad said that he might have lived in a ward. Um...some things are coming back...he might of lived in a ward with um...several other men...maybe like—I when I think of a ward—I think like a hospital ward with nothing in it but like a big long corridor with nothing but beds. You know. As far as the sleeping area was concerned. I don't really know what the school setting or the work setting was like. I don't really know. We never really toured Orient and I know that when I first started working for Resident Home Association there used to be a group in August that would take Orient tours, but Ronnie was never one of those people that wanted to take an Orient tour. He didn't want to have anything to do with Orient.

JM: The um...when he was—when he was living in the community and working, you said he took great pride in his work.

CM: Mhmm.

JM: He loved his—I'm just starting to get—develop a profile of who Ronnie was outside of Orient

CM: Ok...Mhmm.

JM: And it sounds like he had great pride in his appearance and his clothing...

CM: Yes

JM:--fastidious and took care of things...

CM: Yes

JM: Loved his family and—

CM: Except the guitars and the TVs and the knobs and the remotes and stuff like that (laughs) ok.

JM: And was very proud of his work.

CM: Yes. Yes. He got a paycheck.

JM: Mhmm.

CM: And you know, money is power you know. And to get that was one of the things he said, "I got my paycheck today." You know. He didn't really know what the amounts were but he would say, "I got my paycheck today." And you'd ask him how much it was and he'd mention some amount—some amount that made him feel good. He may have said one time, he might have said 3 cents but if 3 cents made him feel good that day, then that's what it was. It might be more than that actually on the paper but um...he was proud of getting that paycheck.

JM: Did he look forward to his birthday?

CM: Yes, we made a big deal about his birthday. His birthday was on January the 1st uh...which is New Year's Day. We always had uh...party for him on his birthday. My other brothers and sisters um...I have um...two siblings that were born in May, two that were born in December, and myself, I was born in June. And we would always have our birthdays together. But his birthday was special because we would have his birthday separately than everybody else. He did not have to share his birthday with anybody. His was separate.

JM: When he was living at Orient did you have a birthday party for him before he went back?

CM: Um...I don't know. I don't know. I don't remember. I don't remember whether we did or not. We--we may have. My mother may have baked him a cake. I'm not—I don't really know. I'm not sure. I'm not—I don't know.

JM: Of course it sounds like you probably would have been anticipating his return in any case so it would have a different feeling to it.

CM: Yeah, because when he would be getting ready to go back, between Christmas and New Year's it would be right after the holidays and that would either---I don't know if it would be on the birthday or the day after. I'm not really sure about that.

JM: Mhmm.

CM: Mhmm. Excuse me. He liked animals. I don't know if I had mentioned that before. He like--loved animals. My mother had a toy Manchester and she had that dog ironically just when he came home from the institution and the dog's name was Toby. And that

dog liked Ronnie more so than anybody in the house. When my mother would go to the doctor that dog would either sit with Ronnie the whole time she was gone or that dog would hide under the TV. Behind the television. But he liked Toby. He had a—he really liked him.

JM: Mhmm.

CM: They had a fondness for each other rather.

JM: If a...if you could summarize one a...idea about in a—in your family's experience, what the impact institutionalizing Ronnie was—not on Ronnie but on your family? What do you think the impact was?

CM: You mean as far as being institutionalized?

JM: Yes, when Ronnie was institutionalized what was the impact on your family?

CM: Um...I can't speak for the rest of my brothers and sisters but as being the oldest child um...knowing that my mom was a young mother and having six children, I would say that the impact that it—that it—had probably would be this. Is that...my parents were able to focus their attention on their other five children as a group and tried to raise us the best way they could and then be encouraged by the fact that Ronnie would be better taken care of in an institution where he could get the special attention that he needed. So I don't know how you would define that. I don't know what word you would use um...but... that would be my opinion.

JM: You know sometimes there's the pluses and the minuses.

CM: Mhmm.

JM: And what you're describing is that the positive impact, that it did free up your parents' time, but was there a negative impact?

CM: I probably um...if there were negative impacts um...probably lost time. Lost part of the relationship of having all six brothers and sisters in the house at one time. Probably there may have been a loss in the relationship of that one individual that is only there temporarily and not there all the time. Um...there were—when we were all younger we started growing up together and then we have a loss. Someone that leaves and we lose that part of that relationship because you really don't get to know that person um...as much as you would like and they don't get to know you as much as you would like them to. Then that person comes back and then you got to form that relationship all over again, which makes it kind of hard because the setting he was in, he was used to a certain type of relationships and we were used to not having him around so when he you know—so just trying to mash and mold uh...that all back together was probably um...might have been the hardest thing we had to deal with. Is forming that relationship all over again and building up the trust with each other and the confidence that we needed

to have in him and he needed to have in us. And just coming together as a family unit once again.

JM: You mentioned uh...something about once you realized that he wasn't going to be coming back, do you think initially that he had some concerns that this was temporary?

CM: Of course, that would only be normal.

JM: Mhmm.

CM: That would only be normal. Uh, and then as time went on probably every um...probably every...five or six days that anxiousness would probably come back. Are they gonna take me back and leave me? And then we didn't him back---

JM: Would he verbalize that?

CM: Um, I don't think, no. Um, and then after that anxiousness would leave and he said shoo, you know. I'm sure he's thinking this up here (points to head). I'm not going back. Then maybe five or six more days it might build up again, you know. I'm not going back. And then pretty soon it just kind of left except for the fact that he did not want to take the Orient trips in August and he no longer wanted anything to do with The Ohio State Fair because that was in Columbus.

JM: Mhmm.

CM: Mhmm. Nothing at all to do with Columbus, period.

JM: Are there areas that you uh, in thinking about coming in today in talking. Are there areas that you wanted to talk about that we haven't covered?

CM: No, you've asked a lot of questions. (Laughs)

JM: That's my job.

CM: (Laughs) You've asked a lot of questions. Um...in—like I said I really—in all—I really don't know what happened while he was there. All of those kind of things are really—don't have a whole lot of input in. So, but um...I think you've asked a lot of questions. I hope I've answered them fairly, for you and um...as-as much as I can remember, you know.

JM: Well you've been very thorough. Um...now look, I just want to talk about you for a second. Uh you currently work "in the field", right?

CM: Yes.

JM: What do you do?

CM: I manage a group home of eight men that live there all together.

JM: Mhmm.

CM: Mhmm.

JM: Do you think that your choice of a career had something to do with uh, your background?

CM: Um, it helped initially when I um...I only started out doing it part-time and then it turned in to sort of like a career temporarily and I left and I came back. Yeah, it helped with the getting the employment most assuredly. Um...and I figured oh yeah that's something I can do, you know. I've got a brother that's you know, mentally retarded and I get along real well with him. I'm sure I can do the job. So, I'm sure it had an impact, yes.

JM: Do you see anything in the—in the current changes in community that you think are positive or negative? Concerning opportunities for people with developmental disabilities?

CM: Sure, I think that there's---there's um...well since I started in like 1985, um...I've never had any direct contact with um any negative—I mean any criticism. We've had neighbors that we were told they don't like you here. They probably never will like you here. It's just some people that are negative about people that are different no matter what the difference is. And I think they will always be that way. They will never change unless something changes on the inside. But I think for the most part uh the community is so more accepting you know, because normal people sometimes don't look abnormal, you know what I mean? So, it's like um...I just think it's—people just have learned to accept each other. Accept differences over the years. I think it's just the change in society. Um...you know, they just...I think community is very accepting. Our a...consumers work, they earn money. They pay their bills. They pay their taxes. I mean, they pay taxes. They get tax money back. I mean they, they have the same opportunities that we do, you know. And um...I think that's a big difference right there. Earning power I mean, you know. It's—It's the--It doesn't matter what the numbers are. I mean the numbers on the paycheck paper are—there's—they still have earning power.

JM: Mhmm.

CM: Still have a lot of potential. And that's what we do in the group home. Is that we try to assist them in developing their potential toward independence.