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Barbara Jones interview for the Lest We Forget Collection of Oral Histories

Barbara Jones

Jeff Moyer

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WRIGHT STATE UNIVERSITY
Lest We Forget Interview Project

Interview date: July 14, 2003

Interviewer: Jeff Moyer

Interviewee: Barbara Jones

Jeff Moyer: This is our first interview in the Akron area. It's July 14, 2003 and I'm interviewing Barbara Jones. Barb, tell us your background with uh these--the state institutions in Ohio. Uh how you first became involved.

Barb Jones: Um...I was employed in 1978 at what was then called Apple Creek State Institute as a speech and language pathologist. Um...and had remained there for 24 years. Um...moved in to various administrative positions but um began working there when it was still a very very large institution. Uh close to 2,000 people lived there at the time in big uh residential institutional buildings. Um...this was eight--about 18 months after the onset of a lawsuit that had been filed by a parent group because the deplorable conditions in which people were living.

In 1976, uh a lawsuit was filed against the then superintendent of Apple Creek--well what is now called Apple Creek Development Center. Um...to facilitate change to create a more humane environment. Um...prior to that lawsuit being filed, people lived in uh conditions. Staffing was often like one to 90. They lived in conditions where they didn't have their own clothing, where they didn't have private showers. They lived in...some folks lived in celled type rooms and were taken down the hall to an open shower room um and hosed off once a day.

Uh...crib wards still existed in 1978 when I started there and this was--this was a large room of probably 90-100 adult sized cribs. And there were just people uh with varying degrees of disabilities that laid in cribs all day long. And staffing ratios were poor in the crib wards. You know, primarily a staff person in--in the course of their shift, would get through every one of those persons, um and changed their diaper once and feed them one meal, and then their shift was over. So the amount of interaction that those people had uh was minimal. The amount of contact was minimal. They basically laid in this--I remember walking into this...this large room with high barred windows that were not covered so bare sunlight came through and there was just row, and row, and row after people--of people uh just staring at the ceiling or staring off to the side. Some folks could only stare in the position in which they were last left in because they didn't have the ability to move their own bodies.

Um...and I remember at the time, thinking what am I doing here? What have I done? How can I do this? How will I survive here? Um...but there were many of us that felt very strongly that change had to happen. And--and it was an exciting time because we were kinda on the cusp of that lawsuit. There were many of us coming in for the first time. There were speech therapists on staff and physical therapists and psychologists and social workers and um we were young and we

were passionate and we were sure that we were gonna make this a better place. And I will say, you know, 25 years later it became a better place. Um...but for many years we--we struggled with issues of dignity. Issues of...respect. Um...it--people used nicknames--staff people uh you know, people who lived there were referred to as 'tards or retards or um...and sometimes nicknames that related to a person's specific disability. Um...

JM: Such as?

BJ: Oh...I recall there was a gentleman that was um hydrocephalic, and one year at Halloween the staff painted his face and his head all green and put these like deely bopper things or something on him and they called him um..."Alien", after that. Um...this person had no verbal skills. This person had no uh...no way to interact functionally with anyone else. Um...I can't guess as to what this person's receptive skills were. Um...that aside, I think that people still understand the mood of--of what's going on. So there were often things like that. Our staff would teach individuals that lived there to um call other people nicknames. I remember one um person was referred to as "Pinhead" because they had taught all the other people that lived with him to called him "Pinhead". And he did in fact have a very small head, but it wasn't really funny. It wasn't really um...it was for some people. Um...but it wasn't funny to see that. I mean those were the things that often gave me pause and made me wonder, you know why do we keep doing this? Why do we continue on?

And this would con--this continued on long after we got through those initial uh devastations. Like once people were able to wear regular clothing and able to--to use a bathroom and able to use a private shower. There were still uh so many indignities. Um...privacy was not at all respected. It--you know I could walk into any area, any living area on that campus as an administrator, and it was nothing to see people in various forms of undress, in common areas um... or pants that were left open or clothing that had been soiled even by uh meal, that wasn't changed. And it would be three or four hours after that meal, you know big pieces of dried food or on clothing or on people's faces.

Um...and staff--there was a--there was a strong delineation between staff and residents. Um...everything was locked. All the exterior doors were locked. All the interior doors were locked. Uh...clothing lockers were locked. Refrigerators, if they existed at that time, were locked. Um...and only staff had the keys. Staff carried a big ring of keys. Um...and there were--I recall there were--a few people that lived there that um found keys or were given keys, abandoned keys, you know that people--and to them it was like a big status symbol to be able to wear keys on their belt, like a staff person could. Um...but everything was locked. We--'till as late as the early 1990s, were still struggling with unlocking doors. Um...they have succeeded in doing that but the very last thing I think to be unlocked were personal clothing lockers and refrigerators because there was still staff there as late as the 1990s that said, but people will get in there. And we would say, but that's the point. It's their stuff. Uh, people should be able to get in there.

Uh, but they wanted to--there was often this--this atmosphere of control. Uh...providing custodial care, but also control. Controlling behaviors. Controlling the way people acted. Controlling what people did. So, um we were well intended at the beginning but pretty unenlightened.

JM: Do you remember your first experience of walking into one of the living situations or the dormitories or classrooms?

BJ: Yes, I do. Um...on the day that I came to interview, there were six buildings um...open at that time. And one of the buildings--the very first building I walked--I had to interview in each separate building because they all had openings for a speech language pathologist--and I walked for the very first time into a building that was a one floor building that housed just over 100 people and there were two day halls. So each day hall had 50 or more people in it. And the noise level was unbelievable. Um...and at any given time there would be two to three staff people in there but...you know there wasn't...any constructive interaction going on. People were mingling and sometimes fighting with each other and sometimes--and I sat at a bench in this hallway that connected the two day halls so people actually crossed back and forth and um the noise level and the chaos and the...again I thought, what am I doing here? How will I survive this? How, you know...and that was actually not the worst thing that I saw there but that was my first experience. I think the worst thing was um the crib wards were certainly disconcerting. Very, very hard to--to understand why people had to live that way. Um...but we also--

Mark Lyons: I'm really sorry.

BJ: That's ok.

ML: That noise (mumbling)

BJ: Ah. It's gonna pick that up.

ML: Oh absolutely.

BJ: Ok, take five. (laughs)

JM: When we get back I'd like you to talk about the impact of the experience. The smell, the sound--

BJ: Ok.

JM: --how many beds in the room. That image of the--

BJ: The barred windows.

JM: The bars on the windows, the wrought iron, and uh fire escapes.

BJ: Oh ok.

JM: Do that for someone who--I mean what you're describing is wonderful but give us the big visceral picture.

BJ: Ok. You know another thing that was--I remember from those days and I don't know that it's appropriate to mention...

ML: So um Apple Creek is still there?

BJ: Apple Creek is still there. They're slated to be closed in 2006.

ML: The uh um...what do I want to ask? The rooms and the buildings that you're talking about, have experienced, are those still standing?

BJ: No. Those buildings have been razed. Um...uh-un.

JM: What were you asking about?

ML: Do you know what that is?

BJ: Oh, they had uh a series of drug busts in the late 70s, early 80s and staff were often at various levels of inebriated and or you know...

JM: Absolutely.

BJ: And that again to me was something that was really hard to fathom. Um...and kind of frightening. And we had people living there that would talk about getting high with somebody or you know. So they were...sharing marijuana with folks. It was so big though, you couldn't...you couldn't actually get a handle on everything that was going on so...um...yeah. Ok, I'll mention that as well.

(long pause)

BJ: Wow, that noise is still going on.

(mumbling among crew)

BJ: This is a nice building isn't it? Do you know this used to be uh a workshop? It was the original workshop for the County Summit Board of MRDD.

Judy Leasure: I didn't pick it up. That--that doesn't seem to have picked up.

Woman: Oh ok, good.

JM: Ok, we're rolling again?

ML: We are.

JM: I'm sorry (unintelligible)

(long pause)

JM: You rolling?

JL: Yep.

JM: Um...I'm sorry Barb when we were interrupted that-- go back to the--you talked about, described the...the two day rooms and the chaos. But what did the buildings look like? What-- what was your...what did they feel, smell? Just describe that whole first shocking experience.

BJ: Sure. They were all large brick buildings. Um...and the interior was concrete block. To this day remains concrete block. Um...I mentioned the noise level was--was tremendous, the amount of chaos um...smells...yes there were lots and lots of odors and um the smell of urine was pervasive everywhere. Um...and often feces. Uh...and just...people that were unkempt. Just a bad smell everywhere. Um...at that time too they had six buildings in operation. Large, residential buildings. They had one central dining hall that was kind of a...it reminded me of an airplane hangar. It was a huge building with a--with a rounded domed uh top and that's where everyone who lived there went for meals. So in the dead of winter, if you were outdoors, or you were on grounds moving from one place to the other you would see people coming out of their buildings as early as seven in the morning um down these outside fire escapes uh in the dead of winter, down three stories so that they could walk over to this large dining hall to have their breakfast. Um...and for some folks that was as much as a ten minute walk.

The grounds of Apple Creek were very large. Uh and they're beautiful. Um...it's a beautiful scenic--like you could drive on the grounds and say this is beautiful and then, you know to see people coming out of these buildings or to see what life was like in these buildings um...showers I recall, weren't divided. There were separate shower heads but they were open rooms. So...I talked a little bit about how privacy was not respected um...again, people would leave their showers, they'd be assisted with the shower and they would walk...sometimes the length of a--of a 30 foot hallway to get back to their bedroom without being clothed, without being properly dried off, without um...you know any kind of covering at all, and it was almost second nature to a lot of people that--well to almost everybody that worked there. Um...so for the first time ever we were tackling those kinds of issues. We were--we were working with developing life plans for people and skill development and thinking about those issues of dignity and respect, but that was very very hard. That was a long time coming. Um...for a long time it was uh...clearly who the second class citizens were and who the staff were.

Um...another thing that was pretty prevalent, at that time was the drug use among staff. There were um primarily and especially second-shift staff, there were a lot of young staffers, um...there were a lot of people who would come to work intoxicated or high or you know sometimes taking hallucinogens. Um...there were two instances that I recall, that the uh Wayne County Sheriff's Department had uh planted a staff person there that resulted in major, major drug busts. And there were people who lived there that would talk about you know, sharing a joint with somebody or getting high with somebody, or drinking beers with somebody in the stairwell.

Um...keep in mind it was such a large place, that it was very very hard to...to actually get a handle on everything that was happening all the time. People had a lot of freedom. Staff people

had a lot of freedom. They were given a lot of trust, which they often violated. Um...abuse. You know, people often had unexplained injuries. Um...often had...you know, broken jaws or that nobody could seem to pinpoint where that came from.

Um...there were incidents...one for sure that I remember...that someone choked because they had stolen food. Um...there wasn't food kept in their living areas. Food was only in the central dining hall but staff would bring in food. Staff would bring in food from home or from a restaurant, and someone stole a hamburger, ran to the shower room to stuff it in their mouth and that person choked and died. Um...you know if they wanted a snack there wasn't a snack to be had. There wasn't a glass of milk if you wanted a glass of milk. There wasn't a bowl of cereal if you wanted a bowl of cereal or a cup of coffee even. Um...those things just weren't there. Uh only when the dining hall was open and only by going there, could you get those things.

And even then...I remember going into the dining hall because initially as a speech therapist, we worked sometimes on eating programs and oral musculature stuff. Um...so you would go to do observations, um...sometimes somebody would be sitting there and their food would be stolen from them, or knocked off the table or uh dropped...whatever, and it wasn't replaced. It wasn't you know, they couldn't guarantee that you were gonna get you know one of those three meals that you were--that you had come there to get. There was no guarantee that you were even gonna get through that without somebody taking it or uh flipping the table over or um...anything could happen so...and it's not like you could go through the line again, that was it.

Or, if a staff person--because I'd mentioned before there were some real control issues--if a staff person felt that...let's say someone had misbehaved, they would just walk right up to them and say, you're done, and take their meal. Whether they were finished or not, they were done because they didn't like what that person had said or how they behaved or um...so there were lots of people out there shooting from the hip in terms of what they felt was appropriate behavioral intervention. And again, that was pretty unenlightened. Um...what we did at that time was classic--classic behavioral conditioning. Um...but there were also lots of pretty aversive stuff going on. Um...we had behavior programs where people were...all their meals were blended, so the only food they could have would be blended unless they behaved. Um...where people were um...you know had noxious substances sprayed in their faces to--to interrupt self-injurious behavior. Uh...people were put in mechanical restraints uh...

JM: Could you describe the noxious substances and mechanical restraints?

BJ: Lemon juice--

JM: Make it a complete sentence.

BJ: Oh, I'm sorry. Um...people you know, they would put lemon juice in spray bottles um...and spray it into someone's face if they didn't behave how the staff person thought they should behave. And I guess I say that because the program was written to target a specific behavior, but staff people were often out there. You know, there were lots of cowboys out there who...if they just didn't like the way you behaved, they would implement that program. Um...and there was

no consistency, because a different shift would come on and they would have a different idea of what this person should or shouldn't do.

So...people weren't even allowed to be angry. I mean we all have anger, we all lose our tempers, but for the most part it just wasn't tolerated. Um...there was that whole competence deviance thing because people were deviant, they just wouldn't tolerate anything at all. Uh it was like the more competent you were, the more you could--the more your behavior would be tolerated. The less competent you were, the less your behavior would be tolerated.

So...it was very disturbing to you know, as an administrator often, I would be in the position where I would have to you know, I'd see someone being squirted with something or see someone be grabbed or see someone being taken down into a floor, facedown restrained, and I would step in and want to know what happened and why it had happened, and you know what brought this about and what's--what's the plan? What's the written plan? What's our intervention supposed to be with this person? Um...and more often than not, it wasn't following the plan at all, it was just because a staff person felt that this was inappropriate. Or a staff person would say, well I wouldn't let my kids get away with this. So there was that struggle of, these aren't your children. These are adults who live here and receive services from you. Um...and that was very difficult. So...

JM: What are mechanical restraints? Could you describe that?

BJ: Um...mechanical restraints are any...what was utilized then were...mechanical restraints primarily are any outside uh I'm at a loss for words right now.

JL: Device.

BJ: Device. Thank you. Yeah, any outside device that's used to restrain movement.

JM: Could you start at the beginning please? (unintelligible)

BJ: Thank you. Mechanical restraints are any outside device that's used to restrict freedom of movement. So we--we had in place um...everything from soft ties, which tied people to their beds, and those were--those were um...like uh lambskin kind of tie device that went around wrists and ankles that would tie a person down to a bed...to leather cuffs that were also used to tie people down to bed. We also used full arm splints that restricted the movement of people's elbows if they engaged in self injurious behavior. If someone hit themselves in the head, then they would be placed in full arm splints, so that they could not bend, which also meant they couldn't eat. Um...so someone who was maybe capable of feeding themselves at meal time, would be fed by a staff person. Uh...just because they couldn't...they couldn't come out of these restraints. They were kept in these restraints 24 hours a day. Except for bath time, usually. Um...so and it wasn't uncommon. Catcher's masks if people bit other people, it wasn't uncommon to--to...to see someone walking around with a catcher's mask on. Just to keep them from doing that.

We had also uh a special needs unit, and there were four people that lived in special needs and there were four cell-like rooms in the basement of the administration building, and these people

were put in special needs because they had...they were considered to have behavior so severe um...self-injurious behavior or physical aggressive behavior so severe that they couldn't live with the general population. And they were staffed two on one, so you know, there was this tremendous reputation uh that these people had on grounds, that you knew that these were--these were really the scary people. These were really the people that would hurt you or themselves or they were really deviant and um they would only be escorted on grounds with two staff people and often held in mechanical restraints. Leather restraints that were held with a leather strap but a staff person on each side so that they could even walk down the hallway occasionally um to go to the commissary maybe, and get a Coke or something. Um...that was pretty horrific. That was a pretty horrific concept. I will say that two of those people remained at Apple Creek Development Center and uh to this day are there and do not display severe behaviors and live just like everybody else lives.

But, um...at the time I think our response to everything was so extreme that we perpetuated extreme behaviors. Also, I think that people were only trying to survive in--in conditions that weren't very survivor able. So...

JM: What uh what type of punishment was used or do you know about?

BJ: There were (sigh) time-out rooms in existence at that time. And some of those were padded um with just a door that closed and a little window that staff could peek through. Those were designed to be used therapeutically, and by therapeutically I mean as--as part of an improved behavior plan where if someone exhibited behavior that could not be brought under control, they were placed in time-out. But, like most behavioral intervention at that time, it was abused. And people were placed in time-out at the whim of--of the staff person they worked with. So...other--other types of punishment that existed were--and some of these boarder on that whole respect and dignity thing too.

Um...people--some people were--I mean it was nothing to walk out on grounds and you would see somebody being escorted because a staff person had their hand on the back of this person's pants. And they were yanking up their pants and holding down their arm and pushing them across grounds. Um...or they had grabbed the back of their shirt and wrapped their hand into it a couple times um to have control over this person and you would see people straining forward um you know, certainly nobody wants to be held like that. Um...to get out of that. But, the staff person felt strongly that they had to exhibit this kind of control or that person would run off. Um...and that was another common thing that would happen too, was the use of labeling. People were called runners. People were called biters. People were called, you know, SIBers uh or slappers or whatever. They weren't called people. They were--and they were--I could walk into a living area and staff thought nothing of pointing out to me who in the room...you know, he's a biter, um she'll slap you, she'll pull your hair. She's a hair puller, she's...um...I can't imagine the indignity of having, you know yourself talked about like that. I mean just, those were things that were very very disturbing.

JM: What would happen if people ran away?

BJ: Um...if people ran away, we--there was an emergency plan that you were supposed to follow that rarely happened. Mostly, staff would jump in their car and go and try and find them. And they would--they would basically run and take them down. And by take them down, I mean full restraint. Um...we were taught at that time to uh do a full take-down restraint which started with a basket weave...and you brought somebody down, facedown and then used your legs to spread-eagle their legs, still holding their arms in a basket weave position and then your body weight would be on top of them. Um...so they would--they would engage in those kind of full body prone kind of take downs, which we now know are very dangerous. But um...or whatever means they could use to get somebody down...to--to stop their progress. Occasionally, uh law enforcement would be involved but usually uh they would just be chased. They would just be chased down and brought back. And usually not very nicely.

So...another aspect that was--was disturbing, was that people lived at Apple Creek Developmental Center, which was originally the uh Apple Creek Home for the Feeble Minded, who had a primary diagnosis of mental health or alcoholism, or um...any other...psychotic disorder and not primarily mental retardation or developmental disability. And they all lived um...together...and some people lived there for years and years and years. There were stories that you know, in the 1940s and 50s that if you had a specific problem, whether it was alcohol or you just sort of snapped one night, that your family could actually drive you in the middle of the night to Apple Creek Developmental Center, and drop you off. And you know...you were sort of--the judge would then rule that you had to stay there and--and.

So there were--there were some very interesting people that I met early on in my career who had no other issues. Uh...one gentleman--we went through a massive deinstitutionalization movement in the 1980s--and there was one gentleman there who was then in his mid-60s who was very lucid. Um...who, according to his records, had a problem with alcoholism, but had lived at Apple Creek Developmental Center for the last 30 years. And he--at that time, it was a working farm, so he was kind of a supervisor of a work crew. He lived there but he supervised other residents that lived there to accomplish...the farming. And he also supervised one of the--the living wards. And when we went through this massive deinstitutionalization...I remember talking to him about looking at options and places that he could live, and he said, don't make me move. I didn't have a job, I don't have any benefits, I worked for 20 odd years for this institution. This is all I have. You know, the least you can do is let me live here until I die. And it was..you know he knew no one on the outside. He--he didn't know how to live on the outside. Um...and it was very powerful. It was very disturbing. That, here was a man--he was a wonderful man. He--he had a wonderful sense of humor. He gardened and um...was very knowledgeable about house plants and--but he had no place to go. And he said, please don't send me out there. I don't know what to do there. And he was right. He was not at all prepared to live in the community. Um...we'd never paid him a wage so you know, in his mind the least we could do was let him live there until he died. And that is in fact what happened. Um...he died in the 1990s. Still at Apple Creek Developmental Center.

JM: Did you ever see the cemetery there?

BJ: Yes.

JM: Can you describe it?

BJ: Um...very stark.

JM: Start with the cemetery.

BJ: The cemetery that was actually on the edge of the grounds of Apple Creek, um...was very stark. Markers were non-existent on some graves. Um...by the time I left there in 2001 they had marked every grave. But some of them were very small and very um...you know, like they would just have...a name. Some of them couldn't even identify the year somebody was born. Um...because those records weren't there or no one bothered to keep those records. So...it was a very disturbing place. They still utilize the cemetery to this day, 'cause there are still a few people there that have no family contact or no known family or um...but they make an effort in the last decade to see that you know graves are marked and there are appropriate markers on the grave and you know, they maintain it. It used to just be very overrun. I remember being there in the 1980s and it was just very overrun and the graves were marked with maybe a rock or two. There wasn't really a--a gravestone. Um...it was kind of a disturbing place, actually. And there were children. There were children's graves there. Um...there are people living there today that--that came to Apple Creek State Institute when they were six years old, which was the youngest that someone could be admitted. Um...and basically were raised by the staff at Apple Creek Developmental Center. And they're now in their 30s and 40s, sometimes early 50s, and are still there.

JM: When you got there, there had been--you were the first wave of change. Do you know about circumstances that happened prior to your arrival that were even more shocking than what you described?

BJ: Mmhmm. Um...the reason that I was able to get there was um...because they were hiring certain professional staff that had never been part of the staffing system there. And that came about as...as...the result of a lawsuit that was filed in 1976. The then superintendent of Apple Creek State Institute, um...Jeff Delaney, was abhorred by the conditions in which people were living. Um...I have seen film footage. I have heard many descriptions. People that were wearing hospital gowns and diapers and um...I know some of the people that I saw in that film footage and they were able later to use a toilet, use a bathroom on their own. Um...and wear clothing, but didn't--they sort of wandered around in big day halls that had big oak benches, um...those were the only places that people could sit. So they sat on the floor or they sat in an oak bench. And the staffing ratios were as high as like 1 to 90. At that time, um families could visit with their family member, but only in an approved visitor's room. So they would come to an administration building um...to the reception area, and they were told who--you know, they would tell the receptionist who they wanted to see, and word was sent out and that person was brought from one of the outlying buildings. They were cleaned up and they were brought from one of the outlying buildings to visit with their family.

Um...Doctor Delaney...well as I said, was abhorred by the conditions in which people were living, and he garnered the support of uh family groups and media. Um...local newspaper, local television media, and...opened his doors. And said, come in. I want you to see. I want you to see

what people are living in. How people are living. What their life is like. Um...you know, we're not gonna keep it isolated any more. Um...he advised this parents' group to sue him. Um...but he took parents into those living areas for the first time. And these--this was so disturbing for these families to see how their children or siblings were living and you know, they wondered how they could even survive in such conditions. Um...and I wonder how they survived in such conditions. I--I--you know I knew many of these people later um...as young adults and um...it's amazing to me that they did as well as they did, given that they spent a lot of their childhood...ignored, um...sometimes they were able to get food, sometimes they weren't.

They never had clothing, other than when they went to visit their families so...so the lawsuit was filed, and um...the result of that was that the State of Ohio was forced to um...allocate...sufficient funding to Apple Creek State Institute to get clothing for people. To put together day halls and common rooms for people. To renovate, to do private bathrooms with private showers and....and by private I don't mean off your bedroom. I'm talking about still one big communal bathroom, kind of like a dormitory setting, where there would be uh...six or eight toilets and five or six showers that were shared by maybe 30 people. But it was much better than just those big tile rooms where people were hosed off prior to that.

So...the lawsuit accomplished funding to make a difference. To bring in professional staff to increase staff ratios, to eventually eliminate crib wards, to divide these large residential buildings into um...smaller living areas within large buildings. Um...but to this day people still live in areas of 12 to 16 people sharing a common living space, and then 1 to 4 people in a bedroom. So...that was about the same time that--that the State of Ohio separated mental retardation and--and--the Department of Mental Retardation and the Department of Mental Health. And--and made a clearer delineation of the types of services and the types of, you know, the amount of funding those um...programs you needed.

JM: When you describe the uh common dining area, people walking--

BJ: Mmhmm.

JM: --down the fire escape, in the dead of winter, were--were they properly clothed? Properly with outdoor--outerwear?

BJ: No. Um...

JM: Complete sentences.

BJ: I'm sorry. Uh clothing that people received in the--in the 1970s and early 1980s was all state supplied. So everybody's winter coat looked the same and everybody's summer coat looked the same, and everybody's um overalls looked the same and everybody's um...um...jeans and t-shirts, and pajamas looked the same. And they were often shared um...people didn't own things like gloves or hats or mittens, or scarves. Um...when I talked about people coming down these--these cold metal fire escapes, to go to the dining room in the dead of winter, they were all wearing like a nylon parka. Um...and most of them, you know, staff had not even bothered to make sure everything was zipped up or you know, they'd be open and blowing in the wind and people didn't

have gloves. People didn't have boots. Uh...people didn't have any protection against the elements. Uh...what they did have might have been worn by someone else the day before. I mean there was a pile of coats and you just put a coat on everybody. Um...there was a pile of underwear that came back from central laundry. They operated a huge central laundry. It was one separate building all by itself. Um...and you took a pair of underwear from that pile of underwear. Uh...or it was divided up and put in--in your locker, but it--you know the day before it was worn by somebody else prior to it being laundered. It--there were no uh individual choices in terms of what people would wear.

Uh...one of the common things too were the heavy cotton jumpsuits that snapped up the front. Uh a lot of the men were clothed in--in cotton jumpsuits um...and they did have like uh work shoe that they all wore. I remember one gentleman um...always wanting to take off his clothes and uh... so what they would do with him is they would put the jumpsuit on him backwards and--and close it all the way to the top and then pin it so he couldn't pull the snaps open. So he was basically stuck in this...this uh jumpsuit that was put on like a...you know it made you think of a...what are those called?

JL: Straight-jacket.

BJ: Straight-jacket because it was--he couldn't get out of it. He couldn't go to the bathroom if he wanted to, without assistance. He couldn't do anything. Um...when in fact, the issue was um...of course this was learned much later, uh those cotton materials were very harsh and very uncomfortable and--and you know, not at all to his liking. Um...he ended up being able to wear soft t-shirts and elastic waist pants um...much later in life. And soft shoes. Um...he--he really, you know his--his tolerance for those kind of heavy, scratchy materials, was just more than he could bear, but there were no other choices. Um...so he was...

ML: Could you say that sentence again about um the gentleman in the jumpsuit, and how it was worn and how it looked like a strait-jacket?

BJ: Sure. Um...one of the...the most common clothing items for men were heavy denim or heavy cotton jumpsuits that--like work suits that snapped up the front. And there was one gentleman who was always wanting to disrobe and take his clothing off, so what staff would do is they would put the jumpsuit on him backwards and close up the back of it and pin it so that he could not open it. So it--it was sort of like a--it reminded you of like a strait-jacket because he really couldn't open it himself. And he was restrained and so to speak, within that...clothing. He couldn't go to the bathroom if he wanted to go to the bathroom, he couldn't take it off, he couldn't um...ok.

JM: When uh...we end at 10:30 again, Judy?

JL: Uh yes, John's coming in at 10:30.

JM: Ok. Um...the expectations that you described about the beliefs, about what people required and the sort of behavioral programs or lack of them that were used, can you describe when

people were moved back into the community, the difference in--did you see any of the same people in one setting and then the other in the difference in--

BJ: Mmmhmm.

JM: --their capacities, abilities?

BJ: Mmmhmm. There was a massive deinstitutionalization effort in the mid-1980s. And...people who had displayed--I remember one gentleman um...who was not in special needs, but was always staffed with two people because of his--his outrage and his physical aggression and he again, had this tremendous reputation and he was to be feared um...was moved into a community group home setting in the mid-1980s into his own bedroom and able to make choices, um...and developed truly into this wonderful, thoughtful, young man. Um...as a matter of fact I saw him um...as recently as about six months ago, and he's now in his late 40s. He takes vacations um...by himself. He goes to...to Disney World um...and meets up with groups there. Um...he flies to Florida, he goes to um...the mountains in--in upstate New York for horseback riding. He was the speaker at uh...a staff recognition uh ceremony uh two years back, where he spoke about the group home--staff home, what a difference they had made in his life.

Now, when I--

JM: Say that he was--

BJ: Sure. He was the speaker at a staff recognition ceremony where he spoke about the changes that--that staff made in his life, this particular group home that he lives in. Um...and he's a very soft spoken, person. And the people who know him now, could not have fathomed what he was like when he lived in an institutional environment. I mean...they're like two different people. And there were lots of stories. Um...I have, since coming to work for the county, I--I've met many people that came from Apple Creek or Cleveland Developmental Center or Orient, who um...if you mention that kind of common bond, um...they'll say, boy I sure didn't like it there. Did you? Um...one woman kept saying that to me over and over again. I didn't like Apple Creek, did you? And I was like no, there were parts of it I really didn't like, you're right. Um...but the difference. People that, I think at the time, staff would not have thought could have ever, ever tolerated living...in a community or living in a residential neighborhood, and not being so deviant that--that they would create problems, have successfully done that. And have jobs, and--and you know, wave to their neighbors and--and I've seen them. I knew them when they lived there. Um...and I see how they live now. And--and the quality of their life, and how much that's improved.

There were also people living at Apple Creek Developmental Center that are very frightened...of change. That are very frightened of making that move. Um...they have spent virtually their whole life--I mean from the age of six through sometimes now some of these folks are in their 40s--in this setting. They--they've undergone a lot of change in this setting. Um...but they're so afraid of having to be out there or in the community or um...and I think what we see now when--when someone is placed from the developmental center, population into the community is um...often you'll see uh an extreme reaction to just that change, you know. They may never have had their own bedroom. Um...so you see some adjustment. Um...but for many many people that was

like an immediate improvement. Uh...I can't imagine being 40 years old and having to share a bedroom with somebody still. I--I mean it would just be...I don't know what that would be like. Um...but then to have to make that kind of change as well is--is very frightening. There are people that will tell you that live at Apple Creek that they don't want to live any place else. Um...but let me say they don't know what it's like to live any place else. It's only because they've never had that experience. Um...as hard as we try, and every effort we made to get people involved in the community, uh...Apple Creek Developmental Center, like many state supported systems, remained a very rural and isolated place. Um...people go into community with a group of other people um...with similar disabilities and they sit at a concert in a park, or they um...go to the grocery store, but they come back to a place where...they don't have a kitchen where they live...so uh...it's just not the same thing. It's never been made the same thing. It's not the same experience. So...

JM: Two topics I want to make sure that you covered when we talked earlier...smoking?

BJ: Yes.

JM: and sex.

BJ: Yes. Um...I had mentioned before that behavioral intervention was fairly unenlightened and often aversive. And...I saw people...and these were degreed psychologists, trained people--trained residents there to smoke cigarettes so that they could later use cigarettes as reinforcers. Um...you know an addiction is a very powerful thing, and you can control somebody's behavior short-term uh with the promise of their next cigarette. But, that's an incredibly cruel thing to do to someone and to--to introduce this addiction into their life um...so that you can use it against them. And it was a fairly common practice. Um...most of the staff too smoked at that time. Smoking was you know, of course a lot more prevalent than--than now, and smoked on the living areas and smoked in the day halls and smoked while they did their jobs. And so some people--some residents that lived there um...wanting to emulate staff, you know also wanted to smoke. And--and they did nothing to--to protect people or educate people about the dangers of smoking. Um...it's not that way now, but it was then. Um...what was the other thing we were gonna mention?

JM: Sex.

BJ: Oh. Um...sexuality was also something that wasn't discussed in--in the 1970s and 1980s. If people had sexual urges, if people wanted to express themselves sexually, they would find a way to be alone, they would find a place to be alone, they were often discovered in bushes or--or uh...bordering wooded areas um...engaging in sexual activity, or in an abandoned classroom, or...more often than not, that would become the object of a staff person's interest or ridicule, or...you know you would hear about this person was caught in the bushes with this person and exactly what it was they were doing. Um...how they were found, what they were doing, and staff would laugh about it as though the residents engaging in that activity had no idea what they were doing and--and it was a source of amusement. Um...so unwittingly, you would...you would have knowledge, intimate knowledge of people's lives that...that shouldn't be something you should know about them. That should be very private and protected.

Um...I will say that um...as the years passed, uh Apple Creek became much more sensitive to those issues. But initially, um...you know it was like a source of--of...entertainment almost...for the staff. Staff people would actually brag about finding someone disrobed or engaged in some sexual act somewhere. Um...when in fact people were...you know there were people there that--that had attractions towards each other. There were people there that moved into the community and still continued to date. Um...but they had no...no recourse. They had no place to go. They had no place to be alone. Um...so they often would go to...whatever kind of privacy they could find, but everything was a public area. So they would be discovered and people would laugh about it, and joke about it, and ridicule about it. Um...even masturbation, people were ridiculed for engaging in masturbation and um...you know they would use like harsh terms. Um...it was very uncomfortable. It was very uncomfortable.

JM: We heard from uh individuals who lived at Orient about sexual abuse and coercion, bribery, and rape. Do you uh have any experience with any of that?

BJ: Yes and no. Um...I'm sorry. Um...certainly there were rumors and there was always uh...we were always vigilant for any kind of sexual involvement between the staff and the residents that lived there. I was aware of uh housekeeping staff who had taken one of the residents into a um...housekeeping closet um...they were both males and the...the staff person had the resident perform oral sex on him and was discovered. And charges were filed and that person lost their job. There was uh...another staff person who was a teacher that often took a young gentleman home with him um...and the young gentleman...you know made charges and allegations about inappropriate sexual contact. Other than that, I--I didn't have any firsthand experience. Um...primarily my experience was that residents would talk about um...masturbation and...staff person telling them to--in very crude terms--you know, tell them to go choke their chicken or um...you know, things like that, and laugh about it. Um...and they would do those things because...I remember one gentleman telling me that uh for a can of pop...you know he would give another resident a blow job, because he would get a can of pop for it. Um...and staff were in the area when things occurred. I mean there was never no staff there. Um...

ML: I think we should try that without the word blow job, maybe oral sex.

BJ: Oh, thank you. Yeah. Yeah, blow job's probably not really cool, huh?

ML: (unintelligible)

BJ: (laughs)

ML: (unintelligible)

BJ: Yeah, that's true. Um...one resident um...I know talked about getting a can of pop if he would perform oral sex on someone else. And he would do that and laugh about it, because it would get him a can of pop. Again, as I mentioned, getting a snack or a treat or uh...you know there was no other meals to do that, unless somebody brought it in for you. Because there weren't

refrigerators, there weren't....you know, so...those could be very powerful things, a can of pop, a Hostess Twinkie, you could get people to do just about anything.

JM: What about medical care and dentistry?

BJ: For as long as I can remember, um...dentistry was available at Apple Creek Developmental Center. They--they actually ran their own dental clinic. Um...which came about just about when I got there in 1978. Medical care...they had on staff physicians, but you know early medical care for this population um...resulted in uh real heavy use of psychotropic medication. And there were staff people that used to talk about the Thorosine shuffle because people were sometimes so overly medicated um...that their gait was impaired, and they would sort of shuffle. Um...the visual image that I'm pulling up right now is--is a man in a cotton jumpsuit shuffling across the sidewalk from one building to another um...you know with their head down and kinda this drool out of the corner of their mouth um...because they were taking--not--you know multiple psychotropic medication in high doses. Um...which really served to do nothing other than...well obviously it sedated people, but it also impaired their ability to learn. You know, to--their ability to--to understand reality. Um...they--Apple Creek actually got very good at minimizing the use of psychotropic medications before I left there in 2001. But it was very very common uh...practice through the 1980s even. For people to be heavily medicated or in--in response to a crisis of--of some sort, if somebody was having an emotional crisis or behavioral crisis to you know, shoot 'em down uh to give them Haldol, IM, you know...was kinda misused.

In terms of routine medical care...people....people got physicals of a very basic--you know they were given an annual physical of a very basic nature. Um...you know kind of check your heart beat and your pulse, and make sure everything else was ok. Uh...that got much better over the years, but I--people weren't ignored. I will say this, if someone was sick or they had uh some condition that just came up, they were--they did receive medical care. They always had physicians on staff. But even they were fairly unenlightened and that got better as years went on so...

JM: Well, we're running very close to the edge.

BJ: Ok.

JM: Do you uh...are there other areas that you think are pertinent that we haven't covered?

BJ: It's--you know, I don't...I hadn't thought about those times for a long time because I was there as we made--made lots of lots of changes. Um...I think the important thing or the most significant thing um...that I recall, were...those issues of uh...neglect. Because even when we started to bring in state supplied clothing and we started teaching people to brush their teeth, and we started teaching people to use a toilet, um...for years and years and years, people were left alone most of the time. People still sat in the corner and rocked, or twiddled their fingers or...um...stared at the wall uh...for a long time. People were just left alone to fend for themselves. I think that's it.

ML: Can I ask one question?

BJ: Sure.

ML: Did you uh ever have any experience in walking into a uh room...um mental handicapped people just surrounding you--

BJ: Mmhmm.

ML: --because of touch? Could you...just describe that situation?

BJ: When I talked about um my first experiences and um...what it was like to first walk into one of those residential buildings, where there were these large congregate day halls and--and lots of chaos, this became kind of the standard um...for the first few years of my career, that when you did walk into an area uh...people living there would just swarm around you and grab you and touch you and--and um some people wanted to hug you and some people wanted to um...it was very um...disturbing because they wanted so much to have your attention. Um...on the other hand, we were also trying to--to demonstrate to people that it's not appropriate to--to wrap your arms around everybody that you see. Um...it was really pretty sad um...that people so wanted social contact and so needed social contact, that um...it didn't matter if they'd ever seen you before or not. They--you know, they were there um...on top of you.

One--one of the other things that um...I saw change over the years, which I think was fairly significant, when I first worked at Apple Creek Developmental Center, if a person was being escorted across grounds, if a resident was being escorted across grounds, um...the staff person--unless they were restraining them by their clothing somehow--would always hold the person by the wrist. Would always escort people by grabbing their wrist. You seldom saw someone put their hand in a resident's hand, because the resident's hand was dirty. The resident's hand had food on it, or feces, or saliva, or...so you led people around by grabbing their wrist and kinda um...dragging them across the grounds. That was always so disturbing to me. That was always so...upsetting to me. To see people being led that way. We had a few staff people that um...would even wear gloves, rather than touch some--you know, just to escort someone. Um...and still escort them by the wrist. Um...it was really just a matter of, you know if someone's hands aren't clean then help them wash their hands. I...I don't know what that would be like to...if you didn't want to touch my hands. Without even knowing me you wouldn't want to touch my hands, just because you would assume that I was somehow unclean. So...that was always disturbing.

JM: Thank you very much.

BJ: Ah, you're welcome. I truly have not thought about a lot of those things for a long time.

JM: Understandably.

