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Terry Alexander interview for the Lest We Forget Collection of Oral Histories

Terry Alexander

Jeff Moyer

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TERRY ALEXANDER

Jeff: Terry, when did your life begin to engage with state institutions?

Terry: I began working for Hope Homes in 1978. We were a brand new organization with kind of a clean slate. We had many people that wanted to live at Hope Homes and so as part of that we would go and meet individuals that were interested in moving into the home and through that process is when I first set eyes on Apple Creek because there were individuals at Apple Creek that wanted to move into the community. So we would go down there and meet individuals who lived there and talk to them about Hope Homes and see if they would be interested in changing their place of residence.

Jeff: Describe that first experience.

Terry: The first time I was at Apple Creek we had what would probably be the nibble tour and there was a very professional individual, I can't remember if it was a staff psychologist or one of the administrators who gave us a very tidy and neat tour. I believe we saw all the best parts of Apple Creek. At the very end of the tour though we walked into a very large room which I believe they called either a rec room or a social room and in this room were probably 30 to 40 individuals with disabilities and they were scattered about the room. The room was empty in the middle with chairs all the way around the room and people were sitting in the chairs in various states of activities. When I say activities I don't mean playing games or doing crafts—I mean self-abusive activities, aggressive activities, sexual inappropriate activities. It sort of took your breath away when you walked in. I don't think our tour guide expected quite that kind of chaos and confusion when he took us into this room. I remember the noise level was very high. People screaming and people talking loudly; the staff, there were three or four individuals that were staff were all grouped at one end of the room. No interaction with the people there. There was a lot of wandering too. People walking and wandering and there were probably three or four of us and we just stood there and it was hard to take it all in. As we stood there and as we watched all these people this older gentleman walked over to us and stared at us and he said, "what the hell are you looking at, this hain't no God damn zoo?" I've never been so humbled in my whole life. I mean that's exactly how I felt. He was so right. This was no God damn zoo and why were we standing there staring at these people and we just turned around and walked out. I went to Apple Creek maybe two or three times after that. The meetings were always very formal. We were never given tours after that. It was just a one-on-one but I have always utilized that philosophy when people want to come into our community homes. I've always remembered this isn't a zoo and I'm very careful about interfering in people's living space. So that was my most intense memory of Apple Creek.

Jeff: When you would have your one-on-one meetings where were they held?

Terry: In an office usually or a little meeting room outside the office with a conference table and the individual would be brought in by a staff person, introduced and if the person was verbal and able to verbalize to us what they wanted, be able to ask questions then it was more a one-on-one. If the individual was nonverbal then the staff person would come in with them and do their interpretation of what they felt the individual might ask, questions they might want to know, things about what living in the community was like.

Jeff: Did you ever see signs of abuse?

Terry: The only abuse of things that I would have ever witnessed would have to go back to the story with everybody in a huge room. If it's abusive to let people engage in the kind of behaviors that they were engaging in without interacting then yes, that's what it probably was, abusive; abusive in the sense maybe more neglectful than abusive. But in that room there were individuals who had stripped naked, were sitting there with no clothes on; no decency. These people were not

respected. They were clumped together in big groups.

Jeff: When people moved into Hope Homes facility that you were beginning to form was there ever a discussion about what life had been like on the inside?

Terry: I did not hear a lot of discussion between our guys regarding past lives especially guys that had come from institutions. I almost had the feeling that they didn't want to talk about it. Every once in a while, Jack was probably the most verbal of all our gentlemen, every once in a while Jack would relay a story about his time at CDC and his time at Apple Creek. But that was not their favorite topic of conversation and a lot of times the other guys would say eh, that was long ago. That was in the past.

Jeff: The people you worked with that moved back into the community did they come out in good dental shape and medical needs properly attended to?

Terry: There were always it seemed questions about medications seemed to be the most concern. People would come out of the developmental centers on an enormous amount of medications. Jack was not one of them but there were other individuals who did. So it would take a while to get community doctors to evaluate and make decisions based on their new lives and needs that they had now in a setting that was way different from where they had been living. I saw that as the hardest medical concern that we had to deal with.

Jeff: Then those doctors did reduce medication levels and change medications?

Terry: Most of the time, it varied, tried different medications, maybe. We had individuals who would come to us on seizure medications who had been on seizure medications since they were a year old. Doctors would run routine tests, EEGs and say this person doesn't have a seizure disorder, why are they on a medication? So that would be a medication that would drop from their list. So there was a lot of good things that happened to that I didn't think they were getting that sort of care in the institutions or that sort of evaluation.

Jeff: How about tobacco use? How prevalent was it among people coming out?

Terry: I didn't see it at all. We only had one gentleman that smoked and he did not come from an institution he came from his family.

Jeff: When people came to you did they come with suitcases and personal possessions?

Terry: Yes, they came with suitcases, most of the time they came with garbage bags filled with clothes. That's how they transported. We were told by some of the staff at the institutions not to bring the clothes into the home. I don't know if you remember that or not. We were told to bring the clothes into the garage and wash everything before it came into the home and was put away. I think there was a real concern about head lice and maybe some other things that I don't really want to think about. That was the first stop was the garage. We'd sort through things. We'd wash them and then pack them away in their closets and drawers.

Jeff: You mentioned I think the smell or did you?

Terry: I didn't.

Jeff: Do you recall anything about when you were in that day room—

Terry: The smell in the day room was horrible. It was a mixture of a lot of sweat, a lot of body odor, certainly I think at that time I wasn't even sure what the smell of overwhelming urine and feces would be but I am sure that was there because I saw people that were wet. But mostly I think it was the body odor of people that had not either showered or had not put on clean clothes for awhile.

Jeff: Was that smell prevalent in the clothes that were in the trash bags?

Terry: Yes, absolutely. The clothes in the trash bags had odors to them of clothes that hadn't been washed, clothes that had; probably there had been inconsistency problems or just an uncleanness to them.

Jeff: Did the gentlemen who came into your homes did they claim these clothes as their own or was there any comment, these aren't my clothes.

Terry: No comment that I can remember from the gentlemen. But I do remember going through the bags and they were all labeled and you would find clothes that were not labeled with that particular gentleman's name. So we would put those to the side. That was a big pile. They came with clothes that weren't in their name.

Jeff: Did people all have appropriate winter clothing?

Terry: I honestly can't remember them having appropriate any kind of clothing. To be honest with you, that was one of the first things that we took joy in doing was taking people out and buying them new clothes and clothes that fit them and clothes that weren't stained or ripped or labeled or clothes that looked like they are meant for a five-year old or a ten-year old. People that came out of the developmental centers and the institutions took great pleasure in going out initially when they came to the group home and buying new clothing that was age appropriate and season appropriate and wasn't hideous colors and stained and torn.

Jeff: Describe the kind of life the people were able to achieve living with appropriate community support.

Terry: And I'd like to talk about Jack specifically because when Jack came to the group home he was just one of these people that just sort of hit the door running and what I mean by that is Jack never hesitated in embracing the fact that he was now in the community and he had these freedoms and he had the ability to make choices that he didn't have before. There was no timidity in Jack which surprised me because most people that came out of development centers—I had one gentleman that came to us from Apple Creek that literally zipped himself up, I'm just saying that. But he put himself into a corner and would not leave the corner for three days he was so afraid and so timid and we had to bring his meals to him and feed him in the corner and just keep talking to him until he was finally willing to join the home. Jack was not like that. I'm sure a lot of that was the fact that Jack had a loving supportive family that supported him throughout all his travels and his residences. But I remember when Jack came in the two things he was most amazed about living in a community home were number one there was a washing machine and a dryer right in the home. And as Marsha had commented that was just very traumatic for Jack. Jack kept going down and checking out the washer and dryer because he couldn't believe that and number two that we actually had a basketball court right outside the home because Jack loved and loves to shoot baskets. All he had to do was walk out the door and there was this basketball court. I think those were the two things that Jack was the most amazed about and he spent a lot of his first weeks just shooting baskets and washing clothes. That was just his beginning and after that he became aware that he had a neighborhood out there with people that waved at him and talked to him and he started walking our neighborhood and it was very rural so Jack would have to walk on the side of the road. He got to a point where people would stop in cars. Of course that was 25 years ago where people stopping in cars wasn't so suspect. But they'd hey, "Jack, how you doing today, beautiful day." Jack would know their names; he'd get to know them. He knew people I didn't know and I lived there too. He was one of these people that everybody just liked and admired. So when Jack came in it was just an amazing thing. Another good memory I have of Jack is I owned a dog and I don't think Jack had ever had the opportunity to have a pet in the institutional setting and Jack was so good with this dog and this dog just loved Jack. So Jack took over the feeding of the dog and let the dog in and out. Jack had a pet,

something he had never been able to do before. I remember vividly him sitting watching TV and the dog would—her head in Jack's lap and Jack petting the dog. They looked so contented. How many years had Jack not been able to have that in this life?

(Running away from you, I'm sorry.)

Marsha: Having a pet, being able to do laundry, being able to visit with neighbors were all returned to the life that Jack had before the institution. In our neighborhood, we grew up in one neighborhood and never moved from that neighborhood. Jack knew all the neighbors. He knew the neighbors better than I did. There were certain neighbors who when I would go back thirty years later to our neighborhood would ask about Jack. There was young man who was from France who Jack taught to read. He would come back every once in awhile and say Jack taught me to read. There were all these people who were important in his life and he was important in theirs. He didn't have that in the institution and all of a sudden he comes back to the community and it's like victories. That he is able to have that again and they're all new discoveries. He had cats, he's writing an autobiography right now but one whole chapter is about his cats and all these quirky cats that we had. And having pets (can't understand) and he loves animals.

Terry: The first summer Jack was living at the group home we had a garden. Because it was a very rural area, I don't know if you remember the garden or not. We decided the guys and myself and my husband, we're going to do this huge garden. We dug out way too much land and planted way too much. You're very enthusiastic at first and the guys were so great. Jack, especially at the beginning, planting because that was fun. Then for awhile they helped me water and that was fun. But as we all know by August gardens become overgrown and gardens become full of weeds and almost all the guys that was the end of the garden for them. They were done with it. But not Jack, Jack was the only one that stuck in there and I would say at dinner okay guys we have to go out after dinner, there's so much weeding we have to do. And the guys would say I'm busy but not Jack. I'd get done with the dishes and I'd go out and there would be Jack pulling up those weeds. Unfortunately Jack had a hard time telling weeds from plants so we lost a lot of vegetables that summer but it was fun to do. I remember right was an avid gardener until the very end when he saw a snake in the garden and I think that was the end of the garden for all of us. I don't think we had quite as big a garden the next year.

Jeff: Expectations have been raised with community living how do you see the people rise to the occasion and what differences do you see the way people lived and expectations in the institutions and what people are realizing today.

Terry: I think the biggest change in expectations from individuals from developmental centers compared to community living is in the ability to make choices about their life and I know that in the community setting the guys initially were very timid about choosing the simplest of things whether it be what do I want to eat to how do I want to spend my Saturday to what I want to wear. I think a lot of that came from not having the ability to make choices when they lived in an institution. So it took a really long time for them to get up that I'm not saying its courage but to come to terms with the fact that hey, I have some control in my life now. Because I don't think they had they when they were in the developmental centers.

Jeff: You've seen people be able to successfully work, self-care work social appropriate behavior just the whole ball of wax such an enormously different life, same people, different setting, different expectations. So frame that in terms of today the people that I work with are working in the community, volunteering, attending church, the whole normalcy.

Terry: It's been a real joy to watch individuals in a group home grow into the best people that they can be. I think it's been so much fun to see them develop their own lives based around their families, their choice of friends. These people participate in their communities now, maybe even more actively than people who have lived in the communities without break. Not only do they

utilize all community doctors and community dentists but they participate in all activities. Almost everyone I know either attends a church, belongs to a church; has some sort of affiliation with a church. It's been nice to see their spiritual side grow. A lot of people have come back into the community and reconnected with family members. Not just their close family members but aunts and uncles and cousins that they haven't seen for a long time. I've like watching that reconnection happen. I think that their lives are so much fuller now than their families ever hoped for them.

Jeff: Knowing the transition that people made were many of these people coming from families that had not maintained contact while they were in the institution?

Terry: There were a few individuals who did not have any family contact when they came into the group home. Some of them never regained that family contact. Some of them eventually did and unfortunately some of our elderly clients their parents had died before they came back into the community.

Jeff: How about sibling contact?

Terry: There was some sibling contact that was rekindled for some individuals.

Jeff: From both of you what are your overall reflections about state institutions, about life in the community, about anything and everything that we have been talking about, anything that we might have missed?

Marsha: I think for Jack, Apple Creek was a storm in his life that he lived through. Now as he has experiences, he's sort of overcoming and he sees every occasion like that as a victory. I took him swimming July 4; we went over to this place called Water Works which has now become a water park but it was the place where I grew up swimming all summer long in our community and we went over there and they have slides and stuff and he said, "I'm going to go over and go down the slides" and I said, "Can you do that?" and he said, "Yeah, I can, I've done it," I forget where. So I said okay. He went up and down it. I could see he was having a great time. So I kind of relaxed and he came back a couple of minutes later and he said, "This place is very different from when I grew up, when they wouldn't let me come here" and I said, "what do you mean by that. Why wouldn't they let you come here?" He said, "I don't know I guess they were afraid I would hurt myself but this time I went up there and they said do you know how to do this and he said yes, so they just let me." I thought that was just a victory that was going back through a place of rejection and saying I can do it this time. And if he hadn't had the opportunity to come back this would have been something that would have been set aside somewhere and not ever talked about but it was a defeat and he has those opportunities every day now to have a rich life and have a life again. He appreciates it immensely and I appreciate it immensely.

Terry: I think for the people that I've worked with and the people that live at the group homes the opportunity to build relationships with individuals. We always stressed that the homes, these people, they're roommates and they're not related to you but guess what. You ? guys live together that makes you a family. I don't think they had the opportunity in developmental centers to have those kinds of relationships with people. People came and people went. Now Jack and his roommates and people that live in our homes have that opportunity to feel like they are part of a family. And families are tough sometimes, we all know that but they have that opportunity to do that. So it's like they've had the opportunity to have two families there, their blood family and now they have an opportunity to have a family that's just based on proximity and being with somebody every day and sharing your daily life with them. I think that's one of the nicest things that's come out of people coming back into the community.

Marsha: Well then Jack, one of the fellows he lives with said hey you want, we don't have to live in a big group home any more, there's this other option. Do you want to live with me? So Jack is living with someone who he chose to live with. Not somebody that an agency said let's

put these guys together but Jack lives with people that he has chosen to live with and the staff there support them and respect them but very much make them feel as though this is their house and the things that we do are because they're the things that you want to do. One guy goes to one church, one goes to another and the staff figures out a way to support that. Jack wants to go see his girl friend, one of the staff helps him do that while somebody else goes and does something completely separate and yet some things they do together. So it's like other people live with just the right level of support and the right level of respect.

Terry: Jack just had the opportunity—he just came back from a visit to Washington, D.C., a vacation. That's something that—

Marsha: He's going on a cruise. That's certainly an improvement. Travel put that down.

Jeff: Wonderful, thank you very much. Judy, any other questions?

(Not sure who is talking in the last few pages where they were going back and forth. I hope I got them correct. Sometimes he mentioned their name and sometimes he did not. Transcriber)