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Bob O'Callahan interview for the Lest We Forget Collection of Oral Histories

Bob O'Callahan

Jeff Moyer

BOB O'CALLAHAN

Jeff: July 15, 2003 interviewing Bob O'Callahan, Akron, Ohio, Lest We Forget project, the Akron series. Bob, how long have you been involved with people with developmental disabilities?
Bob: About 16 years.
Jeff: What experience have you had in working with people within the confines of state institutions?
Bob: The majority of my caseloads right now have been the product of individuals who grew up and spent significant amount of time in state institutions over the last two decades.
Jeff: What is your professional role?
Bob: I work for a community outpatient mental health center in Akron, Ohio. We provide a vast array of psychological services to individuals in the residential and the vocational and school settings.
Jeff: Are you a clinical psychologist?
Bob: Actually it's psychology assistant because in Ohio you need to have your Ph.D. to be licensed. Other states you can be licensed with your masters.
Jeff: Can you describe what you have seen within the walls of state institutions, what's your experience been. What have you seen?
Bob: Not very good, it was kind of the easy way out for the individuals to cluster them, put them together, assign them, stigmatize them and pretty much detach them and ostracize them from the community and attempt to provide services in that environment.
Jeff: Describe the environment.
Bob: My direct experience has been that it's been very nonpersonal in the sense that they try and do things as groups. They try to fit a square peg in a round hole pretty much and they don't look at the individual and the individual's needs as much as they do the entire institution.
Jeff: In your role do you have access to the full range of areas within the institution?
Bob: No.
Jeff: What places did you see when you were there?
Bob: Mostly the common areas and the private bedrooms.
Jeff: How many people shared a common bedroom?
Bob: The few I've seen there was three or four in a bedroom or a wing. I don't know if they called them wings.
Jeff: How about the common rooms?
Bob: In the common rooms there were a significant amount of people; up to twenty I've seen in one common area.
Jeff: And we're talking about contemporary facilities.
Bob: No, they looked like they were old hospitals, old businesses, they weren't very contemporary.
Jeff: I mean contemporary time when this is happening.
Bob: Yes, this was in the last decade or so.
Jeff: What sort of punishment was metered out that you are aware of?
Bob: I have individuals that told me that they were physically struck, struck with a bar inside of a sock because evidently that didn't make bruises. They also report that they lost a lot of their personal possessions. They had difficulty maintaining their dinner or their food at times because other individuals would take it. So it sounds like it was pretty chaotic and a lot of individuals and not a lot of staff.
Jeff: So the punishment included being struck with basically a blackjack.

Bob: Correct and they also reported that they were isolated at times for behaviors or isolated for significant amount of times.
Jeff: Where would they be isolated?
Bob: I guess there were isolation rooms, padded rooms that they would put them in padded rooms.
Jeff: Have you ever seen such?
Bob: No, I've never seen a padded room. They also report they've been restrained; mechanical restraints have been used on them, leather type restraints.
Jeff: Describe mechanical restraints.
Bob: The ones I've seen have been leather and they are akin to a police handcuff except they are leather and they latch over and there is a hook and they connect them either behind their back or behind their legs or in front of themselves and there is also waist harnesses that you can attach your wrist to the waist harness and attach the legs in a similar fashion. There are also some that you could be restrained to a bed for significant behaviors. I've seen that happen.
Jeff: What kind of behaviors?
Bob: Physical aggressions, spitting, property destruction, things of that nature.
Jeff: There's something involved in direct psychological care of people. What do you think the impact is of the institution itself on people's behavior?
Bob: I see a lot of behavior that was created by the institution as opposed to behaviors that were eliminated because of the institution. The behaviors I've witnessed first hand is individuals come out they tend to hoard things. They tend to hide things because evidently other individuals would take it from them. They have a sense that if it's not written down or if it's not documented somewhere it's not going to happen because in their experience and their realty if it's written down and documented it may happen but if it's not there's no chance of it happening. Because when you live in a shift model type situation staff come and go and communication sometimes isn't the best so some staff may tell you this evening we're going somewhere or doing something and if they don't communicate that to the staff on the second shift it doesn't happen. Even if it's written down or documented it may happen. So it's been my experience that they really want a visual representation of what's going to happen and it's their way to kind of facilitate communication between staff. So it's a real common behavior I see from individuals that come out of institutions. If it's not written down it's not going to happen. If it is written down it may happen.
Jeff: There are still well over 1,000 people in Ohio's institutions. The type of mechanical restraints and abuse that you are talking about do you think those are still being used today?
Bob: Yes, I believe they still use mechanical restraints even as we speak.
Jeff: Have you heard reports or have any direct experience of sexual abuse.
Bob: Yes, this was a private institution. This wasn't the state. This was up at Parma dale who is a quasi institution. It's for children. I'm not sure if you are aware of it. It's not a state institution but it's from like Catholic Charities. In fact the priest was just arrested within the last year for allegations of sexual abuse.
Jeff: As you've seen people, you're involved with facilitating people moving back into the community. As people are moved from the institution to the community what do you see in terms of their behavior?
Bob: When people move from the institution to the community I think that really opens up a lot of opportunities for them to experience things they've never experienced in a different format. As far as their behavior when they move to the community at first it's a difficult transition. In institutions everything is regulated. Everything is structured. When they get into the community all of a sudden they have choices they can make. And they're not used to making choices on a daily, hourly basis of what's best for them. There's a difficult time in that transitional period but once

they realize that they are in control, they have choices, they start making some pretty good choices to the best of their ability.
Jeff: The type of behaviors, that you spoke about, when not in the institution were those behaviors reduced?
Bob: At times, when people move into the community they tend to bring the behavior with them. However, as their support system and their environment changes the behaviors tend to go away or become manifested somehow differently. But the aggression, the destruction, the SIB, self-injurious behavior we used to see in institutions they've decreased greatly since individuals have moved into the community in my experience.
Jeff: There is a phenomenon called institutionalized mental illness. Would you describe that?
Bob: Community mental health has a theory for institutionalization mental health. The theory is that people pick up behaviors that they see others doing and it's a vicious cycle. In other words what's abnormal becomes normal. People who do aberrant behavior are immersed with other people who may not have that behavior but over time they pick up those behaviors and it becomes more normal and it's a product of the institution as opposed to a real mental health problem. In other words, it's an environmental phenomenon.
Jeff: You work with people who are considered to have dual diagnosis, in other words cognitive disability and emotional mental health disability.
Bob: The feeling is that people with dual diagnosis especially any kind of disabilities that mental health was not possible or was not a part of their experience or a part of their personality but the reality is people with disabilities have a higher incident of mental health problems than the general public.
Jeff: You describe the mental health aberrations that develop because of institutional life what are the causes do you think relate to what you just addressed?
Bob: I think individuals with disabilities especially cognitive professionals tended to try to explain all their behavior because of that and not look at other possible causes. It's very plausible to have a mental health diagnoses and a disability conjunctively. The treatment is vastly different for that than with some behavioral problems who also happen to have developmental disability. It's only been the last decade or two where professionals are actually looking at the person individually and seeing that yes, they can have some mental health problems that aren't necessarily related to their disability where in the past I think that everything was kind of umbrellaed under their disability and therefore they have these behaviors. So I think in the last twenty years, probably the last decade in this country they've only looked at people individually and really tried to start pulling out and differentiating what's what.
Jeff: What's been your success rate in helping people be reintegrated back into the community?
Bob: I think there's been a lot of individual cases that have been very, very successful being integrated back into the community. Their quality of life is vastly improved; their ability to make choices. They live in more of a family environment. A lot of individuals are currently in foster homes and they experience the things that we experience: holidays with family, shopping trips, family get-togethers, family activities, where in the past the family was their peers in the institution. Now their peers are actually their family again and they have the peer relationship in the workshop setting where they go during the day and they socialize with their friends and their peers and they work with them. So I think they're getting the best of both worlds right now. I do believe there are some individuals that would do very well in an institutional type model at a secure common place where they can access services and that their level of needs is that intense that they require more intense services than a community model can provide.
Jeff: What kind of services do you speak of?

Bob: Individuals with significant behavioral problems that are extremely frequent, intense, severe. Traditionally they have not been very successful in the community in the models that we have set up in group homes or foster homes or semi-independent living. I think there is a missing link between institutions and the community. I don't see it as one or the other. I think there needs to be a continuum where there is this other place that they can go and learn the skill they need to be in the community as opposed to an institution.
Jeff: So for the intensive services you're describing you're not suggesting those services are readily available in current institutional models.
Bob: Correct, institutional models right now are more of a management type model than they are therapeutic. They tend to train manage behaviors as opposed to try and treat them. And the community right now is really not set up for severe behavioral disorders. They are starting over the last couple of years there are new service providers, new agencies that are coming into the field that are coming into the communities that see that there is a need to serve individuals of the community with some behavioral problems and they are fulfilling that gap. In my experience they're doing a good job with it.
Jeff: Do you think that the services provided in isolated aggregate settings such as current state institutions is there a need or does that model have a purpose in today's knowledge and understanding?
Bob: I think the institutions were a good idea in their time but I think their time has passed. I think people didn't know how to serve people in the community, how to provide for their needs, so they tended to put them all together and attempt to do it in unison. Now we are realizing that every individual has individual needs and they're not all the same. They're very different. By looking at that individual's needs we can set up services that fulfill his needs in a community setting both locationally, residentially, educationally, and it doesn't necessarily have to be all under one roof.
Jeff: As you've seen people move back into the community have you been surprised by the capacities of any of the people with whom you worked?
Bob: Yes, I've been very surprised by the capacity for people that integrate back into the community. There's a few individuals, I in my professional opinion would not think they would assimilate and be successful in a community setting. However, they've proved me wrong. Their ability to adapt to their strength, and the service providers around them have allowed them to be successful in spite of their disabilities and their difficulties and that's really surprised me. I didn't think some of them could be managed as well as they are and could do as well as they are in the communities.
Jeff: Do you think that we're at the point that one of the major areas we need to be addressing is the field people's expectations that we see as self-fulfilling experience. So if you put people in institutions and they will act out and you see they need to be there. You have expectations that they can be successful in the community, that's true.
Bob: I think we've gone a few decades without any education for the general public. They look at individuals with disabilities and they don't know what to think. All they know is what they've heard, what they've experienced and a lot of times it's somewhat negative. I think by integrating the people back into the community you are seeing some positive role models. You're seeing some positive interactions. Local restaurants often are employing these individuals and so you're seeing them in a more natural setting and I think a lot of the stigma is starting to go away and they're no longer ostracized as they once were. I think the biggest service we can do is educate the public about what they can and can not do. Because I think the perception is really skewed. If you don't work with these individuals you don't know really what they are capable of doing and what they are able to contribute to society. I think we've done them a great disservice by not allowing

them to contribute to society as we know it. Right now in the Middle East they're about twenty years behind us and they're just starting to institutionalize people. I think before institutionalization what we did we secluded these individuals in their own homes. The parents would keep them home. They wouldn't send them to school. They would pretty much isolate them because that's all they knew what to do. However, the philosophy was that institutions would be able to provide services for them and that's kind of where the continuum went and then over the last two decades, special the last decade people realized that maybe putting them altogether isn't the right thing to do. Maybe they can contribute to society if we give them the opportunity and give them support and the services they needed. So the dilemma is to identify those support systems that they need and the services they need and then go about fulfilling those. And that's been the difficult part because it's all individualized. Every individual is different. They all need different support and they all need different support services to be successful. But I think when you look at an individual and you look at their strengths and you look at their weaknesses what you can do is help them use their strengths to cover their weaknesses. Just like all of us do.

Jeff: If you were being asked to give one statement that would be heard by the legislature ??? on which would hang the vote to continue to provide researches for community integration what would you say?

Bob: I believe the legislative branch in Ohio needs to realize that these people can be very successful in the community. However, they do need significant support and I believe as a taxpayer that that's what our tax dollar should go for. Individuals with disabilities did not choose to have a disability. Most often or not they were born with it and they do need some support and I think the public as a whole is willing to help them and understands that. And is very willing and able to do that and I think they really want to do that. I don't think that past levies or past funding monies from the state has been wasted in other realms that I see. In other words the money went to support these individuals, provide services. They're not throwing money away. These individuals are now successful in the community. They're now participating in things and the government needs to realize that they're individuals and they want the same things you and I want. They want to be successful. They want to live in the community. They want to have choices. They want to have access to family, have access to sporting events, have access to socialize. They have the same desires and wants we do. However, a lot of them do not have the ability to do that themselves. They do need help. They do need support. They do need staff.

Jeff: Are there areas that we have touched on that you would like go into more depth or is there anything that we haven't talked about you think is pertinent?

Bob: I think you pretty much covered everything. The goal is to have an oral history, more for education. I think that the general public doesn't understand the current mental health, mental retardation field. The only information they get is kind of fuzzy, feel good articles that come through periodically which are very nice and they talk about the cute little down syndrome boy but my experience is there's a significant amount of fetal alcohol syndrome, crack, cocaine kids, autistic kids that are now getting diagnosed and receiving services at a much earlier age so their potential is a lot higher and their service need is a lot higher.

Jeff: Do you think there is currently adequate help and support for the level of service you describe?

Bob: No, in fact I see it already taxing the schools. The schools are not prepared for these kids. Over the last decade there's been a significant increase in kids with disabilities and special educations needs in the public school system and the schools right now are trying to manage these behaviors instead of teach. I think because of institutions and because of private schools the public schools were not able to experience and develop the skill they need to help these kids over the last

couple of decades and now because they're getting integrated you don't have the experienced staff to work with them, because they were isolated, they went to county schools, individuals with mental retardation disabilities. Now they're getting integrated back into the public school and I think the education isn't there. It should have been done before the kids were integrated not during and after. I think special education is just going to grow in its scope and its need because kids are getting identified earlier and there are more significant disabilities now because of a variety of reasons in our society.

Jeff: You mentioned managing behavior versus treating behavior in the institutions that you are aware of that exist today is medication used as a means to manage people's behavior?

Bob: Medication is probably overused in institutions. That's been my experience. There are a number of types of restraints, chemical restraint being one of them. If you give them medication for the staff's benefit instead of the individual's benefit I don't think that's fair to the individual. In other words, if you're going to drug someone because then they're going to be complaint and calm and easily redirected; that should not be your goal for medication. However, in the past it's been notoriously used that way.

Jeff: As you've seen people move from the institution to the community what's been your experience with medication, prescription and both in terms of .the nature of the quantity.

Bob: I think as individuals move from institutions into community, community psychiatrists and medical professional are getting more experienced with these individuals. They're realizing that they're not that different from you and me. And they're titrating and bringing down a lot of the medications and seeing that they don't need this amount of medication. I've seen individuals come out of institutions with seven, eight, nine, ten prescriptions. Within a couple of years they're down to a few. So I think again there's a service need though. There's not many community psychiatrists who are willing to take on individuals with disabilities because of the lack of experience and the lack of funding. There's a huge need for pediatric psychiatrists for individuals with disabilities. The waiting lists are unbelievable, parents are frustrated. Primary care physicians are frustrated. There's a huge gap in service delivery and service acquisition for children because in the past there was not a need. These kids were shuffled off into institutions and spent significant amounts of their lives there.