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**ORAL HISTORY VIDEO INTERVIEW WITH
SUE BEECHER**

JANUARY 11, 2013

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VIDEOGRAPHER: PEGGY HOLTZ

RECORD ID: 007-DO

SB: SUE BEECHER

JT: JENNIE TODD

PH: PEGGY HOLTZ

[00:00:10]

SB: Okay. My name is Sue Beecher. And I live in Indianapolis, Indiana. I'm currently retired from the state, but not really done with being busy [chuckle].

JT: Great.

SB: So I'm doing a myriad of activities right now.

JT: Okay. Can you tell me how and when you got into this line of work?

SB: I actually got into this line of work when I was quite young. My mother was involved through the county extension cooperative back in the '70s. And that was a food program but she did much more than distribute the commodity foods for Purdue. She did case management; we didn't even have that term back then. But I would follow along with her. And so I was aware at a pretty young age that in my little rural area of the state, that we had a lot of folks with disabilities, a lot of folks that were struggling in school, work-wise, that sort of thing.

JT: Okay. And I noticed early in your career you worked at Muscatatuck?

[00:01:22]

SB: Actually, I worked at New Castle. It was New Castle State Hospital at that point.

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[00:01:28]

JT: Okay, well here would be the question. So can you tell what the experience was like, and what was it like with people that lived there during that time?

SB: I started working for -- at New Castle State Hospital, was what it was called then, back in 1977 pretty much right out of college. There were approximately 2,000 people that lived on a campus. Although I had a degree in Sociology, I never really received any training [chuckle] or any sort of information about people with disabilities. And so, starting to work at New Castle was really the beginning of my education.

I noted that there were a lot of individuals that walked around with helmets on and I didn't understand what that was, and that was because of their seizure disorders. And also, I noted that there were a lot of folks that seemed to be just as intelligent as I was. And the population was any -- ranged anywhere from children up to elderly adults.

And New Castle had originally been the Village for Epileptics and so you didn't necessarily have a cognitive disability if you were admitted to New Castle. You had a seizure disorder. And it was used also -- my understanding was, in its heyday it had upwards of 5,000 individuals. There were men and women that were separated across a valley. It was quite a large institution in that day and so the men had to remain separated from the women. They didn't want anyone to have children or to quote, "pass on -- pardon me - - the seizure disorder."

[00:03:23]

It would have been very large back when it first started around the turn of the century. There would have been a dairy farm. People worked the fields. There were crops that were planted. People worked in the buildings. People did the custodial work and never got paid for that.

When I started in 1977, when people were admitted they brought with them what was called their death bag. And that included the clothing that they wanted to be buried in, as well as their funeral arrangements. And so the thought was that if you were admitted to New Castle, you stayed there until the day you died. And that was a real shock to me.

The more I worked there, the more I realized that many of those individuals didn't need the custodial care that New Castle provided, that they could have lived on the outside had there been proper supports and understanding of epilepsy.

JT: That was excellent

PH: [inaudible] that's a very good --

[00:04:23]

JT: because we talked to a couple of other people from New Castle and not heard those stories, so that's really...

[00:04:28]

SB: Oh, there's another story that I think really bears telling and again, being young and, you know, thinking I could save the world -- really my education has been daily in this field, it didn't start out that I was all knowing. New Castle in their training for staff -- and initially I worked in an epilepsy outpatient clinic. So we were seeing individuals that didn't have access to neurology care and we had an EEG lab. We could run anti-convulsive levels, all of that.

But one of the proudest things that New Castle had was a training film and it was -- it was spectacular. It showed different types of seizures and it was very well done. But what they had done years later, knowing they had taken people off of their anti-convulsive medication, who lived at New Castle. No informed consent, no way about it, I'm sure they probably said to them, "Would you like to be on camera?"

And they said, "Sure." But there hadn't been any of the research, things that we, you know, abide by now and so while this film was fabulous because you could see what a grand mal seizure looked like, you know pre and post. No one had given those individuals really, much of a choice of their participation. And so there were children and adults that were literally thrown into seizure activity for the greater good.

[00:06:06]

JT: Wow.

SB: Had anybody told you that story, you know, [chuckle] -- yeah.

JT: [Inaudible]

JT: Are there any other New Castle stories or anything about the history of New Castle that you think would be [inaudible].

SB: I know that when I started, there was -- there were some individuals, some case workers that had a vision that people could live out the community and there was what was called the "Family Care Program." And I remember Nate McCaslin -- I think Nate's still around somewhere in the field or maybe he's retired. But they would select, they would recruit individuals that were willing to take folks into their homes in the community or perhaps purchase homes and work with individuals in the community. And that was an interesting program; it seemed to work very well.

The care takers, if you will, ranged from little old ladies to -- there was a young couple in Modoc, Indiana that took children and it was -- it was a great first step towards integrating folks getting them out of -- especially children -- [background siren] getting them out of an institutional setting and really being part of a family, of a community, and that sort of thing.

[00:07:35]

And so I don't want to leave the impression that New Castle wasn't -- you know, that it was only institutional not doing anything right. There were some folks that had some futuristic types of vision and really worked hard to get some individuals out into the community.

[00:07:53]

JT: What was it like for the people that lived there? What did their day look like, what sorts of things?

SB: Oh gosh, you know it seemed to me that they had a lot of time just sitting and -- or walking the grounds and so there wasn't a lot for folks to do. There was an associated patient services which was a group of sheltered workshop-type settings. But only a few people, you know, made it into that. So the folks that weren't able to do some basic sorting or work-type activities pretty much stayed on the units. There weren't many activities off grounds at all. This was also back when behaviorists were still using straitjackets, ammonia sprays, those types of things. And I still have memories of -- we had one individual I believed he's in a waiver now who was smart enough to kind of get out of the straitjacket and escape.

And so he would be running across the grounds with the, you know, the straps kind of flapping. The ammonia sprays were used especially on the children's units and I remember being appalled about that even then. But the psychologist of course, would say well this is what is needed. But their days were not good, the units were overcrowded. Quite frankly if you wanted any privacy there wasn't any way for you to have privacy. And that's probably why people walked the grounds, or got out of the buildings [chuckle] when they could. It was a pretty bleak day for most people even the children. And the units weren't very attractive either in the early days.

[00:09:48]

JT: Well, this has brought a couple of questions in one. But can you talk more about what the ammonia spray is? Again this is for history; so many people won't know what the term means...

SB: Sure.

JT: ...and the straitjackets. And then if people came with death bags and maybe they were young children, if there were children there, they never had any contact with their family again? Or did their family come to see them even though they had planned to just abandon them? You know what was that?

SB: The straitjackets, we -- the young man that I'm thinking of had pretty severe self-injuries behaviors. And so that was one of their behavioral methods, of trying to keep him from injuring himself. But he spent a lot of time in that, which, you know -- and again he got smart enough, he could undo the straps and get out of the straitjacket, [chuckle] kind of a Houdini thing. And so a lot of his day was spent in restraint and straitjackets are a restraint. Your arms are -- you're not able to use your arms that are the idea so that he couldn't do the self-abusive behaviors. The ammonia spray and I can remember this pretty vividly, and I remember a couple of the psychologists and I were friends. It was simply a watered down spray bottle with some ammonia in it which would be quite aversive.

[00:11:23]

I mean having ammonia sprayed in your face, which is where they would spray that would be pretty aversive. I mean ammonia has got a terrible smell to it and then it can be corrosive. And again, they -- this was also before regulations per se, so they would write behavior plans or maybe not even -- I mean staff could just use that when they felt they needed to use it.

[00:11:52]

JT: Can you think of instances, when they would use the ammonia spray if someone was talking back if they were fighting? I mean what would precipitate being dosed with ammonia spray?

SB: My understanding was that it had to be some pretty severe behavior and again, I wasn't -- I worked in an outpatient clinic so my time on the units was minimal. But you know it's interesting when I was on the units, I would see that. So my speculation would be that it was used pretty frequently. And knowing how New Castle worked, my guess is it was used indiscriminately by staff. It was used, whenever they felt maybe they were in danger or the person, was not behaving, or out of control. So I'm not so sure that it was very well organized. I liked to think that the regulations now within group homes and to a lesser extent the waiver regulations really prevent that kind of thing from just being used, you know, indiscriminately any time. But the ammonia spray -- especially, on the children, that was used in the children's units, more so than the adult units.

[00:13:05]

In terms of children being admitted, I assisted with some admissions of children. I'm not proud of that. It was the times, parents who brought them to the outpatient clinic, at times just couldn't control the behavior or the person was total care and the parent was elderly or just couldn't. So when a child was admitted and I'm thinking of three different children, right, we didn't admit a lot of children through the Outpatient Clinic. I'm thinking of three and two of those the family maintained contact, the best that they could. A lot of times the families of individuals at New Castle, just didn't have a lot of economic resources. That was a rural area -- a lot of the folks came from the rural areas and parents they didn't have a lot of cash flow to be able to say hire somebody to help take care.

[00:14:11]

And they had to work, they had other children. One young lady was almost total care and had a seizure disorder where she seized continually, and she happened to be a very pretty young child. And so I believe that probably assisted with her care, she was not aggressive or combative and she was pretty much total care. And the family would come -- the family -- her parents, her mother especially, very fond of her and obviously loved her. Another family again, a rural family, mother wasn't the most likeable person but their son not only had seizure activity, but also had autism. And I'm not sure we even knew it was autism at that time. And so he was a danger to himself and others.

I mean they just could not watch him. They lived on a farm and there was a lot of work to be done and they couldn't live him in the house alone, and he was always in danger of hurting himself or, more so more than hurting anybody else. And he actually -- to New Castle's credit, he improved in some of his behaviors and this would have been late '70s when he came in early '80s. And I know eventually he ended up in a group home, I believe in waiver home.

[00:15:47]

And the third child that I can remember just vaguely, I doubt that the parents had a lot of interaction with that person. And you know, the trend back in the late '70s early '80s was to place children in and at one

point there were plans to expand the children's unit, double it. It was going to be named after Governor Bowen's wife -- first wife Beth. And so the ground was broken for that building, but it was never built, thank goodness [chuckle].

[00:16:25]

JT: That was really good. So, well --

PH: That's a lot of rich history there [chuckle].

SB: I'm surprised no one -- New Castle is such a vivid memory for me. I mean, you know, you're young, you're impressionable and you kind of know things aren't quite right, but you don't really know any better. You know, 20 years later, you're appalled that you participated in that, but...

JT: So it sounded like there were kids and adults there, who had seizures, but basically anyone could come there?

SB: Yes.

[00:17:02]

JT: So how -- if that's true, how did people decide whether to go to New Castle, Fort Wayne, Muscatatuck. Was it geographic? How did -- how did parents decide which institution to send their son or daughter to?

SB: Well, it was geographic and the other thing was that, with New Castle being the Village for Epileptics, that they had two full time neurologists on staff which is unheard of -- or was unheard of past the mid-'80s [chuckle]. They were both older gentlemen but they had obviously a lot of knowledge of epilepsy, and again, there was a laboratory there. There was a laboratory director, there were EEG technicians. And the drug studies for Depakote were also done at New Castle. They used that population to do some drug studies. So probably someone with a mild seizure disorder from northern Indiana would have gone to Fort Wayne and I did have a friend who sent her daughter to Fort Wayne.

So, I think it was pretty loose in terms of where people where people went, although geography was a big deal. And then if you had severe epilepsy, they looked at you at New Castle. I know that the young lady that went to Fort Wayne came to New Castle to be evaluated and her admission ended up being up to Fort Wayne.

JT: Okay. Do you remember much about the closing of New Castle?

SB: I don't. I was at the State Department of Health at that point and I was doing training of new surveyors and so I don't have much information about that whatsoever.

[00:19:00]

JT: Okay. Well I know you spent a lot of time doing case management because that's how I met you. And so I wonder if you would be willing to talk about how that came about, how state -- how case management within the state has changed through the years and just whatever you want to say about case management in Indiana.

[00:19:23]

SB: I was at -- I worked at New Castle for four years before I left and the last year and a half I believe, the state made some move to start deinstitutionalizing the large facilities and to look at community services. That was the trend, normalization that sort of thing. And so the state developed what were called diagnostic and evaluation teams. And that consisted of a psychologist, a physician, a social worker, and OT/PT if needed and the idea was to assess folks, make sure that we knew their strengths or weaknesses, and look at really building some kind of spectrum of services, group homes if you will. There were some in the state and those providers wanted to expand. So I believe that that was the initial case management system, if you will.

And again I was fortunate enough to participate in that; we held the clinics at Hillcroft in Muncie, although we would go out to other agencies. I remember going out to Jay-Randolph and what was interesting about that was that the physician that they could contract with, was a geneticist out of Methodist Hospital who didn't have a lot of experience with people with disabilities. But that process really started people thinking about expanding services in the community and that was the grassroots of case management. And that was back when someone with a degree in Social Work or Sociology with no certification, could do social histories and could make recommendations on folks. But it was a team approach, so you would include everybody and there would be recommendations for what would benefit this person.

[00:21:28]

Shortly after that or during that time, the Bureau of Developmental Disabilities Services was formed and there were case managers within field offices and at one point, I worked in the South Bend office and then supervised the Indianapolis office eventually and that was about a four-year period, as well. So by law the Bureau of Developmental Disabilities Services had placement authority. I believe they still do, I don't know that that law has changed.

So there would be a diagnostic and evaluation process for anyone with disabilities that wanted services -- and -- residential services and then the case managers within those field offices would develop the -- prepare the diagnostic package, provide that to different providers who were seeking to serve people, and then bless the placement. And initially, there weren't overnight visits or that kind of thing; it was really pretty crude at the beginning.

But I think Bureau of Developmental Disability Services got much better at what we did over time. They knew enough that some providers were better at assisting people with behaviors versus other providers just, you know, really needed more of a care-taking role, or just teaching cooking, or whatever. And so that was kind of an exciting time.

[00:23:02]

Quite frankly, there were a lot of group homes being opened, a lot of alternatives for people, elderly parents now could hopefully have their son or daughter placed in the community and, you know, some security that their son or daughter was being taken care of. There were some not so good ideas, one of the group homes were categorized and one of the group homes was an intensive behavioral homes, so you would take eight people with very severe behaviors [chuckle], put them in a home and expect miracles.

[00:23:40]

...And it just wasn't a good -- the thought initially sounded good, but homes would get destroyed, staff would get hurt, people would get hurt, clients would get hurt. So, that was all fine-tuned over the years. When I went to Indianapolis to supervise that office, there had been a court suit over zoning and the state had just won that. So that was an exciting time in Indianapolis we were opening eight to 12 group homes a month. And a lot of folks were coming out in North Willow which is a large -- still a large ICF/MR. I would call it a mini institution. And so a lot of folks were getting out into the community and it was really a neat thing. Case management now as I understand it and it's now contracted with the State of Indiana.

Even when we worked for BDDS it seemed like we had some separation that we could, go toe to toe with the state if we needed to and say this isn't right. We need to look at this. Not so much anymore, the case management companies that worked for the state are on contract, they're not really allowed to advocate per se. And at least one of those companies, a large company -- how it's set up that they pay case managers is you're paid by the number of people you have on your case load. The advocate part of me says that means you get a large number; you don't really serve them but you know-- to get your pay. And I think that probably doesn't lead to very high quality services at this point in time. I think case management's not -- it's been bastardized over the years.

In the early days, with the Bureau of Developmental Disability Services, you could actually do follow along as the case manager. You could actually get involved in that person's life and really be a part of their team of supports, that sort thing and I don't see that these days.

[00:25:53]

JT: Okay. I do remember the D&E [diagnostic and evaluation] teams and it seemed like there was a psychologist, a speech therapist, an occupational therapist, and like you said, someone who did special histories. And they came to our agency frequently in Martinsville.

SB: Okay.

JT: ...and we were only a day service provider. So I was trying to remember, if they were coming from recommendations of people that lived in residential facilities and were doing evaluations or if we requested them. And then I was trying to remember what was the demise, because eventually there was no D&E team. So do you remember what happened to the D&E teams?

SB: Yes, I think we used the day service providers to use their space to be able to have a central meeting area for people to come and do the evaluations. My understanding now, is that within the last few years, there are -- there's one team only is my understanding for the state.

There were regional teams for many years. There was one out of South Bend, one at Fort Wayne, and I'm less familiar with the ones in southern Indiana. I'm not sure why they are not as needed -- so Jennie, I'm not -- I'm just not sure.

[00:27:12]

JT: Okay. I just -- it seems like all of a sudden, they were just gone.

[00:27:16]

SB: You know, it was ...

JT: That was a long time ago.

SB: Yeah, it was mandated early on that people had to have a D&E. That's changed to a level of care through Medicaid is my understanding, so there's still some evaluations. I'm not sure how detailed or whether they're pulling in information from other sources. We didn't do much of that pulling in other information. We just, you know, did it on the spot.

JT: Okay. Is there anything else about case management that you'd like to say, in terms of where they were most effective or least effective or where you feel they should be going?

SB: I think that they were most effective and this is kudos to the day service agencies, I'm not a big fan of sheltered workshops. But one of the things day service agencies still do is that they know those individuals that come through their door. And they're aware of their lives and what's going on in their lives and it's much more of a community. And I think the day providers have always been really good at that and that may have been why we need the D&E teams there because many of the folks coming for the diagnostics were well known to that agency. They had the history. They knew the family. And so I think we've -- it's a rural state and I wish that we could still somehow keep those rural supports in place. Keep people close to the community, keep them involved.

[00:28:59]

I think that some of that's still done but it's pretty sterile compared to what it used to be. Now that's a double-edged sword, because day programs or some of the -- not so much day programs, but some of the other residential agencies, would try to talk up the person's, you know, weaknesses in the hopes that they wouldn't leave and go elsewhere. And I think that there some trepidation on the part of day services too sometimes, to let folks going into a residential setting or leave their family. But I think the process is pretty sterile. I'm not sure -- I think the providers been put in the driver seat without a lot of monitoring and residential providers have their own agenda as anyone does. So I'm not sure how well it's all done any longer.

JT: Okay.

SB: Alright -- my opinion only.

JT: And then I also heard that you were involved with Ticket to Work, is that accurate?

SB: Yes.

[00:30:10]

JT: Okay. So can you tell me about that program, what your thoughts were, some successes, challenges?

[00:30:19]

SB: Ticket to Work was a fabulous program in theory -- it truly was. And the idea was to, you know, Social Security -- there are more people taking monies from that pot and the pot grows smaller.

Social Security knew that they had put a lot of barriers in the way of people wanting to go back to work, that disability is -- can be fluid, that it -- some disabilities -- there are disabilities that are day after day, the same level. And then there are disabilities that disable you but not really enough to prevent you from working or contributing to society and that people with disabilities really would like to work. But there's always been this balancing act that if I made too much money, then my Social Security, then I'd lose that, and it's not so much maybe the funds that I lose.

But it's my Medicaid and my health insurance, because without health insurance that is just one scary thing any longer. So in theory, it was a really good program and -- that was provided to the Protection and Advocacy agencies and there's one in every state and all the territories in the United States. For the Indiana P&A [Protection and Advocacy], the fact that we already had a program that assisted folks going through the vocational rehabilitation process was a real plus. We had a good relationship with vocational rehabilitation.

[00:31:57]

Many beneficiaries will go to vocational rehabilitation if they want to return to work. So that allowed us to do problem-solving pretty early on. And there was -- the P&A and the VR were familiar and we could work with them to hopefully make this program work. I think one of the biggest successes that I remember and the advocates that worked that program were -- they're still with the P&A and they're just extraordinary people.

There was a gentleman who had assigned his ticket or didn't realize it was assigned to the State of Oklahoma and then finished up his training and got a job I believe doing -- calling -- I'm struggling for the word here folks. Something by phone -- phone work if you will and yet he couldn't get his final payment. He was -- he had assigned it to an employment network where they took so much of the ticket money and he was to get so much back.

So, he's done -- he's working, and no one will give him his money, that is owed to him. And so the advocate assigned to the case -- very, very savvy figured out that somehow it had been assigned to Oklahoma. Shouldn't have been pretty much and worked with Maximus and Social Security and got that gentleman the money that was owed him, and it was -- it was fabulous.

Unfortunately, Social Security -- it's so complicated how it works and there are a lot of good work incentives if you will. But still we're still not -- we're just not able to get the word out to people in a way that is understandable, I believe, or a way that takes away their fears of losing their Social Security benefits and their Medicaid.

[00:34:03]

JT: Is Ticket to Work still in effect?

[00:34:07]

SB: I think the legislation is still in effect, but I know that the Protection and Advocacy agencies do not have their PABSS [Protection and Advocacy for Beneficiaries of Social Security] grants which was the part of Ticket to Work where beneficiaries could utilize an advocate to help them, you know, go through all the steps to get back to work and still maintain benefits at an appropriate level and keep their insurance in place.

JT: Because there's a lot about the programs out there and I was just curious if Ticket to Work was still a prevalent program?

SB: Social Security, before I left P&A -- our membership agency, the National Disability Rights Network, was trying to convince Social Security that they did not need Congressional approval to keep that program running.

But Social Security was nervous in this time, I can understand that. So my understanding is that, that program -- the Ticket to Work legislation is still in effect but PABSS -- there's no funding for the PABSS portion of that at all.

JT: Good. All right, and then you are retired from IPAS [Indiana Protection and Advocacy].

SB: From the state.

[00:35:23]

JT: Can you tell me about some of maybe the evolution of IPAS, some of the highlights of working at IPAS, and then also talk about IPAS in terms of how it compares -- how Indiana compares to other states in the advocacy work that they do?

SB: Well IPAS -- I remember IPAS back to the early days when I was still doing case management and originally it seemed like they did a lot of educational cases. Mary Lou Haines was the director back then. And the advocates would travel around and they -- we were very good at doing educational cases and this was before I came on board.

The National Disability Rights Network has worked really hard to inject P&As into every disability program they can and so there are seven federal grants that have been granted to protection and advocacy agencies over time. And so that allowed that work to expand, not only for individuals with cognitive disabilities, but also individuals with mental illness and then individuals that didn't have either of those two labels, maybe just other disabilities.

[00:36:48]

...The Client-Assistance Program to help people navigate through the vocational rehabilitation system and the Assistive Technology program and the PABSS program, which they no longer have, a voting program, and then a traumatic brain injury program. And I was with the traumatic brain injury program and the PABSS program from the beginning and so that was pretty exciting.

I think P&As have a large mandate nationwide and there's so much work to be done in the disability field [background noise]. The National Disability Rights Network would like to see, I think, more litigation from the P&As.

[00:37:35]

Now, litigation is tricky because it can take a long time, you don't get relief right away. So if the client needs something right now, litigation isn't the way to go. But I also understand that litigation can make a global change, versus one person at a time.

So I think that P&As are going to end up being legal agencies before it's all said and done. Some P&As are within the state systems, some P&As -- there's just all kinds of entities that pushes on to get most P&As out of the state systems. It can lead to a conflict of interest.

Now in Indiana, we've gone ahead and sued when we needed to, we've never backed down. We're set up as a state agency, but we're federally funded so the state doesn't have much say in what it is that Indiana P&A does.

I think that the advocates -- it's a good group of advocates that work at Indiana P&A. They really believe in what they do, they're passionate about it. I think in the early days when I first came to P&A, they had had somebody working at the New Castle closing. I was the advocate assigned to Muscatatuck during that closure.

[00:39:07]

JT: Are there any -- highlights of -- examples of good work you may have done on behalf of people with disabilities? Can you think of any?

SB: Oh, absolutely, there are so many stories. You may have recently heard in the news, there was a lawsuit we were -- I'm not going to use the right legal term, but we joined with Kent Faulk's agency in the Indiana Civil Liberties Union. They had to do with mental health within prisons.

And I know my staff ended up going to the correctional facilities a lot under the Assistive Technology Grant pretty much. And our prisons are just not good places for anybody. But if you go in with a prosthetic limb and it gets broken, the chances of you getting prosthesis to replace it are just pretty much zero unless someone really goes to bat for you.

People don't get the healthcare to stay healthy and so -- and then you get offenders with mental health issues.

[00:40:20]

...And so what may be psychiatric symptoms, appear to be mouthing off to the guards and then you stick them in isolation and then that mental issue gets even worse. I remember a young man; we weren't very successful with him. But had murdered his girlfriend was schizophrenic went off of his medications. I don't think he ever had a very good trial. The girlfriend was the daughter or granddaughter of some pretty well-known local politicians in the city where it had occurred. And -- but he ended up in "The SHOE" [The

Secured Housing Unit] at Wabash Valley refusing his meds and he was just sick, I mean just mentally ill even attacked his mother eventually. I don't know what happened to him but at some point, we weren't able to assist any longer. But there have been so many good things. I know years ago, this was before my time, there was a young man -- a child with cystic fibrosis who needed a therapy vest and that's a weighted vest to help break up the secretions -- you get mucus in your lungs and it prevents you from breathing and Medicaid denied that [background door closing].

[00:41:39]

And so P&A fought and fought and got that child that therapy vest before -- yeah, that would help him prolong his life. We've been able to get people the wheelchairs they need, the communication devices. One of the easiest cases I ever had when I had a staff vacancy and I took over a case load [chuckle] was a young lady and I still see her mother occasionally in public and see her at the state fair which is really cool. Needed I think a DynaVox, some kind of communication device and Medicaid would only pay for so much and so it had been denied. And literally all it took was a call -- three calls I think, a call to the provider who made it, and a call to Medicaid, and a call to the mother to tell her we had the device. It just is -- you know, I thought I was going to be in for a fight of my life and all it took were that few of calls to get that child what she needs.

And then how fun for me to be able to see her at the state fair, I think just last summer and, you know, out enjoying her day. So, you know, that's just gratifying. I mean you know -- you've been in the system a long time, but there are many success cases that P&A had. They joined with the Virginia P&A on the recent Supreme Court decision that we do have access to records for people in mental health facilities. It seems like a no brainer but they had to go through the Supreme Court to give us the access rights and that's important because then people can call us and we can assist them. So I think our P&A, I think, despite the recent events has always been a good P&A. I think I mentioned that we were there when the Muscatatuck closed and...

[00:43:35]

JT: That was my follow-up question because you said you were in -- let's see you were in advocate role closing the Muscatatuck. Can you tell me what that means and what that was like?

SB: That was a pretty amazing time. It's a really amazing time. Department of Justice came in and basically, the certification through Medicaid was just -- they were not meeting it. And Department of Justice came in, interviewed several of us -- people within the facility and then myself. And at that point I was going there at least a day a week walking the grounds. I was a member of the Human Rights Committee. [Background talking] Gosh that was '98, '99, 2000.

[00:44:32]

...Okay. In 1998 when I started at Protection and Advocacy, I was assigned as the advocate for Muscatatuck and I remember one of the staff at Muscatatuck saying, "Oh shit, she knows too much." I'd been an ICFMR surveyor and knew the facility pretty well. About a year into my monitoring if you will, and we monitor all the state hospitals, P&A did that. They failed an ICF/MR survey and essentially became the decertified. Department of Justice became a presence there and they were mandated to close. There were -- in my

monitoring, we had seen the care of people becoming progressively worse. At one point, my supervisor and I walked on to a unit and 12 of 14 people in that unit had noticeable bruises, black eyes, it was horrifying.

[00:45:39]

And none of those injuries were recorded or documented. On another unit, I'd been there on Friday, I came back on Monday and one of the clients had a broken limb and nobody knew how it had occurred. The state put monitors in to hopefully fix things. But there wasn't any fixing and it really -- at the time Department of Justice came in, I had been approached by a staff person that worked there who wanted me to intervene on an issue.

The head psychologist was seeing the dentist at Muscatatuck, not a big deal unless the following scenario happens. There was a young man on one of the units, one of the transitional housing units, very bright young man. Probably not really developmentally delayed at all, had some behavioral issues, had been abandoned by his folks, raised by grandparents, had anger issues, had some hoarding issues, that sort of thing.

[00:46:51]

Probably much more the mental health issues than developmental issues and he could very definitely tell you what he liked and didn't like. And initially, he didn't think of me as an advocate and he let me know that, and he had every right to let me know that. And then over time I would stop in to see him, because he could tell me what wasn't going well at that facility. He had teeth that needed fixing and like many of us, hated going to the dentist and refused to go to the dentist, didn't want to go to the dentist. He was not ill from this. I think if you took a poll in Indiana there's probably a lot of people walking with teeth rotting, quite frankly. However, the psychologist and the dentist, without including him, had made an appointment for him to go up to IU Med Center under the guise of some medical treatment, when in reality they were going to put him under and have his teeth pulled, while at IU.

And then they would make sure he was under until they got him back to Muscatatuck. And the staff person, the case manager was appalled and rightly so. Human rights had discussed it, we'd said, "No," and they were still going to go ahead with that plan. So that was one nugget of information that we could share with Department of Justice and they were furious.

[00:48:20]

Another thing that occurred, the restraints in Lincoln Hall were kept in this nice little bench. They had upgraded the appearance of the facility several times over the year and so it was kind of a country -- so it's a little country bench. When Department of Justice asked to see the restraints, they had been put away with blood on them from the previous restraint. And so you can imagine that it did not go well for Muscatatuck and there were just other -- so many stories. At that time, they actually allowed -- gave me a key to -- where I could get into any part of the building, you know so I could look at charts and that kind of thing.

[00:49:06]

...So there was a day when I didn't have my key with me, when somebody from the state asked me to hand it back and I said, "I don't have it." We started doing some night monitoring, there were just -- they didn't have enough staff, people were in jeopardy, there were injuries, unexplained injuries. And so the closure precipitated the state having to literally live down there and do a lot of monitoring and -- you know, really, really watching folks trying to keep them safe and getting people placed out pretty quickly.

JT: In your opinion, how were people getting injured?

SB: Oh, I have no doubt people were being -- there weren't sufficient staff, so they were being neglected. And I also believe because I saw it -- that people were being abused by staff.

JT: Just manhandled?

SB: Yeah. And I can give you another story I took -- we hired an outside attorney to start looking at some of the issues and so I took her down for a day at Muscatatuck. I was not in my blue jeans, I was dressed up. They knew I had an attorney with me [chuckle]. It's not funny, it's just -- but the first thing, we went on to a unit to talk with -- I wanted to see an individual that had had some issues nonverbal and, so they were toileting him and they brought him back out to see from the toilet. And I leaned down to talk to him because he was sitting to kind of get -- and they had not zipped him up, so, you know, and -- well the person who happened to work on that unit, there was one staff who was asleep in the chair and never woke up until staff woke him up. Okay. So then this poor fellow, you know, his privacy's not been -- and the attorney and I are kind of -- you know, so we -- I filled that out as witness statement for the staff sleeping and they removed him right away.

[00:51:16]

And for the lack of making sure that that fellow was covered. So we go to another unit and at that point, I needed to use the rest room. They're heading out for some kind of activity which is fabulous. So I come out of the restroom and there stands the attorney and one of the clients who was a very tall fellow who looked very menacing, he was not. But he was non-verbal and she's got her back against the wall and this fellow is trying to communicate and I'm like, "Well, what's going on?" and she said, "They left and left him." So again, I fill out another incident report, okay.

And it seems to me there was another thing but anyway we headed out and we decided to stop at a Taco Bell to get something to drink. And the attorney went in the rest room and I look up and the staff that's been removed from duty is seated there with his family eating lunch [laughter] and I was like, it's just not a good day. So when she got out of the restroom, we quickly fled.

[00:52:18]

But again, my point is that they knew I was there with a visitor and that was the best they could do on that day. And the attorney was just appalled, I mean just appalled. So neglect and abuse, I think it was just rampant down there and they went through a series of superintendents, one who had been taking somebody off grounds and not signing him out. There were just -- it was struggling and it was not going to

get fixed. It just -- the problems once they were exposed and people could really see, were just overwhelming and you just prayed people were safe.

[00:53:00]

JT: We did some interviewing down there towards the end, tried to collect some stories.

SB: Oh.

JT: Talking to staff, talking to family, talking to people that used to live there and the array of stories was amazing. [Background siren] I was so surprised as to how many people said they actually liked it and how sad they were to see it closed. The only people that we talked to as I recall, that were really happy about it were some of the residents who had lived there and didn't like it. But several people we talked to were -- that were still living there, were not all happy and they didn't want to leave and it was just kind of shocking that people felt that way.

SB: Staff would tell me and this is stuck in my mind from years back -- staff would say I love these residents. I treat them just like my children. Well indeed they did, so they would backhand them and Jennie, I mean more of that went on than I even think I knew.

[00:54:02]

But you cannot walk onto a unit and see visible injuries on 12 of 14 people that weren't there the week before and not suspect something is terribly wrong there. And these folks were non-verbal, so they're not going to be able to tell. On that same unit, I witnessed -- I was in the nurse's office and I witnessed a staff and I would have never dreamed that this staff would do this -- bring somebody back from lunch, she didn't know I was there and she slapped this guy around, I was just stunned. It was a person that needed a one on one. It doesn't justify it but I know that she just was frustrated, and tired, and -- but still -- still and it just -- it was just very sad.

And yeah, I think the people that worked there enjoyed their jobs and liked it and there were some really good staff. But there were just some people that...

JT: It was just a job and there was control issues.

SB: Absolutely, control issues.

JT: I think though -- but I think a couple of times that I did visit, I was most appalled. I'd seen people sitting on the floor in a hallway with a sheet over them or half dressed. Or you know, just running rampant with -- [inaudible] anything but the visual of people sitting out in that hallway, with nothing on but a sheet and maybe some underwear.

SB: Yeah, yeah.

[00:55:27]

JT: And I mean, why aren't you dressed?

[00:55:30]

SB: Well, there wasn't any leadership. I mean you're -- you know I've supervised people. Your staff are only as good as you give them the tools to be good and I remember in Lincoln Hall. I don't mean to beat up on that, there were plenty of buildings that had problems. But in Lincoln, they had been cited on a survey for a roller board device that was a restraint. And so their plan of correction and I couldn't -- they asked me if I wanted to watch some restraint training, I said, "Sure." Well, what they had done was this was a big wooden board and they would strap the person on -- they would get the person on, strap them face up hopefully, strap them in three areas, and then roll them to privacy, okay. So their way of fixing this was to take the wheels off the board. So now you had a big heavy board with straps. And they really thought they were -- and I said, "Now what?"

Okay now you've got the -- and they were like -- they -- they genuinely didn't know. They were like, "Yeah, I don't know. I guess we have to carry it." The whole idea was to re-assess and get rid of that as a restraint because it was just a lot of danger wrestling somebody to a board, strapping them on, rolling them away. But the leadership hadn't given that communication to them and so here are these poor, direct care staff showing me this and I'm saying, "But what happens now? You've got a 300 pound resident," and, you know, it's laughable. It's a good water cooler story, but it's so sad. It was so -- and it was and people weren't getting -- the only work they had for people down there was can crushing and paper shredding.

[00:57:20]

And you know, even when we closed it, no one talked, no one did vocational assessments, no one talked to them about work. I don't think most of them even understood the concept of work. Now -- now the state is going back and looking at that because you've got waiver people now sitting in smaller settings doing nothing.

I mean there's just got to a better way, there just has to be a better way.

JT: Well, that kind of leads us on to the next line of questioning. [Laughter] In looking forward, what do you see as trends and what do you see that would make life meaningful for people with disabilities? You know, what would be some goals or as well would be some future hopes?

SB: We've got to try to keep services as local as possible and keep those natural supports in place. I know the waiver is better than the institutions, probably better than the eight-person group home. You know I was one of eight children, I tease that I grew up in group home but man, I love my privacy, I love -- you know, I love seeing my siblings when I -- on my terms.

[00:58:34]

So anything we can do from the start, I know the preschool services for children, the providing of supports for parents, the respite if, you know, if we can train neighbors to know how to deal with special needs children. There's a neighbor boy that had a feeding tube the first four years and his mother felt comfortable popping him at my house occasionally and I'd do the tube feedings. That's the kind of world we should live in where it doesn't matter whether it's a physical disability, or a cognitive, or a mental illness, that you still support that person.

[00:59:10]

...And that, you know the money isn't going toward, some kind of artificial setting because that's what a waiver is to a great extent. Although I think some people on waivers would say "Yeah, but I get to live in my own apartment and I'm going to work every day," and so that's wonderful. So maybe there just need to be more -- more ability to keep people within that family unit and that community unit before we go to waivers or group homes.

JT: How did we get there? How do we educate and train people coming into this line of work so that these are things that, you know, are natural or first in mind?

SB: Well, I would hope that colleges now that are teaching sociology or social work [chuckle] are at least mentioning working with individuals who have disabilities, that it's not so much in the closet. So I'm hoping that young people have more of exposure today. I mean that's what it takes -- I think that's why my mother -- I think that's why I ended up in Sociology and in disabilities was -- I saw it -- it seemed to be a fact of life, it was just something that happened. And she was careful to, you know, tell eight of us, we all have that attitude.

Disability doesn't frighten us, it doesn't frighten the next generation. When my mother was in a nursing home for four years before she passed, my niece and nephew who were high schoolers visited her, no fear, no. And so I don't know if that makes sense but somehow exposure and just teaching that, you know, disability is a natural aspect of life, it can happen to anyone at any moment.

[01:01:04]

And then making sure that the person with the disability is exposed to all the same experiences that you and I had growing up. So schools need to be funded to do a better job, you know, Special Education was never really funded it was a great idea, but let' really fund it, let's let classroom teachers do non-academic life skills training, you know, really work on things like that. Job resumes, and employers I think there's a movement in Indiana that's pretty excited I see it with voc rehab, that we're exposing employers to people with disabilities.

On the farm we had a few kids that were quote "Slow," that bailed hay for dad. He didn't care if they were great workers and we paid them fair wage and they came back and they were, you know, committed to whatever job they did on the farm. So we've got to get the message out to employers and again I think Indiana with some of their -- with vocational rehabilitation, these local business networks and Project Search I mean all that is just fabulous.

So we need to immerse the culture in disability, we have to have it in their face every day.

[01:02:27]

JT: Yes and knowing people with disabilities is making a huge difference, you know, people with disabilities were invisible through my early life. And they are not invisible to youth today, so I think that's a big change.

[01:02:42]

SB: Well you know the agency you worked for Jennie they were a head of their times, I mean really. Jim McClish right? And Don Patterson? I mean you guys were really, people were earning money. They were doing meaningful things, they were going into the community and working and we needed to learn from some of those folks that had that kind of historical perspective that we're, you know, futuristic thinkers.

JT: We were rebels.

SB: You were, you were and it looked to so well and, you know, there are still rebels in the states, so I think it's all good but you're right they used to be hidden away. [01:09:54]

JT: Alright, we talked about training needs. Are there ideas that you have in terms of training, or specific training, or specific education that we offer people? How do we get people to think outside the box in terms of supporting people with disabilities and I'm talking, both on a professional level and the direct support staff? How would it be creative? How to just be a good person and do what you would want someone to do for your loved one if you were in that situation? You know -- how do we -- what's that training look like?

[01:04:00]

SB: Well, that sent me on another divergent path. First of all, we do not pay direct care staff what they need to be paid. No wonder the pool is so small and I know it's a nationwide crisis, but let's flip flop the pay scale within agencies a little bit. Let's pay those folks a living wage and above and I think the pool of people wanting to do that work, will increase, and you will get some better candidates.

The other thing that Indiana still doesn't have is any kind of registry for direct care staff in the field of developmental disabilities, or I'm thinking of even mental illness in terms of abuse allegations, neglect allegations, that sort of thing.

So, we have to balance the protection of people who are vulnerable with -- by getting that registry. So, I think the training begins from day one and maybe even ahead of time before you -- and maybe professional shadow folks for six weeks.

I mean it's got to be more intense than it is, because you're dealing with people. And so the unknown is going to happen. I mean you and I both know that in working with folks.

[01:05:18]

Years ago, when I was a group home manager and I was terrible at it. They hired me -- it was Dave Kiley because he knew me and thought I was a good person. And so I start managing a group home and I wasn't particularly good at it.

[01:05:32]

I enjoyed the ladies; it was a female group home, eight people. But I had a gal that had behavioral issues and I had no clue how to deal with her anger, with her belligerence and there wasn't anybody to assist me with that. So I kind of made it up as I went along and she didn't end up staying in the group home and that's my fault I'm sure, because I couldn't support her. I couldn't figure out a way to support her. No one should be hired just because somebody knows them and they're good people.

...They should be -- and I would also recommend that we test people that we make sure that they can verbalize. It doesn't have to be an in depth thing but that they understand that they have to read a care plan and they understand what the lowest, lowest level of intervention is for behavior is, that they understand what informal training opportunities are. When I surveyed, it was obvious that direct care staff aren't given that information -- that they think of tooth brushing, training goal as being the goal that you run at seven o'clock at night before you go to bed and so that's the only time. So they forget you're brushing your teeth in the morning. That's a good time to run that program maybe even the day program to run it up to lunch. But there's all kinds of informal opportunities. We don't have to make the training so regimented that the client hates it and staff aren't getting anything from it. I mean it can be much more fun -- I think, and much more -- just a more dignified process.

[01:07:09]

So I think training just needs to start from day one and case management -- or whoever at the QMRP needs to be checking continually on that person, as a staff person how their doing. Talking with them openly what are you comfortable doing, what are you not comfortable doing? Well I don't like running the behavior plan, I don't quite understand that. Okay, maybe you move that staff to the morning shift because that person is a morning person, but the behaviors are afternoon events, you know, maybe you can either are just ways to make it work.

JT: I agree. So are there some highlights in your career that you would like to talk about or are there any things that we have talked about that you feel are important from your own perspective, you know, from your own career, and you own life?

SB: Well, I suspect that I will still be in the field of disabilities within the next few months. I don't think I'm done working per se. And I think that I was very proud at P&A of getting the PABSS and the TBI grants up and running and really serving people in a meaningful manner.

[01:08:28]

In 2011, staff there voted me Advocate of the Year and that was the Terry Whiteman Award -- you remember Terry I'm sure. One of the best people in the world, taught me a lot about disabilities. So that was quite an honor, I was really humbled by that. But I think I've grown a lot since those years at New Castle and I hope that I've got a better feel for the basic rights of people with disabilities and just much more respectful of those individuals and working more toward getting them out in the real world than keeping them, you know, locked away.

[01:09:16]

Met a lot of good people over the years. There's some real – you're probably interviewing some several of them I hope. Yeah, I mean people that impacted me that made me better at what I did. So hopefully, that's still going to grow and there's still going to be people that push forward with the futuristic thinking, you know. Twenty years from now, there won't be waivers because people can just get their own apartments and get their own jobs.

[END OF INTERVIEW]