

CLAWS AND WINGS:

AN ORAL HISTORY EXPLORATION OF DISABILITY IN DELAWARE 1917-2017

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Interviewee: Linda Fleetwood (Referred to hereafter as LF), Volunteer at the Stockley Center, Parent

Topics included: Stockley Center, Lobotomies, Special Education, Epilepsy

Run time: 56:14

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LF: My name is Linda Fleetwood. I currently serve as the volunteer curator of the museum at the Stockley Center. This, the museum has been compiled just in the last few years. Lots of people at the Center as employees and as parents looked around and saw that buildings were being torn down and, and artifacts were being discarded that people in the future might want to have access to. So we have worked with the Iota Nu chapter of Delta Kappa Gamma and assembled many, many artifacts and documents into the museum at Stockley. The state archives has just scanned for us 697 photographs that we provided to them, so all of them will be available eventually, not only online through the Stockley Center Museum, but also through the state archives, since they did the scanning.

We're working closely with the archives and making sure that anything that's of critical importance is at least on file at the archives in addition to on file locally at the Stockley Center so that something that's really, really important doesn't walk out the door or experience any kind of damage, regardless of what nature does.

KB: So you're digitalizing some of the primary documents? [LF: Yes, we are.] Oh, that's great. And where is Stockley? Not everybody knows.

LF: Stockley is located a mile off Route 113 just north of Millsboro. It's between Millsboro and Georgetown. Lots of people may have seen the signs for Stockley Center but the only thing you can actually see from the highway is the very, very tip-top of the water tower, which has been its landmark since it was built, and I'm not sure when it was built. The Stockley Center has been open since 1921, but I don't believe the water tower was placed yet.

KB: So, what about 1921? How did they get started? There's a story of six girls or something. Tell me more.

LF: Well, in the late nine-teens, there was a committee, statewide committee, appointed by the governor to select a location for such a facility. It came down to the Stockley Center or the Stockley Station area was the best location and the, actually the Delaware Colony for the Feeble Minded opened in May of 1921. Mr. Howard T. Ennis was the director. There's currently a school named for him in Georgetown that most Delawareans are familiar with but he was the first director of Stockley. He and his family moved into the first building which was constructed, along with six girls.

Then there was such a demand and people saw it that it as unfair that there was a place for girls and not for boys, and so nine boys were selected and moved into a converted farmhouse for a time until a regular full-sized cottage could be constructed for them.

And over time, residences and medical centers and education buildings and administration buildings and a church have all been constructed on site so that there was a time when it was never necessary for anybody with a disability to go off that campus 'cause all their educational and medical and social needs could be met right there on the Delaware Colony.

KB: Are the, is that Ennis related to Dave and Bruce Ennis who are both legislators?

LF: Not to my knowledge. [KB: No? It's just that...] This Mr. Ennis was the director of Stockley from 1921 to 1951, at which time he retired.

KB: So, something about a committee settled it. What do you know about this early choice of land and why did it end up there?

LF: Well they came down to actually someplace up around Blackbird Forest was one location and the Stockley location was another and submitted, I believe, those two recommendations to the governor who made the final choice.

KB: And who was the governor at that point?

LF: Governor Townsend.

KB: So, what kind of disabilities did these children have? They were called "feeble minded" but they were...

LF: They were called "feeble minded," and in the classification right from the book in which they were registered when they moved in, they were classified as either "idiot," "imbecile," or "moron." And if you look in a dictionary, those are the words that have come to be disused and unkindly used by many, many people, but they used to be the medical terms for certain ranges of mental age. So, just like now, folks are saying, "Well, you shouldn't use the 'R' word," but there was a time in our history when... My teaching certificate says I can teach mentally retarded children. So, there are words that fall out of use because of the unkindness with which some people use those words. But there's, there was nothing wrong with those words when they were being used appropriately.

KB: Let me see. So, they were 18-months to 2-years-old that were put in there? That young?

LF: Many of the original residents were older when they were admitted. There were some folks that just didn't have any place else to go and were kind of slow learners and might have been court-committed. Some of them were referred by their schools, by their parents, by their grandparents, by the lady next door who saw that this kid was having trouble. At that time they assumed that people with disabilities would make out better if they got lots of fresh air and sunshine and so they wanted them to be in a rural setting. So, I think that was the primary reason why the Stockley location came out on top.

And at that time some people were literally "farmed out." Somebody who was a little slow and wasn't quite able to function with polite society might be put with a farm family and work on the farm or work in the kitchen and help with the laundry. And in the state of Delaware that was a pretty common practice. There were hundreds of kids that were farmed out, and some of those as well were then placed at the Stockley Center or at the Delaware Colony.

Particularly children that obviously had something wrong were taken there as soon as they were born or as soon as their parent could bear to let them go. And I'm specifically thinking of children with Down syndrome. They were different in appearance. And we have photographs from historical events in which there are dozens of kids with Down syndrome, because if you had Downs, you just automatically went to Stockley. There was no recognition at that time that there might be some high-functioning children with Downs. It wasn't even called Downs yet, they just called them "Mongoloid" yeah, because of their appearance.

But there, there are many levels of children who have Down syndrome. And some can stay home with their parents and be perfectly fine. But that was not the assumption, that was not the best medical information way back in the '20s, so many, many children with Downs went directly to the Stockley Center.

They also found that the residents from time to time would give birth to a child who would be immediately placed at Stockley and there are indeed people who were born and died at the Delaware Colony.

That led to a widespread eugenics movement, not only in Delaware but throughout at least the United States if not throughout the world, and I have examined at the state archives the census book that documented everybody's admission and everybody's discharge. And one of the columns in the admission book is when they were sterilized and what method was used. So that came to be a very, very standard procedure and if folks weren't sterilized before they got there, they would be soon.

KB: Because they just were... They had human instincts.

LF: Right, human instincts being what they are.

KB: So what about, they were mostly just sort of warehoused there? Did they offer any programs for them?

LF: In the early years there was no such thing as a "program." An individual might be placed in a cottage, which was actually a pretty big house that contained two or three wards, one at the south end, one at the north end, one upstairs. Each one would have maybe 10 or 12 people in them. And, so there was no privacy. There was no personal ownership. You couldn't have your own sweater, your own coat. Some of them did have their own shoes. When it was time to get dressed, if you wore a size 12 clothes they went in the size 12 pants and grabbed you a pair of pants, into size 12 shirts and grabbed you a pair of shirt, and if you needed a coat, grabbed you a size 12 coat, and that was what you wore that day. They did thousands of tons of laundry, and I guess the sorting of the laundry would have just been too onerous a practice to have really staffed. I don't know how they could have done it.

Speaking of the laundry though, the laundry was staffed by residents and the residents worked about 60 hours a week. But there was always one unfortunate soul whose job it was to shovel the coal into the boiler, which made the hot water. He would work 60 hours a week. His only job was to take the coal from over here and put it in the boiler over there. And imagine doing that for 60 hours a week. But the benefit was, somebody with pretty limited intelligence but who was pretty strong could do that and it gave him something to do all day.

But many, many of the people just kind of sat around all day, not doing anything. Not any kind of stimulation. It was really a sad place to be.

KB: And there were no educational programs at all?

LF: Well, there was a building they called the “Education Building,” and certain ages got a certain amount of education, but it really wasn’t a primary focus of the facility at all.

KB: It was more just a place to stick them. [LF: Right.] So, what happened in 1956? That’s, like, 30-some years after it started. Its name was changed to Hospital for Mental Retardation. Did any other changes take place?

LF: Well, in the ’50s the trend across the country and across the world was to find a cure for mental retardation. So they changed the name to a “Hospital for Mental Retardation” and started all kinds of things medically to try and cure the folks that they had. There were, there was use of all kinds of medications. All kinds of therapies came into being. But when it came right down to it, the people were still very limited in what they could do, despite the therapies that were applied by the medical staff. There was a little more education. You know, I almost want to say that in quotes, at that time, but they were really looking, focused on getting a cure for mental retardation at that time.

KB: Any they still didn’t find one, huh?

LF: So it’s, it’s the Hospital for the Mentally Retarded for 25, 30 years.

KB: So, and then, the next step was 1964 with lobotomies and things? Talk about that.

LF: That was awful and that’s one of the things that I have carried up to the state archives because I don’t want all record of that to ever disappear. That was a blot on the history of the state of Delaware. There was a doctor named Dr. Freeman [Editor’s note: Dr. Walter Jackson Freeman II] who came here from California after quite a bit of correspondence. Dr. Freeman was kind of the “Father of Lobotomies” in the United States and he would go and show people how to do it so that they could their own.

Well, at the Stockley Center, Dr. Freeman came in and did 12 lobotomies and then a Dr. Szabo [Editor’s note: Dr. Eugene A. Szabo], who was a Stockley doctor did two more. And I’m happy to report that that was the end of lobotomy in the state of Delaware. They found out they didn’t work. It didn’t, it didn’t have the desired effect and the, the 14 people that were chosen for lobotomy had uncontrollable behaviors. They had tried medications. They had literally tried everything they could think of and then here comes Dr. Freeman who says, “FYou know, these folks might benefit from lobotomy.” And not only did they not become the placid souls that folks had hoped that they would, many of them were blinded by the procedure because it was a transorbital lobotomy, which means they go in through your eye socket.

So, Dr. Freeman went in through their eye socket and cut, cut apart the two sides of their brain and then withdrew his tool. In the informed consent letter to the parents it mentions nothing about blindness. It says this is a fairly noninvasive procedure, they wouldn’t have a bunch of stitches and stuff. Well, because all the damage really was done inside.

But part of our lobotomy file that has since gone to the archives is a series of pictures showing just exactly how the procedure was done. It was done without anesthesia, so

imagine somebody poking a sharp instrument in through your eye socket and digging around in your brain with six strong men holding you down while your head is held back and a doctor sitting at your head is poking some sharp thing in your eye.

I, I just am appalled by the whole thing, but, you know, medicine isn't always pretty and that was a time in history when it was really ugly. But we did continue for a time to correspond with Dr. Freeman and sometime I'm going to go to California and see if I can get into his files and find out just how many of these procedures he did across the country. But he did 12 here and then a Stockley doctor did two more, and that 14 is all that were ever done. Some of those folks are still alive and still resident at Stockley.

KB: Oh, they still have residents there? Wow. [LF: Yes.] How many are there? [LF: Less than a hundred.] But that's a lot.

LF: Well, the folks that live there are people with severe medical needs or people that have always lived there and choose to stay there. They were given choice, And there are some, there's a group of older men that lives back in the back of the campus. That's the only place they've ever been. It's the only place they know and they don't want to live somewhere else.

KB: Isn't that something? So there's some that had this lobotomy that still live there? [LF: Yes.] And they don't, they're not able to talk about it I guess or express themselves very well?

LF: No, most, most of the folks there are nonverbal and non-ambulatory except for the, for the group of guys that live out back.

KB: How old are they? Don't tell me they're our age! [LF: I would say some of them are in their 60s.] Isn't that something? And how old is the oldest? [LF: I don't know.] You don't know?

LF: I don't know. There was an age range from 21 to 94 but I know that the lady that was 94 died and she was one of the people that had had a lobotomy in 1964.

KB: 1964 sounds so recent to me. [LF: Doesn't it?] So...

LF: How could they do something so barbaric? I was in the 7th grade.

KB: I know. We were in school, right? So you became a, a reading teacher at Seaford and you were a phys ed major. How did you end up at Stockley?

LF: Retirement gives you time to do a lot of things. I was a special education teacher and then an administrator and then I worked at the Department of Education, in charter schools, and then I retired from all of that. And, I discovered that I had lots of time on my hands. They, the director of Stockley wanted to have a museum and she didn't have time to do it. So after we had talked about it at Parent Days for several years, I just made an appointment, went into her office one day and said, "Look. You don't have time to do it and you want to do it. And I have the skills, so just let me do it."

KB: Oh, that's...

LF: She said, "Okay."

KB: It was like meant to be, huh?

LF: So they designated an area at the end of the All Star Building, the north end of the building, which is two large rooms and we also have a storage room, and over time artifacts just appeared.

I would go in there to work and there'd be a uniform from the security and then there's another uniform from security. One time I walked in and there was an arm laying on the table, but it's an arm that they used to train people how to do intravenous. But things just show up. I have many, many scary pieces of equipment from the dental office. They did everything over there! I've got syringes this long [Editor's note: about 4"] with needles that long [Editor's note: about 3"] to go with them. It seems to me if you gave somebody a shot very far back in their mouth you'd be sticking that needle out their neck, but I'm not a dentist! [Laughs.]

But we have all kinds of artifacts from, from the whole time of operation although I don't always know when something was used. For example, we have all of the dresses that the girls in the choir wore. So, we have a couple of them on display in the museum, but we've got many more stored in the storage room.

KB: Oh, that's pretty cool.

LF: Yeah. The guys wore shirts and ties and the girls wore these god-awful-looking yellow dresses, but they were very '70s and it was in the '70s so I can pinpoint those just by looking at the dresses.

KB: That's 'cause we wore them!

LF: Right! That looked a lot like the dresses my girls had for bridesmaid dresses! [Laughs]

KB: Isn't that... It's hard to imagine that was so close in time. And kids still live there? Your stepson still lives there?

LF: Yes, my stepson lives there. He was placed there when he was 21 because nobody else would take him.

KB: And what was his disability?

LF: Well, he, he is nonverbal and non-ambulatory and he has epilepsy and he's fed through a feeding tube and, but the primary disability is epilepsy which has in the time that he's had it, since he was 6 years old, it has taken away all of the skills he ever had, including the ability to write his name. And, you know, he was right up to learning how to read and then started having seizures. But they say he could have 60 in a minute. And just little blink-outs. He's had many, many head-drop seizures, where just that [snaps fingers] quickly you lose all of the muscle tone in your neck and your head just drops.

Well, his head has dropped onto the counter in our kitchen several times. He, and he has several times broken his two front teeth. And his two front teeth are now configured so that they don't break any place else but where they've already broken, so that no further damage is done other than what there already is. But he's not having head-drop seizures any more.

But when he was still mobile and up and around and walking around, whenever he was, whenever he was standing or walking, he always had to wear a seizure helmet 'cause you never knew when he was gonna go face-first onto the floor or onto the pavement.

KB: So he was born with this stuff?

LF: No, he was not born with that! He started having seizures when he was six.

KB: I'll be darned.

LF: Before that he was educated right here in the state of Delaware.

KB: So, he was kindergarten, first grade, something like...?

LF: Well, he went to the Sussex Elementary Consortium in Lewes but they never could figure out exactly why he wasn't learning right on schedule with his age. Because if you have somebody whose attention isn't just right, then you throw on top of that seizure activity, how're you gonna say how much intelligence somebody like that has?

One of the social workers down at the Stockley Center will get right in his face and say, "Buddy, I know somebody's in there." [KB: Laughs] Because you know, and on the rare occasions now when he does verbalize it is absolutely situationally-appropriate for whatever's going on. One day sitting in the day room, he sits in a recliner with a heavy weight on his legs to keep his legs from curling up, but he asked one of the aides to get a book out of the cabinet and read it to him. [KB: I'll be darned.]

One time when we thought he was comatose up in the hospital, the Children's Hospital of Philadelphia, in the middle of the night one of the nurses came into his room and he asked for a cup of coffee. [Laughs]

KB: And how old is he now?

LF: He's almost 35.

KB: So he's been there a long time.

LF: He, he has been at the Stockley Center since he was 21. He turned 21 in the Children's Hospital of Philadelphia and then he came down here.

KB: So, were they living down here or did he grow up in Philadelphia?

LF: No, his parents lived down here.

KB: Uh-huh. So, how many residents are there total?

LF: Less than a hundred. [KB: Less than...] At one point it was almost a thousand,

KB: Really, wow? And so they moved 'em out. How did they happen to move 'em out?

LF: Remember, we started doing group, group homes [KB: Yeah] in the late '80s, early '90s, and so some people were able to go in supervised arrangements with a group of people. And then some people were able to return back home. There was quite a lawsuit in the State of Delaware that said you can't keep all these people in these institutions. I forget the names. There are several advocacy organizations involved in the lawsuit and several Delaware officials, including Vincent Maconi, 'cause if, if you hear about the case it's usually Vince Maconi's name that comes up.

KB: Well, I'll be darned. So it wasn't that long ago?

LF: It wasn't that long ago. But people are moving out into group homes. Many, many into group homes all over the state. And folks are choosing to go live there. I think that they probably have the Stockley residency about as low as it can get because there are some... My son cannot go live in a group home unless they're gonna have doctors on call 24 hours a day and some doctor right there 8 hours a day.

KB: And that won't...

LF: And that's not gonna happen. Just the staffing alone would keep that from happening. But there are people with disabilities in the state that are living in, you know, there's one person, or that, one person on duty all the time with one adult with a disability. And so that really means there have to be three people every 24 hours because you need awake staff in case something should happen in the nighttime. And I don't know exactly how they do that. I know I have a neighbor who lives like that, but I don't know exactly how that's managed.

KB: So they have a resident medical staff there?

LF: There is a doctor who works there, you know, 9-5 through the week and is on call. And there are always nurses on, every place there are residents there are nurses, because there are folks with medical problems and, you know, they spend about half their time either administering medication or observing the patients to make sure that the medicine did what it was supposed to do or, you know, that's, that's a huge part of, of patient supervision at this time.

KB: And do they offer activities now?

LF: Oh, yeah.

KB: What kind of things do they do?

LF: They take kids to the ice show, sometimes they go to the movies. I mean, no longer do we have the 24-hours-a-day on-campus like was the case for so many years. And during those years, if there was entertainment, it was brought in. You know, somebody would bring in a dog and show all the tricks their dog could do, but there'd be 150 people watching that one dog. But now, anything that somebody could do out in the community, may have residents from Stockley present. They are right down the road from the Sussex Central High School so, you know, they'll take a van-load of residents and let them watch a baseball game or basketball game, whatever. And I think the kids from Sussex Central should be really getting used to that because it, it happens frequently.

KB: It's good for people to... [LF: Right.] So, tell me: what's a Director of Positive Outcomes? It's such a goofy name. [Both laugh.]

LF: Our name was our mission, the children that came to our school had been to school other places and not done well for lots of different reasons: abuse, neglect, anxiety, depression, cruelty, never knowing where they were going to sleep from one night to the next, never knowing who was going to sleep at their house from one night to next. And if you can imagine anything mean that somebody could do to a kid, it's been done to several of mine, I will guarantee. And I learned by working there that poverty is not the

only risk factor that's important in the lives of children. But our kids had to, or families had to fill out an application and the parent and the child come in for an interview, and at that time the staff determines whether or not that child is appropriate for Positive Outcomes.

Now Positive Outcomes started out as a stepping stone for kids who come out of in-patient treatment for mental health disorders, and so the parent organization, really, for the, for the original school was the adolescent psychiatric department at Kent General Hospital. But, it soon turned into a real school where people recognized that if there were kids with problems, that was a place they could get some help. The population now has become much more involved with the autistic population, but many, many of the kids there have normal intelligence. There's just something that happened to them early on in their life, or maybe during their teenage years, that just made it impossible for them to learn. Maybe they're, maybe they're school-phobic. I mean, we've had some of those, who, you know, skip the entire 6th grade! Their parents got up and went to work in the morning and thought they got on the bus, but they didn't.

But those kids that graduate from that school every year are of "Positive Outcomes." And, you know, they have reviewed the name, they've reviewed the mission statement several times, and have never changed a word because from the beginning it's been a safe place for kids that can't go to school with 1,500 people in their building. Some kids just can't. And, when I was there, director, the population was about 120. And for some kids that was a lot and it was scary for some kids to even come in the building. I mean, we've gone out into the parking lot and talked to kids and said, "Come on, you came in here yesterday. Didn't you get to maybe know a couple of people and, you know, maybe you can end up being friends with them, but they're not gonna come out here to the car and talk to you."

I've really had some rewarding experiences at Positive Outcomes. And so do the kids. The kids that go through that program... See, many alternative programs fix the kid and send him back to their regular school, and Positive Outcomes doesn't have that as a goal. The goal at Positive Outcomes is to graduate from Positive Outcomes. And the kids there meet state requirements. They have the same state standards as every other kid in every other high school in the state, and it is wonderful that these kids who require these special services can go there as a public school that doesn't cost anything.

KB: So, the only kids that attended are residents or are there some from the community that can come in?

LF: Oh! Nobody lives at Positive Outcomes. There are kids from all over the state of Delaware.

KB: That's what I wasn't sure, if it was part of Stockley.

LF: No. It's not, it's not in any way connected with Stockley except that I used to work there and now I work at Stockley. [KB: Okay.] That's the only connection.

KB: Okay, I didn't get that.

LF: But, no, Positive Outcomes is not residential. Transportation is provided by the Caesar Rodney School District for the kids that live within Caesar Rodney or can get to a

Caesar Rodney bus stop. There is a DART bus stop in front of the building so that kids that come from Claymont on the DART bus can nonetheless get dropped off right in front of their school. [KB: Wow.] So we, we do have children from all over the state at Positive Outcomes.

KB: And where is it located?

LF: It's across from the Camden Dairy Queen on Route 13.

KB: [Laughs] I can find that. That's pretty cool. So, when you were teaching, you taught special ed, too. How long did you do that? You really have a unique background to fit into stuff, these programs.

LF: I started teaching in September of 1973 at Seaford High School. I was a special ed reading teacher. But my undergraduate major had been physical education so I was half and half and I did that for my first two years and my last years at Seaford. I was there 18 years altogether. And, in between then, I was all special ed, all day. I was in the classroom for 7 years at, at Seaford High School and then I had thought that I always wanted to work with little children and so I was hired to teach special ed preschool at the kindergarten building in the Seaford School District. And at the end of that year I ran screaming back to the high school, saying, "Please take me back! Please take me back!" Because I discovered that working with little kids wasn't nearly as much fun as working with high school kids, for me. Now, I'm definitely a high school person. But that year I had a three-year-old at home, so I had the morning class, the afternoon class, and night school so all I saw was little tiny people with little squeaky voices and I decided that wasn't how I wanted to do life!

So, the next year I went back to the high school, back to the classroom and met some more great kids at Seaford High School. You know, people are afraid of high school and they're afraid of special ed. They're the greatest kids because most high school teachers teach only a year of something specialized. So it might be that they teach U.S. History and they teach everybody in the building who's a junior. Well, once I got the kids where I wanted them as first-semester freshmen, I could then enjoy them their second semester of their freshman year, all their sophomore year, all their junior year, and all their senior year. They knew me, I knew them, we knew how to make each other happy. And we usually tried to do that. And I, I loved being in the special ed department for that reason. We were the only people that got to interact with the same kids for four years.

KB: Wow, that's pretty neat.

LF: It IS really neat. I mean, well, it's it's just a fun way to do education. The only kids you have any trouble with are the kids who are in the first semester of their freshman year. But you get that all worked out by Christmastime and then, then you're just... You just get to enjoy it.

KB: What a good teacher! So, tell me about ADA. How did that come about in terms of your life, in terms of your son's life?

LF: I am not sure how it has affected me personally, other than making some requirements for accessibility in, like when we, we completely redid the building at Positive Outcomes from the time that we found the building until the time that it

was school with kids in it was only three months, but we had to make sure that we had, that it was accessible for everybody. We had an elevator for, possibly for people that couldn't use stairs and we've had kids that couldn't use stairs. We've never had a, well, in that building, never had a blind kid, but we had the Braille signs. You know, just the general public accessibility kinds of things when I was a teacher or an administrator. So, and I can see that Jonathan benefits from it because there isn't any place he can't go, although he's in a wheelchair. I mean, everybody's got ramps and everybody's got elevators if there's been anything done to their building since ADA passed.

Some of the young people at Positive Outcomes qualify for services under ADA but not under the regular special education legislation and they probably make that happen better than anybody else in the state because they understand it. But as far as, you know, it's mostly the physical disabilities that I see benefitting, although there, I'm sure there are, there are other branches of it that I'm just not aware of.

KB: What about changes? If, if you could wave a magic wand, and change all this stuff, how would you change to make things better?

LF: Well if I had a magic wand, I would cure all the kids and that would be that! Then make it so nobody needed special education or related services or residential services. That'd be wonderful, to just be able to heal everybody, and... That would be nice. If, however, I were just given the power to change the system, and not the people, I would figure out a way to make it less burdensome as far as paperwork goes. Where my son is, every kid has a binder that thick [indicates about 12 inches] that goes everywhere he goes. By the time I got the kids in my special education program at Seaford High School and at Positive Outcomes, they had folders this thick [indicates about 10 inches].

I've never dealt with a kid that could fit in a file cabinet and you can have the prettiest files in the world and not be doing what's right for kids and I would prefer to empower these specially-trained teachers, which they are, these highly-qualified, certified teachers, which they are, to do what's right for the kids without having to spend... Well, the end of the time I was at Seaford High School, my last 7 years I wasn't in a classroom. I'm a good special ed teacher. I love those kids. I have a great relationship with kids. I worked on the files. A full-time person in every building to do files? What could I have taught kids if I wasn't worried about paperwork?

And you multiply that by, there were six or seven of us in the Seaford School District, there were 19 school districts in the state. How many people are not serving kids but are serving requirements in federal laws and compliance? It is absolutely ridiculous. But here are all these people with all this training. [KB: Hmm.] And we know what to do for kids. But if it's not written down, we didn't do it. So you do your job half the time and record it the other half of the time.

I have seen my son's class, when he was at the Sussex Elementary Consortium, at any given point all three of the adults in his classroom of six boys, all three of the adults were recording data to document that they had served these children. It's sad.

KB: So it's a career "butt syndrome."

LF: And, well, I, I don't want to beat that to death, but it's very frustrating when you are a special educator and you know what a child needs and you can't help that child because you were working on compliance. Now, are there some bad special ed programs? Absolutely. Are there people that are not doing their job? Absolutely. But just because you've got pretty files doesn't mean the kids learned anything. [KB: So...]

And another, well, and then there was the attempt by the state at computerized IEPs. We were gonna have all our IEPs on computer. Well, we learned one computer system. And then we learned another computer system. And we learned another computer system. When they came to the 4th one, I said, "I'm not doin' it! I have learned now three systems. Now you can find yourself another special ed coordinator and I'll go back in the classroom and work with kids," which is what I wanted to do anyway.

But, the amount of paperwork in the name of doing good things for children with disabilities is mind-boggling. And paperwork reduction [shakes head], I don't think so. I just don't think so.

KB: So, do you think your voice is heard? How do we get your voice heard? [Laughs]

LF: I doubt it. There isn't a special ed teacher in this country who is in favor of 100% of the paperwork that's being done for special ed kids. Nobody.

KB: So how do you change that?

LF: You don't! I didn't change it during my 45 years. [KB: Never will, huh?] And I, I, I know some people... [Laughs] You know, I know everybody, or I know everybody at that time, that worked in the Delaware Department of Education. I knew some people at the U.S. Department of Education. I talked to the special ed guy. I talked to the, oh what was his...? The Office of Civil Rights guy. I didn't really know that he knew me until we went to a conference one time and I waked past him and he said, "Hey, Linda! How you doing?" I was like, "Oh, great! The head of civil rights for the country knows me by name!"

KB: So they do hear you, right? [Both laugh.] So, tell me about your stepson. How old was he when you got him and what was the involvement there?

LF: He was 7 when I married his dad and his sister was 9 and my daughter was 12. So immediately my husband's two children got a big sister and they weren't too keen on that. Well, because the big sister had always been the responsible kid and the smart kid and, "Hey, [redacted], can you help me out with this?" (I shouldn't have said her name.) "Hey, you, can you help me with this?" Because he had always been labor-intensive.

They didn't decide to call him autistic for many, many years, but he had some of the traits, like if you were walking down the sidewalk with him in the middle of Rehoboth, he might just dart right into the street. Well. You see those people with those little magic backpacks that they put on their kids that have a little strap that mom or dad hangs onto? I'm in favor for those for kids like that and I will never accuse them of having their kid on a leash, because I, I have been there. I have seen that kid and I know what he can do.

He was a very curious, very active young child. He used language like nobody else I had ever heard, and it was his language that got him into, got him into school at age 3. And he did not end up ever being part of the, just the regular schools in Seaford or Laurel.

And...one parent lives in Seaford and one parent lived in Laurel. But, the bus picked him up and took him to the Sussex Consortium whether he was at Mom's house or Dad's house. We had a notebook, a spiral notebook, where we wrote notes to the school every day and they wrote notes to us every day, what kind of a day he was having. If there were any problems. If he hit somebody or bit somebody on the school bus. We got one bus referral one time that had so many things checked on it my husband suggested to them that they should just have a box for "All of the above." Cause if there's something wrong you could do on a school bus, Jonathan had done it that day.

But, he, he's gorgeous. He has, he has big brown eyes and has eyelashes about half a mile long, little blond hair. Just adorable kid. And if you didn't know that there was something wrong you couldn't look at him and tell that there was anything wrong. Just a beautiful kid. But the older he got, the more obvious it was that he was not doing the same things that regular kids were doing.

And then with the seizure activity, he would have some skill just about mastered, then he'd have seizures a couple days and they'd have to completely start over if they wanted him [KB: That's weird, huh?] to develop that skill. As I said to you before the video started, he could write his name like a first grade teacher. Right now he can't even make a "J." He, well his hands are kind of together most of the time and he, he doesn't color or paint or any of that stuff except, you know, if there's a specific activity that requires that then he might paint a little bit, but that wouldn't be an activity he would choose.

Although he is nonverbal, the people that know him know what makes him happy, know what makes him mad, know which activities to avoid. Well now he is, I believe, 100% tube-fed. He has been recently in a position where he could get some food by mouth and we knew which foods he liked and which foods he didn't like, and his dad would make things and take them over to Stockley so that he knew Jonathan was being at least offered foods that he had liked in the past.

But it is so sad as a family to look at him now and know that his skills have taken a downhill spiral which is what is what the doctors at Kennedy Krieger Institute said would happen. When he was 10 years old, his parents were told that he would be totally, permanently disabled and that he would lose all the skills he had developed and he would have no skills left. And that eventually, some of the seizures would burn themselves out. He doesn't have head-drops anymore, but he still has many other kinds of seizures. There are, there are all kinds of seizures. You know, I used to think that grand mal seizure was all there was to epilepsy. Oh, no.

There are kids that just do strange things. There are kids that just stare into space. There are kids that just, whose head drop. There are kids whose arms come up. There are many, many, many different kinds of epilepsy, and Jonathan's, Jonathan has every kind of seizures that there are. [KB: Unclear acknowledgement.]

So we did live in Millsboro and his dad would see him every day. We have lately moved to Seaford so we don't see him as frequently, but there are many, many people that live there who have never had a visitor. And I don't know what, you know, because of confidentiality, privacy laws and so forth, I don't know what anybody's situation is, so I'm not going to say that their family is awful, because they don't ever come see somebody, 'cause there might not be any family. You know, some of these folks are

aging and they might not have any relatives left. I don't know. But there are folks over there that never, ever, ever have a visitor.

KB: Amazing. So, if you were going to have somebody write about you, what would you want them to say about you? [Laughs]

LF: I would want them to say that I loved kids, whether they belong to me or not, and that if I see a kid that hasn't got anybody, lots of times I latch onto that kid. When I was in school I had many kids that called me "Mom."

I'm on Facebook with lots of, lots of kids, although I can't, I can't let that be my whole Facebook, 'cause I have relatives and I have friends, and you know, I don't, don't want everything to be focused on what I have in common with children that have been to a school where I worked. But I, I am friends with fair number and, and see some of them outside of Facebook.

But I... Whatever's in my power to do for kids, that's what I try and do.

KB: That's nice. Anything else you want to say for the good of the cause?

LF: I would like to order that magic wand you spoke about. [Laughs] Imagine if there was no need for special services.

KB: Would be good magic.

LF: That'd be awesome.