

Video Transcript: Interview with sisters of Danny Flavin, who lived for 56 years at Polk State Center

Note: Time stamps in this transcript correspond to the unedited interview, not the video production of the interview.

- Guy Caruso: [00:00:11](#) Hello, my name is Guy Caruso. I'm with the Institute on Disabilities at Temple University. I'm a member of the Western Pennsylvania Disability History and Action Consortium. It's 1:25 [pm], and today is December 14th, [2018]. We're here at StudioME in the East Liberty neighborhood of Pittsburgh. We're here today as part of the multimedia project of the Western Pennsylvania Disability History and Action Consortium. We want to record firsthand accounts of disability history, and the life of your brother, Daniel Flavin, as told by Virginia Flavin Pribanic and Carol Flavin Pursehouse as part of that history. Thank you, Ginny and Carol, for being here today. Daniel Flavin--and I think you refer to him as Danny Boy or Cowboy Danny--was born in 1946. He resided at Polk Center, formerly called Polk State School and Hospital in Venango County for 56 years, beginning at the age of 16.
- Guy Caruso: [00:01:15](#) Daniel was the fifth of seven children born to Frank and Margaret Flavin of Shaler Township, Allegheny County. Ginny, can you tell us a bit about your family? Where did you live while growing up? What did your parents do for a living? What was life like for the family?
- Virginia Flavin...: [00:02:08](#) Well, as you mentioned, we were a family of seven children. My father was a parking lot attendant and my mother stayed at home and cared for the kids. We lived in Shaler Township in a modest community. It was pretty standard for that time. There were three older daughters, my sister [Carol], my sister Peggy and Mary Lou, and there was my brother, Tommy, who died as an infant. Carol was just about [one year] older than Dan. Then Dan was born, he was a gift. He was the boy my father had always wanted. I think when he was first born, they didn't really understand that he had any disabilities, except that he was very small and premature, and a low birth weight. But he was a joy, everybody loved him. I was born 10 years after Danny. I have another sister who is three years younger than me. I think to speak to the time of when Danny Boy came home, and was the family, and how that changed the family. Carol can speak to that better.

- Carol Flavin: [00:03:26](#) Right. When Danny came home from the hospital at first, they were told that he wouldn't live beyond four. He was so small. I forget how many pounds he was, but we brought him home. There were myself, Danny, and my two older sisters at that time, because they [younger siblings] weren't born yet. He was just a little baby. I was the baby myself, so we were only 11 months apart. He just kind of laid [there] and he didn't do much. Then as he got older, he was always very small. But as he got older, my dad would take him for walks and I would always go along. I would just be sitting there watching because Danny needed so much care. Then over the years, my father, he was a boxer also. He had a lot of exercise equipment. He used to bring Danny out of bed at night, put him on the kitchen table, and he would exercise him.
- Carol Flavin: [00:04:33](#) He would have a lot of exercise equipment just to get his muscles going. We would all sit on the steps and watch like it was a movie. We watched as Danny progressed and was able to stand and then walk. He still never talked that well, but we were a pretty happy family. We went everywhere with him. If anything happened to Danny, we were all in trouble, [laughter] but we were happy. Everything was fine. Then when Virginia and Cathy were born, Danny was a little older. Then I think things changed, the dynamics. Because Danny was so close to my dad, and he didn't like anyone bothering my father, so I don't know.
- Virginia Flavin...: [00:05:32](#) There was a lot of sibling rivalry that to someone who is at a mental age of three, was the best thing he wanted to do was get rid of his competition.
- Virginia Flavin...: [00:05:41](#) One night, in the middle of the night, he decided that my younger sister Cathy, one easy way to eliminate her was to take her out of the crib and throw her over the hill, which he did. He did other things that were really... they were amusing, but whenever you're talking about very young kids, you begin to realize that these are life-threatening behaviors. Clearly, when someone is mentally retarded and a mental age of three, there was no intent behind that, of course. It's just emotions and hormones and anger and frustration and jealousy. It became threatening to the other kids in the family.
- Virginia Flavin...: [00:06:24](#) They didn't have alternatives that you have today, where they could've gotten behavioral interventions or other therapies. The only option they had at that point in time was to really put Danny into Polk, a residential community, which was a really, really, very difficult decision at the time. Devastating for my dad. He had dedicated his life. I mean, when Carol talks about

him working with Dan as the boxer and the trainer, it was every night. He'd get home, he'd have dinner, and then the rest of the night was dedicated to his boxer, trainer. Getting him to be able to walk and be able to function, and to build whatever strength he was capable of developing.

- Guy Caruso: [00:07:14](#) It must have been quite amazing when they said that he wasn't going to be able to walk, and your father proved them wrong in that regard.
- Carol Flavin: [00:07:22](#) Right.
- Virginia Flavin...: [00:07:22](#) Right.
- Guy Caruso: [00:07:22](#) There were no other services available.
- Guy Caruso: [00:09:21](#) Ginny, your dad really seemed to be the main person in Danny's life, and really helped him to walk. Were there no other supports or services available to the family at that point in time that you know of?
- Virginia Flavin...: [00:09:33](#) Not professionally. It was a different time. It wasn't a good time in many ways, because people... it was an embarrassment. It was a shame that you didn't really blend into the community. People didn't talk about it. It was a sad time that people should be... Now, my parents never felt that way. Everywhere we went, Dan was with us. But for many people, they didn't see that. They didn't recognize it. They didn't understand it. I think I had my first fight when I was three over neighborhood bullies picking on Dan. That wasn't the last fight because unfortunately, that's the way it is. Bullies tend to be drawn toward the most vulnerable. It was no different then.
- Virginia Flavin...: [00:10:20](#) I think there were a lot of difficulties. Dan had difficulties because he was incontinent. My mother had all these children, and to have a child that was so demanding continuously, you couldn't leave him without supervision at any time. One time, he was left in his room and he wanted to... she went to visit a neighbor. He wanted to get out, so he pushed out the window and jumped out the second story window into a rose bush. He put his fist through a window. It was those kinds of behaviors that were so challenging that really made and took the ability to manage Dan beyond the capabilities and the resources that the family had.
- Guy Caruso: [00:11:05](#) Tell us a little bit about your mom. You talk about your dad coming home and really spending all the time, and training, and

helping Dan walk. But mom was home all day. Carol, can you talk a bit about your mother's role?

- Carol Flavin: [00:11:19](#) Yeah, she really took care of him. Fed him, bathed him, kept him very nice and clean. There was a school in Millvale at the time. It was called Sample School. Back then, I think they just had a playtime. She would take him there. She would get him in a cab and take him down. She would have to pay for the cab, so there were really no services that she could reach out. But she was good with him, he was really such a loving little boy. He was just a sweetheart.
- Guy Caruso: [00:11:55](#) Did your mom have to stay at the Sample School with him, or was she able to drop him off?
- Carol Flavin: [00:11:57](#) She would stay with him.
- Guy Caruso: [00:11:59](#) She would stay with him.
- Carol Flavin: [00:12:00](#) Right.
- Guy Caruso: [00:12:00](#) She really, all during the day and 24/7.
- Carol Flavin: [00:12:03](#) Right.
- Guy Caruso: [00:12:04](#) Was sort of the "on" person.
- Carol Flavin: [00:12:06](#) Right. There were four of us at home then, my two older sisters, and then myself and Danny. My sisters helped a lot also with my mom. At one point, my mother had a nervous breakdown. I think it got harder for her after that because she would be nervous. But she still tried to do her best with Danny.
- Guy Caruso: [00:12:39](#) Right. Any particular activities Danny liked to do, that he liked when he was young?
- Carol Flavin: [00:12:44](#) He loved horses, so he would play with horses. He loved ripping up the newspaper all over the living room. He just kind of liked to sit and watch us and laugh at the things we would do to make him laugh.
- Virginia Flavin...: [00:13:03](#) They used to have these blowup things that were probably about four feet high, that you bought them.
- Guy Caruso: [00:13:09](#) Oh, yes.
- Virginia Flavin...: [00:13:09](#) He loved those, and he loved Etch a Sketches.

Carol Flavin: [00:13:13](#) Right.

Virginia Flavin...: [00:13:13](#) And Slinkys. Those were his...

Carol Flavin: [00:13:16](#) And trains at Christmas.

Virginia Flavin...: [00:13:18](#) Trains. He loved Christmas, he loved Santa.

Carol Flavin: [00:13:20](#) Right.

Virginia Flavin...: [00:13:21](#) He didn't have very many words, but "Ho ho ho" was one of his big ones.

Guy Caruso: [00:13:26](#) Ginny, you were saying, how many words did he have? How did he communicate?

Virginia Flavin...: [00:13:34](#) I'm not a professional at it, but I would guess he had 200 words. Dad, car, tree. Then you got to hear that repertoire over and over and over. It was dad, car, tree. Dad, car, tree, ratty. He cycled through those, but he did have a way of telling you what he wanted.

Virginia Flavin...: [00:13:55](#) He would grab you and wanted something to drink. Today, they would train children in sign language. Dan had developed his own.

Virginia Flavin...: [00:14:05](#) As the family, growing up, we learned what he needed and when.

Guy Caruso: [00:14:08](#) Right. The siblings, and of your parents, who was Dan particularly close to? Or did he sort of treat everyone the same way?

Virginia Flavin...: [00:14:18](#) I think early, he was closest to you [Carol] because you were closest in age.

Carol Flavin: [00:14:21](#) Right.

Virginia Flavin...: [00:14:22](#) Then I think after you went into high school, he was maybe closer to me.

Carol Flavin: [00:14:27](#) Right.

Virginia Flavin...: [00:14:30](#) The jealousy was strongest between my youngest sister and him. We always had to look out for that. They'd be sitting calmly having dinner. All of a sudden, Dan would pick up a fork and throw it at my sister. Uh oh, he's done with you. [laughter]

Guy Caruso: [00:14:44](#) Well, you explained that Dan, when he was around 16, started to get some behaviors that were a bit aggressive and a little bit hard on your mom and the family. Talk a bit about the decision of getting him to Polk, because you mentioned that was a really difficult decision to make. Talk a bit about that if you will.

Carol Flavin: [00:15:11](#) Yeah. Well, my mother had the nervous breakdown. I think that was probably the initial beginning of that. She was having a lot of problems with her nerves after she came... because she was hospitalized. All they kept doing to her was putting her back to sleep because she was exhausted. This was after Danny was a little older, and Virginia and Cathy just came along. Because they were what, two years apart?

Virginia Flavin...: [00:15:41](#) Three, almost three.

Carol Flavin: [00:15:42](#) They were three years apart. My parents had their kids in twos, so they would have two, then seven to 10 years later there would be two more. I think that was the beginning. She was under a doctor's care for that. I think they just started to talk about it more and more that it wasn't really good to have him home, because someone could get hurt.

Guy Caruso: [00:16:06](#) Right. It almost sounds like it was two separate families. The older kids with Dan as part of that group, and then a younger group.

Carol Flavin: [00:16:13](#) Correct.

Guy Caruso: [00:16:14](#) And those younger kids that he was challenging a little bit.

Carol Flavin: [00:16:16](#) Right. I think just like a two-year-old or a three-year-old, he liked my dad. That was his buddy. Anyone that would go near my father, or if you did something different to him. If my sons, if they laid on the couch and fell asleep, that would bother him. He'd go over and grab them. There were some things that he just didn't like, so you had to really be careful of what you did in front of him to keep him happy. That began, and then doctor...

Carol Flavin: [00:16:57](#) Yeah, the doctor suggested that they maybe put him in Polk.

Virginia Flavin...: [00:17:02](#) That was my mother's doctor.

Carol Flavin: [00:17:05](#) Right.

Virginia Flavin...: [00:17:06](#) Had suggested that it was too much for her.

Guy Caruso: [00:17:10](#) How did your dad respond to that?

Virginia Flavin...: [00:17:12](#) He denied it for a long time. He had a brother who was a police officer, who was sort of like the... Uncle Tom was the mentor in his family. It was my uncle who came and had the conversation with him and basically said, "What are you going to do if he kills one of these little girls?"

Carol Flavin: [00:17:35](#) Right.

Guy Caruso: [00:17:37](#) It had to be a very difficult decision to make, both for you as children to watch that as well. Can you talk about the actual move to Polk, the first day that Dan went? How did that unfold? Did you get to go? Did just your mom and dad go?

Carol Flavin: [00:17:52](#) No, we all went in the car and took him up. They took him in, and we didn't stay very long because we couldn't stand it. We left and came home, and my dad was just devastated. That's not what he wanted. I remember him taking a walk. He left the house, and we didn't see him all night. He walked all night, and that was the first time I ever saw my dad really cry. He was so sad that Danny was in the school. He didn't like it for a long time. A lot of times, we would go up to get Danny and bring him home, and my dad would just take him and get him right out to the car. Where as I got older, I would go up and sit in their living room with them. My dad, he didn't want any part of that. He wanted him home.

Guy Caruso: [00:18:49](#) How did Danny adjust? This had to be a big move for him as well. At 16, he's now at Polk. He's away from the family. Can you talk a bit about his adjustment to being at Polk?

Carol Flavin: [00:18:59](#) It was funny because when he first went up, he never wanted to be there. We brought him home so much. We brought him home for the holidays. My dad in the summer would almost bring him home the whole summer, so he was used to being home. As soon as we would get there, or if they knew, if they told him that we were coming, he would sit by the window at Polk and just watch for us. But it was funny, when you took him back, he had this personality that was so great because halfway up, he would still be saying, "Mommy, home, home, home." But then as we got closer and closer to Polk, it was almost like he accepted it. Then we would get to Polk and pull the car in. He'd get out, and he'd kind of walk in front of me.

Virginia Flavin...: [00:19:53](#) He'd sort of dismiss you.

Carol Flavin: [00:19:56](#) Yeah.

Virginia Flavin...: [00:19:57](#) "Get out of here now."

Carol Flavin: [00:19:58](#) Right, then he'd go to the attendants and he'd do the same thing, "Mommy." Because he'd call everyone mommy and daddy. He accepted it, but he knew how to go back.

Carol Flavin: [00:20:14](#) It really didn't take long for him to be like that. But as soon as he got in that car to come home, he'd be saying, "Mommy, home, home, home."

Guy Caruso: [00:20:25](#) Did your mom and dad both go up to pick him up typically?

Carol Flavin: [00:20:29](#) Yeah, we all did.

Guy Caruso: [00:20:30](#) Oh, so as a family you would go.

Carol Flavin: [00:20:31](#) Yeah.

Guy Caruso: [00:20:32](#) And go get him.

Carol Flavin: [00:20:33](#) Actually, we had another family that were cousins. Their boy was Mongoloid or Downs. We would take them, we had a station wagon, and we would take his family and our family. We would all pile in a station wagon. We would pack a basket, and we'd get both of them, and we'd take them up to Sandy Lake. It was a little park. We'd almost do that every weekend, and that was our life. We basically learned to love it because he was so important to us. I always think I have a lot of patience. I always think that's where I learned it, because I had to just sit back and wait.

Guy Caruso: [00:21:19](#) Right.

Carol Flavin: [00:21:19](#) Then when Danny would go to bed and he would finally be asleep, my dad would come and have tea with me. We would have tea parties. My sisters, they would be older and they would go out on their dates. We always got our time. It was a loving Irish family. All my aunts and uncles would come over and help with Danny. When my mother went to the hospital, my aunts would come over. We were a close family. I was probably at the point in my life when all the relatives were young and could run. No one was really sick. I think Virginia and Cathy didn't experience that so much, with the relatives coming and just sitting around the kitchen table with Danny.

Guy Caruso: [00:22:08](#) People probably don't realize, how far away was Polk? How long did it take to drive him there?

Virginia Flavin...: [00:22:14](#) Probably two and half hours then. It's shorter, it's more like two hours now with [Interstate] 79

Guy Caruso: [00:22:18](#) Right.

Virginia Flavin...: [00:22:18](#) ... open. But it was longer. If you had bad weather, which you often had, that's the snow belt that runs right across Polk. You would have some bad weather coming up

Virginia Flavin...: [00:23:05](#) Carol sort of glossed over what was it like when Dan was first there and now he adjusted. I can't talk through this, say this, because I'll cry. But it was horrible when you dropped him off. You would hear him screaming, "Daddy, daddy." [tears up] At one time, he somehow got out the door and was running down the road.

Carol Flavin: [00:23:33](#) It was my dad and I, and he was running down the road chasing the car. We had to just keep going, and then finally he turned around and went back. That was so devastating. We cried all the way home. He really loved us, and we loved him.

Guy Caruso: [00:23:59](#) Were you able to keep in touch with Dan by phone to call him on occasion, or was that not part of the...

Virginia Flavin...: [00:24:04](#) No, that wasn't early on. You can do that today. You can do that probably 10 years ago, 15 years ago. But when he first went up, you couldn't do that. We didn't have that capability.

Guy Caruso: [00:24:15](#) You would just let the staff know that you were coming up, or you just keep-

Virginia Flavin...: [00:24:20](#) You would have to tell them. They had an administration. You actually had to sign him out, and you had to tell him when you were leaving and when you were coming back.

Guy Caruso: [00:24:28](#) Now, was it unusual for someone to come home as often as Dan, and to stay home for the summertime?

Carol Flavin: [00:24:36](#) Yes. A lot of the people up there never got home.

Virginia Flavin...: [00:24:42](#) I didn't realize how rare it was. There was no basis for us to understand that it was not normal, until this was when I first called. One time, this was actually about 27 years ago. We were bringing home Dan from Polk. I called and I said, "Maybe there

are some guys who don't come. Why don't I stop and we'll get them some presents?" I called up and I said, and in Dan's unit there was 100 people. I said, "There must be a few who don't come home. Let me know who they are and I'd like to buy them something." That was when she told me, "Your brother is the only one that comes home." I was just shocked. It never occurred to me, I never knew that.

- Guy Caruso: [00:25:35](#) When you first went up to Polk, what was your impression of Polk itself? The area, the buildings, the...
- Carol Flavin: [00:25:42](#) It was beautiful. It was like a college campus. That's what it always reminded me of. Green farmland, and it was beautiful. A lot of them were babies at that time. They had these cribs that had the sides would be up. Because they had to be careful that they would get out of their crib and hurt themselves. At that time, when Danny first went up, there were 3000 patients.
- Virginia Flavin...: [00:26:19](#) It was a fully functioning farm. It was a fully functioning community. It had its own power, it had its own water supply. It had a lake, it had a dairy farm. It had a farm where they grew their own vegetables. They made their own bread. It really was an amazing community, and it was in the middle of nowhere, which was also I think one of the... To have such a large population of children, because they were of all ages back then, they were completely safe. You weren't in the middle of a neighborhood where people were going to drive through and pick up a few kids. It was just really a self-contained area that was very... it was beautiful. I think that's one thing. As hard as it was to leave Dan there, he was in a beautiful place. It was gorgeous. The air was clean.
- Virginia Flavin...: [00:27:15](#) Everything was gorgeous about it.
- Guy Caruso: [00:27:19](#) You said that you appreciated Polk for its care of your brother. What stands out in particular? What sort of things did the staff do that made you so appreciative of the staff?
- Carol Flavin: [00:27:31](#) For me, it was they just really loved him. Danny was real easy to love. He was gentle ...
- Carol Flavin: [00:27:44](#) He would hug them. People were up there as many years as he was, and they had him in different cottages on any given time. Most of them really got to know him. If I'd go up years later, they'd say, "I remember Danny when he was younger. He was walking around." The other thing is, they got him involved. Danny loved horses, and they would get him involved in these

activities that he would go on a horse, and put him on this horse with his gear on. They would take him to a track. Anything that they saw that he liked in his room, they made it... it was all horses, everything was horses. Everyone, no matter what cottage they worked in, they knew him because he was so sweet. Because a lot of them, they would just sit and they wouldn't say too much. But Danny would never stop talking, even though he couldn't talk. [laughter]

- Virginia Flavin...: [00:28:44](#) He would call you darling.
- Carol Flavin: [00:28:46](#) Yeah.
- Virginia Flavin...: [00:28:46](#) Mommy, daddy. He would kiss your hand.
- Carol Flavin: [00:28:49](#) Right, and he loved the girls that were taking care of him.
- Virginia Flavin...: [00:28:54](#) I think that's really important, is that from the early time at Polk to even today, there was a very strong evolution ... the population declined. The services that were available and the way they were managed declined, it changed. They all changed in a reflection of the way they were changing in society. IEPs [Individualized Education Programs] were being developed for people. They had a new understanding of what kinds of therapeutic training and educational systems. Polk adopted those, and those began to be implemented there as well. We saw that change.
- Guy Caruso: [00:29:39](#) What were some of the activities he was involved in during the course of the day and during the course of the week? What sort of things did he do on the campus there at Polk?
- Virginia Flavin...: [00:29:48](#) Well, everything. Dan had a job. He worked at the gardening center, and he also would help mix cement. They made little lawn ornaments. He went to church every... a couple times a week. He knew the priests and he knew all of the people there. They had dances. Dan wasn't much of a dancer, but he sure enjoyed being around everyone and the music. They had lots of themes. They actually would come down and go to ballgames. They went to the theater. They had people come in and put on shows. They were very active in trying to keep everybody entertained and amused.
- Virginia Flavin...: [00:30:37](#) In contrast, one of the things that was particularly interesting about Polk is that the people who work at Polk, the caregivers, they had a better salary working in the state institutions than you might find at group homes here. They also had a far longer

tenure, so that the average person was far more skilled. They had been at Polk for 20 years, so they knew their jobs. They were dedicated. They valued things. Sometimes, you see a very high level of turnaround where people don't really know anything about any of the residents at all. But at Polk, that's different. They go and they... "John likes it if you throw him a ball." Someone else likes it if they like to wear stuffed animals. All the staff really understands what it is about each specific resident and what they like, and how they can best improve their quality of life.

- Guy Caruso: [00:31:39](#) Right. You said Polk was located at a pretty isolated area. Where did the staff reside? Where did they live?
- Virginia Flavin...: [00:31:48](#) In that area, the Franklin, Venango.
- Carol Flavin: [00:31:51](#) Oil City.
- Virginia Flavin...: [00:31:52](#) Oil City. They come from those...
- Guy Caruso: [00:31:54](#) People came from very close by then.
- Virginia Flavin...: [00:31:56](#) Yeah. I would guess, and I think it's true, I knew it at one time, Polk is the number one employer for that region.
- Guy Caruso: [00:32:03](#) That region, okay. I heard that Danny liked fishing as well.
- Virginia Flavin...: [00:32:06](#) He liked being outdoors. One of the things they have, in a little trail behind Polk, they have a little camping area where they would go out and they would have picnics during the day, and go on fishing retreats. It was fun. Like I said, it's such a beautiful place. It's in a valley where you look, and you're surrounded by green mountains. If you're familiar with Pennsylvania, some of the mountains of Pennsylvania are the most beautiful. I'm not going to argue with Colorado, but we've got some pretty things here.
- Guy Caruso: [00:32:42](#) Good. Were the community outings as well, where he did things outside of Polk?
- Virginia Flavin...: [00:32:46](#) Yes.
- Guy Caruso: [00:32:47](#) You mentioned a ball game. What sort of other community outings might occur?
- Virginia Flavin...: [00:32:53](#) They went on the Gateway Clipper. They had boats. They went to...

Carol Flavin: [00:32:56](#) Vacation.

Guy Caruso: [00:32:58](#) Vacation?

Virginia Flavin...: [00:32:58](#) They went out with us. You're talking about the Polk outings.

Guy Caruso: [00:33:02](#) At Polk, yeah.

Carol Flavin: [00:33:03](#) Yeah, but they went to the beach, remember? They took Danny on a vacation to the beach.

Virginia Flavin...: [00:33:11](#) Oh, did they? I didn't know this.

Carol Flavin: [00:33:11](#) They took a bus load. They would take them to Myrtle Beach, almost anything. Probably things that I haven't done, he's gotten to do. [laughter]

Guy Caruso: [00:33:24](#) It sounds like he had a very active life on campus there, as well as getting off of campus. That also includes coming home to be with you and your family.

Carol Flavin: [00:33:33](#) Right.

Guy Caruso: [00:33:33](#) At the holidays and other times.

Virginia Flavin...: [00:33:36](#) One of the things they do at Polk is they have sort of a cottage center organization, so that there's a central area that may have anywhere between 10 and 15 residents in that area, with a living room and a TV, and a little kitchen area. Then spinning off of that are the bedrooms, so that you have a lot of interaction with other residents, and they know each other. Really, I think that's another benefit of being in Polk, is that he's not isolated. He has his own community of people right there.

Guy Caruso: [00:34:17](#) Right. Did he have classes or school at Polk as well?

Virginia Flavin...: [00:34:22](#) They had training programs. They had swimming programs. They had physical therapy. Again, that evolved. Early on, when they had 3000 people, they didn't have as much of that. But like I said, the offerings and the support systems evolved as they did generally of what's available in society.

Guy Caruso: [00:34:46](#) Okay. One of the things I heard about was the Circus Day in the 1960s at Polk. Can you talk a bit about Circus Day and what that meant to Dan?

Carol Flavin: [00:34:56](#) Every fall, they would have this day that they would build floats. They would have a parade. They would have bagpipers, bands from the local area. It would be an all-day affair, and we would go up and spend the day. I'll just interject that Danny kept grabbing my dad and saying, "Home." [laughter]

Virginia Flavin...: [00:35:21](#) But it was a huge celebration.

Carol Flavin: [00:35:25](#) Right.

Virginia Flavin...: [00:35:25](#) For all the families and all the residents at Polk. It started in the morning, and it was a day of rides. They had amusement parks, sort of like a county fair kind of setting.

Virginia Flavin...: [00:35:39](#) They had competitions and an art show. It was really very much like a small Butler County Fair kind of gig.

Virginia Flavin...: [00:35:47](#) They sold food and they had picnics, and you could bring your own picnic. In the evening, they had a brilliant fireworks display that was put on by Zambelli. The local fireworks. They had these ships that would be in battle with each other with their fireworks, and knock each other down. It was a great day. I remember everybody looked forward to it. It was a fun, fun thing that they did. Each cottage built their own float, and they had bands. It was just really a fun day.

Guy Caruso: [00:36:22](#) Danny went to Polk at the age of 16. He was having some behavioral issues at that point in time. Being at Polk, how did he change, or did he change? How did he behave over the years while he was there?

Virginia Flavin...: [00:36:40](#) I do believe that the behavioral interventions that were developed, and some of the therapeutic things they worked on him with did help. But I also think that the issues that triggered him, and he mellowed. The hormonal issues perhaps and the frustrations. He learned to better deal with those, and he wasn't as jealous with my father. A lot of the tensions and triggers went away. But even up to the end of his life, he'd still have times when he would fly off and become... grab somebody unpredictably. You would never know when. His favorite thing to do was actually grab you by your hair, and pull a little three-year-old by their hair. That's not going to work in public. I think that was one of the things. Dan could not really be easily introduced to the public because of that unpredictability. I don't think that unpredictability is an uncommon feature in many people with mental disabilities, and it's a challenge.

Guy Caruso: [00:37:42](#) Right. When he did come home with the family, did he behave well when he came home on these short visits or during the summertime?

Carol Flavin: [00:37:54](#) No.

Guy Caruso: [00:37:54](#) How did your mom deal with it when he came home?

Virginia Flavin...: [00:38:05](#) Dan kept you tethered home. I think she had a great deal of freedom because the kids were growing. When Dan came home, it was as though you had a toddler back in the house again. It was all of a sudden, he was 24/7 demands on people's times again. There was that strain and that challenge, especially when my father wasn't there. You could do more and more things with Dan, but you couldn't take him to a movie. He wouldn't reliably sit through a movie. He would become agitated, and just couldn't conform to other environments very well.

Carol Flavin: [00:38:46](#) We lived in a community where the people were close. He would go outside and talk to all the neighbors and go to the fence. I always noticed when we first, when I would bring him home after my parents were gone, that all the way home he'd be saying, "Mommy, home, home, home." When we'd pull up, he'd get out of the car, and he'd kind of change his swagger and bebop up to my house. Because I lived right next door to where we grew up, so he knew that place. He would look out the window, and if he saw the new neighbor who lived in our house then, he'd be standing at the window saying, "No, no. Go away. That's not your house." He liked to come home, didn't he?

Virginia Flavin...: [00:39:43](#) He did. I remember one time we had a neighbor who had a motorcycle, and Dan loved the motorcycle. The neighbor was really good to Dan. One day, the neighbor was missing his helmet. It turned out Dan had stolen it. [laughter]

Carol Flavin: [00:40:01](#) Oh, and he could eat. He loved to come home and eat because their food is not that great. But he would come home, and we'd buy him Diet Pepsi. We spoiled him when he would come home.

Virginia Flavin...: [00:40:14](#) He was a diabetic.

Carol Flavin: [00:40:15](#) I know.

Virginia Flavin...: [00:40:17](#) Dan developed diabetes.

- Carol Flavin: [00:40:19](#) From all those trips home. We'd just spoil him, and he'd go in the kitchen. Even though he couldn't talk, he could communicate. He knew what was going on. I'd be in the living room and I'd give him a glass of pop. Then he'd go in the kitchen and I would be sitting in the living room, and I could hear him. He's opening the pop and he'd pour it in his glass. If you got up and went into the kitchen, he'd... just like a typical kid, "I wasn't doing anything." [laughter] Then he'd watch the football games and yell and scream just like he knew everything that was going on. He was a fun guy and everybody loved him. He was just really friendly. The only ones he beat up on was us, or you, or Cathy. [laughter]
- Guy Caruso: [00:41:13](#) In the 1970s, some things were happening at Polk. There was a newspaper expose' at that point in time talking about overcrowding and the use of cages for people who were living there. Did you see any of this? Did you have any indications that this was going on? Because you visited quite often at Polk. What were your impressions?
- Virginia Flavin...: [00:41:36](#) Polk *was* crowded. There were a lot of people there. It was the only resource in the area that was helping people through crisis at that point in time, so the crowding was real. But there was never any abuse that was associated with that. There was never any inappropriate restraints. We never saw anything of that. One of my feelings is a concern, is that for the management at Polk, more and more was asked of them. Budgets were never increased to be able to support the additional... if you add 3000 people into a facility, you need to increase the budget so that you can provide.
- Virginia Flavin...: [00:42:21](#) Instead, what happened is you increase the population without increasing the resources, and then penalize the administrators who were being victimized by that same system. That's what I feel happened to I think Dr. McClelland [former superintendent] at the time. Because McClelland, my family personally knew him. He took the time to interact with each of the many, many, many residents there. He at the time, back then too, all of the staff wore uniforms. They were disciplined, they were professional, they were caring. It was very appropriate. I never saw Danny abused.
- Carol Flavin: [00:43:05](#) Right. As far as the cages, I think I mentioned before that they did have... they had long porches before you went into a cottage. They'd have the beds like cribs, but they came up high. Maybe in some cases, there was a top. But they were open. They weren't tied down, they were just in there and safe. If

that's where they got the definition of cages, I never saw anything like that or any abuse.

- Virginia Flavin...: [00:43:38](#) I saw what I think was described by the media and people who were attacking the system as cages. It was the same thing. They were tall-sided cribs.
- Carol Flavin: [00:43:50](#) Right.
- Virginia Flavin...: [00:43:50](#) I've seen those same things at Children's Hospital. That's exactly the same kind of system they used for kids who are in care there. But again, I think we've all learned too well, the way it's reported becomes the reality in some ways. You can report it in a way that treats it realistically, or you can attack it. I think that was an era of attack.
- Guy Caruso: [00:44:18](#) Now, you as a family, you even indicated it was somewhat unusual that you visited Dan so often and took him home so often, where the other families didn't necessarily do that. I think Carol, you might have said they walked away. You place your child there, and as difficult as it was, you walked away. Did you ever get any indications from other families about how care for their children went, or did you have contact with other families?
- Virginia Flavin...: [00:44:47](#) Well, there's family groups up at Polk. I've never heard any of the families report that kind of abuse.
- Carol Flavin: [00:45:01](#) They were all happy. A lot of them were old. A lot of the patients were old because back in the day, it [disability] was frowned on. They would bring them, and there would be a train real close. They would just come on a train and drop them off. They left and they never came back. These people had a pretty lonely life until the Flavin girls started doing Christmas for them. [laughter] Because some of the people, they would just sit there when we first started going up. Then when they realized that it was for everyone, that they were included... It's really just amazing the way human nature is, that even though they have deformities, they have mental issues, they still are people. They had feelings. You could tell at a time like that. They used to have, I guess they got clothes, I don't know how they got their clothes, but they weren't the greatest things. But when they started doing Christmas, they would come up with all the fashions, and who's the ...?
- Virginia Flavin...: [00:46:17](#) Ralph Lauren.
- Carol Flavin: [00:46:18](#) Yeah, Ralph Lauren.

- Virginia Flavin...: [00:46:19](#) Was a big season.
- Carol Flavin: [00:46:21](#) I remember one time viewing the way they would walk down the hall when they had their old other stuff on. Then when we started going to these Christmas things and they had all the fashion designer things, designer jeans. They would be bebopping down the hall. It was like that fit them. They wanted the same things we all do.
- Virginia Flavin...: [00:47:55](#) During the Depression, families would drop their kids off at Polk for a while. They'd come back and pick them up again when they could afford them.
- Virginia Flavin...: [00:48:10](#) They had schools. They had K through 12, right up there. It wasn't for mentally handicapped children. They were for normally functioning families that couldn't care for their children.
- Ginny, can you talk a bit more about the overcrowding? And equally, what was happening to other institutions in the state at that point in time. Western [Center], down in Canonsburg. What were your impressions of that, and why were these things occurring?
- Virginia Flavin...: [00:48:48](#) I think that represented a point in time where society itself was trying to take a different position, and be more opening and more accommodating and accepting of it, of handicapped and those with mental challenges within the community. Over the time, though, the populations within Polk, because it was the only resource that people had to support families, had really grown to that. The facility was supporting over 3000 residents. You keep putting more and more people into a residence, they didn't have the flexibility at providing them all the resources that you'd want. Instead of what ultimately they had was a living room setting, back in the day when there were 3000 residents, it was more dormitory. Where beds were lined up, and there had to be more regimen.
- Virginia Flavin...: [00:49:39](#) Everybody had very little flexibility when you're managing that many people. Appropriately, I think people started to say, "An institution isn't the right solution for everyone. We do really need to investigate, do some of those people belong in the community and integrated into the community?" And I think [the] Omstead [decision] had started a process of reviewing what were the appropriate placements for people. Many people were taken out of Polk and put into group homes at that point. That eased a lot of the overcrowding that happened in the institution.

- Virginia Flavin...: [00:50:21](#) I think one thing that's really important to keep in mind is the people who were taken from the institutions early were very high functioning, and very able and easily able to fit within the community. As they pulled the healthier and the higher functioning people out, the level of people within the community were more severe and required a higher level of support, so a higher level of medical care. As they continued to transition people into the group home, that happened more and more. So that by the time you go to the '80s probably, mid '80s, late '90s.
- Guy Caruso: [00:50:57](#) Well, 1999 was when the U.S. Supreme Court issued the Olmstead decision that you just mentioned, which ruled that unjustified segregation in state institutions and nursing homes were a violation of the Americans with Disabilities Act, which had come out in 1990. Pennsylvania, like you said, started to move people out of Polk and other institutions. You had a different thought on this whole process. Can you talk a bit about what occurred then, and what your family did, and what you did as sisters of Danny to make sure he was going to be okay?
- Virginia Flavin...: [00:51:32](#) Yes. One of the things, as I said, people began to be removed from the institution and into communities, which were very appropriate settings. People could easily function in the local restaurants, and they could get work. They could have jobs. There were a lot of people who really fit. It was an appropriate transition. But as the transition took over, they started moving people out of the institutions who weren't appropriate placements in a community, people who had... My brother, if you put him on a bus with another child, he could easily grab that child and do harm. You'd never want someone like my brother into the community.
- Virginia Flavin...: [00:52:17](#) Also, not only the potential for harm I think is low. I think what's higher potential is for them to become victimized by the community. They're very vulnerable and subject to theft, subject to crime. What we saw is that the good idea of transitioning out of institutions became a train wreck. The distinction between what was an appropriate placement and wasn't got lost. I believe personally that it was driven by financial motivations. People wanted to get rid of that line item in the state budget. An example of one that closed before, it was Western Center. I was contacted by some of the advocacy people at Western because they knew that I was opposing, broadly, rules for mainstreaming everyone.

Virginia Flavin...: [00:53:19](#) I was contacted by some of the people, so I went over to Western. I walked in, and I drove into the neighborhood of Western Center. I could see there was a development of million dollar homes called Southpointe that had encroached around... the only thing in the middle of this development was Western Center. It was apparent within five minutes that this was not about what was best for the residents of Western Center. This was about some developers needing the land. They closed that property. They took people out of there before they had placement. They put some of the people from residence into a hotel. One of the residents went into a group home that did not have appropriate training for the residents that were placed in there.

Virginia Flavin...: [00:54:07](#) This resident had a history of seizures, but they decided that he liked to be alone in the bathroom by himself when he took a bath. They actually administered the seizure medication while he was sitting in the bathtub. Two hours later, he was dead. That's an example, and not an isolated instance. The level of death for the first five years after being released tripled what it was for people who remained in institution. Again, for the first series of people where they were an appropriate community placement, you didn't have those negative outcomes. But you needed to have someone looking at them with a serious eye to say who belongs in the community, and when is that placement not appropriate.

Guy Caruso: [00:54:58](#) You actually had a lawsuit around this, didn't you?

Virginia Flavin...: [00:55:01](#) Mm-hmm (affirmative).

Guy Caruso: [00:55:02](#) Can you talk a bit about the lawsuit and what the result of that was?

Virginia Flavin...: [00:55:06](#) What was happening at Polk is, people from the state were going into the institution and determining that they would take the resident and move them out. Without contacting family, without contacting anyone. No discussion of it. They were just randomly moving people around the state. We were contacted because there were a group of sisters who were in their 70s. Their relative, who had been in Polk all of her life, they lived here. They were going to move her to Ebsenburg, which was a hardship. Because in their 70s, they couldn't travel there. They visited her frequently.

Virginia Flavin...: [00:55:49](#) They had no ability. Basically, they were told, "She's gone." They weren't told in advance. It was just atrocious. My husband, who is a lawyer, Nick Pribanic, worked with them and filed a pro

bono lawsuit saying that the family had to have input into the decisions to move patients out of institutions. At that time, that wasn't what was practiced, but he contested that. Locally, within Venango County, he won the case that in the future, parents had to be a part, caregivers and guardians, had to be a part of the decision to move people. That's just appropriate. Fortunately for us, the various state legal systems decided to contest the decision. Every time you contested the decision, you made it more broadly acceptable. It ultimately became state law, so we were really proud of that.

- Guy Caruso: [00:56:57](#) Now, your family didn't want Dan to move into a group home. The reasons, again, were what?
- Virginia Flavin...: [00:57:10](#) Safety. At Polk, Dan has 24/7 medical care. And exploring the quality, the level of quality at group homes, what we found is they're not well... there's no oversight. There's not standards. We were told by one group, and this was someone who worked within the group homes, the agency had maybe 20 different group homes. We talked to someone who worked within the group who had left and said, "Why?" They said, "We have two kinds of group homes. The ones that we put the level of standards that we have for people who have family, and the group homes that we put people in who don't have family."
- Virginia Flavin...: [00:57:57](#) The implications were clear. There was no oversight. There's no management, there's no assurances that that doesn't happen. They're being victimized. They're being lost. One study, they took a list of people who were released from institutions, and they couldn't find about a third of them. How many of those became homeless? How many of those ended up in the river? How many of those ended up being victims of crime? How many of those are in prison? It's estimated that one third of our prison population are people who were released from mental institutions or institutions for the mentally retarded. That's my opposition to that.
- Guy Caruso: [00:58:50](#) Well, thank you. Sadly, Danny died this year at the age of 72, after many years of living at Polk. A memorial service was held at Polk. I think you indicated 60 to 90 people attended, and many of those folks were the staff at Polk who knew Dan. At the memorial service for your brother, you said your sister Cathy read a thank you letter to the Polk Center staff. Carol, I was wondering if you wouldn't mind reading a section of that letter.
- Carol Flavin: [00:59:16](#) Sure. Okay, over the years, Polk Center has evolved in many ways. But the one thing that has always been steadfast is the incredible staff of loving caregivers. For them, residents are

family. So many of the residents call the staff mommy and daddy. The staff does so much to make Polk comfortable and homey. They work hard to make all living areas comfortable and inviting. Each bedroom has loving touches that reflect each resident's loves, interests, and passions. Danny Boy's room would have made any cowboy proud. Horses everywhere, family pictures, favorite Western movies, and more horses. They work so hard to make life at Polk special and fun, filled with all the joys of community.

- Carol Flavin: [01:00:10](#) We love Danny Boy's pictures from the themed dances. He loved picnics and outings, especially the horseback riding outings, and he always participated in Catholic Mass. Everything in Danny Boy's life at Polk was designed for his fulfillment, safety, and health. His diet was carefully prescribed. The medical care he received from Polk doctors and nurses was [un]surpassed. Dr. Makkar knew Danny Boy well. He truly cared for him, he loved him. All of those who cared for Danny Boy did. We'd love to mention each of you personally in this letter, but it would become too lengthy. But you know who we're talking about.
- Carol Flavin: [01:00:53](#) All the truly special people who care deeply, who go the extra mile, who protect and love Polk residents each day. Polk is the only place I know where people who are continually bedridden suffer no bed sores. U.S. hospitals consider it inevitable, but at Polk, it doesn't happen. We credit this type of loving care with Danny Boy living to 72, well beyond a normal life expectancy of someone with his type of handicaps.
- Guy Caruso: [01:01:24](#) Thank you, Carol.
- Carol Flavin: [01:01:25](#) You're welcome.
- Guy Caruso: [01:01:25](#) I know neither one of you like to shout out your own good works, but you started a tradition at Polk around Christmas. Can you just share a little bit of that?
- Virginia Flavin...: [01:01:40](#) As I was mentioning, I called one day to see if there were a couple of people that didn't get to go home. I was going to buy a couple of gifts. What I discovered is that in Danny's building of 100, he was the only one who went home. We figured we had to do something about that. The first year, we collected gifts for that building of 100. But the entire institution at the time had about 900 people in it. We couldn't finish until we covered everybody. That was 27 years ago. Ever since then, we have been collecting, gathering, wrapping, and delivering Christmas presents the Saturday before Christmas to everybody in the

building. While the gifts that we bring are great, what we really consider is the gift of our time to be able to spend with each and every one, and just laugh, and practice “ho ho ho.”
[laughter]

- Guy Caruso: [01:02:33](#) Something Danny liked to say, right?
- Virginia Flavin...: [01:02:35](#) Quoting Danny every time we do that.
- Guy Caruso: [01:02:47](#) We know that as Western closed, there's certainly a potential for Polk to close as well. What are your thoughts about that happening?
- Carol Flavin: [01:03:13](#) My feeling is that we need places like that. I'm sure there are many people out in the world that they're not being moved anywhere. They're just sitting who knows where. They could be in the street, they could be right in your own neighborhood and you don't even know that they exist. The group homes are good for certain people, but not for all. If you ever went on a tour of Polk, you'd see what we mean, right?
- Guy Caruso: [01:03:46](#) What are your thoughts, Ginny?
- Virginia Flavin...: [01:03:51](#) I think there's only 200 people being maintained by a facility that employs hundreds of people now. The economics don't make sense anymore ... it will close. It may close as soon as this year or next year, I just think it's inevitable. But I think, and my wish is that for those people who are looking at the future of how we're going to care for people, that they do it thoughtfully. They do it by really closely looking at, how do you segregate the kinds of populations that's there? I don't mean segregate, I mean profile.
- Virginia Flavin...: [01:04:30](#) These are the kinds of needs of group A versus group B, and create solutions that match people's needs so that we're not putting people in situations that are inappropriate to their capabilities, and able to really fulfill their needs. For many people, this group doesn't have a voice, and so they're easy to abuse unless we have a voice for them, and make sure that they look out and they do have solutions that give them and optimize their quality of life. While I think we have to say goodbye to Polk, I hope we can say hello to better solutions.
- Guy Caruso: [01:05:07](#) Thank you. I understand you have a niece who has two sons in their 20s who have the same genetic disorder that Danny had. Can you speak a bit about their lives and how their lives are

different than Danny's at this point in time? Are they different than Danny's?

- Virginia Flavin...: [01:05:27](#) I think from the very day they were born, their lives were different than Dan's, because the level of support is greater. They had continuous support. They had medical support. We understand medically how to optimize behaviors, how to optimize health. My niece Nancy's children are much more higher functioning than Dan was able to achieve. They are very active in this society. They very recently, they're 20 and 23, I believe, they just recently moved into a group home. But the whole time they were at home, my niece had continuous support. That's what's different today. They really are providing the support to the families and to those suffering with disabilities. That made for a much higher quality of life for everyone.
- Guy Caruso: [01:06:27](#) Carol, anything else you'd like to say about the differences you see in your niece's children and what's happening with them?
- Carol Flavin: [01:06:35](#) Right. They're getting much more than we received or that was available to us. The school that my mother took Danny to is no longer there. I'm sure there's a lot of disabled people that are getting the care, but I don't know about the Polk people. They're just gone. We don't know where either. Hopefully something will happen.
- Guy Caruso: [01:07:09](#) I want to thank you both for sharing some of the hard things, and the wonderful things, and the ho ho ho's, and the cowboys. Thank you so much.
- Carol Flavin: [01:07:18](#) You're welcome.
- Virginia Flavin...: [01:07:19](#) Thank you. We appreciated being here.