



Voices
OF OUR REGION
THE DISABILITY CONNECTION

Interviewee: **Nancy Murray**

Interviewee Number: **23**

Interviewers: **Athena Aardweg, Judy Barricella**
& Tony Buba

Date of Interview: **May 22, 2008**

Voices of Our Region
Nancy Murray
May 22nd, 2008

Track 1
0:00:35

Interviewers: Well we're going to start with you giving us your name, where you're from, what part of town you're from and a little bit about your family.

Nancy: Okay. Nancy Murray and we live in Bethel Park, my husband and myself and the only one of our children still living at home is Marissa. And we've also raised two boys and they are both living in supported apartment programs through Citizen Care and they live in Greentree.

Interviewers: Umm. Close by.

Nancy: Close by. And we see them most weekends. And as I said, Marissa still lives at home with us and she's on the waiting list, because she would like to move into an apartment with...with her friends. So we're still hoping that that will happen before I turn 65.

Interviewers: She has friends identified and they all want to live together?

Nancy: Yes. Yes.

Interviewers: Well that's nice.

Nancy: Yes. And if the money came through about 3:00 this afternoon the bags would all be packed by dinner.

Interviewers: Wow.

Nancy: Yeah. They...They have everything all planned.

Interviewers: Yeah.

Nancy: Um hmm.

Interviewers: And these are other friends with dis...or without disabilities?

Nancy: They all have disabilities. One of the young ladies has a physical disability and uses a wheelchair. And the other young ladies have intellectual disabilities. So as I said...

Interviewers: And Marissa... We should have said something about who Marissa is because I know Marissa. Pretend like you don't know anything because we don't know anything. Pretend I don't know her.

Nancy: Okay. So you don't want to disclose that you were her speech teacher x number...31 years ago.

Interviewers: We could do that later on but...

Nancy: Tony you did get that didn't you? Okay. Yeah. Marissa is not my natural child, my...my birth child. My husband and I were house parents for these three children and Marissa came to live with us. They all came to live with us back in 1977. Marissa came first and she was three at the time. And then Mickey and Jimmy followed by Christmas of that...that year, so we had three children in seven months.

Interviewers: Tell...Tell us what a house parent was in those days?

Nancy: Well back in those days there weren't many in the state but house parents were married couples who did not adopt but who basically acted like host home. And today we now call it family living or life sharing. That's exactly what it is but back in those days families, such as my husband or myself, you know, agreed to care for and basically be parents. Because for these three children their parents, you know, for one reason or another were not able to...to have them live with them and care for them.

Interviewers: Um hmm.

Nancy: So.

Interviewers: Um hmm. So the three of them came to live with you...

Nancy: Um hmm.

Interviewers: ...and you raised them?

Nancy: Yes. Yes. We were responsible for, you know, doctor appointments, everything with school, family vacations, you know, special Olympics practices, neighborhood barbeques. I mean we...we were...we were family unit.

Interviewers: Um hmm.

Nancy: And we did everything that any other family would have done, although we had...we just happened to have three kids with Down's Syndrome.

Interviewers: Um hmm.

Nancy: That was the only difference.

Interviewers: Um hmm. So all three have Down's Syndrome and went to...But we di...Did we have early intervention back then? We didn't call it that did we?

Nancy: Yeah. I think...Well we called it a preschool.

Interviewers: Yeah.

Nancy: It was early intervention.

Interviewers: Yeah. Yeah.

Nancy: And two out of the three went to early intervention in Allegheny County. Michael went to early intervention up in Erie County. But they all took advantage or early intervention. They were probably some of the...of the early kids to go through early intervention.

Interviewers: Yeah.

Nancy: Because this...They would have gone through early intervention say 1972.

Interviewers: Um hmm.

0:05:00

Nancy: And from there they all went to Pathfinder school. Because in those days the idea of kids with disabilities going to typical schools was not that common. And back in those days it was more the norm that kids with all types of disabilities, physical disabilities, cognitive disabilities, all went to what we called back then special schools. And back in the '70s there were actually, what, seven...

Interviewers: Um hmm.

Nancy: ...special schools just in Allegheny County.

Interviewers: Um hmm.

Nancy: And each of these schools had hundreds of children just like, you know, typical kind of elementary school today. And kids went there from say kindergarten up until they graduated. And that was the norm. And Michael and Jimmy both graduated from Pathfinder. Marissa actually spent her last four years at Mt. Lebanon High School. Because by the time she got to that point in life, it was now, you know, more widely accepted that kids with disabilities could go to typical schools. So we made the decision that she would go to Mt. Lebanon High School. And she...If she was sitting here with me today, she would say those were the best four years of her life. She had a blast. She had a blast. Every time we happened to drive past Mt. Lebanon High School she always tells me, 'That was my high school and boy I had fun.'

Interviewers: Wow. Um hmm.

Nancy: So. It was...it was...it was the best experience of her life, I think.

Interviewers: She made friends there. She...

Nancy: She made friends there. She started out in the resource room and then each year she spent considerably less time each year in the resource room. And probably the best decision we made there was her...her freshman year. We happened to know the girl's volley ball coach because she had...she knew my husband. She had gone to Baldwin High School where my husband's a teacher. And we approached Linda and we asked her if maybe Marissa could, you know, help out with the girl's volley ball team in some way. As a way to get her involved with, you know, typical kids. And as it turned out she became the manager for the girl's volley ball team for four years. She traveled with the team. And again that was...that was her entrée into knowing some of the most popular kids in the school, because it happened that they went to states two out of those four years. They were some of the most popular girls in the school. And they were not her best friends. You know, our expectation was not that they would call Marissa on Friday night and say, 'Hey, you want to go out?' Got my husband as a high school teacher said, 'You don't want that to happen.'

Interviewers: Um hmm. Um hmm.

Nancy: That was not the expectation. The expectation and the hope was that, you know, during school, you know, in the cafeteria or just passing in the hallway there would be other kids that she would know. And they would introduce Marissa to other kids. So, you know, when these girls as they went through high school and they started dating, you know, kids on basketball team or the football team, you know, they saw Marissa saying... or they saw their girlfriends saying hi to Marissa and they became more interested in who Marissa was.

Interviewers: Um hmm.

Nancy: And at the time that she was there, there were probably only maybe 12 kids with disabilities in all of Mt Lebanon High School. And some of them had very, very, you know, minor disabilities. You know, one was...was...had a visual disability that you wouldn't even know. You know.

Interviewers: Um hmm. Um hmm.

Nancy: One had a hearing disability that you wouldn't know. There were a couple kids who had physical disabilities. One of her best friends actually used a wheelchair part of the day. And then he had walkers.

Interviewers: Um hmm.

Nancy: And, you know, so.

Interviewers: Um hmm.

Nancy: But all in all, the best four years of her life.

Interviewers: What's she doing now?

Nancy: Right now she's a bagger for Giant Eagle. She had a couple of jobs. After graduation she worked in child care for about two years. And she really liked it. She did well, but she was around sick kids all the time.

Interviewers: Um hmm.

Nancy: And really compromised her health.

Interviewers: Um hmm.

Nancy: So after a while we thought this really is not the best job for her. She worked at Bed, Bath and Beyond for about five years and she liked that. And one day she decided she wanted to work in Giant Eagle because she happened to know some people who worked there. And we said, 'Well, okay.' And, you know, we had a job coach for one day. Job coach went with her and helped her fill out the, you know, application...

Track 2

Nancy: ...application and they hired her and the job coach stayed for a day. And then at the end of the day sh...when I went to pick her up she told the job coach, she said, 'Well,

thank you for helping me learn the job.’ And the job coach said, ‘Well, I’ll come back tomorrow.’ And Marissa said, ‘No. I don’t think so. I think I know the job.’

Interviewers: Um hmm.

Nancy: You know. She goes I’ve been watching people as baggers. She goes I think I know the job. So we talked to the manager of the store and the manager said, ‘We don’t need a job coach. We’re fine.’

Interviewers: Um hmm.

Nancy: So, we thanked the job coach and said go help somebody else now.

Interviewers: Yeah. Yeah. Yeah.

Nancy: And again that’s...she’s been there now seven years and she’s very proud. She’s a member of the union. She gets benefits.

Interviewers: Um hmm.

Nancy: You know. And a couple of weeks ago she actually competed in the Best Bagger Contest.

Interviewers: Oh.

Nancy: Took...

Interviewers: How nice.

Nancy: ...honorable mention.

Interviewers: How nice.

Nancy: I think she was probably the slowest bagger but she keeps telling my husband and I, ‘I was slow, but I was accurate.’

Interviewers: I believe it.

Nancy: I said, ‘Okay.’ But again, she and her friend, Jerry, who is also a bagger were they only two people with disabilities there. And it was...

Interviewers: Wow.

Nancy: ...total inclusion.

Interviewers: Great.

Nancy: That's what inclusion...

Interviewers: Yeah.

Nancy: ...is all about.

Interviewers: Right.

Nancy: You know.

Interviewers: Right.

Nancy: And their coworkers were cheering them on as, you know, packing bags.

Interviewers: Where's Jerry a bagger at?

Nancy: Jerry's a bagger at the Shady Side Giant Eagle.

Interviewers: Yes. Um hmm.

Nancy: Do you know Jerry?

Interviewers: I don't...I don't know him personally but I always see him there and he's so friendly.

Nancy: That's Jerry.

Interviewers: All the time.

Nancy: That's Jerry.

Interviewers: I don't know you can have...he's always positive.

Nancy: Um hmm.

Interviewers: When he's leaving he's just as happy...

Nancy: Um hmm.

Interviewers: ...when he's there as when he goes.

Nancy: That's Jerry.

Interviewers: Yeah.

Nancy: So that night Jerry's mom and dad and my husband and I stood there for four hours thinking to ourselves, 'What are we doing here? Oh, that's right. This is inclusion. This is what we've been working for all these years.'

Interviewers: Yeah. Yeah.

Nancy: So.

Interviewers: What Giant Eagle is she at?

Nancy: Village Square in Bethel Park.

Interviewers: That...That...Is that the market district?

Nancy: That's the market district.

Interviewers: That's huge.

Nancy: It's huge.

Interviewers: Um hmm. Yeah.

Nancy: It's huge. But she loves it and it's...it's...you know, the management is super. Coworkers are super. I don't really go anywhere else...

Interviewers: Um hmm.

Nancy: ...because it's...

Interviewers: Um hmm.

Nancy: ...the, you know.

Interviewers: Um hmm.

Nancy: You can do your groceries, the bank...

Interviewers: Yeah.

Nancy: ...the pharmacy...

Interviewers: Yeah.

Nancy: ...the dry cleaners. You can buy stamps.

Interviewers: Right.

Nancy: You know, the florist...

Interviewers: Yeah.

Nancy: ...rent a movie. So I don't see too much of anything else in terms of, you know, retail...

Interviewers: Yeah. Right

Nancy: ...establishments because it's all there.

Interviewers: Yeah.

Nancy: And you know Mersa says, 'Well, you...you have to go to the Giant Eagle and buy it.'

Interviewers: Yeah.

Nancy: I'm like okay.

Interviewers: Yeah. Right.

Nancy: So.

Interviewers: When my kid was working at Shop 'n Save I would make myself go to Shop 'n Save even though it wasn't my favorite store. But now that he doesn't work there anymore I don't have to go there.

Nancy: So you can go to Giant Eagle. It's what you do for your kids.

Interviewers: That's right. Now what about the boys? What are they doing?

Nancy: Michael works for Citizen Care on a mobile work crew.

Interviewers: Umm.

Nancy: And they have a contract at Embassy Suites out by the Airport.

Interviewers: Um hmm.

Nancy: So he's transported out every day and they do a lot of different things at Embassy Suites. I mean they...they make up the rooms. They vacuum the whole place. Clean the mirrors, you know. Make sure that the...the pens and the pads are by the telephones. I mean they do.

Interviewers: Um hmm.

Nancy: They're the cleaning crew.

Interviewers: Um hmm.

Nancy: For Embassy Suites.

Interviewers: Um hmm.

Nancy: And he's been there for quite a few years. And he...he...he...He needs more supervision.

Interviewers: Um hmm.

Nancy: He's...he's...he...he...He was competitively employed years ago. He worked at Burger King. And he was there for probably five years. But soon we realized that there was really no social life there for him.

Interviewers: Umm.

Nancy: Because, you know, people were so trangent

Interviewers: Um hmm. Um hmm.

Nancy: And he's...he's very quiet. And he does not have the language capabilities that Marissa does. So the opportunity came to move him, you know. And a lot of people would say, 'Well, you know, it's a step backwards.' Well, for him it was a step forward.

Interviewers: Um hmm.

Nancy: Because now he's with people all the time.

Interviewers: Um hmm.

Nancy: People who can understand, you know, his language capabilities. And, you know, he makes less money but he's happier.

Interviewers: Um hmm.

Nancy: And that makes...

Interviewers: Yeah.

Nancy: ...more sense to me.

Interviewers: Right.

Nancy: And so he's...he's fine. And Jimmy works at Canvin High School on one of Achiva's cleaning crews. And he's been there for...I've lost track...probably 10 years.

Interviewers: And he likes it?

Nancy: He likes it. And again he's with, you know, he's on a crew so he's with people.

Interviewers: Um hmm.

0:05:00

Nancy: And, you know, it's...it's...it's a social time. You know, I mean we come to work and we socialize with people.

Interviewers: Um hmm.

Nancy: And for a lot of folks with disabilities when they're competitively employed that's...that's fine, they're competitively employed but they're missing out on the social stuff.

Interviewers: Um hmm.

Nancy: And that's part of somebody's success on the job, too.

Interviewers: Um hmm. What do you mean by competitively employed?

Nancy: People who are competitively employed are people who would be in a job just like you or I would be in and they don't require like a job coach to be there with them. They can do the job all by themselves.

Interviewers: Um hmm. Um hmm. We'll here more about this when we go to Working Order because one of the things that Working Order does is help people who can not be competitively employed to get, have a job

Nancy: Um hmm.

Interviewers: ...and then start their own business.

Nancy: Interviewers:

Interviewers: And it's for a lot of different reasons. I mean the people can't be competitively employed. I just wondered what the term meant. Yeah. Yeah. But Marissa has a social life at...at Giant Eagle?

Nancy: Definitely.

Interviewers: Really?

Nancy: Definitely. They...Like there's a café there where people take their breaks.

Interviewers: Yeah.

Nancy: And whenever you go in and you kind of walk by you see this, that they...they all just kind of sit together. So, you know, you, you know, if you were sitting...

Interviewers: Um hmm. Um hmm.

Nancy: ...there on your break and I was just starting my break...

Interviewers: Um hmm.

Nancy: ...I just come in and people just sit together.

Interviewers: Um hmm. Um hmm.

Nancy: It's not like, you know...

Interviewers: Yeah.

Nancy: Well I wouldn't sit with him.

Interviewers: Yeah.

Nancy: You know. And they do a lot of very special things for the employees. There's always a special day, you know, barbeque day...

Interviewers: Um hmm.

Nancy: ...you know, especially around the holidays. Morale boosters.

Interviewers: Um hmm. Um hmm.

Nancy: They just have a lot of different things.

Interviewers: We wouldn't know about that. We work for the county.

Nancy: You...you maybe need to look at a Giant Eagle.

Interviewers: That's right. Cut that out of the tape.

Nancy: Yeah. Hello Don?

Interviewers: It's going to be transcribed you know. But...No, I asked that only because my son, Anthony, worked at Giant Eagle and Shop 'n Save. Now he was at Shop 'n Save it was little different, he was a little older. But he was so quiet and had to really concentrate on what he was doing that there was no interaction among people.

Nancy: Yeah. And of course I...I never saw him at work. But I think it also depends on...on the management at the store and...and the tone...

Interviewers: Yeah.

Nancy: ...that they set.

Interviewers: Right.

Nancy: When Marissa first got there, there was a wonderful woman who was the manager. And I know that they actually transferred her to another store because the morale there...It was a morale issue at the other store.

Interviewers: Ohh.

Nancy: And they...they sin...Actually I saw her at the Best Bagger contest. And she's been moved a couple times because she's excellent at, you know...

Interviewers: Umm.

Nancy: ...foster like team work.

Interviewers: Yeah.

Nancy: And as soon as you do that then morale goes up.

Interviewers: Right.

Nancy: And people that I know that I've...that I've spoken with where their kids have not done well, it maybe the person doesn't have the skills for the job. It may be their social skills are not appropriate. Or often it's just the...the environment that they're placed into. Marissa did work in a retail environment for about six months many years ago. And it didn't work out. This retail store was...was not...They didn't know what to do with a person with a disability. It ju...I mean she knew the job.

Interviewers: Um hmm.

Nancy: I mean, you know, putting clothes on hangers, folding the things, whatever.

Interviewers: Um hmm. Um hmm.

Nancy: It wasn't the job skills. It was'nt her social behaviors. It was the management and the people who worked there had never had a person with a disability. And they just didn't know what to do. And, you know, after...I'd...I'd say it probably wasn't even six months. It was probably three or four months. We thought, you know what, we're not goin... we're not going to stay around. I'm...I'm not going to teach them.

Interviewers: Yeah.

Nancy: I mean it...it wasn't ADA compliance or anything...

Interviewers: Um hmm.

Nancy: ...like that it just wasn't welcoming.

Interviewers: Um hmm.

Nancy: And I thought you know what, I'm not...I'm not going to teach them.

Interviewers: Um hmm. Um hmm.

Nancy: You know. I just don't have the energy to...

Track 3

Nancy: ...to do that and she had already been offered another job.

Interviewers: Um hmm.

Nancy: And I thought, well we'll say goodbye. And now whenever I go in that store if I unfold something, I don't fold it. I just leave it there. You know

Interviewers: Yeah. Yeah.

Nancy: Six years later. You know. Every once in a while I'll do that and my husband will say, 'Well aren't you going to fold that?' No.

Interviewers: Not in this store.

Nancy: No.

Interviewers: Yeah. And you don't hold a grudge.

Nancy: No. No Tony I don't. Remember that...As you sit there with that tape recorder.

Interviewers: I'm getting a little nervous over here. I'm (? - 0:00:31) Giant Eagle because I have market district. I live on Friendship and so I always go to the one on Shady Side.

Nancy: Um hmm.

Interviewers: And, I mean, it is the most pleasant experience no matter how many hundreds of people are there and if there are no carts. There's the same gentleman that's always at the door and always asks me how I'm doing and if I need anything and here's a flyer.

Nancy: Um hmm.

Interviewers: And my boyfriend lives on the South Side.

Nancy: Um hmm.

Interviewers: So we come and go to this one on occasion and it is like two different worlds of Giant Eagle.

Nancy: Yeah.

Interviewers: You know, I mean here I mean you're totally fend for (? - 0:00:59) yourself you're lucky if they even have what you want.

Nancy: Um hmm.

Interviewers: You know, and so I'm thinking of that environment, too and just the different stores like these market districts and...no, it's not the Express but they have one of those convenient stores in between that's almost like a grocery store. Yeah. The Get-Go Express or something. Well there's another one now. There's something else named.. It's a little bigger, yeah. Yeah. And I've noticed that they at least (? - 0:01:19) are just as friendly as the market district. Umm. So I'm wondering if like these different stores now, you know, seem to have more of a morale component to them, because, I mean, it's a big difference. Well, some stores are privately owned and some stores are Giant Eagle.

Nancy: That's true.

Interviewers: Yeah. Some are...Yeah. So it really...

Nancy: Yeah.

Interviewers: Yeah. And the one in Braddock Hills is...I mean it's really friendly, too. But there's a lot of people with disabilities working there.

Nancy: Yeah. I think on whole Giant Eagle is known as a...as an employer who really supports people with disabilities.

Interviewers: Yeah. Yeah. But I will tell you and a lot has to do with who runs...

Nancy: Um hmm.

Interviewers: ...the store. That's true. Because my son went in as a bagger.

Nancy: Um hmm.

Interviewers: And got the job because I knew the head of personnel for Giant Eagle. He was 15. He was the kid at 15 years old to work in that Giant Eagle.

Nancy: Umm.

Interviewers: Umm.

Nancy: Umm.

Interviewers: And he started off as a bagger. And he worked there a year and he wanted to do something else.

Nancy: Um hmm.

Interviewers: They wouldn't...They wouldn't move him. He wanted to...He wanted to do the cash register. He wanted to do something else and...

Nancy: Um hmm.

Interviewers: ...and there are certain jobs if you're not 18 you can't do. Right. In...In a Giant Eagle and grocery store. But he kept telling them and I told them. And I told the personnel director he wants to learn the cash register. Oh, okay. Nothing. Nothing.

Nancy: Umm.

Interviewers: And he was getting to the point where he was beginning I think 10th grade then. He was already 16. He was beginning 10th grade and he was getting more and more disgusted with the place because, and again nobody talked to him.

Nancy: Yeah.

Interviewers: And so he left there. And I...So I know it's who's running the place. Yeah.

Nancy: Um hmm.

Interviewers: He went to Shop 'n Save after he graduated high school. And they...And we never tell...When Anthony goes in, because he doesn't appear to have a disability we never tell them anything. We wait and see how this is going to work out. Um hmm. And Giant Eagle never knew really, unless the guy the head of personnel at Giant Eagle said something. But he went to Shop 'n Save and he started out as a bagger. And going out in the winter getting those carts out of the parking lot and throwing salt...I mean they had to do everything. Throw salt down on the sidewalk. And then he came home one day and he said, 'I'm learning the cash register.' So he learned the cash register. And then he comes home another time and says, 'They're moving me into produce.' And he did...He never worked the deli and he never did filling up the shelves. Um hmm. Stocking.

Nancy: Um hmm.

Interviewers: But he did everything else in that store.

Nancy: Um hmm.

Interviewers: And it was because they needed the help and they saw that he was a good worker.

Nancy: Um hmm.

Interviewers: And that...

Nancy: Yeah. Sure.

Interviewers: ...he was diligent, you know. And he did the gas station. They have a gas station there. He did the gas station.

0:05:00

Interviewers: Right.

Nancy: Wow.

Interviewers: He did every...Like he's learned all of that now because they gave him the opportunity. That's...That's the only problem that I had with Giant Eagle. And I know that Giant Eagle is very, very sort of pro-hiring people with disabilities.

Nancy: Um hmm.

Interviewers: But it really depends on, I think, the front-end manager or the store manager.

Nancy: Oh. I...I know you're right.

Interviewers: Yeah.

Nancy: I know you're right.

Interviewers: Yeah. So it was a kind of an interesting thing because that particular Giant Eagle the people are so nice...

Nancy: Um hmm.

Interviewers: ...and a lot of the employees have been there a very long time. And you know them by name.

Nancy: Um hmm.

Interviewers: So rather than him going up to Fox Chapel which has a lot more stuff but the people aren't as nice. But for him, he just didn't get...wasn't given that opportunity.

Nancy: Um hmm.

Interviewers: So I think it's really...it's really...

Nancy: Um hmm.

Interviewers: ...kind of interesting. And isn't that something that we...we have to continually educate people.

Nancy: Right. And you have to be aware of that.

Interviewers: Yeah.

Nancy: Because not all, you know, you...you could also talk about, I don't know, Citizens Bank.

Interviewers: Um hmm. Yeah.

Nancy: You know.

Interviewers: Yeah.

Nancy: One might be very welcoming...

Interviewers: Right.

Nancy: ...for somebody with a disability. And the one in the next store it may not be that way because of the...of the branch manager.

Interviewers: Right. Right.

Nancy: You just have to be aware of that. I'll leave you with one funny story. And this happened a couple of years ago. You know, we transport Mersa back and forth to work and sometimes we'll go in to pick up something, you know. So this one particular day I went in to pick something up at the end of her shift and I'm coming through the line and, you know, she's still over there working. And the one cashier, and of course we've gotten to know a lot of them, sees me coming in. She says, 'Oh, come here.' She goes,

'I've got to tell you the funniest story.' Well as she's talking to me this...the manager comes over. And I'm thinking, 'Okay, they said it was a funny story.'

Interviewers: Yeah. Yeah. Yeah.

Nancy: So what happened?' This was the story. Sometime late afternoon a gentleman came through the ais...lane. He came through Marissa's, you know. And he had a few things in his basket. And, you know, he was just kind of dressed casually and he just went through the line. He got to the end of the line and he started to help Marissa with the bagging.

Interviewers: Um hmm.

Nancy: And apparently he put the eggs in the bag first.

Interviewers: Uh oh.

Nancy: And Marissa said to him, 'Oh, no, no, no, no.' She said, 'You never put eggs or bread in first.' She said, 'You always put something else in and then you can put the bread in. Or you put the bread and the eggs in one bag but you don't put anything else in there.' She goes, 'Or you'll break your eggs.' So he said, 'Oh, thank you very much.' He said, 'You saved my eggs.' She said, 'Yes, I saved your eggs or they could have been scrambled.' And the man says, 'Well thank you very much.' And he noticed her name tag.

Interviewers: Um hmm.

Nancy: It turned out that it was Mr. Shapiro.

Interviewers: Ahh. You're kidding.

Nancy: Who is the president of Giant Eagle.

Interviewers: Wow.

Nancy: And he just had his jeans on and he was shopping in Giant Eagle. Apparently one of the front-end managers saw him coming through and quick radioed to the store manager, Mr. Shapiro is in the store.

Interviewers: Right. Yeah.

Nancy: So you can just imagine...

Interviewers: Yeah.

Nancy: ...you know, woosh...

Interviewers: Yeah.

Nancy: ...up to the front end and as the store manager's coming up he's hearing Marissa giving Mr. Shapiro a lecture about at Giant Eagle we do not do this. You know. And the cashier said now a couple of them did recognize Mr. Shapiro and they're like, 'What's Marissa saying to him?' They're all like what could Marissa possibly be talking to Mr... Because of course she's taking her time.

Interviewers: Yeah. Right.

Nancy: You know. And they're like, 'What could Marissa possibly be talking to Mr. Shapiro about?' You know.

Interviewers: Yeah.

Nancy: So afterwards, you know, Mr. Shapiro. He...The story goes he was on his way someplace and he needed to buy some things so he stopped in. You know. But apparently he does this when he's out and about he'll stop into stores. Right.

Interviewers: Um hmm.

Nancy: And so they introduced Marissa...He...At the end he introduced himself. He came back to Marissa and he said, 'I just wanted to tell you, you did a very nice job today.' He said, 'And my name is, you know, blah blah Daniel Shapiro.' And she looked at him and she goes, 'I know who you are.' And she...he said, 'You do?' And she said, 'Yeah.' She goes, 'You're the president of Giant Eagle.'

Track 4

Nancy: So he looked at her and he said, 'Did somebody tell you that?' She says, 'No. I knew that.' She said, 'And you're a customer.' And they said they just like...

Interviewers: Yeah. Yeah.

Nancy: ...nobody quite knew what...

Interviewers: Yeah. Yeah.

Nancy: ...to do with that. Like, you know. (? - 0:00:22) So what. He's a customer.

Interviewers: Wow.

Nancy: And he was going to have scrambled eggs if she didn't intercede, you know.

Interviewers: Yeah. Yeah. Yeah. Yeah.

Nancy: So he...he congratulated the store manager on...on the fact that, you know, Marissa...

Interviewers: Um hmm.

Nancy: ...was totally, you know, not correct but very, very careful.

Interviewers: Um hmm. Um hmm.

Nancy: You know. And she was...She...She did...

Interviewers: Um hmm.

Nancy: ...absolutely the right thing and told people that...

Interviewers: Um hmm.

Nancy: ...at Giant Eagle we don't do that.

Interviewers: Um hmm. Um hmm.

Nancy: But she was very welcoming and...

Interviewers: Um hmm.

Nancy: ...you know, and she was the only person there, you know, obviously with a disability packing groceries that day. But he was curious to find out how many other people with disabilities worked in the store. And so he kept the store manager busy...

Interviewers: Yeah. Yeah.

Nancy: ...for a few minutes, you know, talking, you know. So the cashiers just thought this was hysterical.

Interviewers: Hysterical. Yeah.

Nancy: You know. Because apparently the assistant store manager didn't know who Mr. Shapiro was.

Interviewers: Ohh.

Nancy: So the...the...the front end manager was calling on, they have these little...

Interviewers: Yeah. Right.

Nancy: ...radio things...

Interviewers: Yeah. Right.

Nancy: ...and, you know, she gets him on the...on the phone and says, 'You know, you guys better come up here. Mr. Shapiro's in the store.' And he says, 'Who's Mr. Shapiro?' So she let him know, well doppo...

Interviewers: Yeah.

Nancy: ...Marissa knew who he was.

Interviewers: Yeah. Yeah. Yeah.

Nancy: You know.

Interviewers: Right. Right.

Nancy: So they were all like ha, ha, ha, ha, ha. You know. So anyway. So that was our funny story.

Interviewers: Well I expected to hear a pay raise after that.

Nancy: Well, she...she is a member of the union, and as...

Interviewers: Oh, that's right. Yeah.

Nancy: ...you know...

Interviewers: That's right.

Nancy: ...as she...she moves up quite, quite quickly in fact with her and she knows exactly she'll be getting another raise on July 1.

Interviewers: Yeah.

Nancy: She goes to her union meetings and.

Interviewers: Does she?

Nancy: You know, she does. I think she goes because they always have little snacks there at the union meetings, too.

Interviewers: Hey, don't we all go for that?

Nancy: Yeah. What's, you know, what's...what's different there, right. You know.

Interviewers: Well that's great. That is fabulous. Yeah, because I was actually think he lives in the like the Fox Chapel area.

Nancy: I have no idea. I've never met the man. Marissa has, but I've never met him.

Interviewers: Yeah. Because my son who's working with a landscaper this summer has been at his daughter's house...

Nancy: Ohh, okay.

Interviewers: ...doing landscaping.

Nancy: Well you...you...you have...you're up...you're more up to date than I am.

Interviewers: But I wouldn't know him if he walked in here. But Nancy I wanted to ask you when your husband and you, before these kids came into your life, what made you open your home to them?

Nancy: Hmm.

Interviewers: Had something happened in your life or you just...

Nancy: My husband's one brother has a learning disabilities so Joe grew up with a brother with learn...And...And Tommy is, you know, a very, very capable, I mean he lives by himself, drives a car, he's a member of the fire department. Actually he's retiring after almost 30 years as the custodian at the elementary school we all went to so. I mean Tommy is, you know, lives and takes care of himself quite independently. So...But Joe grew up with Tommy. And I grew up with a cousin who was very, very physically involved and as a result of an accident. And back in those days, and you probably remember this, there was the belief that if you could retrain a person's muscles...

Interviewers: Umm.

Nancy: ...that the person would regain use of those muscles. And it was called patterning.

Interviewers: Um hmm.

Nancy: And I patterned my cousin for I don't know how many years. And he...he died. He contracted pneumonia...

Interviewers: Umm.

Nancy: ...and died in adolescence. But, you know, I was...

Interviewers: Um hmm.

Nancy: ...patterning very early in life. And then after college I thought I was going to graduate school in special education. And instead we heard about this opportunity so we took a tangent.

Interviewers: Um hmm. Um hmm.

Nancy: A little bit of a tangent.

Interviewers: Um hmm.

Nancy: And I finally got back to graduate school.

Interviewers: Um hmm. .

Nancy: But it took me off course for a couple of years. So that was really it.

0:05:00

Interviewers: Yeah. Yeah. I...Do you think that's happening the way it should now a days? The life sharing. Could we talk about more about that because we haven't really talked about life sharing and I don't...I just don't that much about it.

Nancy: Life sharing is...Well they think it's new, but for me it's really not too new. Life sharing is a residential model, if you will, that the Office of Developmental Programs is now really focused on. And it's not really for children.

Interviewers: Um hmm.

Nancy: There are very few children that they're looking to life sharing for. Most of these folks would be adults.

Interviewers: Um hmm.

Nancy: But it's basically what we did. It's...It's a single person, you know, a married couple who would like a person with a disability to become a member of their household.

Interviewers: Um hmm.

Nancy: And I think it...Where I've seen it work, it's worked because the...the...a person without the disability has known the person with the disability for a long time. So actually I worked with a family many, many years ago when I was a support coordinator. There was a couple who worked at Polk Center. And the time came for this young lady to leave Polk Center. And we were at a planning meeting and this was probably 1995. And they asked if she could come live with them? And of course, you know, everybody said, 'Oh, no, no. That couldn't happen. You have to go to a group home.' And I sat there and thought, why not?

Interviewers: Um hmm.

Nancy: I mean they knew her. I mean she went to Polk Center as a child.

Interviewers: Um hmm. Um hmm.

Nancy: They've known her for 15 years.

Interviewers: Um hmm.

Nancy: She knows them. Why not? So after some maneuvering with then Nancy Faller, who thought it was a great idea. Because Nancy Faller had done what I did.

Interviewers: Um hmm.

Nancy: She... And to the best of my knowledge she still lives with this family. She did as of last year I know that.

Interviewers: Um hmm.

Nancy: So I think it works when there's already the relationship there. I know that some teachers, some teacher's aides, people who...Like if you worked in a group home now...

Interviewers: Um hmm.

Nancy: ...group home and there's a person with a disability and they've been in this group home and you've know them for three years, five years, seven years. There's a relationship. You might want to go into life sharing. You know.

Interviewers: Right.

Nancy: But you've known them. Where it's really tough is where there's the person with the disability and you try to find the family. And to me that's just bassakwards.

Interviewers: Um hmm.

Nancy: And I don't think the state's going to be as successful doing it that way.

Interviewers: Um hmm.

Nancy: I just...I just...I don't...

Interviewers: Is that what they're going towards then?

Nancy: And that's...that's basically...Well, I mean, they started out like at the state centers if there were employees who wanted to do this. And we...there were a few. And it's working. There are some programs in state where they, you know, they said to current employees, you know, if there's somebody that you're working with, you'd like to consider life sharing. And again, that's happened but a handful of situations. Most of the time it's the person with the disability and then they're trying to find a compatible family. And I'm not going to say it's not going to work. It's going to work. But I don't think to the extent that they think it's going to work.

Interviewers: Um hmm. Um hmm. Yeah.

Nancy: And the other problem that they're facing and it doesn't surprise me at all is, for a person who's...who grew up with a family. They're biological family, the family that they grew up with is not real excited about them going to live with another family.

Interviewers: Um hmm.

Nancy: It's like, well we'd like them to have the apartment living experience.

Interviewers: Um hmm.

Nancy: We're not interested in them having another family. We're their family.

Interviewers: Um hmm.

Nancy: And I'm hearing a lot of push back from families.

Interviewers: Um hmm.

Nancy: Go figure.

Interviewers: Um hmm. Um hmm.

Nancy: You know. Like Marissa would not...why would she go to live with another family?

Interviewers: Right.

Nancy: You know. She wants to go live in an apartment and experience, you know, living in an apartment as an adult with roommates, house mates, whatever.

Interviewers: Um hmm.

Nancy: You know.

Interviewers: Um hmm.

Nancy: So it's...

Interviewers: Um hmm. Um hmm. I know that's just so...that's the first time it's come up I think in any of our interviews. So it's like I didn't, I don't know about. Hmm. I...I was real excited to hear about it. I don't think Allegheny County...

Track 5

Interviewers: ...is talking about it as much as they probably should be.

Nancy: Well, it seems to work...like there's some counties that are doing very well. Now they all tend to be rural counties...

Interviewers: Hmm.

Nancy: ...where first of all they don't have a lot of group homes. And second of all it's a different way that people live their lives.

Interviewers: Um hmm.

Nancy: You know, if you, you know, you live more out in the rural area, farming community, you know, people opening their homes to extended family members.

Interviewers: Um hmm.

Nancy: It's different.

Interviewers: Um hmm.

Nancy: So for example, Crawford County is...is big on family living. But they've always been that way.

Interviewers: Umm.

Nancy: You know. Somebody needs...It wasn't always well let's open a group home. It was always well, you know, so and so takes in people.

Interviewers: Um hmm.

Nancy: It's different. The other thing is there are a lot of counties and Allegheny County is one of them, where the people who are higher on the emergency waiting list are not people who are going to be successful in family living.

Interviewers: Um hmm.

Nancy: They may be people leaving prison.

Interviewers: Um hmm.

Nancy: Or a residential treatment facility. These people need a lot of support. And you're not going to expect a family to be able to meet this person's support needs.

Interviewers: Right.

Nancy: Or a person with, you know, very, very involved medical or behavioral. I mean you just...you're just not going to find a family willing to do that. You know, there's a family that I've been working with for a while and their child is about 14 years old, a lot of medical issues, a lot of behavioral issues. And the support coordinator met with the family a couple weeks ago and said, 'Well, how about life sharing?' And the mother called me like totally distraught. And she said, 'What are they talking about? We're her family.' I mean she was afraid they were going to take her child. I said, 'No, no, no, no.

They're not going to take your child.' But she says, 'Well that's not the answer. She needs like 24 hour support.'

Interviewers: Um hmm.

Nancy: You know. And I keep using the word group home but that's what...

Interviewers: Right.

Nancy: ...you know, people more readily understand. She said, 'She needs 24 hour.' You know. I mean this woman has nurses coming into her home.

Interviewers: Um hmm.

Nancy: Therapists.

Interviewers: Um hmm.

Nancy: You know.

Interviewers: Um hmm.

Nancy: What...What family is going to sign on for this?

Interviewers: Um hmm.

Nancy: Like if their own family needs help.

Interviewers: Um hmm.

Nancy: I said, 'Good point.'

Interviewers: Um hmm. Um hmm.

Nancy: I'm not sure why the support coordinator brought it up either. So there's some people that their support needs are too much that a family can be expected to manage. But I think in Allegheny County's case I can understand it. The people that they are...are next in line on the waiting list are people with extensive support needs.

Interviewers: Um hmm.

Nancy: That you can't meet in family living and that's why I think that's why.

Interviewers: Um hmm. But it also has to be written into the plan doesn't it?

Nancy: In the plan it should say what the person needs.

Interviewers: Umm.

Nancy: The person needs, you know, medical support, behavioral support. It shouldn't say the person needs a group home or family living. It should be the support needs and then you have the discussion as to where...where your needs can be met.

Interviewers: Interesting. When that gets turned off I'll tell you a story.

Nancy: I...I thought there might be a story.

Interviewers: Do you have any questions Tony? No. No. He's quiet today. He might have a couple last minute interjection questions but...

Nancy: He's saving them up.

Interviewers: So what...what's been the best part of raising these people?

Nancy: Probably...Well there are different highlights for each of them. For Marissa it was she played in the international special Olympic games in Ireland back in 2003 in golf.

Interviewers: Um hmm.

Nancy: She got a silver medal. For her that was that.

Interviewers: Um hmm.

Nancy: For Mickey actually it happened earlier this week. And it was very simple, but. I had stopped at his apartment to drop of some things for him and his roommate because we hadn't seen him over the weekend and I was coming by after a meeting and I was just going to drop off some things for them. And I did that but he wasn't home from work yet. And I was getting in my car to go home the person that picked him up at work had dropped him off.

0:05:00

Nancy: And I watched him get out of his car, take his keys and get into his apartment. And he didn't know I was watching. But to me watching him do that, and I know it sounds very simple, but for him that...that's a high level of independence.

Interviewers: Um hmm. Um hmm.

Nancy: Taking that key out, you know, I mean he waved to the man who dropped him off.

Interviewers: Um hmm.

Nancy: You know. So I decided I want to see the rest of this so I, you know. It's a secure building so I had to ring the bell and then the person, the staff person up in the apartment, I told him who it was and I said, 'I just want to go in and say hi. He just got home.' So they let me in and I knocked on the door. And by the time I had gotten in there, you know, he had hung up his coat, he had, you know, put his lunch box in the kitchen, you know.

Interviewers: Um hmm.

Nancy: I saw...Because I'd never seen the afternoon routine.

Interviewers: Yeah. Yeah.

Nancy: You know. And his roommate was there and they were talking about what they were going to have for dinner.

Interviewers: Um hmm.

Nancy: And I was like...I'd...I just never had seen it before.

Interviewers: Yeah.

Nancy: You know. And I got in my car to go home and I thought, this is...this is good. For him this is good.

Interviewers: And it's so typical.

Nancy: Very typical. And the two of them...He and his roommate have known each other since they were little boys.

Interviewers: How nice.

Nancy: Happy as clams in their little apartment.

Interviewers: Yeah.

Nancy: You know. So. It's...I think it's...it's different for everybody.

Interviewers: Yeah. Yeah. What about Jimmy?

Nancy: For Jimmy. I think one of the highlights for him has been also his independence, you know. And...and if...if I had to line them up Marissa has more capabilities than the boys. Jimmy's kind of in the middle of her and Mickey. And Jimmy can get himself in trouble real easily. I mean first of all he's big, he's tall, he's strong, he, you know, makes it known what's going to happen. It really doesn't matter who you are. So he can get himself in trouble. And he has. And I think for him it's the way he's been able to settle down the last maybe five or six years and realized that, you know, he can have more fun, he's going to be more successful if he just settles down.

Interviewers: Um hmm. Um hmm.

Nancy: And he's not as...And I mean I don't mean to imply...I mean he was never on medication and all that kind of stuff.

Interviewers: Um hmm. Um hmm.

Nancy: But he had, you know, behavioral...

Interviewers: Um hmm. Um hmm.

Nancy: ...ups and downs. And I think for him the last couple years, and I think a lot of it was just...I think he was...I think he was in extended adolescence. Well into his 30s.

Interviewers: Um hmm. Um hmm. .

Nancy: And all of a sudden it's like he grew up and all of a sudden he, you know. I...

Interviewers: Go ahead.

Nancy: No. I think he...I think he was able to kind of uhm kinda separate from his parents also.

Interviewers: Umm.

Nancy: And...and he realizes that...And he says it. He'll say to people, 'I'm a man. I have a job. I have an apartment.' And I think there was just a piece of him that needed to just prove to everybody, this is who I am. I'm okay.

Interviewers: Um hmm. Um hmm.

Nancy: You know. So it's been interesting watching that, too.

Interviewers: Um hmm. I think, you know, we used the term delayed. Oh, well he's delayed. Or she's delayed. But thinking that well just because you graduated from high school doesn't mean now your not delayed anymore. And you continue to catch up...

Nancy: Um hmm.

Interviewers: ...as you go through life, 21, 22, 23, whatever.

Nancy: Um hmm.

Interviewers: And that's sort of an interesting process to watch.

Nancy: Interviewers:

Interviewers: You know, whereas your other kids without any kind of disability, well maybe when they're 22 they are really a man, you know.

Nancy: Um hmm.

Interviewers: ...function that way and that...But

Nancy: And then there are some that aren't. That's right.

Interviewers: What about 22 that I'm at? Yeah. But, you know, I don't think it's a surprise that, you know, somebody at 23 is still going to be acting like an adolescent.

Nancy: Um hmm.

Interviewers: You know. And learning.

Nancy: Um hmm.

Interviewers: Who's had the biggest influence on your life?

Nancy: Probably the three kids. Because if it wasn't for them I wouldn't be sitting here today. That I'm convinced of. I probably would have gone into business in some way. You know. But I would never have had the experiences that I've had over all these years.

Track 6

Nancy: So the three of them.

Interviewers: Um hmm.

Nancy: Without a doubt.

Interviewers: Um hmm. Yeah. Do you have a hero?

Nancy: I would say that it's Eunice Kennedy Shriver.

Interviewers: Umm.

Nancy: Um hmm. I can't imagine, what 1960, given the United States back in 1960. I mean we didn't respect Afro-Americans.

Interviewers: Um hmm.

Nancy: You know, we really didn't respect. You know, I mean women...

Interviewers: Um hmm.

Nancy: ...hadn't achieved what they've achieved today. And, you know, she opened her home to establish a camp in her front yard for people with disabilities so they could have a camp. And from there grew Special Olympics worldwide. And as I mentioned before when we went to the world games a couple of years ago, you know, sitting there watching athletes from Iraq and Iran and China sitting next to athletes from the United States and Canada. You know, like where else in the world does that happen.

Interviewers: Um hmm.

Nancy: And this woman had this vision. And she made connections with people. And nothing ever stopped her.

Interviewers: Yeah.

Nancy: Nothing ever stopped her. And I was very fortunate to participate in a symposium when we were there and listen to people and I actually...I actually gave one presentation. But then there were people from all over the world giving their presentations. And one person in particular and I disagreed. And it open to questions and answers, you know, I raised my hand, and I said, 'You know I just respectfully disagreed with one of your comments tonight, blah, blah, blah.' And she came up to me afterwards and of course the Kennedy Foundation has funded this man's research.

Interviewers: Um hmm.

Nancy: But I still disagreed with it.

Interviewers: Um hmm.

Nancy: But I very respectfully said, you know, I just disagreed with this. And she came up to me afterwards and I turned around and like there she stood. You know. And I don't...I don't mind telling the three of you like I almost passed out, you know.

Interviewers: Um hmm.

Nancy: And I said, 'Why?' And she said, 'I have a question for you.' And she said, 'I want to know more about why you disagreed with that point.' Just like that. And I'm thinking, okay well here goes my life, here goes my career.

Interviewers: Yeah. Yeah.

Nancy: And I told her. And she looked at me. She goes, 'That's very interesting.' She said, 'Do you have a business card?' Yes. You know. And she said, 'Thank you very much.' She goes, 'Will you be at our event tonight?' And I said, 'Yes. Yes.' And she said, 'Very good.' And she turned around. And then she turned around and looked at me and she said, 'I just want to let you know. You're absolutely correct.' And she goes, 'I never thought about it that way but you are absolutely correct and he's going to hear about it.'

Interviewers: Ohhh. Wow.

Nancy: And...But that's...And a friend of ours, Ted March.

Interviewers: Um hmm.

Nancy: Remember?

Interviewers: Um hmm.

Nancy: Consults with the Kennedy Foundation.

Interviewers: Now? Today?

Nancy: Today.

Interviewers: Oh, does he?

Nancy: Yeah. And he said that, that's how she is. Like she'll march into a meeting and if you haven't finished but you've supposed to finished or it doesn't look right or if it's like a very simple, maybe a little breakfast, and she'll walk in and, you know, if the coffee's not hot, like things have to be...

Interviewers: Um hmm.

Nancy: ...correct.

Interviewers: Um hmm.

Nancy: And it doesn't matter if you're, you know, a special in coach from Kansas, or you're the president of Coca-Cola.

Interviewers: Um hmm.

Nancy: It doesn't matter to her.

Interviewers: Um hmm.

Nancy: Everything is the right way.

Interviewers: Um hmm.

Nancy: For somebody here or somebody there.

Interviewers: Um hmm.

Nancy: It doesn't matter to her. So I think she is.

Interviewers: Um hmm. She impresses me, if she were here, as being an imposing figure because she is so respectful, you know. I...

Nancy: If she has something to say she'll say it.

Interviewers: Um hmm.

Nancy: But if not, she'll listen.

Interviewers: Um hmm.

Nancy: I mean I've seen here in a couple different venues where you know very respectful of listening to people.

Interviewers: Um hmm.

Nancy: But if you need to be moving faster or something. And...And...And that's what Ted's told me over the years.

Interviewers: Um hmm.

Nancy: He works with her son, Tim.

Interviewers: Um hmm.

Nancy: And, you know, she...I mean she's obviously now up in years and her health is not good but she would come into the office and ream out her son who's really the executive director of Special Olympics.

Interviewers: Um hmm.

Nancy: You know, say we don't do that.

Interviewers: Um hmm. Um hmm.

Nancy: You know?

Interviewers: Yeah. Yeah.

Nancy: But at the same time this woman...

0:05:00

Nancy: ...can call up, you know, the president of any major company and ask for money.

Interviewers: Yeah.

Nancy: Or the heads of state.

Interviewers: Yeah.

Nancy: You know. And the other thing they've done is they've really promoted the health of athletes. I mean, you know, the, you know, Special Olympics was one thing. And now they have Healthy Smiles.

Interviewers: Um hmm.

Nancy: So they tak...And vision and hearing.

Interviewers: Um hmm.

Nancy: So that they've taken physicians all over the world to places where kids with disabilities would never have...

Interviewers: Um hmm.

Nancy: ...had access to hearing aids, or glasses, or dental exams.

Interviewers: Um hmm. Um hmm.

Nancy: So it just did...I mean she saw that that was a vision for her. That this is good. We did this. But there are kids who were coming to participate and they don't have shoes. We need to step back and get shoes for kids. And...

Interviewers: Right.

Nancy: Yeah, when that started I was like yes.

Interviewers: Um hmm.

Nancy: You know.

Interviewers: What did you think about that movie that Johnny Knoxville did that the foundation funded actually. He pretended to be part of the Special Olympics.

Nancy: Oh yes.

Interviewers: I forget the name of it.

Nancy: Yes. Actually I read the script.

Interviewers: Um hmm.

Nancy: And I made quite a few comments. Ted got me involved with that.

Interviewers: Um hmm.

Nancy: They were looking for people to read the script and he said I know somebody.

Interviewers: Um hmm.

Nancy: And I didn't see the final movie.

Interviewers: Didn't you?

Nancy: I had no...I had no desire to really see it.

Interviewers: Umm.

Nancy: And I told Ted, I said, 'Well, I think there are going to be a lot of families who are really going to be put off with that movie.'

Interviewers: Um hmm.

Nancy: And I...I just didn't see why they...why they wanted to do it. There were so many other stories they could have told. I'm...I'm...I just...So I never saw it.

Interviewers: I...I think that when I saw it, what I came away with was seeing how typical the folks with disabilities were. And I mean I wa...That was sort of my hope that people would see that.

Nancy: Yeah.

Interviewers: But...

Nancy: You might be right. I just...I just...It didn't do anything for me.

Interviewers: Yeah.

Nancy: I'll tell you, when...when...the first script that I read my comment was, I hope you have some good attorneys on staff.

Interviewers: Ummm.

Nancy: I mean the language.

Interviewers: Ohhh.

Nancy: What they wanted the Special Olympics athletes to be doing I said do not associate my name with this and...

Interviewers: Yeah.

Nancy: ...I hope you have some good attorneys.

Interviewers: Yeah.

Nancy: The second time I read it, it was a completely different script.

Interviewers: Ahhh.

Nancy: So the script that I read was more like what you saw. But I never saw it. I just...

Interviewers: What was interesting to me was we...when we went to see it the audience had a number...quite a number of teenagers in it.

Nancy: Um hmm.

Interviewers: Teenage boys especially. And I'm sitting there...Mind you I'd never heard of John Knoxville before in my life. So I'm sitting there watching this and these kids are watching this and I'm thinking to myself, I don't know why they're here but I hope they learn something from this. And then I come to find out who Johnny Knoxville is. No wonder these teenagers are here. But I thought well maybe...maybe in that respect we did something positive.

Nancy: Right.

Interviewers: You know.

Nancy: Right.

Interviewers: I don't know. I don't know.

Nancy: I never really heard too much about it though, to tell you the truth. Like...

Interviewers: Didn't you?

Nancy: No.

Interviewers: I can't even remember the name of it.

Nancy: Yeah. I can't either. Well the other thing was the brothers was Finnelly Brothers or whoever it was that produced it.

Interviewers: Yeah.

Nancy: They're really popular with adolescences.

Interviewers: Oh, okay.

Nancy: So they done other stuff. But as I said I just...I never heard too much about it. So.

Interviewers: Okay. Okay. The... Did I miss any questions Athena that I should... The birth parents never got involved with the children again or...

Nancy: Marissa's parents, yes. And Jimmy's parents, yes. And Michael was given up at birth. So.

Interviewers: Um hmm. Um hmm.

Nancy: You didn't...You didn't ask me one question. I have my answer already.

Interviewers: Oh, tell me what it was.

Nancy: What am I most proud of?

Interviewers: Oh, yeah. I...Because I...We have so many things to talk about that have nothing to do with this that my head is spinning with all kinds of questions.

Nancy: Yeah. Here...Here...Here I've got my big answer already. I'm waiting for you. I'm like wait a minute. I'm asking it because the three of them forgot it.

Interviewers: I was like I still going through like the questions we always ask, I'm like we got that, we got that, was that this morning she ask that.

Track 7

Interviewers: What are you most proud of?

Nancy: I helped to found the Down's Syndrome Center at Children's Hospital. You know I might say that.

Interviewers: Um hmm. Um hmm.

Nancy: That was the best job I will ever have in my entire life.

Interviewers: Really?

Nancy: In fact the day that I walked out of the hospital I turned around, I looked at the hospital and I said, 'I'm now leaving the best job I'm ever going to have.'

Interviewers: Oh, wow.

Nancy: And I...I just know that will always be that way.

Interviewers: Wow.

Nancy: And my friend Sheila who when I left she took over as the coordinator. We have a deal that when she gets ready to leave I get first dibs on the job. Because I can see myself going back.

Interviewers: Um hmm.

Nancy: After all this I could see myself going back. But we created a place where people can go for support...

Interviewers: Um hmm.

Nancy: ...for years and years and years.

Interviewers: Um hmm.

Nancy: A place where there's good research. A place where physicians can go to, you know, understand more about what they need to understand in order to care and treat people.

Interviewers: Um hmm.

Nancy: But most of all was the support for people, for parents, especially for brand new parents who just had given birth...

Interviewers: Um hmm.

Nancy: ...to find out they now have a baby with Down's Syndrome. What are we supposed to do? And knowing that that place is still there.

Interviewers: Um hmm. Does that...This woman that we interviewed before you talked about when her daughter was born because they didn't know she was going to have Down's Syndrome. And...but I know she's connected to the Down's Syndrome Center because she...

Nancy: Okay.

Interviewers: ...found out. But I'm wondering is it because she goes to Children's Hospital for her medical...the kid's medical care or has the Down's Syndrome Center really spread out that far?

Nancy: The Down's Syndrome Center at Children's Hospital is now known world wide.

Interviewers: Okay.

Nancy: You know, because of the...the information that's put out. But locally Sheila has an email distribution list. So it's just not patients...

Interviewers: Um hmm.

Nancy: ...that are on that distribution list.

Interviewers: Um hmm.

Nancy: You know, it's professionals, it's other organizations, it's people whom never come through the hospital.

Interviewers: Okay.

Nancy: Who've ask to be put on the list. They've sent information to...so, you know.

Interviewers: Yeah. Yeah.

Nancy: That list. And...And her, you know, when I get her newsletter that she sends out through email, you know, I'll send it out to our families.

Interviewers: Um hmm. Um hmm. .

Nancy: So, you know.

Interviewers: Um hmm. Um hmm.

Nancy: It...It gets out there far and wide.

Interviewers: I was wondering if parents in rural areas really have that same kind of support that people that live closer to Allegheny County.

Nancy: Well, right from the beginning, I mean going all the way back from 1989. I mean we had families from, you know, all over western Pennsylvania.

Interviewers: Um hmm.

Nancy: And then they came for medical care.

Interviewers: Um hmm.

Nancy: But we also would pick...I mean back in those days we didn't have email.

Interviewers: Um hmm.

Nancy: I know hard for you to imagine.

Interviewers: Um hmm.

Nancy: But there has been a time in history when we didn't have email and we'd be picking up the phone.

Interviewers: Yeah.

Nancy: You know. And, you know, copying off something and mailing it to them.

Interviewers: Um hmm.

Nancy: So

Interviewers: Um hmm.

Nancy: A...

Interviewers: Um hmm.

Nancy: I mean obviously it's harder.

Interviewers: Um hmm. Um hmm.

Nancy: Just the geography in the state as we were talking about before that imposes some issues for people. But as far...as far as the Down's Syndrome Center goes, and Sheila and I are still very much in touch with one another, they still get a good percentage of their patients from surrounding counties.

Interviewers: Yes. It's quite an achievement. Really.

Nancy: Um hmm.

Interviewers: Is Dr. Cowen still over there?

Nancy: He's still there.

Interviewers: Hmm.

Nancy: We informed him that he'll just be retiring from there so just, you know. And he turned 60 a couple years ago and there was a party for him, you know. And all of a sudden somebody said something to him about retiring. Sheila and I looked at him and said, 'He's only 60. Keep working.'

Interviewers: Yeah. Right.

Nancy: You know. 'You've got at least 10 more years in you.' You know.

Interviewers: Right.

Nancy: He ne... Obviously he never thought he would be doing this.

Interviewers: Yeah. Um hmm.

Nancy: But he was... I can't think of a better person.

Interviewers: Um hmm.

Nancy: He's perfect.

Interviewers: Um hmm.

Nancy: So. When he decides to leave I'm not sure what will happen, but.

Interviewers: You're not grooming anybody else?

Nancy: He may be.

Interviewers: Yeah.

Nancy: I don't know. Actually there is. There's a physician that's been seeing the adults now for a couple of years. And he's... I don't know how old he is. He's probably in his 40s.

Interviewers: Um hmm.

Nancy: But I'm sure if something happened to Bill tomorrow, Peter would step in.

Interviewers: Um hmm. Um hmm.

Nancy: Yeah.

Interviewers: Good. Good.

Nancy: And then I'll come back so.

Interviewers: Yeah. That's nice. That's nice. Did we ask the most challenging thing? Go ahead ask. What's been your most challenging...

0:05:00

experience or endeavor or obstacle?

Nancy: Well I don't know if it's the most...

Interviewers: But one of them.

Nancy: One of... Closing Western Center. That was just plain ugly.

Interviewers: Explain a little bit more about it.

Nancy: Trying to convince families that they had to make a decision. The place is closing.

Interviewers: Um hmm.

Nancy: The doors are going to close. We're turning the lights off. You need to make a decision as to where your family member is going to live. And then the day that the center actually closed there were still, what 36 people still living there. And, you know, crossing the state police barricade, watching these people being put in vans. You know, just watching their faces, just wanting to cry thinking how frightened they must be.

Interviewers: Um hmm.

Nancy: I mean, we knew where they were going. Half of them went though two hours from here to Ebensburg Center. You know. A couple of them went to other...to group homes. But their parents still, you know, raising cane, across the other police barricade line. State police escorting the vans down the path. You know.

Interviewers: Um hmm.

Nancy: Ohh, standing there watching those vans leave thinking, it didn't have to be this way for those poor people. And the interesting thing is that, you know, a year later, five years later, you know, everybody, you know, the support coordinators, the providers with whom these people live, they're doing great. Better health outcomes. You know, people who couldn't work at Western Center...

Interviewers: Um hmm.

Nancy: ...are now working in the community.

Interviewers: Um hmm. Um hmm.

Nancy: With job coaches, but they're working. You know.

Interviewers: Um hmm.

Nancy: They have their own rooms. They can go to the refrigerator and get what they would like to eat. Families, you know, some of the families that were ready to kill us, you know. And yet there's still three families that their family members are still living at Ebensburg Center.

Interviewers: Because they think that's best for them? Is that(? - 0:07:31)

Nancy: Um hmm. And when I worked for the state, I tried talking to two of them. And it was like, what 1995 all over again. You know.

Interviewers: Um hmm.

Nancy: But the sad thing is that, you know, the issues with their family members are one thing, but to think that these family members spent their entire, you know, last what 20 years, fighting this battle. And...I mean, they're up there in years now. I mean these are not young people anymore. And basically, you know, a lot of them are in ill health and they're going to die. And they're, you know, they're...they're still fighting a battle that they don't have to fight anymore. So, that...that's...

Interviewers: Um hmm. Um hmm.

Nancy: You know. It was...I was an interesting experience. What was the question? Interesting? Hard? Challenging?

Interviewers: Challenging.

Nancy: Oh it was a challenge.

Interviewers: Yeah.

Nancy: That was a challenge. Being able to, you know, coming to grips with the fact that no matter what I say to these people I can't get them to change their mind, you know, no matter how we try to deal with this.

Interviewers: Um hmm.

Nancy: And knowing that if you fail their family members are going to live in an institution, not in a home somewhere. So that was kind of...That was a challenge but it was also gnawing like...

Interviewers: Um hmm.

Nancy: ...I have to be able to do this. And then, three cases we couldn't.

Interviewers: Um hmm.

Nancy: So.

Interviewers: Like I...I sat in a meeting one time where most of the families in the meeting were parents of people that were living at...or sisters or whatever...living at Western and my perception of it is it was all about fear. They were afraid of what would happen to their family members, the left. They...They thought they were protected.

Nancy: Um hmm.

Interviewers: And they...And the family then felt secure in knowing that, okay, they're protected and they can relax.

Nancy: Um hmm.

Interviewers: That was just a perception that I had.

Nancy: No. It was right. And the families did not believe because there was an undercover investigation...

Interviewers: Um hmm.

Nancy: ...and that's what lead to the closure of Western.