

Interview has been edited for clarity. Timestamps correspond to the original, unedited video.

Lisa Silverman ([00:00:00](#)):

Hi, I'm Lisa Silverman and today is January 7th, 2019. It is 10:15 AM. And we are at StudioME in East Liberty, Pittsburgh, Pennsylvania. The purpose of the media history project of the Western Pennsylvania Disability History and Action Consortium is to record firsthand accounts of disability history. Nancy Murray, the president of The Arc of Greater Pittsburgh and her daughter, Marisa Niwa, are part of that history. Nancy Murray is the president of The Arc of Greater Pittsburgh at Achieva, a Pittsburgh-based disability services organization. Since the 1970s, Ms. Murray has worked in the disability field in the areas of public policy, advocacy, family support, supports coordination, healthcare, and state government. Her primary area of interest in study is the resilience of families of children and adults with disabilities and the long-term impact of caring for a person with a disability on a family. Ms. Murray oversees Achieva's Disability Healthcare Initiative, which is focused on access to healthcare.

Lisa Silverman ([00:01:11](#)):

She also serves on the board of directors of the Pennsylvania Assistive Technology Foundation, the Pennsylvania Medical Assistance Advisory Council, and numerous committees through the Pennsylvania Office of Developmental Programs. She is a member of the executive councils of The Arc of the United States and The Arc of Pennsylvania. Marisa Niwa has worked at Giant Eagle Market District for 18 years. Her volunteer work includes serving on the management team for Special Olympics of Allegheny County, working at the food pantry at South Hills Interfaith Movement, and advocacy for people with disabilities. She is a Special Olympian in golf. She is the daughter of Nancy and Joe Murray, and has a brother Mickey. Thank you, Marisa and Nancy for being with us today. So let's begin by talking about your family. Can you tell us what makes your family unique?

Nancy Murray ([00:02:08](#)):

Well, in our family, there's four of us, and we have three last names. So my husband and I have the last name of Murray, Marisa has the last name of Niwa, and Mickey has the last name of Scarselli. And we're a blended family. Marisa and Mickey came to live with us during the 1970s, and they're still with us.

Lisa Silverman ([00:02:32](#)):

And can you tell us how that came about?

Nancy Murray ([00:02:34](#)):

My husband and I were just out of college and my husband got a teaching job in Pittsburgh. We originally were from New Jersey. So we moved out here and I learned about a program called the Host Home program, and what at the time were young, married couples and children with various types of disabilities coming to live with them. So we applied and we were accepted, and Marisa was the first child to come with us, and then six months later Mickey came to live with us.

Lisa Silverman ([00:03:11](#)):

How old was Marisa when she came to live with you?

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Nancy Murray ([00:03:14](#)):

Marisa was three, and Mickey had just turned seven.

Lisa Silverman ([00:03:19](#)):

Did you go through a formal adoption process?

Nancy Murray ([00:03:28](#)):

We did not go through a formal adoption process, there was no need to at that time. As I said, this program is no longer in existence but it was kind of a pilot project back in the 1970s and there were just a few children in Pennsylvania who were blended into families in this way.

Lisa Silverman ([00:03:49](#)):

Obviously it was successful.

Nancy Murray ([00:03:52](#)):

We think so.

Lisa Silverman ([00:03:53](#)):

Okay. Now Marisa, can you tell us about your growing up years? Where did you go to school?

Marisa Niwa ([00:04:00](#)):

I went to Pathfinder School, [and then] Mt. Lebanon High School. My best subjects in high school was biology, art, American history, TV productions. I was at Mt. Lebanon girls volleyball team at Mt. Lebanon.

Lisa Silverman ([00:04:32](#)):

Now, what did you do for the volleyball team?

Marisa Niwa ([00:04:35](#)):

I helped their coach, helping put balls on the rack, doing pep talks during the games, sometimes tournaments.

Lisa Silverman ([00:04:51](#)):

So you helped to manage the team?

Marisa Niwa ([00:04:52](#)):

Yes. Basically, yes.

Lisa Silverman ([00:04:56](#)):

Now, since high school have you been involved with Special Olympics, or did you do it also during high school?

Marisa Niwa ([00:05:04](#)):

I think [during] high school.

Lisa Silverman ([00:05:06](#)):

And what is your activity that you'd like to do most in Special Olympics?

Marisa Niwa ([00:05:14](#)):

Golf.

Lisa Silverman ([00:05:15](#)):

Can you tell me about your experience with golf in Special Olympics and where it's taken you?

Marisa Niwa ([00:05:20](#)):

Well, I went to an international Special Olympics event in Ireland. I came in second place, because my dad was my caddy.

Lisa Silverman ([00:05:38](#)):

Now, is your dad involved in Special Olympics with you?

Marisa Niwa ([00:05:41](#)):

Yes.

Lisa Silverman ([00:05:42](#)):

And what's his role besides being your caddy?

Marisa Niwa ([00:05:45](#)):

I think he's pretty awesome.

Lisa Silverman ([00:05:48](#)):

That's a pretty good answer. I'm sure Mr. Murray would appreciate that. And what's your involvement with Special Olympics? Do you have a role beyond playing golf as an athlete?

Marisa Niwa ([00:06:00](#)):

Especially if it's been like 40 years.

Lisa Silverman ([00:06:04](#)):

Do you work with them on committees to help manage it?

Marisa Niwa ([00:06:07](#)):

I have two parts. On the management team meetings, I follow up the minutes and the agenda. I take the roll call, and my second one is athlete leadership. I help Kathy and Shannon and if some other people want to join. So me and Erin, I am a co-chairperson. Erin is my secretary.

Lisa Silverman ([00:06:50](#)):

Oh, she's your secretary?

Marisa Niwa ([00:06:51](#)):

Yes.

Lisa Silverman ([00:06:52](#)):

Now, can you tell me who Erin is besides being your secretary of your committee?

Marisa Niwa ([00:06:55](#)):

Erin Gannon is my best friend. I know her from 25 years. Her, that's easy.

Lisa Silverman ([00:07:05](#)):

And now, do you volunteer at-

Marisa Niwa ([00:07:07](#)):

I volunteer at SHIM, South Hills Interfaith Movement.

Lisa Silverman ([00:07:16](#)):

Can you tell me what you do for SHIM when you volunteer?

Marisa Niwa ([00:07:18](#)):

I stock shelves.

Lisa Silverman ([00:07:21](#)):

When you stock shelves, is that as part of their food pantry program?

Marisa Niwa ([00:07:24](#)):

Yes, their food pantry. And the second part from SHIM, I do shredding, filing, put everything alphabetical order. I do office work upstairs at SHIM, also.

Lisa Silverman ([00:07:44](#)):

Do you go on a regular basis to SHIM? Do you have a special day of the week for a special time?

Marisa Niwa ([00:07:48](#)):

I go on Mondays. Sometimes Friday where there's like no pantries.

Lisa Silverman ([00:08:03](#)):

So can you tell me where you're currently living? Do you live in an Emmaus Community home?

Marisa Niwa ([00:08:07](#)):

I live in Emmaus. We have the best staff, and my friends. We do like cleaning, cooking, do some activities.

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Lisa Silverman ([00:08:27](#)):

Now, Emmaus is a Pittsburgh organization that helps emphasize having people of all abilities sharing their lives with one another. Do you have housemates?

Marisa Niwa ([00:08:36](#)):

Yes. Erin and Ce Ce, and we know each other for 25 years.

Lisa Silverman ([00:08:42](#)):

How long have you lived with Erin and Ce Ce?

Marisa Niwa ([00:08:45](#)):

About four years. I like it.

Lisa Silverman ([00:08:51](#)):

You like it?

Marisa Niwa ([00:08:53](#)):

We do cleaning, cooking. I like to cook. My favorite foods are pasta primavera and stir fry. Something with seafood, yes.

Lisa Silverman ([00:09:16](#)):

Now, do you and Erin and Ce Ce have some fun in there with all the cooking and cleaning?

Marisa Niwa ([00:09:20](#)):

Oh yes. Actually cleaning helps me do better. I like cleaning, cooking, clean up, we take the trash out every Monday night. We always go to bed by 10:00 on a weekday, 11:00 is during the weekends.

Lisa Silverman ([00:09:50](#)):

So you have a lot of fun on the weekends with that extra hour.

Marisa Niwa ([00:09:53](#)):

Yeah.

Lisa Silverman ([00:09:55](#)):

Now, do either Erin or Ce Ce golf with you?

Marisa Niwa ([00:10:00](#)):

Erin usually does. Now she's into swimming now.

Lisa Silverman ([00:10:05](#)):

Okay.

Marisa Niwa ([00:10:08](#)):

And Ce Ce does figure skating with David Mulgrave, that's Mickey's roommate.

Lisa Silverman ([00:10:17](#)):

Now, who is Mickey?

Marisa Niwa ([00:10:19](#)):

Mickey is my brother. I think he's very awesome. I see him every other weekend.

Lisa Silverman ([00:10:30](#)):

Nancy, can you tell us more about Mickey?

Nancy Murray ([00:10:32](#)):

Sure. Mickey is, actually, he's going to turn 50 this year, and Mickey lives with an organization called Partners for Quality. And as Marisa said, his roommate is David. And Mickey and David have known each other for probably 40 years, and they do not live in a house like Marisa does, they live in an apartment, and in their apartment building there's actually two other apartments where young men with disabilities also live. And Mickey works on a work crew at Courtyard by Marriott out in Robinson Township.

Lisa Silverman ([00:13:26](#)):

Okay. So Marisa, we talked about your brother and we talked a little bit about your mother, but can you tell us about your dad, Joe Murray?

Marisa Niwa ([00:13:33](#)):

I think he's pretty awesome.

Lisa Silverman ([00:13:35](#)):

And what did Joe do when he worked full-time?

Marisa Niwa ([00:13:41](#)):

Stay home and watch TV or exercise downstairs.

Lisa Silverman ([00:13:47](#)):

Now, before he did that, was your dad a teacher?

Marisa Niwa ([00:13:50](#)):

Oh yes, he's a very awesome teacher.

Lisa Silverman ([00:13:53](#)):

Where did he teach? Do you know if he taught at a high school?

Marisa Niwa ([00:13:56](#)):

Baldwin High School.

Lisa Silverman ([00:13:58](#)):

What subject did your dad teach?

Marisa Niwa ([00:14:01](#)):

Physical education.

Lisa Silverman ([00:14:04](#)):

And did he also do any coaching during his career at Baldwin?

Nancy Murray ([00:14:12](#)):

Did he coach volleyball?

Marisa Niwa ([00:14:14](#)):

Volleyball and football.

Lisa Silverman ([00:14:19](#)):

And did he also get involved with you with Special Olympics?

Marisa Niwa ([00:14:24](#)):

Yes.

Lisa Silverman ([00:14:25](#)):

I know he was your caddy.

Marisa Niwa ([00:14:28](#)):

My dad always taught me how to play golf.

Lisa Silverman ([00:14:32](#)):

Okay.

Nancy Murray ([00:14:33](#)):

And did dad help to increase a lot of the Special Olympics sports in Allegheny County?

Marisa Niwa ([00:14:41](#)):

Oh, yes.

Nancy Murray ([00:14:42](#)):

Yes.

Marisa Niwa ([00:14:46](#)):

I do labeling for Baldwin's Summer Games at Baldwin High School today.

Nancy Murray ([00:14:55](#)):

Right. So you do that because dad's in charge of the Summer Games, right?

Marisa Niwa ([00:14:59](#)):

Yes.

Nancy Murray ([00:15:00](#)):

Okay. So he's done the Summer Games for probably about 30 years now.

Marisa Niwa ([00:15:06](#)):

Oh yeah, oh man.

Nancy Murray ([00:15:06](#)):

Right? A long time. He retired, right? Dad retired about nine years ago. But while he was at Baldwin, he started the Partner's Club. And that was kind of new at the time. It's where students with disabilities partnered with students who did not have disabilities, and then they did sports together in phys ed.

Marisa Niwa ([00:15:38](#)):

Yes.

Nancy Murray ([00:15:38](#)):

And it started at Baldwin and now it's at quite a few other schools in Allegheny County.

Marisa Niwa ([00:15:46](#)):

Oh, yeah.

Lisa Silverman ([00:15:47](#)):

So Joe was an innovator of new programming.

Marisa Niwa ([00:15:50](#)):

Oh yes.

Lisa Silverman ([00:15:53](#)):

So Nancy, in your career, you founded the Down Syndrome Center at what is now UPMC Children's Hospital of Pittsburgh in 1989, and served as its first coordinator until 1995. Can you tell us about that experience, how it came about and what the organization has evolved into?

Nancy Murray ([00:16:16](#)):

It was late '80s and there were a group of families in Pittsburgh who heard about Down syndrome centers in other cities. And so we went to a couple, we went to Cincinnati, I think it was Cleveland, and we learned about their centers. And we came home, and for years there had been a Down syndrome group, it was a support group. But we decided that with all of the hospitals and medical knowhow in Pittsburgh, there should be a Down syndrome center in Pittsburgh. So we wrote up a little proposal and we took it to a couple of hospitals. And at the time it was Children's Hospital who was the most interested, and we were the most interested in Children's Hospital because at that time, Children's

Hospital was the only hospital who was doing cardiothoracic surgery on children. And we knew, given the high percentage of children with Down syndrome who had cardiac problems, that surgery was going to be so important.

Nancy Murray ([00:17:22](#)):

So it was probably about after maybe a year, two years at the very most, that the hospital decided that they would give this a try. And as I think back, I'm not sure they ever thought it would be as successful as it's turned out to be. But I think they underestimated the parents that were behind this. So we were slated to open in September of 1989, and we decided, we always had a little conference every year, so 1989 was not going to be an exception, but we thought, "Well, this would be a great time, and we can also announce the opening of the Down Syndrome Center." So we were going to have it that year at Oakland Catholic High School. And over the years we maybe had maybe 100, 125 people come to our little conferences. That year, we had almost 500 people come.

Nancy Murray ([00:18:26](#)):

And the speakers that year were the head of cardiology at Children's, the head of ear, nose and throat at Children's. And we had also invited the president of the hospital because we wanted to make this grand announcement that the Center was soon opening. Well, needless to say, everybody at Children's Hospital was blown away at the fact that we had 500 people come to this little conference. But we opened, and within about six months we had no appointment openings left. Word spread, not just families in Pittsburgh but families throughout Western Pennsylvania. So we had families coming from Erie and Johnstown, because this was a place where people could come with, at the time, children. When we began, it was only for children.

Nancy Murray ([00:19:19](#)):

And the one thing that we were able to do for families was, when families came a distance, they not only came to see the physician and the Down Syndrome Center, we scheduled their cardiology appointment, their ear, nose, throat appointment, their orthopedic appointment. So a family might spend a whole day, but they were able to get all their appointments in. And I can look back at it now and say it was the best job I was ever going to have in my career, and the day I walked out of Children's Hospital I knew I was leaving the best job I was ever going to have.

Lisa Silverman ([00:19:53](#)):

You talked about the physician at the Down Syndrome Center. Can you tell me what your role was in recruiting that physician?

Nancy Murray ([00:20:04](#)):

Well, the first physician actually was Heidi Feldman. She stayed for about a year because she had a lot of other responsibilities at Children's Hospital. And one day she came to me and she said, "Well, there's another physician who I think might be interested in this position. I want you to meet him." His name was Bill Cohen, and he was very well known at the hospital. He was also a family therapist, he worked on the oncology unit. Very highly regarded. He was a developmental pediatrician. And I say was because, unfortunately, he passed away a couple of years ago.

Nancy Murray ([00:20:46](#)):

But it was Bill who really helped to just grow the Down Syndrome Center. We started a Down syndrome interest group so that other centers around the country came together once or twice a year to talk about research and best practices in treating children with Down syndrome. And also very, very happy to say that 30 years later the National Down Syndrome Congress Convention is coming to Pittsburgh in June, and I think that's a testament to the physicians in Pittsburgh who continue to support the center, and now all the younger families that have taken up advocating for the center. Very large Down syndrome group.

Lisa Silverman ([00:21:37](#)):

You also mentioned that being part of the hospital, that you made appointments with other practice groups. What has the impact of the Down Syndrome Center at Children's Hospital been on the teaching aspect of that hospital?

Nancy Murray ([00:21:54](#)):

It quickly became a part of the medical education curriculum, as part of the rotation both for medical students and medical residents. And it's something that I knew back 30 years ago was very important, and it's something that we still do through the medical school. In fact, Achieva's now teaching a mini-elective, working with medical students, not residents but medical students, on the importance of understanding what it means for a family to have a child with a disability.

Lisa Silverman ([00:22:33](#)):

And you mentioned earlier that, when you walked out of the doors of Children's Hospital you knew you were leaving the best job you ever had at the Down Syndrome Center. Your next job was as a case management manager for a unit that served people with intellectual and developmental disabilities. What did that type of position do to enhance your knowledge of the services and the supports that are needed by people with intellectual disabilities?

Nancy Murray ([00:23:06](#)):

So you're referring to Staunton Clinic. Staunton Clinic still exists, it's one of the three support coordinating organizations in Allegheny County. I think at the time we probably served 1400 or 1500 people with intellectual disabilities and their families by providing case management, now known as supports coordination. And what it did for me was, in very short order I learned more about the government benefits, how services for people with disabilities were funded, and also what issues we still needed to really work on to make it easier for families to obtain the services that they need for their family members.

Lisa Silverman ([00:23:53](#)):

What aspects of the services did your experience at Staunton Clinic illuminate for you?

Nancy Murray ([00:24:03](#)):

Well, a couple things. First of all, we have a lot of people waiting for services. We call it the Waiting List here in Pennsylvania, unfortunately that we still have all these years later. At the time also we were embroiled in closing a very large state center known as Western Center, and because of the proximity to Western Center, Staunton Clinic had a lot of people there. So I would say at the time, learning

unfortunately about all the services that people were waiting for, but also closing a state center. Those were probably in the three years that I was there, those were the two things that we really focused on.

Lisa Silverman ([00:24:40](#)):

Can you explain for someone who doesn't work in the disability community, what the waiting list actually is? Is it an actual list where there's names and by number, or is it a general topic or a way to capture the fact that people are waiting for services?

Nancy Murray ([00:24:57](#)):

Sure. It's not like a bakery. It's not like you go in and you get a number and when your number comes up, you get services. But what we have done in the state of Pennsylvania is based on people's needs. We do in a way categorize people. So at any point in time I can go onto that list, and by county look at how many people are waiting. Have they had an emergency need for services, or maybe a less emergency need, but still a critical need for services? And we've worked with state government to use that waiting list as the data that we need to go talk to legislators about every year. So when I left Staunton Clinic and went on to my next position at Achieva, The Arc of Greater Pittsburgh, I became involved with the waiting list campaign.

Nancy Murray ([00:25:53](#)):

So 20 years later, I am still involved with this group of people. And each and every year we're going to meet with legislators to get the funding that we need so that each year more and more people are coming off of that list and getting the community services that they need. So in some ways it is a list. It is by county. So each county knows who is waiting for services and each county has a list.

Lisa Silverman ([00:26:23](#)):

It's really a matter of making sure that the state knows that the person or the individual exists and that they have a need for services.

Nancy Murray ([00:26:30](#)):

Exactly, and unfortunately it doesn't work like a bakery. Because every day somebody else comes onto that list and they may have a more emergency need than the person who might be first on the list in some ways. There may be somebody who comes on with a more emergency need.

Lisa Silverman ([00:26:49](#)):

And they would take a priority for the next round of funding that became available?

Nancy Murray ([00:26:53](#)):

Exactly.

Lisa Silverman ([00:26:54](#)):

Thanks for clarifying that. You also mentioned that when you were at Staunton Clinic, the second greatest challenge that you learned about was the state centers. And I think you mentioned Western Center, is that correct?

Nancy Murray ([00:27:07](#)):

Correct.

Lisa Silverman (00:27:08):

Now, is a state center what we would call an institution?

Nancy Murray (00:27:11):

A state center is an institution. They're large segregated facilities. Right now we have four left in the state of Pennsylvania. Western closed, but we still have four. And approximately about 750 people still reside amongst all four state centers.

Lisa Silverman (00:27:33):

Now, what was your role when Western Center closed?

Nancy Murray (00:27:41):

At the time the Western Center closed, we were providing the case management, the support coordination for the people who left there. So we would go down, meet with people, meet with their families and develop plans for them to move from the state center into a home in the community. And we would take into account their medical needs, their social needs. Could they be employed in the community? Do they want to be employed in the community? Where did their family live? Did they want to stay in Allegheny County? Did they want to move closer to where their family lived? So we were putting the plan together for that person to move out of Western Center and move into a community home.

Lisa Silverman (00:28:25):

Once the plan was in place, was that a seamless process or did you encounter some obstacles?

Nancy Murray (00:28:30):

No, it was anything but seamless at Western Center. Western Center was probably one of the most difficult closures in the history of Pennsylvania. There was a very large parent group at the time, very opposed to the closure of Western Center. There was a settlement agreement in the courts. I think it was tied up for probably eight years. During that time people dwindled out of Western, but it was finally a judge who ordered the closure. And at that point, people were given about two years. And in those two years we had to move a lot of people out of Western Center. Unfortunately not everybody agreed at the last moment. So some people were moved to Ebensburg Center, another state center. The majority did move to community homes, but the opposition of families made it very, very difficult.

Lisa Silverman (00:29:31):

During that process, with the obstacles that you encountered with family's perceptions of what was best for their loved one, did you learn anything new or different that should be considered the next time a center was to be closed?

Nancy Murray (00:29:55):

We, the disability community in Pennsylvania, I think learned a lot [with] the closure of Western Center. We learned a different way of planning for people, and I credit a lot of other people that I worked with in Allegheny County at the time. But we developed a different kind of planning process whereby we've

really tried our best to include families in the planning. We also brought together a lot of the provider organizations that people were going to be supported by. And to this day the process that we built is now used in one form or another during other closures.

Lisa Silverman ([00:30:42](#)):

And have there been subsequent closures in Pennsylvania since Western Center?

Nancy Murray ([00:30:46](#)):

There have been. I think there's been four since Western closed. They all were smaller facilities and they all closed much more easily. And with a lot less drama. Unfortunately now, as I said, we still have four still open and there's a growing amount of opposition from families. This time it's interesting, the family members are getting up there in years, but now a lot of the opposition is coming from adult brothers and sisters. And of course, now we have social media, 20 years ago we didn't have social media. Now we have social media and that's helping to ramp people up.

Lisa Silverman ([00:31:30](#)):

Now, what are the remaining centers? I know that there's a center by the name of Polk, correct?

Nancy Murray ([00:31:35](#)):

Polk is in Polk, Pennsylvania. It's about two hours North of Pittsburgh. Ebensburg is about two hours east of Pittsburgh. Selinsgrove is about 45 minutes north of Harrisburg. And White Haven is in White Haven, Pennsylvania, up in the northeastern part of the state.

Lisa Silverman ([00:31:59](#)):

And if you know, do you know approximately how many individuals reside in state centers currently [across Pennsylvania]?

Nancy Murray ([00:32:06](#)):

There's about 750.

Lisa Silverman ([00:32:09](#)):

So it's a small percentage of the overall population?

Nancy Murray ([00:32:12](#)):

Very small. Right now in the state of Pennsylvania there's about 55,000 people with intellectual disabilities who get some sort of service. So the 750 people living in the state centers are not part of that 55,000. But as you can see, 55,000 people, 750 people. And I have to add that there's another huge difference. People living in the state centers, their annual budgets range anywhere from about \$350,000 a year to half a million each year. The average per person, such as Marisa and her housemates is about \$140,000 a year. And the needs of people in state centers are no greater than the needs of some of the people living in our community homes right now.

Lisa Silverman ([00:33:11](#)):

And living successfully in the community homes?

Nancy Murray ([00:33:14](#)):

Very successful.

Lisa Silverman ([00:33:16](#)):

So when you were dealing with the Western Center closure, I know at the start of it, you were with Staunton Clinic. But at some point you were a Western director for the Office of Developmental Programs for the State of Pennsylvania. And were you in that role responsible for the state centers?

Nancy Murray ([00:33:37](#)):

I was responsible for at the time three state centers, Polk, Ebensburg, and at the time Altoona Center was also open. While I was in that position, we closed Altoona Center.

Lisa Silverman ([00:33:52](#)):

And obviously with much less dissension than Western?

Nancy Murray ([00:33:55](#)):

Much less, but there were fewer people there. Most of the people living there had medical complications, and there were not a lot of family members involved with their care.

Lisa Silverman ([00:34:11](#)):

While you were with the state as the Western director, did you put in place any innovative training programs or other programs that would be notable for us?

Nancy Murray ([00:34:24](#)):

During those years we focus ... We still focused a lot on the state centers. We also focused on ways that we could provide more community services for people living in the communities with their families. So we did a lot of education for families so that they had a much better understanding of what services were already being provided. The funding for services, how they could advocate for their family member so that their family member was getting the services that they needed. And I think we did a good job, although there's still a lot of work to be done on supporting families to think differently. Not everybody needed to live in what we at the time called group homes. You know, back in those days there were group homes for six and eight people. And we didn't look at those as really homes.

Nancy Murray ([00:35:28](#)):

So we helped families to really think more about different ways that their family members could be living in the community. At the time we really focused on something called Life Sharing, where if a person with a disability no longer had a relationship with their family, but there might be another family out there that would like to have them come and live with them. We did a lot of work trying to get more people excited about Life Sharing.

Lisa Silverman ([00:36:00](#)):

And about different ways to actually serve the individual in the community? So that's when you speak of community services, it means how do we support the individual in the community?

Nancy Murray ([00:36:13](#)):

Yes. And we also started looking more at how people spent their days. At that time the majority of people went to sheltered workshops, and there were a lot of people in sheltered workshops who really could work. They could be employed, they could work in places like Giant Eagle and hotels. So we really started at that time to really put more of an emphasis on people getting out of workshops and looking for real jobs.

Lisa Silverman ([00:36:40](#)):

And in that role with the Office of Developmental Programs, did you work with folks in Harrisburg?

Nancy Murray ([00:36:47](#)):

Yes.

Lisa Silverman ([00:36:47](#)):

Could you tell me what your role was interfacing with the folks in Harrisburg?

Nancy Murray ([00:36:53](#)):

So I was based in Pittsburgh, but I was probably in Harrisburg like once a week. And I reported to the Deputy Secretary for the Office of Developmental Programs, Kevin Casey, at the time. And he reported to the Secretary of the Department of Human Services. And my role specifically was to kind of represent him throughout Western Pennsylvania, whether we were working on state center issues or we were working on community issues.

Lisa Silverman ([00:37:26](#)):

Okay. And did you help to develop policy for the ODP as well?

Nancy Murray ([00:37:31](#)):

I did. One of the things that actually I did that still hasn't really gone too far was Micro-boards. And, again, that was something that families in Eastern Pennsylvania had gravitated toward. Never really took off in Western Pennsylvania, still don't know why. But I worked on that and I also worked on policies for waivers to try to, again, educate more families about Medicaid waivers. And I guess at the time putting into place a lot of information that when I left state government, I then took and used in my role at Arc of Greater Pittsburgh.

Lisa Silverman:

How did this period where you were working with Staunton Clinic and with ODP influence your thinking when you moved [back] to The Arc of Greater Pittsburgh [in 2007]?

Nancy Murray ([00:38:33](#)):

Well, I learned after about two years of working for state government [in the Office of Developmental Programs, beginning in 2005] that I'm not a bureaucrat. And I learned a lot and I made a lot of connections in Harrisburg, but I realized I was not a bureaucrat. That was not the place for me to be. And when you work in state government, you're really limited in terms of really what influence you're going to have because the directions come down. So even though you might know there's a great idea

out there, if it's not on your boss' radar, it's not going to happen. So I realized that although I learned a lot, made a lot of good connections, if I was going to make change, I needed to be on the outside. So, when the opportunity came about to [again] work at The Arc of Greater Pittsburgh, Achieva, [in 2007] I figured, that's "the outside," that's where I needed to be.

Lisa Silverman ([00:39:32](#)):

And you've been there for [a total of] 19 years?

Nancy Murray ([00:39:34](#)):

I have, and I have to say, I knew a lot about The Arc of Greater Pittsburgh, because I actually had served on the board of the organization many, many, many years ago.

Lisa Silverman ([0:49:33](#)):

Nancy, before we get into your career change to The Arc of Greater Pittsburgh, can you tell me a little bit more about what you observed when you were responsible for the state centers? For instance, when you went to visit them, what observations did you walk away with about how they operated in the needs of the individuals?

Nancy Murray ([00:49:53](#)):

So the best way to describe a state center is that, and you use the term, it's an institution, it is not a home. Families of people who reside there say it's their home, but it's not a home. Institutions are large. Right now there's 250 people that, that live in them, in each one. They are older buildings. Polk was built, I think it was in the 1870s. [Editor's note: Polk was built in the 1890s.] So we're talking about old buildings. On each campus some buildings are not being used. They're crumbling. People don't have a lot of privacy. There are people who have their own bedrooms. Bathrooms are shared.

Nancy Murray ([00:50:56](#)):

Everybody eats in a dining hall. It's not like smaller homes where maybe two or three or even maybe four people live where it's a house where people have their own bedrooms. They cook in a kitchen, they eat in a kitchen or a dining room. They watch TV in the living room. In a state center you're always around people. There's always a lot of noise. People living at state centers just don't walk out their front door and get in a vehicle and go to Giant Eagle. It's a process by which people have to get permission. There are drivers in state centers. You just don't go to your kitchen and you cook. That's why they have a dietary department. You just don't go off the campus very often. Maybe some people go off maybe once or twice a month, but it's not like they just go out their front door, get in a vehicle and maybe just go to Rita's for ice cream.

Nancy Murray ([00:52:11](#)):

And they're very cold places. Even for people who have a lot of abilities who have decorated their rooms, they're cinderblocks for the most part, and they're just not homes for people. And there's no reason that a person living in a state center cannot live in one of our community homes. The community over all these years have developed the medical supports, the behavioral supports, the psychiatric supports, the employment supports the therapeutic supports. We can provide everything that somebody living in a state center needs. We can provide it in the community because for everybody living in a state center, that person has a twin someplace living in the community, somebody with the

same medical issues and behavioral issues and psychiatric needs, there's somebody living in, in the community, just like that person.

Lisa Silverman ([00:53:15](#)):

And that being the case, what was your observation of the concerns that family members had with respect to the closure of Western Center? Because you said a lot of families were really concerned and opposed the closure.

Nancy Murray ([00:53:32](#)):

Right.

Lisa Silverman ([00:53:32](#)):

So I'm curious what their concerns were about?

Nancy Murray ([00:53:36](#)):

Right. So I always grouped families in this way. There were families who were rightfully concerned about how the community could support their adult child. Keeping in mind that a lot of people living in state centers have lived there since childhood. They have lived there for decades. Family placed them there during childhood, or maybe early adolescence, thinking this is where you're going to spend the rest of your life and you're going to be safe here and I'm going to go live my life. Oftentimes it was a doctor, physician, a parish priest, the rabbi who said, it's going to be better for you and the rest of your family if you take your child and take them to the state center.

Nancy Murray ([00:54:35](#)):

And unfortunately it was just about two years ago, I heard that a family was considering an admission to a state center because the doctor had —it was in the year, I guess, 2015— somebody was still thinking that. But years ago families made the decision and they became accustomed to life in the state center where everybody's needs were met in the state center, the doctors, the nurses, the dietary people, everybody's there.

Nancy Murray ([00:55:14](#)):

And then we come in saying, "But your son or daughter can be supported living in a house in the community." And families would say, "Well, how can that be?" So we spent a lot of time with families helping them to understand that just because your child has Down syndrome and a heart defect and maybe a very low IQ, well, he can still live in the community. And for many families was just hard for them to imagine because they had been associated with the state center for so long.

Lisa Silverman ([00:55:49](#)):

And it felt safe.

Nancy Murray ([00:55:51](#)):

And they felt safe. Unfortunately, abuse happens in the state centers, just like abuse happens in the community. And it was because of rampant abuse at Western Center that Western Center closed. But it was very hard to convince families that abuse happened.

Nancy Murray (00:56:09):

So there were many families where we would spend one year, two years, there was one family in particular that I worked with for three years before that family believed that we could get the same supports for their family member in the community. And they were opposed, but they were willing to work with us. Those were very rewarding experiences. Then there were families who were just downright opposed. They didn't want to hear about the community. They were not going to any planning meetings. They were the ones who dug their heels in. They were the ones going to court. You couldn't have a conversation with them. And those were people who frankly had made the decision years ago for their family member to live in a state center. And they weren't about to revisit it. And they just, frankly, did not want the headache of having to think about their family member living any place else. Some of those families also had not been to visit their family member for years and years.

Lisa Silverman (00:57:30):

So you mentioned that you had one family in particular that you worked with for three years, was that transition to community living ultimately successful?

Nancy Murray (00:57:38):

Yes, because there was a lot of planning upfront.

Lisa Silverman (00:57:46):

And you mentioned also earlier that you're now seeing with the centers that still remain open, that it is now siblings of the individuals.

Nancy Murray (00:57:59):

Mm-hmm (affirmative).

Lisa Silverman (00:57:59):

who are in the centers who have concerns about any closures.

Nancy Murray (00:58:03):

Mm-hmm (affirmative)

Lisa Silverman (00:58:04):

Can you tell me what types of concerns those siblings are expressing?

Nancy Murray (00:58:08):

Well, again, there are some siblings who, again, just like parents, they can't imagine how after all these years, their brother or sister is going to be able to be supported in the community. So just like their parents we would sit with them and we'd go through the planning process with them. And then there are some brothers and sisters who made the promise to their mother and father on their deathbed that they would at all costs, oppose the brother and sister moving to the community. And those are very difficult conversations to have with people. Sometimes you don't get anywhere with them because on their parents' deathbed, they made that promise that "I will make sure my sister stays in that institution as long as she lives."

Lisa Silverman ([00:59:02](#)):

So there's so many layers of emotions and wanting to honor their parents' wishes.

Nancy Murray ([00:59:07](#)):

Right.

Lisa Silverman ([00:59:08](#)):

All right. So where you are now with Arc of Greater Pittsburgh, after seeing the concerns that families expressed and the evolution in the state's understanding and the understanding of families' needs. Can you tell us how you have been able to try to meet the needs of both the families and the state's needs in your role at Achieva at The Arc of Greater Pittsburgh?

Nancy Murray ([00:59:40](#)):

I will always meet with a family member of somebody living in a state center to try to help them to understand that all of the services their family member's getting at the state center we can provide in the community. Of course, I'm not a support coordinator anymore, but every once in a while I get a call from a support coordinator saying, "Would you be willing to talk to a family?" I will always be willing to talk to a family. On the other hand, the time has come in the state of Pennsylvania where we still have thousands of people waiting for services. We have families who desperately need supports. We have families that are providing 24/7 care for somebody every day. Those families need help. And we frankly cannot continue to pay a half a million dollars a year to keep one person in state center when we've got thousands of people waiting.

Nancy Murray ([01:00:48](#)):

At the same point, I look at people living in the state centers and it's not fair to them that they have to continue to live in an institution. Years ago there was a young lady who was in a state center. She had a lot of medical complications, no family, and the opportunity came for her to live in the community. And I worked with the support coordinator. I worked with staff at the state center. She moved out of the state center. She was very frail. She only lived for a year, but in that year it was probably the best year for life living in the community. She got to go to Kennywood, she got to go to a baseball game. She had a Christmas tree. She lived life for a year and people then said to me, "Well, why did you move her? She only lived there for a year," and I said, "Because it was the best year of her life. And she had every right to experience what a lot of other people have had a lifetime to experience. I would do it all over again."

Nancy Murray ([01:02:12](#)):

So it's not fair to the people who are living in state centers that they don't have the opportunity, regardless of what their families are saying, they're adults and they have a right to live in the community too. And to enjoy things that we all take for granted.

Lisa Silverman ([01:02:29](#)):

So it sounds like there's a complete lack of self determination or decision making.

Nancy Murray ([01:02:41](#)):

There are people living in the state centers who do not have family involvement. So for those people, obviously it's much easier to sit with them and develop a plan and help them move to a community

home. For others there are families who as I said, it takes a while, but you work with them and in time their family member will move. Then there are some who are totally opposed. They go for legal guardianship and they're the ones whose family members will be the last ones to leave.

Lisa Silverman ([01:03:20](#)):

So previously you mentioned that you left the state government because you want to be able to think creatively and a little less within a hierarchical paradigm. Can you tell me how The Arc of Greater Pittsburgh has permitted you to do that in general?

Nancy Murray ([01:03:39](#)):

Well, let's see, a couple of things When I got to Arc of Greater Pittsburgh, one of the first things it's never far from my thoughts is healthcare for people with disabilities and access to healthcare. And that goes all the way back to my days at Children's Hospital. It's not just a matter all the time of somebody having insurance. It's a person being able to find a physician who has the experience to treat somebody with a disability and willing to take Medicaid, which is the insurance that most people with disabilities have. [To Marisa] You have Medicaid, right?

Marisa Niwa ([01:04:17](#)):

Yes.

Nancy Murray ([01:04:18](#)):

Medicare?

Marisa Niwa ([01:04:19](#)):

Yes.

Nancy Murray ([01:04:19](#)):

Okay. So one of the first things we did was we established the Achieva Disability Healthcare Initiative. And over the last couple of years, we've worked on a couple of projects, transition to adulthood for young adults, with disabilities. Access to dental care, access to care for women and girls with disabilities. And right now we're working with the University of Pittsburgh Medical School to infuse more disability medicine education into their curriculum. So that medical students and residents, when they graduate feel much more at ease treating patients with disabilities.

Lisa Silverman ([01:05:07](#)):

So you're teaching the medical community how to interact with individuals who have disabilities. Question: When I hear about access to dental care, access to health care, is it a matter of there not being physicians in the area where the individuals live or not physicians who are comfortable and capable of interacting with people with disabilities that you addressed?

Nancy Murray ([01:05:31](#)):

It can be both. Especially when it comes to dental care. There are a lot of dentists who simply are not going to accept Medicaid. The other issue is transportation. Pennsylvania is really a rural state. Yes, we have Pittsburgh, we have Philadelphia and then we have a large rural state in between. And so for some

people, they have to travel multiple counties to get to somebody who is willing to accept their insurance and somebody who has the experience of working with people with disabilities.

Lisa Silverman ([01:06:13](#)):

As part of the dental care initiative that The Arc pursued, was there any innovative programming that came out of that study or model that is now helping individuals find that dental care?

Nancy Murray ([01:06:29](#)):

Yeah. A couple of things. We have been very fortunate to be grant-funded to continue to do this work. We've provided a lot of information for individuals and families and support coordinators and providers on how you access care. We've also reached out to other organizations who are doing this work. The federally qualified health centers, the Dental School at [the University of Pittsburgh]. So that we are training dental students each and every year. So that they're more comfortable working with people with disabilities. That's now embedded in the dental school curriculum. We've also reached out to University of Pennsylvania and Temple University that also have dental schools to do the same thing with them that we've done here in Pittsburgh. We're also working with [dentists], it's called the Mission of Mercy. So at least once a year, we're working with them to provide free dental care to people who simply cannot access dental care any other way.

Lisa Silverman ([01:07:42](#)):

And is it for people with disabilities or any people who can't access dental care?

Nancy Murray ([01:07:45](#)):

Some people with disabilities, especially mental health disabilities, but anybody.

Lisa Silverman ([01:07:54](#)):

And do you know how many individuals?

Nancy Murray ([01:07:58](#)):

Mission of Mercy, last time it was in Pittsburgh, last summer, I think the number was close to 2,000 people came through over a two-day period. During those two days, there were extractions, dentures, cleanings.

Nancy Murray ([01:08:19](#)):

The dentists, dental students, dental hygienists, dental assistants, all giving their time to make sure that people who stood in line for hours got the care that they needed.

Lisa Silverman ([01:08:33](#)):

Can you explain the relationship between The Arc of Greater Pittsburgh and Achieva?

Nancy Murray ([01:08:50](#)):

Sure. Achieva is the parent company. So under Achieva we have The Arc of Greater Pittsburgh, which now includes Allegheny County, Beaver and Westmoreland. We have the Achieva Family Trust which, as the name implies, is a family trust. There's about 2,400 beneficiaries now and I think they manage about

\$120 million. And they educate people with disabilities and families about trusts and wills. Special needs trusts, I should say. And then we have Achieva Support and, as that name implies, that's where all of our support services are housed. It's everything from early intervention for young children with disabilities, employment, housing, residential services, and in-home and community supports. That's the largest part of Achieva. And then The Arc of Greater Pittsburgh, we are the part of Achieva that provides advocacy, family support, older adult protective services, and all of our little grant-funded projects.

Lisa Silverman ([01:10:09](#)):

What is your primary role as president of The Arc of Greater Pittsburgh?

Nancy Murray ([01:10:29](#)):

So I still do a lot of different things. I still am there for family calls on any particular day to offer them some emotional support. I still go to a number of plan meetings every year, but primarily my role is with governmental affairs and advocacy. So I still spend a lot of time in Harrisburg working on issues, such as closing the state centers, the waiting list, I serve on a lot of different committees through the Office of Developmental Programs. The list continues to be endless in terms of the issues that we're working with. Another issue that's on the horizon is managed care for people with intellectual disabilities. Don't know where that's going to take us, but that's probably the newest issue that's there. Another issue is the fact that we don't have enough direct support professionals. Marisa mentioned her staff before, some of the best staff around.

Marisa Niwa ([01:11:37](#)):

Why yes.

Nancy Murray ([01:11:37](#)):

Right?

Marisa Niwa ([01:11:37](#)):

I love my staff.

Nancy Murray ([01:11:38](#)):

I know you love your staff and we don't have enough staff and we don't pay them enough for the work that they do. So that is another huge issue that we're working on. Funding for all these programs, that's an annual issue. Every year, the governor will propose his budget and we will start working with members of the legislature to make sure that the funding is there for the programs that we need.

Lisa Silverman ([01:12:09](#)):

You mentioned that you work frequently with folks in Harrisburg. Do you also engage in advocacy at the federal and at the local level?

Nancy Murray ([01:12:18](#)):

We do. Locally what we do is we'll try to meet with both state and federal legislators as local as possible. It's much easier to meet with them in their local offices, but we do go to Harrisburg to meet with legislators, and once or twice a year, we go to Washington, D.C. to meet with our federal legislators. But as people have heard me say over the years, always try to schedule your meeting locally because when

you're in Washington or you're in Harrisburg, whoops, they can always be called away to a meeting if they don't want to meet with you anymore. When they're in their office, obviously they can't be called away to a meeting, so it's much better to meet with them here.

Lisa Silverman ([01:12:56](#)):

Okay. While you've been with The Arc of Greater Pittsburgh, have there been any notable issues that you've been involved with in advocacy that you'd like to highlight?

Nancy Murray ([01:13:11](#)):

I'm not sure this is advocacy, but one of the things that I'm most proud of and I'm glad that Achieva saw the merits in, is we created something called A Home of My Own. I don't supervise this directly anymore because it was successful and it got too big and it's really now a service. But the whole idea about A Home of My Own was, as the name implies, a lot of people don't really need or they don't want to live in a community home.

Nancy Murray ([01:13:48](#)):

We created a way that people could maybe rent an apartment, maybe have a housemate or maybe not, but in working with families and people with disabilities to figure out all the resources that they have, what support needs they need, and how could they move out of their family home and into a home of their own? I think now there's close to 50 people that are benefiting from A Home of My Own, and I think there are dozens and dozens in the wings waiting. Maybe 20 years from now, when we look back, I think we're going to see where this is not just a new idea, but the way that a lot of people are going to be receiving their supports as adults.

Lisa Silverman ([01:14:47](#)):

Just to clarify is, is the Home of My Own different from a traditional service model?

Nancy Murray ([01:14:53](#)):

It is very different. In A Home of My Own, a couple of things are different. First of all, the person chooses where they want to live. Okay? They can choose to live in an apartment, they can choose to live in a house if they can afford it, but it's not like, "Well, here's the community home, and if you want to receive services, this is where you're going to live." The person gets to choose their home. They get to choose their housemate. As I said, some people want to live by themselves, so that's okay. They get to choose their staff, which is not the case in traditional community homes. In A Home of My Own, we have people who apply, and the people interview their staff.

Nancy Murray ([01:15:37](#)):

In fact, one young man, and Marisa knows him, he was going to move into his own apartment. They brought a young man over who they thought would be a very compatible staff person. The interview was over, and this young man looked at the person from A Home of My Own and said, "I don't think we're going to hire him. I don't really like him. Do you have anybody else?" The story came back to me, and I thought it was the best story I had heard in weeks. I thought, "Now we have it. This is perfect. He just didn't click." A week or so later, they brought another young man over, and they got along famously. After the interview, looked at the support broker from A Home of My Own and said, "Let's hire him. I like him." I think they've been together now probably about 18 months.

Lisa Silverman ([01:16:46](#)):

Question: When you said you'd looked at the individual's resources to help them figure out what they can afford, is A Home of My Own then a combination of private and family or individual dollars and then their supports come from public dollars? Is that what makes it unique?

Nancy Murray ([01:17:02](#)):

Well, in a way. We separate it out this way. You have your housing and your supports. For your housing, that's your rent, your utilities, maybe a security deposit. You have to pay for that. Then over here are your supports. Your supports we can pay for through the Medicaid waiver. Your living expenses, well, that's your social security, your wages, anything mom or dad might pop in to help you.

Marisa Niwa ([01:17:35](#)):

Taxes.

Nancy Murray ([01:17:37](#)):

Taxes. You pay taxes, right?

Marisa Niwa ([01:17:39](#)):

Yes.

Nancy Murray ([01:17:39](#)):

That's right. You have to think about how you're going to pay your taxes, right? We help the person and the family figure out. Now, the other thing is people will get energy assistance. They will get SNAP, which we used to call food stamps. It's been amazing. When you put resources together, people are able to move out or they know what their goal is so that maybe they have to work five hours a week more, or maybe they can't afford that big apartment. They need to find a smaller apartment. But before you know it, you have those discussions, and decisions are made, and somebody can move.

Lisa Silverman ([01:18:22](#)):

The individual then is an integral part of the process?

Nancy Murray ([01:18:25](#)):

Very much so. Very much so. One story that... this was pretty early. We had two young men, and they chose an apartment up in the North Hills. There was a pool, an indoor pool, and a workout room. I think the rent was about \$2,000 a month. I went to the planning meeting because I've known the families for many, many years, sat down with the two families and these two young men, and they had it all set up already. They were going to move until we put all the finances down. Of course, their parents knew before the meeting they were not going to be moving there, but it was a wake-up call for these two young men. But we were able to find them a lovely apartment. It just didn't have the indoor pool and the extravagant workout room. But two years later, they're happy where they are.

Lisa Silverman ([01:19:22](#)):

With a little less, but they still live a nice life.

Nancy Murray ([01:19:24](#)):

Exactly. They go to the Y, and they can swim there.

Lisa Silverman ([01:19:27](#)):

Much more cheaply than the \$2,000 a month.

Nancy Murray ([01:19:28](#)):

Much more cheaply. Right. But to your point, they were involved in that decision. Their main goal was they wanted to move out of their parents' homes. "Well, to do that, you can't move there, but you can move there, and you can go to the Y to swim." "Okay. That's fine."

Lisa Silverman ([01:19:45](#)):

Have you found that once individuals find that place, that it's a more successful placement with less changes than if it were in a traditional model?

Nancy Murray ([01:19:58](#)):

I think we're not far enough down the road yet to answer that question. To the best of my knowledge, there's only been one person that decided to go back home, although she still calls her support broker about maybe trying it again. I think all in all it's been successful. We've learned a lot, and it's been interesting too. People are applying to work as the direct support professionals more into that program than into other programs. We don't call them staff. We call them life coaches because that's really what they're doing. They're coaching a person. They're mentoring. They're teaching. They're not there as the staff.

Lisa Silverman ([01:20:57](#)): You previously mentioned that The Arc of Greater Pittsburgh, greater than Pittsburgh, also serves Beaver and Westmoreland counties.

Nancy Murray ([01:21:10](#)):

Right.

Lisa Silverman ([01:21:10](#)):

Was that always a part of The Arc of Greater Pittsburgh's service community, or did that change during your tenure?

Nancy Murray ([01:21:17](#)):

No. That changed over the last couple years, where The Arc Beaver merged in and then Arc Westmoreland. Achieva as a whole provides most of the services in Beaver, Westmoreland, and Allegheny, but then, for example, early intervention is in multiple counties in Western Pennsylvania. The Achieva Family Trust that I mentioned before, they're in a couple states in addition to Pennsylvania. Depending on the service, you might find us in a different county also.

Lisa Silverman ([01:21:52](#)):

Now, I've heard of **T**he Arc. Is **T**he Arc of **G**reater Pittsburgh affiliated with the greater Arc of the U.S.?

Nancy Murray (01:22:01):

Well, we're affiliated with both Arc of Pennsylvania and then Arc of the United States. Yes, we're affiliated with both.

Lisa Silverman (01:22:08):

And this is the Arc of Greater Pittsburgh chapter a large chapter?

Nancy Murray (01:22:18):

Again, in part, because we're part of Achieva, but we're still considered one of the largest in Pennsylvania, and we're also one of the most highly recognized because historically... Well, first of all, we've been around for almost 60 years, but second of all, we've been involved in some very important pieces of legislation along the way. Other states have heard about The Arc of Greater Pittsburgh.

Lisa Silverman (01:22:45):

Can you talk about what those important pieces of legislation that the Arc [of Greater Pittsburgh] been involved with?

Nancy Murray (01:22:50):

Yeah. Early 1970s, at that time it was [called] Arc Allegheny, became a plaintiff in a lawsuit that ended in the right of children with disabilities to be educated in regular schools. No longer did children with disabilities have to go to special segregated schools. They could go to their neighborhood school, the school they would go to if they didn't have a disability. Of course, it didn't happen overnight. It still took 20 years for everything to shake out, but that paved the way for the federal legislation that guaranteed children with disabilities the right to go to school and to receive a free and appropriate public education.

Nancy Murray (01:23:39):

Arc Allegheny [forerunner of Arc of Greater Pittsburgh] was also at the forefront of legislation to close the state centers. We're one of only a few Arc chapters in the country that has a Family Trust. The other thing that Achieva has done is to pave the way, making the decision to close all of our sheltered workshops. We're one of the few organizations in the country that have done that. It's not always just The Arc of Greater Pittsburgh, but Arc of Greater Pittsburgh as part of Achieva.

Lisa Silverman (01:24:39):

Are you still involved with educational advocacy?

Nancy Murray (01:24:42):

I do not do educational advocacy, but we are very fortunate to have four educational advocates who do that. You almost need to be an attorney these days to be an educational advocate. That is not something that I do anymore.

Lisa Silverman (01:25:01):

But The Arc of Greater Pittsburgh, which you supervise, does?

Nancy Murray (01:25:03):

We do. We do. We provide life span advocacy all the way from a family member receiving a diagnosis all the way up to end of life issues that families face.

Lisa Silverman ([01:25:20](#)):

Now, I'm going to shift gears a little bit. I know that you've maintained a close relationship with the former Pennsylvania governor and U.S. attorney general, Dick Thornburgh, and his wife **Glnny**...

Nancy Murray ([01:25:40](#)):

Yes.

Lisa Silverman ([01:25:41](#)):

... both of whom have worked on disability rights in Pennsylvania and at the national level. Can you tell me what your thoughts are about the impact the Thornburghs have made in that regard?

Nancy Murray ([01:26:00](#)):

Yes. I count Ginny and Dick Thornburgh as very good friends and mentors. They're probably Pittsburgh's greatest citizens when you think about it. Dick Thornburgh was obviously governor of Pennsylvania. He was the attorney general of the United States, ambassador to the United Nations. Between the two of them, they have worked on access to religious services for people with disabilities. That was Glnny's big area of interest. Dick was one of the architects of the Americans with Disabilities Act. He was the attorney general at the time and was right there with President Bush when it was signed. He also worked at the United Nations to draft the U.N. charter on rights of people with disabilities. Unfortunately, the United States is still not a signatory to that document, but we never lose hope. I think the other thing, both as governor and then as attorney general, he really helped to shed light on other pieces of legislation and policy that over the years have now become laws of the land.

Lisa Silverman ([01:27:45](#)):

Thanks. You are known as a thought leader in the area of disability rights and supports for individuals. How did you become interested in this area and in becoming a blended family with Marisa and Mickey?

Nancy Murray ([01:28:09](#)):

Everything in life is pretty much an evolution. When I was in high school, there was a family whose son had a traumatic brain injury. This was early 1970s. The family relied on volunteers to come and spend time with him. A friend of mine, she was on her way to nursing school. She and I decided, "We'll do that." We helped the family and him do exercises and that sort of thing. I also had a cousin who was very, very severely involved both physically and cognitively. He did not live very long.

Nancy Murray ([01:28:58](#)):

I think he passed away when he was about seven or eight years old, but he always kind of stayed with me. Then my husband has a brother who has a learning disability. Being around people with disabilities was not something new to us. When we moved to Pittsburgh, as I said, Joe became... we came here because he received a teaching position. One day, I learned about the idea of becoming Host Home parents. I thought, "Well, that's something that we could do for a couple of years. That sounds pretty cool." So here we are 40-some years later.

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Lisa Silverman ([01:30:04](#)):

Let me ask you, Marisa, what's been most important to you in your life and in your career and volunteer efforts? Tell me a little bit about that.

Marisa Niwa ([01:30:19](#)):

I like my job at Giant Eagle, and I volunteer. Then I come home. I want to relax, watch TV, do something with my staff, who are my friends.

Lisa Silverman ([01:30:35](#)):

You have a pretty rich life.

Marisa Niwa ([01:30:38](#)):

Yes, exactly.

Lisa Silverman ([01:30:40](#)):

Nancy, what are your strongest beliefs with respect to your life and your career in the disabilities community?

Nancy Murray ([01:30:52](#)):

Obviously, over the last 40 years or so, we've made a lot of progress, but we still have a lot to do. I'm still hoping that in my lifetime we will close the remaining state centers and they will become just part of our history and that they not be a choice for families down the road, and that, at the same time, we're continuing to listen to what families need and working very, very closely with families as we design services in the future.

Lisa Silverman ([01:31:30](#)):

Thank you both for your time and for giving us this wonderful history of your life in the disabilities community in the Greater Pittsburgh area.

PART 4 OF 4 ENDS [01:32:15]