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

Mary Hartley (00:00:01):

The purpose of the media history project of the Western Pennsylvania Disability History and Action Consortium is to record firsthand accounts of disability history. The careers of disability rights advocates Randy Gorske of Crawford County and MJ Bartelmay of Mercer County are part of that history. Randy Gorske served as the executive director of The Arc of Crawford County in northwestern Pennsylvania for 26 years, from 1988 until his retirement in 2014. His career in disability services began a decade earlier when he was a student at Edinboro University, earning a bachelor's in social work and a master's in counseling. During college Gorske worked at a group home operated by the Erie-based Barber Center and was a camp counselor at Camp Cornplanter in McKean County, a wilderness camp for children with learning disabilities.

MJ Bartelmay is the parent of an adult son, also named MJ, who was diagnosed with intellectual disabilities and autism. A long-time advocate for disability rights for his son and others, Bartelmay is past president of The Arc of Mercer County and The Arc of Pennsylvania. Currently he serves on the board of the Pennsylvania Office of Vocational Rehabilitation and Education Law Center, Pennsylvania, and is an emeritus board member of The Arc of the United States.

Mary Hartley (00:02:05):

MJ Bartelmay became involved in disability advocacy when his infant son started early intervention services at The Arc of Mercer County in 1992. Thank you, Randy and MJ.

MJ Bartelmay (00:02:32):

Thank you.

Mary Hartley (00:02:34):

Randy, you served as executive director of The Arc of Crawford County for 26 years, from 1988 until 2014. Tell us how you came to choose this career.

Randy Gorske (00:02:56):

Well, interestingly, I started the career accidentally, if you will, in that I was an unemployed college student and [a person referred by my high school guidance counselor] knocked on my door one day and said, "Hey, we heard that you are a social work major and might be interested in working for this camp, Camp Cornplanter. I was an umpire for Little League for exactly two weeks before I realized that this was not going to be my career choice. So I decided to try it. [I] visited Camp Cornplanter and became a counselor. And that consumed my summers for three years through college.

Randy Gorske (00:03:38):

And so that led me to, in college, really pursue and look at [working with people with disabilities]. One of my professors was very good friends with an awful lot of the staff at the Gertrude Barber Center. And so almost all of my internships that I had to do as projects for [my social work] degree were done

through the Gertrude Barber Center or an associated type of agency working with, primarily, adults. I really never did much with the children at the Center, but primarily working with adults in a variety of capacities.

Mary Hartley (00:04:13):

Can you talk a little bit about [your uncle named] Coach?

Randy Gorske (00:04:16):

Yeah. So interestingly also here I am now working in the field of people who have intellectual disabilities and visiting Polk Center, an institution in northwest Pennsylvania, and talking to my grandfather and not really understanding that his brother whose name was Coach, we all knew in our small town, he swept the sidewalk outside the little newsstand. Inside, he was a fixture there, everyone knew him. Everyone said, "Hey Coach, how you doing?" I found out months later that Coach actually, the family decided, the professionals decided, I guess, for them, that he should be placed at Polk Center. And they did it. And my grandfather [said] they didn't like [Polk Center] to begin with, but they were, sort of, coached. They were encouraged that this would be best for Coach.

Randy Gorske (00:05:10):

And so Coach spent a few years there and my grandfather, he says it this way, "When we thought he was about to die there, because they felt he would die very prematurely, they decided to move him back home into the community." And so unbeknown to me, I'm in the field working and never really knew much about my Uncle Coach, who was an adult with intellectual disabilities, the person everyone in town knew. If you went to the newsstand, you knew who Coach was and the family recommitted. And that was an important part of our family is that they saw what Coach's life would be outside the family and realized that it was not a good thing for him. And the family realized that and made a concerted effort to bring him back home. And the community was happy too, to know that this person who was a fixture, no one really understood where he went and why he went away. And so that story never really was told all those years that I was growing up.

Mary Hartley (00:06:09):

You could talk a little bit, there was a neighborhood girl?

Randy Gorske (00:06:12):

Yeah. So I always say that when I think about disability, and some of my friends remember this time, we are poker-playing kids. And so we used to get together at various people's houses to play poker on the weeknights, sometimes weekends. But I remember as a little kid walking down, I lived on Willow Street, was a very hilly street, walking down and I get midway down and there was a girl that would be sitting on her porch in a wheelchair. And now I know it as spastic quadriplegia, then I didn't know what the heck was happening, but I'd be walking by and she would spasm and I would get scared to death. I probably was seven or eight years old. I immediately get to the other side of the street and always walked down that side of the street, fearful of that person.

Randy Gorske (00:06:59):

When I became a teenager, it happened one night, we decided to play poker at her home with her brother. And so we're gathered in the living room, and before I knew it, this girl had inched up to me

with her wheelchair and she was nonverbal, drooled a little bit, but was happy to be close to somebody. And I just naturally started, I would show her my hand, "What you think? Is this a good...? Am I going to win this hand?" “Guys, I got a coach here.” Slowly and honestly, one or two times did I ever really interact because we didn't play poker often at that family's home. But I realized how quickly my fears were allayed by just her coming up to me. And now I understood a little bit better.

Randy Gorske (00:07:44):

And all the years when I was a little kid, I would see them, they'd have to carry her to the car. Just fear, total fear. And so for me, it was the beginning of my realization that, “Hey, even though I don't know if this is going to be my career or what I want to do, I felt really comfortable with it.” And I felt that maybe it was not even hard for me to interact. And so I always think back to that, is that I went from a fearful person as a kid to really understanding. And that led me to feel very confident in my career and moving on towards that.

Mary Hartley (00:08:18):

Can you talk a little bit about Camp Cornplanter? Because it's an interesting piece of history in Pennsylvania and New York.

Randy Gorske (00:08:34):

Okay. So Camp Cornplanter. Again, I was given the opportunity.  A neighborhood person popped up to my guidance counselor and said, "Randy Gorske would probably do well as a counselor." And so they visited me and went out bought a sleeping bag and something, probably clean underwear. I'm not sure. Off to camp I went. It was a little bit intimidating. These were old Civilian Corps cabins, rustic cabins out in the Allegheny National Forest of McKean County. And here, lo and behold, would be six cabins, three for children, three for adults.

Randy Gorske (00:09:08):

My first year I was put with young adults. Probably up to age 18, something like that, assistant counselor. And again, our goal was we had programming all through the summer in the rustic wilderness camp. Pit toilets, outhouses, showers that weren't necessarily warm. And I think about that. That's amazing any parent sent their child to camp, but that began my really understanding. And it's fearful at times too, I admit. Late at night you've got people climbing over you because we put the beds across the doorway so that we would know if somebody tried to get out. But out in the lobby of that cabin was a little toilet that you had to empty every morning into the outhouse.

Randy Gorske (00:09:49):

So at night you're sound asleep, someone's crawling over you. You wake up seeing a lot of people with disabilities who had a lot of different issues. Things I didn't understand, a lot of different syndromes that I never had experienced. I learned a ton. But one of the common themes that I found having worked there, three summers, everyone who worked there came away with it as being a life-changing event for them, in many ways. Some people stayed in the field like I did the rest of my life and continued to do so. Some worked there in the kitchen, but have the memories of the people. One of the men who was killed in the shooting here recently [at Tree of Life Synogogue in Pittsburgh] was a Camp Cornplanter [camper], regularly came all summer.

Randy Gorske (00:10:34):

And immediately on the Camp Cornplanter website that we maintain people started having "I remember Cecil, Cecil Rosenthal." "I remember Cecil." The nurse says, "I also remember the diet Cecil came with." People remembered the individuals, people embraced it. And for me, I was there in 1977, long time, but people remember all the folks that lived there or came there. All the people that participated. Staff became very good friends and we still, we continue to get together. We have a scholarship fund in memory of one of the founding families, the Bollinger family. So our Annabelle Bollinger Scholarship Fund is meant to help people in school that's going for a degree related to special education or social work, that type of thing. But the camp, again, I was amazed at families. Pittsburgh families were very big sending kids. Buffalo families. Nine weeks, we'd be there. And it was rough sometimes up and down the hills, woods, bears, deer.

Randy Gorske (00:11:38):

You were literally out in the middle of nowhere. Medical emergencies, we had no ambulance, nothing. We would put them in the back of a pickup truck and drive nine miles through the woods to the nearest hospital. And that happened regularly because we would take folks that had seizure disorders and other things. So, but from that, it was a hard job in the sense of, you worked a lot of hours for very little money, but the most rewarding job, probably, anybody that ever worked there felt that way about it. And we had people that would travel the world, but come back to the summer, they use that as their grounding point, come back, work nine weeks then off they would go travel the world again the rest of the year. And so it was really humbling to realize what fun we created, what fun we had. And it was all done with this idea that being an outdoor camp, which it truly was.

Mary Hartley (00:12:37):

MJ, you are a longtime volunteer in The Arc at the local, state and national level. What initially brought you to involvement with The Arc back in 1992?

MJ Bartelmay (00:12:50):

August, 1992, our oldest son was born. MJ stands for Merton John. It's an old Welsh name. I'm named for my father. So I'm MJ Jr. And we had no idea that our son is going to be born with the disability. The day he was born, we discovered he had Down syndrome. As time progressed we learned about the autism, but we had decided we were going to name him, Merton John III, and so he's MJ III. Most people hear me calling him Mer. But my reaction to things typically is, what do I have to do to fix it? Now I knew better than that I wasn't going to fix Down syndrome. But I worked with the gentleman at a bank holding company who was on the board of a local chapter of The Arc and they ran the early intervention program.

MJ Bartelmay (00:13:50):

And it was at that time still center-based. Now it's done in the home and in the community. Said, "I've got to get my son in this." He said, "Well, you have to go to a base service unit and fill out these forms and determine eligibility and so on." And I said, "I don't have time for that. We got to get him in it." So he started at the age of six weeks, and later I dotted the i's and cross the t's. And I was just thrilled. We were watching him thrive and develop. And anyone familiar with autism knows that it tends to set on a little bit later in the development of the child, but I made the fateful comment to one of the staff members, if there's anything I can ever do for you, let me know. We went to Florida to visit my family. My mom and dad were retired and down there, and came back, there was a voicemail, "Congratulations. You've been elected to the board of directors."

MJ Bartelmay (00:14:58):

Back at that time, the Arc chapters, especially in places like Mercer County and Crawford County and Warren, Forest, they were still family-driven. They might be providers, they might even be very large agencies, but they were run by the families for the family members. And so I got started there and over time, as I was helping my son navigate through the early intervention system, into the school-age programs and learning about IEP, et cetera, I would get asked by other families if I could give them a hand, and I would. And eventually I became president of that agency. And while I was president of that agency, I was asked to take a position with The Arc of Pennsylvania. The Arc of Pennsylvania was struggling at the time financially. Organizationally they needed an overhaul. They've been around for close to 60 years and were still functioning the way they were when they were this loose-knit group of families who just cared about our kids because, quite honestly, nobody else did.

MJ Bartelmay (00:16:22):

Our only entitlement in Pennsylvania was institutional placement, which was not acceptable for us. And it wasn't acceptable for many. And I think Randy and I are probably [going to] talk more about that, but that led me to service at The Arc of Pennsylvania and on the state task force for the Right to Education and which helped and continues to enforce the PARC Consent Decree from 1972, that has led to the Individuals with Disabilities Education Act for all kids in the country. And again, because of my efforts, I was also then given a presidential appointment to the board of The Arc of the U.S. where I served for eight years, treasurer, secretary. And in both the case of The Arc of Pennsylvania and The Arc of the U.S., I think I was brought on as much for some organizational skills, as advocacy skills that came at times that we restructured, developed new bylaws, new financial reporting, and new ways to finance the organizations. And I had some success on it. And it's kept me involved to this day.

Mary Hartley (00:17:46):

Great. Okay, now, for both of you, Randy and MJ, the two of you came to know each other through the involvement with The Arc over more than 25 years, what values, beliefs or affinities do you share?

MJ Bartelmay (00:18:05):

Well, I think going back to the 90s, when I first met Randy, I was in a chapter that there was a Supreme Court decision called the Olmstead decision, I think it was 1999, but it had been in process. And we had already begun to see the effects of the deinstitutionalization movement, which was very scary for a lot of families. It meant bringing their children home to, what they perceived as, a very unsafe place. I knew nothing about the institutions at the time. So one day I heard about a monitoring visit up at Polk Center up in Venango County, had no idea, but I'm the parent of a young guy, and I said, "I got to find out what this is about." So I drive up there and I met Randy that day, I don't know if he remembers it. I just remember being overwhelmed by the whole experience.

MJ Bartelmay (00:19:12):

I did the monitoring visit. And then a few months later there was a large event in Oil City that I think you [Randy Gorske] might have facilitated with pro-institution people at it. And many state legislators were there. And I remember sitting with my state legislator at the time, because this really was a challenge for people. Should we be doing this? Should we be trying to shut down institutions? How are we going to care for people in the community? The infrastructure isn't there yet. Will the money follow the person out of the institution into the community? So that's where we met. And I realized pretty early on that Randy and I had similar values.

Randy Gorske (00:19:59):

Yeah, I think you referenced a couple of things. So when you said you want to fix things right away, one of the things that I think we shared is that, there was a lot of controversy, a lot of issues, a lot of discussion about things. So sometimes contentious at times, and it's easy to get caught up in that. It's easy to get frustrated by that, but I think MJ and I both felt maybe we're a little more balanced in the approach that, there's a lot to be discussed. There's a lot of processing to be done. Let's not panic right away. And actually that [community meeting about downsizing institutions] in Oil City opened my eyes a great deal though. Here we had an advocacy movement. We had Arc chapters there, representatives, both board and executive directors. And [the people opposed to downsizing] were mean to the [facilitator].

Randy Gorske (00:20:47):

I happen to be one of them. I wasn't offended by it but I remember from Philadelphia and I blanked on her name all day today and I'll figure it out eventually, but she came very well known in the movement. Again was promoting a lot of things. She was actually the facilitator. I was there as the help, but people were just calling her out, wanting to start things. And she was very calm and collected. And I think, MJ, we just sat back and listened and understood and realizing that it was fear. There's a lot of fear about change. The legislators were fearful of their job because Venango County, Polk Center was a humongous employer. Good well-paying state jobs, history of it. They did not see what was to be had if you move people out. They saw it as a loss of jobs and they saw it as their constituents being really angry about it.

Randy Gorske (00:21:46):

And I remember, [an interim director of Polk Center attended a tour we] led a tour at Polk Center. And again, this is how some of the values, and we were talking with the legislators about, and the institutional director, who was interim said, "Wouldn't you want for your family to live in a three-bedroom home in a community versus living here?" And I was like, "Wow." That was shocking to me that somebody within the system would put it that way. Again, legislators didn't see it that way, but we went to a lot of things together. And I think that the value that we shared is that this is all about the son or daughter that we had as a child or the people that we care about. It's all about them. And it took a while for the system to catch up. And not that I was a forward thinker, but I wondered about a lot of these things and these values were there waiting to be unleashed from me. And I think MJ realized that.

MJ Bartelmay (00:22:41):

Yeah, I think that's a real good comment. It unleashed a set of values that was in us at the time. And just so you understand, The Arc in Pennsylvania had roughly 40 chapters. And we had about 2000 nationwide at that time. And this almost tore The Arc movement apart, we had chapters leaving, threatening to leave. We had chapters thrown out of The Arc because of the position they took in support of institutionalization, including the one that I was on target to become president of and I didn't support institutionalization, but we worked through issues locally. We worked through them with The Arc, and I'm proud to say that there's still a chapter, but it led to a convention in Birmingham, Alabama, probably in 2002 or 2003, where another Pennsylvanian was now the executive director of The Arc of the United States. Steve Eidelman, a name that'll be familiar to many people.

MJ Bartelmay (00:23:47):

And we attacked the whole issue of what does it mean to be an affiliate of The Arc. And The Arc went from over 2000 chapters to roughly 700 chapters. Some of the chapters aligned with another

organization, some went independent, but it was quite a tumultuous time in the organization. And Randy's right, there were people on both sides that were at times very, very angry with each other. These were executive directors in neighboring counties or... And it was difficult. And so there were a few cooler heads among the volunteers and the professionals alike.

Mary Hartley (00:25:09):

So I'll just throw this out there. But one of the things that we've noticed when we've gone up to Polk [in recent years], but also have had a lot of conversations with them about were the "Friends of Polk." So there was sort of this division in our own Allegheny County and regional area. And there was this parents-against-parents kind of thing happening. And there were the parents under the Polk umbrella who were very strong amongst themselves and still in some ways exist.

MJ Bartelmay (00:26:55):

Well, the "Friends of Polk," if you want me to tell you a little bit about that, because I knew two of the leaders of that organization well. They were from Mercer County and from Lawrence County, the two chapters in Pennsylvania that were threatened with expulsion by The Arc of the US for adopting a pro-institutional bias. And I don't need to mention names, but the one family in Mercer County, I guess first name is okay, their son, David, was a wonderful young man, but he occasionally would get violent and he caused physical harm to family members. So Polk was what that family felt was the safest environment for him, not only to protect him from harm, but to protect them from harm. They would go up every weekend and they would take them out on day trips, even overnight if staff reports indicated that David had been stable.

PART 1 OF 4 ENDS [00:28:04]

MJ Bartelmay (00:28:02):

David had been kind of stable, but things would set him off. But by the same token, and I know Randy probably could give you more horror stories. I can remember going up with a mother one time, they called their living units cottages, even though they weren't cottages. They were just sections of this massive building built at the turn of the last century. But in any event, David had fallen out the window of his cottage they believe, or he was trying to get out and he wasn't on the first floor, he was on the second floor, and he'd been injured. And I went up and all the medical care was fine, but mom was just in a panic and we had both volunteers and paid staff who would help that family out.

MJ Bartelmay (00:28:55):

Another time, even though the family had full guardianship, which was a whole other discussion, the dental staff pulled all of David's teeth. And David is now in a group home in Mercer County. The last time I had any contact with anyone was about two years ago and he was in a home by himself, but he had received some great behavioral supports. Some communication skills were developed, and anybody who's raised a child like mine could tell you all behavior relates to communication, plain and simple. And I'm sure anybody in the field would agree with me. So there were successes, but there were a lot of families like that. That was the only safe thing. If you put my son in a group home, he'll get out and he'll wander and he's going to wander the neighborhood and he might hurt somebody. And then he's going to be hurt because police will be called or whatever. So they were legitimate fears, but that needed to be addressed, not fought over. The writing was on the wall that the institutional model was not really a humane model, so.

Randy Gorske (00:30:20):

…[Y]ou mentioned David and there are other families. You mentioned Lawrence County. The common thread often was a very difficult person to care for in the home environment. And at that time, the institution still was a preferred method to deal with it. There were, wasn't really a lot of good behavioral specialists in the community yet. But if you can imagine the families they're talking to their legislator and advocates talking to their legislator, and they're saying two different things.

Randy Gorske (00:30:51):

And I remember one time, actually it was at Polk Center. We had a big forum there and a lot of the various representatives were there. I think mainly they're there themselves because the issue of closing institutions was the subject and there were lots of heated arguments about it. But I remember one of the senators that I respected and knew a little bit, actually out of Mercer County, I said to him, "What do you actually think about all of this?" And he says he just sits back and looks at the professional disagreement. If we can't come together and figure it out ourselves, what do they expect the legislators to do? They're confused, conflicted. They recognize on the right hand that there is an economic loss to the community if they close, downright close it down, they recognize that there is sort of an unfounded system. The community is a big, big potential, but they don't know.

Randy Gorske (00:31:45):

And so the unfortunate part is you had groups playing the legislators of course. They were trying to promote or advance their theme. And others were saying, "No, this is the way it should go." You know, they went back and forth. I mean, I think one of the things that helped most with that was actually when you had strong leadership from the state government. You had people that were in the positions of deputy secretaries who looked at this issue and they helped those families. They had been the one who was contacted by the legislator's office. And they would say, "Well, let me spend some time and send representatives out." And I remember the fellow from ... One of the fellows actually, he was from Venango County, had a son, very large son who beat up his wife, very fearful of what will happen. And they put him at Polk. And I remember vividly at some of these meetings him speaking out against all these plans and being angry.

Randy Gorske (00:32:38):

But I also remember the deputy secretary taking him aside and saying, "Let's talk." And they worked through it. And I believe the last I knew was that they did place him out of Polk Center into a community-based facility. Again, it had to be specially dealt with, it may not have happened in Venango County, but it had to be within recent distances. Because that's the same criticism we had about four families is you place your loved one two hours away at Polk Center you have no ... The accessibility is diminished.

Randy Gorske (00:33:11):

So a lot of that was there was so much disagreement, and there still is today. You still have opposing groups. Actually I think one of the groups you mentioned about at the national level was the Voice of the Retarded.

MJ Bartelmay (00:33:25):

Exactly.

Randy Gorske (00:33:27):

And I think that's important to understand that there's a group out there that see the people with intellectual disabilities that we're advocating for and working with as merely “the retarded.” And I always, in some ways I always thought it's great that they do that [in that] it just shows how, in some ways how ignorant they actually are. That they're promoting something so backwards, so disagreeable and here we have a movement that is really trying to move beyond that. But they create a lot of ... They stirred up a lot of anomie, and a lot of legislators heard their voice, and their voice was loud and it may still be to this day, I'm not sure.

MJ Bartelmay (00:34:07):

It still is loud. And your comment about their name, that is who I was referencing and that they probably use a slur as part of their name just astounds me. But I think one of the things, and you'd probably remember this too. Many of these families like David's mom and dad, I've sat with them while they cried, “We did the best thing we could at the time, there wasn't anything else.” And suddenly they felt like from some of the people who were less reasonable, that they had just been these horrific parents, abusing their child by sending them to Polk. And to a certain degree, and it's a much lesser degree, believe me, I can see the same analogy happening with what we're going through with the sheltered workshop environment right now in the system. You know, a lot of people look at that as: “This is a safe place for my child. This is a safe place to not only protect him, but to protect others.”

MJ Bartelmay (00:35:21):

And all of the fears we're so much more aware of in society today. But at the end of the day, I think we all know that we were created to live in community. We weren't created to live in isolation. And that's been proven through so many different models, not just the institutional or workshop model in the field that we've been involved in. But I think throughout society we know how that fails.

Mary Hartley (00:35:57):

Great. Thank you. That was really instructive. So Randy and MJ, do you think that chapters of The Arc in rural areas have different advantages and challenges compared to ones that are located in more urban areas? Please elaborate.

MJ Bartelmay (00:36:14):

Oh, absolutely. I keep a picture on my cell phone of, I don't even own the car anymore, but a horse and buggy tied up beside my Lincoln Continental. Because I'd come to Pittsburgh and we're talking about, and I'm not going to get too carried away, but new CMS [Centers for Medicaid Services] definitions, so on. And I'm always talking about transportation, transportation. We have one taxi cab in our county; not *company*, one *taxi cab*. We don't have Uber. We don't have Lyft. That's a huge issue, so yeah. But there's also certain advantages as well. I think that, I didn't grow up in a rural area, but we have 112,000 people in the whole county.

MJ Bartelmay (00:37:04):

And I take my son out in the community and everybody knows him. I'm not MJ Bartelmay anymore, I'm MJ's dad. I'll be in Walmart and somebody I've never ... Had no idea come up and say, "Hi, MJ," and my son is nonverbal. So I have to turn to them and say, "Hi, I'm MJ's dad, and you are?" And I'll hear, "Oh, he used to be in school with me," or whatever. And I think it's great. I love it. It's exactly what you want

to have happen. It doesn't matter if your child has a disability or not, you want to see him out involved. And I see that all the time.

MJ Bartelmay (00:37:42):

And so yeah, I think, but so we have certainly the small town feel, might be a little less hectic and pressured and a little easier, but by the same token, I have to drive to Pittsburgh for dental care and medical care, you know? So I have an 80-mile drive for anything short of quick check his heart, put the blood pressure cuffs on and make sure we could continue the script or whatever, but you know, so.

Randy Gorske (00:38:20):

I think you may use the taxi story, which is a great story, because rural areas lack resources: medical, dental, transportation. And so I think what a lot of The Arc chapters formed is that we have nothing here, but yet we're parents who don't want to send their children away to an institution. Now, what are we going to do? So slowly, like in Meadville we had a little camp that had ... It was at the park just during the summer. Families came together and it's your turn to sit and watch the kids. It's my turn. They created what was called the Blue Barn. It was the first education program in Crawford County. It was still blue and still a barn and it was before my time. But I hear the parents talking with pride about the fact that they created something.

Randy Gorske (00:39:05):

And I think in a lot of ways, that's the history of The Arc is families coming together, creating and advocating, but it even gets harder to be able to grow your Arc, money does need to be raised. And there's a lot of ways. For many, many years we'd do a pie sale. I'd get hundreds of pies made by moms and dads of The Arc movement. We'd go out to a shopping mall and sell them. In Pittsburgh or in some of the urban areas they'd have a dinner and raised a hundred thousand dollars. So resources are limited, but I think that's also the rural sentiment, the rural feeling of taking care of their own.

Randy Gorske (00:39:42):

That a lot of times we didn't need to have money because we'd take care of her own. And there were a lot of families that knew about The Arc that never took advantage of it, but they knew we were there. And actually, I use this always, a man approached me and said, "Randy, I appreciate that The Arc is there. We don't need you right now. But if we ever feel we do for our daughter" (who now is in a life skills program with The Arc), "we will approach you. We like what we see." So a lot of times, depending on the age of the child, because they're in school it wasn't needed. But I think that resiliency of there are a lot of farm families that took care of their own. And I used to go out to farm auction or livestock auctions, not because I wanted to buy cows and goats, although that was fun. Because that's where I would find people in the community that I never knew existed. They would be with their families.

MJ Bartelmay (00:40:32):

I have a friend in Mercer County, we have a substantial Amish population. And Mose's brother-in-law has an intellectual disability, Amish. He's not served by anybody, but Mose will go down to the corner where a community payphone is and call me and I'll come out and visit periodically. And he allows me to bring his brother-in-law model airplanes, because his brother-in-law just will spend hours outside looking to catch an airplane flying by. And I think that's one of the other things that happens in rural areas is there's a lot of folks who, because of a more reclusive nature and not just Amish, but they don't,

they just have a tendency to be self-sufficient and I'm going to take care of this. And I don't need an agency. I don't want to go talk to somebody from the county, you know? So.

Mary Hartley (00:41:35):

Thank you. So the Supreme Court Olmstead decision came about in 1999. The court ruled that unjustified segregation of people with disabilities in institutions and nursing homes is a violation of Title II of the Americans with Disabilities Act. The decision requires public entities to provide community-based services to individuals who want them. How did the Olmstead decision affect the work at The Arc chapters you were affiliated with?

Randy Gorske (00:42:10):

I think the interesting thing about that is that what we've learned very quickly, our families that didn't care what the Olmstead decision was all about. They did not want to leave go of institutional care. So if anything, it made us have to work a little bit harder because now again we had to get back to understanding that feeling. I think you referenced a little bit parents feeling like they weren't a good parent to their kid by sending their kid to an institution. Never really wanted to focus on why you had your son or daughter go to the institution. We want them to focus on, "Hey, look, what's available. Look what can happen." Some of those parents embrace that. Again in others it sort of started somewhat of the infighting that ... Because we had to discuss it, but it created opportunity.

Randy Gorske (00:42:57):

And I served as personal advocate, I think because I was an Arc person that was visible at the institution. There are people without families. And what I remember is suddenly they were talking about [coughs], "She *could* live in the community," but before they said, "She will *never* live in the community." There was a pressure put forward that we needed to consider. What would it take? How could it happen? And suddenly someone who may have been self-abusive, who's nonverbal, that people viewed as unable to leave those walls of Polk Center were being looked at, "Well, you know what? She's 78 years old now. And she probably would do fine in the little group home," if especially we've got to deal with the behavioral, the self-abuse, some of that issue. But it created an atmosphere where professionals had to ask those questions. And I can say some of the institutional staff didn't want to ask those questions. They didn't want to bring up those subjects, because their feeling was, these people are here for a reason. They can't leave, that's too unsafe, whatever the term was.

Randy Gorske (00:44:10):

So it made our job easier, but at the same time more difficult, because now we had to help deal with some of those feelings of, those parents did feel inadequate. Why isn't it fine for my son or daughter to stay here? What does the Supreme Court know? What do *you* know, Randy Gorske? Do you really understand my dilemmas? So I think the Olmstead, actually up until my retirement, I think we were still talking Olmstead decision at a lot of The Arc meetings, that things weren't moving along quite the way we had expected it to. And so it started a process. It started us thinking differently and it still required an awful lot of advocacy, I assume, to this day too.

MJ Bartelmay (00:44:55):

Yeah. I don't think that's changed. I mean, Pennsylvania, this year we closed the [Hamburg State] Center as many people are aware. But we've still got four [institutions] open, I think. And we've still got ways to go. But I think that there was some resentment on the parts of parents. They started these chapters of

The Arc. The Arc movement itself is just over 60 years old. So Olmstead was 20 years ago, now the ADA [Americans with Disability Act] was 26, 27 years ago roughly. So you know, these were the founding members still who were meeting in church basements and library meeting rooms, wherever they could, supporting each other and caring for their kids. Because their kids didn't even have a right to go to school. That right wasn't won until 1972 in Pennsylvania. And it took a while for it to spread.

MJ Bartelmay (00:45:54):

So their only right was to place that child in the institution. And that had to be just a gut-wrenching decision. I just can't even imagine. And we've talked briefly about my son, but my son is non-verbal and can't feed himself, and requires pretty much 24-hour-a-day, seven-day-a-week care. So, had he been born probably even 10 years earlier, I may not have taken him home. It's just amazing. And one of the other issues I remember, Randy, and you might be able to speak to this better was, we had a huge labor issue. We had these community providers and to this day, direct service providers are not well-paid jobs. They're minimum wage or slightly more. In the same job back at Polk, I could remember, it might not have been the first time I was up there with you. But it wasn't, it's been a number of years ago, seeing jobs posted for $40,000 [per year] with government benefits that would pay $18,000 [per year] and no benefits in the community.

MJ Bartelmay (00:47:13):
And so there was a lot of effort to protect that. And those were also union jobs and what the AFSCME [American Federation of State, County and Municipal Employees] union and civil service. And so Randy had alluded to earlier, this was a tough decision for legislators. So at our local chapters, it had an impact. We had over--I don't remember the exact number, I remember it was in the 50s--families that were members and active in our chapter. There were over 50 individual members, family members in Polk. And suddenly we're talking about pulling your kid out, and I'm a board member sitting in front of these people when I'm this young guy with a three, four, five, six, seven year old kid [saying], "This is progressive." And I think there was a lot of, "Who does he think he is," you know? College-educated, white collar kind of jobs in a rural community that was full of steelworkers and farmers. I don't think that that necessarily was well-received to be honest with you.

Randy Gorske (00:48:34):

Well, when you attack and not even attack, but when you question someone's foundational beliefs, like there was a belief that Polk Center, the institution, would take care of my son or daughter the rest of their life. And now you've got a decision that is sort of throwing that out of the way a little bit. That was a tough one because we celebrated in the advocacy community, if you will, that, "Hey, the Supreme Court recognize this," and self-advocates who spent a lot of years talking about their life in an institution who were able to speak about. Everyone was excited, but then that was the other part of that really was very difficult. And I honestly don't, it may be different at Mercer and Crawford. I don't recall that it changed our life in the sense of anyone coming out [of the institution].

Randy Gorske (00:49:25):

We had already been successfully taking people out of the institution where we could. There were people that were more medically involved and who were behaviorally involved, where the questions then began to be asked, "Can they live? And what would it take?" And in some cases, the answer wasn't coming back to Crawford. The folks I was at, the individuals I act as an advocate for, actually moved into

Pittsburgh because there were more availability of homes to meet their needs. And I was fine with that, because again, the goal was look at, “Why is she still here at 78? Why don't we do something?”

Randy Gorske (00:50:02):

But that, it brought up good feelings and bad I guess in my mind. And I really never felt comfortable. Like you said, when parents, like you’ve dropped the shoe. I was telling them the institutions no longer can take care of their child.

MJ Bartelmay (00:50:17):

I know from our perspective as a board, we really felt a sense of urgency to improve our residential options. And we had run, what's now known as life sharing, at the time we called it family living. We had supportive living, which was helping individual out in their own apartment with whatever level of care they needed. Sometimes it might only be a few hours a week to make sure that they're paying their bills and buying groceries, et cetera. But we developed a couple of what we refer to as the medical model and behavioral model group home. We did things like these were still three or four bedroom homes where everybody had their own bedroom and they were in community neighborhoods, but we get ranches and we'd make sure all the doors were 36 inches wide.

MJ Bartelmay (00:51:17):

And that we didn't have [door]knobs, we had paddles. And we would install sprinklers systems discretely, we didn't have pipes running along the ceiling. We poured a huge amount of money into some of these homes. When I tell you we would put two times the cost of purchasing the home in renovations, and then we would have awake around-the-clock staff. And typical group homes would have a time when there would be still staff on site, but they could sleep. And we would even have homes where we would have on-site nurses, whether it was one day a week or seven days a week during the awake hours to help, and nutritionists, et cetera.

MJ Bartelmay (00:52:08):

So this was a real shock. And in many cases the funds weren't available. So one of the things that The Arc could do was they could go out and raise funds, because we were family-driven. So in Mercer County, we formed a foundation just for that purpose so that we could generate funds and then take care of those extras that we needed to. So we had a lot of success, but it's still it's tough. It was tough on everybody.

Mary Hartley (00:52:43):

So Randy, you had experience at Polk Center as a personal advocate for a few people who were transitioning out, and as a member of the Human Rights and Behavior Committees. What did you observe over those years?

Randy Gorske (00:52:55):

Well, interesting. I always tried to make sure everyone knew Human Rights Committee was an external committee that really looked at some of the issues. And if you follow the paper with Polk Center, there were some big issues. Medical care was an issue. There were some doctors that were fired over some medical care issues. I was always proud to say that we knew about them and the Human Rights Committee minutes were reviewed by the state or federal inspectors. And the interesting part that we

didn't go do detective work throughout the facility, it was the fellow employees that also served, representing Polk Center, that often brought to our attention things like that.

Randy Gorske (00:53:36):

And so, as one I remember very vividly, we had a psychologist who was very confident we'll just say. She was very confident about her position. She wasn't threatened, but the medical director said, "I'm taking away all of these drugs," and he named them, because they're the highest cost drugs that we utilize in the institution. And there were people who literally had been on … Alidol, some of the older meds that are very, very known for being very strong and very difficult to wean people off of. And people were successful on those meds.

Randy Gorske (00:54:14):

And I remember that coming to the Human Rights Committee. We were all shocked. We never would have known that because that was somebody saying, "This is a violation of," and she had the name of the clients that she felt this would be most counterproductive for. And we went through that. And again, certainly I think we invited the medical director and beat him up a little bit verbally about the idea, but we were staunch in that that made no sense to us. That the cost of a medicine versus the healthcare of a resident should not ever be taken into consideration if there's any potential issues.

Randy Gorske (00:54:51):

So I came away from that really respecting the institutional staff. Again, you always have somebody that doesn't do their job. But in general, I found that most of the issues that came to Human Rights Committee sometimes came from residents, we always had a resident that served on Human Rights, but more likely came from some of the staff that were observing things that bothered them. They did not feel it was right for that. There are other things that were systems issues. There are people placed at Polk Center because when they were younger, they did something in the community and it was considered dangerous to the community. Although today we look at and think of it as being such a minor thing. And they got labeled as somebody that could not return to their community, whether it's sexual predation or violence, whatever, and Human Rights Committee often got faced with that.

Randy Gorske (00:55:39):

And again, unfortunately there are some issues that the state government regs got in the way of people's human rights. And so in some ways I was happy to be part of that debate. But then other times I was not always happy that the outcome was not always what Human Rights would like.

PART 2 OF 4 ENDS [00:56:04]

Randy Gorske (00:56:03):

And I don't know to this day if it's still true, but back when I was on Human Rights, [a] male and a female who wanted to have consensual sex was one of the issues. There was a feeling then, that there's no ability to consent. And I don't know if that's still true to this day.

Randy Gorske (00:57:38):

We had great advocates. We had great staff on that. I think we had a pretty good job. And we saw results in the sense that the surveyors would mention, “We saw the Human Rights minutes of March,

April and June referencing someone bringing to bear …" And I don't know if you recall this, but one of the issues was that a doctor who was doing stitching up residents without anesthesia. And the one that came to Human Rights was someone who was total care, had to wear a diaper, and for whatever reason, sometimes the tabs would slash his skin, and it was his penis at one time. And so it was a fairly involved wound and that doctor stitched him up without anesthesia. And again that came to Human Rights. So the first thing, we have to be fair, yes, fair is fair. To us, it makes no sense. That doctor I believe was fired, I think, if I recall.

MJ Bartelmay (00:58:33):

I think he was.

Randy Gorske (00:58:34):

But another doctor was implicated in some other issues, ended up suing successfully the state over some issues that, again, there was not a common ... the way it's dealt with, there was not a common way. Even though we may look at it from a medical profession, they may say they often stitch up little kids quickly without anesthesia. I don't know if they still do that, but in the old days. Because by the time you give him a shot they're going to squirm and jump around and boom, boom, you're done. I never bought that argument, but those were the tough decisions that came to Human Rights. And again, we debated. And again, we were an advisory, no authority necessarily. So our advice back sometimes was taken and sometimes it was said, "Well, thank you for your concern and we have to follow our own protocol," type thing.

Randy Gorske (00:59:27):

Behavior management. I learned a lot, one of the families that was part of the Friends of Polk that we referenced earlier, his daughter was a very self-abusive woman that lived at Polk Center. And serving on the Behavior Management Committee, we looked at all restrictive programs. And I would drive down once a week to serve as an outside advocate, listening in. The people, they would explain the program and then they would be approved by the committee, despite my ... If I said "no," it still was approved because I was out-voted often. But what's significant about that is that [a] family member was so upset with the Behavior Management Committee questioning a program that worked [for their daughter, who was a Polk resident]. It was a spray mist program. And if you know about spray mist program, [it was meant to address a resident's self-abusive behavior]. If you go to hit yourself, they spray you with some sort of water. It used to be a noxious substance, maybe vinegar. Thinking that that would stimulate you to not want to do that. Whether it works or not, I don't know if it every worked.

Randy Gorske (01:00:31):

But that family member thought it [the spray mist program] was so important to his daughter that he advocated very strongly, spoke against it ever going away. And the last I knew, and I don't know if his daughter is still alive, that at the time the deputy secretary annually had to give approval to the Center to implement that spray mist program because it was controversial, and still is. So it goes to show you that sometimes families are like, "What's the injury of my daughter? Self-inflicting her own injury is more important to me than them using a behavioral method that may seem noxious to an outsider."

Randy Gorske (01:01:14):

So those were the debates. Those were strong debates about how do we deal with somebody who's behavioral ... because again, mainly it was behavior plans and restrictions that were put into place to

protect their own life. And so those were important things. Luckily, we never had to deal with the self-abusive [residents] [by] using shock-type stuff, that never was utilized in Pennsylvania to my knowledge during my time. And so that would've been a tough one too, because again, that is controversial for sure. But I always felt good though that they [Polk Center] allowed me to come in. And you [MJ] said about, "Who are you?" The first thing the doctor in charge asked me is, Who am I? Why do I ... Who am I to be on this Behavior Management Committee? And I said, "Well, I worked at the Gertrude Barber Center." And they accepted that as I had the experience at least; I'm not just a yay-hoo coming in to make trouble.

MJ Bartelmay (01:02:09):AF

And funny quick story. We had a new director of curriculum when my son was in school. And I went to my first IEP [Individualized Education Plan] meeting and she was the LEA [Lead Education Agency]. And a number of people weren't there, but they'd signed the attendance sheet that they were. And I said, "What's this?" And she said, "Oh, they've reviewed the plan and they don't have any problem with it." I said, "No, they need to be here." She didn't know me. She didn't know that I'd actually helped, because I was on the State Task Force with the new IDEA [Individuals with Disabilities Education Act] forms when it was reauthorized a number of years ago. And I put her through the ringer. And at the end of the meeting she said, "Are you an attorney?" And I said, "No, I'm one mad dad." And she became a staunch advocate of my son. But you needed to do that.

MJ Bartelmay (01:03:09):

I mean Randy it was in ... It's almost unbelievable for a lot of people when I share some of this, it was in 2005, 2006 that we were still tearing apart position papers that were shared at the state, national and local level over things like forced sterilization to prevent a sex drive ... and other things like that, to try to give people rights. And it's lack of knowledge and it's fear. And I personally believe the best thing we can do is to bring our children out in the community. Even some of the most challenged ones become the strongest advocates just by seeing them live happily.

Mary Hartley (01:04:07):

Randy, I have a couple more questions for you about your Polk work. Can you talk a little bit more about what it was like to transition people out of Polk? Like sort of before and after stories?

Randy Gorske (01:04:17):

Well again, the nice part was we're talking about people that, at one point, I was their advocate just to ... they would have somebody to call to report that she [a certain resident] hurt herself again. We weren't even talking about transition. And so when the Olmsted [decision] did come that suddenly now our meetings, we're going to talk about whether or not she [a certain resident] can transition out of Polk Center, timeline, and how we're going to do that. So that was a totally different conversation. My advocacy went from being… I think every time there was a death at the facility, it was reported to me also. So that I was looked at as being the liaison to The Arc community. But again, it had to be very purposeful of a transition. And again, we know the term transition, but it's easing someone into it. And so first is, what is it going to take for that person to be successful to leave Polk Center?

Randy Gorske (01:05:18):

Now as MJ mentioned, the cottages are usually 16 people in an area. [A certain resident] was getting older so she's in a retirement area. So I looked around and I'm like, "Okay, she's with 16 people and a

couple of staff. And so when she [starts] hitting herself, being self-abusive, we don't know what triggered that, but [possibly] 15 other people making noises? So smaller has to be better.

You start thinking about little things, smaller has to be better. What little things make her less likely to hit herself? What things make her happy? How do you build that into a program that she's going to go to? And actually that's very easy to do, you just start talking about people have observed her for years. They know her. And this is again several ladies that were up in their age.

Randy Gorske (01:06:06):

And so we've literally just started going from square one, if you will, looking at that. It didn't matter what the address was. She has no family, I'm her advocate. I'm saying, "It's fine. Whoever offers the best program, that's what we want." And so that became, "Okay, now we need to figure out." So the word went out through the county of who was interested. I think, in her situation, I'm trying to remember if they were taking more than one or two out. So she may have moved in with other people that were already out or not. In other cases, they were trying to move towards three at a time. But I mean, that took months, that took over a year time period to really address those issues.

Randy Gorske (01:06:47):

Once it happened, it happened. And for a while I kept in contact to find out if there were any issues, mainly “any problems? any problems? any problems?” When I stopped hearing about any problems and she was doing fine they stopped calling me;  I stopped calling them. So it was a pretty smooth transition, but again, properly prepared, properly thought-through. And also the positiveness that now it could happen. Before almost everyone that I was involved in being taken out of Polk Center at some point, anyone who had come in from Polk Center generally said, "Well, I hope it works. I don't think it will, but I hope it works." There was just that attitude that the community was a scary thing. And it was for some of the people leaving, but the staff didn't think it would ever work. Very few. I met some later that began to understand, and some that participated--very, very involved in making sure it happened. But I think that attitude change is what really started things moving where people really started to believe that.

Randy Gorske (01:07:49):

And understand that you're 78 years old, you've lived at Polk Center for 60-some years. You still have self-abuse issues, but yet those can be dealt with in a smaller place. You could go to retirement community. You can leave your 16-bed unit and drive DELETION HERE in the van somewhere and have a better, or a more involved life. Once they believed it then it was much easier to be able to see that through. And in every case, again, there were naysayers. So you had to address the issues that they brought forward. Why the person they felt that all their years of experience, just address those issues. But again, it took some work to figure it out. When I look at it in retrospect, it wasn't really that hard, but yet it took time. It was a time-consuming issue.

Mary Hartley (01:08:38):

So can you talk about Christmas holiday and taking people home?

Randy Gorske (01:08:43):

Yeah. Well, I made an interesting observation when I was younger. Maybe I was smarter when I was younger. Here I'm going home for Christmas. And I got people in my group home, this is when I worked

direct care in the group home, who have nowhere to go. Interestingly, the one that came home with me for a lot of the years with my family, his aunt told me [that] his mom placed him at Polk Center when he was five. And the family wanted nothing else to do with him. So here he is living in a group home in Erie. His aunt lives up the street. His aunt calls up, says, "Come up, I'll give you Christmas gifts for him." Well, here I am, I can go home, take somebody with me. Do it voluntarily so we don't violate any Labor and Industry laws about working and volunteerism. And the Barber Center was fine with that.

Randy Gorske (01:09:31):

But for about 20 years at least I would bring home one of the residents to our family. And we traveled, we never stayed in our own home. We traveled generally 100 miles. And again, as part, every holiday I did that for those 20 years. And again, it was a no-brainer in my mind. It meant we had to drive two cars because I had four kids. I had David and all our stuff for holidays. But it was so much enriching to our family. My kids remember it. My kids have always been involved in the disability movement by default for being around me. It touched my in-laws, so much so that later they became life-sharing providers for the county they lived in. And that county allowed two individuals per home. So for many years they had two ladies living with them until their health became an issue.

Randy Gorske (01:10:28):

So it really, again, no one really questioned that David has Down syndrome and he lives in a group home. The family goes, "Is David coming? What should we get David? What can we do?" He had no teeth. You mentioned about teeth being pulled at Polk Center. When he came out, he had no teeth. And I was always amazed. “How in the world do you eat with your gums, anything?” And he liked to eat, and so again, the holiday feasts you watch him enjoy simple things. He played harmonica. And so every year we bought him a harmonica. So the kids would, "Quiet now, David's going to play his harmonica," right until he opens it. So for me it just brought it all together for my family and for us, that here's a little thing that we do for David. And after I left, as I became a supervisor of the group home and went on to bigger and bigger things, but I always tried to find where he was living.

Randy Gorske (01:11:25):

The Barber Center eventually went to four-bedroom group homes from seven and eight. In the early years it was seven and eight people per group home. So David moved to a completely different community where they didn't really want these people to live, but they worked through it and I would go up and visit him in his new neighborhood. And none of his neighbors knew him. So I felt like, again, it's like they're in a neighborhood, people are still a little fearful. This is the first time they have a group home. And I felt really good about going to visit him, getting to do things with him, just take him out. And so again, to me, it puts the humanity on that we're not just there to collect a paycheck and go home at the end of the day and say, "Oh, do I have to go back tomorrow?" No, it was really all about what we were trying to do with the people that lived there, and make them part of that community.

Randy Gorske (01:12:13):

And I got lots of stories about making people part of the community, because I really worked hard to do that. It was controversial in some ways at times because not everyone likes to see people have, I say, freedom. When you give people freedom there's fears of what's going to happen. You let them go down the street to the neighborhood bar. What's going to happen? Well, the bar patrons who get to know him will bring them back without me having to walk down. I know that'll happen. So you just have to build over those fears, but regulation gets in the way a lot at times. Or it used to get in the way that, “No,

someone who is in an ICFMR [Intermediate Care Facility for Individuals with Mental Retardation] care cannot walk down the street by themselves unless they have a formal plan." And hey, the bar's two doors down. You've been doing it for 20 years. Now we are under ICFMR. So, okay, "line of sight." Perfect. I can look out the window. So you work through those things.

Randy Gorske (01:13:09):

And then again, I was happy that I always worked with people that saw it that way too, but not everybody does. And that's the hard part of community is that we tend to lose, I think you said sometimes we don't remember what community's all about, and it's even getting worse in society these days. And so to integrate people into community when you don't even have a community sometimes can be a little more challenging until you remember what it's all about.

MJ Bartelmay (01:13:39):

I always think of the group homes when we would bring some people into them. And they'd say things like we've learned that they smoke cigarettes. And 20 years ago that wasn't such an uncommon thing. And how do you accommodate this? And you have regulations. And it's a home. If you want to smoke, smoke. I mean you have to work with your roommates, et cetera, but that's true in any family. Right? And sometimes we wouldn't look at it that way. I wanted to comment, Randy, one of the things you said is you developed those plans. We talked a lot back then about person-centered planning, because we were moving from programming to person. Instead of thinking about what bucket can we throw him in where we're done and we don't have to worry any longer, we started to look at people as individuals and what they wanted, and giving them value and worth. And it made a big difference. And it continues today. I mean, we use many of the same buzz words, but we have a tendency to change things and make up new acronyms like any other field.

Randy Gorske (01:15:07):

Well, the system had a built-in, made it harder. I'm here, I'm a 20-year-old, graduated from college. The next day I move into a group home, which I was familiar with because I've worked there, seven people living together and you're talking ... but then we weren't talking about individualized program. Seven people, I was one-to-seven. Now it would be unheard of to do that. But we were one-to-seven going to the local pub regularly. We were one–to-seven  went out to eat. Again, it just challenged me more that I got to find a place. If we go out to dinner somewhere it can't be the little neighborhood place that has three seats. We have to think bigger, think differently.

Randy Gorske (01:15:46):

Interesting, I mentioned about David, the day he was dropped off at the group home is again instructional in my mind. He moved from Polk Center to … At the Barber Center they had residents, 43-bed unit where people came to transition. So he was living there. They said, "David, we got an opening. We're going to bring him out to see the group home." Literally dropped him off and left. David looked at me and scooted down West 26th Street in Erie, which is a major street. And I ran after him with a bag of cheese puffs or whatever. It was, "David, do you want to have a snack? Come back, come back, come back." It worked. I'm like, "Okay." Like me, he likes cheese puffs. He likes food. Got him back, calm, sitting and realize, "What a hard transition." Five years old, I move to an institution. And he'd fold his clothes, he's the best folder I ever met in my life. He'd fold his clothes immaculately.

Randy Gorske (01:16:41):

Now you're in a new home, strange people, maybe some you know from Polk Center. But just dropped, and the fear. And I felt that in my own heart. I'm like, "Yeah, I moved to Erie. I was a small-town boy and I'm up in Erie in West 26th Street, it scares me at night when people are screaming and hollering." And then I couldn't externalize or internalize that feeling he was having to what I was feeling like being new to a city. And that's why I guess I felt for David that like, "Here's a spirited fellow that is going to be fun to have around, he'd like to keep to himself. Nonverbal also, so you couldn't have a conversation, but you could have the conversation in a different way.

Mary Hartley (01:17:53):

We have a couple of key questions for Randy, this idea of sort of reunions with families from Polk, kind of the before and after . That, and how people felt after people left. Like, they *got* it. When did that sort of epiphany happen for families that they were like, "Oh, it's working"?

Randy Gorske (01:18:19):

I think when it started to work.

Mary Hartley (01:18:22):

Right, right. So if you can talk to us a little bit about that. But the first thing would be this idea of family reunions.

Randy Gorske (01:18:32):

Yeah. I had that personal experience with a couple of those situations.

Mary Hartley (01:18:38):

Yeah, if you could talk about that.

Randy Gorske (01:18:38):

All right. So one of the things that was, again, a lot of these interactions sometimes really kind of broke my heart but at the same time encouraged me. But one day a knock on the door at the group home I worked at, David's brother showed up. Because he visited Erie from Oklahoma and saw his aunt up the street. And he said, "My aunt told me my brother David's alive." I said, "Oh." And went on to say that when he was placed at Polk Center his family told him his brother had died. And he was slightly younger than David, I believe. Not much, but slightly younger. So all his life in Oklahoma, he was actually a Walmart manager long before I even heard of Walmarts, he thought his brother had died.

Randy Gorske (01:19:20):

And so again, we wanted to do something for David. What's he like? Get him a harmonica, get him snacks. You do this, do that. He has no teeth. So we were talking about that. He and his wife spent the day. Just joy. I mean, pure joy. And I was like, "Oh wow, this is going to be great." Now David wasn't so joyful in the sense of like, "Oh, who is this guy?" He doesn't know who is this guy. "Who is this lady?" Once they bought the harmonica and brought it, then he got the connection that this is somebody I wanted to take and be friends with or take notice of. But that lasted essentially a few hours during the day that they were there. They moved back to Oklahoma. Every year we would send something out to them, once in a while they would call him.

Randy Gorske (01:20:04):

And the system is kind of weird in the sense that, all right the brother was found. So now all the decision-making about David goes through the brother who saw him for seven hours on a certain date. And even as David's health declined, he started to show signs of dementia and decisions had to be made for him. I knew him better than the brother did 20 some years plus, but the brother would be called, and he never did come back to visit him. But I realized that, again, not so much David didn't embrace it so much, but that brother, to see the fact that, "I never understood anything about my brother dying, I didn't even know what Polk Center was," and to see that and work through that with a family, as a counselor, going into counseling, so it was really kind of neat for me. But I saw that, I saw that whole embracement of David now is somebody that we want to know more about, at least for that time period. And that was very heartening for me to see that.

Randy Gorske (01:21:04):

One of the other guys in the group home, Leo, a similar type of thing. You ask how families sometimes felt about it. Leo came from a family that all the brothers were in the war. And he was slow, a slow learner. He was not intellectually disabled I don't believe by testing. I don't think they ever ... But he at 16 got retinitis pigmentosa, which rendered him blind. And so they shipped them to Polk Center where he stayed until he was 60-something years old. I forget whether it was 62 or 65. But Leo was smart. He was slow by their definition, but smart by my definition. He took in everything at Polk Center. He was a historian. Unfortunately Leo has long been gone. But when I saw ... His family was actually from my same county, I grew up in Elk County. And I'd end up talking to [Leo's] brother when I would take him over to talk before holidays. His brother [would say], "We'd like Leo to come over. Just for the day though, we don't have the accommodations."

Randy Gorske (01:22:09):

They were a drinking family, whiskey rounds. So I'd go over. And "I'm on duty, remember this. I'm on duty." "But you got to drink, you got to have a whiskey," Leo says. And his brother said, "Yeah you got ..." But that family, again, all those years apart, they didn't visit Leo much. They didn't really. But once he was in a community and they knew where he was at and that somebody would take him to them (they didn't come get him generally), they embraced him again. And it was just like they picked up where they had left off if they were a family together. "Hey, the holidays are tradition. Everybody drinks a shot of whiskey, and we go on."

Randy Gorske (01:22:45):

So that was my experience with most families that saw people come out. Either they were totally standoffish, and a lot of families moved away. They moved to Florida, would check in. Or they were very grateful. And I never really felt any family members say their [the former Polk resident's] life was worse since they left [Polk]. Any time there was an issue, "Oh, that would have happened at Polk Center." Well, they fell because they had a medical emergency. They would've fallen wherever. But in general I think, I only saw good things come from the people that left, and people being very grateful for it. Because they knew the difficulty of the care for their loved one, and knew that somebody was going out of their way to care for them. So I don't know if you had similar experiences with families?

MJ Bartelmay (01:23:35):

No, not to that extent. I wasn't involved in the frontline of families like you were.

Mary Hartley (01:23:43):

So Randy, you and your family have been a life-sharing family for 25 years with Matthew who joined your family at age 13 and is now 38.

Randy Gorske (01:23:52):

Correct.

Mary Hartley (01:23:53):

And life-sharing is a living arrangement in which a person with an intellectual disability shares a home and is supported by another person or family. What has life-sharing meant for your family?

PART 3 OF 4 ENDS [01:24:04]

Randy Gorske (01:24:04):

Now again, my kids were already well-versed growing up about what disability was. But, in Matthew's situation, again, I liked what you [MJ] said about fixing things. Sometimes I like to fix things too. And I get in trouble with the regulations sometime. But Matthew had left his home when he was age eight. And we were his fourth life-sharing family. Well, about a year, and a lot of behavioral stuff, whatever. And so, here was Matthew now failing, if you will, two weeks in an inpatient mental health at a community hospital. And they're saying, "What's the plan? He's leaving. You got to have a plan." I was The Arc director at that point. What's the plan? I'm thinking, okay. Gee, I could take care of Matthew in my own home. And I talked to the kids, the family about it. And so, we agreed we'll do it.

Randy Gorske (01:24:57):

First night didn't go so well. Matthew likes to do things, but I also understood how to deal with behavior. That, if you don't allow it to occur, you make sure there's some understanding that can't happen. We do it. And, still to this day, I have to remind him that when we go out to a family gathering, we just went out to a birthday party in Erie, went out to eat. The whole way on the way home before we left as a family, "We're going out to dinner, there's no swearing, there's no this, there's no that. If you do, I will take you and we will leave." That's the rule, because after 25 years. And the kids begin to appreciate it because they know now what to anticipate too. And they're pretty good about doing it.

Randy Gorske (01:25:41):

But again, taking someone who has some difficult behaviors into your home always puts a stress on your family. There's no doubt about it. But my kids all embraced it. I mean, they've been happy with it. One of the things I thought might happen, I'm not sure it's going to, is now that my children have their own children, they're not as willing as I have been to want to do that in-home care. So, my only concern for the future of Matthew is that, at some point, I may not be able to do it. And I had expected that, and again, it's a bad expectation, you shouldn't expect that your children will take over necessarily. They help out respite whenever I need it, that type of thing. But, yeah. I mean, I always thought it was weird.

Randy Gorske (01:26:25):

Actually, Nancy Thaler, I always give her credit. I listened to everything Nancy Thaler said, who was the Deputy Secretary for the [Pennsylvania Office of Developmental Programs]. She said, "Shouldn't we learn to walk the walk and talk the talk?" And it's interesting that I got criticized. I'm the director of an

agency, not for doing this. I have someone living in my home who was being served by the agency. So, the conversation started coming up. “That's a conflict of interest.” “Well, how is it a conflict of interest? Explain it to me so I understand it,” back and forth, back and forth. I finally gave up arguing and moved his service. A separate agency oversees his services, which is fine. I'm no longer affiliated with The Arc. I retired. We could go back there, but we've been with that agency for a lot of years.

Randy Gorske (01:27:13):

So, in some ways, I thought that there was a time where the system was recognizing, we got to do more. We got to do more with trying to promote life-sharing. And, at one time, in Crawford County, there were at least 50 people or 50 families that were doing life-sharing. It was a big program, continues to be, because we had families that really were concerned, got to know folks, and wanted to see if this could be a possibility for them.

Randy Gorske (01:27:39):

So, it challenges my family. It makes life more difficult sometimes. Here I'm in Pittsburgh. My wife is at home. His program ends at three. She's got to be there at three for the person to drop him off. So, overall, I think it's given my kids an understanding. And actually, my daughter works in the field. She has worked with The Arc in Anchorage, Alaska, for many years and loved it. Still works part-time now with children. My son has worked in group homes. Both sons have done that.

Randy Gorske (01:28:12):

So, it's given them an understanding. And I say, I've recruited some good workers for the future. If they can't find a job ever in what they want to do, they always would consider working in the field because of seeing and understanding David and Matt, how we as a family cared for them. And they genuinely enjoy when they come home to visit, the fact that all the memories of Matthew, whether it's good and sometimes good, bad, or just funny, funny moments. That's part of our whole family structure now. He is part of our life. And 25 years later, it's hard to believe it's 25, so.

Mary Hartley (01:28:47):

That brings to mind something I noticed when I was in Altoona recently. That there's a lot of life-sharing in rural areas. Can you guys talk about that? Because we don't see it a lot in an urban setting.

MJ Bartelmay (01:28:59):

I was a little surprised when you said that earlier, because I don't remember what our census was 25 years ago, but it was not uncommon. And, in some cases, it was similar to what Randy said. There were a number of people who had made a decision that they were going to be in this field for a living. And it was a very natural thing for them to do, to start to invite somebody to come over for dinner, or to bring them home for Thanksgiving dinner, because they were just going to sit in a group home who didn't have any family and relationships that develop.

MJ Bartelmay (01:29:42):

And they'd say, “You know what? I think I'd like John to move in with me.” Or “I think I'd like Betty to move in with me.” And they would. And then, they do, of course after they did all of the proper procedural things to make sure that they were acceptable and things were put in place by the agency.

And I'm sure it's true today. I haven't been involved at that level, but where the home was subject to inspection and not just when they moved in, but I don't remember if it was annual or how long.

Randy Gorske (01:30:18):

It's annual.

MJ Bartelmay (01:30:19):

Different things to make sure that... and I think the stipend has improved, but I still don't think anybody is doing it to get rich. They receive a stipend, but they probably, in many cases, don't even break even, to be honest with you. But I think some of that just comes from the nature of small-town community. You have a tendency to help your neighbor more. I've lived in outside of New York City, Columbus, Ohio, where you didn't know the guy in the apartment next door to you. And, like I said, in Mercer County, I'm MJ's dad. Everybody knows my son. So, and I'm sure that's true up where you live.

Randy Gorske (01:31:06):

Well, I think the beginning, because I was at the beginning of life-sharing, and we'll call it family living. We never called it... we changed it because families said, you're paying somebody to care for my loved one in family living. And some objected to that, even though they wanted them to move on to something different. So, it became life-sharing through family living. But the initial stipend difficulty of care was really small, at least in Crawford. It was $10,000, everybody, no matter how complex your care.

Randy Gorske (01:31:38):

What I think has happened in rural communities is, I'm not taking in this person just for a couple months. This is a life-long commitment. And I think of a family that they've had a man. They were his foster parents. They became life-sharing. And that sort of said, now it doesn't end at 21. He is 40-something years old. They have to get help in the home, which luckily the system provides, to lift him out of bed at night and for morning care. They could not see anyone else caring for him in his life, and the chances are good that another family could take that level of care and do it because he’s a big strapping young man.

Randy Gorske (01:32:24):

So, I think in rural areas that, a lot of times, you had people had relationships with their families or other people. They get into small-town relationships and it was all about, “I want to do it.” And I got to know him and I don't plan. Economically, it has gotten better. And so, some families that has been looked at as, “Hey, I can stay home and care.” And some of the support systems that have come into play make it possible for a family to still have a life. The person goes to some sort of day program. So, it makes it easier to be able to do it. But, yeah. For a while we had just tons of people scrambling, but we also had people scrambling that we would never approve to be life-sharing providers.

MJ Bartelmay (01:33:08):

Sure.

Randy Gorske (01:33:09):

I remember a vivid call. “I saw your ad in the paper … I got a spare bedroom out back and I'll be happy to have one of your people (and he used a slur) live there.” So, we realized that it's not about advertising

and finding people. It's about creating relationships first or identifying those. And that's how it was successful. There were a lot of relationships when we started looking. Wow, this person comes to take him to church. And he would like to live with that person, how can we make it happen, or with that family? Life-sharing. And it got better and better. And then, actually I would somewhat disagree with you a little bit. The reimbursement has gotten better with the new rates.

MJ Bartelmay (01:33:55):

Oh, I know it has.

Randy Gorske (01:33:56):

Yeah.

MJ Bartelmay (01:33:57):

But, I mean, it's still not that much.

Randy Gorske (01:33:58):

Oh, yeah. You don't. But those people have been doing it for all these years. If you give them a little extra money, they're already going to do it. And I think it's just so respectful of them to know that, hey, you've done this for 20 years, 25 years. So, actually, I went like, “What? That's going to be the new rate?” Actually, I immediately wrote the agency says, “I see, you're going to get a lot of extra money here. What are you going to do for Matthew? How can you help our family?” And they, to their credit, they started talking to me about things. And I was like, I was really happy with that.

MJ Bartelmay (01:34:31):

I think my favorite life-sharing story was I got a call just a few years ago. Somebody had been given my name because of my involvement with The Arc of the U.S. And it was a family in Mercer County. And they had an individual with them. I never met the family or the individual, but they had him with them for a number of years. And the family had to move to Virginia for work. Well, anybody who has been around knows that the funding stream doesn't cross state lines. And that's a whole other discussion. But they knew that I probably knew some people in Virginia. And that's what I did. I called The Arc in Northern Virginia, because I'd had good experience with them, with their allowing self-advocates to be involved. And I'm not sure if they landed with a chapter of The Arc as a provider, but The Arc helped them navigate the Virginia system so that the care continued. Reimbursement might not have for the entire time, but it eventually was picked back up.

MJ Bartelmay (01:35:52):

And I just thought that was so cool that they're getting ready to leave and, not only are they worried about what school are my kids going to be in and where do we want to live, we've got this adult man who has grown up with my children, with an intellectual disability. And he is part of our family. He's going with us. I never did get to meet the family. I would have loved to, but that wasn't what was important. And I just think that life-sharing opportunities are fantastic.

Mary Hartley (01:36:25):

I agree. Very cool. So, MJ, as a board member and as an officer of The Arc at the local, state, and national level, you've helped ensure that the organizations are operating at a high level, so they can do

their important work. You've said that your faith drives your efforts, that you are called to serve, and that your son, MJ, was the catalyst for where you chose to serve. Can you elaborate?

MJ Bartelmay (01:36:52):

When my son was born, my ex-wife and I got married relatively late in life. When my son was born, I was 36 years old. She was 33, which is relatively old for a first child. And we had no idea that our son had a disability. And, about 12 hours after his birth, the head of pediatrics at Sharon Regional told us, we strongly suspect that your son has Down syndrome. And there were enough physical indicators that they were 99% sure. And I had grown up and would have called myself a Christian. I wouldn't say that we were active church-goers. If the weather was nice out, we would probably camp. But, if it was too rotten out, we were just not going out. But we grew up like a lot of people who grew up in this, were born in the '50s and '60s, the baby boomer generation. That was just part of our life.

MJ Bartelmay (01:38:05):

But I remember holding my son and looking at him and realizing what I was facing. I had had experience with people with intellectual disabilities and in a work environment, a job I'd had previously. I'd had some experience even with an institutional environment, the old Youngstown Developmental Center. It was a small institution in Youngstown, Ohio, just over the state line. And I remember thinking, “How is this in your image, Lord? He's broken.” And rejecting God.

MJ Bartelmay (01:38:45):

And I found myself in a real funk and in a real dark place that I shouldn't have been in. But my wife and I, at that time, had been married less than a year. And we had decided we both, even though we weren't active church-goers, thought that this is something that you should do raising a kid. And I had a great pastor. And the guy was a lot smarter than I realized that the time. He kind of led me along. But I remember sitting with him. And I can't tell you how many times we talked. But asking him questions, how does this happen and so on. And him saying, I don't have the answer. But maybe we can figure it out. Well, of course, he had his scriptural take on it.

MJ Bartelmay (01:39:42):

But, long story short, after a few months of talking together and him giving me passages of the Bible to read. And I had read the Bible before and I just couldn't stand that, the language and everything else. So, I don't know if any of you ever read the Living Bible. It was a Bible that was popular in the '70s and it was kind of a paraphrase. There were no thee’s and thou’s and any of that. But he gave me a copy of that. And I remember one day we were talking about Paul's letter to the church of Ephesus, Ephesians, in particular, chapter two, verses eight, nine, and ten. Because one of my concerns was I had always heard that, for my son to be saved, he had to proclaim Jesus as his Lord and Savior. And I'm like, how does a kid who, I don't know if he'll ever talk, read, any of this, going to do that?

MJ Bartelmay (01:40:43):

Well, lo and behold, Trumbo knew. Reverend Trumbo was his name, knew right where he was leading me. And those verses say in short that you aren't saved by works. It's nothing you do. It's by faith. But God prepares good works in advance for you to do. And I felt like the weight of the world went off of my shoulders. And I said something to Trumbo about verse ten, God prepares good works in advance for you to do. And he looked at me and he said, did you ever think that your son was your ministry? And that opened my eyes.

MJ Bartelmay (01:41:28):

And, as I said, I volunteered with the local chapter of The Arc. And, whenever something would come up that they would need help with, whether it was fundraising or, in my case, I helped with quite a bit with some difficult issues over the years in terms of position statements and things like that. I think Randy will remember when I was with The Arc of PA, we were kind of in the middle of, seemed like every day there was a new storm brewing because of the changes that were just happening to the system at the time, as we moved into a person-centered and started to give the folks we served a voice.

MJ Bartelmay (01:42:18):

So, that continues to drive me. I believe in the value of all life. I don't think that my life is worth any more than any other human, regardless of ability or disability. And I think it's an issue we're dealing with again in society, but it's a cyclical thing that I think we go through. And I'll continue to advocate for the civil rights of people and, in particular, people with disabilities.

Mary Hartley (01:43:31):

So, Randy, you've said that your years of working with people with disabilities has shown you that it does not take all that much to help someone thrive. Just offer opportunity, you've said. Can you elaborate?

Randy Gorske (01:43:42):

Well, again, I said, when I started in the field, I was like the field of intellectual disability, can it possibly be that much of a learning type of thing? But yet, there were so many changes, there are so many debates, all these things. But, when I started to look back at it, I still am involved in kind of a different way. I don't do direct service necessarily. I mean, I do life-sharing, I'm guardian of several individuals for the courts. But what I realized, even with something like that, I'm the guardian of two people and power of attorney of a third. That doesn't mean I have to take away their voice. I don't have to take away. All I have to do is be the guy that is somewhat balanced to say, “Well, let's hear what they want to say. Let's give them this opportunity. I support it, as their guardian, to try. And we know that there could be some issues. We'll identify those issues.”

Randy Gorske (01:44:34):

So, I guess that was the thing that, all throughout my career, I kept realizing is that there's so many obstacles put into place of people with disabilities, that society says, “You can't do it.” People, even within the field, say, you can’t do it. All we really need to do is sort of open the door and give them a chance and start to look at it. And so, like I was at the beginning of the life skills program, now Community Habilitation, whatever the... but that's what that was all about was that you don't know what's out there because you've never been given the chance. So, all we need to do is figure out how we give you a chance. How do we give you a chance to go be part of your community, to volunteer, to pursue an employment opportunity?

Randy Gorske (01:45:15):

And honestly, the answer was pretty simple. We just need to create a little bit of an infrastructure. And the last I knew, at least The Arc of Crawford County, the life skills program was booming. We couldn't find enough staff to be able to support the number of people that wanted it, just as an interest. And so again, when we started focusing. And I always liked the person-centered [concept]. That was choice, all

these words. It always made sense to me that, if we focus on the individual, it's what they want. And not always what they say, but what they ... observe them, and see what they like, and really use that as our guide, we'll go a lot further in life. And to me, that was like, in retrospect, you look at that, wow. That was like a 'wow' moment. That wasn't really that hard, but it was hard to come to that conclusion. And it took a lot of different incarnations of different ways of looking at things before we actually got there.

Randy Gorske (01:46:10):

And again, sometimes parents, I hate to say it, MJ. Sometimes parents were an impediment to that, especially older parents.

MJ Bartelmay (01:46:18):

Absolutely.

Randy Gorske (01:46:18):

You see that, that older parents were protective. And I always use a story to represent that. We had a board member, beautiful woman, I loved her, and her son, and her husband, that were part of The Arc movement. And I started talking about, "Now, it's probably time that we need to start introducing some level of sexuality into our education. These are now adults." And she looked at me and smiled politely. And, "Randy, that is the best idea, but don't include Johnny in that program." And I learned from that is that, we have to help the parent to allow it.

Randy Gorske (01:46:53):

And so, again, in some ways it's simple, just opening the door, letting them have a little bit of freedom to learn and us supporting that, knowing that it doesn't matter if you choose [and] you didn't like it. You don't need to feel bad. You thought you wanted to be a mechanic down at the local garage and we get you down there and you realize, "No, it's work. I don't want to do it." It's okay. And so, I think that sort of is guiding me a lot more throughout my career. And unfortunately, there are times where being an administrator, that becomes hard, not for me to expect, but the regulations sometimes try to prevent good things like that from happening.

MJ Bartelmay (01:47:33):

Yeah.

Randy Gorske (01:47:33):

And, I mean, I get frustrated. I don't want to be a paper pushing son of a gun. I want to be out there on the floor with people, and experiencing their lives, and helping them, so.

MJ Bartelmay (01:47:51):

I think you called it 'life skills' in Crawford County. But it's a habilitation aide program. And that's primarily the service I've secured for my son. My son goes out in the community and he experiences things. And we're working on some skills that are very simple life skills. Some, I would argue, are even pre-vocational skills. He goes to a facility, but he doesn't spend time at it, just to pick up their laundry. And he and a hab aide go to the laundromat. And he sorts and shoves it in the washer. And nothing makes him happier than putting quarters in a machine and seeing something happen. He doesn't care what it is that happens, just something. He's not interested in winning prizes. He's interested in that. So,

it's great. Like I said, he's out in the community. And it's been a wonderful thing. And it gives him a chance to be loved and to love, so.

Mary Hartley (01:49:04):

Well, thank you. This has been incredible, and instructive, and just terrific to watch both of your stories intersect and work in parallel. It's really exciting. Thank you. Thank you.

MJ Bartelmay (01:49:16):

I just wanted to be clear. I was never one of those problem parents. [laughter]

PART 4 OF 4 ENDS [01:49:24]