00;00;09;25 - 00;00;31;18

Bonnie Shannon

Eventually I decided I'm going to go into a field where I'm helping other families. I knew what it felt to be isolated. I knew what it's about. Having all these things thrown at you that you have to navigate. And I thought, I can help people.

00;00;35;29 - 00;01;03;22

Courtney Ringstaff

Welcome to Adjusting the Sales, a podcast for parents, caregivers and service providers for Children with Disabilities. I'm your host, Courtney Ring Staff, and this is my co-host, Melina Danko.

Melina Danko

Hi, everyone. We are so glad you've joined us.

Courtney Ringstaff

Melina is the assistant director of communications and marketing at the Center for Excellence in Disabilities and the project director of the West Virginia Family to Family Health Information Center.

00;01;04;03 - 00;01;31;00

Courtney Ringstaff

I am a licensed social worker in Morgantown, West Virginia, and I've created this podcast to be a platform for parents, caregivers and service providers and come together, exchange information, educate one another, and find support and connection through the relatable topic discussions. We cannot change the direction of the wind or the strength of the storm, but together we can adjust the sails.

00;01;35;19 - 00;01;58;02

Bonnie Shannon

Bonnie Shannon I'm a parent network specialist at the Paths for Parents Program at the WVU. I'm just here to talk about my son Tony, who inspired me to do the job that I'm doing now as well as my previous job with birth. Two, three. I always wanted children. I always wanted a fairly big family. I wanted lots of kids.

00;01;58;14 - 00;02;22;05

Bonnie Shannon

At least three or four before I had Tony, before I got pregnant with Tony. I actually did get pregnant before that with my first child, and I miscarried at five and a half months. I had to actually deliver that child, that placenta separated from the baby. When that happened, that was traumatic. But like my aunt has said to me, she said things happen for a reason.

00;02;22;05 - 00;02;43;14

Bonnie Shannon

So I went through that fairly well and the doctor tried to reassure me that it was probably not going to happen again, that I could get pregnant and I should be fine. I wish he would have been a little bit more cautious about things because that when I did get pregnant again with Tony, everything went well. Everything was going well.

00;02;43;15 - 00;03;10;11

Bonnie Shannon

Pregnancy was good at about four and a half, five months. I noticed that my son wasn't moving as much while I was working. At the time. I was doing a hostess job and some other another job on the side, helping a friend of mine clean. I mean, I was doing like really physical work, and I noticed that during the day you wouldn't take very much, but the doctor would check me and say You're okay.

00;03;10;12 - 00;03;34;17

Bonnie Shannon

They knew my history, so I thought, it'll be okay. It'll be all right. But unfortunately, at about 27 weeks, I went into labor in the middle of the night, had to be rushed to the E.R.. The doctors there did try to stop the labor or that medicine didn't work. I laid for a very long time trying to stop everything.

00;03;35;01 - 00;04;02;16

Bonnie Shannon

And then my water broke and they kind of had to go forward with it. So I was really quite a mess at that time. I wasn't expecting to actually. I thought they would just send me home. I thought it was just, you know, maybe something that they could fix with the medicine. But he ended up coming and he was very small at almost 28 weeks, but it was 27 weeks and he was £2, 13 ounces.

00;04;02;16 - 00;04;31;28

Bonnie Shannon

Very, very tiny. 37 years ago, that was a really tiny baby. He had a lot of issues. He had lung issues. Premature babies also have brain bleeds, which they usually score from 1 to 5. And Tony had a 2 to 3 that diminished. And I asked the doctor, okay, what does that mean? And he said, Well, it can mean anything from being slow in math to a more severe disability.

00;04;31;29 - 00;04;55;00

Bonnie Shannon

So I didn't really know. I was hoping against hope that it was just something mild that he wouldn't get over. He went through quite a bit in the Nikko, the neonatal unit. He stayed in for almost four and a half months. They have to learn how to eat from a bottle. They have to gain enough weight, usually over £5.

00;04;55;00 - 00;05;23;15

Bonnie Shannon

They will consider them to go home. And he did. He eventually learned how to eat from a bottle, but he ended up coming home on the supplement, which was he had the bottle, but he also had nasogastric feeds, which was taking a tube down through his nose, into his stomach. And I had to learn all that. And it's tough enough being a new mom, but I can honestly say that learning how to do a lot of nursing things.

00;05;23;15 - 00;05;48;16

Bonnie Shannon

He had oxygen, he had monitors. So by the time he came home, it was like bringing home the whole hospital. I mean, it was it was a lot to get used to and a lot to learn on my part. At that time, of course, didn't have any other diagnosis. They put him into a pediatric high risk clinic, so they kept an eye on him and they were watching him very closely.

00;05;48;23 - 00;06;13;22

Bonnie Shannon

He was doing really well. He was he graduated off of the tube, feeds the end aids. He was taking a bottle. He was doing really well. He was starting to grow. But then they noticed that he had a lot of reflux and he was not gaining. So they actually put him in the hospital. This was probably at about seven months, eight months old.

00;06;13;22 - 00;06;32;25

Bonnie Shannon

And he ended up going through what they just said was a battery of tests just to make sure they were kind of covering all their bases to see what was going on, why he wasn't gaining weight, if it was indeed just the reflux, then they did all kinds of other tests. In fact, we had such a list of tests that I was it.

00;06;33;00 - 00;06;52;02

Bonnie Shannon

It was hard to keep track of everything they were checking, but they did check his hearing. And at that time, the one doctor that came in to tell us about the hearing test was not his regular pediatrician. And he came in and he said, we did a hearing test. And I said, Oh, I didn't know they were doing that today.

00;06;52;02 - 00;07;15;27

Bonnie Shannon

And he said, Yeah, we did a hearing test. And your son's death? He clapped his hands by my son's ears. Of course, my son didn't react at all. He said, See, he's deaf. I was just in shock and so was my husband. Even if we had questions, I don't think I could have actually asked the questions at the time.

00;07;15;27 - 00;07;32;23

Bonnie Shannon

But the doctor really didn't ask that. He said, We'll talk more about this later with the other results that we have for the other tests. He just walked out of the room. He just didn't really give us much to go on. So it was kind of a shock with the death diagnosis. From what I had found out later.

00;07;32;23 - 00;07;50;29

Bonnie Shannon

That does sometimes happen with preemies. It can affect their hearing. And I didn't know that until then. I didn't know anything about that. I just decided at that point in time I looked at my husband and said, Well, I'm not going to treat him any differently. I'm just going to treat him like he can hear everything I'm saying, you know?

00;07;50;29 - 00;08;10;07

Bonnie Shannon

And just whatever I have to learn beyond that, I'll figure it out. So that was that was how we found out he was deaf. Later on, of course, he went in and out of the hospital quite a bit. WVU and Ruby just became kind of a second home because we were there so often in and out of the hospital.

00;08;10;16 - 00;08;39;00

Bonnie Shannon

So he actually did pretty well. He went in and out, wasn't really diagnosed with anything else. The pediatrician in the high risk clinic said he was developmentally delayed to me, delayed means, gee, maybe he'll catch up. It'll just take a while. He's. He's a preemie. He's tiny. He's had a lot of obstacles to overcome. So I thought eventually he'll pick up and he'll catch up on things.

00;08;39;06 - 00;08;59;19

Bonnie Shannon

So that's kind of deceiving to parents. You know, you think that they're going to actually catch up one day. He went into the E.R. once, and I'm not even I can't even remember what it was for the doctor in the E.R., as if he had cerebral palsy. And I was just dumbfounded. I was like, nobody has said anything like that to me.

00;09;00;11 - 00;09;20;18

Bonnie Shannon

That's the first time I'd heard it. I went back to his pediatrician and I said, Does my son have cerebral palsy? And he said, Well, that's kind of a garbage can term. And I was like, What? What do you mean that's a garbage can term? That doesn't make sense. And he said, Well, it can mean a variety of things.

00;09;20;18 - 00;09;39;10

Bonnie Shannon

And cerebral palsy can be, you know, maybe they just have a limp or maybe they have trouble holding things or it can be very severe. So I don't know where he's going to fall in there, but I was like, Yeah, but I would just like to have the diagnosis. I would have like to know that he had that.

00;09;40;07 - 00;10;15;27

Bonnie Shannon

That was another shock. And I think when parents of children with disabilities get that diagnosis, that's more severe. It's something that you can actually you can actually understand and start researching and start finding out about. But it's also a shock. It's also what I used to tell my friends. It's almost like went through a grieving process because when you're pregnant, you have this idea of what your child's life is going to be like, what your family's going to look like, what your family's going to be, what you're going to do with your child.

00;10;16;14 - 00;10;43;02

Bonnie Shannon

That all completely changes it. It's a complete turnaround. And you have to adjust to it. And it's not like all the dreams die. It's just that certain things kind of have to be adjusted. You had your thought processes, the way you looked at things, the way you celebrate their accomplishments and what they learn to do. And in it, it becomes a little bit more just adjusting to things.

00;10;43;13 - 00;11;14;18

Bonnie Shannon

So that's what we ended up doing was I just ended up saying, okay, well, we'll just do whatever we need to do and we're going to keep going and just go forward. You do need the emotional support around you. You do need to have that emotional connection with your family, with friends. And I did have that. I did have wonderful family members, wonderful friends, but none of them had been faced with a child with a disability years ago.

00;11;14;25 - 00;11;47;07

Bonnie Shannon

There wasn't as much inclusion in schools. I had never been exposed to a child with a disability in my family or at school, so I wasn't really sure what the journey was going to be, so I just had to take it one day at a time. My son was very alert, very aware, so that made things a lot easier because he sometimes people would say they thought he could hear they saw it, you know, because his senses of sight and he was very alert.

00;11;47;07 - 00;12;06;00

Bonnie Shannon

He would notice when a door was opened or notice and they're like, I swear he can hear. And I'm like, no, he really can't hear. And he's just making up for it. He just is very alert and very aware. That was just something that we had to get used to with Tony. That was pretty easy. He was pretty easygoing guy.

00;12;07;08 - 00;12;32;27

Bonnie Shannon

After being in the high risk clinic, he ended up into the early intervention programs. There was O.T. and Speech Petey, and he had that usually at home, sometimes we had to take him places to to do things. He was through the speech and hearing clinic. He went to Allen Hall to get hearing tests. They even did try a hearing aid at one time.

00;12;33;05 - 00;13;04;21

Bonnie Shannon

He really wasn't hearing much of anything, even with a very strong hearing aid. So they kind of we kind of abandoned that that effort. And and I said, why train him to get used to the hearing aid when it wasn't really helping him much? I started looking more into deaf education and how that would go. When he started, we we were lucky to be plugged in to Valley Healthcare, which helped us with waiver get signed up for waiver.

00;13;04;21 - 00;13;26;25

Bonnie Shannon

They didn't have a waitlist back then, which is amazing. And they said there was a slot open and I didn't know anything about waiver. They explained in a little bit to me and I was very thankful because with someone like my son who has such medically complex needs, keeping a job was almost impossible. It wouldn't have mattered what job it was.

00;13;26;25 - 00;13;51;11

Bonnie Shannon

It really was tough because it was constant care. It was total care. I didn't have nurses back then or any support staff or respite or anything like that and due to the fact that I had kind of a chaotic marriage, it was like being a single mom. It was it was basically on me. His dad loved him. He would watch him occasionally.

00;13;51;11 - 00;14;13;02

Bonnie Shannon

But I think as far as his dad and my family, people would get scared if they had to watch him or be around him for very long. You know, even if it was me running to the store or running to do something, I had to do, they would they were like, what do we do? You've got to show us how to do this.

00;14;13;02 - 00;14;37;06

Bonnie Shannon

You've got to show us what what happens with the oxygen. Does he have to have that all the time? Eventually, he didn't have to have oxygen all the time. He eventually had to just have it when he was sleeping, but he had to be on monitors. You had to check to make sure everything was going well. He did eventually graduate to eating pureed foods, baby foods, and then even ate table foods.

00;14;37;06 - 00;15;00;24

Bonnie Shannon

So he actually did really well for someone who has cerebral palsy because they have a lot of trouble with eating and swallowing. And he did really well with that. He even graduated to using a straw, which I was so happy when he did that it made things a lot easier. He really did learn that very quickly. So that was a really good thing that that helped us along.

00;15;01;05 - 00;15;32;02

Bonnie Shannon

And he and his even his doctors were kind of surprised that he ate eight table foods. And I was like, oh, yeah, he's he's doing really well. He would surprise you on some things as actual diagnosis or C.P was affected cerebral palsy that means that he didn't have like if any control so he couldn't sit on his own, stand on his own, walk on his own, without assistance or without equipment.

00;15;32;02 - 00;15;53;14

Bonnie Shannon

I thought that maybe he would learn eventually how to do that at home and at school. He had standers and walkers and and we did try to do everything we could to try to teach him how to do those things. But at some point we realized, you know, he's just not able to. He's just he has that he love to be in standard as in walkers.

00;15;53;14 - 00;16;18;23

Bonnie Shannon

And my sister would hold him and try to get him to walk and he would just laugh the whole time. He thought that was hilarious and he loved trying to do it. It's just that he just didn't do it on his own. As far as school, like I said, he had early intervention. He went to early pre-K. He went to, of course, a special ed classroom.

00;16;18;23 - 00;16;53;25

Bonnie Shannon

They weren't all inclusive back then. They really didn't mix until he got quite a bit older into regular ed classrooms and stuff. He didn't go into the regular Ed setting a lot. He did try to do certain things. If the teacher would agree to letting him join in, maybe on a, you know, physical education classroom or something like that, he he did stay very involved with the school, but it was a constant battle as far as services.

00;16;54;09 - 00;17;35;18

Bonnie Shannon

They didn't quite know what to do as far as the deaf education, because there's there was only one classroom in Montana that was considered a deaf education classroom. And nobody in that none of the students in that classroom had physical disabilities. So they weren't set up in that particular school for his disabilities. Now, they did offer me a whole IEP where we went down to the school, we talked to the teacher, we had a very good IEP meeting, but I realized at that time that the teacher felt uncomfortable with having him there.

00;17;35;18 - 00;18;03;03

Bonnie Shannon

And that's part of the battle is the teachers not in on, gee, let's try this, let's see how it works. And that's not that wasn't her attitude. And so I stopped the IEP meeting, which for me that's kind of the point where I got more of a voice for my son because in IEP meetings that I started out very early with him, you would walk into a room of 13 or 14 people.

00;18;03;03 - 00;18;25;02

Bonnie Shannon

That that was overwhelming for me. That was I didn't they were experts in their field. They they knew their opinions on what should be done. But I, I would just for the longest time go along with it and say, okay, let's try it, let's, let's do it this way. But at that point, I wanted him to have a deaf education.

00;18;25;03 - 00;18;54;16

Bonnie Shannon

I wanted him to be too, for that part of it to be addressed. His physical disability was being addressed through physical therapy, through the school, through O.T., through a lot of the therapies he was getting. But I wanted him to have a chance to have that deaf education. It really wasn't possible all through that classroom, so we had to look at something different and possibly getting an interpreter.

00;18;54;16 - 00;19;16;21

Bonnie Shannon

As he got older and I did start sign very early with him, he understood once and needs he could sign it, he could sign, drink, he could sign just basic signs back to me. And I wasn't really sure how much he understood of those signs, but the more that they did them at school, the more that I did.

00;19;16;21 - 00;19;42;25

Bonnie Shannon

He seemed to pick it up fairly quickly. He tried to read lips, which I know that's hard for the most deaf people. You think that they can read lips easily, but that's not true. But Tony had to depend on that from the beginning, so he depended on that before he knew sign language. Before I knew sign language. So he watched and he was very in tune with what you were trying to get him to understand.

00;19;43;08 - 00;20;05;08

Bonnie Shannon

The only problem with Tony is he was very agreeable. So a lot of the time he would say yes, and you knew he meant no. And I would try to say no, that's not what he means. So so that was something that I had to try to get him to say no more often. He did eventually, though, pick up a lot of sign language.

00;20;05;08 - 00;20;28;25

Bonnie Shannon

He he I think he surpassed me pretty quickly. I couldn't do as many signs as he could now because of Tony's physical disability that posed a problem, most people sign in front of them. They sign so you can see them. They sign in a certain area right in front of their face or in their chest. That's where they sign.

00;20;29;04 - 00;20;54;11

Bonnie Shannon

My son, because of his disability, would sign down to the side of his wheelchair or he'd have his hand down in a different location or to the side and or would use both hands. He would use just one. So whatever was easier for him, he would do. And the teacher had noticed that and she said I was trying to get him to sign outside and he wasn't doing it, wasn't doing it.

00;20;54;11 - 00;21;16;07

Bonnie Shannon

And then whenever aides said, yes, he is doing it, but he's doing it off to the side. So they were like, Oh, okay, well, he knows how to sign, you know, when to go outside. And so she said, I felt so bad, but they just had to watch him differently. You had to look at him differently as far as signing was concerned.

00;21;16;11 - 00;21;43;10

Bonnie Shannon

So he he learned that really fast. But they did not put a deaf educator in the classroom. They did have a teacher that was trying to sign with him. Of course, the speech therapy was a little perplexing because a speech therapist has to be really trained to try to get some words out of them or some communication that way.

00;21;43;10 - 00;22;07;25

Bonnie Shannon

And there's other ways to communicate. But they tried pictures that worked with Tony. They tried some simple devices, and those would work with him. The biggest thing is they were trying to get him to point to pictures that wasn't always really accurate because of his spasticity, because he was shaking and he couldn't actually get really accurate on it.

00;22;07;29 - 00;22;32;03

Bonnie Shannon

But they knew he understood. They knew he understood what they were trying to do. They just the device had to come along that would actually sit him, which took a little bit of the technology to to kind of increase and get better before that happened. As far as school, like I said, he didn't have a deaf education. He didn't that was more at home.

00;22;32;06 - 00;22;54;05

Bonnie Shannon

That was more through the therapies we were getting privately as well as at school. And the problem with that is the speech therapist was really kind of perplexed and she she actually said one meaning, I don't know what to do. I don't know how far to go here. And that's where I really need deaf educator to help him progress more.

00;22;54;07 - 00;23;27;16

Bonnie Shannon

And that didn't happen until I really started fighting with that. He was actually clear into high school before or we had a deaf educator that came and started working with him, and because of his physical disabilities, it was really hard to prove to the school system that he understood that he could use an interpreter if they had one full time, that he could use a deaf educator because they would see him sign wants and needs and stuff like that.

00;23;27;16 - 00;23;54;02

Bonnie Shannon

And they didn't think he could go any further. They were like, Oh, that's all he can do, you know that? I said, No, he understood hands a lot of sign and he understands what I'm asking him to do. Once the deaf educator started working with him, which was really funny because I think that sometimes therapists and practitioners feel that mom is just bragging, Oh, he understands, he knows, he knows what you're doing, you know?

00;23;54;02 - 00;24;20;22

Bonnie Shannon

And the deaf educator just kind of shook his head and said, Oh, sure. Okay. And then he actually apologized to me later because he said, I started working with your son. And he understands not only wants and needs, but he understands questions that I'm asking him, like more abstract things. Like, how many of those do you want? Tell him, you know, hey, do you want, you know, different things that he would ask him?

00;24;20;22 - 00;24;48;29

Bonnie Shannon

And he said he actually does understand those things. He actually does understand more than just wants and needs. So that worked out really well because I finally got validated for what I was trying to tell them. Even the director of Special Education had visited the classroom and I had fought with her for years over getting communication, deaf education, something else for him to use in school.

00;24;49;10 - 00;25;18;09

Bonnie Shannon

She was a level five sign language interpreter and she said she had a whole conversation with him. She actually used my son as an example in some of her speeches after that because she was so shocked that what I was trying to tell her was true, that he could understand a lot of sign language that is, when he just thrived using sign language.

00;25;18;09 - 00;25;47;13

Bonnie Shannon

And like I said, he surpassed me. And I think that finally they did get a full time interpreter in the classroom. I still speak to her to this day. She was hearing impaired, but she could hear a little and she could speak. She said he understood almost everything she was saying, so it was definitely validation. There. When Toni was about two and a half, I ended up getting pregnant again with my daughter.

00;25;47;18 - 00;26;11;20

Bonnie Shannon

They did have me in high risk at that time. They did actually tell me I had to have total bedrest, which with my son that certainly was not going to happen. I did the very best I could to be careful, to be very careful about what I did with my son, how I listed him, what was going on with him, and to be careful about what I did.

00;26;11;20 - 00;26;34;21

Bonnie Shannon

But I definitely could not have total bedrest. She ended up coming early. They made sure that her lungs were developed enough and they took her at £5, four ounces. And she so she was tiny but very healthy. She came home within three days. It was a totally different world with her. Tony just absolutely loved her. He adored her from the start.

00;26;35;05 - 00;26;52;05

Bonnie Shannon

He was so glad to have a playmate that he would get around on the floor. When I brought her home, Toni did what was almost like a crab crawling on his back. You had to get out of the way because he would go really fast, but I would put her down and he would be so careful with her.

00;26;52;05 - 00;27;14;09

Bonnie Shannon

He was he would go around her. I would sit there with them. And I was so shocked that he could control that he he was just like so happy to be around her. So she did really well. She grew really fast, had no health issues, but it was also since I was pretty much like a single mom and it all kind of fell on me.

00;27;14;17 - 00;27;39;14

Bonnie Shannon

It was like having twins because my son was still being held, he was still being taken care of and changed and said, and so I would just take care of him, then her, him, then her, those back and forth a lot. It was a totally different world when my daughter was healthy, so I was happy for that. I was blessed.

00;27;39;14 - 00;28;15;10

Bonnie Shannon

We did have an issue when he was in school. He had a wonderful teacher that was amazing with him. She would go into those big IEP meetings and she was kind of my ally. She would fight for him and this was about middle school, the end of middle school. She had him for a whole year and she was actually the next year right before he transferred, he was going to go to high school, yet she had to switch jobs and she moved over to the high school.

00;28;16;03 - 00;28;51;13

Bonnie Shannon

And so he was going to have a new teacher. Well, they didn't find one before school started. They had a substitute and Tony was in a wheelchair. He he could get rambunctious and kind of start slapping his arms around and kind of getting excited. And this teacher ended up slapping him. I didn't find out the day it happened, but I found out on an after school field trip the aide took me to the side and she said, I wanted to tell you what happened.

00;28;51;13 - 00;29;22;13

Bonnie Shannon

And we're like trying to deal with all of this. And I was just serious, especially for someone in a wheelchair. There's absolutely no reason you could you could just push Tony away if he was getting into behaviors or any trouble or anything like that. There was absolutely no reason for him to do that. I contacted the board office, told them what had happened and said, I want my son completely away from him and I want this guy fired.

00;29;22;13 - 00;29;47;19

Bonnie Shannon

He needs to go. I pursued it through charges, through the police. They were shocked, but they tried to charge him with something, but he was already fired from the school system. He actually tried to contact me. I didn't handle that very well. They did not charge him. He was never charged with anything. I think he took off to Pennsylvania.

00;29;47;19 - 00;30;07;12

Bonnie Shannon

That's where he was originally from. And I told the school system that I didn't want my son in that school anymore. I said, You've got to transfer him. I want him to be with the teacher in high school that he was with before. And I said, If you can transfer him, I want to be transferred now. And they did.

00;30;07;23 - 00;30;28;29

Bonnie Shannon

They actually put him in high school early. He was with the teacher that I trusted before and she was happy about it. She was thrilled. She was like, This is great. I'm glad they did what you ask. I think they were extremely concerned about the fact that they had a teacher that was employed with them, that that did something like this.

00;30;28;29 - 00;30;52;07

Bonnie Shannon

And he actually had hit another student as well that we found out about. And that child, he was autistic, Tony, and went to school with for years. And I knew them on. We talked on the phone constantly and we did our best to try to get something, some kind of consequences for this teacher that should not be in the system at all.

00;30;52;08 - 00;31;20;25

Bonnie Shannon

And I don't know, we tried to contact anyone that may have known him so that they knew someone else wouldn't hire him to work with vulnerable children. And the funny thing is, my son came home the day that it happened and he used to get around on the floor and do that crab curl thing. And I would put him down on the mat and that day I put him down and he went across the floor so fast and was like hitting everything.

00;31;20;25 - 00;31;40;22

Bonnie Shannon

And I was like, What in the world is going on? He was trying to show me that something had happened. He was trying to tell me that something was wrong and I knew immediately something was up. I just didn't know what it was. A lot of the time with Tony, it was a process of elimination, trying to figure out what was going on.

00;31;41;00 - 00;32;04;08

Bonnie Shannon

Luckily, the aide did tell me on that field trip, I wish they would have told me that day that it happened, but they didn't. But I was definitely I knew something was going wrong, that he did transfer early, went to high school early and did great over there. He used to go through the school and help deliver the mail.

00;32;04;19 - 00;32;26;26

Bonnie Shannon

So he got to know everybody. He got to be around everybody. My son was a charmer. He can he smile big. He laughs. T He had reactions to you when you would talk to him almost as though he could hear the a hold me to the side. And when he was in high school and she said, we go around deliver the mail.

00;32;26;26 - 00;32;53;13

Bonnie Shannon

And I said, Yeah, I know you do that morning. And he would go on the elevator. She said, I wanted to tell you your son is actually trying to get girls to join him on the elevator and and I said, Yeah, he's getting to that age where he's interested in girls. And she said, He definitely is. And he would point to them and like point to the elevator trying to get him.

00;32;54;16 - 00;33;24;10

Bonnie Shannon

So he had a lot of personality. So he and he d charmed nurses. He charmed teachers. He knew how to charm everybody, especially women. And I did have some nursing help through waiver that started only when he was about 18, 17, 18, because he was in school. So when he was in school, I really didn't need that help.

00;33;24;10 - 00;33;46;11

Bonnie Shannon

He could, you know, by the time he came home, then he was tired. We did what we need to do and I didn't have him. 24 seven So that made things a little easier. Although keeping a job at that time, it still was tough just because they would call when he was sick or when things were going wrong or when things weren't going well for Tony.

00;33;46;11 - 00;34;09;04

Bonnie Shannon

And I would have to leave work. I would have to call off. I would say that made it tough keeping a job. He did well, though, in the high school until about that age. I started out getting nursing services about three days a week and that was approved through waiver and they would do that each year through your budget.

00;34;09;04 - 00;34;32;04

Bonnie Shannon

Eventually we increased to seven days a week, which is unheard of now and that was amazing. That was just wonderful. I didn't get a lot of sleep because I had to monitor him a lot. So even just taking a nap was amazing because it was a chance for me to take a little bit of a respite from from constant care.

00;34;33;11 - 00;34;59;24

Bonnie Shannon

It was amazing that they were able to approve that. Now, that didn't last very long. They started reducing the budget down to I think we were approved for like five days week and then back down to three days a week. So and then eventually as Tony got older, his spasticity increased his some of the medical issues started increasing and having more problems.

00;35;00;11 - 00;35;22;02

Bonnie Shannon

And at that time, the nursing was getting reduced and reduced and reduced so that we were kind of going back to the way it was before, where it was just me taking care of him. I know that we would fight for more nursing and try to get more nursing services and try to get more hours. But the biggest problem ended up being staff.

00;35;22;02 - 00;35;52;24

Bonnie Shannon

There wasn't enough staff. They didn't have anyone available for even three or four days a week. They didn't have anyone. So that became a problem. As he grew older and is spasticity grew just unbelievably. He was on medication to control that for a very long time. That cuts and usually is what we used for that. And when he got to about 12 or 13, he started having severe spasticity.

00;35;53;07 - 00;36;19;13

Bonnie Shannon

It was so severe eventually that it dislocated one of his hips, the school system. He was in high school and they called me and said, there's something really wrong with this. He's he's done something really bad. And so I went and picked him up, took him to the emergency room. They said, yes, he's dislocated his hip. And it's actually from this Festus Ali that that happened.

00;36;20;05 - 00;36;56;21

Bonnie Shannon

So at the time, he was seeing his neurologist and she recommended that he see a neurosurgeon for a possibility of getting a backless and pump. And I didn't know anything about the back of some pump and what a bathtub pump is. It's a device that they implant that is about the size of a fucking pack. And they put it on his abdomen and it there's a lead that goes back into his spinal canal and it actually delivers medicine through that intra cycle pump that actually controls that spasticity.

00;36;56;21 - 00;37;21;26

Bonnie Shannon

And I was like, Oh, would be wonderful. Although it was a little scary implanting something in him. We managed to see a wonderful doctor that did an amazing job putting the pump in. They have to once they put the pump in to control the spasticity, they have to adjust it. And Tony's kept going up and up and up and up because it was extreme spasticity.

00;37;21;26 - 00;37;50;11

Bonnie Shannon

So before they even had that implanted, they had made plans and scheduled his hip surgery. And before they could get he had they had surgery had to actually take off the femur of his hip. They didn't put any pins because if they would have put in pins, he would have pulled them out. So they said that's not even an option because of his extreme spasticity.

00;37;50;23 - 00;38;17;10

Bonnie Shannon

He did have that surgery. That was a traumatic surgery for him and for me. He went through so much pain on that for that hip surgery and he did that. And then we had tried to schedule getting the back of and pump implanted. But before we could do it. He dislocated his other hip. So and this was about the time that he started having so many surgeries.

00;38;17;10 - 00;38;40;07

Bonnie Shannon

He ended up having surgery on that other hip. He did go through children with special health care needs from the time he was very little. They were wonderful at helping with care coordination, helping him get to clinics, to the orthopedic doctors, to the neurologists, to all the appointments that he had to have. So that was wonderful to have that care coordination in place.

00;38;40;17 - 00;39;05;15

Bonnie Shannon

But before we could get all that. Stensholt To have that implanted, the second hip was dislocated and actually his leg got contracted, so his left leg was completely bent, so they had to do more intensive. P.T. and get more intensive care for that. Then once they started working on that, they did get him scheduled for the part to be implanted.

00;39;05;15 - 00;39;29;25

Bonnie Shannon

That was implanted and he did wonderful with it. He did amazing. I couldn't believe how much it controlled the spasticity. Very happy with what they did. And they monitored it very closely. The back also has a battery in it that lasts five years, so they have to redo it every five years. They have to it. He had it for about 12 years.

00;39;29;25 - 00;39;53;11

Bonnie Shannon

And like I said, that wonderful neurosurgeon that took care of him really well, the only problem with the back some pumps for Tony was he already had weak lungs. So the back flips of the pump can suppress breathing. So any time he got pneumonia or he got sick or was having trouble with his lungs, they had to adjust it.

00;39;53;15 - 00;40;19;18

Bonnie Shannon

They had to turn it down, which, you know, was tough on him. It takes a while for backup to get out of the body. So it took a while for him to adjust to all those adjustments. But having the backups in place and having the pump in place meant that he didn't have to have as much medicine, to have to have as much oral medicine or didn't have to swallow those things.

00;40;19;18 - 00;40;41;27

Bonnie Shannon

So that was wonderful. He had the same doctor that did that for 12 years and then he was coming up on a replacement for his pump. He eventually had the biggest pump that they made that way, he could have as much medicine as possible. The doctor that normally did his surgeries last and we had to go with a different doctor.

00;40;41;27 - 00;41;04;19

Bonnie Shannon

Now, this doctor didn't listen to me as much. He didn't listen to what I was trying to tell him. I told him that due to Tony's spasticity, when he has surgery, he has to have a pressure over that for two weeks just to leave it alone, not touch it. He didn't listen to me. He didn't do what I suggested that he do.

00;41;05;06 - 00;41;32;22

Bonnie Shannon

And the pump ended up getting infected. So they had to take it out. And it took him months to get over that infection. He had IVs at home. He had he had to go to the wind care clinic. He had to be monitored all that. Then on top of that, he had withdrawals from the pump and from not having all that medicine in place.

00;41;32;29 - 00;41;56;25

Bonnie Shannon

So that was really tough on him. That was hard. And then he had to increase to having he had almost 12 pills a day. So it was a lot of medicine for him to take. So and it didn't control it the same. The pump just worked so much better and so, so well as far as controlling spasticity, it works really well for him.

00;41;56;25 - 00;42;20;10

Bonnie Shannon

So they asked me if I wanted to put it back in and I just didn't want to deal with not having the doctor that I wanted and not having someone listen to what I needed to have. And I was just kind of afraid to go back into that situation. But he eventually got it under control. More with the spasticity and with oral medication.

00;42;20;17 - 00;42;48;04

Bonnie Shannon

We did okay. He still had extreme spasticity. There was times that he would have bouts of it that I would even take pictures so the doctor could see that he was just struggling through. You couldn't give him a lot of pain medicine. He had some because once again, you couldn't suppress his breathing. My son had over 12 bouts of pneumonia and then he had aspiration pneumonia several times.

00;42;48;13 - 00;43;13;06

Bonnie Shannon

Eventually, after having aspiration pneumonia so much, they decided that he needed to go on pure foods instead. So we went back to period foods. He did fine on those, did really well. He eventually had to have they can liquids. He couldn't have just regular liquids. The older he got, like I said, the more the CPE progressed it it made things much more difficult.

00;43;13;21 - 00;43;41;10

Bonnie Shannon

He was in and out of the hospital, still quite a bit. And any time that he had anything go wrong, the one thing that we ended up losing as he got older was transportation. He always had transportation through his Medicaid card, through the county bus, through Jan Care Ambulance Services. We could make sure that he got into a preventative appointment with the doctor and got checked out before he got.

00;43;41;10 - 00;44;00;27

Bonnie Shannon

Too bad. And it ended up in the E.R.. We tried to avoid the ER at all costs. When you have a child with a physical disability, when you take him into the E.R. he's laying on a bed that he's not used to being in, he has no support at home. He had a hospital bed that can be adjusted, that it was a nice bed.

00;44;00;27 - 00;44;23;23

Bonnie Shannon

You would go into the emergency room and you didn't have what you needed that you had at home. They had the the oxygen and the monitors and all that. But it was tough to be in the E.R., so we avoided that at all costs. And there were times that he was in the E.R. for 15, 16 hours at a time, just trying to get admitted to the hospital.

00;44;23;23 - 00;44;59;20

Bonnie Shannon

And I couldn't leave. I mean, when I took my son into a care setting, any care setting, he was deaf. So the doctors needed to speak to me. They needed to go through me to ask him questions and to make sure he was not just being agreeable or maybe he did understand part of what they were saying. He wasn't going to understand what a doctor was asking him, so I had to stay with him almost all the time, even leaving him in a monitored situation like step down or surgical ICU or anything like that.

00;44;59;20 - 00;45;26;00

Bonnie Shannon

There's somebody there most of the time, but they also can't speak to him. They can't talk to him like I can. So any time that he stayed in the hospital for an extended period of time, I had either had to stay right there with him or if I went home to get anything or or take a break or just go home to shower or do anything like that, I would have to get back as quickly as possible.

00;45;26;11 - 00;45;46;15

Bonnie Shannon

There were even times when I left and he was monitored in a stepdown unit. I came back one time and he had his leg out hanging off the bed. So and I would warn them ahead of time. I said, He gets around, he moves, he tries to take things out, tries to take off the oxygen, take out tubes.

00;45;46;15 - 00;46;09;28

Bonnie Shannon

And I would warn them ahead of time. I was like, he'll he'll take things out. My son was very determined. And that's that's one thing that kept him here so long is he was he was a fighter. I remember a story once and surgical ICU. He was intubated and he was awake and alert. And I told them, I said, I'm going to run down to the cafeteria.

00;46;10;09 - 00;46;33;16

Bonnie Shannon

And there were two people standing by the bed. And I said, don't let him pull that out. He will actually activate himself. He pull that right out of there. They just looked at me and smiled, you know, and I left. As soon as I got down to the cafeteria, I heard them page the doctor, and I went, Oh, no, because I knew exactly what happened.

00;46;33;16 - 00;47;02;05

Bonnie Shannon

So I went back up there like, yep, he pulled that tube right out of there and they were both right there by the bed. He was very determined. He pulled out, he pulled off oxygen, he pulled out innovation tubes. He pulled out central lines. He he was very determined. Another thing that made that really hard is in the hospital, when they have children that do this, they will sometimes restrain them.

00;47;02;26 - 00;47;32;04

Bonnie Shannon

When, Tony, you're restraining somebody who communicates through sign. So I had a real battle with that. I knew why they had to do that. And I knew that sometimes it was life threatening. He couldn't pull out the tubes. He couldn't take those things off. But it's also you're taking away his communication. If he's trying to show me something or trying to do something, how would he do that when his hands or how he communicates?

00;47;32;11 - 00;47;56;19

Bonnie Shannon

But I did have, like I said, wonderful doctors that they would say, listen to listen to mom. She knows what she's talking about. And I would thank you so much. Thank you. Because sometimes they just they have make sure that things get done in the hospital and done the way they need to have it done. It's just that with Tony, there was always kind of an exception to that rule.

00;47;56;19 - 00;48;11;25

Courtney Ringstaff

So now you're in a role where you were starting to help families connect to resources, and now you're using all of your experience to help guide them through that. How did you decide that you wanted to do this type of work?

00;48;13;19 - 00;48;34;27

Bonnie Shannon

I think with Tony, eventually I did try to go back to school after my daughter was born and Tony was going to school and I thought, this is maybe a good time to do this, to to try to go back to school. And I wanted to be an LPN because I liked medicine I was doing. I mean, I had learned so much about medicine and what to do and what not to do.

00;48;34;27 - 00;48;59;11

Bonnie Shannon

So I thought maybe this is an option for me to do this. The biggest problem was I did not have any nursing care or any respite at that time. So I had to depend on my husband at the time. And that didn't work out too well. My family members, like I said, they would try to help, but they were always a little scared to be there very long with him or or keep him for very long.

00;48;59;11 - 00;49;22;18

Bonnie Shannon

I tried to go back. I did test to get a slot for LPN training and I think they had like 20, 24 or 28 slots. I can't remember, but I didn't make that. But I was an alternate, which really shocked me because there was probably over 250 people that showed up for that. And I was shocked. I was like, I can't believe I'm an alternate for this.

00;49;22;18 - 00;49;43;22

Bonnie Shannon

And they said, Well, we can offer you the surgical technician program. I didn't even know what that was. They had to explain it to me. They explained what it was and what it entailed, and I said, Sure, I'll do that. So I started that training, went for a few months and really tried hard, but with no care for either one.

00;49;43;22 - 00;50;07;00

Bonnie Shannon

On my children. That was test because when they would call from school to say you was sick, when they would call and I had there is nobody else to go get him except me. There were pretty strict rules about missing any classes that you missed that didn't work out. So I wasn't able to finish that. And I actually really loved that program.

00;50;07;00 - 00;50;34;22

Bonnie Shannon

It was something I really wanted to do. Eventually I decided, I've got to go into a field where I'm helping other families. I knew what it felt to be isolated. I knew what it felt, having all these things kind of thrown at you that you have to navigate and I thought, I can help people. I know what I've been through and I know how it feels to be isolated, even when you're surrounded by a lot of people, a lot of them don't understand what you're going through.

00;50;34;23 - 00;51;02;24

Bonnie Shannon

They don't get no matter how much you try to explain it, they you have to almost connect with other families have the same similar experiences that you have. I did attend some support groups through Easterseals and. Got connected to families that way too, and met other families. But eventually I did talk to one of my friends that I was connected with and she said, You should a job with birth.

00;51;02;24 - 00;51;43;04

Bonnie Shannon

Two, three. So I said, Yeah, that sounds like a really good idea. So I did that. That worked out well. I could set up of my own hours. Tony was older, but my daughter was older, so that made it easier. And I really enjoyed helping families. I really said, Is the field I need to be in? This is where I need to share my lived experience and share what we've been through so that they understand there's a light at the end of that tunnel and then connected with the very same friend that said you might want to try for that position at the C D.

00;51;44;13 - 00;51;55;09

Bonnie Shannon

And so that's why I ended up where I'm at and I'm very happy I did.

00;51;55;09 - 00;52;28;21

Melina Danko

You now have seen medical care evolve 40 years almost from the time that your son was born and started having some health conditions, complications until now. And some of the things that you experienced early on were pretty tough and I'm just curious, have you seen a change in that? And if so, how do you think that that helped you?

00;52;29;13 - 00;52;55;10

Bonnie Shannon

Yes, it has improved quite a bit. Yeah. You still have to go in. And no matter how much is in that file that your child has, you still have to go over it again and again, something that you've explained a million times and it's okay. I want them to know as much as they can about my son. I would do that with nurses, doctors, therapists, whatever they needed to know.

00;52;55;10 - 00;53;28;19

Bonnie Shannon

You know, I wanted to make sure they were well-informed on my son. Doctors did change. They there were bad experiences that I had. Most of them usually were because they were rushed. They were not connecting really well with my son or with me, a lot of them. Now that as he got older, they did a much better job of listening to what you were saying and being present in what you were doing and knowing that it affects the whole family.

00;53;28;19 - 00;53;50;20

Bonnie Shannon

You know that when they say, Well, how's everything going with you? How are you holding up to this? That made all the difference in the world? Because most of the time you were just lucky to get in exactly what you wanted to say. I would actually go in with a notebook of questions or concerns that I had because I would get in there and forget things.

00;53;50;20 - 00;54;09;17

Bonnie Shannon

I would get in there and forget to ask them something or forget to because they were rushed and they were trying to get through their appointments. And the one neurosurgeon that I had, we had to wait. I think it took most of that day to get to see him because he took so long with his patients. He took a very long time.

00;54;09;17 - 00;54;30;29

Bonnie Shannon

And I like that. I really did like that. I didn't care if I was waiting as long as he got to us eventually and he took a good hour. And that's just unheard of. I mean, he wasn't rushed. He wanted to talk about everything that was going on with Tony and everything that that I was concerned about. He wanted to explain it in detail.

00;54;30;29 - 00;54;57;10

Bonnie Shannon

And and that made a huge difference that I did. And but there were doctors along the way that were just insensitive about things. One doctor I had to go to a clinic to get my son Wade because the clinic that he was going to didn't have a wheelchair scale. You couldn't weigh in. There was no way to weigh him, just getting him out of his bed.

00;54;57;10 - 00;55;16;26

Bonnie Shannon

The only way they normally weighed him was when he was in the hospital, in a hospital bed, because they could actually weigh him in that bed. So even medicines and stuff like that, you had to kind of get him weighed. So I wanted him to be weighed and I went over to a different clinic. I had a heck of a time getting him there.

00;55;16;26 - 00;55;39;19

Bonnie Shannon

I did have a modified van. My son at that time had graduated from a regular wheelchair to a power wheelchair. Actually pretty early on in his life. We took him everywhere and did everything with him. So a power chair just made sense. He couldn't drive it alone. I had to do most of the driving. I had a really bad day that day trying to get him loaded up.

00;55;39;19 - 00;55;55;28

Bonnie Shannon

When you had to load him up, you had to practically stand on your head to get him strapped in and get him all where he needed to be. And you had to do that four or five times just to get him where he was going and get him home. So I was about 5 minutes late, not much more.

00;55;55;28 - 00;56;19;17

Bonnie Shannon

And they had actually offered valet service at the hospital to park your vehicle. So I went ahead and did that because I was one running behind and to it was just so much easier to say, you know, I loved him here, take it out of the car. And it was really crowded that day. So there wasn't a lot of openings for handicapped parking.

00;56;19;17 - 00;56;38;25

Bonnie Shannon

So I had them park it. I was about 5 minutes late and the doctor was so he was like, You're late. And I was like, Are you kidding me? That Just floored me because I was like, If you had any idea what I just went through to get here, you would not have said that. You would not have said a word to me about.

00;56;38;25 - 00;57;04;28

Bonnie Shannon

And I knew if you're late, you're late. That happens, you know, to everybody. That just floored me. But there were always times that doctors said and did things that they didn't really think about. They didn't think about what you had just went through to get there. But it has changed. It has improved. It has. I do think that more medically complex children need that special doctor.

00;57;04;28 - 00;57;32;13

Bonnie Shannon

They need that doctor that connects with them. And with my son being non-verbal and deaf, some people would come in and not even acknowledge him. They wouldn't even look at him. And I wanted them to acknowledge him. He he would smile, he would react to them. So it wasn't like they weren't getting any reaction. You know, there are children that don't have that reaction, don't have any reaction to it.

00;57;32;14 - 00;57;57;28

Bonnie Shannon

You should still address them. They're they're the patient. And that always was important to me. That was once they did that, if they came in and said something to him, I was like, okay, at least we've got somebody who understands that this is this is his appointment, not mine. We did take my son everywhere. We were lucky enough to have family members near the beach and near amusement parks and.

00;57;57;28 - 00;58;20;29

Bonnie Shannon

I took him everywhere. Now, that was when he was a little smaller. It was a little easier to maneuver. When you have a child that has a disability that's younger, hardly anyone notices. You're, you know, you're in a stroller, you're in a regular car seat. But as they grow, you have to have modified everything wheelchairs, modified seats, modified everything.

00;58;21;08 - 00;58;50;20

Bonnie Shannon

When you go somewhere, you have to map it out. You have to know where you're going to go to change them. You have to know. Sometimes I used first aid stations. Sometimes I would go into the park and talk to the management immediately, like, where's your locations? Where's places I can go? Because then they didn't have changing stations for anyone and we had some episode in the beginning that I was like, I've got to figure out a better way to do this.

00;58;50;20 - 00;59;12;24

Bonnie Shannon

Mainly it was just checking with the places that we would take him first to see where we could go, what was accessible, what wasn't accessible. He would he would ride log rides and he would we would go on a fierce wheels and merry go round and we went on everything we could possibly get him on. What was really nice is they would let you go around several times.

00;59;12;24 - 00;59;38;01

Bonnie Shannon

So that would sort of we even took him to Disney World in my mom and dad's RV and he absolutely loved it and they just did a wonderful job with him. So I was really pleased that he really got to experience a lot of wonderful things in his 37 years. He did pass, he went through quite a bit.

00;59;38;01 - 01;00;04;19

Bonnie Shannon

It was mainly because of his lungs. That right lung was always one of his worst lungs. It had collapsed a couple of times before this and he just ended up having a lot of trouble breathing and ended up in the E.R. and that was a lot. He acted a lot different. It looked a lot different to me. He had of probably five or six different tubes coming out of him.

01;00;05;01 - 01;00;24;07

Bonnie Shannon

And eventually he wasn't reacting to me as well. I even had them do a CAT scan because I thought maybe he had had a stroke or something like that. But they said no is. And the doctor then started talking to me about, well, do you want long term care or do you want, you know, what do you want to do here?

01;00;24;07 - 01;00;49;10

Bonnie Shannon

And I said, I don't want him having anything put in him. I don't want breathing tubes, feeding tubes, none of that. I said, Well, just let me take him home. And he lasted another seven days. And that was surprising because I didn't think he would go that long, but he did, and I miss him every day. He was an amazing teacher for me.

01;00;49;10 - 01;01;03;23

Bonnie Shannon

I have something that I can offer back to others and tell them there. There's help out there. There's people that can reach out and help you through this time and through your own journey.

01;01;03;23 - 01;01;16;26

Courtney Ringstaff

I just I just want to say, I can't imagine what those seven days felt like for you like that. Yeah. Very courageous of you to let him go peacefully at his home and comfort. But I can't imagine what that was like for You.

01;01;19;07 - 01;01;38;27

Bonnie Shannon

He smiled when they brought him in the ambulance. He was smiling from ear to ear, I mean, just ear to ear. And I was still trying to do treatments. I was still trying to do the best so he could breathe. I was still and I knew in the back of my head, this is really just be it.

01;01;38;29 - 01;02;03;29

Bonnie Shannon

This is not good. I reached out to that hospice group and said, It's time. And all this happened right after Christmas. It was right around that December time and we really hadn't it actually happened right before Christmas. So he stayed in during Christmas and during New Year's. And we family came in and saw him and celebrated with him and stuff.

01;02;03;29 - 01;02;12;22

Bonnie Shannon

But he was just so extremely sick. He was just not reacting like he normally does.

01;02;12;22 - 01;02;42;01

Courtney Ringstaff

I just want to thank you for sharing all of your story with us. And I also can't help but notice how positive you are through. Even when you were talking about the things that were really tough, your outlook and just the positivity that you just emit from every story is really nice and thank you.

01;02;42;29 - 01;03;04;25

Bonnie Shannon

Not easy to be positive when you when you're faced with that. It's not it's it's not something I think sometimes that's my personality. I try to find the good part of what you're looking at. I try you start to feel negative and you're like, okay, I've got to find something else to grasp on to to make it more positive.

01;03;04;25 - 01;03;29;15

Bonnie Shannon

And even with his life, my work and what I'm doing with families that honors him. That makes all the difference in the world. He showed me my path. My brother always says to me, You have a slow and steady resolve and you'll get it done. And I said, Yes, I do. And sometimes it's a little too slow, but that's okay.

01;03;30;09 - 01;03;53;25

Bonnie Shannon

But I do try to find the positive part of it. And I think that was Tony's personality. I think, you know, when the nurses said, oh my gosh, she's going through so much, how could you smile? And I'm like, Yeah, he's going to smile right through it. As long as you have some connections, as long as you have a little bit of support from someone somewhere, you can find that.

01;03;53;25 - 01;03;59;15

Bonnie Shannon

And, and that's what I tried to do to the families that I work with.

01;04;02;03 - 01;04;17;22

Melina Danko

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