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EHDI Annual Conference

Collaboration of our Family Based Organization (FBO), Family Connections for Language and Learning and Parent to Parent of Pennsylvania – How, Why and Can this be Replicated in Other States?

March 19, 2024

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>> Good day all, my name is Jamie, I am the room monitor. If you have any questions about where things are, please come back and see me. Just to let you know there is four exits in case of an emergency, one in the back, two on the sides, and one behind me. There is also some water and some pens and paper.

We are going to be starting in just about one minute. Thank you.

>> ANNE GASPICH: Good morning everyone, we are so glad you chose to join us in our session.

I am Anne Gaspich, program coordinator for our family based organization in Pennsylvania, and we are family connections for language and learning. Can I have a show of hands if there is anyone who the term family based organization is new to you?

All right, we are good.

>> NICOLE LINDSAY: Good morning everyone, I'm Nicole Lindsay, database coordinator and manager for Parent to Parent of Pennsylvania. Same question, is that a new term to anyone, Parent to Parent?

>> ANNE GASPICH: You have a Parent to Parent chapter in your state? It looks like some do. Excellent.

>> NICOLE LINDSAY: Just so everybody is aware, Parent to Parent USA, P2P USA dot org does have a list, you can choose your state and see if you have an organization in your area. It might not be under that exact title, but it might be a Parent to Parent USA affiliate.

>> ANNE GASPICH: Family connections is Pennsylvania's family based organization, and we are very specific in the services and the population that we provide services and support to. So we are specific to children who are Deaf, hard of hearing, or Deaf/Blind, and we are an affiliate program to Parent to Parent of Pennsylvania. In our state Parent to Parent had been around forever and was very well established within the early intervention community. So we had a large buy-in to making referrals to Parent to Parent.

>> NICOLE LINDSAY: And Parent to Parent of Pennsylvania connects families of children and adults with developmental delays, disabilities, and special health care needs throughout their journey. We cover all kinds of conditions and needs and we do birth through adulthood. So we go back and forth with family connections to refer if they need special considerations for hearing.

>> ANNE GASPICH: This is my son Brent. Brent was born on November 2, 2006, and immediately in the delivery room I could see a physical difference in his ear. The response of the staff is that I was a very overly critical mother and they quickly put a hat on him and proceeded to forget about the fact that he had a physical difference in his ear. And you can see that difference, if you take a close look you can see his right ear is significantly smaller than the left. If you are an artist or plastic surgeon you may also notice asymmetry in his facial features. One side of his face is significantly smaller than the other, especially if you change your point of view and we turn this picture upside down. Our brains automatically correct for asymmetry, so we see him as a beautiful child who looks really great to us.

But people who have that training to look for the asymmetry can certainly see his asymmetry. So it was quite a shocking diagnosis. And there was really not a message that was sent to us of positivity. We got a call from an administrative type person in the hospital telling us that our child might likely have hearing loss and we should follow-up.

We immediately were asking well, what can you help us with for information? We don't know anything about this, what do you have to send to us, what should we do next. And she literally said I know nothing, I'm a secretary. And I just feel so bad.

So that was our introduction to the world of Brent being a person who is hard of hearing. But just showing you that we grew over time, and you can hear more about that in my presentation this afternoon about our journey through high school, just going from the complete unknown to begin -- having so much fun and realizing that Brent as our fourth child was an amazing addition to our family. And realizing how quickly he just looked perfect to us in every way.

>> NICOLE LINDSAY: On the right side of the screen you will see my two kiddos. I have a seven-year-old daughter and a nine-year-old son. My daughter is the one who brought me into this world. Her name is Alison, she was born in September, 2016. It was a completely normal pregnancy, a completely normal delivery. Everything went really well.

After delivery we noticed her color was a bit off. They didn't seem very concerned about it. Carried on as normal, they did bring her to the nursery for a little bit of monitoring. And then she was sent back to my room later that night. We went home as normal.

In the hospital they brought the equipment in, they did the newborn hearing screening which my son who is nine, two years prior, I didn't even remember this happening. Obviously it had not been done but it wasn't something I was made aware of.

They mentioned after the screening that there were some things that looked a little bit off, and they would be coming back the next day to check. So they came in the next day, without okay, we are about to be discharged, let's get this test done and head out. Then they told us you will need to go back for an outpatient.

Don't worry, it's fine, this happens all the time. We came back a few does later the hospital, same thing happen, they told us again it happens often in there is probably fluid in her ears. We are going to refer you to an audiologist at which point we kind of start to panic a little bit. No one in our family had any experience with this. But we went and met with a few of the wrong people first before we were connected with the right people.

We had the AVR, we went through the whole thing and we were finally officially given a diagnosis which I now realize we were very fortunate to have such an early diagnosis.

Before we even had her hearing aids, as soon as we were given the diagnosis they asked if we wanted some time to process and think about our next steps. And our response was what are the next steps? The recommended hearing aids, and we said can we get them today?

So we were fitted and of course it takes some time to come in. And she has hearing aids in both sides. Before they even came in, we got a call from Marianne from the local Scranton school for the Deaf and she got us all connected through her own intervention. We were connected to Anne for family connections, and that is really when our journey started. We were meeting other families and children who had hearing loss and all kinds of different devices and were Deaf and hard of hearing plus before she had her hearing aids.

So it's a really fortunate story for us. She is doing amazing right now, she was mainstreamed in first grade.

My son was in fourth grade does not have hearing loss, he does have a bit of a speech delay. But we were able to use the tools we learned through early intervention with our daughter to also help our son. And that is so I can define Parent to Parent.

Four years ago now I began my position as a regional coordinator, and then was promoted to a supervisor. And now I get to help families all of the time.

So now talking about Parent to Parent as a program. Parent to Parent of Pennsylvania, when someone asks what we do we say we empower and support families throughout Pennsylvania. We connect them with families of children and adults with disabilities, developmental delays, or special health care needs who have had similar journeys. The peaks and valleys they experience along the way might sometimes feel a little overwhelming. So we are driven to ensure no parent feels alone. Ever. How? By providing the emotional support they need to help overcome whatever life throws at them. We share our own experiences and let them know whatever happens, you've got this.

We all need a little help sometimes. Connecting families to resources and supports including Parent to Parent of Pennsylvania has to be done within the context of families and our referral partners. We rely on early intervention partners to drive referrals to families who are in need of support.

This is one of our referred parents, her name is Melissa. I am going to read a quote that she had given us on her evaluation. The Parent to Parent match encourage me to reach out to my peers supporter was specific questions and began to develop our relationship in a new way. Melissa's story is unique. Person is a very rare diagnosis and she found support through an online support group. When she calls for support, we ended up connecting her to a family who she already knew from the online group. Having access to a one-on-one people match has been a valuable experience, and I spoke to her after the match at another conference. I ran into her and we were talking to men and her and of parent she was connected with actually ended up starting their own very specific support group for that very recognition in their area. So it's amazing.

How do we receive referrals. Referrals come from, like I mentioned, our early intervention partners, other agencies across our state, and directly from families who find us online or through social media. We can accept referrals through our toll-free line, our website, by email, or by calling anyone of our regional coordinators directly.

All of our contact information is listed on the website, Parent to Parent dot org.

We have been, as Anne mentioned, we have been around for quite some time. We are over 25 years now a providing support, we have over 1100 peer supporters in our database, we have supported thousands of families across our state, NDRN alliance member of Parent to Parent USA. Like I mentioned earlier you can find out if your state is a Parent to Parent chapter, and it may be under a different name other than Parent to Parent.

We have over 1100 active peer supporters in our database. They include parents, grandparents, guardians, and foster children. Our foster parents of children with developmental delays, disabilities, and health care needs.

These are actual peer supporters.

We do also offer a training to our peer supporters in the areas of our processes and procedures, cultural humility, confidentiality, active listening skills, and self care needs. We currently have over 220 trained peer supporters in our database, and it grows every day.

After a referral is made, like I said we get it through phone, website, however it comes to us. One of our regional coordinators will reach out to the family. We try to do it within one or two days. They connect with the family and do what they call an intake, so they learn about the child, their support needs, what they are going to need. If at that time we determined that the child that they are calling about has a hearing difference, we would refer them to family connections for language and learning.

Then after the intake the original corner work to find a peer supporters that is appropriate. They connect them. The referred family member then steers the conversation. They decide how often they will make contact, whether they are using phone, email, text, if they are near each other and they would like to meet up they can do so. If they have a few questions and only want one conversation, or lifetime friendships have formed as well.

We always perform follow-up after. Someone from our staff will follow-up with the referred parent to make sure everything is okay and see if they would like an additional match.

Parent to Parent of Pennsylvania recognizes that families who learned that the child is Deaf, hard of hearing, or Deaf/Blind often may have questions about a child with a hearing difference and are unsure of the next steps they need to take. They need very specific unbiased support and information, and all of the communication opportunities available to the family. Therefore when we receive referral for a family was child is under the age of five and has a hearing loss, our regional corners then refer them to family connections for additional support in their specific area of need.

>> ANNE GASPICH: As family connections for language and learning, we offer families parent mentors, Deaf or hard of hearing mentors, and we actually get direct referrals from our Pennsylvania Department of Health for 100 percent of the babies to have a diagnostic report submitted by their audiologist. So we recognize that there may be babies who slip through the cracks whose early intervention refers to Parent to Parent, and that is one of the reasons we have this warm handoff between the two organizations.

We also recognize that 40 to 260 percent of children born Deaf or hard of hearing of additional disabilities and could utilize specific support from a peer supporter who has a child with the same or similar condition.

We do also get voluntary referrals from early intervention for our babies. For example who move from out of state and don't have cooperative agreements with neighboring states. And then sometimes we will get that late diagnosed baby will be in early intervention and then found to have a hearing loss.

So our team consists of trained experienced parents, and they are trained specifically to support families who have a child with a hearing difference. And our main goal is to help families build a toolkit of information by giving them the most unbiased information on all possible communication opportunities, and many, many resources that they can put into their tool basket and take out and examine and make a decision for what they are going to do within their own family to help the child become the most that that child can possibly be.

So all babies, again, who have that confirmed diagnosis get a direct referral to our program. Our services don't cost the family anything, and the parent mentor is provided until the child turns free. But they can continue their Deaf or hard of hearing mentoring services until the age of beginner. So technically it may even go to six or seven if the child does not get enrolled in school. So they will continue to have the support of me as the program coordinator, and a Deaf mentor.

What is the most important thing we do? I would like to say that the feedback we get is that they are able to enjoy their baby. Right away, we are giving them consent to enjoy their baby. It's one of the most important things we do for families, because they are so concerned or so grief stricken, so unsure of what to do. The biggest thing we believe is to help them first enjoy and bond with their baby.

We actually have access to the complete -- well, not the complete, but to a large amount of Department of Health database information. So we can actually study the record before we make our first phone call, so we are informed as to where his family may be. For example, some babies may still be in the NICU. Some babies may be in a different setting as far as what home they are in, for example. What their risk factors were for the hearing loss diagnosis. And it really helps us to make a best first call with those families.

So reach out to our referred families via phone, text, email, any type of online visits. And before Covid we were doing in person visits. We are getting back now to in person activities, and we will be starting in person home visits again.

We have also found that postal mailings are really successful. We live in a state with a large portion of out of birth babies -- out of hospital births, I'm sorry. So anyway, but we have a large community population that we can reach with a mailing. And we find we are able to connect with those populations who may be underserved in other states.

I think we have gone over this. We help families really make connections, not only with us as the other parents, the Deaf community, other families experiencing a similar journey. And we also help them meet professionals with expertise in the field. So we as an organization are working on relationships with our EI providers throughout the state, and experts in audiology, medical conditions, we are making those connections as an organization. And sometimes we can really help parents avoid that mountain that is in front of them. We can explain you don't have to just away from mountain the rest of your life. We will help you go around that boulder.

That means getting them into the next appointment much quicker, and maybe getting a second opinion and making that three-way phone call. A big part of our role is making those three-way phone calls with the family. For example if their child has a craniofacial difference, we would make a three-way phone call with them to make sure they get that enrollment done and have access to that service.

Counting on parents to make that call themselves can be a really risky situation. They have the best intentions and no time.

So it's important that we get our babies enrolled in high-quality early intervention based on the hearing diagnosis. We will have babies getting PT, getting OT, and maybe they have not disclosed that their child has a hearing loss even. So we help them make that connection to be getting services from a teacher of the Deaf, and ASL instructor, or a speech language pathologist.

We create community opportunities and we also make them aware of opportunities that already exist from our partner organizations. We have virtual and in person events. And we do a mailing to every family of two packages. The first thing they get is what is called a rack card. It is the business card and information on the program with a board book. That is a way to get them to answer the phone. So we say hey, we sent a mailing to you, you should have gotten this really cute touch and feel board book. And they are like oh, that is who you are.

Than the next mailing they get it is an AAP document, a care coordination plan. We put that together in a whole binder, and that is one of our roles, to help the families organize that binder of information where they can include their early intervention worksheets, different materials they get. And to be honest a list of who all of us are because it is really hard to know who is your parent mentor and who is your early intervention providers and service coordinator, who is that?

We also help families giving them information on the first 100 signs. We send out a little document that was being handed out this week over in the ASDC area on the first 100 signs. We give them information on cued speech as well. And of course listening is spoken language. But within our program we are able to teach them the first 100 signs. It is not to supplant early intervention but to supplement that getting started.

So we have actually partnered with the Deaf children at the school for the Deaf and have a YouTube channel with the first 100 signs. If anyone wants that afterwards, feel free to come talk to me.

We help families complete all of the next steps which in Pennsylvania means you have to apply for it but your child is guaranteed to get it. You are guaranteed to get medical assistance, medical assistance transportation program, WIC, and they can also apply for Social Security income if they are financially qualified.

We respect family choice. We are never telling a family what to do. We are giving them the information and giving them time to process, sort it out, build that toolbox. And we will support them no matter what they choose and no matter whether they take to use technology or decline technology altogether.

Let me see. I think this is just sort of a review. But one of our most important things is listening. We are there to listen. We go in without an agenda because we could have the most beautiful agenda and it would be completely inappropriate for the family. So the first thing is we read the case file. We get a little background information. Then we introduce ourselves and start listening and asking them questions. The focus is on their family. It is never about our story.

I mentioned to you the percentages, and I have realized we need to update this slide for the newer data that I gained this week. But acknowledging that is a real concern of our families. And they may not be so concerned about the hearing loss. They may be struggling with life or death situations. So if we know our referral is not enough, we have Parent to Parent to partner with and we can match them with a peer supporter.

So again, that handoff goes both ways. It comes our way and goes their way as partners in our state to best support all of our families.

We are here and we will remain in the hall if you guys have any questions for how we got these referrals, and how we do the warm handoffs. So we are happy to tell you more, and if we have a moment or two we will take any questions.

>> I was just curious as far as the direct referrals how parents receive that. Like emotionally, like what is the timeline when you contact parents that they are receptive to your help? Because we all know there is that grieving process. So are they receptive immediately, or do you see there is a few months lapse. I was just curious about that.

>> ANNE GASPICH: I would say it is very individualized. We get referrals sometimes the very next day after the diagnostic. So we are doing the mailing. And if they are not answering their phone the very first day, they are getting a mailing pretty quickly with the board book and the information. They are also getting a mailing from our Department of Health. They pretty much know we are going to call.

For families that we do get a referral and they answer their phone, we do try right away. Because we can be there to let them grieve with us or to let them be concerned, confused. So the reception to be honest, if the answer their phone, they want to chat. If they don't answer the phone, that gives them the time they need because we are doing the two mailings.

And then eventually it clicks that there is someone out there that cares about their journey. So we don't give up on families. I have had families that I have called for the full three years, and that two years and 11 months they have said I think we need your help.

So we generally don't just shut people down unless they make it clear that -- like they may live in an urban area that has huge supports already set up. If they are in Philadelphia, they may not need an additional mentor because of just the whole system there. So we just go with whatever, how the family receives us. And we really make them exactly where they are at in that moment.

And to be honest the program coordinator, myself, or one of our very experienced mentors is making that first call. So generally it's a me. But if not mean it is someone who is very experienced. It would never be in our judgment appropriate for a new mentor to be doing that. You are learning as you go and you will make all kinds of mistakes in the beginning.

Thank you so much.

>> NICOLE LINDSAY: Thank you, guys.