

Will Eiserman.:

Welcome to Earworm, Dialogues on Hearing Health You Can't Stop Thinking About. Earworm is brought to you by the National Center for Hearing Assessment and Management at Utah State University known as NCHAM. I'm Will Eiserman and I'm the Associate Director of NCHAM and I'm your host today.

The joy of welcoming a new child can be mixed with surprise and various emotions when families are also learning that their child is deaf or hard of hearing. Suddenly faced with needing to understand their child's needs and finding ways to support their success, these families are fortunately not alone. A range of dedicated professionals, including audiologists, healthcare providers, teachers of the deaf, speech language pathologist, early intervention specialists, are all there ready to support, assist, and educate. Each offers unique and crucial support.

Additionally, the value of parent to parent or family to family support can be immense, providing not just emotional support to one another, but also practical information and guidance and real life examples of success for nurturing the growth and development of deaf or hard of hearing children.

In this episode of Earworm, we'll delve into the various aspects of family to family support and explore how it can significantly benefit families with deaf or hard of hearing children, emphasizing the importance of having easy access to valuable, unbiased resources. Our guest today is Janet Des Georges, parent of a child who is deaf and the Executive Director of a national family-based organization called Hands & Voices. Hands & Voices is a parent driven organization dedicated to providing unbiased support to families with children who are deaf or hard of hearing.

The importance of providing unbiased support relates to key decisions families need to make about things like language modality, will a child use American Sign Language for example, or listening and spoken language along with technology to support hearing or maybe some combination of those. Or it could be other decisions about the type of school or intervention used. Hands & Voices makes it clear upfront that they are a place for everyone regardless of the choices families make in the best interest of children who are deaf or hard of hearing.

Janet, welcome. I want to start by asking you to tell us a little about Hands & Voices and who you are as an organization.

Janet Des Georges:

Sure. Hands & Voices started in 1996 here in Colorado. It was called Colorado Families for Hands & Voices, and I was also a part of a grant at the University of Colorado, the Marion Down Center where I began to have the opportunity to travel to other states that were at the time establishing newborn hearing screening and just started sharing the model of what we were doing at Hands & Voices in Colorado. And that began to create a shift in opportunity for other states who wanted to look at our mission and vision.

Will Eiserman.:

Yeah, tell us what is the mission and vision?

Janet Des Georges:

We support families without a bias towards communication and modality. The other kind of primary principle of Hands & Voices that was established from the beginning, which is the idea that we're a parent driven organization and professionally collaborative. There was huge alignment with a lot of individuals, both families and professionals, around the idea that is there a space or a place where we could come together that got beyond just the modality question of does your child sign or speak or cue

or do a combination of all. Beyond the modality question or language that our kids use, it also applies to school, where our kids go to school, whether it's mainstreaming or residential schools for the deaf, self-identity as a deaf person, whether families or children as they grow, identify as big D deaf or little D deaf or that self-identity as well.

Everyone is welcome in our community and we try to create space so that people when they come into our organization don't walk out with a sense of being judged by the decisions that they've made. So we established in 2004 Hands & Voices as a national organization and began to help support other states establish chapters.

Will Eiserman.:

So the organization has grown.

Janet Des Georges:

Almost 20 years later just from our national movement, yeah, we now have 41 chapters in the US and Canada. Our work at headquarters is to really help support and establish parent leadership and the health and integrity of our organization through our chapters.

Will Eiserman.:

Tell us exactly what is involved in what we're calling family to family support.

Janet Des Georges:

Family to family support could be described as support, information and resources in order for families to make good decisions and then the third would be modeling. The effect that it has when you've never really experienced the context of raising a deaf child to being able to see other families in a natural environment where they're raising their kids.

Will Eiserman.:

So what does emotional support include?

Janet Des Georges:

At Hands & Voices when we think about emotional support, we actually do a training for those who provide support to other parents, and we've entitled that and think about this concept called Encountering Emotions. Typically when we think about family process and emotions, often the conversation about the grief cycle gets attached, which is relevant and research based around this. However, in our experience in providing support to other families, we've found that families encounter this knowledge of having a deaf child identified in their family in a lot of different emotional responses.

So when we think about emotional support for families, we don't want to make any assumptions about that emotional process they're going through. So we really try to meet families where they're at, to respond in terms of whether they are grieving that and maybe the length of grief for different families. Some families take a lot longer to get through. Other families, literally, I've seen families maybe, and they wouldn't even describe it as grief, they would talk about it as surprise or shock, but really in a healthy way move towards action in a pretty quick way, where other families really struggle emotionally. And so being with a family and being where they're at in their emotions is really important for us.

Will Eiserman.:

Such a good reminder that there is a diversity of responses families experience associated with their child being identified as deaf or hard of hearing. So initially the emotional support that you provide must be related to the ways families start to wrap their heads around this unexpected discovery that their child is deaf or hard of hearing.

Janet Des Georges:

Yes, and we know as parents the emotional part of the journey is never just a linear experience or just in the beginning. It is a lifelong experience that comes up in different ways and different forms, particularly through transitions from early intervention into school years, from school years into adulthood and or even transitions that might be happening personally within families or as a child themselves moves through their own self-identity as a deaf individual and being able to respond to their emotional experience of the journey.

Will Eiserman.:

Yeah, I can see it's one thing to adapt initially to the news about diagnosis, but there can be many other times where the family faces new moments that are challenging, including those experienced solely by the child.

Janet Des Georges:

And I can give you an example. When our daughter, Sarah was seven years old, she'd been in a park and got into our car and said, "That's it. I'm never talking to anyone about my hearing aids again," because kids had been asking her about her hearing aids. And so I was in a moment where I was like, "No, Sarah, you should be proud of who you are as a deaf person. This is your opportunity to educate." And where she was at it emotionally, she was just done with it. And I had to learn as a parent to allow her to both love her deafness and hate her deafness in any given moment. And so it's not only supporting families in their own emotions, but being able to have the healthy aspect of that journey so that we can empower our own children but allow them to experience their emotions however they're experiencing them as well.

Will Eiserman.:

So when a family or a child has one of those punctuated experiences, it can be really helpful to share it with another family who has maybe already experienced something like that themselves or whom you can trust will at least understand the implications of it. But here I want to just pause and ask, as uniquely valuable as emotional support can be from other families, we don't really want to only look to family, to family supporters for emotional support, do we? Really, everyone in the lives of these families can be emotionally supportive in their own ways, I would think.

Janet Des Georges:

Absolutely. This multifaceted support that families need from professionals, parents, deaf and hard of hearing individuals, from their own extended families and communities. Good professionals are great at being across from families and providing emotional support. As well as deaf and hard of hearing individuals who have the lived experience that can be there with a family in a moment who's struggling emotionally. So it's getting this richness of diversity of perspective from the different areas.

Early intervention providers have served hundreds of families, so when they're across from a family, they can bring their perspective of how other families have gone through it as well. And of course when we're talking about parent to parent support, it's that organic, safe feeling of being across from someone who has to some degree experienced what you are going through right now. And that just creates a moment of trust and vulnerability that allows you to maybe voice some of your feelings that you can't in other spaces.

Will Eiserman.:

It really does take some skill, doesn't it? For a family supporter to know when to share one of their experiences and even how to do that. And these support providers may have a lot of experiences that come to mind that they need to select from when they're listening to someone.

Janet Des Georges:

One of our trainings is called, What Do I Say When? And we've taken, over the years, some of the first 30 to 40 questions that families ask in the very beginning and a part of our training is to say, "How would you respond to this question?" And so not only are we there to be there for the family, to be really in tune with what their questions and our concerns and are, but to bring in our expertise and experience of being with hundreds of other families. And so not to manipulate the conversation, but to also be able to say, some families think about this or that.

Will Eiserman.:

Let's talk about the information and resources piece now. Family support, as you described, includes several different elements. We've talked about emotional support and then there's this big, perhaps daunting need for information that most families face as they learn about their child's condition, various resources and services that are available. We know they need to make informed decisions. So how do the people in their lives, and in particular, the family supporters offer all of that without overwhelming families?

Janet Des Georges:

The very act of giving information and resources often ties back to the emotional experience, that the very thing that families need in order to get over the hump of certain emotions that they're having is information and resources. They begin to build some confidence and competence about the idea of how they're going to raise their deaf children or make decisions based on information and resources, and that lends itself to a more emotionally healthy space.

So I think these two things are really combined and I am always an advocate that we should, any of us, whether we're parent supporters or professionals, should not be the gatekeepers of deciding when and how much families get. The best way to figure that out is to ask families, "Do you want more information now or would you like to wait on this?"

Will Eiserman.:

That makes a lot of sense. Families do need to have the information and I guess the support necessary to receive it, even if it may be overwhelming at times.

Janet Des Georges:

I know our early intervention provider just would give any and all information that I asked for and sometimes I remember this one particular article that she had provided to me. I picked it up and started reading it and I had to put it down. It just created so much emotion in me that I wasn't ready. And then about a month later, wherever I was at, I was like, "Where is that article? I'm ready to read that now." And I was so glad that it was next to my bed, not that I had to go out and search for it because someone decided I wasn't emotionally ready to receive that information.

So I think the trained parent supporter should be someone who knows the information resources that are available so that when families ask, we can say, "Oh, I can get you four resources on that from a variety of different perspectives."

Will Eiserman.:

So I can see that an organization, like Hands & Voices, that in particular takes the time to train family to family supporters can be so helpful in being able to quickly access information of a wide variety and then point people in the right direction to learn about whatever it is that has come up for them in that particular moment.

Janet Des Georges:

Information and resource delivery is dependent on a parent supporter who knows where to find good information and resources. And so that's some of the work we do at Hands & Voices is to know a lot of the resources that exist. And we use a lot of resources outside our own organization to provide families. One example of that is within an hour one day, my phone rang twice. One family from one part of the country was wanted more information on listening and spoken language. So when I got off the phone, I was able to send her about 10 links and resources to that.

And then about a half an hour later, a family called and said, "I really would like more information about American Sign Language." And so I got off the phone and was able to send that parent all the information and resources, and it just happened to be a moment for me that epitomized who we are at Hands & Voices, which is helping families get the information that they're interested in getting.

Will Eiserman.:

Janet, do family to family support providers sometimes find themselves in situations where they're listening to a family discuss a concern or a decision they're trying to make, and you realize that perhaps the information the family has isn't exactly accurate or maybe is somehow incomplete?

Janet Des Georges:

Sometimes families have only received limited information based on who has come into their life at a certain point. And so getting information and resources from a lot of different perspectives has to be built into the system as a family is moving through their decision making. When we think about trained parent supporters are able to navigate conversations with families is when families share information that may be skewed towards bias is to just say, "There's different thoughts about this if you're interested in exploring this conversation in different ways."

So let me just use a different example besides language and communication, like school decisions about whether a child should be in the mainstream or a residential placement or a center-based programming. Sometimes families will come in and you can tell that the only information they've received is about one particular school setting and only the benefits of that.

Will Eiserman.:

So because you and your family supporters have time to spend with families and access to so much information, you can potentially identify times when additional information or another perspective can be offered for the family to consider, just so they know there are options. But that raises another potential need, doesn't it? And that's how to make decisions of this kind or magnitude if you haven't ever really had to do that before.

Janet Des Georges:

We have a communication decision guide we use which helps families look at the pros and cons of each approach or each decision because the truth is there's never any one decision that families make that would only all line up in the pro area. You have to understand both the pros and cons of any decision. And so that's one of the things we'll sort of help support a family and say, "Look at both the benefits and challenges," is maybe a way to say so that you're... To me, when I think about the word informed decision making, as you haven't only heard about the possible benefits and/or the challenges of that.

Will Eiserman.:

I imagine there are times, maybe especially at the beginning or now that I think of it at any new point that wasn't really anticipated, when a family may not even know what questions to ask.

Janet Des Georges:

Over the years, Hands & Voices in different projects and collaborations have been able to develop some lists of things that families might ask in the beginning that we provide to families. So there's a whole series of questions to ask your audiologist, questions to ask your ENT, questions to ask your early interventionists and the way we use that resources to say, "Here's some questions that other families have asked that you could look through and just check mark and say here's the ones that you're interested in asking."

Will Eiserman.:

That's such a valuable kind of support. I can also see that the family, maybe with the help of their support provider, can identify some new questions they have, but they may not really know who of the various professionals in their lives they should take the questions to.

Janet Des Georges:

In the parent to parent support context, when a family asks the question, we'll say, "That's a really good question for you to ask your physician or your audiologist." So part of our role is not always being the answer person to say, "Here's the individual or group that would be best to answer that question," including modality and language questions.

At Hands & Voices, we tend to send families to other organizations that are the experts in particular language. So the National Acute Speech Association, AG Bell, American Society for Deaf Children, those are three fantastic organizations that really have focus particularly on maybe one modality or language stream. So we often, as a parent support provider, we should never feel the pressure to answer every question, but to say, "Hey, go here or go there. Here's some other people who might be able to answer that."

Will Eiserman.:

And to turn it around, I'm guessing it would be good if healthcare providers or early interventionists recognize when it would be helpful to encourage families to ask a question of another family.

Janet Des Georges:

I think parents appreciate professionals who say, "I don't know the answer to that. I'm going to help you find that." So just like as parents will say, "That's a good question to ask an audiologist," we would hope that professionals in context to some of the conversations that parents might be asking them to say, "This would be really good for you to talk to another parent about." And to have the freedom and let go of fear that other parents may lead families astray. So professionals who have real trust in, for example, Hands & Voices in the work that we do, they have a really strong ability to be with families as well and say, "That's a great question to ask another parent, get their perspective on."

Will Eiserman.:

So we've talked about emotional support and the importance of giving unbiased information. Let's talk about modeling. What exactly is modeling in the family to family support context?

Janet Des Georges:

I think it's pretty simple in that what modeling is, when we think about it in context to parent to parent support, is the opportunity for families, not just to hear our words, but having the opportunity to see families and how they're interacting with their own children. So when we think about the parent to parent support construct, we shouldn't always think about it in just the one-to-one encounter, but when families are able to get together and experience and watch how other families are communicating with their kids, that really opens, I think, the door in the mind.

Particularly to see the different ways families do it that lead to success. It really frees you from the idea, especially if you've maybe been told that the only one right decision that you can make for your child is this particular modality. And then you go and you experience families who are communicating in all different ways. You begin to understand oh wow, there's different avenues towards success of how families are interacting with kids.

Will Eiserman.:

And there are so many different variations across families, different strategies and solutions that professionals couldn't possibly have the time or maybe even the insight about to be able to offer.

Janet Des Georges:

I think the messiness of life is a great model for other parents. So I've got a couple examples. When an audiologist tells a parent they need to keep their hearing aids on at all waking hours, when families get to see other families both modeling that, that families are working really hard to do that, that's a really positive model. And also the understanding that it's just almost impossible to do in real life. There's just sort of a release to like, "Okay, I'm doing the best I can. And so is that parent."

Will Eiserman.:

That's a great example. Not only can families learn strategies from each other, but it's got to feel good to know that you aren't the only one who struggles with something that seems so important and yet is so difficult at times.

Janet Des Georges:

There was a parent supporter who was contacted by an early intervention provider and said, "I've got a family I'm serving that has refused to take their young child out of the house. They can't get over the hump of that visual representation of their child's difference."

Will Eiserman.:

The stigma?

Janet Des Georges:

Yeah, the stigma. The early intervention provider said, "I've tried everything. I don't know what else to do. Could you come and meet the family?" And so this mom went with her own daughter to the house and just was with them, talked about them, introduced her child to them. So this parent support provider invited them to a picnic that was coming up that weekend. Four days later, that family took that young child out of the house for the first time.

There was this freeing experience of seeing another family thinking of this as normal, having overcome the stigma of it. And what I always appreciate and challenge individuals with is why was connecting to another parent the last resort for that professional? It should be ingrained in all providers to be thinking about not just as an add-on, but integral to the support that they are also providing. And I would guess that that early intervention provider was doing a lot of really good things with that family too. It wasn't that they weren't, it was just that the crossover experience that really helps families.

Will Eiserman.:

That example underscores that family to family support can potentially prevent barriers from building up over time, if they have those opportunities all along the way and early. How else does family to family support help? You've emphasized, Janet, that Hands & Voices aims to provide unbiased support, but families may still have received bias information or incomplete information that could have started to shape their opinions going forward.

Janet Des Georges:

Particularly if you've been given information that one particular option is going to be bad for your child and then you begin to see other families that have actually chosen that and are doing well, it opens your mind not only for the moment, but in the future too. In the event that as you move, families need flexibility. No choice is set in stone and we have to be able to respond to whether our children are achieving the goals and outcomes that we had hoped early on in the decisions we had to make, sometimes in a sense, in a vacuum.

Will Eiserman.:

And so those opportunities to meet other families and to see how they're implementing other choices that are different from what you may have chosen may come to serve you later down the road, if you reach a point where things aren't going as well as you'd like and you need to make some new choices.

Janet Des Georges:

So our motto at Hands & Voices, really sums up who we are, which is what works for your child is what makes the choice right. And so the decision-making process that families make for children is an evolution over time of understanding what is working for my child. And that's part of the family

construct, but we can't separate the family or the child from that decision making process. What works for your child is what makes the choice right.

Will Eiserman.:

And so to circle back, by providing family to family emotional support, the freedom to provide and discuss information, and then the opportunity to meet and get to know people who have made a whole array of choices, some like yours and some different from what you may have chosen, dramatically increases the chances that a family will be an informed decision maker and find what works best for their child. So what do all of these kinds of support look like? Am I right in thinking that different aspects of family to family support get blended in lots of different ways?

Janet Des Georges:

When we think about where and how families receive family to family support, every family is individualized in how they want to receive it. So we think about both passive and active ways. Families in the comfort of their own home, at their own pace, could be able to receive information, even parent to parent support. So an example of that would be a recording of a video of another parent talking where a parent could just sit. They don't want that one-on-one encounter, so passive ways, email lists, Facebook, things like that where families can sort of pace themselves about what they're getting and how they're getting it.

We think that's important as well as sort of active parent to parent support where you have the ability to just speak face to face. There's nothing like that. Particularly through the pandemic we found our parent to parent support through Zoom was, if not as effective as face-to-face encounters, really authentically good, phone calls, texting. Some families literally like to process some conversations through text, whatever the family needs. And so I think where and how families have the opportunity to get the parent to parent support should be delivered to them in a variety of ways.

Will Eiserman.:

I've seen on your website, Janet, which is handsandvoices.org, that you also offer a variety of different events in the various communities where you have chapters. So what kinds of events do you offer that you'd want healthcare providers and other professionals in the lives of these families to know about?

Janet Des Georges:

We hold all kinds of events from social picnics to workshops where we dive deep into educational law, topical sessions like Parenting Fathers and Deaf Kids, technology, all different kinds of events and opportunities for families. So our chapters do a great job of creating different types of spaces and places, including families with very young children all the way through the school years.

Will Eiserman.:

Janet, when a family makes an initial contact with somebody from Hands & Voices, how does that relationship typically start?

Janet Des Georges:

Yeah. Our model at Hands & Voices through our chapters and our guide by your side program is often families are initially hooked up with another parent guide in the guide by your side program based on geographic location. But within the very first encounter, if that family would like to speak to other

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families who are maybe representative of a particular modality they're exploring, the network of what we have here allows for families to be connected to other families from their own preference base as well.

Will Eiserman.:

Thank you so much, Janet. That was Janet Des Georges, the Executive Director of the family-based organization Hands & Voices. To learn more about family to family support for families who have a child who is deaf or hard of hearing, go to handsandvoices.org. I'm Will Eiserman from the National Center for Hearing Assessment and Management at Utah State University. Check out earwormpodcast.org for other episodes of Earworm, Dialogues on Hearing Health You Can't Stop Thinking About.

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