

A Global Conversation about Education

Presented by GPODHH - The Global Coalition of Parents of Children who are Deaf or Hard of Hearing

TRANSCRIPT

Jodi Cutler:

Okay, we are live. And this is extremely exciting, because this is the first official Global Coalition of Parents of Children who are Deaf or Hard of Hearing, GPODHH, webinar. All of us are parents. We are all here to offer some words of wisdom from our own personal experience regarding the scholastic experience we have had with our children.

Jodi Cutler:

The Global Coalition of Parents of Children who are Deaf or Hard of Hearing is an international collaboration of parent groups dedicated to promoting improved systemic protocols and practices which encourage informed choice, and the empowerment of families with a deaf or hard of hearing child throughout the world.

Jodi Cutler:

I am honored to be co-chairing this event with Janet DesGeorges, the executive director of Hands & Voices. And there's something that we need to tell everyone before we begin. We've had an issue with the captioning, whereas usually Facebook Live auto-generates the captions, I have been trying to make sure that works, and it has not been working for the past four days.

Jodi Cutler:

So we decided to incorporate webcaptioner.com, which unfortunately is only captioning my voice. So that is going to make things a little more complicated than we had anticipated, because one of our top priorities is rendering our webinars, and anything we do as a coalition, accessible to our audience.

Jodi Cutler:

We are going to do the best we can. Please be patient with us because, unfortunately, we've had this issue. And I'm going to give the word to Ann Porter, who is the co-chair. And Ann is from Australia, and she's going to introduce herself and give the introduction, as well as Snigdha Sarkar, who is a co-chair and the Director of Global Parent Advocacy, and Snigdha is from India.

Jodi Cutler:

So, after that, Janet will take over, and we will do our best to keep this as accessible as possible, despite the complications. Thank you again for your patience. Ann, please take it away.

Ann Porter:

Thanks so much, Jodi. So as Jodi said, I'm one of the co-chairs. My name's Ann Porter, and I'm one of the co-chairs of GPODHH, so the Global Coalition of Parents of Children who are Deaf or Hard of Hearing. I'm based in Australia. It's 5:00 AM here, so it's pretty early. Our other co-chair is Snigdha Sarkar from India, and she'll introduce herself in a minute.

Ann Porter:

GPODHH is an international collaboration of parent groups from around the world, and we're working together to improve services and support for families whose children and young people are deaf or hard of hearing. We come from many different countries with very different resources and support structures. But this really is not a barrier to our ability to work together to advocate for change and build knowledge amongst parents trying to make a difference where they live.

Ann Porter:

Our groups are all run by parents, and we promote informed choice. Funding is a significant obstacle for our local parent groups, and GPODHH is no different. Everyone generously volunteers their time and expertise to achieve our common goal. Language is always challenging when people meet from around the world. We have a dream that parent leaders speaking or signing in their home language will one day be able to participate effortlessly in our organization.

Ann Porter:

Unfortunately, at the moment our members need to be able to speak or read English, as is the case today. I just want to apologize again that the captions aren't working as smoothly as we had hoped. We will try and keep people up-to-date with conversations in the comments box. Okay, Snigdha, over to you now.

Snigdha Sarkar:

As Ann said, I am Snigdha from India. I'm happy to be here today, joining our webinar, a global conversation about education of children and parents who are deaf or hard of hearing where we shall learn from parents about their journey with their children on their own education. We think it is essential for us as parents to come together to talk about issues that concern our children across the countries, the choices, scopes and right to communication with education, inclusion.

Snigdha Sarkar:

We also want to have the parents voices heard in different platforms to acknowledge parents as potential resources in terms of bringing up their children with hearing loss. One of the ways we do this is through our membership of the World Hearing Forum of the WHO.

Snigdha Sarkar:

The goal of the World Hearing Forum is to facilitate the implementation of the World Health Assembly 70.13 resolution and support World Health Organizations adoptions in the field of hearing. It is necessary that the voice of the people with the lived experiences of deafness is included in forums where decisions are made that will affect the lives of those we love and support.

Snigdha Sarkar:

As a coalition, our members meet every second month online, and we come together every second year at the International Congress FCEI, Family-Centered Early Intervention that takes place in Bad Ischl, Austria. I will now hand over to the organizers of the webinar, Janet DesGeorges from the US and Jodi Cutler from Italy. Hope you will enjoy today's session. Thank you.

Jodi Cutler:

Thank you so much Snigdha and Ann for what you have discussed. I am trying to type as we go along to give a general summary of what our parents and co-chairs are saying and our speakers. So keep your eye on the comments box as we move along. Ann gave a wonderful introduction as did Snigdha. Snigdha discussed the fact that the GPODHH is a member of the World Hearing Forum and it is our top priority to make sure that the parental voice is present in any type of action that occurs, because we are the ones front and center dealing with all issues and trying to promote advocacy so that best practice occurs. Now I will give you Janet.

Janet DesGeorges:

Hi, everyone, this is Janet. As everyone said, we're so pleased to be here with you today. I don't know how many people are joining us today. I have no idea where you're sitting in the world, what time of the day it is for you. We knew that we wanted to be able to discuss the journey of raising our kids together, and particularly for today about the education of our deaf and hard of hearing kids.

Janet DesGeorges:

We want to start by telling you that our goal for today is for you to walk out feel supported, encouraged and not judged. Each one of our kids that we represent here today have their own unique needs, different communication modalities and languages that they're using. We have different educational systems that either are supporting our kids by law, or maybe there aren't systems there to support you.

Janet DesGeorges:

So what we really hope today is that that we all can be learners, that if someone gives an example of something they've done in the education of their child, that you can take that as a parent and think about it. Does that apply to you? Does that apply to your child? There might be some examples here that are specifically in sync with what your child needs, but what we really hope to do...

Janet DesGeorges:

I know for me as a parent, I didn't know what even ask for or advocate for, until I started being around other parents and beginning to understand both the accessibility needs and the communication needs of my daughter in school and education. So we invite you to sit back relax, keep your child in your mind and heart as we discussed these things.

Janet DesGeorges:

I think all of us as parents typically come into this experience without a lot of knowledge. And so that is our hope from the GPODHH that we'll be able to just encourage you in that way today. There's different people and experiences that you need to hear from in order to gain knowledge and today we're doing it through parent to parent support.

Janet DesGeorges:

We also need to hear the voices and lived experiences of deaf and hard of hearing adults to help us frame our decisions that we make for our kids. The professionals in our lives that also have a lifetime often of wealth and experience of the deaf experience to help us think through those things, as well as in good information.

Janet DesGeorges:

And information comes from websites, from parent to parent support groups, and that. And of course, we also have to include our community that existed before we even had a deaf child, our family members, community members, places of worship. All of those things will lend itself to thinking about how can we ensure the integrity of outcomes, so that our kids can truly live a successful life.

Janet DesGeorges:

So today's conversation, we're really excited to have some parents from all over the world who will just be sharing their hearts, about what they hope for their kids. Also, what challenges they face, maybe you'll think about some of the challenges that have faced you and then some of the victories along the way.

Janet DesGeorges:

We know today's short period of time together won't answer all the questions, won't have all the viewpoints in the world. But we hope this is just a start for you today. So Jodi is going to now help us introduce our parent panelists, and we'll get right into the questions.

Jodi Cutler:

Okay. I'm just about there. Janet, thank you for that. Greatly appreciated. We are honored to have three exceptional parents. And for those of you who are following who had some difficulty, because we're having problems with the captioning, as we said, I've typed somewhat general statement of what Janet was talking about and you'll find that inside the comments.

Jodi Cutler:

We do have some people who are with us who are watching, who are making some excellent points about who on the panel is deaf? Who's a native BSL user? Where are the interpreters? As we said at the beginning, perhaps you joined us a little bit late, we are having issues with the accessibility, we are all volunteers and we are doing the best that we can.

Jodi Cutler:

We did try to secure two ISL interpreters that unfortunately, we were unable to do. So we would like to thank you in advance for listening to the message that we're trying to convey to everyone by following what captioning we have tried to make available, and by reading the comments that are in the caption box. We are extremely aware that we need to do better and we need to be better, but we have to start somewhere. And right now, we hope that those few people we are able to reach are able to get some good information from what we're trying to do. So thank you for your patience on that matter once again. I'm going to say that right now we have three parents in addition to Snigdha and Ann and Janet and myself who you've already met.

Jodi Cutler:

They are Bianca Birdsey from South Africa, Joyce Nalugya from Uganda and Daiva, who's going to pronounce her last name because I would much rather she do that successfully for you who is from Austria. And so I'm going to give the word to Bianca first, who is the Director of Global Family Support Initiative as well for GPODHH. Bianca.

Bianca Birdsey:

Sorry, I wonder where [inaudible 00:14:38] unmute oneself. Thank you so much for the invitation. I actually think just to make a note on this captioning difficulty is that we often find ourselves as parents met with challenges that we do everything in our power to try and make as good as possible and sometimes at the end of the day, it just doesn't work.

Bianca Birdsey:

And so for me the issue we're having with the captioning is a bit of a metaphor to what certainly I've experienced on my journey parenting my three deaf children. I have three deaf children. They're all under the age of 10. I haven't got the T-shirt yet, like some of the other moms on the panel. But they are a joy and this journey really has taught me more than I ever thought my life was ever going to teach me. So thank you so much for the invitation.

Jodi Cutler:

Thank you, Bianca, please keep... Okay, I'm going to now pass this over to Joyce. Joyce one second for some reason your microphone is not unmuting. Okay, there you go.

Joyce Nalugya:

Thank you so much. I said, I'm so excited to be here to meet parents of deaf children all over the world. I bring you greetings from Uganda. We have the National Association of Parents of Deaf Children, which works to promote the rights of deaf children in Uganda. We mobilize ourselves as parents to form parent support groups. And in that we learn how to communicate with our children in sign language. So I'm so happy, I'll share more as time goes by. Thank you.

Jodi Cutler:

Thank you so much Joyce. And now Daiva.

Daiva Trečiokaitė:

I'm Daiva Trečiokaitė from Austria and I'm a mother two. I have two daughters, a nine and 11 years old, and my 11 years old daughter, she's deaf. I'm working as a Parent-to-Parent support provider in one clinic and I'm engaged in our parent organization in Upper Austria, GPODHH member too. So thank you very much for invitation. And I think this is really, really very important to talk about it, how it is with education for our children in other countries. I'm very interested how to know the world.

Janet DesGeorges:

This is Janet, thank you so much for those introductions and let's just get into the conversation now. My first question for our parent panelist is what is your dream for the education of your deaf or hard of hearing your child? And what would success look like to you in getting a successful education? Bianca, I'll start with you.

Bianca Birdsey:

Thank you. So success is an interesting word and it's one that I often jump around trying to define for myself, because it's often not what we sometimes perceive and certainly not what the world's messaging is. So I'd say an overall umbrella summary of what success would look like for my kids, would be that they would be so full of joy in knowing the purpose that they have, and that they are not meeting barriers that are stopping their purpose from becoming realized in any way.

Bianca Birdsey:

I'd love for them to be able to dream the same way that any other child is able to dream. That they see themselves as not being broken, but rather different and that the differences are such gifts to those around them and the world at large. I'd love for them to have relationships that are meaningful and deep and that they really don't feel like anything's missing or broken.

Bianca Birdsey:

I'd love for them to not have any regrets or any chips on their shoulder or any difficulties in the way they engage with people because of the experiences that they've had. I'd rather see them empowered and full of joy. But basically showing the world that diversity is not a bad thing.

Bianca Birdsey:

And so in terms of just the educational side, something that certainly steered my decision has been that I've really wanted them to be completely literate. And that's been a practical desire. I've also wanted them to not ever feel like anyone's trying to make them hearing, but rather embracing them as deaf people.

Bianca Birdsey:

In my country, that's been the greatest difficulty, is getting a balance between allowing them to access the foundation for education that will essentially enable them to become independent learners as a result of having really good literacy, but still be able to embrace their deafness as unique, amazing little people without having to just fit into a hearing space.

Bianca Birdsey:

So for me, that's been one of the greatest challenges. But my dreams for them are the same dreams I would have had, had they been hearing but also, even just more than that to say, "Well, you're different and that difference has to mean something extraordinary."

Jodi Cutler:

I love that. Oh, my God.

Janet DesGeorges:

This is Janet. Thanks Bianca. I'm going to ask you a question. I know you're not prepared for. But thinking about being a parent, three deaf children, how has it impacted your understanding of unique needs versus all deaf children need A, B or C. How did you evolve as a parent having three different deaf children and how did you meet each have their unique needs?

Bianca Birdsey:

Well, isn't that the same for any child? I think any child with a hearing, deaf, blind, seeing - whatever it might be they have unique needs. And I think the moment they become deaf or they put into this label, I'd see and experience even with myself thinking there must be one way.

Bianca Birdsey:

But there isn't one way for any job. So why should a deaf child be any different and certainly my experiences have been that they are different. When it comes to education, a real gift that this journey

has given me is it's forced me into being completely intentional and purposeful about absolutely everything that we do and understand.

Bianca Birdsey:

I don't think I would have been that parent had my kids not been deaf, and I hadn't being forced into this. I'm very grateful for that. And one of them is for example, learning what type of learner they are. And that's not an area I would have explored.

Bianca Birdsey:

So one of my deaf daughters is an auditory learner. It's been really strange to experience that and problem solve what works for her and others aren't. So it's been amazing to just have no choice but to embrace the fact that they're all different.

Bianca Birdsey:

They have different ways of topping up, their love tanks, they have different things that work for them, they have different interests. Two of my daughters are identical twins yet they're so extremely different. And so even though their genetics is as similar as could possibly be real, they have been built differently.

Bianca Birdsey:

Their opinions about their deafness is different. The way that they use language has been different. And they're personalities are different, but Janet, I think worth just to say that deaf children are like every other child in that they are unique.

Janet DesGeorges:

Yeah. This is Janet. Thanks Bianca. Joyce, will you talk a little bit about your dreams for what you hope for in the education of your deaf child.

Joyce Nalugya:

Yeah. Thank you, Janet. Maybe I didn't tell you that my daughter is now at university. But that's not the big issue. The issue is that for deaf children to have success in education, I took it at the family level first. Because here we look at education - Yes, they are getting the training at school, but most of the learning is really at home and in their environment.

Joyce Nalugya:

So I took success in education to be like someone is able to apply whatever they are learning in their lives. And for this deaf child, they are able to respect, to appreciate their own rights, but also respect other people's rights. It is not enough for a deaf child maybe to learn from nursery, primary, secondary, as we have it in Uganda and then go to university, but losing the social relationships, not being productive in their society.

Joyce Nalugya:

So for a deaf child to be successful in education, it has to come back to the family inclusion, they're able to communicate with everybody, they are able to learn from everybody, because what we learn from school is really too little.

Joyce Nalugya:

We learn majority from what we hear, from our friends, from our colleagues from our family members. And here in Uganda a child is raised by a family not only the nuclear, but also the other people we come to meet in our lives.

Joyce Nalugya:

So I take it to that for a child to succeed in education, they must have the environment which supports them to succeed both at home and at school. The children should have teachers who believe in them. And it's really a challenge for some of us here in our countries.

Joyce Nalugya:

Like we have very few institutions which appreciate, which can remove barriers for the deaf children, which have teachers who can ably communicate with their deaf children. I think that for a deaf child to be successful, we... And even society will ask, "This person is educated but they cannot even respect people, what are they doing for their communities?"

Joyce Nalugya:

Even if you have degrees, masters or PhDs, without really having what society expects you to do, they may not consider you successful. So we need to give to our deaf children the support that they need right from home for them to be successful in their lives and even in education. Thank you.

Janet DesGeorges:

This is Janet. This is so rich Joyce. I think about my own journey and learning how to advocate for my daughter in school. And it wasn't until I really began to focus on how what she was learning both advocacy and actual learning, applying into real life. So I've loved what you said about that. That's just so true. Thank you. Daiva, what does success look like in deaf education?

Daiva Trečiokaitė:

I think this successful is when a deaf child is going to the school with pleasure. My daughter she wants to go to the school. This is really successful I think. Once the children can participate in the class, and once they are active in the class [inaudible 00:27:30] understand what's the need, what they hear, what they see.

Daiva Trečiokaitė:

They understand it all and they are included in this class. I think this is important too. And when the communication with children is adapted for child needs. I mean, one child needs sign language, then this child has sign language. When the child needs a spoken language, he has it, and when child needs technical support, it's possible to get it.

Daiva Trečiokaitė:

I think this points are important and what my child feels. So to be normal child in the school this feeling for her is important to feel really like all children to be maybe special children and sometimes another child, but to be so like all.

Daiva Trečiokaitė:

It is interesting now in this class of my daughter one child said about it that, "Hmm, I don't know who is in the school in my class has hearing disability." That's mean in the first days. This guy he didn't see that exist some children who doesn't hear.

Daiva Trečiokaitė:

He didn't see this from the first moment, of course, because in the classes will be the teacher to use sign language and all children learn the sign language. And for him at the beginning it was so like, "Who is here deaf and who is hearing child." I mean, this class where I integrated all normal hearing children and deaf children. They're learning together. And this I see as a success that's been for me to actually get the same possibilities to be educated to learn. [29:57]

Janet DesGeorges:

This is Janet. Thank you. I can't agree with you more, and it made me think about a question that someone has asked on the Facebook chat. How do parents feel about schools hiring under-qualified signing staff to support deaf children? And you talked about Daiva, children getting what they need in the school setting. I think the answer to that question is often as parents, we go to schools and expect that either the school system or the school experts will have the things in place that our kids need.

Janet DesGeorges:

That's just not always true, and I think that's a worldwide consideration, no matter where you live in the world, that as parents and as advocates, as we grow in our knowledge of what are our kids need, that we also take those expectations to the schools in order to make sure that the people that are serving our children, are competent to do so. Thank you all three of you for your insights into success. I thought that was all really beautiful. Jodi is now going to ask the next set of questions.

Jodi Cutler:

Okay. All right. The next question is, what are the biggest challenges you have faced in your country, school et cetera, in ensuring that your child can be successful? Which is the perfect question to ask after the question that Janet just addressed.

Jodi Cutler:

So we're going to move into that and the idea of expectations, what Janet said about how we grow and we start to make our voices heard. So what happens when you have those challenges, and what do you do to ensure that your child can be successful?, and I'm going to ask that Daiva begins, if you don't mind to answer the question.

Daiva Trečiokaitė:

For me the biggest challenge was to decide which school is the best for my child. To really think about it, what needs my child and what is possible. Which schools are possible? Is this possible at a regular school? In our city in Linz, we have integrational school with integrational classes.

Daiva Trečiokaitė:

This means that children deaf and hearing children learn together. This means that in the class we'll be more than... Not only my daughter in this class, but more children. And to decide what is better for my

child? Is this better? Maybe I am to learn something, to learn sign language and to have another professionals who understand what does it mean to be deaf.

Daiva Trečiokaitė:

But this was new for me, maybe will be too much focus for deafness or to be sometimes the people can be a statement for other viewers, and to be from another side, to be so like all children, so that my child could be like all children. Maybe, could be better in regular school.

Daiva Trečiokaitė:

But will she be happy in this regular school? So for me this decision it was the biggest challenge to decide which school can be the best school? Which education, where my daughter can get the best education? In one school, in another school. But I mean that I can try it, of course when I could live somewhere where it doesn't exist, this possibility to choose the school, to trust the school can be another thing.

Daiva Trečiokaitė:

I think for me, it was really very heavy decision. I look at as much possible more information, I spoke with a lot of people, and I think that that what we decided, and when we were sure for this decision, it was easier and this challenge was... We managed it, I could say.

Daiva Trečiokaitė:

And when I see today that my daughter, she's happy for school, so I'm happy too. And I think that it was high decision. But it was the biggest challenge really. In the old days every day, of course, we have smaller or bigger challenges, we manage it one or another problem in the school too. And this is not so easy.

Jodi Cutler:

Daiva, how many children are there in her class?

Daiva Trečiokaitė:

In this class, normally are 15 children who are normal hearing and five deaf children, hard of hearing children, and very different children. Sometimes you need to use sign language, sometimes they need spoken language but all children will learn the sign language at the school.

Jodi Cutler:

How old was your child when you were deciding which school to send her to? At what age did you start having this challenge?

Daiva Trečiokaitė:

Our decision was really early because in the first time, we decided for kindergarten when my daughter was two years old, and we said, "Okay, which system would we like to have for our daughter?" So she began in this integrational kindergarten with 11 hearing children and four children with hearing closed or hard to hearing in the group.

Daiva Trečiokaitė:

The next step was to decide, "Okay, which school now need our daughter with six years?" Six years is begin from the school in Austria, and this was really, not so easy decision. We can't say that we have this way. We began this way with two years, but it was one more time. Every step with a lot of information, and a lot of really new challenges and new talks about it. What we can expect from one or other system, from regular school or for [inaudible 00:36:56].

Jodi Cutler:

I can encourage you by telling you that the choices will happen in middle school, high school and the university. So it's a never ending cycle of hard choices to make. And that's probably why we have the opportunity to really get to know our children, their strengths, their difficulties, and how we can improve their situations by really looking at all of the options, looking at our children and making the best decision.

Jodi Cutler:

The interesting part of having this discussion with families from around the world is that we really see that we are one huge community, and many of the challenges that we face are universal. So let's hear what Joyce has to say from Uganda. Thank you Daiva.

Joyce Nalugya:

Sharing with our education system, we have nursery, which is equivalent to early child development program. Then we have that primary, which lasts seven years, and secondary which is six years in school. Then they can go to university or a higher institution of learning, like vocational.

Joyce Nalugya:

First of all, we don't have many schools in Uganda. We have schools for the deaf, which specialize in deaf education at primary, but they are very few and not accessible to many parents or many deaf children and they are far away. Like, you can have a district... I don't know the equivalent of a district in your countries, but you can have one school serving a number of districts.

Joyce Nalugya:

So we don't have very many schools. So for me, as a parent, as an individual, the challenges that I faced really, at all levels, as Jodi has said. First of all, as I said, we don't have many Early Child Development Programs in the pre-school years, so children really start school late. That is a challenge. They start like around seven years.

Joyce Nalugya:

I was lucky that I got to know about this a little bit earlier, maybe because I had friends who supported me early and overcame the challenges of grief early. So I accepted that my child will be accessing the education as other children.

Joyce Nalugya:

So we went to a deaf school for the primary section and there I must say, the challenges there, like we have already mentioned, we have teachers who have experience teaching deaf children, but also we have teachers who are teaching because they have interest in the deaf children but not necessarily

having the knowledge of teaching deaf children. So there is a challenge there and the teachers need that support.

Joyce Nalugya:

At secondary school, as Jodi said, the choices continue. The challenges continue, where do we want to go? And there we chose to go to an inclusive school, but the challenges are many. First of all, the student population is high, the student-teacher ratio is high in our countries, and you expect maybe from now what we see at least a teacher should be teaching maybe five to eight children, but now you see one teacher, teaching maybe 30 children deaf and the schools...

Joyce Nalugya:

Deaf children learn mainly by seeing so their eyes are very important. So the visual materials that the teachers need to support them while teaching deaf children usually are not accessible. In many places as you move away from the cities, they can't even access internet, like they can't download materials or even be able to teach.

Joyce Nalugya:

So the quality of education can also be compromised. And so what we try to do as parents is to see how we can support teachers, because many parents come to us and say now, "If I say something, the teachers are going to identify my child as that child's parent is stubborn." But we try to create a relationship between parents and teachers so that they parent this child together.

Joyce Nalugya:

It is not easy for the teachers and it is not easy for the parents, so we need to support each other. We don't want to blame parents and we don't want to blame the teachers, but we need to work together because when the resources are few, we need to see how to utilize those few resources together for the benefit of the child. So the challenges are really many. And also like I said-

Jodi Cutler:

You-

Joyce Nalugya:

Sorry.

Jodi Cutler:

No, I was going to say that you raised many important points. But one thing that really struck me was obviously the importance of forming a relationship for the good of the child, and the idea of sharing resources, because when resources are limited, we really need to collaborate and work together to make sure we offer everything possible to the education system to assist our children.

Jodi Cutler:

Once again these are universal concepts that it's incredible to hear because it's my first time listening to parents speak from other countries. Joyce, we all live on different levels. I have internet access where I am, I can't imagine how difficult it must be to not have access to internet when you're talking about collecting important resources.

Jodi Cutler:

So your perspective and everything that you shared is extremely important regarding challenges that we face in making sure our kids have success. You've obviously done an amazing job, because your daughter's moving right along. So Bianca thank you Joyce. I'm sorry what did you want to say?

Joyce Nalugya:

Sorry.

Jodi Cutler:

Sorry, go ahead.

Joyce Nalugya:

Sorry. I just want to say that now that with this COVID pandemic, the children who are deaf... Now all schools are closed, children cannot go to school, but they are continuing to learn. It's only the children who can access internet, who can access maybe radios, but deaf children do not hear. So you can imagine the challenges that deaf children go through in this part of the world.

Jodi Cutler:

Absolutely. And it is a huge, huge problem, because... It's just not right. So yes, in fact this is definitely an important issue. I don't know how to resolve that, but the important part is that we start the discussion about it. Bianca, how are things? I'm curious to know what you would like to contribute to this argument.

Bianca Birdsey:

If we're talking about challenges in this question, one of the sets of challenges have been challenges that I've internally had to face. And some of them have included things like grappling with just the fluidity of this journey. I'm quite an organized plan person and I like to have my ducks in a row ahead of time.

Bianca Birdsey:

This is not a journey that enables you to do that. While I've certainly experienced it that way, but rather to just know that things might change. My journey of educating my kids has changed significantly. We've literally explored three very different models, which haven't been ever wrong for a season, they've been right for their season.

Bianca Birdsey:

And I think that's been one of my learning points is that there's no necessarily a right answer that you have to get right at the first time you decide what school to send your kid to. And that was actually really difficult for me to grapple with. I was so desperate to make the right decision for the next 12 years, but realized there isn't anyone necessarily for that.

Bianca Birdsey:

Another internal challenge was daring to be disliked, because if you challenge anybody's perspective on things, it generally doesn't go too well, and makes other people uncomfortable. And then realizing that my kids were worth the discomfort I was at times feeling and for them to also see that. And realizing ultimately that just because we might be told that a certain way is good enough, it doesn't have to be.

Bianca Birdsey:

If you don't think it's good enough for your kid, it's not. And even if you're the only voice that feels that way, that's okay. So those are some of the internal challenges that are definitely felt a reality. The structure of deaf education in South Africa is the second challenge. And that is the fact that there're polar ends of choices. There's nothing in the middle.

Bianca Birdsey:

So for the average deaf child, the only option really is a school for the deaf. It's no secret that the education is not of the highest standard, certainly not of an equal standard. Children generally, often leave schools for the deaf, relatively illiterate and there are many different reasons for that and reasons in our country's history that contributes to that.

Bianca Birdsey:

But if you want anything else, we talking an exclusive hearing environment, and often sign language is even documented in the policy of not being permitted, even on the property. So there's two extremes and our families never fitted in one extreme. We've always sort of fitted somewhere in the middle and as having three slightly different with each of them.

Bianca Birdsey:

So that has been my greatest challenge of trying to just find a system that enables us to educate them with their own unique needs, while and as they're getting older, introducing their own desires and thoughts and all of that in the process. It's no longer just my journey and my desires and my choices but now it's theirs too.

Bianca Birdsey:

And certainly the juggle with three different personalities can be interesting. And then I think, certainly a reality for us a huge challenge has been the sacrifices we've needed to make. Massive life decisions that we've had to put on hold, time that we've needed to give up, the money has been extreme. So just different levels of challenges that we have faced and are still facing. But I think my greatest lesson has been the fact that everything in its season, in different seasons, for different things, and that's okay.

Jodi Cutler:

Wow, you totally blew me away with your introductory and how you talked about your challenges and the idea of being fluid and when you think that... You're used to organizing and having things go a certain way, and suddenly you need to learn to adapt, and you need to learn to adapt in three different ways.

Jodi Cutler:

And you keep coming out with these expressions that I need to quote and I'm struggling to type everything as you're talking and I'm thinking, "Hmm that's something I really want to go back over." All I can say is that, thank you to the three of you for what you've shared about your challenges about, each environment represents different challenges, the type of classroom, the economical.

Jodi Cutler:

Aside from the economical, the environment that they find themselves in, the two different, one is a type of school facing only on deaf education, the other focusing on listening and learning. And while there are differences between the two and you find yourself in the middle. It's important to listen to parents and it's important to focus on your children and seeing what their needs are.

Jodi Cutler:

I'll never forget because my son, he was in a situation where he went to a certain high school, he was bullied, he wasn't happy in that high school. For him to leave that high school, he would have to go to a really difficult high school.

Jodi Cutler:

So I'm looking at my child, and I'm thinking, whatever you want to do I will support you. And I'm thinking, "But is he going to be able to succeed in a more difficult environment." And I'll never forget that one of the support groups I was on, there was a parent and her name was Paula Rosenthal, she said, "Don't you ever underestimate your child. You focus on your child's abilities and you are his greatest supporter, and if he wants to change schools, he'll change schools and you will help him find a way to make that a success. Don't ever put words in his mouth and don't ever think he can't do it."

Jodi Cutler:

So I supported him, he made the change, and he faced the challenges. We need to know that we can face the challenges because the ultimate goal is that success, and success comes in many forms, as Bianca discussed. Depends on your child, each of our children is unique. And so now I'm going to give the word to Janet, take it away.

Janet DesGeorges:

This is Janet. This is such a great conversation. I think as parents, and as hearing people, most of us come into this journey, not understanding or having the lived experience of being deaf. We learn from other deaf and hard of hearing adults, we learn from deaf parents of deaf kids.

Janet DesGeorges:

And yet when it comes to our own children the responsibility and accountability on our side to make the best decisions we can for our children, I often think about education is in terms of what do our children need? And how do we get that? It's kind of twofold.

Janet DesGeorges:

What our children need as deaf hard of hearing learners in whatever school setting they're in, is something that evolves over time. Our confidence and our strength. I think Jodi, and the rest of you talked about being able to advocate for your child's needs in the school setting, that is really about the how do you get it?

Janet DesGeorges:

But I know for me even understanding what my child needed, I needed to have good information and resources. I needed to be able to hear from other families and I talked about this earlier about where we learn that from professionals, from other parents, from deaf or hard of hearing adults. But let's focus for a minute, I'm going to ask the panel's focus for a minute.

Janet DesGeorges:

Once you begin to understand what your children needs, we often go into systems where there aren't qualified providers or there isn't a clear understanding of a holistic experience of deafness beyond the technology our kids might or might not be wearing.

Janet DesGeorges:

So how do you advocate? I'd like each of you to share a little bit of maybe some moments in your life where you found that you had to advocate for your child and how you went about that. I'm going to start with you Joyce. I think you're on mute.

Jodi Cutler:

Okay I got you, your good. Go ahead.

Joyce Nalugya:

After our child completed primary seven, we had to go to secondary school. And she chose to go to a hearing school. We looked for many schools and they would say, "We don't have a service for deaf children. We don't have a service." But we managed to get this one and our schools have really big populations up to over 1000 students.

Joyce Nalugya:

And she was going to be the only one deaf child. So what we did, we went to the Uganda National Association of the Deaf, we got deaf role models, we got awareness materials, we requested the head teacher to give us a day for the whole school population.

Joyce Nalugya:

So we met, we had a very big gathering, the teachers, the students, and we had the whole day. So we created awareness on deafness, we allowed them to ask questions. We brought this very good role models who are learned, they went driving and they had never seen any deaf adults driving and talking and teaching, the hearing.

Joyce Nalugya:

So we set that background and we made sure that also her siblings because we didn't want her to be there in that school alone in that big population. So the siblings also accepted to join that school. It was a good school, the teachers... But because this child had been included at family level, she doesn't really have problems with staying with hearing people or people who do not know how to sign.

Joyce Nalugya:

What I must say is that what we did the first day, we went there before the child joined the school. And when she joined the school, she was a friend to teachers, she was a friend to everybody. And that did not start that day, it started right from home.

Joyce Nalugya:

As she was growing up, we had included her, we would take her to communities of hearing people, so she knows how to interact with hearing people. And I think this was really very good for her and

contributed to her success. Because there what I must share with you is that the students that she started with in senior one, they learned how to sign even better than adults.

Joyce Nalugya:

And even now, when she meets them, they communicate very well as colleagues. So I think this was really a success. And what I must say that professionals really love the deaf children, but they don't know. Like us the parents, we didn't know, we didn't have any experience with deafness. But once they get engaged, you get involved and awareness is created, they are really willing to support the deaf children.

Janet DesGeorges:

This is Janet. That's so good. And it also brings to mind our understanding of advocacy and thinking about us as advocates as parents. Ultimately, what our whole advocacy is for is so that our own children become self-advocates and can navigate communication and education in their world.

Janet DesGeorges:

That eventually our advocacy moves to our children and we're more of a support system, to our children rather than the primary decision maker. And that's such a good experience, thanks for sharing that Joyce. Who wants to go next? I can't remember where we're in the line-up. Bianca or Daiva? Daiva why don't you go ahead.

Daiva Trečiokaitė:

From my personal experience, so successful I felt as we as parents, we talk with the teachers before the school year about this would meet our daughter. So Joyce, you communicated about this relationship to teacher. And I think it's important to build this relationship before the school, and I felt really the success in this moment when I spoke with teachers before my daughter started to go in the school.

Daiva Trečiokaitė:

And later, I have seen that really the teachers here could hear us what we need, what we said. And I think this is really good feeling. From our parent organization experience. We collected some years ago, we collected for our small newspaper, some tips about the school, from parents, from experiences from other parents. And so we write it all in this newspaper, and I see this information is approximately two years old.

Daiva Trečiokaitė:

Yeah, two years ago. We made it and I see how the parents needed this information now, and I meet a lot of parents, I speak with more parents and they ask, "Do you have something? What written information?" And when I can give this newspaper and to say, "Yes, we have and we collected this," I feel good that we made something, what can help for other parents.

Daiva Trečiokaitė:

And in our parent organization actual we have some changes in the system for counseling for children, deaf or hard of hearing children in regular schools in Upper Austria. And we're invited from the director. This just means we as parent organization were invited to discuss about it. But this was our initiative.

Daiva Trečiokaitė:

So we write a letter and they answer it, "Yes, you are invited to discuss about it." This is really the feeling of success, to be success, but this is the first step and what will be after this discussion, I don't know but this is first step it's okay. Can speak about it with education director and maybe change something to make better for our children.

Janet DesGeorges:

This is Janet, that's for sure advocacy is always an ongoing thing. And you have to start somewhere. There's always a first step, Bianca.

Bianca Birdsey:

This is a difficult question because it's got so many different elements to it. I think, for me just understanding what advocacy was. Maybe, I had a preconceived idea that advocacy was always something that would feel like a fight, just from its word. But realizing that, for me certainly in my experience, more of a relationship building with the people who you are bringing into this team, has been a far more effective approach.

Bianca Birdsey:

In my personal experience, I've tried both, and the relationship building was more successful. I also think that I learned quite early on that the best advocates were actually my kids. That I could be explaining and really summing up how amazing they were and how much potential they had, and how much big my dreams were there for.

Bianca Birdsey:

But actually people needed to see them, people needed to see them interacting, people needed to meet them, before what I said actually held much worth. And that's what I started to see. So certainly, if I need anybody to fight for me, I bring them along and within a few minutes, they want to fight for us in a good way.

Bianca Birdsey:

And so I think what's hard, it's also what Daiva was saying is that, you feel like you're in a continuous state of problem solving - 10 steps ahead of when the problem even comes up. And that's exhausting. And that is why we need other parents, and certainly professionals that are willing to bear the burden with us, because it certainly is this element of burden, and it's very real.

Bianca Birdsey:

And so thinking about things, I mean, I'll just give a very real example related to COVID. And that was just very early on in the day, I suddenly woke up in the middle night realizing that face masks was going to be a very real issue and lost much sleep over that, wondering whether my kids would actually be able to go to school at all, if that was something that the teachers were going to be forced wear because very quickly, it was becoming something that was mandatory for everybody.

Bianca Birdsey:

But this was before people were even talking about that. And being able to start problem solving that and figuring out what would be safe, but still allow access in the future, became something I realized we

needed to do. Otherwise, we weren't going back to school, if the teacher was needing to wear a mask at the front of the classroom.

Bianca Birdsey:

And that was going to be devastating, because my kids actually only started a new school at the beginning of this year and learned to love it and then COVID happened and we went home. So this was a very big deal. It was certainly keeping me up at night and needed to be faced.

Bianca Birdsey:

But by engaging with people and sharing honestly, our thoughts, our fears, engaging the kids and problem solving with them what some of the opportunities and solutions might be, I think we came to a really good solution, and then certainly felt that the burden was being shared. So that was one of the best examples.

Bianca Birdsey:

Another example was, as I mentioned my kids have started a new school this year. And it's intimidating for a school, especially in an education system that says, they're inclusive but it isn't really because most children with special needs go to special schools in our country.

Bianca Birdsey:

So to approach a school that has awesome intentions, but to expect them to take something that's, very foreign to them is really, understandably quite an intimidating thought. And so building a relationship with them over a year, allowing my kids to visit here and there just enabled us to take the next step and it was one of mutual understanding, mutual respect and mutual desire to see the kids and be basically their best selves.

Bianca Birdsey:

So that's been the approach that's worked best for us, as opposed to one that's necessarily required for a fight, which I know will come at times in different situations. But I think this is a journey where one needs to pick your battles, and try and do it with caring relationships as much as possible.

Janet DesGeorges:

This is Janet, I'm going to hand it back over to Jodi, all of your answers were so beautiful, you guys. And I'm also thinking about something Jodi, you talked about in terms of your experience with keeping expectations high. And I think some of the weariness for ourselves as parents in advocacy is it is hard work.

Janet DesGeorges:

And it does take courage to speak up when no one else is, but that's directly correlated to our expectations and the belief that our children also have a right to education and so, your motivation to advocate often comes from deep within and it does require courage because sometimes you are the only one in the room who's going to stand up, and advocate for the rights of your kids. And the most success really does come through relationship building, as we talked about it's really good. Jodi, do you have our last question for our panelists?

Jodi Cutler:

Okay, just before I do go to that question, I want to bring it back to something Janet said, and to get to what Janet said, I want to go back to what Daiva started with the idea of trying to choose which school to send your child to, and the challenges that you have to face before you can make that choice.

Jodi Cutler:

And it's a whole process trying to decide what is the best choice. And as a parent you're always terrified to make the wrong choice. All of your intentions are good, but you're terrified because it's all on you and your child doesn't have that voice yet.

Jodi Cutler:

Taking it back to what Janet said, and that we need to be advocates for our children and use our voices until our children can use their voices. One of the most successful moments I believe I had, was also one of the most difficult moments.

Jodi Cutler:

When my child was in the last year of pre-school and it was the moment where he had to transition to elementary school and the pre-school teachers were saying, "No, I don't think you should send your child to elementary school you should hold them back one more year because I think he could be violent," and this and that.

Jodi Cutler:

And as a mother, I realized that my son was bored. He needed a new environment, he needed to grow and so I didn't listen to the professional as much as I respected the professional. Sometimes we have to make those hard choices, that may go against the current because we know what's best for our child.

Jodi Cutler:

And when my son came home from middle school, and he said to me, "Mom, I just want you to know that today on the first day when we introduced ourselves, I told everyone in the class that I was deaf, and I explained what my cochlear implants were." So for me, that was one of the highlights of my life that he finally used his own voice to explain part of who he is.

Jodi Cutler:

And so, advocating is a process, it's never easy, but it is worth it. All of the stress, anxiety and tension, because at the end there's only love because that's what it takes to get you from there to here. And now for the last question. What are the best resources that have helped you? What are the best resources that have helped you in this journey? Who would like to begin? Three-

Bianca Birdsey:

I'm happy to-

Jodi Cutler:

Okay.

Bianca Birdsey:

The best resources on this journey for me have been other people. So it's been the likes of those of you on this panel and getting to know you and having your voices become my inner voice, telling me that more is possible and to expect greatness. That's been life changing for my family and will be forever.

Bianca Birdsey:

And then deaf and hard of hearing adults, hearing their stories, having perspectives shared that would never have come up with on my own. I would never been able to imagine that. And having that in the back of my mind with all the decisions that we make. And then the professionals that are *for* us, the professionals that fight for us, and just getting strained from that being able to pass the burden on when it feels heavy and to be able to share in that.

Bianca Birdsey:

Those have definitely been the best tools that I've found. Yes, we do have access to some policies, that have rights associated to them. Something that we find, sometimes in our country, is that the policies might look really great, but implementing them is a different story. And I do also think that policies are difficult because they are often written in a way that you don't really know what they're trying to say or when it comes down to the crunch what it really means.

Bianca Birdsey:

Is this just a nice to have? At times that actually, when there's limited resources, they can't be actualized. So policies are hard. And I think sometimes we give up too easily when we see that we can't get someone else to do it on our behalf of a policy. But to say, actually, we can. And sometimes you got to make what doesn't exist.

Bianca Birdsey:

That's certainly been what we've experienced. But just to really appreciate the other people in one's life, the perspectives of those that have gone before you, I definitely say there's more my practical tools that I've taken from this journey.

Jodi Cutler:

Thank you very much. Joyce.

Daiva Trečiokaitė:

Daiva. So my resource-

Jodi Cutler:

Daiva, sorry. Go ahead.

Daiva Trečiokaitė:

I'm agreeing with Bianca and my resources are another parents too. Because to speak with them and to read about it, but to speak with another parents. In the first time, to speak with hearing parents because they can feel the same what I feel. At the begin, regardless what I must decide when my child is a baby, I need to speak with this hearing parents what they feel.

Daiva Trečiokaitė:

When my child is school boy, school girl I need to speak for the first time with them. And of course I need to speak with deaf people. What decisions they did, and why they did this decisions, and what they say. So from their point of view, for me it's important to hear and with other people and with children, other deaf children or hard of hearing children to speak and to see them and to see how my child is integrated in this world with hearing and deaf people, that they are together and my daughter have good feeling to be there. This is my resource.

Jodi Cutler:

Thank you very much Daiva. Joyce. One sec Joyce. Okay, go ahead.

Joyce Nalugya:

My first resource is family. Here I tell you, everybody now... What we are saying now, someone is interpreting for her. So her siblings, with the parents or the family, here we have extended family also. And also we have the church which we go to, they are really very supportive. And the deaf role models are really a great resource for us.

Joyce Nalugya:

And my fellow parents, I shared that we form parent support groups. We really share experiences, and we learn from each other, we share information, we decide now, "How do we handle this issue?" For example, when it comes to examinations, we had to go to the Uganda National Examinations Board, UNEB.

Joyce Nalugya:

And we are telling them, "These students can learn, they can really read for themselves this questions, if the language used can be written in such a way that a deaf child can really comprehend easily." But also the professionals. I remember when I got the news that my child is profoundly deaf, the doctor and the nurse were aware of the schools.

Joyce Nalugya:

They told me, "Joyce don't worry. There are schools where your child can go to, she can study, you can also learn how to communicate with." And these were professionals talking to me. So that relationship with professionals is good and also the schools, the teachers. I don't want to forget the interpreters.

Joyce Nalugya:

Because like now, for the lower primary school, there are schools for the deaf. But as you move higher, the child is most likely go to an inclusive setting. And there we need the interpreter services. Really very supportive. And I want to say that this work, the work that we do with deaf children, need to be supported.

Joyce Nalugya:

So I want to appreciate those organizations which have come up to support the parents work. And I can't leave this session without mentioning Deaf Child Worldwide. They are supporting us. As I said, we mobilized ourselves, we learned sign language but also we get lots of materials from their website.

Joyce Nalugya:

We get lots of materials, lots of information, we read, and we share with our fellow parents who cannot get those materials. Like I said, very few of us can access internet, but there is a wealth of materials. And I'm so happy for GPODHH. When I learned about GPODHH, through my colleague, Josephine, she's the one who first attended the conference that Jodi talked about.

Joyce Nalugya:

And I went to the website and I have really got lots of information there that I share with my colleagues about parenting, parent to parent mentorship. So we have these resources which have helped us and are still helping us. Thank you very much.

Jodi Cutler:

Joyce, thank you for your comment and for all of the interesting information that you included in your comment and all the love behind that comment. Because when you speak, I can see all of the passion, respect and love that you have put into your journey and that you are paying forward to other families because in everything you discussed, you discussed how any...

Jodi Cutler:

Your main concept is community, family and the idea of sharing and working together to give a foundation that will allow for success. So for me it's been an honor to hear you speak, as it has to hear Bianca tell her experience and Daiva to talk about her experience. As far as resources go, what we have shared here has been individual. The aspect of GPODHH that I truly appreciate, is that these are different associations from different countries and everyone makes their experiences available.

Jodi Cutler:

Hands & Voices, for example, when I was looking for materials and resources to educate pediatricians, Hands & Voices assisted me by giving me the resources they created to give educational courses and sensibility training to pediatricians that they used in the United States.

Jodi Cutler:

And just the idea of sharing and having somebody available to give you something that's already done, made my life so much easier to provide resources to families in Italy. Resources here, thanks to technology that we have available, thank God, we put everything on the forum, that I run in Italy, and it's a collection of associations on a national level.

Jodi Cutler:

So every activity they provide is something that we make available so that every local area can incorporate that activity when there are funds available, when there is an information pamphlet about COVID, we don't need to reinvent the wheel. What we have created here is a pool of resources that have already been created so that we can share them to improve the situation globally. I would like to thank the people who have been following this webinar.

Jodi Cutler:

As we said, in the beginning of the webinar, we have unfortunately had major accessibility problems. We have tried and done our best during this first experience to do some... I've been trying to give some summaries in the comments and we realized that this is very lacking. So we appreciate your patience

and understanding that we're doing the best we can. We did try to get sign language interpreters, ISL interpreters, but unfortunately we were unable to do that.

Jodi Cutler:

The purpose of this webinar was to give a parental perspective, individual experience so that other parents navigating the journey don't feel as alone. So that other parents navigating the journey can maybe take some little piece of information that Joyce gave, that Bianca gave, that Janet gave, that Daiva gave.

Jodi Cutler:

And maybe just one little sentence could have been enough to improve their journey. And that's why we're here. Janet, please take it away. I would like to thank you for all you have done to create this webinar, to structure it and to make it possible because you are just amazing.

Janet DesGeorges:

This is Janet. I also want to add my thanks with Jodi to all of our panelists today who gave a lot of thought about the questions we wanted them to address. And again, for all of you who joined us. I think we should always start and end conversations about our deaf children with joy. I wanted to just share a quick story if you know me, you may have heard this story, but it keeps resonating with me and my own family's journey of having a deaf child in our family.

Janet DesGeorges:

Recently, one of my hearing daughters was nine months pregnant and we were in the kitchen with my deaf daughter and we were laughing and talking about the experience of my pregnant daughter going to the hospital and whether her baby would be screened for hearing or deafness or not. We were just having a conversation about making sure we were all there when it happened.

Janet DesGeorges:

And my hearing daughter she was standing in the kitchen nine months pregnant and with her hands on her belly and she looked over at my deaf daughter and she said, "Wouldn't it be great if my baby was deaf." And for me that epitomizes the moment in our family's life of this journey.

Janet DesGeorges:

Whether it's through education, in their advocacy, our kids' self-identity, our own acceptance as parents, that this is actually a life of joy. And I'm so grateful to be here with you, all of you from all over the world. And we hope to be together again another time. I don't know if Snigdha and Ann wanted to say a final goodbye as our co-chairs of the GPODHH?

Janet DesGeorges:

But otherwise, we want to thank you for being here. It's hard to leave, we'll do it again. We'll do it better, more accessible and hopefully in the future too, we'll bring another perspective. We understand there's other perspectives - professionals, deaf and hard of hearing adult. But for today, at the core of who we are, we want to just start our conversation as parents and we'll see you again. Again, if you need more support, we're at www.gpodhh.org and we're glad you're a part of our community. Thank you for being here.