



Perspectives from a Virtual Parent Community

Uma Soman, Director
Uma Mididaddi, Board President

EHDI 2023 | Cincinnati, OH



Objectives

1

Describe the formation of parent led virtual communities

2

Explore the benefits families derive from engaging in a virtual community with other families

3

Examine how professionals can empower families to become catalysts for change





**TRANSFORMING LIVES OF CHILDREN WHO ARE
DEAF OR HARD OF HEARING, AROUND THE WORLD
THROUGH PARENT EMPOWERMENT,
PROFESSIONAL DEVELOPMENT, AND PUBLIC AWARENESS**

✉ info@ListeningTogether.com

🌐 ListeningTogether.com

📷 [ListeningTo_DHH](https://www.instagram.com/ListeningTo_DHH)

WE WANT

- Children who are deaf or hard of hearing (DHH) to have access to rehabilitation and educational intervention to achieve their full potential
- Families of children who are DHH to engage in family-centered intervention in partnership with professionals to achieve their desired outcomes
- Professionals in school, center, or hospital based ear and hearing care programs to have training in provision of high-quality intervention and access to resources for ongoing development



Our Work



Children & Caregivers
Direct Intervention
Parent Support



Professionals
Trainings
Mentoring



Communities
Awareness
Advocacy



The Origin Story of Our Virtual Parent Community

Led by Ahladhini Rao Dugar (EI & ToDHH) with support from Uma Mididaddi (parent) till August 2022.
Now is being led by Uma Mididaddi (Parent) with support from Uma Soman (ToDHH).

- Examination of the ground reality - access, power, connection
- We created a shared, safe space - whatsapp group (50), and bi-monthly sessions (20)
- We asked, listened, and responded.
- We built content and conversations around what we were hearing from the families.
- We facilitated conversations within families without the "professional expert" giving the answers.




Virtual Parent Community Activities

- Group sessions focused on
 - LSL strategies to develop communication
 - Topic specific discussions
- Parent led projects
- Storytelling and sharing
 - Families
 - DHH young adults, teenagers, children
 - Siblings



Information Sharing




[Redacted]

Hello parents, now with school starting how do u tie up your daughters hair to hold implant in place with no chances of falling.. especially in active sports classes

3:37 AM

It will be nice if you could give a boys perspective too

3:37 AM



[Redacted]

[Redacted]

It will be nice if you could give a boys perspective too

For boys - we have got a head band in cochlear and we are using it when he goes for sports class and in school PE sessions. Couple of years ago have heard with some other families that they have made a home made cotton band stitched along with Velcro for so multiple usage. Very affordable too... they said.

8:23 AM



Storytelling & Perspective Sharing



Hello Everyone, Based on the conversation in our community session last Friday thought the following video from the US based parent run organization Hands and Voices would resonate with all of you. 😊

7:34 AM

An Interview: The importance of families connecting with Deaf/Hard of Hearing Adults with Janet DesGeorges and Karen Putz

7:34 AM



█ and █ thank you so so much for sharing the different stages of your journey... honestly the confidence was breathtaking..the way you both answered the questions promptly was so commendable..

my takeaways:

1. Child lead is very important ..
- 2 . SELF ADVOCACY is a MUST...
3. Figure out all the ways to make sports Music Dance (and what not) possible ...

Thanks a ton to the entire LT team for giving us beautiful Mentors , inspiring models (█ and infact all the kiddos)and the amazing parents for being so supportive and non judgemental..



11:52 PM



Hi all,

I am █ from █ and My son █ is 4yo and he is a bilateral cochlear implantee. I wanted to quickly share an incident that happened as an after effect of the recent wonderful mainstream sessions that we had. I am planning to put my son in a mainstream school in June and I wanted to quickly check how much my son can answer if someone question him about his implants. Below is the conversation that we had.

Me- (pointing to his processors) and asked him ' what will you say if anna, akka and your friends at school ask you what this is? '

█ - 'cochlear implants'

Me - 'ok good, so why are you having them? '

█ - 'if I have them I can hear. If I don't wear them, I can't hear. '

Me - 'super ... How are they sitting on your head? '

█ - (after couple of seconds) 'using magnets... '

I was very happy that day and the complete credit goes to all the mentors (both professional and parents) here. Without Maya and sid book, my son wouldn't have said the technical terms like cochlear implants and magnets. This is just a sample of how much our family has received from this community and I am truly grateful for this.

2:14 AM

Fostering Parent Leadership



A shout out and special thanks to [REDACTED] who took wonderful notes and shared it with the parents who had missed the session in the weekly group. Uma M suggested requesting [REDACTED] to share her notes. @ [REDACTED] thank you for giving me permission to share your notes with the SUNO community. 😊

9:34 PM

Parent- [REDACTED] Notes from last Saturday's Session with Uma S & Uma M:

9:35 PM

Information about Academics and resources- Shared by Uma Soman

1. Understand the pre-teaching of concepts and vocabulary to benefit the child and to know from school on how to get information on the topics that will be covered.

2. Preparing them ahead

Communication tips with Teachers, - Shared by Uma Middadi

1. Partnering with school and teacher

2. Regular PTM's may be 3 to 4 in a year.

- Facilitating parents to take action on what they see as gaps
 - Book project
 - Music project
 - Vocabulary project

AJA

Research Article

Revised Conceptual Framework of Parent-to-Parent Support for Parents of Children Who Are Deaf or Hard of Hearing: A Modified Delphi Study

Rebecca J. Henderson,^a Andrew M. Johnson,^a and Sheila T. Moodie^{a,b}

HANDS & VOICES
FAMILY LEADERSHIP IN
LANGUAGE & LEARNING (FL3)



FAMILY-TO-FAMILY
SUPPORT

FAMILY-TO-FAMILY SUPPORT PROGRAM
GUIDELINES FOR ADDRESSING THE NEEDS
OF FAMILIES WHO HAVE CHILDREN WHO ARE
DEAF/HARD OF HEARING (D/HH)

HANDS & VOICES
HANDS & VOICES Headquarters
PO Box 3093
Boulder, CO 80307
303-442-6203

Listening
Together

✉ info@ListeningTogether.com

🌐 ListeningTogether.com

📷 ListeningTo_DHH

Perspectives on Parent to Parent Connections

It's amazing to be connected together on LT forum , not only as parents we get to discuss about our child's progression, developments but also concerns . As parents we are always seeking suggestions and recommendations from our mentors Uma square

Firstly parent to parent connection has helped me to accept my situation more confidently and with much more ease. It helped me to understand that I am not alone here.. Then these connections have opened a new world of possibilities , answered the tiniest of doubts and concerns whether it is related to academics , peers, choosing sports, self advocacy, using FM and many many more. Heartfelt Thanks to LT team for creating awareness and empowering all of us.



Perspectives on Parent to Parent Connections

For me.... People help me a lot I don't have any words to describe it but whenever I am stuck with any kind of problem they recover me with their logical answer @Uma Soman thank you for everything @Uma Mididaddi massi thank you for everything. Lastly Thank you Each and every family of LT you guys tolerate me a lot 😊

With LT parent community it's been a wonderful, very connected and helping journey in my child's progress and growth. It's always amazing when parents to parent connect each other and support each other. And LT parent community is a very helpful platform in terms of connections. I personally got connected with so many parents and could share my small day to day problems and thoughts with other parents and benefited.

Thanku so much LT parent community





Perspectives on Parent to Parent Connections

This parent to parent connects is very important as it helps us to overcome day to day challenges. You learn about new strategies and ways to deal with the concerns. This connection and listening to other parents also helps me to get calm down whenever I have anxieties. 🙏

Parent to parent support has kept me motivated always. I could get practical/creative ideas from other parents. I could discuss every issue that bothered me. Taking advice, gaining knowledge on opportunities or solutions for problems. When ever there is a pressure or feel low, this connects or talks with these parents would bring me on toes and motivated again. Thank you.



Perspectives on Parent to Parent Connections

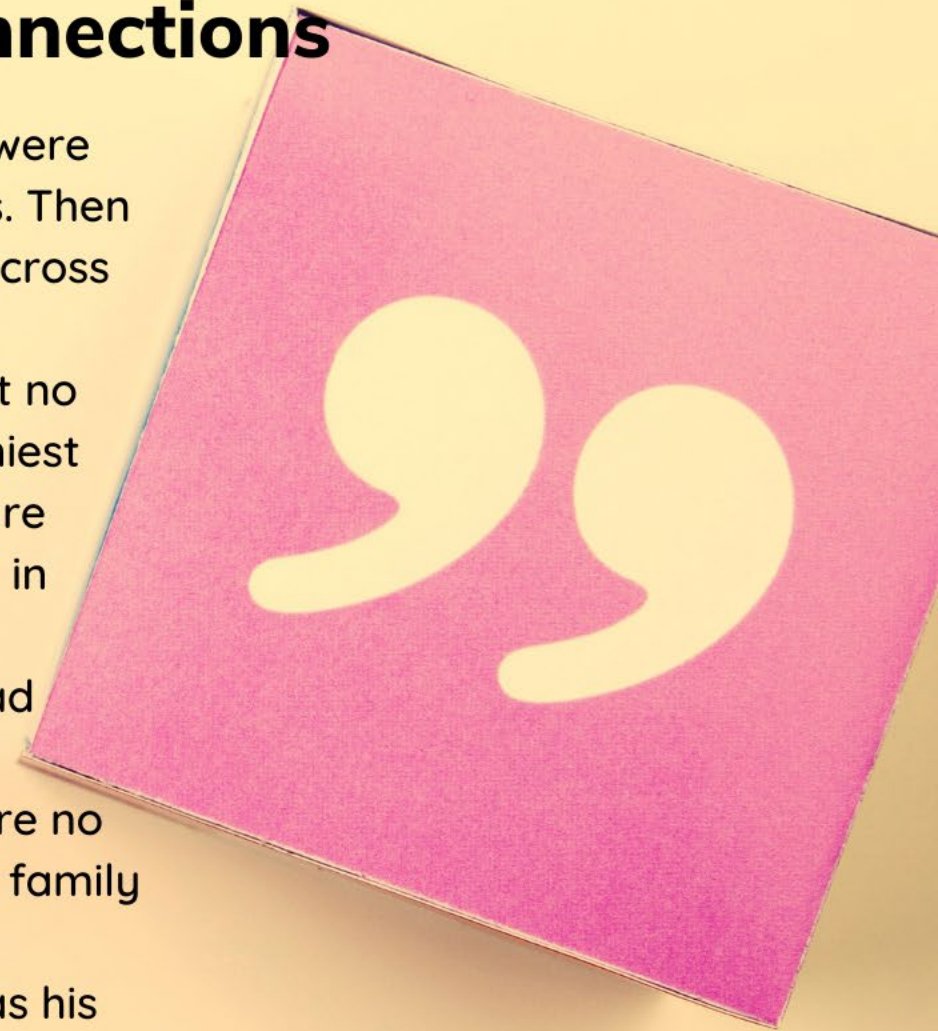
As we were just starting on the journey of raising a DHH child, we were completely blank and our hearts were filled with a zillion questions. Then came our angels of LT team and brought along parents from all across whose kids were at different stages.

-Meeting other families consistently at weekly LT sessions makes it no less than a virtual family. Its a safe place where I can share my tiniest joy and they know exactly why it needs to be celebrated, I can share my silliest concern without being judged because we are all sailing in the same boat.

-Also, it is a huge motivating factor to see kids who are much ahead in their journeys doing so well academically, pursuing sports and even managing to dive in the sky. It puts me at peace that there are no boundaries for our kids. And whenever I am in doubt, I know which family to reach out.

-I feel its not just me but my son as well who see's the fellow kids as his 'Cool Cochlear' friends.

Heartfelt thanks to the entire LT Team for making this happen for us! ♥



Lessons Learned

- Building trust and a safe space is possible virtually. It is not a "back up" option, it is not less than in-person gatherings.
- Community priorities change over time, and being responsive to this change is important to maintain momentum.
- Interest and availability of community members will impact engagement.
- Any change in leaders / facilitators will change the group dynamics and momentum.
- A virtual community of support can be implemented in other groups of individuals.



Currently working with a small group of professionals to create the change we want to see!



Connect with Us



Uma Soman, PhD, LSLS Cert AVEd.
Co-Founder & Director
Teacher of DHH Students
LSLS Auditory Verbal Educator
uma.soman@listeningtogether.com



Uma Mididaddi
Board President
Parent Liaison
uma.mid@listeningtogether.com



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