

Uniquely Delivering Family to Family Support Within EHDI Systems and Beyond

Hands & Voices
Family Leadership in Language and Learning
2018 EHDI Conference Pre-Session



Janet DesGeorges

- Credentials: M.O.M. (*“Mom, you wouldn’t have a job if it wasn’t for me.”*); our family story
- Systemic involvement for over 20 years (medical, educational, community, leadership development)
- Executive Director and Co-Founder, Hands & Voices Headquarters (almost 50 chapters in the U.S. and abroad)
- Certificate of Completion at the University of North Carolina- Chapel Hill MCH Public Health Leadership Institute



Today's Goals/Objectives

- Explore the evidence-based practices and preferences of parent-to-parent support and provide current program and methods of delivery models offered by Hands & Voices, which can be passive (newsletters, fact sheets, websites) to active (retreats, social media networking, one-on-one and group interactions).
- Address the ways in which parents with newly identified children who are D/HH access information and need different kinds of support in different formats – including the needs of low resourced communities, hard to engage families, culturally diverse families etc.
- Offer innovative strategies and new creative solutions pulled from the diversity of resource dissemination practices across states and territories and discuss the pros and cons of virtual parent engagement.
- Promote integration of adults who are deaf and hard of hearing in families' lives
- Provide concrete goals and objectives that EHDI systems can incorporate to fulfil the MCH directive of providing families the opportunity for family-to-family support (during the interactive segments of the workshop).

Today's Participants

- Parent Leaders
- Family Based Organization Leaders
 - EHDI System Leaders
- DHH Adult Role Models/Mentors/Leaders
 - Professionals
 - Other



Family Leadership in Language and Learning FL3



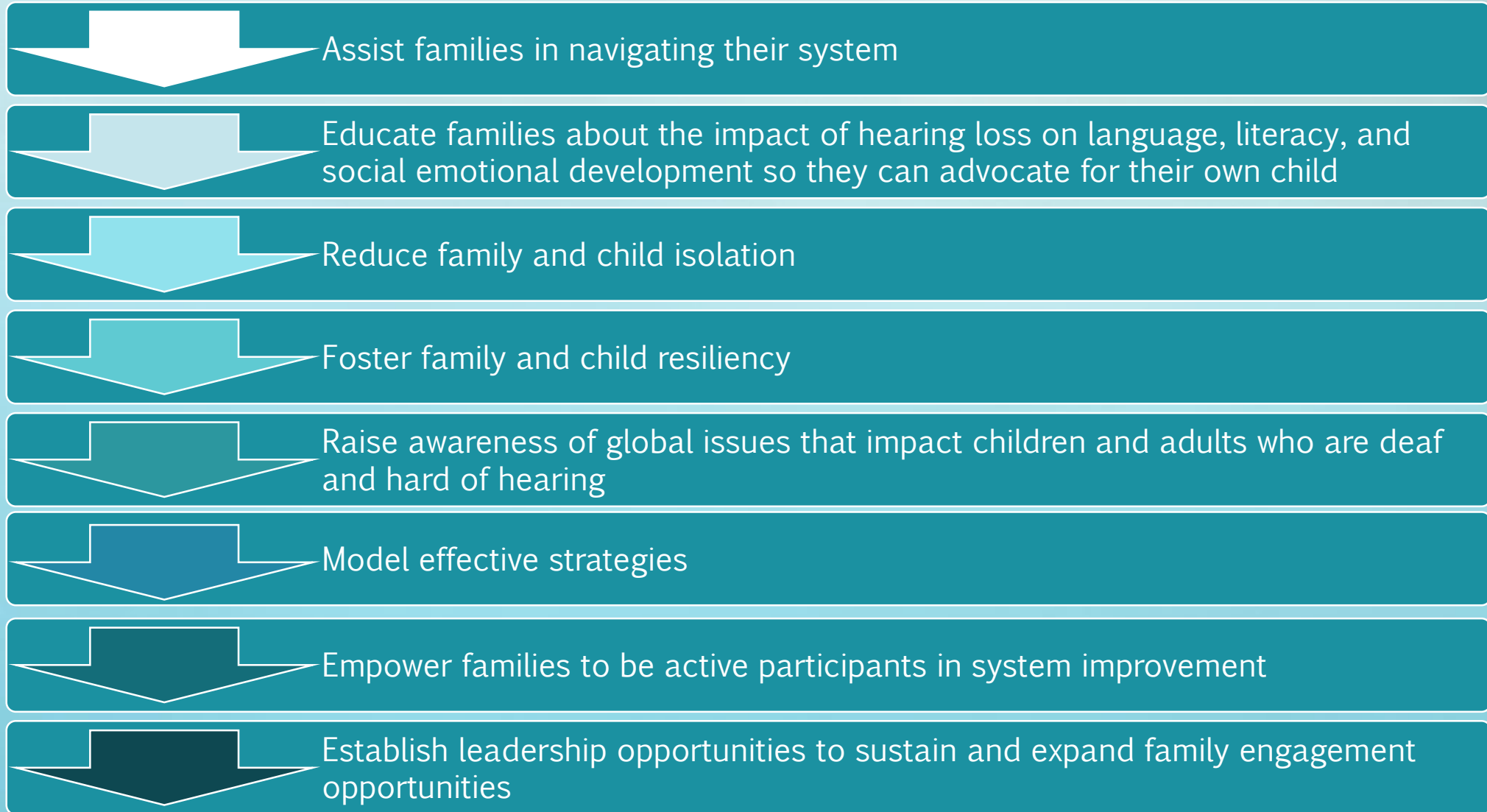
- Imagine if...
 - every family had the opportunity for Family to Family Support no matter where they lived
 - every family had the opportunity to meet and interact with a Deaf/HH adult to help form an understanding of the ‘lived experiences’ of D/HH individuals in the world
 - every family could grow in their knowledge and skills for their own child’s, unique language, literacy, and social-emotional growth
 - every state and territory EHDI system had meaningful partnerships with family based organizations
 - every family leader could build their leadership skills in a meaningful way to support their involvement

Candace Lindow-Davies



- H & V Director of Outreach
- H&V FL3 Co-Director
- Former Director of MN Hands & Voices for 16+ years
- Parent of an adult who is deaf “plus”

Goals of Family-to-Family Support

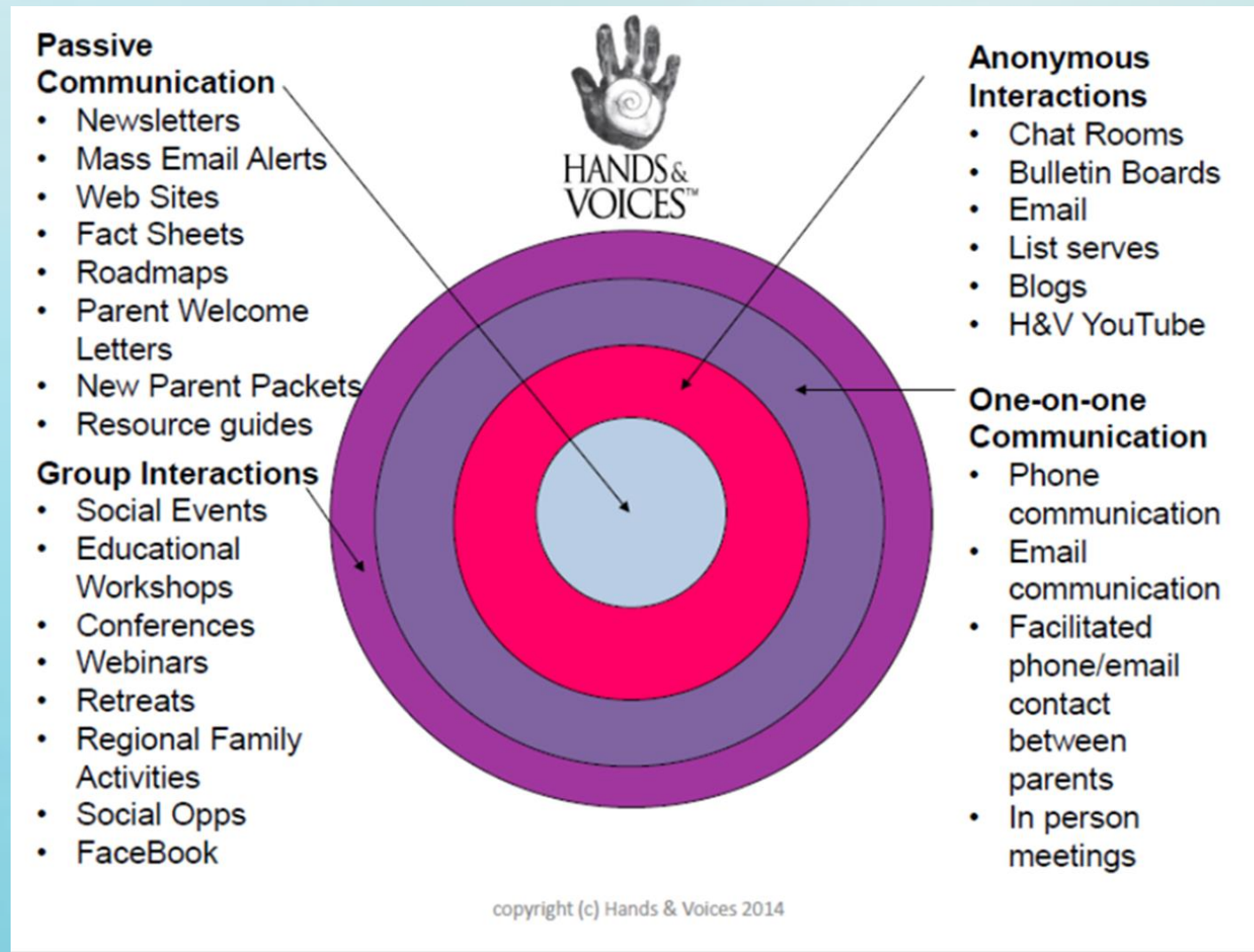


Determining the Focus of Family to Family Support

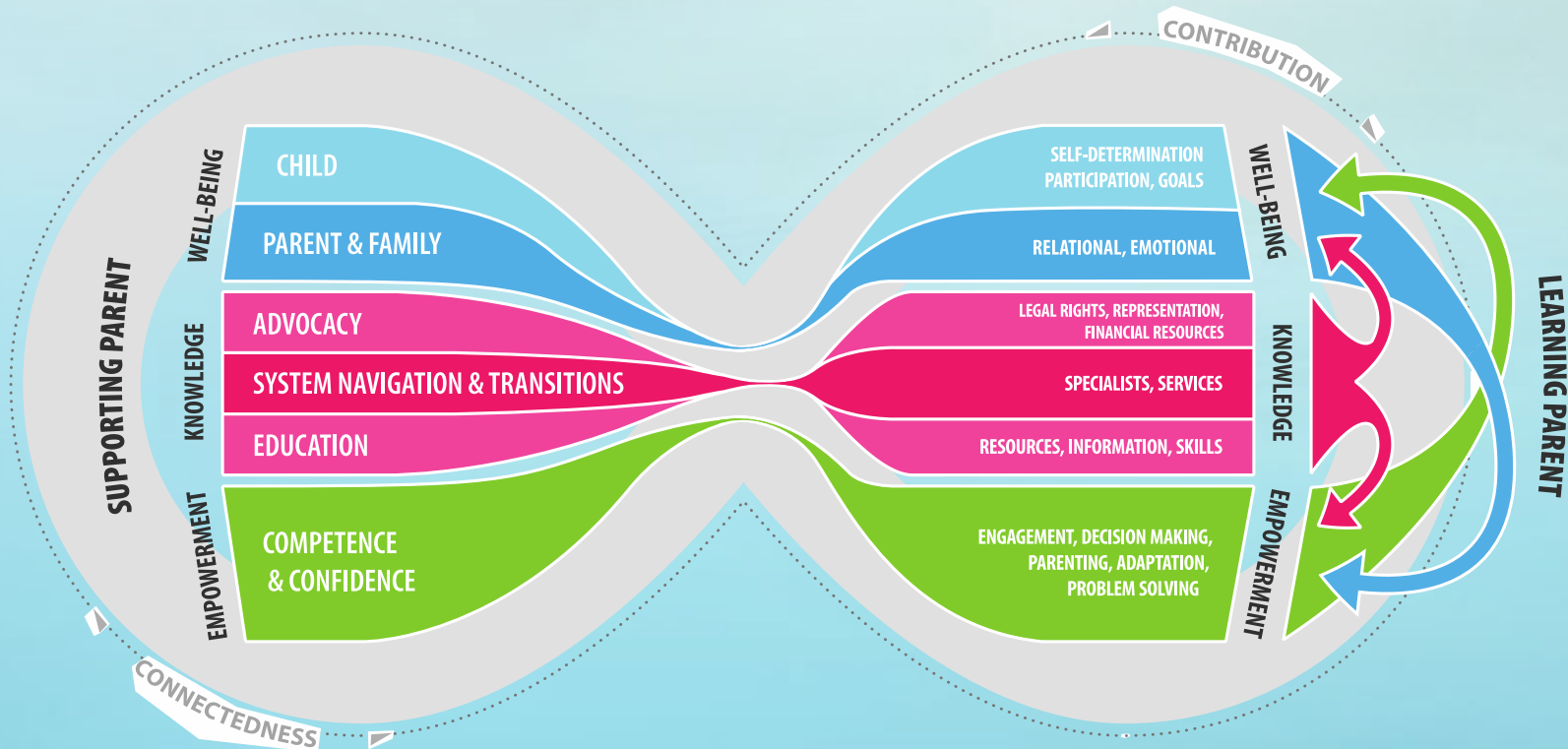
- Community Needs Assessment
- Co-production of planning for services to families by family-based organization and EHDI system
- Involvement of a variety of parents, stakeholders, and D/HH adults in decision-making/planning/implementing



Family-to-Family Support Continuum: Passive to Active Engagement to Leadership



Parent-to-Parent Support for Parents of Children who are Deaf / Hard of Hearing: Revised Conceptual Framework



Henderson, R., Johnson, A., & Moodie, S.T. (2014). A conceptual framework of parent-to-parent support for parents with children who are deaf or hard of hearing. *American Journal of Audiology*, 23(4), 437-448. doi: 10.1044/2014_AJA-14-0029

© Henderson, Johnson & Moodie

Henderson, R., Johnson, A., & Moodie, S.T. (submitted). A revised conceptual framework of parent-to-parent support for parents with children who are deaf or hard of hearing. *American Journal of Audiology*.

Core Components of D/HH- Specific Family-to-Family Support

Training/procedures/policies for:

- Providing emotional support and promoting parent and child well-being in context to choices made
- Supporting families with respect for diversity and without bias
- Sharing information and resources for the full continuum of communication, educational and technology opportunities
- Responding to questions/empowering families in decision-making and advocacy specific to deafness
- Maintaining confidentiality and safety of participants within small communities
- Partnering with d/hh-specific professionals and community stakeholders as well as other non-d/hh-specific
- Integrating adults who are deaf and hard of hearing
- Acquiring continuous professional development in deafness/other areas





Family-to-Family Support Mapping Activity

Map out current family support services and gaps in service for your states/territories using the concentric circle diagram

Passive Communication

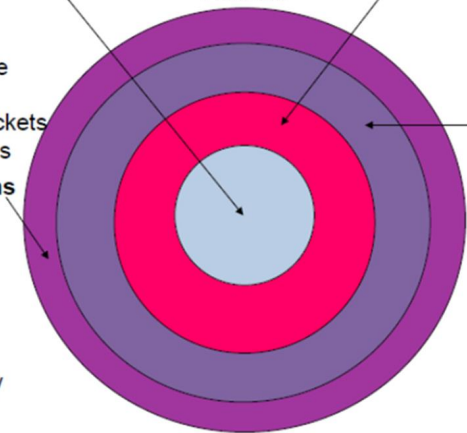
- Newsletters
- Mass Email Alerts
- Web Sites
- Fact Sheets
- Roadmaps
- Parent Welcome Letters
- New Parent Packets
- Resource guides

Group Interactions

- Social Events
- Educational Workshops
- Conferences
- Webinars
- Retreats
- Regional Family Activities
- Social Opps
- FaceBook



HANDS & VOICES™



Anonymous Interactions

- Chat Rooms
- Bulletin Boards
- Email
- List serves
- Blogs
- H&V YouTube

One-on-one Communication

- Phone communication
- Email communication
- Facilitated phone/email contact between parents
- In person meetings

Terri Patterson



- Director of Chapter Support
- Former GA Chapter Director/GBYS Coordinator
- Parent

Lisa Kovacs



- Director of Programs
- Former IN Chapter President/GBYS Coordinator
- Parent

Where the Rubber meets the Road



CONNECT | LEARN | SHARE

SC STATE FAIR
October 11th – 22nd

"The greatness of a community is more accurately measured by the compassionate actions of its members"
-- Coretta Scott King

SCHV NEXT FAMILY GROUP MEETING
Thursday, October 5th

IN PERSON OR VIRTUAL! Do you have questions you'd like to ask other families who are on a similar journey? Advice, frustrations, tips, or joys you want to share? Are you looking to meet other families of children who are D/deaf or hard of hearing in your community? Come join us at our Family Support Group, the 1st Thursday of every month, 6:00-7:30pm! Our meetings are open-conversation format, and everyone is invited to participate. You can join us in person in West Columbia or [online](#). Coming Soon! New 2018 Family Mingle Schedule 3rd Saturday of each month. Check our [website](#) for updates.

ENTERTAINMENT: THE HERE TO HEAR TOUR
A cross-country road trip with deaf comedian D.J. Demers for the entire month of October (Disability Awareness Month). D.J. has hearing loss and has been wearing hearing aids since he was 4-years-old. During the tour, D.J. will be giving FREE stand-up comedy shows to students at 20 universities. D.J. will also talk about hearing loss and help inform other students how they can receive FREE hearing technology from their university. To learn more and to sign up for your local area, click [HERE](#).

SC DEAF & HARD OF HEARING SUMMIT
Friday, October 27th

The goal of the South Carolina Deaf/Hard of Hearing Summit is to explore strategies to enhance literacy outcomes for South Carolina students who are deaf/hard of hearing. The event will be held from 9 AM – 4PM at Stone Bridge Gardens and Events, 3506 Bush River Road, Columbia, SC 29210. Registration fee for professionals is \$25 and parents or students at \$10 with lunch provided. Click [HERE](#) for more information and registration form (coming soon).

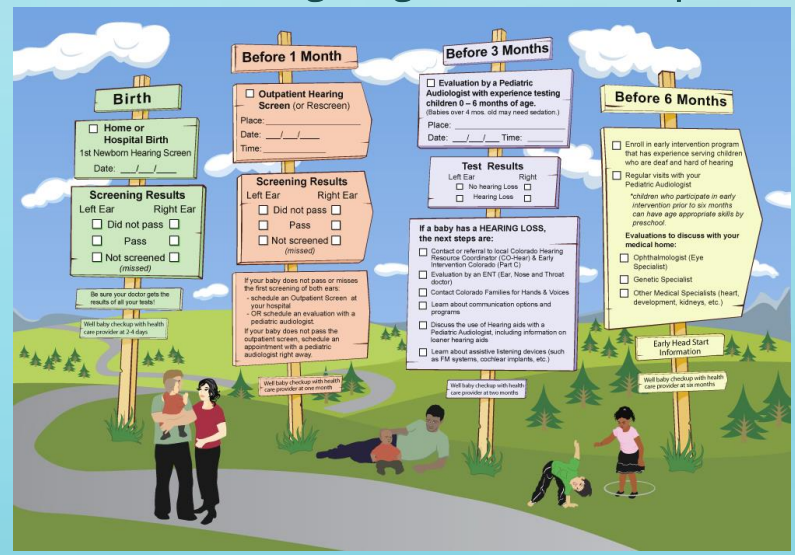
IN THE KNOW – SCHV will have a vendor table at the SC Deaf and Hard of hearing Summit. Be sure to visit the booth to say hello and learn how we can

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Passive Communication

- Benefits
- Examples
- How can YOU implement?

The Colorado Infant Hearing Program: A Roadmap for Families



Anonymous Interactions

- Benefits
- Examples
- How can YOU implement?

*georgia*H&V
Guide By Your Side 

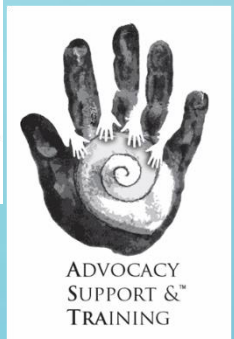
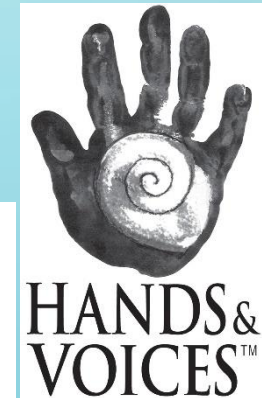
the *georgia*H&V Guide By Your Side program provides unbiased, emotional support and resources to families of children who are Deaf or Hard of Hearing (D/HH) by trained parent guides. This blog has been created so these parents of children who are D/HH can share personal stories and experiences with you.



OH and MI H&V Chapters
Lunch & Learn; A Webinar Series for
Parents of Children who are Deaf or Hard
of Hearing
YouTube
Free
Mon, Mar 12 12:00 PM

One-on-One Communication

- Benefits
- Examples
- How can YOU implement?






Group Interactions

- Benefits
- Examples
- How can YOU implement?

Nevada Hands & Voices
February 21 at 9:56am · 🌐

Tomorrow is Thursday, which also means it's almost Friday Eve! Don't forget to set your alarms for our Facebook Chat tomorrow night from 6-7pm. Log on to our Facebook page from your favorite device to join the conversation about Technology and how it can help families and kids who are deaf or hard of hearing! 📱 🖥️



THU, FEB 22
Friday Eve FB Chat: There's an App for That

You like Nevada Hands & Voices

INTERESTED



2018 EHDI Family Conference

Hosted by Indiana Hands & Voices



Saturday, March 3rd
New Hope Presbyterian Church
Fishers, IN 46037
(126th Street & Brooks School Road)

*The conference is FREE for parents & caregivers of deaf and hard of hearing children.
* Lunch & snacks are provided for all adults & children.
*Childcare with a variety of interactive activities; all children must be preregistered @ www.inhandsandvoices.org/store/p19/2018_Conference_Childcare.html

8-45am to 9:15am Check-in for Conference & Childcare
9:30am to 10:45 Keynote Speaker: Anita Dowd
10:45am to 11:45am Networking Activity
11:45am to 1:00pm Lunch and Call on Exhibitors & Vendors
1:00pm to 2:00 Dr. Ryan Mitchell
2:00 to 2:15 Cookie Break
2:15 pm to 3:00 Dad Panel
3:00pm to 3:30 Childcare Pick-up

For more information and to register, visit www.inhandsandvoices.org
Questions? Email inhandsandvoices@gmail.com

NEW ANNOUNCEMENT

2018 EHDI Family Conference presents:

SIBabilities


This activity is especially designed for the siblings. It is co-facilitated by an Occupational Therapist and Mental Health Counselor from MiniMinds LLC. (<https://www.miniminds.org>). Children will be given the opportunity to meet other siblings in a relaxed and recreational setting. We will explore the common joys and challenges experienced by siblings and discuss how to handle various situations that siblings face every day. Parents will also be given strategies to support their children's relationships, both for today and for the future!



Hosted by Indiana Hands & Voices
Saturday, March 3rd
New Hope Presbyterian Church
Fishers, IN 46037
(126th Street & Brooks School Road)

For more information and to register, visit www.inhandsandvoices.org
Questions? Email inhandsandvoices@gmail.com





MOMS NIGHT INN 2018

CENTRAL Illinois <i>Sat. March 3rd — Sun. March 4th</i> Wyndham City Centre Springfield, Illinois	NORTHERN Illinois <i>Sat. April 14th — Sun. April 15th</i> Hyatt Regency Lisle, Illinois
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Register today at ilhandsandvoices.org/mni

Mom's Night Inn is an overnight retreat for moms or female caregivers who are raising children of ALL ages who are deaf or hard of hearing. It is an amazing way to meet and share experiences with other moms who share similar experiences. Woven into these moments are the connections you make- the experience of sharing your personal journey with another mom and hearing about their journey.

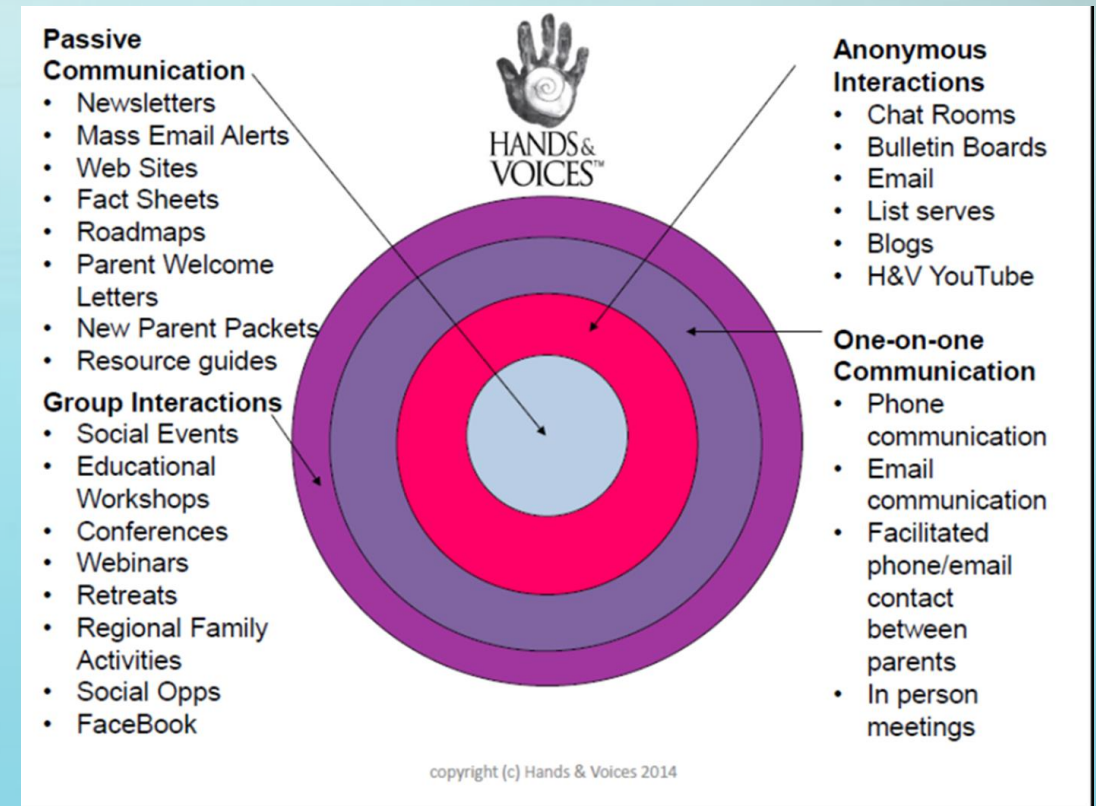
This Event Includes:

• Overnight Accommodations	• Dinner and breakfast
• Time to relax	• Downtime to bond with others
• networking	• Lots of sweet treats to eat
• Panel discussion Sunday morning	• Keynote speaker

Regardless of where you are on your journey, the choices you have made, or the choices you are exploring—there is the common bond of raising kids who are deaf or hard of hearing. It is a wonderful feeling to share our journeys together and our retreat makes this possible.



Diversity of Individuals within a Family



Low Resourced, Culturally Diverse, Challenging to Engage

1. Are these the same or different and why?



1. How would you describe each?
 - Low resourced
 - Culturally diverse
 - Challenging to engage



Activity

1. Each table work together to generate one strategy each:

- Passive
- Anonymous
- One-on-one
- Group

For your assigned family group
(either low resourced, culturally diverse, or challenging to engage)

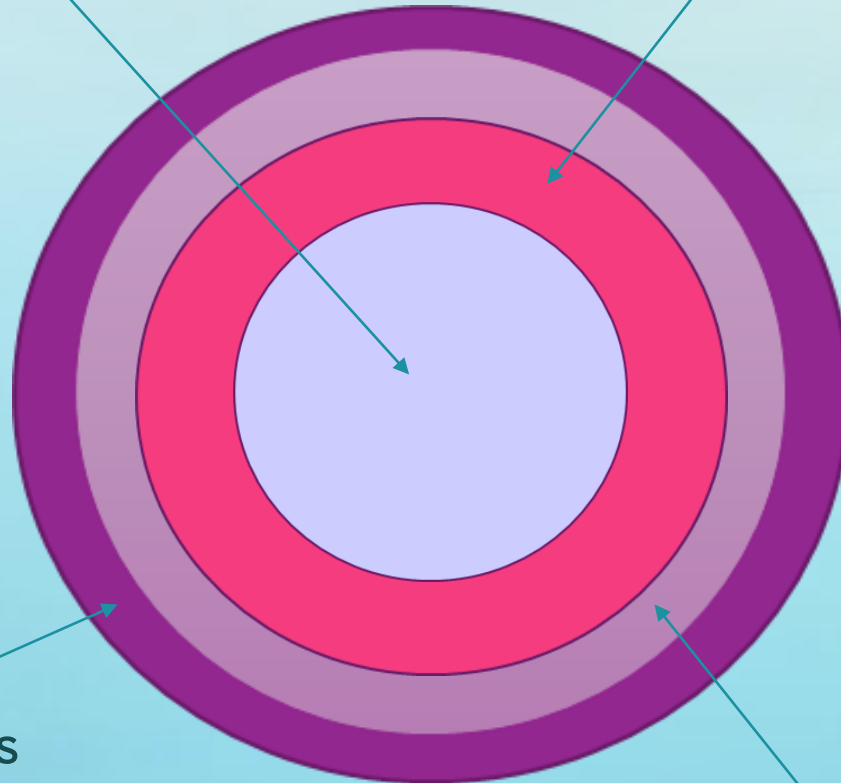
- 5 minutes

WORK FAST – SPEED WORK

2. Report out to the large group – 10 minutes

Passive
Communication

Anonymous
Interaction



Group
Interactions

One-on-One
Communication

Break



Hands & Voices HQ D/HH Infusion Co-Directors

Karen Putz



- Illinois Hands & Voices Co-Founder
- Deaf Mentor, Early Intervention
- Author of “The Parenting Journey”
- D/HH adult
- Mom to three D/HH kids

Stephanie Olson



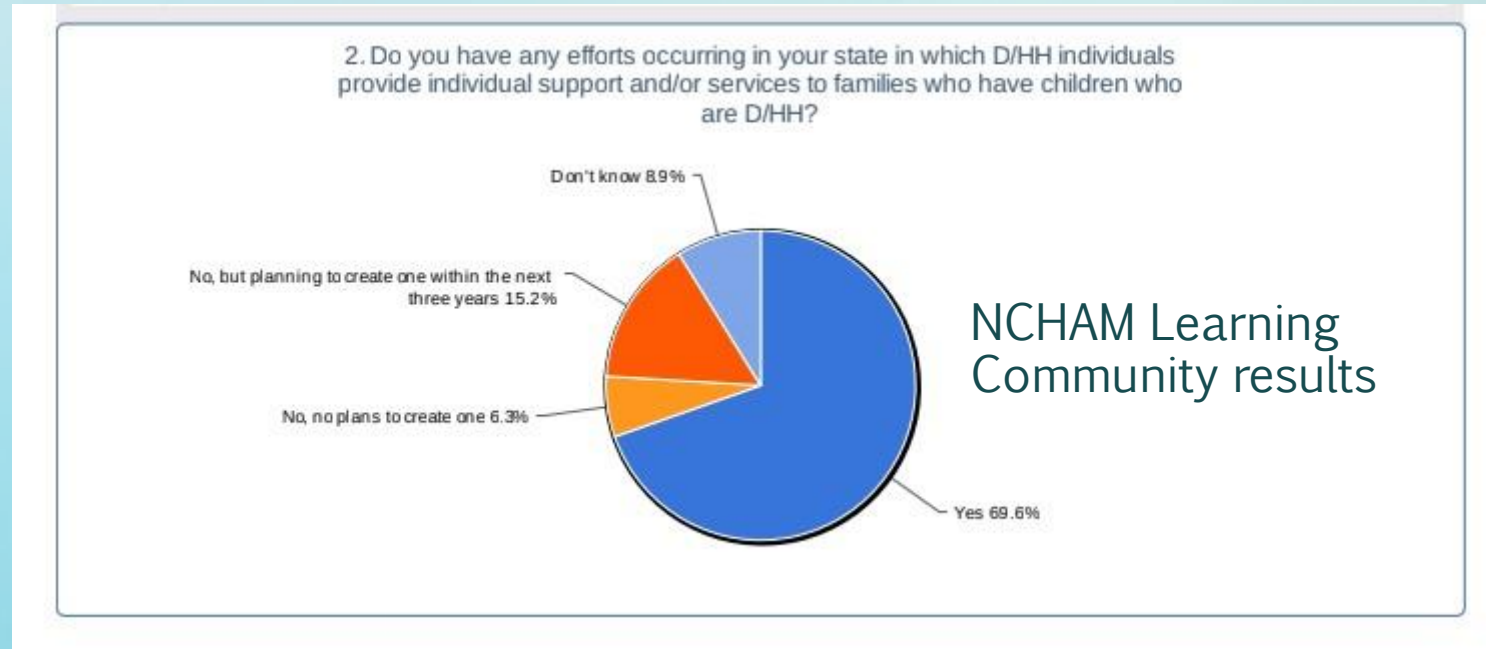
- Colorado Hands & Voices
- Children’s Hospital Colorado-Family Consultant
- D/HH Guide/Trainer
- D/HH adult

Reason for D/HH Involvement

- Beyond D/HH: skills, strengths and expertise
- Where are the D/HH individuals in the systems?
- National, state, local, medical, boards, chapters and community involvement
- Will this become a natural and seamless process for your state, territory or province?
- When is the right time for D/HH adult involvement and who decides when the right time is?
- Volunteer vs. paid positions
- Partnering with parents
- Deaf/HH parents as a tremendous resource



DHH Infusion: Needs Assessment and NCHAM Survey



D/HH Infusion Objectives

- Design supports for meaningful inclusion of Deaf and Hard of Hearing individuals within national, state, and territory EHDI systems.
- Demonstrate collaboration with deaf-based organization that operate Deaf mentor programs to learn best practices and to integrate new knowledge into disseminated resources and training curriculums.
- Develop training and resources for state/territory EHDI system and family to family support organizations to parent with organizations that serve the Deaf and Hard of Hearing community.
- Support the establishment of Deaf mentor/guide/role model* programs for families with Deaf or Hard of Hearing infants and children in all states/territories.
- Partner with NCHAM/EHDI to train, educate professionals and increase connecting with Deaf mentors, guides/role models in EHDI systems.

FL3 Guidelines for Deaf and Hard of Hearing Mentor/Guide/Role Model Programs

- FL3 Guidelines : <http://handsandvoices.org/fl3/fl3-docs/DHH-Guidelines.pdf>
- Purpose: Intended to offer suggestions for EHDI systems as to recommended practices in provision of D/HH mentor/guide/role model services to families/children.
- Stakeholder advisory group
- Guidelines suggest best practices for programs and are not mandatory
- Definitions: described in the FL3 to encourage consistency
- Value of Community Needs Assessment

Definitions: How Do They Fit in with Parent Support?

- Terminology:
 - Mentors: Associated with the SKI HI Curriculum
 - Guides: Hands & Voices Guide By Your Side Program
 - Role Models: Not restricted to early intervention
- Full definitions: www.handsandvoices.org/fl3
- What is the difference?
- Why does it matter?





Connecting Families

Why does this continue to be a challenge for systems and families?

Discuss...



Connecting D/HH Adults with Families: It's Possible!

- Videos and articles featuring D/HH teens and adults:

<http://www.handsandvoices.org/fl3/topics/dhh-involvement/resources.html>

- Connecting with D/HH adults:
 - Deaf Clubs (Deaf Women United, Sports Clubs, Deaf Olympics)
 - Associations (National and state associations of the Deaf or Hard of Hearing)
 - Colleges, Tech Programs & Schools
 - Community Non-Profits
 - Deaf Coffee Gatherings
 - Service providers (AVT Therapists, SLPs, CI Centers, Audiologists, ASL instructors, etc.)
 - Disability Services at colleges
 - Teachers of Deaf/HH who keep in touch with graduates
 - Parents of Adults who are Deaf and Hard of Hearing

Activity

In the Spirit of
“Hidden Figures”

Who are the Hidden Figures
in our system?

Let's find out!



Yiesell Rayon



- H&V Director of Latino Support
- California H&V Board Member
- NCHAM Family Advisory Committee (FAC) Member
- Parent of a Deaf Child

Including Spanish Speaking Families at Events



Recommended Action Plan

- Different models:
 - Including Spanish speaking families at all events.
 - Events specifically for Spanish speaking families.

Before the Event...

- Communication to Families About the Event
 - Written Invitation
 - Invitation by Phone
- Plan Ahead - Even Without RSVP
- Elements to Consider
 - Is Event Free?
 - Will Children be Included at Event?
 - Will Child Care be Provided?



Before the Event...



Language Access at Events

- Spanish Interpreters
 - Certified Interpreters
 - Volunteers
- Considerations for Interpreters
 - Vocabulary
 - DHH Culture
 - Privacy
- Finding Interpreters
 - Local College/University
 - Other Agencies
 - School Districts/Schools for the Deaf

At the Event...

Recommended Materials Needed in Spanish for DHH Family Events

- Event Signs
- Sign-in Sheet
- Organization Brochures
- Membership Forms
- Release of Photos
- Event Flyers
- Resources



Activity

Cultural Competency

“Creating a Personal Commitment to Valuing Cultural Diversity”

Write 2 things you can do from now on to learn and experience more about other people’s cultures to better serve them.

Q&A

Suggestions for FL3 Staff



Contact Information

Hands & Voices HQ:

www.handsandvoices.org

<https://www.facebook.com/handsandvoices/>

@HandsandVoices

303-492-6283

FL3:

<http://handsandvoices.org/fl3/index.html>

FL3@handsandvoices.org

