International Resources and Supports for Families

Janet DesGeorges, Hands & Voices
Global Parents of Deaf/Hard of Hearing Children (GPODHH)
Global Coalition for Hearing Health
Phoenix, AZ
October 25th, 2019







Presenter:





Always start with

Janet DesGeorges

Parent of a young Deaf Adult

Co-founder and Executive Director Hands & Voices

www.handsandvoices.org

Principal Investigator Family Leadership in Language and Learning "Where Love, Language, and Learning thrive."
(HRSA funded project -grant number UJ1MC30748-01-00)

Committee Member Global Parents of DHH Children (GPODHH) http://www.gpodhh.org/

Special Thanks

Thanks to Phonak for walking the walk

when it comes to parent input and involvement in the products, resources, and trainings that they do!



Jackie Odour, Nairobi Kenya - "I went back to my doctor and said, 'aren't there any other parents like me?'..."

Her daughter Jasmine, "every person, no matter where they live in the world, deserves to have a chance to live a normal life..."

Please quote me....

"If half the people would use half the resources that are available half the time, our kids would be doing twice as well..."

-Janet DesGeorges

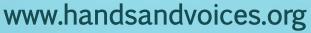
A taste of Hands & Voices....

- 1 Chapter 1997
- 47 Chapters 2019 (US/Canada)
- 26 Guide By Your Side programs
- 9 ASTra Programs (education)

 Serving over 16,000 families a year

 -with a reach of over 30,000 on FB



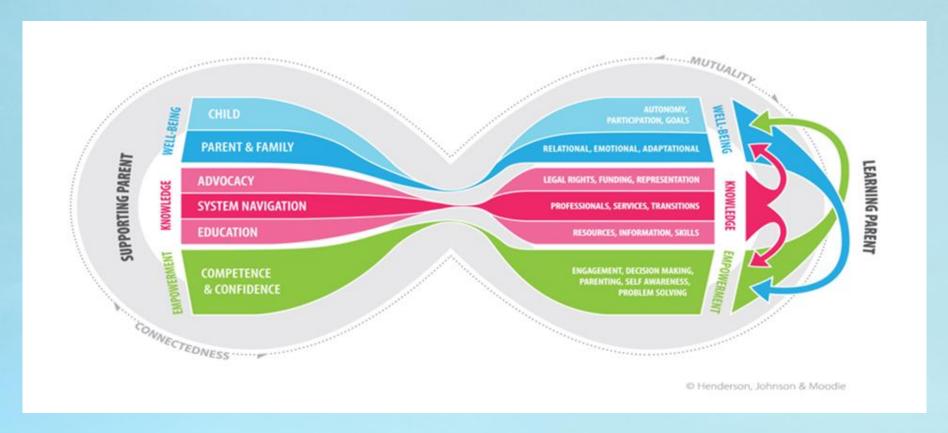






Hands & Voices
Headquarters
Staff

What should we be focusing on for families?



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

Revised Conceptual Framework

Full Article:

http://aja.pubs.asha.org/article.aspx?articleid=2527221

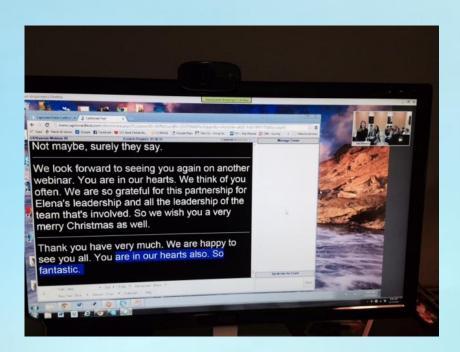
Thoughts about resource creation....

- Who is the audience? 'speak their language; teach their language'
- Wordsmithing by consensus (aka 'death by wordsmithing')
- Don't recreate the wheel
- Keep disseminating
- Measure impact
- Use Multiple Channels (social media, print, face-to-face, video...)

The Essential Question - Does "Parent Involvement/Support" cross over from country to country?

Find your answer here.... GP











Thrive (South Africa) and Hands & Voices (U.S.)

Programming ideas and Cross training - Guide by your Side and Buddy Program

Topics discussed – poverty, low levels of education, no early ID, limited early intervention, lack of choices, challenges in education, Cl's not an option for most.... "What we do have! Shared spirit of 'ubuntu' – an understanding of shared burden"

Shared conversations: power of parents coming together, *support, information, modeling*, and hope!

Information from some International Parent Leaders

Issues Identified:

- Stigma
- Oppression
- Isolated
- Lack of Information
- Parents don't see/understand their role
- Systems don't recognize the parent role
- From a meeting with H&V (US), China, Russia, and Kenya reps.

Comments from the parents:

"We keep knocking until our knuckles bleed."

"On days I cannot walk, I crawl."

"If the parent believes there is stigma, so will the child."

"The love and respect of the parents to the child is what can provide the example."

Similarities and Differences Between Countries

Similarities

- Love for our Children
- Desire to Communicate
- Empowerment Happens (even in cultural contexts where there is 'deference to authority')
- Hope and miracles
- Knowing what's best for our Kids (when given information, support, and modeling)

Differences

- Systemic structures
 - Dad from Ethiopia
- Educational Opportunities
 - Mom from Kenya
- Rights under the Law
 - Russian Federation
- The Poverty Gap
- What poverty means in different places
- Informed choice when there is no choice
 - Story of family from South Africa



Parent Involvement and Support via

GPODHH

• GPODHH Position Paper http://www.handsandvoices.org/resources/whitePapers/GPOD.pdf

- WHO WHF World Hearing Forum
 - Bringing focus to
 - Pediatric Hearing loss
 - Children's Safety





1st meeting 'under the tree' 2008

- Reps from over 20 countries and counting...
 - Connect families around the world
 - Help with resources in local regions
 - Systemic protocols for supports to families
 - Coalition Reps for the FCEI EI Principles

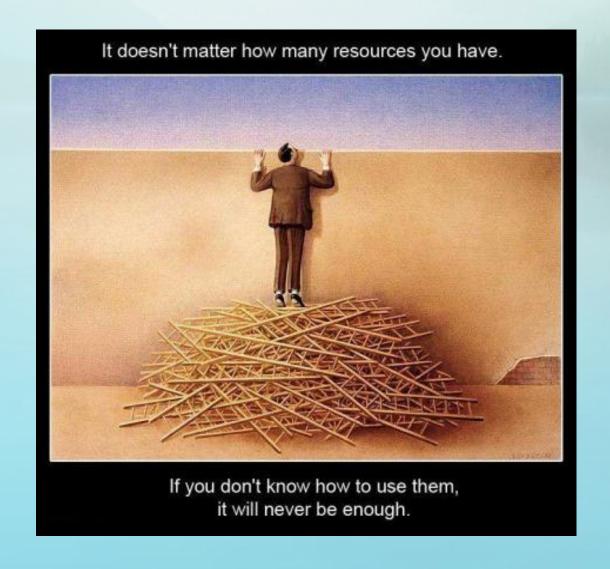


HOW TO use Resources.....

The Power of connections -

- -Professional to Parent
- -Parent to Parent
- -DHH Adult to Parent





Guide for parent-professional partnerships in the hearing healthcare setting



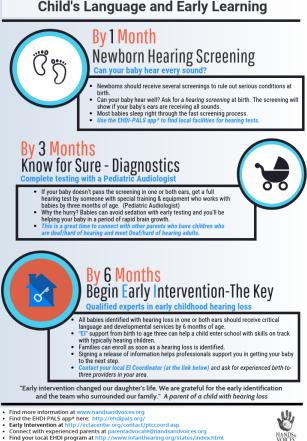
https://www.phonak.com/content/dam/phonakpro/gc_hq/en/resources/counseling_tools/documents/Brochure_BtBtC_Guide_parents_and_professionals_Hand_and_Voices_210x280_EN_V1.00_028-1956-02.pdf

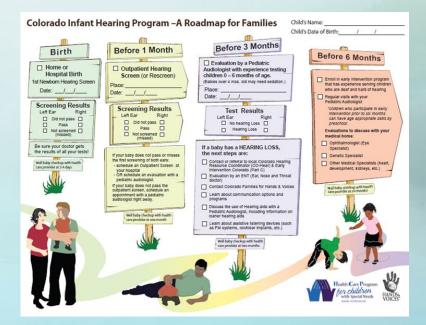
1-3-6 Infographic

developed through a partnership with Hands & Voices and the U.S. Center for Disease Control (CDC)

This is available to modify for your country system

Count 1-3-6 Steps to Open the Door to Your Child's Language and Early Learning





The Colorado Road Map

http://www.cohandsandvoices.org/newsite/roadmap-for-families/

SHOW THE WAY....

Data Questions? Contact the Centers for Disease Control site at http://www.cdc.gov/ncbddd/l
 Giving consent to share data will assist EHDI programs in getting you to the services you need

FL3 Parent-Takeaways

- Cognitive Development
- Early Literacy Development
- Language Development
 - Semantics
 - Syntax and Morphology
 - Phonology
 - Child Pragmatics
- Visual Language Development
- Social Emotional Development
 - CURRENTLY BEING TRANSLATED INTO SEVERAL LANGUAGES







Parent Take-aways **Social Emotional Development**

LAYS THE FOUNDATION FOR EARLY SKILLS INCLUDE

- AND EXPRESSES EMOTIONS:
- ABOUT HIM OR HERSELE:
- HOW YOUR BABY LEARNS TO REGULATE EMOTIONS AND INTERACT WITH YOU AND OTHERS IN HIS OR HER ENVIRONMENT.

of hearing within the first weeks of life can prompt many emotions, some of which may be challenging. This is a common experience among is important to work through these feelings.

Continue to interact with your baby! Maintain focus on your emotional well-being, as this can impact the emotional well-being of your child. who is deaf or hard of hearing may change some things about how you interact and communicate with your child, however there are many ways to support your child's social-emotional

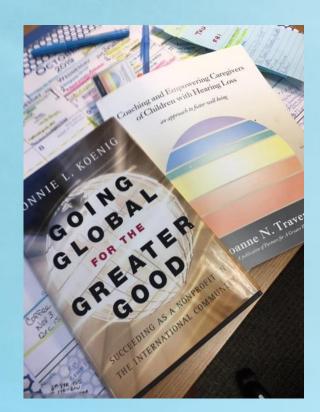




- ✓ Sing to your baby.
- Engage in turn-taking games, such as pat-a-cake, peek-a-boo, tickle games, and making faces at one
- Build predictable routines
- Respond to emotional states with understanding and calmness. Recognize your role in your child's well
- Use language to describe your feelings and those of your child. Build a strong vocabulary of words/signs for emotions.
- Look for your child's pleasure in accomplishing new things and let him or her know that it brings you pleasure.
- Read stories and talk about the emotions of others
- Provide opportunities for your child to play with other children and observe how your child engages with
- Play with your baby as often as possible. Experience the joy of parenthood!
- Interact with diverse deaf and hard of hearing adult

UJIMC30748-01-00 for Family Leadership in Language And Learning for \$1,500,00.00 This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be interred by HRBA, HHB or the U.S. Government.*

- See Parent Take-aways on the Hands & Voices website, https://www.handsandvoices.org/fl3/fl3-docs/parent-take-aways.html
- or take a deeper dive into the H&V FL3 Project in these areas here, https://www.handsandvoices.org/fl3/topics/lang-lit-soc.html.



Coaching and Empowering Caregivers of Children with Hearing Loss – Joanne Travers

https://www.amazon.com/Coaching-Empowering-Caregivers-Children-Hearing/dp/1733823506/ref=sr_1_1?keywords=coaching+and+empowering+caregivers&qid=1559238627&s=books&sr=1-1



https://www.amazon.com/Going-Global-Greater-Good-International/dp/0787966762

Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement

http://jdsde.oxfordjournals.org/content/18/4/429.full

International UHL Guidelines for Families

- In process -to mirror peer-reviewed journal article and Phonak Quick Guide/journal article
 - Principle: Components of the principle as it appears in the Quick Practice Guideline
 - What this means to me: Brief description of what the principle means to your family
 - Things to think about: Ideas about what your family may want to consider
 - Additional resources

- International Journal of Audiology
 - https://www.phonakpro.com/com/en/products/clientprofiles/pediatric/pediatric_uhl.html

Contact Janet at:

- Janet DesGeorges
- janet@handsandvoices.org
- H&V Headquarters/Offices PO Box 3093 Boulder, CO 80307 303-492-6283

