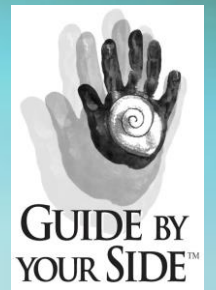


# International Resources and Supports for Families

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



Presenter:



Always start with  
joy...



Janet DesGeorges

Parent of a young Deaf  
Adult

~

Co-founder and Executive  
Director

Hands & Voices

[www.handsandvoices.org](http://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...”*

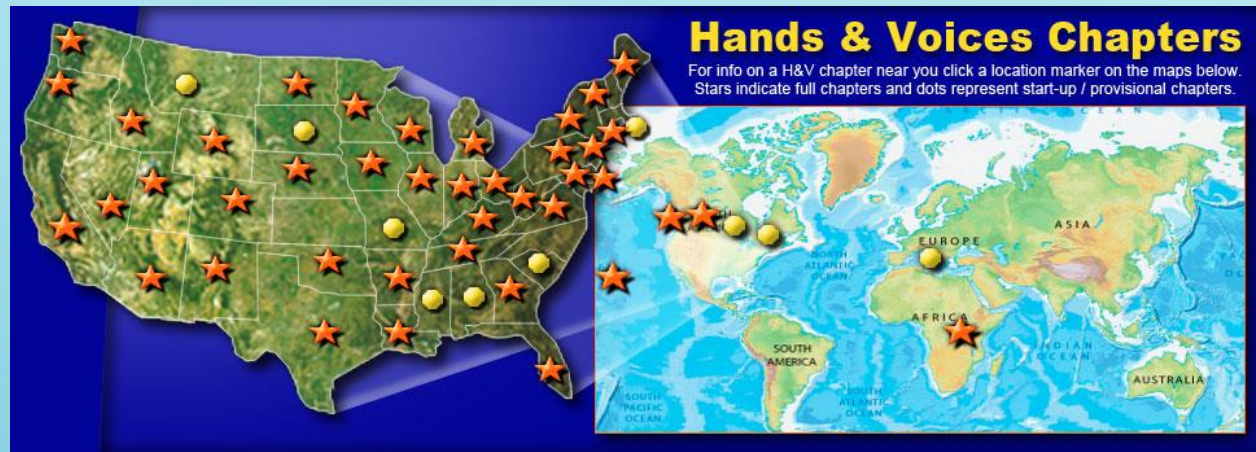
– Janet DesGeorges



# A taste of Hands & Voices....

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

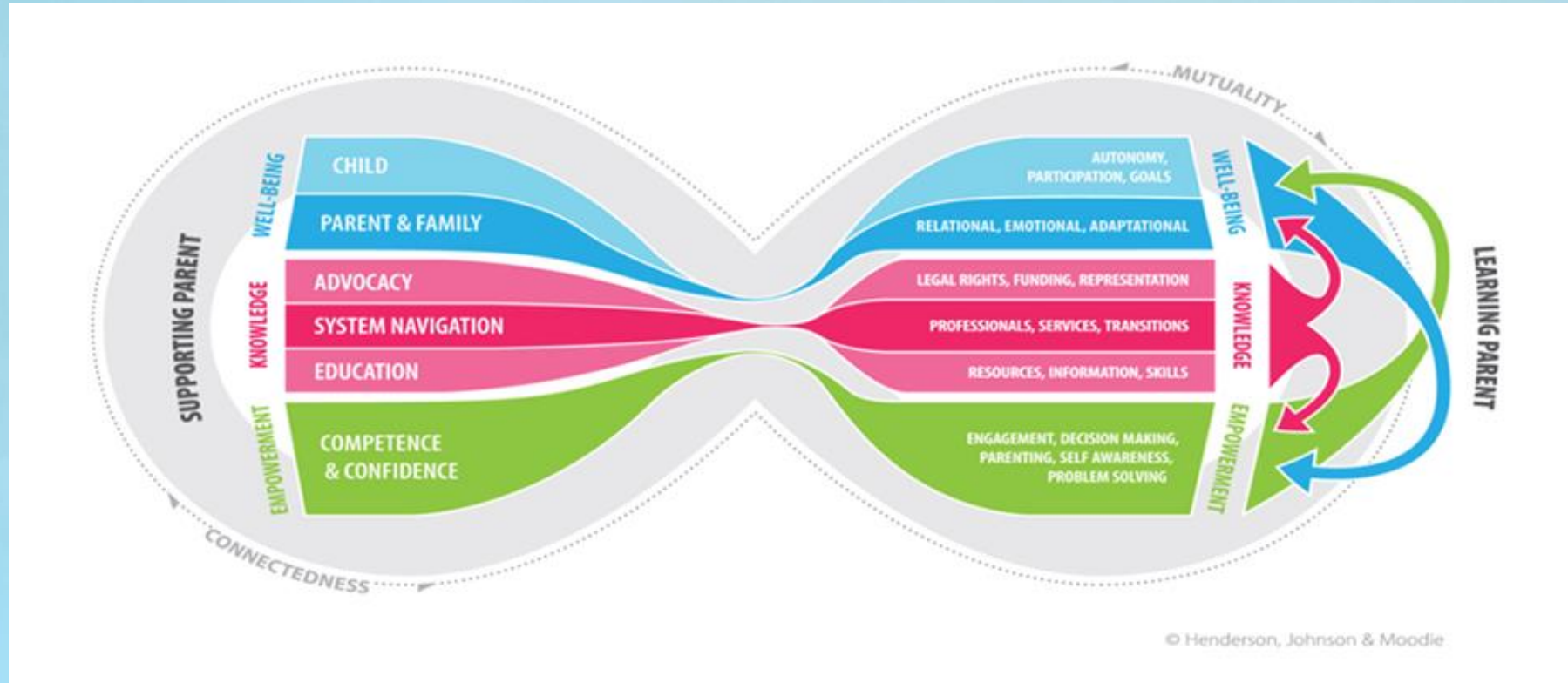
*Serving over 16,000 families a year  
-with a reach of over 30,000 on FB*



Hands & Voices  
Headquarters  
Staff

[www.handsandvoices.org](http://www.handsandvoices.org)

# 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>

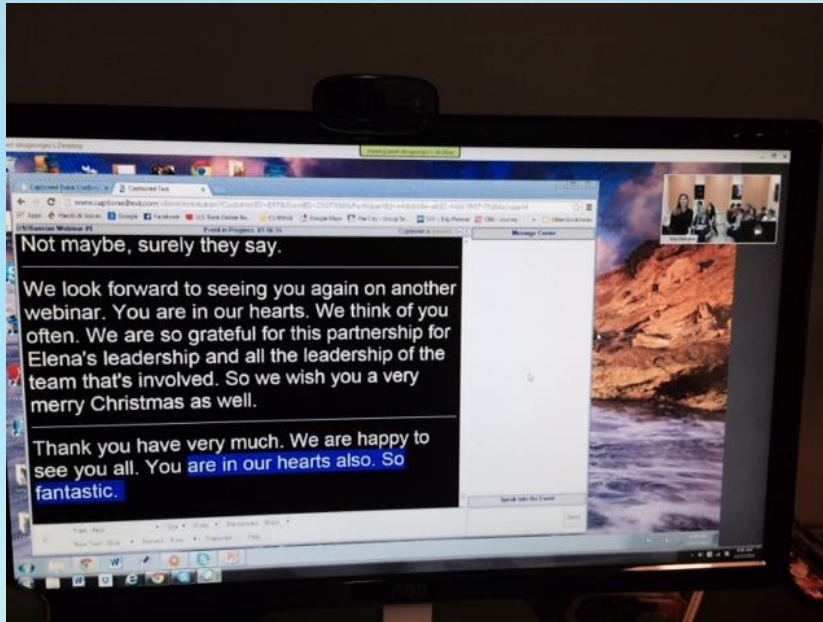
# Thoughts about resource creation....

- 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....  
[www.gpodhh.org](http://www.gpodhh.org)







## 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, CI'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



- 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



1<sup>st</sup> meeting 'under the tree' 2008



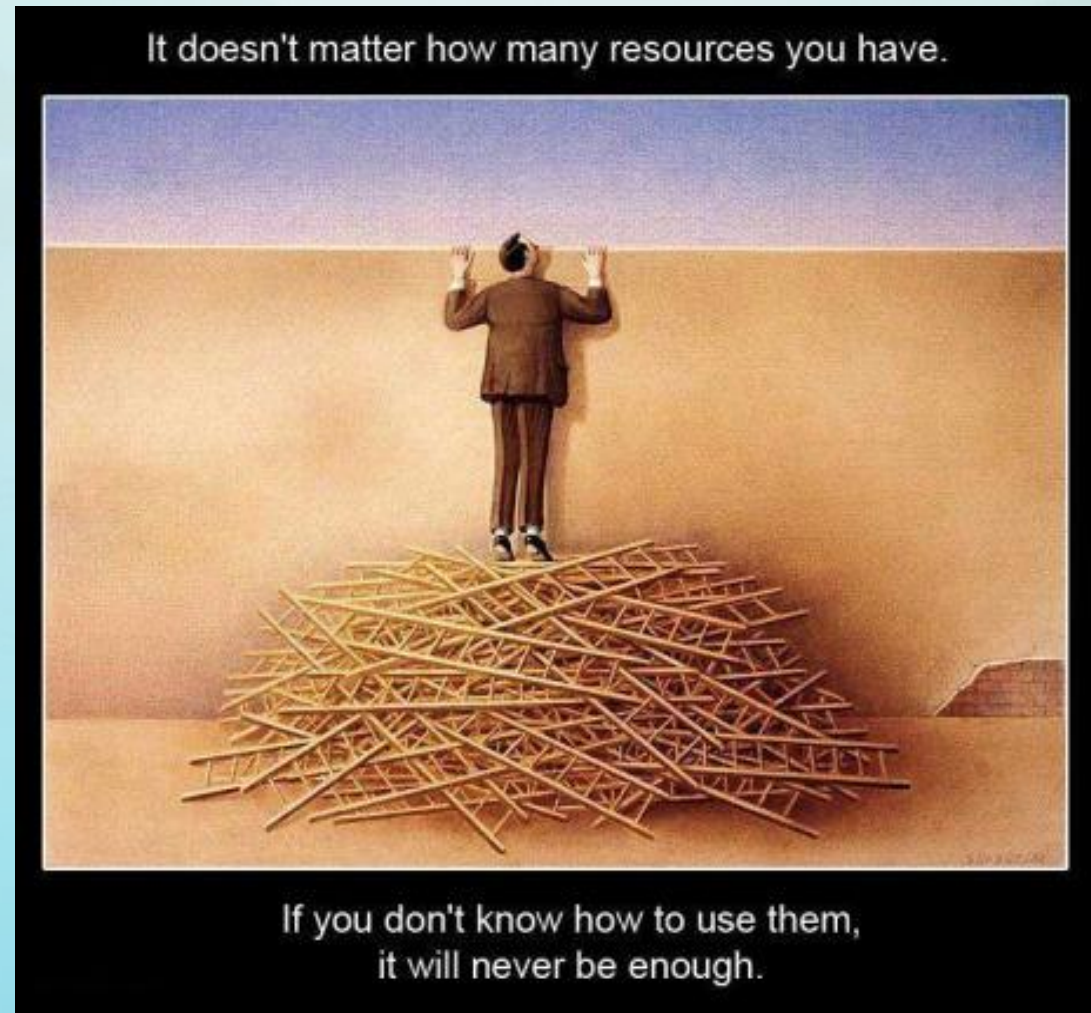
2018



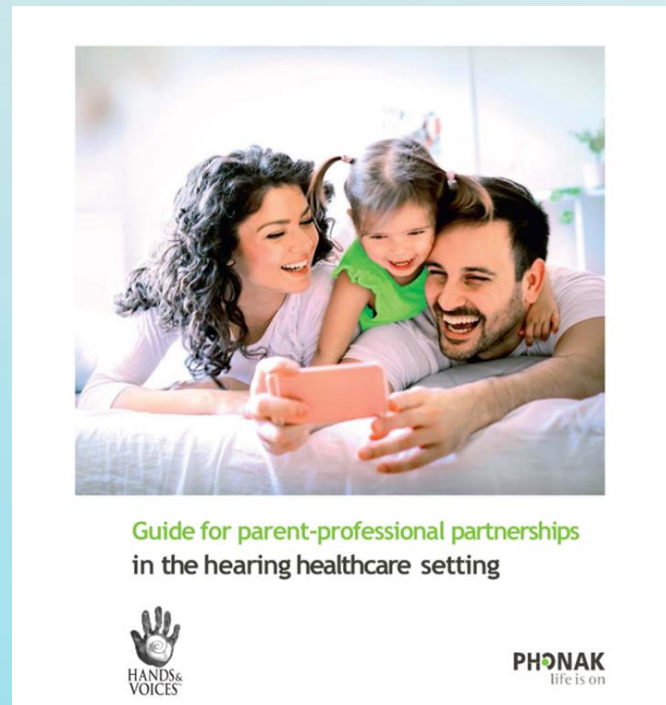
# HOW TO use Resources.....

## *The Power of connections -*

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



# Guide for parent-professional partnerships in the hearing healthcare setting

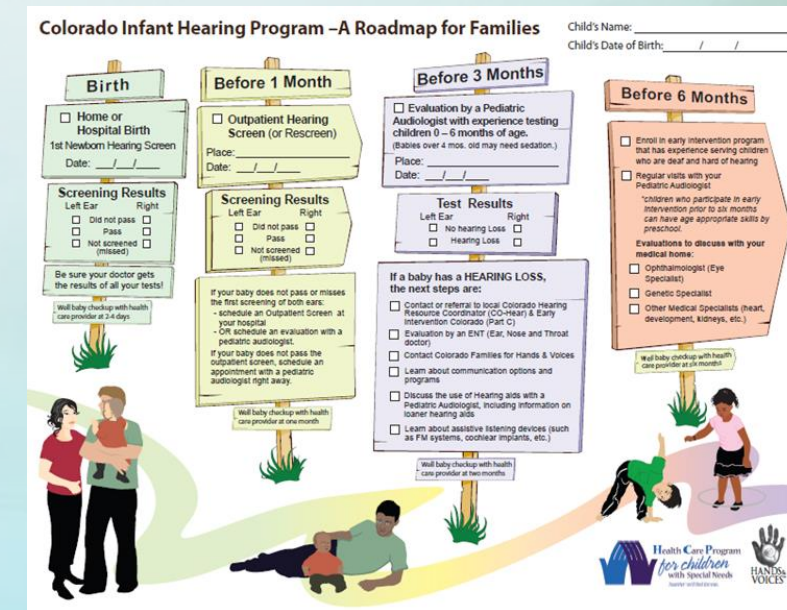
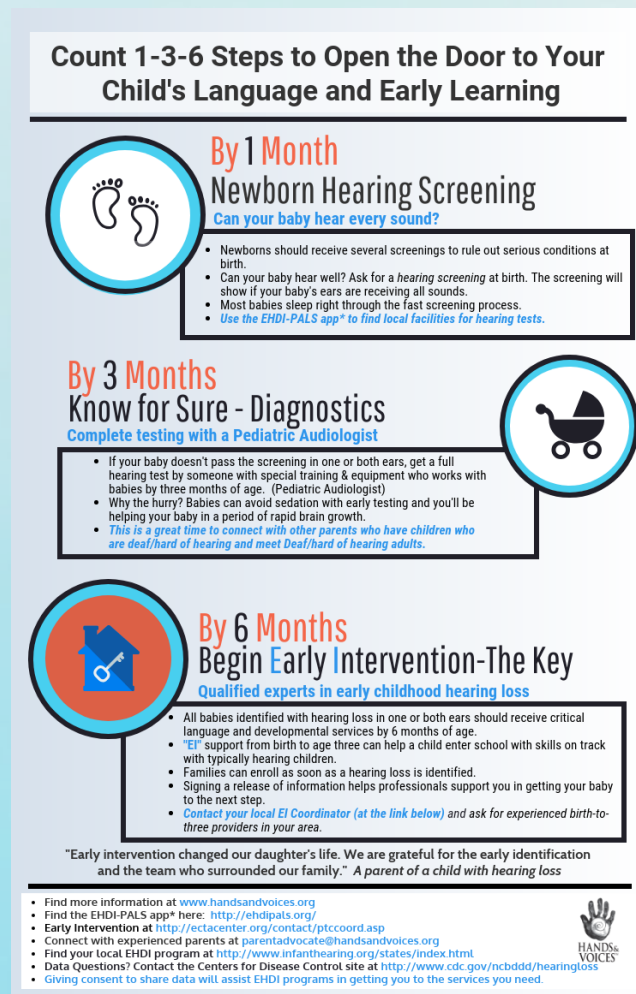


[https://www.phonak.com/content/dam/phonakpro/gc\\_hq/en/resources/counseling\\_tools/documents/Brochure\\_BtBtC\\_Guide\\_parents\\_and\\_professionals\\_Hand\\_and\\_Voices\\_210x280\\_EN\\_V1.00\\_028-1956-02.pdf](https://www.phonak.com/content/dam/phonakpro/gc_hq/en/resources/counseling_tools/documents/Brochure_BtBtC_Guide_parents_and_professionals_Hand_and_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



## The Colorado Road Map

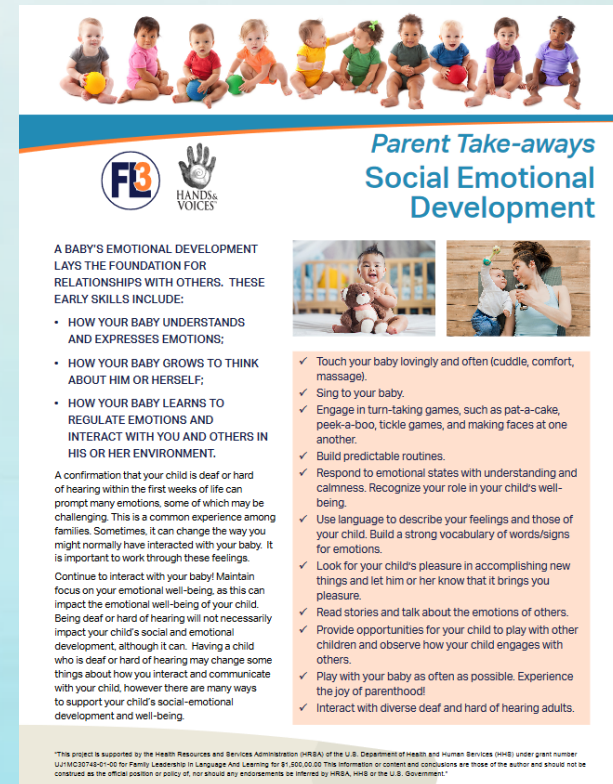
<http://www.cohandsandvoices.org/newsite/roadmap-for-families/>

SHOW THE WAY....



# 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



- 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=b&sr=1-1](https://www.amazon.com/Coaching-Empowering-Caregivers-Children-Hearing/dp/1733823506/ref=sr_1_1?keywords=coaching+and+empowering+caregivers&qid=1559238627&s=b&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/client-profiles/pediatric/pediatric\\_uhl.html](https://www.phonakpro.com/com/en/products/client-profiles/pediatric/pediatric_uhl.html)

# Contact Janet at:

- Janet DesGeorges
- [janet@handsandvoices.org](mailto:janet@handsandvoices.org)
- **H&V Headquarters/Offices**  
PO Box 3093  
Boulder, CO 80307  
303-492-6283

