



**A Community of Support:**  
Connecting Families of Children  
who are Deaf or Hard of Hearing Plus (DHH Plus)  
with Resources and Support

**2022 EHDI Annual Meeting**

# Presenters

## Candace Lindow-Davies

- Parent of DHH Plus adult
- Director of Outreach, Hands & Voices HQ



## Teri Urban

- Parent of deaf child
- Chairperson, Virginia Hands & Voices



## Michele Berke

- Parent (and grandparent) of Deaf children
- Hearing; raised in a Deaf family
- Principal, Early Childhood Education California School for the Deaf (Fremont)



## Why are we involved?

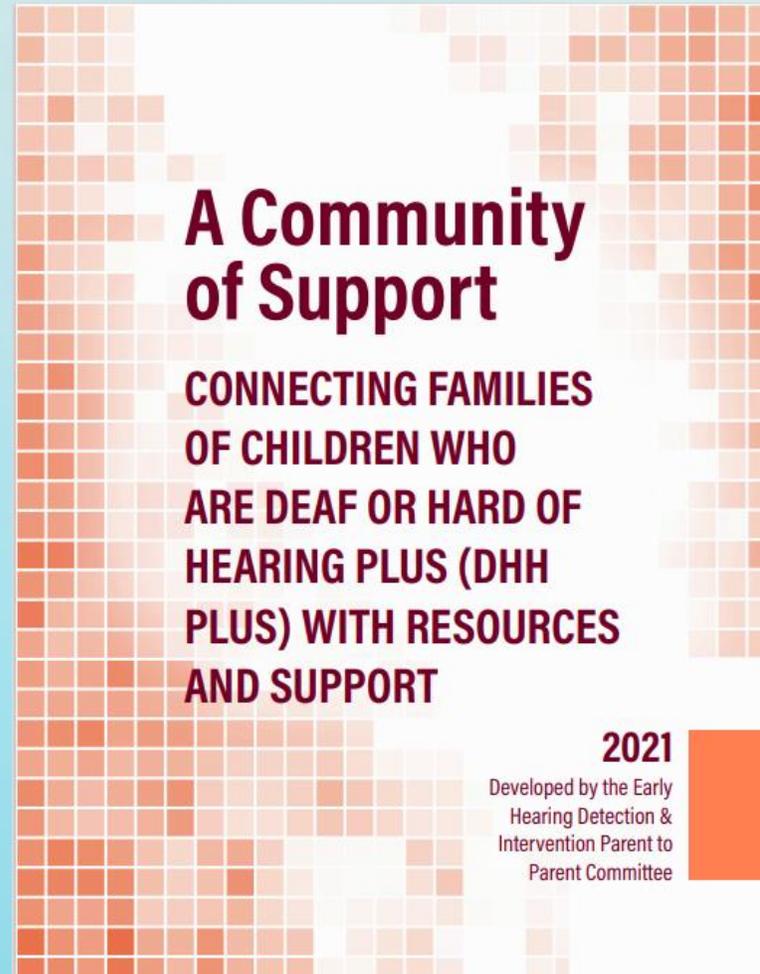
*“I wish that I had trusted my instincts as a parent and listened to what I knew was healthiest for our family. I would have done things differently if I had actually believed in myself and my ability to parent my own child.”*

# Who Created this Guide

- This Guide was developed by the Early Hearing Detection and Intervention (EHDI) Parent to Parent Committee, which is a national, interdisciplinary, interagency/ inter-organizational and diverse parent/ professional group.
- This committee is open to anyone who is interested – professionals, parents, DHH adults.



# A Community of Support Document



# Terminology

- DHH Plus: For the purposes of this document, this term refers to children who experience different hearing levels and may have additional considerations adding to complexities in support and services for the whole child.
- Those additional considerations may be medical, developmental, sensory, cognitive, physical and/ or social-emotional in nature.
- DHH Plus is meant to indicate the child's unique needs and the expanded team, including the parents, necessary for positive future development.
- Other designations/terms we want to acknowledge are Deaf Disabled, Deaf/hard of hearing Disabled, Deaf Plus, Deaf/hard of hearing Plus, deaf with disabilities, DeafBlind and others.

*definitive* /defɪˈnɪtɪv/ *adj.* 1 (of a decision, etc.) clearly defined, not subject to question  
*definitively* *adv.* [Latin: related to *define*]  
■ **Usage** See note at *definitive*  
**definite article** *n.* the word (*the* in English) preceding a noun and implying a specific instance.  
**definition** /,defɪˈnɪʃ(ə)n/ *n.* 1 a definition  
**b** statement of the meaning of a word etc. 2 distinctness in outline, esp. of a photographic image. [Latin: related to *DEFINE*]  
**definitive** /drɪˈfɪnɪtɪv/ *adj.* 1 (of a decision, etc.) decisive

# Guide's Purpose

- To ensure the family knows how, where, and why to access expertise, resources and information for their child who is DHH Plus.
- To share information about the benefits and availability of connections to other families and adults who are DHH Plus, so families know they are not alone.
- To assert a family's right to have high expectations for their child.

# Guide's Topics

- Topic 1: Identify and Prioritize Needs
- Topic 2: Language Development
- Topic 3: Who is on our Team? Benefit from Different Specialists for Different Needs
- Topic 4: Family to Family Support and DHH Individuals to Family Support
- Topic 5: Social-Emotional Development and Identity
- Topic 6: Parent Self-Care
- Topic 7: Educational Advocacy

## Areas to Explore Within Each Topic

- What this means to me
- Things to think about
- Where I can learn more

# Example of Content - Topic 3: Who Is On Our Team?

## TOPIC 3: WHO IS ON OUR TEAM? BENEFIT FROM DIFFERENT SPECIALISTS FOR DIFFERENT NEEDS

*"After years of trying different team members, I feel more confident in seeing who has the personality and vision for my kiddo- saying yes to them and no to those that might not have that vision. I feel like starting with the right people means everything!"*

— Parent

### What this means to me:

It is important for parents to recognize areas where team members are qualified/ proficient and areas where additional outside expertise is needed. Having a diverse team of professionals (including DHH adults) who communicate effectively, allows your child to be supported better overall. Each provider interprets your child through their speciality to

offer varying explanations and recommendations to benefit your child. According to the Individual Disabilities Education Act (IDEA), you as the parent are considered an integral part of the team to meaningfully participate and contribute your expertise on your child. Your child who is DHH Plus may have complex needs and could benefit from the expertise of a variety of team members specially trained and experienced in the additional health needs of your child, such as: Experts in physical needs (Occupational and Physical Therapy or Adapted Physical Education), Early interventionists (Teachers of the Deaf and Hard of Hearing, Teachers of the Deaf/Blind and Interveners for the Deaf/Blind, Audiologists, SLP, ASL Specialists), Medical professionals (Gastroenterologist, Cardiologist, Otolaryngologist, etc.) , Psychologists and Social Workers, Applied Behavior Analyst, State Deaf/Blind Project staff, Diagnosis-specific support organizations.



### Things to think about:

- Appropriate assessments, progress monitoring, and qualified evaluators who are experienced in your child's needs.
- Support sought from a variety of places/people, including professionals, other parents, DHH Adults (also including Adults who are DHH Plus, as much as possible).

- You can advocate for resources/providers who have appropriate qualifications to provide services and have the right to request the credentials of the service provider.
- You can advocate for continued consultations between providers and educators and administrators even if direct services are no longer required. Example: OT/PT consults for programming that may involve need for safety precautions, etc.
- Parents, being knowledgeable about their child, should feel confident when encouraging the team to presume competence and maintain high expectations for the child, particularly complex children.
- Team should foster opportunities for independence for your child as soon as and whenever possible.
- Team members and administrators whom your child will meet would benefit from in-service trainings from experts such as DHH educators or Deaf/Blind professionals, to explain additional needs, considerations, including cultural considerations, communication, and advice.
- Parents are an equal participant on any team related to their child. Ex: IFSP, IEP, medical, regional centers, Vocational Rehabilitation (VR).
- Your child is the central member of the team, and over time as your child develops/grows, their participation is vital.
- Teams should recognize that ADA requires an interpreter or other communication accommodation be provided for any DHH adult on the team who is appearing at a meeting or appointment as a companion of the parent and/or child.
- Skilled providers with expertise in childhood hearing are critical to maximizing your child's success. Specialty providers in other areas of need may also be necessary (mobility specialists, vision, system navigators [insurance/waivers]). Sometimes, parents may have to advocate for the inclusion of these providers on the interdisciplinary team. Services should always be a coordinated and collaborative effort.

### Where can I learn more:

- [Make-up of the IEP team](#)
- [NAD Advocacy Letters](#)
- [Local advocacy and support groups for families with children who are Deaf/Hard of Hearing Plus](#)
- [NCDH Practice Guide: Appropriate Assessment Strategies](#)
- [Children who are Deaf/Hard of Hearing Plus](#)
- [Scope of Practice in Audiology](#)
- [Roles of Educational Audiologists and TDDs](#)

# Tips for Sharing the Guide

## Professionals & Parent/DHH Leaders:

- Share Guide with individual families
- Host an event for DHH Plus families
- Add to your website/packet for new parents
- Distribute on social media and newsletters
- Encourage families to join [DHH Plus Parent groups](#)
- Ideas???



*“It’s very important to keep positive people in your circle and people that have already been down the road you are traveling. Demonstrate what your child CAN do rather than letting people tell you what they CAN’T do so assumptions are not made about your child without asking first!”*

- DHH Plus Parent

# Next Project

## Fathers Task Force

- Create handout for new fathers from experienced fathers
- Already halfway through the project
- Sign up to get updates:
  - \* email Candace Lindow-Davies or Sara Kennedy



# Past Projects

[Questions You May Want to Ask Your Child's...Audiologist, ENT, Geneticist, etc.](#)

[Decision Guide to Communication Choices](#)

[Making a Plan for Your Child: IFSP Considerations for Children who are D/HH](#)

[A Community of Support: Connecting Families of Children who are D/HH with Individuals who are D/HH](#)

# Contact Information

- Janet DesGeorges  
[janet@handsandvoices.org](mailto:janet@handsandvoices.org)
- Candace Lindow-Davies  
[candace@handsandvoices.org](mailto:candace@handsandvoices.org)
- Sara Kennedy  
[sara@handsandvoices.org](mailto:sara@handsandvoices.org)
- Michele Berke  
[mberke@c sdf-cde.ca.gov](mailto:mberke@c sdf-cde.ca.gov)
- Teri Urban  
[vahandsandvoices@gmail.com](mailto:vahandsandvoices@gmail.com)

