

Deaf Without Deaf: The Path to Effective DHH Infusion

EHDI Annual Meeting 2024

Karen Hopkins, Emily Burke, Elizabeth Shuler-Krause

Hands & Voices HQ

Can we successfully serve children in the EHDI system with limited or no access to the expertise and investment of DHH Leaders?

- Programs for DHH children must include DHH leaders
- Why does representation matter? (MCHB Blueprint for Change)
- Is there DHH leadership within the EHDI system in your state?

Did you notice we are using black background with yellow text?
This increases accessibility for folks who are DeafBlind/Blind/low vision

The How: Strategies to Support Effective DHH Infusion

How we do it at Hands & Voices HQ:

- In Collaboration with Parent Leaders
 - Avoid Tokenism
- Actively seek engagement and guidance of DHH Leaders
- Think about DHH infusion at every level of your system

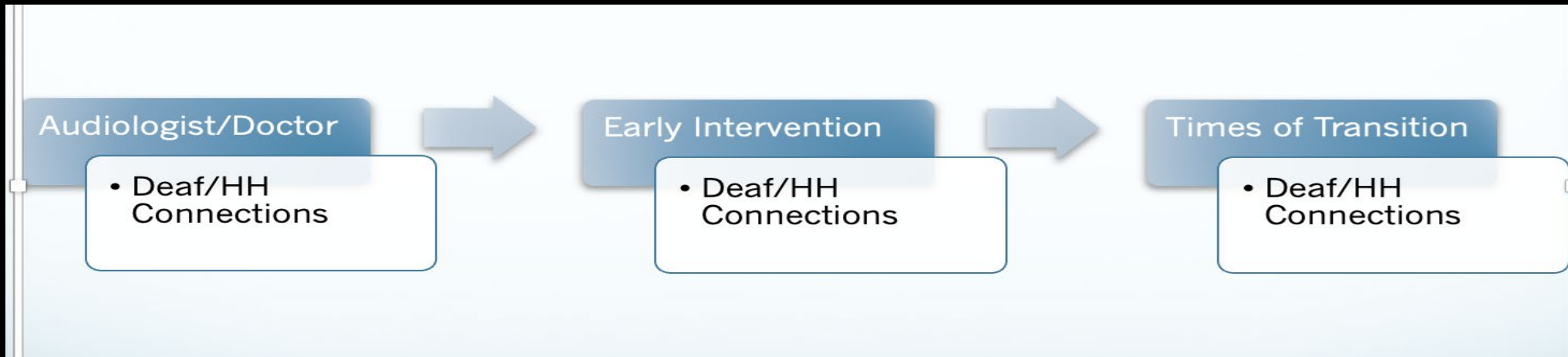
The How:

Strategies to Support Effective DHH Infusion Cont'

- Implement DHH advisory committees
 - Consultation Approach
 - Collaboration with DEIA
 - Board Leadership
 - Resource development

The How: Strategies to Support Effective DHH Infusion Cont'

- Ensure family events (Schools for the Deaf, family organizations, other events) include DHH adults
- Take the lead in your state to ensure DHH are available to support
- Connect with your state's EHDI coordinator and Early Intervention to inquire about funding possibilities
- Look at every window opportunity in your system to include DHH adults



Are DHH Leaders being actively pursued for engagement in the EHDI system?

- Do you have formal partnerships with Deaf-led organizations in your state?
- Do you invite DHH Leaders to participate on boards, advisory councils, to apply for leadership positions, etc?
 - Do you invite DHH Leaders to events, conferences, networking opportunities?

What are families saying? What is the research showing us?

An Investigation of Families Perception of Empowerment in Maine's Exploring Language and Communication Opportunities Process
Hopkins, K. (2023)

- Qualitative study - 12 families of DHH children
- Explore parent's perspectives of **empowerment** through participation in Maine's statewide, coordinated and comprehensive early intervention process for deaf and hard of hearing children

Research Theme

The Opportunity to meet individuals with lived experiences empower families of DHH children:

- **The impact of engaging with deaf and hard of hearing adults is empowering to families.**

Important Finding:

- **11 participants felt empowered after meeting Deaf and hard of hearing adults and parents of deaf and hard of hearing children**

Thoughts from Families....

“If I could have met deaf people earlier, meet more than one, get a broader understanding of the many ways that deaf and hard of hearing people exist in the world it makes those first few weeks easier. We need to meet someone that’s deaf or hard of hearing earlier. ”

“For those parents that are struggling to find a starting point early on. I feel if you could bring someone in to meet them that is deaf before they make their initial decision that would be so helpful. It was so heartwarming to meet a deaf adult. “

“There were days I couldn’t figure how I was going to be a mother to my son. My Deaf Mentor just made it so comfortable to ask whatever questions I needed and to ask what it is like to be deaf. Instead of being connected to doctors and therapists and being a patient... we are now in this community, and we are a part of something amazing. It was then I realized I could be the mother I wanted to be. “

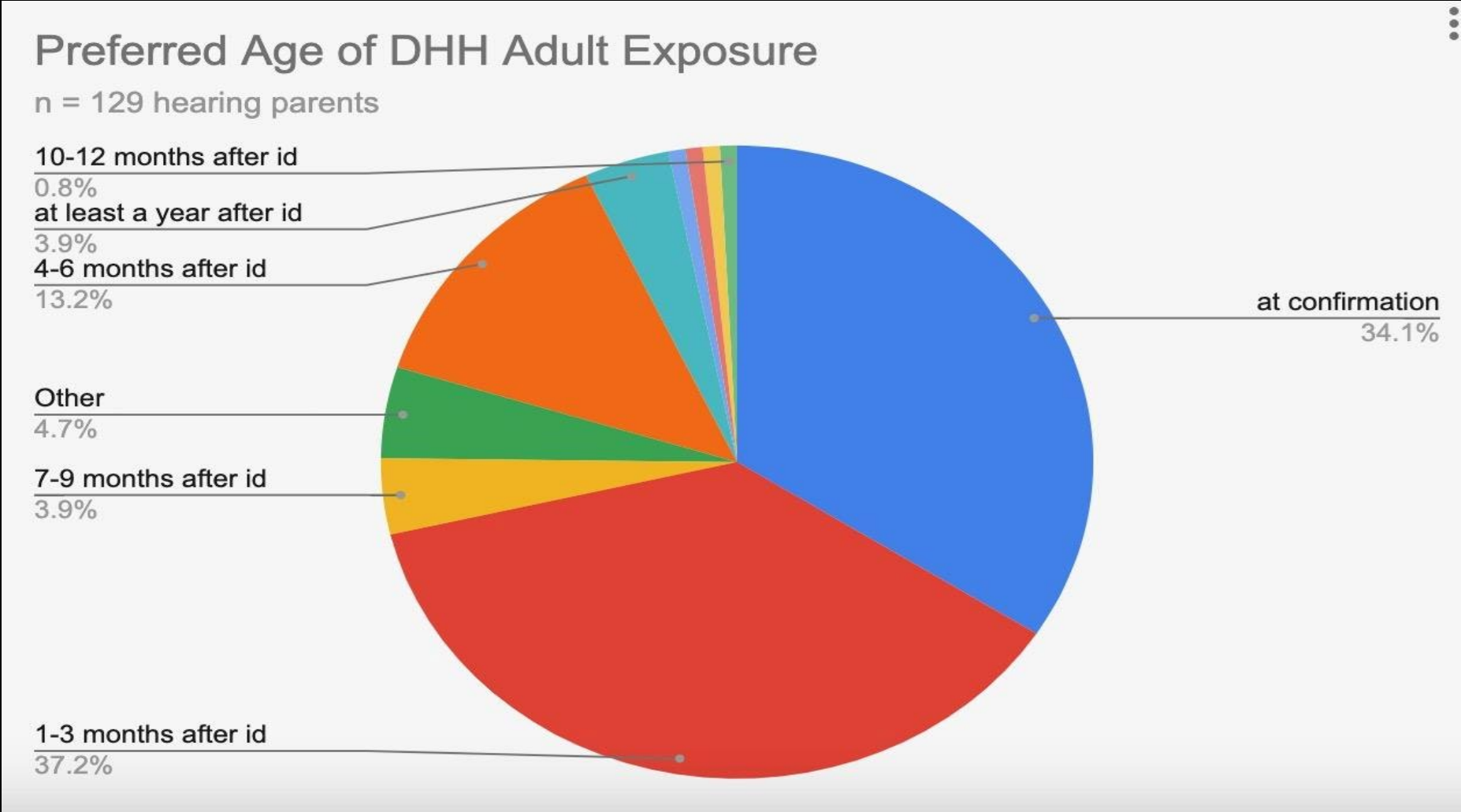
What is the research showing?

Exploring Parent Perspectives and Experiences: When Should Professionals in Early Intervention Offer Families Access to Deaf Adults?

- **Survey responses from 165 parents of DHH children 129 throughout the US**
 - **Survey responses from 129 *hearing* parents of DHH children**
- **any age DHH child**
- **Data Collection: March 2023 to July 2023**

Gale, E., Hopkins, K., Rems-Smario, J., & Olson, S. (2024)

What is the research showing?



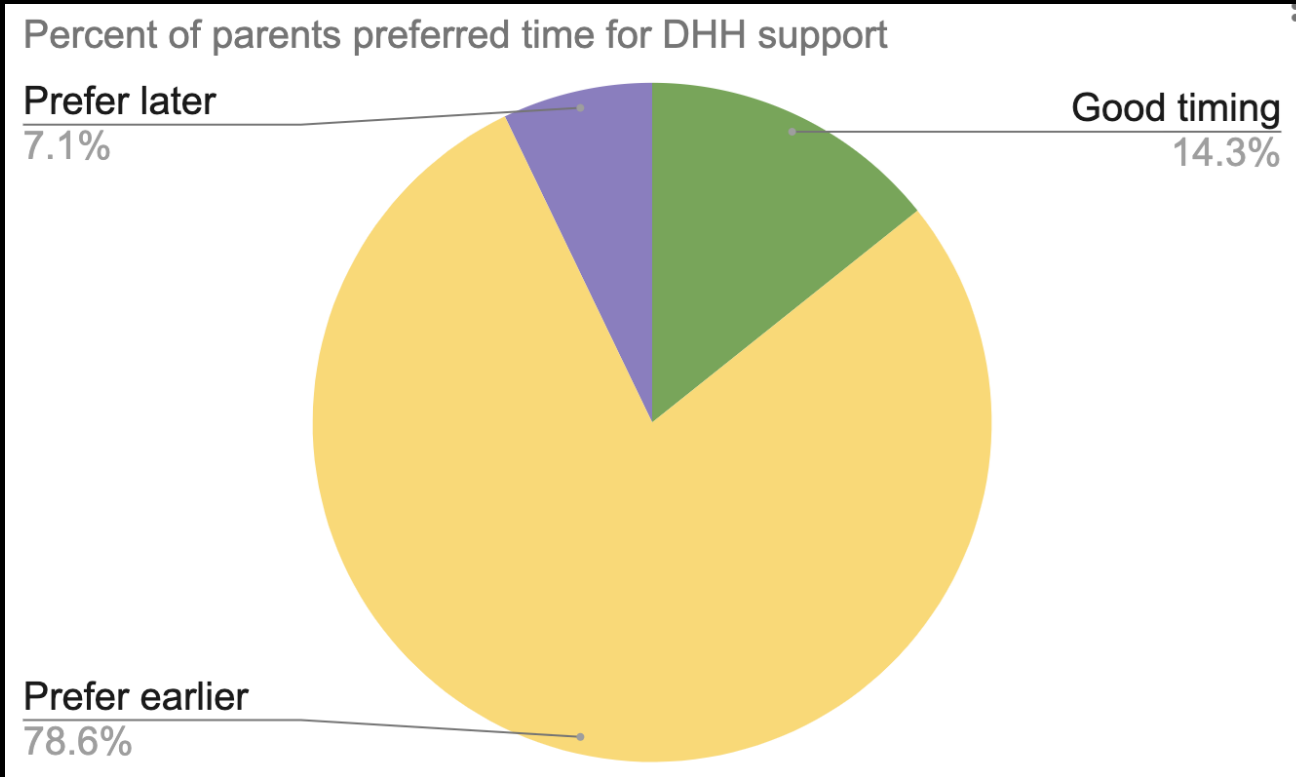
85%

**of hearing families
surveyed wished
they had met a
DHH adult 0-6
months after
identification**

71%

**of hearing families
surveyed wished
they had met a
DHH adult 0-3
months after
identification**

What is the research showing?



83%
of families eligible
for EI services
after 2020 prefer
DHH exposure
before 3 months

Gale, Rems-Smario, Hopkins, Olson, 2024

Do parents receive direct support from DHH Leaders in your state?

Imagine DHH Leaders in all roles within EHDI system

- DHH Guides
- DHH Mentors
- DHH Role models
- DHH EI and Educators
- DHH EHDI Coordinators
- DHH Audiologists
- DHH Pediatricians
- DHH SLP/Language Specialists
- DHH Data Scientists
- DHH Researchers
- DHH Consultants
- DHH Interpreters

AND MORE!

Will you commit to working towards DHH Infusion?

Write down 2 goals you have (SMART)


Write down 3 strategies you plan to utilize


Share on _____app

#DHHinEHDI


#DHHInfusion

Resources

DHH PARENTS & ADULTS - TIPS FOR MEANINGFUL PARTICIPATION IN EHDI SYSTEMS 



TIPS FOR MEANINGFUL PARTICIPATION



TIPS FOR MEANINGFUL PARTICIPATION BY PARENTS AND ADULTS WHO ARE DEAF AND HARD OF HEARING SERVING IN EARLY HEARING DETECTION AND INTERVENTION (EHDI) SYSTEMS*


*Specifically, Advisory Committees and Learning Communities

“The goal of early hearing detection and intervention is to maximize the linguistic and communicative competence and literacy development for children who are deaf or hard of hearing.”¹

Purpose:

Local EHDI Advisory Committees and Learning Communities are created to advise and assist the EHDI program in a state/territory to successfully implement program goals and to promote and improve effective collaboration between parents of children who are deaf and hard of hearing (D/HH) and the professionals who serve them.

Parents who have experienced the EHDI system for their own child/family and adults who are D/HH can provide rich input and expertise into the implementation and improvement in one or more of the following areas: medical, educational, and other services to families.² They will have a range of experiences with the EHDI system. Some may be very experienced and represent a vast stakeholder group, while others may have limited knowledge in one or more of the following areas: medical, educational and other services for families. Additionally, personal experience of the individual may have occurred in the distant past and/or limited to certain geographic locations.

 A RESOURCE GUIDE FOR EARLY HEARING DETECTION & INTERVENTION

Chapter 19

Deaf Professionals & Community Involvement with Early Education

Jodee Crace, MA; Julie Rems-Smario; & Gloria Nathanson, AuD

Terminology

The following provides clarification of terminology in this chapter:

Deaf with capital “D” emphasizes the unique visual and linguistic strengths of Deaf individuals. It is inclusive of children with all hearing levels and linguistic-social usages, including those who are seen as or identify as Deaf, deaf, or hard of hearing. The term “deaf or hard of hearing” is used when cited in the original source.

Deaf specialist applies to Deaf adults who provide services for birth-to-3 children and their families, such as Deaf Mentor, Deaf Role Model, Sign Language Specialist (or Instructor), and Deaf or Hard-of-Hearing Guide.

Deaf community includes individuals who share a wide variety of experiences and values relating to visual language acquisition and who experience a mutually-shared connectivity by virtue of being Deaf. Families with Deaf children are important members of this supportive global community that values Deaf culture and full language access. Based on this connection, relationships are formed that serve to support and protect one another—banding together for a variety of life opportunities and challenges, including rights.

The basic reason for becoming involved with Deaf adults . . .

We are your children grown. We can, in many instances, tell you the things your child would like to tell you if he had the vocabulary and the experiences to put his feelings and needs into words.

—Fred C. Schreiber,
Executive Director of National Association of the Deaf (NAD), 1966-1978

and Intervention (EHDI) programs refer parents/caregivers to resources that support their positive parenting with appropriate and comprehensive information. In the majority of cases, these parents are unfamiliar with the lives of Deaf children or adults. They depend heavily on professionals to give them the information, support, and services they need.

Introduction

When a baby is identified as Deaf, parents embark on a new discovery path. At the very beginning, Early Hearing Detection

Families meet doctors, audiologists, speech-language pathologists, Part C early intervention providers, and geneticists for evaluations, services, and follow-ups. The professionals they encounter—most

eBook Chapter 19 • Deaf Professionals & Community Involvement with Early Education • 19.1

https://www.infanthearing.org/ehdi-ebook/2022_ebook/19%20Chapter19DeafProfessionals2022.pdf

https://www.handsandvoices.org/fl3/fl3-docs/Final-DHHadults-in-EHDI_8-30-2018.pdf