

A photograph of a diverse family of four. A woman with long dark hair is smiling and holding a baby. A man with a beard is smiling and holding a young girl. The background is a bright, indoor setting.

U.S. National Survey of Family Based Organizations and Connections to EHDI Program Websites

Lisa Hunter^{1,2}, Lisa Kovacs³, Samantha Redmond¹, Katelyn Wargel¹, Janet DesGeorges³, Sheila Moodie⁴

¹Cincinnati Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program; ²Cincinnati Children's Hospital, ³Family Leadership in Language and Learning (FL3) Center, Hands & Voices, ⁴Western University, School of Communication Sciences & Disorders, The National Centre for Audiology, London, Ontario

- “I was hanging in a bit of a limbo zone ... So, it was like we know there’s something here, we just don’t know exactly to what extent it is.... I was an emotional wreck every time I had an ABR appointment. And we had several to get the complete picture.
- They were really hard on me.”

Photo by [Kelly Sikkema](#) on [Unsplash](#)



Learning Outcomes

Define

- Define 3 optimal characteristics of supporting parents in family-based organizations (FBOs).

Describe

- Describe the availability of parent-led FBOs across the US.

List

- List factors that enable FBOs to optimally support parents of deaf and hard-of-hearing children.

The EHDI System Recognizes the Importance of Family-to-Family Support

EHDI Legislation

- Referral to... **including family support**
- Programs and systems shall offer mechanisms **that foster family-to-family support** and deaf and hard of hearing to consumer-to-family support

HRSA EHDI Program NOFO

JCIH Recommendations/Best Practices Guidelines

- Goal 8: Families will be **active participants** in the development and implementation of EHDI Systems at the State/Territory and local levels.
- Goal 9: All families will have access to other families who have children who are D/HH and **who are appropriately trained** to provide **culturally and linguistically sensitive** support, mentorship, and guidance.

Establishment of the FL3 Center in 2016

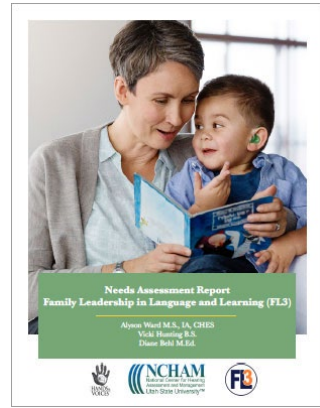
- The purpose of the FL3 Center is to provide technical support to national, state and territory, and local EHDI systems of care in order **to increase family engagement and leadership, and to strengthen family support for families...**

Other important factors to consider:

- **Direct referrals** make a difference in offering equitable family-to-family support
- We've made significant progress in tracking enrollment into family-to-family support (FEHDI)
- **Evidence-based model** – Conceptual Framework of Parent-to-Parent Support

Information we had: Hands & Voices FL3 Center 2018 Needs Assessment

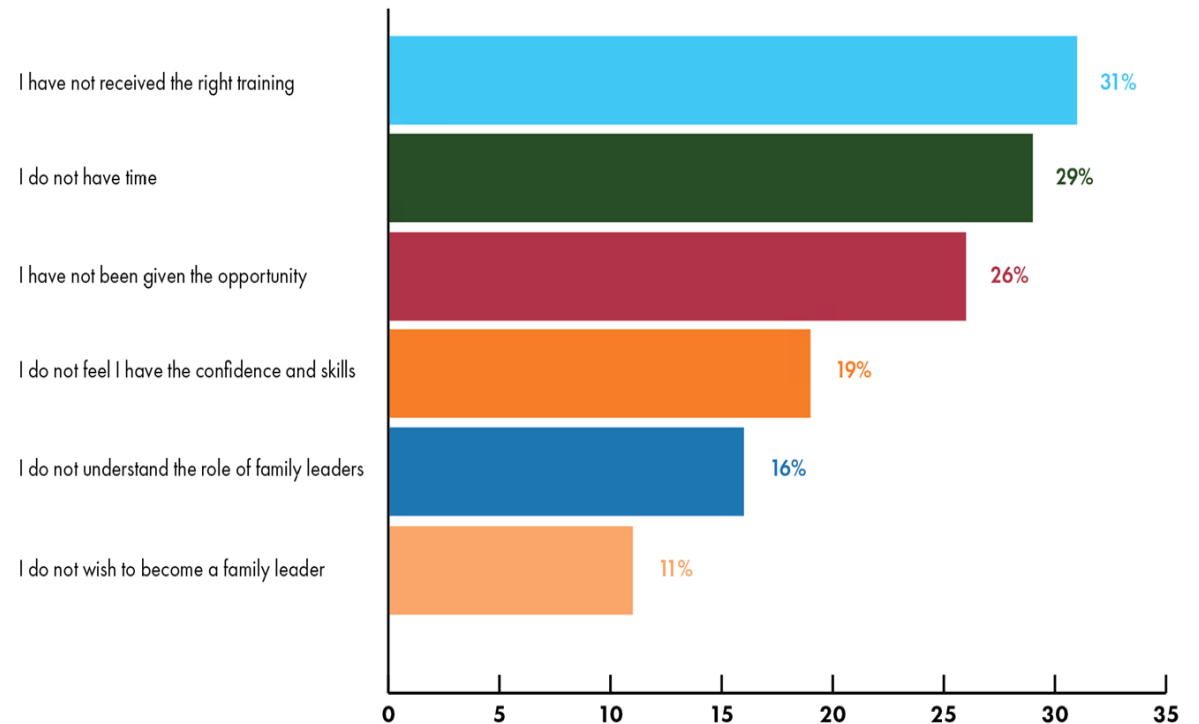
<https://www.handsandvoices.org/fl3/resources/needs-assessment.html>



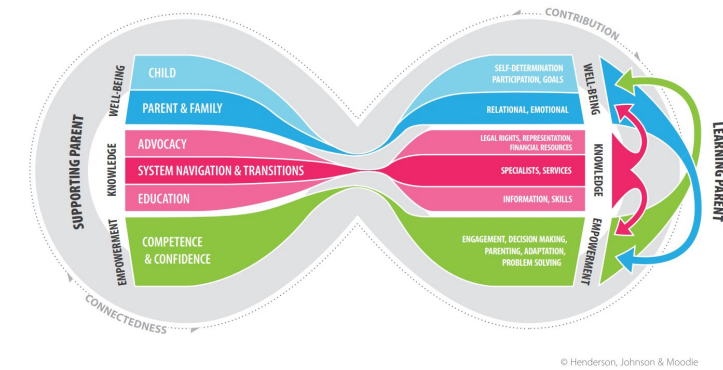
Parents reported: Involvement with Programs and Challenges Faced

How involved are you?	EHDI	FBO
I didn't know about this program	19%	12%
Not involved, but would like to be	21%	15%
Not involved and would NOT like to be	9%	1%
I have visited their website	14%	24%
I follow them on social media (Facebook, Twitter, Instagram, website)	9%	28%
I have participated in their activities or programs	21%	42%
I am an EHDI family leader Builds partnerships, advocates for D/HH children locally, participates on EHDI committees	4%	N/A

Figure 4
Challenges families face in becoming leaders



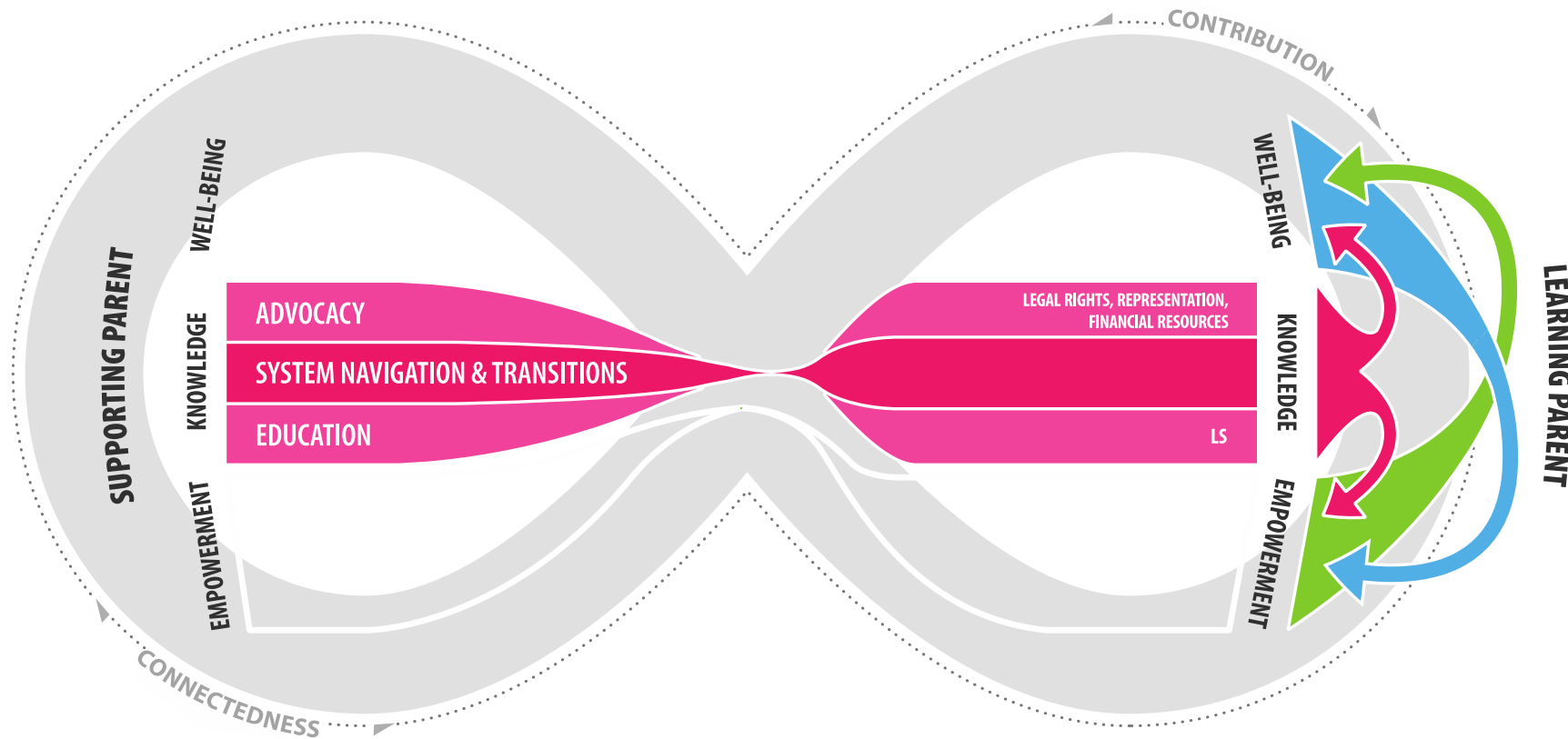
Literature review that informed development of the conceptual framework of family-to-family support



*just to highlight a few – for full list - https://www.handsandvoices.org/fl3/fl3-docs/Henderson_etal-2016-AJA_famfam-givesupport.pdf

- *“For parents of children who are DHH, parent-to-parent support has an important role in helping parents provide assistance to their children.”* – Jackson 2011, Munoz, Blaiser, & Barwick, 2013 and several other references.
- *“When a child is identified as Deaf or Hard of Hearing, the majority of these children are born to hearing parents who were not expecting the diagnosis.” “Peer parents can provide empathetic support, knowledge, and skills to facilitate the navigation of this new experience.”* – Bagatto, Scollie, Hyde & Seewald 2010
- Best Practices in Family-Centered Early Intervention for Children who are DHH- an International Consensus Document Principal 4: *“ensure all families have access to parent-to-parent support from other families...recognize the key role of parent-to-parent support in promoting social-emotional well being of the family...and actively support parent organizations for direct parent-peer support opportunities.”* – Moeller, Carr, Seaver, Stradler-Brown & Holzinger 2013
- *“Families are connected to support systems so they can accrue the necessary knowledge and experience that can enable them to function effectively on behalf of their DHH children.”* – Moeller et al., 2013

Conceptual framework of family-to-family support (Henderson, Johnson, & Moodie, 2016)



© Henderson, Johnson & Moodie

“It gives a sound overview on the most important variables that have to be considered when working in the context of parent-to-parent support.”

Purpose

Family-to-family networks provide vital support to parents of children who are DHH.

The conceptual framework of family-to-family support has been defined, but it is unclear how often this framework is followed, and the extent to which EHDI websites include information about FBOs.

Our goal is to better understand the status of FBOs serving DHH children across the U.S., how they encompass factors from the conceptual framework, and integration within EHDI program websites.

Methods

A national survey was developed in collaboration with the Family Leadership in Language and Learning (FL3) Center and with stakeholder input by parent leaders, audiologists, and EHDI experts.

The survey was sent to FBOs serving DHH children in U.S. states and territories in March 2022 and was open through June 2022.

A structured internet search was simultaneously carried out in March 2022 to investigate the availability, accessibility, breadth of programs provided, and diversity displayed online for PTP organizations and EHDI websites in all U.S. states and territories.

Results

Completed surveys were received from 35 states and territories with 43 PTP organizations responding

The surveys assessed the breadth and depth of services provided by PTP mentoring networks

- * Congruity with the accepted structural PTP framework
- * Availability and diversity of parent guides and parents served
- * Funding support, parent training, measured outcomes, PTP program visibility, diversity of parent mentors, and integration with EHDI programs

Selected Survey Questions Assessed

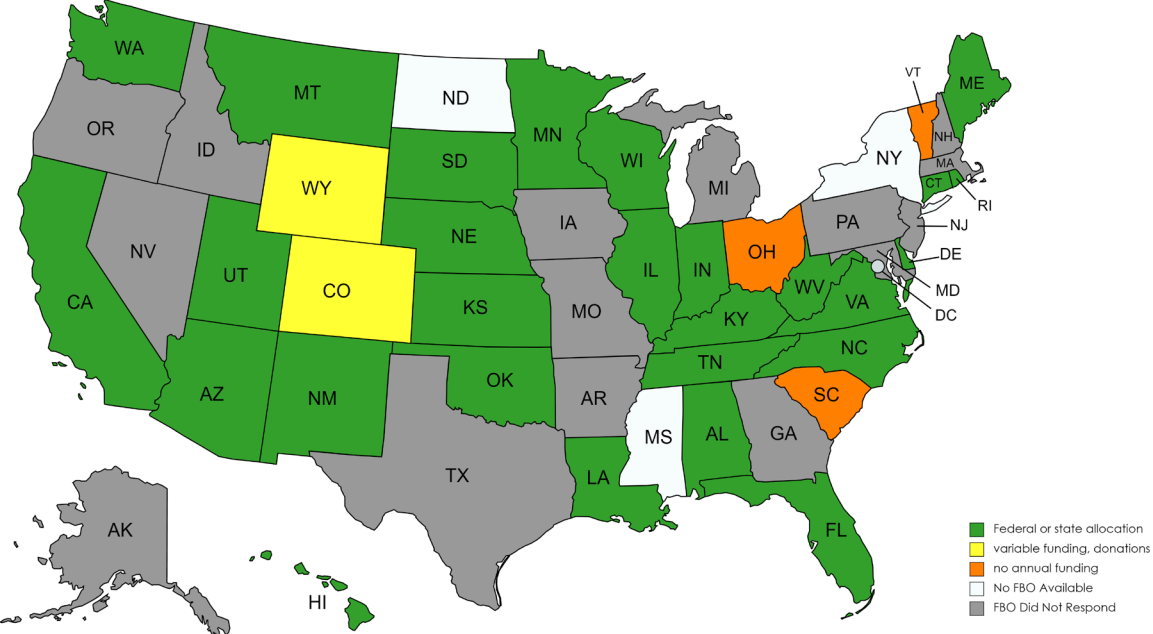
- 1) Is the organization led by a parent of a child who is deaf or hard-of-hearing?
YES = 29 (67%)
- 2) Does the program use a specific training or curriculum for support?
YES = 27 (63%)
- 3) Does the program receive annual funding and pay parents?
YES = 32 (74%)
- 4) Does the program receive direct referrals from the state/territory's EHDI providers?
YES = 31 (72%)
- 5) Does the program try to match families within the family-to-family support program on age, location, diagnosis, etc?
YES = 39 (91%)

Selected Survey Questions Assessed (con't)

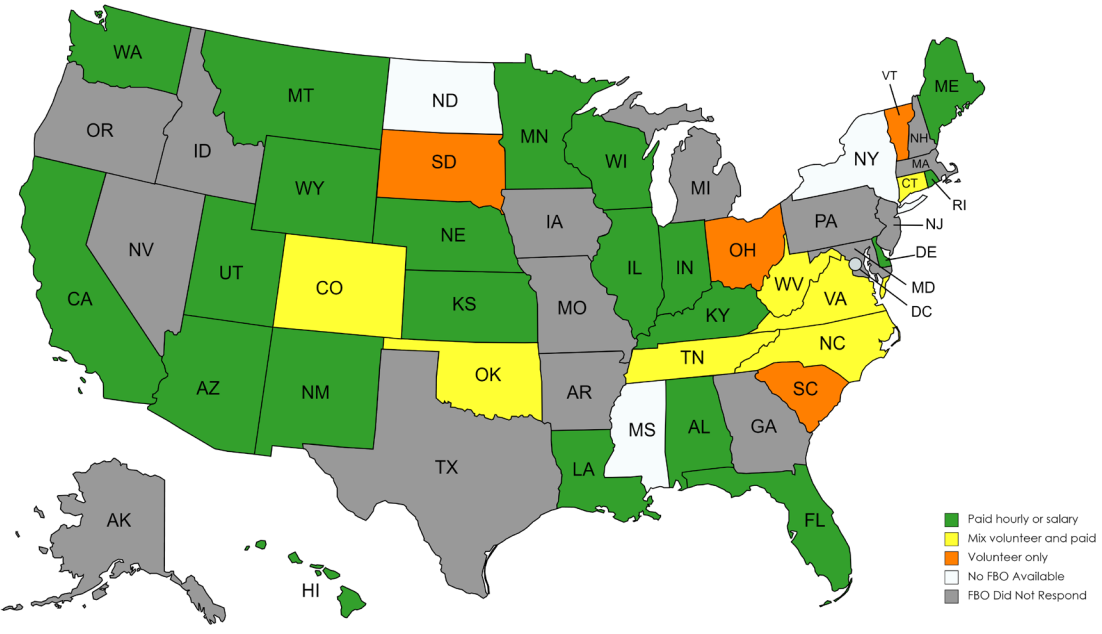
- 6) Is support for wellbeing/emotional, knowledge, health system navigation, resources, empowerment, education/advocacy, transition planning provided? **YES = 40 (93%)**
- 7) Are learning parent outcomes collected? (examples: knowledge of services, rights, and resources, sense of empowerment, well-being, decision-making, problem-solving) **YES = 27 (63%)**
- 8) Are supporting parent outcomes collected? (examples: self-assessment, goal setting) **YES = 23 (53%)**
- 9) Adequate number of supporting parents relative to number of D/HH children **YES = 21 (49%)**
- 10) Any diversity of supporting parents? (language modality, race, ethnicity) **YES = 15 (35%)**

Annual Funding

Supporting Parent Pay

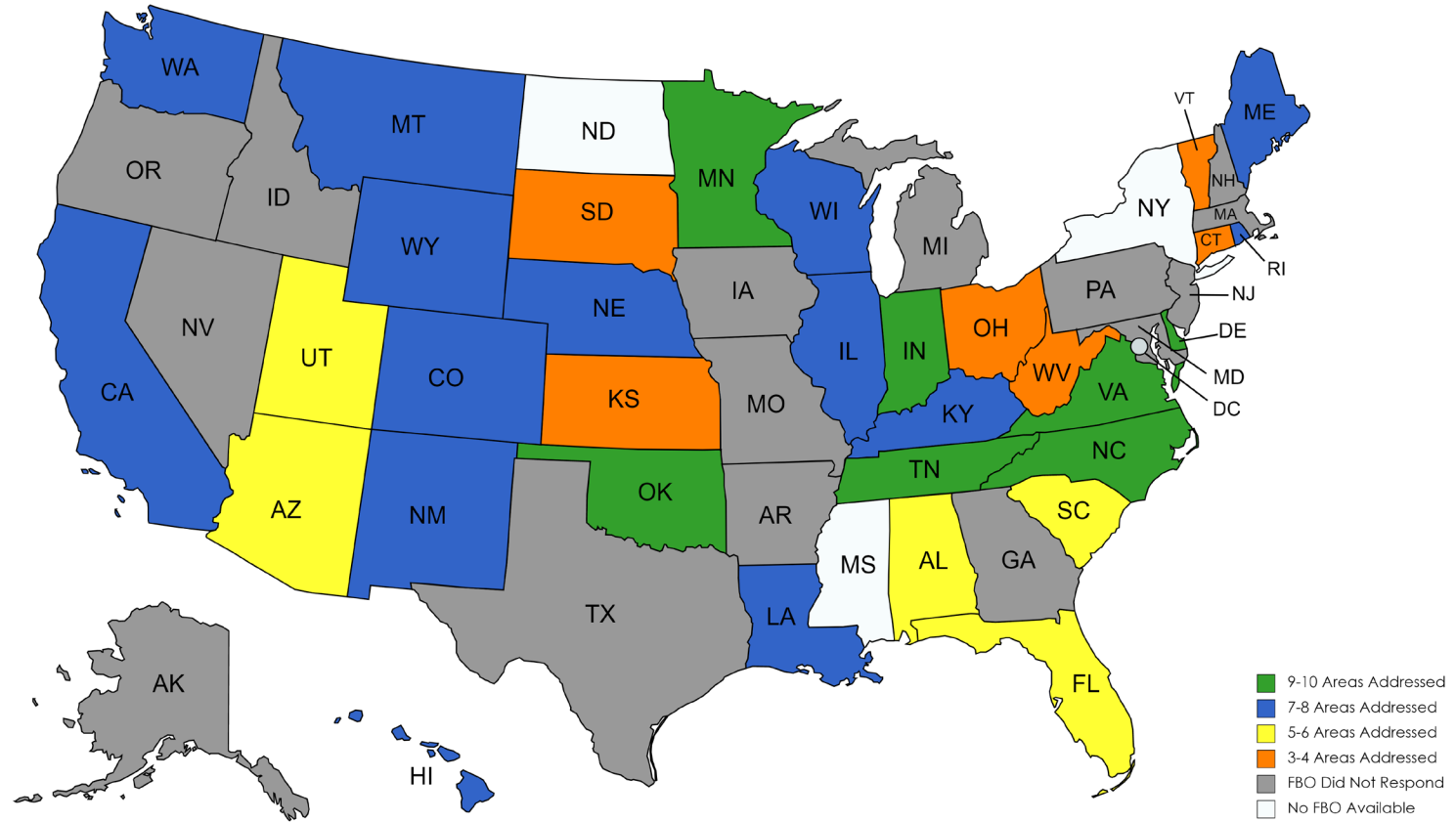


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State of Development Across 10 Most Important Factors



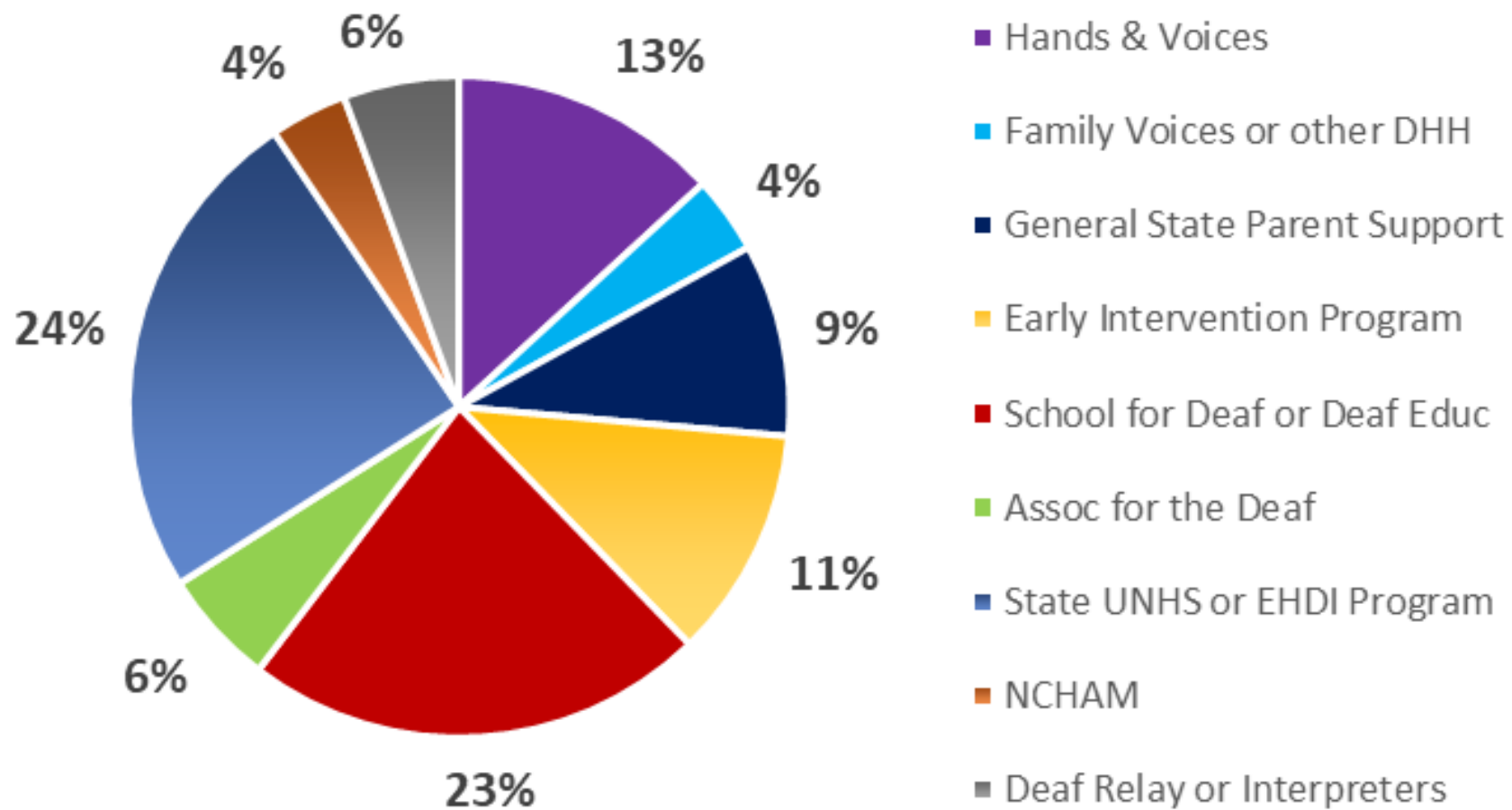
Key Take-Aways and Areas of Need

- 1/3 of states did not respond after several repeated requests; we plan to re-open survey after EHDI for programs to respond.
- Specific training or curriculum is vital to ensure quality parent support.
- Predictable funding sources translate into more children served and allow parents to be paid for their time.
- More diverse supporting parents are needed to reflect diversity of learning parents.
- Connections and referrals from EHDI programs allow more children to be served.
- Well-being, knowledge, resources, system navigation, empowerment, education & advocacy key factors addressed by FBOs.
- Need for outcomes to be documented and shared to support the need for FBOs in all states, funding and connections with EHDI programs.

Website Review Project – Parent to Parent Orgs

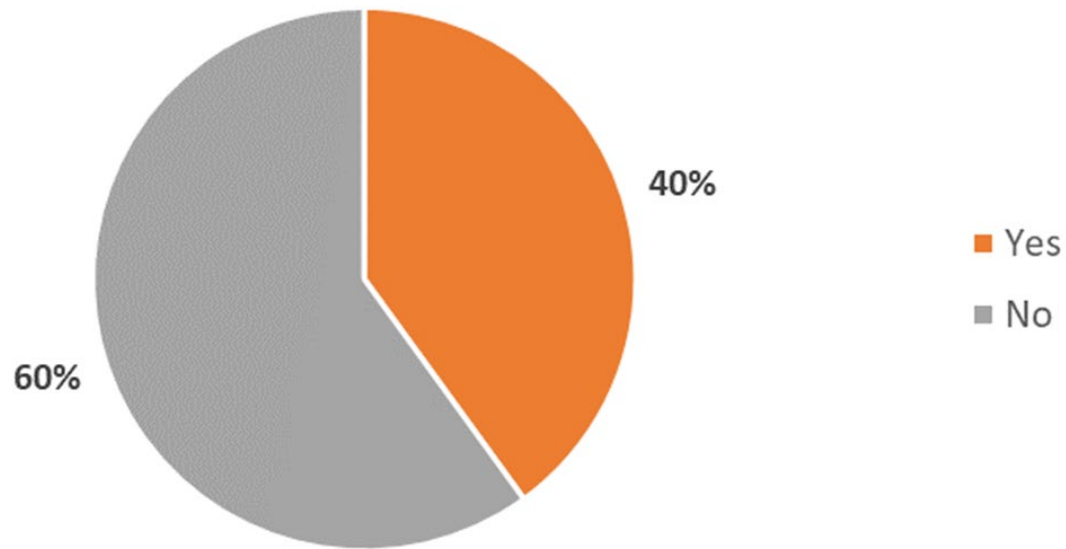
- Web search for FBOs in each state using Google Search terms:
 - [State] parent support for deaf hard of hearing infants; [State] newborn hearing screening; [State] Hands & Voices
- Data from this search was gathered in the following categories
- Top Organization in first search, All Organizations available in the state
- Programs provided, Resources, Number of staff listed and their background (i.e., as parents of deaf children)?
- Subjective assessment of diversity in the website pictures and content
- A search of each state EHDI program was completed to assess which parent support organizations, if any, are listed as a resource

Top Line Internet Search "Parent support for deaf hard of hearing infants"



EHDI Inclusion of FBOs and Website Problems

EHDI Website Lists Parent Support Organization



Hands & Voices		
Issue Type	States	Territories
Limited/No Existing Website	11/50	5/5
Website Problems (Broken Links, Navigation)	1/39	N/A
P2P Support Programs on Social Media Only	1/39	N/A
Lack of Diversity	11/39	N/A
EHDI		
Issue Type	States	Territories
Limited/No Existing Website	0/50	4/5
Website Problems (Broken Links, Navigation)	1/50	0/1
No Listing of P2P Support	25/50	0/1
Lack of Diversity	17/50	0/1

Website Review Summary

- Results indicate that it may be difficult for parents of children diagnosed with D/HH to identify local parent support.
- Parents new to this community may have difficulty navigating the online resources to identify family support, particularly if they are unaware that these networks exist.
- Most websites did not visually reflect racial, ethnic, or language diversity in parent mentors or families served, which may feel alienating or unwelcoming to families with diverse backgrounds.
- To raise awareness and better connect parents to family-to-family support:
 - EHDI websites should include links to local parent support resources
 - Parent support organizations should ensure their websites are functional, easy to navigate, and welcoming to diverse families
 - Providers could include resources about parent support when providing diagnostic results



Anchor

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FL3 Center Resources: Implementation of Family-to-Family Support in the EHDI System

HANDS & VOICES
FAMILY LEADERSHIP IN
LANGUAGE & LEARNING (FL3)

FL3

FAMILY-TO-FAMILY SUPPORT

FAMILY-TO-FAMILY SUPPORT PROGRAM
GUIDELINES FOR ADDRESSING THE NEEDS
OF FAMILIES WHO HAVE CHILDREN WHO ARE
DEAF/HARD OF HEARING (D/HH)

Hands & Voices Headquarters
P.O. Box 2019
Boulder CO 80507
303.442.4393

www.handsandvoices.org

Hands & Voices

PARENT EVENT GUIDE

HANDS & VOICES

FOR FAMILIES WITH CHILDREN WHO ARE DEAF AND HARD OF HEARING

December 2022 Version

FL3 Office Hours

Office Hours is a place where **family leaders** providing direct support to families with children who are D/HH **gather to share strategies and resources** around planned topics facilitated by FL3 staff and invited guests.

[Register](#) [Previous Topics](#)

CHECKLIST: PROGRAM IMPLEMENTATION OF UNBIASED SUPPORT FOR FAMILIES WITH D/HH CHILDREN

Programs offering support to the entire community of families with children who are deaf and hard of hearing must be unbiased to the many choices families may make about communication, educational placement, technology and more. Unbiased delivery of information involves careful consideration of each program component and commitment to on-going assessment. The following checklist is provided as a tool to conduct a review of a family support program in order to develop a plan to address areas of need / improvement.

HANDS & VOICES | ONLINE ACADEMY

Library of Recorded Webinars

Deaf/Hard of Hearing Adult to Family Support

H&V LEAD COURSE
Leadership Enhancement And Development

REGISTER HERE

DATA COLLECTION 101 TO INFORMATION IMPACT

FL3

HANDS & VOICES

SUPPORTING FAMILIES WITHOUT BIAS

Presented at the 2019 H&V Leadership Conference
Gallaudet University, Washington DC
Sept 20, 2019



Spotlight on Success

"Spotlight on Success" is a series of brief articles appearing in the FL3 eNews, featuring strategies family-based organizations/family leaders and Early Hearing Detection and Intervention (EHDI) programs are implementing to foster family engagement.

[Read Articles](#) [Submit Article](#) [FL3 eNews](#)



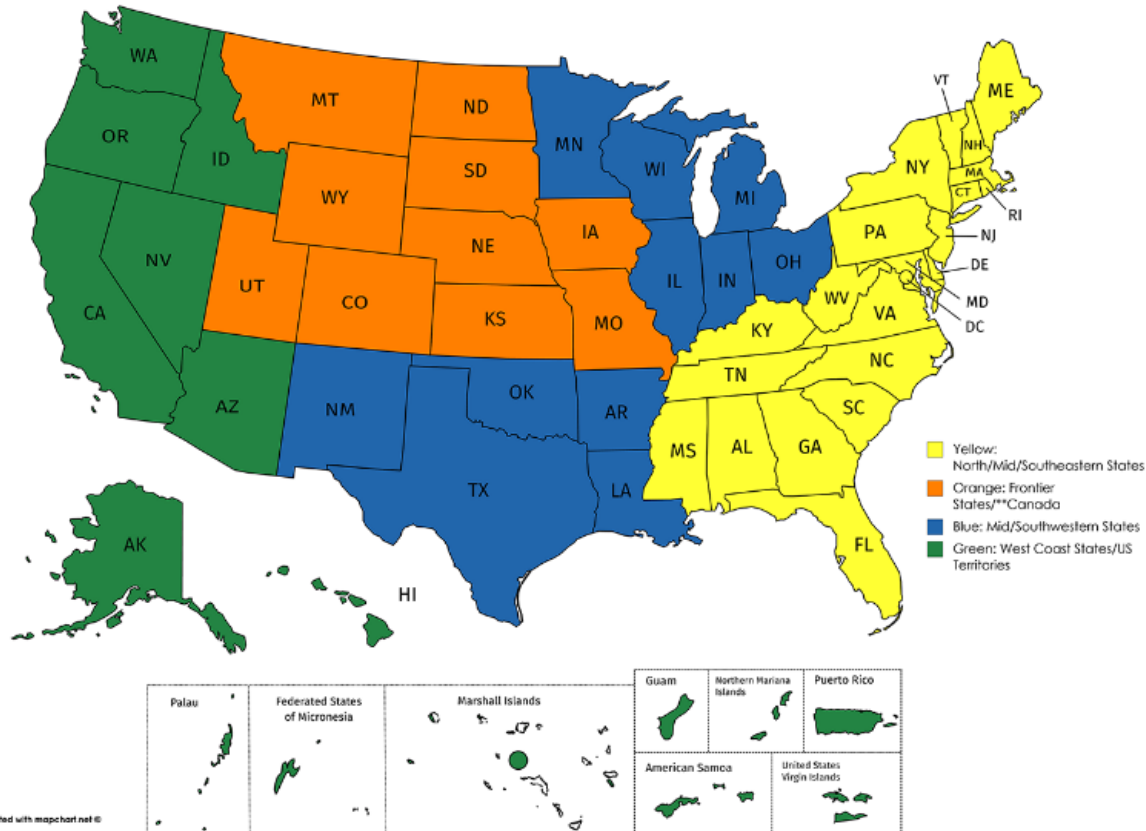
A CASE FOR DIRECT REFERRALS TO PARENT-TO-PARENT SUPPORT PROGRAMS FOR FAMILIES WITH CHILDREN WHO ARE DEAF/HARD OF HEARING

Programs offering local parent-to-parent support to families with children who are deaf and hard of hearing(D/HH) are most effective when they are able to reach all families, regardless of the family's ability to initiate contact. Direct referrals from Early Hearing Detection and Intervention (EHDI) programs and diagnosing audiologists in a timely manner ensures health equity by providing all families access to trained parent-to-parent support providers who offer resources, information, and emotional support. The following information provides guidance to EHDI system stakeholders including but not limited to; state/territory EHDI programs and family-led parent-to-parent support programs to increase the number of families who are offered parent-to-parent support including those from underrepresented populations. ¹



FL3@HANDSANDVOICES.ORG

Contact us anytime!



Hands & Voices/FL3 Center Technical Assistance Advisors

Yellow TAA: Terri Patterson

Orange TAA: Sara Kennedy

Blue TAA: Lisa Kovacs

Green TAA: Candace Lindow-Davies

