



**HANDS &  
VOICES™**

*"What works  
for your child  
is what makes  
the choice right"™*



**Family  
Leadership in  
Language &  
Learning  
(FL3)**



July - August E-news

## Partner Spotlight



### How HRSA Supports EHDI

HRSA's Early Hearing Detection and Intervention Programs enable states, territories, families, and providers to develop complete and coordinated systems of care so that newborns, infants and young children who are deaf or hard of hearing are identified and get the care they need when they need it. Early involvement can help these children meet age-appropriate



Greetings!

We hope that your summer is off to a great start! We continue to work on the goals of the FL3 with some of this work being guided and completed by our two Advisory Boards - the [Deaf and Hard of Hearing Advisory Board](#) and the [Scientific Language and Literacy Advisory Board](#).

language, social, and other developmental milestones.

HRSA supports a coordinated portfolio of programs that support state and territory health departments, departments of education, academic institutions with universal newborn hearing screening programs, and family and provider organizations to develop a system of services for children who are identified as deaf or hard of hearing and their families. They support the EHDI system with technical assistance, by fostering family engagement, supporting workforce development and training, and working with pediatricians and health care providers.

Learn more about the initiatives [they support](#).



## Family Based Organization Survey

On June 19, 2019 all EHDI Family-based Organizations (FBOs) should have received an email outlining a request to complete a survey to assist the FL3 with our annual report to the Health Resources Services Administration (HRSA), Maternal Child Health Bureau (MCHB). We are asking organizations to provide information about their FBO; programs provided, numbers of families served, etc.

The Deaf and Hard of Hearing Advisory Board consists of adults who are deaf and hard of hearing. This board is chaired by the Co-Directors of D/HH Infusion and receives technical assistance from other members of the H&V staff. This Board makes recommendations based on the results of the National Needs Assessment of families regarding Deaf Mentor/adult role model/deaf and hard of hearing guide opportunities. The Board also assists in increasing involvement of deaf/hard of hearing individuals in EHDI systems, participates in discussion groups, and aids in developing trainings and materials for individuals who seek involvement in EHDI systems, such as guidelines for state/territory EHDI Advisory Committees. Make sure to [check out](#) the great work that this Advisory Board is doing with us!

As always, if you have questions or need help please don't hesitate to reach out to us. You can direct any FL3 questions to the [FL3 Team](#)

Warm wishes,  
The FL3 Team



## Needs Assessment: Did You Know?

As part of the National Needs Assessment published in July 2018, contracted Family-based Organizations (FBOs) were asked if they received direct referrals (names and contact information) from

their EHDI program for all children newly identified as D/HH. Forty-four percent of the responded "yes" they were receiving this information from EHDI programs, 31% indicated that they did not receive this information and 19% indicated "Other". Other responses stated that they were in the process of gaining access, some programs have an "opt in" in order to have their contact information shared.

This discussion provides insight to the challenge's families have in accessing family support. FBOs that do not receive referrals from EHDI may not have the same success at finding and supporting families as FBOs who do receive direct referrals. One of the program requirements for the FL3 is *"To increase by 50 percent from baseline, the number of families that receive family-to-family support by*

Individual FBO responses will be kept confidential and only summarized results will be shared. Responses are due back by end of **day Monday, July 1, 2019**. If you did not receive this email, please contact Vicki Hunting via email at [vicki@handsandvoices.org](mailto:vicki@handsandvoices.org) or [FL3@handsandvoices.org](mailto:FL3@handsandvoices.org).

Thank you in advance for the work you do everyday to support families who have children who are deaf or hard of hearing.



## H&V Leadership Conference



**"Every Child, Every Family, Every Leader"**

**Washington D.C.  
September 20-22, 2019**

The Hands & Voices Leadership Conference brings together family leaders from all over the world to develop skills and receive training on how to provide leadership to others and affect systemic change

*the end of the three-year project period.*" It is concerning if EHDI Programs are not referring families to FBOs for direct family-to-family support, it makes it difficult for FBOs to find and connect with families who have children at risk for or identified with a permanent hearing loss and therefore families are not receiving the support they'd like to receive. Do you know the reasons in your state/territory around why (or why not) referrals can be provided? Is it time for a national discussion on this topic?

[View the Full FL3 Needs Assessment Report.](#)

## Spotlight on Success Reflections on Partnering with the state EHDI Program by Karen Wisinski Assistant Director: Michigan Hands & Voices

When the HRSA grant came out, Michigan Hands & Voices proposed to Michigan EHDI that we would 1) operate a robust Guide By Your Side program, and 2) train parents to be involved in efforts to improve outcomes related to the 1-3-6 goals. The latter is called our 1-3-6 Parent Representative program.

The mission of our 1-3-6 program is to use Parent Stories to help improve the Michigan EHDI medical and educational systems. In the first two years, this is what we have accomplished:

For Goal 1 - screen by 1 month of age:

- 25 parents are now trained to share their newborn screening and diagnosis stories.
- 33 meetings included parents sharing their stories in small staffings, webinars, and presentations for diverse audiences including managers, bedside staff, and students.
- 100% of respondents of one presentation said the speaker was effective. One Attendee's reaction: "Personal story really accentuated the importance of follow-up."

For Goal 3 - diagnose by 3 months of age:

- We are scheduling visits along with EHDI staff to ENT offices where we will discuss the challenges parents face in completing the diagnostic process.

For Goal 6 - intervention by 6 months of age:

- 7 meetings have included parents this year in Local

where they live. It is the only conference of its kind devoted exclusively to train family members, with children who are deaf or hard of hearing, to be effective agents of change.

Learn more about the conference, see the agenda, and registration materials.

[Learn more here.](#)

### Early Bird Pricing thru August 15th, 2019



Interagency Coordinating Councils, which are advisories for local Early Intervention programs.

- Parents represent the needs of children who are deaf or hard of hearing, and professionals can immediately put the shared information to use.
- Examples of what parents have shared:
  - "Brought up the need for reaching more families with Unilateral hearing loss and getting them plugged into Early On<sup>R</sup>."
  - "I talked about the 1-3-6 initiative and our interest in improving early intervention. I also talked about the value of teaching empathy and inclusiveness, so even if a meeting topic does not directly impact families, they can still benefit from any discussion at these meetings."

In addition to the local engagement efforts, our Parent Reps are involved in statewide and regional collaboratives/advisories, at a rate of about 12 meetings per year.

As we have worked in collaboration with EHDI to build this program, we have enjoyed successes and learned lessons. We are grateful for our close relationship with EHDI staff. It has helped us through the transition from a 1 parent consultant model to a having a seat at 36 meetings and presentations per year!

## How are you using the Just in Time Resource with your Families and Partners?

The National Center for Hearing Assessment and Management (NCHAM) has revised their Just in Time tool to help connect families of children who are DHH with family-to-family support organizations as well as other important resources. This tool was developed in part because:



### "Just in Time"

Resources to Support  
Families of Children Who  
Are Deaf or Hard of Hearing  
(in English & en español)

- NCHAM's EI SNAPSHOT study (<http://www.infantheating.org/ei-snapshot/>) revealed that families and providers often don't know about these resources.
- Family-to-Family support was identified as one of the most important unmet needs faced by families.
- Many organizations, including some state EHDI programs, Part C programs, and even FBO's don't have this information on their websites or have such a tool to give to families who are in need of help.

The ["Just in Time" tool \[PDF\]](#) is designed especially for family organizations to help them in their job to support families. It contains the most essential resources identified by both families and professionals to address hearing-related needs. Here are ways you can get the word out:

- Post it on your website, allowing the hyperlinks to take the reader directly to critical information.
- Highlight the resource in your next staff meeting or conference call.
- Talk with your local state partners about the value of the tool, encouraging them to also post it on their websites.
- Have it available as a hard-copy handout to share with families who prefer that format.
- Note the emphasis on resources with information available in other languages.
- [Download the "Just in Time" tool \(en español\) \[PDF\]](#)
- [Click here to post this badge on your website](#)
- [Click here to post the Spanish language badge on your website](#)

NCHAM and the FL3 would love to hear from you about how you're using this tool. Please contact [candace@handsandvoices.org](mailto:candace@handsandvoices.org) to share your experiences.

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