Quarterly News & Updates 3rd Quarter July 2023





Happy Summer from the FL3 Center!

I'm very fond of summertime for several reasons. I love the longer hours of daylight, weather that allows for outdoor activities, and although life always seems so busy, something about summer seems to slow life down a tad. Just today, I took a minute to reflect on how fortunate we are to have systems in place to support families and their children who are Deaf or Hard of Hearing. Although we are all striving for improvements in these systems each day, it is also good to take a minute and celebrate all the work that has been done to be where we are today! I encourage you to take just a minute to recall some work you and your team are proud of and celebrate it!



"When all these pieces come together, not only does your work move toward greatness, but so does your life. For, in the end, it is impossible to have a meaningful life without meaningful work. Perhaps, then, you might gain that rare tranquility that comes from knowing you've had a hand in creating something of intrinsic excellence that makes a contribution. Indeed, you might even gain that deepest of all satisfactions: knowing that your short time here on earth has been well spent, and that it mattered." – Jim Collins, Good to Great

We hope to see you at the Hands & Voices Leadership Conference October 1-3 inGrand Rapids, Michigan. Early Bird <u>registration</u> ends on August 15. Get registered so we can come together as a community to learn and celebrate our work with each other!

In partnership,

Lisa Kovacs Hands & Voices FL3 Center Director

FL3 Office Hours
Thursday, July 27th, 2023
1 PM ET/12 PM CT/11 AM MT/10 AM PT
(One hour)

Virtual Town Hall:
Charting a New Course for CYSHCN
July 27th, 2023
12 PM ET/11 AM CT/10 AM MT/9 AM PT

(One hour)

"Family Support

Activities/Events" What are innovative ideas for family support services and events?

Facilitator: Carrie Balian, IL H&V **Audience**: All parent and D/HH leaders, Family Based Organizations, and EHDI Stakeholders are welcome.

Captioning provided; please request other accommodations by July 20th.

Register Here

Office Hours Topics for 2023-2024 available here; registration will open 2 months prior. Summaries of previous Office Hours discussions available here.



SAVE THE DATE

FL3 Webinar
Thursday, Aug 10, 2023
1 PM ET/12 PM CT/11 AM MT/10 AM PT
(One hour)

Building and Fostering Connections Between Your FBO and the EHDI Program

Presenters: Ginger Mullin (IL EHDI Program Coordinator) and Carrie Balian (IL H&V GBYS Coordinator)

Audience: Family leaders, family-based support organizations, Deaf-based organizations. EHDI program staff, EHDI systems stakeholders, and Pediatric Healthcare Professionals

Do you want to create or expand upon your partnership with your state EHDI program or FBO (Family Based Organization)? Hosted by the National Center for
Systems of Services for Children
and Youth with Special Health Care
Needs (CYSHCN) On the agenda:

- An overview of the Blueprint for Change: Guiding Principles for a System of Services for CYSHCN and Their Families
- Share the vision for improving the system of services for CYSHCN.
- Launch of the new National Center. Learn about its goal and objectives, technical assistance, and activities.

Open to the public: clinicians, families/caregivers, public health professionals, and any other partners serving CYSHCN are encouraged to join.

Register here.
Questions?
Contact Melannie Vallejo



SEEKING SUBMISSIONS for the 2024 Issue of Odyssey Language-Rich Environments in Deaf Education

The next issue of <u>Odyssey</u> will focus on deaf and hard of hearing students' access to language-rich environments, which serve as the "least restrictive environments" that provide the most access to language and communication. This access, in turn, impacts academic and social-emotional development. The annual magazine is produced by the Clerc Center.

What can you do by next week to get started? How can FBOs help the EHDI program fulfill their parent-to-parent support objectives and metrics?

Click here for complete abstract and to register. Click here for flyer.



Emerging Practice: CMV Targeted Screening Program in Maryland

The American Academy of Pediatrics (AAP) EHDI program is excited to share an emerging practice describing a targeted CMV Screening program in Maryland for infants who did not pass their newborn hearing screening.

As an Emerging Practice through coordination with the medical home, the program successfully implemented a protocol for identification, monitoring, and connection with early intervention services to support the care of children who are deaf or hard of hearing and their families. Ideas for how the medical home team can support this work are highlighted.

For more information on the AAP EHDI program, click here.



The Space Gal **New Series from Emily** Calandrelli

DCMP very excited to introduce a

Submissions accepted July 3rd - December 4th, 2023.

Click here for more information.



Registration Now Open

Early-Bird Pricing Ends August 15, 2023

2023 Hands & Voices Leadership Conference "From Why to How: Dive IN!"

Sunday, October 1, 2023 thru Tuesday, October 3, 2023 Location: Grand Rapids, Michigan Hosted by Michigan Hands & Voices

General Information

Agenda and Presenters



The **Seaver Vision Award** was established in 2012 and is given annually to a parent, professional, organization, or agency that exemplifies the values and extraordinary commitment of Leanne Seaver, one of our original founders, to the Hands & Voices vision.

Nominations will be accepted until

brand-new series from Emily
Calandrelli, <u>The Space Gal</u>. Emily
is an MIT-engineer turned Science
Communicator with a goal to
make science and space feel
more welcoming to more people.
The Space Gal series showcases
science experiments and other
STEM-related content for families.

The <u>DCMP</u> provides services designed to support and improve the academic achievement of students with disabilities. We partner with top educational and television content creators and distributors to make media accessible and available to these students.



CMV Public Health and Policy Conference (CMV-PHP) Salt Lake City, Utah October 8th-10th, 2023

The goal of the congenital CMV Public Health and Policy Conference (CMV-PHP) is to present the latest research on diagnosis and treatment, raise awareness, delineate prevention efforts, provide information about early intervention options, and disseminate family support resources in an effort to reduce the number of babies born with CMV and connect families affected by CMV with the resources they need to improve their quality of life.

Registration now open.

Click here for more information.

August 21st, 2023.



1325 Boylston Street Suite 500 Boston, MA 02215 www.decibeltx.com

Decibel Therapeutics is pleased to announce that information about Decibel Therapeutics' DB-OTO Phase 1/2 CHORD clinical trial is now publicly posted allowing for broad access to study details.

Click here for details.



Intervener Survey:
Needs and Ideas for National
Intervener Certification
Due August 4th, 2023

The National Center on Deaf-Blindness (NCDB) is gathering input on sustainable national intervener certification options. In addition to individual responses, we encourage people interested in intervener certification to meet to discuss this issue and share their collective thoughts and ideas.

<u>Click here</u> for more information and a ten-question survey. <u>Click here</u> for information and survey in Spanish. Survey may also be completed in a WORD Doc. <u>English/Spanish</u>

Questions? Contact Krisi Probst

H&V Reads: Leadership Book Club Thursday, August 7th, 2023 3 PM ET/2 PM CT/ 1 PM MT/12 PM PT (One hour)

The Heart of Leadership: Becoming a Leader People Want to Follow by Mark Miller

Facilitator: Melinda Ray



Welcome to STEM Stories with Deaf/HH Professionals!

Hands & Voices, in partnership with the NTID Regional STEM Center at RIT/NTID, created this interview series with Karen Putz, who recorded stories of Deaf/Hard of Hearing professionals working in STEM fields. Each video is a free-flowing conversation with a variety of questions about career, home, and fun!

Watch all four episodes <u>here</u>, and choose your accommodations.

Ally's Act needs your advocacy! Learn about this bipartisan bill at the Ear Community webpage. Ally's Act, or H.R. 2439 or S.1135 was reintroduced this March 30, 2023 and needs your contact with legislators in Washington D.C. to move out of committee.

This is a bipartisan national bill that will ensure that private insurance companies provide for osseointegrated hearing devices, including "Baha" and cochlear implants for children and adults, birth to age 64. Currently, many families pay out of pocket, making this a health equity issue.

The Heart of Leadership: Becoming a Leader People Want to Follow is a short, easy-to-read fable that reveals the five habits that underlie leadership character and that determine leaders' success, and teaches leaders how to develop these important habits.

<u>Click here</u> for more information. <u>Registration</u> opening soon.

Five Reasons to Say YES to Assessments: new infographic and other resources for New Families

Hands & Voices recently released an infographic in partnership with the University of Colorado Boulder. The infographic, Five Reasons to Say YES to Assessments in Early Intervention, is available in English and Spanish.

8 Reasons to say YES to Early Intervention for your child who is Deaf/Hard of Hearing(D/HH) is also available in English and Spanish.

<u>Click here</u> for additional resources to share with New Families.



Early Hearing Detection and Intervention (EHDI): The Role of the Medical Home

The American Academy of Pediatrics announced an update to a favorite resource.

The Role of the Medical Home EHDI presentation is a customizable presentation to assist in linking the medical home in the EHDI system. This resource is primarily for pediatricians/other pediatric physicians or clinicians however can also be used by state EHDI coordinators, family partners, and others in the EHDI system. Included in the



presentation are the national EHDI data, EHDI Algorithm 1-3-6 Guidance for Medical Home Providers, and helpful resources.

Two versions are available:

<u>Full PowerPoint download</u> with speaker's notes <u>PDF version</u> an overview of the slides without speaker's notes for sharing.

Deaf Friendly Audiology

Check out this accessible, online and regularly updated resource for individuals and families to find Deaf friendly audiologists and speechlanguage pathologists who provide services in



American Sign Language. Many of the audiologists and speech pathologists listed have graduated from Gallaudet University graduate programs and have valuable experience working with Deaf and Hard of Hearing individuals and families from different backgrounds and with various hearing, speech, and language goals.

Click here for the Deaf Friendly Audiology website.



Emma Everyday Series

Books by C.L. Reid Illustrated by Elena Aiello

These delightful books for early readers and preschoolers feature Emma, a spunky and persistent Deaf girl as the hero. In the series of 16 books (four soon to be published), children see Emma enjoying swimming, riding, biking, and writing stories. She sees every day as a chance to learn, grow and have fun. Emma both

speaks and signs, uses a cochlear implant, and lives with her parents and older brother who sign, also. The author, C.L. Reid, is deafblind herself and a mom of three, one of whom is deafblind. She has included ASL fingerspelling in the text, charts, and glossary and content questions to make it easy to expand language with young readers. The author holds an MFA degree in writing for children and young adults which is evident in her storytelling. With titles like *Going on a Field Trip, The Writing Contest,* and *Friendship Goals*, there is something for everyone. Find them at your favorite bookseller or library.



Stronger Together in Minnesota

By Anne Barlow, Director MNH&V and Bridget Walde, MPH, MDH EHDI Program

Years in development, the successful partnership between MDH EHDI and the family support organization in Minnesota continues to produce changemaking efforts for families of children who are deaf/hard of hearing. Minnesota Department of Health (MDH) Early Hearing Detection and Intervention (EHDI) program and Minnesota Hands & Voices (MNH&V) have a strong and collaborative relationship. Minnesota both benefits from and reflects this relationship. In 2007, Minnesota state statute 144.966 was passed and authorized the Minnesota EHDI program. Part of this statute states that family support services must be provided to families with children who are deaf/hard of hearing (DHH); specially through a contract with a nonprofit organization to provide support, unbiased information on communication, educational, and medical options, and assistance to families. MNH&V has been the family support grantee in Minnesota (MN) for many years, and the MDH EHDI program has been making direct referrals to MNH&V for over ten years. When an infant or child up to age 11 is identified through audiology as DHH in MN, MDH EHDI uses a secure data-sharing system to direct refer families to MNH&V. A Guide by Your SideTM Parent Guide at MNH&V will then reach out to the family, connect with them, and provide information back to MDH EHDI through the same secure data sharing system.

Audiologists are encouraged to make direct referrals to MNH&V after identifying a child as DHH, as this is the fastest way to connect a family to parent support. While some families are referred through multiple sources, (self-referral, schools, or hospitals/clinics) about 60% of referrals come from MDH direct referrals alone. Family support is an important aspect of how families of children who are DHH feel supported, and without the direct connection between MDH EHDI and MNH&V, these referrals would be missed. MNH&V averages a rate of 89% in connecting with families at least once. (Even that one time connects families with a local Parent Guide, ongoing "passive" support (regular enews blasts, print quarterly newsletters, social media groups, access to specific information for their child's journey). We currently provide most of our direct outreach in the first few years after identification and referral. After the first three years of being enrolled, it is up to families to reach back to us if they want information, resources, or support.

The collaborative relationship between MDH EHDI and MNH&V provides not only funding and structure but also support and opportunities to participate in work groups and other endeavors to improve services for families.

A recent example of collaboration between MDH EHDI and MNH&V was their participation in a learning community of seven entities from across the US and territories that endeavored to improve surveys of family outcomes. The learning community was facilitated by NCHAM (National Center for Hearing Assessment and Management) and H&V. Members from both MDH and MNH&V participated, and the result was a bank of questions that any family-based organization (FBO) can use to assess family outcomes in the realms of Knowledge, Empowerment, and Wellbeing. MNH&V is committed to using the information as a Quality Improvement measure to update our family surveys to assess not only family satisfaction but also our impact on important family outcomes in these three categories.

Evolving Efforts in Family Support

Another collaborative endeavor that is related to outcomes is an assessment regarding our framework for outreach.

MDH EHDI is working with MNH&V to construct a framework for conversations that Parent Guides will have at each of four transition points, based on MNH&V's work groups that identified the topics that are most likely to be of interest at each point.

Our intention is to contact families at these four key transition points throughout their child's development and make sure they have access to the information and resources that will help them make decisions as their child grows and changes. While we anticipate that Parent Guides will still provide the majority of information and outreach in the initial years of birth to 5, we will reach out to families roughly every 5 years to check in and see how they are doing and offer to send (or resend) information that is relevant to their current situation. We have heard from many families that the amount of information they received at the very beginning was overwhelming. Our goal is to make sure they have continued support and feel the connection and sense of community not only at the onset but throughout their journey as parents of a child who is DHH.

One of our programs that can have a powerful impact on families is our **DHH Guide Program**. By reaching out to families at transition points, we are able to offer a connection to DHH Adults when new questions or situations might arise. Being able to talk to an Adult Role model who uses similar technology or language modality can give insights that help inform decision-making, as well as help foster a sense of belonging and connection. Our DHH Guide program has developed a new framework for facilitating guided conversations with children and families that uses our "The Hero Within" Superpower character traits trading cards that were developed 7 years ago and that have been used across the state.

Another program that may be useful in different ways at different times to families is the H&V educational **Advocacy Support and Training (ASTra) program**. By reaching out at transition times, we can make sure that our trained ASTra advocates are available to support families as their child advances through school and on to adulthood.

Both of these programs are either relatively recent additions to our mission or have seen evolution and improvement in recent years. By reconnecting with families over time, we have the opportunity to share new resources with them as well as resources that we have improved upon--all of which have the potential to help families be empowered to create better outcomes for and with their child. Our state's community of family support sees constant change and improvement as well, and shifting our outreach will help us share not only our own evolved resources but those throughout the state.

MDH EHDI embraces and encourages innovation and evolution. They provide time, space, and resources for MNH&V to grow and improve. Our collaborative relationship is key to our success.

How to Submit a Request for FL3 Technical Assistance

Requesting technical assistance from the FL3 team is easy! Click here for the online form.



Hands & Voices | P.O. Box 3093, Boulder, CO 80307

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