Quarterly News & Updates 3rd Quarter 2022





Greetings and Happy Summer from Hands & Voices and the FL3 Center.

Most parent leaders are leading in their EHDI system today because of an internal passion to assist families like their own with children who are Deaf or Hard of Hearing (DHH). Some also had a



little nudging from a fellow parent leader and/or professionals in their state/territory. Many did not grow up dreaming of or going to school to become a parent leader but every parent leader brings with their own education, training, previous work experience, and, most importantly, their unique lived experience of parenting a child who is D/HH into the work of EHDI.

Speaking as a parent leader myself, leadership is not always easy. Some challenges arise that can lead us to say to ourselves *"I just wanted to help other families."* I am sure that thought has resonated with parent leaders a time or two. I just recently participated in one of the FL3 Center Leadership Book Clubs, discussing the *Guide to Nonprofit Leadership* by Joan Garry. I found many nuggets of good advice in this book. While it was hard to take time away from my everyday tasks, I am glad I took some time to invest in my own leadership growth. A few of my favorite pieces of advice from the book include:

Your mission statement is your North Star. The big thing that matters most. Your role as a leader is to keep the organization focused on the mission.

Let the love of your organization lead the way.

Motivate folks by stirring their emotional connection to work. Give them a voice and allow them to have a strong sense of autonomy and do all this through the lens of clear roles and goals.

The FL3 Center was established in 2017, funded by the Maternal and Child Health Bureau HRSA-20-051, with the program goal to increase family engagement and leadership, and strengthen family support in EHDI systems of care. Here at the FL3 Center, we keep this program goal at the very center of all that we do.

Over the next few months, I challenge all Parent Leaders to pick at least one FL3 Center training and education opportunity and invest in yourself as a leader.

Leadership Book Club

FL3 Center Office Hours

Leadership Webinars

Hands & Voices Online Academy

At the Table with Hands & Voices Podcasts Series

In partnership with you,

Lisa Kovacs

Director of Programs Hands & Voices, FL3 Center Director

Language and Literacy Parent Tip Sheets now Available in Spanish

Thanks to Lilianna Herrera, Arizona Hands & Voices for translating these practical parent resources. <u>Click</u> <u>here</u> for all eight parent tip sheets.

Watch what a parent has to say about the Parent Tip Sheets. Captioned in English and Spanish.





The National Research & Training Center on Blindness and Low Vision Releases a New App

The <u>4to24 app</u> is a free resource for parents of children and youth who are blind, have low vision, or are deaf-blind with additional disabilities. For more information, <u>click here</u>.



Hands & Voices has released the fourth Online Academy course: **Data Collection 101 to Information Impact.** Register and take advantage of this self-paced learning when you need it to support the nuances of tracking, monitoring and analyzing information in your organization. <u>Click here</u> to register and view the other courses.



NCHAM Webinar Thursday, July 21st 2 PM ET/1 PM CT/12 PM MT/11 AM PT

"An Interdisciplinary Approach to Earlier Identification and Intervention of Hearing Loss in



Odyssey: New Directions in Deaf Education 2023 Issue-Call for Articles

Odyssey magazine is published annually by the Clerc Center. Each issue is theme-based, focusing on topics of importance as they relate to research, philosophy, and application and practice of instruction in the deaf education classroom. <u>Click here</u> for more information and to subscribe.

Article submissions for the 2023 issue of Odyssey on the topic "Access and Equity in Deaf Education" are still being accepted.

<u>Click here</u> for the 2023 Call for Submissions. ASL version below.





Celebrating its 55th Year Upcoming offerings from ASDC

Reunión del Grupo de Padres Latinos - Derechos Básicos del IEP (Basic IEP Rights) Monthly ZOOM meeting Monday July 25th 7 PM ET/6 PM CT/5 PM MT/4 PM PT

Blanca Zambrano will present the basic IEP rights that every parent should know about.

Medically Complex Infants" with clinical audiologist Kelly A. Baroch, Coordinator of the Inpatient Audiology and Infant Hearing Screening Program at Cincinnati Children's Hospital.

For more information and to register, <u>click here.</u>

FL3 Office Hours Thursday, July 2th 1 PM ET/12 PM CT/11 AM MT/10 AM PT

How do we ensure equity in providing family support services to underrepresented populations? Join this interactive one-hour session with **Mariana Barquet** and **Rosabel Agbayani on EHDI program requirements** for **Diversity, Equity and Inclusion Plans.** What is your Chapter or FBO doing?

Register here.



Upcoming L2L Webinar Thursday August 11th 1 PM ET/12 PM CT/11 AM MT/10 AM PT (1 hour)

Diverse Family Leaders: Making Progress and Showing You How! (Part of our ongoing Leadership Development series.)

Join the Hands & Voices Family Leadership in Language and Learning (FL3) Center for a look at how to recruit and empower new family leaders from diverse cultural backgrounds to become leaders in the systems that serve families with children who are This group is just for parents.

Register here

Questions? Contact Yiesell.

Beginning ASL four-part course Tuesdays in August ZOOM Platform

This 4-week online class will cover fingerspelling, vocabulary, conversations and more. Cost: \$100.**ASDC members**, save \$25 on registration. <u>Click here</u> to register for the ASL class.

For information about all ON-LINE courses offered <u>click here</u>.



"ASL-English Bilingualism: Theory and Practice" Wednesday, August 10th 7 PM ET/6 PM CT/5 PM MT/4 PM PT (90 minutes)

Join <u>CueSign</u>, Inc., for presentations by Daniel Koo, Ph.D., and Angela Kuhn, M.A., as they share some of the whats, whys, and hows of Cued English, along with how to use ASL and Cued Speech in bilingual programs with deaf/hard of hearing students.

This online event is hosted and sponsored by <u>Language Matters</u> <u>Academy, Language Matters, Inc., and</u> <u>CueSign.</u>

Click here to register



Deaf or Hard of Hearing. Drawing from their own experience as culturally diverse family leaders, Marbelly Barahona (LA Hands & Voices) and Lydia Hernandez (IL Hands & Voices) will engage attendees in a presentation that will share innovative strategies and creative solutions through different models to support underrepresented families, as well as support diverse parent leadership development.

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

Register here.



Hands & Voices Leadership Book Club Friday, August 26th 3 PM ET/2 PM CT/1 PM MT/12 PM PT (One hour)

Good to Great: Janet DesGeorges will facilitate a discussion of the Jim Collins' classic text for the Leadership Book Club. His team sorted through mountains of company data and interviews to discover the key determinants of greatness. The findings of the Good to Great study will surprise many readers and shed light on virtually every area of management strategy and practice. STARTS HEAR National Awareness Campaign VEAR ONE Register here.



a program of the American Academy of Pediatrics

AAP EHDI Improving Vocabulary Outcomes

The American Academy of Pediatrics (AAP) Early Hearing Detection and Intervention (EHDI) program recently shared an updated resource: *Improving Vocabulary Outcomes in Children who are Deaf or Hard of Hearing (D/HH)*. This resource supports pediatricians and other partners caring for children who are D/HH and their families to meet all of the EHDI guidelines to increase vocabulary outcomes and receive comprehensive and coordinated care within the medical home model that maximizes language outcomes.



Important Deadlines

Hands & Voices Leadership Conference "Leadership: More Than a State of Mind"

Sunday, September 18th - Tuesday, September 20th Location: Fairport, NY (30 minutes outside of Rochester, NY) Hosted In partnership with NTID with support from New York Hands & Voices.

Have you <u>registered</u> yet? Price increases by \$50.00 on August 16th.

Have you booked your room? The Woodcliff Hotel & Spa Special Room Rate Only Available until August 18th \$149.00 per night

<u>Click here</u> for the reservation page, input the dates you are booking, and enter 2209HAND in the promotional code box. Applicable room types for the guaranteed rate of \$149.00 will display.



2022 Family Voices Family Leadership Conference Moving Forward: Embracing Change and Transformation October 18 – 20, 2022 Washington DC + Virtual

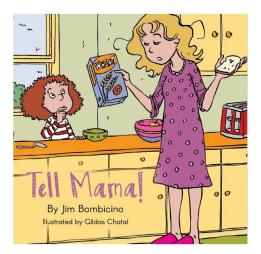
This conference is for family-led organizations, state Title V agencies, and other professionals in the children and youth with special health care needs (CYSHCN) field. For more information, visit <u>here</u>.



Congenital Cytomegalovirus, or CMV, is the most common viral infection and the leading nongenetic cause of hearing loss in the United States. Every pregnant woman is at risk of acquiring CMV. Why do only 9% of women know about it?

For more information about the National CMV Foundation, visit <u>here</u>.

For information about the CMV Public Health & Policy Conference August 21-23, 2022, visit <u>here</u>.



Book Review Submitted by Sara Kennedy

Tell Mama! Written by Jim Bombicino Illustrated by Gildas Chatal

A colorful, engaging short child's picture book about a day in the life of a child's daily routines – a child who has brand new hearing aids. This book encourages a child to "tell Mama!" about what they are thinking as they get dressed, have

breakfast and dinner, go to childcare, experience new sounds, realize batteries need

replaced, help with dishes, and share a book at bedtime. A parent can easily expand beyond the text with the pictures, and of course, change it up to "Tell Daddy!", too! Sign language is also mentioned. Representation does matter, and this cheerful book allows a child to see themselves in the story, hearing differences included. A beginning book for toddlers and preschoolers that will be brought to parents to read often and could be shared in early childhood programs. Find this book by author Jim Bombicino, a retired audiologist, school psychologist, and author of other books for kids and teens. It was published with support from Oticon Pediatrics <u>on Amazon</u>



Louisiana EHDI/Hands & Voices Partnership Submitted by Jill Guidry and Team

Collaboration is key to a successful EHDI partnership. The Louisiana Early Hearing Detection and Intervention program (LA EHDI) team partners with Louisiana Hands & Voices (LA H&V) to ensure early, quality family engagement. At the heart of LA EHDI's work is the understanding of the value of family-to-family support so that families of newborns, infants, and young children identified as deaf or hard of hearing receive the support that they need as early as possible. The LA EHDI team respects the value of support to families, as well as the value of the parent perspective in the EHDI Program. They also share the H&V vision for a world where children who are deaf or hard of hearing (D/HH) have every opportunity to achieve their full potential.

First, the processes in place are important. When a child is identified, the audiologist submits a Follow-up Services Report in the LA EHDI - Information System (LA EHDI-IS). The LA EHDI-IS includes newborn hearing screening, followup, early intervention, family-to-family support, and deaf/hard of hearing guide data for all children born or transferred into Louisiana. When a child is diagnosed as D/HH, the LA EHDI Early Intervention Coordinator contacts the family to explain all available support and services, including early intervention and family-to-family support in an "opt-in" system. With parental permission, referrals are facilitated to EarlySteps (Part C early intervention), and the Parent-Pupil Education Program through LA School for the Deaf (Non-Part C early intervention), and LA Hands and Voices Guide by Your Side (GBYS) for family-to-family support. Additionally, each family is mailed two informational brochures: 1) "Your Baby Has Been Diagnosed as Deaf or Hard of Hearing - What Families Need to Know" which provides information about the importance of timely early intervention and family-to-family support, and 2) "Communication is Key - An Introduction to Communication Options". This timely coordinated referral system provides families with an understanding of timelines. who will be contacting them, and a general idea of how these pieces fit together to support their family.

Documentation of all referrals to GBYS is recorded in the LA EHDI-IS, as well as reasons for no referral, such as family declined, moved out of state, child medically fragile, or unable to contact. Additionally, each Parent Guide updates an Excel spreadsheet of family referrals with the date of initial contact or reason for no contact, which is likewise entered into LA EHDI-IS by the GBYS Coordinator each month. The LA EHDI-IS can generate a report of all families referred to GBYS, along with the date of initial contact. Data reports are regularly

generated and reviewed to ensure continual growth and improvement in family-tofamily support. Incremental progress toward timely enrollment in family-to-family support is evident with each birth cohort. In 2018, 43/73, (59%) of children diagnosed as D/HH before 6 months were enrolled in family-to-family support by 6 months of age. In 2019, 52/75, (69%), and in 2020, 44/50 (88%) of children diagnosed as D/HH before 6 months were enrolled in family-to-family support by 6 months of age. A system to reach back out to families who originally declined began in 2021. If a child is medically fragile, follow up occurs with the audiologist to get an updated status. In addition, data for Deaf/Hard of Hearing guide support is beginning to be collected and tracked in LA EHDI-IS. The LA GBYS works collaboratively with EI through LSD PPEP (an outreach program provided by the Louisiana School for the Deaf) to ensure that families get connected for additional help in EI or the transition period to Part B.

Ongoing communication is essential for processes to work. The LA EHDI Coordinator, Terri Ibieta, the LA H&V Director, Jill Guidry, and the LA H&V GBYS Coordinator, Nicole DeLeon, meet every two weeks via zoom to review goals and provide updates on activities. This ongoing frequent communication enables us to clearly delineate each of our roles, responsibilities, and expectations to ensure that we are connected and understand each other's perspectives. Additionally, we can identify barriers and brainstorm solutions together. We continually strive for quality improvement and often utilize Plan, Do, Study, Act (PDSA) cycles to test changes. Our longstanding collaborative working relationship has led to the development of mutual trust and respect, which is a benefit to both H&V and EHDI. In addition to all of our regularly scheduled calls and meetings, each of us feels free to reach out to each other at any time for support. Essentially, it's a win-win for us and the families we serve.



Two national-level bipartisan bills to expand technologycoverage and therapy services are making their way through federal committees and are of interest to the EHDI community.

Ally's Act H.R. 477 and companion Senate bill S. 41, supporting bone-anchored hearing aids and cochlear implant coverage for children and adults who qualify, birth to adult in every state, is close to getting a hearing this year. <u>Click here</u> for more details.

The Ensuring Lasting Smiles Act would close a coverage gap to ensure that health plans cover medically necessary services related to a child's congenital medical conditions, including craniofacial differences, covering dental, oral/facial/hearing-related equipment or care to maintain or improve health and overall function. <u>Click here for more details</u>.

How to Submit a Request for FL3 Technical Assistance

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



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