Quarterly News & Updates 4th Quarter October 2023





Hello from the FL3 Center,

Time certainly flies by quickly. I can't believe it is fall already! When I think of the fall season, I'm reminded of the wonderful opportunities to gather as families and enjoy time together.

It's important that children who are deaf or hard of hearing have full access to family time, so I want to remind you of some of the FL3 Center's Language & Literacy Resources for families found on the Language Resources webpage.



Here, you will find eight tip sheets for parents/caregivers that include fun, everyday activities to enhance a child's language development. You will also find a Family Activity Plan to help parents/caretakers schedule their language learning activities, write notes, and jot down questions for their Early Intervention provider. These can be hung up on the refrigerator as a reminder to include language learning in a child's day. To accompany these resources, the FL3 Center has been fortunate to partner with several experts in language and literacy who share, through videos on this same webpage, their thoughts, and ideas with families on how to use the Tipsheets. One final resource I'd like to highlight is the Hands & Voices Maximizing Your Child's Visual Access – Tips to Create a Visually Rich World for Your Child who is Deaf or Hard of Hearing.

I wish you all a wonderful Fall season and time to "Smile at each other, make time for each other in your family." Mother Teressa

In partnership, Lisa Kovacs FL3 Center Director Place

Hands & Voices
ASTra Webinar Series

Thursday, Nov 9, 2023
1 PM ET/12 PM CT/11 AM MT/10 AM PT
(One hour)

Early Intervention:

NCHAM Webinar

Thursday, Nov. 9, 2023 2 PM ET/1 PM CT/12 PM MT/11 AM PT (One hour)

Assuming Competence:
What to do if you don't know what

Advocacy in the Early Years

Presenters: Elizabeth Shuler-Krause and Sara Kennedy, Hands & Voices HQ Audience: All parent and D/HH leaders, Family-based organizations, early Interventionists, and EHDI stakeholders

While newborn hearing screening programs report over 98% of all infants in the U.S. had their hearing screened at birth, this is only the first step. Providing quality early intervention services to all families with deaf/hard of hearing children with services that meet their family support and education needs remains an ongoing challenge.

<u>Click here</u> for full description and presenter bios.

The first in a series of four webinars. See the schedule here.

Register Here
ASL and Captioning provided.



Practical Family Resources on Deafblindness

The National Center on Deaf-Blindness (NCDB) received funding for a five year cycle beginning October 1, 2023 to improve technical assistance, information services, and partnerships. NCDB will expand efforts to improve systems for children who are deafblind by engaging with partnership groups that bring together representatives from family organizations, early intervention agencies, school districts, state education agencies, OSEP-funded projects, professional organizations, and institutes of higher education.

Please share these updated resources.

Family Key Topic: Including Deafblindness on the IEP

This resource provides information families can share with educators and

to do!

Presenter: Michelle John, President,

Vermont Hands & Voices

Audience: All parent and D/HH leaders, Family-based organizations, early interventionists, and EHDI stakeholders

Assuming competence is a phrase that isn't often used regarding young children, especially those with multiple disabilities. In this session, participants will hear from a parent perspective of a child with multiple disabilities (DeafBlind Plus), and how those in Early Intervention did not assume competence in either the child nor the parent; how this created confusion and turmoil will be reviewed. First-person stories will be shared, so participants can understand where areas of need may exist in their own family or practice, and how with the changing of a mindset, one can easily begin anew, starting today!

<u>Click here</u> for full description, presenter bio., and to register.



H&V Reads: Leadership Book Club

Thursday, December 14, 2023 3 PM ET/2 PM CT/ 1 PM MT/12 PM PT (One hour)

Doing Good Better! How to be an Effective Board Member of a Nonprofit Organization by Mark Miller

Facilitator: Terri Patterson, Hands & Voices HQ

Doing Good Better is approachable wisdom. Edgar Stoesz has made Doing Good Better a guidebook for both board members of nonprofits, whether new to the task or highly experienced.

administrators on practices for identifying, assessing, and educating children who are deafblind.

Available here.

Overview of Deafblindness Factsheet Now available in Spanish

This popular factsheet is now popular factsheet is now <u>available in Spanish!</u>
Like the the <u>English version</u>, you'll learn what deafblindness is, how many children are affected, and how children who are deafblind communicate.



Ally's Act needs your advocacy!

This bipartisan bill is featured on 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 four committees.

This is national bill will ensure that private insurance companies provide for hearing devices such as bone-anchored systems and cochlear implants for children AND adults, birth to age 64. Currently, many families pay out of pocket, making this a health equity issue.

Sponsors include Rep. Joe Neguse (D-CO), cosponsor Brian Fitzpatric, (R-PA), Rep. Mike Thompson (D-CA) and Sepator Shelley Moore Capito (R-WVA) and Elizabeth Warren (D-MA).

Learn more here.

Educate your legislators today and ask them to co-sponsor if they haven't already.

Ensuring Lasting Smiles Act (ELSA)

In the United States, health plans routinely deny claims and appeals for

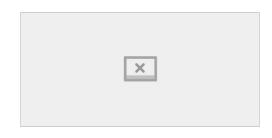
<u>Click here</u> for more information. Register <u>here</u>.



Gallaudet football team makes history...again!

On Thursday, October 5, AT&T and Gallaudet University unveiled the firstever 5G-connected football helmet. This helmet was used for the first time in NCAA history on Saturday, October 5, when Gallaudet played Hilbert College. The helmet contains a heads-up display. Gallaudet's head coach uses a tablet computer with the team's playbook installed on it. He sends plays to the quarterback over 5G, and the quarterback sees them in the display above his right eye. The quarterback then relays the play to his team. This results in instantaneous, clear communication and reduces mistakes and penalties.

Click here for media coverage.



The O.U.R. Children's Project:
Joy as a Tool for
Protection and Safety
Tuesday, November 14th, 2023
12 PM ET/11 AM CT/10 AM MT/9 AM PT
(One hour)

Facilitators: Emily Burke, DHH Infusion CO-Coordinator and Fostering Joy Project, Janet DesGeorges, O.U.R. Children's Safety Project and Executive Director, Hands & Voices
Audience: Open to all interested

stakeholders

Join the Fostering Joy Project for a joint

medically-necessary procedures related to congenital abnormalities or birth defects.

This practice leaves the burden to families of how to pay for their child's treatment or procedures that are required to repair function -- and to help kids enjoy happier, healthier childhoods. About 4 percent of children have congenital anomalies that affect the way they develop, function, or look, often for the rest of their lives.

The Ensuring Lasting Smiles Act (ELSA) would require all private insurance group and individual health care plans to cover medically necessary services resulting from congenital abnormalities. That coverage would include services and procedures for any missing or abnormal body part necessary to achieve normal body function, including teeth.

<u>Click here</u> for complete information.

Learn more about advocacy efforts <u>here</u>, including sample letters to legislators.



Hearing First is celebrating Audiology Awareness Month

The best pediatric audiologists don't simply treat ears. They serve the needs of the entire child and their family.

You may be facing challenges that make it difficult to focus on your child's needs related to hearing loss. Pediatric audiologists can identify resources and other professionals in the community who can help you overcome any problems you're experiencing, so you're able to meet your child's needs related to hearing loss.

It's important to voice your needs.

discussion about how children's safety and fostering joy can work together. See full details and registration: here.



SEEKING SUBMISSIONS for the 2024 Issue of Odyssey

THEME: Language-Rich Environments in Deaf Education

The 2024 issue of Odyssey 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.

For more information, previous issues and to submit ideas **click here**.



ASDC's ASL Stories Directory

Are you looking for Halloween or fall-themed resources to engage your kids? The ASDC's ASL Stories Directory website offers a wide range of goblins, superheroes and more, ranging from funny to scary.

Click <u>here</u> for the Halloween/Fall resources Click <u>here</u> for the ASL Stories Directory.

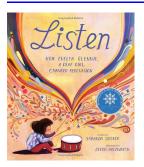
To learn more about building a strong partnership with the professionals working with your child, watch this video.



Do you have or know a 3-to-6-year-old who uses hearing aids or cochlear implants? Families with children who use hearing devices are invited to participate in a research study to determine if a strengths-based parenting support program is beneficial. All study activities happen remotely, and families will be compensated for their time. Open to families in the US only.

Visit here for more information.





Listen

By Shannon Stocker

Illustrated by Devon Holzwarth

Learn more about musician and percussionist Evelyn Glennie in a new picture book.

"No. You can't," people said.

But Evelyn knew she could. She had found her own way to listen.

From the moment Evelyn Glennie heard her first note, music held her heart. She played the piano by ear at age eight, and the clarinet by age ten. But soon, the nerves in her ears began to deteriorate, and Evelyn was told that, as a deaf girl, she could never be a musician. What sounds Evelyn couldn't hear with her ears, though, she could feel resonate through her body as if she, herself, were a drum. And the music she created was extraordinary. Evelyn Glennie had learned how to listen in a new way. And soon, the world was listening too.

Learn more about how this extraordinary musician encourages kids to write their own story.



Serving Families through Missouri EHDI

By Lydia Sergeant, Deaf/Hard of Hearing Family Partner, Missouri Department of Health and Senior Services Special Health Care Needs Family Partnership

My daughter was identified with a hearing difference at 2½ years old. She also has a rare syndrome that had been diagnosed a year prior. We had so much support for the rare syndrome but felt completely alone and lost with the hearing diagnosis. We struggled to find help for her. With all of her other needs, the hearing seemed to be the smallest



challenge. I became a Deaf/Hard of Hearing (D/HH) Family Partner to assist other families because I never wanted another family to feel the way we did on our journey.

In 2017, the State of Missouri Early Hearing Detection and Intervention (EHDI) program joined with the Bureau of Special Health Care Needs (SHCN) to add a Family Partner who had a child who was D/HH. In 2019, SHCN added another Family Partner for D/HH. In Missouri, the D/HH Family Based Organization (FBO) is a part of the FBO that works with families who have children with special healthcare needs, not specific to D/HH. That program is called the Family Partnership Initiative. The Family Partnership has six Family Partners, with two of the six serving specifically families who have children that are D/HH. Both of the Family Partners for D/HH have children who are D/HH, one of whom has other disabilities (D/HH Plus).

Within this program, the D/HH Family Partners contact families that have children who have been identified with permanent hearing differences. Our program and the state EHDI program are housed under the umbrella of the Missouri Department of Health and Senior Services. We receive referrals from the state's EHDI program and are usually able to connect with families within a month of the referral to assist them with resources and information. In 2018, we added D/HH families to the annual Parent/Caregiver retreat hosted by the FBO for families that have children with special healthcare needs. In 2023, the D/HH Family Partners also began hosting monthly Parent Chat video calls.

Some of the ways that we have achieved goals for the joint collaboration between EHDI and the FBO is that we are available to fully and attentively listen, answer questions, and provide information or resources to our families. Families are able to connect with other families throughout the state by attending the annual retreat or through the monthly Parent Chat video calls that we host. It has been rewarding to build relationships with families and caregivers. We know our program has been impactful due to the increase in our retreat registration for D/HH families. In 2018, 20 registrants identified as D/HH compared to 44 registrants in 2023. We also hear from families that they appreciated being called early in the diagnosis. They like having another parent to talk to who understands what they are going through. No one should ever feel alone. Often, families just want to feel like their stories are being heard and that they matter. Our families benefit by being able to connect to other families, but also by having stress levels lowered by knowing our program is here to assist them. We like to tell families that we are here to do the research for them, so they can enjoy their children.

We have implemented a few Plan-Do-Study-Act (PDSAs) strategies through the years. In order to increase our general Family Partnership enrollment numbers (not specifically for the retreat), we have attempted to contact families at different times of the day and even on the weekends. Although this PDSA was unsuccessful, we are continuing to search for more ways to increase enrollment, such as adding texting as an option for contact. Our current PDSA is adding a personalized letter that will be mailed to the family after a failed attempt to contact via telephone. We are hoping to have success with this PDSA to ensure all Missouri families have the resources and information needed. Our best advice to other Family Based Organizations is to meet families where they are. Often, they are not ready for resources, but they are ready to be heard and encouraged. Building relationships is the start.

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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