





Greetings and Happy Spring from Hands & Voices and the FL3 Center

April 2021 marks the kick-off for year two of the FL3 Center HRSA Cooperative Agreement, UJ1MC30748. This also marks year two of EHDI programs' funding cycle.



All of us have a part in ensuring families have access to a comprehensive and coordinated state/territory EHDI system of care. As we all move to jumping headfirst in our second year of planned activities, I encourage you to take some time to celebrate your accomplishments from year one, especially with the unforeseen challenges we faced with the COVID-19 pandemic. On behalf of the FL3 staff, we are honored to work with and along side all of you as EHDI system stakeholders, and we look forward to what we can accomplish together in this next fiscal year!

Here are just a few year one highlights we are celebrating:

Online <u>TA request portal</u> via the <u>FL3 Center website</u>: Launched in July 2021, the FL3 Center so far has responded to 360 requests for support from family-based support organizations including Hands & Voices (H&V) Chapters/Programs, EHDI Program recipients, and family leaders.

#### Bi-monthly virtual office hours, topics included:

- Fostering Joy
- Parent Leadership in Systems
- Training DHH Adult to Family Support Providers
- · Raising Up Diverse Leaders
- Family Event Planning
- Engaging Fathers and Extended Family
- COVID-19 pivoting support to families/taking care of parent leader workforce

## Newly released resources:

- COVID-19 webpage
- Say Yes to Early Intervention
- · Fostering Joy Family Tip Sheet
- Engaging in Your Child's Education at Home
- Resource document: <u>Making a Case for Direct Referrals to Parent-to-Parent Support</u>
- Training video of a parent sharing her experience with tele-intervention. Available in <u>English</u> and <u>Spanish</u>.

### **Educational webinars:**

- Creating an EHDI System that Partners with Deaf and Hard of Hearing Adults
- Time Management as Self-Care
- Building Collaborative Relationships for Families
- The How-To of Human Resources at a Non-Profit Without a 'Human Resources Department'
- The Hands & Voices Virtual "Something Extraordinary" Leadership Event

And much more, so check out our<u>resource tool box webpage</u>, <u>trainings and webinars webpage</u>, <u>past Enewsletters</u>, <u>spotlight on success - promising practices of family leadership</u>, <u>engagement</u>, and <u>family-to-family support</u> webpage.

Here are some resources you can look forward toin the coming year from Hands & Voices and the FL3 Center.

**Virtual Waiting Room** for families that will include resources for families using tele-audiology services and tips for families while waiting for appointment.

New Hands & Voices Virtual Learning Platform, courses planned include:

- Family Support Academy
- Self-Guided Leadership Module
- DHH Adult-to-Family Support Program

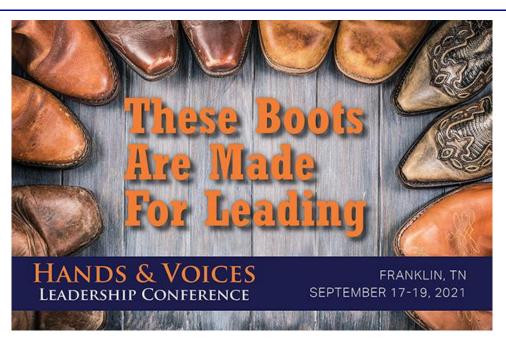
Podcast series regarding family leadership, engagement, and family support.

This is just a short glimpse into what the <u>FL3 Center</u> has planned, and we look forward to this upcoming year of activities with all of you!

In partnership,

Lisa Kovacs, FL3 Center Director Director of Programs Hands & Voices

# **Upcoming Events**



Registration Now Open for the 2021 Hands & Voices Annual Leadership Conference September 17th-19th, 2021

For more Information and to Register



"Learning from the Landscape: Strategies in Early Childhood Health Equity"

Webinar Thursday, April 29<sup>th</sup> 1 – 2 PM MT



Helping Your Child Learn to Talk Virtual Workshop

Tuesday, June 15 - Friday, June 18, 2021

The Moog Center for Deaf Education is pleased

During the last decade, there has been an increasing understanding of how the social determinants of health (e.g., systemic and environmental challenges such as poverty, poor housing, and poor health care) affect the health and well-being of young children and their families. The multi-faceted nature of these challenges has led many communities and states to build – or expand – initiatives composed of representatives from multiple sectors, disciplines, and systems to join to address disparities in early experiences and outcomes for young children.

The Early Childhood Health Equity (ECHE) Landscape Project set out to understand and highlight promising strategies to address key issues such as sustainability, data use, state and local relationships, cross-sector partnerships, and operationalizing health equity within the context of early childhood health equity initiatives.

Register here for Webinar

to announce that the 2021 Parent Workshop will be presented virtually via the Moog Center Teleschool Program. The Moog Center will use Zoom Meetings to provide sessions about hearing and hearing loss and helping one's child with hearing loss learn to talk. An abbreviated version of the onsite workshop, this four-day event will provide opportunities for families to meet other families and to learn from leaders in the field of Listening and Spoken Language.

Each day will include a variety of morning sessions and a variety of afternoon sessions. Additionally, a 30-minute Parent Support/Coaching session with you and your child will be provided daily.

Participants will be limited to ensure plenty of opportunities to ask questions, engage in discussion, participate in parent support/coaching sessions, and to address each family's individual needs.

For more information and to Register



Gallaudet Summer Youth Camps/Webinars are designed for middle and high school students up to the age of 19. Our programs provide stimulating summer learning and experiential opportunities that blend excitement, education, and enjoyment in a bilingual environment rich in cultural diversity and located just minutes away from the U.S. Capitol.

Summer Youth Webinars: Designed for deaf, hard of hearing, and hearing students entering Grades 7-12. We offer various webinars of different lengths. Please click here for more information.

Registration for our 2021 Summer Youth Webinars can be found here.

Hearing First Live Chat "Let's Talk LSL" Thursday, April 22, 2021 12 – 12:45 PM MT



Parents of a child who was just diagnosed with hearing loss or

parents who have been on the Listening and Spoken Language journey for a while are invited to join a small-group meeting to connect virtually with other families who know what it is like to have a child who is D/HH. Parents are encouraged to bring questions and share thoughts on supporting their child's listening, language, and literacy development.

Sign Up Here

> FL3 Office Hours Thursday, May 27<sup>th</sup>, 2021 6 – 7 PM MT

"Strengths and Challenges of Providing Support to Rural and Remote Communities"

Facilitated by Beth Jones from NV H&V and



Hands & Voices Headquarters provides an innovative delivery of supports and services including events in different formats and platforms.

Please click here for upcoming events.

Stanley Ruemgol from Federated States of Micronesia EHDI Program

Audience: Family Leaders and FBOs

Captioning Provided. Please email <u>Candace</u> by May 20<sup>th</sup> for any other communication access requests.

Register here for Zoom link and password

# **Resources and Opportunities**



**COVID Resource** 



NCSA Membership and DCLP
Parent Kits



"ODDACE: Outcomes &
Developmental Data Assistance
Center for EHDI Programs"

"Telehealth Visits for Children Who Need Hearing or Vision Help" is a webpage of information for families with children using telehealth who have vision loss and/or are deaf or hard of hearing. This resource and other resources provided by HealthyChildren.org from the American Academy of Pediatrics.

Other resources available on the Hands & Voices COVID page.

The National Cued Speech
Association (NCSA) is offering
a free Deaf Child Literacy Project
(DCLP) Parent Kit for
parents/caregivers new to using
Cued Speech with their child.
Families who sign up for a kit will
automatically receive a one-year
free membership to the NCSA,
free access to a Cued Speech
course, and one DCLP box every
three months for one year.

The ODDACE website aims to increase understanding of the factors that impact the outcomes of D/HH children, between birth and 6 years of age. Through the support of the Centers for Disease Control (CDC), the site strives to expand public health capacity to gather, analyze, and use intervention and developmental outcome data at the state and national level.



Hands & Voices and the National Center on Deaf-Blindness (NCDB) are collaborating to educate families and family leaders about the importance of early identification of dual sensory loss and referral to appropriate services and providers. Please click here to see resources shared by NCDB.



In the most recent JEHDI publication, peer-reviewed articles include: "The Effects of Early Intervention on Language Growth after age 3 for Children with Permanent Hearing Loss," "The Role of Early Intervention in Parental Self-Efficacy for Parents of Deaf and Hard of Hearing Children," and "Canadian Families' Decisions of Communication Options\* for Children Who are Deaf or Hard of Hearing: An Initial Exploration." Click here for the entire issue.



The FL3 Scientific Advisory Committee developed 8 different language, literacy and social emotional development Parent Tip Sheets. These resources were created for parents and caretakers of children who are D/HH to use with the support of an Early Intervention provider with experience working with children who are D/HH. Through the generosity of Arizona Hands & Voices, the "Early Literacy Development" Tip Sheet is now available in Spanish.



#### **Family Advocate Telehealth Training**

The Western States Regional Genetics Network (WSRGN) has launched a free on-line telehealth training course for family advocates and other program staff to help families access services by telehealth and use them well. The course gives a foundation of knowledge about telehealth and where to find telehealth resources to help families connect to services by telehealth. Click here for information on modules and how to register.



A Case for Direct Referrals to Parent-to-Parent Support Programs 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-toparent support, including those from underrepresented population. 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.





**Expectations towards Hearing Aids for Children & Teens.** 

As a parent of a child with hearing loss, it is important to understand that children of different ages have different needs, but the need to maximize quantity and quality of sound is important at every age.

Phonak takes a holistic approach to help the social, emotional and cognitive development of children with hearing loss from the moment they begin their hearing journey. Our products aim to make the most of every interaction while being easy to use, high performing and reliable solutions at the same time.

In order to constantly improve our hearing solutions, we are interested to learn more about the specific needs and expectations of children and teens who currently wear hearing aids. Therefore we invite all parents of children/teens aged up to 18 years as well as older teenagers (15-18) to participate in an online survey (duration approx. 15 minutes). Your input is greatly appreciated and will help us to further develop our pediatric hearing solutions.



**Click Here for Survey** 

## **Spotlight on Success**

## An Impact On All Submitted By: Carrie Balian, IL H & V GBYS and Ginger Mullin, IL EHDI

When IL Hands & Voices GBYS (Guide By Your Side) kicked off in 2009, it was built on the premise of "build it and they will come". A strong foundation of communication and partnerships was built, but it was not as sustainable as we believed.

The partnership adhered to continuous quality improvement principles and was fueled by commitment and passion. Both parties desired to partner so that referrals could be received directly by GBYS from the Early Hearing Detection and Intervention (EHDI) program. Challenges with formal agreements, infrastructure, and funding were obstacles to the shared mission. It took time, patience, and finding others who understood the need to finally put a plan into place. But giving up was not an option. Over a decade after the state's GBYS launch, a signed DBA (Doing Business As) agreement became a reality. Today, the Illinois EHDI program can make direct referrals to GBYS and the gates have been opened for other meaningful quality improvement opportunities.

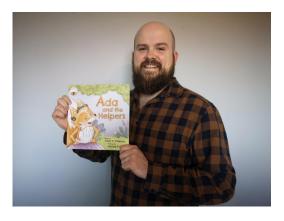
The rainbow at the end of the 10-year shared vision includes:

- Greater likelihood of providing parent to parent support within the national benchmark.
- Family data including time of enrollment, resources sought and what type of amplification (if any) the family has chosen freely communicated with the EHDI Program.
- Renewed sense of purpose that fosters IL guides to feel more effective, impactful, and connected
  to the parent professional role.
- IL GBYS connecting families to the next steps of Early Intervention (EI) and clarifying the roles of the EI providers appropriate for a child who is deaf or hard of hearing.
- IL families receive knowledge of national, state, and local resources as well as access to the
  private online social support group.
- Most importantly, IL families have a parent-professional to talk with and gain a better understanding of the journey ahead.

Through the shared undertaking, Illinois rolled out our direct referral process in July 2020, during the pandemic. In October 2020, a Transition Specialist was incorporated into the IL GBYS program through quality improvement processes to the program partnership. The specialist follows up with families transitioning out of Part C/ El and into Part B (U.S. special education services under IDEA.) The specialist documents EI enrollment status and history, educates the family on the upcoming transition, answers questions and provides resources. The transition specialist asks the family to answer two questions on a scale of 1-5 (5 being the highest). For the first question, 81% of families reported a 1, 2 or 3 related to Individualized Education Plan (IEP) preparedness. The other question rates helpfulness of the outreach. To date data shows, 87% of the families reported a 4 or 5. In February 2021, the third role, Lost to Follow-up (LTF) Specialist, was introduced to our EHDI parent support team through a COVID 19 pilot project. Due to the impact of COVID 19 Illinois' GBYS Program was able to facilitate follow up with families. The specialist asks if the family has a follow up appointment scheduled, helps families find a testing site, answers questions and provides support for parents navigating the process with insurance. One of the first families the specialist encountered shared that her family did not see the need to follow up because she saw her child responding to sounds. The specialist empathized and shared that she responded similarly with her own child, however, follow up testing determined that her daughter was hard of hearing. The mom expressed appreciation for the input and was then ready to set an appointment. Mom closed by stating that she would feel awful if she delayed a diagnosis and was thankful for the call.

It may have taken over 10 years for the unicorn to land, but the numbers do not lie. The DBA has allowed Illinois' continuum of EHDI care to assist more families sooner (often while parents are still on maternity or paternity leave, leading to more connections with fathers) compared to as an opt in program. Before direct referrals, the program connected 40 families to support and resources in 2019 compared to 122 families in 2020, a 205% increase. Prior to our direct referrals (from Jan. - June 2020), 29 families were enrolled in parent-to-parent support. After the DBA was implemented, (from July - Dec.) the number tripled to 93 families! And the demographics of the families have changed by serving more families with children who have unilateral, mild, and conductive losses, more rural families who may straddle borders for care, and families who identify as other than Caucasian increased from 36% to 52% of families. The collaborative impact is shown in the significant increase from 2019 to 2020 ... and that was during the pandemic! Direct referrals assist programs to meet national benchmarks, revitalize parent guides and most of all serve families earlier in their journey.

As program collaborations between the parent-to-parent support organizations and the state EHDI program evolve, NEVER GIVE UP. Continue to share the rainbow and unicorn dreams, educate one another, accept each other's current circumstances and be willing to work outside of the box. The personal investments by all can pay off at unpredictable times.



Ada and the Helpers is a new book written by Travis D. Peterson. Travis shared his story on the Hands & Voices blog: Figuring Out Fatherhood.

"I think each parent, hearing and D/HOH alike, process differently the news that his or her child is deaf," Travis shared. "The way I processed it was by looking for ways that I could bring awareness to cochlear implants, while also demonstrating that those who have disabilities can also possess amazing strengths and talents! As a print designer myself, that

naturally took the form of a book."

<u>Ada and the Helpers</u> features a hero (a fox) with cochlear implants who loves to dance. On her way to a dance show, Ada meets three new friends and helps them discover something they are good at.

Travis wove in educational tools throughout the story—introducing ling sounds and 14 words spelled out in American Sign Language. The dust jacket also doubles as an ASL chart.

Ada and the Helpers can be found on Amazon or ordered directly from the author

# How to Submit a Request for FL3 Technical Assistance

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

