FY 2023

# ANNUAL GRANT REPORT

### Illinois Hands & Voices Guide By Your Side

Oct 2022-Sept 2023

Report by: Carrie Balian Program Coordinator

Approved by: Andrea Marwah Executive Director



### **WHAT IS**

### Illinois Hands & Voices Guide By Your Side

The Illinois Hands & Voices Guide By Your Side (ILHV GBYS) mission is to provide Parent Guides (parents of children who are deaf/hard of hearing) who are hired and trained as subject matter experts to provide education, support, follow-up, and resources to families of children with a suspected or confirmed hearing loss (atypical hearing). Through the program's network of resources and the personalized support of their assigned Parent Guide. families can make informed decisions about their child's future, educational options, the changing landscape of assistive technologies, and many other issues facing families with children who are deaf/hard of hearing (d/hh). This specialized support allows families an opportunity to receive comfort and reduce stress from someone who has "been there, done that." Their Guide helps families understand the roles their child's service providers play and what the next steps are and give a glimpse into the "crystal ball" of their child's future so they can prepare for what may come ahead. The ILHV GBYS program also has specialists to help provide support, information, and equitable services to families in key timelines of their parenting journey. These specialists are our Lost to Follow up (LTF) Specialist and our Transition Specialist. The LTF Specialist contacts families that have not made it back for diagnostic testing after newborn hearing screening, providing resources and information and answering questions. The Transition Specialist reaches out to families who have a child who will be transitioning out of Early Intervention to answer questions and provide resources. The Transition Specialist also contacts families a year after their enrollment to check-in and see if their needs were met while they worked with a Parent Guide. Transition to the Families for Illinois Hands & Voices chapter occurs when a family has completed one-on-one parent-to-parent support and needs universal parent support by a parent organization specific to deafness that serves children birth - 21 years.





# THE KEYS TO SUCCESS

Over the course of the last year covered by this grant, we successfully achieved all the outlined objectives in our work plan. What's more, we collaborated effectively, expanding upon those objectives. We extend our gratitude to our partners at IL EHDI (Early Hearing Detection & Intervention) for their invaluable guidance and financial support throughout this period. Their assistance not only improved our services to families but also bolstered leadership skills within our team. We appreciate their recognition of the significance of parent-to-parent support and their commitment to exceeding the standard of care. As we continue our partnership with the IL EHDI program, we eagerly anticipate the positive impact on families with children who are deaf or hard of hearing in the future.

### Illinois Hands & Voices Guide By Your Side



Andrea Marwah ILHV EXECUTIVE DIRECTOR SINCE 2010



Carrie Balian ILHV GBYS COORDINATOR SINCE 2009



Jaclyn Urbanski TRANSITION SPECIALIST SINCE 2010

### **MEET THE TEAM**

These are the hardworking team members who contribute to our program's success!



Kelley Hemesath LTF SPECIALIST SINCE 2011



Anita Cervantes-Bowen LEAD DHH & SENIOR PARENT GUIDE SINCE 2012



Alicia Aaron PARENT GUIDE SINCE 2020



Ramona Martin SENIOR PARENT GUIDE SINCE 2020



Sarah Esparza SENIOR PARENT GUIDE SINCE 2020



Corie Fulton SENIOR PARENT GUIDE SINCE 2022



Maira Nava SENIOR PARENT GUIDE SINCE 2022



Crystal Johnson PARENT GUIDE SINCE 2022



Megan Christoffel
PARENT GUIDE SINCE 2022



Crystal Rico PARENT GUIDE SINCE 2023



Elsa Huerta PARENT GUIDE SINCE 2023



Giovanna Turovets PARENT GUIDE & DHH GUIDE SINCE 2023



Hanna Swearinger PARENT GUIDE SINCE 2023



Kari Taylor DHH GUIDE SINCE 2023



Reyna Garcia PARENT GUIDE SINCE 2023



Sara Siddiqui DHH GUIDE SINCE 2023



Lace Mandrell PARENT GUIDE & DHH GUIDE SINCE 2023



Lloyd Baker PARENT GUIDE SINCE 2023



# **GBYS TEAM**Achievements

### **QUICK STATS**

Children served, 6 months old or younger **105 children** 

Referrals received from IL EHDI FY23

### 322 families

Total families enrolled, FY23

### 181 families

Area Deprivation Index (ADI) score, between 1-3 of families enrolled

### 56 families

Area Deprivation Index (ADI) score, between 4-7 of families enrolled

### 87 families

Area Deprivation Index (ADI) score, between 8-10 of families enrolled

### 38 families

- During the grant year, we were able to hire and train nine additional guides.
   The additions to our team expanded our geographical coverage, brought on additional experiences, offered more Spanish speaking support, and provided relief to the caseloads of the current team of Parent Guides. Four of the new guides represent our new DHH Guide support.
- New materials and updates to existing letters were reviewed by several Quality Improvment workgroups.
- Two special Quality Improvement workgroups were hosted. One with parents whose primary language was Spanish and the other workgroup consisting of parents who identified as Black/African American. These workgroups reviewed materials for language access and focused on overall representation through a diversity lens.
- Our original 17 SNIPPETS were translated into 10 additional languages and 8 more SNIPPETS were created.
- Annual reviews for all Parent Guides and Specialists were held in September.
- Promotions within the Leveled Recognition Program (LRP) over FY23 include have us at 9 members at the Guide level and 8 at the Senior level.
- One Guide participated in and graduated from the H&V HQ 2023 L2L (Leadership to Leadership) program, and another guide was accepted for the 2024 L2L cohort.

### **DIVERSE CONNECTIONS:**

# Strengthening Family Bonds Through Multifaceted Parent Guides

Funding from HRSA (Health Resources & Services Administration) stipulates that EHDI programs strive for enrollment in parent-to-parent support services by no later than 6 months of age. Due to our business agreement with the IL EHDI program, we have been able to greatly improve our connection with families earlier on in their journey.

Nevertheless, our scope extends beyond merely connecting families with another parent. Our objective is to emphasize diversity within our team, facilitating connections that not only cater to familial links with a Parent Guide who understands their ethnic background, language spoken at home, and amplification and communication choices for their child but also encompass a broader range of diagnoses, hearing levels, and communication preferences. The incorporation of these diverse elements into our team enables us to establish strong and trustworthy connections with families.

In July, we expanded our team by welcoming nine new guides. Among them, three identify with additional ethnic groups, five have experiences as deaf or hard of hearing (d/hh) individuals, and we've introduced a male role model to connect with the fathers in our incoming families. Furthermore, our team now includes parents with expertise in unilateral, mixed, and late-identified hearing loss. This amalgamation of unique perspectives and knowledge enhances our ability to genuinely meet the diverse needs of the families we serve.

"GBYS helped give insight on resources I never knew about, thanks to our Guide!"





# SHARING OUR KNOWLEDGE THROUGH PRESENTATIONS AT:

- EHDI Conference
- Statewide Parent Conferences
- Mom's Night Inn
- ITDHH Conference
- Vision/Hearing El Mini-Conference
- Preschool Institute

Our dedicated team of board members and guides have showcased our expertise and initiatives on a national and statewide level. Through engaging presentations, we have shared valuable insights and experiences with diverse audiences. Our presentations focused on:

- Materials Available: Our team has actively contributed to the development of impactful materials.
   These resources serve as valuable tools to educate and support parents, offering practical guidance and fostering a sense of community.
- Emphasis on Parent Support: Our presentations underscore the vital role of parent support in fostering healthy and thriving families. By highlighting the significance of a supportive network, we aim to empower parents in their journey and contribute to overall family well-being.
- Fostering Joy Movement: We passionately advocate for the Fostering Joy movement in our presentations. Sharing our experiences and the principles of this movement, we strive to inspire others to prioritize joy, positivity, and well-being within their families and communities. In addtion, all participants received a complimentary Fostering Joy journal to capture their personal reflections from their journey of raising a child who is d/hh.

These presentations serve as opportunities to connect with a broader audience, building a network of like-minded individuals and organizations. By fostering collaboration, we aim to amplify the impact of our initiatives and contribute to positive change on a larger scale.









### QI Workgroups (QIW) Basics:

- We utilized a Google form to collect applications to be part of the OIW.
- The application questions allowed us to select a diverse group of ages, races, diagnoses, and hearing technology used.
- There were QIW consisting of parents who had children with a hearing loss and another of professionals who work with children who have a hearing loss.
- We laid out expectations and homework through an email.
- The QIW would review materials independently before our live meeting. Typically, we assigned them to review 1.5-2 hours on their own, and then we would meet in virtually over Zoom for 1-1.5 hours. Each QIW that was hosted was a total of 3 hours of work for that month
- Participants were paid \$19/hr for their time.

### **QI WORKGROUPS**

Learning, sharing and adapting based on the needs of the families we assist.

"Thank you for the opportunity to be a part of these meetings. I have enjoyed learning about these resources!"

**Quote from QI participant** 

### QI Workgroups (QIW) Tasks:

Each month the QIW had different materials or items to offer feedback on. Here are the items reviewed during the nine sessions:

- Illinois Sound Beginnings website parent tab and professional tab
- Illinois Sound Beginnings Resources and training tab
- PEP (Promoting EHDI Practices) parent resources
- Fostering Joy roll-out and resources
- Feedback on events opportunities for families including the fliers
- · DHH Guide marketing materials
- Feedback on the Family Support Activity Guide
- Black/African American and Latino workgroup to review IDPH letters, transition card and GBYS letter

# 2023 EHDI

The IL H&V GBYS and Early Hearing Detection & Intervention (EHDI) programs partnered to recognize those in the field who are making an impact within the EHDI goals of 1-3-6.



Inese goals ensure babies have their hearing screened by 1 month of age, receive a diagnostic hearing evaluation no later than 3 months of age and that all infants with hearing loss enroll in Early Intervention no later than 6 months of age. In 2023, we had the pleasure of recognizing Tracy Meehan, Maribeth Lartz, Kelley Hemesath, Maira Nava and the HiTrack team facilitated by James Fritzler for their ability to create change and improvement within these benchmarks.











### **2023 AWARDEES**

Recognizing and highlighting the hard work of those within the EHDI system of care.

Since 2011, Illinois Hands & Voices Guide By Your Side has been acknowledging parents with deaf or hard of hearing (DHH) children who demonstrate exceptional dedication to serving other families. The award aims to uplift parents, encouraging them to recognize their unique contributions and empowering them to make a positive impact within both families and the systems that support us.

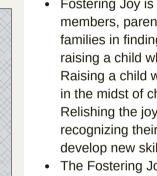
In 2023, we proudly honor Anita Cervantes-Bowen as the recipient of the Parent Achievement Award. Anita has served as a Lead Parent Guide with IL GBYS since 2012, and her contributions extend beyond, as she holds a position on the Illinois Hands & Voices board and serves as the Director of Illinois Deaf Campers. As a mother of four children and with numerous other remarkable accomplishments to her name, Anita embodies the spirit of this prestigious recognition.



Early Childhood



- The Cornerstones for Kindergarten Readiness Project is to enhance programs such as Early Intervention and Early Childhood Education; by offering modules that are accessible, interactive, and educational in the following development areas: Communication, Language, Hearing, and Vision- for parents and professionals to use.
- The tools are meant to educate and empower caregivers to monitor and support child development while providing confidence for caregivers to advocate for children's needs.
- This can improve timely identification and intervention, leading to well rounded development for children and kindergarten readiness.



Fostering Joy

tering Joy

- Fostering Joy is a collaborative effort among family members, parent leaders and professionals. Supporting families in finding, focusing on, and celebrating the joy of raising a child who is deaf or hard of hearing (DHH). Raising a child who is DHH can be challenging; yet, even in the midst of challenging times, it is possible to find joy. Relishing the joyful moments with your child and recognizing their amazing growth as they learn and develop new skills can be intentional acts of fostering joy.
- The Fostering Joy goal is to build and encourage loving and supportive interactions in everyday moments.
- Presentations to families and professionals were held throughout the year in addition to a introduction video that was recorded and can be found on the Illinois Sound Beginnings website. Journals were also provided to those that enrolled in GBYS over the year as well as to those that attended any of our Fostering Joy presentations.



- Continuation of the essential work outlined in the Joint Committee on Infant Hearing (JCIH) recommendations from both the 2016 and 2020 workgroups.
- Dedication to the goals set by the Audiology Early Intervention and Communication Subcommittee, ensuring that the recommendations specific to these areas are effectively implemented.
- Special attention and efforts directed towards the Growing and Engaging Developmental Therapists for Hearing, reflecting a commitment to enhancing the availability and quality of developmental therapy services for children with hearing differences.
- Final report of work done and goals for FY24 are available.

### REFLECTIONS OF THE YEAR

Over the past year, our organization has achieved significant milestones that reflect our commitment to diversity, excellence, and the well-being of the families we serve. Notably, we've successfully fostered more diversity within our team, recognizing the importance of varied perspectives in addressing the unique needs of our community. This inclusivity has enriched our collaborative efforts and broadened the scope of our impact.

Our dedication to best practices remains unwavering, as evidenced by our continued involvement in quality improvement workgroups and Joint Committee on Infant Hearing (JCIH) workgroups. This ongoing commitment ensures that our services are aligned with the latest research and standards, fostering an environment of continuous improvement and excellence.

In our pursuit of family well-being, the rollout of the Fostering Joy initiative has been a notable accomplishment. By placing emphasis on positivity, resilience, and support, this initiative has created a more nurturing environment for families under our care. Additionally, the development of leaders within our team has been a priority, encouraging them to share their expertise at both local and national conferences, contributing to the broader discourse on best practices in our field. As we celebrate these achievements, we eagerly anticipate continued growth and positive outcomes in the time ahead.

We express our gratitude for the grant's financial support and appreciate the unwavering dedication of the IL EHDI staff to furnish resources, services, and individualized support to families with children who are deaf/hard of hearing. The following quote is a beautiful testament to the impact and vision of our programs. It is a genuine honor to collaborate with such a devoted and visionary team.

"When my son was diagnosed with sensorineural hearing loss shortly after birth, it was overwhelming. My husband and I were not familiar with hearing loss and did our best to research everything we could. Our discussions with our son's doctors and audiologist were helpful, but I needed more than the facts of the diagnosis. I needed to connect with another mom who had been in my position. Without GBYS, I wouldn't have been able to do that, as I didn't know of anyone in the hearing loss community. It made a big difference to have our Parent Guide as a resource while navigating new and unknown territory."

### WHAT'S NEXT FOR US

### **RESOURCES**

- Create additional SNIPPETS on topic areas in need as identified by the IL GYBS team.
- Translate SNIPPETS made during previous fiscal year into ten different languages.
- Evaluate and enhance Illinois Sound Beginnings website to increase accessiblity for all users.
- Produce short video clips for providers and parents to highlight various program components.
- Create two professionally made videos. One targeted for families promoting the importance of parent support and the second video targeted towards professionals focusing on the importance of the EHDI goals of 1-3-6.
- Design a professional development section within the Illinois Sound Beginnings website for providers to access education on EHDI topics for credit.

### **QI WORKGROUPS**

 Continuing to host ongoing QI workgroups to evaluate newly created materials. Continuing conversations with diverse populations in an effort to improve our service connection and delivery within these communities



### **LEADERSHIP**

- Help current team members with growing their leadership skills by:
  - providing an opportunity to attend the National Hands & Voices Leadership Conference.
  - participating in state and national committees.
  - submitting presentation abstracts for state and national conferences.
  - providing opportunities to learn program skills and roles outside of the guide roles.

### **OUTREACH**

- Host exhibitor booths at upcoming statewide confereces such as ILAA and ITDHH. The booths will provide us with opportunities to reconnect with stakeholders and share what is new within our services and resources.
- Attend and present at LIC (Local Interagency Council) meetings over the upcoming year to reach and educate EI providers and CFC personnel on our program and resources.