

October 2022

ANNUAL GRANT REPORT

**Illinois Hands & Voices
Guide By Your Side**

FY22: Oct 2021-Sept 2022

**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 three 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, our Transition Specialist, and our Diversity & Equity Infusion Specialist (DEI). 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. Our DEI Specialist assists our program in providing resources and support in the family's home language. 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.



COLLABORATION IS KEY

During the past year of this grant, we were not only able to deliver on all the objectives within the work plan, but, through collaboration, we were able to build upon them. We are grateful for our partnership with our IL EHDI (Early Hearing Detection & Intervention) team. Their guidance over the past year and the financial support through the grant have not only helped enhance our services to families, but also increased and strengthened the leadership capabilities within our team. We thank them for understanding the importance of parent-to-parent support and for their willingness to provide more than the standard of care. We look forward to seeing what the future has in store for families with children who are d/hh through our continued partnership with the IL EHDI program.

MEET THE TEAM

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



Andrea Marwah
ILHV EXECUTIVE DIRECTOR SINCE 2010



Carrie Balian
ILHV GBYS COORDINATOR SINCE 2009



Jaclyn Urbanski
TRANSITION SPECIALIST SINCE 2010



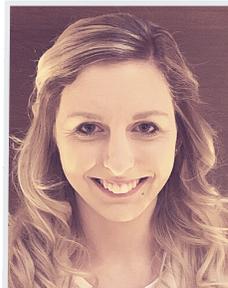
Kelley Hemesath
LTF SPECIALIST SINCE 2011



Anita Cervantes-Bowen
LEAD PARENT GUIDE SINCE 2012



Lydia Hernandez
DIVERSITY & EQUITY SPECIALIST SINCE 2013



Andrea Johnson
SENIOR PARENT GUIDE SINCE 2018



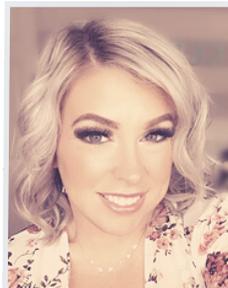
Amy Keslinke
SENIOR PARENT GUIDE SINCE 2020



Alicia Aaron
PARENT GUIDE SINCE 2020



Ramona Martin
SENIOR PARENT GUIDE SINCE 2020



Sarah Esparza
LEAD PARENT GUIDE SINCE 2020



Corie Fulton
PARENT GUIDE SINCE 2022



Maira Nava
PARENT GUIDE SINCE 2022



Christina Ceballos
PARENT GUIDE SINCE 2022



Crystal Johnson
PARENT GUIDE SINCE 2022



Megan Christoffel
PARENT GUIDE SINCE 2022

GBYS TEAM Achievements

QUICK STATS

Children served, 6 months old or younger

97 children

Referrals received from IL EHDI FY22

324 families

Total families enrolled, FY22

163 families

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

63 families

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

68 families

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

32 families

- During the grant year, we were able to hire and train six 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.
- We added training to increase knowledge of EHDI goals and resources as well as diversity training focusing on bias, privilege, allyship, and covering.
- New materials and updates to existing letters and resources such as SNIPPETS, script messaging, newsletters, and the Illinois Sound Beginnings Website were translated.
- Annual reviews for all Parent Guides and Specialists were held in August.
- Promotions within the Leveled Recognition Program (LRP) over FY22 include 6 at the Guide level, 2 at the Lead level, and 3 promotions to Senior level.
- One Guide participated in and graduated from the H&V HQ 2022 L2L (Leadership to Leadership) program, and another guide was accepted for the 2023 L2L cohort.
- The Program Coordinator was awarded the 2022 EHDI Family Leadership Award.
- In September, the ILHV GBYS team was recognized with the GRACE award by Baby's First Test and Expecting Health for their collaboration with the IL EHDI program.

HRSA BENCHMARKS

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.

As you can tell from the information below, our program has experienced a complete flip due to this business agreement and receiving referrals directly from the IL EHDI program.

“Finding out that you have a child with hearing loss can be devastating at first; but, with GBYS, it was so comforting to talk to a parent who has gone through it and could show you the ropes. I am so thankful for GBYS.”

EARLIER SUPPORT

Before Direct Referrals

12%

Enrolled in GBYS no later than 6 months of age



After Direct Referrals

80%

Enrolled in GBYS no later than 6 months of age

These percentages reflect infants who were enrolled in GBYS.

COMMUNICATION

- Ongoing meetings
- Targeted emails to audiologists
- Illinois Sound Beginnings Website
- Quarterly Reports
- Newsletters

- Through consistent and detailed communication, we have been able to share our successes, intentions, and needs with the IL EHDH team. Regular meetings allowed us to track the progress of projects and to use Quality Improvement strategies when needed to make adjustments and try again.
- We also started an email campaign with state audiologists to share specific resources, news, and information each month. These targeted emails have brought more awareness of both the IL EHDH and ILHV GBYS programs.
- The Illinois Sound Beginnings website, which houses resources, information, and links for families and professionals, underwent a massive update. It is now housed on a new platform which provides easier access to edit and is, overall, more user-friendly. This site is still in transition, but the parent section is complete and has even been reviewed by the Quality Improvement workgroup (QIW). Suggestions of the workgroup were taken into consideration and changes were made to reflect those recommendations.
- Our Quarterly Reports were also created and submitted each quarter of the grant. These have an updated look with more room to share the accomplishments of the quarter.
- We continued to create and disseminate three newsletters this year. The newsletters are in English and Spanish, and the formatting for these were updated and also reviewed by the QIW.



QI Workgroups (QIW) Basics:

- We utilized a Google form to collect applications to be part of the QIW.
- The application questions allowed us to select a diverse group of ages, races, diagnoses, and hearing technology used.
- Our initial goal was groups of 5 members meeting once a month for a period of 3 months; however, after the first QIW, we found it best to start with 6 members. This way, if someone didn't show, we still had enough participants.
- We laid out expectations and homework through an email and found it important to send a text to the QIW after emails were sent to make them aware.
- 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.
- Participants were paid \$19/hr for their time at the end of the 3-month period.

QI WORKGROUPS

Learning from the families we serve

"This was fun, and I was glad to be of help to something so important."

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:

- ILHV GBYS website page
- Illinois Sound Beginnings website parent tab and front page
- IL EHDI parent packet and annual report
- 17 SNIPPETS
- Transition resource guide, protocol, scripts, and birthday card
- GBYS letters, scripts, exit survey, and protocols
- IL E.A.R.S newsletter
- JCIH (Joint Committee on Infant Hearing) information for parents

In collaboration with the state EHDl program, we have had the opportunity this past year to acknowledge several providers that have been EHDl Innovators during the pandemic, supporting the 1-3-6 benchmarks of Healthy People 2030.

Dawn Violetto received her EHDl Innovator award during a special surprise assembly at Child's Voice school, where she serves families as an audiologist. Dawn often provides support, resources, and insight to the IL EHDl team and helped troubleshoot concerns around Lost to Follow up. Andrea Marwah and Ann Freiburg were recognized for their efforts for improvement to services within the Early Intervention system with a surprise presentation during the annual Illinois Teachers for the Deaf/Hard of Hearing. For championing quality improvement initiatives within the screening process, a virtual award among her peers was presented to Perinatal Network Administrator, Connie Thompson. Randi Winston-Gerson was also recognized virtually for her tireless efforts in updating the Newborn Hearing Screening Training Curriculum and overseeing the progress of the Virtual Site Visit program. These projects support EHDl program training efforts and resources for birth facilities and those performing Newborn Hearing Screening.

EHDl INNOVATORS

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



OUR SPECIALISTS



Jaclyn Urbanski
Transition Specialist



Kelley Hemesath
LTF Specialist



Lydia Hernandez
DEI Specialist

Specialist Descriptions:

- As Transition Specialist, Jaclyn reaches out to families who have a child who will be transitioning out of Early Intervention (EI) to answer questions and provide resources.
- Kelley is our LTF (Lost to Follow Up) Specialist. Her role is to contact families that have not made it back for diagnostic testing after newborn hearing screening, providing resources, information, and answering questions.
- Lydia is our DEI (Diversity & Equity Infusion) Specialist. She provides outreach and help for families within underserved communities connecting them to resources that meet their needs. She also provides support and diversity training to our team.

What the Specialists have to say:

- Jaclyn shared, "So many families have been open and very appreciative of my calls to check in about the EI transition process. Even though many families are in EI and are aware of the process, they may still be unsure what the process looks like. For the families that have no idea that EI will end on their child's 3rd birthday, they have been the most appreciative, and, even though they are overwhelmed, I reassure them that we are here to provide one-on-one parent support."
- Kelley shared, "I had a family whose baby was born in January, and I reached out to them in April. The phone number was no longer in service, so I sent a HV GBYS LTF letter. I reached out again in October after EHDl was able to provide a new phone number for the family. The baby is now 9 months old, and the mother stated, "I tried to take the baby back to the hospital where they were born for a follow-up hearing test, but they told me the baby was too old, and they couldn't perform the test." I proceeded to explain that at that hospital, they will only see babies that are younger than 30 days old, but that I had another location in the same city as the hospital that does provide outpatient hearing tests to babies older than 30 days. She was glad to hear that and asked me to text her the contact information for the facility."
- Lydia shared, "Being a first-generation Mexican American means more than a language barrier. Culture, ethnicity, patience, and representation matters. Underserved communities need and deserve equal resources."

REFLECTIONS OF THE YEAR

This past year has been one filled with many fantastic achievements for our team and program! Even though the grant was not officially signed by DPH until the start of 2022, we were still able to accomplish all of the grant activities on time.

There were times when we had to pivot and alter our original plans, such as with the EHDI Innovator awards, management and editing of the Illinois Sound Beginnings website, developing EHDI-related materials to distribute to stakeholders, entering annual follow-up data points into Hi-Track, and being able to provide families support and resources in their native language. The key to being able to pivot and find a way forward was our consistent and constant communication of the barriers with the IL EHDI team and the ability to brainstorm ideas together.

We are grateful for the financial support of the grant and of the overall commitment from the IL EHDI staff to provide resources, services, and one-on-one support to families with children who are deaf/hard of hearing. The quote below is a beautiful testament to the work and vision of our programs. We are truly honored to work with such a devoted and visionary team.

"GBYS was an essential tool for my family as we transitioned into a new life. We had a newborn who had a heart condition which would require surgery...we knew about this condition while I was pregnant but then we were blindsided with the news of his hearing deficit on top of that. GBYS gave me an outlet to get things off my chest about the whole situation without feeling judged or misunderstood. It provided me with the link I needed for more information on what to expect and what sorts of help and support there are for children with these deficits. It also gave me some hope; at that time, it was very hard to see the bright side of things with all that my precious newborn had going on. My guide was very reassuring and was sort of a leading light for us. Her guidance helped ease my worries and made me feel a little more in-control, confident, and knowledgeable."

WHAT'S NEXT FOR US

DHH GUIDES

- Hiring and training deaf adults who can share their experiences of living with a hearing loss
- Developing introductory videos of the DHH Guides to share with families to spark interest and participation

RESOURCES

- Creating additional SNIPPETS on topic areas in need as identified by the IL GYBS team
- Interpreting and captioning videos that support educating professionals and parents of children who are deaf/hard of hearing



Coming
Soon

FOSTERING JOY

- Distributing *Fostering Joy* journals to families who enroll into the IL Guide By Your Side program
- Facilitating families working through the journal with their Parent Guide and DHH Guides
- Providing webinars on Fostering Joy

QI WORKGROUPS

- Continuing to host ongoing QI workgroups. Additional sessions will be held with a focus on diverse populations in an effort to improve our service connection and delivery within these communities.