SEPTEMBER 2024 VOL 17 | ISN 3



ILLINOIS E.A.R.S



E.A.R.S = EVENTS AND RESOURCES STATEWIDE

"What works for your child is what makes the choice right."™

WHO ARE WE?

The Illinois Families for Hands & Voices mission: A parent-driven, non-profit organization that supports families with children who are deaf and hard of hearing without a bias around communication modes or methodologies.

The Illinois Hands & Voices Guide By Your Side mission: Provides free, unbiased emotional support and resources by trained Parent Guides to families with children who are deaf and hard of hearing.

If you are looking for resources, parent support, events or anything else, we want to help! View our contact information on page 26.



Dear Readers,

As parents, we often think of leadership as something for CEOs or politicians. But in reality, leadership begins at home, with us. Every day, we have the opportunity to lead by example and inspire change in our families and communities. It doesn't have to be monumental—it starts somewhere small.

Whether it's showing kindness to a neighbor, helping a child navigate challenges, or speaking up about something that matters, our actions set the tone for those around us. Children, especially, are keen observers. They watch how we react under pressure, how we treat others, and how we handle setbacks. When we model empathy, resilience, and courage, we empower them to adopt those same qualities.

Change doesn't happen overnight. It takes consistent effort, patience, and belief in the values we want to instill. By leading in our homes and neighborhoods, we show our kids that leadership is not just about titles but about actions. They learn that anyone can be a leader by taking responsibility, making thoughtful decisions, and positively impacting others.

I chose this topic because without parents stepping up to the plate we would not have IL Hands & Voices or Guide By Your Side. I once thought, "what do I have to offer, my child is so young and we are still learning" which really I think was a crutch, thinking someone else would take charge. However, getting involved in small ways showed me I did have a place. I am so grateful and proud of the parents that I've worked alongside and for the providers that encourage our leadership. I encourage you to visit pages 6-8 in this newsletter to learn more about leaders in our organization and consider what you may have to offer. I would be happy to chat with you and explore which ways you can help us make a difference.

Let's embrace this responsibility together. Let's commit to being the example of the change we wish to see, knowing that even the smallest acts of leadership can inspire others and ripple outward, creating meaningful change in the world around us.

Leading by example,

Carrie Balian
Parent of a son who is DHH
ILHV GBYS Coordinator
HV HQ Region V Coordinator
HV HQ GBYS Program Lead

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ILHV Board Spotlight

Learn more about a member of our Board.



DeafBlind Difference

Suggestions for children who have vision and hearing loss.



Board Recognition

Annual recognition of years of service.



A Fond Experience

A family shares their experience meeting a DHH Guide.



All Things SPED

Information and support for all things Special Education.



IL H&V Wrap-Ups

Check out what has happened the past few months!



Resources For All

New SNIPPETS are available to learn more about various topics!



Events For All

From in-person to virtual, there are events for all! Check out all the pages so you don't miss out!



Acronyms

So many acronyms!
Start here to learn what they stand for.





by Andrea Marwah, ILHV Executive Director



MICHELLE CLYNE

Michelle has been with the IL Hands & Voices Board of Directors for 2 years. Her background in Deafblindness is a significant asset to our organization. I had the pleasure of interviewing Michelle and getting to know her a bit better, now I share her with you. If you have questions for Michelle, you can reach her at the contact information below. Enjoy getting to know her!



Michelle.....

- ·lives with her husband John in Lombard.
- ·is the coordinator for the IL DeafBlind Project.
-started her career in music therapy where her first job was with a deafblind school, now Phillip Rock. She loved the energy of these kids and has since obtained a teacher license in vision and certificates for deaf education from Gallaudet.
-shared that her most proud accomplishment was working with a team to get 'deafblind' intervention in IL School Code.
-would be "Pippy Long Stocking" if she had to be a fictional character.
-would tell her younger self to "take a typing class", who knew how much we'd have to type!
-would ask her older self "what do you wish I would have done differently?"

Michelle's advice to families:

"When you're ready join some parent groups that include parents who have children that are older than your child, none of them will have one exactly like yours but you will still find kernels of wisdom that will support and nourish you."

Fun Facts about Michelle:

- Michelle's loves to be the 'devils' advocate', exploring both pros and cons to every situation.
- · She has a blue belt in Karate.
- She loves wearing hats, both actual and literal!
- One bucket list item is national parks, some by train for her husband John.
- If she had a talking pet she would like to have a dog to tell her how great she is but she would also want a cat to tell her the truth..
- Michelle volunteered for 5 weeks in Malaysia without knowing anything about the job, she just showed up.
- She chose Rob Zombie's "Living Dead Girl" as her stage entry song! Go out and listen, very cool!

Michelle Clyne
Illinois DeafBlind Project Coordinator
mclyne@philiprockcenter.org
630-790-2474



Illinois Families for Hands & Voices is a 501c3 Non-Profit Organization, EIN 06-1724201

www.ilhandsandvoices.org

THE DEAFBLIND DIFFERENCE

Teaching Choice Making

Written by: MICHELLE CLYNE, ILHV BOARD MEMBER

I have heard parents drop off children for school and say, "Make good choices!" But young children with combined vision-hearing differences may need some support in learning how to make choices. Sometimes children do not know a choice is being offered, or vision differences hide or make unclear all the options when a choice is available. Sometimes children have difficulty expressing preferences clearly. Here are a few ideas that support early choice making skills...

Embed opportunities for choice throughout the day within daily routines.

Offering choices throughout the day ensures that children get practice making choices, using communication and language, and feeling like they have a say in their lives. Often (but not always) giving choices that you have already approved helps avoid power struggles and tantrums. Some routines that are wonderful places to embed routines include:

Dressing: Choosing between two weather appropriate outfits (even if a favorite hat or boots are always part of the ensemble). Choosing between putting on tops or bottoms first.

Grooming: Washing face before or after brushing teeth. Which flavor of toothpaste to use today.

Meals: Which bib to wear. Which snack do you want?





Help make option clearer with visual techniques or other senses.

Clear viewing: Show choices against a plain wall, blanket, or couch. During meals, a contrasting placemat can be a backdrop for choices of snacks.

Move choices into best vision:

Sometimes, children do not see equally in all fields of vision. Where does your child see best (towards the left or right? Upper or lower field?) Put both items for the choice in that field and separate them enough so they appear as two different items but are both still in the "sweet spot." Sometimes, that means having one item above the other instead of them being side by side.

Use more senses:

If vision or sound alone does not give enough information to know what the choices are, add ways to enhance information with touch, smell, or taste. Children can feel toy choices and take or keep the toy they want. Smelling or tasting a bit of a snack can confirm what children are seeing.

Understanding expressions:

Children often begin choice making by having their gaze linger on the item they like. They might also increase their body movement, smile, or vocalize when they see, hear, or experience the item they like. Many children with sight begin to reach to things they want, and then point to them. A child with a vision difference may not reach or point when their sighted peers learn those gestures. We can teach reaching and pointing for choices using hand-under-hand to show children how to shape hands and move arms. Remember, early choice-making is part of self-determination and selfadvocacy!

VOLUNTEER SERVICE RECOGNITION Autority Autor



Carrie Balian **15** YEARS OF SERVICE

ILLINOIS



Tina Grieco-Calub

5

YEARS OF SERVICE



Michelle Clyne $oldsymbol{2}$

years of Service



Kelly Fulton-Armer

2
YEARS OF SERVICE

IL Hands & Voices Board of Directors volunteer their time to make our vision a reality for families in Illinois. In 2024, we recognize these amazing individuals who volunteer their time to help run our organization.

Help us to celebrate them.

WWW.ILHANDSANDVOICES.ORG



Illinois Hands & Voices Guide By Your Side

PROMOTIONS





Lead Guide





Alicia Aaron

Alicia is the mother of two children one who is hard of hearing. Alicia and her family live in Cook County.



www ilhandsandvoices.org

"What works for your child is what makes the choice right."™





GROWING OUR LEADERSHIP

Written by Amy Keslinke, IL H&V President



Illinois Hands & Voices is full of great people and leaders, and part of fostering our leadership skills is our participation in the Leadership-to-Leadership, or L2L, program run by Hands & Voices headquarters. This year-long program (spanning from one Leadership Conference to the next) incorporates peer-to-peer interaction, mentoring, and learning experiences in the areas of personal leadership, leading others, and systems leadership.

Our Illinois chapter has been highly active in the program, with at least one member in every cohort since 2020. At the Hands & Voices Leadership Conference this September, Board President Amy Keslinke graduated from the program. This year, our chapter had two members accepted into the cohort, which kicked off just after Amy's graduation. Congratulations to Hanna Swearinger and Maira Nava!

Some of the excellent leadership content is available for everyone, as triannual webinars are open to anyone and recordings are available on the L2L website:

https://handsandvoices.org/121/

Pictured to the left are Hanna Swearinger, Amy Keslinke, and Maira Nava.



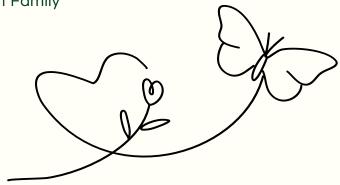
How Illinois Hands & Voices Has Supported Our Journey

Illinois Hands and Voices is such a stable source of support for our family. My daughter Sonny was born deaf in her right ear and has had difficulty with her speech as a result. It has felt others do not understand how this particular hearing loss impacts Sonny. I came across Illinois Hands and Voices after doing a google search as a very stressed out mom looking for any support. I was experiencing a lot of stress in trying to advocate for Sonny with our local public school. I wrote the longest email to Illinois Hands and Voices letting all my concerns out. I thought they are going to think I have lost it. I got a quick response with words of reassurance that I am not alone and there is support. I have had the privilege of working with Ramona as a parent quide. I still work with Andrea Marwah as a IDEA parent advocate with ISD and Sara Siddiqui Deaf/Hard of Hearing Guide.



I have learned so much from these beautiful women each offering a valuable perspective and experience. They have helped me to not feel alone. They have educated me and offered words of reassurance at times of both uncertainty and certainty. We are extremely grateful for Illinois Hands and Voices.

With Gratitude, Lambert Family











https://tinyurl.com/ilhvdonate



Double Your Donation!

Help us support IL families with children who are deaf and hard of hearing!



Double your impact! Many employers offer matching gift programs that can double or even triple your donation to Illinois Hands & Voices! Check with your HR department to see if your employer participates.

For more details from IL Hands & Voices, send an email to: executivedirector@ilhandsandvoices.com

Illinois Hands & Voices is a 501c3 Non-Profit Organization EIN 06-1724201 "What works for your child is what makes the choice right." $^{\text{TM}}$



Information and support

ALL THINGS SPecial EDucation

Andrea Marwah is a special education advocate supporting families with children who are deaf/hard of hearing. She is the Executive Director of IL Hands & Voices, Special Education Advocate at the IL School for the Deaf Outreach and national ASTra trainer for Hands & Voices. She is also the parent of a young deaf adult.

Did you know that the law provides valuable protection to families who have children with disabilities? Many families are aware that their school provides special education but are not aware of the legal obligation of parent involvement. Under IDEA the parents are equal members of an IEP team and under the Rehabilitation Act a 504-planning meeting member. For this article I am going to discuss parent involvement and rights pertaining to IDEA – Individuals with Disabilities Education Act, a federal law designed to protect your student and you! You have legal rights when it comes to the educational planning for your child. A few things to note about this important part of the law:

- Parents are provided procedural safeguards. IDEA §1415 discusses in detail what these safeguards must include, this is your protection, your rights as parents to be active participating members of the team that makes decisions for your child. You should receive a copy of these procedural safeguards at every domain, eligibility, and IEP meeting. READ THEM!! They are your legal rights.
- Parents must give consent for evaluation or re-evaluation. IDEA <u>§1414</u> discusses evaluation, eligibility determination, Individual Education Plans and Educational Placement.
- Meetings must be held at a mutually agreed upon time and date, it is not appropriate for your school to provide you with only 1 date option. If this happens and the date/time does not work for you, request other date/time options. Part B of IDEA stature 300.322 describes this section of the law.

It is important to understand the basic principles of special education law to ensure that your child receives appropriate services. Knowing that you are listed as a team member in the law should give you're the comfort of knowing that you too have a voice at any meeting with your school pertaining to your child's special education.

You can view basic SPED webinars here:

https://www.illinoissoundbeginnings.com/2019-parent-infant-recordings

You can request state funded Special Education Advocacy Support through the IL School for the Deaf Outreach Department here:

http://www.illinoisdeaf.org/Outreach/Special%20Education%20Support.html

AVOIDING LINGUISTIC OVERPROTECTION:

Ways to build on your D/HH child's vocabulary skills

Written by Caitlin Gomez, IL H&V Board Member

As families ring in the new school year, many parents of D/HH children are looking for ways to grow their child's language and foster connection. Daily routines that allow for targeting of both of these goals include the rides to and from school, and family meal times. These daily opportunities create space for the child to share their experiences with caregivers and siblings. Engaging in these types of conversations strengthens family cohesion, or, the level of emotional bonding between family members. All the while, the child is learning to develop more complex language including: telling narratives. answering questions, and expressing emotions. Language allows the child to connect and share his or her experiences with the people that matter most. But what happens to these important connections when a caregiver has concerns for understanding child the vocabulary surrounding more complex topics such as emotions or new experiences?

SCARED

TERRIFIED

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JEEBIES

We not use sinde a fed

#EndLinguisticOverprotection

Photo credit: Sara Miller, M.S.Ed./ @adventuresindeafed (2020)

adventuresindeafed

(Continued on page 12)

(Continued from page 11)

Linguistic overprotection is a term that describes when a parent/caregiver (oftentimes with normal hearing) reduces the linguistic or cognitive complexity of their message to their D/HH child. This is used to avoid any misunderstanding from the D/HH child and ensure comprehension of the general message. Linguistic overprotection often includes using simpler yet less specific words in exchange for more complex words. For example, a parent may describe an overripe apple as "bad" or "no good" instead of using words such as "spoiled", or "rotten", because they assume the child understands what bad/no good means, but assume the child doesn't have word knowledge of the latter words. Although the intentions are to ensure comprehension, this often leads to missed language learning opportunities and the caregiver limiting the home language environment for the child. Moreover, 90% of D/HH children are born to hearing parents with limited previous knowledge of American Sign Language (ASL). Parents who have chosen ASL as a language for their child may shy away from using more complex vocabulary due to not yet knowing the sign for the concept themselves, or assuming that the child won't understand or benefit from the caregiver fingerspelling the concept. In actuality, early exposure to fingerspelling concepts paired with providing additional context to further describe the concept, is an important skill in ASL. Below are some tips to avoid linguistic overprotection and further grow your child's language skills:

- Check for comprehension! Check-in with your child by asking questions about what you just said. For example, "I just mentioned the Bears game went into overtime!" Do you know what that means?
- Provide context proactively. For example, "The Bears went into overtime last night. That means the game was tied when the clock ran out so they needed to play longer until one of the team's scored!"
- Play language enrichment games focused around teaching complex vocabulary around an already-known concept. For example, when the snow starts to fall, take a walk as a family and take turns describing the snow. There are likely some known concepts such as "cold" or "white", but aim to make new connections with words like "frigid", "dusting", "sparkling", and "crunchy".
- Ask specific questions during conversation. This gives the child the opportunity to be more specific, and likely more complex, with their answer. For example, instead of asking "How was school today?" You might ask "Can you tell me something about school that made you really excited today?"
- Narrate your own emotions and experiences. Children are often observing and absorbing much more than we realize. For example, if you happen to yawn in front of your child, you can share with them, "Mom didn't sleep well last night and it's been a long day. I'm feeling exhausted or really really tired!".

Sharing thoughts, experiences, and emotions with your child is a wonderful way to bond with them. Being proactive and building on their current language skills and thus avoiding pitfalls like linguistic overprotection can help continue strengthen your child's bond with the entire family.

HANDS & VOICES LEADERSHIP WRAP UP

By Andrea Marwah, IL Hands & Voices Executive Director

Weaving the Threads of Leadership. What does that mean? To leaders, it means bringing together those who support and encourage you. Those who live similar lives and "get" you. The annual Hands & Voices leadership conferences this year did not disappoint. It was attended by members of our chapter. Our Executive Director, President, Vice President, Guide By Your Side Coordinator and Lead Guide. We were also joined by a representative of our state EHDI program. We traveled to the beautiful state of Washington and spent 4 days in Spokane. The theme was Weaving the Threads of Leadership. This year's sessions were abundant with parent leaders worldwide sharing their tips, tricks, and expertise. Chapter leadership, educational needs, impact, and program management were a few of the topics presented. Our chapter presented a couple of sessions as well, our Executive Director presented on the Theory of Mind (ToM) and how it can impact our children, and our Guide By Your Side team presented on the Early Years project that we are partnering with IL State EHDI to provide (https://www.illinoissoundbeginnings.com/the-early-years).

Our chapter was awarded our 20th-year certificate, and two of our leaders (Carrie Balian and Andrea Marwah) have been in attendance with the chapter for 16 and 15 years respectively. This is a major milestone for our chapter. We have grown so much since the chapter's inception in 2004.

We also give kudos to Amy Keslinke, our Board President, for graduating from the L2L (Leadership 2 Leadership) program this month (see page 8). Hands & Voices offers a 1-year leadership development program which is an amazing way to enhance our Illinois leaders to bring better programs and support to the families we serve. We have 2 new leaders entering the 2025 program cohort, Maira Nava and Hanna Swearinger. These 2 ladies will have the opportunity to learn and strengthen their leadership skills over the coming year and we will celebrate them at the next Leadership conference.

As we say goodbye to our fellow leaders in Spokane we look forward to seeing them again in 2025 in Panama City Beach, Florida on October 5-7.









Celebrating Back-to-School Together

Illinois Hands and Voices loves to wrap up the summer with a picnic, and this year was no exception! We had a great picnic on August 24th at Play for All Park in Itasca. We were so excited to try out a new--and accessible!--playground, and it did not disappoint! Our group consisted of kids from 2 to 16 years old, and parents and professionals got to meet, chat, and enjoy some treats. We were even having too much fun to remember to get a group photo! We hope to see you next summer!





SNIPPETS are:

- Simple
- Concise
- Easy to read
- Shareable
- Educational
- Information at your fingertips

Languages available:

- English
- Arabic
- Chinese
- French
- German
- Korean
- Polish
- Russian
- Spanish
- Tagalog
- Vietnamese

Scan the QR code to view our SNIPPET library



Current List of SNIPPET Topics:

- · Agency & Program Acronyms *
- · Auditory Neuropathy Spectrum Disorder
- · Aural (Re)habilitation
- All about ASL (American Sign Language)
- Audiologists
- Benefits of Music
- · Bone Conduction Hearing Aid
- CHARGE Syndrome
- Choosing a Daycare
- CMV Prevention
- Common Acronyms
- · Communicating with your Child
- · Communication Tips
- · Conductive Hearing Loss
- · Developmental Therapist Hearing (DT/H)
- · Early Intervention (EI) Clearinghouse *
- Fostering Joy
- · From Culture to Connection
- Hearing Device Tips
- Magnetic Resonance Imaging (MRI)
- Microtia / Atresia
- Mixed Hearing Loss
- · More Than Hearing Loss
- Navigating Early Intervention (EI) in Illinois *
- Pediatric Ear, Nose and Throat Specialist (ENT)
- Receptive Language
- · Recommended Tests
- Sensorineural Hearing Loss
- Speech-Language Pathologist (SLP)
- State Funded Resources *
- Unilateral Hearing Loss / Single Sided Hearing Loss
- · What is Cytomegalovirus (CMV)?
- What is DSCC? *

*These topics are specific to Illinois (IL)

For more information or to suggest future topics email ilhvgbys@gmail.com





08.24 Flier

Deaf & Hard of Hearing Guides share with families:

- ▶ Their unique lived experiences
- ▶ Technology tips
- ▶ How they navigate social situations
- ► How they developed their personal identity
- ► And so much more



NOW

Contact us to get connected for free!

AVAILABLE!

224.343.1873 Voice/Text ilhvgbys@gmail.com





Resources for Families

Illinois EHDI

Early Hearing Detection and Intervention

Everything you need to know about hearing screening, diagnostics to intervention and beyond.

Illinois EHDI Program

at Illinois Department of Public Health

Phone: <u>217-782-4733</u>

Email: DPH.newbornhearing@illinois.gov



Join our Fostering Joy zoom meet up

Register to receive a free journal and learn more!

October 8th 7:30 pm on Zoom







Register at: http://tinyurl.com/ILHVSignup2024

"What works for your child is what makes the choice right."™

Illinois families for Hands & Voices is a 501c3 Non-Profit EIN 06-1724201

Celebrating our Children Focusing on Joy

Live O&A

THURSDAY, NOVEMBER 7TH 8:00 PM

> What do you like to do for fun?

Join us for an opportunity to ask questions and learn more from our team of deaf and hard of hearing (DHH) Guides.

Register through the QR code or at http://tinyurl.com/DHHteammeet to receive the zoom link.









ILLINOIS

Is it hard

to make

friends?

"What works for your child is what makes the choice right."™





7:00 - 8:00 PM CST 9/18, 10/16, 11/20

GETTING TO KNOW YOU

Please join us on an informal Zoom meeting to get to know other families with children who have a hearing loss from across the state of Illinois.

PLEASE REGISTER AT THIS LINK HTTP://TINYURL.COM/GETTINGTOKNOWYOUIL





THIS EVENT IS HOSTED BY OUR ILLINOIS HANDS & VOICES GUIDE BY YOUR SIDE PROGRAM. ALL FAMILIES WHO HAVE A CHILD THAT HAS ANY TYPE OR DEGREE OF HEARING LOSS ARE WELCOME TO JOIN THIS EVENT.

"WHAT WORKS FOR YOUR CHILD IS WHAT MAKES THE CHOICE RIGHT."@

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"What works for your child is what makes the choice right."™

RESOURCES



ZOOM EVENT

This month will focus on what to know after diagnosis

NOVEMBER 12, 2024 7:30PM



Join us for an opportunity to ask questions and learn more from the resources we share.

Register through the QR code or at https://forms.gle/DsK553QYQk36dNni8 to receive the zoom link.



DADS MEETING OTHER DADS



Join us for an informal Zoom meeting to get to meet other dads of children who are deaf/hard of hearing across Illinois.

All dads or father figures of children who are deaf/hard of hearing are welcome to join this safe space to talk about you and your kids.

Wednesdays 8-9pm

August 28
September 25
October 23
November 27







https://forms.gle/jWnbd1aABGFoqzXP7

You must register to receive a zoom link to attend the event.

ADA requests must be made within 1 week of the event,

don't delay — register today!



"What works for your child is what makes the choice right." TM





Starnet IV is for the Southern 38 counties in IL to find your local
Starnet visit www.starnet.org



RSVP!

tinyurl.com/59bfk9r7

900 E 57th St. Chicago, IL 60637

ACRONYMS

HERE ARE SOME ACRONYMS THAT YOU MAY SEE THROUGHOUT THIS NEWSLETTER OR IN INFORMATION ONLINE

1-3-6 - Hearing screened by 1 months of age, Diagnostic testing by 3 months of age, and enrolled in Early Intervention and parent support by 6 months of age

AAP - American Academy of Pediatrics

ADA - Americans With Disabilities Act

ASL - American Sign Language

CMV - Cytomegalovirus

DBA - Doing Business as Agreement

DEI - Diversity & Equity Infusion

DHH - Deaf Hard of Hearing

EHDI - Early Hearing Detection &

Intervention

IDEA - Individuals with Disabilities

Education Act

IDPH - Illinois Department of Public Health

IEP - Individualized Education Program

ILHV - Illinois Hands & Voices

ISRC - Illinois Service Resource Center

GBYS - Guide By Your Side

JCIH - Joint Committee on Infant Hearing

LTF - Lost to Follow-up

L2L - Leadership to Leadership

NCHAM - National Center for Hearing

Assessment and Management

PG - Parent Guides (parents of children who

are deaf/hard of hearing)

SNIPPET - Simple N Informative Parent-to-

Parent Education Tools

Learn more on common acronyms here:

https://www.illinoissoundbeginnings.com/acronyms

Illinois Hands & Voices, Guide By Your Side does not support or endorse any specific organization, communication or amplification choice.

The information in this newsletter is to simply share with families and professionals the resources and events available to them.

FIND US HERE...



Follow us on Social Media:



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