

# MINNESOTA HANDS & VOICES Supporting families with children who are deaf & hard of hearing

# Language Access for Kids who are DHH, We Don't Know What We Don't Know

Babies are born with a unique set of characteristics, yet blissfully oblivious to any characteristics that may stand out. They are resilient and adaptable as they experience their environment. Babies who are identified as deaf or hard of hearing (dhh) readily accept what they can hear or cannot hear as their normal experience. Their needs are simply to feel comfortable, be fed, and to be loved. They don't know what they don't know.

"My son was born 'perfect'," a MNH&V mother quipped about her son who is deaf. "It was our big idea to add sound to his world."

For many parents it is usually unexpected to learn their child is dhh. Statistically over 90% of children who are dhh have parents with typical hearing. After their initial reaction to the news that their child is dhh parents begin to put together what it means to raise a child who is dhh. It means a higher level of responsibility for parents to make a myriad of decisions on their child's behalf. How will their child best access language? No matter what form or shape language is administered to your child who is dhh the key is access, access, access.

"Infants' brains are wired for language that is accessible to them through either visual (signs) or auditory (spoken) modalities," writes Marilyn Sass-Lehrer, Gallaudet University, in the Oxford University Press Journal. "The achievement of language milestones in

either sign language or spoken language is crucial to the overall development of the child."

Research shows the optimal language learning years are from birth to age 5 years. Communication is made up of two important parts, receptive and expressive. In the first few years children often understand the language they have access to or "received" long before they begin to use language expressively. For children with typical hearing 90% of what they know is overheard, 10% is taught. Overhearing spoken language can be greatly diminished or nonexistent for children who are dhh. Families, along with the Individual Family Service Plan (IFSP) team and dhh educators, are essential partners in providing access to language. For children who are dhh communication can take longer to establish and it is heavily reliant on how much access to language they have experienced. The challenges for the family and the team are to develop a workable plan and, as it is said, "don't give up before the miracle happens".

"If you know,
to recognize that you know,
If you don't know,
to realize that you don't know:
That is knowledge."

— Confucius

"Input, input, input, my job is to 'feed' my littlest students as much language as possible in a language-rich environment; its not until years later sometime in grade school, when the magic happens," said an early childhood DHH educator referring to a child's expressive language skills. "I don't always get to see it happen, but I know it will."

Do not underestimate what your infant or child who is dhh can see or hear or feel. Language access of any kind can never start too soon or be too much. The question of how much sound access does an infant who is dhh really have cannot easily be answered and it varies from child to child. Understanding your child's audiogram is important, but nothing can truly simulate for parents the sounds of speech that are available to your child even with amplification. Plus, many other factors can affect language access, from distractions and interest level to overall health and environmental noise. There are a lot of unknowns, but one thing is for sure: your child who is dhh is ready to access language.

Start today! Try the ideas professionals on your IFSP team have suggested and do everything you can to make language accessible at home and wherever your child is. Dance, play, read, explore, work, celebrate, and learn together what will bridge your child's language learning.

More Language Access Tips in the Parent-to-Parent Pointers article on page 5.

# **Cued English Classes**

# Sponsored by the Cued Speech Association of Minnesota

Classes are sponsored by the Cued Speech Association of Minnesota, August 7 and 8, from 9:00 am to 4:00 pm. Located at Falcon Ridge Middle School, Apple Valley.

## **Beginning Cue Class**

Learn the cued speech system.

# **Cued Speech Skills Class**

Practice words, phrases, and sentences.

#### **Transliterator Cue Class**

Practice transliterator skills.

**Kids Cue** For kids ages 8 to 13.

Fee per adult: \$75/members \$60, kids: \$50/members \$45. For more information and class registration go to www.cuedspeechminnesota.org

# Save the Date • Saturday, Oct 13 **TRANSITION EVENT**

This event is FREE for families with children who are who are deaf, DeafBlind and hard of hearing wanting to learn more about transitioning to adulthood. Featuring national speakers, a panel of young adults who are deaf, DeafBlind and hard of hearing, vendors, and Vocational Rehab Counselors available for brief consultations.

10:30 am to 2:30 pm Refreshments Provided St. Paul College, St. Paul, MN

Any questions please contact Anne Barlow, MNH&V Events Coordinator, at 651-265-2400 or email at AnneB@lifetrack-mn.org.

Register for the Transition Event online at www.eventbrite.com/e/deaf-deafblindand-hard-of-hearing-student-transitionevent-ages-14-tickets-45293161064

# Thanks for your contribution! We rely on your generous support to build better lives for children who are deaf or hard of hearing. Make a tax-deductible donation today.

# Hands & Voices Leadership Conference

# Cheyenne, WY September 14 to 16, 2018

This conference is for Hands & Voices (H&V) Chapter Leaders, H&V Guide-By-Your-Side, ASTra Program, parents of children who are deaf or hard of hearing (dhh), and professionals.

The H&V Leadership Conference brings together family leaders from all over the world for training on how to affect systemic change where they live. It is the only conference devoted exclusively to training family members to be effective agents of change they want to see in their communities to empower all children who are dhh.

If you are new to H&V or not normally involved in activities, attend the conference to learn more about what H&V is all about, have conversations with leaders, and receive up-to-date news and information.

For more information, conference agenda, and registration go to http://www.handsandvoices.org/conference/2018/index.htm

# Phonak Teen Advisory Board

# Teens Age 15-18 Can Apply Now Through July 27

Make a difference by sharing your experiences with other teens and help contribute to the development of hearing technology through Phonak.

Candidates who apply for the Phonak Teen Advisory Board

- Must live in the US or Canada
- Commit to a 1-year term, with the possibility to extend it to 2 years
- 15-18 years old
- Fluent in English

Important time line

- Apply now through July 27
- Select candidates will move into public voting phase: Aug 1 to 10
- Guardians of selected candidates to be called by Phonak: Aug 13 to 14
- Teen Advisory Board kick off weekend: Sept 28 to 29

Teen Advisory Board responsibilities

- Bi-monthly meetings with Phonak representatives and other advisory board members
- Contribute regularly to Phonak blogs and social media team
- Spokesperson at school and the community, representing Phonak

Benefits of being on the Phonak Teen Advisory Board includes training and coaching on topics to help you develop new skills. The 1st year, participate in the kick-off meeting at Phonak US. If you sign up for a 2nd term, you will visit Phonak Headquarters in Switzerland and receive the latest in Phonak technology.

Find more information and apply for the Phonak Teen Advisory Board at https://a.cstmapp.com/p/25984

FOCUS is published bimonthly by Minnesota Hands & Voices, a program of Lifetrack. Information in this newsletter about other organizations does not imply endorsement by MNH&V or Lifetrack.

**Newsletter editor: Mary Stadelman** 



# **MNH&V Events**

# Wednesday, July 25

How the Endrew F Case Strengthens IEPs

## 3:00 pm to 6:00 pm

Gooseberry Mound Park Moorhead, MN

# Thursday, August 2

Annual Family Picnic Metro

# 5:00 pm to 8:30 pm

Como Park Midway Pavilion St. Paul, MN

# **Tuesday August 14**

Southwest Region

Annual Family Picnic

5:00 pm to 7:30 pm

Sibley Park, 900 Mound Ave., Mankato, MN

## Saturday October 6th

"Daily Technology"

1:00 pm to 3:00 pm

Engwall's Corn Maze Hermantown, MN

# Saturday, October 13

"I Wish I Knew Then

What I Know Now": Students & Parents

Share Insights

10:00 am-12:00 pm

546 5th Ave NE, Melrose, MN

#### Saturday, October 13

"Deaf, DeafBlind and

Hard of Hearing

Student Transition Fair (For students ages 14+)

# 10:30 am to 2:30 pm

Saint Paul College, St. Paul, MN

# Saturday, October 27

Topic TBD

1:00 pm to 3:00 pm

Paul Bunyon Land, Brainard, MN

# **Registration Now Open**

# Workshop Titled "Understanding Deafblindness and the Role of the Intervener"

The MN DeafBlind Project and Northeast Metro 916 Intermediate School District present Understanding Deafblindness and the Role of the Intervener on August 15, 2018, from 9:00 am to 3:30 pm. Workshop location is in the Pavilion Room at the Holiday Inn & Suites, 8511 Hudson Blvd., Lake Elmo, MN. Early check-in at 8:30 am, a light breakfast and lunch is provided.

This interactive workshop will explain the impact of deafblindness on the communication, cognition, learning and social/emotional development of students who are deafblind. Also, the role of a deafblind intervener in an educational setting and the importance of collaboration with the education team.

Presenter, Dr. Jerry Petroff, is an associate professor at The College of New Jersey and is the Project Director for the New Jersey DeafBlind Project and has been professionally involved in the education of students with deafblindness for over thirty years. Dr. Petroff is nationally recognized as an expert in the education of children with deafblindness.

NO FEE—the cost of the workshop is supported by a grant from MN Department of Education.

For questions about the workshop contact Cathy Lyle by phone at 612-638-1526 or email cathy.lyle@metroecsu.org.

Registration questions contact Deanna Rothbauer by phone at 612-638-1531 or email deanna.rothbauer@metroecsu.org

Registration open until August 1 at https://metroecsu.myquickreg.com/register/event/event.cfm?eventid=15326

# Hands & Voices, Family Leadership in Language & Learning

Hands & Voices (H&V) is a parent-driven and professionally collaborative organization interested in supporting families with children who are dhh. Explore options, discover new resources, learn from one another, and share with other families who are also raising a child who is dhh.

H&V FL3 has five main goals

- Families with children who are dhh and organizations serving families are early intervention partners in every state
- 2. Support families in becoming leaders in the early intervention system
- 3. Increase family to family support
- 4. Families increase their knowledge of language, literacy, and social emotional development for children
- 5. Increase involvement of adults who are dhh as mentors and role models in the early intervention system.

Sign up to receive newsletter emails from H&V FL3 Project at https://visitor.r20.constantcontact. com/manage/optin?v=001GEb4cqp7jx65pmV65ULBhohdkqWbE-K

Find more information about FL3 at FL3@handsandvoices.org

# **MNH&V SOURCE**

# Keep Up to Date with the Latest MNH&V News & Events

Sign Up for the MNH&V SOURCE, which offers the latest news and events in the MNH&V community and other community organizations of importance to families who have a child who is dhh. To receive the MNH&V SOURCE weekly email, request to be signed up by email at www.mnhandsandvoices.org

# Iam MNH&V

Chad and Joyce Dressler with their three daughters.



"We have three strong, creative, and awesome daughters, " said Joyce Dressler when asked to tell us about her family.

Joyce and Chad Dressler are active volunteers for MNH&V. At last year's metro area annual Family Picnic the couple were asked to be Parent Ambassadors there to welcome other families and answer general questions. Joyce volunteers regularly in the MNH&V metro office helping organize information and events materials.

Their middle daughter was born in Massachusetts where she had a newborn hearing test at the hospital. Two weeks later she was identified as hard of hearing, bilateral sensoneural mild to moderate. The couple both have a family history; Joyce's sister is dhh and Chad had a great grandmother who was dhh. They were quick to get their daughter fitted with loaner hearing aids in Massachusetts.

"One thing that we found very useful was the ability to say 'Yes' to everything,"

said Joyce, "For example when we were told there was a family sign program, we said 'Sign us up!' 'What's cueing?' ... they have lessons for that ... we signed up. Private speech too ... let's make an appointment."

Chad was born and raised in Lake Crystal, MN. Joyce was born in South Carolina, but grew up in the Philippines where she lived for 17 years and learned to speak and write Filipino. The couple met in Utah and moved from Utah to Minnesota to Massachusetts and back to MN. Minnesota is now home to live closer to Chad's parents and girls' only living grandparents.

"It is such an important thing to know that you have a tribe to go to when you have worries and questions ... People who know what you are experiencing and who have been there," said Joyce, adding, "People who are tirelessly working to make sure they can support you in your journey and witness, and celebrate your failures and successes. H&V has been that for my family."

# VOLUNTEER OPPORTUNITY MNH&V Annual Family Picnic Metro

Minnesota Hands & Voices (MNH&V) is looking for volunteers for this year's Annual Metro Family Picnic on Thursday, August 2, from 5:00 - 8:30 pm. We are looking for volunteers to help in several areas during the picnic, such as welcoming families through registration and helping children with activities and crafts. American Sign Language Interpreters and **Cued English Transliterators** will be available at the picnic to provide access, but we welcome any parent or student volunteers who have communication skills, too. Volunteers are also needed to arrive early to help set-up and/or stay late to help clean-up. Please let us know what your "super powers" are and what you might want to do to make this event more special for MNH&V families.

> "Many hands make light work."

— John Heywood

Over the years we have been fortunate to have an active MNH&V community of volunteers who have made the Annual Metro Family Picnic a success. Please consider joining us this year. Volunteer registration is easy, but takes time to process properly so as soon as you can commit please contact Anne Barlow, MNH&V Metro Parent Guide & Events coordinator, at 651.265.2400 or email at AnneB@lifetrack-mn.org.

# Language Access, What Parents of a Child Who is DHH Can Do to Help Putting the Wheels in Motion

First, never underestimate the language connections your child who is dhh is already making. Guessing at what they can or cannot hear or whether they are watching or not watching, paying attention or not paying attention misses the point. The emphasis is on ACCESS to language; when they want it, wherever they want it, and however they want it. Parents cannot control how much language their child consumes; they can only do everything in their power to provide language. Your child may seem passive about learning language, but their little brains are soaking it up. It is surprising how skilled children are using their peripheral vision, overhearing what they can, and understanding symbols equals text equals information. In a language rich environment your child will start to make sense of the signs, symbols, and sounds that surrounds them and begin to find it useful.

### Here are a few suggestions

- Start today! A good rule of thumb of when to provide language access is if a child with typical hearing has access so should your child who is dhh.
- Approach language on all fronts and in any form: auditory, spoken, listening, acoustic, visual, signs, cues, gestures, pictures, written, captioned, interpreted, transliterated, devices, technology. A child will begin to gravitate to any combination of efforts to find what works for them.
- Have piles of books available to your child. Thrift stores literally have children's books a dime a dozen.
   Children's reference books with labeled illustrations and photos are especially helpful. Hand-made personalized books with labeled pictures of family and friends or of vacations or cultural holidays are great ways to help your child make connections.

- Turn on captioning on all screens and devices. It's never too early to be exposed to letters as meaning, letters as phonemes. Like books, captioning has been proven to improve literacy.

  IMPORTANT: TV screens and digital devices are everywhere. On your family vacation have the hotel TV captioning on. Visiting family or friends' houses if they have the TV on captioning should be turned on. Find a movie theater in your area that offers captioned movies.
- Make sure hearing devices are fitted, charged, and working properly.
   IMPORTANT: See your audiologist right away if your child refuses to wear their hearing devices. If your child finds hearing devices useful they will want to wear it, so find out why they won't.
- Reduce noise wherever your child spends their time. Sit, close your eyes, and listen to the background noise; analog clock ticking, radio in the other room, TV, ceiling fan, heater or air conditioner, laundry machines, computer keyboard, etc.
   NOTE: Any sound your child is alerted to is an opportunity to show value in

to is an opportunity to show value in listening. Touching your ear say, "Did you hear that?" Point to the object and say, "Let's go look!" Then together solve the mystery.

- Make it a family rule: when asked, everyone must answer the question, "What?" If it was important enough to say then it is worth repeating and even if it isn't worth repeating, your child is still interested in what was said. To dismiss them with, "Nothing" or "Never mind" leaves them feeling left out or not important enough to be included.
- Commit to an approach or modality and fearlessly give it your all! Who better to practice with than your prelanguage child? Mistakes are easily forgotten in the beginning and before

# Parent to Parent POINTERS

long you and your child will support each other in learning.

NOTE: Learning a new language takes work so ask for help, find a mentor, take classes, attend workshops, network with others, and practice, practice, and practice. If you are learning American Sign Language (ASL) or visually representing English through Cued Speech you might feel self-conscientious in public at first. You are not going to be perfect. Check your ego at the door and view criticism as a lifeline to better your skills. Over time, as your skills improve, your child begins to respond expressively, and communication starts to flow you will stop caring what you might look like and just enjoy the conversation.

• Know your child's rights by law through the Americans with Disabilities Act (ADA). Often an ASL interpreter or cued language transliterator is the responsibility of the company or public facility to provide. It requires families to plan far in advance and work with organizations on what service is needed. Children who use or will use interpreters or transliterators when they begin school can benefit from early exposure, a variety of styles, and a chance to practice their receptive skills.

The National Association of the Deaf (NAD) website puts it succinctly by offering this advice for parents: "No decision needs to be forever. There will be many twists and turns throughout the life of your child and family. Be flexible enough to stay with approaches that work and to modify those that don't. Take your cues from your child. Observing your child's development will help guide you on this sometimes difficult, yet rewarding path." https://www.nad.org/resources/early-intervention-for-infants-and-toddlers/information-for-parents/

# The View from Greater Minnesota



Welcome to MNH&V's newest friend from greater Minnesota. Adopted from the Congo, our young friend was given a choice of welcome gifts. She was delighted to pick the American Girl Doll, saying, "She cooks!" Our friend had seen a movie about the American Girl Doll and was familiar with her story. Plus, it included a book!

# MNH&V Benefits Families of Any Age

Families raising an older child who is newly identified as dhh can benefit by contacting MNH&V just as much as families with a newly identified infant. Especially MNH&V Family events can help meet some of the social/emotional needs of children who may have been unidentified since birth or who have a progressive or sudden hearing loss due to illness. Connecting with other families and role models, sharing tips and learning more about others' experiences can go a long way in creating a sense of identity and belonging.

Help us spread the word to other families, professionals, and educators that MNH&V is committed to providing support and information to families with a child who is dhh at any stage of their journey.



Raising Readers Event for the MNH&V Spanish Speaking Community, on May 19, 2018, was held at Lifetrack in St. Paul, MN. Interactive activities, healthful-snack, crafts, play acting, and interpreters in Spanish and American Sign Language brought to life two classic stories, The Very Hungry Caterpillar by Eric Carle and Caps for Sale: A Tale of a Peddler, Some Monkeys and Their Monkey Business, by Esphyr Slobodkina.

# Back-to-School Checklist Starter for Parents with Children who are DHH

Parents with a child who is deaf or hard of hearing (DHH) have additional considerations before their child heads back to school in the fall. The more parents can get done this summer to prepare their child for the school year the better they can focus on learning.

#### **Health and Wellness**

Schedule annual appointments far in advanced during summer break or for after-school to minimize disruptions in your child's learning.

#### ☐ Well-care Visit

A well-care visit establishes a baseline of your child's general health with a doctor you can trust. Many children who are DHH have ongoing health issues that can be noted as part of the child's baseline health. Should your child become ill, the well-care notes along with a doctor who is familiar with your child can streamline a diagnosis for any new concerns.

# ☐ Update Immunizations

Remember to ask for a copy of your child's immunization records. This saves time filling out health forms for fieldtrips, activities, emergency health cards, etc.

# ☐ Medication Check

If your child is on medications have a doctor double-check the dose for their age, weight, effectiveness, etc. Extra time for your child to adjust to changes in medications would be helpful before school starts. Make sure your child's current prescription is filled and ready before school starts.

# ☐ Physical Paperwork

Sports, camps, summer school, etc. often require health forms signed by a doctor. Bringing the forms to their appointment will save time. Doctors can sign forms any time, but it can take extra time to process.

☐ **Visit the Dentist and/or Orthodontist** Schedule appointments sooner rather than later, because the best times fill up fast.

#### □ Vision Check

Children who are DHH need to have optimal vision. An annual eye exam is recommended whether your child wears corrective eyewear or not. If your child has glasses, in addition to checking the lens prescription, check for scratches that can obscure their vision. Make sure their frames are the right size with no pressure points and adjusted to fit properly.

# ☐ Audiologist Visit

Before school starts have your audiologist check the working order your child's equipment, make sure the program is set for optimal sound and amplification. If possible create a separate program for any auxiliary equipment used at school. Your audiologist can answer any questions and make sure you and your child understand how to change programs, batteries and general care of the equipment. Remember to have for your child's old CI processors and hearing aids programmed as up-to-date as possible. Old equipment is a viable back-up plan should something happen to their newer equipment.

TIP: Take notes for your school audiologist or bring their contact information to give to your general audiologist. You'll need to sign a HIPAA form, but then the two can work together on optimizing sound in different learning environments.

# ☐ Review Insurance and Warranties

Depending on your child's age, maturity, and many other variables it can be unsettling to send them to school with expensive equipment. Reduce anxiety by having a plan should something happen to their equipment. Most homeowner insurance does not cover this equipment. Talk to your audiologist, check product warranties and contact your healthcare customer service to figure out the most economical insurance coverage available.

#### At Home

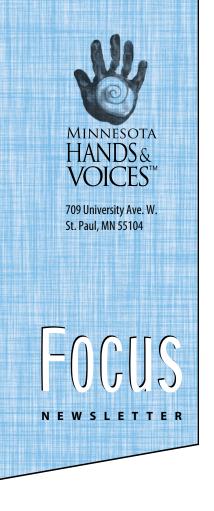
☐ Find a safe and accessible place to charge batteries and keep equipment.

- ☐ Label everything going to school.
- ☐ Set up a distraction-free place to study and keep extra school supplies.
- ☐ Have your child memorize their home address and important phone numbers to reach their parents if need be.
- ☐ Update your contact list to include the bus service, IEP manager, DHH and general ed teacher/s, school nurse, attendance line, food service, etc.
- ☐ Check the school website for important dates: parent/teacher conferences, school events, and a list of days school is not in session.

#### At School

- ☐ Check for a VISUAL alert system and review safety plans with your child.
- ☐ Check tech devices for captioning capabilities; computers, televisions, etc.
- See the school nurse if your child has severe allergies or takes medications during the school day.
- ☐ Visit the school audiologist to touch base about your child's equipment and the auxiliary equipment used at school.
- ☐ Send extra CI or hearing aid batteries to use for back-up if needed.
- ☐ Check your child's classroom for ways to best accommodate their access to language in each environment.
- ☐ Together with your IEP team review your child's accommodation needs with school administrators and, if appropriate, with fellow students.
- ☐ If your child's accommodations includes interpreters, transliterators or a captionists make sure there is a back-up plan for unexpected absences.

For parents of a child who is DHH there is no one back-to-school checklist that covers personal choices and their child's unique situation. Develop your own checklist you can add to over time. You'll have peace of mind and more time for summer fun!



**Minnesota Hands & Voices FOCUS Newsletter** 

July-August 2018

# 2018 Annual \* Minnesota Hands & Voices \* Metro

Date: Thursday, August 2nd

**Time:** 5:00-8:30 pm (rain or shine)

Where: Como Park Midway Pavilion

1199 Midway Pkwy, St Paul, MN

**Free for Families:** 

- **★ Fun Games**
- ★ Entertainment
- **★ Face Painting**
- **Door Prizes!**

graciously

HANDS & VOICES



Calling all the Superheroes in the MNH&V Community!

Dust off your superhero costume or come as you are to join our Hands & Voices' League of Heroes!

Find more details online at www.mnhandsandvoices.org/news-events/current-news-events.aspx