

**EHDI 2008**



**We Are Hands & Voices**  
**GUIDE BY YOUR SIDE**



**HANDS &  
VOICES**



**GUIDE BY  
YOUR SIDE**

Leeanne Seaver, M.A., Executive Director  
Elizabeth Seeliger, M.A., Wisconsin Sound Beginnings Director  
Stephanie Olson, M.A., Director of Deaf/Hard of Hearing Mentors/GBYS  
Laura Godfrey, Minnesota GBYS Parent Guide

**Copyright © 2008 Hands & Voices**

# Our Mission Statement



- ⌘ Hands & Voices is dedicated to supporting families with children who are Deaf or Hard of Hearing without bias around communication modes or methodology.
- ⌘ We're a parent-driven, non-profit organization providing families and the professionals who serve them with the resources, networks, and information they need to improve communication access, social and educational outcomes for their children.
- ⌘ Our outreach activities, trainings, parent/professional collaboration, and advocacy efforts are focused on enabling children who are deaf or hard of hearing to reach their highest potential.

# Hands & Voices...

## what makes us tick



- ⌘ ***We are a parent-driven, parent/professional collaborative group that supports families without bias about communication modes and methods.***
- ⌘ ***We believe that there is no one communication choice that will work for all children who are deaf or hard of hearing. We think families need access to good information that's free from a sponsoring agenda or ideology.***
- ⌘ ***We believe that “What works for your child is what makes the choice right.” ©***
- ⌘ ***We get meaningfully involved in early hearing detection and intervention programs, educational advocacy, and other systems to improve them from an end-user perspective.***
- ⌘ ***We exist to help our children/students reach their highest potential.***
- ⌘ ***We believe our children have a fundamental human right to communication, regardless of their mode or method of communication.***

# Supporting Families the H&V Way



- ⌘ Support that's parent-driven
- ⌘ Programs that are “end-user” tested
- ⌘ Treatment of all modes & methods of communication with respect and equity
- ⌘ Services that acknowledge all stakeholders

# Direct parent-to-parent and peer support: **Guide By Your Side**



GUIDE BY  
YOUR SIDE

- ⌘ Born in Wisconsin from parent feedback on what helped them the most when their baby was identified.
- ⌘ Collaboratively developed for replicability to authorized H&V chapters & partners from Hands & Voices National



# Guide By Your Side



Goal 1: provide parents with the opportunity to establish a supportive relationship with an experienced parent of a child who is D/HH soon after they learn of their child's hearing loss.

Goal 2: provide an understanding of the unique needs of infants who are deaf or hard of hearing.

Goal 3: provide unbiased information regarding communication options.

Goal 4: Link families to resources available locally, regionally, and statewide

Goal 5: Ensure that families are linked to their county Birth to 3 Program or local school district

Goal 6: Ensure that families are connected to other parent to parent resources

Goal 7: Ensure that families have an opportunity to create context for their own child's life by connecting to D/HH Mentors and adult role models.

Goal 8: Ensure that families' voices are heard in the systems that are serving them.

# The Wisconsin GBYS Model



- ⌘ Idea was sparked from a Parent Summit 2003
- ⌘ 28 Parent Guides
- ⌘ Divided into Regional Parent Guides / Specialized Statewide Parent Guides
- ⌘ GBYS Coordinator is a parent of a child with hearing loss hired by the Department of Public Instruction and a WI Hands & Voices board member
- ⌘ Coordinator also works as a Parent Guide

# WI GBYS Structure

- ⌘ Parent Guides are contracted employees with the WI Educational Services Program for the Deaf and Hard of Hearing – Outreach (<http://www.wesp-dhh.wi.gov/>)
- ⌘ Quarterly trainings of which 3 of 4 are mandatory
- ⌘ GBYS is embedded in WI's State System – Referrals are submitted by audiologists to the WI Sound Beginnings Program (DHFS) following diagnosis
- ⌘ Some referrals come directly from parents or early intervention programs
- ⌘ Parent Guides support families in their region, coordinate regional activities for newly identified families
- ⌘ WI GBYS supports families with children newly identified as deaf or hard of hearing for up to 6 hours
- ⌘ If family wants ongoing support they are connected to Hands & Voices parent to parent match program



# WI GBYS Goal: Reducing Loss to Follow Through...

If this information feels confusing or overwhelming, Parent Guides are available to help. If you would like to talk about what the screening results mean with a Parent Guide, fill in your contact information and give it to your nurse.

Your Parent Guide \_\_\_\_\_ will contact you in a week or so to answer any questions you might have. Together you can make certain that your baby's hearing is re-checked and find additional help if you need it.

This card was funded in part by grants from the Maternal & Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services.

Wisconsin Department of Health and Family Services  
Division of Public Health  
Bureau of Community Health Promotion  
Program for Children with Special Health Care Needs

\_\_\_\_ Yes, I give permission for my contact information to be shared with my Parent Guide and I understand that they will contact me.

The best way to contact me is by  telephone/TTY  e-mail  mail.

Telephone/TTY \_\_\_\_\_

E-mail address \_\_\_\_\_

Mailing address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

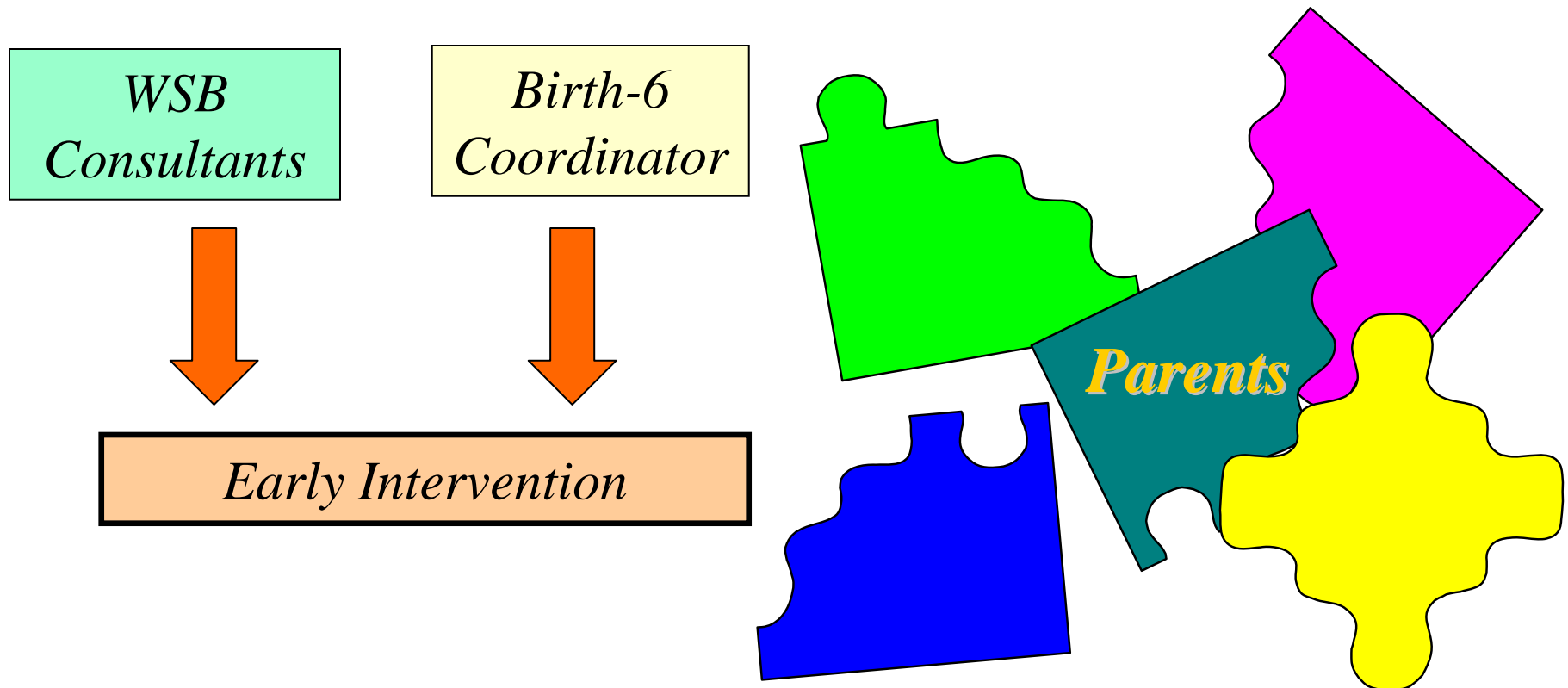
Parent Signature \_\_\_\_\_

# WI GBYS Follow-through Program: Reducing Loss to Follow-up

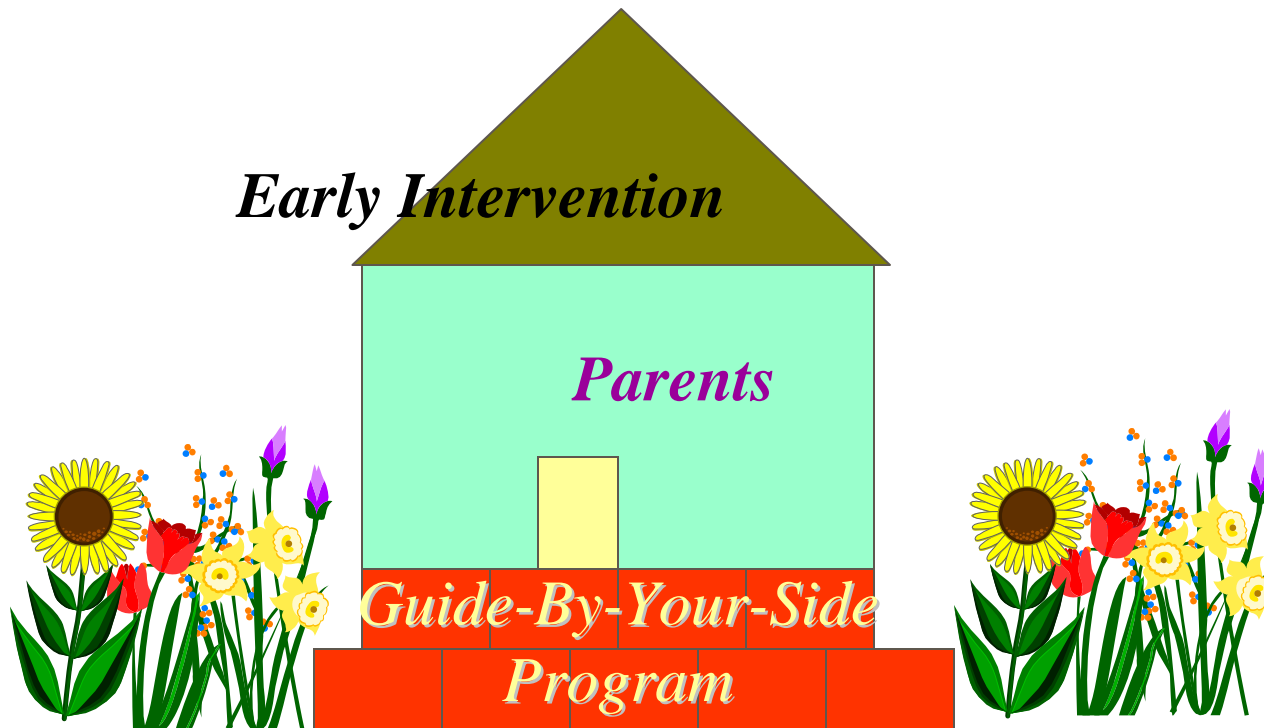
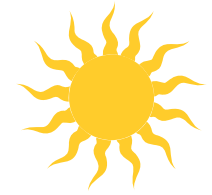
If you do not want a  
Parent Guide to contact  
you but have further  
questions about your  
baby's hearing, please  
call the toll-free  
Guide-By-Your-Side Hotline  
at 1-888-656-8556



# Top-Down Approach...



# Bottom's Up Approach...



# Family Satisfaction Surveys

(N=12)

## 1. Convenient Scheduling

- 12 /12 indicated yes

## 2. Additional Visits

- 5 indicated wanting additional visits
- 4 indicated not needing more visits at this time but would like them in the future
- 2 Did not feel that they wanted more visits

## 3. Program Satisfaction: Scale of 1= unsatisfactory to 5 =Outstanding

- ⌘ Knowledge of resources: 5 (9) 4 (3) 2(1)
- ⌘ Ability to share resources: 5 (11) 4 (1) 3(1)
- ⌘ Ability to listen and be supportive: 5(10) 5+ (1) 5+++ (1)

## 4. Shared information in a objective/unbiased way; 12 Yes! 0 No



**“Our Parent guide was outstanding in every aspect. She made us aware of programs and gave us support to pursue them. She was the boost we needed to find resources for our daughter. Thank you! Thank you for offering the GRYS Program!**

# Other Features/Options of GBYS: D/HH Mentors

Parents & Professionals report:

- ☒ Children don't know what it is like to be an adult with hearing loss
- ☒ Children don't understand how they can become "successful" adults
- ☒ Parents don't know what to expect of their child
- ☒ Parents sometimes experience prolonged feelings of anxiety about their child's hearing loss
- ☒ Teachers need more exposure to adults to help them prepare students

## The Crystal Ball Effect

- ⌘ Provides children with an opportunity to identify with an adult
- ⌘ Allows parents to "see the future" for their child
- ⌘ Allows participants to hear real life experiences from another person with hearing loss

# What do Guides & Mentors do?



## Do...

- . Know how to share their story concisely & appropriately
- . Let the family set the agenda
- . Share resources and information in a comprehensive, fair manner
- . Maintain ethical standards and actively develop their knowledge-base

## Don't...

- . Sway a family's opinion through bias
- . Manipulate a family towards a decision
- . Air their personal issues & put themselves in the spotlight
- . Provide intervention or professional services

# **GBYS Deaf & Hard of Hearing Mentors**



Guide By Your Side provides not only Parent Guides, but trained Deaf or Hard of Hearing Mentors to families with newly identified babies, young children or to seasoned parents with teenagers who are deaf or hard of hearing.



# What do DHH Mentors Do?



- ⌘ Exposure to D/HH adults can provide families and D/HH children/youth with invaluable perspectives that come from personal experience.
- ⌘ GBYS does not “proscribe” what a DHH mentor does for/with a family...that directive comes from the family—based on what they want from a mentor.
- ⌘ Emphasis on matching adults with families and kids of like communication modality is commonly practiced, but not necessarily required. This element may require the hiring of additional deaf or hard of hearing guides and specialized training.

**When we first received our son's diagnosis,  
I looked at the doctor,  
he was hearing  
I looked at the audiologist,  
she was hearing,  
And as we walked out,  
I looked back at the receptionist  
and she was hearing.  
I had no idea what this  
(raising a deaf child)  
would look like  
until you, (Deaf adult) walked in the door.  
-- Shelley Strickfaden -parent**



# Goals of a GBYS DHH Mentor



- ⌘ To increase awareness about hearing loss and deafness
- ⌘ To share information through personal experiences of Deaf/Hard of Hearing individuals
- ⌘ To answer questions from children, parents, and professionals about hearing loss or deafness.

## **Involve a Deaf or Hard of Hearing Mentor at the Time of Identification**




- ⌘ Introduce the child and family to a new community...”Should I quit playing my guitar?”
- ⌘ Help normalize this new world of experiences and feelings in a positive and optimistic light.
- ⌘ This opportunity may be as close as we get to a crystal ball.
- ⌘ Parents may appreciate a personal perspective from a D/HH mentor.

# Why involve a DHH Mentor?



- ⌘ A D/HH mentor may increase the families openness to examining issues with greater depth.
- ⌘ Articulates what the child cannot.
- ⌘ Ability and credibility to speak for the child's upcoming future needs.
- ⌘ Families who see Deaf and Hard of Hearing adults as valuable members of THEIR community, begin to understand the potential in their child.
- ⌘ Because...

**The baby's reality is different  
than that of the hearing parents!**



We can get so wrapped up in the diagnosis, but, we still need to love, nurture and care for the whole child.

***“The job of an infant is to give the parent joy.”***

***-Jules Kluger M.D***

***Forest Heights Lodge***

# Building Strong Families at Home



- ⌘ Parents may feel that they have lost a modality forever...a DHH Mentor can assist the parents in building a relationship with the modalities at hand.
- ⌘ The D/HH mentor:
  - ☑ models communication and relationships
  - ☑ develops and innovates with strategies

# Something to look forward to...



- ⌘ New ways of communication and thinking become the new normal for families:
- ⌘ “Step into the light”! Flashlights, the glow from a cell phone or watch, driving with the lights on.
- ⌘ Breathing and hearing...dishwashers, garbage disposals and Harley Davidson motorcycles.
- ⌘ So close and yet so far...understandings and misunderstandings.
- ⌘ Watching for opportunities to close the gap, (incidental learning).




# What does a DHH Mentor do for families?



- ⌘ Calms anxiety
- ⌘ “Norms” their child within their world.
- ⌘ Build relationships with the modalities at hand.
- ⌘ Communication: One cannot have a relationship without communication.
- ⌘ Models effective communication and relationships.
- ⌘ Allows the family to explore the sticky topics.

# Addressing your questions from the heart...




- ⌘ Educational and reading levels of Deaf and hard of hearing adults
- ⌘ Cochlear Implants
- ⌘ Were you teased?
- ⌘ How did you get a positive self esteem?
- ⌘ What did your parents do right or did not do?
- ⌘ Why don't you wear hearing aids?
- ⌘ Do you wish you could hear normally?
- ⌘ Why does your voice sound different?
- ⌘ Why don't you sign?
- ⌘ Why don't you use your voice?
- ⌘ Other sticky topics?

# Advice for a GBYS Mentor:



- ⌘ Sharing difficult experiences: “My parents made the best decisions for me based on the information that they had at the time.”
- ⌘ Sharing why or how something was wonderful or powerful for you without saying, “This is it! You have to do this for your child.”
- ⌘ How to gracefully *not* know the answers. Families don’t expect one person to know all the answers. Empower families to seek out additional information, attend meetings, ask the people on their team and to meet other role models.
- ⌘ Acknowledge the family’s expertise.
- ⌘ Answer questions based on relevant experiences rather than persuading families to feel one or another.

**“I’ve had some of my best conversations with strangers,  
she said, because they have no dealing  
who they are dealing with.”  
-- Brian Andreas**



Who are these people that we are connecting to families?

⌘ GBYS DHH Mentors:

- ☑ Enjoy being with children and families
- ☑ Live in various geographical regions
- ☑ Open minded in communication approaches
- ☑ Interpersonal skills which empower
- ☑ Aware of biases
- ☑ Open and honest and communication
- ☑ School, job skills and ability to be employed are a part of the mentor’s whole person.
- ☑ Positively resolved about their life.

# Minnesota GBYS



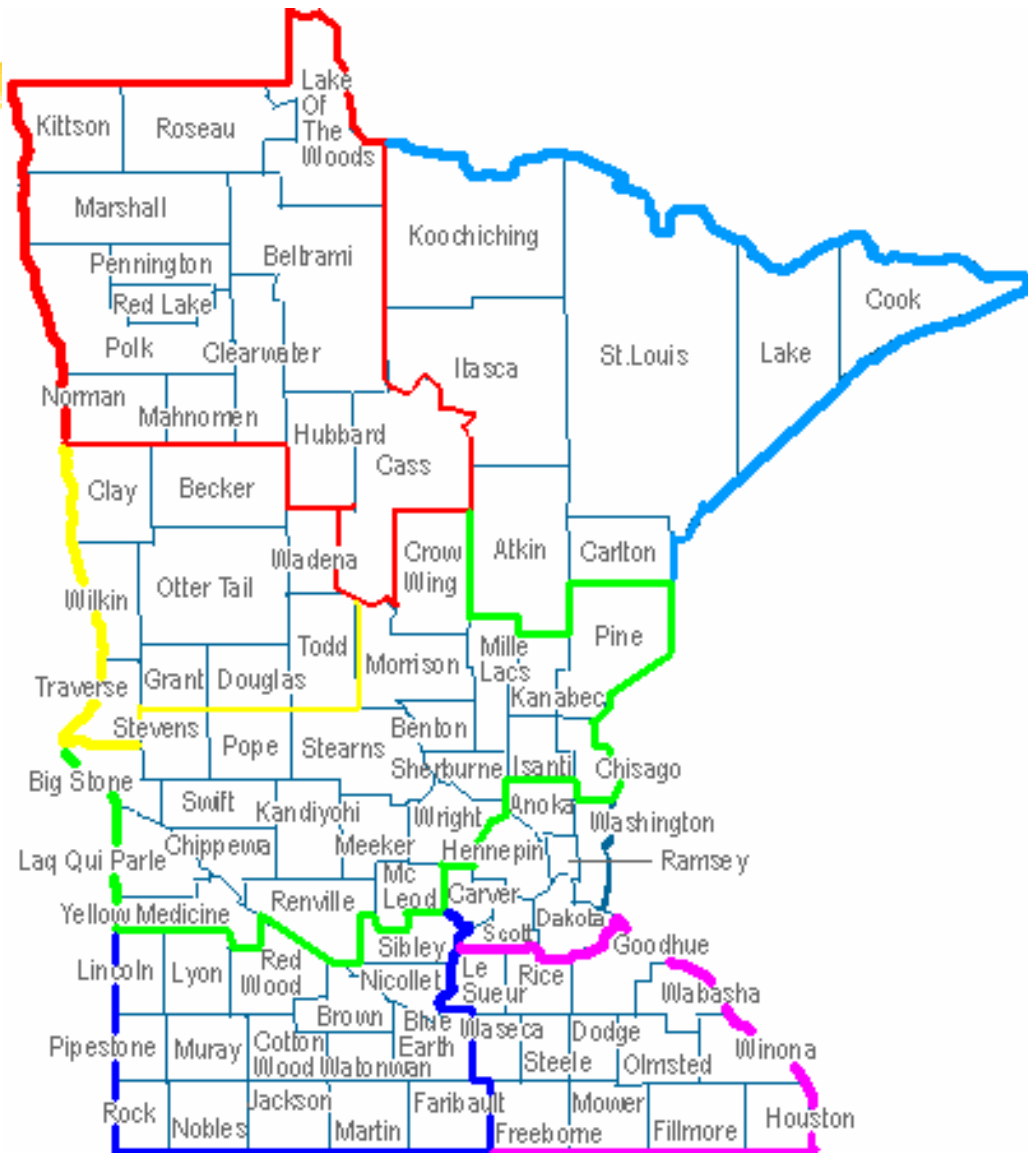
- ⌘ Funding secured in late 2005
- ⌘ Six Out-State Regional Parent Guides hired in 3/06
- ⌘ Three Metro Parent Guides – Total of 9 for the State
- ⌘ Initial Kick-off/ 1<sup>st</sup> Annual Training in 4/06 in conjunction with MN UNHS/EHDI Summit
- ⌘ 2<sup>nd</sup> Annual Training 5/07
- ⌘ 3<sup>rd</sup> Annual Training 4/08

# Funding MN GBYS



- ⌘ Seed money secured through capital campaign—private foundation
- ⌘ Confirmed funding for 2007 through MN Dept. of Health
- ⌘ Success in 2007 Legislature- obtained \$199,000 for two years
- ⌘ Will return to MN legislature in 2009 with support for permanent funding at a higher level
- ⌘ Still pursuing other sources: foundations, United Ways, individual donors, Federal Family Support dollars, Sertoma's, Lions, etc.

# Minnesota Regions



# A MN GBYS Success Story!

- ⌘ MN Department of Health referred Suzanne Iwainat to MN Hands & Voices following her daughter's diagnosis.
- ⌘ Metro Hands & Voices contacted Suzanne, answered questions, gave support and sent a packet of information based on her needs
- ⌘ Since Suzanne was in Greater MN, she was referred to Regional Parent Guide, Brenda Hommerding
- ⌘ *“When I have a question, Brenda is the first person I call because I know I will reach her right away. She's more like a friend, someone who understands...another mom who knows. This is a great connection. Of all the programs out there, this has been the most helpful.”* Suzanne Iwainat
- ⌘ *“Families like Suzanne's make our job so worthwhile and make me realize why I was chosen for my position. I am beginning to realize the reason why I have a hearing loss and why my girls have a hearing loss...we are able to share our stories with others and help them, too!”* Brenda Hommerding



# MN GBYS Program Structure

- ⌘ Parent Guides are part-time employees
- ⌘ Parent Guides attend monthly Teleconferences, Semi-Annual In-Person Trainings, Quarterly Advisory Meeting Participation
- ⌘ GBYS is embedded in MN's State System – Referral comes through MN Dept. of Health following diagnosis
- ⌘ Some referrals come directly from diagnosing audiologist
- ⌘ Parent Guides support families in their region, collaborate with other agencies to conduct regional activities, contribute to monthly newsletter, sit on regional advisory committees, etc.
- ⌘ For multicultural families, collaborate with PACER Center to do joint home visits with PACER's culture-specific Parent Advocate
- ⌘ MN GBYS supports families with children of all ages (diagnosis to transition)



GUIDE BY  
YOUR SIDE



HANDS &  
VOICES

Hands & Voices National

Leeanne Seaver, M.A.

Executive Director

*Director*

PO Box 445

Carthage IL 62321

*Business Office*

PO Box 3093

Boulder CO 80307

866-422-0422 toll free

217-357-3647

**GBYS@handsandvoices.org**

**www.handsandvoices.org**