

*ands & oices presents...*



## **Customizing Parent-to-Parent Support in State EHDI Systems**

Leeanne Seaver, Hands & Voices Executive Director

Ginger Mullin, Illinois GBYS

Candace Lindow Davies, Minnesota GBYS

Sara Kennedy, Colorado GBYS

Elizabeth Seeliger, WI GBYS



## **Guide By Your Side™**

is a Hands & Voices program that embodies our strong values for direct peer connections and networking.

It promotes self efficacy and hinders isolation by exploring our common bond, shared experiences, challenges, wisdom and insight.





## What do GBYS Guides do?

### Guides Do...

- . Know how to share their personal story concisely & appropriately
- . Provide unbiased, non-judgmental emotional support
- . Go with the family's agenda
- . Share resources and information in a comprehensive, equitable manner
- . Maintain ethical standards and actively develop their knowledge-base to help families make informed decisions.

### Guides 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
- . Give medical advice or share medical/clinical opinions about services or providers

Hands & Voices Guiding Principles  
are constant, but  
**GBYS custom applications**  
are a fixture of the program!

Postcard  
photography





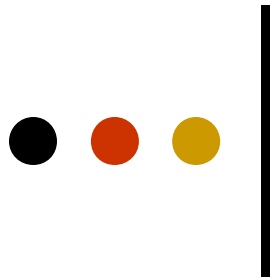
# ILLINOIS NEEDS FORMAL PARENT TO PARENT SUPPORT

- Illinois Hands & Voices
  - Karen Putz
- CHOICES for Parents
- Illinois Newborn Hearing Program



# Guide By Your Side in the Mid-west....

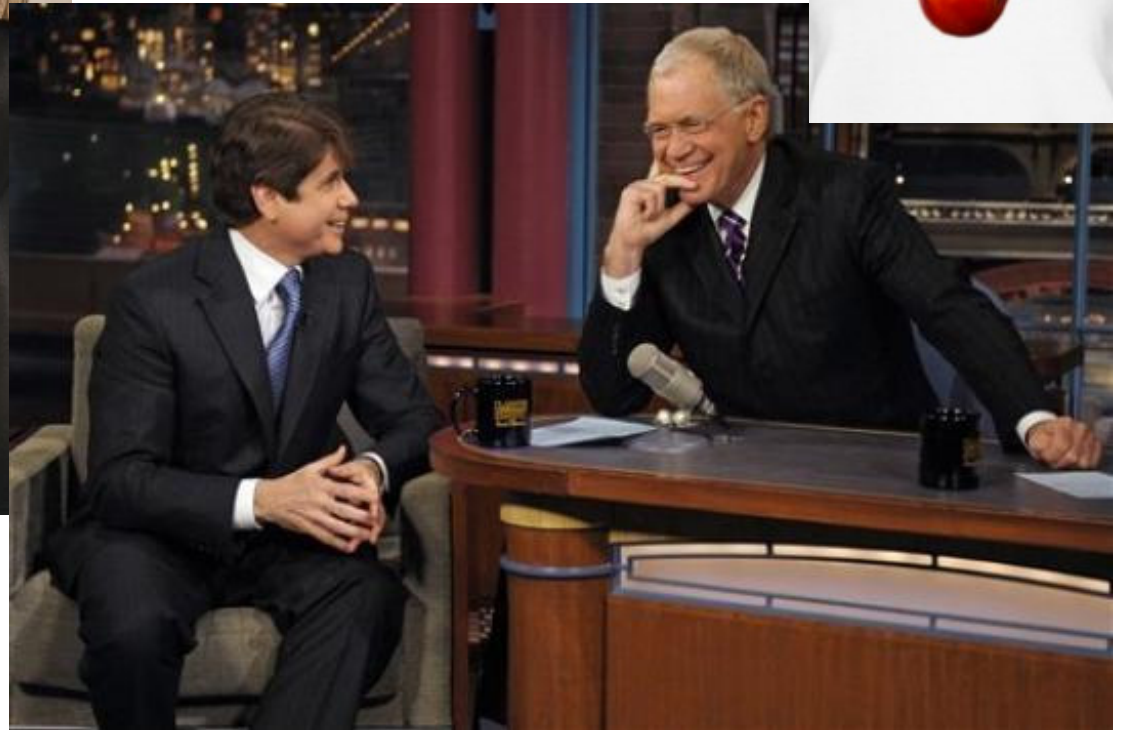
## Who was missing?





Illinois may have celebrities

but neither have given us...



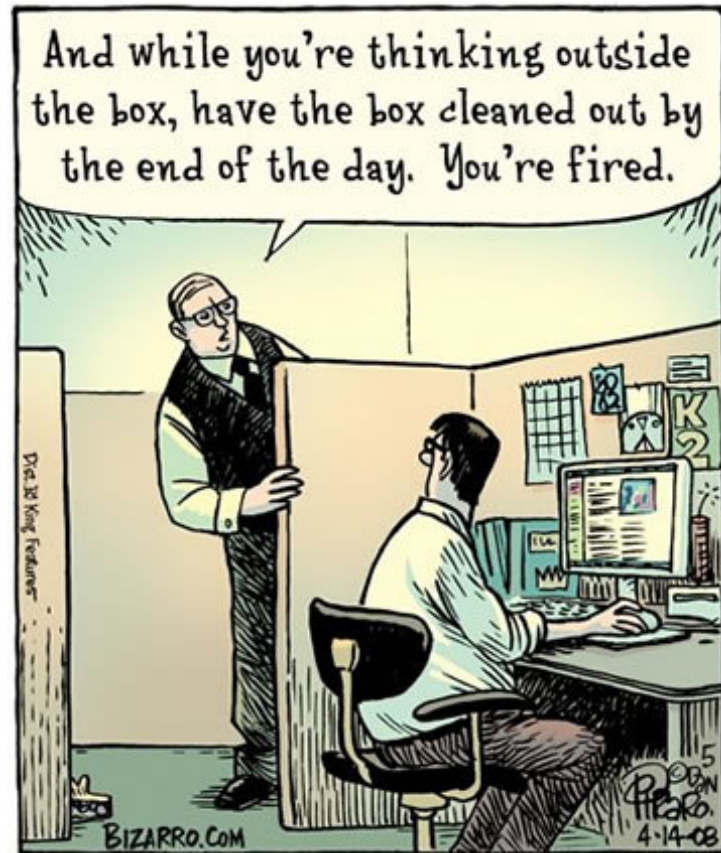


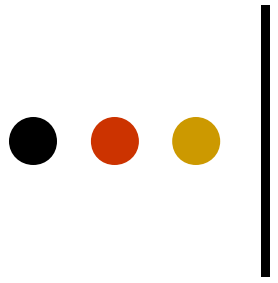




2 years

???State and private partnership???





# Illinois Guide By Your Side

**ILLINOIS PRESENTS A  
COLLABORATION:  
ILLINOIS HANDS & VOICES,  
CHOICES FOR PARENTS  
AND THE ILLINOIS NEWBORN  
HEARING PROGRAM**





# Supporting Individuals/Organizations

- Barbara Murphy
- Carrie Balian
- Chicago Consulting Physicians
- Children's Memorial Hospital
- Chicago Hearing Society
- Child's Voice
- Choices For Parents
- Division of Specialized Care for Children
- Foundation for Hearing and Speech Rehabilitation
- Greg Hubert
- Hands & Voices
- Hearing & Vision Connections
- IL Newborn Hearing Program
- (DHS, IDPH, DSCC are program partners)
- IL Service Resource Center
- IL Supervisors of the Hearing Impaired
- International Center on Deafness and the Arts
- Illinois Chapter of the American Academy of Pediatrics
- IL Chapter of AGBell, Sinai Children's Hospital - Deaf Access Program
- University of Chicago – Pediatric Cochlear Implant Program



# Funding for IL GBYS

- Financially:
  - DSCC, CHOICES for Parents, private donations
- In-Kind:
  - Hearing and Vision Connections, Illinois School for the Deaf, Department of Human Services
- Additional fundraising
  - Shop With Scrip program & 2009 Walk 4 Hearing
    - [www.shopwithscrip.com](http://www.shopwithscrip.com) - Enter **ED2CCL6419145** to have your purchases support the Illinois GBYS program
    - 2009 Walk 4 Hearing will be in October in the Chicagoland area

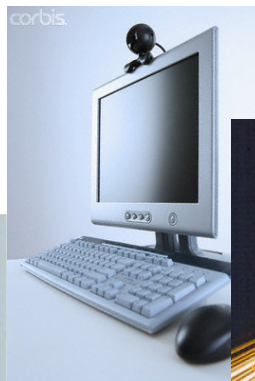


# Illinois Timeline

- o Interview/hire Program coordinator (Feb. 09) **DONE**
- o Interview/hire Parent Guides (Mar. 09)
- o GBYS initial training May 15-17 2009
- o Summer 2009 start to serve families

# Overview of a Parent Guide/Family meeting

- Parent Guides will attempt to meet with a family face to face at least once during their six engagements. Illinois will maximize technology for outreach.





# Future of Illinois GBYS

- Statewide and Regional conferences
  - Host, Support and Collaborate
- Additional Guides
  - Representing various cultures & languages



# Contact Information

- Interested in participating in GBYS?
- Do you want to offer support either financially, through resources or In-kind donations?
- Want to refer a parent to be a Parent Guide?
  - Carrie Balian, GBYS Program Coordinator  
847.431.0760
  - Karen Aguilar, CHOICES for Parents  
866.733.8729
  - Ginger Mullin, DSCC 800.322.3722
  - Beth Donofrio, IL Hands & Voices  
877.533.5279





# Minnesota GBYS History

- Fall 2000: MN Hands & Voices founded
- Fall 2005: Funding secured for Guide By Your Side
- March 2006: Out State Regional Parent Guides hired 3 Metro Guides = Total of 9 Guides for the State  
(1 Part-time Administrative Assistant)
- April 2006: Initial Kick-off/ 1<sup>st</sup> Annual Training in conjunction with MN UNHS/EHDI Summit
- May 2007: 2<sup>nd</sup> Annual Training
- April 2008: 3<sup>rd</sup> Annual Training 4-08 and MNHV becomes 1<sup>st</sup> Point of Contact for MN Dept of Health EHDI





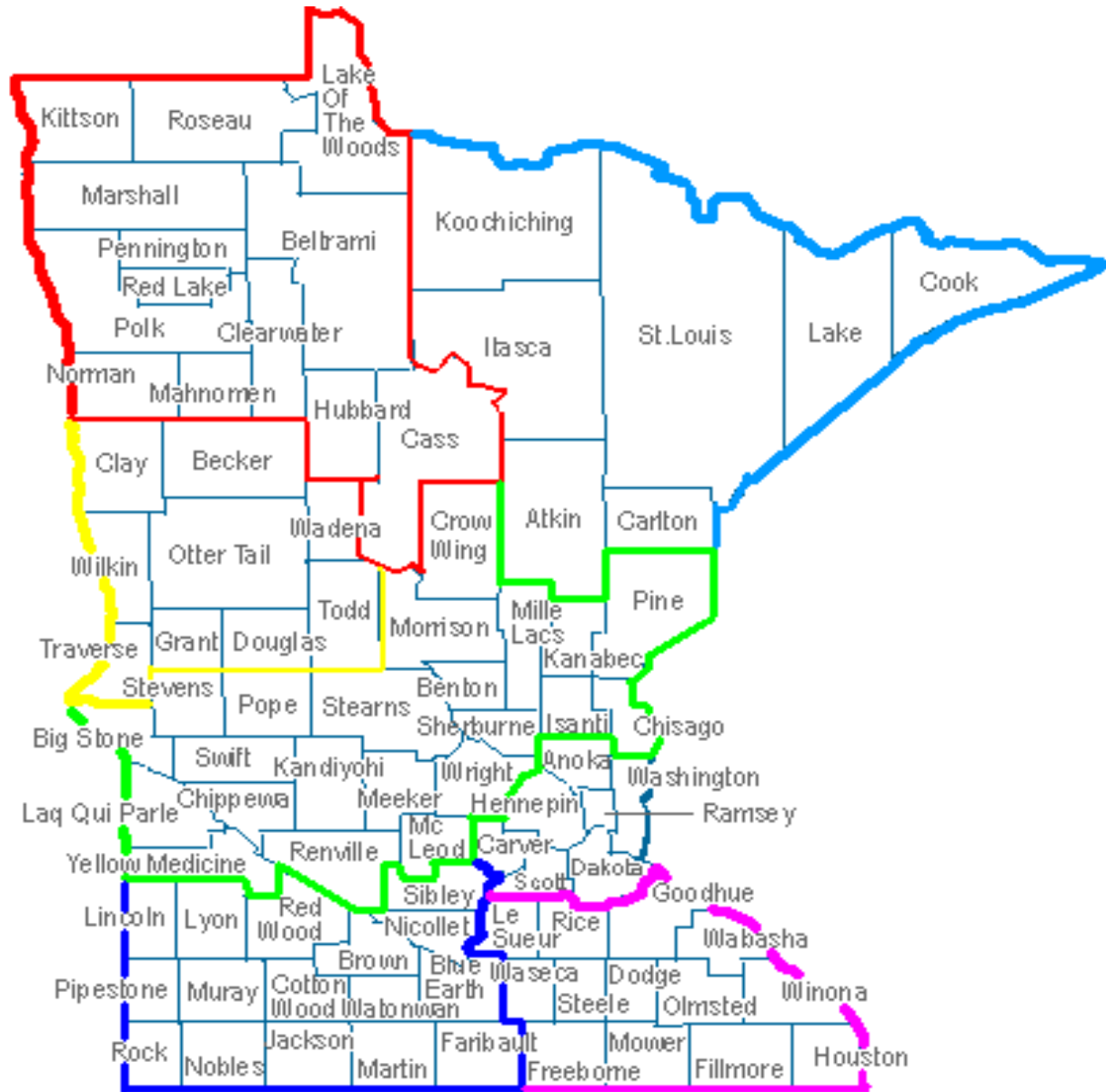
# MN GBYS Structure

- 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 – MNHV is 1<sup>st</sup> point of contact for EHDI at MN Dept. of Health
- 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)

# Minnesota GBYS Funding

- Seed money secured through capital campaign—private foundation
- Confirmed funding for 2007 through MN Dept. of Health
- Success in 2007 Legislature- obtained \$199,00 for 2 years (ends June '09)
- Have contract extension with MN Dept. of Health through June 2010 for over \$200,000 from their funding through hospital blood spot fee
- Still pursuing other sources: foundations, United Ways, individual donors, Federal Family Support dollars, Sertoma's, Lions, etc.





**MN GBYS Regions**



# Signs of MN GBYS Success

- 2008 served 929 families and professionals (368 increase over 2007 and attributed to 1<sup>st</sup> point of contact for MDH)
- 100% of returned parent surveys indicated the MNHV information was “helpful” or “very helpful.”
- 91% of parents indicated that they did increase their support network or they intend to pursue connections/resources in the future.
- 97% of parents indicated the Parent Guide was “helpful” to “very helpful.”

## Survey Comments:

- “I never felt like I was alone during this difficult time.”
- “We like that we can get connected with people quickly and that they provide lots of information about education and events that I wouldn’t be able to go out and find quickly with a new baby”
- “They helped me at the moment I most needed it and they cared as much as I do about the health of my child.”  
(Translated from Spanish)

# Colorado GYBS Program



HANDS&  
VOICES

**Sara Kennedy**  
**Assistant Director,**  
**Colorado Families for Hands & Voices**  
**EHDI Conference 2009**



## **A Patchwork of Funding**

- HCP/EHDI program funding
- MCH Grant
- Colorado School for the Deaf and the Blind
- Kennedy Trust Fund Grant
- Phonak, Sertoma, CRID fundraising, membership dues, private donations,
- Employer donations
- Annual Gala



## **The Parent from Hell, The Cookie Mom, the PhD, the Good Friend**

Guide Program CoDirectors

Statewide support:

- Two Spanish speaking Guides
- One School for the Deaf campus Guide
- One UHL Guide
- One Deaf Dad

Regional support: 6 parents of children with bilateral loss, from mild to profound, ASL, SEE, Oral, CI, ... from age 3 to 11





# One Bite at a Time

- Last year - 201 family contacts, 51 additional home visits, 21 IEP's or IFSP's attended.
- 1750 parents and professionals on email lists, with hundreds of contacts monthly to and from Guides.
- Each guide typically contracts for 10-15 hours a month at \$18.00 an hour, plus approved expenses.
- Training is provided through staff meetings, presentations (SFWOB, etc) support to attend selected conferences, mentoring and contacts with other states through the GBYS listserv.



## Referrals: Where We Find Families

70% from COHear program after  
confirmed diagnostics through  
EHDI system

- 10% from audiologist directly
- 10% self referred
- 10% Referred from Community:  
Easter Seals, TOD, in line at Target...



# Services Offered

- Support birth to 21
- Parent matching
- IEP and insurance advocacy
- Connection with local resources
- Two events in each region per year, social/educational/collaborative
- Email listservs for regional information



## **Systems Representation and “Products”**

Colorado Infant Hearing Advisory Committee,  
Regional EHDI teams, Hearing Aid Legislation Task Force  
Deaf Education Reform, Interpreter Advisory Committee,  
Cochlear Implant Consortium,  
CSDB strategic plan task forces,  
Colorado Home Intervention Program advising,  
Local school districts, LICC’s, and and many more

*Statewide Symposium and Parent Strand*

*Colorado Resource Guide (updated biannually)*

*Colorado Parent Funding Toolkit (currently being updated)*

*Bridge to Preschool*

Colorado Website information, Guide Stories

[www.cohandsandvoices.org](http://www.cohandsandvoices.org)



# A Look at the Future

- Contact Manager Software
- More online courses
- Ambassadors
- Mining our Database
- All Unilateral - eligible for Part C
- “interesting times”

WISCONSIN FAMILIES



FOR HANDS & VOICES

# Guide By Your Side

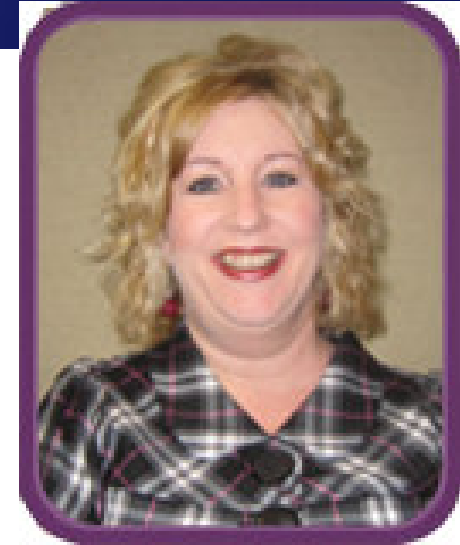
Elizabeth Seeliger, Wisconsin



# WI GBYS Infrastructure & Administration

GBYS Program Coordinator is:

- Laurie Nelson, parent of a 14 yr old daughter who is hard of hearing
- the Vice President of WI Families for Hands & Voices
- employed as a .60 FTE by the Wisconsin Educational Services Program for the Deaf and Hard of Hearing – Outreach Program (WESP-DHH)
- GBYS Program Coordinator and responsible for planning and consultation on other policies and programming that may impact families





# Infrastructure & Program Administration

## ○ Parent Guides are:

- LTE employees of WESP-DHH
- Members of Wisconsin H & V
- A team!

## ○ Parent Guide Team Composition

- 23 parent guides
  - 2 parent guides are bilingual
  - 2 have children with AN/AD
  - 2 have children who are deaf blind
  - 2 have children who are deaf with additional conditions





## Funding

- IDEA Preschool Discretionary Grant Dollars
- GPR allocation to the WI School for the Deaf
- Federal OSEP DPI resources
- MCHB Grant Funding



## Program Components

- EHDI Loss-to-Follow-Up Activities
  - At referral on inpatient hearing screening
  - At referral on outpatient hearing screening
- Direct Parent- to-Parent Support
  - Immediately after identification (6 hours)
  - At transition out of Part C (2 hours)
- Representation at the Systems Level
  - EHDI Advisory Committee
  - Learning Collaborative Community Teams



## GBYS Program Outcomes

- 100% of GBYS families are connected with the Wisconsin Part C Program
  - only 50% of total identified children are enrolled in B-3
- Type of service provided:
  - 48% Support
  - 32% Information (i.e., communication mode options, hearing evaluation/hearing aids, impact of hearing loss on child)
  - 20% Resources



## Hands & Voices: Parent-to-Parent Match

### Parent-to-Parent Match Application

- I wish to be immediately matched with another family.
- I wish to allow other families looking for a match to contact me.
- Both; I would like an immediate match AND I would like future families to contact me.



## Quotes from WI Parents

"Our 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 for offering the GBYS Program."



**Try GBYS in your state!**

Contact us for  
More information:

[gbys@handsandvoices.org](mailto:gbys@handsandvoices.org)

[www.handsandvoices.org](http://www.handsandvoices.org)



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YOUR SIDE™**