

# **2011 State of the World Hands & Voice Report**

## 2011 BOARD OF DIRECTORS

- Janet DesGeorges
- Susan Elliott
- Cheryl Johnson, President
- Harold Johnson
- Candace Lindow Davies
- Ruth Mathers
- Djenne-Amal Morris
- Karen Putz
- Leeanne Seaver
- Elizabeth Seeliger
- Teresa Kazemir
- Christine Yoshinaga-Itano

### Demographics of 11 members

- ~ 7 parents, 5 professionals
- ~ 2 are DHH consumers
- ~ 1 Sibling
- ~ 1 African American, 1 Asian American, 1 Native American,

## STAFF

- Leeanne Seaver, Executive Director
- Janet DesGeorges, Outreach Director

## SPECIAL PROJECTS

- Vicki Hunting and Terri Patterson, Chapter By Your Side Coordinators
- Stephanie Olson, Guide By Your Side DHH Guide Coordinator
- Jeannene Evenstad, Administrative Support
- Joseph DesGeorges, Director of Technical Communications
- Sara Kennedy, Editor, The H&V Communicator
- Lisa Kovacs, GBYS National Program Coordinator
- Lisa Eberlein, Director of Development & Fundraising

**Harold Johnson, BOD**



**Candace Lindow Davies**



**Karen Putz**



**Christie Yoshinaga-Itano**

**Djenne Morris**



**Elizabeth Seeliger**



**Ruth Mathers**



**Teresa Kazemir**



**Susan Elliott, BOD**

**We are  
Hands & Voices...**

Our illustrious leadership team (be afraid):



from left: Janet DesGeorges, Outreach Director  
Cheryl DeConde Johnson, Board President  
Leeanne Seaver, Executive Director

# Staff



**Lisa Eberlein, H&V Dir of Dev  
& Fundraising with Ford & Stella**



Joe DesGeorges,  
Tech.Communications



Lisa Kovacs, GBYS National  
Program Coord., with son, Anthony



Stephanie Olson,  
GBYS DHH Coord.



Terri Patterson w/Riley  
Chapter Support



Vicki Hunting,  
Chapter Support



Jeannen  
Evenstad  
Admin.

# HANDS & VOICES CHAPTER COUNT

## 26 APPROVED

Colorado (flagship),  
Arkansas, Arizona, Delaware,  
Idaho, Illinois, Indiana,  
Iowa, Georgia, Kentucky  
Louisiana, Maine  
Michigan, Minnesota,  
Pennsylvania, Nebraska  
New Mexico, Nevada, Ohio,  
Oregon, Texas, Vermont, Washington,  
West Virginia, Wisconsin, Wyoming

## 11 PROVISIONAL

California, Connecticut,  
Florida, Hawaii, Military  
H&V, New Hampshire,  
North Dakota,  
Oklahoma, Utah,  
Virginia, Tennessee

6 POSSIBLE: Alabama, Montana, Kansas, New York,  
South Carolina, Missouri

# INTERNATIONAL H&V GROWTH

## 2 APPROVED

- British Columbia, CA
- Kenya

## 3 POSSIBLE

- Australia H&V
- Hands & Voices Italia
- Nigeria H&V

## 3 PROVISIONAL

- Ontario H&V, CA
- Kamay at Boces/Philippines
- Pacific Hands & Voices (Guam, Saipain/CNMI et al)



# Hands & Voices goes Global

**Global Coalition of Parents of Deaf/Hard of Hearing Children** [www.gpodhh.org](http://www.gpodhh.org)

Mission Statement: The GPOD promotes a communication-unbiased parent perspective to early identification and intervention systems, educational systems, and support services for families with children who are deaf or hard of hearing. GPOD is an international collaboration of parent groups dedicated to promoting improved systemic protocols and practices which encourage informed choice and the empowerment of families with children who are deaf or have hearing loss.

- GPOD completed a parent survey representing 32 countries worldwide
- Tallied responses & wrote “Recommended Practices in Family Support” & presented to UNHS Industry at NHS 2010, Como Italy



Deaf Children  
Australia





# *Hands & Voices is co-sponsoring...*

1st International Congress on Family-centred Early Intervention  
for Children who are Deaf or Hard of Hearing



- H&V is working with parent leaders in GPOD and other organizations to develop and host the Parent Strand of the FCEI Conference in Bad Ischl, Austria, 2012
- We will be presenting a keynote on GPOD Recommended Practices in Family Support
- H&V has successfully lobbied for funding of parent leader participation from MedEI, the corporate sponsor

# What does national H&V do for state chapters?

- National website that links parent inquiries to local contacts in their own state
- **Simultaneous top-down/bottom up agenda leverage**
- H&V branding and credibility
- National network for instant info, feedback and advisement
- **High-quality, recognizable products and services**
- Access to vast vetted resources
- **Parent-to-Parent “rare” connections**
- **Representation at the national DHHA**
- National issues awareness to state chapters
- Program replicability
- **Strength in numbers!**

# Tech Support to Chapters:

- State Listservs (yahoo and others) are utilized to get the word out on legislation/events/conversations
- Start-up support & mentoring including non-profit guidance, SOPs, etc...
- All State chapters receive basic Filemaker Pro for database gathering; Database collection leads to information collection about who/what we are!
- Quarterly issues of *The Hands & Voices Communicator* provide...
  - cutting edge information
  - quality-controlled image & exposure
  - credible sources
  - on-going mechanism for communication to locales
  - national networking & issues reach
- Website start up tech support & events calendar

# Current H&V Affairs...



GUIDE BY  
YOUR SIDE

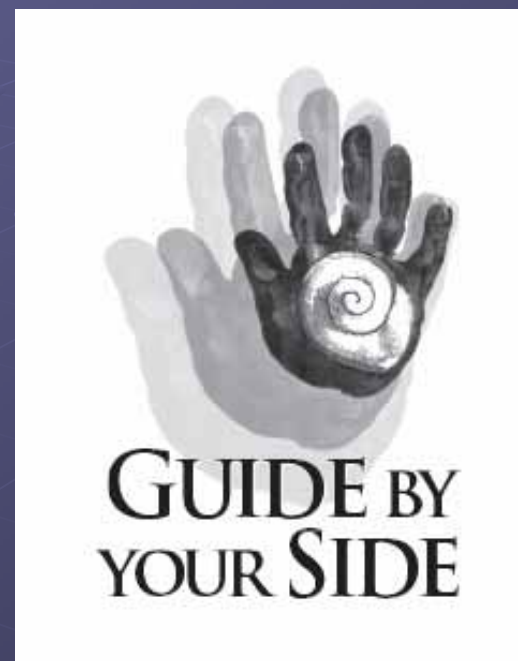
- A program based on direct feedback from families sharing their opinions on what is most helpful to them: **direct support from experienced trained parents of deaf/hh children.**
- Modeled after H&V unbiased support philosophy and replicable in early intervention systems.



## 17 GBYS Implemented Programs

- Arizona: Jeanne Hollabaugh
- Colorado : Janet DesGeorges
- British Columbia, Canada: Teresa Kazemir
- Delaware: Julie Johnson
- Illinois: Carrie Balian
- Indiana: Lisa Kovacs
- Iowa: Susan Hagerty
- Kentucky: Susan Franke
- Maine: Deb Riddell
- Michigan: Laurie Lange
- Minnesota: Candace Lindow Davies
- Oregon: Helen Cotton-Leiser
- Pennsylvania: hiring now
- Texas: Debbie Kopp
- Washington: Christine Griffin
- Wisconsin: Laurie Nelson
- Virginia: open

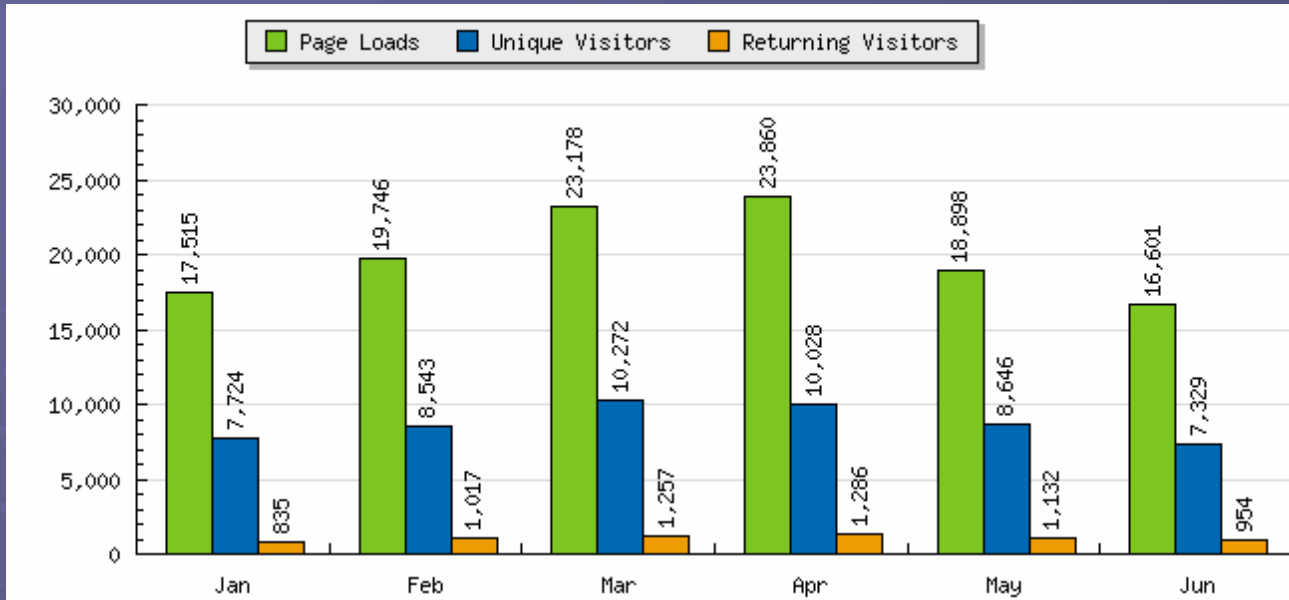
## H&V GBYS Programs



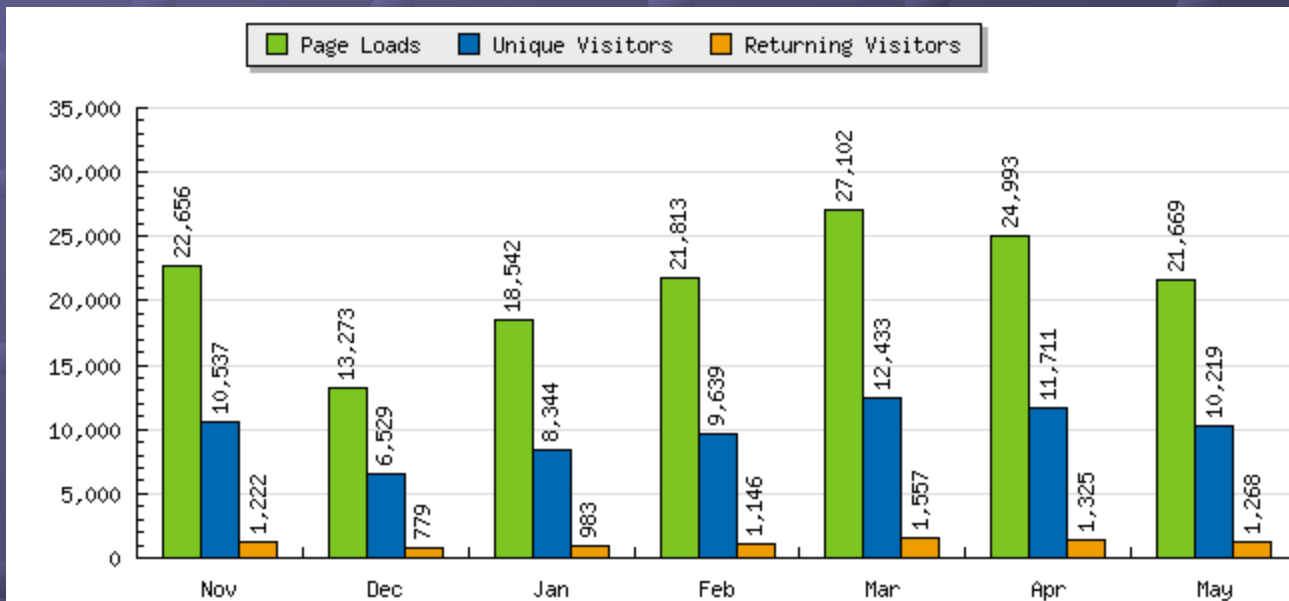
1 GBYS START-Up  
(Pending)

- Arkansas: Mandy McClelland

2010



2011



# 2011: website useage stats show increase in every category!

	Page Loads	Unique Visitors	First Time Visitors	Returning Visitors
<b>Total</b>	<b>150,048</b>	<b>69,412</b>	<b>61,132</b>	<b>8,280</b>

<b>Average</b>	<b>21,435</b>	<b>9,916</b>	<b>8,733</b>	<b>1,183</b>
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Month	Page Loads	Unique Visitors	First Time Visitors	Returning Visitors
May 2011	21,669	10,219	8,951	1,268
Apr 2011	24,993	11,711	10,386	1,325
Mar 2011	27,102	12,433	10,876	1,557
Feb 2011	21,813	9,639	8,493	1,146
Jan 2011	18,542	8,344	7,361	983
Dec 2010	13,273	6,529	5,750	779
Nov 2010	22,656	10,537	9,315	1,222

## 2010

	Page Loads	Unique Visitors	First Time Visitors	Returning Visitors
<b>Total</b>	<b>119,798</b>	<b>52,542</b>	<b>46,061</b>	<b>6,481</b>
<b>Average</b>	<b>19,966</b>	<b>8,757</b>	<b>7,677</b>	<b>1,080</b>
Month	Page Loads	Unique Visitors	First Time Visitors	Returning Visitors
Jun 2010	16,601	7,329	6,375	954
May 2010	18,898	8,646	7,514	1,132
Apr 2010	23,860	10,028	8,742	1,286
Mar 2010	23,178	10,272	9,015	1,257
Feb 2010	19,746	8,543	7,526	1,017
Jan 2010	17,515	7,724	6,889	835



# DHHA: Deaf Hard of Hearing Alliance

- Alexander Graham Bell Association for the Deaf and Hard of Hearing
- American Academy of Audiology
- American Academy of Otolaryngology-Head and Neck Surgery
- American Society for Deaf Children
- CAID/Council for American Instructors of the Deaf
- Conference of Educational Administrators of Schools and Programs for the Deaf
- Cued Language Network of America
- Hands & Voices
- Hearing Loss Association of America
- Media Access Group at WGBH
- National Association of the Deaf
- National Court Reporters Association
- National Cued Speech Association
- TDI
- TEC Unit

## ISSUES...

- ESEA/NCLB & EHDl Reauthorization
- Recommended federal funding of DHH programs
- Collaborative & coalesced unity on hot topics:
  - Audism debate
  - Protests at AGBell
  - Media misrepresentation of DHH issues
- Fractious, divergent outlooks from individual orgs who tend to do their own “hill walk”
- Obama Administration encourages alliance; Kareem Dale is special advisory on disability (1<sup>st</sup> time ever position)

# The Book of Choice ©

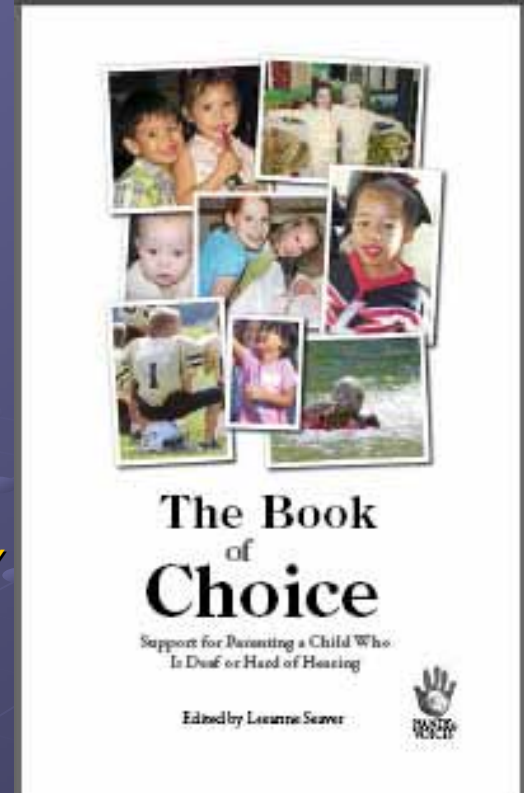
*~ Parents sharing what they know now that they wish they'd known from the start.*

*~ A comprehensive, vetted glossary*

*~ Featuring our most popular topics from the H&V Communication Considerations A to Z™ series*

*~ Order on-line on our website*

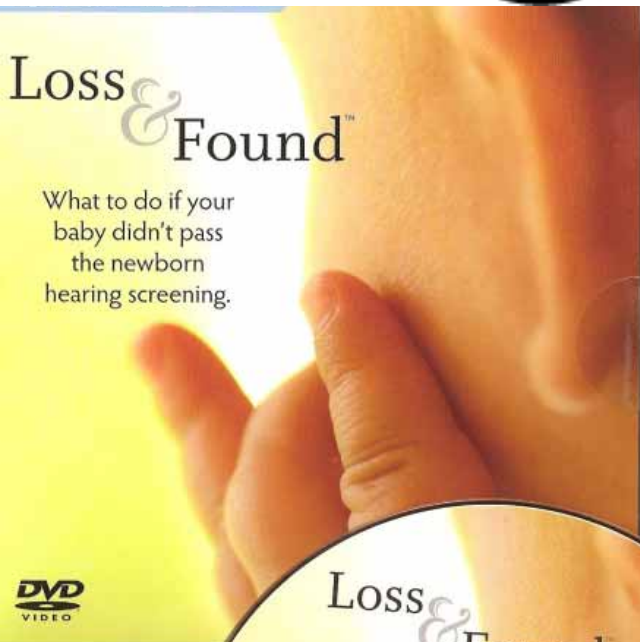
- **Approx. 3200 sold to date**
- **Features adults who are deaf or HH reflecting on “what my parents did right”**
- **Now available in Spanish, courtesy of funding from Texas and Minnesota H&V network**
- **Selected as the text for numerous Teacher of the Deaf training programs!**



# ***The Hands & Voices Communicator™***


- Our newspaper is published quarterly, and mailed to 29 states and two countries. Its distribution is over 5000 and rapidly growing. Secondary and tertiary readership from subscriptions to schools, libraries, service provider waiting rooms (like audiologists, ENTs, speech therapists, etc...) brings the reach of *The Communicator* to an estimated 15,000 quarterly.
- *The H&V Communicator* covers cutting edge topics, current technological trends, stories by families, adults who are D/HH and articles by well-known authors and experts in the fields of research, technology, education, psychology, and medicine. It is a balanced presentation of diverse topics so there's always something for everyone.

# Loss & Found™



Loss & Found™

When parents find out their baby didn't pass the newborn hearing screening, what they'll do next depends a lot on the timing and accuracy of the information that's provided to them. Too often, the issue is dismissed or the next steps are not clear, and parents do not follow through with diagnostic testing. Loss & Found™ features parents who have "been there, done that" sharing a compelling message that's sure to inspire every viewer to follow through and do the right thing for their child.




**HANDS & VOICES**

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

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[www.seavercreative.com](http://www.seavercreative.com)

**DVD VIDEO**

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Please call 1.866.422.0422 for information on how to order this DVD.



"Powerful... this DVD will help us find the babies who get lost without completing their follow-through testing."

Albert Mehl, M.D., Chair,  
Colorado Infant Hearing  
Advisory Committee



An H&V DVD that can find families who are lost to follow-thru featuring parents who've *"been there, done that"* talking about the importance of follow-up testing after a failed newborn hearing screen.

Videostreaming on our website!

Sponsors: Arizona, Colorado, Illinois, Indiana, Massachusetts, Michigan, Nebraska, Virginia



# Hands & Voices Parent Training

**We Are Hands & Voices** . Supporting Families Without Bias. **Is This a "Deaf Thing?"**  
. **A Parents Wishlist for Professionals** . **Special Education Law & DHH Students** .  
**Advanced Advocacy for DHH** . Beginning With the End in Mind . **What Do I Say**  
**When...** . The Art of Story . Communication Conflict Management . **SIBLINGS** .  
**Encountering Emotions** . Communication Considerations & Decision Making .  
**Methods, Modes & Matches** . Parents As Allies . **Deaf Cultural Sensitivity &**  
**Etiquette** . **Spanish Speaking Family Support** . Parents at the Podium . **DHH**  
**CASE LAW** . The Turbo IEP . What Parents Need to Know About  
**Recommended Practices in Deaf Ed** . **The Deaf/HH Child's Bill of Rights** .  
**Headin' Em Off at the Impasse** . A is for Access: How to Provide Full & Effective  
Communication Access for DHH Students . Parents from Hell & Other Advocacy  
Myths, **Chapter Management**, **FUNDRAISING**, *and more!*

# Our Speaker's Bureau is growing...



Djenne-Amal  
Morris, NC Parent  
~ Deaf Plus issues  
~ Parenting a  
Deaf Child with  
Multiple Needs



Karen Putz,  
Deaf Adult  
~Deaf and  
Parent  
perspective



Keith Garrett,  
AZ Parent  
~ Holistic  
Parenting  
~ Grief & Loss



Lisa Kovacs, IN Parent  
~ Hands & Voices topics  
~ GBYS



Terri  
Patterson,  
GA Parent  
~H&V  
Chapter  
Development



Teresa Kazemir,  
BC, Canada Parent  
~ Unilateral/Microsia  
~ H&V Topics



Robt & Katherine Baldwin, TN Parents  
~ Real world parenting with  
3 deaf children  
~ All our kids are deaf—all different



Susan Elliott, Deaf Adult & Nat'l  
Teacher of the Year Finalist '09  
~ Deaf Sensitivity Training  
~ 21<sup>st</sup> Century Learners  
~ H&V Topics



Dane Seaver, Young Deaf Adult  
~ Growing up in a hearing family  
~ Understanding Deaf Perspectives  
~ D/hh Youth Group Leader

# **H&V sponsors the National Deaf Education Project Now**

- **H&V funds & maintains [www.ndepnow.org](http://www.ndepnow.org)**
- **Clearinghouse of all deaf education reform including states where new legislation has passed like DCBR**
- **Links to The National Agenda website**
- **Promotes The Summit on Deaf Education and provides a record of conference proceedings**
- **Provides technical support to inquiries regarding the Deaf/HH Child's Bill of Rights**

# CDC/Marion Downs Center

## THE NECAP STUDY:

- Looking at Developmental Outcomes for kids in different states
- Utilizing state H&V chapters to access parents, and increase project usage through relationships with professional counterparts
- **2011 OR H&V GBYS Program first to use GBYS guides to meet and collect the NECAP data from families**

Research on parent satisfaction, perspectives, participation and involvement in systems development

- Help in characterizing EI systems in states through interviews



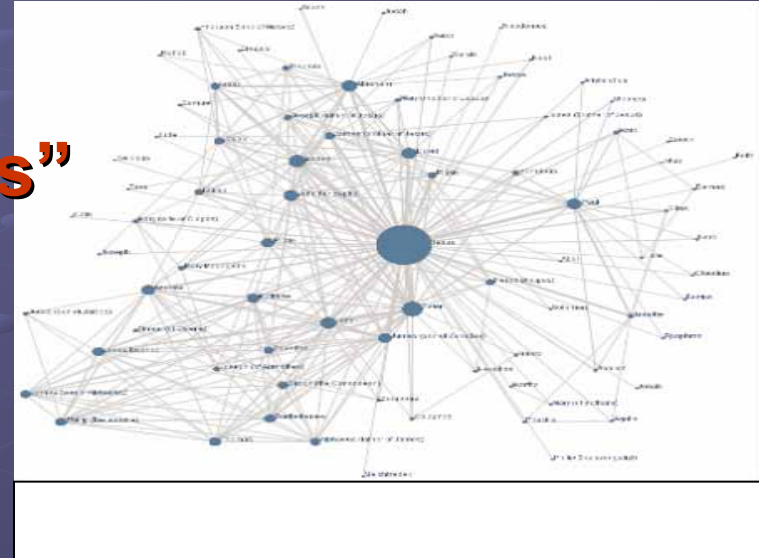
# NCHAM: National Center on Hearing Assessment & Management

- H&V provides thought leadership and parent input to EHDI systems by promoting our organization leaders onto committees (ex: EHDI planning committee)
- NCHAM developed national brochure on communication for newly ID'd families—H&V weighed in
- 2010-15 NCHAM Grant from MCHB allocates family support funding to H&V
- NCHAM/EHDI Parent Advisory Committee begun in 2011 is chaired by Janet DesGeorges

# Observe . Understand . Respond

*DHH Child Abuse/Neglect Study: A research project  
with H&V and Michigan State University*

**Where are the “bright spots”  
that indicate we’re doing  
something effective  
and helpful?**



Child abuse and neglect is a reality. Unfortunately, it is a reality our children are at even greater risk to experience. In recognition of this risk, Hands & Voices has taken a leadership role to address this problem. This leadership, as supported through the work of faculty and staff from Michigan State University, ChildHelp, and the National Exchange Club Foundation, has the potential to reduce the odds that our children will become victims.

Project Director, Harold Johnson, PhD, H&V BOD

# ASTra: Hands & Voices

## Advocacy Support and Training Program



ADVOCACY  
SUPPORT &™  
TRAINING

**Problem:** How do we support d/hh kids in school with educational advocacy that recognizes their unique needs related to communication access?

### **Solution: ASTra**

This intensive educational advocacy training covers the fundamentals of special education law all the way through advanced advocacy strategies and case law.

**H&V ASTra programs now in place in Wisconsin, Georgia and Colorado.**

**Is your chapter ready to take this on?**

# CDC Parent-to-Parent Subcommittee

- Committee Chairs with H&V roots
  - Past chairs: Candace Lindow Davies, Molly Martzke
  - Current chairs: Terri Patterson, Janet DesGeorges
  - H&V leaders as members
- Products created:
  - Questions to ask...(audiology, ENT, PCP, SLP, etc.)
  - Communication Decision Guide
  - **IFSP Communication Guide (2011)**
- Presentations at national EHDI conference

H&V's Cheryl Johnson founded this event & H&V is well represented at...

## **The National Summit on Deaf Education**

- Begun in 2005 as an opportunity to acknowledge the problems in the field of deaf ed, and identify solutions; has continued annually since
- Promotes collaboration and engagement with three main stakeholders: 1) a parent leader, 2) a representative from the state department of education and 3) a representative from the state school for the deaf (who must register as a team)
- Charges states with developing action plans to address the underachievement of DHH students (dare we say “reform”?)
- For Summit proceedings, visit [www.ndepnow.org](http://www.ndepnow.org) (an H&V sponsored website)

# The National Investing in Family Support Conference

- 6<sup>th</sup> annual event this year in Raleigh, NC. October 26-28  
*(H&V attendance is always good, but we are no longer officially rep'd on the planning committee)*
- Sponsored by NCHAM [www.infanthearing.org](http://www.infanthearing.org)
- States are encouraged to bring a team comprised of parent leaders and professionals in EHDI/0-3 Systems
- Developing a stronger system of family support and making states accountable for having family support programs in place
- State teams have the opportunity to learn about models of family support (including examples from other states) then do some state team work on site to develop their own plans

# NICHQ

- National Initiative for Children's Healthcare Quality
- Currently in it's 4th Newborn Hearing Screening Learning Collaborative
- National Parent Chair (Janet)
- Almost every state's participating parent on the teams are H&V parents!!
- New 'parent' projects emerging: Parent Road Maps, Parent Surveys etc.

## The Deaf/Hard of Hearing Child's Bill of Rights (BOR)

- State legislation that strengthens the IDEA's "special considerations for deaf students" mandate by providing more specific directions on what issues should be addressed in the IEP of a DHH student.
- In most states, a BOR requires a "Communication Plan" as an addendum to the student's IEP that address that child's individual communication needs.
- This legislation is beneficial to all DHH students regardless of their mode/method of communication; it is not promotive of one approach over another.
- More information on which states have this law in place plus states where there is BOR-type language within state law, see: [www.ndepnow.org](http://www.ndepnow.org) (sponsored by Hands & Voices)



# Next steps for Hands & Voices...

- Sustainability and continuity efforts grow as a national organization (attend policy/procedures meeting Saturday at 7:00 am!)
- Hands & Voices on Twitter: 509 followers!
- H&V Teen network now in collaboration with NTID: creates a mechanism for teens to find each other for friendship and social opps regardless of communication modality!
- Hands & Voices Worldwide Expo (*working title*) creates a conference opp for families & professionals to come together the H&V way for learning, social connections and resourcing!
- Regionalization has established 10 geographic locales for H&V chapter interaction—shared conferencing and training already underway.
- Table-4-Ten Fundraiser now implemented with (>>>) chapters
- ASTra grows: Educational advocacy H&V certification program that supports families directly with a trained team for each chapter to attend IEP meetings, conduct advocacy workshops, and influence educational systems.
- Push for more research that translates directly into something families can access, understand and apply to help their children.



**Everything you do for  
Hands & Voices is making  
a world of difference.**