



HANDS &
VOICES

Supporting Families
With Children with Hearing Loss
In the Military

We are...



- Janet DesGeorges

Executive Director, Colorado Families
for Hands & Voices; Outreach Director,
Hands & Voices, Inc.

- LT Anne Jarrett, Au.D, USNH
Yokosuka Japan

What we didn't know we were getting into....



“There are many people who think they want to be matadors, only to find themselves in the ring with 2000 pounds of bull bearing down on them, and then discover that what they really wanted was to wear tight pants and hear the crowd roar.” – T. Pearce

Families



As audiologists we may provide our service, give resources, and then make our recommendation. After the appointment, the family must find their way.

Families can have different service needs: follow-up to newborn hearing screening or school hearing screenings, needs within the first year after the initial diagnosis, and needs for the parents with older children with hearing loss (HL DX for several years now)

When you look at the whole family – coordination is not just audiology (with or without hearing aids) but educational and medical (acute and chronic)

Military families tend to be very transient and have different needs at different stages of the PCS move (disconnect period, transitional period, connection period). Families can even find themselves moving between branches.

Parent to parent support and access to information is important

Where Do Families Get Support?



The Importance of Parent Involvement



- Research indicates that the single-most important factor in predicting successful outcomes of newly identified deaf/hh babies in early intervention is the active participation of their parents. (Yoshinaga-Itano, Coulter & Thomson, 2000)
- Benefits of Parent involvement include higher reading scores, higher grades on homework, improved attitudes towards school, improved relationships between parents and teachers. (Donahoo, 2001)

How do trained, motivated parents get involved?



- Parent led, centered, involved, directed...
 - *For their own child*
- Parent-to-Parent...
 - *For each other*
- Parent participation through advocacy...
 - *In the System*

Parents learn leadership skills....



- Through our children
- from others (parents, mentors, workshop leaders, professionals....)
- In a variety of places (informal conversations, networking, advisory meetings, at home every day)
- By getting involved on a systems level

What are the burning issues we hear about?

EHDI Issues:

- “Our child was screened, but sent on to an audiologist who doesn’t know how to diagnose infants”
- “Our Part C System doesn’t ‘get’ deafness” – the support is generic

School Age Advocacy Issues:

- “Help, they tell me my son is not eligible for special ed. Because he’s doing ‘too well’?”
- “Help, they’ve assigned a new interpreter to my daughter who uses ASL, and the terp uses SEE?”
- “Help, my school just assigned an SLP who has never worked with deaf kids, and my child just got a CI”

Social/Emotional Issues:

- “My child doesn’t have any friends”
- “My child is being bullied”
- “We’re not sure if our child belongs in the ‘deaf world’ or the ‘hearing world’”

Do you understand the communication considerations & the complexity of the issues *for this family?*

- **Age of Identification**
- **Onset of Hearing loss**
- **Degree of Hearing loss**
- **Benefit from Hearing Aids**
- **Family Dynamics:**
 - Siblings & Extended Family
 - Lifestyle
 - Bilingual issues
 - Culture & Values
 - Attitude & Commitment
 - Finances
- **Multiple Issues or Labels**
- **Family Support System**
- **Urban or Rural**
- **Availability of Resources**
- **Technology**
 - Parents can choose sound
 - Validity of testing
- **Society issues**
 - Beliefs about Disability
 - Social Isolation
- **Child's Innate Abilities:** learning style, personality, development, inclinations
- **Peers & Social Outlets**
- **Educational Options**
- **Long term Goals**
- **Validity of information**
- **Flexibility and fluidity of choice-making process**
- **and more...!**

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.***

Hands & Voices supports and represents...

- Kids with mild, moderate, severe, profound, unilateral, conductive, auditory neuropathy, congenital, acquired, deaf +, or age progressive hearing loss or deafness
- Kids who speak, kids who sign, kids who do both, kids who cue, kids who are aided or not aided, and/or kids who have cochlear implants
- The families of these children and the professionals who work with them in all capacities *from birth through high school graduation*



The Shaping of a System through Parent Involvement

- **Representation:** parent perspectives in the system on advisory boards, committees, forums, taskforces, projects, etc...
- **Collaboration:** partnering with professionals in medical, educational, and government agencies
- **Advocacy:** quality improvement initiatives; doing what those inside the system can't
- **Legislative:** giving “voice” to constituency of minors; putting a “face” on the issues
- **Accountability:** Investing the ‘end-user’ in the development of the product & on-going evaluation

Debunking the Myths



- Parents from Hell: The “angry” parent
- Relegated roles i.e., “the cookie mom”
- Parents can only represent their own experience
- Parents don’t understand ‘systems’
- Parents won’t be able to step out of their own ‘bias’
- If parents are paid by the ‘system’, they can’t represent true parent perspective

Parent Impact on Systems...

- Parent involvement/Leadership provides:
 - Unique perspective of a vested stakeholder
 - Motivated and personal commitment to improvement of the system
 - Lifelong case manager: Understands how different systems/seasons of life relate to each other
 - Systems that are appropriate for and acceptable to families
 - The 'system' is relevant to the actual diverse life experiences of families
 - Better outcomes for kids
 - Parent tested

The Power of Parents



- 1 Parent = A fruitcake
- 2 parents = A fruitcake and a friend
- 3 parents = Troublemakers
- 5 parents = “Let’s have a meeting”
- 10 parents = “We’d better listen”
- 25 parents = “Our dear friends”
- 50 parents = A powerful organization

From the Parent Leadership Associates www.plassociates.org

Hands & Voices Growing Network:

□ Highlighting a few State Chapters in U.S.A:

- **Idaho:** Point of first contact with families
- **Nevada:** First State chapter to HOST national conference outside of CO!
- **Wisconsin:** Unifying other parent groups & functioning as “Parent Guide by Your Side” (GBYS) statewide
- **New Mexico:** State RFP created NM H&V
- **Illinois:** Founded by a deaf parent
- **Michigan:** GBYS Infused into Newborn Hearing System
- **Iowa:** Parent-to-Parent Focus...58 members within 10 mos!
- **Colorado:** Systemic impact, Guide network, Deaf/HH adult mentors, advocacy powerhouse, & more!
- **Oregon:** Start-up efforts from a group of 15 parents & professionals
- **Minnesota:** 15 GBYS Mentors statewide, new legislative funding
- **Georgia:** Official chapter 15 mos. After 1st meeting, with over 30 paid members and 175 committed contacts.

□ International Connections:

- *Australia, Pakistan, South America, New Zealand, England*
 - *with “provisional” start-ups in Canada, Philippines, Italy, Kenya, and Saipan*

Military Hands & Voices



- Start up Efforts:
 - Format for chapter? ‘virtual’ and ‘in person’
 - Forming a committee of parents/professionals
 - Website: www.militaryhandsandvoices.org
 - Identifying the needs specific to military families
 - Connecting families with our state chapters

National Support to State Chapters




- Strategic Leadership and Planning
- Conference Calls
- Annual National Leadership Conference
- Resources: Grant Templates, articles, presentation and workshop support etc.
- National Newspaper and Website
- Common Culture
- The Hands & Voices “Guide By Your Side” Program
- Database Program
- Board Development Strategies

In Summary:

Hands & Voices Branded Activities

- Point of Contact for Newly Identified Families and on-going mentoring from *“Guide By Your Side”*
- Parent & Professional **Training Curriculumms and On-Site Workshops**
- Local/National/International Parent/Professional **Networks**
- Parent **Advocacy & Education** Seminars
- Newspaper/**Website/Resource Guide/Funding Toolkit/Videos/DVDs**
- **Representation** on Committees and Boards locally & nationally
- **Thought-Leadership** for Systems
- New! Hot off the press... ***The Book of Choice***
- **Focused & Effective** on **Deaf Ed Reform**, Deaf Child’s Bill of Rights, **Universal Newborn Hearing Systems**, Early Intervention, Social/Emotional, **Health**, Hearing Aid & other Funding, Medical Home, Legislation, **Systems Change**, Communication Access

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- Families with children newly identified as deaf/hard of hearing may have intense needs
 - **Families' needs continue long past the initial identification**
 - Family support systems need to incorporate children who are identified later and children past identification
 - Tools exist to provide comprehensive and effective family support
 - Military families share many things with all families, but have unique needs as well.

**Leeanne Seaver, M.A.,
Executive Director**

217-357-3647

leeanne@handsandvoices.org

**Janet DesGeorges,
Outreach Director
303-492-6283**

janet@handsandvoices.org

MILITARY Parent Leaders :

**Karen Markert
Deb Schwedhelm**



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