

Early Hearing Detection and Intervention Quality Improvement Project Learning Session

Parent and Family Perspective Strategies for Pediatric Practices



HANDS &
VOICES

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GUIDE BY
YOUR SIDE™

Hands & Voices

Mission

Hands & Voices is a parent-driven organization that supports families with children who are deaf or hard of hearing without bias around communication modes or methodology.

Vision

We envision a world where children who are deaf and hard of hearing have every opportunity to achieve their full potential.

Motto

“What works for the child is what makes the choice right”



Why Families Need Support

- 95% of all children who are deaf or hard of hearing are born into hearing families (Mitchell & Karchmer 2004)
- 90% of these families have no background in deafness or connections to the deaf community (Center for Demographic Studies 1984)

“The key to a successful integration of hearing loss into a family is the degree to which parents are able to integrate hearing loss into their lives” (D. Luterman, 2006)



Where Families Find Support

- Formal Parent Support Groups
 - △ Deaf Specific
 - △ General Disability
- Informal Parent Support

Parent-to-Parent

- Mentor
- Role Model

Adults Who Are Deaf/ Hard of Hearing

family

Information

- Internet Websites
- Brochures
- Books
- CDs/DVDs/Videos
- Resource Guides
- Curricula

Professionals

- Service Coordinator
- Parent Educator
- Early Interventionist
- Audiologist
- Medical Home/ Physician
- Speech/Language Pathologists
- Teacher
- Hospital Staff
- Communication Instructor/Specialist

Existing Communities

- Family
- Friends
- Neighborhood
- Places of Worship/Spiritual



Passive Communication

- Newsletters
- Mass Email Alerts
- Web Sites
- Fact Sheets
- Roadmaps
- Parent Welcome Letters
- New Parent Packets
- Resource guides

Group Interactions

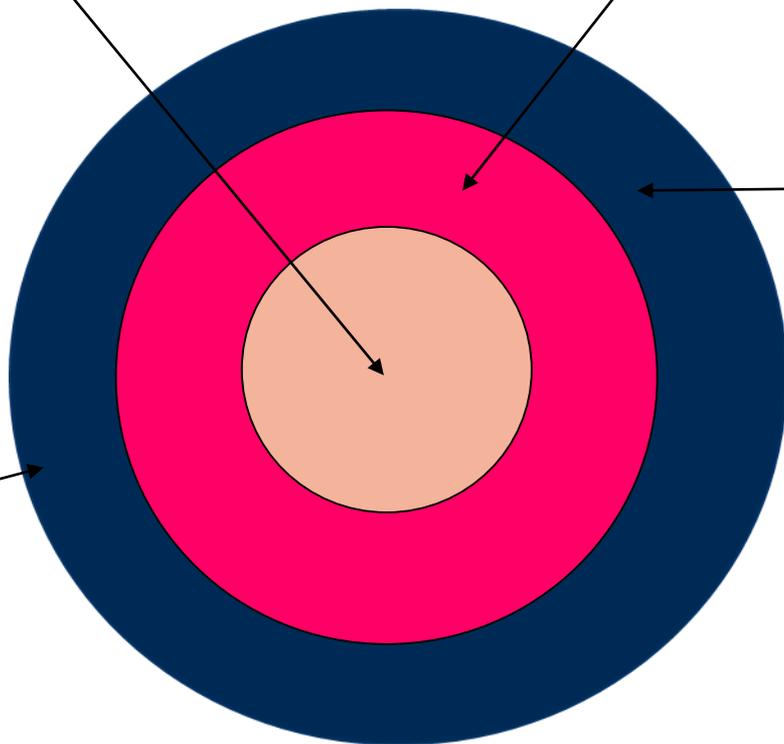
- Social Events
- Educational Workshops
- Conferences
- Webinars
- Retreats
- Regional Family Activities
- Social Opps
- FaceBook

Anonymous Interactions

- Chat Rooms
- Bulletin Boards
- Email
- List serves
- Blogs
- H&V YouTube

One-on-one Communication

- Phone communication
- Email communication
- Facilitated phone/email contact between parents
- In person meetings



<http://www.handsandvoices.org/chapters/starts.htm>

- Kentucky – Sarah Roof Executive Director

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One Family's Journey – Meet Zuzanna and her sweet daughter Matylda

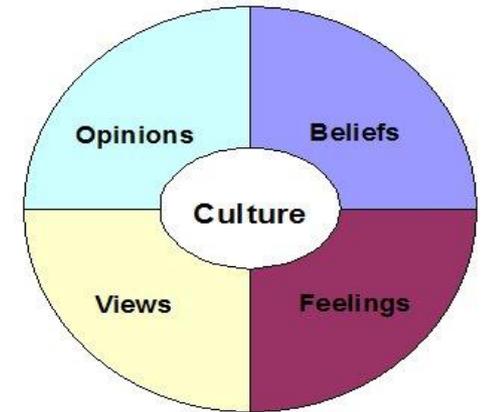


What Parents Report they want from their Medical Home

- ‘Systems’ that collaborate
 - Help in getting from screening to identification to intervention
 - Connecting to the ‘next’ step in the process
- Basic knowledge by physicians about EHDI systems
 - Sense of urgency
 - Don’t provide a “permission not to worry”
- A physician who has knowledge about the basic systems we as families have to navigate (health, education, insurance etc.)
- A physician who can help families understand deafness in context to other health concerns and linkage to developmental milestones
- Respect for the information and expertise they bring to the process



Culture must be considered...



- When the family is from another culture:
 - Cultural Considerations: View of disability, navigating the medical system, interpreting, supports and interventions, what other supports may be needed?
- Deaf Culture: The overarching principle that is shared within the Deaf community is that Deaf individuals recognize being Deaf is a driving part of their identity, and it is a source of pride and cultural connection.
 - Traditionally these individuals refer to themselves as Deaf (spelled with a capital 'D'), or collectively as the Deaf community. "Culturally Deaf" is also a term that is sometimes seen in reference to this community.

MEDICAL MODEL	DEAF CULTURE MODEL
Communication options	Communication opportunities
Hearing loss	Hearing level, status, abilities or differences
Intervention	Involvement or identification
Failed hearing test	Refer with explanation
Diagnosis	Identification
Fix the ear	Modify or cope
Deafness	Deaf, deaf people, being deaf
Hearing impaired	Deaf or hard of hearing
Vocationally limited	Unlimited opportunities
Grief process	Journey
Disability (cannot)	Cultural (adept)
Auditory technology	Visual and auditory technology

Just as hearing people are unique and differ from each other in terms of their preferences, individuals in the Deaf community participate in a variety of different ways.

Parent Partners



Patient- and family-centered medical homes encourage a cooperative partnership between doctors, nurses, other medical staff and the patients' families to provide the **best possible care for children**. One way to demonstrate family-centered care in a pediatric medical home is to invite families to assist with evaluating, planning and improving the practice. **Family Health Partners can play an integral role in a practice's transformation into a medical home and in its continuous quality improvement.**

Family Engagement Guide: The Role of Family Health Partners in Quality Improvement Within a Pediatric Medical Home



<http://medicalhome.nichq.org/resources/family-engagement-guide>

Tips: Engaging Parent Partners

- Articulate to families the value of their experience and how sharing their experience can impact quality improvement efforts.
- Explain the reason and the purpose of the project and what you will do with the information they provide.
- Share an example of how a parent experience/story has made a change in your work/practice.
- Consider easy access and possible cost incurred by the parent in order to participate (childcare, mileage, and other possible cost). If possible offer a stipend or other form of support to family members for their participation.
- Adjust meeting times in order to accommodate a parent partner's schedule. Consider providing solutions for virtual meetings when parents are unable to join in person.
- Consider engaging multiple parent partners to ease the experience for parents and many times hearing other parent's experiences will elicit other thoughts.
- Ensure intentional effort is made to actively engage the parent partner(s). This may include the following: pausing to ask the parent partner(s) their perspective on all aspects of care being discussed; having the parent partner(s) lead certain aspects.

Tips for Parent Partners

- Share your insights and information about your experiences in ways that others can learn from
- See beyond your own personal experiences and represent the needs of other families including: other special needs, medical/cultural viewpoints of deafness, different communication modes, and more
- Respect the perspectives of others
- Speak comfortably in a group with candor
- Work in partnership with others
- Don't be afraid to speak up
- Ask for clarification
- Get input from other parents
- Be motivated to impact systems
- Learn the **system** (e.g., EHDI, QI, “change package,” medical home)

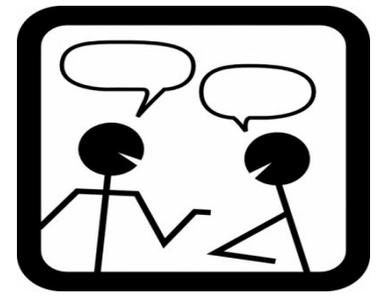
It's a journey



- NBHS
- Diagnostics
- Medical Home
- Early Intervention
- IEP Team Member
 - Advocate
- Role Model and Teacher
 - Transition Expert
- Observer and Supporter



Final Thoughts: Parent Perspective



- It's **not** just about the documentation... The **conversation** with families is most important
- Please don't give families "permission" to not follow-up or to wait
- Get to know your EHDI program and facts to share with families
- Send the message "**you owe this to your child**"
- Learn about family support opportunities in your area and refer families
- Keep **hearing** on your "**radar**"
- Share language milestones and emphasize the importance monitoring progress with families

Thank YOU!



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