EARLY INTERVENTION
WHOLE CHILD
WHOLE FAMILY
WHOLE TEAM

7TH Annual Loeb Family Foundation Symposium
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Disclosures:
Financial — Children’s Hospital Colorado employee
Hands and Voices Headquarters consultant
Nonfinancial— Hands and Voices, Board membership
Identified at the age of three, severe to profound hearing loss
Fitted with hearing aids
Cochlear Implant 2006
Information/options/support
School, speech therapy
Camp for Deaf/hard of hearing children
Sign language
Teaching background
Colorado Early Intervention Program
Hands and Voices
DHH Mentor/Guide
Children’s Hospital Colorado
Creating a Climate of Support

- Serve as a liaison between the clinical professionals and the families
- Treating everyone as valued community members can draw all into relationships of respect
- When communication is strong, teams flourish
  - Teams stay focused
  - Honor all questions
- Work from a strength based philosophy
  - Focus on what is the child doing well
  - Focus on what the team members are doing well
  - Lend a personal perspective into the day to day issues of a hearing loss
Who is on your team?

- Child
- Family
- Pediatric audiologists
- Early interventionist
- ENT/Otolaryngologist
- Speech pathologist
- Social worker
- Child life specialist
- Deaf educator
- Tele-health
- Genetics counselor
- Chaplain
- Family consultant
- Community
- Mentors/Guides HH
Moving beyond the hearing loss

- Babies first, hearing loss second
- Becoming informed will boost your confidence and keep you engaged with the professionals in your child’s life
- Families that can explain the hearing loss can also alleviate the anxiety or questions of other family members
- This is your child, not your profession
Family Life and Early Intervention/Involvement

- Families need to know where to go for support
- Language/communication options
- Basic life needs
- Parent to parent support and resources
- Involvement of professionals with hearing loss
- Multiple therapies
- Families’ voices and opinions are valued in the systems
- The whole child
What do families bring to the visit?

- possible feelings of guilt, shame, fault or anxiety
- fear of the unknown
- feeling that they have little control
- overwhelmed-a new baby
- perspectives of deaf/hard of hearing people that may not be positive
- scary statistics
- fear of rejection or isolation
- being judged by others
- curiosity
- relief that it’s not something worse
- open mind-willing to do anything and everything
- excitement to learn new skills
- desire to have professionals make decisions and do the therapy
- eager to develop new relationships
- internet and video information
Appointments that benefit the whole family

- Early Intervention
  - Siblings are an important part of the process
  - Sleeping babies = sibling opportunities
  - A new activity/toy or book for the sibling to try out
  - Lends to child centered play
  - Siblings create a foundation of acceptance
  - Developmental milestones

- Clinical appointments
  - Multiple, lengthy and boring
  - Sit next to audiologist - be in charge of the lights
  - Acknowledge emotions shared in appointments
  - Try on hearing aids, select colors
The early years

- Language, communication and access
- We value the whole family – siblings, relatives, the community

“These are the places where the foundations for self worth are created.”

*The Circle of Courage* Brendtro, Brokenleg, Van Bockern

- Daycare
- Preschool
- Places of worship
- The car
- Holidays
- Activities
- Family life
Parent Perspectives

“"I was so unprepared for the news.”
“"I want to know what my child is hearing.”
“"All the providers have different goals for our child.  Shared goals would be nice.”
“"The research didn’t fit our child. We had to make a decision based on her.”
“"We don’t fit the typical hearing loss story.”
From the parents...

- “I felt that I had to find out information for myself and then find the professionals who were willing to help me.”
- “Parent to parent support is critical and alleviates the sense of isolation.”
- “Consistent and effective communication is a challenge.”
- “I thought a good hearing test meant that my child’s hearing was improving!”
- Progressive hearing loss

“People tend to underestimate my child”
Involving HH Professionals

- Move beyond asking deaf/hard of hearing people to help at certain times (personal to professional)
- Locate connections within the organization and outside the organization
- Become open and flexible to unique ideas
- Assist parents in becoming the experts
- Families do not need to be in a crisis to benefit from ongoing interactions with deaf/hard of hearing professionals
- Empower families and children to succeed in real life
During a visit to the NASA Space center in 1962, President Kennedy noticed a janitor carrying a broom. He interrupted his tour, walked over to the man and said, “Hi, I’m Jack Kennedy. What are you doing?”

“Well Mr. President” the janitor responded, I’m helping put a man on the moon.”
What are we doing?

We are going to put a deaf/hard of hearing child on the moon!
What I wish I knew then, that I know now...

I wish I had known that children with hearing loss could become whatever they set their minds to.

*I wish knew that my life would be full of options and potential that I could not have possibly imagine while growing up.*

I wish I had known that a cochlear implant would be come a reality.

*I wish I had the confidence that a CI would just change what I hear, not who I am.*

I wish I could have known and realized that you would become the beautiful person that you are today.

*Thank you mom, and I wish I knew then that being angry at you for worrying about me wasn’t fair to either one of us. Book of Choice Hands & Voices*
Thank you!

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