

Creating a Program of Family-Focused Web based Resources

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Sources of Information



- Websites
 - Hospitals, Universities, Advocacy Groups
- Information from companies
- Online chat rooms



Parent Focus Groups



- Immensely grateful for information
- Clear about additional needs
- Primarily
 - Information they forgot from appointments
 - Basic information, available to share with grandparents, schools, etc.
 - Neutral information
 - Share their own feelings, read others



Perspective of the Parents



- They like to learn from people talking
- They like information relevant to their center
- They want to share feelings and experiences, but not online chats
- They want to get information to teens



Program Plan So Far



- Videos that reinforce information on cochlear implants
- Video by teens for teens - CI
- Experience journal
- Webinar on hearing loss for the important 0 - 3 years
- “Targeted Topics” accessible on web



All Resources...

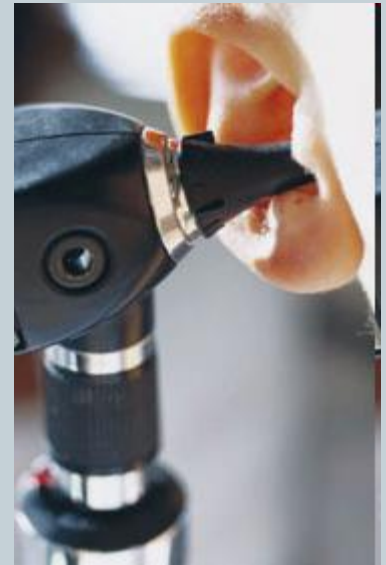


- Respect all forms of communication
- Emphasize on choice
 - Cochlear implant
 - Schools
 - Communication
- Present all sides - good and bad
- Have a child and family focus



Cochlear Implant Informational Videos

- Parents wanted DVDs
 - Take home
 - Share with families
 - Take to school, day care
 - Watch as many times as needed
- Also accessible to anyone
 - CHB website
- Funding
 - Caroline Bass Fund, Hothouse Productions



HOTHOUSE PRODUCTIONS

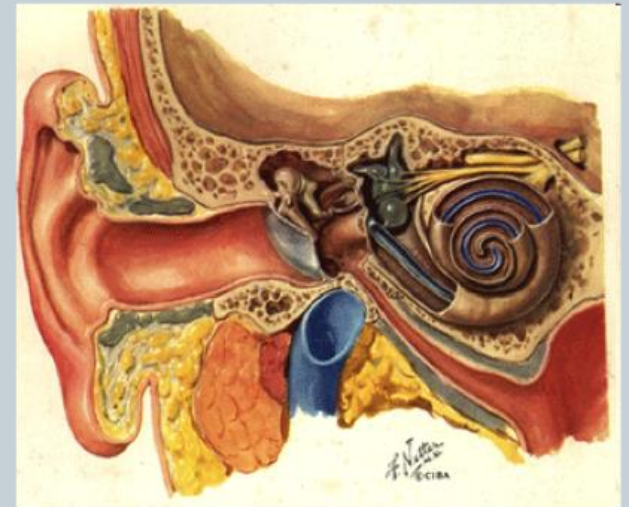
- Boston University
- Garland Waller
 - garwal@bu.edu
- Student run
- Client driven
- 1999
- One of multiple clients



Audiologist's Perspective



- Basic information about cochlear implants
- Include
 - Pictures of implant
 - Pictures of ear
 - Elements of surgery
 - Rehabilitation
 - Mapping
- Information that parents forget
- Pre-decision

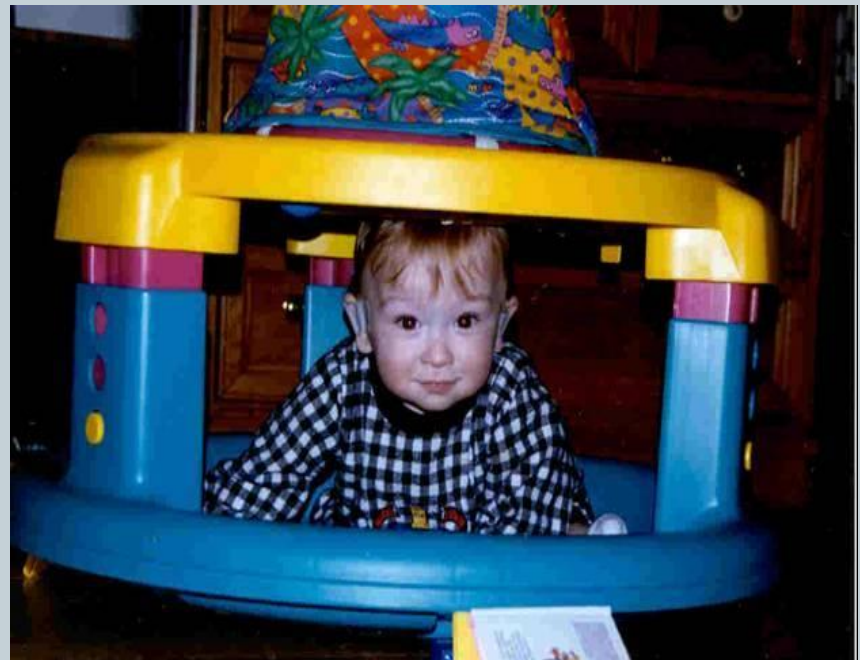




Surgery



- Anxiety topic
- Child focused
- “Friendly” surgeons
- Extended family
- Feedback
 - Anxiety reduced
 - Multiple times
 - Siblings talked



Your Cochlear Implant

Teens



- Teens listen to teens
- Video less formal, more age appropriate
- We let them speak, not scripted
- Whole child, whole life, not just ears
- Fears, adjustments, friends
- Parents of babies loved it!





ExperienceJournal.com



The screenshot shows the Experience Journal website interface. At the top left is the logo for Experience Journal Children's Hospital Boston. To the right is a circular icon with an open book and the text "Our Experience Journal Research Studies". Below this is a paragraph: "The Experience Journals are designed to promote the healthy coping of children and their families who must contend with significant physical and emotional illnesses. The Experience Journals are collections of stories, pictures, and personal experiences from families about what it has been like to live with their children's illnesses. They represent the 'collective wisdom' of these children and their parents as well as their health care providers. We welcome family members to enter and explore any or all of the Experience Journals. The following Experience Journals are available:". Below the text are twelve circular icons representing different conditions: ADHD, Bereavement, Asthma, Cardiac, Cerebral Palsy, Depression, Diabetes, Hearing Loss, IBD, Overweight, and Transplant. At the bottom left is the "Editorial Board" logo, and at the bottom right is a "Search" button with the Google Custom Search logo.

- Children's Hospital Boston
- Series
- Personal experiences
 - Families
 - Children
 - Professionals
- "Collective Wisdom"
- Entries are screened by panel



A Parent's Reaction to Diagnosis



"I remember feeling that something was wrong and this can't be right. I think it was all at once."



"How can that be? Why? A question that keeps coming up is Why? I can't figure out how this happened..."

"In the long run it's not that big of a deal. First it was disbelief, then it was questioning why it all happened, but then you come to 'this is what it is' and you just deal with it."

Child's Reaction to CI Surgery



“It was five minutes until I was supposed to go in the OR, I got nervous. My mom told me it is going to be ok. The surgeon is the head of patient safety, and he knows what he is doing, he went to school. And that was helpful.”

- Molly, 8

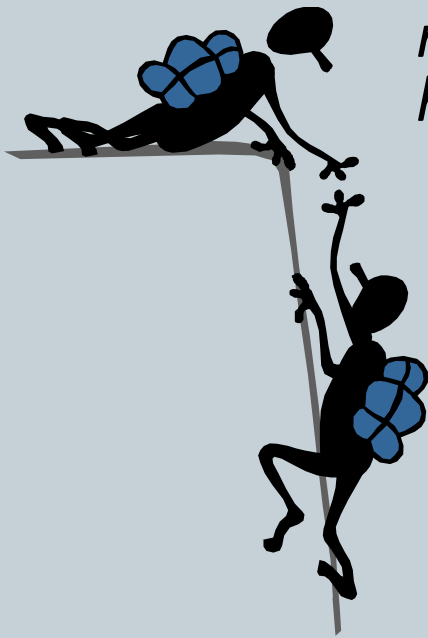


A Sibling's Thought



"Sometimes if she's fighting with my brother I'll stand up for her, but not that often. But that's not because she has a hearing loss. It's because he's being a jerk!"

- Bryce, 12



True About Me



True About Me

By: 9 yr old girl who uses a cochlear implant and hearing aid

| | |
|------------|-----------------|
| Creative | Organized |
| Moody | Neat |
| Caring | Relaxed |
| Comforting | Determined |
| Family | Cautious |
| Silly | Hospital |
| Calm | Hearing Loss |
| Fun!! | Normal |
| Chatty | Hard of Hearing |
| | Fighting |

Favorite things: Blue & Pink, Blue Jeans, Mysteries, Magic, Soccer, Pizza, Earrings, Friends

Multimedia



- Quotations
 - Interview, Email, New additions
- Pictures
- Videos
- DVDs



Building Blocks of Intervention



Hearing Loss in Children 0 – 3 Years

- Webinar funded by grant from Verizon Foundation
- Interdisciplinary Team
- Parents and Early Intervention Specialists
- Makes it possible!



Building Blocks of Intervention



Assuring early access to language and Understanding hearing loss



Optimizing access to sound through amplification

Launching communication through Sign Language



Accessing audition through cochlear implants

Promoting communication in the home



Understanding the impact of hearing loss on the family system

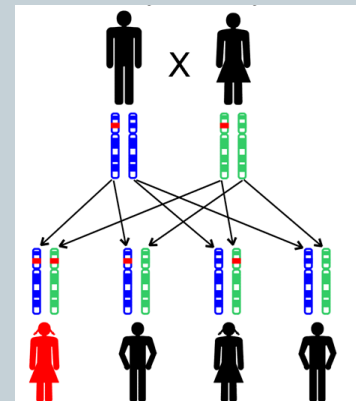
“Targeted Topics” 2010-2011

- 15 web-accessible topics
- Wide range of areas
- From parent and professional feedback
- “Dynamic” format-topics can be added
- Funded by Verizon Foundation



Examples of topics

- Techniques of audiological assessment
- Genetics of hearing loss
- Assistive devices for accommodating everyday living with hearing loss
- Anticipated language acquisition milestones for deaf and hard of hearing children



Available in...



American Sign Language

Arabic

English

Mandarin

Portuguese

Spanish

Family-Focused Models



- Focus groups
 - Formal, informal
- Multiple web based formats
- Creative funding
- Updating when possible
- Feedback, feedback, feedback



Thank You

We appreciate all who contributed to creating these resources.

We are grateful to our colleagues in the Department of Otolaryngology and Communication Enhancement at the Children's Hospital Boston with whom we work.

And, we are especially grateful to the children and families from whom we learn.

