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!
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
“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
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  Mandarin
Arabic                Portuguese
English               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.

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