

# Counseling Families Of Early Identified Infants

## The Family Consultant: Supporting Families from a Non-Clinical Perspective

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*Making life better... one individual at a time.*

# Making the case for something different:

- 95% of parents of newly deaf or hard of hearing children are hearing themselves, and 90% of these parents have no experience or background knowledge in deafness or hearing loss (Center for US Demographics, 1986).
- Cultural perspectives
- Technology
- Communication choices and issues
- Not a learning issue, it's an access issue
- Changes the identity of the family

# Navigating with families: finding their way back home after the diagnosis

- Universal newborn hearing screening
- Diagnosis
- Timeline for habilitation
- Intervention
- Technology
- Acknowledgment
- Families are allowed to be where they are in the process
- Grief and emotions honored will empower new dreams
- Acceptance

# Babies and families

- Babies are not clinical beings, they are human beings in family systems
- The diagnosis is about facts, not the feelings
- The diagnosis will tell the family what the child has, but not where the child is going
- How the family *feels* will shape the work to come
- Technology does not define the child
- Personalities – helping families not to lose sight of their babies as babies

# Supporting Families



# Family Centered Care

- Families become partners in their child's treatment
- Families and professionals develop trust
- Families are enabled to make informed choices
- Children and families receive optimal care and outcomes

# Bill Daniels Center for Children's Hearing: Family Centered Care Team

- Otolaryngologist
- Genetics Counselor
- Pediatric Audiologists
- Speech-language pathologists
- Social Worker
- Deaf Educator
- Family Consultant
- Family Advisory Council
- Community Resources

# Family Consultant

- Serves as a liaison between the clinical professionals and the families
- Facilitates connections between parents, support organizations and mentors
- Establishes supportive relationships with families
- Provides resources and information
  - Clinic-specific resources
  - General community-based resources
- Discusses unbiased communication choices and options
- Lends a personal perspective into the day to day issues of a hearing loss
- **Families do not have to be in a crisis mode to benefit from family support.**



# Enhancing the medical model

## • **Supporting Parents**

- Emotional support & counseling
- Allows families the time to absorb the diagnosis
- Address immediate concerns of the heart
- Reduces the feeling of being alone
- A unique perspective is gained when an individual with personal experience with the disability is a part of the family centered care team

## • **Supporting Professionals**

- Reduced work stress
- Prevent burnout
- Check for understanding
- Learning styles
- Awareness of family situations
- Follow up with resources and community contacts
- Bring the practical day to day experiences into appointments

# What does this connection provide to families?

- Calms anxiety
- Begins to build a relationship with the “person” that parents imagine that they have lost
- Demonstrates new ways of communicating
- Increases the family’s openness to examining issues in greater detail
- Parents who utilize deaf and hard of hearing adults as valuable members of their team, are better able to understand and see the potential in their child

# Mentor/Guides:

- People have lived with and managed hearing loss for a long time
- Families don't have to figure this all out now or on their own
- A safe place to ask questions
- First hand expertise to a variety of communication modes and methods
- An awareness and sensitivity to issues faced by Deaf and Hard-of-Hearing people
- Stories and experiences
- Social networks, coping and friendships



# **Babies and Families**

# Respecting Family Decision Making

- Families need to be given time to gain the knowledge to make their decisions
- Choices need to be based on the needs of the child and the family
- Choices are a personal decision
- Choices may change as the child grows
- Have confidence in the choices that the family makes for their child
- There are very few decisions that cannot be changed

# Choices:

- Check in: Listen to what the parents have to say about their current decision/choice
- This will give the audiologist an idea of where the family is at
- There may be a difference of choices within the family
- The professional may gain insight into the family's ability to make choices
- Plan ahead for future appointments
- Reassure

# Tips and Family Feedback

*You can change what you are doing based on what you see, not what you have read*

- Repeat and review the diagnosis
- Repeat and review the audiogram
- Balance content with sensitivity
- Develop a relationship: “In the beginning I got my strength from my audiologist.”
- “My audiologist reminded me it was okay to focus on the basics.”

# Tips from the trenches:

- Testing and the booth: Parents want their babies to “test” well and can’t help but wish for better results
- Kids want to have fun!
- Hearing aid fittings: “Let us see what the hearing aids will look like on our child, that’s all we are thinking about”
- Prepare us for life outside the sound booth booth



# **FAMILIES AND THEIR HOME COMMUNITY**



# Going home with hearing aids:

- The accountability that parents have to the professionals
- The guilt that they carry (data logging hearing aids)
- The responsibility that overwhelms
- Going out in public with hearing aids

# Connecting the Family to their Home Community and Resources

- Guided web-based searches
- Community based services urban/rural/state
- Early Intervention System
- Schools
- Activities, clubs, sports
- Family gatherings
- Parent to parent support
- Empower parents to advocate for their child

# Working together to become aware of:

- Incidental Learning
- **Never** say “Never mind”
- Become aware of “table scraps” of conversations
- Share family traditions, jokes, values and beliefs which give meaning, purpose and quality to our interactions
- Values and beliefs help develop self awareness and perspectives
- Labels - Take your cues from the families

# In the end...

People will forget what you said,  
they will forget what you did,  
but they will never forget how  
you made them feel.

Maya Angelou



The Children's Hospital  
it's all better™

***“My hearing loss is normal...”***



# Thank you Phonak



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