

Parents Informing Practice

Presented by staff of the
Deaf and Hard of Hearing Program
Children's Hospital Boston

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Deaf and Hard of Hearing Program



Amy Szarkowski, PhD
Post-doctoral Fellow in Psychology



Terrell Clark, PhD
Director Pediatric Psychologist



Charlotte Mullen,
MA, FAAA
Audiologist



Denise Fournier Eng,
MA, CCC-SLP
Speech-Language
Pathologist

Early Influences on Parents' Perceptions of Raising a Child with a Hearing Loss:

- Expectations
 - What do I know about hearing loss?
- Fears
 - Will my child lead a “normal life?”
- Early encounters with professionals
 - What is their agenda?
- Being overwhelmed
 - How much support are the parents receiving?



Development of a Parent Type

- Stage theories do not apply –
Development of a positive perspective is not linear
- Vygotsky suggests that growth occurs in the presence of confusion and crisis – by resolving problems
- General, overarching ways of viewing the experience of parenting a child with hearing loss
 - Positive Parents
 - Struggling Parents
 - Not-So-Positive parents



Positive Parent Type

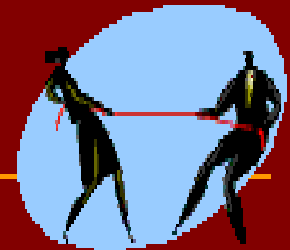


- Consistent with their child
- Easily identified positives
- Readily noted changes in themselves
- Flexible in approach to their child

Struggling Parent Type



- Fairly consistent
- Identified positives and negatives about their experience
- Expressed a desire to be more positive, but felt stuck
- Guilt and uncertainty about their decisions



Not-So-Positive Parent Type



- Not consistent
- Struggled to identify fewer positives
- Strictly followed the advice of professionals
- Felt powerless and overwhelmed by the experience

Switching Parent Types

- Parent Types are not static, nor are they rapidly changing
- Factors affecting Parent Type:
 - Personality, temperament, attitude
 - Level of Subjective Well-Being
 - Overall degree of positive affect relative to negative affect
 - Happiness and sadness are not polarities
- Influence of the Professionals...



Interdisciplinary Team approach

- Integrating medical & audiological & developmental information
- Listening to, responding with, and supporting parents
- Learning from parents –
The journey involves a two-way street

Hence ~ Parents Informing Practice

Professional Responses

- Attempt to supply too much information
- Struggle with displays of emotion
- Rush through procedures
- Refer on to additional specialists
- Offer reassurance





Parental responses

- Vary considerably
- May not be apparent during face-to-face appointments
- Are not static or immutable

Struggling – even Not-so-positive

- Paralyzing despair
- Situational depression



In the short run...

- Numerous appointments
- Each encounter resulted in more “bad news” and more “to do”
- Constant worry and vigilance
- Virtual neglect of infant



Working with the family...

- Focus on infant's responsiveness
- Record developmental accomplishments
- Encourage responding to baby's lead



In the longer run...

- Child is on par with age peers in language
 - Enrolled in public school – doing well academically & socially
- Parents are together, active, involved
- Their journey serves as an inspiration to the team of professionals who share that journey
 - The dad frequently offers his advice to professionals
 - “If you learn nothing else, learn this...”



From initial diagnosis through audiological management



Audiological Evaluation Process

- Diagnosing hearing loss in infants and young children is an ongoing process.
- Many parents fear these appointments as they are a reminder of the “disability” and/or the worry that hearing will be have worsened.



Hearing Aids

Parents are asked:

- To understand & use technology that is foreign to them
- To insure that the child wear HA
- To use HA despite comments or stares from strangers



Positive scenario



- Hearing loss Dx at 3 weeks of age
- HAs fit by 2 months
- Both parents attend all scheduled appointments
- Enrolled in EI Program + specialized program for hard of hearing children

Struggling scenario

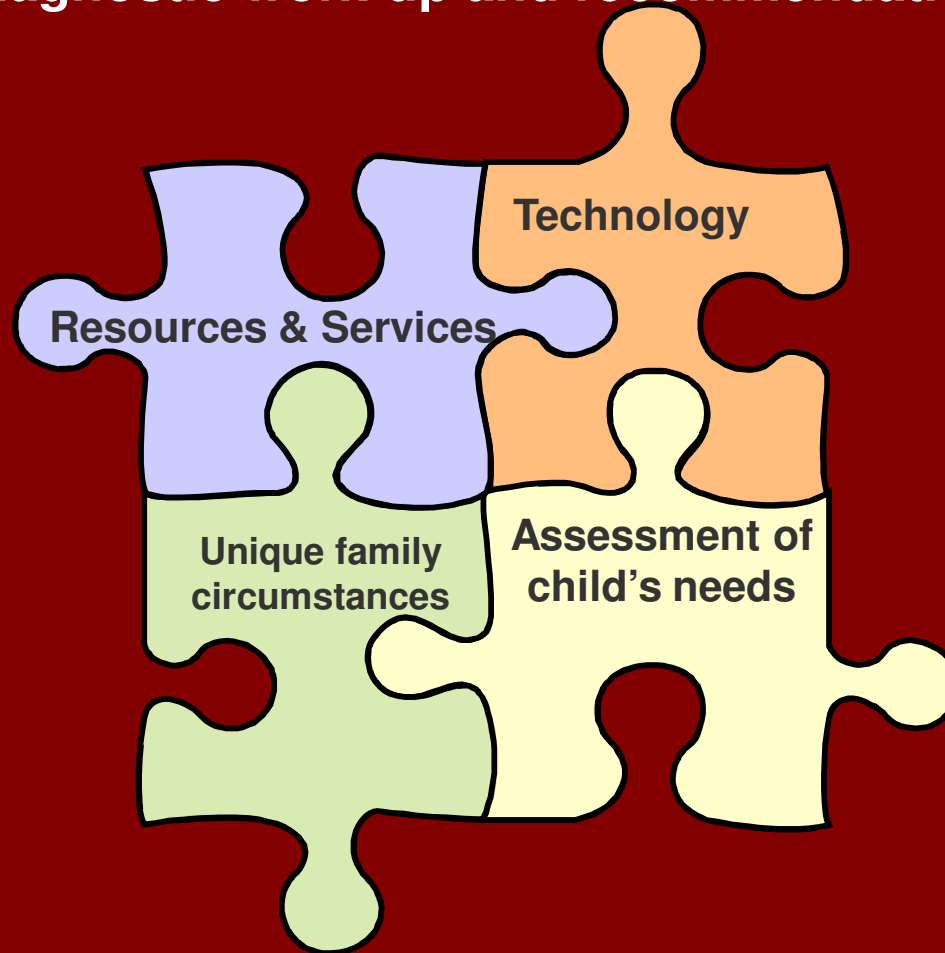
- Bilateral referral on newborn screen
- Dx delayed until 9 months of age due to overwhelming medical issues.
- HAs fit by 12 months of age
- Appointments were inconsistent due to the large number of other medical issues.
- Child would not tolerate hearing aids despite mother's regular efforts to put them in.
- Mother continued to persist with HAs, enlisting the help of EI providers.
- Full time hearing aid use was finally established.

Not-so-Positive scenario

- Progressive hearing loss diagnosed in pre-school
- Hearing loss due to Pendred syndrome
- Appointments inconsistently kept (often cancelled due to other children's activities)
- HAs fit, but worn at school, not at home
- Mother unsure of services being provided at school
- Does not believe changes in hearing unless plotted on a serial audiogram

What is our agenda? Part I

- As professionals, we have our preferred and customary regimes for diagnostic work-up and recommendations for intervention.



What is our agenda? Part II

- To support the child in achieving access to and competence in language for communication, learning and literacy.



What needs to happen

- Regular and ongoing re-evaluation of all components of the system:
 - Child's needs & progress
 - Family circumstances
 - Technology
 - Resources/Services
- Communication & Collaboration
- Make necessary changes



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- Future research and novel options in utilizing parental strengths and overcoming potential barriers to families accessing services.

