



Contact between Audiologists and Families: Close Encounters of the Parent Kind

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A day in the life of a pediatric audiologist.... (aka-how EHDI gave me an identity crisis!)

- Screener?
- Diagnostician?
- Counselor?
- Early Interventionist?
- Life Saver?
- Family Supporter?





...but I'm a do-gooder

- The goal must not be seen as “doing for people” but rather the strengthening of functioning in ways that make families less dependent, not more dependent, upon professionals for help.
 - Dunst, Trivette, and Mott (1994)



Why all the talk about Family Encounters?

- Ninety-five percent of all deaf children are born to hearing families (Mitchell & Karchmer, 2004)
- Family choice and decision making occur at all levels of family involvement in the intervention process.



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Why all the talk about Family Encounters?

“There has to be a better way...” Parent





Why all the talk about Family Encounters?



- A father said he was puzzled by terms... When he was told about an FM trainer, he expected some kind of fitness instructor



Why all the talk about Family Encounters?

He's not even 1 now and so he is under one state program , but when he turns 3 he is no longer under the health co-op program and they'll send him to something like a pre-school...I think...that's what I'm trying to still figure out myself...I'm not sure why it is so complicated for parents... Parent



Parent Power

- “Unfortunately, the diagnosis is unfair, unpleasant, unwanted and cannot be undone. But, it must be dealt with...
– Atkins, 1994

“Even though we love our audiologist now, at the time I thought for a moment I might be physically ill...my husband said he felt like he had been punched in the stomach...”



“Counseling in audiology has historically employed a medical model with an emphasis on providing content/informational counseling, and rarely providing emotional support” *ASHA Guidelines*





The Joint Committee on Infant Hearing

The most important role for the family of an infant who is deaf or hard of hearing is to **love, nurture, and communicate** with the baby.

From this foundation, families usually develop an **urgent desire** to understand and meet the special needs of their infant.

Families gain **knowledge, insight, and experience** by accessing resources and through participation in scheduled early intervention appointments including audiologic, medical, habilitative, and educational sessions.

This experience can be enhanced when **families choose** to become involved with parental support groups, individuals who are deaf or hard of hearing, and/or their children's deaf or hard-of-hearing peers. (p. 902)



ASHA

- ...achieving benchmarks (i.e. positive language outcomes) in early detection is facilitated when *family counseling* and *emotional support* are actively infused into audiologic care with a systems-driven paradigm



Family-Centered Care...

more than a buzz word

- **The Definition: Family-Centered Care** assures the health and well-being of children and families through respectful family/professional partnerships. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice that results in high quality services.



“We’re all about Families”

- The foundation of Family-Centered Care is the partnership between families and professionals:
 - Families and professionals work together in the best interest of the child and family. As the child grows up, s/he assumes a partnership role.
 - Everyone respects the skills and expertise brought to the relationship.

“...everyone thinks I should know what to do because we have two other kids, but what I really need is some positive feedback to know that I am doing things right, right now!” -parent



Principles of Partnerships

- Trust is acknowledged as fundamental
- Communication and information sharing are open and objective
- Participants make decisions together
- There is willingness to negotiate
- Successes are celebrated!

She never left my house without telling me, “You are doing an important job. It is very hard work and you are doing it well”. I always waited for her to say that...

-Parent



Family Voices, Inc.

Partner: one who shares with another or others for a mutual benefit

Essential Components:

- **Building trust; nurturing trust**
- **Actively listening & engaging; open & honest**
- **Open to new opportunities for learning; sharing power and moving forward**
- **Establishing clear expectations, roles & responsibilities**
- **Acknowledging mutual respect for each others' cultures, values and traditions**



Family Support Principles

- Staff & families work together in relationships based on equality & respect.
- Staff enhance families' capacity to support the growth & development of all family members.
- Families are resources to their own members, to other families, to programs, & to communities.
- Programs affirm & strengthen families' cultural, racial, & linguistic identities.
- Programs are embedded in their communities.
- Programs advocate with families for services & systems that are fair, responsive, and accountable.
- Practitioners work with families to mobilize formal & informal resources to support family development.
- Programs are flexible & continually responsive to emerging family & community issues.
- Principles of family support are modeled in all program activities.

...C. J. Dunst, Family Support America



Learning Styles

- Convenience Sample of 93 parents of D/HOH
- Preferred Learning Styles (could choose more than 1):
 - 34 selected Reading Booklets/Info Sheets
 - 86 selected One-to-One Discussion
 - 44 selected Hands-on



What we learned...

- Parents have different learning styles; It is our responsibility to modify and adjust to meet their informational needs...
- One size doesn't fit all!





As part of a collaborative team, we have
the responsibility to meet the challenge of
working with families with
caring, compassion and expertise.

Perigoe, 2004





What's *your* attitude?

- Don't worry...**professional** help is here
- I'm here to **fix** what is wrong with your child and family
- I've got **lots of experience** so can tell you the solution
- ...**not enough sense** to get out of the rain
- ...if it were **my** child



Reporting Styles

- The “Drive-by”
- The “Steam roller”
- The “Pollyanna”
- The “Fortune Teller”

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Reporting Styles

- Moeller (2002)
 - “My way or the highway”
 - “It’s a chevy, not a cadillac”
- Ready? Set? Go!
 - Try a “tailor-made” approach



Tailoring your approach

- View family as a unit
- Recognize child and family strengths
- Respond to family priorities
- Individualize service delivery
- Respond to changing priorities
- Support family values and lifestyles

“There has to be a better way...”

Parent



Counseling Revisited...

- *Counseling Children with Hearing Impairment and Their Families*, Kris English, '02
- Audiologists “**know about**” psycho-social problems of hearing loss
- Audiologists may lack the “**know-how**” to help with these problems



Counseling Revisited...

- ***But I'm not so good a 'splan-er'!***
- Informational counseling
 - One way street
 - Talk time dominated by professional
 - Communication mismatch
 - affective statement responded to with information



Counseling Revisited...

- Personal Adjustment Counseling
 - matches an affective statement with an affective response
 - open-ended vs one way talking
 - neutral and non-directive
- Are you having a “meeting of the minds” or a “heart to heart” ?



Personal Adjustment Counseling

- Views client, not counselor, as “expert”
 - *Congruence*: genuine in interactions
 - *Empathy*: sharing the frame of reference
 - *Unconditional positive regard*
 - assume the client’s goodwill
 - refrain from judgement
 - Keeps the client’s agenda in focus



Walk the Talk Examples

- Hold your Baby
- Swimming Teacher
- Parents Sign Classes
- Pockets and Bows
- Sibling Involvement
- Play Group
- Junior Counselor



The minute we walked through the front entrance with Grace Ann, it was apparent that we were in a place that knew about babies and families! Even though it we had been to two other places about her hearing since she was born, and even though we were scared and nervous, my mom and I both felt like we had found the place that was going to help us get Gracie figured out. It was a huge relief. Parent



Communication Skills

- TALK LESS
- LISTEN MORE
- LISTEN ACTIVELY



Screening to Diagnosis

- Fail Screen
- Diagnostic Testing
 - Identify hearing loss
- Counsel family
- Fit hearing aid
- Refer to Early Intervention (EI)
- Simple Huh???



We forgot....

- The family



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Screening Scenario

When we were on our way out of the hospital, after my husband had the car pulled around and I was on my way out the door, they said that our baby didn't pass her hearing exam and that I needed to take her to a specialist to make sure her hearing was fine. They said that since she was a C-section baby, she probably had fluid in her ears and that caused her to fail... When I got home with my baby, I thought, "Surely she can hear, because she would be in her bassinet crying, and I would walk up the stairs and into her room and I'd say, 'Mommy is here', and before she could see me, she would start to quiet." I didn't realize at the time that she only felt the vibrations of my feet on the floor, and that's how she knew I was coming. She had us fooled for a good long while. Parent



Informational Counseling

- Newborn Hearing Screening:
 - Audiologists (or someone carefully trained by an audiologist) should be the professionals who communicate with parents when a baby does not pass screening.
 - Recommendations for further testing must be presented in a positive manner that emphasizes their importance
 - Information must be presented to parents confidentially, in a family focused manner free of technical jargon
 - Parents given the opportunity and encouraged to ask questions



Adjustment Counseling

- Newborn Hearing Screening:
 - WE are the professionals the parents NEVER hoped to meet!
 - We must LISTEN to fears and concerns expressed by families
 - We must support whatever decision the family makes regarding the screening process.
 - We must recognize that our manner of delivering screening results may interfere with parent-child bonding



The Evaluation

- The setting, our expectations for families
- *We live almost three hours away from the audiology center. My instructions were to keep Ben awake on the drive down so he would sleep through the test...have you ever tried to drive to an unfamiliar place, miles away, with a two month old in the back seat who is used to nursing on demand? Parent*



The Diagnosis

- How to deliver the news....

I remember looking at my sweet baby girl who looked so tiny on a big hospital bed with all those wires. I am a professional person who is comfortable with technology so I stared at the monitor with all these squiggles moving around on the screen trying to figure out what they meant and wondering what that had to do with how our baby could hear. Was she “doing good” on the test? Was it bad or good that it was taking so long? Parent



The physical setting

- Smaller rooms are more intimate
- Make sure no one can walk in on you
- No phones, fax, pager going.
- Angle the desk-chairs
- Sit arm-length apart
- Relaxed but not TOO relaxed—body language important
- Eye contact



Counseling After the Evaluation

- Family Centered
 - Want to “fix it”—make it right for the families
 - Need to focus on families’ abilities to master problems
 - Often focus on things to do
 - Reinforce what they are doing well
 - Continuum of Responsibility: We are the experts initially. Goal is to partner with family so they learn to advocate and be in the expert about their child’s hearing loss



Understanding the Hearing Loss

- Acoustic simulation of hearing loss most effective
- Least effective explaining audiogram and defining hearing loss as mild...

Primus & Pitt, 2000

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Adjustment Counseling

- Confirmation of Hearing Loss:
 - MUST recognize the following:
 - The family's fragility during the EHDI process
 - The impact of diagnosis of hearing loss on the entire family, including extended family
 - The family will need to identify and seek the assistance of supports outside the audiological community
 - The family's strength and special needs within the context of their cultural and value system
 - The need for continuing emotional support of the family



Mothers who reported high social support were rated as better adjusted despite degree of hearing loss or life stress.

Social support accounted for 43% of the variance in mother's reported negative life stress. (*Calderon, R., & Greenberg, M. 1999*)

When they finally diagnosed her with a moderate to severe hearing loss, I was devastated. I watched my child who I thought was so perfect playing on the floor, realizing for the first time that she wasn't hearing anything that was going on in the room. Parent

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The lyrics to one of my favorite songs say, “Life is a roller coaster.” I remember after our daughter was diagnosed at about two months old, but we didn’t have her hearing aids yet, I didn’t know if she was hearing me or not. And I remember thinking, “If she can’t hear what I’m saying, then maybe she can feel it.” So, I would lay her on her side with her ear up against my chest, so she could feel my heartbeat and my throat moving when I was singing or talking and I thought, “Okay, maybe she can get some of what I’m saying.” For me, as a parent, that was a low point, because I didn’t really understand much about hearing loss. Parent



I was so proud of our big girl the first time we went in the soundroom. I could tell she was “listening” to the sounds and even though I couldn’t tell how loud they had to be for her to respond, I could tell she knew what she was suppose to do. It was an important milestone for us and I put it in her baby book, just like the first time she rolled over and when she cut her first tooth. Parent



Counseling

- Often times counseling sessions seem to go well. Mom and/or dad seem to leave with understanding, don't seem distraught and seem to understand what to do next and what hearing loss means. But—you never hear from them again...or the family tells the EI person that they don't really understand hearing loss, the hearing aid.....



- Do we ever ask them about extended family/others who may have questions and how they handles those questions?

My dad was having a hard time believing that his first grandson needed to wear hearing aids. He had a complete turnaround after he went to an appointment with me and got to sit in the booth and watch Jarod respond—it was like he finally got it...it was such a load off of my mind because it was one of those times in my adult life when I really needed my dad to be there for me, and inviting him to the audiology appointment did the trick. Now he is the proudest grandpa and has even learned how to use the internet so he can help me figure everything out. Parent



We had to travel to several different places in the United States to learn about different opinions—we were very confused as to what to do. Parent



Informational Counseling

- Intervention and Habilitation:
 - “Audiologists are responsible for providing families with unbiased information, recommendations, and appropriate educational and communication options based on family decisions and informed choices. As such, audiologists are responsible *to* families, not *for* families.”*ASHA Guidelines*



But, did you know...?



- 85% of what we know we learn by **listening**
- However, 75% of the time we are **distracted, preoccupied or forgetful**
- We have **~50% recall** immediately after talking with someone
- We listen at **125-250** words/minute and think at **1000-3000**



Providing Information as Family Support

- ~20 million people speak **poor** English; 10 million speak **no** English
- ~66 million patient/professional encounters occurred **across language barriers** in 2002
- ~330 **languages** are spoken or signed in the US, not including the 550+ recognized Indian tribes
- <60% of the population has English as a **first language** (US Census Bureau 02, OMB 02)



What Parents-Patients Remember

- ~50% of information is retained
- ~50% of this is remember incorrectly



I told my friends at church that we want the same thing for Dominic that they want for their children...we want him to be independent and do everything, to socialize, to be able to fit in and to always feel like he belongs. Parent



Impede Collaboration

- Poor attitude toward parents (cold, rude, patronizing)
- Inadequate privacy
- Insufficient time (rushed approach)
- Lack of self confidence
- Withhold information
- Lack of family-centered care i.e. prescribe care
- Emphasis on families deficiencies
- Low or haphazard follow-through in case management
- Lack of sensitivity to family schedules



Family Stresses

- Depression:
 - Common stress related response for parents
 - Mothers more likely to experience than fathers
- Overprotection and overindulgence:
 - Over dependent children
 - Compromised developmental progress
- Grieving
 - Common response to hearing loss
 - A complex response that may be triggered at multiple stages in the child's life



Adjustment Counseling

- Early Intervention
 - Consider the family's readiness to proceed
 - Coping skills
 - Support structures
 - Resources
 - Challenges
 - Facilitate knowledge of options and opportunities
 - Family to family support critical at this stage!





Adjustment Counseling

- Beyond Infancy:
 - Parents often form a deep bond with their first audiologist
 - Families often experience complex feelings through the grieving process at transitions throughout the active years of parenting
 - Emotional support needs change, but do not necessarily diminish, as the child ages



Factors Affecting Recall

- Intelligence
- Familiarity with information
- Simple, easy-to-understand format better
- Less is more
- Categorizing the results
- Specific recommendations



Tips for Maximizing Retention

- Concrete instructions as to what to do next
- Short words and sentences
- Stress those things you want remembered
- Categorize the results
- Repeat important information
- Limit the information—not too much
- Supplement with written material



Points to Remember

- Identification of hearing loss in infancy puts parents in the position of receiving a diagnosis without the benefit of direct observation delivering difficult needs requires careful consideration of how information is present and the dialogue that follows
- Parent's initial level of concern or emotional upheaval is usually unrelated to their child's type or degree of hearing loss



Points to Remember

- The stress and anxiety experienced by most parents at the time of diagnosis is a normal reaction to unfamiliar and unforeseen circumstances
- Interactions between the audiologist and the family at the time of diagnosis can set the tone for future interactions





Points to Remember

- Audiologists need to be forthright in providing information to parents, but also willing to listen and reflect on the concerns and priorities
- Inexperienced clinicians may provide more information that a family can comprehend, especially at the time of diagnosis



Points to Remember

- When delivering difficult news, give families an opportunity to respond and express their feelings; don't be afraid of a little silence
- Families need hope based on the knowledge that much can and will be done to help them and their child
- The support of other parents is vital to many families



Points to Remember

- At the outset of each clinic appointment ask families what they are hoping to accomplish visits. Return to their priorities at the conclusion of the visit to determine if their goals were met and confirm agreement on next steps
- Observe parents interacting with their child and praise their efforts
- Simple phrases “look how he responds to you “are encouraging empowering to parents.



Points to Remember

- Present information in parent's primary language
- Use professional interpreters when needed and whenever possible
- Use language that is below the parent's language, keeping sentences short.



Points to Remember

- Remember the family is the 'patient'



- Respect the family's rights to chose
- Think of the family as a partner



Avoid



- Giving too much information at one time—it can be overpowering
- Delivering news in a manner that is overly positive fails to consider the seriousness of the situation
- Delivering news in manner that is negative or pessimistic can hinder the family's progress toward achieving a hopeful outlook for the future



Avoid

- Assuming that they know how a family feels or what they want for their child.
Trusting and collaborative relationships develop slowly over time
- Using jargon



Evaluate your practice—Do you?

- Help families see what they are doing well?
- Have an easy to talk to approach?
- Regularly ask parents what they think of your service and how to improve?
- Give families time to talk about their experiences and things that are important to them?
- Respect the level of involvement the family chooses in making decisions?
- Help the family feel more confident that they are their child's expert?



The End

