Audiology Support for Children who are Deaf and Hard of Hearing and Their Families

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Support for Children who are Deaf and Hard of Hearing and Their Families
- Case Study
- Counseling practices
- Support through Identification
- Sources of Support
- Support through Intervention
- Tools to Teach and Foster Engagement
- Case Study

Case Study 1
- Age 1-3:
  - SF testing consistent with previous ABR.
  - CNT ear specific over the course of 4 separate appointments
  - Less than 1 hour per day of HA use on average
  - Mother was counseled on importance of HA use but no change
- Age 3
  - Child begins pre-school for D/HH children
  - Continued difficulty obtaining ear specific information
  - Datalogging 0.4 hours/day. Patient will not tolerate hearing aids, so they aren’t used.
  - HA settings based on previous ABR

Case Study 1
- Age 3.5:
  - Datalogging is ~4 hours/day. Consistent with use at pre-school only.
  - Mom reports difficulty getting earmolds in.
  - New earmolds made
- One month later:
  - Pre-school teacher attends audiology evaluation appointment. Brings favorite games from school.
  - Ear specific results showed improvement in hearing in one ear.
  - Limited parental consistency
Case Study 1

• For the next year and a half:
  • Results in subsequent months are stable for hearing sensitivity, datalogging, preschool status and parent report.
  • During that time:
    • Daily intervention to help child wear hearing aids at school.
    • Accurate hearing assessment
    • Get each of 3 caregivers on board
    • Properly fitting earmolds
    • Datalogging checks at school
    • Counseling patient himself about importance of hearing aids everyday

• During that time...

During that time...

Case Study 1

• Then it happened...

• Age 5
  • Datalogging indicated 8 hours of use each day

• What changed?

Role, Knowledge and Skills: Audiologists Providing Clinical Services to Infants and Young Children Birth to 5 Years of Age

"...acknowledges the unique and complex nature of providing audiologic services to infants, young children and their families."

ASHA, 2006

Audiologists are...

Audiologists are...

But first...

But first...

• The Four Agreements By Don Miguel Ruiz
  • Don't make assumptions
  • Don't take anything personally
  • Do your best
  • Be impeccable with your word

Why You Should Be Gentle With People

Why You Should Be Gentle With People
Support for Children who are Deaf and Hard of Hearing and Their Families

- Case Study
- Counseling practices

How Audiologists Can Support

- Informational Counseling
- Adjustment to Hearing loss Counseling
- Family Centered Care/Early Intervention

Informational Counseling

- Sharing important technical information with parents and families using non-technical terms
  - Evaluation results, interpretation
  - Amplification/technology
  - Educational options
  - Communication options
  - Advocacy, public health, education policies (ASHA, 2008)
  - Provide adequate information to assist families with decision making

Challenges

- Parent/Caregiver recall can be poor. (Watermeyer et al, 2012)
  - 4/5 were able to recall diagnosis and recommendations.
  - Caregivers struggled to understand and recall explanations of audiological tests.

*How important is it for parents and families to understand the test procedure vs. the results, functional implications, and recommendations?*

Adjustment to Hearing Loss Counseling

- "Support provided by audiologists to families as they learn of their child’s hearing loss, and attempt to recognize, acknowledge, and understand the realities of having a child with hearing loss” (ASHA, 2008)
- Addresses the emotional and psychological reactions to hearing loss.

Challenges

Answering "feeling" questions with "thinking" (English, 1999)

Parent: "I’m feeling depressed after the diagnosis"
Audiologist: "Studies have shown that children with mild to moderate hearing loss can meet age related language milestones with consistent hearing aid use and early intervention"
Adjustment to Hearing Loss Counseling

Answering “feeling” questions with “thinking” (English, 1999)

Parent: “I’m feeling depressed after the diagnosis”
Audiologist: “Why do you think you are feeling that way?”

- Joyful, playful communicative interactions
- Overall enjoyment of parenting roles
- Family well-being
- Engagement
- Self efficacy

It is:
- Culturally Competent
- Evidence Based

Family Centered Care/Early Intervention

Flexible, holistic process that recognizes families’ strengths and natural skills while promoting:
- Joyful, playful communicative interactions
- Overall enjoyment of parenting roles
- Family well-being
- Engagement
- Self efficacy

Why is this important?

Family involvement and early enrollment in Early Intervention contributes to positive outcomes in language development. (Moeller, 2000)

Parental communication skills can result in higher language outcomes (Calderon, 2006)

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- Case Study
- Counseling practices
  - Support through Identification

Joint Commission on Infant Hearing and Early Hearing Detection and Intervention (2007)

How can we support parents and families through this process?
Prior to Follow Up: Opportunity to Prepare
- Be familiar with materials given to families at time of screening.
- Phone call prior to appointments with instructions and appointment flow
- Answer any questions
- UWO Family Centred Early Intervention Lab “Hear On” Videos: Your ABR Appointment https://youtu.be/3WWmUEZrh0g

Sharing Results: How
- Ensure adequate time
- Consider the environment
- Do your homework/ask questions
- Choose words with care
- Silence is golden
- Be or become comfortable with emotion or lack thereof
- Observe and tailor

Sharing Results: Information
- Discuss results-functional terms
- Parent questions must guide amount of information and level of detail
- Early intervention referral
- Discussion of amplification
- Continuity of Care (Haddad, et al. 2019)
  - Follow Up and next steps/additional appointments
  - Contact information

Sharing Results: Information
- Discussion of amplification
- EHDI Packet
- Insurance coverage/funding options for amplification
- Discussion of cochlear implants
- Parent/Family Support Groups
- Pediatric Hearing Clinic/Specialty Clinics

Consider making a follow up call within a few days of initial appointment

NBHS Follow Up
- Put patients and families at ease
- Identify who is in the room
- Ask about previous results and/or tests at other facilities
- Confirm pediatrician
- Case history
- Review what will happen in the appointment
- “What do you want to leave here knowing today?”

BTNRH Materials Given to Families at the Time of Identification
- Informal report of hearing sensitivity
  - Names of tests that were done.
  - Results
  - Recommendations
  - Contact info
- EHDI Packet
  - Parent/family support groups
  - Information about hearing loss
  - Communication options
  - Amplification information
  - Funding options
  - Pediatric Hearing Clinic Brochure
Higher vocabulary abilities were noted in children who met each component of the EHDI 1,3,6 guideline. (Yoshinaga-Itano, et al. 2017)

Sharing Results: Confirmation
- Rapport is established
- "What do you want to leave here knowing today?"
- Follow up questions
- More information
- Earmold impressions
- Hearing aid selection
- Next steps-Continuity of Care

Consider making a follow up call within a few days of this appointment

Sharing Results: Confirmation
- Discussion of amplification
- EHDI Packet
- Insurance coverage/funding options for amplification
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- Parent/Family Support Groups
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Consider making a follow up call within a few days of initial appointment

Responding to Results
"I have two other kids, they’re older than my daughter and they have normal hearing. For me, it was a complete shock because neither side has hearing loss"

Haddad, et al., 2019

States of Grief
- Shock
- Denial
- Anger
- Guilt
- Acceptance

Kurtzer-White & Luterman, 2003

Parent Responses
- Stress is a common response
- Degree of hearing loss does not predict amount of parent reported stress
  - Some studies have shown parents of children who have lesser degrees of hearing loss report higher stress (Kurtzer-White & Luterman, 2003)
- For parents of children who are deaf/hard of hearing, parental stress is highly correlated with child’s socioemotional problems. (Hinternair, 2006)
- Parents may experience depression (ASHA, 2008)
Coping

<table>
<thead>
<tr>
<th>Emotional support</th>
<th>Knowledge and competency</th>
<th>Empowerment</th>
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<tbody>
<tr>
<td>Audiological Rule</td>
<td>Facilitation and advocacy</td>
<td>Family Growth</td>
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</table>

In practice...

- Appointment and Care Coordination
- ENT
- Other specialists (Ophthalmology, Infectious Disease, Craniofacial Team, Speech Pathology, Genetics, etc)
- Hearing Aid Selection and/or Fitting
- The number of appointments and making time for appointments was identified as a challenge and struggle by parents. (Haddad et al. 2019)

Support for Children who are Deaf and Hard of Hearing and Their Families

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- Support through Identification
- Sources of Support

Patient and Family Centered Evaluation of Pediatric Hearing Loss

- Pediatric Otolaryngologist
- Speech Language Pathologist
- Other Specialists: Pediatric, Developmental, Genetics, Neurology
Audiology Care Coordinator  
Cincinnati Children’s Hospital and Medical Center  
- One audiologist, Lori Garland, serves as ACC  
- Primary focus is 0-3  
- Following ID, the ACC contacts the family:  
  - Guides the family through the initial process  
  - Quick access for questions, concerns, support  
  - Families may opt in or out  
  - Families enter and exit support as needed  
- Other support:  
  - Transitioning care and establish services in other areas  
  - In-patient to out-patient  
  - Collaborate with care managers of medically complex needs

Haddad et al. 2019;  
Garland, personal communication, 2019

Support for Parents and Families: Parent-to-Parent

“A parent-to-parent support system creates a sense of social identity, social connectedness, affirmation, and belonging which contributes greatly to parental well-being” (Henderson, Johnson, & Moodie, 2014)

Parent-to-Parent Support Groups

(Henderson, Johnson, & Moodie, 2014)

Organizations For Parents and Families

- Organizations may have different goals or interests  
  - Hands and Voices  
  - Guide By Your Side  
  - Alexander Graham Bell Association (AG Bell)  
  - American Society for Deaf Children  
  - Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPOD)  
  - MyDeafChild.org  
  - Children’s Craniofacial Association  
- Know what is available locally

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Parent Support?

- Facebook groups  
  - Close monitoring of information received through group is necessary. (Stock et al. 2018)

- The Internet...  
  - Prominent source of information for identifying resources and technical information (Fitzpatrick, 2008)  
  - Parents desire reliable online resources (Haddad et al. 2019)  
    - babyhearing.org  
    - heartolearn.org  
  - Value in audiologists or other professionals providing reliable sites to parents and families
How Audiologists can Support Parents and Children: Amplification

- Recognize family concerns:
  - Funding sources for amplification
  - Cost of amplification and appointments
  - Device management and retention (Haddad et al. 2019)
- Families need ongoing information
  - Parents reported a "strong need" for information at the time of identification, and continued need for current information e.g. technology moving forward (Fitpatrick et al, 2008)

Address Initial Concerns

- Loaner hearing aid sources
- Familiarity with funding sources
- Assistance in completing applications
- Utilize social work services
- Connect with early intervention

Why is amplification important? What factors are related to success with amplification?

CHH Are at Risk for Depressed Language Development

* CHH differed significantly from SES-matched age-mates.

Audibility Over Time Influences Language

First (Lowest) Benefit
Third (Highest) Benefit
10-point difference (2/3 of a SD)

Epidemiologic sample of children with HL
6m – 6y 11m
English spoken in the home
No major secondary disabilities
Permanent mild to severe HL
- PTA of 25-75 dB HL (.5, 1, 2, 4 kHz)
Cohort of normal hearing, age-matched children

CHH Are at Risk for Depressed Language Development

CHH

<table>
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<tr>
<th>Age</th>
<th>CHH</th>
<th>d=25</th>
<th>d=44</th>
<th>d=51</th>
<th>d=64</th>
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<td>4 year</td>
<td>mm=80.144</td>
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<td>5 year</td>
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<td>6 year</td>
<td>mm=125.129</td>
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</table>

* p<.0001

Tomblin et al. 2015
Hearing Aid Use Over Time Affects Language Growth

![Graph showing hearing aid use over time affects language growth](Tomblin et al., 2015)

Clinical Implications

- May not see immediate results from wearing HA!
- Counsel on realistic expectations & stress importance of auditory access in the long run.
- Optimal development occurs with early fitting, good audibility, and consistent use of amplification.

Audiologist’s Role: Hearing Aid Fitting

- Evidence Based and Best Practice Protocols
- Real-Ear to Coupler Difference (RECD) measurements
  - Eliminating error (Moodie et al. 2016)
  - Re-measure RECD & verification after change and/or new earmolds

Speech Intelligibility Index (SII): Proportion of Speech that is Audible Above Thresholds

![Graph showing SII for different PTA levels](Bagatto, et al., 2015)

Aided SII is Not the Same for Everyone Who Wears Hearing Aids

- For PTA of 50 dB HL, SII ranges from ~65-87.

Matching targets → Better audibility

About Half of Children’s Hearing Aids are not Fit Within 5 dB of Targets

Children with deviations from target across multiple input levels and at 4 kHz had poorer speech recognition in quiet and in noise than children with HAs fitted closer to prescriptive targets.

How Can We Ensure Optimal Audibility?

• Monitor thresholds regularly.
• Measure RECDs frequently (and adjust gain accordingly).
• Match to target as closely as possible.
  • Appropriate HA verification—speechmapping with measured RECDs

Audiological Follow-up & Monitoring for Hearing and Amplification

At HAPC/Hearing evaluation:
• Verification
• Questionnaires: LittlEars, PEACH
• Aided and Unaided Speech Testing:
  • Ling 6, WIPI, NU CHIPS, PBK-50, CASPA

• Questionnaires are excellent sources for discussion with parents and EI.
• Allot enough time in the appointment to accommodate discussion.

This may look like:
• Age 2 months: Confirmatory ABR
• Age 3 months: Hearing aid fitting
• Age 4 months: First follow up HAPC (check HAs in test box)
• Age 6 months: Behavioral eval (SAT in SF), EMIs
• Age 6.5 months: HAPC (measure RECD, HA in test box)
• Age 9 months: Behavioral eval (SAT inserts and pure tones), HAPC, EMIs if needed.
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Hearing Aid Fitting and ORIENTATION

Hearing Aid Fitting and Orientation
Prior to appointment:
• Encourage other family members to attend
• Be prepared
Beginning of the appointment:
• “What do you want to leave here knowing today?”
• Questions
• Road map
Verification:
• Provide appropriate explanations

Device Orientation:
• Checklist/written material
• Hands On Practice
• Listening Check and Trouble Shooting

Device Use:
• Integration into daily routine (Muñoz, Preston, and Hicken, 2014)
• Goal setting

What family factors relate to HA use?
• SES (Walker 2013)
• Parent challenges with HA management (Muñoz 2014)
  • frustration
  • confusion
  • lack of confidence
• Perception of benefit with hearing aid
• Child behavior

How do we address this?

More efficacious parents → more HA use!

Specific Barriers to Device Use

http://www.phsa.ca/our-services/programs-services/bc-early-hearing-program#My--baby--has--hearing--loss
https://thecookiebitechronicles.wordpress.com/2010/08/06/hearing-aid-maintenance-for-beginners/
https://www.etsy.com/shop/thebebopshop?ref=l2-shopheader-name
Monitoring HA function: Lights on ears on?

- Calibrate yourself to how each aid should sound with a listening check using a stethoscope or listening tube
- Ling 6: mm, oo, ah, ee, sh, ss
  - low-high frequency
  - low-high intensity

Klein et al., 2019

Listening Checks: Partnering in Audibility-Increasing Familiarity

Why is it important to check audibility?

- Intermittent— one minute it is working, the next it is not.
  - Change batteries, try dehumidifier.
- Distortion—fuzzy speech or static noise.
  - Clean microphone covers, check for water build-up in tone hook and earmold, and try dehumidifier.
- No sound
  - Change batteries.
  - Check if earmold is plugged— take earmold off and listen to HA only.

Discussing Datalogging

- Set the stage at the hearing aid fitting.
  - Describe datalogging feature
- Hearing aid use is part of an ongoing conversation.
  - First follow up
    - Recognize positive
    - Recognize change in routine
  - LISTEN to parents and families report challenges
  - Work together to come up with a plan
- Future appointments:
  - Fostering behavior change

Muñoz et al., 2014

Infant HA use over time

Children of mothers with some college were more likely to be routine users.

Children of mothers with high school degree 9-18x more likely to be low users.

10%

Walker et al., 2015

EI-Partners in Hearing Aid Use

- Share key results, challenges, strategies, progress monitoring and outcomes with Early Intervention team. (Muñoz et al., 2014)
  - Ensure all members of the team are supporting objectives in the same way.
- Follow up phone calls to parents and EI team members after appointments.
Offering Strategic Support: Revisit & Repeat

• Developmental discoveries
  • Emphasize the positive: How capable! Clever!
  • Provide information on responses and tools.
  • Talk with parents who overcame the challenges.

My family needed this bonnet from the time I was 12 to 16 months old...then I decided to leave my ears alone!

Muñoz et al., 2019

Datalogging Increased with Retention Strategies

Muñoz et al. 2014

Everyone Gets a Retention Device!

https://www.uwo.ca/cca/fci/hearns/unsupervised_videos.html

Family Engagement

“When parents feel safe to be open about their underlying struggles, and audiologists are responsive in ways that facilitate the problem-solving process, parents may be more likely to learn how to successfully manage their children’s hearing aids.”

Muñoz et al. 2016

“Missed opportunities were observed, including not validating patients’ emotional concerns, providing technical responses to emotional concerns, providing information without determining patient desire for the information, and not engaging the patient in a shared planning process.”

Coleman et al. 2018
Engaging Families

- Audiologists are not professional counselors.
- Conventional/Counseling Toolbox is often used:
  - Encouragement
  - Hearing loss simulations
  - Hearing aid demonstrations
  - Support from other parents
  - Connect with D/HOH adults
  - Refer to social worker or family therapist
- When families are “stuck” conventional counseling/toolbox may be insufficient

Question Prompt Lists (QPL)

- Have been used by other professions for >20 years
- Typically fact based questions
- FCC Panel recommended both fact based AND adjustment based questions
- Developed by clinicians, validated by parents

Childhood Hearing Loss QPL for Parents

- Familiarize yourself with questions
- For resource based questions, pinpoint referral sources

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http://docs.google.com/document/d/1nrxbK0v-NoezshB_kXS8_aLapAgM98Xow8PIWHT-p/edit?usp=sharing

Table 1: Counseling Elements Identified in Sessions and Definition of Terms

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<thead>
<tr>
<th>Category</th>
<th>Counseling Elements</th>
<th>Definition of Terms</th>
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</thead>
<tbody>
<tr>
<td>Asking</td>
<td>Coached questions</td>
<td>Clarifying the issue and providing specific feedback or information.</td>
</tr>
<tr>
<td></td>
<td>Open-ended questions</td>
<td>Encouraging thorough exploration of issues and providing insight.</td>
</tr>
<tr>
<td>Responding</td>
<td>Coached questions on the patient</td>
<td>Facilitating patient feedback and providing specific feedback or information.</td>
</tr>
<tr>
<td></td>
<td>Open-ended questions</td>
<td>Encouraging thorough exploration of issues and providing insight.</td>
</tr>
<tr>
<td>Providing</td>
<td>Information</td>
<td>The transfer of knowledge or information to the patient.</td>
</tr>
<tr>
<td>Planning</td>
<td>Agenda setting</td>
<td>The process of determining who will be present and addressing who will participate.</td>
</tr>
<tr>
<td>Action planning</td>
<td>The process of determining two steps:</td>
<td>The process of determining two steps: evaluating framework, specific behavioral steps to accomplish the plan, timeline, and medium/vehicle for delivery.</td>
</tr>
</tbody>
</table>

Coleman et al. 2018
More Information and Free Training
Learning.phonakpro.com

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Case Study 2
• Hx of Cleft palate, micrognathia, stenotic ear canals, cupped pinna. Followed by craniofacial team since birth.
• ABR at 5 months of age confirmed moderate conductive hearing loss left ear and moderately severe to mild CHL right ear.
• Fit with hearing aids bilaterally at 6 months
  • Aided SII has always been at least 75 of more for both ears.
  Parents are engaged in process.
  Enrolled in EI.
  Family using spoken language and sign support at home
  Retention concerns: Toupee tape + plus frequent earmold remakes
  History of OME and multiple sets of tubes.

Case Study 2
• 1.5 yrs
  • Receives speech therapy through EI and also private services at local hospital.
• 2.5 yrs
  • Concerns for patient’s speech progress.
  • Audibility has always looked good
  • Delays noted on both LittlEars and PEACH
  • Consider switch from HAs to AOD?
• 3 yrs
  • Showed progress in sign communication, verbal expressive and receptive language skills
  • WIPI=unaided word recognition 72%
  • Continue with HAs

Case Study 2
• 3.5 yrs:
  • Enrolled in pre-school.
  • FM in classroom
  • Now receives speech at school and privately by the same SLP.
  • Pre-school worked on verbal language and sign
  • PECS picture book for expressive language was briefly utilized
  • Binaural aided WIPI=84%
  • LittlEars and Peach both WNL
  • Diagnosed with apraxia

Case Study 2
• 4.5 yrs:
  • Diagnosed with rare genetic craniofacial disorder
  • Unaided speech scores improved as language scores improved: 90% on PBK
• Currently:
  • In mainstream classroom.
  • Intelligible around 90% of the time without sign support
  • Recently was a Hyena in the Lion King ☺
Audiologists are...

Acknowledgements

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