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## Counseling & Support for Children with Hearing Loss

Presenter: Jane R. Madell, PhD, CCC A/SLP, LSLS Cert AVT

Moderator: Carolyn Smaka, AuD, Editor in Chief, AudiologyOnline

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## COUNSELING AND SUPPORT FOR CHILDREN WITH HEARING LOSS

AUDIOLOGY ONLINE  
2/4/15

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### Learning Objectives

As a result of this continuing education activity, participants will be able to:

1. Talk to children about hearing loss
2. Help children describe feelings about being a child with hearing loss in a mainstream school
3. Help children advocate for themselves about issues related to hearing loss

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### What Is The Issue?

- Most children with hearing loss are now educated in mainstream settings
  - Advantages of mainstream education
    - Normal language models
    - Normal developmental, academic and social expectations
    - Better opportunities as adults
  - Disadvantages
    - They do not have significant contact with other children with hearing loss
    - May have more limited social opportunities

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### What Kind Of Support Do Children With Hearing Loss Need?

- Mainstreamed kids
  - Higher academic goals
  - Better language models
  - Frequently isolated
  - May not know other kids with HL
  - Friends may not understand HL
  - As they get older, social issues can become significant
- Kids in special education
  - Less isolated
  - Lower expectations
  - Need assistance dealing with people outside of school
  - Depending on school program, may not be able to communicate with most people outside of small community



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### Types Of Counseling

- Informational counseling
- Support counseling



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### Informational Counseling

- Providing information about hearing loss and management
  - Little of no information about feelings and emotions
- Parents are counseled at diagnosis
  - Children are too young to be counseled at that time
- As kids get older, we need to provide the same info to kids
  - Understand the audiogram
  - Degree and type of HL
  - Effect of HL on language, academics, literacy
  - Advocacy



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**Issues**

- Social skills are dependent on language skills.
  - Children socialize well with other children as long as they have the language to communicate well
- As children get older and more aware of hearing loss and the fact that they are “different” they begin to resist things that can help
  - FM, Therapy, advocating for themselves
- Children with disabilities may experience bullying
  - What can we do to help our children deal with bullying?

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**HOW DO WE PROVIDE SUPPORT TO PARENTS**

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**Supporting Parents**

- Most hearing loss is now identified at birth
  - Advantages
    - Listening age = Chronological age
    - Children can be fit with technology and start therapy early
    - Language delays can be eliminated or minimized
  - Disadvantages
    - Parents do not get to know and love the child before having to deal with the disability

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### Client-centered Counseling

- Client-centered counseling in the diagnostic process begins at this initial contact with the parent or child.
- If the child is being identified at birth, parents will not have observations or information about the baby to share
- If the child is being diagnosed later, the parents have likely compiled a list of experiences and observations about their child.
- Parents need the opportunity to share anything they feel may be important.
- They need to be allowed a chance to tell their story
  - What have they observed?
  - What do they suspect?

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### Involving Parents in Diagnostics

- Active involvement of the parents in the diagnostic process
  - diminishes the **denial mechanism** and
  - strengthens the bond between the audiologist and the parents.
- Parental satisfaction with follow up testing of children who failed newborn hearing screening is a function of parents being **empowered as partners** in the process.
- This may be difficult in a school setting but parents should be given the opportunity to participate in evaluations.

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### The Parents Have A Vital Role

- Involve the family **actively** in the test procedure.
- Engage the family as much as possible in eliciting or scoring responses.
- Have the family participate fully in the evaluation.
- When parents fully understand testing they can better deal with getting children to cooperate.
- **Ideally, the interpretation of test results will be made together.**

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### Steps To Including Parents As Co-Diagnosticians

- Encourage the parent to be at your side during
  - Let parent's see what the child responds to with and without technology.
- In corroborative testing in the sound booth have one parent sit with you if possible.
  - Describe what you are looking for
  - Enlist his or her help in observing the child's responses.
- In speech-language-educational evaluations let parent observe testing and comment on performance
  - Parents are often surprised with difficulties children have in testing because they are not seen at home
  - Demands at home may be less
  - Parents may anticipate what the child needs not requiring the child to listen

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### Steps To Including Kids As Co-Diagnosticians

- Discuss the reason for each test
- Discuss expectations
  - What is "good enough"
  - Is the score on a speech perception test good enough?
    - Would it be good enough on a math test?
- Remember, kids with HL do not know what they are missing
- Talk about how test results will impact different school activities
- Discuss reasonable expectations
- Talk about the concept of the "Listening Bubble" and what it means for school functioning

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### The Listening Bubble

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### Bubble in the Classroom

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### Discussing Understanding Speech

- Speech perception test results are usually described in percent – but not all people really understand the concept of percent loss
- Describe the results in terms of a number of pieces missing from a picture puzzle.
  - 12 pieces missing from a 100 piece puzzle
  - 30 pieces missing from a 250 piece puzzle
  - 60 pieces missing from a 500 piece puzzle
  - Will you be able to understand the picture?

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### Counseling Parents Initially

- All decisions are based on the parents desires
  - Parents need to be educated about the choices
- How do clinicians empower parents at this stage?
  - We help parents identify **their** goals for their child.
    - Where do you want your child to be at age 10, 20 etc
  - Provide information about **all** options and what they mean.
    - Be honest, all options are not equal
    - Different expectations for children in an auditory program vs a sign program



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## Decision Making

- Families need to make their own decisions
  - “What is your goal for your child?”
  - “What does it take to get there?”
- When we make decisions for the family
  - Sends messages that the parent is not competent/able to handle certain situations.
  - Successful outcomes are attributed to the professional rather than family
  - Family does not learn to become responsible for decisions and for doing what it takes to help child succeed




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## Helping Kids Make Decisions

- Help kids understand effect of not hearing
  - What happens when you do not hear
    - In school
    - Socially
- Short vs long term considerations
- “What is your long term goal for yourself?”
  - “What do you want to be when you are grown up?”
  - “What does it take to get there?”



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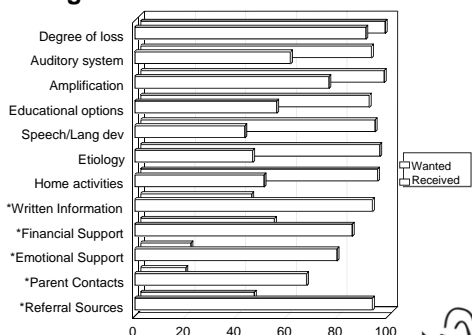
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## Information Wanted vs. Received by Parents at Hearing Loss Confirmation



Martin, George, O'Neal, & Daly (1987); \*Sweetow & Barrager (1980)  
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### How Do We Deal With Difficult Decisions

- “I can see that you are having a hard time with this decision.”
- “Can you tell me more about why this decision is so difficult?”
- Do you have questions I can answer to help you make a decision?
- ....



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### Counseling About Habilitation

- Routinely and actively engage both parents and kids in dialogue about goals, and progress
- Effective dialogue requires clinician to
  - Help everyone define success
  - Discuss what it takes for success
  - Know normal speech, language, auditory, and cognitive development
- Listen to parents and to kids. Recognize their stress and let them talk about it.
  - Arrange support
    - Counseling
    - Parent to parent
    - Kid to kid
  - Validate feelings



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### Parent Support Groups

- Advantages
  - Communicating with people who have been through the same experience
  - Audiologist, teachers, SLP, AVT and physician have not had the experience personally
- Types of groups
  - Newly diagnosed parent groups
  - Topic based
    - How to maximize your child’s speech and language
    - Transitioning to school
  - Mother’s group
  - Father’s group
  - Grandparent’s group
  - Siblings group

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### Scheduling Parent Groups

- During therapy
- Evenings
- Afternoons
- Weekends
- Occasional vs monthly vs weekly

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### The Counseling Role And Older Children



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### COUNSELING CHILDREN

- We counseled parents at diagnosis
- When do we start counseling children?
  - First showing grief about HL at 8-9 years
  - We need to address grief in children
- What do we need to talk to children about?
  - Informational counseling
  - Support counseling
  - Feelings about hearing loss
  - Social issues related to hearing loss
  - Self advocacy
    - It's okay to ask for help
  - Give them permission to grieve

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### How Do We Counsel Kids?

- Discuss test results at the time of the evaluation
  - Understanding the audiogram
  - Describe what the hearing loss means
  - Discuss how this effects listening every day
    - Effect of HL on academics
  - Long term effects of HL
  - How does technology help
  - Be careful not to provide too much information
    - Judge what the child wants to know
    - “Tell me what you want to know about your hearing loss”



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### Support Counseling

- Answer kids questions
  - “When will I be old enough not to need hearing aids?”
  - “Will it go away?”
  - “Will it get worse?”
  - “What will happen if I don’t wear hearing aids?”
- Respect a child’s wish not to discuss anything



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### Support Groups for Kids

- With today’s technology, most children are educated in mainstream settings.
- They may not have contact with other children with hearing loss
- Organize support groups for children with hearing loss
  - Gives them the opportunity to have peers who have the same experiences
  - Gives them someone else who understands
  - Gives them the opportunity to say what they feel
    - Don’t have to worry about upsetting parents
    - Don’t have to worry about what classmates think
    - Don’t have to worry about what teachers think



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### KIDS SUPPORT GROUPS

- Pizza Party
- Group by age and communication mode
- Don't worry about degree of HL
- Intro
  - Name
  - Age
  - Grade
  - Degree of hearing loss
  - Type of technology
  - Favorite activity

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### Rules for the Group

- Everything we say here stays here
- Respect what everyone says
- Only one person talks at a time
- Go around in a circle
- If you do not understand, ask for clarification
- No one has to speak if s/he doesn't want to

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### Topics

- Tell me something funny about having a hearing loss
- Name 5 things friends and family know about you?
  - Is HL included?
  - Where on the list does it fall?
- Is there anything good about having a hearing loss?
- What are the problems about having a hearing loss?
  - Go around in a circle first just listing the problems
  - What can we do to improve this problem
    - Group suggestions about solving individual problems
- Social issues
- Bullying, teasing

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
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### Counseling Issues with Children

- Denying the hearing loss
  - Concern about expense of getting hearing aids
  - Fear of ridicule from siblings or other children
  - Peer pressure
- Refusal to wear hearing aids or FM
  - With young children, often related to the attitudes of parents
  - With older children, often related to attitudes of peers
- Talk with parents and kids about their concerns about their child wearing hearing aids.
  - Provide support and sympathy
  - What is the effect of your child not wearing a hearing aid? How will that effect his speech, language and learning?
  - What is your goal for your child? Where do you want him to be when he is 5, 10, 20 years old?
- Interference from grandparents, siblings etc.

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### Helping Children Talk About Problems Listening

- Ask the child about his/her concerns:
  - *Do you only hear part of what is said sometimes?*
- Encourage the parents to share their concerns.
  - *What have they observed?*
  - *What behavior under what conditions?*
  - Have child present to hear
- Discuss that everyone has problems hearing sometimes.
  - *Let's discuss where you have trouble hearing and we will see what we can do to make it better.*

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### Helping Older Children and Teenagers Understand Hearing Loss

- Test speech perception in the loud speaker
  - At normal conversation (50 dBHL)
  - At soft conversation (35 dBHL)
  - In competing noise (babble) at +5 or 0 SNR)
- These speech perception results will more clearly illustrate the hearing problem to the parents and child than the pure tone testing.
- Talk about how this makes you feel
  - "I know this is difficult. I am sorry you have to do this."
  - Let the child express frustration

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## Approaching Teenagers

- Discuss speech perception results in each test condition
  - Normal and soft conversational levels
    - Quiet and noise
  - Pieces of the puzzle missing
  - Most difficulty when new or complex information is being presented (like school)
  - More fatiguing –you are doing extra work just to hear whereas other students only have to listen and understand
  - What do other students think?
  - The effects of a hearing loss can be subtle but WILL be noticed by others

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## Approaching Teenagers

- Talk about lifelong impact of HL
  - Adults with hearing loss who wear hearing aids make 50% more during their lives than those with hearing loss who don't wear hearing aids and try to 'get by'
  - About 30% of people in prison have hearing loss meaning people who don't hear everything and choose to not do something about it can end up making bad choice

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## Self-Concept

- Internalizing others' reactions to self
- Children not ready to "tune out" those reactions
- Children with hearing loss may have relatively poor self-concept
- Children with hearing loss may have fewer opportunities for peer interactions
- Less practice to learn "social rules"
- May interpret social interactions inaccurately
- The better a child hears, the better they are likely to communicate, resulting in better self concept

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### Self-Concept and the HA Effect

- It is the wearing of the device which ‘amplifies’ the difference between child and peers
- Children with hearing loss may have fewer opportunities to socialize

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### Experience With Self Expression

- Make sure children with HL have the vocabulary to express their emotions
- Talk about emotions
- Help them learn to recognize emotions in others.

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### Social Competency (Greenberg & Kusch, 1993)

1. Good communication skills
2. Capacity to think independently
3. Capacity for self-direction, self-control
4. Understanding feelings of others
5. Flexibility
6. Ability to tolerate ambiguity, frustration
7. Maintain healthy relationships

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### Child Peer Relationship Scale

- Not a test!
- Eight discussion points to broach topic of friendship development

Mostly,  
other kids  
like me

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Sometimes  
other kids  
don't like  
me

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Other kids  
don't really  
like me



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- I like school / School's OK / I don't like school.
- I have some good friends at school / I have one good friend / I don't have a good friend at school.
- I have a best friend / I sort of have a best friend / No one is really my best friend.
- I usually see friends after school / Sometimes I see friends after school / I don't see friends after school

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- No one teases me about my HL / Sometimes kids tease me / Other kids tease me a lot
- I know other kids with HL / I know one other kid / I don't know other kids with HL
- I really like my HAs/CI / My HAs/CI are OK / I hate wearing my Has/CIs

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### "I Start/You Finish" (Cappelli 1995)

- I am happy when \_\_\_\_\_
- I am sad when \_\_\_\_\_
- The thing I like most in the world is \_\_\_\_\_
- The thing I would change in the world is \_\_\_\_\_
- Because I have a hearing loss \_\_\_\_\_

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### Self-Assessment for Teens

- Self-Assessment of Communication - Adolescents (SAC-A) *and*
- Significant Other Assessment of Communication - Adolescents (SOAC-A)

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### We Can Also Discuss Scenarios

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### Exercise: To Disclose or Not Disclose?

Hiding a HL		Acknowledging a HL	
+	-	+	-

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### “Keeping the Door Open”

*Actively* indicate child was heard and understood:  
Listening is not passive!

- Minimal Encouragers
- Paraphrase
  - Check your understanding
  - Show that you heard
- Acknowledge feelings

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### Discuss Bullying

- Bring the topic up at every evaluation
- Bring the topic up at every support group
- Ask
  - Do you know what bullying is?
  - What is the difference between bullying and teasing?
  - Is it ever okay to bully?
  - Have you observed any bullying?
  - What do you do if you see bullying?
  - How does it make you feel to be bullied? To see bullying?
  - What is your school’s plan to deal with bullying?
    - Who do you go to if you see bullying?

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Case Example:

- 10 year old boy tells school he left HAs at home; tells family he left them at school
  - How do we manage this situation
    - Why is the child doing this?
    - What can we do to change the behavior?
  - Talk to the child
    - “You must really be upset about wearing hearing aids ”
    - “It must be difficult in school ”
    - “Do hearing aids help? ” “When do they help? ”

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Summary

- At all stages it is essential that professionals empower parents and kids and help them process the emotions associated with hearing loss.
- Involve both parents and kids as co-diagnosticians
- Simulations and descriptions using dB levels and the “listening bubble” are more helpful than labels and audiogram interpretation.
- Encourage parents to identify their goals for their child and present them with unbiased information about all options.
- Encourage kids to think about goals
- Counseling is important for kids
- Testing in noise is critical for older children and teenagers
- Provide fact-based information about the life-long impact of hearing loss with older children and teens.
- Give kids the chance to express feelings.
- There are both positive and negative help-giver responses. Resist the urge to rescue!

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