Counseling and Support for Children with Hearing Loss

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COUNSELING AND SUPPORT FOR CHILDREN WITH HEARING LOSS

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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

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

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
Types Of Counseling

- Informational counseling
- Support counseling

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

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?
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

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?
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.

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.

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.
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?

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

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
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?"

Information Wanted vs. Received by Parents at Hearing Loss Confirmation

- Degree of loss
- Auditory system
- Amplification
- Educational options
- Speech/Lang.dev
- Etiology
- Home activities
- *Written Information
- *Financial Support
- *Emotional Support
- *Parent Contacts
- *Referral Sources

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?
- ...
## 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

## 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

## Scheduling Parent Groups

- **During**
- **Evenings**
- **Afternoons**
- **Weekends**
- **Occasional vs monthly vs weekly**
The Counseling Role And Older Children

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

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”
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

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

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
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

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

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.
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.

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

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
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 choices

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

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
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.

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

Child Peer Relationship Scale

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

Mostly, other kids like me

Sometimes, other kids don’t like me

Other kids don’t really like me
• 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

• 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

“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 ____________
Self-Assessment for Teens

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

We Can Also Discuss Scenarios

Exercise: To Disclose or Not Disclose?

<table>
<thead>
<tr>
<th>Hiding a HL</th>
<th>Acknowledging a HL</th>
</tr>
</thead>
<tbody>
<tr>
<td>+</td>
<td>+</td>
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<td>-</td>
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</table>
“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

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?
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? ”

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!