• If you are viewing this course as a recorded course after the live webinar, you can use the scroll bar at the bottom of the player window to pause and navigate the course.

• This handout is for reference only. It may not include content identical to the PowerPoint. Any links included in the handout are current at the time of the live webinar, but are subject to change and may not be current at a later date.

© continued.com, LLC 2017. No part of the materials available through the continued.com site may be copied, photocopied, reproduced, translated or reduced to any electronic medium or machine-readable form, in whole or in part, without prior written consent of continued.com, LLC. Any other reproduction in any form without the permission of continued.com, LLC is prohibited. All materials contained on this site are protected by United States copyright law and may not be reproduced, distributed, transmitted, displayed, published or broadcast without the prior written permission of continued.com, LLC. Users must not access or use for any commercial purposes any part of the site or any services or materials available through the site.
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

Technical Assistance: 800-753-2160

CEU Total Access members can earn credit for this course
  - Must complete outcome measure with passing score (within 7 days for live webinar; within 30 days of registration for recorded/text/podcast formats)
  - Questions? Call 800-753-2160 or use Contact link on AudiologyOnline.com

This handout is for reference only. It may not include content identical to the powerpoint.
COUNSELING AND SUPPORT FOR CHILDREN WITH HEARING LOSS

AUDIOLOGY ONLINE
2/4/15

Jane R. Madell, PhD,
CCC A/SLP, LSLC Cert AVT
www.JaneMadell.com

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?

HOW DO WE PROVIDE SUPPORT TO PARENTS

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

The Listening Bubble

Jane@JaneMadell.com  www.JaneMadell.com
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

<table>
<thead>
<tr>
<th>Information Wanted</th>
<th>Information Received</th>
</tr>
</thead>
<tbody>
<tr>
<td>Degree of loss</td>
<td>80</td>
</tr>
<tr>
<td>Auditory system</td>
<td>70</td>
</tr>
<tr>
<td>Amplification</td>
<td>60</td>
</tr>
<tr>
<td>Educational options</td>
<td>50</td>
</tr>
<tr>
<td>Speech/Lang dev</td>
<td>40</td>
</tr>
<tr>
<td>Etiology</td>
<td>30</td>
</tr>
<tr>
<td>Home activities</td>
<td>20</td>
</tr>
<tr>
<td>*Written Information</td>
<td>10</td>
</tr>
<tr>
<td>*Financial Support</td>
<td>90</td>
</tr>
<tr>
<td>*Emotional Support</td>
<td>80</td>
</tr>
<tr>
<td>*Parent Contacts</td>
<td>70</td>
</tr>
<tr>
<td>*Referral Sources</td>
<td>60</td>
</tr>
</tbody>
</table>

Martin, George, O’Neal, & Daly (1987); Sweetow & Barrager (1980)
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 therapy
• 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

Jane@JaneMadell.com www.JaneMadell.com
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 affect 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 loudspeaker
  - 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

Jane@JaneMadell.com  www.JaneMadell.com

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

Jane@JaneMadell.com  www.JaneMadell.com

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

Jane@JaneMadell.com  www.JaneMadell.com

CONTINUED
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 & Kusce, 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/CIs / My Has/CIs are OK / I hate wearing my Has/CIs

Jane@JaneMadell.com  www.JaneMadell.com
“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

CONTINUED
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>
</tr>
<tr>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</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!