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Providing Support to Families of Children with Hearing Loss

Jane Madell, PhD, CCC-A/SLP, LSLS Cert AVT

Moderated by:
Carolyn Smaka, AuD, Editor in Chief, continued

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Providing Support to Families of Children with Hearing Loss

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Learning Outcomes
After this course, participants will be able to:

- Explain effects of hearing loss on families and the support that parents need when a child has hearing loss.
- Explain key components of support groups for parents of children with hearing loss, and of support groups for children with hearing loss.
- Describe ways professionals can help children with hearing loss and their families to advocate for themselves about issues related to hearing loss.

Effect of Hearing Loss on Families

- With the advent of newborn hearing screening babies are identified at birth
- Families have no time to recognize that something might be wrong.
- They are stunned when hearing loss is identified
- 95% of children are born to families with no history of hearing loss.
- Families do not know about hearing loss and don’t know what to do or what to expect.
What Support Do Parents Need?

- Help families accept hearing loss
- Help them understand that hearing loss is a manageable disorder
- Discuss what has to be done.
  - Medical evaluations
  - Technology
  - Auditory verbal therapy
- Support groups

When Do Families Need Support

- Parents need support at the beginning
- They also need support at all transition points
  - Change of technology
  - CI surgery
  - Starting school
  - New school
  - Bar or Bat Mitzva, Confirmation
  - Marriage
  - Marriage of friends children
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
Scheduling Parent Groups

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

Parent Support Groups

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

- Informational groups
  - Technology
  - School
  - Dealing with other family members
- Support groups
  - Dealing with emotional issues
  - Groups for mothers
  - Groups for fathers
  - Mixed groups
  - Sibling groups
  - Grandparents groups

Basic Information About Technology

- Hearing aids work well for children with mild to moderate hearing loss
- Cochlear implants work well for children with severe and profound hearing loss
  - Before children are considered for cochlear implants they will have had a trial with hearing aids
- Some children with moderately-severe hearing loss will do well with hearing aids and others will need cochlear implants
- All children with hearing loss will need an FM system to enable them to hear at a distance and in competing noise.
The Roles of Different Practitioners (Short Summary)

- **Audiologist**
  - Diagnosis of hearing loss, evaluation and management of technology, counseling parents and children about the effect of hearing loss, help school staff understand how to manage a child with hearing loss

- **Speech-language-auditory pathologist/ listening and spoken language therapist**
  - Evaluate speech-language-auditory skills, develop treatment plan for building skills, provide therapy, monitor progress

- **Physicians**
  - Medical evaluation and treatment

- **Educational Psychologists**
  - Psycho-educational evaluations to identify learning issues

- **Social work**
  - Counseling and support for families and children
The Beginning of Client-Centered Counseling

- Client-centered counseling in the diagnostic process begins at this initial contact with the parent.
- 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 of their child.
- It is important to let them 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 clinicians and the parents.
- Parental satisfaction with follow up testing of children who failed newborn hearing screening was a function of parents being empowered as partners in the process.
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 diagnosis.
- Ideally, the diagnosis will be made together.

Steps to including parents as co-diagnosticians

- Encourage the parent to be at your side during
  - look for responses on the auditory brainstem response (ABR) or otoacoustic emissions (OAE) equipment, in behavioral testing, and in therapy.
  - Let parents 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
The ‘listening bubble’ concept
Karen Anderson

- Describe the loss in terms of the child having a smaller ‘listening bubble’
- A smaller listening bubble explains why the child will respond sometimes (loud sounds or those close to them) but not others
- The listening bubble is even smaller in noise
- Different voices can be easier for the child to detect – bigger listening bubble for Dad than for Mom
- This concept is also useful for children as they get older and try to understand their hearing loss

When speech understanding

- 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.

A lack of 12 pieces from a 100 piece puzzle doesn’t seem like much, but 60 from a 500 piece puzzle (a better representation of complex speech) is enough to make the picture difficult to recognize.
The counseling role following diagnosis...

- 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.
- 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

How much should we answer?

- Parents: If Andrew was your child, what would you do?
- Professional: if Andrew was my child.....

- Making the decision for the family
  - Sends messages that the parent is not competent/able to handle certain situations.
  - Successful outcomes is 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
Other counseling tools

- “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?

The counseling role in the habilitation process:

- Routinely and actively engage parents in dialogue about the child’s goals, progress, home carry-over
- Effective dialogue requires clinicians to
  - be knowledgeable regarding what it takes for success in each of the options
  - be familiar with normal speech, language, auditory, and cognitive development
- Listen to parents. Recognize their stress and let them talk about it.
  - Arrange parent support
    - Counseling
    - Parent to parent
  - Validate parents feelings
SUPPORT WHEN CONSIDERING COCHLEAR IMPLANTS

Pre-Cochlear Implant (CI) Counseling

- Always stressful for parents
- Making the decision for implantation is difficult
- Help parents understand why it will help
- Demonstrate why hearing aids are not working
- SLP needs to demonstrate why speech-language skills are not progressing at a sufficiently fast rate
- Social work services to be sure that families have realistic expectations and to provide emotional support
  - Cannot expect child who has no language to speak in sentences after surgery
  - Need to understand that it takes time to build skills
  - CI alone does not provide benefit
  - Requires auditory therapy and mapping of CI on regular basis
What is the issue?

- 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
  - Better 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 become significant

- Kids in special education
  - Less isolated
  - Lower expectations
  - Need assistance dealing with people outside of school

Types of Counseling

- Informational counseling
- Support counseling
Issues

- Social skills are dependent on language skills.
  - Children socialize well with other children as long as they have the language to communicate well
- By age 8 or 9 years children begin to recognize they are different
- 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
  - Remote microphone technology (RM), Therapy, advocating for themselves
- Children with disabilities may experience bullying
  - What can we do to help our children deal with bullying?

Informational Children

- We counseled parents at diagnosis
- What do we need to talk to children about?
  - Understand hearing loss
  - Technology
    - Types, what is needed when
    - Remote microphone technology why and when
  - Feelings about hearing loss
  - Social issues related to hearing loss
  - Self advocacy
    - It’s okay to ask for help
  - Give them permission to grieve
The counseling role and older children

How Do We Counsel Older Kids?

- Discuss test results at the time of the evaluation
  - Describe what the hearing loss means
  - Discuss how this affects listening every day
  - 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”
- 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
Counseling and Therapy

- Help children understand why therapy is needed
- Discuss skill levels and what they need
- Talk about language and what can be done to build skills
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, etc.

Kids Support Groups

- Group by age and communication mode
- Don't worry about degree of hearing loss
- Getting started
  - Tell me something funny about having a hearing loss
  - Name 10 things friends and family know about you?
  - Is there anything good about having a hearing loss?
  - What are the problems about having a hearing loss?
  - What can we do to improve this problem
    - Group suggestions about solving individual problems
    - Social issues
    - Bullying, teasing
- Follow-up
Counseling Issues with Children

- Denying the hearing loss
  - Fear of parent anger (they have been yelled at in the past for not hearing)
  - Concern about expense of getting hearing aids
  - Fear of ridicule from siblings or other children

- Refusal to wear hearing aids
  - With young children, often related to the attitudes of parents
  - With older children, often related to attitudes of peers

- Talk with parents 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?

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 (SNR = signal-to-noise ratio)
- 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
  - Pieces of the puzzle missing
  - Most difficult 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 impacts
  - 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 anything 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 often have relatively poor self-concept
- Children with hearing loss have fewer opportunities for peer interactions
- Less practice to learn “social rules”
- May interpret social interactions inaccurately
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 have fewer opportunities to socialize, especially if language skills are not at age level

Less Experience in Self Expression

- Make sure children with hearing loss have the vocabulary to express their emotions
- Talk about emotions and help them learn to recognize emotions in others.
Child Peer Relationship Scale

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

1. Mostly, other kids like me
2. Sometimes other kids don’t like me
3. 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

HL = hearing loss  
HAs = hearing aids  
CI = cochlear implant

“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

1. This teacher is talking. He’s in front of the class. Does your teacher do that? Is it hard to hear his speaking?
“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

Acknowledging Feelings

- “…any indication that you are struggling to understand the emotional content of what the other person is saying.”
- “People almost never change if they do not feel understood.”

- Stone et al., 1999
Counseling Misstep: “Counseling by Persuasion” (Luterman, 2001)

I have all this information and training.
You do not.
I will help you see it my way.

Case Example:

- 10 year old boy tells school he left hearing aids 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 parents as co-diagnosticians for children of all ages.
- Simulations and descriptions using decibel 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.
- 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 everyone the chance to express feelings.
- There are both positive and negative help-giver responses. Resist the urge to rescue!
References


