

Beyond the Audiometer: Supporting Children with Hearing Loss and Their Families

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Introduction:

The impact of hearing loss extends far beyond the physiological and anatomical basis of the deficit. Both the American Academy of Audiology (2004) and the American Speech, Language and Hearing Association (2004) agree that personal adjustment counseling falls within the scope of an audiologist's practice. With the wide acceptance of universal newborn screening programs, we have the opportunity to diagnose hearing loss at a very early age. With this also comes the opportunity to support our patients and their families through the earliest stages of psychosocial development. The proposed guidelines (see appendix A) in this paper suggest steps the audiologist can follow to support children with hearing impairment and their families following the diagnosis of hearing loss as well as during distinct psychosocial developmental stages. Throughout this process, it is crucial to bear in mind our primary goal: to support the development of our patient.

Support at Diagnosis:

Ideally, audiologists set the tone for the relationship with a patient and family from the first encounter. Audiologists can show empathy for the families they work with by allowing families to set the agenda during the initial interview. Parents often come to these visits with deep concerns, and they need an opportunity to tell their story and have their concerns heard by the audiologist. Audiologists can do this by listening and validating what the family is saying. Listening skills such as reflecting back what is said, not multitasking while the family is speaking, and taking the time to allow families to express all of their concerns are all ways to meet the needs of parents. By allowing families the time to "tell their story" and by responding to them affectively, audiologists help families to become engaged in the treatment process.

Once a diagnosis of hearing loss is confirmed, the audiologist needs to deliver this information in a manner that responds to the family's needs. In a survey completed by Roush and Harrison (1998), parents indicated that emotional support and education were a priority in services they received from their audiologists. Specifically, they noted that audiologists need to:

Be aware and supportive of the grieving process that parents experience upon learning of their child's hearing loss; Be honest but positive in describing the child's hearing loss and to view each child as an individual; Give more

information generally and more information regarding intervention options in particular; and avoid professional jargon when explaining test results and other technical matters.

Sharing the news of a diagnosis of hearing loss is always challenging. Even though it is difficult, it should be done in an honest and respectful manner. Audiologists need to avoid “looking for the brighter side” and deliver the information with accuracy. That said, audiologists should also express hope and confidence in the child and the family to make choices that provide optimal outcomes for the patient.

An information counseling checklist (see appendix B) can be used by the audiologist to structure (outline) and document what information has been shared with a family. This checklist was not designed to give the audiologist a list of topics that should be covered with a family. It was developed to assist audiologists in providing information when families are ready to learn. As can be seen on the form, many information topics such as anatomy of the ear, communication methods and types of audiological evaluations are listed. Information about these topics can be elaborated on at different visits depending on the families’ learning objectives. The checklist gives the audiologist documentation of what areas have been discussed. There are multiple checkboxes by each topic to remind the audiologist that information may need to be re-taught at several visits.

People learn in different ways (Kolb, 1976). Some people learn more effectively through visual stimulation, others may learn better when information is presented orally. Families should be given information in a variety of ways including discussions, demonstrations, in-service programs and videos (Clark & Martin, 1994). Families should also leave the diagnostic appointment with written information including: the diagnosis, the plan for follow-up, appointment dates and times, as well as contact information and other resources to help the family as they reflect and seek additional information.

Emotions:

There are many emotions that can accompany the news of a hearing loss diagnosis, including shock, denial, anger, guilt, sadness and any combination of these (Clark and Martin, 1994). Families may express all or some of these emotions. They do not happen in any specific order and, although their feelings may at first seem unproductive, all have beneficial purposes. For example, anger can provide parents with the energy and motivation to deal with the tasks that lie ahead (Clark & Martin, 1994). Later, it can fuel their advocacy for their child’s needs and rights and to request a “level playing field” in school and in the community.

Shock:

One emotion that might be expressed is shock, which can help protect the mind and body against becoming overwhelmed (Bruce, 2002). Because this happens, families may not remember or have processed any information that was told to them after they learn that their child has hearing loss. It is important that audiologists recognize that this happens and meet the family's needs for information. When sharing information, the audiologist can ask a family about their priorities for topics to cover, such as possible etiologies of the child's loss, intervention options, or further diagnostic testing that needs to be done.

Denial

If parents are in apparent denial (e.g., not following up for recommended visits, questioning test results; Luterman, 2001), the audiologist can help involve them in the testing process, or recognize that they may not have had the chance to express their concerns.

Anger:

It is a natural response for a person to respond defensively when faced with anger. It can be a challenge for audiologists to receive the anger that parents can express when they are working through the emotions following diagnosis. An effective use for this anger is to re-direct the energy and use the emotion to accomplish challenging tasks such as enrolling their child in early intervention or finding financial support for hearing aids.

Guilt:

Some emotions, however, can have a negative impact on both the family and the child. Guilt can result in unhealthy changes within a family. For example, a father who feels that he cannot fix his child's hearing loss can become over-bonded with work. A mother who feels that her child's hearing loss is the result of something she did or did not do during her pregnancy can become "super-mom" and aim to never fail her child again. Family roles can also shift to meet the demands of a new diagnosis. A mother may decide to leave her career to devote more time to her child's education.

When unhealthy relationships persist, an audiologist can acknowledge the imbalance and support work toward re-establishing a healthy family system. It is certainly not suggested that audiologists become marriage counselors. However, with the objective of providing optimal support, audiologists can help by acknowledging the feelings that led to the imbalance in the family system. We can see the value of the anger for a frustrated parent and help the parent use their anger for their child's and their own benefit. We can brainstorm with families about ways to involve family members who have become detached or over-bonded with other areas of their life.

Acknowledgement:

Audiologists need to recognize these potential emotions and react to them in a productive way. Acknowledgment – putting expressed or perceived emotions into words - can show families that the audiologist is actively listening to their concerns. This can give families the needed release for these emotions and help them recognize what they are feeling, work through the emotions and use them productively.

Attachment:

If we are successful at diagnosing hearing loss very early in life, we can have a positive impact on the attachment between a child and their caregiver. Healthy attachment has been described as a deep, enduring connection between a child and caregiver that is a learned ability. Attachment develops between birth and three years of age and is the result of ongoing reciprocal nurturing interactions that include love, trust, protection, need fulfillment and limit setting. Helping parents and caregivers establish consistent, predictable and effective communication strategies, along with the recommended amplification is a key step towards insuring the attachment process between child and parent.

Factors that disrupt a family system can have a significant negative impact on attachment (Berger, 2003). Children who do not establish a healthy attachment with their caregiver can develop multiple social concerns including: impulsiveness, hyperactivity, inattention, poor self-image and paucity of friendships. Such children are often oppositional and defiant, disruptive, manipulative and possess a sense of internalized helplessness (Levy, 2000). As noted earlier in this report, the diagnosis of hearing loss can be devastating to the family. Audiologists should be aware of the potential impact that the diagnosis of hearing loss can have on the development of healthy attachment, and that they can support healthy attachment by teaching families about this bond, supporting consistent use of technology and recognizing that positively resolving parental grief aids the child's achieving healthy attachment.

Post-Diagnosis Support:

During the emotional period following diagnosis, parents need to make critical choices about intervention options. Audiologists should actively involve families in the decision making process. It is very important that we avoid making strong recommendations or choices for the family because only they know what will work best for their family system. For example, an audiologist may feel that a child with severe to profound hearing loss may need to use sign language to best meet their communication potential. This child, however, may be part of an extended family that is unwilling to immerse itself in learning sign language and therefore an oral communication method may be the better alternative for the child and family. We need to convey hope for all communication methods/educational settings so that in the event the family needs to

change methods, hope exists for the necessary change. Discussing all options in a positive manner also conveys to families that there are no failures except to ignore the loss altogether.

Veteran Families:

Veteran families -- those who have children with hearing loss and who have worked through this devastating diagnosis -- can be a valuable resource for new families. Roush and Matkin (1994) asked families to offer suggestions to audiologists on how to improve the support we provide. One of the suggestions offered by families was for audiologists to recognize that “parents want and need the support of other parents. Many families report an emotional turning point when they connect with a supportive group of other parents” (Roush, 1998, p. 164). An audiologist can provide assistance by facilitating development of support groups or by introducing caregivers to veteran families who are willing to share their experiences.

Supporting Psychosocial Development:

Audiologists have at their disposal both auditory (Palmer & Mormer, 1999) and speech and language milestones that are used as benchmarks for monitoring development. Traditionally, however, we have not used milestones of psychosocial development to track progress or to provide guidelines to parents to support development. Fortunately, several tools exist that can help to assess specific components of psychosocial development. These include:

- 1) the Meadow-Kendall Social-Emotional Assessment Inventories for Deaf and Hearing-Impaired Students (Meadow, 1983),
- 2) the Children’s Peer Relationship Scale (English, 2002) and
- 3) the Self Assessment of Communication - Adolescent and its companion version, the Significant Other Assessment of Communication – Adolescent (Elkayam & English, 2003).

There are also a multitude of curricula available that offer the audiologist and the family specific guidance in encouraging positive development of specific social skills such as: Self- Advocacy for Students Who are Deaf or Hard of Hearing (English, 1997) and Teaching Social Skills to Youth: A Curriculum for Child-Care Providers (Dowd & Tierney, 1995). While this report seeks to integrate many of the concepts established by these tools, the reader is referred to these publications should more in-depth information be sought.

Efforts to integrate psychosocial development and audiological deficits exist in the literature. For example, Schum (1991) proposed a model of psychosocial development for children with hearing impairment in which he suggested that atypical development was the result of impaired communication. He noted that

some deaf children do not receive the full environmental experience necessary to construct higher levels of interpersonal understanding. That is, due to hearing loss, these children lack access to incidental learning, the primary source of social information and social skill learning. As a result, they remain fixated at lower stages of development and manifest behaviors that are judged abnormal compared with hearing children their age (p.321).

Schum (1991) proposed that the perceived “problem” behaviors of the child with hearing impairment may be appropriate behaviors if one considered the developmental stage the child was in rather than using his chronological age as a reference. He also noted that the keys to promoting development were language and communication ability.

Other authors have used the work of Erik Erikson to describe psychosocial development in hearing impaired children (eg., Schlesinger, 1978) and the development of relationships between audiologists and families they work with (eg., Luterman, 2001).

Erikson’s Stages of Psychosocial Development

The guidelines proposed in this paper utilize Erikson’s model of development to suggest ways that an audiologist can support healthy psychosocial development rather than to account for abnormal development. Erikson described psychosocial development as a series of stages or developmental challenges through which children progress. At each of these stages, success or failure is dependent upon “the interaction between the individual’s characteristics and whatever support is provided by the social environment” (Berger, 2003, p.38). Effective communication can be a major contributor to success or failure during these critical stages. It is the premise of these guidelines that, by appreciating the stages of development and supporting positive outcomes to the challenges children encounter, we can support a child’s psychosocial development.

In the earliest stage of development, from birth through 18 months of age, children learn to trust their environment. If their basic needs are met – they are kept warm, fed, shown affection – children learn that they can depend on their environment. If these needs are not consistently met, children develop a sense of mistrust. Once children learn that they can trust, they begin to explore the world immediately around them. Through successful exploration and gaining control, children from 18 months through 3 years of age gain a sense of autonomy or independence. If children consistently experience failure when trying to manipulate their surroundings, they will develop shame and doubt in their abilities.

At age three years, a child who has learned that they can successfully control their surroundings will attempt new tasks and with positive experience will gain a sense of initiative. If these attempts at new skills are met with criticism, children can develop a sense of guilt in their abilities.

During the early school years, children are challenged to use the skills they have developed to meet the challenges of society and develop a sense of competence in their abilities. Erikson described this stage as one where a child becomes industrious (competent) or develops a sense of inferiority, dependent upon the success or the failure of their experiences.

The challenge for adolescents is to establish their identity. This is accomplished by accepting or rejecting the rules and values of their families, peers and community. An adolescent who has met the challenges of all of the previous stages, developed trust, autonomy, initiative and competence is ready to define “Who am I?” and start planning for the future. Adolescents who have failed at previous stages will be unprepared to make choices for themselves and may experience “role confusion.” (Berger, 2003).

Audiologists can support successful experiences at each of Erikson’s stages by working with the child and family to: 1) ensure that a child has the opportunity to fully participate in their environment by providing access to auditory and/or visual environmental cues; 2) inform families about developmental milestones; 3) provide the tools for the child, family and educators to develop good communication skills, including amplification, assistive devices and instruction on creating effective listening environments; 4) encourage the development of appropriate social skills; and 5) coach caregivers on creating positive and successful experiences when the child attempts new skills (Rall, 2007).

Development of Self-Concept

Self-concept is a person’s understanding of who one is. This starts when children learn that they are a separate being from those around them. Initially, for the first few years of life, infants view themselves as part of their mother. Sometime between 12 to 15 months of age, infants start to identify themselves as separate beings in a process known as self-awareness. Self-awareness becomes self-concept as a child begins to define him or herself with factual or concrete labels around two years of age (e.g., “I am a girl” v. “I am a boy”). A child’s self-concept eventually becomes evaluative and forms the earliest roots of self-esteem that continue into adulthood (Berger, 2003).

The audiologist can support the development of a positive self-concept and self-esteem by providing resources that optimize the chances of positive experiences for the child. This can be achieved by evaluating whether the limitations a child has, as a result of auditory deficits, are resulting in negative experiences. If so, the audiologist can work with the child and his or her family to explore ways to circumvent these limitations such as maximizing benefit from amplification, consistent use of effective communication strategies, use of good listening environments, increasing the amount of information that is visually available in the home and preschool setting, initiating use of assistive devices (FM, DAI, ALDs etc.), and adding additional communication methods for peer interactions.

Supporting Social Competency

As the child ages, the audiologist should work with the parents (and in later stages, the child) to assure age-appropriate social skills are developing. Social skills can be as basic as properly greeting someone or as advanced as coping with the feeling of being “left out.” Children with hearing loss can be at a disadvantage for developing appropriate social skills because they may not have access to incidental learning of these skills by “overhearing” other successful or unsuccessful attempts at use of these skills or other cues that support learning these behaviors (Schum, 1991).

Dowd and Tierney (1995), in their curricula for teaching social skills to children, explain that fundamental elements of a youth’s social behavior and skills include the context or situational variables in which they occur (antecedent events), the behavioral components that the youth is capable of performing (skills) and the consequent events that affect future performance. Also, in order for the youth to become socially “competent,” he or she needs to be capable of recognizing the subtle social cues emitted by others in the course of an interaction and be able to make appropriate behavioral adjustments. (p.13)

Children with hearing loss can experience challenges with each of these elements. They may not recognize the social cues that trigger the use of a particular behavior (e.g., hearing the doorbell ring or a person asking for their attention) or overhear another child modeling a common turn taking skill such as “can I have a turn?” A child with delayed language skills may not be able to express their feelings in words or signs appropriately (e.g., stating “that makes me feel frustrated” versus throwing a temper tantrum). Children with hearing loss may not be aware of the consequent event’s cues that positively reinforce a good behavior (e.g., they may not hear their parents’ verbal praise).

Audiologists can help support the development of age-appropriate social skills by:

- 1) informing parents of the need to monitor and support their child’s social skills because of the impact hearing loss can have on normal social skill development.
- 2) exploring with the family any problem behaviors that are reported by the Parent or observed during the visit. Audiologists can work with the family to evaluate the events that may trigger the behavior, the child’s skills for addressing the event and how the child’s behavior is either being reinforced or corrected. Audiologists need to consistently monitor how the child’s hearing loss may be interfering with the development of social competence at home, school and other settings with peers.

Summary:

From the initial diagnosis, there are many steps an audiologist can take to provide our pediatric patients and their families the information and support they need. As a profession, we need to acquire additional training in the area of counseling and importantly, know when to refer to the professional mental health community. There is also a need for our profession to evaluate evidence-based intervention strategies to learn how we can most effectively support our patients.

Appendix A

**Center for Childhood Communication
The Children's Hospital of Philadelphia
Counseling Guidelines: Birth - Adolescence**

I Diagnosis:

- ❑ Allow families to “tell their story”
- ❑ Show kindness, empathy
- ❑ Be honest
- ❑ Express hope and confidence
- ❑ Parent should leave with: written information (info packet), a plan, phone number (to call whenever clarification is needed) and the next appointment scheduled in writing

Within 4-6 months of diagnosis:

- ❑ Recognize/acknowledge the emotional responses
- ❑ Facilitate healthy attachment between child and caregivers
- ❑ Acknowledge imbalance and support work toward re-establishing a healthy family system
- ❑ Actively involve family in intervention choices - avoid “rescuing” – convey hope with all communication methods/educational settings – convey that there are no failures
- ❑ Support involvement of extended family – siblings/grandparents – direct contact with audiologist with parental consent
- ❑ Connect to other families with children of same age/similar hearing loss and to veteran families

II. Birth to Three Years – Trust vs. Mistrust and Autonomy vs. Shame and Doubt

Accessibility to:

- ❑ Alerting devices: Telephone ring and Doorbell/knock
- ❑ Entertainment/Education: Audio tapes, Television, Noise making and/or musical toys
- ❑ Telephone
- ❑ Include child in conversations about hearing/hearing loss
- ❑ Provide opportunity for interaction with other (children and adults) with HI
- ❑ Model good effective communication behaviors
- ❑ Have the child participate in care of equipment

III. Three through Six years of age – *Initiative vs. Guilt*

- ❑ Continue to model effective communication behaviors - in and out of educational setting (separation from parent)
- ❑ Accessibility to: Community, extracurricular and religious services, Computers, Safe outdoor play (bicycle riding) and Telephone
- ❑ Provide information to parents on social skill development
- ❑ Increase child's responsibilities for care of equipment

IV. Six through eleven years of age – *Industry vs. Inferiority*

- ❑ Monitor child's awareness of the permanence of their hearing loss and develop a plan with the parent for helping the child cope with and resolve grief.
 - ❑ Have some time alone with Audiologist for informational counseling – emotional reactions to diagnosis
- ❑ Empower child to explain new skills/information to parent with Audiologist coaching and giving feedback.
- ❑ Need to practice stating communication needs, creating good listening/communication environments for themselves across settings.
- ❑ Child should be developing good friends. Playing regularly with friends.
- ❑ Develop familiarity and skill with variety of assistive technology and accessible communication (email, instant messaging, fax, amplification for telephone, telephone or video relay service)
- ❑ Accommodations for sport activities – Time Out! I Didn't Hear You
- ❑ Independently care for equipment
 - ❑ Begins to independently and safely respond to alerting signals: Alarm clock, Smoke alarm – fire drill, Door bell and Telephone ring
- ❑ System for privacy in the home
- ❑ System to ensure family information is accessible to all and available to Child with HI

V. Eleven years through adolescence – *Identity vs. Role Confusion*

- ❑ Use tools that assess effectiveness of communication as perceived by the teen and significant others (parent, siblings, close friends)
- ❑ Interact directly and primarily with adolescent with informational counseling on full gamut of information covered with parents in early stages (hearing loss, aids, ALD options). Interact with parent as backup to adolescent and secondary consumer.
- ❑ Fine tune self-advocacy and assertiveness skills for effective listening/communication environments/strategies.
- ❑ Re-evaluate adequacy of chosen communication method and/or amplification system at home and school (take into consideration teen's demonstrated English comprehension, teen and parents' language and communication skills)
- ❑ Teen/family may want to consider adding additional communication methods (taking up sign language as a family, cueing to enhance speechreading/English development,

etc) as alternatives for unaided times (nighttime, swimming), or for alternate social settings (communicating over long distances, outside).

- ❑ May need to reconsider other assistive devices, supports for classroom and extracurricular activities (C-print, give FM system microphone to teen, oral or sign interpreter, note taker)
- ❑ Introduce teen to vocational rehabilitation services and Post-secondary education programs network (PEPNet) www.pepnet.org

Appendix B

The Center for Childhood Communication

The Children's Hospital of Philadelphia
3405 Civic Center Boulevard
Philadelphia, PA 19104

**Audiology Program
Informational Counseling Checklist**

Name: _____ DOB: _____ MR#: _____
Clinician: _____

Date: ____ ____ ____ ____

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- Type and degree of hearing loss
- Impact of hearing loss on communication
- Types of audiological evaluations
- Hearing aids
- Cochlear implants
- FM systems
- Other assistive technology
- Therapeutic approaches/Educational programs
- Auditory-oral
- Auditory-verbal
- Cued speech
- Total communication
- Manual communication
- Bilingual-Bicultural
- Family Wellness Program
- Community support
- Resources - Financial

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- Referrals:
- Primary Care Provider
 - Otolaryngology
 - Speech Language Pathology
 - Early Intervention/Educational Consultant
 - Ophthalmology
 - Genetics

Name: _____
DOB: _____ MR#: _____
Clinician: _____

Date: _____

Dispensed:

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Parent Information Packet
Medical Clearance for Hearing Aid Use form
Report of Diagnosis
Cochlear Implant Information Packet
Hearing Aid Flow Sheet
Oberkotter video
Genetics booklet (bilateral SNHL)
Parent Education Network publication

By signing here, I acknowledge that the above checked information and referral items were discussed and understood, and the dispensed items were received.

Date Signature Relationship to patient

Audiologist

Date Signature Relationship to patient

Audiologist

Date Signature Relationship to patient

Audiologist

Date Signature Relationship to patient

Audiologist
Comments:

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