

# Empowering parents to help their newly diagnosed child gain communication skills

By Amy McConkey Robbins

When mothers and fathers take on the job of parenting a child with hearing loss, they usually have no knowledge or experience to guide them. In the early weeks and months following identification of their infant or toddler's hearing loss, parents often rely on their audiologist as their primary source of guidance.

Audiologists typically concentrate on the important issues of verifying the degree of hearing loss and fitting amplification as soon as possible. However, this article proposes another critical role that audiologists should play: advising parents on how to interact with their child at home to preserve and develop foundations for communication development. The giving of such advice and the way it is conveyed to parents can influence the course of progress for both the child and the parents.

## ADVISING PARENTS: THE AUDIOLOGIST'S CHANGING ROLE

The scope of this article is limited to the days, weeks, and months immediately following diagnosis of hearing loss in infants and toddlers. This period may encompass only a few weeks or can last up to 6 months. A 6-month period is discussed here because by 6 months post-diagnosis almost all families are enrolled in an intervention program. Once that occurs, the source of much of the parents' on-going guidance regarding their child's communication will shift from the audiologist to the speech-language pathologist, early childhood specialist, and/or deaf educator.

Three phases occur within the post-diagnostic period discussed in this article. Phase I begins on the day of diagnosis and lasts until the initial fitting of hearing aids. Phase II encompasses the early weeks, just after initial fitting of amplification. Phase III begins after hearing aid adjustment and may continue until about 6 months after diagnosis. The audiologist's advice to parents varies at each of the three phases, largely because what parents need and are able to process is quite different at the three phases. Therefore, I will address each phase separately.

Note that selection of communication mode is beyond the scope of this article. Rather, what it covers are universal issues of auditory and speech development that should be relevant to children regardless of communication methods. The reader should be aware that modification of the

suggestions provided here may be required depending on the age of the child when diagnosed, the presence of other handicaps, and the general family situation. Some families may require more information, some less. How well families cope with the news of hearing loss often reflects how well they cope with life in general. The audiologist will want to be sensitive to the family's reactions and be prepared to make referrals to professional counselors or other specialists, as needed.

### *Phase I: From diagnosis to fitting of amplification*

During this first phase, parents may be shocked by the news of their child's hearing loss and feel overwhelmed by the task before them. Professionals must use caution in supplying parents with an appropriate amount of information during Phase I, as parents need time to absorb the news and react emotionally. If too much technical information is given early on, parents may be unable to process it.

If the audiologist is uncomfortable dealing with parents' feelings, it may be tempting (but inadvisable) to use a "technical jargon" approach, as described by Hersch and Amon.<sup>1</sup> Conversely, if the audiologist provides the diagnosis without enough accompanying information (what Hersch and Amon call the "hit and run approach"), parents may feel lost and powerless to effect change.

Some parents have reported that it was the sitting and waiting for upcoming appointments (further audiologic testing, hearing aid evaluation, visits to therapists, etc.) that they found most depressing in

the initial stages after diagnosis because there was nothing they could do. As one mother said later, "I felt so helpless after they told me my child was hard of hearing. I wish I had had just a few things to do at home so that I felt we were taking some kind of action." It is critical, therefore, to give parents enough to do that they feel empowered to have a positive effect on their child's communication. Audiologists should not simply tell parents that a speech pathologist or teacher will eventually give them communication suggestions, since it could be weeks or even months before therapy services begin.

During Phase I, I advise audiologists to tell parents, "There are three important things you can do at home right away that will be helpful to your child's communication. You should start doing these as soon as you feel ready. You

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don't need to wait until your child is fitted with hearing aids." Clinical experience suggests that the following ideas for home communication are helpful during Phase I:

(1) Continue to talk to your child, no matter what degree of hearing loss has been identified. Speak close to his or her face and use animated facial expressions and gestures. Even if your child can't hear everything you say, you are forming an important bond and teaching eye contact and communication turn-taking. Sing songs, recite nursery rhymes, and do finger plays, just as you would with any other child.

(2) Begin a journal about your experiences with your child. Write down feelings that you have, emotions you are experiencing, as well as observations about your child's hearing and any responses to sound that you see. The journal is your outlet as well as a way to document your child's development. When your child is older, you will look back and marvel at how far s/he has come!

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(3) Contact the John Tracy Clinic (800/522-4582 or [www.johntracy-clinic.org](http://www.johntracy-clinic.org)) to enroll in a home correspondence course for parents of hearing-impaired children. Through this program, you will receive videotaped and written information along with lessons to work on at home with your child. After each lesson, you will return the packet to the clinic and receive written feedback and encouragement.

It may seem somewhat premature to suggest enrolling in the John Tracy program immediately after initial diagnosis, and the audiologist must use sensitivity in doing so. However, there is sometimes a lengthy delay between the initial contact made by the parent and receipt of the first lesson. For this reason, I suggest that parents make a contact as soon as they are ready. Regardless of the therapy program the child eventually enrolls in, the John Tracy lessons will augment and support home communication. Much of this pro-

gram's success lies in the fact that it sends a message to parents that they have the power to influence positively their child's communication and, in the long run, their child's future.

### *Phase II: After initial fitting*

At Phase II, parents have a new focus, that of auditory responses, because their child has received hearing aids (quite likely, loaner aids at this point). Clearly, acceptance and full-time use of the hearing aids are prerequisites to spoken language development. Therefore, at Phase II, communication advice to parents is really an equipment issue, and involves the child's use of hearing aids during all waking hours.

To support parents, audiologists should recommend that parents keep a dedicated weekly hearing aid calendar in which they record the number of hours of hearing aid use each day, as well as any pertinent information such as equipment problems, the

child's resistance to putting aids on, or the child's pulling the aids out. Parents may also note whenever their child responds to sounds, as well as the nature of the response, such as a startle, cessation of activity, or eye widening.

It is incumbent upon audiologists to explain that without full-time hearing aid use during all waking hours, except sleeping or in water, other listening or speaking goals are futile. For some families, it may be necessary to fax the audiologist the hearing aid calendar at the end of each week as a way to discipline themselves. Families should bring the calendar to all audiologic appointments to discuss hearing aid use and problems.

The other three goals at Phase II deal with more traditional communication issues. The audiologist may introduce these goals by saying, "Your follow-through with the three communication goals has been excellent. Let's continue to do those things at home. But now that

Susie has hearing aids, there are some other important things you can do at home to promote her communication." The audiologist may then outline the following:

(1) Having your child learn her name is very important. Refer to your child by name often. When face to face with her, you can say, "Hi, Susie. ....There's Susie. ....I love you, Susie," focusing clearly on your child. Typically developing babies recognize their own name before 1 year of age,<sup>2</sup> so we want to establish this skill as soon as possible in babies with hearing loss. Remember that if you call your child's name, always have a purpose. If you call her name just for the pleasure of seeing her alert but don't give her any feedback or attention, you may inadvertently extinguish the child's response. Note that additional suggestions for working on name recognition may be found in Robbins<sup>3</sup> and in Zara.<sup>4</sup>

(2) Use the hands-to-ears response at home when sounds occur. As soon as the sound occurs, point to your ear, use a surprised expression, and say, "I hear that!" This draws your child's immediate attention to listening to sound and helps your baby learn that sound is something to pay attention to.

(3) If your child is wearing her aids full-time and benefiting from them, we expect to hear changes in the sounds she makes. In fact, changes in vocalization are often a better indicator of device benefit in infants and toddlers than are auditory responses. Listen to the sounds your child makes with her aids on. Can you distinguish a fussy cry from a painful cry from a hungry cry? Does your baby use mostly vowels or consonants when making sounds? Does she squeal or scream? Does your baby ever seem to be imitating another's speech or "singing" along to music? Are there any sounds that will quiet or comfort your baby? Take careful notes in your journal about these changes, as your observations will be invaluable to the audiologist in determining hearing aid benefit.

### *Phase III: From hearing aid adjustment to formal communication intervention*

In Phase III, the family is typically well adjusted to the use and care of hearing aids and, hopefully, equipment struggles

are no longer an overriding issue. At this phase, the family can focus on communication development with the baby, and is usually ready for more direct suggestions regarding how to do so. The parents may have already secured a therapist who will have taken over the role of communication advisor.

However, many families at Phase III still do not have a regular therapist and need the audiologist to provide communication advice. In addition, because of the dramatic increase in the number of babies being diagnosed via newborn hearing screening, families in some communities may be unable to find a therapist who is trained and experienced in working with babies with hearing loss. These parents will require the expertise of the audiologist for an extended period of time to augment other professional input.

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At Phase III, the audiologist may introduce home communication goals by saying, "I'm impressed with how well Johnny has adjusted to his hearing aids. That is because you have been firm and consistent with him. Now that he is learning to listen, there are some additional things you can work on at home. Keep doing the things that we've already talked about because they are still important. But, I also want you to add three more goals." The audiologist may then describe the following:

(1) Imitate your child's vocalizations back to him, as soon as he says them. Try to mimic the same intonation pattern and sounds that he uses. With his hearing aids, it's likely that Johnny can perceive all or some of your speech. By repeating back what he says, you are reinforcing his "talking" and will make him vocalize even more. In addition, babies learn early about communication turn-taking, and Johnny will enjoy "talking," then waiting for his turn while you talk, and so on.

It's also fun to talk back to your child

as if his vocalizations really mean something. If your child says, "Eeee daaa eee," you can say, "Yes, you see a doggie," even if your child is young and not speaking yet. Studies have suggested that parents who credit their child with speaking may accelerate communication progress.

(2) Encourage an anticipatory response to sound in your child. You've been using songs, nursery rhymes, and finger plays with your child. With his hearing aids, we hope he is hearing the rhythm, melody, and words within these. Now we want to develop an anticipatory response from your child. This means that your child anticipates what comes next just through hearing and shows excitement. For example, if you've played "How big is the baby? Soooo big!" face-to-face with your child, try initiating the game from behind him when he can't see you. Notice if,

through hearing alone, your child anticipates the game and raises his arms when you ask, "How big is the baby?" This indicates he is attaching meaning to what he hears and is a very encouraging sign of listening development. Similarly, if you rock and clap whenever music is playing, see if your child starts doing this on his own when music starts, without your initiating it.

(3) Select three common sounds in your home that will help your baby learn. Often, the first three sounds are things like knocking on a door, the telephone ringing, and the dog barking. However, you may want to choose other sounds that are more common and relevant in your home. The important thing to remember is that these early environmental sounds should be clearly audible and occur frequently throughout the day. In addition, it is particularly helpful if the adult has some control over the target sound. That way, you can decide how many times you want to knock on the door, etc.

Babies are more likely to listen to a

sound that occurs and stops, such as a telephone ring, rather than one that is continuous, such as a fan. Present these sounds repeatedly to your child, use the hands-to-ears response, and label the sound. "Johnny, I hear the doggie. Listen. (pause) Do you hear the doggie?" You might take your child directly to the sound source. This activity in Phase III is an extension of the earlier hands-to-ears suggestion in Phase II because we are now labeling and identifying the sound, rather than simply drawing the child's attention to it.

## THE MOST IMPORTANT DECISIONS

The final piece of guidance that audiologists can offer to families might be the most important of all. As Moeller and Condon have noted,<sup>5</sup> most of the decisions parents are required to make immediately after diagnosis are about such things as communication mode, hearing aid selection, educational choices, and the therapist they prefer. But, remind parents that the most important decisions they make are not these technical ones, but rather: (1) the decision to have high expectations for their child; (2) the decision to give the child autonomy and responsibility; and (3) the decision to be confident in their ability to parent a child with hearing loss. When they make these decisions with conviction and with the support of the audiologist, families will be ready to take on the challenges and rewards that await them in raising their child with hearing loss. (HJ)

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