

Parent Involvement: The Magic Ingredient in Successful Child Outcomes

Improving parent participation using the ELF and the CHILD

By Karen Anderson, PhD

**What is the secret ingredient
for producing successful
outcomes in children with
hearing impairment? The
answer is parent involvement.**

**This article is intended for
audiologists and early
intervention service providers
(eg, auditory verbal
therapists, aural
habilitationists, parent
advocates, speech language
pathologists, and teachers)
who are looking for new ways
to involve parents in their
children's hearing habilitation.**

**It looks at the usefulness of
two new tools for achieving
this: the ELF and the CHILD.**

If you were charged with the task of writing the ideal recipe for working with young children who have hearing impairment, what would you include? What would go into the formula of the provision of successful outcomes by school age? Some key ingredients in this recipe might include:

- Years of audiology training and dedication to developing expertise in working with children;
- Continue to stir in enthusiasm to learn in a profession that is constantly updating information and technology;
- Pounds of knowledge, experience, and confidence in obtaining reliable electrophysiological and audiometric evaluation results (even on tiny infants);
- Liters of skill in hearing instrument selection or cochlear implant mapping to meet the child's auditory perception needs at different levels of input for maximum audibility of speech;
- Strongly seasoned with finesse in making frequent sets of earmolds for growing little ears;
- Mastering the technique for obtaining RECD measures before the child even notices what you're doing;

- Patience kneaded with a sense of humor with all challenging toddlers;
- Liberal amounts of parent training and nonjudgmental listening, reapplied as often as possible to result in a relatively smooth mixture.

So What is Missing?

Think back on the families that you have come to know while providing audiological management services to their children with hearing loss. One child may have a severe hearing loss and can develop intelligible speech and normal language skills by age 5. Another cognitively normal child may have mild-to-moderate hearing loss and struggle with speech production and have significant language delays before age 5.

The skill and knowledge of the hearing care professional, although always changing and improving, probably did not significantly change enough while working with these two children to really explain the differences in developmental outcomes. Likewise, each child's audiogram and their presumed audibility based on the hearing instrument fitting is not a thoroughly reliable predictor of children who will and will not develop language as expected.

The expected rate of language development for infants and toddlers is one month of language development for every one month of early intervention, which typically includes amplification use. The amount of time the audiologist spends in training and listening to the concerns of the family also does not always tell us which parents have children with the greatest developmental needs.

So what is the magic ingredient?



Karen Anderson, PhD, is a longtime educational audiologist who now works in the field of early intervention for infants and toddlers with hearing loss in the state of Florida.

Parent Buy-In!

It is crucial that parents "buy in" to the fact that:

- Their young child really has a hearing loss;
- The hearing loss will really cause the child to develop or learn differently from other children if no intervention is obtained;
- The hearing loss will not go away;
- Hearing loss typically means having some useful hearing (ie, not totally deaf);
- Having some hearing loss does not mean that the child can learn to "get by" without intervention, just because he or she is a smart or exceptional child;
- There is more to intervention than putting hearing aids on the child;
- The hearing loss will still be an issue in how the child is able to access communication in different listening situations;
- *Communication access* is the real issue, not the hearing loss;
- *Parents, caregivers, and peers* are the "magic ingredients" that ensure the communication access that will allow the child to develop at as normal a rate as possible.

The job of the audiologist working with young children is very difficult. Immediately after the diagnosis of the hearing loss, the family will need to learn much information about how the hearing loss may influence their child's listening, learning, and future, as well as their role in preventing delays in development. However, at the same time that the parents have the greatest need for this information, they also have the greatest emotional barriers to being able to process the information that the audiologist takes great care to provide to them.

Due to universal newborn hearing screening (UNHS), increasing numbers of young children are diagnosed with hearing loss in the first month of life—well before most parents have enough experience with the child to begin to suspect a hearing problem. Therefore, unlike a number of years ago, parents often do not have a bank of experiences in which they questioned their child's auditory responses to call on to assist them in believing the diagnosis. This is one reason why it is so crucial to have both parents or the child's main caregivers present at the time of diagnosis. In the meantime, while the parents are

still staggering under the reality of having a child with a diagnosed hearing loss, the audiologist feels professionally driven to get amplification on the child as soon as possible, typically within a month of the confirmation of the existence of a hearing loss.

Without parent buy-in, the manner in which the early amplification is fit to the child will not matter if the parent does not have sufficient intrinsic motivation to pursue the task of having the child utilize amplification consistently throughout each day. Similarly, parent groups have begun to send a strong message to hearing care professionals: Do not make decisions for our family and our child! Great resentment by parents has festered when audiologists, ENT physicians, or early intervention professionals have presented "final" decisions about communication options that are appropriate for a child based on his/her audiogram or the type of educational program convenient to the locale. Whether the influence has been toward sign language/manual communication or cochlear implantation, the message is clear: parents want information about communication options that *they can then use to decide* what feels right to their family dynamics, support system, and goals for their child. Providing parents with the names of other parents who have a child with hearing loss is a critical step for the audiologist and the early interventionist to include, as these relationships can become rich in emotional support and information at a time when parents of newly diagnosed children need it most.

Skills are learned by doing and knowledge is built and reinforced by experiencing. Likewise, a daily commitment to practicing results in a higher level of expertise and success. Raising a child who is deaf or severely hard of hearing can be compared to a parent knowing that a child has great athletic talent—and a parental desire for him/her to be the star of the team. Even a child with athletic talent will not develop great skill if the appropriate athletic equipment and/or coaching and experiences are not provided. What good is the best baseball mitt and bat if there is no one to play with and learn the rules of the game? What benefit is there to bringing a child to a skating rink for lessons, even private lessons, if the skates are left home? What is the outcome when a beautiful piano and expen-



Figure 1. Get within the child's listening range.

sive weekly lessons are provided if the parent does not support and assist the child in regular practice?

In the case of hearing impairment, amplification is the equipment, intervention professionals are the coach or trainer, but it is the *parents and caregivers* who are the child's teammates. All children are wired with an amazing talent to learn language, if only they are provided consistent access to communication experiences. Professionals who work with the family to help them facilitate auditory skills will assist in producing hearing aid benefit. However, just as in the sports examples above, the key to becoming a "star" is the parent buy-in, or motivation to participate, support, follow through, and prioritize this goal in the daily life of the family.

The ultimate potential for the child to become a successful language-user is directly related to parent involvement. *Parents are the magic and parental buy-in is what makes the magic work!*

Methods for Improving Parent Buy-In

Think again about parents who just received the diagnosis that their infant or young child has a hearing loss. First comes shock; the blanketing emotional response that prevents adults from becoming hysterical, angry, or otherwise overwhelmed with information that they are not immediately able to handle. This is a normal response. Unfortunately, this is also typically when the audiologist tries to provide the parents with information about the hearing loss. A few parents can process some of this information, usually in bits and pieces, craving the details as a means to control their overwhelmed feelings. Others will only remember the words, "Your child has a hearing loss," and will remember noth-

ing else that was said during the audiological appointment.

The parents go home and they cry. They share, they experience emotional storms, and then in a moment of calm they get out a fry pan or other object and make a noise so that they can see for themselves if their child "hears." The desire to make sense of the diagnosis, to make it "real," is normal. Parents who have shared the stories of their experiences soon after diagnosis usually mention testing to see if their baby really has a hearing problem. This can start the parent on the road to acknowledging the reality of the diagnosis—both intellectually and emotionally.

Hearing loss is not easy to understand. Having some hearing is not the same as having normal hearing. Having severe hearing loss is not the same as being deaf. People hear better in quiet than in noise. Sometimes, speech from 9 feet away is inaudible but at 4 feet away the child can perceive the speech. Providing the parents and caregivers with a means to gather this information on their child in their home under circumstances typical of the child's every day life will benefit the understanding of the parents and caregivers of what it means to have a child with a hearing loss.

Two parent completion instruments, the Early Listening Function (ELF) and the Children's Home Inventory of Listening Difficulties (CHILD), are available and can assist in developing parent buy-in. Both of these instruments ask the parent to observe the child's responses to auditory stimuli under varying conditions.

Author's Note: The ELF and CHILD are available to download for clinical and educational use at <http://www.phonak.com> and soon to be available at <http://www.otticonus.com>. Special thanks goes to these and other manufacturers who are diligent in providing hearing care professionals with current, valuable, and practical information for the benefit of the children and families we serve. Additionally, the CHILD has been available on the Educational Audiology Association's Website (www.edaud.org) since 2000.

Early Listening Function (ELF) for Infants and Toddlers

The Early Listening Function (ELF) instrument was designed to encourage parents' participation in the hearing loss discovery process. The ELF defines 12 contrived listening activities that can

easily be performed in the home environment. Quiet, typical, and loud activities (four each) are specified. Parents are to do the activities in the child's typical environment and determine if a behavioral response can be obtained at 6 inches, 3 feet, 6 feet, 10 feet, and 15+ feet (next room). Responses are to be observed in both quiet and noise. Often the early intervention service provider can assist the parent or daily child-care provider in observing the child's responses during the ELF activities.

The objective of caregivers performing the ELF contrived listening activities and observing their child's responses is *not* to double check to see if the audiological diagnosis is correct. The objective of the ELF activities is to assist the caregivers in better understanding the effect of their child's hearing loss on the perception of speech in typical listening environments. A more elemental objective is for the parents to gain experience and understanding of what the child's hearing range, or "listening bubble," is in different situations. Revealing the size of a child's listening bubble is something an audiogram does not provide. Calibration of the loudness of ELF activities is not as important as having the listening environment and the voices of caregivers as "typical" as possible.

As the parents gain comfort in estimating the size of their child's listening bubble, these observations can be very valuable in the audiological management of the child. As in all interactions with the parents, it is important for the audiologist to treat the parents as equals who have valuable and unique information about their child to share—and their information is vital to audiological management. Fluctuating hearing loss due to middle ear infections, progression of sensorineural hearing loss, benefit of amplification fittings, and changes in hearing instrument maps, programs or features can be identified through the keen observations of an involved parent or caregiver.

Another advantage to developing parental expertise in understanding hearing loss as affecting the listening bubble is that it provides them with a means to describe the child's hearing impairment in a way that is more meaningful to people than saying the degree of hearing loss alone. For example: "Samantha has a severe hearing loss. This means that, with her hearing aids, she can hear my voice and even some soft sounds when I am 6 feet away from

her and it is quiet. But, if the room is noisy, I have to come within 2 feet of her before she really can hear my voice!"

This kind of description is much more informative to a baby-sitter or neighbor than stating that Samantha has a severe hearing loss and wears hearing aids. It is long recognized that most people believe that hearing aids will restore normal hearing just as glasses restore normal vision. The key issue for children who have hearing loss is *full communication access*, not the hearing loss per se. Caregivers who understand the conditions under which the child can perceive speech will be best equipped to arrange the environment and dynamics of interaction so that their child can truly access as much spoken (and/or visual) communication as possible.

As previously mentioned, ELF observations can assist in validating amplification benefit. Audiologists have precise procedures for fitting hearing instruments to a child's hearing loss and auditory needs. These hearing aid fitting targets are verified by specific measures and need to be repeated every time a child outgrows their earmolds. The audiologist verifies that the hearing instrument is providing sound that is not uncomfortably (or dangerously) loud to a child, as well as estimating maximum audibility of speech at different loudness levels. Use of the ELF observations will assist the audiologist in validating that the best possible hearing aid fitting has been obtained so that the child can perceive the most speech under the most frequent listening conditions—hearing their caregivers or parents talk at home or child care.

As the child develops in the first few months of life, their responses to sound will likely become somewhat more sensitive. The ELF allows the parents to observe the child's natural development of auditory skills. It is also an effective way for the audiologist and early interventionist to discuss the hierarchy of auditory development and observing responses to sound from detection alone, to identification ("That's a doggy barking"), discrimination ("That's the squeaky horn, not the bell"), and finally comprehension ("Time to go bye-bye").

Children's Home Inventory of Listening Difficulties (CHILD)

Like the ELF, the CHILD employs the parents in the role of observer of their child's behavior. The 15 situations

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specify typical home communication at different distances, in background noise, and varying child interest levels. It is appropriate for the family to begin to use the CHILD when the toddler with hearing loss begins to play with peers in a participatory manner, rather than in parallel play. It can be employed typically at a developmental age of about 3-12 years.

The ELF contrived listening activities are aimed at detection alone, whereas the CHILD questions relate to dynamic communication situations. The CHILD also is sensitive to the subtle difficulties experienced by children with mild, fluctuating, or unilateral hearing loss.

The parent reads each question and then determines how well the child appears to be able to hear and understand under different listening situations (typically over a period of time). An 8-point scale has been provided for the parent to choose from as they estimate their child's listening abilities. The scale is "parent friendly" and is called the "Understand-o-meter." The CHILD instrument is designed to provide valuable information to the parents about the access their child has to the typical communication dynamics of the family.

Again, the key to improving child language outcomes is optimal and consistent communication access. As with the ELF, the CHILD can provide useful information to validate the fitting of new amplification or indicate if new amplification instruments may be beneficial to try. If a child appears to have difficulty listening in noise, waking up, talking on the telephone, etc, the CHILD tool provides a basis for the audiologist and the parent to discuss the need to try different assistive devices that will allow the child to become more independent.

These discussions are particularly critical as a child begins school. The need for accommodations, such as an FM system, should be considered by the parents and school team as a foundation for listening success in the classroom. Information obtained from the ELF and CHILD can provide powerful documentation to the school to illustrate that appropriate classroom acoustics and FM amplification (desktop FM or personal FM) are necessary to allow the child to access verbal communication in a typical of a classroom environment—listening across distances and in the presence of background noise.

Use of the CHILD can also provide the family with a reality check of what

communication difficulties exist in the child's daily life. Even successful amplification users who have developed good speech and language skills will experience more listening challenges than their normal-hearing peers. Sometimes parents who have been highly involved in supporting their children's skill development throughout their early childhood consider their language development and conversational skills as being "normal" and therefore not needing any special consideration at school. As children move from small and insular home, child-care, or early preschool environments into school classrooms, it is imperative that the parents understand their child's auditory skills. This understanding will assist in their buy-in to the child's level of auditory challenge, and will enable the parents to describe their child's hearing loss to the school team in terms of the need for appropriate accommodations. Preferential seating and "I can tell she's a good lipreader" are not appropriate ways to address the communication access needs of children with hearing loss. Specific information on the child's listening limitations under different conditions will assist the school team in developing individualized appropriate accommodations to meet the child's need for equal access to verbal instruction and peer communication.

As the child becomes older, a version of the CHILD can be completed by the young person with hearing loss. This self-report questionnaire is typically not reliable until a child is approximately 8 years old and is appropriate for use up to approximately age 12. When completed, the parent and child responses can be compared and issues related to self-esteem, awareness of social interactions, communication dynamics, and peer relationships can be discussed with the parents. These issues may also occur in the school setting and could be addressed with the child's teacher or other education personnel involved.

Parent buy-in is the magic ingredient in the recipe to a child's successful developmental outcomes at school age. Hearing care professionals should involve and embrace the participation of parents and caregivers in the process of discovering what hearing loss means in the day-to-day interactions of the child and the family. ▀

Correspondence can be addressed to HR or Karen Anderson, PhD, email: karenlander@earthlink.net.

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Correspondence can be addressed to HR or Mark C. Flynn, PhD, Oticon A/S, Strandvejen 58, Hellerup, DK 2900, Denmark; email: mcf@oticon.dk.