


Hear My Dream

BY MEGAN D. FORD



During audiology consultation appointments, it is not uncommon for parents to request contact information of other local families of children with hearing loss. A local support group could provide a venue where parents could freely exchange contact information as desired. However, support groups for parents of children with hearing loss are inconsistently located few and far between across the country.



Have you ever looked into the eyes of a parent as you provided the life-changing information that his or her child has permanent hearing loss? Chances are, the parent heard you loud and clear. This is because over 90 percent of babies with congenital hearing loss are born to parents with normal hearing (Mitchell and Karchmer, 2004; Palmer et al, 2009; National Institute on Deafness and Other Communication Disorders [NIDCD], 2010).

Breaking the news to parents with normal hearing that their child has permanent hearing loss has to be one of the most difficult scenarios an audiologist can encounter. This is not because having hearing loss is a terribly bad thing—if anyone can foresee that a child with hearing loss can grow up to be more than okay, it is the audiologist. The difficult part is that we are breaking news to parents who likely do not currently know another parent of a child with hearing loss, and chances are, they are not currently equipped with the knowledge of how to raise a child with hearing loss. For many parents, their child will be the first person with hearing loss that they will ever meet.

In the fifth paragraph of the popular handout *So Your Child Has a Hearing Loss: Next Steps for Parents* (AG Bell Association for the Deaf, 2010), often given to parents immediately following the diagnosis of hearing loss, it reads:

Deaf parents of deaf children are not necessarily prone to grief because they are already familiar with living in a world without sound. Deaf parents may feel more comfortable with a child who is deaf, because this seems natural. However this isn't the case for most hearing parents, who probably know little or nothing about hearing loss and who may never have known a child with a hearing loss.

The vast majority of the time, they are not deaf parents but, rather, parents with normal hearing.

UNHS Is Wonderful, Isn't It?

As advocates for the tool of universal newborn hearing screening (UNHS), we often witness firsthand the amazing benefits of early identification. However, there are some critics of UNHS who believe we are communicating bad news

to parents shortly after they have given birth. In reality, the news we deliver is not “bad” but, rather, “difficult,” the descriptor preferred by the Audiologic Counseling

identification—would otherwise be impossible. Being able to take part in providing early access to sound so that a child can be mainstreamed by kindergarten is a priceless reward.

Soon after parents learn the news that their child has hearing loss, many are faced with the duty of making life-changing decisions.

Evaluation (ACE) tool when breaking the news to parents (English and Naeve-Velguth, 2006; English et al, 2007).

It's true, hearing loss often appears to define the child who is identified at birth; however, the experienced audiologist knows that hearing loss will not define the child for long. Many audiologists discover their livelihood among those amazing, spoken conversations with five-year-old “deaf” children that—without UNHS and early

So why do some audiologists feel the way that they do? The answer is simple—hearing loss is usually only perceived as bad news when the parent has normal hearing. This is because when we diagnose a child of normal-hearing parents with permanent hearing loss, those normal-hearing parents likely have no prior education regarding how to raise a child with hearing loss. They have been thrown into a world they were not expecting to enter; they arrive completely unprepared, and they don't know a soul. Soon after parents learn the news that their child has hearing loss, many are faced with the duty of making life-changing decisions. Often these decisions are time sensitive, as we're dealing with interventions that impact development. It is clearly not an easy situation but rather difficult for the parent who was not expecting this diagnosis.

A formal family support network is necessary to help families through a diagnosis of hearing loss and rehabilitation options.



FIGURE 1. A family support network is needed to supplement professional counseling.

Contact with families who have children with hearing loss would be helpful to my acceptance and understanding of my child's hearing loss.



FIGURE 2. Peer contact is needed to aid in acceptance and understanding.

The Need

The first three national goals of Early Hearing Detection and Intervention (EHDI), better known as the One-Three-Six plan, are as follows:

1. All babies should have their hearing screened by one month of age,
2. All permanent hearing loss should be identified by three months of age, and
3. Appropriate services and intervention should be in place by six months of age (Centers for Disease Control and Prevention [CDC], 2010).

One of the roles an audiologist may fill is the fitting of amplification on very young newborns that are identified with hearing loss through the UNHS process. When

appropriate, audiologists talk to parents about cochlear implantation and help parents to navigate through all of their options. Audiologists often help parents understand their child's hearing loss and make sure proper services are coordinated.

During audiology consultation appointments, it is not uncommon for parents to request contact information of other local families of children with hearing loss. This can be quite helpful, though difficult to coordinate when considering privacy laws and HIPAA regulations. A local support group could provide a venue where parents could freely exchange contact information as desired. However, support groups for parents of children with hearing loss are inconsistently located few and far between across the country. In the area where I practice, no such group had existed in the recent past. I had heard of rumors that there used to be a parent-driven support group many years ago that fizzled once the children with hearing loss grew up.

Motivated by a few parents who were reaching out to meet other local families, I decided to study parent needs a little closer. I discovered that the two most important needs of parents in this situation are peers and education. To try and get an idea of what would be most helpful to parents, I conducted a survey. For example, I asked parents to rank the need for a family support network to assist in the facilitation of understanding their child's hearing loss and rehabilitation options. Most parents feel a need to have a family support network to supplement the help they receive in the clinical setting. (FIGURE 1) In another question, parents were asked to rank how helpful contact with families who have children with hearing loss would be to the acceptance and understanding of their own child's hearing loss. Peer contact ranked very high in aiding acceptance and understanding of their child's hearing loss. (FIGURE 2)

The Dream

In July 2007, I founded the Hear My Dreams support group for parents of children with hearing loss. After gathering a group of about a dozen parents, we discussed locations, convenient times, and how often we should meet. Since this was a volunteer effort on my part, I felt comfortable offering my services about six to seven times a year toward this project. Weekends were busy for most people—many did not want to sacrifice time during Saturday or Sunday, and many parents worked during the day, as did I. After dinnertime and around the time most children are getting to bed was the most popular vote for time of day to meet. Together, the parents and I decided that to keep it simple; we would meet on a regular basis

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AT THE POINT OF THEIR CHILD'S HEARING LOSS DIAGNOSIS

- >> 100% parents did not know another parent of a child with hearing loss.
- >> 100% of parents did not feel fully equipped with knowledge of how to raise a child with hearing loss.

SINCE ATTENDING HEAR MY DREAMS SUPPORT GROUP

- >> 100% of parents found peer relationships helpful.
- >> 89% of parents feel they have obtained information, education, and knowledge to help raise their child.

every second Tuesday of every odd-numbered month (odd months are those with the least holiday interference) from 7:00–9:00 pm. The key is that the meeting time and day is consistent and reliable.

As for location, I envisioned meeting in a neutral location near a major birthing hospital with easy access for all (if parents were able to access the birthing hospital to have their child, then they should be able to access that same region near the birthing hospital to attend a support group meeting). I searched around and looked at local libraries, local churches, and other public locations. A local hospital kindly agreed to allow use of a conference room in an off-site building with free parking six nights a year at a convenient location that many families were already familiar with.

All are welcome to attend. The idea behind this support group was to design a place that meets the needs of parents and caregivers of children who were identified through UNHS as having permanent hearing loss of any type or degree. Where the child receives clinical services is irrelevant. Professionals are also welcome to attend—and when they do, they later testify how extremely informative and eye-opening the experience was for them. Parents have traveled from towns 52 miles west and 59 miles north to attend. Such a large catchment area testifies to the need for parent support groups such as the Hear My Dreams support group in additional, more convenient locations.

Collective Responsibility

It makes sense to me that the professional who delivers the life-changing information to the parents that their child has hearing loss (collectively this is usually none other than the audiologist) be held accountable to make sure that parents are getting the peer support and education that they need to raise their child appropriately. Often, parent-driven support groups cease after the founder's children grow up. However, to keep it consistent and active longitudinally, it is imperative to be facilitated and driven by professionals. As supporters of UNHS, we need to follow through beyond the One-Three-Six plan.

It is our responsibility to follow through with the aftermath after we diagnose a child with hearing loss. If audiologists support UNHS, then we need to be held accountable, as professionals, to be there, not just for the hearing aid consultation or cochlear implant counseling session. Audiologists should also offer and provide a place to go outside of the clinic where parents can receive ongoing education in areas where they need it. Parents should be “guided” by a professional facilitator who has the perspective that the parent is not alone.

I have been facilitating the Hear My Dreams support group meetings for almost four years now. I felt called to volunteer and hope that this article inspires and motivates other audiologists to volunteer their time doing something they're really good at. It is a rewarding aspect to the profession, plus it only makes sense that the professional who informs parents that their children have hearing loss be the founder, organizer, and facilitator of this very important step toward successful outcomes for these children. If telling parents their children have hearing loss is the most difficult thing about being an audiologist, you may find that volunteering in this area is the best thing about being an audiologist. Plus, volunteering is a wonderful way to give back to the profession.

The Design

In designing the meeting, I took the theme of "peers and education" and divided the two-hour meeting up accordingly. The first hour is dedicated to peer-relationship development.

First, written ground rules are passed out and read aloud for all newcomers. This is very important for



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emphasizing privacy so that attendees can feel secure that what is spoken at the support group stays at the support group. Next, introductions (and name tags) are made, which often includes updates of each child's progress and sharing photos around the room. A contact sheet is passed around where parents can voluntarily provide e-mail addresses or phone numbers that they'd like to share with others. To elicit a guided conversation, predetermined talking points are often discussed. The interactions that occur during these discussions can only take place via parent-to-parent contact and simply cannot be duplicated in a clinical setting or by a professional, no matter how empathetic he or she may be.

The second hour of the meeting is dedicated to parent education. The topics are chosen based on parent request for information. We've had a variety of guest speakers including:

- A literacy specialist
- A psychologist
- Speech language pathologists
- Audiologists
- The Massachusetts Commission for the Deaf and Hard of Hearing
- Massachusetts Department of Public Health UNHS parent advocates
- A geneticist
- A teacher of the deaf
- A panel of successful young adults who grew up with hearing loss, including those who use both oral and manual forms of communication
- A panel of parents who raised successful young adults that grew up with hearing loss

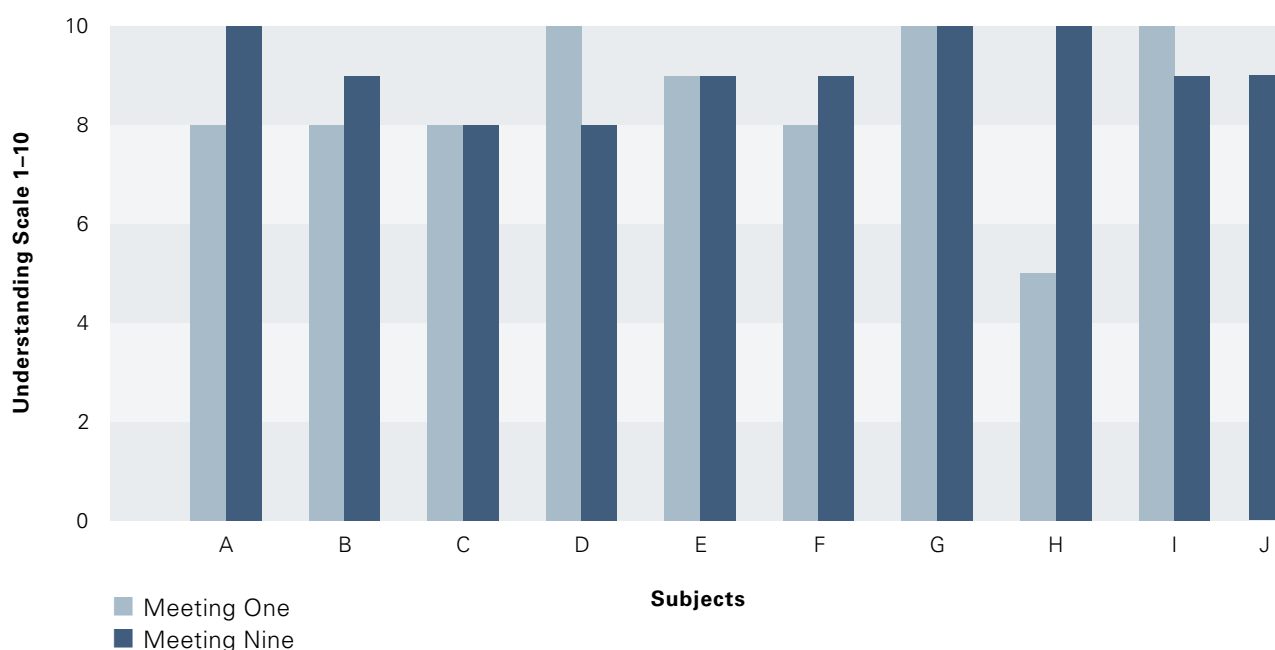


FIGURE 3. At meeting one, variation among subjects in understanding their child's diagnosis and treatment options. At meeting nine, less variation in understanding diagnosis and treatment options with higher mean score.

In addition to the evening meetings, there is an annual summer meet-and-greet potluck picnic where children, extended family, and professionals (highly comprised of past invited guest speakers) can mingle, play, socialize, and have a great time.

A simple Web site allows parents to check out the upcoming guest speaker. The Web site, www.hearmydreams.com, has been viewed over 13,400 times by over 4,400 visitors with an average of almost five hits per day. About 50 percent of the visitors are repeat hits, and about 50 percent of the visitors are new and unique.

From the key word searches that bring people to the Web site it is apparent that there are people across the nation and perhaps around the world who are looking for this type of support group and the information that it has to offer.

Business cards have been designed with the location and meeting times for the Hear My Dreams support group. These are handed to parents on the day of diagnosis with the date of the upcoming meeting written in like an appointment, to accompany other appointment cards that may be made for the child, such as a hearing aid consultation.

Outcomes

After attending several meetings, parents were surveyed again. It was discovered that the majority of parents found the peer relationships extremely helpful, and many felt they obtained the knowledge and education needed to raise their child.

When asked at their very first parent support group meeting if they understood their child's diagnosis and treatment options, parents displayed variation in their response. When asked that same question at their ninth support group meeting, however, there was less variation in the response, with a higher mean score noted in understanding their child's hearing loss and treatment options.

This support group model addresses parent needs, which have been identified as peer relations and education. Specific educational needs may vary locally across the nation based on available local resources, early intervention (EI) programs, and other factors. Parental educational needs will also change over time not just with the age of the child (i.e., parents may need initial support during times of acceptance, but then they may need information at age three that pertains to their rights when transitioning from EI to public schools) but also as times change technologically, culturally, and socially. Specifically, the educational needs of local parents are best realized through a simple study, which can be completed in the form of a survey.

Vision

In the acknowledgment section of his recent best seller, *Outliers: The Story of Success* (2008), Malcolm Gladwell uses the term "internal finder" when discussing his editor. Apparently his editor was a huge influence on him and worked with him for so long that Gladwell now has what he likes to call the "internal finder," a self-correcting voice inside his head that gives him the benefit of his friend's advice and support, even when he is not present. He states that *finders*—both *internal* and *external*—were invaluable to him (Gladwell, 2008). My vision, or dream if you will, is that a parent support group can be a *finder* for parents. They may be faithful attendees who go to each meeting or they may only have attended one meeting. But hopefully, while facing challenges in raising their child, they can carry with them an *internal finder*—the peers and education found at the Hear My Dreams support group.

This support group is not where you will find a room full of people sitting around crying and feeling bad for themselves. When you enable parents by offering them



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the tools they need, through education and peer support, you empower them to overcome their fears, their pain, and their loss. This support group is about parents learning that their child is going to be okay. This group is about parents getting relief because now they know what they need to do. Just because their child has hearing loss does not mean that their dreams need to end. They learn how to form new dreams for their child, because now they have the framework for this sort of dream.

Perhaps one day there will be parent support groups with similar format, consistency, and occurrence, located near all major birthing centers. At the point of diagnosis, audiologists will make an appointment for parents to attend at least one parent support group meeting, just as one recommends a hearing aid consultation appointment for their child. Consider the idea of a One-Three-Six-P plan where “P” represents parent support with the goal being a universal parent support group (UPSG) to accompany universal newborn hearing screening.

UNHS is mandated and realized in most states, yet there is a need for a standard support system for parents of children identified through this process. A support group enables parent participation and education and promotes positive outcomes. I propose that the availability of support groups, such as the Hear My Dreams parent support group, be included as an accompaniment to mandated UNHS programs. If this were to happen, it would be my dream come true. 

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References

- AG Bell Association for the Deaf. (2010) *So Your Child Has a Hearing Loss: Next Steps for Parents*. <http://nc.agbell.org/NetCommunity/Document.Doc?id=414>.
- Centers for Disease Control and Prevention (CDC). (2010) *National EHDI Goals*. www.cdc.gov/ncbddd/ehdi/nationalgoals.htm.
- English K, Naeve-Velguth S. (2006) *Audiologic Counseling Evaluation (ACE): Informing Parents of Their Child's Hearing Impairment*. <http://gozips.uakron.edu/~ke3/ACE.pdf> (accessed September 23, 2010).
- English K, Naeve-Velguth S, Rall E, Uyehara-Isono J, Pitman A. (2007) Development of an instrument to evaluate audiologic counseling skills. *J Am Acad Audiol* 18:677–789.
- Gladwell M. (2008) *Outliers: The Story of Success*. New York: Little, Brown.
- Mitchell RE, Karchmer MA. (2004) Chasing the mythical ten percent: parental hearing status of deaf and hard of hearing students in the United States. *Sign Lang Stud* 4(2):138–163.
- National Institute on Deafness and Other Communication Disorders (NIDCD). (2010) Quick Statistics. www.nidcd.nih.gov/health/statistics/quick.htm (accessed September 23, 2010).
- Palmer CG, Martinez A, Fox M. (2009) A prospective, longitudinal study of the impact of GJB2/GJB6 genetic testing on the beliefs and attitudes of parents of deaf and hard-of-hearing infants. *Am J Med Genet A* 149A(6):1169–1182.



Also of Interest

“Externalizing and Personifying Hearing Loss: A Psychological Tool for Audiologists,” by Dr. Michael Harvey (*Audiology Today*, Mar/Apr 2010, pages 58-66).

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