

A U D I O L O G Y T O D A Y
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FOCUS TOPIC

COORDINATION OF COCHLEAR IMPLANT SERVICES



Caring for America's Hearing

FOCUS TOPIC:

Coordination of Cochlear Implant Services



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Focus Topic Editor

editor's introduction

Many years ago, before I worked in a cochlear implant center, I referred patients to other centers when it was time to consider a cochlear implant (CI). On one such occasion, a mother called me with some questions and concerns after visiting the center. I called the center to try and discuss the mom's concerns. The audiologist at the center told me, in no uncertain terms, that the child was now their patient and that I no longer had anything to discuss with them. She then hung up.

I learned a great deal from that interaction. Because I was not involved with patients after they received their implants, I really did not know what kind of benefit to expect. If I were not going to have contact with patients who were referred for a cochlear implant, it was clear that I would never fully understand how well a cochlear implant patient could do. The experience confirmed for me what we all know at some level - that we can accomplish more for our patients if we work together.

The CI team is, in fact, a large one. First on the team is the patient who is team captain, and the patient's family. If the patient is a child, then the parents are the captains of the team. (While we frequently consider ourselves to be the captains, it is worthwhile to remember that the patient is in charge. The patient or the patient's family decides what services they want and where they will receive them. We can make recommendations, but we are not the final arbiters of what is done.)

Team members from the cochlear implant center will include an audiologist, a surgeon, a social worker, an auditory therapist, and possibly a psychologist and an educa-

tor. Also on the team is school staff personnel such as the classroom teachers, assistant teachers, speech-language pathologist, auditory therapist, teacher of the deaf, and/or tutors as well as school principal and other supervisors. Some children will have auditory therapy or speech-language services from clinicians outside of school and who included. If the child has services not directly related to hearing (occupational and physical therapy), these service providers are tangential team members. Other team members may include primary care physicians, other audiologists, otolaryngologists, and other medical staff. Adults may include work force personnel on the team if they need assistance with employment issues.

We all need to recognize that the CI team is a large one. While it is difficult to communicate with people who do not work at our facility, we have learned that we if we can develop good communication systems and learn to work as a team, the patient and patient's family benefit - and we benefit too by providing the best possible hearing health care.

This special section of *Audiology Today* has articles about coordinating efforts for cochlear implant patients written by team members from a number of different work settings. They include an audiologist, surgeon and educator from a CI center, a school audiologist, an auditory therapist in private practice, a speech-language pathologist specializing in adult aural rehabilitation, the parent of a young CI user, an adult CI user, and an audiologist who works for a CI manufacturer. It should be good reading for audiologists in all work settings since the coordination of services issues is not limited to CI patients alone.

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Coordination Between Audiologists at the Cochlear Implant Center and the Hearing Aid Center

Jane R. Madell, PhD

Audiologists who have been responsible for hearing aid management of a patient may feel cut out of the loop when a patient is ready to consider a cochlear implant. The audiologist may have been managing the patient for a number of years dealing with hearing aids, and providing support as the patient's hearing loss becomes increasingly severe. It is likely that when the hearing loss progresses, both the patient and the audiologist will be reluctant to part and to have the patient referred to another audiologist for care. As a result, many patients do not get referred for cochlear implant consultation as early as they might. In addition, since the patient does not usually return to the audiologist following the implantation, the clinical audiologist frequently does not have a good sense of how well people do with their CI. This results in the audiologist making fewer implant referrals. If audiologists in general practice were more involved with CI patients and could observe first-hand the benefit received from implants, they might refer patients earlier. This alone, is a good reason to improve communication between the general audiologist and the CI center.

Once patients are referred for a CI consultation, the CI center will evaluate the patient to determine appropriate candidacy. A significant part of the evaluation is based on the determination of the patient's current benefits with amplification. It is sometimes determined that the hearing aid the patient is wearing is not adequate and that, with better amplification, the patient is capable of functioning well enough to not consider a CI at this time. However, if it turns out that CI is appropriate, the patient will not be returning to the general audiologist.

The patient might be better served if contact with the clinical audiologist could be continued. This could be done in a number of ways. When a patient comes for a cochlear implant evaluation, the implant center needs audiological and amplification information that could be provided by the audiologist who has been following the patient. The CI center audiologist should communicate with

the clinical audiologist in the same way in which we communicate with other referral sources. With patient permission, the general audiologist should receive reports describing test results, recommendations, and progress reports with the implant. This is a courtesy to the referring clinical audiologist and will likely encourage future referrals.

After successful cochlear implantation, patients may consider using a hearing aid on the unimplanted ear. Audiologists at both centers should continue to work together by having the clinical audiologist continue to manage the hearing aid on the patient's unimplanted ear. This is a reasonable consideration since the clinical audiologist may well know more about current hearing aids than the audiologist in the implant center.

Coordination between CI Center and Otolaryngologists outside the Center
Otolaryngologists who are not involved in cochlear implantation may have similar reservations about referring patients. CI centers which make an effort to communicate well with referring otolaryngologists are likely to increase referrals and reduce concern about loss of patients. Otolaryngologists involved in cochlear implantation are usually also involved in other aspects of otolaryngology practice and can take over generally otologic management of a cochlear implant patient. However, returning the patient to the referring otolaryngologist for non-cochlear implant issues may make good sense in building relationships for future referrals.

Coordination between CI Center Audiologist and the School

It is critical that there be good communication between the school and the CI center. This may happen by having CI team members visit the school or having school staff visit the CI center. The school staff needs to know how to troubleshoot the CI, how to select and use FM systems, how to know when the CI needs repair, adjustment or additional tuning, and how to maximize functioning in the classroom. The audiologists

at the CI center and at the school can develop good communication patterns. If there is an educator on the implant center team, the educator may be the person who can facilitate communication between the school and the center. The educator will understand best how to improve functioning in the classroom. Each team will need to develop its own methods of maximizing functioning, but the overall program will work best if everyone understands that the team consists of many people from different work settings.

Coordination between CI Center Audiologist and Speech Pathologist or Auditory Therapist

Many children with cochlear implants will be receiving services from auditory oral or auditory-verbal therapists in or outside of the school system. These clinicians can provide a great deal of information that will be helpful in improving cochlear implant MAPping. The CI center audiologist will need to provide the auditory therapist with the same information that the school needs including how to troubleshoot the implant, how to select and use FM's, and how to know when a new MAP is needed. The implant center will benefit from information that the therapist can provide including situations in which the child is hearing well, not hearing well, and specific phonemes that the child cannot perceive. This information can be used to assist the CI center audiologists in modifying cochlear implant maps to provide improved benefit. The therapist can assist the CI center in helping to communicate with the family and helping to monitor use of the implant at home.

Coordination between CI Center and the Workplace

While it is clear that there needs to be communication between the CI center and a child's school program, there is less agreement on what is needed for adults with CIs. Some adults will be able to advocate for themselves in the workplace, but others will need assistance. It is important for the CI center team to discuss workplace issues with adult patients and ask if assistance is

needed. When a CI patient goes to an employer and asks for a phone device, a desk away from a noisy area, or assistance hearing in groups, the employer may view the person as “difficult.” CI center staff who meet with the workplace staff or supervisors will be in a better position to explain what the person can and cannot hear with the CI,

and what can be done to improve communication. As is frequently the case, an outsider can often make a point that cannot be made by the patient directly.

Improved communication among and between professionals can only benefit patients. It can also make work more pleasant and open up more doors.

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Cochlear Implantation: The Expanded Role of the Surgeon

Ronald A. Hoffman, MD

The role of the surgeon has evolved and changed with the increased access to cochlear implantation as a preferred form of auditory habilitation. Cochlear implantation, in the past, has been part of an inverted pyramid with the entire implant program sitting on the shoulders of “the surgeon.” This is typical of new medical interventions that involve a complex surgery. It is analogous to cardiac surgery in the late 1960’s - 70’s. If you needed heart surgery and you could afford it, you went to Texas and saw Michael DeBakey or Denton Cooley. Now, you see your local internist, go to your local cardiologist and have your heart surgery at your local hospital.

The same is true of cochlear implantation. In the early years it was a search for the “big name doctor.” Today, cochlear implantation is a routine surgical procedure with relatively low risk. The inverted pyramid has been flipped and the foundation is no longer the surgeon but rather the Hearing, Speech and Language Center. Children and their families come to the Center for diagnosis of hearing loss, amplification,

educational consultation, speech and language therapy and, at the end of the day, cochlear implantation if necessary.

Since surgeons have “disproportionate” power and influence in the hospital environment it becomes the surgeon’s responsibility to assure that the “foundation” of the pyramid is robust. The Hearing and Speech Center must offer all necessary services to both adults and children. Excellence in care of children, in particular, is maximized by an active outreach program. Such an initiative involves educating all professionals and paraprofessionals who deal with the hearing impaired child. This includes teachers, speech and language professionals, audiologists, physicians and, importantly, parents and family members.

The Cochlear Implant Center should offer in-house conferences for teachers, speech and language professionals, audiologists, physicians and parents and family members. We survey school programs in our geographic area and arrange for regional meetings as well. Our presentations involve all members of the patient care team including a

presentation by one of our staff physicians, if possible. The role of the physician is important for two reasons. First, the physician has information to impart about medical candidacy criteria for surgery, what is involved with the surgery, and the risks and expectations. Secondly, the surgeon has the opportunity to emphasize the importance of the key issues that will be covered by the audiologist, speech pathologist and educator in their talks. The presentation of a unified and consistent philosophy and approach to management reinforces each of the elements.

Cochlear implantation has evolved as a prototypical team approach to health care. The surgeon is one key player on that team and it is his/her responsibility to be involved in both in house management and outreach programs. This reinforces continuity of care and dissemination of the best and most useful knowledge.

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Coordination Between the School Audiologist and the Cochlear Implant Audiologist

Rebecca Kooper, AuD

Educational audiologists and CI audiologists need to establish a good working relationship. These people will be sharing many clients over the years and a positive outlook regarding the role of each in the CI process is essential. Both parties have unique per-

spectives that can contribute to the assessment of the child’s cochlear implant candidacy and ultimate success with an implant.

The educational audiologist often sees the child when the child enters an early

intervention program. The early intervention program provides language, speech and auditory therapy for the child as well as support for the parents. The educational audiologist’s role during this time is varied. Skills and tasks needed at this time include:

- Staying up-to-date on the constantly changing criteria for cochlear implant candidacy.
- Providing parents of children who meet the audiological criteria for candidacy, (information about cochlear implants). Although other factors may preclude a child from becoming a cochlear implant candidate, it is the role of the cochlear implant center to make that final determination.
- Identify older students who may now be a candidate for a cochlear implant. Since criteria has expanded over the last 10 years, older students who were not considered for cochlear implant years ago, may now qualify for a cochlear implant. These children may include those with other handicapping conditions and those students who are not in oral/auditory only programs.
- Ensuring (with the clinical audiologist) the use of appropriate amplification in order to provide the maximum audibility of speech sounds to the child.
- Referring a child to a cochlear implant center when appropriate.

It is essential that accurate results regarding the nature and degree of hearing loss be determined for the pediatric CI candidate. Communication between audiologists and comparison of audiological test results will result in a more accurate assessment. The educational audiologist may have the opportunity to see the child more often and in a familiar setting which can improve test reliability. An open communication about these findings is essential, especially when there is a disagreement about the test results. Neither party should be defensive when test results are not in agreement. It is important to remember that the child should be the center of the discussion, not the audiologist's testing abilities. Excellent audiologists can get different results on very young children. Working together to resolve the differences will only ensure optimum test results.

Children who have good pre-implant auditory skills will usually adapt to the CI with ease. The educational audiologist will work with an early intervention expert, the teaching staff, to make sure auditory skills are progressing commensurate to the degree of hearing loss. The educational audiologist can then report these auditory levels and responses to the cochlear implant center

to assist them in deciding candidacy. At the same time, the cochlear implant center needs to keep the educational staff apprised of the progress of the CI evaluation. The educational audiologist can then support the parents through this process. Parents are often overwhelmed during this process. Questions often arise immediately after leaving the cochlear implant center or days after an appointment at the cochlear implant center. The educational audiologist can serve as a resource for the parents. Parental anxiety can be alleviated when they hear the same information from both the CI team and the educational audiologist and staff at the educational program. This coordination is essential since parents are often apprehensive at this point.

The cochlear implant team's role is to make the final determination regarding cochlear implant eligibility. Once this decision has been made, preparing the child and the parent for surgical and post surgical procedures is done by the audiologist at the cochlear implant center. However, for the older child, having school staff review stories regarding hospitals and surgical procedures may be helpful. The staff that works with the child in school must be prepared to answer questions that the child may ask regarding the surgery and the cochlear implant. The educational audiologist needs to let the cochlear implant team know about any unusual reactions that the child may be showing in school. Either the school or the cochlear implant team may want to provide extra counseling for the child who is demonstrating unusual apprehension regarding the cochlear implant.

On the day of surgery, the audiologist at the CI center works with the surgeon to ensure that the implant is working and that the auditory nerve is responsive to stimulation. After CI surgery, the educational and CI audiologists should work together to arrange for some members of the educational staff to attend the initial mapping. The initial CI mapping is done by the CI center staff who will then review the speech processor with the parents and child. An initial schedule for the use of different maps will be developed by the CI audiologist to be shared with the families and the educational audiologist. The educational audiologist should share this information with the

school staff who will be checking speech processor settings at the beginning of the therapy/school day.

After CI surgery, both the cochlear implant and educational audiologists will become members of an educational team that will make recommendations regarding the child's placement, related services and need for FM technology in the classroom. Both audiologists should meet prior to a team meeting to develop a unified recommendation for the child.

Once a decision regarding education placement and services has been determined, the audiologists need to plan workshops collaboratively. Periodic workshops are essential to provide information and support with personnel who are providing daily therapy/education to the child with a cochlear implant. School personnel typically include a speech therapist, teacher of the deaf, teacher of a regular mainstream class, teacher specialists who work with the child including gym, art, music, library and computer teachers. While it is often difficult for the audiologist from the cochlear implant center to go to schools for monthly workshop presentations, the topics to be covered should be a result of input from both audiologists. While the educational audiologist usually presents these workshops to the staff with whom she works, it is recommended that the audiologist from the cochlear implant center come out to the school at least annually to support the educational audiologist and to provide their unique perspective to staff. Workshops should include but not be limited to the following topics:

- How the cochlear implant works and the different progress that can be expected from children depending on the age of implantation, length of time that child was deaf, level of pre-implant auditory, speech and language skills and other factors unique to a specific child including cognitive levels, and existence of other handicapping conditions.
- How the speech processor works and how to do a daily check of settings. What "mapping" the speech processor means and why children will often have a schedule of map changes, especially during the months immediately following implantation. School personnel need

to work with parents to note observations of the child's auditory responses to the different maps.

- Instruction on how to identify a need for re-mapping so that therapist and/or teacher can be on the alert for the need for a new map.
- Teachers working in schools for the deaf and hard of hearing often have children with different types of speech processors in one class. Providing written information on each processor is essential.
- How to do basic troubleshooting of the processor is critical. Batteries will often go dead in the middle of the school day. Teachers need to feel comfortable changing batteries in the speech processor.
- Providing information on auditory skill development and expectation is essential. Children with a cochlear implant should make consistent and steady progress in their development of auditory skills. This progress can only occur if the personnel working with the child understand the need to continually expand auditory skills and to incorporate those skills in the classroom and therapy session. Lack of auditory skill expectation will significantly hamper a child's progress. The therapist and teacher must

understand how important their role is in the child's successful use of his/her cochlear implant. Special techniques for auditory expectation of children who use sign language should be reviewed, as auditory only opportunities need to be provided during the day for these children.

- Providing information on electrostatic discharge management will reduce the number of problems with implant functioning.
- Providing information on the need and proper use of FM system in the classroom is also critical. While a cochlear implant will provide much more benefit than is available for a hearing aid, it is still necessary to use an FM system if the child is going to maximize listening in the classroom.

Other Considerations

The educational audiologist is usually the person who makes recommendations regarding the use of an FM system in the classroom. The teaching staff needs to learn how to perform daily listening checks of the FM system and basic troubleshooting, when needed.

The educational audiologist often sees the child on a regular basis when he/she comes in for therapy/school.

The audiologist can observe the child in a therapy session or classroom and can obtain information from the therapists regarding the child's auditory, speech and language development. This information can be shared with the cochlear implant team so that they can make any necessary adjustments to the speech processor to ensure continued auditory skill progress. The educational audiologist and CI audiologist will work out procedures to follow when the speech processor is in need of repair. The school may choose to keep certain spare parts on hand such as cables, batteries and transmitting coils for emergency repair.

Cochlear implants have brought auditory access to speech and language to many children who would have been precluded from this experience with hearing aids alone. The educational audiologist and the CI audiologist should consider themselves part of the same team. Together, they can enjoy the experience of providing new opportunities to deaf children who use cochlear implants.

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Working Together: The Educational Consultant and the School

Susan Cheffo, MS

The Role of the CI Center Educator

The educational experiences of cochlear implant children can best be managed if there is an educator from the CI clinic working together with the school. This develops a partnership where the educator and school share information about the child and are working toward a similar goal of maximizing the youngster's educational experience. Although children who receive cochlear implants show significant improvement in speech and language, their ability to hear in noise may be problematic. Hearing in the classroom and within the school environment can impact learning and socialization. The educator needs to provide information about cochlear implants, hearing loss, acoustics, etc.

while the school needs to be open to making adjustments for the child and communicating with the CI center when problems develop. Providing information about student performance is important for the educator from the CI center who needs to be tuned in to the needs of the school while keeping in mind the child's functioning ability. With a positive connection, a true partnership can be formed and the child's educational experience will flourish.

The educator from the CI center is the liaison between the school, family, and cochlear implant center and, therefore, needs to develop the skills to maintain a good relationship. Since educators from cochlear implant centers strongly believe in maximizing each child's auditory, speech and language poten-

tial, the emphasis toward an auditory/oral program is preferred whenever possible. The educator works with staff toward that direction by helping to modify teaching techniques and working with speech therapists to use effective remedial approaches. This can be a sensitive issue for some schools that feel confident in their educational program and are not open to change.

Maximizing Communication

Educators need to develop an ongoing relationship with various schools or programs for children of all ages. Some means of developing these relationships are the following:

- Find a "contact person" within the school via parent or district person who should be called after implant candidacy is established. Begin on a positive note with this person, offer-

ing information to staff working with the child. Be friendly and ask how the school may need the educator's help.

- Set up a workshop or small meeting with school personnel who work with the child. Include all members of the child's team such as speech pathologist, audiologist, teacher aide, interpreter, etc.
- Be well prepared for this workshop. Although the educator cannot know everything about every implant and teaching method, s/he should gather knowledge about the child's cochlear implant, classroom acoustics, modifying teaching techniques, providing auditory learning techniques, etc. Having printed handouts of this information is helpful for personnel to read after the workshop.
- Meet school administrators. It is important to develop positive public relations skills in meeting administrators, secretaries, and other school staff. Once administrators understand the importance of FM equipment, a positive acoustical environment, teaching modifications, team collaboration, and parent participation, there is greater assurance of a successful educational experience.
- Use diplomacy. Make sure the educator acknowledges the staff who work with the child and their knowledge of the child's academic performance. Listen effectively to school personnel and acknowledge the positive learning experiences they have provided for the implanted child.
- Be a resource to school personnel. Provide additional information to staff when requested, such as where to find picture cards for the Ling 6-Sound Test, or where to buy acoustic absorption tiles. Always get back to the school once information is obtained.

It is important to observe the child during individual sessions such as during an itinerant session or speech. Observing a child during a private speech session such as during an Auditory-Verbal therapy session will give the educator information about how this child functions optimally. The educator will then understand better

the need for school personnel to increase their expectations for the child.

How does the educator address the lack of expectation or insufficient teaching methods to school personnel without damaging their relationship? This is where the art of diplomacy and using good, common sense is necessary. To write or not to write observations/suggestions must be constantly addressed by the educator. If the educator observes areas that need improvement, should it be put in writing for follow up, verbally addressed with staff, both of those, or put under the table for a later time. The educator needs to have a good understanding of the school and its personnel. If s/he is asked to write suggestions by an administrator or supervisor, then writing would be valuable. Make sure suggestions and/or observations are written in the third person and cite examples when available.

It is a good idea to communicate with administration regarding suggestions to help the child in class. After mentioning these suggestions to administration, ask if s/he wants the educator to talk to the teacher about these suggestions, whether they should be put in writing, or whether administration wants to handle it.

Educators should use caution when observing in the mainstream setting. There may be itinerant teachers working with the child who work other centers. Writing observations/suggestions may conflict with recommendations provided by others. An example of this is involves an educator who observed a third grade student in his mainstreamed school. During that observation it was noted that the desktop speaker was not giving the child full benefit because it was placed on a hook behind the child and not on the child's desk. The educator placed the speaker in a more beneficial location by relying on student response, and proceeded to write this to the school as a "suggestion." The program that supported itinerant service provider read this and immediately called the clinic to express concern. "How could this be put in writing before discussing it with us?" Even with many apologies, it took a long time

before that relationship was repaired.

What Does the Clinic Educator Need from the School

In turn, what does the educator need from the schools? The school can do the following:

- Inform the clinic as to any changes in listening ability, change in voice quality, or speech production. These may indicate the need for a new MAP. The educator can be the liaison.
- Communicate with the educator regarding any changes in academic performance. This may be an indication of the need to modify teaching techniques, equipment, or of deeper issues.
- When educators go to the school, greet them positively. Sometimes a long drive or train ride is necessary and a smile and open door would be greatly appreciated.
- Follow the schedule set up for the visit. Any changes should be discussed with the educator prior to arriving.
- Notify the clinic/educator if a child is absent. That way a wasted trip can be eliminated.
- Share information graciously, without being defensive. Having the educator and schools collaborate will only benefit the child.
- Make parents part of the team. The school and educator need to plan how to express concerns to parents. Progress and school successes should also be shared.

With the educator providing ongoing support to the schools, and the schools sharing information with the clinic, a reciprocal relationship can develop that will benefit the child with a cochlear implant. Working together is the key to a positive educational experience for all deaf and hard of hearing children.

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Cochlear Implant Services and the Speech-Language Pathologist

Lois K. Heymann, MA

The team is everything

A spirit of collaboration and mutual respect among professionals, parents and school staff is the key to success in the use of cochlear implants and related therapy for hard-of-hearing and deaf children. As an independent speech-language pathologist working with hard-of-hearing and deaf children, it is crucial to establish a team approach from the outset. This includes strong professional alliances which provide input, feedback, perspective and even inspiration. A close partnership with the child's parents or caregivers which is central to an effective auditory-oral therapy program.

By having a parent in the therapy room, "teaming" becomes natural and vital to the process. Working closely with the child's school, other therapists and, of course, the audiologist, leads to better and more informed therapy. When a child receives a cochlear implant, that child and his or her family also gain an implant team - another key partnership that must work effectively to achieve results.

Communication, respect, professionalism

The three principles that guide the best teams are communication, respect and professionalism.

When a child is referred for auditory-oral (auditory-verbal) therapy -whether the child is newly diagnosed, pre-implant or post-implant - the initial team contact is most often the audiologist. Cultivating a good relationship with the audiologist, based on communication, respect and professionalism, is a critical foundation for effective therapy overall.

In most instances before implantation, auditory-oral therapy with hearing aids or FM systems has been initiated, and important data has been gathered. Is the child alerting to sounds? Is the child attending to and responding to sounds? Is the child discriminating sounds? Is the child vocalizing? What is the quality and quantity of the vocalizations? What are the parents' questions and concerns?

This information is extremely important to the implant team both pre- and post-implant. Other members of the team continue to conduct assessments, the results of which need to be considered and incorporated into the therapy program. The therapist needs to know the results of preliminary tests and assessments done by the audiologist, speech-language pathologist (often done by another therapist for baseline information), social worker and surgeon, the dates of implantation, activation and initial MAPpings. The therapist needs to know:

- What CI processing strategy is being used.
- What MAPing changes have been made from one program to the next in threshold levels and in comfort levels.
- How the child should move through the programs, (i.e.: stay in each program until changes in performance indicate the need to move on, or coordinate each program change according to the time of the next MAPing.).
- If there is a high- or low-frequency focus to the MAP program.

The best way for this information to reach me is simply putting it on a cover page to the MAPing data, (See Figure 1) which the parent can bring to the therapy session. I can then keep a copy in my file and refer to it as I conduct listening therapy and observe the child's responses.

At the same time, my responsibility to the team is to clearly convey observations and data about how the child is responding to the programs, and if there are difficulties or problems. Typically I communicate this information to the team via the audiologist.

In addition, with the information provided by this form, the therapist can help parents understand the MAPing changes and educate them about the effects these changes have on the child's listening and learning.

Including school staff

Communicating with the team's educational consultant also needs to be initiated

Figure 1: Sample MAPping report form
(Pediatric Cochlear Implant Report, The Cochlear Implant Center, Beth Israel Medical Center, NY)

NAME: _____ Type of Implant: _____

SPEAK: _____

PROGRAM DIRECTIONS:

Prog 1 _____

Prog 2 _____

Prog 3 _____

Prog 4 _____

Optimal setting Volume: _____ Sensitivity _____

Next appointment date: _____

Comments: _____

Audiologist: _____

and maintained. Having the consultant observe therapy helps to strengthen awareness of the child's progress and any difficulties the child may have in acquiring listening, language and speech skills, which have a direct impact on education.

The consultant's input is also invaluable at IEP meetings. In conjunction with the auditory therapist, the consultant can improve and increase in-service education to the school staff, which will help to successfully mainstream a child with a cochlear implant. Most public school teachers have little or no experience educating a hard-of-hearing child, so the presence of CI team members at these meetings will help the school staff understand this new situation and develop appropriate support services and expectations in the classroom.

Educating the professional community

Finally, the CI team can help professionals outside the team through continuing education. In this instance, the implant team can educate the professional community about working effectively with the cochlear implant, updates on changes in implant criteria and capabilities, and therapeutic and educational strategies. Workshops for speech-language pathologists, teachers of the deaf, mainstream school staff, parents, and audiologists can be necessary to keep everyone informed and current.

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Aural Rehabilitation for Adults with a Cochlear Implant

Patricia Rothschild, MA

The onset of severe or profound hearing loss for an adult who has had normal hearing or who had made the adjustment to milder levels of hearing loss, is devastating. Although hearing aids do not restore normal hearing or normal communicative functioning, they often do make it possible for individuals to maintain employment, family and social contacts and community involvement. These abilities slip away as the severity of hearing loss increases and the benefit from hearing aids decreases. It is not unusual for such a person to approach cochlear implant candidacy with anxiety and trepidation. The process often continues to be fraught with these emotions as one struggles to keep hopes high but expectations in check; to worry about impending disappointment in store for well-meaning and caring family and friends who sometimes seem to believe that a cochlear implant is the “miracle cure” for deafness and all its related problems. Indeed it is not. Although implants provide significant benefit to many people, they are not an instantaneous or a miracle cure. It is no wonder that, after getting through the surgery and any post-surgical difficulties that may occur, by the greatly anticipated day of initial stimulation, the patient is under great stress. No matter how prepared a person is for the day of initial stimulation, it is likely that the implant will not provide the benefit hoped for on the first day. No matter what the experience on that day, it generally fosters feelings of relief that at the least, the device works, provides hope that hearing will improve over time, and increases motivation to do anything and everything that is suggested by anyone to achieve the best possible benefit from the cochlear implant.

While the level of technology of cochlear implant devices and programming strategies has resulted in higher levels of performance after shorter periods of time, especially for post-lingually deafened adults, there continues to be a continuum of performance for cochlear implant users and no one in the field

appears to be comfortable making guarantees or even predictions of success.

If indeed longer periods of experience with the use of the device will result in improved hearing and understanding, it stands to reason that an aural rehabilitation program will do the following:

- Qualify, quantify and describe areas of auditory strength and difficulty
- Offer specific guided practice in using audition to recognize and comprehend speech
- Develop a meta-linguistic understanding of perceptual errors and general communication functioning
- Provide a forum for ongoing communication and for support to the implant audiologist regarding programming, and the possible need for special programs to meet unique needs
- Explore benefits from the use of assistive devices
- Assure understanding and the proper use of cochlear implant accessories to facilitate understanding and augment performance
- Respond to the motivation to work hard to attain the best possible benefit from the implant, and foster a feeling of positive empowerment in the recipient.

Who is an appropriate candidate for Aural Rehabilitation (AR) and when should it be initiated?

Every adult who receives a cochlear implant should be seen for an aural rehabilitation evaluation. The reassurance and gratification of learning that progress has been shown in developing auditory perception of speech and general communication functioning goes a long way toward satisfaction, empowerment and peace of mind. An appointment for this evaluation should be scheduled about four weeks after the date of initial stimulation. This session should evaluate the patient's functional communication in real world situations. On the basis of the patient's performance and if motivation exists, a compilation of goals and practice materials including audio tapes and work on tele-

phone communication, at that individual's specifically appropriate level, can be provided. A follow up assessment appointment three months later can also be scheduled. It is common for patients to report initially the euphoria of greatly improved hearing, which is later clouded by the reality of those situations, speakers, or sounds that emerge as persistently difficult. This follow up appointment can address such concerns, as well as providing a plan for continued self-directed practice.

What should be included in the AR assessment?

A general interview highlighting the patient's feeling regarding hearing well being, environmental sounds and especially speech that is now heard and understood and the reports from family and friends, is the basis of the AR assessment. The patient should describe the communication demands he generally experiences and how well these demands are being managed. A clear picture should be obtained of how well the patient reports understanding speech in a quiet one to one communication setting, in group settings, in noise, at increased distances, for television, and when using a conventional or cellular telephone. It is important to provide a receptive environment for sharing feelings of joy, satisfaction, disappointment, worry or concern related to the any aspect of the cochlear implant. It is also essential that the professional have the knowledge to answer any question posed, or at least know where to go for the answer, as well as the ability to “troubleshoot” situations, speakers and words to determine what aspect of a reported problem to address.

Using both analytic and synthetic assessment, a communication profile is outlined. A phoneme recognition profile is developed including vowel recognition, initial consonant and final consonant recognition using monosyllabic CNC words. Specific misperceptions are noted and a feature analysis of perceptual errors gives insight into the fre-

quency or timing cues that are not being perceived correctly. It is possible to determine whether patterns emerge, for example, misperception of the voicing feature at the end of words, perceptual confusion among the voiceless plosives, or the phoneme /b/ substituted for /f/ in the initial position of words. These are all frequently seen perceptual errors. Providing the patient with this information can be extremely helpful in understanding difficulties he is experiencing. Providing an explanation of why this may be occurring as well as instruction in how to utilize this knowledge to maximize understanding can be a powerful rehabilitative tool. This information must also be communicated to the audiologist who can then work with the patient to improve speech processor programming. Comprehension of connected discourse is assessed to determine whether such factors as rate of speech, length and/or complexity of the message, presence of contextual cues influence the ability to comprehend auditorily.

For pre-lingually deaf individuals who use American Sign Language as their

primary mode of communication, the scenario is very different. These individuals do not generally have an auditory representation of spoken language, the rules of grammar and phonology to act as a framework for what is heard. It is necessary to think of the date of initial stimulation as day one in terms of "listening age", although it is not realistic to build the mosaic of spoken language one word at a time, as one would do for a young child. An abbreviated and more sophisticated way of doing so must be provided for these individuals, as they are at great risk for disappointment and non-use of the device. The program must be intensive and long term, and goals and objectives must be focused and systematic. Auditory and spoken language experience and expectations must expand at the same time that ASL continues to be the language of life. Results can be excellent when motivation is supported and the team works closely together to address and resolve issues as they emerge.

In practice, numerous individuals in their 70's and 80's have successfully received a cochlear implant. While

results vary and can never be guaranteed, virtually all recipients report improvement in their ability to hear environmental sounds and speech, and most enjoy considerably improved ability to understand speech in all situations with far less effort and stress. Because of the factors noted above, aural rehabilitation for this group is particularly helpful and often essential to attain satisfactory benefit.

For all adults who receive a cochlear implant, the partnership and support afforded by an aural rehabilitation program is powerful in terms of instilling empowerment and motivation and fostering more rapid progress to higher levels of auditory performance.

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Ensuring Success for Children with Cochlear Implants: What Every Audiologist Should Consider

Cecile Major Seth

As parents raising a hearing impaired child, we have benefited tremendously from the wisdom of professionals and parents who made this journey before us. In the three short years since our son, Ryan, was implanted, cochlear implant (hereafter CI) technology has evolved, implant ages have decreased, and techniques have adapted, thus dramatically improving prospects for today's hearing impaired children to thrive in the hearing world. I would like to share factors we believe essential to our family's success and the success of others. The first five factors, ranked in order of importance, apply to all hearing-impaired children, while the last five focus on CI candidates.

1. Act quickly Brain plasticity is a huge factor in very young children. As a result, early identification, amplification and parental education are invaluable.¹ Our biggest frustration was that so many professionals and parents seemed so content to "coast" and procrastinate decisions and actions. Advise parents to cram as many sounds into amplified ears in the first 18 months as possible. A child must hear thousands of repetitions before words start to have meaning. Professionals and parents need to understand just how much of an impact they can make by acting quickly.

2. Amplify! Amplify! Amplify! Amplify children within hours or days of identification, not weeks and months. Powerful hearing aids are difficult to fit on rapidly growing toddlers without feedback. A body-worn FM system is quick and easy to fit, with better chance of reduced feedback at high levels of amplification. Most parents would happily use the extra equipment if they understood how dramatically it increases their child's chance to be literate and go to college.

3. Educate parents aggressively. Do not assume all parents will be incapacitated with grief. With time at such a premium, parents do not have the luxury of grieving anyway! Parents need to realize that they have to quickly climb a steep learning curve, and will need to digest a large amount of information rapidly. Our own implant center pointed us to some great resources on our first visit that focused our home therapy.^{2,3}

4. Shoot for the moon – maybe you will land on the top floor! CI children may catch up with their hearing peers quickly if, and only if, we expect them to. If, based on past experience with older technology, we have unambitious expectations then mediocre results are all we will get.

5. Focus on listening skills. We initially tried Total Communication and then an Auditory Oral approach. We knew we had a winner when in his first Auditory-Verbal session, Ryan spoke more than he had done in an entire week! After 22 months of seeing and not hearing, he always prioritized visual inputs over auditory ones. When forced to listen, and only listen, his speech improved immediately and dramatically.

6. Choose a CI center carefully. In addition to a center with a multi-disciplinary, team approach you should look for the following from your Cochlear Implant Center (CI Center):

- **Select a CI Center you are comfortable with.** CI's are complicated. Well-informed, confident parents make the best decisions. Parents, referring audiologists, teachers and therapists need to feel comfortable asking their CI center questions and getting answers they understand. Before making our choice we inter-

viewed every implant center and school for the hearing impaired in the NY tri-state area. The extra effort was well worth it.

The initial activation of a CI can be scary for a child. Ryan developed an aversion to the mapping room, as many toddlers do. Luckily, Ryan had established a strong relationship with our implant team. When his aversion to the mapping room became more pronounced, our CI center allowed us to come early & play in the mapping room.

- **Adjust maps to address specific speech errors.** Our auditory verbal therapist regularly gives me a list of specific speech errors to give our audiologist when mapping. For example, Ryan's intelligibility decreased dramatically as we began to work on more complex sentences. He could hear specific sounds in isolation, but would lose them in connected speech. After the audiologist finished gathering information for the new primary map, additional maps with a high, medium and low frequency boost, were developed. If we worked 's' endings in therapy we switch to the map boosting high frequency. These timely map adjustments allowed Ryan to acquire target sounds much more quickly.
- **Assist with placement decisions & IEPs.** The educational coordinator from our CI center was invaluable in giving us the confidence to make Ryan's primary placement a mainstream one. Ryan had started 3-year-old preschool with 2 placements each day: am and pm. He was in tears daily because he was so exhausted. Our educational coordinator observed Ryan in both placements, provided a reality

check, a sounding board and a font of wisdom.

- **Practice play audiometry at home**
Advise parents to practice mapping & sound booth skills at home, making a game of it. We started at 18 months during Ryan's implant candidacy period. Even at 4.5 years old, Ryan gets better maps if we practice a few times at home during the week before each appointment.

Enabling a hearing impaired child to flourish in the mainstream is a long journey. Early decisions can dramatically improve a child's ability to thrive in the hearing world. If parents were

to understand the profound significance of brain plasticity and the dire consequences of procrastination most would opt for an aggressive management plan such as ours. In order to make good decisions for their children and families, parents deserve honest and timely information. Each family will then navigate its own path. While some parents can sail solo in fair weather, it takes a multi-disciplinary, team approach to get us through the inevitable and frequent storms.

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The New Adult Cochlear Implant Recipient

Donna L. Sorkin, MCP

For many deaf and hard-of-hearing people, the workplace poses the most difficult communication challenges.

Multiple speakers in diverse environments, ranging from the telephone to meetings in noisy conference rooms to social events in dark restaurants to presentations in large reverberant spaces-present a constantly changing set of listening difficulties for anyone with a hearing loss. Workplace settings are also complicated because the person with hearing loss is concerned about how his co-workers perceive requests for special accommodations. Speaking from personal experience, I found that when my own hearing underwent a marked change as a young adult pursuing a career, work was by far the most complicated part of the hearing loss puzzle to piece together.

Audiologists have a valuable role to play in aiding patients who have recently received a cochlear implant with job-related transitions, whether the individual is re-entering the workforce because of their improved ability to communicate via a CI, or is someone remaining in a job they held prior to cochlear implantation.

Depending upon the audiologists time commitments and comfort level in getting involved with patients outside of the clinic

setting, this assistance can take any number of forms. At a minimum, counseling and written materials can be provide and patients can be encouraged to use these to let his co-workers know what to expect and also how they can help. Another option would be for the audiologist to visit the workplace to serve as a resource and meet with those people with whom he works with on a regular basis. A third possibility is to suggest that the individual ask an advocate from their CI manufacturer to accompany her to a brownbag lunch or other informal opportunity at work. Regardless of which approach the person selects, make available videos and written materials for the person to distribute to co-workers.

The Five Golden Rules

1. *Setting Appropriate Expectations.* Although outcomes with cochlear implants have improved steadily over the past ten years, there is still variability in how individual recipients perform and also how long it takes for each person to maximally benefit from the technology. Often, an individual's excitement about the technology leads co-workers to expect a dramatic and immediate improvement in hearing outcomes. Although such rapid changes sometimes occur, we should always counsel recipients to expect their hearing to improve slowly over a 3 to 6 month period, or even longer.

Give the person the background he or she needs to explain the process of learning to hear with a CI to her co-workers.

2. Promote use of listening therapy.

Auditory verbal therapy (or other listening approaches) are commonly recommended for pediatric CI patients but may also be helpful for adults who receive cochlear implants—depending upon their duration and history of deafness. Such structured listening programs can take a number of forms such as one-on-one therapy, a computer-based program, or some other method. Particularly if the individual is not “surrounded by sound” at work or at home, adults should be evaluated for listening therapy.

3. Encourage use of assistive devices. Even experienced “star” CI performers sometimes face difficult listening situations and need the extra help provided by assistive listening devices. With the wide variety of convenient technology – some designed to interface directly with a CI, there is no excuse not to make use of such devices. If the person had little open-set speech discrimination prior to implantation, he probably was not using assistive devices and may need a gentle nudge to try them out. Keep a loaner device in the clinic for patients to borrow to see if they want to pursue assistive devices further.

I attended a conference on classroom acoustics that was held, ironically, in a meeting facility with horrible reverberation. At the first break, I gave the speaker my microphone to wear and attached the receiver to the back of my ear level speech processor. I listened comfortably to the remaining lectures while the people with normal hearing struggled to understand the speakers. An assistive listening device that aids communication in the workplace is a “reasonable accommodation” under the Americans with Disabilities Act (ADA). Hence, the recipient could ask his or her employer to purchase a device for use at work.

4. Help your patient participate in the telecommunications revolution. If the new CI recipient has not been using a voice telephone, it may take time (and some encouragement) for him to regain this valuable workplace

skill. Recommend that he practice at home with a patient, “safe” speaker before he attempts any work-related phone use. Demonstrate the various options (e.g., telecoil, direct linkage to the phone, acoustic coupling) and discuss the pros and cons of each. Ask a CI company advocate to provide details on how to use the various peripherals that connect the cochlear implant to telephones.

Be sure to tell the patient that even the most successful CI users have preferences among the various models of wired or wireless telephones. I have relied on my favorite “work” telephone for 10-1/2 years through three different jobs – my telephone comes with me wherever I go. My employers have assisted by adapting the office telephone system to accommodate my old AT&T “clunker,” which is still my preferred telephone.

Many employers now purchase wireless phones and pay for service contracts for employees, if the phone is needed for the job. When the CI recipient progresses to the point of being able to use a wireless phone, encourage her to test activated phones before committing to a contract; there are substantial differences in how various phones perform for someone with a cochlear implant. Keep a list of the makes and models of wireless phones that work best with cochlear implants. (In general, if a phone works well for hearing aid users, it will also be a good choice for someone with a cochlear implant.) Some cochlear implant users become quickly discouraged because the first wireless phone they try doesn’t work for them. Encourage your patients to try various phone options and also talk to other CI recipients who use cell phones.

My own favorite telephone accomplishment was the successful completion of my first conference call. Because conference calls became commonplace after I lost my hearing, I had never participated in one before I had a cochlear implant. Conference calls can be overly challenging if participants interrupt each other when they talk, or if participants are participating via a conference phone and everyone does not speak directly into the

microphone. Encourage your patient to set ground rules so that call participants know what they need to do to help her.

5. Emphasize the importance of having a hearing “buddy” at work. Even with the markedly improved speech discrimination enjoyed by most cochlear implant recipients, as with anyone with a hearing loss there will be some occasions when even the most successful CI user misses information. Help him to realize that just because he has difficulty in some situations, does not mean he is not doing well with his CI. Rather than bluffing, encourage him to take a proactive stance in every aspect of communicating at work. Having a hearing buddy helps in any environment—including the workplace. Further emphasize using typical coping strategies employed by people with hearing loss, such as paraphrasing or other methods of confirming verbal discussion.

These are five strategies for helping a cochlear implant recipient make a positive adjustment in the workplace and certainly there is other guidance that you might also provide. Perhaps the most important general advice you can give your new CI patients in the workforce is to combine the opportunities afforded by improved hearing with a renewed look at attitudes and practices that make sense for anyone in the workforce—pursuing training to improve skills, seeking challenges, and developing positive relationships with co-workers and others. After all, it is the individual’s own efforts and the way he or she relates to others that most impacts on one’s achievements. A cochlear implant may help a person to be more confident and relaxed about his or her abilities but it is an individual’s own efforts, irrespective of hearing loss, that determines success in the workplace and in life.

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The Cochlear Implant Manufacturer: Collaboration and Customer Focus

Kristine Rafter, MA

Each cochlear implant company has a mission statement, clearly directed toward improving the quality of life of each individual who can benefit from a cochlear implant. The primary commitment of the manufacturer, assuring a lifetime of service and support, is accomplished most often through the clinical, technical, and customer service teams who are the most frequent liaisons between the recipient and the manufacturer. Although sometimes quite remote from the user, engineering, software, research and development teams, and reimbursement specialists advocating for a successful insurance environment for both service providers and individuals, provide a significant contribution to success at all spokes of the cochlear implant wheel.

So how do we make a successful connection between the manufacturer and each of the other professionals and caregivers involved with the cochlear implant recipient? Educational backgrounds, communication biases, and previous exposures to other cochlear implants vary widely among those surrounding each cochlear implant recipient. Mutual recognition of, and respect for, the sincerity of the manufacturer and its representatives, the audiology team, the surgeons, the speech-language pathologists, the educators, the therapists, the (re)habilitationists, the psychologists, and the family and friends are the bases of the successful connection geared to optimize the experience of the child, or adult, with a cochlear implant. Each participant brings input and opinion that must be valued and considered by all others. There is not a single person involved with a cochlear implant recipient who understands all aspects of the technology, the programming, the academic or intellectual skill, learning style, communication style, auditory history and development, social history and style, family dynamic and other challenging conditions and medical concerns. As a team, a cohesive team, there is an opportunity to be successful.

For the manufacturer, representatives work at developing relationships with the cochlear implant specialists in their regional communities. The primary focus is the implant center and the implant center audiologist because most other connections stem from that individual. How are these regional teams organized? There are likely differences from one manufacturer to another, but essentially the map is divided into regions.

The regional teams are composed primarily of experienced cochlear implant audiologists, and supported by cochlear implant users and, in some cases, educators. Additional staff based at the home offices supports the regional teams. Along with educational teams based at the home offices, these well-trained and experienced field representatives provide introductory level and advanced level training on cochlear implant candidacy, counseling, theory and programming. Additional topics include troubleshooting, use of assistive listening devices and rehabilitative methods. Training may be delivered in the form of group workshops held at the manufacturer's home office, within the region, or at the center.

Presentation of manufacturer research, customer research, and changing trends in cochlear implantation around the continent are key to advancing the field. These events are often coupled with larger cochlear implant gatherings attracting cochlear implant service providers with different backgrounds, practicing in different parts of the world.

Manufacturers provide technologies, support and oftentimes research-support, for those cochlear implant teams interested in augmenting their clinical work with cochlear implant research. In this way, the manufacturers contribute to the scientific advancement of cochlear implants, again with the ultimate focus on the individual.

The primary liaison between the manufacturer and the cochlear implant audiologist

is the clinical specialist. Clinical specialists provide on-site assistance with patient programming, installing, upgrading, and training in software, and demonstrating and troubleshooting new hardware. In most cases, clinical specialists will attend any first-time event for a cochlear implant audiologist. New audiologists and other cochlear implant professionals continue to enter the field and require training. That is the good news. Many leave for private practice, raise families, pursue other careers, or to join the manufacturers. The challenging news is that there are insufficient numbers of cochlear implant specialists to meet the demand for current, and likely future, needs. For this reason, and to assure quality cochlear implant services in the future, the cochlear implant manufacturers participate in the support of cochlear implant training at programs across the country.

Research has demonstrated that programming expertise and creativity contributes to user success and satisfaction. Clinical specialists are frequently called to assist with challenging cases and for those whose performance is in question. The clinical specialists, often supported by technical engineering specialists, provide diagnostic measures designed to optimize fittings. In some cases, thorough testing may identify the recommendation for reimplantation. While our clinical and technical support persons perform their services with passion and commitment, the manufacturer is not a clinical service provider. Medical, clinical, and rehabilitative services are provided by hospitals and clinics. Our clinical and technical support is made available at the request of the clinician, or cochlear implant center.

Comprehensive pediatric cochlear implant programs have educational consultants in place to act as the liaison person for the young cochlear implant recipient or student. These staff persons are committed individuals and play a central role in the success of a young cochlear

implant recipient in the community and in the school. For implant center educators, speech-language pathologists, teachers of the deaf and hard-of-hearing, auditory-verbal therapists, and other habilitationists and rehabilitationists, a variety of services are now being offered to support their efforts within the range of educational settings currently providing services to cochlear implant students of all ages.

Each manufacturer is involved in the reimbursement process to assure access to technology for as many individuals as possible. Our roles are key to all those providing services to cochlear implant candidates and recipients, and to the majority of individuals who choose to receive cochlear implant technologies who would not be able to do so without considerable contribution from insurance.

Manufacturers are involved at the policy level by advocating for appropriate coverage and reimbursement by Medicare, Medicaid and private insurers. While considerable in commitment and depth, this aspect of the manufacturers' activity may often go unnoticed by the majority of the cochlear implant community.

Our participation that has the highest profile, is most requested, and perhaps, most appreciated, occurs at the claims level. Manufacturers have highly trained, dedicated, and tenacious staff persons who provide assistance to centers and individuals in obtaining coverage and payment from public and private insurance carriers. For an individual, this involvement may begin at the time one begins to consider a cochlear implant, follow through the assessment and pre-certification process, for surgery, and for post-operative programming and rehabilitation. As hardware needs replacement, we may assist with gaining coverage for the more incidental, but ongoing maintenance costs for replacement cables, headpieces and rechargeable batteries. As technology progresses and new sound processors become available, particularly those that can provide better hearing in more diverse listening situations, the manufacturers' reimbursement teams play a valuable role in assuring success.

What about the individual? How does the manufacturer provide support? In addition to providing continuing education and support to the professionals working with the cochlear

implant recipient, the manufacturer provides direct support to the user. The manufacturer is accessible to the candidate, user, family and friends via a number of pathways including voice phone, TDD, email, websites, printed materials, videotaped materials, and regional volunteers. Audiologists are available via a toll-free number and users via email.

Websites cover most of the hot topics and frequently asked questions regarding cochlear implant technologies. Supplies may be ordered by contacting customer service specialists on the phone or by accessing catalogues included in the websites.

Manufacturers respond to inquiries regarding technology, candidacy, locating cochlear implant centers, reimbursement, troubleshooting, educational issues, therapies, assistive devices, and performance concerns.

The primary contact, though, should be the cochlear implant center. Whether a candidate in research mode, or an existing user with concerns, the manufacturer believes that the cochlear implant professionals familiar with the individual are the best source for reliable information and guidance.

How do the customers assist the growth and success of the cochlear implant manufacturer? Manufacturers have learned an important lesson. First and foremost, it is necessary to listen to the cochlear implant recipient, the user of the technology, to plan, prioritize and develop new products and services. As the diversity within the cochlear implant recipient population expands, the demand for new accessories and interest in more specific and challenging listening environments will beckon the manufacturer to create and market the right products, that is, if we continue to listen to the customer.

Those of us involved in cochlear implants understand that the best outcome for those we serve is born of a collaborative effort. At times this may be daunting, at times exciting, and within the medical community quite unique. It is an ever-expanding circle of individuals who work hard, ponder long, and share joys together.

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Commentary:

Court Ordered Cochlear Implant Mapping

Cheryl DeConde Johnson, EdD

On February 5, 2003, the US District Court of New Hampshire upheld a New Hampshire Department of Education Independent Hearing Officer's decision that the local school district was responsible for providing cochlear implant mapping services [Stratham Sch. Dist. v. Beth and David P., 103 LRP 4317 (02-135-JD, 2003 DNH 022)]. Based on the premise that the child could not benefit from his educational program without his cochlear implant being properly mapped, the court ordered that the district reimburse the parents' mileage to the mapping center (100 miles away) as well as pay their insurance co-payment for the mapping service provided by the implant center audiologist.

This decision was based on the following premises:

Because the child's present mode of communication involved the use of the cochlear implant, the cochlear implant had to be mapped for educational benefit.

Mapping was a related service under audiology; audiology services cited in IDEA were not intended to be exclusive [34CFR300.24(b)(1)].

Mapping services were not a "medical" related service because they were not provided by a physician in accordance with the definition in IDEA of medical services [34CFR300.24(b)(4)].

Audiology as a related service was the core of this case. The parents wanted audiology services on their child's IEP to assist their child in benefiting from special education. They contended that mapping services were included as part of audiology services. Further, since the school district did not employ a "specially trained" audiologist to conduct the mapping services, the parents requested that the district pay for the audiology services as well as the transportation costs to the implant center to receive them.

Other significant points in the testimony of the initial hearing and subsequently considered in the appeal include:

The school district acknowledged the parent's choice in mode of communication and developed the child's IEP to support auditory/oral communication. In doing so, the district contracts with a private, specially-designed

auditory-oral preschool where he receives services from a speech-language pathologist and deaf education teacher. He attends the district's special education preschool in the afternoon.

The school district agreed that it was responsible to make sure that the implant was functioning and included this service in the IEP. They argued, however, that the actual mapping was a medical service, because the implant could not function without being mapped, and, therefore, it was not a related service under audiology.

The school district did not include audiology services as a related service on the child's IEP, because they felt that mapping was a medical service. However, the school did offer to pay for an annual audiological evaluation and update that would exclude the actual mapping of the cochlear implant.

The audiologist who testified on behalf of the parents was employed by the manufacturer of the child's cochlear implant. She stated that "in addition to mapping services, the audiologist must provide sound field testing to track speech perception and should be in communication with the educators and family to insure that the implant is working and programmed best to fit the needs of the child, and that if the school had an audiologist on staff, there would be no need to take the child to the implant center."

The district argued that the implant was not a hearing aid nor an assistive technology device but rather a life-long device that was needed outside of school as well as in school. The audiologists testifying for the district described a cochlear implant "as an electrical device implanted to stimulate the auditory nerve. It is not an assistive learning device. It is an artificial sense organ. Mapping is an adjustment of electrical current levels to a surgically implanted device and is not a form of habilitation." The audiologist testifying on behalf of the parents stated that the implant was not strictly a medical device but "also an educational device because it is tied to a cognitive function."

The district also argued that the cochlear implant was not a covered device and service, because neither IDEA, nor its regulations, identified it as such under the context of an aid, or acoustical hearing aid.

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In response to the district's concern regarding potential implications for schools beyond mapping services for cochlear implants, or services for other biomedical devices, the parents specified that they were only seeking mapping services.

QUESTIONS/IMPLICATIONS RAISED BY THIS DECISION

Can the cochlear implant operate without being mapped? If not, is the processor an extension of the surgery required to make the device function?

While this case limited its request to mapping, will schools also be required to provide the processor, software upgrades, and related parts to maintain the device so that the child can receive benefit from his/her educational program? Could this mean the external components of the implant are considered "educational" and separate from the implanted portion?

If mapping is required for the child to receive educational benefit, it can be construed to be an educational service. Since most educational services are provided at school, should schools be required to provide it as part of their routine on-site audiology services? Can the school determine who provides these services as long as the audiologist is qualified? Who defines "qualified" audiologist? Are school audiologists prepared to undertake the special skills necessary to provide mapping services?

Although poorly reimbursed, mapping services are currently covered by insurance. Can the school bill the insurance company if its audiologist provides the mapping service?

Schools are currently required to insure that hearing aids used in school are functioning properly. For personally-owned devices, does "insure" mean the identification of problems and notification of parents so that programming or repairs can be made by the dispensing audiologist, or does it mean that the school is also required to provide the programming and make the repairs? For personally owned devices, most schools provide services that include electroacoustic analysis of the hearing aid, real ear measurements and/or listening checks. They usually perform troubleshooting services that include minor hearing aid repairs

such as replacing batteries and unclogging earmolds. The common practice is to notify parents of other problems so that the hearing aid can be taken by the parents to the dispensing audiologist for repair at the parents' expense. Shouldn't the responsibility for cochlear implants be treated the same? In doing so, I believe that most school programs currently conduct daily listening checks of the implant, replace coils, and perform auditory and speech perception measures to evaluate the effectiveness of the cochlear implant. However, when problems are identified, the audiologist notifies the parent and refers the child back to the implant center for mapping or other services.

This case decision only discussed educational "benefit" while IDEA specifies services that provide "reasonable educational benefit." How does this difference apply to cochlear implant performance?

As a personal device required 24/7, how does the cochlear implant compare to a personal hearing aid? Are schools also expected to provide hearing aids for home/personal use 24/7 outside of the definition of assistive technology?

Must mapping services be provided when school is not in session, e.g., during summer? What about infants and toddlers under Part C?

DISCUSSION

As one can imagine this ruling could have significant implications for school audiology services. Some issues I believe we must consider are:

Personal vs Medical Device. Cochlear implants are medical devices and mapping is required for the device to function. As an implanted device it is part of the child and utilized 24/7. As such, as an educational device anymore than a pacemaker required to keep a heart beating or the school dispensing insulin to diabetic children.

Insurance. We have all experienced the declining coverage of insurance. Lack of hearing aid coverage has been particularly frustrating and even though cochlear implants are included in most policies, the coverage is often far less than the cost of the device, surgery, mapping, and rehabilitation or habilitation services. Coverage for speech therapy and other

related services has decreased significantly, because insurance companies know that schools must provide these services under IDEA. Decisions such as this one further erode the insurance company's obligation to provide necessary cochlear implant follow-up. Parents need to clearly understand expectations for follow-up appointments and covered services. These provisions need to be detailed throughout the pre-implant process. Implant centers must continue to bill insurance companies. Manufacturers should continue to aggressively educate reimbursement officials regarding necessary cochlear implant services and reimbursement rates. If schools provide mapping services through their audiologists, they must be prepared to bill the insurance companies for that service. However, doing so still does not negate the risk that insurance companies will view this as an educational service, thereby limiting or eliminating mapping as a covered service.

School Resources. School resources are limited. The federal government only pays for about 12% of special education costs; state and local school districts pay the balance. Therefore, this decision puts further stress on education programs that have limited resources. If one child gets more services, another usually gets less. But if it is "the law", insurance companies, advocacy groups, implant centers, and parents know that schools must provide the service. Schools cannot deny services as insurance companies are able to do. Schools also need to be careful stewards of taxpayer money, and taxpayers will not be happy to learn that schools are now required to maintain medical devices, pay insurance premiums, and function as defacto insurance policies. In my opinion, schools should not be the "payer of last resort" for costs that are not specifically tied to educational benefit. However, because most schools are not prepared to provide mapping services in-house, most will like bear the cost of sending children to implant centers.

Role of Advocacy Groups. Advocacy groups provide parents with information and support to obtain appropriate services for their children who are deaf and hard of hearing. As a professional and parent, I have always been a supporter of these programs and continue that role as

a board member of a national parent organization. However, I believe that at least one organization, AG Bell, has taken this program too far. AG Bell's Education Advocacy Program coaches parents to obtain AVT-certified therapists for their children in schools and as well as cochlear implant mapping services. The stated goal of this program is "to pursue test cases in order to set legal precedence for appropriate educational services" (Volta Voices, Jan/Feb 2003, p. 4). They employ a legal service and may even provide funding to support families in this goal. AG Bell filed a "friend of the court" brief in support of this case. AG Bell attorney Arthur Ackerhalt was quoted in the Portsmouth (NH) Herald stating, "We're very please with the result. This is what we advocated for when we filed the friend of the court brief. We believe it's the correct legal decision" (Feb 15, 2003).

While these services may help individual children, they are not changing the education system in a positive way. I recognize and fully support the need for major education reform if we are to improve outcomes for *all* deaf and hard of hearing children, including those who are oral and who use cochlear implants. But who is looking out for the children of families who do not have the ability or resources to assure services? The employment of AVT-certified therapists and provision of mapping services will not change the system. Instead, these misguided practices by AG Bell may result in further alienation of schools and school professionals. Rather, we should be using our resources to train our teachers and therapists in schools in appropriate techniques to maximize auditory and communication development, whether it be with a hearing aid or an implant. To their credit, AG Bell does have a Program Assistance Project under their Public School Caucus that is beginning to provide this type of support. However, as an AG Bell program it is limited to programming for oral children even though the training could also strengthen auditory skill and speech development for children in simcom/total communication programs.

Liability. Implant centers recognize and accept the liability associated with medical devices. If schools begin altering a medical device that has been surgically implanted, what are the potential liability considerations for both the school and

the implant center? I do not think parents fully understand the importance of continued monitoring and mapping through the implant center, nor do they always realize that this will be a life-long requirement for the cochlear implant to function properly. Further issues arise when families move and require services from centers where their children were not implanted. Parents must be made aware of and accept this responsibility as their own prior to implantation.

IDEA. Is it time to revise the definition of audiology and proper functioning of hearing aids in IDEA to include cochlear implants but also to delineate the responsibilities of parents and the education system in providing services for these devices? IDEA reauthorization is occurring right now. We have an opportunity for action.

The Future. I recognize the critical necessity of appropriate mapping for children to benefit from their cochlear implants. I am in favor of schools working with cochlear implant centers to facilitate mapping services. Presently, these services include device troubleshooting and sound field and speech perception assessment to determine that the implant is providing appropriate stimulation for the child and notification to the implant center when it is not. We know that distance from the center for many families is a significant barrier to adequate follow-up. However, these issues need to be addressed and solved during the pre-implant process. I do believe that many school audiologists can and will provide mapping services in the future. Before this can happen however, technology must be refined, equipment and software must be available, training must be provided, and experience must be gained. Tele-medicine for remote mapping holds promise as an important step in this process.

I also believe that mapping should not be a required service, but rather one that school districts could offer should they have the resources to do so. It is appropriate for schools that specialize in programming for students with cochlear implants such as Central Institute for the Deaf, Clarke School for the Deaf, and St. Joseph Institute for the Deaf, as well as large urban public school programs, to be able to offer these services. However, most of these schools are private, not

public ones. As private schools, they are able to bill insurance for these services just as implant centers do.

ACTIONS YOU CAN TAKE

1. Establish a forum for communication. Audiologists in schools and in implant centers need to talk and, together, discuss this issue with parents as well as local and state parent advocacy groups. Everyone needs to own up to their responsibilities. Professional organizations also need to carefully consider what they tell parents in their education and advocacy training. Manufacturers have a responsibility by letting implant centers and professional organizations know that they do not condone this practice.
2. Discuss this case with your school special education administrators and state department of education officials. Ask them to provide input to IDEA reauthorization to exclude services for biomedical devices, specifically cochlear implant mapping. Talk to your school district and state legal counsel about this issue. Help them be knowledgeable should a case arise.
3. Write a letter to AG Bell explaining your concerns. Copy your letter to your local implant centers, implant manufacturers, national and state professional organizations, local and state parent advocacy groups, and anyone else you feel needs to be aware of this issue.

In closing I would like to applaud the efforts of the Stratham, New Hampshire, School Board in their decision to fight this issue on principal. For a very small school district (about 600 students) it was a costly and time-intensive investment. It would have been much easier for them to pay the fees for mapping and transportation for this student. They deserve an award for attempting to preserve the integrity of "educational services" and for recognizing the implications of this decision.

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Commentary: Response to DeConde Johnson

K. Todd Houston, PhD

I am in receipt of your letter dated March 8, 2003 regarding the Hunter P. case.

Although I understand your concerns about the effect of Hunter P., let me share with you a somewhat different perspective of the case and its impact under the IDEA.

The Alexander Graham Bell Association for the Deaf and Hard of Hearing established an Educational Advocacy Program (EAP) for the purpose of promoting and advocating the rights of students who are deaf or hard of hearing, under the IDEA, to a Free Appropriate Public Education (FAPE). This came about because of the hundreds of calls to AG Bell every year from parents of oral deaf and hard of hearing children. Although we know there are many school districts that do a fine job, sadly there are too many parents who have been unable to secure an appropriate program to meet the needs of their children.

AG Bell filed an *amicus curiae* (friend of the court) brief with the New Hampshire District Court in support of the hearing officer's decision requiring the Stratham School District to pay for the mapping of a child's cochlear implant (over and above the payments from the parents' health insurance carrier). AG Bell's *amicus curiae* brief emphasized the necessity of mapping in order for Hunter to benefit from his educational program since his IEP was based on oral communication. Without the proper mapping, Hunter would not be able to understand classroom instructions, participate with his peers in class, or advance in an educational setting. In particular, AG Bell was, and is, concerned that the impetus of the IDEA, which is to provide meaningful access to an education for children who are identified as "disabled," applies to all children, including children who are deaf or hard of hearing.

The legal issue underlying the Hunter P. decision was a narrow one, i.e., whether mapping services by an audiologist is a "related service" as defined in the IDEA. Under the federal law, "related services" include "transportation, and such developmental, corrective and other supportive services (including audiology services.) as may be required to assist a child with a

disability to benefit from special education." At the hearing level, the school district's own witness (certified as an expert) testified that if the cochlear implant were not functioning properly, Hunter could not access information auditorily nor could his IEP be implemented.

All the Hunter P. case does is apply the law already in existence to provide meaningful access for a child with a hearing loss. This decision is not an expansion of the law, but rather a modest application of what Congress and the courts have said must be provided for children with disabilities.

The U.S. Supreme Court, following the intention expressed by Congress, has broadly interpreted "related services" to cover a non-exhaustive list of services required in order for a child with a disability to benefit from special education. In particular, the Supreme Court in *Cedar Rapids Community School District v. Garret F.*, 526 U.S. 66 (1999) and in *Irving Independent School District v. Tatro*, 648 U.S. 883 (1984) respectively held that the IDEA requires a school district to provide a ventilator-dependent student with a full-time nurse and to provide the services of in-school catheterization, even though these services are not explicitly stated in the federal regulations. The Court distinguished "related services" from "medical services" which it explicitly defined as those services provided by a physician, and concluded that any service by a non-physician will not be considered medical and would be eligible as an educationally related service. The Supreme Court created "a bright line test" to distinguish between medical services and related services: services provided by a physician are medical and services provided by a non-physician are not medical and are eligible as educationally related services.

You mention that a cochlear implant is a "medical" device and ask if mapping a cochlear implant is any different than a school district's obligation to monitor a pacemaker or to dispense insulin to a child with diabetes. The answer (according to the United States Supreme Court)

is that if monitoring or dispensing of insulin can be performed by a nurse or other non-physician, it likely would be a "related service." In fact, many insulin-dependent children throughout the country now have nurses not dispensing insulin, but administering it. To do otherwise would deny those children the opportunity for meaningful access to an appropriate education.

An apt comparison to mapping would be the typical example of a child who has a prosthetic limb. The school district is not required to pay for the cost of the artificial limb, any more than it is required to pay for the cost of a cochlear implant (which was not requested in Hunter P.). If physical therapy to enable the child to function better with the prosthesis and the impaired limb were required to address educationally related concerns, physical therapy would be a "related service." If a physician were needed, such services would be considered "medical" and not the responsibility of the school district.

If a child with juvenile diabetes has an insulin pump that fails and the school nurse is capable of correcting a problem with the pump, she could, and should, do so as a "related service." If a physician were required, such services would be considered "medical" and would not be required nor reimbursable. A school district would not be required to pay for the insulin pump (nor were Hunter's parents requesting payment for the cochlear implant).

You also mention that a cochlear implant, as an implanted device, benefits a child all of the time, even outside of the educational setting. However, the IDEA has always covered services that provide benefit outside of the educational setting, as long as those services are necessary for the child to benefit from special education. For example, if a child has a prosthetic limb, that child would be eligible to receive physical therapy at the expense of the school district, even though the prosthetic limb is used at home as much as it is used in school. Also, please note that, unlike the services related to a prosthetic

device, insulin pump, or a tracheotomy tube, the mapping of a cochlear implant relates directly to permitting a child meaningful access to an education.

You also point out that schools are currently required to ensure that hearing aids used in school are functioning properly and ask whether schools are also required to repair hearing aids (other than routine adjustments or trouble shooting). School districts are not (and should not be) required to repair hearing aids, nor are they required to repair prosthetic limbs for students (who are entitled to physical therapy) or pay for surgery related to children on ventilators (who are entitled to nursing services in school). Likewise, school districts should not be required to "repair" a cochlear implant, which was not at issue in *Hunter P.*, but mapping is not a repair, it is a routine adjustment.

You also point out that school resources are limited. Indications are, however, that the provision of mapping services will not cost school districts much money. In the case at hand, parents only asked the district to pay the portion of the cost not covered by health insurance, which was \$10.00 per visit, and the cost of transportation to and from such appointments. Because implant surgery costs tens of thousand of dollars, it seems likely that few individuals without health insurance (private insurance or Medicaid) would undergo such surgery. Consequently, it seems likely that most children who have had implant surgery would have health insurance that covers most of the cost of mapping services.

Also, you state that schools should not be the "payer of last resort" for costs that are "not specifically tied to educational benefit." However, the law requires that a school district pay for catheterization services and even a full-time nurse for a student on a ventilator and must do so as an educationally related service. Yet, you would suggest that a school district should not be required to provide mapping services for a child whose IEP provides for an oral mode of communication, and the "educational benefit" is obvious! We are not unmindful that school districts have limited resources, but at the same time, we are mindful that children who are deaf or hard of hearing are entitled to the same services under the law, which are permitted and being provided to students with other disabilities. In short, students whose disabilities involve deafness or hard of hearing should not have a "second class" disability within the meaning of the IDEA.

You also suggest that there is a "risk" that insurance companies will limit or eliminate mapping as a covered service. Yet, since inception of the IDEA, school districts have for many years routinely accessed third-party payors for other related services such as speech therapy. In any event, the "risk" of not requesting services for children who are deaf or hard of hearing, notwithstanding that such children are entitled to services under the law, raises greater negative ramifications. If the law (as interpreted and implemented) requires a full-time nurse for a child on a ventilator, a lap top computer for a child with cerebral palsy and sophisticated assistive technological devices for a child with severe dyslexia, the withholding of mapping services for a child whose IEP is based on the use of a cochlear implant would mean that children who are deaf or hard of hearing are in effect entitled to a lesser FAPE than children with other disabilities under the law.

Lastly, you speak of the role of advocacy groups and express the belief that AG Bell is "misdirected" in its endeavor. I could not disagree with you more. AG Bell is advocating that children who are deaf or are hard of hearing should receive a Free Appropriate Public Education. Whether school audiologists are trained and capable of performing mapping in-house (similar to speech therapy, occupational therapy or physical therapy services) or whether the school provides for such services by contracting with an outside audiologist, children who are deaf or hard of hearing should be entitled to access mapping of a cochlear implant, as a related service, as long as it assists the child to benefit from special education. Parents have been clamoring for years that they have nowhere else to turn in order to access the services that their children are already entitled to under the law. AG Bell is advocating that the law should be fairly and properly implemented.

K. Todd Houston, PhD is the Executive Director/CEO, Alexander Graham Bell Association for the Deaf and Hard of Hearing, Washington, DC.