

# Did I Forget to Mention?

## *Asking ALL the Questions Before the CI*

*The subject of cochlear implantation is, without a doubt, the most controversial topic in Deaf education since the Milan Conference in 1880. This article is not intended to sway parents in either direction, but rather to provide some "food for thought" to help open more comprehensive dialogues between parents, educators and clinical service providers.*

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**by Brad Ingrao**

The premise of Cochlear Implantation is that the deaf child's peripheral auditory system, primarily the cochlea, is so damaged that conventional hearing aid technology cannot provide enough audibility and discrimination of speech to learn language through that channel (auditory oral). It is supposed that the cochlear implant will provide more information to the auditory centers of the brain and that, with rehabilitative services, the child will learn to use this information to in meaningful ways to integrate the speech sounds they hear into the symbols and rules of the spoken language where they live.

In the United States, the Food and Drug Administration (FDA) has provided a guideline for the selection of candidates who will likely have the best prognosis for success with cochlear implants. The current criteria is:

- At least 18 months of age
- Severe sensorineural hearing loss in both ears
- Little or no benefit from conventional amplification
- Realistic parental expectations
- Enrollment in an auditory-based education program

I would like to examine each of these criteria and play "devil's advocate" in an attempt to clarify these vague criteria.

**Age:** There is nearly universal agreement that the earlier a child has access to a language rich environment, the more normally that child will develop the critical cortical (brain) functions of language (i.e. attention, vocabulary, turn taking, etc.). We also know that there appears to be a "critical period" of language development between birth and 5 years old. The current FDA recommendation of 18 months is reasonable given the risks of general anesthesia and the need to gain a complete audiologic profile and establish hearing aid benefit. It is important that during these 18 months, the child has access to the greatest amount of language content possible,

as well as ensuring that language content is not distorted to the point of being useless for the neural mapping of language.

At this stage of the game, it is more important for the child to learn the concept of language than a specific language, or modality of language. The idea that their thoughts, desires and needs can be related to another person is the cornerstone of all future language function. It behooves us to make certain that communication form does not take precedence over communication function.

Many myths persist regarding the interaction of American Sign Language (ASL) and spoken English development. It is interesting that a recent book, *Baby Signs*, promotes the use of ASL with hearing infants to stimulate language development, but parents of Deaf children are still warned that use of Sign may infringe on the "critical period" of oral language development. It is also interesting that the majority of hearing children of Deaf, signing parents, have equal or superior language function than their peers from hearing families. By the way, these children of Deaf parents have two languages in which they are competent upon entering kindergarten.

I would caution parents to carefully weigh advice that promotes one and only one communication system for a deaf or hard of hearing child. If presented with statements like, "Signing prevents (retards, interferes with) spoken language development," simply ask for the reference of that statement. My most powerful tool as the parent of a Deaf child, is the sentence, "Can you make me a copy of the research that supports that statement?"

**Little or no benefit from amplification:** This is a very tricky part of the FDA criteria, since it offers no description of what "benefit" means. Does it mean aided pure tone thresholds? If so, at what level? There are many factors that can impact the benefit

*(continued on page 16)*

and it is vitally important that the team making this judgment considers and controls for at least the following:

- *The position of the child during the aided testing.* The American National Standards Institute (ANSI) requires that Soundfield audiometric testing be performed under very strict, calibrated conditions. Deviations of a few inches in height or angle can have a significant affect on aided thresholds, particularly in the higher frequencies. Testers should make a point to verify that your child's head is in the proper reference position (I keep an old Yellow Pages around to boost little ones).
- *The type of hearing aids used to establish benefit.* There have been tremendous changes in the available hearing aid technology over the last ten years. While there are differing opinions regarding the efficacy of these technologies for children with severe to profound sensorineural hearing loss, they should at least be up for discussion. I often hear that parents are the first to discuss programmable or digital hearing aids with the audiologist. If you begin to hear reports of "limited benefit" be sure to ask if all possible hearing aid options have been evaluated. Ask what the audiologist's level of experience is with these newer technologies, and again, ask for the academic research that the team is basing their comments on.
- *The configuration of the earmolds.* If your child's aided audiogram looks grim, ask about the earmold. A simple change of earmold tubing style can increase the amount of high frequency sound reaching the child's eardrum by as much as 18 dB. This can mean the difference between hearing and not hearing critical speech sounds like "s" "t" and "p." If the response is "it doesn't really matter." Again, pull your "Request for references" card out of your sleeve.

**A commitment to an auditory-oral education.** This is the biggest problem I see in the current system of determining who is a good or poor candidate for implantation. The students who have the best results with CI's are those who attend early intervention and primary programs, as well as receiving

intensive auditory-oral rehabilitation services. There are many such programs across the country, but these programs are very specialized and employ professionals with a very specific and intensive background. It is unlikely that your local school district can provide a similar program for your child. Ask the implant evaluation team about the programs in your local area. How long have they been operating? How many children do they serve per year? What are the average standardized test scores and literacy levels of their graduates? While your local district has a legal responsibility to provide an appropriate program for your child, you must ask yourself if you want your child to be a "learning experience" for the school. We chose a Bilingual/Bicultural approach for our son and have moved 6,000 miles and 3 states to find the program that best meets his needs rather than "slugging it out" with the local folks. I believe that part of the commitment of cochlear implantation is to ensure that your child can spend at least part of his or her education in a place where having an implant is the norm. They will spend the rest of their lives in the hearing world. We owe it to them not to take any chances on the quality of their preparation to succeed in it. For many families, this means moving to another state. This brings us to the next point that is seldom discussed.

**How strong is your marriage?** The logistics of all the appointments, funding, maintenance (wires, magnets, batteries etc) can be daunting. Add to that battles with the school district (there are always battles), the need to always be explaining the implant, deafness and your choice to every Tom Dick and Harry you meet, and you have the makings of many an Alka Seltzer moment. Keeping your humor, and keeping your identities as spouses, lovers and friends can be difficult. Ask the implant team about family counseling services, support groups and opportunities to meet other families with kids who have implants.

**Does your family have realistic expectations?** No matter that choice you make for your child, it is rare indeed for the members of the child's extended family to have a really clear picture of the scope of the issues you as parents deal with. If you choose to implant your child, be prepared to re-educated

well-meaning relatives who have inevitably read an article on the "miracle" of cochlear implants. Be sure to tell them that no two implant users have the same history or the same results.

**By the way, who's paying for all this?**

While many insurance plans cover the surgery and initial hook-up, you can't always assume yours will. Check your policy carefully for exclusions. Also check to see how much follow-up care is covered. Certified Auditory-Verbal Therapists, Speech-Language Pathologists, and Rehabilitative Pediatric Audiologists all are necessary components in your child's success, but carry a hefty price tag. Your local school district may help a bit, but you need to have a clear picture of all the costs associated with this decision going in.

**If your child is old enough to vote, do they want the implant?**

If your child is over the age of 5 or 6, they really should be involved in this choice. Take some time to investigate their feelings about their own deafness. Be sure to introduce them to children and adults who have implants as well as those who chose not to have them. This choice will be a major defining moment for your child. The effects, good, bad or indifferent, will stay with them long after they are no longer in your direct care.

I hope this discussion will stimulate some discussions and assist you in making a more comprehensive, well-rounded decision about cochlear implantation.

*Brad Ingrao received his Masters Degree in Audiology from the State University of New York. During the day, he is a mild-mannered audiologist at a great metropolitan dispensing practice. At all times, he is the proud father of a Deaf son and a hearing daughter. Prior to becoming an audiologist, he worked as a Sign Language interpreter and has been an active member of local, state and national associations for the Deaf and Hard of Hearing for over 15 years. In his "spare" time, Brad is the editor of the EDEN - The Electronic Deaf Education Network, an informational website for the families of Deaf and Hard of Hearing Children at <http://www.bradingrao.com>*