

Cochlear Implants in Children: Ethics and Choices

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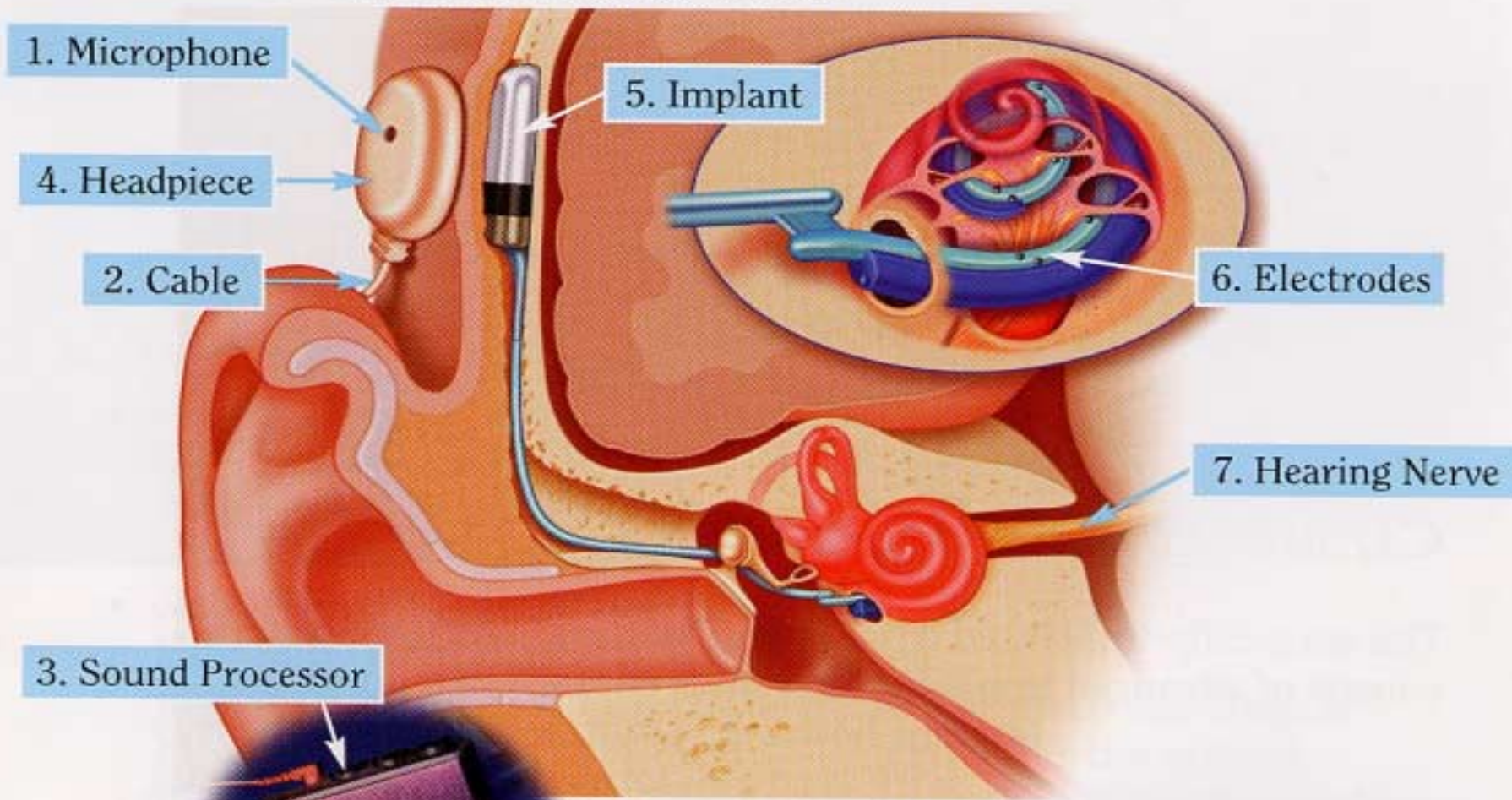
Some issues for today

- The numbers of children with cochlear implants are increasing.
- What are their diverse needs?
- Can we accommodate them within signing programs?
- Can we make recommendations about best intervention practice with this group?
- Today represents a start.

Highlights of our book

- **To set the stage for the conference we'll talk about:**
 - **Motivation for writing the book.**
 - **What is a cochlear implant?**
 - **Some statistics on CI use.**
 - **Research findings regarding parent perspectives of pediatric cochlear implants.**
 - **The deaf community and their changing perspectives on implants.**

appreciate how advanced CLARION is, follow the step-by-step outline of how the technology works.



3. Sound Processor

1. Sound waves enter the system through the microphone located in the headpiece.
2. This sound is sent to the sound processor via a thin cable.
3. The sound processor converts sound into a

- **A CI is designed to do the job of the non-functioning hair cells in the cochlea and stimulate the auditory nerve fibers.**
- **Implants do not completely restore hearing, although they usually enable the recipient to perceive sounds that otherwise would not be heard with a hearing aid.**
- **The ability to benefit from an implant usually requires a good deal of time and hard work.**

A few brief statistics on CI use

- 1990: 5,000 CIs; 90% adults
- 2002: 45,000 CIs; 50% children under 18
- Caveat:
 - The number of users is less than the number of recipients, but the exact number is unknown.

Research: What's in the book?

- Findings from two recent research projects that focus on understanding parent perceptions on a number of issues, such as:
 - How parents discovered their child was deaf
 - Reactions to this usually unexpected news
 - Searching for “solutions”
 - How parents learned about cochlear implants
 - Relationship with the cochlear implant center and surgical/insurance issues

What's in the book? (con't)

- How their child is doing with the implant
- What type of school their child attends and school adjustment
- What type of special services are needed
- The extent to which their child signs post-implant
- Overall satisfaction or dissatisfaction post-implant
- Note: Not all of these issues will be discussed today! 😊

Data from:

- *GRI study (Spring 1999)*: 12-page questionnaire distributed to 1,841 parents of children with implants around the U.S.; 439 returned (24%).
- *Christiansen and Leigh study (Summer and Fall, 1999)*: 56 interviews with parents of 62 children with implants (and one without) in 15 states and Australia.
- **Caveat**: Sample biased in favor of implants due to difficulty in recruiting parents with negative experiences.

Searching for “solutions”

- One parent said: *“The scariest part of it is that you don’t know what you’re supposed to do next. And no one’s telling you; there is no road map.”*
- A mother of a 4-year old girl said: *“I have a distant cousin who did a graduate degree at Gallaudet. She’s hearing....The first thing she said to us was, ‘Don’t trust anybody in this business.’ And she was right on the mark.”*

“Solutions” (con’t)

- **Communication was very important to parents pre-implant, and hearing aids and learning to sign were common first steps for many parents.**
- **Parents were starving for information, and help from other parents were seen as most useful, as were early intervention programs.**

Learning about implants

- Interviews showed that most parents of children with implants did *not* jump into the decision to get an implant for their child. Many parents went through a lot of soul searching before deciding to go ahead.
- Reasons for getting the implant included:
 - Safety (GRI: 25%) *“... if he could hear a car coming, and he’s riding his bike ...we felt that it was just another option for him .. we never planned on him becoming only oral, because he already was using sign language so well. His language was fine.... We just wanted to make...his life with other people outside of school and his immediate family a little easier.”*
 - The opportunity to learn spoken language (GRI: 52%)
 - Having more “options” in the future

As far as education is concerned...

- Parents enrolled their children in many different types of programs (oral and signing), both pre-implant and post-implant.
- Many children with implants *are* mainstreamed, but virtually all of these children continue to require services of some type, and some are not performing at “grade level” yet.
- Parents often have to fight for services which are important because 59% of children are judged by parents to be far behind hearing peers in reading and 37% in math (GRI study).

From the GRI study

■ *Current educational placement:*

Public school: 72% Private school: 28%

■ *Current educational environment:*

- Fully mainstreamed 34%
- Partially mainstreamed 24%
- Self-contained classes 13%
- Commute to residential school 10%
- Live-in at residential school 5%
- Other placement 14%

From the GRI study (con't)

■ *Classmate characteristics:*

- Deaf 32%
- Hearing 30%
- Both 38%

■ *Current mode of communication:*

- Speech 51%
- Sign 4%
- Speech and Sign 43%

From the GRI study (con't)

- *Special support services the implanted child currently receives in school:*
 - Sign language interpreting 40%
 - Teacher aide in the classroom 37%
 - Resource room help 28%
 - Media captioning (closed/real time) 24%
 - Itinerant teacher support 22%
 - Remedial work/tutoring 17%
 - Classroom amplification 16%
 - Personal assistive device 15%
 - Oral interpreter 13%

From the GRI study (con't)

■ *Implanted child's interaction with hearing children at school:*

– Almost never	6%
– Very little	11%
– Fairly often	23%
– All opportunities	52%

From the GRI study (con't)

- “*Greatest advantages*” of using a CI in “the school or other instructional setting” (illustrative responses):
 - Awareness of sounds, hearing music, hearing language, better classroom participation, better communication, hearing the teacher more easily.
- “*Most frustrating things*” about using a CI in...
 - Lack of others’ understanding that a CI does not make the child fully hearing, background noise is a problem, hard to hear in a big group, rechargeable batteries do not last a full day, kids can be heartless at times, sometimes the headpiece falls off.

From our study

- Most of the parents who talked about their child's personality noted stability or improvement in social relationships post-implant.
- Very few parents noted psychological difficulties after implantation.
 - When difficulties occurred, these were related to being implanted during adolescence when not willing.
 - Note: Most of the adolescent ci users we interviewed in a separate group who got the ci during adolescence had wanted it and were happy with it.

Overall post-implant satisfaction

- Most parents of children with implants were generally pleased with the results and would like to have been able to implant their child earlier.
- From the GRI study:
 - 62% of the parents wish they could have gotten their child implanted earlier as it would have better facilitated spoken language.
 - After the first year with the CI, 54% were very satisfied with their child's progress.
 - At the present time, 67% said they were “very satisfied.”
- One parent said: *“It’s just definitely been a miracle for us in all the ways that it could be....It’s not perfect, life is not perfect, it doesn’t work that way....Did I expect he would be finishing first grade and doing what he’s doing? I mean he just finished first grade, he just turned seven...no, I didn’t expect any of these things.”*

But not all parents are satisfied

- The mother of a boy implanted when he was a teenager said that the implant: *“Failed to meet my expectations.”* Father: *“Mine, too.”* Interviewer: *“What exactly did you expect?”* Mother: *“I expected him to grow to love it like he liked his hearing aids, and being better than the hearing aids.”* Father: *“I expected he would have speech, improved speech, more speech.”* Interviewer: *“Is there any way that it met your expectations?”* Father: *“Just that it brought his hearing up to a mild to moderate loss from a profound [loss].”* Mother: *“But, just because he can hear the sounds does not mean that he understands.”*
- **General consensus: Implantation in adolescence is not ideal unless the adolescent is very motivated.**

The Deaf community and cochlear implants

- Until recently, strong opposition to pediatric implants while generally neutral towards adult implantation.
- An implant will delay a deaf child's acquisition of sign language (a deaf child's "natural language") and assimilation into the deaf community.
- People can lead full and satisfying lives without emphasizing speech when they are part of the deaf community (learning English is important, learning speech is less so).

National Assoc. of the Deaf position

- 1991 position statement of the NAD: *“deplores the FDA decision to approve pediatric implantation as being unsound scientifically, procedurally, and ethically.”*
Claimed that *“parents are often poorly informed about the deaf community...and its promising futures...”*
- New NAD position paper in October 2000 (www.nad.org):
 - *“recognizes the rights of parents to make informed choices for their children...”*
 - Emphasizes taking advantage of technological advancements that have the potential to improve the quality of life for deaf and hard of hearing persons, and *“strongly supports the development of the whole child and of language and literacy.”*

The Deaf community and cochlear implants (con't)

- Also in 2000: Establishment of a Cochlear Implant Center at Gallaudet University.
- Spring 2000 survey: A statement about whether “*Gallaudet University should do more to encourage students with cochlear implants to attend*” drew 59% agreement and 23% disagreement, with 17% expressing no opinion. Most of the deaf (54%), hearing (71%), and hard-of-hearing (65%) respondents [faculty, staff and students] agree.

Conclusion

- **Longitudinal information is critically needed.**
- **Children are benefiting from the CI, but there is no guarantee.**
 - **Variables include etiology, interventions, processing problems.**
- **Cochlear implants do not work by themselves.**
 - **Intensive habilitation is required.**
- **Your role is to find ways and means to help children with cochlear implants take full advantage of their listening potential and maximize full psychosocial and educational development.**