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Understanding cochlear implants: a guide for parents and educators

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UNDERSTANDING COCHLEAR IMPLANTS: A GUIDE FOR PARENTS AND EDUCATORS

By

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A capstone project submitted in partial fulfillment of the requirements for the degree of:

Doctor of Audiology

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Introduction

The world of technology is rapidly changing and includes cochlear implants, which have undergone significant improvements and persevere to advance more each day. Cochlear implants have improved steadily since the first devices were produced and continue to improve upon the design and intelligence of the device (Clopton & Spelman, 2003). With enhanced technology, recipients continue to surpass professional expectations and the perceived limitations of the equipment, thus bringing those who are deaf back into the world of the hearing. When cochlear implants were first introduced recipients were only able to gain some voicing information, whereas today's sophisticated devices allow users to achieve on average about 40% open-set word recognition (Clopton & Spelman, 2003) to greater than 80% (Spencer et al, 2004).

One population who can greatly benefit from cochlear implant advancements is children who are prelingually deafened. With the help of a cochlear implant, profoundly deaf children have the potential to develop oral speech and language at an easier and faster rate (Nikolopoulos et al, 2004). This process requires extensive family support and professional habilitation.

Parents, educators, family members, and anyone in contact with implant users should understand cochlear implants as much as possible. With knowledge, one can realize the difficulties of the hearing impaired and understand the limitations of the equipment they may be in contact with.

A cochlear implant is not a hearing aid. While both help to make sounds audible, a hearing aid tends to make sounds louder and an implant stimulates the auditory nerve with electrical impulses to represent all sounds in the environment. Much of the technology associated with hearing aids is beginning to be adapted to cochlear implants, however an implant is a much more complicated process of hearing and does not represent the acoustical signal naturally. The normal pathway of hearing includes an acoustical signal transmitted across the

outer, middle, and inner ear to the auditory nerve. A cochlear implant bypasses every part of the pathway up to the auditory nerve and stimulates the nerve directly to represent signals in the environment electrically (Advanced Bionics, 2003).

To be considered a candidate for a cochlear implant, a person must have a documented hearing loss in the severe to profound range, limited benefits from hearing aids, and poor speech perception abilities. A severe to profound hearing loss indicates that there are few or no surviving sensory cells in the inner ear, which are normally used to transmit messages to the brain. An implant acts on behalf of the missing cells to stimulate the nerve directly. The greater the hearing loss is, the harder it is to reach detection of sound at soft levels. With a hearing loss in this range, hearing aids may only provide minimal benefits of environmental awareness or partial speech signals. Hearing aids have limitations to the amount of amplification they can provide and may hinder speech perception abilities due to distortions of the acoustical signal (Advanced Bionics, 2003). When a hearing aid is required to produce high output levels there is a greater chance of feedback. This limitation forces the hearing aid gains to be decreased in order to diminish the feedback produced, thus not providing the listener with the amount of amplification that may be needed. While current hearing aids with digital technology may provide detection abilities similar to those of an implant, detection of soft level sounds does not guarantee similar discrimination abilities for those sounds. For those with severe to profound hearing losses, a cochlear implant may provide more information than that obtained from hearing aids and a new access to sounds, especially speech information, which was not available before (Zwolan et al, 2004). There must be an auditory signal that is understood before spoken speech and language can be developed. Fryauf-Bertschy and colleagues (1997) noted that the amount of daily use will predict how well a child will use their implant and develop speech.

Uchanski and Geers (2003) compared the speech of 181 8 and 9-year-old children with cochlear implants who had worn the device for at least four years to the speech of 24 normal hearing 8 and 9-year-olds. Results from several acoustic measures of the deaf children's speech were within normal values, or very close. Another study with the same sample population of 181 8 and 9-year-old children with cochlear implants examined the language skills of children with cochlear implants. Geers (2004) noted that 43% of the subjects implanted before the age of 2 and 16% of the subjects implanted before 4 years of age achieved speech and language skills equivalent to their normal hearing peers. Furthermore, of the subjects who lost their hearing after birth and were implanted within a year of deafness onset, 80% had normal speech and language skills (Geers, 2004).

The results noted above are not typical for children with similar hearing losses but only the use of hearing aids. Tobey and colleagues (2003) report that deaf children with cochlear implants have better speech production skills as compared to children with profound losses who use hearing aids. In their study with the same sample population of 181 8- and 9-year-old children with cochlear implants, the average speech intelligibility across the group was 63.5%. These scores are much higher that those in previous studies of profoundly deaf children with hearing aids or cochlear implants.

It is difficult to predict how a person will perform with an implant. It may take many years of extensive training for a child to learn how to use their implant to its full potential. The training period with children is more intensive than it may be for adults because children are learning language for the first time whereas adults already have a formal language system in place. With all of these possibilities, it is no wonder why family support is crucial for adequate implant use. An important realization with cochlear implants is that the implantation affects the

lives of the whole family and not just the child (Incesulu, Vural, & Erkam, 2003). Parents, educators, and family members need to understand how the cochlear implant functions in order to help the implant user. This will also bring understanding to the implant user's difficulties with speech and language.

Literature Review

The field of cochlear implants is relatively young from a historical point of view, with the first developments starting around the mid twentieth century. Animal studies began in 1968, which then lead to the development of the first single channel device in 1969 by Bill House, the "father of cochlear implants" and founder of the House Ear Institute. The single channel device was solely used with deaf adults and only provided some information about voiced aspects of speech with no frequency specific information given. Even so, this sparked the field of cochlear implants and a burst of advances in medical technology continued for the next fifteen years leading to Cochlear Corporation's development of the first multichannel device. This device was released in 1978 and the first human adult was implanted with Cochlear's Nucleus 22-channel device in 1982 (Cochlear Corporation, 2002). At that time, the device was only used as experimental, as approval for public use was not obtained until 1985.

In the United States, the Federal Food and Drug Administration (FDA) monitors and evaluates the safety of products for public use such as: medications, implantable devices, and recommendations regarding medical procedures. In order for a manufacturer to obtain FDA approval of their device, clinical trials must be conducted to demonstrate the safety of the device. Clinical trials of a device usually start with adult candidates and, if proven safe and effective, are also done with children before approval for public use. Currently, there are three devices approved by the FDA for use in the United States: Nucleus, Clarion, and Med-El.

Cochlear implants were approved by the FDA for use in children over the age of two years in 1990. At this time, the only device available was the Nucleus cochlear implant device by Cochlear Corporation. In 1996, another company, Advanced Bionics, received FDA approval for adult use with the Clarion device. Approval for use with children over the age of two came within the next year. The third available device for use in the United States is the Med-El, which obtained FDA approval for use with adults and children in 2001. In 2003 the approved age of implantation was decreased and now currently stands at twelve months old. The lowering of the age of implantation may benefit severe to profoundly deaf children by providing an earlier access to oral speech and language (Manrique et al, 2004). Research has shown that the sooner a child is exposed to speech and language, the better the outcome that can be expected due to the critical age of language development being from birth to six years old (Henkin et al, 2003). Most profoundly deaf children will develop language abilities at half of the rate of normal hearing peers. A major benefit of early cochlear implantation is a minimized gap between a child's language age and their chronological age (Miyamoto et al, 2003). Geers and Brenner (2003) note, "early cochlear implantation is a cost effective procedure that allows deaf children to participate in a normal school environment with hearing age mates." Other studies have noted that for children who lose their hearing after developing speech and language skills, the shorter the period of deafness, the better the outcome will be for the child to regain speech and language skills (Geers, 2004).

While technology has improved over the past twenty-five years, the basic design of implants has not. A cochlear implant contains parts external to the skin and those surgically implanted into the mastoid bone and inner ear. In general, a microphone picks up sounds in the environment and transfers the information to the speech processor. The message is then changed

into a digital code based on the speech processor's programmed "map." The code is sent to the headpiece, connected by a magnet to the internal parts, and the coded message is transferred across the head. The internal array, or electrodes, converts the coded signal into an electrical pattern, which directly stimulates the auditory nerve. The auditory nerve delivers the signal to the brain, which interprets the message as speech. The implant does not restore hearing to normal.

The most important part of the process is the information contained in the speech processor's programmed "map." A "map" is the unique programmed settings developed for every user individually and consisting of the levels obtained for maximum and minimum current on each electrode (Advanced Bionics, 2003). These settings are determined by an audiologist, who will also adjust the parameters of the speech signal for optimal use by the recipient. The "map" will present the speech signal in a digital code based on the modified settings. Each "map" created is uniquely set for the users individual needs.

The digital code sent to the electrodes from the "map" in the speech processor is referred to as a coding strategy. The coding strategy is a formula used to deliver pitch, loudness, and timing information and helps to further define how the signal will reach the brain. The set maximum and minimum current levels of the "map" determine how much current the electrodes will apply on the auditory nerve. Depending on the coding strategy used, only a certain number of the electrodes will be available for programming (Chute & Nevins, 2002). The number of electrodes used determines the speed of processing for the coding strategy to convey information to the brain. Each manufacturer will have at least two coding strategies available with their device, each a different way to convey the speech signal. No one coding strategy is the best for all users, and each strategy will have performers across a wide range. An audiologist will select

which strategy will be used based on which strategy they believe will result in optimal performance. A well-fit map will increase the child's abilities to hear speech and develop oral skills (Skinner et al, 1997).

Coding strategies have been a major area of improvement in cochlear implant technology. The strategies have led to stronger performance outcomes for children with cochlear implants. Ostroff et al (2003) noted that regardless of preimplant factors or speech scores, developments in speech processing technology can account for a good portion of the observed improvements in speech performance. The improvements in coding strategy technology have all developed from the same basic elements. With the first single channel cochlear implants devices the focus of coding strategies was to provide feature extraction of speech amplitude information (Wilson, 2000). This minimal information of the speech signal represented the voiced information of vowels and the fundamental frequency with little information given about the consonants in the speech signal. As devices developed and became multichannel, coding strategies continued to improve as well. Additional information could be extracted to help the listener understand speech with more channels available to separate and deliver the signal. High frequency filters and more filter banks allowed for information from F1 and F2 to be obtained along with the fundamental frequency. These developments advanced technology to the more modern coding strategies, such as SPEAK with the Nucleus 22 devices. SPEAK presented the signal in spectral peaks of speech energy across many electrodes at an overall rate of 2,500 Hz (Wilson, 2000). Another coding strategy created soon after was Continuous Interleaved Sampling (CIS), with a similar version available with all three manufacturers now. The CIS strategy allowed the electrodes to fire at a faster rate, which could be in the range of 14,000 to 18,000 pps depending on the manufacturer of the device. This results in better frequency

resolution. The latest coding strategies continue to build upon the positive features of strategies in the past. For the Nucleus 24 devices, the coding strategy of choice is Advanced Combination Encoder (ACE), which is a combination of SPEAK and CIS that represents the speech signal with high spectral quality and fast temporal representation (Nucleus, 2002). ACE has an overall rate of 14,400 Hz. For the Med-El devices, the CIS strategy is recommended, however the rate of processing is much faster now than it was in the past at 18,000 pps. For the Clarion devices, most new users will utilize Hi-Resolution coding strategies, which have the fastest processing capabilities of any strategy available (Advanced Bionics, 2003).

While it may take up to three years for some children to show benefit or progress in speech development with their implant, better strategies are showing faster results (Incesulu, Vural, & Erkam, 2003) and improvements for speech in the presence of background noise (Pasanisi et al, 2002). In comparison studies of old strategies to improved strategies, children repeatedly achieved increased speech perception skills when using updated coding strategies (Geers, Brenner, & Davidson, 2003). Pasanisi et al (2002) compared coding strategies in the Nucleus software, where it was found that using the ACE strategy, the most recent for Cochlear Corporation, improved children's speech perception abilities. Performance was also noted to be significantly better with Clarion's latest strategy, Hi-Resolution, when compared to older strategies for all subjects in the sample, especially when listening to speech in noise (Ostroff et al, 2003).

In a majority of the comparison studies of old and newer coding strategies, recipients also preferred the quality of the improved strategies to that of the older strategies (Clopton & Spelman, 2003). An important factor in speech performance measures is how well an audiologist programs the device. A well-fit "map" contributes substantially to how well a child

will hear speech (Geers, Brenner, & Davidson, 2003). It should also be noted that children with cochlear implants should continue to improve upon their speech and perception skills every year after implantation.

In addition to improvements in speech perception performances among children with cochlear implants, users are also exceeding expectations in other related aspects. Skinner (2003) suggests that ideal goals of understanding speech and communicating easily for implant users can be achieved if there is motivation to develop speech and language. Children with profound hearing losses who are implanted at a very young age, and have no other contraindications for speech development, should demonstrate age appropriate receptive and expressive language abilities to their normal hearing peers at a sooner age than those who only use hearing aids (Waltzman et al, 2003). Some children have also been able to develop a second spoken language, however this depends on the environment and interventions available. The development of language skills in children with cochlear implants also relates to the development of literacy and writing skills. Spencer, Barker, & Tomblin (2003) compared normal hearing children to those with a cochlear implant and found that the implanted children performed within one standard deviation of the normal hearing children under the domains of language comprehension, reading comprehension, and writing accuracy. Another study noted that 67% of their subjects demonstrated grammar comprehension close to their normal hearing peers within five years after implantation (Nikolopoulos, 2004). With the proper services, habilitation therapy, and family support, the expectations for a child with a cochlear implant should not be greatly limited.

The three cochlear implant manufacturers are committed to their devices and research on performance (Chute & Nevins, 2002). One recent development includes the use of a cochlear

implant in one ear and a hearing aid in the other ear. This helps to stimulate the remaining sensory cells in the opposite ear and may preserve their function for future developments in cochlear implants. While benefits from the ear with a hearing aid may be minimal, research has shown that some binaural advantages can be provided (Tyler et al, 2002). Along with intensive research, constant improvements and developments of implant technology are continuously being introduced. Developments in the near future for cochlear implants include: cochlear implants in both ears, smaller external parts, better FM system compatibility, and the combination of acoustic and electric hearing in the same ear. With advances in technology in the near future, recipients will continue to surpass professional expectations and the perceived limitations of the equipment, thus bringing those who are deaf into the world of the hearing.

Geers, Nicholas, & Sedey (2003) note that continuing advances in coding strategies, cochlear implants, and earlier ages of implantation are likely to further increase the language abilities of deaf children to perform more like their hearing peers. However, this process will always require extensive family support and professional habilitation.

This project was developed to create a better understanding of cochlear implants and current technology for families of children with cochlear implants. Providing a basic understanding of cochlear implants will enable parents, educators, and equals to recognize the limitations of cochlear implants and have realistic expectations for the implant recipient. This booklet is not intended to be used as a stand alone when educating parents of a cochlear implant candidate, but rather a take-home supplement to intensive counseling.

Background Information

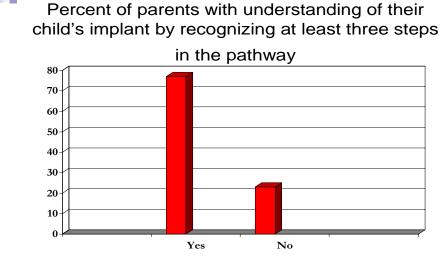
In order to assess understanding and determine the needs of parents of pediatric cochlear implant users, twenty parents (and equals) were asked to participate in an interview about their

understanding and attitudes towards their child's device. The parents selected to participate had a child with a cochlear implant who was currently enrolled in an oral school, or was mainstreamed in a regular classroom. All of the children had been implanted for at least six months at the time of the interview. Fifteen parents and equals consented to being interviewed. Questions asked during the interview included:

- What is the name of the manufacturer for your child's device?
- What features are unique to the implant that your child has over other manufacturers' devices?
- What is your understanding of how your child's cochlear implant works?
- Which coding strategy does your child use?
- Are there any advantages to using this strategy?
- Do you feel your child is receiving benefit from their cochlear implant and please give examples of benefit?
- What characteristics are most important in determining successful or beneficial use of an implant?
- Have your expectations for your child and the cochlear implant been met, please explain?
- What advice would you give parents who are just beginning the process of cochlear implant candidacy?

From the responses obtained during the interview sessions, the areas of information needing more education for parents, educators, and equals was assessed. Review of the basic processing pathway with a cochlear implant was the first area of information addressed. Parents were asked to describe how the cochlear implant works in their own words and were rated by the

number of steps in the processing pathway they were aware of. A correct understanding required knowledge of at least three steps, and 75% of the parents interviewed met these criteria.

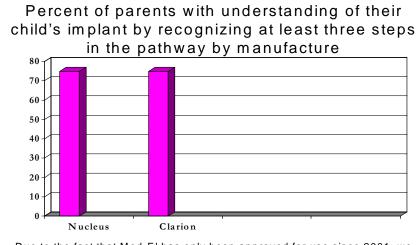


Parents were rated by the number of steps in the processing pathway they were aware of. A correct understanding required knowledge of at least three steps.

Comments from these parents included the following:

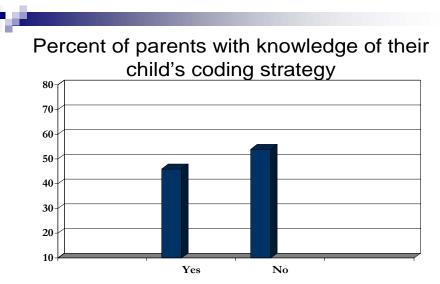
- "Sound is picked up through the microphone, sent to the processor, converted to the electrodes, and the brain interprets."
- "Sounds go through the processor and are transmitted to the electrodes surgically implanted inside where the nerve is directly stimulated."

The understanding of a child's cochlear implant by recognizing at least three steps in the pathway was also assessed across manufacturers. Due to the fact that Med-El has only been approved for use in the United States since 2001, a fair representation of parents whose child has a Med-El device could not be obtained. Therefore, only the Nucleus and Clarion devices were assessed, each resulting in 75% of the parents having a correct interpretation.



Due to the fact that Med-El has only been approved for use since 2001, we were unable to find a fair representation of parents whose child has a Med-El device

Knowledge of the child's coding strategy was also assessed during the interviews, with only 45% of the parents interviewed knowing the specific name of the strategy their child used. A correct understanding required knowledge of the specific name of the strategy used currently by their child. Some parents could explain the function of a coding strategy, but were unaware of the specific name for the coding strategy used currently.



A correct understanding required knowledge of the specific name of the strategy currently used by their child. Some parents were aware of what a coding strategy was but could not name the specific one used.

Comments from these parents included the following:

- "It is the electrical code to provide sound"
- "It is part of the computer program that is adapted to meet the needs of my child"
- "It is the timing of the electrodes"

Knowledge of a coding strategy was also assessed across manufacturers. Only the Nucleus and Clarion devices were assessed, each resulting in 50% of the parents having a correct interpretation.

Percent of parents with knowledge of their child's coding strategy by manufacturer 50 45 40 35

35 30 25 20 15 10 5 Nucleus Clarion

Due to the fact that Med-El has only been approved for use since 2001, we were unable to find a fair representation of parents whose child has a Med-El device

A guidebook for parents and educators to further their understanding of cochlear implants has been developed based on the information obtained during the parent interviews. The booklet can be found in the appendix section of this paper. All of the basic issues related to cochlear implants have been attempted to be addressed in an effort to provide a general overview of cochlear implants that is helpful to everyone. This guide should be helpful through all stages of having a child with a cochlear implant including: candidacy, initial stimulation, follow-up mapping, and troubleshooting. Every possible effort was made to address each of the cochlear implant manufacturers equally and is not intended to bias the reader towards one manufacturer

over another. The usefulness of this booklet and how it may help families and educators understand the complexities, limitations, and benefits of cochlear implants was assessed for this project by distributing the guidebook to educators and surveying those participants on the effectiveness of the information presented.

Methods

In order to assess the benefit of the booklet, twenty-eight educators with minimal experience with cochlear implants were asked to review the booklet and participate in a survey. The educators selected to participate were attending a workshop related to learning about cochlear implants and tests of language development with hearing impaired children, due to their limited interaction with cochlear implant children. These participants' responses were compared to those from ten deaf educators with an average of five years experience with cochlear implants.

Participants were asked to rate their overall satisfaction of the booklet on a five-point scale, with one meaning poor and five meaning excellent. Aspects of the survey included:

- Overall quality of the presentation.
- Organization of the guide
- Overall content
- Overall benefit
- Content area needing greatest improvement
- Advantages of this booklet
- Level of difficulty for parents

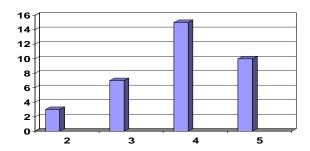
Results

From the responses obtained in the surveys, the areas of overall satisfaction, amount of benefit, best qualities of the booklet, and content area needing most improvement were assessed.

In the initial evaluation of the data obtained there was no difference noted between the responses from either group, therefore the data from both groups of educators was combined for the following results.

Overall satisfaction was the first area addressed. Using a five-point scale, participants rated the presentation as a whole. 75% of the participants felt that the booklet was more than adequate to address basic needs and issues related to cochlear implants.



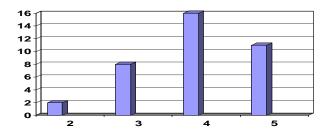


Participants rated their overall satisfaction with the booklet on a five-point scale, with one meaning poor or not satisfied to five meaning excellent or highly satisfied

Participants also rated the amount of benefit provided to parents and educators through the guidebook. Similar to satisfaction ratings, 71% of those surveyed felt the guidebook would be of benefit to those wanting to learn more about cochlear implants.



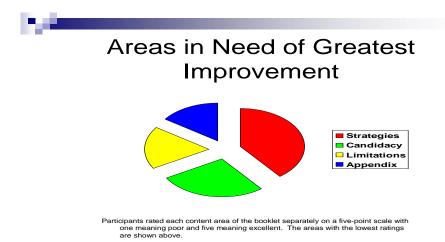
Amount of Benefit to Parents



Participants rated the amount of benefit parents may receive from the booklet on a five-point scale, with one meaning poor or not satisfied to five meaning excellent or highly satisfied.

Participants were also asked to give general comments on areas of strength and weakness in the guidebook. Overall, most participants felt the guidebook was most beneficial due to its use of graphics, photos, and ease of reading. The most common comment on areas needing improvement related to the organization of the guidebook and lack of a table of contents for quick reference. These issues will be addressed in future developments.

Each area of the guidebook was also evaluated in terms of content, presentation, and benefit. The four areas receiving the lowest ratings were judged to be the topics in need of the greatest improvement. General comments from participants stated that the area in need of greatest improvement related to the organization and simplicity of the content in all areas of the booklet. Many of the educators surveyed felt that the booklet was too much information for a parent to read at one time. It was suggested numerous times that a table of contents be added or have the guide be broken down into chapters. Specific content areas receiving low ratings included coding strategies, candidacy for implant, limitations of implants, and the appendix of more technical information. It is thought that the lower ratings for these sections relates again to the intensity of the information given at one time.



Discussion

It is hoped that this guidebook will be used as a resource for parents and educators. This includes the use of this booklet with educators of mainstreamed children with cochlear implants. In the future we plan to address the suggestions of our survey participants and update the booklet as developments arise. A common comment from participants was the lack of need for the strategies section and the technical appendix. Many educators noted this section and the high level of detail were not needed. Another popular comment was to simplify and shorten the guidebook by making the information more basic for parents to understand and taking out the technical parts. All of the suggestions made will be given serious thought in the near future. Other changes may include updating the devices section as manufacturers introduce new equipment and changes to the candidacy section as trends in implantation evolve. The booklet can be found in the appendix section of this paper. In an effort to provide a general overview of cochlear implants, we hope that everyone may find this guidebook helpful.

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Appendix A

Understanding Cochlear Implants: Guidebook Evaluation

Appendix B

Understanding Cochlear Implants: A guide for parents and educators