



Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Group - Teleconference Agenda
July 2001

Agenda for July 2001

- I. WELCOME AND ANNOUNCEMENTS**
June Holstrum

- II. NATIONAL ASSOCIATION FOR THE DEAF (NAD) POSITION STATEMENT ON COCHLEAR IMPLANTS**
Nancy Bloch

- III. EFFECTIVENESS OF COCHLEAR IMPLANTS and AGE at IMPLANTATION**
Karen Kirk

- IV. COCHLEAR IMPLANTS FOR CHILDREN with AUDITORY NEUROPATHY**
Charles Berlin

- V. COCHLEAR IMPLANTS FOR CHILDREN WITH AUDITORY NEUROPATHY**
Jon Shallop

- VI. COCHLEAR IMPLANTS: Other Issues to Consider**
Barbara Raimondo

JUNE HOLSTRUM:

Hello everybody. I'm June Holstrum from the Center for Disease Control and Prevention, and welcome to the July teleconference on Early Hearing Detection and Intervention. Thank you for joining us. Remember to mute your phone when you're not talking. Today's conference is being recorded and the transcript will be available on the Internet.

Before we start our scheduled program, are there any announcements or comments from any of our listeners? (NO RESPONSE) If not, then we'll get started right away, and our first speaker is Nancy Bloch from the National Association for the Deaf to talk about their position paper on cochlear implants. Go ahead, Nancy.

NANCY BLOCH: The following statement on cochlear implants is from the National Association of the Deaf ([NAD website](#)) and is being used in place of comments from Nancy Bloch. You can use the above, highlighted NAD link to find other related information about cochlear implants and the NAD.

The National Association of the Deaf (NAD) is an education and advocacy organization committed to promotion, protection, and preservation of the rights and quality of life of deaf and hard of hearing individuals in the United States of America. The targeted audience for this paper includes parents of deaf children, deaf individuals, medical professionals, and the media.

The NAD recognizes that diversity within the deaf community itself, and within the deaf experience, has not been acknowledged or explained very clearly in the public forum. Deafness is diverse in its origin and history, in the adaptive responses made to it, and in the choices that deaf adults and parents of deaf children continue to make about the ever-increasing range of communication and assistive technology options. Diversity requires mutual respect for individual and/or group differences and choices.

The NAD welcomes all individuals regardless of race, religion, ethnic background, socioeconomic status, cultural orientation, mode of communication, preferred language use, hearing status, educational background, and use of technologies. The NAD also welcomes deaf, hard of hearing and hearing family members, educators, and other professionals serving deaf and hard of hearing children and adults.

The NAD subscribes to the wellness model upon which the physical and psychosocial integrity of deaf children and adults is based. The general public needs information about the lives of the vast majority of deaf and hard of hearing individuals who have achieved optimal adjustments in all phases of life, have well-integrated and healthy personalities, and have attained self-actualizing levels of functioning, all with or without the benefits of hearing aids, cochlear implants, and other assistive devices.

The NAD recognizes all technological advancements with the potential to foster, enhance, and improve the quality of life of all deaf and hard of hearing persons. During the past three decades, technological developments such as closed captioning, email and the Internet, two-way pagers, text telephones, telecommunications relay services, video interpreting services, visual alerting devices, vibro-tactile devices, hearing aids, amplification devices, audio loop and listening systems have had an important role in leveling the playing field. The role of the cochlear implant in this regard is evolving and will certainly change in the future. Cochlear implants are not appropriate for all deaf and hard of hearing children and adults. Cochlear implantation is a technology that represents a tool to be used in some forms of communication, and not a cure for deafness. Cochlear implants provide sensitive hearing, but do not, by themselves, impart the

ability to understand spoken language through listening alone. In addition, they do not guarantee the development of cognition or reduce the benefit of emphasis on parallel visual language and literacy development.

The NAD recognizes the rights of parents to make informed choices for their deaf and hard of hearing children, respects their choice to use cochlear implants and all other assistive devices, and strongly supports the development of the whole child and of language and literacy. Parents have the right to know about and understand the various options available, including all factors that might impact development. While there are some successes with implants, success stories should not be over-generalized to every individual.

Rationale

The focus of the 2000 NAD position statement on cochlear implants is on preserving and promoting the psychosocial integrity of deaf and hard of hearing children and adults. The adverse effects of inflammatory statements about the deaf population of this country must be addressed. Many within the medical profession continue to view deafness essentially as a disability and an abnormality and believe that deaf and hard of hearing individuals need to be "fixed" by cochlear implants. This pathological view must be challenged and corrected by greater exposure to and interaction with well-adjusted and successful deaf and hard of hearing individuals.

The media often describe deafness in a negative light, portraying deaf and hard of hearing children and adults as handicapped and second-class citizens in need of being "fixed" with cochlear implants. There is little or no portrayal of successful, well adjusted deaf and hard of hearing children and adults without implants. A major reason implantation and oral language training have been pursued so aggressively by the media, the medical profession, and parents is not simply because of the hoped-for benefits that come with being able to hear in a predominantly hearing society but more because of the perceived burdens associated with being deaf.

Because cochlear implant technology continues to evolve, to receive mainstream acceptance, and to be acknowledged as part of today's reality, it is urgent to be aware of and responsive to the historical treatment of deaf persons. This perspective makes it possible to provide more realistic guidelines for parents of deaf and hard of hearing children and for pre-lingually and post-lingually deafened adults.

Wellness Model

Many deaf and hard of hearing people straddle the "deaf and hearing worlds" and function successfully in both. There are many people with implants who use sign language and continue to be active members of the deaf community and who ascribe to deaf culture and heritage. There are many deaf and hard of hearing individuals, with and without implants, who are high-achieving professionals, talented in every imaginable career field. They, too, are successfully effective parents, raising well-adjusted deaf, hard of hearing and hearing children. As citizens, they continue to make contributions to improve the quality of life for society at large. Deaf and hard of hearing individuals throughout the ages have demonstrated psychological strength and social skills when surviving and overcoming society's misconceptions, prejudices, and discriminatory attitudes and behaviors, thus attesting to their resilience, intelligence, and integrity.

Given the general lack of awareness about the reality of the wellness model, the NAD strongly urges physicians, audiologists, and allied professionals to refer parents to qualified experts in deafness and to other appropriate resources so that parents can make fully informed decisions--that is, decisions that incorporate far more than just the medical-surgical. Such decisions involve language preferences and usage, educational placement and training opportunities, psychological and social development, and the use of technological devices and aids.

The Cochlear Implant

The most basic aspect of the cochlear implant is to help the user perceive sound, i.e., the sensation of sound that is transmitted past the damaged cochlea to the brain. In this strictly sensorineural manner, the implant works: the sensation of sound is delivered to the brain. The stated goal of the implant is for it to function as a tool to enable deaf children to develop language based on spoken communication.

Cochlear implants do not eliminate deafness. An implant is not a "cure" and an implanted individual is still deaf. Cochlear implants may destroy what remaining hearing an individual may have. Therefore, if the deaf or hard of hearing child or adult later prefers to use an external hearing aid, that choice may be removed.

Unlike post-lingually deafened children or adults who have had prior experience with sound comprehension, a pre-lingually deafened child or adult does not have the auditory foundation that makes learning a spoken language easy. The situation for those progressively deafened or suddenly deafened later in life is different. Although the implant's signals to the brain are less refined than those provided by an intact cochlea, an individual who is accustomed to receiving signals about sound can fill in certain gaps from memory. While the implant may work quite well for post-lingually deafened individuals, this result just cannot be generalized to pre-lingually deafened children for whom spoken language development is an arduous process, requiring long-term commitment by parents, educators, and support service providers, with no guarantee that the desired goal will be achieved.

Parents

Parents face challenges when their child is born deaf or becomes deaf. At least ninety percent of deaf and hard of hearing children are born to hearing parents who usually want their children to be like themselves, to understand sound, to use their voices and verbally express their thoughts through spoken language, and to hear the voices and spoken language of those around them.

However, language and communication are not the same as speech, nor should the ability to speak and/or hear be equated with intelligence, a sense of well-being and lifelong success. Communication and cognition are vital ingredients of every child's development, regardless of the mode in which it is expressed, i.e., visual or auditory.

Despite the pathological view of deafness held by many within the medical profession, parents would benefit by seeking out opportunities to meet and get to know successful deaf and hard of hearing children and adults who are fluent in sign language and English, both with and without implants. The NAD encourages parents and deaf adults to research other options besides implantation. If implantation is the option of choice, parents should obtain all information about the surgical procedure, surgical risks, post-surgical auditory and speech training requirements, and potential benefits and limitations so as to make informed decisions.

Cochlear implant surgery is a beginning, not an end. The surgery decision represents the beginning of a process that involves a long-term, and likely, life-long commitment to auditory training, rehabilitation, acquisition of spoken and visual language skills, follow-up, and possibly additional surgeries. Whatever choices parents make, the primary goal should be to focus on the "whole child" and early language development/literacy and cognitive development. The absence of visual language opportunities can result in developmental delays that can be extremely difficult to reverse. Since the first six years are critical for language acquisition and usage, concurrent acquisition of visual and written language skills should be stressed.

Further improvements to cochlear implant technology and greater experience with educating and supporting pre-lingually deafened children and adults may later result in better outcomes for both of these populations than are achieved at present. In the meantime, though, parents of deaf and

hard of hearing children need to be aware that a decision to forego implantation for their children does not condemn their children to a world of meaningless silence. Regardless of whether or not a deaf or hard of hearing child receives an implant, the child will function within both the hearing and the deaf communities. For these reasons, parents of pre-lingually deaf children presently have a reasonable basis upon which to decline implantation for their child. Parents must feel comfortable with their decision, whether they choose implantation or not.

Once parents have arrived at a decision, they want their decision to be validated. They seek reassurances often solely from within the medical and professional hearing health care community. This is a serious and major concern to the NAD. By releasing this position statement, the NAD seeks to alert, educate, and inform parents about deafness and the deaf community.

Recommendations

The NAD hereby makes the following recommendations for action:

Professional Training

Medical professionals have historically been the first point of contact for parents of deaf children. Their expertise is valuable but is primarily limited only to their medical areas of expertise. They should not be viewed as, nor should they function as, experts with regard to larger issues such as the educational, psychological, social, and linguistic needs of the deaf child. Medical professionals may be experts regarding the mysteries of the inner ear, but they are not experts regarding the inner lives of deaf children and adults. Psychological, social, educational, cultural and communication aspects of deafness, including the wellness model, must be a significant part of every medical school curriculum, especially within the specialty of otolaryngology. In-service training programs should be implemented for all interdisciplinary staff at cochlear implant centers that would include guidance and counseling methods with parents of deaf children and adults considering cochlear implants. These training programs should be conducted by professional counselors who are trained, qualified, and competent to work and communicate with deaf and hard of hearing children and adults and their families.

Early Assessment of Hearing Aid Benefit

It is widely understood and accepted that a trial period of hearing aid use is necessary prior to cochlear implantation. Advanced digital hearing aids should be explored. The NAD encourages that this effort be earnest and of appropriate duration for adequate assessment by objective testing and skilled observation of behaviors and communication skills. This assessment is complicated by the child's lack of prior auditory experience, and inability to communicate what s/he is hearing. The length of this trial period will vary with the individual. Further research by the medical and educational communities regarding objective hearing assessment and hearing aid trials is strongly encouraged.

Cochlear Implant Team

Candidacy assessment and surgery must be performed in a medical setting that has a close working relationship with a team of professionals that will provide ongoing long-term support to implant recipients. To be a responsible implant center, caution must be taken when describing the potential benefits of implantation, including risks, limitations, and long-term implications. Parents of deaf children and adults must be assisted in developing realistic and appropriate expectations. Critical to both pediatric and adult cochlear implantation and the long-range medical, audiological, psychological, social, emotional, educational, and vocational adjustment is access to implant centers fully complemented by an interdisciplinary staff, including rehabilitation specialists, psychologists and counselors. Implant center personnel must also work with and involve deafness professionals in education and in the helping professions. It takes a coordinated team of specialists, parents, educators and counselors to raise an implanted child and to support an implanted adult over an extended period of time. The implant team is also morally obligated to

recognize when the implant experience has been unsuccessful and provide alternate strategies for language training.

Habilitation

An essential component of the cochlear implant process is habilitation. Parents and professionals must make a long-term commitment to integrating listening strategies throughout the child's day at home and at school. It is important to recognize that a newly implanted child is unable to understand spoken language through listening alone. Therefore parents and professionals should continue to use sign language to ensure age-appropriate psychological, social, cognitive, and language development.

Insurance Coverage

The NAD recommends that medical insurance carriers also provide fair and equitable coverage for hearing aid devices and associated support services.

Media

Reporters, journalists, anchors and directors of newspapers, television networks and film are encouraged to research and prepare their material more carefully and without bias. There is a serious need for a more balanced approach to fact-finding and reporting.

Research

Longitudinal research is critically needed, including a more thorough analysis of those for whom the implant is not working. Future research should involve highly controlled, manufacturer-independent and unbiased research on the long-term outcomes of childhood implants on auditory and communicative development, academic and intellectual development and achievement, psychological, social and emotional adjustment, and interpersonal relationship functioning. Comparative research on children without implants receiving parallel support services should also be conducted, especially those for whom sign language is the primary form of communication. Research findings relative to children with and without cochlear implants in educated lay terms must be made available and disseminated to deaf individuals, to parents of implanted children, to those in the helping professions, and to those contemplating implants.

Parents

The NAD knows that parents love and care deeply about their deaf children. Since the decision to perform implant surgery on the deaf child is made for the child, it is necessary for parents to become educated about cochlear implants-- the potential benefits, the risks, and all the issues that they entail. During this critical education process, parents have both the need and the right to receive unbiased information about the pros and cons of cochlear implants and related matters. The NAD knows that parents want to make informed decisions. Parents also would benefit by opportunities to interact with successful deaf and hard of hearing adults, as well as with parents of deaf and hard of hearing children.

Deafness is irreversible. Even with the implant and increased sound perception, the child is still deaf. Cochlear implants are not a cure for deafness. The most serious parental responsibility from the very beginning is total commitment to, and involvement with, their child's overall development and well-being. Throughout the developmental years, the deaf child -- implanted or not, mainstreamed or not --should receive education in deaf studies, including deaf heritage, history of deafness and deaf people, particularly stories and accounts of deaf people who have succeeded in many areas of life.

Support Services

Parents must understand that, after suitability testing and the decision-making process, the actual surgical procedure is just the beginning-- a prelude to a lifetime proposition for the child and years of commitment by the parents. Implanted children are still deaf and will continue to require

educational, psychological, audiological assessment, auditory and speech training, and language support services for a long period of time. Services for families and children should be provided in a manner that is consistent with standards set by the Individuals with Disabilities Education Act (IDEA), with focus on the whole child and the family. It is imperative that psychological support be available, including counseling services. Such services are to be available throughout the child's developmental years, often until adulthood.

Visual Environment

The NAD has always and continues to support and endorse innovative educational programming for deaf children, implanted or not. Such programming should actively support the auditory and speech skills of children in a dynamic and interactive visual environment that utilizes sign language and English. In closing, the NAD asserts that diversity in communication modes and cultures is our inherent strength, and that mutual respect and cooperation between deaf, hard of hearing, and hearing individuals ultimately benefit us all.

JUNE HOLSTRUM: I think most people are at least aware of it and have some familiarity with it but maybe not all the details of it.

CHARLES BERLIN: This is Chuck Berlin. I have read the old position. I have not read the new position, but I have verbal communication about it from one of the people who says he helped revise it.

KAREN KIRK: This is Karen Kirk. I have read the new position paper on the website.

JUNE HOLSTRUM: Any other questions for Nancy? (NO RESPONSE)

Thank you, Nancy. We appreciate your being with us and we certainly support the rights of parents to make that choice and would want to support them in whatever their choices would be.

Our next speaker is Karen Kirk. She's going to be talking about the effectiveness of cochlear implants in relation to age of implantation. Karen, go ahead.

KAREN KIRK: Thank you. I appreciate the opportunity to participate in this conference.

I thought I would just give you a little bit of background first. Cochlear implants were first approved for use in children in 1990, and at that time, they were approved for use in children who were two years of age and older. And in those early days, the children who received cochlear implants were typically older, usually older than five, and they were completely deaf and received absolutely no benefit from a hearing aid. And the early results, speech understanding, speech perception results for the children were really very modest. So the children were able to get some information about the timing and rhythm of speech or vowel information, but their ability to perform open-set word recognition, to comprehend and understand spoken language through listening alone was really very limited. And since those early days, we've seen tremendous advances in the -- technological advances in the design of implant systems and we've also seen quite a broadening of cochlear implant candidacy to include very young children and also those children who have some residual hearing.

So today, the current candidacy guidelines for implantation in children include: children who are 12 months of age or older; for children who are under the age of two years, those children should be profoundly deaf; children who are two and older can be severely to profoundly hearing impaired; and all of the children who are considered for an implant should show a lack of auditory skill development and minimal hearing aid benefit. So they all need to have an appropriate trial period with hearing aids.

For older children, minimal hearing aid benefit would be shown through aided speech testing, word recognition testing; and for very young children, we typically use parent questionnaires to track auditory skill development. And as we've seen cochlear implantation through the last 15 years or so, ten to 15 years, as we've seen it extended clinically to younger and younger children and we've also seen continued improvements in implant design, we've seen very large increases in children's ability to recognize and process spoken language. And I would kind of like to talk to you today about what some of the current findings are and what we've been experiencing in our study.

At Indiana University, we are conducting a longitudinal study and it's been ongoing for the last 15 years, and it's funded by the National Institutes of Health. And our study is -- the purpose is to evaluate the benefits of cochlear implant use in pre-lingually-deafened children. And the primary aim is, first of all, to assess long-term benefit of implantation in children and then also to try to identify factors that are associated with the development of communication abilities.

So through the years we've followed more than 200 children who have cochlear implants as part of our research, and I'll tell you a little bit about that now.

All of the children in our study are pre-lingually deafened, and in our study we define that as deafened prior to the age of three years. As I said, they're severely to profoundly hearing impaired, and I would say probably 99 percent of them or more are profoundly deaf. The children have English as the primary language in their home and they have no additional handicapping conditions. And in our recent study, we've been looking primarily at children who have a cochlear implant by the time they are five years of age.

Now, in our study, we have both oral children and we also have children who use total communication. And by total communication, we are referring to the combined use of signed and spoken English, not use of American Sign Language, unspoken language. All of the children in our study, because they are pre-lingually deafened, they need to use the sound provided by an implant, not only for speech understanding but also to develop intelligible speech or speech that can be understood by others and they also use the sound from their implant to learn about their -- and acquire their surrounding linguistic system.

So in order to assess benefit then in our study, we administer the children a very large battery of speech perception, speech production, and language tests. And we test the children before they get a cochlear implant and then we test them every six months following cochlear implantation. And typically, children remain in our study for at least three years following implantation and many children have continued to participate through five, six, or seven years of cochlear implant use.

So we do -- the point about doing longitudinal studies is very important and not something that we are conducting here.

Just to summarize some of the performance results that we've seen, the majority of children in our study who receive a cochlear implant before the age of five years demonstrate the ability to understand at least some speech through listening alone and we see that, in fact, many of these children acquire very substantial word recognition abilities. As always, we see a lot of variability, so some of the children are able to understand and follow connected speech through listening alone and others have more limited benefit. But in general, we see that word recognition abilities emerge during the first year of cochlear implant use and that they continue to develop over a very long period of time. So even after five years of cochlear implant use, we see that children are continuing to improve and develop new skills and we really don't see a plateau.

When we look at the word recognition abilities of the children with cochlear implants and compare those to their deaf peers who use a hearing aid rather than a cochlear implant, we find that

children -- the implanted children have significantly higher levels of word recognition and sentence recognition and comprehension than do the children who continued to use hearing aids. And we also see the same kind of result when we look at the children's speech intelligibility and, again, by that we mean how much of what they say can be understood by others.

So we find that children with implants make gains in their speech intelligibility in a consistent fashion. And Dr. Mario Saberski [phonetic] in our lab did a study of 44 implant users over a period of three years, and he found that with each year -- increased year of implant use, we saw significant improvements in the speech intelligibility of these children. So by three years of implant use, on average, about 50 percent of what they could be -- what they said could be understood by others who are not familiar with the speech of deaf talkers, and that's very encouraging because, first of all, this was a very difficult task. So they didn't have any kind of contextual cues to help them hear what the child was saying, they just heard the words and had to write down what they thought the child said.

And the other thing that is encouraging about that finding is that in a -- that in a previous study of speech intelligibility in high school students, we found -- or it was found by Clarissa Smith that, on average, about 20 percent of what the students said could be understood by peers -- or by listeners with normal hearing.

We also looked at receptive and expressive language abilities in these children and we've done a number of studies in that area. Again, some of this work was done by Dr. Saberski [phonetic] in our laboratory.

In our laboratory, we've done studies looking at the language development of children with profound deafness before they get a cochlear implant. And on average, we find that children without an implant develop English language skills at about half the rate of their peers with normal hearing. So by that, we mean that for every one year of increase in their chronological age, we see only about six months of gain in their language abilities. So every year that they are relying on a hearing aid, they fall farther and farther behind their normal hearing peers. And then in our research, we found that after the children get a cochlear implant, the average rate of their English language development begins to approximate that of normal children -- normal hearing children. So that is, they make about one year gain in language skills for every one year increase in their chronological age. And so they don't close that gap that was there originally, but they begin to -- the gap doesn't get any wider once they get a cochlear implant. So this finding suggests to us that early intervention with an implant might help to prevent a large delay in language from occurring.

So just briefly to summarize, we found that, in general, children with cochlear implants show significant improvements in word recognition and speech understanding, in speech production and speech intelligibility, and in receptive and expressive language development after an implant, and they also have significantly higher skills in these areas than their deaf peers who continue to use hearing aids. But as we've said many times, there's a great deal of variability from these average results. So some children do extremely well and other children show more limited hearing from a cochlear implant. And across all of our studies, there are two factors that emerge as always having an impact on the development of communication skills, and those are age at implantation and the communication method that these children are using.

So in a recent study, we looked at the rate of speech perception and language development in about 73 children and, again, they all were implanted before the age of five years and they all had current cochlear implant systems, current technology. And we took these 73 children and we divided them into two groups based on communication mode. So in one group, we had children who used oral communication and in another group we had children who used total communication. Then within each of these two communication groups, we further stratified them by whether they were implanted before or after the age of three years. And what we found was

that both age at implantation and communication mode had significant effects on the rate of development of communication skills. So we found that children implanted -- as a group, children implanted before age three had significantly faster rates of language development than the children who were implanted after age three. And we also found that children who used oral communication had significantly faster rates of language development than the children who used total communication. And in fact, what we found was that the rate of English language development in the oral children who got an implant before the age of three was very similar to that that we would expect for children with normal hearing. So what we find for these very early implanted children who are in programs that emphasize the development of speaking and listening skills is that they are acquiring language in an age-appropriate fashion and demonstrating age-appropriate abilities in communication, in spoken English communication. And in contrast, many of the children who use total communication had language delays, especially in the expressive language area.

So we're continuing to look at this issue of age of implantation. We have preliminary data that shows implantation prior to age two may also have a significant effect on the development of English language skills. And what we find -- or what we expect is that with universal newborn hearing screening and with the goal of early detection and intervention, it's very likely that we'll be seeing potential implant candidates at a younger and younger age. They will have been identified, fit with a hearing aid, and found not to benefit from that. And it appears that early intervention with cochlear implants may eliminate or reduce any delays we typically see in the development of English language skills in these children, and our results do suggest that early implantation is beneficial but, as yet, we don't know where the boundaries of these sensitive periods for implantation might be.

So I think that pretty much summarizes what we're doing here. Any questions?

Yusnita Weirather Yes. This is Yusnita Weirather from Honolulu. How are you?

Why do you think the the oral group had more expressive language benefits than the total communication group? And number two, when you did the study, do you also measure the signing level or use -- looking at their total expression?

KAREN KIRK: I'm sorry, I didn't get your last question. I was looking at the signing in what way?

Yusnita Weirather: Do you also measure the signing level?

KAREN KIRK: When we measure language -- Okay, let me answer your first question.

Why do I think that the oral children have a greater rate of language development than the total communication children? I can't tell you the exact answer to that. I think it has something to do with the nature of their linguistic environment and the fluency of their parents in providing a signed model. Oftentimes, with these young children, parents are kind of learning signed English along with their child and I think they may not sign as often as they speak or they may not feel comfortable signing all of the time. I -- Just based on my many years of experience, I think that might have something to do with it.

The other question about measuring their signing, when we assess speech perception, we test the children through listening alone, but we instruct them in whatever their mode of communication is and then we give them the words or the sentences and ask them to respond appropriately. When we assess language with our children, we assess it in the child's own modality because we're not interested in what they can perceive through listening alone, we're interested in comprehension and expression of language.

So the total communication children were tested in total communication with the combined use of signed and spoken English. The oral children for the language tests were tested in the oral modality, through listening and lip-reading alone.

YUSNITA WEIRATHER?: Thank you.

KAREN KIRK: You're welcome.

ARLENE STEDLER-BROWN: This is Arlene Stedler-Brown. I have two quick questions.

One is, are you exploring bilateral implantation? And the other is, can you tell me which language tests you're using in your study?

KAREN KIRK: Yes. We are -- We have not implanted any patients bilaterally, although we are in discussions about participating in clinical trials of bilateral implantation in the United States. And the language measures that we use for the younger children, we use the Renauld Developmental Language Scales because it has a great deal -- it's been used a great deal with children with hearing impairment or children who are deaf and it also has a real hierarchy of language structures that can allow you to test a number of different skill levels. And it's normed on normal hearing children. We're interested in how our implant children compare to their normal hearing peers, and so that's what we're looking at.

For the older children, we also use the SELF, and then we also administer the Peabody Picture Vocabulary Test for a vocabulary recognition measure.

ARLENE STEDLER-BROWN: Thank you.

KAREN KIRK: You're welcome.

TOM MAHONEY: Karen I have a question on the -- when you compared the hearing aid kids and the cochlear implant kids, did you control the amount of therapy or rehab?

KAREN KIRK: That's a very good question. We don't control for that because we -- each child goes out to his or her own school district and, you know, some parents can provide additional therapy besides that and others cannot. However, we do require that children who get a cochlear implant at our center are enrolled in programs. Whether they use a signing system or not, we ask that they be enrolled in programs where they do get auditory training and practice in the development of auditory and speech skills, but it is the case that some children might get more therapy than others in our study.

TOM MAHONEY: Thank you.

KAREN KIRK: You're welcome.

LISA HOLDEN-PITT: Karen, this is Lisa Holden-Pitt from OSEP. I was wondering if you had plans or had looked at reading comprehension. Are these kids old enough for that?

KAREN KIRK: We have not measured reading comprehension specifically. We are finding that with these children who are getting implants at a very young age -- we have a number of them now who got implanted under two and they've now had their implant for three or four years and many of them are now going into normal hearing -- or going into regular mainstream kindergarten situations and in the classroom with other normal hearing children. Bruce Tomlin has actually looked at some measures of literacy and found that after -- Bruce Tomlin from the University of

Iowa -- and found that after implantation, these children are acquiring reading skills at a much more rapid rate than they had been previously. But he would be a good person to contact to ask for more information about that.

UNIDENTIFIED SPEAKER: [Inaudible] from the American Academy of Pediatrics.

Have you looked at the social-psychological [inaudible] and the impact that cochlear implants will have on that?

KAREN KIRK: We have not looked at that specifically. Someone -- Actually, interestingly, we had a visitor from Sweden here today who was asking me that. Many of our very young children, I think, have -- who have cochlear implants have mostly hearing peers and socialization opportunities with other hearing children. Some of the children in our program are in self-contained classrooms for hard-of-hearing children and some are in -- go to our school for the deaf, and I think the children differ greatly and they're allowed individual variability in where they feel comfortable and where their sense of identity falls. We haven't specifically measured that, although -- of course, we're quite concerned that children develop a good identity and have good social opportunities and things like that. But we haven't done any formal assessments of that.

JUNE HOLSTRUM: Karen, thank you so much for that very interesting presentation, and we hope you'll keep us updated as you have new findings as you do your research.

CHARLES BERLIN: Okay. Karen, you have children who have a gap in their language development after their implants. Has anybody used FastForward with them?

KAREN KIRK: We have not done that. There is a therapist here in town who is interested in trying that and I know that she's done it with a couple of high school students. We have not seen a large change in language -- in closing that gap in those older students, but it hasn't been looked at with our younger implant users.

CHARLES BERLIN: Thanks.

KAREN KIRK: You're welcome.

JUNE HOLSTRUM: All right. Let's just move right along, and we have Charles Berlin and he's going to be talking about auditory neuropathy. Go ahead, Chuck.

CHARLES BERLIN: Good afternoon, ladies and gentlemen. Thanks for the opportunity to talk to you today.

First, I should start by saying that auditory neuropathy is, unfortunately, poorly named because it implies that there's always a neural damage or damage to the primary auditory nerve. This is simply not accurate and I would like to call your attention to a recent paper in the archives of Otolaryngology in June of this year that shows that premature children and in children with histories of distress, neonatal distress, the pathology is primarily selective loss of the inner hair cell. Now, what that means is that the nerve fibers are robust and healthy for an indeterminate period of time and the outer hair cells are usually perfectly normal. The end result of that is you have what looks to be like an audiological paradox, that is, the nerve fibers can't be accessed because the inner hair cells are missing or compromised and you get no ABR or very desynchronized ABR. Whereas, if you use otacoustic emissions as a test, then you get perfectly normal function. So the paradox occurs when anyone who uses those two tests believes that they are hearing tests per se. So then you get one hearing test that says the child is normal, the otacoustic emission, and the other hearing test, in quotes, that says the child is deaf. And in fact,

the child is neither. What happens is that these are often the children whose parents are subjected to the criticism that they don't accept their child's deafness. The children actually hear a great deal. So let me demonstrate for you the difference between ordinary cochlear deafness, which can affect primarily outer and inner hair cells and nerve fibers and then this so-called auditory neuropathy or better named auditory dysynchrony. First, I'll give you normal speech as follows: Time present and time passed are both contained in time future. And now speech as it would sound to someone with a very severe high-frequency hearing loss who would benefit from hearing aids and management in an ordinary hearing-impaired class. [Speaking] You see that's muffled and distorted. Now listen to what it would sound like if you had auditory dysynchrony or neuropathy. This was prepared by Dr. Fang Gang Zing [phonetic] in a method I'll talk to about in a moment. [Speaking] Now it will improve slightly. [Speaking] And slightly again. [Speaking] And one more time. [Speaking] And finally normal. [Speaking] The voice there is Dr. Arnold Starr, one of my colleagues who has been a leading figure in this study.

Essentially, what happens is that the auditory nerve can't be fired synchronously. And what you get is this desynchronized static that is particularly unusable in noisy situations or when there are competing messages. You can also visualize that hearing aids are not at all useful for patients like this. They reject them quickly because their outer hair cells are normal and their cochlear mechanics are not impaired.

So the end result here is that you have the perfect child to exemplify what deaf culture and the NAD tell us we should recognize, and that is that there are children who simply cannot learn to hear and speak with hearing aids. And if you cover your mouth and force them into auditory verbal therapy, they will fail. These children have been with us for centuries. We've gone to schools for the deaf and find that they exceed 10 percent of the population in schools for the deaf. They will not benefit from hearing aids in a sample of 100 children we followed. They do not learn language auditorially, but they learn language very well visually, either with signs, or lip-reading, or cued speech. Now, with the combination of cued speech and lip-reading or cued speech, signs, and lip-reading, these children do very well in learning language. And then if they are implanted, my colleagues are telling me -- and you should hear from Jon Shallop as he's there -- they do extremely well and they do sometimes much better than the ordinary run of a hearing-impaired child. Let me clarify why.

When one studies the temporal bones of deaf people, you can see an entire panoply of options. You can have no nerve fibers and not even a cochlear. You can have normal inner hair cells and not outer hair cells, normal nerve fibers, et cetera. There are many different combinations of things that can go wrong. And management, at least from the physiological point of view, therefore has to be different. From the sociocultural point of view, on the other hand, if you want someone to be a member of the deaf culture, they can adopt that from any of those positions. On the other hand, children with auditory neuropathy have a great deal of difficulty if they've lost all or most of their inner hair cells. In joining the hearing world, because -- If they're forced to wear hearing aids and go through auditory verbal therapy, the signal they get is not basically usable.

So, to summarize, I have to tell you that approximately 10 percent of children and probably more who are screened as being deaf, if they're screened only with ABR, might have normal otacoustic emissions. And these children don't benefit from hearing aids or traditional auditory verbal therapy until they're properly identified and then the auditory verbal therapy is the parent's choice if and when the children get implanted. If they're not implanted, we urge the families to consider visual languages, cues and signs, and our goal in helping parents make these decisions is to raise a literate taxpayer -- that is someone who can read, write, and make a living -- and their choice of culture and choice of language is a familial decision, but the access to spoken English is really blocked in auditory neuropathy for the most part.

That's all I really have. Thank you.

JUNE HOLSTRUM: Any questions for Dr. Berlin?

YUSNITA WIERATHER: Yes. This is Yusnita Wierather.

When [inaudible] these children with the auditory dyscrania [inaudible] otoacoustic emission, is that kind of -- there is a sense that will go away in one [inaudible] or, you know --

CHARLES BERLIN:

Yes. Actually, we have seen these children follow five or six different paths. They all have very large cochlear microphonics that represent normal hair cell function, but after time, their microphonics as well as their emissions disappear. Now, the use of hearing aids will destroy otoacoustic emissions if the hearing aids are strong enough. So if a child has normal emissions and someone puts hearing aids on them, it will actually destroy outer hair cell function.

Now, in our sample of 100 children with auditory neuropathy, seven of them seem to have outgrown some of the problems and have become quite auditory and quite verbal by themselves, provided they don't have hearing aids and they are just left alone to develop language. We're still not sure if they will continue through life to perform normally, but they're doing better than anybody expected. But all those children in our sample had histories of jaundice rather than prematurity. And therefore, the likelihood that they had lost hair cells is small, only that maybe the hair cells were disabled by premature deposits.

KAREN KIRK: Chuck, this is Karen Kirk. Could I ask a question about those seven? Of those seven children, at what age did they begin to show signs of outgrowing auditory neuropathy, and did they have any -- did those children differ in any way in terms of audiological testing or results from the other 93 that didn't show that?

CHARLES BERLIN: That's interesting. First of all, all the children who are outgrowing this in our sample, with one exception, continue to show an absent ABR. The outgrowth problem is reflected in their normal development of babbling, speech perception, and child language. Now, these are children who show this between four months and a year of age. And then by two years of age, they seem to be doing right up there with their peers.

KAREN KIRK: Okay.

CHARLES BERLIN: However, we've recently heard from some of these parents that the children seem to be plateauing -- or at least one of them that I know of is plateauing and mama is concerned that his ability to hear noise and his ability to follow conversations is not nearly normal even though his reception and his expression are said to be normal by the speech and language people they're working with.

So it's a -- you know, the jury is still way out on whether these are really recoveries.

KAREN KIRK: I see. Thank you.

UNIDENTIFIED SPEAKER: One last question. What unilateral [inaudible]?

CHARLES BERLIN: We have seen eight of them. They are written up in the literature, not by us alone, but by a number of other people. I can give you a reference if you need it, but the -- they are common. And the way to make the diagnosis is to compare, with every new diagnosis, to do tympanometry reflexes and emissions.

UNIDENTIFIED SPEAKER: Okay.

CHARLES BERLIN: And if your reflexes are absent and the emissions are present, you are very high at risk for auditory disyncrany.

Now, there is a paper by Conradson [phonetic] in 1996 Audiology on four children with unilateral sensory neural hearing loss and we have some similar experience.

HALLIE MORROW: Chuck, this is Hallie Morrow from California. And I have a question about the incidence of auditory neuropathy. I thought I heard you mention it, but what I heard didn't -- 10 percent of kids in a deaf school versus 10 percent of children screened?

CHARLES BERLIN: Ten percent of children in a deaf school that -- actually, we sampled about 1,100 children now, and we find about 100 children with signs of auditory otacoustic emissions. And 10 of those 100 have enormous emissions and the other 90 have compromised emissions but certainly emissions that don't belong there if they were profoundly deaf.

HALLIE MORROW: Right. But what about in the general population?

CHARLES BERLIN: In terms of children screened -- Well, no, this is only children who have been diagnosed as being deaf by ABR, approximately 10 percent will show normal emissions.

HALLIE MORROW: Okay.

CHARLES BERLIN: Now, if you use as your screening tool otacoustic emissions, you won't see these children.

HALLIE MORROW: So we don't really know what the incidence of auditory neuropathy is in the general population in terms of screening technology for a universal screening program?

CHARLES BERLIN: No. My prediction is we're going to see a lot of this and it will be caused by universal screening programs.

The other thing is that we are screening now all our central auditory disorder patients who come in with so-called CAPD and may be one in 20 or one in 30 who has no ABR and no middle ear muscle reflexes, and they have all kinds of diagnoses, but they really do have auditory disyncrany.

BRANDT CULPEPPER: Chuck, this is Brandt Culpepper at Galadet, and I was wondering what age group you looked at for the children in the school for the deaf.

CHARLES BERLIN: The ones that were residential schools we went through, I would say they ranged from about three up to adulthood.

BRANDT CULPEPPER: Okay. Because at Galadet, we've tested about 600 or 700 and we've only found two students with auditory neuropathy.

CHARLES BERLIN: That's about the large group. I'm sure those are the ones who have very large emissions, but if you looked at the ones that have two and three Db emissions sticking out over the noise backgrounds, those are the ones that we included in our sample because they also wore hearing aids for long periods of time. And we've also seen patients who lose their emissions altogether and they fall into a category you could never pick out and discriminate them from ordinary deafness. But I'm glad you found two, Brandt.

BRANDT CULPEPPER: Yes. One of them was an international student. And your 10 percent, to me, seems a little bit high with what we are seeing here.

CHARLES BERLIN: Again, it might be based on the criteria that you use and how you collected the emissions. Did you use distortion products or [inaudible]?

BRANDT CULPEPPER: We used both.

CHARLES BERLIN: And in a quiet room, I would presume.

BRANDT CULPEPPER: In a sound booth.

CHARLES BERLIN: Well, I'll be glad to show you the data that we used.

BRANDT CULPEPPER: Oh, I would love to look at it.

CHARLES BERLIN: To look at them, and you'll see that what we had to do was to set a criterion of a three Db noise floor. That is, if anything popped over three Db from the noise floor, we considered that a potential emission.

BRANDT CULPEPPER: On the first product or on the transient?

CHARLES BERLIN: Transient.

BRANDT CULPEPPER: Okay.

CHARLES BERLIN: And then -- a potential emission. And then we repeated that three times. And if we kept getting the same thing, we called that a hit.

BRANDT CULPEPPER: Okay. I would love to look at it.

CHARLES BERLIN: Okay.

JUNE HOLSTRUM: Thank you so much. Dr. Berlin had mentioned he had several references and he will be sending those to me and I will e-mail them out to all of you so you will have a list of references on this topic.

Let's go right on to Dr. Shallop and he's to talk about cochlear implants for children with auditory neuropathy.

Jon?

JON SHALLOP: Well, good afternoon, everyone. It's a pleasure to hear you. Well, we've implanted now 11 children with auditory neuropathy and we've also implanted three adults. And the bottom line on what we've seen with our cases is -- from a diagnostic point of view is very much what Chuck said and I won't reiterate any of that.

The first two children I want to highlight for the group -- Incidentally, as a reference, this information is published now in Laryngoscope in April of this year. And we published the results of cochlear implants in five cases with post-operative findings and progress, and beyond that, as I said, we've done a total of 11 children.

The children as a group, especially this first five group -- the first five children, because we have more data on them, have shown a remarkable progress, well in line with some of the things that Karen has said in terms of their development of their language and their overall speech perception, but a couple of things have surfaced that I want to call to your attention that were not anticipated.

Of the first five children, two of them have a motor apraxia that, of course, there was no way appraise that -- I mean, a motor speech apraxia -- and are being treated for it. Their language is progressing commensurate with the other children, but their motor speech development is somewhat delayed. Within the first 11 children, or a total of 11 children, we have four children that are siblings, that is, Case A and B and Case E and F are from the same family. Case A and B are from our local area and they are sister and brother and Case E and F are two sisters. And we are not pursuing that, but I know others are looking at the genetic aspect of this and some of these families have participated in those genetic studies, one at LSU and the other one at Boy's Town, and I am sure there are probably others going on as well.

Another thing I would like to mention in addition to the speech and language outcomes that we're seeing with these children -- and I don't distinguish from our other children other than what I have already said -- is that we see immediate restoration of the ABR, as well as in the cases where they've received an appropriate implant such as the Nucleus 24, we get neural potentials on these children. So, obviously, something has happened to restore neural synchrony, and I agree with Chuck's definition of that because that's what we're seeing. We're following -- As an aside here, one of the adult cases, which has also been examined recently by Dr. Starr, does appear to have a real auditory neuropathy, because we see some unusual findings in the auditory brain stem response as well as in the eighth nerve potentials that we get binaural response telemetry. So we're looking at that case very carefully to see if we can discern what the implications of that might be. From a hearing point of view, she and the other adults are doing very well. So that doesn't preclude speech understanding in this case. On sentence scores, she's getting 90 percent plus on open sentence recognition which is typical of the other adults.

So, to summarize, what we've been seeing with the cochlear implants in our cases of auditory neuropathy is that they are performing at a level commensurate with other children who don't have auditory neuropathy of the same age and age of implant. And I didn't go into the details of the age at implant, but all of that is in the article that I mentioned.

Any questions?

KAREN KIRK: Jon, this is Karen Kirk.

Did these children with auditory neuropathy demonstrate any detection to sound in the sound field before they got a cochlear implant?

JON SHALLOP: Thank you, Karen. Yes, they did. And that hearing detection varied. For the most part, these children were in the severe-profound range, but it was very typical of them to show sound detection. And the interesting thing was, in cases where you would expect them to get good benefit from amplification, as Chuck described earlier, they did not. And all of the children had trials with hearing aids. The typical response of these kids is they don't like their hearing aids.

KAREN KIRK: Right.

JON SHALLOP: One little child told us, she said, "It sounds like I'm listening to rain," which really reminds me of that demo that Fang Yang has developed.

KAREN KIRK: Right, right. We have a patient who has been identified as auditory neuropathy, but he seems to show detections in the moderate -- he's not acquiring language, but he shows detection at 40, 50. And have you seen anything like that and what would you do with a patient like that?

JON SHALLOP: Well, that's a fascinating question. The two sisters I mentioned, the first one that we implanted, she was about age four. Her sister was about two at the time we implanted the older one. She had a severe to profound loss and was very typical of what I described. However, her sister who also has auditory neuropathy had much more hearing. She was around 50 Db. And we were wondering if she was going to improve, so we put off any consideration of an implant and watched her speech and language development. And we tried hearing aids with her. Even with a 50 Db loss, she wouldn't tolerate amplification. And her parents got more and more frustrated, as did her educators --

KAREN KIRK: How old was she, Jon?

JON SHALLOP: She was two when she was diagnosed, because she was identified -- well, the minute her sister was identified when she was four, then we tested the younger one --

KAREN KIRK: I see.

JON SHALLOP: -- who had -- who obviously had more residual hearing. And she had -- she had more speech and language -- she had more oral communication than her older sister, which is kind of interesting, but she didn't progress. So she received a cochlear implant at about age three and she's making good progress now.

KAREN KIRK: Okay. So you've followed her for about a year?

JON SHALLOP: Yeah. We were very cautious on that one. We didn't jump into that one too soon.

KAREN KIRK: Okay. Thank you. That's very helpful.

CHARLES BERLIN: This is Chuck. I would like to just ask my audiology colleagues out there if you have found that you need to follow the audiogram in cases like this or the physiology? We are asking our people to follow the physiology rather than the detection audiogram.

JON SHALLOP: Well, we do both, but I agree with you, Chuck, it's very important to follow the ABR, reflexes, emissions, et cetera.

JUNE HOLSTRUM: Thank you, Jon. If you could send me that complete reference of the article you were talking about, I can add that to the list that I'll be sending out. Also, Karen, if you have some particular references that --

KAREN KIRK: I could send you some, sure.

JUNE HOLSTRUM: I will add that to the list as well and send it out to everyone. This is certainly a topic we could spend a lot more time on, very fascinating.

Our next speaker is Barbara Raimondo, and I've asked her to talk a little bit about some of the other issues that a parent might want to consider when they're trying to make a decision as to whether to implant or not to implant.

So go ahead, Barbara.

BARBARA RAIMONDO: Thanks, June.

First, I want to talk a little bit about ASDC, the American Society for Deaf Children, for people who aren't really familiar with us.

ASDC is a parent-run organization comprised of families and professionals who advocate for full communication access for deaf and hard-of-hearing children. ASDC was founded in 1967 to provide support and information to parents who chose to include signs in their communication with their deaf and hard-of-hearing children. And I'm sure a lot of you are aware that it was around this time that people started using total communication and that term was becoming popular.

ASDC children use a range of assistive technology, including hearing aids, cochlear implants, [inaudible] systems, captioning, and more. Their use of sign language varies, including the use of signed English, American Sign Language, and sign-supported spoken English. ASDC children are found in all educational settings, including local schools, regional programs, and day and residential schools for the deaf.

ASDC sees deaf and hard-of-hearing adults as their own deaf and hard-of-hearing children grown up and values the knowledge and advice these individuals have to share. ASDC has a toll-free number for parents, and I'm the person who gets those calls. So I have had quite a number of conversations with parents of newly-identified children and other parents considering an implant for their child. And very often they really struggle with this decision. You know, they find it very difficult. The whole idea of having a deaf child is new to them and they are receiving all sorts of advice from all sorts of people. Some of the advice is helpful, some of it is not correct, and a lot of times they are told that they have to make decision about this soon. So they're in a quandary very often over what they should do. And I've come up, along with some help from my colleagues on the ASDC board, some questions that we would ask parents to think about as they're making this decision based on what we've seen and what we've heard from parents.

And the first question that I want to talk about is the idea of a meaningful trial with hearing aids, and I know that every cochlear implant center will say, oh, yeah, of course, we wouldn't do a cochlear implant without a hearing aid trial first, but I would also caution you that it should really be a meaningful trial. If we think about young children and hearing aids, constantly pulling them out, they outgrow their ear molds very quickly, they get a lot of the whistling anytime they're in their high chair or their car seat and various places or if they're being held by a parent, and it's kind of difficult to really know what the parameters are of what they are hearing. We know that pediatric audiology is an inexact science. So it might be kind of difficult to ascertain how much benefit they get from the hearing aids. So we would encourage parents to really give some thought about that and be very cautious about what they're looking at and what conclusions they draw based on a hearing aid trial.

Another question that obviously has to be looked at is how much therapy is necessary and how much time is the parent able and willing to devote to it in light of their family responsibilities. We all know that the ability to interpret the sounds coming through an implant doesn't come automatically and it requires a large time commitment by parents and professionals both at home and in the professional therapy room. And it's interesting, I've heard about -- Excuse me, thank you. I've heard recently, in fact, a couple of comments about this professional sort of looking -- kind of a negative remark about a parent saying, oh, well, they thought this was going to be a hobby for them, and then I've heard from parents feeling like, oh, gee, if we had known it was this difficult, it might have made a difference in our decision. So that whole idea of what's the therapy time and what the therapy involved really has to be looked at.

And then something else that's really important is what is the parent's definition of success for the implants? I mean, what will it take for them to feel like this was really a successful thing and what will they do if that version of success isn't achieved and what is their time line to achieve this success. So that might be something for them to think about because they may also want to be considering other options at the same time.

Something else that is very important to our organization is how much the parents know about the deaf community. Deaf culture is rich and vibrant, and a lot of people who are deaf have professional-level jobs and very satisfying personal lives regardless of whether they use of any kind of technology, hearing aids, or implants, or no hearing technology at all. And a lot of parents of newly-identified children really are not aware of this, and I know I could certainly speak for myself when I say that the very first question I had after I found out my daughter was deaf, what do deaf people become when they grow up. I had never met a deaf adult in my life. So very often parents really don't have this opportunity and that could have an impact on the decision that they make.

Something else that parents often think about is, is it possible for the child to use sign language and maintain a deaf culture identity and use the cochlear implant? We've heard of programs that really discourage parents from using sign language with their child, but we know other families who really find that approach beneficial. So that would be something for them to look at, and some families think they automatically understand or appreciate the idea of their child having a connection with the deaf community and other parents feel, no, that doesn't seem like it would really work with our family. But the idea that there could be a combination should also be explored.

And another really important factor in all of this is the influence of the media and what we call implant miracles, you know, these -- the media sort of likes to tell that kind of thing. You know, they like to have a very dramatic story, but we know that the stories aren't always quite so dramatic, and also how much influence and how much pressure is there for medical professionals and family members and friends of the parent. Parents do report feeling pressured to choose this because people in the mainstream sort of have this attitude, well, gee, if your child is deaf, why wouldn't you make your child hearing. But those of us who work with deaf children and their families and are little bit more familiar with this technology know that that's not quite -- the answer is not quite that simple, that the decision is really a serious one and an individual one and all the facts really need to be taken into account, not -- you know, it shouldn't be made under pressure or under the idea that there's going to be some kind of miracle involved.

Obviously, this is a very big topic and I could go quite -- on quite a long time, but I know that we're really low on time, but I just wanted to close with a statement -- I guess ASDC's advice to professionals, you know, just a nutshell of advice. ASDC believes that medical, hearing health, and educational professionals serving deaf children and hard-of-hearing children and their families have a responsibility to be informed about the successes of deaf persons from all walks of life, including those who use American Sign Language as their primary language and those who do and do not use cochlear implants, to recognize the benefits of early language, including sign language, and work to ensure that deaf children's language development, whether signed, spoken, or both, progresses at a rate equivalent to that of their hearing peers. And professionals have a responsibility to refer parents to a wide range of information sources, including deaf individuals, families with deaf and hard-of-hearing children, schools for the deaf, and local, state, and national parent and deaf adult organizations. And I'll be happy to answer any questions.

JUNE HOLSTRUM: Any questions for Barbara?

JON SHALLOP: Yes, I have one. This is Jon Shallop in Rochester, Minnesota.

Could you tell us what is the cost of educating a child today -- a deaf child in a traditional state school for the deaf, on average, in the United States?

BARBARA RAIMONDO: I don't really have that number, and I'm sure that that would vary quite a bit from state to state and also depending on whether the child was there residentially or as a day student, and also depending on what else the child needed. Because very often we find that schools for the deaf are used kind of very, very selectively in that the state policies discourage school districts from placing children in a school for the deaf until they have severe language delays or unless they have multiple disabilities. So, obviously, a child in that kind of situation would require more services and the cost would be higher to serve the child versus the child who came into the school at a young age with full language and full -- the general curriculum in the very beginning.

JON SHALLOP: If I could do a follow-up question, and it relates to the same topic, about what are the current findings about language and reading skills of children who grow up learning American Sign Language?

BARBARA RAIMONDO: Well, the studies that are on deaf children from deaf families show that they do better than deaf children from hearing families, and the theory is that they are surrounded with language from birth, that deaf families tend to accept the child as being a normal child and not somebody with a handicap. So those children do tend to do a little bit better than deaf children from hearing families.

JON SHALLOP: But how do they compare, say, to normal hearing children or children with hearing aids or cochlear implants?

BARBARA RAIMONDO: Well, now, that I don't really know, but all I can really talk about is -- because I'm not a researcher, so I don't have all the research at hand, but I can certainly talk from personal experience, what I see with the children that I see who have deaf parents and who do have a fluent language model using American Sign Language. I don't know. I don't have an exact number for you. I'm sorry I'm not able to quote a statistic, but they certainly -- I don't know. I guess the one that comes to my mind is with my own child, which is not really what you're asking. But I'm sorry, I don't have the exact statistics.

JON SHALLOP: Okay, thank you.

JUNE HOLSTRUM: Any other questions?

UNIDENTIFIED SPEAKER: I just have a question of, do you know what the rejection rate is for cochlear implants?

BARBARA RAIMONDO: I'm sorry. What do you mean, rejection rate?

UNIDENTIFIED SPEAKER: Well, not -- just the physical rejection of the implants that have been put in and the body itself rejects them. We have a child that that was the case, that they had the implant and for some reason the body would not accept the implant. But I had also done some research and was looking for cochlear implants for another family that was interested and came upon some letters that that cochlear implant adult felt like it was such a big push for the family, that the parents wanted them to hear so much, that they became -- that when they became adults, they just took the implants out.

KAREN KIRK: In response to your first question -- This is Karen Kirk -- we have implanted somewhere between 400 or 500 patients at our center. Our implant program has been ongoing

since the last 1970's and we have never had a patient which body rejected the implant as a foreign substance. So I've never -- it's highly unusual.

BARBARA RAIMONDO: As far as the second one about students -- or young adults, as they get a little bit older, not using it anymore, again, I don't have any statistics on that, but what I have seen from people who I have met is that sometimes they do go through a stage of just taking it off completely and sometimes it stays off. Sometimes they put it -- they decide later, oh, I kind of like it after all and I'll use it sometimes. So it really -- there's some variation. And again, I don't really know the numbers, and I would be very surprised to know if there would be any research on that at all.

UNIDENTIFIED SPEAKER: That would be interesting.

KAREN KIRK: I would like to commen. And again, this is anecdotally as well. Our experience is that sometimes teenagers may not want to wear their cochlear implant for cosmetic reasons or perhaps for peer pressure from others who encourage them not to. Typically, the ones who choose not to use it are those who are getting less benefit from it. The children who get a great deal of auditory information and rely on that, we rarely see those teenagers take the cochlear implant off.

UNIDENTIFIED SPEAKER: Okay, thank you.

JUNE HOLSTRUM: We are a little bit over time and that's okay. We haven't been cut off yet, so we can continue until we are. I want to thank our speakers and all of our listeners. That is our program for today. Our next meeting will be on September 4th, and thank you again for joining and we'll talk to you in September