



RESEARCH AT GALLAUDET

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Spring 2000

Gallaudet Forum Addresses Cochlear Implant Issues

By Robert Clover Johnson

On Friday, March 24, 2000, approximately 50 individuals from units all across the Gallaudet campus assembled in the Gallaudet University Kellogg Conference Center for a day-long "Cochlear Implant Campus Forum." This forum resulted from grassroots efforts to bring faculty and staff interested in cochlear implants together for information sharing and discussion of possible future collaborations. Identification of participants and planning were coordinated by Dr. James Mahshie, chair of the Department of Audiology and Speech-Language Pathology and member of the Clerc Center Task Force on Cochlear Implants and Debra Nussbaum, a Clerc Center audiologist and chair of the same task force. Support for the event was provided by the Graduate School and Research, the Laurent Clerc National Deaf Education Center, and the Department of Audiology and Speech-Language Pathology. Mahshie opened the forum by saying the day would be devoted to increasing awareness of a broad range of ongoing cochlear implant-related activities at Gallaudet and would aim to help define the role Gallaudet must play in addressing the complex issues raised by the ever-increasing use of cochlear implants nationwide.

Cochlear Implants and Gallaudet

Dr. Mahshie said that although the technology of cochlear implants would not be the focus of the day's discussions, it was important that everyone have some orientation toward the technology and the current extent of its use. He said that although experiments began as long ago as the 1950s, the first studies of the efficiency and safety of implants did not begin until the early 1970s. At first, only single-electrode devices were implanted. In

recent times, more refined 22-electrode devices have become the norm. Efforts are ongoing to find ways to encode incoming speech signals so implant recipients can hear more

See Cochlear Implants on page 5

INSIDE: Focus Group Discusses Standards of Health Care for Deaf and Hard of Hearing Adults, page 11.

You Say Tomato . . .

Sociolinguistic Variation in American Sign Language

By Sara Gerhold, 1999-2000 Walter Ross Fellow

No two speakers of a language speak exactly the same way; nor does any individual speak the same way all the time. For example, we often see variation in the vocabulary (lexicon) of a spoken language, some speakers of English using the word *soda*, while others say *pop* or *soft drink*. Similarly, in American Sign Language (ASL), there are many signs for the concepts BIRTHDAY, PICNIC, or HALLOWEEN.

For a number of years, sociolinguistic variation in ASL has been the subject of a research project in Gallaudet's Department of ASL, Linguistics, and Interpretation. This study is being undertaken by a team of researchers led by

principal investigator Dr. Ceil Lucas and has been funded by two consecutive grants from the National Science Foundation since 1994 (grant numbers 93110116 and 9709522). Results of this study will help linguists determine what aspects of variation characterize all kinds of human language and what aspects are characteristic exclusively of spoken languages or of signed languages. On a more practical



Ceil Lucas

level, results will also help educators, interpreters, and service providers become more aware of the variations they may encounter in the signing of deaf students and clients.

Why Variation Occurs

Variation in languages, Lucas says, can occur either as a result of factors internal to the language itself (such as pronunciation modified by the production of adjacent sounds or signing affected by the location of adjacent parts of signs) or as a result of such personal factors as the speaker's or signer's socio-economic class, gender, ethnic background, geographic location, occupation, sexual orientation, or age. Lucas describes the latter as "external factors," since the resulting variations are a product of *who* is speaking or signing, rather than of the internal

Continued on next page



TOMATO: Assimilated ASL sign with "1" handshape on both hands.



TOMATO: Widely used non-assimilated form with non-dominant hand in "O" handshape.



TOMATO: Variation found among black, middle class females in New Orleans.



TOMATO: Variation found among black and white, male and female informants in both Boston and New Orleans.

Figure 1. Variations of TOMATO¹

mechanics of language production. Sometimes variation occurs for *both* internal and external reasons. An example of an internal constraint in spoken language would be the deletion of the sound [t] or [d] in a word preceding another that begins with a consonant, as seen in the word "mist" in the following sentence: "The mist covered the city." This type of phonological deletion is seen less in words that precede others beginning with a vowel as in "mist over the city." An example of an external factor affecting spoken language would be those regional differences seen between the accents of people who live in the south and those who reside in the north.

Two basic theoretical questions inspired Lucas' project: (1) Can *internal* constraints on variation such as those defined and described in spoken languages be identified and described for variation in ASL? and (2) Can the *external* social factors on variation such as those defined and described in spoken languages be identified and described for variation in ASL?

Lucas believes it is important to find answers to these questions for two reasons. The first is simply to begin to describe the nature of variation in sign languages, at all levels of structure. The second is to compare this description to what we know about variation in spoken languages—to therefore be able to contribute to what is known about variation in human language in general. Sociolinguists also hope that by comparing variation in sign languages and spoken languages they will be able to tell whether variation in sign language is characterized by unique features *not* found in spoken language variation.

To find answers to these theoretical questions, it was clear that a large amount of videotaped data would be needed, specifically of conversational ASL. The re-

searchers wanted a collection of videotapes representative of ASL as it is used in the United States today, representative of different regions, ethnicities, ages, genders, and socioeconomic levels. The sample also had to be large enough to permit the kind of quantitative analyses that have been so valuable in the examination of spoken language variation—such analyses require large numbers of examples of specific variations.

To create a representative ASL videotape collection, seven sites in the United States were selected: Staunton, Va., Frederick, Md., Boston, Ma., Kansas City, Mo. (and

Research at Gallaudet is available free of charge. Address postal inquiries or comments to *Research at Gallaudet*, Gallaudet Research Institute, Gallaudet University, 800 Florida Ave., NE, Washington, DC 20002. Phone: (202) 651-5995 (V/TTY). Readers may add or update their mailing address or comment on articles at the following e-mail address: gri.offices@gallaudet.edu. Mailing addresses can also be added or changed at the website: <http://gri.gallaudet.edu/mailling.html>. Contributing to this issue were Robert Clover Johnson, Editor; Sara C. Gerhold, 1999-2000 Walter Ross Fellowship recipient; and Carol Traxler, GRI research scientist. Special thanks are due to Ms. Debra Nussbaum, Dr. James Mahshie, and Dr. Ceil Lucas for their advice concerning articles in this issue and to Sue Hotto for the graphics on pages 9 and 10.

Thomas E. Allen, Dean
The Graduate School and Research
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¹Drawings in Figures 1 and 2 by editor Robert C. Johnson, modeled by author of article, Sara C. Gerhold.



EARLY: Citation form ASL



EARLY: Variation found among working class black males aged 15 to 25 in Kansas City.



EARLY: Variation found among middle class white males over age 55 in Washington state.

Figure 2. Variations of EARLY

Olathe, Ks.), New Orleans, La., Fremont, Ca., and Bellingham, Wa.. All of these sites have thriving communities of ASL users. In addition, Staunton, Frederick, Boston, Fremont, and Olathe are the sites of residential schools for deaf children, all with long-established surrounding Deaf communities.

In each site, ASL users in three age groups (15-24, 25-54, 55 and up) and in two socioeconomic groups (middle class and working class) were videotaped in natural conversation. In-depth interviews were done with a subset of each group, with questions relating to language use in the family, educational, work, and leisure situations. A total of 207 ASL users participated in the project; the Boston, Fremont, New Orleans, and Kansas City sites included both white and African American signers; the Staunton, Frederick, and Bellingham sites included only white signers. Researchers studied several areas of variation in ASL, including syntax. Due to limitations of space, the rest of this article will only focus on the variation found in ASL phonology and vocabulary.

Phonological Variation

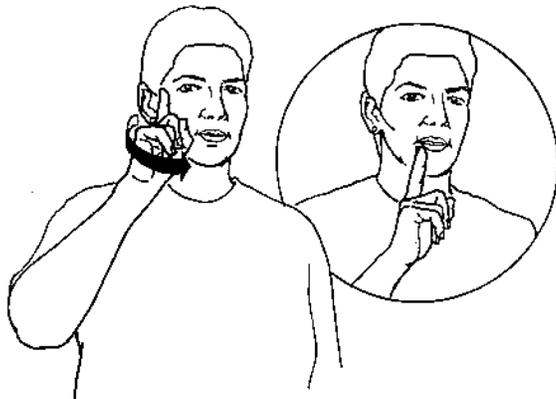
In simple terms, "phonology" refers to the segments of speech or signing that are combined to make words or signs. Often, speakers of a language alter their phonology to suit a particular situation without even realizing it. Many large-scale studies have been undertaken on variation in spoken languages, such as the work done by American sociolinguist William Labov. In *Socio-linguistic Patterns* (1972, Philadelphia: University of Pennsylvania Press), Labov examined the pronunciation of words such as *car* and *park* in New York. New Yorkers sometimes pronounce an [r] in these words, and sometimes do not. Although Labov was unable to tell which specific words were likely to be pronounced with [r], and which without, he found that he could predict the percentage of [r] sounds each socio-economic class and each age group would use in any given type of speech.

As was suggested earlier, in spoken English, speakers often delete the final consonant in words that end in clusters of consonants, such as *test*, *round*, or *past*, the result being *tes'*, *roun'*, and *pas'*. In ASL, an example of phonological variation can be seen in signs such as BORED or DEAF, usually signed with a 1-handshape (index finger extended, all other fingers closed) but sometimes produced with both the index finger and the pinky finger extended.

Lucas' project has concentrated on the study of three specific phonological variables in ASL. These variables were chosen because they occurred frequently in the data. The first target variable involves the sign DEAF, which in "citation form" (the form of the sign that appears in dictionaries and is taught in sign language classes) is signed from ear to chin. This sign is variable, in that it can also be signed from the chin to ear or as a contact on the cheek. (See Figure 3 on page 4.) The second target variable is a class of signs exemplified by the sign KNOW, signed in citation form at the level of the forehead but produced also at locations on the cheek or even in the space in front of the signer. The third target variable being analyzed involves signs with a 1-handshape, that is, index finger extended and all other fingers and thumb closed. 1-handshape signs exhibit considerable variation and may be produced with the thumb open, thumb and all fingers open, and so forth.

Originally, the researchers hypothesized that the variation observed in all three of the above-mentioned variables could be explained by phonological factors, that is, characteristics related to the location or handshape of the signs preceding or following the target variable. However, an analysis of almost 10,000 examples of the three target variables (1,618 for DEAF, 2,862 for the location signs, and 5,356 for 1-handshape signs) has shown that while phonological factors do play some role, the major factor in explaining the variation is grammatical function.

Continued



DEAF: Citation form, ear to chin.

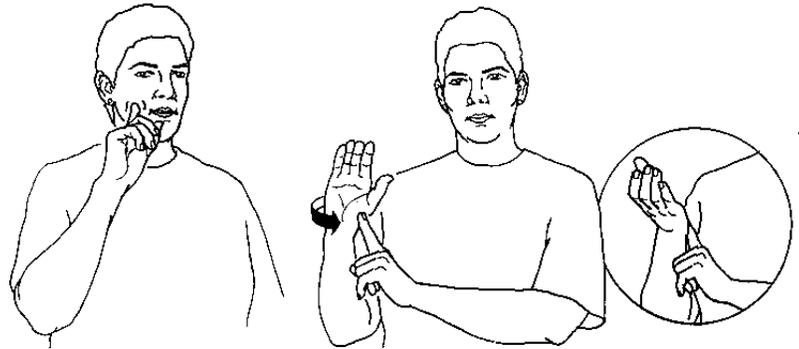


DEAF: Chin to ear variation.

Figure 3. Variations of DEAF²

Grammar involves items such as adjectives, nouns, verbs, and predicates which have specific functions in a sentence. A predicate is the part of the sentence or clause that expresses something about the subject. It regularly consists of a verb and may include objects, modifiers, or complements of the verb. The predicates of the following simple sentences are enclosed in brackets: *The house [is white]. The man [hit the dog].* Project researchers have discovered that the sign DEAF can function as an adjective, as a noun, or as a predicate. Non-citation forms, such as chin to ear or simple contact at cheek, are much more likely to occur when DEAF is a simple adjective, as in DEAF CAT, or the adjectival part of a compound sign, as in DEAF^CULTURE, while citation forms are much more likely to occur when DEAF is a predicate adjective, as in the ASL sentence PRO.1 DEAF (in English: *I [am deaf].*).

The research team has also discovered that citation forms tend to be favored when signers produce signs always identified with specific locations on the body



DEAF: Contact cheek variation, preceding CULTURE.

(called “location signs”), but this is especially true with verbs. For example, although the sign KNOW has variations, it still, more often than not, is produced at the forehead. On the other hand, in the case of function words such as prepositions and signs that move down and away from the body like WHY or FOR-FOR, non-citation forms tend to be favored.

Project results indicate that third person pronouns and content signs (i.e., nouns, verbs, and adjectives) tend to be produced with the 1-handshape in citation form, index finger extended and all other fingers closed. First person pronouns, however, tend to be produced in non-citation form (often with the thumb extended) and second person pronouns are signed in citation form roughly half the time.

The researchers found many intriguing correlations between sign language variation and social factors. For example, older signers consistently preferred the citation form of location signs, while middle-aged and younger signers preferred non-citation forms. Young and middle-age signers in six of the seven sites preferred the non-citation forms of DEAF (chin to ear and contact at cheek), while signers in all age groups in Boston preferred the citation form (ear to chin).

It is widely accepted that for spoken languages, phonological factors account for sociolinguistic variation more than grammatical factors, even though the latter do play a role in spoken language variation. Preliminary results of this project, however, suggest that in ASL, variation may be more dependent upon the *function* of a particular sign—that is, if the sign is a predicate, then its citation form is most likely to occur. This is contrary to what the researchers expected to find and they are currently investigating why this may be. Sign languages clearly exhibit sociolinguistic variation, just as spoken languages do, but the details of the variations and what prompts them may indeed be different.

Lexical Variation

During the last part of each videotaped interview, participants at all seven sites were shown the same set of pictures to elicit vocabulary or “lexical” signs. Earlier studies have shown nouns to exhibit the most lexical

²Drawings in Figure 3 by Lois Lehman-Lenderman, modeled by MJ Bienvenu.

variation, particularly in signs for food and animals. The 33 stimuli used in this project included 25 nouns (9 for food, including TOMATO, Figure 1), 4 for animals, 4 for clothing, 3 relatively new technological signs (COMPUTER, MICROWAVE, and RELAY), 2 signs for geographical locations, and 3 abstract nouns, 6 verbs, 1 adjective, and 2 adverbs. The responses are now being analyzed to determine the distribution by region, age, and socioeconomic class.

Project researchers are still attempting to determine the extent to which different signs with similar meanings have developed independently or as phonological variations of one basic sign. They are also searching for evidence of phonological change in progress. Earlier research has shown that signs once produced with two hands evolved into one-handed signs and signs once produced on the face later were produced on the hands. Researchers would like to know what kind of light this project's data sheds on such earlier findings. They are also interested in determining whether or not most lexical variation occurs in nouns, as is generally expected.

Finally, researchers are studying lexical innovation, as with the signs for JAPAN and AFRICA. Currently, at least two signs co-exist for each, one an older ASL sign and one an innovation. Researchers hope the project's data will tell more about the adoption of newer signs by the Deaf community.

Conclusion

The final report of Lucas' project will be published in 2001 by Gallaudet University Press in the form of a book titled *Sociolinguistic Variation in ASL* (volume 7 in the *Sociolinguistics in Deaf Communities* series, of which Lucas is the editor). In addition, a final goal of the project is the preparation of a videotape and accompanying manual, designed to provide an introduction to sign language variation. The audience for these "community materials" will be residential schools for the deaf, undergraduate deaf studies programs, training programs for teachers of the deaf and for sign language interpreters, and the community at large. It is hoped that both the publication and the community materials will serve as models for investigation of sociolinguistic variation in sign languages around the world.

For more information regarding this project, please contact Dr. Ceil Lucas, Department of ASL, Linguistics and Interpretation, Gallaudet University, 800 Florida Avenue NE, Washington, DC, 20002, or at ceil.lucas@gallaudet.edu.

Note: Collaborators in the data collection for this project include Clayton Valli, Susan Schatz, Ruth Reed, and Leslie Saline. Collaborators on the analysis include Robert Bayley, Mary Rose, Alyssa Wulf, Paul Dudis, and Laurie Sanheim.

Cochlear Implants, Continued from page one.

decipherable sounds. The three primary manufacturers of cochlear implants today are Nucleus, Clarion, and Med-El. Nucleus currently produces the majority of implants and has alone implanted 26,000 patients worldwide, 13,000 of those in the U.S. Of the American recipients, half are

adults and half are children.

Children are increasingly being implanted in infancy. Mahshie said that although recipients do not thereby have normal hearing, the technology has demonstrably helped people—when combined with extensive practice and training—to identify and discriminate speech. He said that more and more deaf children are entering educational programs with cochlear implants and that,



James Mahshie

beginning in the not so distant future, the population from which Gallaudet has traditionally recruited new undergraduates will include vastly increasing numbers of students with implants.

Mahshie said that although Gallaudet has not been involved in the development of implant technology, the university is playing an increasingly important role in addressing the following unresolved issues:

- ! the ethics of implanting children,
- ! the role of sign language in families with implanted children,
- ! the optimal way to educate children with cochlear implants, and
- ! how best to advise parents concerning cochlear implant options and optimal use.

He said that the subject of sign language use with cochlear implantees is controversial because the notion that sign language may still be needed after implants are activated does not match everyone's expectations or wishes. The optimal role of sign language for implantees consequently needs to be studied more thoroughly at Gallaudet.

Mahshie said it is important for Gallaudet as an institution to take a "thoughtful, active approach" in determining the educational, psychosocial, and linguistic needs of students with implants. He said Gallaudet must conduct research to determine the optimal levels of adjustment that can be expected and aim as an institution to help ensure that those levels are reached by incoming implanted students.

The Impact on Families with Implanted Children

Dr. John Christiansen of the Department of Sociology then presented preliminary findings of an ongoing qualitative study of families with implanted children. Christiansen said that two years ago he was awarded a Gallaudet Research Institute (GRI) Priority Grant to



Julia Wells and her father Steve Wells with Dr. John Niparko (right) who performed Julia's implant surgery at Johns Hopkins University Medical Center. Julia was 18 months old when this picture was taken—the day her implant was activated.

interview parents of children with implants and thereby learn more about the impact of implants on recipients and their families. To find subjects, he was allowed to add a question concerning willingness to be interviewed to a special GRI survey sent to parents of nearly 2,000 children nationwide identified by the GRI's Annual Survey of Deaf and Hard of Hearing Children and Youth as having cochlear implants. Of the 439 responses to the survey, positive responses to this question, plus e-mail inquiries based on cochlear implant-related Internet sites, enabled Christiansen to arrange interviews with parents from 57 families all over the U.S. He said that he and co-investigator Dr. Irene Leigh (Psychology Department) are currently developing this interview material into a book.

Each interview, Christiansen said, was 90 minutes long. The interviews were audiotaped or videotaped and the tapes have now been transcribed. Parents were asked how and when their child's deafness was identified and about the kinds and quality of information they initially received concerning deafness. They were asked about conflicting advice, whether or not most information came from medical practitioners, and whether or not they received advice from the deaf community. They were asked about hearing aid use and about who was involved in the decision-making process that led to getting a cochlear implant. They were asked how they selected an implant center and about insurance coverage. They were asked about the child's initial and subsequent reactions when the implant was activated, about apparent audio-logical changes, about communication used with the child, and how communication mode was determined. Parents were asked about the extent of post-implant time and effort they devoted to helping the child understand and acquire speech and whether or not they felt, in the long run, that they had made the right decision in getting the implant.

Christiansen said that he and fellow researchers are currently using a software program to code aspects of the responses given during the interviews. Though a year or more will be required before a definitive report can be issued from the study, he presented the following preliminary, over-all impressions:

1. Hearing parents had been upset over their child's deafness, but the deaf parents interviewed had been more accepting of their child's deafness. (Deaf parents saw the implants as giving their deaf child some advantages rather than as repairing a calamity.)
2. Parents continued to see their implanted child as "deaf" with audition added by the implants.
3. Parents would be disappointed but would be accepting if the child stopped using the implants.
4. Parents did not strongly object to signing with their implanted child.
5. Parents have generally not appreciated negative comments made about implants and their choice to get one by members of the deaf community.
6. Parents went through considerable soul-searching before having their child get an implant.
7. Parents experienced many hassles with insurance companies.
8. Results were generally discouraging in the first year after the device was implanted.
9. Many parents wish their child had been implanted earlier.
10. Parents were generally motivated by hope that an implant would help give their child a better future.

Christiansen cautioned that these results were not from a truly random sample, so they can't be considered fully representative. He said that of the 57 families represented in interviews, most of the implanted children were still using their implants at the time of the interview.

Mental Health Issues

Dr. Lauri Rush of Gallaudet's Mental Health Center (MHC) presented on a collaborative relationship between the MHC and the Listening Center (LC) at the Johns Hopkins University Medical Center. She said that Dr. Barbara Brauer, Executive Director of the MHC, sought out Dr. John Niparko, head of the LC, more than a year ago. Cognizant of present day reality that cochlear implants are here to stay, that several Gallaudet students are already implanted, and concerned about many requests for a support group, Dr. Brauer suggested that the MHC and the LC establish a cooperative relationship. Niparko agreed to the offer, which has resulted in several interesting visits to Johns Hopkins by MHC staff, Gallaudet faculty, and graduate students. Similar visits will occur in future semesters.

Rush said that during those visits, Gallaudet visitors learned about Johns Hopkins' medical staff, equipment, surgical procedures, and pre- and post-operative care of

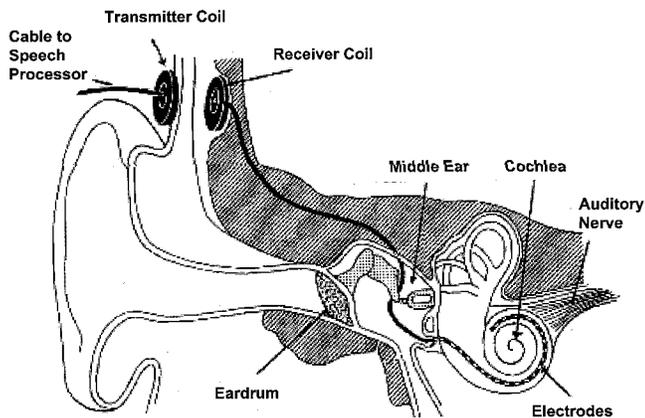


Figure A. Diagram of Ear with Cochlear Implant. Speech signals are sent from a speech processor to a transmitter coil, then from a receiver coil to an array of electrodes in the cochlea that can stimulate the auditory nerve.

patients, most of whom are children. They learned that Hopkins staff had been encouraging parents to use sign language with children prior to getting implants, but had not always done so after implantation. During meetings with LC staff, Gallaudet visitors have had the opportunity to urge Hopkins not to discourage sign language use after implantation, saying that a visual language approach would help ensure that young children in particular would not miss language input during a critical period for language acquisition. They urged that both sign language use and attendance at residential schools be retained as options after implantation and that these options, if taken, should not be seen as signs of the failure of the implants.

Rush said that as a result of these ongoing exchanges, staff at the Learning Center are now referring some prospective and post-operative implant recipients to the MHC for psychological assessment and counseling. Also, LC directors have come to understand that they need to hire more staff who are proficient in sign language. The MHC has set up two support groups for Gallaudet students and members of the deaf community who either have implants and are struggling with identity issues or are considering getting implants and need more information. Information gleaned from working with LC staff is integral to this group process.

Dr. Allen Sussman, a professor in the Counseling Department's Mental Health Program, reported that statistics on ever-increasing numbers of students with implants entering school systems nationwide have prompted the department to incorporate more information about implants into its curriculum. Faculty and students have visited Johns Hopkins' LC to learn about the devices, the surgery involved, and the medical perspective toward deafness. Counseling graduate students—many of whom are deaf themselves and some of whom have implants—have strong feelings on the subject, some negative, some positive. The department has deliberately invited presenters with varying views to talk to students so

they will be able to understand all perspectives and work with people whose views may differ from their own. Sussman pointed out that in his private practice as a mental health counselor, he is beginning to work with deaf people with implants who are struggling with identity issues and fear rejection by the deaf community. He said that the medical community needs to be aware that adjustment to implants involves not only arduous work to increase speech recognition, but also work in the inter-personal arena to increase the patient's mental health. He said that more needs to be known about deaf people who have adjusted well to having implants, so that this information can be shared with troubled implant recipients.

Cochlear Implants and Deaf Culture

Dr. Benjamin Bahan, chair of Gallaudet's Department of Deaf Studies, said the issues surrounding implants affect him profoundly, since he is not only deaf, but also the father of two deaf children. Conflicting perceptions about implants, he said, have put the deaf community and the medical community on an apparent collision course for many years, but he added that this appearance of opposition may be the result of misconceptions about implants. When implants are seen as being capable of changing deaf people into hearing people, members of the deaf community naturally see them as threats to their cultural identities. When viewed as devices that can help make the hearing world more accessible to deaf people, however, implants appear more like hearing aids, devices which deaf Americans, by and large, have come to accept. Bahan pointed out that deaf people are as interested as anyone in participating in what might be called "hearing culture"—reading books, going to movies, etc.—so the two cultures in fact always overlap in deaf people's lives. If deaf children with implants are allowed to use sign language and maintain contact with other deaf people, then implants may be seen simply as helping them enlarge their scope of awareness without destroying their identities as deaf people.

Audiology and Speech-Language Pathology Department Defining its Role

Susanne Scott of the Department of Audiology and Speech-Language Pathology said the department offers an Au.D. clinical doctorate in audiology and an M.S. in speech-language pathology, as well as a host of clinical services, including audiological services and services related to improving spoken communication. Naturally, she said, the department is vitally interested in cochlear implants, which affect all of the above. Scott said her department's general philosophy regarding implants is that the devices are tools that can give deaf individuals auditory information otherwise unavailable to them, including speech sounds. The decipherability of these speech sounds seems to vary and training and practice appear to be necessary before implant use can become optimally beneficial. Recipients and their families will undoubtedly require

support services after implantation and in many cases sign language will continue to be needed as a communication option.

Scott said the department intends to play an increasingly important role as part of a campuswide cochlear implant team, offering clinical services to implant recipients and their families, preparing professional audiologists and speech-language pathologists equipped to work with implant candidates and recipients, and conducting research regarding optimal use of implants. The department is also working with cochlear implant manufacturers to obtain sometime this summer the necessary instrumentation and training to program implants for optimal use with individual implant recipients.

Two implant-related research projects are already underway in the department. OneCa longitudinal project that received a GRI Priority Research GrantConcerns the self-monitoring abilities of implanted adults. The other is a study of changes in brain activation patterns due to increased auditory information resulting from implants.

Cochlear Implants and Family-Centered Early Education

Dr. Marilyn Sass-Lehrer described the work of the Family-Centered Early Education program in Gallaudet's Department of Education. She said that graduate students in this program work with preschool-aged deaf children and their families to help prepare the youngsters and their parents for the developmental and educational challenges that lie ahead. The program is working collaboratively with other Gallaudet units on the issue of early identification, which—as a result of new technology—is increasingly likely to occur in the first month of an infant's life. Sass-Lehrer also said that students in the program are working much more frequently than in the past with families in which the young child already has a cochlear implant. She said that the education department is in the process of developing a comprehensive approach to such children in an effort to ensure that advice offered to parents will truly match the needs of this special population.

Laurent Clerc National Deaf Education Center

Debra Nussbaum, an audiologist in Gallaudet's Laurent Clerc National Deaf Education Center (which serves children from birth through high school) and chair of the Clerc Center Cochlear Implant Task Force, reported that the task force—established to address the needs of students with implants—has been planning and implementing a number of activities in the areas of professional development, campus collaboration, direct service provision for students, and family education.

Nussbaum said the task force has arranged information-sharing meetings of Clerc Center faculty and staff to provide general information and promote a positive attitude toward cochlear implants. In December, 1999, a forum called "Cochlear Implants; Where We Are—Where We Are Going" was held. In March, 2000, Myrna and

Phil Aiello, culturally Deaf implant users, were invited to share their experiences in a presentation.

Task force members have been attending workshops, visiting and working with the Listening Center at Johns Hopkins University Hospital, and speaking with programs and specialists nationally and internationally who are working with children and adults with cochlear implants. The task force will be surveying attitudes and knowledge levels among Clerc Center faculty and staff and plan to collaborate with NECCI (Network of Educators of Children with Cochlear Implants) in organizing future staff development.



Debra Nussbaum

To involve parents of Clerc Center students in the process of learning about cochlear implants, a full day family education workshop was provided on this topic in April, 1999. Similar workshops designed to meet family education needs are under discussion. Families may obtain information on implants routinely through individual meetings with Clerc Center audiologists.

Nussbaum said the Clerc Center is currently seeking funds to support a Cochlear Implant Center at Gallaudet that could work toward the following goals:

1. Acquire the necessary equipment and training to enable in-house audiologists to cope with programming and troubleshooting associated with implants—much as they currently do with hearing aids.
2. Conduct research aimed at determining optimal strategies for language development among children with implants, exploring in particular the effects of a bilingual (ASL and spoken-and-written English) approach to instruction.
3. Serve as a national clearinghouse for parents and others seeking information on cochlear implants.
4. Establish partnerships with Gallaudet graduate students in various disciplines (psychology, etc.) who are interested in working with students with implants.
5. Develop outreach materials aimed at the medical community, promoting support and understanding of the role of sign language among implanted children.

Nussbaum said that further discussion and investigation will be needed to establish best practices for integrating students with cochlear implants into the visual language environment at the Clerc Center. She said that although families tend to choose an implant to increase the ease with which their child can communicate through spoken language (see next section on GRI survey), student outcomes in this area vary and many children and their families continue to use sign language. The Clerc Center aims to implement programs that will promote the

development of spoken language skills among students with cochlear implants, but it will recognize that these students still are still deaf and in need of many of the same supports beneficial to other deaf children, including sign language.

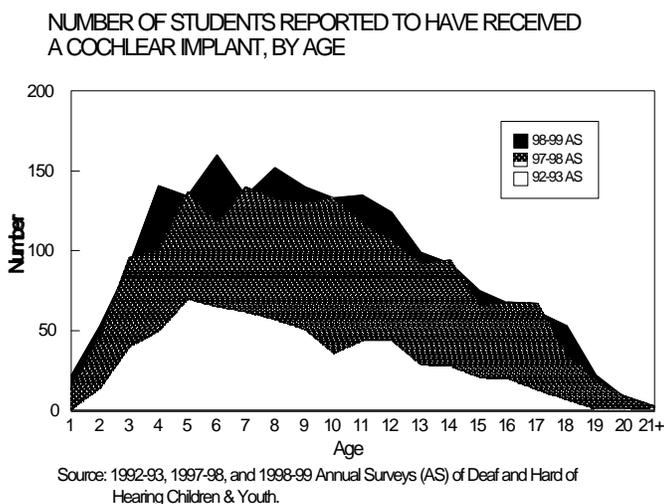
GRI Survey of Parents of Pediatric Cochlear Implantees

Dr. Thomas E. Allen, dean of the Graduate School and Research, then described preliminary results of the GRI’s survey of parents of children with implants that was alluded to in Dr. Christiansen’s presentation. Allen said the 12-page survey included questions recommended by people in many Gallaudet units and was truly a collaborative endeavor. The GRI’s annual survey has reports on approximately 48,000 deaf and hard of hearing children and youth nationwide. Of these, 1,739 reportedly had implants, hence, the cochlear implant survey form was sent to the parents of those children, plus a small number of additional parents identified through world-wide web searches. Of all the surveys mailed out, 439 were returned with responses.

Allen said that comparisons of current and past annual survey data show an enormous increase in recent years in the numbers of children with implants. Such comparisons (shown in Figure B) also show that more and more children are being implanted at younger ages—most in the 18-month to 3-year age range. The data also suggest that no “plateau” is in sight; that is, the numbers keep increasing every year. In 8 or 9 years a considerably increased proportion of deaf prospective college students will have implants, so Gallaudet must be prepared to create an environment hospitable to such students.

Figure B

According to annual survey data, Allen said, the ethnic background of children with implants differs significantly from that of deaf and hard of hearing children in general. Seventy-five percent of children who reportedly have



implants are white, even though only 56% of the children reported to the annual survey overall are white. Among respondents to the cochlear implant survey, the percentage of white children represented was even higher—83%. Socioeconomic data gathered by the survey also suggest that the sample consisted of a relatively wealthy population. Allen emphasized that these ethnic and socioeconomic biases must be kept in mind when interpreting results of the survey.

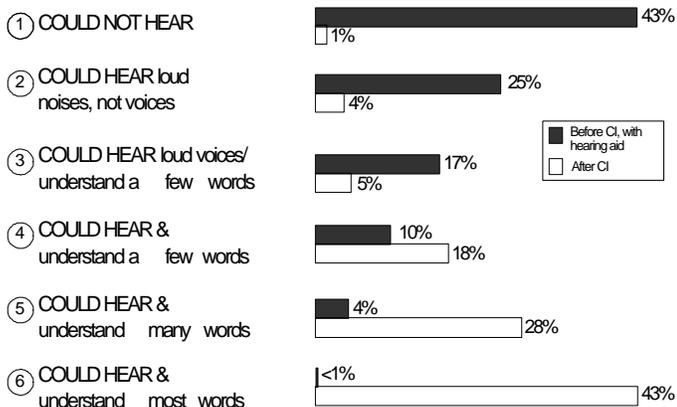
Ninety-six percent of the parents’ implanted children were using their implants at the time of the survey. Fifty-two percent of the parents selected as their “main reason” for deciding to have their child implanted was to provide greater “ease in development and use of oral spoken language.” Twenty-five percent selected the “child’s safety and environmental awareness” as a primary consideration. Only 8% selected “to gain hearing” and only 6% selected that they were responding to the “child’s expressed desire for an implant.” Although the parents indicated that they had been quite aware at the time of surgery of medical risks associated with the surgery itself, they also indicated that they had been significantly less aware of psychological or social problems associated with having an implant.

Information gathered concerning insurance indicates that while the surgery itself was generally well-covered by insurance, there had been considerable variability in the length of time post-surgical speech and auditory training was covered. Only 23% had insurance paying for speech and auditory training lasting a year or more. Dr. Allen expressed the hope that as children with implants increase in numbers, schools may pick up some of the responsibility for post-surgical training needed but not covered by insurance.

Although parents overall indicated they were very satisfied with the progress their children were making as a result of getting implants, they were somewhat less satisfied about their children’s progress developing spoken language than with other areas. This finding is probably related to the parents’ high expectations in this area.

One of the survey’s most significant findings relates to parents’ perceptions of their children’s hearing characteristics, before and after the cochlear implant. As is shown in Figure C on page 10, 68% of the respondents indicated that before the implant their children either “could not hear” or “could hear loud noises but not voices.” After receiving implants, however, 43% of the respondents indicated that their children “could hear and understand most words,” 28% indicated their children “could hear and understand many words,” and 18% said their children could “hear and understand a few words.” Although it is important to factor in parents’ possible

Figure C

① Usually **COULD NOT HEAR** even very loud noises.PARENTS' PERCEPTION OF CHILDS HEARING CHARACTERISTICS,
BEFORE AND AFTER THE COCHLEAR IMPLANT

- ② Usually **COULD HEAR** very loud noises (e.g., a moving train near by, a low-flying plane overhead), **BUT** could not hear the voices of people talking at a conversational loudness level across a quiet room.
- ③ Usually **COULD HEAR** the voice of a person talking very **LOUDLY** from a distance of 10 feet across a quiet room, **BUT** could understand only a **few** of the words spoken.
- ④ Usually **COULD HEAR** the voice of a person speaking at a conversational loudness level from a distance of 10 feet across a quiet room, **BUT** could understand only a **few** of the talker's words.
- ⑤ Usually **COULD HEAR** the voice of a person speaking at a conversational loudness level from a distance of 10 feet across a quiet room, **AND** could understand **many**, but not most, of the talker's words.
- ⑥ Usually **COULD HEAR** the voice of a person speaking at a conversational loudness level from a distance of 10 feet across a quiet room, **AND** could understand **most** of the talker's words.

biases, these results do seem to suggest that children with implants can hear significantly more spoken communication after the surgery.

Parents indicated that their use of spoken communication with their implanted child increased significantly after receiving an implant. Nevertheless, the majority of parents continued to use sign language to a lesser or greater extent. Sixty-two percent of the parents indicated that they "continued to use sign communication as a support" after their child received an implant. Only 5% continued to use sign communication as a primary means of communication.

Parents' perceptions of the speech intelligibility of the implant recipients varied greatly. As a general rule, it appeared that the children's speech intelligibility improved over time, but many variables, such as age at time of receiving the implant, appeared to complicate these results and confound efforts to discern generalizable patterns.

Educational placements for the 439 implanted children varied widely. Although 38% were main-streamed in regular classrooms, many were not, and a full 40% were taking advantage of sign language interpreting in the classroom. Interpreting was the most frequently reported special service for these students, but it is clear that children with implants continue to need a wide array of support services in the classroom after receiving an implant.

Dr. Allen concluded by stating that the survey supports the position that sign language is likely to be needed as a communication support indefinitely after implantation. He said that even though parents reported impressive gains in their children's ability to hear and understand speech after getting implants, these results are no doubt based on the quieter one-on-one communication situations that are more likely in a home than in a class-room. Although hearing and speech discrimination appear to increase significantly after implantation, deaf children are likely to continue to need an array of special supports and to continue to form friendships with deaf as well as hearing people throughout life.

Dr. Allen added that the qualitative data from in-depth interviews being examined by Drs. Christiansen and Leigh will be invaluable for helping fill in gaps in the survey's quantitative study. Findings from these research projects, combined with practical experience gained over time, should help Gallaudet formulate recommendations for optimal adaptation to implants and to create an environment conducive to optimal benefit for implanted students at Gallaudet.

Note: A chartbook of graphic displays of data from the GRI's survey of parents of pediatric cochlear implantees is currently being prepared for publication by the GRI. It should be available for purchase sometime in the fall of 2000 and will be advertised in this newsletter.

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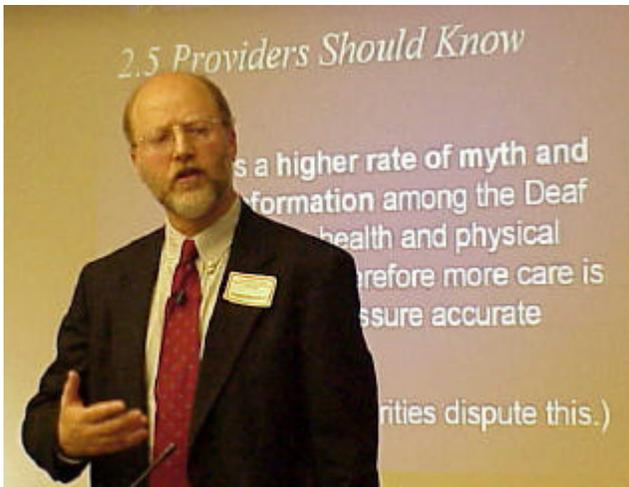
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for helping improve our mailing list! If you notice errors in your address label or would like to add an address to our list, please either write us at the address on page 2, send an e-mail to gri.offices@gallaudet.edu, or use our website: <http://gri.gallaudet.edu/mailing.html>. Expect a Fall Issue!

Meeting on Health Care Services to Deaf and Hard of Hearing Adults

By Carol Bloomquist Traxler, Ph.D.

The Executive Boardroom of the Gallaudet University Kellogg Conference Center was the setting for a high-powered meeting on "Standards for Health Care Services to Deaf and Hard of Hearing Adults" on March 31, 2000. This meeting was part of a project being conducted by Delmarva Foundation for Medical Care with the Gallaudet Research Institute under the support of the Health Care Financing Administration (HCFA), the federal agency that funds Medicare and Medicaid. The ultimate purpose of the project is to propose to HCFA a



David Boan, Vice President for Information Technology, Delmarva Foundation

set of standards for providing health care services to deaf and hard of hearing patients. At the meeting, a distinguished focus group of 20 panelists discussed the draft of standards that had been proposed by another expert panel, a "virtual panel," that had met on-line for several months. Like the virtual panel, the focus group that met face-to-face at Gallaudet included experts representing a wide spectrum of health care services recipients and providers. Along with deaf and hard of hearing individuals who had received health care services, there were advocates and representatives of organizations serving deaf people—interpreters, social workers, health educators, attorneys—as well as providers such as physicians in private practice and in HMOs. In the gallery approximately 23 individuals observed all or part of the day, including representatives from HCFA, representatives from Senator Harkin's Office and the Maryland Medicaid Program, and Gallaudet faculty and staff.

Led by Dr. David Boan of Delmarva and Senda Benaissa of the GRI, the focus group examined the 11 categories of standards encompassing 57 standards or guidelines proposed by the virtual panel. Some of the categories of standards relate to terminology, what providers should know, what providers should do, interpreting, staff training and communication, equal access, hospitals and other settings, and what consumers should know.

There was intensive discussion about the standards, followed by a review of the revised standards at the end of the day. Further comments have been received by e-mail, and the standards are now being revised based on the focus group's input. The revised standards will be re-turned to the virtual panel for a final vote of approval, and then again to the focus group members for their final vote. The standards will ultimately be posted at the project web site for public comment. The web site includes a discussion forum for people interested in ongoing public discussion with others who share their interests.

To help the project team assess the impact and burden of the standards on providers of care, health care providers interested in being interviewed about their opinion of the standards may contact the project team directly.

The project team is also collecting "case stories" from the public—especially the deaf community but also the medical community—to illuminate the standards. Deaf and hard of hearing individuals are encouraged to visit the web site for the project at <http://deafness.dfmc.org> to complete a confidential permission form and submit their case stories, detailing their own experiences with health care services. Case stories can also be given to the project team members.

Those who are interested in learning more about the project or in contributing to it should contact the project team via the web site, e-mail, or telephone/tty. Gallaudet's project team members are Dr. Carol Traxler (202-651-5881), Senda Benaissa (202-651-5400), and Sally Dunn (202-651-5400); their offices are in the Gallaudet Research Institute in Hall Memorial Building.



Panelists (from left to right, foreground) Michael Lotke, M.D. of Mount Sinai Hospital Medical Center, Lisa Harmer of the University of Rochester Medical Center, Susan Finisdore of United Cerebral Palsy, and John Lopez of the National Hispanic Council of the Deaf and Hard of Hearing.

New Directory of Mental Health Services for Deaf People Available

The provision of appropriate mental health services to deaf individuals has always posed a challenge to the mental health and deafness fields. Potential deaf clients and mental health service providers alike often have difficulty locating service providers who have identified themselves as being able to offer such services.

The Gallaudet Research Institute (GRI) is pleased to announce the availability through the GRI of the new *Mental Health Services for Deaf People: A Resource Directory—2000 Edition*. The document is an updated version of a similar directory published by the GRI, the American Deafness and Rehabilitation Association, and University of California, San Francisco, Center on Deafness in 1992. The new edition, developed by staff in Gallaudet’s department of counseling, contains a comprehensive listing of over 300 programs across the United States and Canada that have submitted information indicating they provide mental health services to deaf clients. For each program, the directory includes information about the services offered and how to contact the program. The developers of this three-hole-punch volume (which can be periodically updated) believe it represents a significant step towards improved accessibility and accountability in this special field.

The Gallaudet Research Institute
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Washington, DC 20002-3660

Spring 2000

Mental Health Services for Deaf People: A Resource Directory is available from the GRI for \$12.95 per copy plus postage and handling. To order, photocopy this page, fill out the order form, and mail with a check or money order payable to Gallaudet University to: *Mental Health Services for Deaf People: A Resource Directory*, Gallaudet Research Institute, Gallaudet University, 800 Florida Ave., NE, Washington, DC 20002.

Note: For orders of ten or more copies, please inquire about discounts and postage charge.

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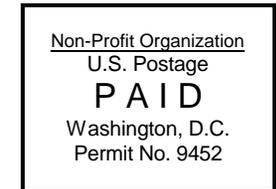
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