An Anthropological Study of Deaf Adults and Health Care

By

Richard Kuo-pin Sun

A.B. (Northwestern University) 1983
M.A. (Northwestern University) 1983

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

Health and Medical Sciences

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, BERKELEY

Approved: Nancy Schuyler Hugueny 5/18/86
Chairman

Date

Antonio D. Roman 5/14/86

Gaylene Broken 5/16/86
ACKNOWLEDGEMENTS

I would like to thank the members of my thesis committee——Nancy Scheper-Hughes (University of California, Berkeley), Octavio I. Romano (UCB) and Gaylene Becker (University of California, San Francisco)——for their time in reading and commenting on this work.

Thanks to the deaf and hearing informants who taught me so much about deafness and without whom this thesis would not exist. Thanks also to Kate Brown of the Health and Medical Sciences Program, UCB, who gave encouragement and advice throughout the research process.

The final product is my responsibility, as are any omissions or inaccurate statements found in it.

CONVENTIONS IN CITATIONS

"P.O." indicates my "personal" or "participant" observations. These may represent my unsupported opinions, or statements made by other persons outside a formal interview setting.

A set of initials (e.g., "Z.Z.") indicates information from an interview with an informant. To protect privacy, the initials have been assigned to informants randomly (i.e., "Z.Z." may refer to John Doe). Where the text contains information that might be used to match initials to an informant, no specific citation is given. The interview sources are listed in the "Interviews Cited" section.

A complete last name with a year (e.g., "Nemon 1980b") indicates information from the literature. The literature sources are listed in the "References Cited" section.
1. INTRODUCTION, DEFINITIONS, AND RATIONALE

Researchers have studied certain features of the Deaf community in the United States using anthropological methods, but only one researcher (Nemon 1980a) has applied such methods systematically to the problem of understanding experiences with and opinions of health care in the Deaf community. This study was designed not only to test the conclusions of Nemon (1980a) but also to provide a basis for future studies concerning the problem by relating it to broader issues than did Nemon. To explain the importance of the problem, it is first necessary to outline linguistic principles concerning sign languages and sign systems, to discuss characteristics of deaf people in general, and to define the boldface key terms used above.

1.1 Linguistic background. American Sign Language (ASL) is a "visual-gestural" or "sign" language. Historically, ASL is descended from a sign language used by deaf Americans up to the early 1800s and from French Sign Language which was imported at that time by Laurent Clerc and Thomas Hopkins Gallaudet (Baker and Cokely 1980:48-53). ASL is thus related to French Sign Language, but is unrelated to other sign languages such as British Sign Language or Chinese Sign Language. As in any language, there is some sociolinguistic variation in ASL, for example by region, race, sex, age, and situation (Baker and Cokely 1980:83-101), and by whether a person learned ASL as a first or second language (P.O.). Perhaps the most conspicuous variation is that older white signers tend to incorporate fingerspelled words more often in their conversations than younger white signers. Fingerspelling is the use of a distinct handshape for each letter of the alphabet to represent English words letter-for-letter.
"PSE does not have one specific set of rules"; instead, "there exists a continuum of PSE varieties——some more like ASL, others more like English" (Baker and Cokely 1980:73-75, P.O.).

Other methods to "bridge the gap" between ASL and English for pedagogical purposes have been created by educators and are named "Manual Codes for English" (MCEs). These methods are "codes" somewhat akin to Morse code, not true languages in themselves like ASL, in that MCEs attempt to represent English sentences word-for-word¹. Facial expressions are used even less in MCEs than in PSEs. The most commonly used MCE at present is "Signing Exact English," commonly abbreviated and pronounced "SEE." Although many young deaf students are learning MCEs in schools, most deaf adults who sign seem to use PSE or ASL for everyday communication (Baker and Cokely 1980:65-71, P.O.)².

An illustration will clarify the linguistic points in the previous few paragraphs. Although the printed page cannot represent signed sentences well, consider the spoken or written English sentence "last week I went bowling with my friends" and its possible translation into ASL, PSE, and SEE (Baker and Cokely 1980:76):

-----topic-----

**ASL:** ONE-WEEK-PAST, ME FRIEND GROUP FROM-here-GO-TO-right BOWLING-right.

[6 ASL signs. The syntax is very different from English syntax. The first sign, accompanied by a characteristic facial expression ("topic"), sets up the time at which the action took place. The second through fourth signs indicate that the signer is referring to himself in a group of friends. The fifth sign incorporates an indication of the direction of movement of the group, namely to where bowling was taking place.]

**PSE:** PAST WEEK I W-E-N-T BOWLING WITH MY FRIEND +S.

[6 ASL signs, 1 modified ASL sign ("T"), 1 fingerspelled word "W-E-N-T," and 1 extra fingerspelled letter to indicate plurality.]
at which age most hearing children have acquired a significant amount of speech. Prelingually deaf persons have a smaller chance of developing understandable speech than other PD persons (P.O.).

Several characteristics of the PD population deserve mention. First, approximately 90% of PD persons have hearing parents; only 3% have two hearing-impaired parents. Second, although a relatively low percentage of PD persons marry compared to the percentage among hearing persons, approximately 80% of the PD who marry choose a deaf spouse. Third, in the U.S. the rate of prevocational deafness in, and the absolute number of, whites is greater than the corresponding figures in nonwhites, so that the PD population is largely white (Schein and Delk 1974). Fourth, "[PD] adults cluster in urban areas where access to special education, community services, jobs and social life is more likely to be found" (Schroedel 1984:623).

The fifth point concerns the English language ability of PD adults. In 1971, the average reading comprehension for hearing-impaired (not necessarily deaf) 18-year-olds in school was measured to be at the 4th-grade level (DiFrancesca 1972). Recently this average has decreased to the 3rd-grade level (Gallaudet Research Institute, in press). Although controversy exists regarding the significance of these figures and other figures related to the English language ability of PD adults³, it is commonly accepted that PD persons on the average read and write English at a rudimentary level.

Finally, the socioeconomic status (SES) of PD adults seems to be lower than that of hearing adults in terms of representation in white-collar jobs, unemployment rates, and annual income. It should be noted that the data on the extent of disparities between the SES of PD
1.3 "The Deaf community." Many PD persons "do not consider themselves handicapped, but rather as a minority group—similar to a non-English speaking group" (U.S. DHHS 1981:7). This subset of PD persons, whom researchers refer to as the "Deaf," has unique social and cultural characteristics.

1.3.1 Social Characteristics. Padden and Markowicz distinguished between the terms "deaf" and "Deaf" as early as 1976:

...we shall use the convention of capitalizing the first letter of the word "Deaf" when we are referring to the ethnic group, its culture, or its membership. We shall continue to write "deaf" without capitalization to indicate an audiological condition of deafness (p.408).

Researchers still recognize this distinction as important, although the editor of a major journal lower-cased all the capitalized "Deaf"s in a paper for publication (Reagan 1985:277, footnote).

Several authors have somewhat refined these definitions. Baker and Cokely (1980:54-58) state that a person needs to have an underlying Deaf attitude as well as fulfill audiological, political, linguistic, and social criteria to be considered a part of the core Deaf community. The audiological criterion is somewhat flexible, since "so long as there is some degree of hearing loss" the extent of hearing loss does not affect membership in the community (Reagan 1985). Politically, core Deaf community members participate in organizations that affect the community "on a local, state, or national level" (Baker and Cokely 1980:56). The linguistic criterion is knowledge of ASL, as described in section 1.1. Opportunities for social interactions within the community include religious organizations and deaf clubs. There is considerable endogamy (intermarriage) within the Deaf community (see also section 1.2). If a person does not satisfy
children who attend these schools form close bonds with each other and begin to separate from the "hearing world" (Becker 1980:30-38). In contrast, mainstreamed programs, in which deaf students are sent to public school classes, and oral schools, which emphasize speech and lipreading, are oriented towards integration of deaf children with hearing children. Many Deaf persons feel that mainstreaming and oralism are unsuitable for many deaf children (Jacobs 1980, P.0.).

After graduation from secondary schools, deaf students may attend postsecondary programs for the deaf, the oldest and largest of which is Gallaudet College in Washington, D.C. Gallaudet is in many ways a microcosm of the Deaf community. PD persons who have not attended a residential school experience "a sudden transposition to an alien culture" (Padden and Markowicz 1976:407) upon entrance to Gallaudet, presumably because of their lack of interaction with other Deaf persons. Many graduates of Gallaudet proceed to become leaders in the Deaf community, although not all leaders graduated from Gallaudet (Higgins 1980:56-57).

1.3.2 Cultural Characteristics. Deaf persons might be said to share a common culture, if one uses the definition adopted by Clifford Geertz:

The concept of culture I espouse... is essentially a semiotic one. Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs.... (Geertz 1973:5)

It ["culture"] denotes an historically transmitted pattern of meanings embodied in symbols, a system of inherited conceptions expressed in symbolic forms by means of which men communicate, perpetuate, and develop their knowledge about and attitudes toward life. (ibid., p.89)

The "pattern of meanings" I suppose would include folklore (e.g., humor that Deaf persons but not hearing persons appreciate, Rutherford
(1981), and Jacobs (1980). These four works will be cited extensively in the following discussions. Although Jacobs is not an anthropologist by training, he is a leader in the Deaf community, and had deaf parents, a deaf wife, and a deaf child. Because Jacobs is thus in a sense a continual participant observer and ethnographic interviewer, I consider anthropological his book detailing his views on the Deaf community and education for the deaf.

1.5 "Health care." I will focus on the areas covered by Harwood's (1981) edited volume Ethnicity and Medical Care. In that volume, the following information is provided for each ethnic group considered, and therefore each item listed below falls within the scope of what Harwood considers "medical care" (ibid., pp.17-21):

I. Identification of the ethnic group.
II. Evaluation of the existing data.
III. Epidemiological characteristics.
IV. Concepts of disease and illness.
V. Becoming ill.
VI. Coping with illness outside the mainstream medical system.
VII. Encounters with mainstream medical practitioners.
VIII. Adherence to biomedical treatment.
IX. Recovery, rehabilitation, and death.

The reason I chose the term "health care" over "medical care" is that the former has broader denotations. Items IV-VI above, as well as the concept of preventive care, seem to me to fall within the realm of "health care" but not "medical care."

Harwood's volume exemplifies the contribution of anthropological methods to the study of health care of the groups considered (urban blacks, Chinese, Haitians, Italians, Mexicans, Navajos, and Puerto Ricans). Many of the characteristics of the groups, especially items IV-IX, can be examined most effectively through anthropological methods. For example, Kleinman, Eisenberg, and Good (1978) document
2. LITERATURE REVIEW

Works concerning deaf persons and health care can be divided into three broad types: autobiographical accounts of contact with the health care system, collections of suggestions for health care professionals (hereafter referred to as the "applied" literature⁴), and academic studies examining specific hypotheses. Autobiographical accounts include Jordan (1971) and Landers (1982). The applied literature discussed here has been aimed at hospital administrators (e.g., Metro Deaf Senior Citizens 1984), nurses (DiPietro 1979, Jensen 1983), doctors (Brown 1977), and emergency medical technicians (U.S. DHHS 1981). Although there exist many other examples of applied literature, the content of the works overlaps significantly. The academic studies include Lass et al. (1978), McNeil (1984), and Nemon (1980a), among others. Because of its methodological similarity to the present study, the Nemon (1980a) study will be discussed in some detail. Most of the academic studies include recommendations for health care professionals in their conclusions.

The works have focused mostly on three interrelated issues: communication, beliefs and practices, and attitudes. It is beyond the scope of this paper to attempt detailed definitions of these concepts which overlap somewhat, but all fall within the realm of "culture" as discussed in section 1.3.2. A broad overview of the three issues will be presented here.

2.1 Communication. McNeil (1984) studied the attitudes of 100 physicians towards deaf people and the actual modes of communication the physicians used. Regarding communication, the major findings were:

Physicians who attended a greater number of medical continuing education meetings or who had seen a greater number
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Percentage Using</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Speech</td>
<td>Writing</td>
</tr>
<tr>
<td>McNeil (1984)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Physicians</td>
<td>79</td>
</tr>
<tr>
<td>Nemon (1980)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Nurses</td>
<td>54</td>
</tr>
<tr>
<td>Schein and Delk (1980)&lt;sup&gt;c&lt;/sup&gt;</td>
<td>Deaf</td>
<td>55</td>
</tr>
<tr>
<td>Lass et al. (1978)</td>
<td>Deaf</td>
<td>22</td>
</tr>
<tr>
<td>Harte et al. (1973)&lt;sup&gt;d&lt;/sup&gt;</td>
<td>Deaf, Physicians, Nurses, Social Workers</td>
<td>Physicians (p.139): &quot;written notes and verbal language&quot;</td>
</tr>
</tbody>
</table>

All studies allowed for multiple responses. NA = not available.

a. McNeil (1984:84) classified methods of communication in detail. Percentages given are for her entire sample (physicians with few as well as physicians with many contacts with deaf patients) and for "often" or "occasional" use. Fingerspelling was used by 6% of the physicians and gestures by 69%. Among the physicians using signing, 3% used ASL, 13% used MCEs, and 16% used "basic signs." The range of usage of interpreters represents different types of interpreters (i.e., office staff, professional, blood relative, friend, or spouse).

b. These are the "types of communication used if [the respondent had] more than passing contact with deaf [people]" (Nemon 1980b:209) and thus may not reflect methods of communication used between respondents and patients. The response rate and the percentage of health care workers (ibid., p.97) in Nemon's sample was low, so the figures reported here reflect the characteristics of the comparison group which was mostly composed of nurses working in hospitals (ibid.,p.100).

c. Responses from inpatients versus outpatients, and expressive (i.e., when the patient wanted to communicate with staff) versus receptive (i.e., when the staff wanted to communicate with the patient) communications are combined. Gestures were used by approximately 8% and "other" modes of communication by 1%.

d. Although the questionnaires of Harte et al. (1973) asked about methods of communication used (pp.157,174), the results of these questions are not reported in any further detail than given here.
McNeil's (1984) study showed that "over 90% of the physicians judged interpreting to be an effective communication mode, yet actual usage varied from 12-58%." Physicians who had taken a sign language class were more likely to have used an interpreter than physicians who had not taken such a class. In the Schein and Delk (1980) study, it was found that 80.5% of the respondents would suggest an interpreter to improve communication, but actual usage was about 7 percent. None of these authors suggests a reason for the discrepancies between opinions of and usage of interpreters, but there exist at least two suggestions in the literature concerning why the patient or the provider may reject the presence of an interpreter in medical settings:

a. Invasion of privacy by a third party, especially if the interpreter is not the patient's own (hearing) child (Nemon 1980a).

b. Possible inaccurate interpretation (Cokely 1982).

Cokely's (1982) paper is the only videotape-based study of health care professional - interpreter - deaf patient communication. He studied two structured interviews between a nurse and a patient using two different interpreters, and classified the errors made by the interpreters into those of perception, memory, semantics, and performance. From the limited data (perhaps two hours of videotaped material), Cokely was unable to draw any general conclusions about professional-interpreter-patient interaction, but he did recommend that interpreters should familiarize themselves with medical terminology and should meet with the health professional before an interview in order to ascertain that the professional understands the interpreter's role.

2.1.5 Breakdown of Communication. Several types of problems may interfere with clinical communication, according to Kleinman (1982:96-
providers continually ascertain how much the patient truly understands by questions on the topic just discussed (e.g., DiPietro 1979:19).

2.2 Beliefs and Practices. Several studies are concerned with beliefs and practices of deaf persons in relation to health care. Lass et al. (1978) trained five interpreters to interview 36 subjects using a set of questions about knowledge of certain medical issues, attitudes about "health, health personnel, and health care facilities," health practices, and problems in receiving medical care. Half the subjects were black, a higher proportion than in the deaf population at large. The median age was 24 years, and the median level of education was high school graduate, so the sample was younger and more educated than the total PD population.

Concerning beliefs and practices, Lass et al. found that a significant proportion of the sample did not know the meanings of medical terms such as "nausea" or of the importance of symptoms such as chest pain. Only 24% knew the answer to "what is a normal body temperature?". The lack of a hearing comparison group or breakdown of results by demographic variables is problematical, as discussed in the paper. The potential problem of variability in interpreter skills (Cokely 1982) was not discussed.

In a community such as the Mayan Indian village that Shuman (1980) studied with a high proportion of deaf persons (12 out of 300), deaf people may be fully knowledgeable as to the meanings of illnesses due to the ability of all the other villagers to communicate with the deaf. Shuman argues that studying how well deaf people "know how to get sick" in a culturally appropriate manner will enable the anthropologist to determine the degree of interaction that the
entirely clear, but it seems that a Deaf man who knew that he had AIDS (Acquired Immunodeficiency Syndrome) was admitted to a hospital when his condition worsened. The staff communicated inadequately with the worried patient concerning his situation and did not provide an interpreter. Since the staff believed that the patient's repeated gesturing for pencil and paper was self-destructive, the staff "found it necessary to put restraints on his hands and feet." The measures effectively "silenced" the patient, who struggled against the restraints for four hours before being untied by his companion. The restraints deeply affected the patient emotionally, as reflected in a statement by the patient's sister: the episode was "critical... [in creating] psychological stress [that] could have been avoided" (Lubrano 1986, elaborated upon by a friend of the patient's in the San Francisco Bay Area Deaf community).

The reason for the stress, I would surmise, is the association of restraints with powerlessness. This is best demonstrated in the made-for-television movie And Your Name Is Jonah, in which the deaf boy Jonah is restrained by hospital personnel when they cannot keep control his thrashing. To the Deaf, the hands are a source of communication and thus of power, and thus should not be restrained unless absolutely necessary. Even grabbing a person's hand while she is signing is considered rude, something akin to stuffing a rag into a hearing person's mouth as she is talking (P.O., Jensen 1983:90).

2.3 Attitudes. Autobiographical accounts provide clues concerning deaf patients' attitudes towards health care providers and vice versa. For example, the physician treating "D.T." (Landers 1982) insulted the deaf patient by being curt and by saying "It's so hard
and knowledge of sign language were correlated with positive attitudes towards the deaf.

Darbyshire and Kraus (1983) surveyed 85 nurses and 95 persons from the general population with 58 different questions concerning attitudes towards deaf persons. The nurses' responses were very similar to the others' responses. Most striking about the Darbyshire and Kraus report are the attitudes of the authors themselves, exemplified by the following:

[The attitudes of both groups were] significantly more positive than negative towards the hearing impaired. ... Both groups were not only fairly lacking in information on the deaf as a group... [but also] there was a remarkable absence of logical thinking based on everyday knowledge. ... [For example,] On item 34, "The deaf have as many interests as the hearing," the average response indicated mild to strong agreement in both groups implying, therefore, that deafness does not limit an individual's activities. ... "Deafness makes people less capable in general," which is clearly true for any major handicap, was contested by both groups. ... The results are cold comfort.... [emphases mine, RKS]

The authors believe that "handicap actually has a handicapping effect" and that the subjects' responses to the contrary indicate the need for education to allow "more positive interaction between the deaf and society."

In the McNeil (1984) study, "physicians were found to have generally positive attitudes toward the deaf" which were not related to the communication methods used (p.115). Physicians who had fewer appointments with deaf persons, no experience with sign language, and fewer continuing education classes had attitudes reflecting "less accurate information" about the deaf.

A few studies examine professionals' attitudes towards deaf patients informally or indirectly. Nemon (1980a) states that two of
coworkers, parents of deaf children, and educators. As professionals, most physicians would be classified as "completely hearing" or Type III, a group which also includes church people, oral deaf, organized helpers (such as those on the boards of speech and hearing societies).

Nash and Nash (1981:73-74) state:

Professional people surround themselves with an aura that is both impenetrable and attractive to the deaf. On the one hand, they represent hope for some new breakthrough; on the other hand, past experience reveals that they are aloof and often concerned with such small segments of the deaf person's biography that even minimal communication is impossible. Types of persons in the professional category include doctors; audiologists; hearing-aid dealers; [etc.] ... These people are not, all in all, particularly valuable to the deaf; and the deaf often are not of primary interest to them. The deaf believe that they are merely objects of studies and experimentation, a source for fees, and so on. [emphasis mine, RKS]

Because the authors do not describe their research methods in detail, the validity and usefulness of this typology is unclear.

Lass et al. (1978:964) state that over 70% of their sample was satisfied by the "intelligence of doctors," "service by nurses," "personal attention," "speed of service in admissions," and "cost" of their care in hospitals. Although the question upon which these results are based (ibid., p.966) is rather simplistic, the results do indicate that the Deaf are mostly satisfied with their health care.

One of the fundamental ideas in medical anthropology is that "distinctive value orientations and behavioral norms associated with ethnicity... may interfere with doctor-patient relationships" (Kleinman 1982:97). If the Deaf constitute a minority group, then (1) they may share attitudes towards health care which may differ systematically from those of their hearing providers, (2) there exists the
cations of Section 504 are that hospitals are required to provide and pay for interpreter services, and to have access to TTYs. Hospitals' compliance with Section 504 seems to be rather poor (Metro Deaf Senior Citizens 1984:15-16).

Anesthesia, drugs, or an illness may cause altered states of consciousness in deaf patients. These situations require skilled personnel to assess the patient's orientation (DiPietro 1979:22-23). Finally, some authors recommend that a deaf person carry some sort of identification such as a Medic Alert tag to warn emergency personnel that the person is deaf (U.S. DHHS 1981:10).

4.5 Concerning Students. Although some efforts have been made to teach students training to become health care professionals about deafness (e.g., Rose and Yust 1975), this subset of students has not been extensively studied concerning their attitudes toward or knowledge about deaf persons. Nemon's (1980b) sample contained a few nursing students, but their characteristics were not separated from the other members of the sample. Joiner's (1978) study examined medical students' views of factors affecting social and educational development of the deaf and referral behaviors concerning hypothetical deaf patients, but her sample was small and her questionnaire brief.
contacts—teachers, classmates, friends—for the names of deaf persons to interview. The informants were in turn asked for names of other persons, and so forth. At points, the "snowball" slowed appreciably; that is, people to whom I was referred would refuse to be interviewed. As Higgins (p.188) suggests, this phenomenon may reflect a lack of trust in the Deaf community. Interviews were scheduled at the times and places convenient for the informants, who were paid five dollars for the (usually one-hour) interview.

Altogether I interviewed nine deaf persons. All were severely to profoundly deaf, and all became deaf prelingually. Although all of them were white and lived near an urban area (i.e., in the East San Francisco Bay Area) the sample was otherwise not representative of the prevocationally deaf population (see section 1.2). All considered their reading and writing skills to be good, which corresponded with my impression of their English skills. Three persons were retired from occupations that seemed to me representative of working-to-middle class socioeconomic status (e.g., manufacturing, teaching); two were students at colleges; and the other four were working full time in mostly middle class positions. Two informants had deaf parents and siblings; one had deaf siblings but hearing parents. The others had hearing siblings and parents. Many informants did not answer a question concerning annual income because they did not know their income or did not want to answer the question.

One informant had not associated closely with other deaf persons since graduation from an oral school and a high school without a special program for the deaf, and thus was not part of the Deaf community. The other persons who graduated from oral schools or
Justifications for each set of questions will be found in Appendix 1. I added the last question ("How do you think other deaf people you know would respond...?") late in the course of research in response to the rather limited sample.

The language used varied from interview to interview. The informant who was not a member of the Deaf community used speech and lipreading as primary modes of communication. Another group of informants signed and spoke at the same time, necessitating a variety of PSE that was close to English. A few informants used no speech during interviews, and tended to sign a PSE variety closer to ASL than the informants who used "simultaneous communication." The highly structured questions 7 through 11 I usually handed to informants on a piece of paper.

3.3 Data Recording. Almost all anthropological literature is based on interviews with hearing persons; however, crucial differences exist between interviews involving speech and those involving sign language. Because of these differences, I contend that recording of information from interviews needs to be a major concern in anthropological research with deaf persons. The researcher must balance the factors of faithful recording of information, minimal interference with the interviewing process, and time expended in data analysis. This section documents the advantages and disadvantages of each attempted method of data recording.

3.3.1 Recollections of the Interview. From my coursework in anthropological methods, I knew that Becker's (p.12) and Higgins's (p.190-191) primary method of writing up their notes after the interviews is extremely unreliable. Simple experiments performed in my
recording devices; I felt the devices did not disrupt any interviews.

I was able to videotape one interview, but the use of video recording presented several unforeseen difficulties. For one, setting up and taking down the equipment wasted valuable time. In addition, if I missed a point during the interview, I would not ask for clarification, but believed that I could review the videotape to understand the point. When I did review the videotape, the point was often no more clear. Finally, as I learned from a deaf informant involved with sign language research, the transcription of signed dialogue is fraught with perils. It takes an hour to transcribe a few minutes of videotape; in addition, the non-manual behaviors (section 1.1) that add to the overall communication process are difficult to capture in transcription. While the videotaped interview yielded the most reliable data, the sacrifice of time and energy was disproportionate to the amount and quality of data gathered.

Two informants who used speech consented to having their interviews recorded on cassette tape. The transcription of these audiotapes was considerably less time-consuming than the transcription of the videotape, but still required a lot of time. In addition, most deaf persons I met did not have speech clear enough for me to understand.

3.3.4 Methods Not Attempted. One informant suggested that I use an interpreter for interviews. In this way, the interpreter could sign for me, and I would be able to take notes more easily. I never used this method because qualified interpreters would have cost at least $20 an hour, and because I thought that the presence of an interpreter might have limited the information gathered from deaf
4. RESULTS

The results obtained in fieldwork will be compared with the literature discussed in chapter 2.

4.1 Communication. Almost all informants were concerned about the accuracy and quantity of information received from their doctors. Some believed communication to be the only important issue.

4.1.1 Speech and Lipreading. The medical students overestimated the lipreading ability of deaf persons (Appendix 2, Question 6). Deaf persons who have understandable speech, both by self-rating and by my estimate, state that they have problems lipreading, so that no informant used lipreading as a sole mode of receptive communication. Even informants who considered themselves good lipreaders, which tended to be those who had some residual hearing amplified by hearing aids, used writing once in a while. In disagreement with suggestions given in the literature, two informants said that doctors' lips tended to move little and were thus difficult to lipread (B.S., N.M.). They wished that doctors would move their lips more. One informant also noted that some doctors nodded their heads too much, impeding her efforts to lipread them.

4.1.2 Writing. All informants used some writing in communicating with health care professionals. The English language skills of the informants tended to be good by my estimate; however, they knew of other deaf persons whose English was inadequate to the task of accurate communication in medical situations. One informant said that doctors should always use writing with their deaf patients unless the deaf person was "low verbal" with "broken English" in which case an interpreter should be summoned promptly. Not only providers' notes to
ence, I often received comments such as "it's so wonderful that you can sign!" after I informed people that I would become a physician in two or three years. This occurred in spite of my own perception of my signing skills as adequate for leisurely everyday conversation but inadequate for fast signing or critical situations.

Some informants wanted health care professionals to learn how to sign. An informant who said "I was always satisfied with my doctors, but none of them learned sign language... I wish they would, it would save time and money" also suggested that each hospital have some nurses who could sign. "One time I fell and broke my hip... The nurse said she wanted to learn sign language, I was so pleased."

Most Deaf informants (e.g., K.K., T.S., N.U.) thought that if hearing health care professionals wanted to learn sign language, they should learn ASL, not SEE. One informant's spouse had a frustrating encounter with a doctor; the spouse used ASL almost exclusively, but the doctor used SEE. The informant, realizing the lack of communication occurring, had to interpret from ASL to SEE and vice versa for the spouse. Another informant who considered himself a member of the Deaf community said that SEE was acceptable for hearing persons, including doctors, who want to learn sign language. ASL, the informant stated, can be difficult for hearing people to learn properly. In any case, the medical students surveyed had little idea of the purpose of MCEs in general (Appendix 2, Question 16), indicating a need for education measures in this area.

At least one person suggested that doctors should at least learn how to fingerspell to provide basic communication. In my experience, a hearing person can learn how to perform fingerspelling proficiently
several informants (E.T., T.G., S.N.). Even persons who know how to obtain professional interpreters may not do so on a regular basis because of perceived importance of the medical problem ("I don't call an interpreter if I go to the doctor for a cold"); misunderstandings that arise with some inexperienced interpreters (N.I., C.K.); force of habit in not using interpreters; and satisfaction that the methods already used, for example lipreading and writing, were sufficient for adequate communication (N.M., C.K.). Interpreters were sometimes seen as resources to be used only for deaf persons with low English abilities, in which case the interpreters needed to simplify the doctor's language.

In no case did someone state that confidentiality was a issue. One reason for this might be that most professional interpreters belong to the Registry of Interpreters for the Deaf (RID), which on paper suggests that members follow a Code of Ethics (T.G., T.K.). This Code specifies that interpreters are to keep all interactions confidential, but I do not know how strictly the Code is followed in practice.

A question often directed to me during research was "whose responsibility is it to provide interpreter services?" (T.G., T.S.). People wondered if the hospital, the deaf person, or the government should be responsible. I never knew exactly how to answer this question, instead resorting to my understanding of hospitals' legal responsibilities to provide interpreters under section 504.

Interpreters themselves mentioned the variability in skills among interpreters. A given interpreter may be skilled in gesturing, which is effective for those deaf persons who know a foreign sign language
Organized, self-directed health education efforts in the Deaf community seem to be fairly infrequent. A workshop on prevention and treatment of cancer was poorly attended (P.O.).

I was unable to detect how knowledge about health diffuses informally through the Deaf community if at all. In terms of formal education, one informant, who was a teacher in a residential school for many years, stated that deaf children learn very little about health in residential schools. The children need to know how to use the medical system, for example how to fill out insurance papers.

Three hearing informants (E.B., T.G., C.Z.) stated that deaf patients need not interpreters not so much as interpreter-advocates, that is, interpreters who knew something about medicine and about the legal rights of deaf persons so that they could actually intervene for deaf persons who did not know about their rights. But one of these informants mentioned the problem of equality: no group in society is given the "across-the-board" opportunity for such interpreter-advocates in health care settings (i.e., persons who could tell patients "what the doctor really means"), so "why should deaf persons be treated so specially?"

4.3 Attitudes. The informants as a group held an attitude of respect and trust for doctors and other health professionals, but felt "left out" in regard to information. An informant who relied mostly on speech and lipreading for communication, and who was satisfied with the actual communication that occurred in encounters with health care professionals, used the health care system only when she had problems with her hearing. She narrated her frustrating experiences with otolaryngologists and related specialists relating to attitudes:
desire to have television decoders in their hospital rooms. Although friends' visits can be comforting (K.K., N.I.), a long hospital stay often entails nothing to do for the deaf patient. In addition, informants mentioned that videotapes are an effective medium for presenting information to deaf patients. The Office of Civil Rights in San Francisco is trying to prepare a videotape that could be shown to deaf persons to obtain a brief medical history.

Informants complained that many hospitals did not have TTYs. If a hospital does not have a TTY, the deaf person must use a relay service in order to call the hospital. This entails a significant loss of privacy and uncertainty, since a third part must interpret between the patient's TTY and the hospital's voice communication (P.O.). Even if a hospital has a TTY, staff in the hospitals may not know how to use them appropriately (there are special rules for turn-taking in TTY conversations); the TTY is broken; or the TTY is inaccessible to the hospital staff (G.I., T.S.). These data suggest that hospital compliance with section 504 is poor.

As stated in the literature, standard procedures in a hospital often inhibit communication. Several persons experienced anesthesia, which affected their vision and level of consciousness (N.M., E.B., D.T.). After an operation, these deaf persons fortunately had access to a skilled interpreter, relative, or friend who informed medical personnel as to the person's level of functioning.

No informant I queried indicated that he carried a Medic Alert or identification card to indicate his deafness, but all informants felt that such identification would be a good idea in emergency situations.
language. Even if a hearing researcher stays in the field for several years, he may not learn ASL but rather PSE through his interactions with Deaf persons. When the researcher encounters a Deaf person fluent in ASL but with minimal English skills, the researcher will then be stymied. Thus I would expect hearing researchers' ethnographies of the Deaf community to be biased towards those with better English skills, as in my sample. A Deaf researcher may be able to transcend language difficulties to substantiate statements concerning the nature of the Deaf community.

On the other hand, a member of a local Deaf community needs to confront another problem in performing anthropological research. Hearing researchers have noted that gossip, both "social control" and "social glue," is pervasive throughout the Deaf community (Becker 1980:90, Nemon 1980a:22, Schlesinger and Meadow 1972:175-176). Several informants (e.g., K.K., N.U.) told me that fear of gossip among the Deaf limited my opportunities to find other informants, and I imagine that a Deaf person with strong ties in a local Deaf community would also encounter difficulties in finding people to interview due to possible gossip. A Deaf person outside a local community might be perceived to be less of hazard regarding gossip and might thus be able to find more informants by convenience sampling.

5.1.2 The Sample. As Schroedel (1984:622-623) might have predicted, the convenience sample of deaf persons was of higher socioeconomic and educational status than the deaf population at large. One cannot even be certain that the small sample accurately represented the population of deaf persons of high socioeconomic and educational status.
performed with Deaf persons, the only way to begin to comprehend the multiple factors affecting health care among the Deaf is to use anthropological methods.

Yet several improvements could have been made in the methodology of this study. No informant was interviewed twice to check for consistency or omissions in the data, and no participant observations involving any informant were performed. As Pelto and Pelto (1978:74) state, "key-informant interviewing is used to best advantage when it is closely integrated with participant observation." But the design of a future study need not be different from the designs Nemon and I used; as Pelto and Pelto (1978:286) note, "patient hesitation, recycling, and replication" is valuable for improving the state of anthropological research.

5.1.4 Specific Issues for Future Studies. Throughout the research, the role of the Deaf community in health care was poorly characterized. My tentative impression, in Gordon's (1964) terms, is that the Deaf community is culturally assimilated with the hearing population with respect to health care but not assimilated in other aspects. In the research I collected no information relevant to health beliefs or practices that might mark a particular subculture (in the sense of Harwood 1981) among the Deaf. Such a subculture may nevertheless exist; perhaps my sample and methods were too limited to detect such a phenomenon.

Provider-patient communication emerged as a dominant theme in this study, but one difficult to characterize due to limited information. The findings concerning interpreters clearly need to be elaborated. One way to study communication and beliefs among the Deaf
professional fields can be studied fruitfully. Studies of students can identify characteristics that may be associated with quality of later interactions with deaf patients. They can thus complement anthropological studies of health care for deaf adults, which must concentrate on the interaction between the deaf persons and the professional "finished products."

5.2 Conclusions. Anthropological methods can advance the understanding of the relationship of Deaf adults to health care beyond giving "helpful hints" on communication to analyzing problems of beliefs, practices, and attitudes. They can also complement other types of studies to explore the items in Harwood's (1981) inventory. I hope that this paper can serve as a blueprint for future studies concerning Deaf adults and health care by giving relevant background information, by pointing out the methodological limitations of the present study, and by suggesting new avenues for research.
2C. NATURE OF THE VISIT
---Did anyone else go with you? (If yes) Who?
---What actually happened after you arrived?
---How well did the provider(s) meet your expectations?
---How did you communicate with the provider(s)?
   ---Writing (If yes) Did you bring a list of problems?
   ---Speaking/Lipreading
   ---Signing/Fingerspelling
   ---Through an Interpreter (If yes, ask who & how found.
      If no, inquire into opinion of interpreters.)
---Were these methods the ones you would have preferred to use?
---How well did you understand the provider(s)?
---How well did the provider(s) understand you?
   (Everything, Almost Everything, Some, Very Little)

JUSTIFICATION: Some of these questions were used by Lass
et al. (1978). I wanted to ask a tactful question about
the phenomenon of pretending that Nemon (1980a:21) dis-
cussed, but I could not find the right wording for such
a question. I suppose I could have asked "Have you ever
heard about other deaf people pretending to understand
health care providers when they didn't really?"

3. AFTER LEAVING
---What did the provider(s) tell you to do after you left?
   Did you follow the advice?
---In retrospect, how did you feel about the entire
   experience? Could any aspect of it have been improved?

JUSTIFICATION: These questions follow Harwood's concern
with "adherence to biomedical treatment" (item VIII).

4. ALTERNATIVE CARE
Have you ever sought care from an alternative care provider
(such as a chiropractor, acupuncturist, herbalist)?
(If yes) How did you decide to do so? (go to question 2B)

JUSTIFICATION: These are based on Harwood's (1981) item
VI, "coping with illness outside the mainstream medical
system."

5. FAMILY AND FRIENDS
Has anyone else in your family been sick recently?
(If yes) Who? What happened? (go to question 2A or 2B)
How do your family & friends influence your decisions about
health care?
If your family and friends do not influence you, how do you
learn about health care issues?

JUSTIFICATION: Since I did not have a comparison group,
I wanted information about the opinions and experiences
of persons close to the informants.
9. EDUCATION

---What schools have you attended and for how long?
---What type (oral, residential, mainstream, etc.) were they?

JUSTIFICATION: Educators assert that type of education is significant in determining outcomes in later life. In addition, attendance at a residential school is one marker for membership in the Deaf community.

10. COMMUNICATION: Please rate your skills (Good, Fair, Bad, None) in:

---Expressive ASL Signing
---Receptive ASL Signing
---Expressive English-like Signing
---Receptive English-like Signing
---Fingerspelling
---Reading Fingerspelling
---Speaking
---Lipreading
---Writing
---Reading

JUSTIFICATION: Schein and Delk (1980) asked for a self-assessments of communication ability for comparison with communication methods actually used.

11. MISCELLANY

---How old are you?
---What race are you?
---What is your occupation?
---How much income do you and any other family members earn in one year? That means pay, profits, welfare, pensions, etc. Please tell me the correct letter:
  A. 0-$10,000
  B. $10,000-$20,000
  C. $20,000-$30,000
  D. $30,000-$40,000
  E. $40,000 or more
---What type of medical insurance do you have?
---Is there anything else that I missed during the interview that you think is important for me to know?
---How do you think other deaf people you know would respond to the questions I asked?

JUSTIFICATION: The first four questions in this set ask for information on the standard demographic variables. The last two questions gave me information on how the interview schedule might be improved and how my results might have been different if I had a larger sample.
2. **HOW MANY DEAF PERSONS HAVE YOU HAD CONTACT WITH? (CIRCLE ONE)**

   Zero 1 or 2 3 to 5 more than 5
   (10) (8) (2) (4)

3. **PLEASE BRIEFLY DESCRIBE YOUR RELATIONSHIP TO THE ONE OR TWO DEAF PERSONS YOU HAVE HAD THE MOST CONTACT WITH. (CLASSMATE/CO-WORKER/FRIEND/RELATIVE/ACQUAINTANCE/ETC.? HOW MUCH CONTACT DO/DID YOU HAVE WITH THE PERSON?) [Space given for person #1 and person #2.]**

4. **WHAT METHOD(S) OF COMMUNICATION DO/DID YOU USE WITH THE ONE OR TWO DEAF PERSONS DESCRIBED IN QUESTION 3? (CIRCLE AS MANY AS APPLY)**

   **PERSON #1:**
   GESTURES SPEECH/LIPREADING FINGERSPELLING/SIGN LANGUAGE WRITING AN INTERPRETER OTHER: ____________________________

   **PERSON #2:**
   GESTURES SPEECH/LIPREADING FINGERSPELLING/SIGN LANGUAGE WRITING AN INTERPRETER OTHER: ____________________________

[Methods of communication are coded as GEST, SPCH, LPRD, FGSP, SIGN, WRIT, and INTR respectively. For some deaf persons, respondents circled only one or the other of "speech/lipreading" and "fingerspelling/sign language." I estimated the closeness of each deaf person to the respondent based on the answers to question 3, and listed the deaf persons below in decreasing order of estimated closeness.]

<table>
<thead>
<tr>
<th></th>
<th>GEST</th>
<th>SPCH</th>
<th>LPRD</th>
<th>FGSP</th>
<th>SIGN</th>
<th>WRIT</th>
<th>INTR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Best Friend In College</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Close Friend</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daughter Of A Friend</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Summer Roommate</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ASL Teacher</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-Worker</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Children In Swim Class</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friend On Swim Team</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boy Who I Grew Up With</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Classmate In College</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grandmother</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Choir Member's Partner</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Male Friend &amp; His Lover</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Acquaintance</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Friend Of My Parents</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friend At Summer Camp</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Friend Of A Friend</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Man In ASL Class</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Patient At Free Clinic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Preschool Kids</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Acquaintance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Sister Of A Friend</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Man And Wife</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

**Totals** 10 17 19 7 8 6 6
PLEASE CIRCLE THE LETTER OF THE BEST ANSWER:

10. OF THOSE WHO MARRY, APPROXIMATELY WHAT PERCENTAGE OF PERSONS DEAF FROM CHILDHOOD MARRY OTHER DEAF PERSONS?
   a. 10% (3) COMMENT: Several surveys have shown
   b. 30% (3) the percentage to be about 80%. I
c. 50% (6) don't believe any more detailed
d. 70% (8) Correct research has been performed concern-
e. 90% (2) Correct the nature of this phenomenon, but
No Response (2) anecdotal evidence indicates that
community play a role in choice of hearing or deaf spouse.

11. APPROXIMATELY WHAT PERCENTAGE OF PERSONS BORN DEAF HAVE 2 DEAF PARENTS?
   a. 10% or less (17) Correct COMMENT: Only a small percentage
   b. 20% (3) of deaf children are deaf due to
   c. 30% (1) genetic causes. In addition, the
   d. 40% (0) number of deaf persons is very
   e. 50% or more (2) small compared to the number of
   No Response (1) hearing persons, and so the number of
parents due to nongenetic causes is less than the number born deaf to
hearing parents due to such causes.

12. THE PERCENTAGE OF PERSONS PROFOUNDLY DEAF FROM AGE 2 YEARS AND WHOSE SPEECH IS UNDERSTANDABLE TO STRANGERS IS APPROXIMATELY:
   a. 5% (6) Correct COMMENT: It probably depends on who
   b. 15% (7) the "stranger" is; people who have
   c. 25% (7) worked with the deaf may be
   d. 35% (2) accustomed to "deaf speech." I'm
   e. 45% (1) not aware of any detailed surveys on
   No Response (1) this topic, but the percentage is
the separate but unanswerable question "what percentage COULD have
developed good speech, but didn't have the opportunity?" which is very
hotly debated. In any case, persons who become deaf after age 3 have
an excellent chance of developing usable speech if they have already
started to talk.

13. A PROFESSIONAL SIGN LANGUAGE INTERPRETER INTERPRETING FOR A
   HEALTH PROFESSIONAL SHOULD SIT OR STAND:
   a. next to the patient (1)
b. next to the doctor (10) Correct
c. about midway between the doctor and patient, a little to the side
   d. unobtrusively out of the way (3)
COMMENT: The deaf person receives all of his/her information through
the eyes, so that he/she must be able to see both the interpreter and
the doctor at the same time to pick up nonverbal cues from the doctor.
ENDNOTES

1. (Page 3) To represent English sentences, MCEs require (1) many modified ASL signs (usually in the form of substituting one handshake for another) to achieve a one-to-one correspondence with English words; (2) invented signs for words that have no equivalent sign in ASL (e.g., "she," "the," "was"); (3) invented signs for affixes such as "un-" and "-ness"; and (4) forced meanings or roles (e.g., noun instead of verb) for existing ASL signs that may not correspond with their meanings or roles in ordinary ASL. Any of these four features of MCEs can be found in PSE, but features (2) and (3) are especially rare in PSE (P.O.).

2. (Page 3) Signing Exact English is commonly called "SEE" but more accurately called "SEE II" since an MCE invented previously, "Seeing Essential English," also had the acronym "SEE." Another MCE, "Signed English," may be gaining in popularity in educational programs for deaf children, but all other types of MCEs seem to have disappeared from general use (Reagan 1985, Baker and Cokely 1980, P.O.).

3. (Page 5) The problems with the figures cited are as follows. First, grade equivalent scores on standardized tests may not correspond well to raw or percentile scores. Second, any changes in reading level after deaf persons leave school has not yet been documented. Third, the figures may serve a self-fulfilling prophecy as do statements concerning social maturity of deaf children (Delgado 1982). Finally, confounding factors such as SES, additional handicaps, and type of schooling (oral, mainstream, residential) are not considered.

Nevertheless, that increasing hearing loss corresponds with lower levels of education (NCHS 1982) and with lower scores on the Paragraph Meaning section of the Stanford Achievement Test (DiFrancesca 1972:12, 18, 24, 29, 35) suggests that the average reading level of PD adults is quite low indeed.

4. (Page 13) One article (Roberts and Franklin 1983) is not aimed towards professionals but rather lists "guidelines for hearing-impaired patients [which] may enhance the ease and effectiveness of their interaction with health care providers." These guidelines include: (1) telling providers that one is hearing-impaired; (2) using interpreters appropriately (e.g., signing slowly when necessary for the interpreter to understand); (3) arranging for compensation and minimal inconvenience for the interpreter; (4) describing the medical problem concisely and scientifically; and (5) requesting that "complicated or confusing medical instructions be put in writing."

5. (Page 32) The experiments referred to demonstrated that a person's recall of interview data is colored by previous experience. Suppose that the informant narrates a story of an election in a small town. On recall, the interviewer may omit important details such as the "rows of burnt-out lightbulbs in the school gym which symbolized the incumbent's incompetence." In addition, the interviewer may add details not present in the story; if the interviewer believes that all polling places have voting booths, he will recall the presence of the booths even when there were none.
# INTERVIEWS CITED

<table>
<thead>
<tr>
<th>Initials&lt;sup&gt;a&lt;/sup&gt; and Year</th>
<th>Hearing/Deaf</th>
<th>Data Quality&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>E.B. 1985</td>
<td>hearing</td>
<td>2</td>
</tr>
<tr>
<td>T.G. 1985</td>
<td>hearing</td>
<td>1</td>
</tr>
<tr>
<td>G.I. 1986</td>
<td>deaf</td>
<td>2</td>
</tr>
<tr>
<td>N.I. 1985</td>
<td>deaf</td>
<td>3</td>
</tr>
<tr>
<td>K.K. 1985</td>
<td>deaf</td>
<td>2</td>
</tr>
<tr>
<td>T.K. 1984</td>
<td>hearing</td>
<td>1</td>
</tr>
<tr>
<td>N.M. 1985</td>
<td>deaf</td>
<td>3</td>
</tr>
<tr>
<td>S.N. 1985</td>
<td>hearing</td>
<td>2</td>
</tr>
<tr>
<td>B.S. 1985</td>
<td>deaf</td>
<td>3</td>
</tr>
<tr>
<td>T.S. 1985</td>
<td>deaf</td>
<td>2</td>
</tr>
<tr>
<td>D.T. 1984</td>
<td>deaf</td>
<td>1</td>
</tr>
<tr>
<td>E.T. 1985</td>
<td>deaf</td>
<td>1</td>
</tr>
<tr>
<td>N.U. 1985</td>
<td>deaf</td>
<td>2</td>
</tr>
<tr>
<td>C.Z. 1984</td>
<td>hearing</td>
<td>1</td>
</tr>
</tbody>
</table>

<sup>a</sup> Initials are assigned randomly to informants to protect privacy. As stated on page 1, "Where the text contains information that might be used to match initials to an informant, no specific citation is given" in the text.

<sup>b</sup> "3" indicates use of a recording device (videotape or audiotape); "2," notes taken at the time of the interview; "1," notes taken from memory after the interview. More than one method was used for some interviews; the method of highest fidelity is listed in these cases. In general, interviews with hearing persons were more informal than those with deaf persons (see section 3.1).
Gallaudet Research Institute
in press Deaf Children in America.

Geertz, Clifford

Gordon, Milton M.

Harte, Thomas J., et al.
1973 Differentials in the Health Care of the Sensory Deprived. Catholic University of America, Department of Sociology, Studies from the Bureau of Social Research, No. 6.

Harwood, Alan, ed.
1981 Ethnicity and Medical Care. Cambridge, MA: Harvard University Press.

Higgins, Paul C.

Jacobs, Leo M.

Jensen, Karen M.

Joiner, Allie M.
1978 A Study of Third/Fourth Year Medical School Students' Knowledge of Deafness. National Leadership Training Program, National Center on Deafness, California State University at Northridge.

Jordan, Jerald M.

Kleinman, Arthur

Kleinman, Arthur, Leon Eisenberg, and Byron Good
Öwusu, Maxwell

Padden, Carol, and Harry Markowicz

Pelto, Perti J., and Gretel H. Pelto

Purtile, Ruth

Reagan, Timothy

Roberts, Carolyn F., and Robert R. Franklin

Rose, Susan, and William Yust

Rutherford, Susan D.

Schein, Jerome D., and Marcus T. Delk

Schlesinger, Hilde S., and Kathryn P. Meadow

Schroeder, John G.

Shuman, Malcolm M.