

## Genetic Counseling for Deaf Adults: Communication/Language and Cultural Considerations<sup>1</sup>

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*It has been estimated that at least 50% of congenital or early onset deafness loss has a genetic etiology. Genetic services have traditionally been utilized by hearing parents of deaf children. Deaf adults could also greatly benefit from genetic counseling services. However, many deaf adults do not seek genetic services due in part to the communication/language and cultural differences of this group. Deaf people communicate in various ways including the use of sign language, oral communication, writing, or a combination of these modes. Also, while some deaf individuals are part of the hearing culture, others are part of the Deaf culture which has its own language, values, and traditions. Culturally Deaf individuals do not see themselves as handicapped or disabled. The genetic professional's awareness of the communication/language and cultural needs of this group, as well as their agency's responsibilities under section 504 of the Rehabilitation Act of 1973, may increase the accessibility of genetic services and contribute to the provision of successful genetic counseling for deaf adults.*

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**KEY WORDS:** deafness; Deaf culture; sign language; interpreters; oral communication; 504 law.

<sup>1</sup>Throughout this paper, the term "deaf" will be used to denote a person who audiotogically has a hearing loss which may range from mild to profound and may be sensorineural, conductive, or mixed. However, the term "Deaf" is used to denote cultural deafness.

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## INTRODUCTION

Almost 21 million Americans have been reported to have some type of hearing loss, which may range from mild to profound (Hotchkiss, 1989). Deafness is heterogeneous, having many genetic and environmental causes. Genetic types of deafness may be congenital or develop in childhood or adulthood. To date, between 175–200 different types of genetic hearing loss have been described; approximately one-third of these occur as part of a complex syndrome. These types can be distinguished by the pattern of inheritance, audiologic characteristics, age at onset, and clinical course (Konigsmark and Gorlin, 1976; McKusick, 1990).

The incidence of congenital severe to profound deafness in the United States is approximately 1 in 1000 births, representing between 2000–4000 infants born each year (Bergstrom, 1980). Complex segregation analysis has been used to determine that at least 50% of these cases have a genetic etiology, with approximately 60–80% inherited in an autosomal recessive model, 15–30% through a dominant mode, and 1–2% X-linked (Fraser, 1976; Rose *et al.*, 1977). Recent DNA linkage technology has been applied to the localization of genes for various types of hereditary deafness (Barker *et al.*, 1990; Foy *et al.*, 1990; Kimberling *et al.*, 1990; Lewis *et al.*, 1990). This technology has great potential for increasing our understanding of the specific genes involved.

The need for genetic counseling for deaf individuals and their families has been recognized by Nance (1971, 1977) for several years. Traditionally, genetic counseling has been utilized by hearing parents of deaf children who may be concerned with the etiology of deafness in their child, medical intervention, and the “risk” of having other deaf children. Nance and co-authors (1977) suggested that counseling may be even more relevant for deaf adults who want to learn about the cause of deafness in themselves and who have questions related to child-bearing issues. Even individuals with known environmental causes of hearing loss can benefit from genetic counseling. Genetic counseling may provide the first opportunity for the deaf individual to discover how the environmental event actually caused the hearing loss, and how this may affect future children. Deaf people with Congenital Rubella syndrome may have an increased risk of developing diabetes and thyroid disease (Clarke *et al.*, 1984; Shaver *et al.*, 1984). Genetic counseling that includes information about these risks can be an important part of the overall health care of these individuals. Additionally, the deaf adult, as a member of the general population, may also be “at risk” for birth defects or genetic conditions based on maternal age, family

history, and/or ethnic background, and may seek genetic counseling for information related to these issues.

Although the need for genetic services for the adult deaf population has been recognized, health care providers have had little exposure to the communication/language and cultural factors that may present barriers when deaf people attempt to access medical services and receive quality health care (DiPietro *et al.*, 1981). Recently, there has been increased awareness that large segments of the United States, including the deaf population, are medically underserved due to religious, cultural, and linguistic differences, geographic isolation, and/or poverty (Biesecker *et al.*, 1987; Paul and Kavanagh, 1990). More attention has been given to the special communication needs of the deaf adult in the medical setting (Dav-enport, 1977; Langham-Brown, 1981; DiPietro and Knight, 1982; Wood, 1987; McEwen and Anton-Culver, 1988; Meyers *et al.*, 1989), as well as to issues specific to genetic counseling (Boughman and Shaver, 1982; Arnos, 1990; Israel, 1989). These recent efforts may help to reduce barriers and increase access to medical services.

Deaf individuals are part of a minority group based on their audiologic commonalities. However, deaf people are also individuals whose language, communication modes, and cultural beliefs may vary. This paper addresses some of the communication/language and cultural differences that exist in the deaf population, some of the potential barriers in accessing and utilizing medical and genetic counseling services, and some methods that may increase quality genetic services for this population.

## COMMUNICATION AND LANGUAGE PERSPECTIVE

### Communication Choices Among Deaf People

There is a wide range of communication options used by deaf individuals in the United States, which may include manual communication (sign language), speech/speechreading, and writing/reading. Some deaf individuals may be proficient in only one type of communication. Other deaf individuals may use a combination of different communication systems depending on the setting and whether they are communicating with deaf or hearing persons. Telephone communication for the deaf individual may occur through voice with the assistance of hearing aids and telephone amplifiers, through the use of interpreters or relay services, or through assistive devices called telecommunication devices for the deaf (TDDs).

## Sign Language

Sign language is the preferred means of communicating for many deaf individuals. Sign language is a general term that may include a variety of different types of manual communication. In the United States, the language used by many Deaf people is American Sign Language (also called ASL.) ASL is a linguistically recognized language that differs from English. It is a visual-gestural language created by Deaf people and has its own grammar, syntax, idioms, and history. The grammar and syntax of ASL are expressed through specific movements and shapes of the hands and arms, eyes, face, head, and body posture (Baker and Cokely, 1980; Bellugi, 1980).

ASL differs from other forms of sign communication. A number of systems have been created to represent English manually. Although these manually coded English systems may borrow from American Sign Language, they make use of English grammar, syntax, and meaning. Some systems used today include Signing Exact English and Signed English (NICD, 1987a). Some users of English sign systems simultaneously use spoken English. Another form of sign communication is Pidgin Signed English (PSE) which is a combination of elements of ASL and English that evolved naturally from situations in which users of ASL interacted with users of English (Baker and Cokely, 1980).

Knowledge of and/or proficiency in one type of manual communication does not indicate that a person can communicate effectively using another type of sign language. ASL structure is so different from English structure that it would be impossible for a person to simultaneously speak full English sentences and sign the same message in ASL (Johnson *et al.*, 1989). Additionally, sign language varies from country to country and may even vary within regions of the same country. Therefore, deaf and hearing people who know one sign language cannot necessarily communicate with other deaf people around the world. However, a separate international sign language (Gestuno) has been developed, which allows deaf and hearing individuals from across the world to communicate with others who know this sign language.

## Oral Communication

Some deaf individuals communicate orally, through the use of voice and speechreading (lip reading). Others may use this mode in combination with a signing (English) system, or in situations where they would not otherwise be understood. A deaf person's use of voice or voice quality may not be an indication of the degree of hearing loss or of the person's ability

to understand speech. Speech therapy, residual hearing, the use of hearing aids, and the onset of hearing loss after the development of speech may all contribute to a deaf person's use and quality of speech. Profoundly deaf individuals may have very intelligible speech but may be unable to hear a conversation and speechreading skills may vary.

Speechreading may be defined as the ability to understand a speaker's spoken communication by watching the movement of the lips, face, and body. Situational clues and prior knowledge of the language being used are important tools. Factors that may contribute to a person developing good speechreading skills include the amount and type of training and the degree of language comprehension (Kaplan *et al.*, 1987). Speechreading training requires instruction about visually confusing phonemes, which are the smallest unit of speech that distinguishes one sound from another (Katz, 1985). For example, the visual information on the lips accompanying the production of many sounds is identical to that accompanying other sounds (homophenes), and many sounds may be either invisible or difficult to see (Rodel, 1985). However, it is also felt that some individuals have a natural aptitude for speechreading. Kaplan and co-workers (1987) conclude that intelligence, degree, and duration of hearing loss, and educational level do not seem to be associated with the level of speechreading skill.

Several factors can interfere with accurate speechreading. If the speaker limits his/her mouth opening or lip movements, this can make it difficult to speechread. However, speech that is exaggerated or slowed down for the benefit of the speech reader may distort the visible patterns of speech. Other factors that can interfere with accurate speechreading include mumbling, talking with hands over the mouth, or poor eye contact. Men who have mustaches and/or beards may make it more difficult to speechread if their mouth is partially or totally covered. Additional factors may include settings where the deaf person is likely to experience anxiety, stress, fatigue, unfamiliar terminology, and poor or inadequate lighting (DiPietro *et al.*, 1981; Kaplan *et al.*, 1987). While some deaf individuals may be skilled speechreaders, others are not and/or may prefer not to rely on this form of communication. Therefore, effective communication through speechreading may be dependent upon a combination of factors including the skills of the deaf person and hearing speaker, as well as the situation and setting where the interaction takes place.

### Telephone Communication

Some deaf individuals are able to communicate on the telephone through the use of voice, with the assistance of hearing aids and/or tele-

phone amplifiers. However, many people with severe to profound deafness are not able to communicate on the telephone using voice. Assistive devices for the telephone, called telecommunication devices for the deaf (TDDs, previously called TTYs—teletypewriter machines) enable deaf people to type phone messages over the telephone network directly to another person who has this same equipment. A TDD may be portable and resembles a typewriter with an additional device that accommodates the handset of a regular telephone. The conversation is printed on a display area, so that communicators can see the conversation. Some TDDs have the ability to print the entire conversation on paper so that a record can be maintained.

A TDD message-relay system is an alternative for a deaf person who wants to contact someone who does not have a TDD. Through a service operator a deaf person can indirectly contact a person who uses voice phone, and *vice versa*. The message is relayed word for word through the operator to the deaf and hearing persons.

### Language Acquisition for Deaf People

Many factors contribute to a deaf person's communication preferences and/or abilities and the acquisition of English (manual, verbal, and/or written) and ASL. The age at onset of hearing loss may be a significant factor. The deafness may occur at or close to the time of birth or may develop at an age following the acquisition of a verbal language. Additionally, the degree of the hearing loss and the benefit of hearing aids and/or use of residual hearing may be contributing factors. Whether parents or family members are deaf or hearing, what their primary language is, and how the family communicates may also have a significant effect on a young child's acquisition of language and his/her educational and communication choices.

In the United States, both parents of approximately 90% of deaf individuals have normal hearing (Rawlings and Jensema, 1977), and the primary mode of communication in the home is spoken English. For these hearing parents, the diagnosis of deafness in their child may be their first exposure to deafness; there may be many uncertainties about the choices they must begin to make about their child's education, and how the child and family will communicate.

Language acquisition for the hearing child of hearing parents begins in infancy and occurs through the continuous exposure to language that is heard through interaction with or around others, including family, peers, neighbors and through television and radio contact (DiPietro *et al.*, 1981; DiPietro and Knight, 1982). For many deaf children whose parents are

hearing, these same opportunities for communication, acquiring language, and learning about the world may not be present. As a result, when a deaf child of hearing parents enters elementary school, that child often lags behind children with normal hearing in the area of language skills (spoken English or sign language), general knowledge about the world, and social adaptability. Many of the 10% of deaf children who are born to deaf families have access to the acquisition of the natural language used by their deaf parents (ASL) and have a greater knowledge base about themselves, their family, and the world around them (Johnson *et al.*, 1989; Meadow-Orlans, 1990).

Formal education also has a profound influence on language acquisition and refinement. The type of school the person attends, the communication mode that is used, and the interaction the deaf person has with other deaf peers and adults in the school and home environment, all contribute to a deaf person's acquisition of a spoken, written, and/or manual language. Educational options may include residential schools for the deaf in which deaf children live and study at school, day school programs exclusively for deaf students, self-contained day classes through public school systems, and mainstreamed classes where deaf children attend classes with hearing classmates for all or parts of the day (NICD, 1987b). The communication focus of these educational settings may differ; some programs use one or a combination of sign language systems (ASL and/or English), and some schools utilize lipreading and speech exclusively (oral communication). Other programs adopt a philosophy of total communication which accepts and uses a range of methods of communication, including sign, spoken English, and lipreading.

Deaf education over the last two centuries has been faced with much conflict and debate over how deaf students should communicate, and how, where, and what they should be taught (Moore, 1990). Although there has been an increase in educational opportunities for deaf individuals, many researchers believe that our educational system has failed to meet the needs of deaf students (Johnson *et al.*, 1989). Studies of school achievement have shown that deaf students continue to fall behind hearing children throughout their school years. In 1983, the scaled score performances on the reading comprehension and the mathematics computation subtests of the Stanford Achievement Test were measured for deaf high school students. The mean reading level of 18-year-old deaf high school students was at a third grade level, and the mean mathematics performance was at a sixth to seventh grade level. Hearing students' reading and math performances by the same testing at 15 years of age (few students over 15 years take the Stanford Achievement Test) showed a median performance of a tenth grade equivalent in both areas (Allen, 1986). It was concluded that hear-

ing-impaired students lag behind their hearing counterparts in reading and mathematics. However, the researcher cautioned that careful descriptions of subgroups of the population, including region of the country, school program, ethnic group, degree of hearing loss, and additional handicaps, must be taken into account when evaluating student performances. Through research and program development, professionals in the fields of education, anthropology/sociology, psychology, mental health, and linguistics continue to explore these complex and controversial issues in educational and developmental aspects of deafness (Moores and Meadow-Orlans, 1990).

### COMMUNICATION NEEDS IN GENETIC COUNSELING

The communication preferences and needs of deaf people can present one of the most significant obstacles to health care delivery (Lass *et al.*, 1978; Schein and Delk, 1980; DiPietro *et al.*, 1981; McEwen and Anton-Culver, 1988). The genetic staff's knowledge of the communication and language issues that are related to deafness is the first step toward challenging this potential barrier.

In genetic counseling, there is no single mode of communication that will work best for every deaf client. The type of communication that is used with each deaf client will depend on the deaf person's preferred means of communication, which may be through sign language, oral communication, reading and writing, or a combination of these modes.

### Legal Issues

In 1973, Section 504 of the Rehabilitation Act was established to protect the deaf person's right to effective communication in health agencies that receive federal financial assistance. In accordance with this law, each health care agency develops a central office within the agency which is responsible for coordinating communication services for deaf patients. This office has a full list of available communication options for the agency's deaf patients, which may include qualified sign and oral interpreters, flash cards, supplementary hearing devices, and written communications. If an interpreter is requested by the deaf client, the agency has the responsibility to obtain an interpreter at no additional cost to the client (National Center for Law and Deaf, 1988, 1989). Hospital administrators, the U.S. Department of Health and Human Services, and/or the National Center for Law and Deaf at Gallaudet University can assist health care staff in learning how they can be in compliance with this law.



In health care agencies that receive federal funding, TDDs are mandated by the 504 law. More recently, Title IV of the Americans with Disabilities Act (ADA) of 1990 requires telecommunication services to be expanded to benefit individuals with hearing loss. Within 3 years after the date of enactment of the ADA, telephone companies will be required to provide both intra- and interstate telephone relay services. The ADA will require that relay services be available 24 hours a day, 7 days a week, without any restrictions on the type or length of the call, or the number of calls that can be made by a relay user (Strauss, 1990).

The availability of telephone communication for deaf individuals—either directly through the use of TDDs within the genetics center or hospital, or indirectly through relay services—can reduce barriers to accessing genetic and medical services. Additionally, these services offer a means for deaf individuals to follow-up on questions that may develop and/or clarify information following a visit.

### Using an Interpreter

Interpreters (sign and oral) can offer one of the most effective ways of facilitating communication between hearing and deaf persons (N.J. Department of Human Services, 1990). The role of the interpreter is to convey accurately all messages between deaf and hearing individuals. The interpreter has the obligation to interpret everything that is said, using the communication mode that is most easily understood or preferred by the deaf person. If the deaf person's preferred mode of communication is an English sign system, the message may be presented word for word. If ASL is used, the interpreter may depart from the exact words, where concepts and idioms are presented in a more descriptive way. The interpreter strives to convey as accurately as possible the speaker's thoughts, feelings, and attitudes, so that the meaning of the original message is retained. The interpreter does not enter into the conversation, voice personal opinions, or edit the conversation while interpreting (Reisman *et al.*, 1977; N.J. Department of Human Services, 1990).

The Registry of Interpreters for the Deaf, Inc. (RID) has established a national certification system to test the skills, ethics, and professional behavior of interpreters. There are different levels of certification depending on the interpreter's skill in the languages of ASL and English. Oral interpreters may also be certified (Frishberg, 1986). The 504 law does not require that interpreters be certified, but they must be qualified. A staff person who "knows sign language," may not be qualified to interpret adequately. Additionally, successful communication may not occur when a fam-

ily member or friend is used as an interpreter because of confidentiality and/or emotional issues that may be involved.

Just as there are different levels of interpreters based on their signing skill, there are specialty areas in which an interpreter may or may not be proficient. These areas may include legal, mental health, and medical matters. Medical interpreters may be knowledgeable about some of the procedures involved in a genetic counseling appointment, such as the terminology used in taking a family and medical history and the physical exam (Barnum and Siebert, 1987). However, interpreters may have limited exposure to some of the technical genetic terminology. Contacting and/or meeting the interpreter before the appointment to review the counseling process and genetic terms that will be used may help facilitate communication during the session. Some interpreters may find it useful to have a list of words with their meanings prior to the counseling session. In 1983, Gallaudet College published the booklet "Signs for Genetic Counseling" (Boughman and Shaver, 1983) with the cooperation of geneticists, linguists, native deaf signers, and other individuals with backgrounds in biology and sign language. This booklet was an attempt to standardize some signs that are commonly used in genetic counseling and it is still considered by the authors of this paper to be a valuable resource for this purpose.

Working with deaf clients through an interpreter or directly through oral and/or written modes is a challenge to the counselor's goal of accurate and clear communication. Table I provides a list of tips that may improve communication when it is provided directly or when an interpreter for the deaf is used. In either situation, it is essential that the counselor assess the deaf client's understanding of the information throughout the session. Nodding by the client, as if indicating understanding, should not be interpreted as comprehension. It may be useful to rephrase information if a point is

Table I. Tips on Communication with Deaf People<sup>a</sup>

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1. Face the deaf individual. If using an interpreter, speak directly to the client; do not use "tell him" or "ask her."
  2. Maintain eye contact with the deaf person while speaking.
  3. Be aware of your facial expressions and body language when talking.
  4. Have adequate lighting, so that the deaf person can see your and/or the interpreter's face without interference of bright light.
  5. Speak clearly at a normal pace and volume. If the deaf person does not understand what you have said (directly or through the interpreter), try rephrasing or rewording the sentence.
  6. When speaking, do not cover your mouth or have objects such as pens close to your mouth.
  7. Have only one person talk at a time.
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<sup>a</sup>Kaplan *et al.* (1987); New Jersey Department of Human Services (1990).

not clear, or ask the client to summarize what you have discussed to check on his/her understanding of the material. Clear, concise, organized information which is complemented by the use of visual charts or illustrations whenever possible may help describe concepts (Jensen, 1985). Due to the communication needs of deaf clients, modifications can be made in "how and when" visual charts are used. For example, a hearing client can "listen" to an explanation and focus on an illustration at the same time (and does not need to maintain eye contact with the counselor during this time). This process is different for the deaf client who is relying on visual cues for communication. In this situation, the counselor must continue to maintain eye contact with the deaf client while an explanation is given before moving to the illustration. In this way, valuable information will not be missed during this client's transition from one visual medium to another.

### **Medical and Family History Information**

As with all clients, an understanding of the deaf person's educational background and previous exposure to medical terminology is needed from the outset of the session. Many deaf individuals may have little exposure to medical terms (Schein and Delk, 1980; McEwen and Anton-Culver, 1988) and may never have had a biology or genetics course. For many deaf individuals, there may be a lack of exposure to medical terms and discussions of health at home, work, or school. There may be fewer opportunities for incidental learning about the health care process through TV and radio. Although printed materials about health care topics may be available to the deaf person, this information may not be written at the appropriate reading level for the average deaf adult. In a study by Lass and co-workers (1978), the words "nausea" and "allergic" were found not to be well understood by a deaf population when presented in written form. Similarly, McEwen and Anton-Culver (1988) noted that fewer than 50% of their population could correctly identify the meaning of "gallbladder, stools, sober, anxiety, erection, and nausea." DiPietro and co-workers (1981) report that some deaf college students have been known to confuse the terms "constipation" and "diarrhea" or believe them to be identical. Some deaf individuals may have a limited knowledge of their past medical history. Since the majority (90%) of deaf persons come from hearing families, there may have been fewer opportunities for interaction and communication with family members to learn about health care and their own past medical history. Additionally, because of communication barriers between themselves and the medical community, facts about their medical history may not have been fully understood (DiPietro *et al.*, 1981; DiPietro and Knight, 1982).

Therefore, medical history may need to be documented through requests for medical and audiological records. Family history information may also be limited for many deaf individuals. Knowledge of the family history or access to this information may again result from poor communication at home and should not be considered a reflection of intelligence or desire to learn this information. To help the deaf client obtain this information, forms written at an appropriate reading level with questions about the client's medical and family history can be sent in advance of the appointment with recommendations that the client share this form with his or her family. Additionally, the genetics professional can offer to contact the client's family directly to review this information.

Communication barriers may contribute to a deaf person's lack of knowledge and/or understanding of the health care process. These obstacles may also limit a deaf person's access to genetic services and interfere with successful genetic counseling. However, deaf persons' perception of genetic counseling may also be influenced by their cultural definition of deafness, how they view their own deafness, and their preferences for deaf or hearing children.

### CULTURAL PERSPECTIVE

Deaf persons' cumulative experiences through family and school environments and their social interaction with deaf and hearing peers and adults, help to shape their cultural perspectives. Some deaf adults are part of the hearing culture, other deaf individuals, although they live and work with hearing people, are members of Deaf culture. Additionally, there are a large number of people who have a progressive hearing loss, or develop hearing loss in adulthood who may feel that they are caught in between hearing and deaf cultures. A great sense of isolation may result. Communicating with the hearing world becomes difficult or tiresome; speech may no longer be understood without visual clues, and the use of voice telephone is difficult or impossible. These individuals may also feel uncomfortable with culturally Deaf individuals because of beginning signing skills or lack of common experience.

"A culture is a set of learned behaviors of a group of people who have their own language, values, rules for behavior, and traditions" (Pad-den, 1980). The Deaf population in the United States is a closely knit group bound together by history, common experience, and language. A Deaf person may be born into Deaf culture, as is the case with those who have Deaf parents, or may become enculturated later in life. Since the majority of deaf individuals are from hearing families, in contrast to most cultures,

the great majority of individuals who are part of the Deaf culture do not join at birth but choose this culture themselves (Padden and Humphries, 1988).

An “all important” value of Deaf culture is respect for its language—ASL (Padden, 1980). Through ASL, Deaf people learn about their culture and share their experiences (Baker and Cokely, 1980). The exact number of Deaf people in the United States is not known, however, it is estimated that ASL is used by 250,000–500,000 people in the United States and Canada (Baker and Cokely, 1980; Padden and Humphries, 1988).

In general, Deaf people disassociate themselves from speech. Among other Deaf people, speech is almost never used. The fact that a deaf person does not use speech may not be an indication of that person’s ability to use speech, but may rather be a reflection of their Deaf cultural values. However, some Deaf persons may use their speech in situations where they would not otherwise be understood, such as with hearing persons (Padden and Humphries, 1988). A person’s degree of hearing loss does not necessarily determine a person’s cultural identity. There are many Deaf people who audiologically have a mild or moderate hearing loss. Conversely, there are individuals with a severe to profound loss who are not culturally Deaf.

Culturally Deaf people do not see their deafness as a “disability,” but as a cultural difference. Padden and Humphries (1988) state that:

... “disabled” is a label that historically has not belonged to Deaf people. It suggests political self-representations and goals unfamiliar to the group. When Deaf people discuss their deafness, they use terms deeply related to their language, their past, and their community (p. 44).

This view may be reflected by the preference of the Deaf community to use the term “Deaf” (cultural viewpoint) or “deaf/hard of hearing” (from an audiologic viewpoint) rather than “hearing impaired.” Bienvenu (1989) describes “hearing impaired” as a derogatory, negative term which does not show respect for the Deaf community. However, other individuals (deaf and hearing), including parents of a child with hearing loss, may prefer to use “hearing impaired,” seeing this as a more polite, less threatening term. Therefore, how individuals refer to themselves (or to a family member) may give important information about their cultural ties and perspective on deafness.

Deaf people tend to socialize within their cultural group. Across the country there are Deaf clubs and organizations, both social and political, where Deaf people interact. Approximately 90% of deaf people (culturally Deaf or not) marry another deaf person (Schein, 1989). Additionally, many Deaf persons feel that it would be more desirable to have deaf children

because of the communication ties that will exist and the strong desire to preserve Deaf culture (Bienvenu and Conomus, 1985).

For the deaf client who may not view his deafness as a handicap, and who may have a great sense of pride in being Deaf, traditional medical terms used in genetic counseling may create barriers to accessing genetic services and for effective genetic counseling to occur (Arnos, 1990a). Terms such as "risk," "affected," and "abnormal," tend to suggest that deafness is a handicap and may reflect a hearing cultural bias. Culturally Deaf individuals may see geneticists as professionals who want to change or "cure" genes for deafness. Therefore, the Deaf couple who prefer to have deaf children may lack the motivation to seek genetic counseling in a setting where their cultural and communication choices are perceived to be misunderstood. The genetic professional's conscious use of neutral words, such as the "chance" to have "hearing" or "deaf" children may contribute to successful communication.

### SUMMARY AND CONCLUSIONS

Deafness is heterogeneous, having many genetic and environmental causes. Genetic types of deafness may be congenital, develop in childhood or adulthood; the degree of hearing loss may range from mild to profound and can be progressive. It has been well recognized by geneticists and other professionals that deaf individuals and their families would clearly benefit from genetic services to learn about the etiology of deafness, medical considerations, and childbearing issues. Traditionally, genetic centers across the country mainly serve hearing parents of deaf children, but have seen relatively few deaf adults in genetic counseling who may be seeking information related to the etiology of their deafness and/or for unrelated issues. This may be due in part to the communication/language and cultural differences of this group. When deaf adults do seek genetic services, communication/language and cultural factors may also create barriers to successful genetic counseling.

Deaf people are individuals whose communication/language modes and cultural beliefs may vary. Some deaf individuals may communicate through sign language, others may prefer oral communication through speech and speechreading. Communication through writing may complement other modes of communication. However, for some deaf individuals who have poor reading and writing skills, communication solely by written form may not only be time-consuming, but there may be limitations to what the deaf person can understand.

In preparing for the deaf client, it is essential that the counselor have a knowledge of the deaf person's preferred mode of communication. The deaf client can be asked in advance whether a sign language interpreter (ASL or English sign language), oral interpreter, or direct communication is preferred. If an interpreter is requested, the administrative office within the hospital or agency can be contacted to determine who is responsible for coordinating communication services for deaf clients. Health care agencies that receive federal financial assistance are required by Section 504 of the 1973 Rehabilitation Act to provide an interpreter at no additional cost to the client. Private agencies that do not receive federal financial assistance may not be required to provide interpreters. In these situations, deaf clients may need to make their own arrangements for interpreters. Genetic centers can develop communication guidelines on how to work with deaf clients based on their hospital's/agency's requirements. Local interpreting services and/or the Registry of Interpreters for the Deaf, Inc., a national organization, located in Rockville, Maryland can provide additional information on the availability of interpreters in specific regions of the country.

Telephone communication through telecommunication devices for the deaf (TDDs) and relay services may help to increase the utilization of genetic services by deaf people. Genetic counselors spend countless hours on the telephone with clients making appointments, discussing the genetic counseling process, and gathering information for visits and for follow-up information. For deaf people who are unable to use voice telephone, the lack of easy telephone communication with genetic centers can create barriers to accessing services. TDDs are relatively inexpensive and are portable. Some genetic centers that serve or expect to serve many deaf individuals may want to purchase a TDD for their center's own use. Agencies that receive federal funding will have a TDD available for general use by all staff members. An alternative to using a TDD for communication is a relay service, which may be state or volunteer funded.

Deaf people may view their deafness in different ways. Some deaf individuals who are part of the hearing culture, may see their deafness as a "handicap" and may be concerned about the "risk" for future children to be deaf. Other deaf individuals are culturally Deaf who do not see their deafness as a "disability" but as a cultural difference. These values may be reflected in a Deaf's person's views on marriage and family; deaf children may be preferred and hearing children may be considered a "risk." Neutral medical terms that reflect an understanding of Deaf culture, such as "chance," "deaf," and "hearing," can be used in place of traditional medical terms such as "risk," "affected," and "normal."

Individuals who are deaf may feel part of the hearing or deaf culture, or may feel that their needs are not met by either group. There are several national organizations, including the National Association of the Deaf (NAD), A.G. Bell Association for the Deaf, Self Help for Hard of Hearing People, Inc. (SHHH), and the Association of Late Deafened Adults (ALDA), which provide social support and advocacy for these different groups of individuals.

Lectures and workshops may be provided to deaf groups, parent groups, medical professionals, audiologists and special interest groups in deafness. With an awareness of the communication/language and cultural issues that may influence genetic counseling, geneticists/genetic counselors can network with professionals who serve deaf clients, and also educate deaf individuals and their family members about the benefits that can be received from genetic counseling services.

Genetic counseling for the deaf adult population offers many challenges for genetic professionals. Attention to the communication/language and cultural issues and choices that exist for the deaf population will help to increase the accessibility of genetic services and the success of genetic counseling.

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