

Health Care Delivery and Deaf People: Practice, Problems, and Recommendations for Change

Lisa M. Harmer

University of Rochester School of Medicine

Due to complex individual, interpersonal, and systemic factors, deaf and hard of hearing (d/hoh) individuals often receive inadequate, inappropriate, and unethical health care. This article begins with a review of the relevant socioeconomic and legal issues and the health status of d/hoh individuals. I then review health care starting with the patient's knowledge base, personal experiences, and understanding of health care relationships. I discuss the Deaf community's perspectives, providers' views about disability, communication between providers and deaf patients, and barriers encountered in health care delivery. The article concludes by assessing these factors' effects on health care delivery to d/hoh people, reviewing the ethical implications, and making recommendations for change.

What the scalpel is to the surgeon, words are to the clinician. . . . [T]he conversation between doctor and patient is the heart of the practice of medicine (Swartz, 1998, p. 43).

From the first day of medical school many future physicians are told that the majority of diagnoses are the product of a thorough medical history developed through conversation with the patient. "[I]t is primarily through language that the physician works to establish rapport and trust. Good physician-patient communication is fundamental to good health care" (McEwen

& Anton-Culver, 1988). The doctor-patient relationship is often viewed as the cornerstone of health care delivery (Epstein, Campbell, Cohen-Cole, McWhinney, & Smilkstein, 1993; Stoeckle & Billings, 1987). Studies have shown that effective communication between a patient and his or her doctor can have a significant positive effect on patient satisfaction and health outcome (Kaplan, Greenfield, & Ware, 1989; Starfield et al., 1981).

Deaf and hard of hearing (d/hoh) individuals in the United States must often cope with extraordinary communication barriers when working with their health care providers; receive health care services that are inadequate, inappropriate for their needs, and unethical due to the interplay of numerous complex individual, interpersonal, and systemic factors; and have a poorer self-reported health status than the general population. Within the subset of the U.S. population that uses English as a second language, deaf individuals may be at greatest risk for poor physician-patient communication (McEwen & Anton-Culver, 1988).

Approximately 9% of the U.S. population (roughly 21.2 million people) have a hearing impairment, making hearing loss the single most common chronic physical disability in the country. Of that group, roughly 1.8 million Americans are deaf (Steinberg, 1991).

Despite the prevalence of hearing loss in this country, the delivery of health care services to people with hearing loss is poorly understood by the average physician. In addition, the limited research that has been done on this subject to date is inadequate to properly

Funding for this work was provided by the University of Rochester School of Medicine. The views expressed in this article are not necessarily those of the university. I thank Sarah Trafton, JD, Robert Pollard, PhD, and Steven Barnett, MD, for their support and guidance in the preparation of this manuscript. Correspondence should be sent to Lisa Harmer, Box 212, University of Rochester Medical Center, Rochester, NY 14642 (e-mail: Lisa_Harmer@mc.rochester.edu).

define the problem or identify ways to improve the quality of health care services offered. Yet, in 1990, the Americans with Disabilities Act included legal criteria about what constitutes "adequate communication" between health care providers and d/hoh patients. As a result, substandard communication between d/hoh patients and their doctors, and the receipt of health care services substantially different from those received by hearing individuals, is often illegal. Health care providers and administrators would be wise to learn more about health care delivery to this population both to improve the quality of care offered and to avoid costly legal entanglements.

Some of the difficulties in health care service delivery to people with hearing loss stem from societal prejudices towards people with disabilities. American society has a strong tendency to set a single definition of "normality" as the most important goal for all individuals. This bias has been internalized by many health care providers in this country and can affect every aspect of a d/hoh child's life (Roush, 1986; Schlesinger & Meadow, 1972). This prejudice makes it even more important for the health care provider to understand the issues involved in health care delivery to this population, appropriate communication strategies, the impact of hearing loss on an individual and his or her family, and Deaf culture.

This article examines the factors affecting health care delivery and d/hoh patients, reviews the relevant literature, discusses associated ethical issues, and recommends needed changes. It is intended to benefit health care providers and other professionals involved in the delivery of services, allocation of resources, and development of health care programs.

I begin with a review of pertinent background issues, including socioeconomic factors, the current health status of d/hoh people, and relevant legal issues. Then I review health care delivery using a progressively larger focus, starting with the patient's health care knowledge base. A review of the typical deaf patient's personal health care experiences, his or her understanding of health care relationships, and the perspective of the Deaf community follows. The provider's perspectives on disability issues, communication between providers and deaf patients, and the barriers en-

countered in health care delivery to this population are then discussed.

The article concludes with an assessment of the impact of all of these factors on health care delivery to d/hoh people, the ethical implications of the current standard of care, and recommendations for change. I hope that this information will allow providers to offer a higher quality of care to d/hoh individuals and their families than has been available previously.

The Deaf Population

Definitions and causes. Many definitions of "deaf," "Deaf," and "hard of hearing" have been used over the years. Here, "deaf" and "hard of hearing" will refer to individuals who have a hearing loss of any magnitude. "Deaf" will refer to individuals who share a common language (American Sign Language, or ASL), experiences, and set of beliefs that are different from the white, hearing, middle-class norm in U.S. society (Glickson, 1994; Padden & Humphries, 1988).

Hearing impairments can be caused by genetic factors, environmental conditions, and illness. To date, nearly 200 types of genetic hearing loss have been described. Of these causes, roughly a third occur as part of a complex syndrome that can produce significant health problems (Israel, Cunningham, Thumann, & Arnos, 1992). These individuals need more complex health care services than the average patient and also face significant barriers in their efforts to receive this care.

Population statistics. The number of people in the United States who are d/hoh is not known precisely. As I remarked above, one report notes that 22 million Americans have a hearing loss, and of these people 1.8 million are members of the Deaf community (Rich, 1993). Yet another study identified 4.3% of the U.S. population as having a severe to profound bilateral hearing loss (this would equate to roughly 8.8 million people) (Meyers, Melhado, & Frances, 1989).

As the U.S. population has aged between 1971 and 1991, the incidence of hearing loss in the United States has increased 53%. Of the 20.3 million persons (86 per 1,000 persons) identified as having hearing trouble,

11.5 million had a significant loss, and of these, 4.8 million could not hear and understand normal speech (U.S. Department of Health and Human Services, 1991). These trends likely will continue well into the next century as the baby boomers age. Notably, more than 50% of people over the age of 80 have a significant hearing loss (Zazove & Doukas, 1994).

One in 1,000 children is born with severe to profound hearing loss, and four to five children per 1,000 have a hearing impairment significant enough to affect language acquisition (Lotke, 1995). It has been estimated that 25% of all profoundly deaf children have an additional handicap, most frequently a learning disability (Brookhauser & Moeller, 1986). Learning disabilities often affect a child's ability to learn and integrate health information, and physical disabilities only increase an individual's need for high-quality health care.

Socioeconomic, educational, and sociocultural issues. The U.S. Department of Health and Human Services (1991) census report noted that people in the United States who identified themselves as having trouble hearing also identified themselves, on average, as having a lower income, a greater level of unemployment (70.8% vs. 29.4%), less education (did not complete 12 years of education, 44.1% vs. 27.1%) and more careers in blue collar and service industry jobs (40.2% vs. 27.1%) than the general population. The report also found that "persons with trouble hearing had proportionally more annual bed days because of health problems, more annual doctor visits and greater limitation of activity due to chronic conditions, than persons with normal hearing had. This relationship holds across the entire age span and within specific age groups."

All of these factors (less income and education, greater unemployment) have been shown to correlate with lower level of physical health and greater difficulty understanding and communicating with health care providers (Byrne & Edeani, 1984). In addition, the number of blue collar jobs in the United States, jobs frequently held by deaf individuals, is declining (Smith, 1992).

Moreover, low-income deaf individuals also tend to be un- or underinsured. The combination of poor insurance benefits and inability to pay privately further

contributes to difficulty obtaining health care services (DiPietro, Knight & Sams, 1981).

Deaf individuals who belong to an ethnic minority group are at an even further disadvantage than white deaf people. In a study of support services for parents of deaf children, nonwhite parents and those who did not attend college reported receiving much less support than well-educated white parents (Meadow-Orlans, Mertens, Sass-Lehrer, and Scott-Olson, 1997).

White deaf youths are more likely to be mainstreamed and have higher levels of academic achievement than nonwhite deaf youths. In addition, socioeconomic level also affected students' elementary school placement and level of academic achievement in high school. Deaf students from a higher socioeconomic bracket have been shown to be more academically successful than low-income deaf children (Kluwin, 1994).

In a nonrandomized survey, the children of nonwhite deaf adults stated that their parents "had far less access to economic and educational resources than the already restricted opportunities available to European-American deaf people" (Preston, 1996). In a study by Meadow-Orlans et al. (1997), minority parents of deaf children reported that deafness had had a more negative impact on their family, that their deaf children had more behavior problems, and that these children made less progress in language development than their white peers.

People who are deaf and also belong to an ethnic minority group can find themselves trying to learn and negotiate three or more languages and cultures. They include the culture and language found in their home, the culture and language of the Deaf community, and the culture and language of the hearing American community (Hindley, 1997). For example, a study by Walker-Vann (1998) showed that more than half of the deaf Hispanic children surveyed were exposed to three distinct languages and cultures. Spanish, with one set of cultural expectations, was the preferred means of communication in the home, English and community behavioral norms were needed in the students' neighborhoods, and sign language and a third set of behaviors were necessary to communicate in school and with deaf peers. Becoming fluent in any one of these languages would be difficult for any deaf child who has

limited exposure to the target language. Mastering three would be an extraordinary feat.

Wu and Grant (1997) detailed the myriad issues that can arise when working with Asian-American families with a deaf member: the family's immigration history; description of their child's characteristics; home environment, including language and intergenerational relationships; school environment; the needs and priorities of the family relative to the needs and priorities of any one individual; and the native culture, gender, age, and birth order of the child in the family. These issues can have a tremendous impact on the family's interactions with health care providers and other professionals. The authors point out that understanding these forces is crucial in learning how the family communicates with nonfamily members, responds to stress, recognizes and treats health and illness, understands deafness, solves problems, and seeks help, for example. Many, if not all, of these factors likely would also apply to any other family that has recently emigrated to the United States.

Gender issues. Deaf women must counter discrimination against disability, deafness, and their gender. "Disability, particularly early onset disability and disability that severely limits functional abilities, conditions the manner in which women perceive themselves and their place in society, as well as the manner in which society responds to them and makes its resources available to them" (Nosek et al., 1995).

Smith (1992) cites a study demonstrating that deaf women have less income and education and higher levels of unemployment and divorce than hearing women. In addition to the fiscal and social problems brought on by these factors, they also further reduce a woman's opportunity to access health insurance through a spouse.

Recognizing that the culture of health care institutions is often distinct from the dominant culture of a society, Phillips (1996) writes:

Within a hospital culture the viable ideas and values of cultural minorities may be devalued, discredited and marginalized, thus becoming twice removed from the dominant culture. If these ideas come from women the ideas and values become

three times removed, and if these women are disabled the ideas and values become four times removed and thus further marginalized from the dominant culture and from credibility in the eyes of the dominant institutions.

The most subjugated and underprivileged individuals tend to be deaf women of color. On average, they are poorer, less healthy, and less educated than white women. Minority deaf women also have the greatest difficulty accessing services due to cross-cultural differences in value systems, languages, lifestyles, and goals (Becker, 1981). It appears African American deaf women are at the greatest disadvantage of all deaf people (Wells, 1991).

Holcomb (1984) notes that "the most serious barriers to careers and education [faced by disabled women] are not physical, but attitudinal." In addition to the numerous communication and educational barriers all deaf people face when attempting to interact with hearing society, Smith and Kirkpatrick (1985) list additional issues, including self esteem, body image, dependence, social and sexual vulnerability, accessibility, and lack of role models.

The communication difficulties between deaf children and their hearing parents further restrict the health care resources available to many deaf individuals. During childhood and adolescence deaf children living in residential schools learn to rely on their school-age deaf peers for information and support. As adults, they continue this pattern. For example, most deaf women receive significantly less support and guidance from their mothers and other female relatives than hearing women do. By necessity they tend to turn to each other for information and assistance. This dependence on and identification with the Deaf community "is reinforced by negative experiences in the hearing world that underline the difficulties of communication. As a result, deaf women have extremely restricted resources, usually limited to their peers and to the few agencies that serve the deaf community in any locale" (Becker, 1981).

Health care information. As Braithwaite and Lythcott (1980) observe, "Poverty and powerlessness create circumstances in people's lives that predispose them to

the highest indexes of social dysfunction, the highest indexes of morbidity and mortality, the lowest access to primary care, and little or no access to primary preventive programs.”

Nosek et al. (1995) note that women who are uninsured or poor are the group least likely to have had a Pap smear or mammogram in the past year. Women who do not use screening services and then contract cervical or breast cancer are diagnosed at a later stage of disease than those who received regular screening. Late-stage cancer is less treatable; thus, these women experience higher mortality rates than those who access screening services.

Conducting surveys of the health care status of and service utilization by d/hoh individuals is very difficult. Identification of a homogenous, randomized sample; communication challenges; researcher bias; and distrust held by individuals in the Deaf community of hearing people have all contributed to the challenges in this area.

In recent years a number of studies on the health status, knowledge, and service utilization of d/hoh people have been conducted. However, the results tend to be colored by a nonrandomized and small sample size; inappropriate methodologies or use of testing instruments; lack of differentiation between pre- and postlingually deafened individuals and subjects who identify themselves as being deaf, Deaf, or hard of hearing (Schroedel, 1984).

The use of fortuitous samples of deaf adults, often individuals associated with a social organization or those who respond to advertisements seeking study subjects, imposes serious limitations on any study. These sample populations tend to be better educated and have a higher socioeconomic status than the average deaf individual. In addition, this sampling technique tends to underrepresent people of color, women, younger adults, and those with fewer financial and social resources. Therefore, the results of the study may include significant bias if the results are extrapolated to represent the deaf population as a whole (Schroedel, 1984).

Not surprisingly, the results of many of these studies often conflict. For example, some studies note that deaf patients visit the doctor more frequently than average hearing patients. Other studies state that deaf patients visit less frequently. The following paragraphs

present a chronological review of health care research conducted in the United States in the past 30 years.

Lass, Franklin, Bertrand, and Baker (1978) assessed the level of health knowledge and practices of a fortuitous sample of 36 deaf adults. The vast majority of respondents had a lower health information knowledge base than the hearing population, 44% said they had “trouble communicating with their doctor,” and 41% lacked the literacy skills to understand simple medical prescriptions.

Nemon (1980) conducted a survey of d/hoh individuals to learn their degree of satisfaction with their health care providers and assessment of their health status. Those individuals who had more health problems *and* believed they received sufficient information from their physicians experienced greater satisfaction and less stress about their health status than those individuals who felt they were physically healthier but also believed they received insufficient information. Survey respondents frequently felt their doctors rushed through their appointments, wondered if this was done because they were deaf, or believed their health care providers “discounted and disbelieved” them.

Kurz, Haddock, Van Winkle, and Wang (1991) attempted to analyze the effect of hearing loss on use of health care services through analysis of the 1971 and 1977 National Health Interview Surveys. They found that individuals with hearing loss visited the doctor significantly more often than did hearing persons. However, the authors combined the responses of individuals with unilateral and bilateral hearing loss into one group to compare with the general population. The educational, cultural, medical, and sociological experiences of an individual with unilateral hearing loss will likely be very different from someone who has a bilateral loss. In addition, the age of onset of hearing loss (pre- or postlingual) was not addressed. The experiences of pre- and postlingually deafened individuals are typically very different, which has a significant impact on the health care sought and received by the individual.

A nonrandomized survey of d/hoh people by Zazove et al. (1993) reported that deaf people visit physicians more frequently than do hearing people, but the deaf individuals report less satisfaction with the health care services they received. Fifty-nine percent of those surveyed stated they understood their physician

“sometimes” or “not at all.” Zazove hypothesized that deaf individuals may keep returning to physicians to seek assistance for problems and answers to questions that were not understood in prior visits. In that study d/hoh individuals also said when they attempted to exchange written notes with their doctor, the doctor’s writing was often illegible, or the physician wrote at a level that was beyond the literacy skills of the patient. In addition, patients regularly underwent tests or received prescriptions without understanding why the action had been undertaken.

Barnett and Franks (1997) analyzed the health status and health care use of d/hoh individuals using the 1990–1991 National Health Interviews Survey data. The study showed that prelingually deafened adults had fewer physician visits in the preceding year in comparison with both postlingually deafened adults and the general U.S. population.

In the mental health arena, a survey by Steinberg, Sullivan, and Loew (1998) asked a group of Deaf adults about the barriers they perceive surrounding mental health services access. Those surveyed discussed their general mistrust of providers as well as their concerns about communication processes in therapy, and they demonstrated ignorance about mental health terminology and available services. Participants viewed “both mental health institutions and practitioners as authoritarian, restrictive, and prejudiced.” Deaf mental health patients were perceived as powerless victims of the prejudiced hearing providers, and many survey participants believed that deaf individuals may be mistakenly committed to a mental institution because of the communication barriers, not due to the existence of psychopathology. Thirty of the 54 adults surveyed stated they were unable to locate mental health services that were perceived to be accessible.

Rendon (1992) has reported that deaf individuals have an increased incidence of alcohol and substance abuse than the hearing population. The author notes that the deaf community tends to view these illnesses as a “moral problem” of the individual rather than an illness that requires health care services. Those deaf individuals who do seek services for substance abuse are usually unable to find appropriate, accessible treatment programs (Guthmann & Sandberg, 1998).

In the areas of sexual abuse and sexually transmit-

ted diseases (STDs), the situation is even worse. Many deaf teenagers lack basic information about human sexuality, birth control, and related topics. These gaps make deaf youths more vulnerable to abuse and places them at increased risk of unwanted pregnancy and STDs (Kleinig & Mohay, 1991; Sullivan & Knutson, 1998).

Sullivan, Vernon, and Scanlan (1987) reviewed four studies that had attempted to evaluate the prevalence of sexual abuse of deaf youths living in residential schools. Deaf students were asked if they had ever been sexually abused. The rates of abuse reported by these students in the four studies were significantly higher than the rates reported by hearing students. These studies had serious flaws. Among other concerns, the definition of “sexual abuse” used in the studies was not specified, and the living situation (a residential school, institution, or home environment) of the hearing students used as a comparison group was not included. In addition, cultural norms surrounding disclosure of sexual abuse may differ in Deaf and hearing communities. However, it does appear that deaf students living in residential schools are at higher risk for sexual abuse than the average child in the United States.

Individuals who have been sexually abused are at tremendous risk for short- and long-term emotional damage; they are more likely to contract STDs, to sustain other physical injuries, and to experience an unplanned pregnancy. Sullivan and Knutson (1998) cite a study that demonstrated that “boys who are deaf and attending residential schools who have been victims of both physical and sexual abuse are more likely to develop drug and alcohol problems and become perpetrators of sexual abuse” than nonabused peers.

Sullivan et al. felt the deaf students were at greater risk for sexual abuse than hearing children due to the communication difficulties they experience, isolation in residential schools, naiveté about sex in general, and lack of education about appropriate behavior in relationships. In addition, deaf children are typically taught to comply with authority figures, and that training, combined with all of the typical reasons children do not report abuse (fear of reprisals or retaliation, fear they will not be believed, bribery or rewards for complying, fear of removal from their homes or schools) may make deaf children both more vulnerable and have

fewer support systems in place should they attempt to seek help. Even worse, Sullivan believes some staff working with deaf students may lack the necessary sign language skills or vocabulary to understand a deaf child should they attempt to report molestation or other abuse (see also LaBarre, 1998).

Mertens (1996) described factors that contribute to sexual abuse in residential schools for deaf students. Staff members at one residential school were asked why they felt deaf students were sexually abused. Some staff blamed the victims, the residential school system (poor supervision of students), or Deaf culture itself (one respondent said that “sexual abuse [was] a behavior that members of the deaf culture tolerated”). Other staff denied that a problem existed.

However, it should not be assumed that deaf children living in residential schools are at increased risk for abuse than deaf children living in other settings. The lack of research on deaf children living in nonresidential environments makes it impossible to know if those children are abused more frequently, less frequently, or at the same rate as children educated in a residential setting.

In the past 15 years the AIDS epidemic has had a significant impact on the deaf population, but few health care providers seem to know it. Doyle (1995) cites a report noting that the Deaf community is approximately 8 years behind the hearing population in AIDS knowledge and awareness. Most deaf people “have been exposed to very little information about sex in general and about AIDS in particular. They think AIDS is a hearing person’s disease. Or, if they accept that a deaf person could get it, they think it’s only a gay disease” (Anonymous, 1995a).

It has been estimated that 7,000 deaf individuals in the United States currently have AIDS. The deaf population as a whole has a seropositive (HIV-positive) rate double that of the hearing population (Anonymous, 1995b), and up to 26,000 deaf individuals in the United States are currently HIV-positive (Van Biema, 1994). However, many deaf individuals have only a rudimentary understanding of human sexuality, ways to protect themselves and their companions from STDs, methods of birth control, access to “safer sex” education programs, and HIV education and support services (Anonymous, 1995b; Peinkofer, 1994; Taylor, 1993).

A study by Luckner and Gonzales (1993) showed that deaf adolescents “demonstrated important gaps in their knowledge of HIV and AIDS. For example, when asked if junior and senior high school students could contract the disease, 19% of the deaf adolescents said this was not possible, and 21% stated they did not know the answer to the question.

Baker-Duncan, Dancer, Gentry, Highly, and Gibson (1997) attempted to assess the AIDS knowledge of deaf high school students living in state residential schools through an anonymous survey. Five of the 43 schools contacted agreed to participate. The students in the participating schools demonstrated “extremely limited” core knowledge about AIDS, and their knowledge level changed very little as they progressed through high school. Furthermore, “there is the very real possibility that students in the [38 schools] that did not participate . . . have an even lower knowledge of AIDS than those who did participate” (Moores, 1993).

Legal issues. On the legislative scene two federal laws have been enacted in the past 25 years that have had a profound impact on the d/hoh populations and health care delivery: the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. In addition, individual state policies and regulations on health care delivery, allocation of resources, and related topics also affect health care delivery at the local level. The Rehabilitation Act of 1973 required most institutions receiving federal funds to make their programs and services accessible to people with handicaps, including ensuring “effective communication” with people with hearing loss (Golden & Ulrich, 1978).

The second, the Americans with Disabilities Act, included a section guaranteeing the right of people with disabilities to equal access to health care and health education programs as those without disabilities. Health care providers are required to provide aids to their d/hoh clients so that the communication between the deaf consumer and provider is equal to that between hearing consumer and provider. These aids may include qualified sign language interpreters, notetakers, written materials, assistive listening devices, and other services. The costs of these accommodations are to be viewed as one of the general costs of doing business and are not to be billed to the patient, nor are they

to be directly equated with the health care service fees paid by the deaf individual (National Center for Law and Deafness, n.d.).

The expectations of individual health care providers mandated by the Disabilities Act depend on their health care setting, the needs of each patient, and other factors. In general, any health care provider who is offering health care services, training, or educational programs to the general public is required under the act to make these programs and services equally accessible to d/hoh people (National Center for Law and Deafness, n.d.).

Recent surveys of practicing physicians have demonstrated an extraordinary level of ignorance about the act and the doctor's obligations under this legislation. All of the 165 physicians surveyed at recent conference "displayed ignorance about their legal obligations under the" act to their deaf clients. Education about the act is needed by physicians, clinic hospital administrators, and others so they can offer comparable health care services to their deaf consumers and avoid legal entanglements (Ralston, Zazove, & Gorenflo, 1996).

In recent years a growing number of d/hoh patients have begun suing their health care providers for failing to comply with the Disabilities Act (Charmantz, 1998; Crocker, 1997a; Zazove, 1997) and many are winning. Recent rulings have regularly supported the right of some deaf patients to be provided with qualified interpreters when working with their doctors in both inpatient and outpatient settings. These rulings include *People v. Mid-Hudson Medical* (1995).

In other rulings, a deaf woman was awarded \$250,000 against two New York hospitals. The hospitals failed to provide her with interpreter services during one hospitalization and offered only sporadic interpreter services during subsequent hospitalizations (Crocker, 1997b).

In 1998 four patients were awarded \$700,000 after their local hospital consistently denied them interpreters over the past 10 years (Charmantz, 1998). That lawsuit is only one of six filed by attorney Clara Smit on behalf of deaf patients who were denied interpreters and other services while receiving health care. As of July 1998 two suits have been settled in favor of the plaintiffs, and four are still pending (Gold, 1998).

In *Tugg, Ponder and Carpenter v. State of Florida De-*

partment of Health and Rehabilitative Services (Tugg v. Towe, 1994), the court went even further than simply requiring providers to provide interpreters for those patients who need them. In this case the U.S. District Court in Florida found that counseling and other mental health services provided by a hearing health care provider and an interpreter was not of the same quality as services received by hearing patients, and were therefore in violation of the Disabilities Act. The court ruled that the Department of Health and Rehabilitative Services hire, when available, health care providers "with sign language ability, who possess by training, education, or experience an understanding of the mental health needs of the deaf community."

Patient Health Care Knowledge Base

Adequate treatment requires that the patient understand what is wrong and be motivated to follow through with the proper therapy. . . . Efficient utilization of medical services by patients presupposes knowledge of proper hygiene, nutrition, medical terminology, basic health care procedures, and familiarity with common diseases and the health care system. The limited knowledge of many deaf patients because of the communication handicap further complicates health care delivery. (DiPietro et al., 1981)

The "average" deaf person has a lower level of English literacy, a smaller fund of health care knowledge, and fewer health education opportunities than his or her average hearing counterparts. All of these characteristics are vital to the patient's understanding of health and illness, access to both care and information, and awareness and utilization of treatment options. Furthermore, this lack of knowledge has a significant impact on initiative, assertiveness, the types of medical services sought, and quality of services delivered throughout the patient's lifetime.

English literacy and general education. Individuals who were prelingually deafened tend to have significantly poorer English skills and are more likely to have attended a residential school than postlingually deafened people. A low level of English literacy will have a pro-

found effect on an individual's health and body awareness knowledge. When one lacks good English skills, it is very difficult to benefit from health education brochures and books, it is harder to read a newspaper and gain current health information, it is difficult to write and understand notes between the health care provider and patient, and it is difficult to read and understand prescription instructions, consent forms, and other documents associated with health care services.

More than 90% of deaf children are born to hearing parents (Moore, 1996), a fact that influences the educational and cultural development of the child. Since most parents do not know sign language, the young child's opportunities to learn any language are significantly reduced. Acquisition of signed or spoken language is the main challenge facing deaf youngsters (Committee on Disabilities of the Group for the Advancement of Psychiatry, 1997). Those d/hoh children who do not receive significant language training during infancy and toddlerhood have missed the key age for language acquisition "without really acquiring any language at all" (Davenport, 1977). It has been noted that "communication also breeds communication, as the language produced for and by young children fosters subsequent language development as well as social and cognitive development" (Vacarri & Marschark, 1997).

Studies have shown that delayed language acquisition can have a profound, lifelong impact on a child's ability to use language (McDonald, 1997) and learn (Bergstrom, 1980). Deaf children who are not exposed to language during this key time are often left with significant linguistic and cognitive deficits and may suffer permanently "from what has been described as a preventable form of mental retardation" (Solomon, 1994).

Most deaf adults over age 40 did not begin school until they were 6 years old and so were not exposed to language education at a younger, more appropriate age. In spite of the increasing availability of preschool education, many deaf children still start after 3 years of age. If parents do not provide their deaf children with opportunities to learn an accessible language at home, language acquisition takes place primarily at school. The number of hours these children have to learn language is therefore significantly reduced (Davenport, 1977).

Deaf children of hearing parents often begin ele-

mentary school with fewer language skills (both spoken and signed) and a reduced fund of information about the world than the average hearing child (Israel et al., 1992). By the age of 5 almost all hearing children have developed a vocabulary of 5,000 to 26,000 words (Schlesinger, 1969). Smith (1992) cites a study noting that the average hearing 5-year-old has mastered basic grammar rules and sentence construction and learned roughly 80% of the vocabulary he or she will use in a lifetime. In contrast, the study points out that the average deaf 5-year-old knows 10 English words.

The best way to communicate with and educate deaf children has been hotly debated in the United States for more than 100 years. "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" (Israel et al., 1992). Studies have shown that the mean reading level of deaf high school students (ranging in age from 16 to 18) is between the third and fourth grade level (Baranowski, 1983; DiPietro et al., 1981). In comparison, 15-year-old hearing students have a median reading level of the tenth grade (Israel et al., 1992). This language and literacy lag can be a tremendous barrier in daily life, the workplace, and health care settings.

Only a small percentage of deaf students go on to pursue postsecondary education. "Almost one-half of deaf high school students either drop out or receive only a certificate of attendance" (Moore, 1996, p. 336). Moore summarizes a 1985 study by Ouellette: "One-third of the deaf postsecondary students surveyed intended to pursue a bachelor's degree, but only 5% actually received one. The rest . . . received degrees or certificates at or below the associate of arts level (p. 329)."

A study by McEwen and Anton-Culver (1988) looked at the language skills of English as a Second Language (ESL) students and deaf individuals. Both groups had significant difficulty understanding words commonly used by health care providers. However, the deaf individuals reported that their doctors understood them less often than the ESL students, and the deaf patients were also less likely to try to re-explain themselves.

A recent study showed that adults with poor liter-

acy skills incur higher medical costs than individuals who read at the eighth grade level or above. Although the researchers were able to demonstrate a clear correlation between low literacy and higher costs, it is not known if limited reading skills are the cause of these higher costs. The researcher hypothesized that low literacy is not the cause, but that poor reading skills are “a marker for disconnectedness . . . from society in general” (Jenks, 1992). Those with the lowest literacy skills also had a self-reported lower level of physical and psychological health than the general population, regardless of income. This may occur because these patients are unable to gather information about their health care or may not understand how to use the health care system effectively (Weiss, Hart, & McGee, 1992).

Formal health education. Many of our most serious health problems can be traced back to lifestyle choices and personal decision making by individuals (diet, exercise, use of drugs or alcohol, smoking). Poor choices in these areas can lead directly to preventable illness, morbidity, and death, and these choices are almost always made or developed during the school years. Therefore, some argue, public and private schools are uniquely suited to provide health education and decision-making skills training that will promote and enhance a child’s physical and mental health throughout his or her life. Furthermore, “because health is a means necessary to virtually all other educational ends, health education should be considered a central part of the school’s curriculum” (Seffrin, 1990).

Unfortunately, “today hardly anyone is pleased [about the state of deaf education in the United States], and one of the few points of agreement in the present debate is that deaf education is distressingly bad” (Dolnick, 1993). In addition to tremendous variation in the quality and quantity of the “three Rs” provided to deaf students across the United States, these students also tend to receive little or no education in the basic sciences (biology and anatomy) or general health education.

A recent survey of deaf schools in the United States by Getch, Young, and Denny (1998) demonstrated that 13% of those responding had no established or formal curricula that addressed sexuality education, including

basic concepts, STDS, birth control, abuse, and appropriate relationships. Those schools that have developed a formal program note tremendous difficulty finding appropriate teaching materials that did not require modification. In addition, these classes were most frequently taught as part of a previously existing class, and may be, as the authors wrote, “too little information too late.”

In addition, deaf students are typically unable to communicate easily with their parents about health information and have fewer opportunities for incidental learning than hearing students (Israel et al., 1992). “Often peer information is a young [deaf] student’s sole source of information, or at least the only information the student believes” (Durkin & Coryell, 1984).

Studies have shown that those children with greater exposure to health information during childhood are able to demonstrate a higher level of health knowledge and better health care practices than those who were not exposed (Kleinig & Mohay, 1991). It has been suggested that even modest improvement in health education in deaf residential schools would simultaneously improve the quality of life for these students and save billions of dollars in future health care costs. The health education offered in residential schools needs to include both hygiene as well as health promotion and illness prevention (Clark, 1995).

Studies have compared the body awareness knowledge of deaf and hearing children. In one, the children were matched by age, gender, and academic abilities and asked to identify as many body parts as possible. At every age the hearing children listed significantly more parts than the deaf children (84 parts vs. 27 parts) (Badger & Jones, 1990). In a second study, groups of 8- to 10-year-old deaf and hearing children were asked to list as many internal body parts (bone, blood, etc.) as possible. Again, the hearing children were able to list significantly more (on average, 11 vs. 9) parts than their deaf peers (Gibbons, 1985).

Deaf students are typically naive about many health topics and are confused about many basic health concepts. A questionnaire administered by Kleinig and Mohay (1991) to both deaf and hearing high school students showed that the hearing students’ level of health knowledge was higher than the deaf students at all ages. The deaf students had limited understanding

of medical terminology, were unable to properly respond to common emergency situations described in the questionnaire, and were typically unable to accurately interpret prescriptions.

Deaf students attending Gallaudet University have attained a degree of academic success reached by very few deaf individuals. However, even these individuals typically do not have the same level of health knowledge as hearing college students. In a 1993 health education workshop at Gallaudet, more than half of the students had never heard of spermicide. A significant number of these same students still believed it was possible to acquire HIV infection by donating blood (Joseph, 1993). Peinkofer (1994) cites a study in which Gallaudet students were asked how they obtained information about sexuality and related health topics. The students said they most frequently got this information, which was often erroneous, from their peers.

The majority of deaf individuals do not attend college (Moores, 1996). Therefore, the formal health education offered to these individuals often ends in high school. It is not surprising that surveys have shown that deaf adults tend to have a limited knowledge base in reproduction and sexual development (Chacko, Buttler, & Kirkland, 1987), health care, health maintenance, and other topics vital to a high quality of life (Lass et al., 1978).

In one study of deaf adults, 76% did not know what a normal body temperature is, and the average respondent could not define 6 out of 16 common English health terms (Lass et al., 1978). In another survey of deaf adults less than half of the respondents could correctly identify the meaning of stool, sober, anxiety, erection, or nausea (McEwen & Anton-Culver, 1988).

Adult access to health information and education programs.

Deaf individuals also experience significant difficulty in accessing health care information as adults for numerous reasons (DiPietro et al., 1981; Gannon, 1998). First, the lack of access to ambient information is a major problem (Davenport, 1977). The volume of incidental information hearing individuals are exposed to each day without realizing it is staggering. This includes noncaptioned TV shows and public service announcements, all radio programs, and overheard conversations in both public and private.

Second, the typical deaf individual may have an insufficient fund of information or literacy level to benefit from many health education segments on TV that are captioned. That is, many deaf people may lack the requisite background information necessary to understand and evaluate the information presented in a captioned TV show.

Third, low literacy skills severely restrict access to health education materials of all types. These include books, magazines, brochures developed by for-profit and nonprofit health organizations, prescription instructions, informed consent papers, and all other documents associated with health care delivery.

Fourth, a lack of awareness of—or inability to access—public health education programs, including first aid, CPR, childbirth education classes, and the like is also a problem. Even those classes that provide a sign language interpreter may not be appropriate for the average deaf individual. For example, a typical childbirth education class at a local hospital presupposes that the students have a moderate literacy level and health information (including sex education) knowledge base and that they are able to learn from traditional teaching tools (handouts and noncaptioned videotapes). The average deaf adult does not meet these criteria and will probably have great difficulty participating in and benefiting from such a course (Baranowski, 1983).

Finally, the barriers deaf adults must face in an effort to learn about HIV or other stigmatizing health conditions are extensive. Inadequate schooling about human sexuality and scarcity of appropriate educational programs (especially outside the largest U.S. cities) are only the beginning. Some deaf adults may be so afraid of the stigma and isolation that can be imposed on an individual with AIDS or other undesirable conditions by others in the Deaf community that they may be too frightened to use those few HIV-related medical and social services that are available to them (Peinkofer, 1994).

Personal Health Care Experiences

More than 90% of deaf children are born to hearing parents, and most parents are stunned to learn that their child has a hearing loss. Health care professionals involved in the care of a deaf child must learn how to

effectively inform parents of a patient that their child has a hearing loss. The attitude of the provider, along with the information he or she conveys, is a critical opportunity to shape the perspective of a family that may need to work through a difficult process of shock, denial, anger, guilt, and sadness (Hindley, 1997; Miller, 1987). Failing to take advantage of this opportunity may carry lifelong consequences for the child and her family.

The extreme anxiety experienced by many parents of newly diagnosed deaf children also provides the physician with a unique opportunity to intervene and shift the family's outlook on the situation in a positive direction. These efforts can improve the parent-child relationship, and the quality of life of all family members. Unfortunately, during the early phase of diagnosis, parents typically reported that their health care providers were unable to provide substantial amounts of information about hearing loss and also failed to offer adequate support to the family (Schlesinger & Meadow, 1972).

Parents will often turn to the doctor for answers to very complex questions. "Why did this happen to me/us/our child?" "What does it mean to have a hearing loss?" "Maybe this would not have occurred if I had done. . . ." It is critical to explore with the parents "their ideas about the cause of deafness, alleviate guilt feelings and misunderstandings with known facts, and help parents develop positive avenues for beginning to cope and live with deafness in their family" (Arnos, Israel, Devlin, & Wilson, 1992).

Vaccari and Marschark (1997) reviewed a number of studies that have shown that mothers and families who received greater social supports in working with their deaf child, including early intervention programs, were more positive when interacting with their deaf child, interacted with the child more frequently, and their deaf child demonstrated better social interactions with both family members and preschool-age peers than families who received less support. Meadow-Orlans et al. (1997) list numerous studies that have shown the benefits reaped by deaf children and their families from early diagnosis and comprehensive intervention services.

Once diagnosed, the deaf child is typically perceived as having departed from the established norms of society. Parents may turn to the medical community

hoping to find a way to remove this difference and "fix" the child (Crouch, 1997). The deaf child may begin spending significant amounts of time visiting pediatricians, audiologists, otologists, speech and language pathologists, surgeons, and other health care providers. Many of these professionals will focus on the child's "broken ears," and few are likely to give much thought to the child as a whole.

In the home, parents with limited ability to communicate with their deaf child may shorten the phrase, "Brush your teeth so you don't get cavities" to simply "Brush your teeth" (Durkin & Coryell, 1984). In addition, general family health information (what health problems run in the family, a grandparent's cause of death, and related facts) may not be conveyed to the deaf child. Those children living away from home will not even be able to see the health and illness experiences of their family members (Israel et al., 1992; Kleinig & Mohay, 1991).

Typically the child will visit the health care provider with the parent, the parent and the provider will converse, and the child will have little if any understanding of what transpired or why (Durkin & Coryell, 1984; Israel et al. 1992; Kleinig & Mohay, 1991). Parents and providers are often unable to communicate complex information to the child during these visits or they do not make the time or effort to do so.

The same lack of participation is often true of deaf children living in residential schools (Nemon, 1980). The residential school student "learns that health problems, whether they are minor or severe, are to be treated by a medical professional in a health care facility. Wellness skills or self-care techniques for minor health problems never have a chance to be developed" (Durkin & Coryell, 1984). The school nurse or other providers may care for the child without including him or her in the process, again depriving the student of the opportunity to acquire health information, or develop health maintenance or illness prevention skills. Some authors believe that deaf students' dependence on others to handle their personal health care needs increases as the number of years spent in the residential school environment increases (Nemon, 1980).

Due to these experiences and ongoing communication challenges, the deaf individual may become a passive or complacent recipient of health care services

(Durkin & Coryell, 1984). The deaf adolescent and young adult may have learned to depend on others to recognize and address his or her health care needs and as a result may not even know how to accomplish it. The deaf patient has learned that health care is something that is “done to” the patient, rather than involving him or her as an active participant. These individuals may lack the initiative or self-assertiveness often needed when accessing health care services today (Jackson, 1990).

As adults, these individuals may also have significant difficulty in reporting their own health history. They were never told that an illness they experienced was the “measles,” may not have understood procedures, and have no experience actively working with providers. DiPietro et al. (1981) noted that it’s “not unusual for a hearing sibling to know the medical history of his/her deaf sibling better than does that sibling, nor is it unusual for deaf adults to have to write to a parent or school official for information about their own past medical history.”

The communication difficulties with providers also continue. Misunderstandings over any aspect of a patient’s health, including diagnosis, treatment, or procedures, can easily occur. “A hospital admission, which can be anxiety-provoking for anyone, may be nothing short of terrifying for the deaf person” (Mohay & Kleinig, 1991). The deaf patient may undergo procedures they do not understand, be unable to alert hospital staff when they need assistance, and have little opportunity to gain information about their condition (Schein, 1989).

A survey conducted by Nosek et al. (1995) asked a group of physically disabled women about their health care experiences. Several themes emerged, including the impact of the women’s experiences as children with health care providers. Particularly in the 1950s and 1960s, children were often uninformed about medical procedures in both the doctor’s office and as hospital inpatients, pain management was poorly handled, and children were often forced to comply with treatment regimens through threats, physical restraint, or violence.

Women with physical disabilities were more likely to experience emotional, physical, or sexual abuse by health care providers or personal attendants than

nondisabled women. Thirteen percent of the disabled women surveyed reported being physically or sexually abused in the preceding year. These experiences often left the women permanently scarred and had numerous significant negative effects on their lives, including unwillingness to access health care services as adults (Young, Nosek, Howland, Chanpong, & Rintala, 1997).

A lifetime of negative or highly stressful medical experiences will affect anyone’s perspective of the health care system. As a result, an individual may be unwilling to visit health care providers until absolutely necessary. Delay in seeking health care services may result in more expensive treatment, a longer recovery time, or a worse outcome than might have been experienced had the individual sought care earlier.

Patients’ Understanding of Health Care Relationships

Due to their previous medical experiences, and lack of access to information, deaf patients may have a poor understanding of the health care system and the need for personal responsibility in health care settings. They may also be unaware of their legal rights and responsibilities or be unable to work with providers effectively.

Effective health care consumers in the United States today have mastered at least three skills. These individuals have gathered information about available health care services and their alternatives, have an understanding of which services they need at a given point, and possess the skills to obtain those services through self-advocacy and persistence (Blanche, 1996). Deaf individuals are at a distinct disadvantage in all of these areas.

As a result of their prior health care experiences, limited health knowledge, and limited access to information, many deaf adults seeking health care services today may be poorly prepared to do so. These patients may be unaccustomed to sharing responsibility for their health care, have little or no experience with self-advocacy in the medical environment, or have difficulty selecting the proper venue for their health care needs.

Deaf adults may be frustrated if they attempt to continue their current health care relationships in the same manner as those they experienced as a child. Underprivileged individuals may also become intimidated

or feel out of control because they do not understand the structure, function, and expectations of the health care provider's service (Blanche, 1996).

Shared responsibility for health care. As previously noted, during childhood and adolescence deaf patients are typically passive participants in their health care. Most, if not all, of their health care needs are identified and resolved by their parents or residential school staff. The deaf adult may not realize his or her health care providers will expect him or her to take a more active role in health care. They may expect the deaf patient to diagnose and treat minor health problems at home and to make appointments and request an interpreter or other communication aids in a timely manner for moderate problems. Furthermore, they will expect the patient to give a reasonably detailed medical history and provide information about health insurance, drug allergies, and other related information. All of these tasks may be difficult for the deaf adult.

The health care provider may also expect the deaf consumer to relay this information efficiently, with a focus on the most pertinent details and a minimum of extraneous information. The healthcare "culture"—one that emphasizes rapid diagnosis and treatment, efficient use of services, and a minimum of interaction—is quite different from Deaf culture. The Deaf patient's tendency to relay information as a story, his or her greater use of facial expressions and display of affect than the average hearing person, and other cultural features may be grossly misinterpreted and unappreciated by the busy and task-oriented hearing health care provider (Phillips, 1996).

Deaf individuals seeking mental health services may also enter therapy with a poor understanding of the process. They may have little idea of what will happen or expect the mental health professional to "magically fix their problems by intervening for them in the outside world" (Hoyt, Siegelman, & Schelsinger, 1981).

Negotiation and self-advocacy in the health care setting. The rapid proliferation of managed care organizations may also pose a challenge to deaf clients. These health insurers often have stringent rules about when, where, and how patients may access care. Such rules might in-

clude seeing a primary physician for a referral, requesting permission to visit an emergency room, and using only approved health care providers.

Deaf individuals have limited opportunities to learn all of these rules and regulations. They may also be unaware that decisions made by a health maintenance organization (HMO) (or any other health insurer) can be appealed. Even if the deaf patient has this information, the insurance company may not have mechanisms in place to accept and process phone calls from deaf individuals who wish to make an appeal or even ask questions about their health care coverage.

The lack of awareness by some deaf individuals and many health care providers about the Disabilities Act, and the lack of qualified sign language interpreters, also makes the deaf patient's efforts to receive appropriate services more difficult. For example, the hospital or physician's office may not have a protocol for requesting a sign language interpreter or other accommodations, and staff may reject such requests out of hand simply because they have not made such efforts in the past. In those instances where a formal policy exists, individual staff members may not have received proper training in these regulations or may be unable to use the equipment properly.

Finally, even in those instances where deaf individuals are aware that their rights have been violated, they may be unable or unwilling to protest this treatment. Inability to access an appeals process, not having the funds to hire an attorney, or fear of future reprisals, including having the doctor refuse to provide care, could easily dissuade a deaf individual from pursuing needed health care services or accommodation in the health care setting.

Selecting proper venue for care. Deaf individuals may select their health care providers based on ease of communication rather than on the quality and appropriateness of care offered, the cost, or convenience of services.

A study of mental health service use by Pollard (1994) reviewed the services provided by community mental health centers in Rochester, New York. The study revealed that deaf clients received a disproportionately high percentage of services that required limited communication (e.g., case management) and a

smaller percentage of fundamental services (e.g., assessment and therapy) than hearing clients. In addition, the number of deaf individuals seeking services in accessible programs was significantly higher than the number of deaf people seeking care at sites that did not offer interpreter services or other accommodation.

Deaf individuals may also select an inappropriate venue for health care, again because communication is easier. Some hospitals provide sign language interpreters in their emergency rooms (ER). In these instances a deaf individual may prefer to visit the ER for care, where the communication is better, despite the fact that it is impossible to establish long-term relationships with health care providers there, no preventive care is provided, and the societal cost is higher.

The deaf consumer may also drive long distances to access care at accessible offices or hospitals. The resulting delay in treatment of emergent conditions, and the increased cost to the patients if they leave the cachement area of their health insurer, can affect a patient's health. However, the quality of care delivered once the patient arrives at the medical center is likely to be better than care that would have been received at a closer but less accessible center.

At times deaf consumers may not know which venue (an appointment in a physician's office, a walk-in clinic visit, or emergency room treatment) is appropriate for their current health problem. Some deaf individuals have gone to their local emergency room for treatment, unaware that their health problem could have been successfully treated at home and simultaneously avoided excess cost and use of services (Starr, personal communication, August 14, 1998).

A Medical History of Deafness, Education, and Health Care

History. In the United States deaf individuals have often been seen as defective, in need of the help or assistance of the able-bodied, and are usually expected to try to "overcome" the unfortunate condition that has been thrust upon them. In addition, hearing people often assume that deaf individuals would give anything to be able to hear. Some deaf or hard-of-hearing individuals may agree with this opinion; others do not

(Christiansen, 1991). The efforts of the health care community to restore a deaf person's hearing, and the classification of hearing loss as a pathology, are often resented by Deaf individuals.

Traditional research on deafness has been conducted using the perspective of the hearing majority. Lane (1988) reviewed numerous professional books and journal articles written between 1967 and 1987 and compiled a list of words used to describe the perceived characteristics of deaf people. These articles were written by the "experts" on deafness and used to educate and train future doctors, teachers, and others involved with deaf people. Lane notes:

The list describes the deaf client that the experienced practitioner imagines is seated across the table: socially isolated, intellectually weak, behaviorally impulsive, emotionally immature. The list of traits . . . is inconsistent: they are both "aggressive" and "submissive"; they are "naive/shrewd, detached/passionate, explosive/shy, stubborn/submissive, and suspicious/trusting." The list is, however, consistently negative. Nearly all the traits ascribed, even many in pairs of opposites, are unfavorable.

Lane hypothesizes that these assessments were a result of the paternalistic attitude of the hearing professionals making the judgments.

This bias has existed since the time of ancient Greece. Aristotle believed deaf individuals were comparable to animals and assumed the sense of hearing was necessary for cognition. Therefore, he reasoned, deaf people had no capacity to reason or learn.

Michel Abee de l'Epee (1712–1789) demonstrated that deaf children could learn, despite Aristotle's predictions. Once l'Epee demonstrated the value of education for deaf individuals, "professionals vied over the route [deaf students] should take to become more human" (Schlesinger, 1969). These ongoing efforts have included attempts to restore a deaf individual's hearing and highly controversial debates on the best way to educate deaf children.

The nineteenth century. The efforts undertaken to restore hearing during the nineteenth century were, at times,

barbaric. In the 1840s a French physician, Jean-Marc Itard, applied electricity to the ears of deaf children at the school for deaf students in Paris. He thought this process would stimulate hearing that had been “paralyzed” in the same way that an electric current had been shown to make a paralyzed bit of skeletal muscle contract. Itard went on to pierce the eardrums of some students and placed leeches on the necks of others, thinking that local bleeding would help. When those efforts did not restore the students’ hearing, and killed one of them, Itard tried other methods. He inserted a probe into students’ Eustachian tubes, used caustic acid to burn the ears of others, fractured the skulls of some children by hitting them behind the ear with a hammer, and finally placed a string through a student’s neck. Itard believed the purulent drainage from the wound would allow the child’s “bad humours” to dry up and cure the child’s deafness. All of these efforts failed (Lane, 1992, 1993).

As the 1800s drew to a close, a series of scientific and cultural changes swept Europe and the United States, ushering in a new attitude toward sign language and people affected by hearing loss. Itard’s successor at the French school wrote, “The deaf believe that they are our equals in all respects. We should be generous and not destroy that illusion. But whatever they believe, deafness is an infirmity and we should repair it whether the person who has it is disturbed by it or not” (quoted in Lane, 1993, p. 283).

After Itard’s experiments failed to restore hearing, it was decided that if deafness could not be “cured” or corrected by medical science, then the modern society of the late 1800s must teach all deaf children to speak and should prevent future deaf children from being born. This perspective arose in part from Darwin’s recently published theory of evolution and growing awareness of Mendelian genetics. Some reasoned that if humanity had “evolved” in its means of communication from primitive gestures to speech, then sign language was “a language low on the scale of evolutionary progress . . . supposedly forming a link between the animal and the human” (Baynton, 1993, p. 98). Furthermore, it was believed that those who could not speak could not become Christian and were “prey to the devil” (Shapiro, 1993, p. 90).

Oralism, the teaching of speechreading and speech

to deaf students and use of vocal instruction in deaf classrooms, took hold in the United States and abroad. In the 1800s nearly all U.S. schools for deaf students used sign language as their primary means of instruction and communication. By 1920 almost 80% of deaf students sat in classrooms that banned sign language entirely, and some physically punished students who were caught signing outside of class. Oralism retained its popularity among hearing educators until sign language began to reemerge in U.S. classrooms in the 1970s (Baynton, 1993).

The educational success of deaf students declined dramatically as oralism spread. Attending a class in an oral school can be compared to watching a teacher move his or her mouth all morning without uttering a sound. Deaf students who attended the American Asylum (now School) for the Deaf in Hartford, Connecticut, in the 1850s—and were instructed in sign language—were as literate as their hearing peers. As oralism spread, the academic achievements of deaf students declined, and many deaf students in oral schools were functionally illiterate (Shapiro, 1993).

Many hearing people in the 1800s incorrectly assumed that deafness was usually passed from a deaf parent to a deaf child. Nineteenth-century researchers then reasoned that laws needed to be passed to prevent deaf people from marrying and reproducing, thereby “preventing” the continuation of “inferior” human beings.

The twentieth century. In the early 1900s Alexander Graham Bell was one of the leaders of the fast-rising eugenics movement and threw his name and his money behind the American Breeders Association. The goals of the group centered on efforts to remove “socially unfit” classes from human reproductive stock. These “unfit” individuals included those with physical disabilities, paupers, vagrants, lawbreakers, epileptics, and orphans. Over the next 25 years 30 states passed mandatory sterilization laws of individuals who were diseased, disabled, or “otherwise degenerate” (Lane, 1993; Lane, Hoffmeister, & Bahan, 1996). As the first half of this century unfolded, the inaccurate perceptions of deaf individuals as being emotional immature, mentally deficient, and psychologically disturbed became more entrenched in both popular literature and professional journals (Pollard, 1993).

In the 1950s and 1960s, the primary causes of deafness among young children began to change. Prior to this time most causes of deafness were the result of illnesses (e.g., meningitis) that occurred after the child had learned English. After the advent of antibiotics, the sheer numbers of postlingually deaf children began to decline, and those conditions that continued to cause deafness were much more likely to occur before the child mastered English. These conditions (e.g., prematurity) were also more likely to cause multiple disabilities than those illnesses that typically cause postlingual deafness. As a result, a growing proportion of deaf children were both multihandicapped and prelingually deaf (Ludders, 1987).

The recent development of cochlear implants (CIs) has been seen by many in the Deaf community as the latest effort by hearing individuals in general, and the medical community in particular, to eradicate Deaf culture and hearing loss. Although the FDA has approved use of CIs in both children and adults, little independent research has been done on the efficacy of these devices in children. (It has been shown that late-deafened adults who receive CIs shortly after their hearing loss, possess some residual hearing, and are good speechreaders typically benefit from the surgery [Crouch, 1997; Summerfield & Marshall, 1995].)

The results of the use of CIs by prelingually deaf children have been highly variable (Purdy, Chard, Moran, & Hodgson, 1995). A few deaf children who have received CIs have experienced significant improvement in their sound and speech recognition skills and speech production. Many others, despite years of rehabilitative therapy and extraordinary cost, have received little or no benefit. To date, studies have been unable to determine criteria that will identify those prelingually deaf children who are most likely to be helped by the surgery. For a review of the literature of deaf children and CIs, please see Lane (1995) and Hindley (1997).

Several factors make the CI debate very controversial in both the medical and deaf communities. First, more than 90% of deaf children have hearing parents, and the majority of these parents have had no experience with individuals with hearing loss (Moore, 1996). Loudermilk (1998) notes that hearing adults typically have little or no awareness of life with deafness, do not

understand the complex and controversial issues surrounding the selection of a mode of communication with their deaf child, and have rarely met deaf adults to see how these individuals function as independent members of society. Instead, Crouch (1997) notes that these parents tend to turn to the medical community in the hope that the doctors can restore their child to “normal” or to “avert what they believe will be the tragedies of a life bereft of sound.” Further, Crouch points out that CIs were approved by the FDA for use in children in the early 1990s. Therefore, it is impossible to make any assessments of the long-term impact of CI use on both the audiologic and general health of the pediatric patient with an implant.

In addition, Pollard (1996a) notes that individuals who have gained information about CIs from the popular media or consumer literature prepared by CI manufacturers may have developed inaccurate expectations of the implants. These perceptions may have developed from the coverage of “star” patients—individuals who have experienced extraordinary benefits from their CIs—while failing to emphasize the results experienced by the majority of CI users.

Despite these limitations, the use of CIs in prelingually deaf children is expected to rise dramatically in the coming years. In 1997 one deaf child in ten had a CI (Loudermilk, 1998). Clay (1997) predicts that one in three deaf children will undergo CI surgery in the next 10 years.

Other recent developments in medical research are also of concern to many deaf people. The unprecedented interest in genetics has spurred research to identify the genetic causes of inherited hearing loss. The researchers who request the participation of deaf individuals in their work may have the long-term goal of eradicating those causes. The deaf volunteer, on the other hand, may have very different feelings or motivations for participating in the work.

Deaf subjects may wish to help society by participating in the research. Like many deaf adults, they may also wish to have deaf children and may volunteer for a research study to learn more about this possibility—a goal that may surprise many hearing researchers. At the same time they may feel that their participation in research “proves” they have adopted the perspective of the medical community, or that others may take their

participation as evidence that they hope others will not be born deaf (Grundfast & Rosen, 1992). Few researchers are aware of these issues or perspectives.

As a result of all of these events, going back to the time of Aristotle, it is not surprising that the typical Deaf adult has felt oppressed by the hearing community (Lane, 1992). The medical profession in particular is seen as having a primary focus on both eliminating the Deaf community and eradicating hearing loss. Therefore, some Deaf individuals are understandably cautious and wary when interacting with health care providers.

Deaf community grassroots health care resources. Due to this history and individual personal experiences, many members in the Deaf community feel cut off from professional health care services and are unable to access mainstream health education materials. They are often unable or unwilling to access appropriate care and frequently do not understand their health care providers when they do seek services.

In response to this situation, some members of the Deaf community, who tend to have better English skills or more formal education than the average Deaf person, are seen as grassroots health care resources. These key informants provide information and advice to deaf individuals, perhaps providing missing information or explanations, or sending them to more deaf friendly health care providers (Steinberg et al., 1998).

If, for example, a deaf woman has questions about a medication that has been prescribed for her, she may not ask her health care providers about it because she may be unable to communicate with the doctor clearly or is wary of the general goals of health care practitioners. Instead, "she may approach a [Deaf] person she considers knowledgeable, hold out the medication, and ask, 'Is this all right for me to take?'" (Becker, 1981). This woman has elected to receive potentially inaccurate information from her social circle rather than making further attempts to receive information from her health care providers.

It is unlikely that most physicians are even aware that these grassroots relationships exist. If they knew of these well-respected individuals, perhaps productive working relationships could be formed that simultane-

ously further educate the Deaf individual and improve the quality of health information reaching the Deaf community.

Diverse Perspectives on Disability and Deafness

Many physicians hold paternalistic, ethnocentric attitudes towards their patients. Doctors also tend to view disabilities as deviations from the mainstream norm that should be corrected if possible. These beliefs and preconceptions affect both provider and patient expectations, interactions, and decisions. Additional problems occur when the physician fails to recognize or appreciate the different frames of reference used by hearing and Deaf individuals when viewing many situations, including health care delivery. Deaf individuals may not perceive hearing loss as a disability and may have different goals and priorities in their health care treatment than their hearing health care provider. All of these topics are discussed below.

Disability as pathology. Physicians and other health care providers are affected by the cultural stereotypes and prejudices prominent in mainstream U.S. society. Our society tends to support three general themes toward individuals with disabilities. First, disabled people are perceived as being defective, damaged, and otherwise less marketable than the nondisabled. Second, disabled people should work to "overcome" their disabilities and try to achieve a life as similar to mainstream society as possible. Finally, our society tends to believe that disabled people prefer to "be with their own kind" (Phillips, 1990). Roush (1986) hypothesized that health care providers "may be actual perpetuators" of these negative attitudes.

The U.S. media publicize success stories of real individuals who have triumphed over illness or disability against all odds. In addition, fictional disease-of-the-week movies are regularly churned out that emphasize the tragedy involved in disability and illness, the general saintliness of affected individuals, and their inevitable victory over whatever problems they face.

In addition to accepting these general societal beliefs, many health care providers have also internalized a medical model that affects every aspect of their pro-

fessional work. The central tenet of the medical model in the United States is

the presumption of normality. Both disease and disability are assumed to be deviations from an absolute norm. . . . Once a medical diagnosis is made, the disabled person is involved ad infinitum in regimens of medical treatment, surgical restoration, and rehabilitation. Since the majority of those with a permanent disability can never be cured, restored, or normalized, they perceive themselves to be suspended between the sick role and normality, between wrong bodies and right bodies. (Phillips, 1990)

The typical health care provider is also usually ignorant about the impact of physical and mental disabilities on the day-to-day lives of his or her patients. Physicians tend to perceive all disabled individuals as being both abnormal and in need of normalization and employ interpersonal distancing to psychologically separate themselves from their disabled patients. These efforts affect the accessibility and quality of medical care offered, the physician's ability to employ the ethical tenets of medicine, and the patient's opportunity to participate in and consent to appropriate health care services (Pollard, 1996a; Scofield, 1983).

During their medical education, physicians typically receive training on the pathology of hearing loss and, as a result, tend to medicalize deaf patients in a way that can be interpreted as paternalistic. These perspectives can interfere with the physician's ability to perceive their deaf consumers as healthy and well-adjusted human beings. "Because of their views of Deaf people as 'disabled,' the medical practitioner often deals with them in a condescending manner that betrays their inherent belief that 'deaf and dumb' is not a misnomer" (Schein, 1989, p. 184).

Najman, Klein, and Munro (1982) showed that patients who ask "too many" questions, who are not "sufficiently grateful" for their doctor's efforts, or who interfere with the typical routine of the health care provider or his or her staff, are negatively stereotyped. These undesirable patients are seen as having chosen to deviate from the prevailing white, middle-class, American value system and failed to consent to the

mainstream society perception of the "sick role." Klein, Najman, Kohrman, and Munro (1982) stated that "there is some evidence to indicate that a physician with negative attitudes is more likely to withhold treatment from or to provide inferior treatment to the negatively perceived patient than a physician with neutral or positive attitudes." Klein et al. went on to note that many of these negative stereotypes could be explained by the Protestant ethic, a value system widely held in the United States. The Protestant ethic, and ways in which patients can be perceived as failing to meet this standard, are described in detail by Klein et al. and summarized here.

First, the Protestant ethic includes "a strong faith in the ability of applied science [including medicine] to solve mankind's problems." To date, deafness cannot be solved. Second, there is "a stress on hard work, self-sufficiency, and achievement." In part due to a poor system of deaf education and barriers to communication, access, and employment, many competent deaf individuals face almost insurmountable odds in their efforts to be independent. Third, "Stoicism and persistence in the face of adversity, and an obligation to exert rational efforts to improve one's situation" are included. As previously discussed, many d/hoh individuals may not wish to receive CIs, which may not be perceived as a "rational" choice by a hearing health care provider who does not understand the Deaf community's perspective on CIs. Fourth, there is "an emphasis on austerity, self-denial, self-discipline." Some health care providers may believe that "self-discipline" is the only requirement needed to speechread. Therefore, any d/hoh individuals who do not speechread perfectly have simply failed to focus. And fifth, one notes "a high regard for the professions of medicine." As a result of hundreds of years of paternalistic and sometimes abusive behavior, and a lifetime of health care that may have been confusing and frightening, many Deaf individuals do not hold doctors in "high regard." Klein et al. hypothesize that physicians who adhere to the Protestant ethic may possess little tolerance for patients who violate it.

Johnson, Kurtz, Tomlinson, and Howe (1986) postulate that the doctor may also perceive undesirable patients as not being reliable historians. The doctor may

reject their patients' account of their health or illness history, perceptions of their health problems, or discount significant clues that the patients relay, as the doctor attempts to diagnose the individuals' current health problems.

Ralston et al. (1996) surveyed 165 physicians and demonstrated that all of these doctors were ignorant about their professional obligations under the Disabilities Act as it pertains to d/hoh clients. Those physicians queried about their interactions with deaf patients also noted that they had greater difficulty communicating with those patients, had greater difficulty understanding deaf patients, and were more likely to believe that their deaf patients did not trust them in comparison with physicians queried about their hearing clients.

The negative stereotypes held by many health care providers about d/hoh individuals can affect patient care in many ways. First, these beliefs may directly affect health care delivery as doctors make decisions about treatment plans for an individual patient and can affect patients' own beliefs about themselves. Second, an indirect effect can also be felt when the doctor or other health care providers share these inaccurate, potentially stigmatizing beliefs with other health care providers, medical students, the public, family members, employers, and teachers. Finally, the opinions of doctors and other health care providers are involved in the allocation of scarce health care resources. If the doctor has an inaccurate, negative perception of individuals with hearing loss, this may affect the way in which monies are distributed, or for approval of health insurance coverage for some treatments (Asch, 1998; Duckworth, 1988; Hordon, 1994; Paris, 1993; Potts, Katz, & Brandt, 1986).

Not surprisingly, many people with disabilities complain that their health care providers seem unable or unwilling to see them as people. The provider has a tendency to focus on the disability and does not recognize the individual, his or her interests and abilities, and may even have difficulty assessing a patient's health problems or illnesses unrelated to the individual's particular disability (Shapiro, 1993).

Deafness as culture. "Culture informs the meaning we assign to behavior, the judgment we form of another's ac-

tions, and the conclusions we draw about the quality of others' lives. . . . Like other minority groups for whom English is not the native language, [deaf people] are disabled only when they mingle with the majority culture" (Phillips, 1996).

Unbeknownst to most hearing individuals and health care providers, there is a unique Deaf culture in the United States. The Deaf community has developed and supports its own traditions, values, behavioral expectations and definitions of politeness, social and political organizations, arts, churches, recreation centers, print and electronic publications, and sporting events (Charrow & Wilbur, 1989; Swanson, 1997). Furthermore, "Nonmanual behaviors, such as use of eye contact and physical proximity, attention-getting maneuvers, greeting and parting rituals, and concepts of privacy and confidentiality may differ significantly [in the Deaf community] from behaviors in mainstream American culture" (Steinberg, 1991).

Deaf culture has evolved in the United States since the country was formed and is enthusiastically passed on from one generation of Deaf individuals to another (Padden & Humphries, 1988). As a result, the American Deaf community is "a closely knit group bound together by history, common experience and language" (Israel et al., 1992).

The perspective of many Deaf individuals is often very different from the society's majority view of disability. Many deaf individuals do not believe that their deafness should be corrected. Instead, the Deaf community feels it is a linguistic minority that is by its very existence entitled to the same respect given to other subsets of the American population (Padden & Humphries, 1988). They know that deafness is more than a physical pathology—it can be a "cultural phenomenon in which social, emotional, linguistic and intellectual patterns and problems are inextricably bound together" (Schlesinger, 1969).

Many deaf individuals have learned to be wary of hearing people in general, and health care providers in particular. This perspective has developed from a lifetime of exposure to hearing people who perceive deaf individuals as disabled, impaired, and otherwise undesirable, and health care providers who typically focus on the pathology of hearing loss. Although many Deaf individuals understandably feel this distrust is "war-

ranted and adaptive behavior” (Phillips, 1996), hearing people may view this same behavior as hostile or even paranoid due to the hearing person’s lack of understanding of the experiences of many deaf people.

A meeting of two worlds. Groups of individuals, whether citizens of different countries or members of different medical subspecialties, often have different perceptions of a single situation and adhere to different sets of cultural norms. The diverse frames of reference may result in a health care provider and a patient who view deafness and hearing loss through very different perspectives. Significant conflict may occur as they work together simply and solely because they view the same event differently (Pedersen, 1995).

“Culture . . . is a dominant influence that tends to be underestimated because, in many respects, it is so subtle” (Arnold, 1983). Arnold notes that both members of the dominant culture and members of the minority group may each hold prejudiced attitudes towards the other. If the health care provider fails to recognize that some of the norms in Deaf culture are different from those held by both the hearing majority and the medical profession in the United States, the provider may make inaccurate assumptions about the Deaf patient that could adversely affect health care delivery.

Communication Between Providers and Patients

Misunderstanding medical words or terms may interfere with all aspects of health care, including history taking, diagnosis, treatment, and prevention education. (Davis, Crouch, Wills, Miller, & Abdehou, 1990).

Most providers have limited understanding of the communication needs and preferences of deaf individuals and tend to make erroneous assumptions about speechreading, the efficacy of written notes, and the English literacy skills needed in the health care setting. Many doctors may also believe that as long as the doctor understands the patient’s verbal remarks, the patient must understand all of the doctor’s speech. This lack of understanding creates unreasonable and unat-

tainable expectations and a consequent decrease in the quality of care offered and received.

Recognition of inherent challenges in communicating with Deaf individuals. Lass et al. (1986) wrote that there is a “strong need for more information on and exposure to hearing loss in pre-service academic training in programs in . . . medicine, and rehabilitation counseling as well as in continuing educational programs for these professional groups.” The authors surveyed 62 physicians, and 33.9% of those surveyed stated they “had never had a course that included discussion of hearing and/or hearing disorders” during medical school. In general, physicians who have had some exposure to hearing loss have typically taken courses that focused on the etiology, detection, and treatment of hearing loss itself, rather than on broader cultural or communication issues (Committee on Disabilities of the Group for the Advancement of Psychiatry, 1997).

During their medical education, few doctors receive training around communication or cultural issues with deaf individuals. Ebert and Heckerling (1995) conducted a survey of 102 internal medicine physicians at one university medical center to examine their understanding of the communication needs of their d/hoh patients. All respondents stated that they needed to spend more time and effort when working with d/hoh patients. Thirty-seven percent believed that writing notes or speechreading offered the best ways to communicate with deaf patients. Forty-one percent of those surveyed said they relied on writing notes for their deaf patients more than half of the time. Only 19% regularly employed an interpreter. Remaining physicians used speechreading, gestures, or asked family members to interpret for the patient. In a survey of 165 doctors, the majority stated they had difficulty communicating with and understanding their deaf clients (Ralston et al., 1996). Finally, in a survey of 87 deaf people, 60% of whom were prelingually deaf, 59% stated they understood their doctor “sometimes” or “not at all.” The patients also noted their health care providers often wrote illegibly or wrote notes that were beyond their literacy level (Zazove et al., 1993).

These data provide evidence that physicians do not know how to communicate clearly with their deaf patients. Furthermore, the inability to use fluent spoken

English may cause the provider to focus on communication efforts rather than on the patient's illness or health status (Woloshin, Bickell, Schwartz, Gany, & Welch, 1995).

Provider communication training. During medical education physicians devote countless hours to the mastery of thousands of anatomical and technical words and medical jargon. Virtually all of these words and phrases are unfamiliar to lay people. In addition to providing precise communication between health care providers, the "special language" of medicine can be used as a linguistic barrier between the professional and the realities and stressors involved in health care delivery (Coombs, Chopra, Schenk, & Yutan, 1993).

This unique vocabulary can produce two problems for deaf patients. First, as previously noted, most deaf patients have a limited health care knowledge base. Second, the health care provider has learned to use complex words and phrases when explaining health information to patients. For example, doctors often use the word "oxygen" but the word "air" is more straightforward and easier for the deaf patient to understand.

It has been shown that health care providers significantly overestimate the average hearing patient's knowledge base of medical terms (Byrne & Edeani, 1984). If the difference between the staff's estimation of the hearing patient's comprehension is so broad, it is reasonable to assume that the deaf patient is even less likely to understand various medical terms.

Doctors are typically not trained to communicate or provide patient education using nonverbal means. The ability to show or demonstrate information (e.g., drawing a picture of a viral infection) must be developed over time (Joseph, 1993). Unfortunately, this topic is rarely covered during medical school and residency, even though teaching health care providers how to communicate with their patients, both deaf and hearing, using simple language and employing a number of different communication modalities (pictures, models, drawings) would significantly improve communication with all patients.

Providers also rarely receive training in available assistive listening devices, including 1:1 communicators and FM systems. Most do not know how to use a TTY and are unaware that a phone relay service exists that allows communication between a voice telephone

and a TTY. Health care facilities that possess such equipment may not have a related training program to educate and inform staff. In those instances where such programs do exist, the equipment may be so troublesome to use (or so difficult to find) that the fact that the equipment is owned by the institution is irrelevant (Lotke, 1995). Even those providers who are aware that their office has assistive listening devices may refuse to employ them. They may not wish to spend the time necessary to find and assemble the equipment, or may believe that reliance on these devices is proof that the doctor cannot cope with a deaf patient independently.

Speechreading. Most health care providers do not understand the limitations of speechreading. In a recent survey 66% of the physicians surveyed estimated that 85% of all English words could be understood by deaf individuals trained in speechreading. Another 6% stated that 100% of English words could be speechread (Ebert & Heckerling, 1995). In actuality, less than 30% of the sounds used in English are visible on the lips. Many words and phrases, with drastically different meaning, look exactly the same on the face and lips. Examples include no new taxes/go to Texas, suffering much/son of a bitch, fifty/fifteen. In addition, almost 50% of the consonant sounds appear identical, including f/v, t/d/k/g, and p/b/m.

The ability to speechread depends on a variety of factors. Individuals who are postlingually deafened tend to have better speechreading skills than those who are prelingually deaf. People with greater residual hearing, and those with better English literacy, also tend to be better speechreaders (Joseph, 1993). In addition, it appears that some people are simply more "gifted" in this area than others, much like some individuals are better visual learners than others.

Another factor that improves a person's speechreading comprehension is the ability to predict the subject of a conversation. For example, when we stand in line at the grocery checkout counter, we expect to be asked "paper or plastic?" When one is in a strange environment, or experiencing a health problem for the first time, it is virtually impossible to predict both the vocabulary and what questions or statements will be made next.

Even under the best of circumstances speechread-

ing is a highly frustrating process that forces the individual to exert tremendous effort and make innumerable educated guesses about what one's companion has said (Hoyt et al., 1981). Under ideal conditions—a well-rested individual with excellent English skills, perfect lighting, no background noise, and a health care provider who has a clear speaking pattern and remembers he or she must constantly face the deaf individual—only 47%–83% comprehension can be achieved. On average ~60% comprehension is achieved under these optimal conditions (Davenport, 1977).

When deaf people are ill, tired, frightened, anxious, or taking some medications, their understanding of spoken English declines dramatically. Other complicating factors include poor lighting, a speaker who does not present clear lip patterns, and beards or mustaches (Mohay & Kleinig, 1991).

In addition, many aspects of the health care environment are not conducive to speechreading. For example, staff members may be sitting behind a glass pane at a reception desk, may cover their mouths or turn away while talking, or exhibit other behaviors that make speechreading more difficult. Staff may also begin speaking to the deaf client without first obtaining the individual's visual attention. When conducting procedures that require masks, it becomes impossible to speechread. Background noises, which may impair an individual's ability to use residual hearing, also make speechreading more difficult.

English competency requirements and expectations. The literacy requirements needed to successfully navigate the health care environment are staggering in light of the literacy skills of most Americans. The average hearing adult in the United States reads at the ninth grade level (Moore, 1996). Twenty million Americans are functionally illiterate, reading at or below the fifth grade level (Jubelirer, Linton, & Magnetti, 1994). These individuals tend to come from “high-risk” groups, including the poor and elderly, the chronically ill, recent immigrants, and members of minority groups. These are also the same individuals who make up a significant percentage of hospitalized patients in the United States (Dixon & Park, 1990). Keep in mind that the average deaf individual reads at or below the fourth grade level.

Individuals who are functionally illiterate are likely

to have tremendous difficulty in the health care setting. It has been shown that an incredible 55% of all Americans have reading skills that are “marginal for meeting specific requirements of adult living. These individuals would have trouble comprehending newspaper articles, blue-collar and armed services work manuals, and antidote instructions on a can of pesticide” (Davis et al., 1990). Plimpton and Root (1994) note, “Half of the adult population needs easy to read materials and the other half who do not need them want them anyway. People under stress have limited ability to understand, and otherwise-able readers prefer their information brief and concise.”

Despite the poor literacy skills of so many Americans, numerous studies have shown that the written materials presented to hospitalized patients require an average literacy level of at least the eleventh grade level. These materials include vital information such as surgical consent forms, prescription information, health care proxies, Do Not Resuscitate orders, and health education brochures (Jubelirer et al., 1994). Davis et al. (1990) noted, “Patient education materials and hospital forms are given to patients with little regard for their ability to read them.”

Furthermore, as health care delivery in this country continues to change, a greater emphasis is being placed on patient education in the hospital. As the volume and complexity of information patients are expected to internalize have risen, the literacy requirements have also risen (Dixon & Park, 1990). Comprehension of health care information by patients and their families is a prerequisite to health education and patient compliance.

Surveys of patient education materials show that they also tend to be written far above the literacy skills of the average American. For example, 51 of the patient education books printed by the American Cancer Society in 1992 were analyzed for literacy requirements. More than half of their materials were written at the twelfth grade level or higher. Only one was written below the sixth grade reading level (Meade, Diekmann, & Thornhill, 1992). Examination of patient education booklets published by government groups and health organizations showed that the average booklet required a literacy level at the tenth grade level. Eighty percent of the materials were written at ninth grade level or above (Meade & Byrd, 1989).

A study by Davis et al. (1990) evaluated the letters physicians sent to their patients. On average, the reading level required to understand this correspondence was above the sixteenth grade level. This is well beyond the comprehension of more than half of the adults, hearing and deaf alike, in this country. The authors also evaluated local newspaper articles on health and well-being, and found these articles required reading levels between the twelfth to fourteenth grade level, again beyond the literacy skills of the majority of Americans.

One hospital studied 2,659 individuals who received care at their institution. Forty-one percent of those studied could not read prescription information, more than a quarter were unable to read the appointment reminder postcard, and 59% could not read the standard consent form (Moore, 1996).

Health care providers are often unaware of both the literacy requirements of hospital and health education materials and the illiteracy problems in the United States (Dixon & Park, 1990). This may be due to the fact that these professionals have unusually high personal literacy levels. The ability to read may be seen by health care personnel as being such a basic part of everyday life that the difficulties encountered by more than half the people in the United States are not comprehended by the typical health care provider. In addition, these individuals may not realize how basic a paragraph must be at the fourth grade reading level. As a result, low literacy patients must contend with both their reading difficulties and a health care system that, in large part, does not seem to recognize that a problem exists (Plimpton & Root, 1994).

Low literacy levels are a concern for deaf patients for many reasons. One, the vast majority of deaf individuals cannot read the materials provided by their doctors, health organizations, and commercially available health education materials. When ill or stressed, even competent deaf readers, like all patients, will experience greater difficulty reading and comprehending complex information (Plimpton & Root, 1994). Second, they are at a distinct disadvantage when exchanging written notes with their health care providers. In addition to deciphering their doctor's handwriting, these patients may also struggle to understand the meaning of the words they can discern (Schein & Delk, 1980). Third, a doctor who is rushing through the day

is likely to make fewer comments using pen and paper than when interacting verbally with patients. So the deaf person is forced to try and gain comprehension about health care needs through a medium (written English) that is very difficult for them, and with less information than hearing individuals receive.

Finally, deaf patients with low literacy skills will also find it more difficult to present their questions and concerns to their doctor. Without a solid command of the English language, it is difficult to ask complex health care questions. Unfortunately, few providers understand the literacy challenges faced by deaf patients, and may erroneously interpret the stilted questions and poor writing skills of the deaf patient as evidence that the individual is retarded.

Instead, many health care workers expect deaf individuals to write notes in English that clearly express the thoughts or questions of the individual and to read lips perfectly. No other subset of Americans who use English as their second language are expected to do this, nor are they presumed to be retarded when they fail at these efforts. Deaf individuals, on the other hand, are expected to do both (Lotke, 1995).

Interpreters. The use of a sign language interpreter is often the only way nonsigning individuals can communicate effectively with deaf people. However, health care providers have historically been resistant to the necessity of employing and using these professionals, despite the Disabilities Act and other laws that mandate use of an interpreter under certain situations.

Numerous potential problems may arise when considering or utilizing interpreter services, particularly in three major areas: issues associated with the provider's perceptions or prejudice, issues of interpreter availability and cost, and issues associated with other patient or provider priorities, including confidentiality.

Health care provider ignorance or prejudice can play a large role in whether an interpreter is used and how successful the interpreting experience will be. First, providers may not understand the extent of the communication barriers. That is, the doctor may feel that because deaf persons can sometimes make themselves understood by the staff, the patient must also understand everything that the staff says to the patient. Second, some providers may feel they will be admitting

a professional failing of some sort by so publicly acknowledging their inability to communicate with their deaf consumers.

When an interpreter is hired, it is critical that physicians recognize the limitations of the interpreted health care appointment. It cannot be assumed that the presence of an interpreter guarantees adequate communication between provider and patient (Steinberg et al., 1998). Instead, the physician must regularly check with the clients about their understanding of the material being discussed and ask individuals to repeat back to the doctor the instructions or other information just provided.

Interpreter availability, and the cost of these professional services, can also be a barrier. Many physicians and staff members do not know how to go about finding an appropriate and qualified interpreter, how to work with the interpreter once he or she has arrived, or how to evaluate the quality and value of the interpreting services rendered at the end of each visit. Some physicians may feel that hiring an interpreter is an expensive luxury; in some instances the cost of the interpreter is greater than the fee charged by the physician for the patient's visit.

In other instances, the doctor may welcome the use of an interpreter but insist that friends or family fill this role instead of a professionally certified member of the national Registry of Interpreters for the Deaf. In other situations, it is impossible to locate a qualified interpreter when one is needed. Such events might include visits to the emergency room, rural locations that do not have nearby interpreter services, or competing demands for a single interpreter.

During those times, the physician may insist—or be forced—to use family, friends, volunteers, or hospital employees with some degree of sign language skill. All of these options are fraught with numerous communication and ethical problems. For example, these individuals frequently have only limited signing skills that may result in reduced quality of care. And individuals who have a personal relationship with the patient may intentionally or unintentionally omit, reframe, or rephrase the information being provided by the doctor or the patient. This might be done to avoid publicizing information that may embarrass the family, or to “protect” the patient from bad news. In another scenario an

abusive husband who is translating for his wife may not relay her explanation of recent injuries. The resulting poor level of communication and violation of the patient's confidentiality is unacceptable (Mohay & Kleinig, 1991; Phelan & Parkman, 1995; Woloshin et al., 1995). Finally, in all instances the lay-person who is functioning as an interpreter may be affected by the news he or she is conveying in positive and negative ways (Haffner, 1992).

Numerous instances have been published in which young hearing children have been forced to interpret for their deaf parents. In these instances both the parents and the doctor may be unwilling to provide clear and accurate information as they try to avoid embarrassment or protect the child. In other situations a youngster may be expected to translate, and then explain, complex medical information that they simply do not understand and that may also come with significant emotional stress.

So there I was. I don't know. Probably five or six. And the doctor is saying, “Tell your mother she needs a mastectomy.” I didn't know how to spell it. [Starts to cry.] And I didn't even know what it meant. And my mother is looking at me like, “What? What did he say? (Preston, 1994, p. 146)

In another instance a young hearing child was asked by the doctor to witness his mother's exam and then interpret information about feminine hygiene that was both confusing and embarrassing to the boy. In this instance the physician demanded the child interpret because the doctor was “too busy” to write notes (Schein, 1989, p. 183).

Schein (1989) also notes that a doctor's desire to protect patient confidentiality, or a patient's desire to keep medical visits private, may affect interpreter use. Doctors may feel that bringing a third person into the doctor/patient communication loop will violate a patient's confidentiality. Other physicians may be reluctant to include a third person in the exam room when working with deaf patients, for fear that the interpreter might be used as a witness for the defense should the patient ever sue for malpractice.

At other times, the doctor may feel an interpreter is necessary, but the deaf patient may not want one. The local Deaf community, and the pool of interpret-

ers, is small in most areas of the United States. If a deaf client has had prior interactions with an interpreter, or expects to see one again in social or professional situations, it is impossible to provide the deaf individual with the same sense of privacy as that routinely given to hearing individuals (Nemon, 1980; Steinberg, 1991). The deaf patient may not wish the interpreter to learn about details of his or her health care for fear of embarrassment or gossip. This situation may also encourage some deaf people to keep silent about worrisome health concerns or fail to seek care at all.

Despite the misconceptions or concerns a doctor may have about using an interpreter, several studies and anecdotal reports have shown that deaf people believe communication with their doctor is improved when an interpreter is involved (Hoyt et al., 1981; New York State Assembly, 1994a, 1994b; Schein & Delk, 1980). Other studies have shown that those patients who have access to an ASL interpreter when using health care services are more compliant, engaged in more health maintenance activities, and were more satisfied with their health care experiences than deaf individuals who accessed health care services without an interpreter (MacKinney, Walters, Bird, & Nattinger, 1995).

Outcomes

Individuals (deaf or hearing) who have limited health education, limited opportunity to practice autonomy and initiative in health care settings, limited understanding of the health care delivery system, and limited understanding of physician instructions are less compliant. This situation probably results in more negative outcomes and higher cost for both the patient and the provider, and it may reduce a deaf patient's desire to seek medical attention in the future (Mohay & Kleinig, 1991).

Health care providers who harbor conscious or unconscious biases against deaf individuals, lack proper training to work effectively with them, and do not understand their patient's perspective cannot provide good health care. The individual disincentives faced by providers when offering care to deaf consumers, and the barriers that effectively prevent many deaf individuals from accessing appropriate care, also have a major

impact on the outcome of health care services provided to d/hoh people. All of these issues are addressed below.

Unable to access proper services. Poor communication between health care providers and patients can have numerous short- and long-term consequences. Patients may be unable to access preventive care and physical and mental health care programs entirely (Briccetti, 1987; New York State Assembly, 1994b; Pollard, 1994). Even those deaf individuals who can access health care services may delay seeking care until their health problems are severe due to the difficulties encountered in the health care setting. Then, treatment will be more expensive, more complicated, and carry greater risks for the patient. Furthermore, had treatment been sought sooner, a better outcome may have resulted.

In those instances when the deaf patient met with appropriate health care providers, the patient may still become sicker because he or she did not understand the doctor's treatment plan or prescription information. Patients may also pass on infectious diseases because they did not take their prescriptions properly or did not understand how to avoid infecting others.

In addition, physicians can also make incorrect diagnoses, or miss a medical condition entirely because they did not understand a patient's description of the problem. Doctors may order unnecessary, potentially risky, and expensive tests to make up for their lack of patient information. Physicians may also provide treatment to a patient without his or her full understanding or consent (Fein, 1997).

Noncompliance. Put simply, "Patient comprehension is a prerequisite to patient compliance with medical instruction and health education" (Jubelirer et al., 1994). A survey by Nemon (1980) has shown that poor compliance with treatment and follow-up care by deaf individuals was often due to the patient's poor initial understanding of what was expected of him or her. Patient instructions or behavior changes recommended by the physician that are not understood by the patient cannot be followed. Communication barriers, including low literacy skills, may be closely linked to lack of compliance (Meade et al., 1992).

A survey by MacKinney et al. (1995) has shown that those deaf individuals who reported increased sat-

isfaction with their physician/patient communication (through use of a qualified interpreter) also reported greater levels of patient compliance. Deaf people who were able to communicate more easily with their providers were also more likely to engage in health care screening tests (Pap smears, mammograms, rectal exams) than deaf individuals who could not employ the services of an interpreter. This trend occurred even though those who had better communication were, on average, poorer and more isolated than the control group.

Studies have shown that hearing patients with low literacy skills are at greater risk for poor health, perhaps because these individuals have difficulty understanding how to use our health care system. Those who do access care may not understand the information provided, which may result in either over- or underuse of medications or health care services. Either outcome is likely to increase the fiscal costs of the medical care received and reduce the health benefits the patient might gain (Weiss et al., 1992). It seems likely that deaf patients with equally low literacy skills are at an even greater disadvantage than their hearing counterparts.

The ongoing changes in health care delivery in this country are placing increasing emphasis on brief hospital stays and the patient's ability to independently execute preventive and health maintenance procedures that have been learned through health education materials or conversations with providers. Deaf individuals are at a disadvantage when asked to assume a growing level of responsibility for their own health care through the use of written materials or in conversation with nonsigning physicians.

Individual disincentives to provide care. Individual health care providers may experience a number of disincentives when deciding whether to provide care to d/hoh patients. These disincentives include scheduling, financial, psychological, educational, and attitudinal challenges.

To begin, many doctors realize that they need to spend more time working with the average deaf patient in comparison with the average hearing patient. Time is needed because physicians often need to provide deaf clients with longer explanations of their diagnosis, treatment, and follow-up plans than are provided to

hearing patients, and the communication barriers take time to be circumvented. Most doctors cannot afford to spend a great deal of time with any patient.

Moreover, those doctors who bill their patients on a fee-for-service basis are essentially penalized when taking on individuals who require more time (DiPietro et al., 1981). For example, if a doctor could see two hearing patients in the time it takes to see one deaf patient he or she would make twice as much money.

Some doctors receive a set fee per HMO member enrolled in their practice, regardless of the number of times the patient visits the doctor. Those patients who require additional time or services due to communication barriers or serious illness are less desirable to the physician, who is reimbursed for the total number of patients served, as these individuals require more of the doctor's valuable time and staff resources. The patients who rarely access health care services and pose no time-consuming problems for the doctor provide greater profit for the physician.

Other financial disincentives include the cost of interpreters. In a routine office visit in a fee-for-service setting, the patient may pay the doctor \$50. If the doctor needs to pay an interpreter \$60 or \$70 for services during the visit, the doctor has lost money by seeing the deaf client. Although the Disabilities Act instructs health care providers to consider the cost of interpreters as another cost of doing business—and notes that these costs should not be directly compared with the fees generated by the patient's visit—it is easy to see that such a comparison can be made almost without intentional thought.

Deaf or hard of hearing women who belong to lower socioeconomic brackets or have poorer health insurance are at higher risk for health problems. These problems include higher-risk pregnancies and a greater chance of delivering a baby with health problems. Some doctors may be unwilling to pay the higher malpractice costs associated with providing obstetrical care to high risk women (Nosek et al., 1995).

In addition, some physicians may experience psychological barriers to providing care to d/hoh individuals. It is common for health care providers who have little or no experience to deaf individuals to run through a series of feelings ("shock-withdrawal-paralysis") when suddenly forced to work with a deaf

consumer. Health care providers may be so uneasy they may be unable to give their full attention to the deaf patient or may provide ineffective help to the client (Schlesinger & Meadow, 1972).

Finally, working effectively with deaf clients requires education. The health care provider and staff must understand how to communicate with d/hoh individuals, how to use the state relay service, how to hire a qualified interpreter and then learn to work with him or her. Few doctors are even aware that learning these skills is critical to the doctor/patient relationship. Those who wish to learn may have a hard time accessing the needed information, as few resources exist for health care providers to learn about these nonmedical features of life with hearing loss.

Systemic barriers. In addition to the individual disincentives to provide care, a number of systemic barriers also reduce the typical deaf patient's access to health care services. These barriers include issues concerning awareness, insurance, interpreter, access, geography, education, service, systemic bias, and communication.

First, individuals with limited health education may be unaware of the availability or importance of health screening tests. If one does not know that mammograms, prostate exams, and Pap smears can identify serious health conditions when they are in their earliest, most treatable, stages, the patient will not consider seeking these services (Nosek et al., 1995).

Second, many deaf people are un- or underemployed. This may require them to pay more for health care services than those individuals with traditional benefits from a good job. Deaf individuals with little or no income may also postpone or fail to seek care due to the cost.

Third, there is a shortage of qualified sign language interpreters, particularly those with training in medical interpretation, in the United States. In rural areas no professional interpreter may be available at all. This forces the deaf patient to access care with poor communication with the doctor (using written notes and gestures) or to ask family or friends to interpret.

Fourth, deaf individuals have great difficulty even accessing some doctors' offices, health information services, and related individuals and services. Many offices and health care institutions now employ complex tele-

phone menus ("Press 1 for New Appointments, Press 2 for a Nurse, Press 3 . . ."). Deaf individuals are forced to use the state relay service to access this information. However, by the time the relay operator has typed all of the telephone menu's options to the deaf caller, and the caller has responded with her answer, the window of opportunity to enter a preference has passed and the caller has been disconnected from the doctor's office phone line for lack of response.

The same problem is true if the deaf individual is attempting to reach government health education services at the local, state, or national level (e.g., NIH, the local public health department, and so on) or access patient advocacy organizations. The use of telephone menus and typical lack of training of most phone operators working in health care settings make use of the phone as a tool to gain information very difficult.

Fifth, geographic realities can pose significant barriers to service delivery. Deaf individuals may travel great distances to receive accessible health care. This effort typically takes them outside of their insurance carrier's local catchment area, and the patient's "out of town" status typically makes him or her ineligible to benefit from the sliding scale fees that may be available to local health care consumers at community clinics (Pollard, 1994). In addition, if a health care provider is pulling in deaf clients from a large geographic area, the time needed to work out the necessary paperwork per client will be greater for these consumers than the time expended for local deaf or hearing clients (Schlesinger & Meadow, 1972). This additional time costs money.

Sixth, the limited deaf education received by health care providers and health program administrators poses a significant barrier. For example, it is unlikely a state or regional health care compliance officer, or patient advocacy board, has the necessary background on hearing loss and Deaf issues to incorporate those concerns into their programs. Nor do these groups tend to include d/hoh professionals in delivery of services. As a result, the communication needs and preferences of d/hoh clients cannot be incorporated into the organization's programs, services, or advocacy efforts, and both present and future programs cannot effectively meet the needs of d/hoh constituents.

Many physicians lack an understanding of the Dis-

abilities Act and their obligations under this civil rights legislation. Without education and compliance in this area, entire health care systems can be inaccessible to the deaf consumer. In addition, these providers typically do not know how to advertise their programs or services to members of the Deaf community. As a result, many deaf persons may be unaware of their treatment options in both traditional and alternative medicine.

Seventh, few services specifically target deaf individuals. These problems can be particularly acute when a continuum of care is needed. For example, a deaf individual who is receiving inpatient mental health services may improve and be ready for outpatient care, a halfway house, or other support programs. However, if appropriate services are not available when the patient is ready for discharge from the hospital, it is unlikely he or she will be discharged. As a result, the entire system backs up. Deaf patients are not discharged from the hospital because there is no place for them to go. Deaf individuals in need of services cannot be admitted to the hospital because the beds are full (Pollard, 1996b).

Eighth, there is some evidence that in mental health services deaf patients are diagnosed with certain conditions far more often than hearing individuals, and in such a way as to suggest clinician bias rather than true psychopathology. In addition, deaf individuals receiving services at community mental health centers were far more likely to receive services that required little communication than the more difficult, but sometimes more appropriate, assessment and treatment services (Pollard, 1996b). Similar biases likely exist in physical health care delivery, but it appears no studies have yet been done to test this theory.

Finally, communication bias also plays a large part in creating barriers to health care services. The literacy and communication requirements of anyone attempting to access health care services in a large medical center are significant. The individual must be able to read and comprehend directional signs, maps, patient rights placards, consent forms, and the other written materials used incessantly in the health care system.

The use of auditory cues or exchange of verbal information also occurs regularly in the medical setting.

Sources of information typically consist of public address system remarks, receptionists who speak through glass windows or look away from the consumer while simultaneously answering questions and doing other work, and information desk staff who have little or no training in communicating with people with hearing loss. The nurse or physician's assistant calls the name of the patient in the waiting room when it is time to see the doctor. The pharmacist calls out the names of those whose prescriptions are filled. Hearing patients use the intercom system built into their hospital bed to receive information from or to contact their nurses. The x-ray technician tells patients when to hold their breath and when they can breathe during an x-ray (Mulley & Ng, 1995). None of these methods, written and auditory, works for the majority of deaf clients, but few if any medical centers have developed appropriate alternatives.

Next Steps

Improvement in health care delivery to d/hoh individuals is needed in the areas of health outcomes for d/hoh individuals, education, systemic issues, and research for ethical, legal, financial, and resource allocation reasons. Educational efforts should include provider, patient, and health professions students. Systemic changes to remove barriers to service delivery are needed at all levels, from the local doctor's office to national health care planning boards. The development of appropriate, low-literacy health education materials is also critical for many deaf and hearing individuals in this country. Finally, additional research is necessary to better understand the current treatment and services being offered to d/hoh individuals, their baseline health status, their unmet health care needs, and the cost of providing accessible care in relation to the long-term impact of not doing so.

Ethics. Zazove and Doukas (1994) have written a seminal and much-needed article on the ethics of health care delivery and deaf patients. This article is used as a basis for the following discussion.

Health care delivery in the United States is expected to stand up to four ethical tenets. This series of beliefs includes the concepts of *nonmaleficence*, *auton-*

omy, *beneficence*, and *justice*. In Latin nonmaleficence is conveyed by the phrase “*primum non nocere*,” or “first, do no harm” (Spike, in press). Physicians are expected to remember that heroic efforts are not always appropriate, and the wishes of the patient must always be taken into account when evaluating the costs and benefits of treatment. This cannot be done if the doctor is unable to learn about the deaf patient’s personal treatment goals and priorities.

If autonomy is offered in a health care relationship, the liberty of each individual is respected. To exercise their right of autonomy, patients must be able to provide truly informed consent. To do this, patients must understand all of the pertinent information about their health condition, available treatments, and the probable risks and benefits of each treatment option. If a patient is so informed, he or she can make a decision based on his or her own values and beliefs, free of coercive influences from any source.

The concept of informed consent consists of two parts: technical consent and phenomenological consent. In technical consent the patient understands the treatment services being offered and the potential risks and benefits of the treatment. Phenomenological informed consent requires that a patient has made a decision without “undue bias based on ignorance or unfounded beliefs about life” if he or she refuses the treatment (Pollard, 1996a). That is, does the patient understand what the likely outcome will be at the sociological, psychological, and physical levels if one does nothing about a particular health condition, and what effective adaptations can one make if one chooses to do nothing?

For example, most hearing parents of deaf children have limited understanding of deafness, Deaf culture, and life with hearing loss. When deciding if CI surgery is appropriate for their child, parents are often making this decision without phenomenologically informed consent. That is, they may not fully understand what their child’s life will be like if they choose a path that does not include surgery. The same would be true of an adult who is late deafened and elects to receive a CI without receiving information about other adaptations or options.

Zazove and Doukas (1994) note that the communication barriers experienced by the vast majority of d/

hoh individuals prevent them from providing informed consent. Furthermore, it is difficult for a deaf patient to develop and maintain a confidential relationship with a health care provider due to the involvement of interpreters. Both of these factors may violate the patient’s right to autonomy.

The ethical concept of justice has been achieved if a society has fairly and equitably distributed the costs and benefits of life among its members. That is, no one individual should receive more benefit, or more harm, than any other. However, it has been shown that d/hoh people do experience a lower level of self-reported health, more medical problems, greater difficulty obtaining accessible health care, and an inequitable distribution of federal monies and health care resources than the hearing population.

If beneficence has been achieved, the health care provider has made sure that each patient has received the maximum benefit and the minimal amount of harm possible for the greatest possible “net gain.” If, for example, services have been delivered by a health care provider who did not gain informed consent from the client, or if the provider has failed to get a complete medical history from a patient, then beneficence was not achieved. In fact, the majority of physicians are unable to provide health care services for their d/hoh consumers that meet the minimal ethical requirements of the profession. The correction of this situation requires action at the individual, organizational, regional, state, and national level.

Education. The need to improve the educational level of all health care providers and administrators, current and potential patients, and students in the health professions is critical (Ralston et al., 1996). The majority of health care providers offer care to d/hoh patients on an infrequent basis. When this situation unexpectedly presents itself, the treatment team may be overwhelmed with the initial communication barriers (Pollard, 1996b). A more relaxed approach, beginning with education during health care training and followed by ongoing continuing education credits to receive updates in this field, is more likely to provide both provider and health care consumer with a more enjoyable relationship, and the delivery of higher quality health care services.

Providers and administrators also need a better understanding of the Disabilities Act and their responsibilities and obligations under this civil rights legislation. In addition, these professionals need a better understanding of the impact of hearing loss on both the day-to-day lives of individuals and its impact on health care delivery.

Current and potential d/hoh patients also need a better understanding of their rights and responsibilities under the Disabilities Act, improved health care knowledge (Berger, Inkelas, Myhre, & Mishler, 1994), improved ability to advocate for services in the health care system, improved awareness of service options, and better health insurance coverage of services and devices related to hearing loss. Improvements in health education might be obtained by including decision-making skills, health maintenance and preservation techniques, and general health information at all educational levels. Programs for older students should include specific information about reproduction, family planning, and STDs (Durkin & Coryell, 1984). In addition to formal health education, many deaf individuals may benefit from assertiveness training to counteract the prejudice and stigma developed and maintained by mainstream society (Smith & Kirkpatrick, 1985) and health care providers.

Increasing the number of d/hoh individuals who are themselves health care providers and researchers will also help. Greater access to the profession by these subsets of our community would educate the professional's colleagues and patients in a way that cannot be obtained in any other fashion, and it is likely to improve the quality of care offered to d/hoh individuals.

Studies have shown that medical and nursing students may be better able to adjust their attitudes toward people with disabilities than health care providers at all future career stages (Najman et al., 1982). When properly designed, educational programs have been shown to positively affect the attitudes of students towards individuals with disabilities (Donaldson, 1980).

Some evidence supports the idea that students who understand both their own value systems and the ways in which patients may not adhere to the same set of beliefs, are able to reduce the intensity of their negative responses to patients perceived as being different from the students' accepted norm (Klein et al., 1982). By

making students aware of the prejudices and stereotypes that they may have unconsciously internalized, and by helping them to understand the perspectives of individuals who are different from themselves, potential barriers to health care delivery can be avoided entirely (Johnson et al., 1986; Smith & Hasnip, 1991).

Students in the health care fields, including medical students, nursing students, social workers, and others, may be the best place to begin improving health care delivery to d/hoh individuals. By including d/hoh issues that go beyond the typical pathology of hearing loss in medical education, an entire generation of future providers can be taught to hold more positive attitudes towards people with hearing loss.

Exposure to deaf individuals in a respectful and egalitarian setting may also increase the students' awareness and understanding of the abilities, rights, and general preferences of people with hearing loss. Educational programs have been offered at the University of Rochester School of Medicine for students and health care providers that were produced by a committee of medical students and deaf advocates. These programs were very well received by the students and significantly increased the participants' understanding of hearing loss and the impact of communication barriers in the health care setting (Harmer, 1997; Richards, Harmer, Pollard, & Pollard, in press).

Identification of those individuals who function as health care resources in the Deaf community is also important. Productive working relationships may be formed between these well-respected individuals and health care providers to improve the quality of health information reaching the Deaf community.

Systemic changes. The inclusion of d/hoh individuals in all aspects of health care delivery and medical education—as patients, colleagues, faculty, and deans—could provide a tremendous education for students, patients, and faculty (McCrorry & Marrone, 1984; Pernice & Lys, 1996; Pollard, in press). The inclusion of d/hoh individuals in the development and execution of health care programs is probably the fastest and most efficient way to ensure that issues pertinent to these communities are included in future health care delivery programs.

Other needed changes include development of ap-

appropriate health education materials, the purchase and maintenance of assistive listening devices, and training of staff to use the equipment. Concentration of services in areas with a large deaf population—which also freely admit deaf individuals and health care providers from more sparsely populated regions—and advertisement of these services to potential clients through deaf-supported organizations and publications, are also important.

Development of appropriate patient education materials is crucial (Jubelirer et al., 1994). These efforts should include production of low-literacy written materials for all levels of health care delivery (educational materials, intake questionnaires, consent forms, patient rights, etc.); captioned videos; models, flip charts, picture books, and other visual aids; and sign-language interpreted videos and educational programs (Lawson, 1985; Meade & Byrd, 1989). The appendix provides examples of patient education materials at their original literacy level and after revision to accommodate the lower reading skills of most Americans.

Other systemic changes include the inclusion of d/hoh issues in staff training programs, development of low-literacy signage throughout medical centers, use of nonauditory cues to inform patients when their prescription is ready or the doctor is ready to see them, and a reduction in background noise to improve the ability of hard of hearing individuals to understand what has been said (Mulley & Ng, 1995). The installation, and training of staff to use, TTY equipment and relay services is also important.

Instead of including interested deaf individuals in programs developed for the general population, at times it may be necessary to develop public health education programs targeted for the deaf population. This group of individuals may require a slower review of the target material, educational materials written at a lower literacy level, and more background information than is offered to the typical hearing group. Offering a special class that addresses all of these issues, and simultaneously develops informal support networks, may be the most effective way to present health information (Baranowski, 1983).

Whether a program is offered to a largely hearing audience with one or two deaf participants, or an audi-

ence that is mostly deaf, it is critical that these services are delivered in a culturally appropriate way. An example of appropriate programming would include two genetic counseling programs specifically developed to meet the needs of individuals who have an interest in learning about the inheritance patterns of hearing loss. Approximately half of all cases of hearing loss are caused by genetic factors, and one-third of these conditions can also carry significant medical problems. In addition, many deaf parents hope to have deaf children, while hearing parents with one deaf child may wish to learn the chance that other children will also have a hearing loss. Therefore, these programs must be designed to provide complex information in a neutral manner that demonstrates cultural sensitivity toward the diverse preferences of both Deaf and hearing society.

In these genetic counseling programs, individuals who sought counseling services were given their choice of communication mode (various sign languages, speech reading, or speech). After the client's medical history and the history of the extended family were taken, the individuals were told, when possible, the cause of their deafness (or the deafness of their parents or children). When possible, they were also informed of any health concerns or medical conditions that may also be associated with inherited forms of deafness.

In addition to providing information in the client's preferred language, the culturally biased words such as "risk," "affected," "abnormal," "normal," and "mutant" were replaced with more neutral terms such as "chance," "hearing," "deaf," and "changed." Furthermore, all of this information was conveyed using visual aids and specially designed materials that met the diverse learning styles, languages, and literacy levels of the client population (Arnos, Cunningham, Israel, & Marazita, 1992; Jensen, 1985).

In other areas, the Disabilities Act requires hospitals and other large medical centers that have such amenities as pay telephones or phones in patients' rooms to offer equally accessible TTYs and other services to deaf consumers. Unfortunately, many institutions are unaware of their obligations in this area, do not know how to meet these requirements, or intentionally choose to ignore them in the hopes that any

deaf consumers who receive care there will not have the fiscal resources or psychological strength to complain or sue.

The lack of action in this area leaves many institutions exposed to serious legal risk and deprives d/hoh clients from accessing a comparable level of care. It is possible to purchase relatively inexpensive kits of materials from major commercial vendors that include TTYs, visual alert systems, and other nonauditory-dependent equipment that help meet the obligations of the act. To fail to do so due to ignorance or intentional neglect seems foolhardy in light of the numerous successes d/hoh individuals have had when suing non-compliant institutions. In addition, ignorance is not a valid excuse for failing to meet the law's requirements.

Using modern technology, sign language interpreter services can also be concentrated in a major city and simultaneously provided to a large number of outlying areas. This is possible through the use of computer technology and telemedicine. In one example of direct delivery of health care services, the South Carolina Department of Mental Health uses telemedicine to expand its offerings of mental health services to sign language-using individuals. The department has only one psychiatrist on staff who is fluent in ASL, yet its actual and potential clients are scattered across the state.

Prior to the development of telemedicine technology, the doctor spent hours each day driving from one client to another. To resolve this problem, the department purchased a number of computers with video cameras and installed them in the doctor's home and community mental health centers across South Carolina. By sitting in front of the computer's video camera in her home, the doctor can now carry on live conversations, in sign language, with clients who are using the same equipment at their local mental health center. The technology has allowed the department to use staff time far more efficiently, while saving money and providing more services to their clients (Craft, 1996).

Telemedicine technology can also be used to provide sign language interpreter services to individuals in remote locations. For example, an ASL interpreter, based in a regional medical center, can provide inter-

preter services for deaf patients and their health care providers located in remote hospitals. The deaf patient and hearing health care provider might gather at one monitor in the emergency room of a rural hospital, while a sign language interpreter with experience in medical interpreting is able to work from his or her office in that region's most sophisticated medical center. The deaf patient would sign to the interpreter, the interpreter would convey the patient's remarks to the physician verbally, and then relay the physician's spoken remarks in sign language back to the deaf patient. Telemedicine can allow even rural hospitals to meet the requirements of the Disabilities Act without incurring the costs of a part-time interpreter, removes travel expenses for interpreters entirely, and provides highly trained sign language interpreters 24 hours a day, 7 days a week to an entire region (Pollard, 1998).

Taken a step further, telemedicine technology can be used to connect individuals at three locations. A group of deaf individuals who have gathered at the local deaf club can be "plugged in" to a physician sitting in an office and the sign language interpreter located at a distant hospital. Formal health education programs could be delivered on a regular basis that allow all of the individuals (patients, providers, and interpreters) to remain in a convenient and comfortable environment. These programs could consist of a professionally developed curriculum, or could be as simple as bi-weekly or monthly "ask the doctor" forums. Other health care professionals already at the local hospital, including dietitians, pharmacists, and social workers, could also be scheduled to make regular appearances through this technology.

Research. There is tremendous need for increased research on health care delivery to d/hoh individuals. The quality and quantity of professional journal articles addressing this topic has been rising steadily in recent years (e.g., Asch, 1998; Baker-Duncan et al., 1997; Barnett, 1999; Committee on Disabilities, 1997; Crouch, 1997; Gannon, 1998; Guthmann & Sandberg, 1998; Steinberg et al., 1998; Swanson, 1997; Wu & Grant, 1997; Zazove, 1997), but this is not enough. Randomized surveys of the current health status and healthcare utilization by d/hoh individuals are critical.

Assessments of the barriers to service, from the perspective of both consumers and providers, are also badly needed. In addition, the fiscal costs of providing accessible care should be compared with the long-term costs of failing to respond to the needs of deaf individuals, to demonstrate the potential cost-effectiveness of different service options.

Other pertinent research areas include development of simple, effective ways to identify the literacy requirements of a hospital's written patient materials and ways to quickly improve the quality of written communication between deaf individuals and hearing providers (Davis et al., 1990). Research on the needs of minority families with deaf children, including their perceptions of hearing loss and health care services offered, coping strategies employed, and the interaction between individual cultures and deafness are also important.

Closing. Hundreds of thousands, if not millions, of d/hoh individuals across the country lag far behind hearing people in their health status, access to, and use of health care services. Health care providers, deaf and hard of hearing health care consumers, health professions students, and advocates must become familiar with the basic issues surrounding health care delivery and this population. This is necessary so that the health care needs of deaf patients can be met, and the legal, ethical, and moral obligations of those who have pledged their professional careers to serving others and doing no harm can be maintained.

Appendix

Examples of Simplified Text

Excerpt from a consent form for HIV testing: "A positive HIV test indicates that you are infected with HIV and that you can pass the virus to other people. Inaccurate positive and negative test results occur occasionally. For this reason, a negative test result does not guarantee that you are not infected. Rarely, a positive test result is inaccurate and indicates that you are carrying HIV even when you are not" (Plimpton & Root, 1994).

A modified consent form: "A positive HIV test most likely

means that you have the HIV virus and can pass it on to others. Sometimes the test results are wrong. If your test is positive, there's a very small chance you don't really have the virus. If your test is negative, there's still a chance you may have the virus" (Plimpton & Root).

Consent to operation: original (25th grade level): "I consent to the performance of operations and procedures in addition to or different from those now contemplated, whether or not arising from those now contemplated, whether or not arising from presently unforeseen conditions, which the above-named doctor or his associates may consider necessary or advisable in the course of the operation" (Davis et al., 1990).

Revised (sixth grade level): "I agree to other operations or treatments. My doctors may learn more in surgery. They may think I need other treatments. My doctors will decide in surgery. I agree to let them do the things they think are necessary" (Davis et al., 1990).

References

- Anonymous. (1995a). HCWs urged to be aware of deaf patients needs: Community faces heightened AIDS risk. *AIDS Alert*, 10(2), 27-29.
- Anonymous. (1995b). Stigmatized and isolated, the deaf have unique needs. *AIDS Alert*, 10(2), S1-S2.
- Arnold, B. (1983). Attitudinal research and the Hispanic handicapped: A review of selected needs. *Journal of Rehabilitation*, 49(4), 36-8.
- Arnos, K., Cunningham, M., Israel, J., & Marazita, M. (1992). Innovative approach to genetic counseling services for the deaf population. *American Journal of Medical Genetics*, 44(3), 345-351.
- Arnos, K., Israel, J., Devlin, L., & Wilson, M. (1992). Genetic counseling for the deaf. *Otolaryngologic Clinics of North America*, 25(5), 953-972.
- Asch, A. (1998). Distracted by disability. The "difference" of disability in the medical setting. *Cambridge Quarterly of Healthcare Ethics*, 7(1), 77-87.
- Badger, T., & Jones, E. (1990). Deaf and hearing children's conceptions of the body interior. *Pediatric Nursing*, 16(2), 201-205.
- Baker-Duncan, N., Dancer, J., Gentry, B., Highly, P., and Gibson, B. (1997). Deaf adolescents' knowledge of AIDS. *American Annals of the Deaf*, 142(5), 368-372.
- Baranowski, E. (1983). Childbirth education classes for expectant deaf parents. *American Journal of Maternal Child Nursing*, 8(2), 143-146.
- Barnett, S. (1999). Clinical and cultural issues in caring for deaf people. *Family Medicine*, 31(1), 17-22.

- Barnett, S., & Franks, P. (1997, November). *Healthcare utilization by prelingually and postlingually deafened adults: A new look at the 1990-91 National Health Interview Survey data*. Poster presented at the annual meeting of the American Public Health Association Meeting, Indianapolis, Indiana.
- Baynton, D. (1993). "Savages and deaf mutes": Evolutionary theory and the campaign against sign language in the nineteenth century. In J. Van Cleve (Ed.), *Deaf history unveiled: Interpretations from the new scholarship* (pp. 92-112). Washington, DC: Gallaudet University Press.
- Becker, G. (1981). The invisible isolation of deaf women. *Journal of Sociology and Social Welfare*, 8(2), 249-262.
- Berger, D., Inkelas, M., Myhre, S., & Mishler, A. (1994). Developing health education materials for inner-city low literacy parents. *Public Health Reports*, 109(2), 168-172.
- Bergstrom, L. (1980). Continuing management of conductive hearing loss during language development. *International Journal of Pediatric Otorhinolaryngology*, 2(1), 3-9.
- Blanche, E. (1996). Alma: Coping with culture, poverty, and disability. *American Journal of Occupational Therapy*, 50(4), 265-276.
- Braithwaite, R., & Lythcott, N. (1980). Community empowerment as a strategy for health promotion for black and other minority populations. *JAMA*, 261(2), 282-283.
- Briccetti, K. (1987). Mental health services for deaf students in California. *American Annals of the Deaf*, 132(4), 280-282.
- Brookhauser, P., & Moeller, M. (1986). Choosing the appropriate rehabilitative track for the newly identified hearing impaired child. *Annals of Otology, Rhinology & Laryngology*, 95(1 pt 1), 51-59.
- Byrne, T., & Edeani, D. (1984). Knowledge of medical terminology among hospital patients. *Nursing Research*, 33(3), 178-181.
- Chacko, M., Butler, J., & Kirkland, R. (1987). Communication and special health care needs of a profoundly hearing impaired adolescent. *Clinical Pediatrics*, 26(8), 395-367.
- Charmatz, M. (1998). The ADA, deaf people, and medical care. *NAD Broadcaster*, 20(7/8), 13.
- Charrow, V., & Wilbur, R. (1989). The deaf child as a linguistic minority. In S. Wilcox (Ed.), *American deaf culture: An anthology*. Silver Spring, MD: Linstock Press.
- Christiansen, J. (1991). Sociological implications of hearing loss. *Annals of the New York Academy of Sciences*, 630, 230-235.
- Clark J. K. (1995). Health education curricula in residential schools for the deaf. *American Annals of the Deaf*, 140(5), 410-414.
- Clay, R. (1997). Do hearing devices impair deaf children? *American Psychological Association Monitor*, 28(7), 1, 29.
- Committee on Disabilities of the Group for the Advancement of Psychiatry. (1997). Issues to consider in deaf and hard-of-hearing patients. *American Family Physician*, 56(8), 2057-2064.
- Coombs, R., Chopra, S., Schenk, D., & Yutan, E. (1993). Medical slang and its functions. *Social Science & Medicine*, 36(8), 987-998.
- Craft, S. (1996). Telemedicine services: Serving deaf clients through cutting-edge technology. *Focus On Mental Health Issues*, 1-5.
- Crocker, C. (1997a). Deaf child files ADA lawsuit. *DeafNation*, 2(9), 1, 7.
- Crocker, C. (1997b, August 22). Deaf woman wins suit against hospitals. *Bergen Record*.
- Crouch, R. (1997). Letting the deaf be deaf: Reconsidering the use of cochlear implants in prelingually deaf children. *Hastings Center Report*, 27(4), 14-21.
- Davenport, S. (1977). Improving communication with the deaf patient. *Journal of Family Practice*, 4(6), 1065-1068.
- Davis, T., Crouch, M., Wills, G., Miller, S., & Abdehou, M. (1990). The gap between patient reading comprehension and the readability of patient education materials. *Journal of Family Practice*, 31(5), 533-538.
- DiPietro, L., Knight, C., & Sams, J. (1981). Health care delivery for deaf patients: The provider's role. *American Annals of the Deaf*, 2, 106-112.
- Dixon, E., & Park, R. (1990). Do patients understand written health information? *Nursing Outlook*, 38(6), 278-281.
- Dolnick, E. (1993, September). Deafness as culture. *Atlantic Monthly*, 37-53.
- Donaldson, J. (1980). Changing attitudes towards handicapped persons: A review and analysis of research. *Exceptional Children*, 46(7):504-514.
- Doyle, A. (1995). AIDS knowledge, attitudes and behaviors among deaf college students: A preliminary study. *Sexuality & Disability*, 13(2), 107-134.
- Duckworth, S. (1988). The effect of medical education on the attitudes of medical students toward disabled people. *Medical Education*, 22(6), 501-505.
- Durkin, M., & Coryell, J. (1984). Strategies in health education for the deaf consumer. *Gallaudet Today*, 1, 9-13.
- Ebert, D., & Heckerling, P. (1995). Communication with deaf patients: Knowledge, beliefs, and practices of physicians. *JAMA*, 273(3), 227-229.
- Epstein, R., Campbell, T., Cohen-Cole, S., McWhinney, I., & Smilkstein, G. (1993). Perspectives on patient-doctor communication. *Journal of Family Practice*, 37(4), 377-388.
- Fein, E. (1997, November 23). Lack of a common language can hinder care. *New York Times*. 147(50, 985), p. 1, 20.
- Gannon, G. (1998). The deaf community and sexuality education. *Sexuality and Disability*, 16(4), 283-293.
- Getch, Y., Young, M., & Denny, G. (1998). Sexuality education for students who are deaf: Current practices and concerns. *Sexuality and Disability*, 16(4), 269-281.
- Gibbons, C. (1985). Deaf children's perception of internal body parts. *Maternal-Child Nursing Journal*, 14(1), 37-46.
- Glickin, S. (1994). Health care for deaf adolescents. In *Adolescent medicine: State of the art reviews* (pp. 345-358). Philadelphia: Hanley & Belfus.
- Gold, J. (1998, February 13). Deaf patients suing to get interpreters. *Bergen Record*.
- Golden, P., & Ulrich, M. (1978). Deaf patients' access to care depends on staff communication. *Hospitals, JAHHA*, 52, 86-90.
- Grundfast, K., & Rosen, J. (1992). Ethical and cultural considerations in research on hereditary deafness. *Otolaryngologic Clinics of North America*, 25(5), 973-978.
- Guthmann, D., & Sandberg, K. (1998). Assessing substance

- abuse problems in deaf and hard of hearing individuals. *American Annals of the Deaf*, 143(1), 14–21.
- Haffner, L. (1992). Translation is not enough: Interpreting in a medical setting. *Western Journal of Medicine*, 157(3), 255–259.
- Harmer, L. (1997, November). *Promoting awareness in healthcare, medical and deaf: A medical student initiative*. Presented at the annual meeting of the American Public Health Association Meeting, Indianapolis, Indiana.
- Hindley, P. (1997). Psychiatric aspects of hearing impairment. *Journal of Child Psychology & Psychiatry & Allied Health Disciplines*, 38(1), 101–117.
- Holcomb, L. (1984). Disabled women: A new issue in education. *Journal of Rehabilitation*, 50(1), 18–22.
- Hordon, L. (1994). Attitudes of medical students toward disabled people. *British Journal of Rheumatology*, 33(3), 203–204.
- Hoyt, M., Siegelman, E., & Schlesinger, H. (1981). Special issues regarding psychotherapy with the deaf. *American Journal of Psychiatry*, 138(6), 807–811.
- Israel, J., Cunningham, M., Thumann, H., & Arnos, K. (1992). Genetic counseling for deaf adults: Communication/language and cultural considerations. *Journal of Genetic Counseling*, 1(2), 135–153.
- Jackson, C. (1990). Primary health care for deaf children: Part II. *Journal of Pediatric Health Care*, 4(1), 39–41.
- Jenks, S. (1992). Researchers link low literacy to high health care costs. *Journal of the National Cancer Institute*, 84(14), 1068–1069.
- Jensen, K. (1985). Communicating the diagnosis to the deaf family. *Birth Defects: Original Article Series*, 21(2), 69–84.
- Johnson, S., Kurtz, M., Tomlinson, T., & Howe, K. (1986). Students' stereotypes of patients as barriers to clinical decision making. *Journal of Medical Education*, 61, 727–735.
- Joseph, J. (1993). Peer education and the deaf community. *Journal of American College Health*, 41(6), 264–266.
- Jubelirer, S., Linton, J., & Magnetti, S. (1994). Reading versus comprehension: Implications for patient education and consent in an outpatient oncology clinic. *Journal of Cancer Education*, 9(1), 26–29.
- Kaplan, S., Greenfield, S., & Ware, J. (1989). Assessing the effects of physician-patient interactions on the outcome of chronic disease. *Medical Care*, 27(3S), S110–S127.
- Klein, D., Najman, J., Kohrman, A., & Munro, C. (1982). Patient characteristics that elicit negative responses from family physicians. *Journal of Family Practice*, 14(5), 881–888.
- Kleinig, D., & Mohay, H. (1991). A comparison of the health knowledge of hearing-impaired and hearing high school students. *American Annals of the Deaf*, 135(3), 246–251.
- Kluwin, T. (1994). The interaction of race, gender, and social class effects in the education of deaf students. *American Annals of the Deaf*, 139(5), 465–471.
- Kurz, R., Haddock, C., Van Winkle, D., & Wang, G. (1991). The effects of hearing impairment on health services utilization. *Medical Care*, 29(9), 878–889.
- LaBarre, A. (1998). Treatment of sexually abused children who are deaf. *Sexuality and Disability*, 16(4), 321–324.
- Lane, H. (1988). Is there a "psychology of the deaf?" *Exceptional Children*, 55(1), 7–19.
- Lane, H. (1992). *The mask of benevolence: Disabling the deaf community*. New York: Vintage Books.
- Lane, H. (1993). Cochlear implants: Their cultural and historical meaning. In J. Van Cleve (Ed.), *Deaf history unveiled: Interpretations from the new scholarship* (pp. 272–292). Washington, DC: Gallaudet University Press.
- Lane, H. (1995). The dispute concerning the benefits to be expected from cochlear implantation of young deaf children [letter]. *American Journal of Otolaryngology*, 16(3), 393–399.
- Lane, H., Hoffmeister, R., & Bahan, B. (1996). *A journey into the deaf-world*. San Diego, CA: Dawn Sign Press.
- Lass, N., Carlin, M., Woodford, C., Campanelli-Humphreys, A., Judy, J., Hushion-Stemple, E., & Boggs, J. (1986). A survey of professionals: Knowledge of and exposure to hearing loss. *Volta Review*, 88(7), 333–349.
- Lass, L., Franklin, R., Bertrand, W., & Baker, J. (1978). Health knowledge, attitudes and practices of the deaf population in Greater New Orleans—A pilot study. *American Annals of the Deaf*, 123(8), 960–967.
- Lawson, M. (1985). Deaf couples experience rewards of child-birth education. *Health Progress*, 66(6), 78–80.
- Lotke, M. (1995). She won't look at me. *Annals of Internal Medicine*, 123(1), 54–57.
- Loudermilk, S. (1998, April 13). Breaking the sound barrier. *Baltimore Sun*.
- Luckner, J., & Gonzales, B. (1993). What deaf and hard-of-hearing adolescents know and think about AIDS. *American Annals of the Deaf*, 138(4), 338–342.
- Ludders, B. (1987). Communication between health care professionals and deaf patients. *Health and Social Work*, 12(4), 303–310.
- MacKinney, T., Walters, D., Bird, G., & Nattinger, A. (1995). Improvements in preventive care and communication for deaf patients: Results of a novel primary health care program. *Journal of General Internal Medicine*, 10(3), 133–137.
- McCrory, D., & Marrone, J. (1984). The physician and the disabled patient: A challenge to medical education. *Journal of Medical Education*, 59, 429–431.
- McDonald, J. (1997). Language acquisition: The acquisition of linguistic structure in normal and special populations. *Annual Review of Psychology*, 48, 215–241.
- McEwen, E., & Anton-Culver, H. (1988). The medical communication of deaf patients. *Journal of Family Practice*, 26(3), 289–291.
- Meade, C., & Byrd, J. (1989). Patient literacy and the readability of smoking education literature. *American Journal of Public Health*, 79(2), 204–206.
- Meade, C., Diekmann, J., & Thornhill, D. (1992). Readability of American Cancer Society patient education literature. *Oncology Nursing Forum*, 19(1), 51–55.
- Meadow-Orlans, K., Mertens, D., Sass-Lehrer, M., & Scott-Olson, K. (1997). Support services for parents and their children who are deaf or hard of hearing: A national survey. *American Annals of the Deaf*, 142(4), 278–288.
- Mertens, D. (1996). Breaking the silence about sexual abuse of deaf youth. *American Annals of the Deaf*, 141(5), 352–358.
- Meyers, J., Melhado, J., & Frances, D. (1989). Hearing-impaired

- patients: The medical setting. *Journal of the American Osteopathic Association*, 89(6), 780–782.
- Miller, R. (1987). The pediatrician, the disabled child, and the family: A special relationship. *Pediatrics in Review*, 8(7), 195.
- Mohay, H., & Kleinig, D. (1991). Providing medical care for deaf patients. *Medical Journal of Australia*, 155, 498–499.
- Moore, Sister B. (1996, May 29). Rx: Clear communication—Highland Hospital combats patient confusion. *Democrat and Chronicle*, p. 11A.
- Moores, D. (1993). HIV/AIDS and deafness. *American Annals of the Deaf*, 143(1), 3.
- Moores, D. (1996). *Educating the deaf: Psychology, principles, and practices*. 4th ed. Boston: Houghton Mifflin.
- Mulley, G., & Ng, K. (1995). Problems encountered by hearing-impaired people in hospitals. *Lancet*, 345(8965), 1640.
- Najman, J., Klein, D., & Munro, C. (1982). Patient characteristics negatively stereotyped by doctors. *Social Science Medicine*, 16, 1781–1789.
- National Center for Law and Deafness. (n.d.). *ADA questions and answers for healthcare providers. The Americans with Disabilities Communication Accommodations Project*. Gallaudet University. [Pamphlet]. Washington, DC: Author.
- Nemon, A. (1980). Deaf persons and their doctors. *Journal of Rehabilitation of the Deaf*, 14(2), 19–23.
- New York State Assembly. (1994a). *Communication barriers in health care for persons who are deaf, deaf-blind, or hard of hearing*. Testimony from a 10/13/94 hearing in New York City.
- New York State Assembly. (1994b). *Communication barriers in health care for persons who are deaf, deaf-blind, or hard of hearing*. Testimony from a 11/15/94 hearing in Rochester, New York.
- Nosek, B., Young, M., Rintala, D., Howland, C., Foley, C., & Bennett, J. (1995). Barriers to reproductive health maintenance among women with physical disabilities. *Journal of Women's Health*, 4(5), 505–18.
- Padden, C., & Humphries, T. (1988). *Deaf in America: Voices from a culture*. Cambridge, MA: Harvard University Press.
- Paris, M. (1993). Attitudes of medical students and health-care professionals toward people with disabilities. *Archives of Physical Medicine and Rehabilitation*, 74(8), 818–825.
- Pedersen, P. (1995). Culture-centered counseling skills as a preventive strategy for college health services. *Journal of American College Health*, 44(1), 20–26.
- Peinkofer, J. (1994). HIV education for the deaf, a vulnerable minority. *Public Health Reports*, 109(3), 390–396.
- People v. Mid-Hudson Medical Group, 6 N.D.I.R. 118 (S.D.N.Y. 1995).
- Pernice, R., & Lys, K. (1996). Interventions for attitude change towards people with disabilities: How successful are they? *International Journal of Rehabilitation Resources*, 19(2), 171–174.
- Phelan, M., & Parkman, S. (1995). How to do it: work with an interpreter. *British Medical Journal*, 311, 555–557.
- Phillips, B. (1996). Bringing culture to the forefront: Formulating diagnostic impressions of deaf and hard-of-hearing people at times of medical crisis. *Professional Psychology Research and Practice*, 27(2), 137–44.
- Phillips, M. (1990). Damaged goods: Oral narratives of the experience of disability in American culture. *Social Science and Medicine*, 30(8), 849–857.
- Plimpton, S., & Root, J. (1994). Materials and strategies that work in low literacy health communication. *Public Health Reports*, 109(1), 86–92.
- Pollard, R. (1993). 100 years in psychology and deafness: A centennial retrospective. *Journal of the American Deafness and Rehabilitation Association*, 26(3), 32–46.
- Pollard, R. (1994). Public mental health service and diagnostic trends regarding individuals who are deaf or hard of hearing. *Rehabilitation Psychology*, 39(3), 147–160.
- Pollard, R. (1996a). Conceptualizing and conducting pre-operative psychological assessments of cochlear implant candidates. *Journal of Deaf Studies and Deaf Education*, 1, 16–28.
- Pollard, R. (1996b). Professional psychology and deaf people: The emergence of a discipline. *American Psychologist*, 51(4), 389–396.
- Pollard, R. (1998, August). *Providing psychological and healthcare services to deaf individuals via telehealth technologies*. Paper presented at the annual meeting of the American Psychological Association, San Francisco, California.
- Pollard, R. (in press). A consumer interview seminar that enhances medical student attitudes toward persons with disabilities. *Journal of Behavioral Science in Medical Education*.
- Potts, M., Katz, B., & Brandt, K. (1986). Sex differences in medical student and housestaff attitudes toward the handicapped. *Journal of the American Medical Womens Association*, 41(5), 156–159.
- Preston, P. (1994). *Mother father deaf: Living between sound and silence*. Cambridge, MA: Harvard University Press.
- Preston, P. (1996). Chameleon voices: Interpreting for deaf parents. *Social Science & Medicine*, 42(12), 1681–1690.
- Purdy, S., Chard, L., Moran, C., & Hodgson, S-A. (1995). Outcomes of cochlear implants for New Zealand children and their families. *Annals of Otology, Rhinology and Laryngology*, 166(suppl), 102–105.
- Ralston, E., Zazove, P., & Gorenflo, D. (1996). Physicians' attitudes and beliefs about deaf patients. *JABFP*, 9(3), 167–173.
- Rendon, M. (1992). Deaf culture and alcohol and substance abuse. *Journal of Substance Abuse Treatment*, 9(2), 103–110.
- Rich, K. (1993). Communicating with the hearing impaired. *American Pharmacy*, NS33(6), 39–42.
- Richards, J., Harmer, L., Pollard, P., and Pollard, R. (in press). Deaf Strong Hospital: An exercise in cross-cultural communication for first year medical students. *Journal of the University of Rochester Medical Center*.
- Roush, S. (1986). Health professionals as contributors to attitudes toward persons with disabilities. A special communication. *Physical Therapy*, 66(10), 1551–1554.
- Schein, J. (1989). *At home among strangers*. Washington, DC: Gallaudet University Press.
- Schein, J., & Delk, M. (1980). Survey of health care for deaf people. *Deaf American*, 32, 5–6, 27.
- Schlesinger, H. (1969). Beyond the range of sound: The non-otological aspects of deafness. *California Medicine*, 110(3), 213–217.

- Schlesinger, H., & Meadow, K. (1972). A conceptual model for a program of community psychiatry for a deaf population. *Community Mental Health Journal*, 8(1), 47-59.
- Schroedel, J. (1984). Analyzing surveys on deaf adults: Implications for survey research on persons with disabilities. *Social Science Medicine*, 19(6), 619-627.
- Scofield, G. (1983). Ethical considerations as stigmatisers and destigmatisers of diseases: Alcoholism and leprosy as examples. *Social Science Medicine*, 17, 385-393.
- Seffrin, J. (1990). The comprehensive school health curriculum: Closing the gap between state-of-the-art and state-of-the-practice. *Journal of School Health*, 60(4), 151-156.
- Shapiro, J. (1993). *No pity: People with disabilities forging a new civil rights movement*. New York: Times Books.
- Smith, L. (1992). Communicating with patients who are deaf. *Journal of the American Academy of Physician Assistants*, 5(1), 37-46.
- Smith, M., & Hasnip, J. (1991). The lessons of deafness: Deafness awareness and communication skills training with medical students. *Medical Education*, 25, 319-321.
- Smith, S., & Kirkpatrick, M. (1985). Changing attitudes of disabled females through assertiveness training. *Rehabilitation Nursing*, 10(6), 19-21.
- Solomon, A. (1994, August 28). Defiantly deaf. *New York Times Sunday Magazine*, pp. 38-45, 62, 65-68.
- Spike, J. (in press). Ethical and legal issues in patient care. In O. Sahler & J. Carr (Eds.), *Behavior Science*. Orlando, FL: W. B. Saunders.
- Starfield, B., Wray, C., Hess, K., Gross, R., Birk, P., & D'Lugoff, B. (1981). The influence of patient-practitioner agreement on outcome of care. *American Journal of Public Health*, 71(2), 127-131.
- Steinberg, A. (1991). Issues in providing mental health services to hearing-impaired persons. *Hospital and Community Psychiatry*, 42(4), 380-389.
- Steinberg, A., Sullivan, V., & Loew, R. (1998). Cultural and linguistic barriers to mental health service access: The deaf consumer's perspective. *American Journal of Psychiatry*, 155(7), 982-984.
- Stoeckle, J., & Billings, J. (1987). A history of history-taking: The medical interview. *Journal of General Internal Medicine*, 2(2), 119-127.
- Sullivan, P., & Knutson, J. (1998). Maltreatment and behavioral characteristics of youth who are deaf and hard-of-hearing. *Sexuality and Disability*, 16(4), 295-319.
- Sullivan, P., Vernon, M., & Scanlan, J. (1987). Sexual abuse of deaf youth. *American Annals of the Deaf* 132(4), 256-262.
- Summerfield, A., & Marshall, D. (1995). Preoperative predictors of outcomes from cochlear implantation in adults: Performance and quality of life. *Annals of Otolaryngology, Rhinology and Laryngology*, 166(suppl), 105-108.
- Swanson, L. (1997). Cochlear implants: The head-on collision between medical technology and the right to be deaf. *CMAJ*, 157(7), 929-932.
- Swartz, M. (1998). *Textbook of physical diagnosis: History and examination*. 3rd ed. Philadelphia: W. B. Saunders.
- Taylor, C. (1993). An investigation of knowledge and sources of information about acquired immunodeficiency syndrome among deaf gay males. *Dissertation Abstracts International*, 54(4-A), 1249.
- Tugg v. Towe*, 864 F. Supp 1201 (S.D. Fla. 1994).
- U.S. Department of Health and Human Services. (1991). *Vital and Health Statistics: Prevalence and characteristics of persons with hearing trouble: United States, 1990-91*. Washington, DC. Series 10, no. 188.
- Vacarri, C., & Marschark, M. (1997). Communication between parents and deaf children: Implications for social-emotional development. *Journal of Child Psychology & Psychiatry & Allied Health Disciplines*, 38(7), 793-801.
- Van Biema, D. (1994). AIDS: In one community, silence equals death. Thousands of Americans have never learned the details about HIV and AIDS, and their ignorance is killing them. *Time*, 143(4), 76-77.
- Walker-Vann, C. (1998). Profiling Hispanic deaf students: A first step to solving the greater problems. *American Annals of the Deaf*, 143(1), 46-54.
- Weiss, B., Hart, G., & McGee, D. (1992). Health status of illiterate adults: Relation between literacy and health status among persons with low literacy skills. *Journal of the American Board of Family Practice*, 5(3), 257-264.
- Wells, S. (1991). Clinical considerations in treating minority women who are disabled. *Occupational Therapy Practice*, 2(4), 13-22.
- Woloshin, S., Bickell, N., Schwartz, L., Gany, F., & Welch, G. (1995). Language barriers in medicine in the United States. *JAMA*, 273(9), 724-728.
- Wu, C., & Grant, N. (1997). Asian, American and deaf: A framework for professionals. *American Annals of the Deaf*, 142(2), 85-89.
- Young, M., Nosek, M., Howland, C., Chanpong, M., & Rintala, D. (1997). Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine & Rehabilitation*, 78(12 suppl 5), S34-S38.
- Zazove, P. (1997). Understanding deaf and hard-of-hearing patients. *American Family Physician*, 56(8), 1953-1954.
- Zazove, P., & Doukas, D. (1994). The silent health care crisis: Ethical reflections of health care for deaf and hard-of-hearing persons. *Family Medicine*, 26(6), 387-390.
- Zazove, P., Niemann, L., Gorenflo, D., Carmack, C., Mehr, D., Coyne, J., & Antonucci, T. (1993). The health status and health care utilization of deaf and hard-of-hearing persons. *Archives of Family Medicine*, 2(7), 745-752.