

Chapter 2

Research in Audiological Rehabilitation: Current Trends and Future Directions The Consumer's Perspective

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Summary

This chapter describes some of the factors that Self Help for Hard of Hearing People, Inc. (SHHH) considers when developing short- and long-term priorities for rehabilitation research and policy. National data on the demographic, hearing, employment, and health characteristics of the hard-of-hearing and deaf population are described based on existing research, literature, anecdotal information, and policy. Collectively, this information is used to suggest a need for further research which addresses both the population and subpopulation needs of individuals who are hard-of-hearing. The effect of variables such as age at onset, gender, age, race, and degree of hearing loss help establish that the hard-of-hearing population is heterogeneous with respect to rehabilitation needs, and research efforts should reflect this variability.

Consumer Trends

Whether research is undertaken to acquire basic knowledge about hearing loss, or to improve services provided to people who are hard-of-hearing, the common denominator is the consumer's interest. Even with basic biological research relating to hearing loss, there is an implicit if not explicit assumption that humans will ultimately benefit by the research outcomes in some way.

Research concerning "hearing-impaired" persons has historically focused upon one component of a larger population. Or, as Schein (1987) aptly stated:

There is a rule that research occurs in inverse proportion to the size of the population affected: the fewer persons, the more studies. With respect to hearing impairment, the rule further specifies that as age at onset increases, research interest declines: the earlier the onset of deafness, the more studies. (p. 12)

This "rule" is probably more applicable to educational research than it is to audiological rehabilitation. Nonetheless, it was one of the motivating factors that led to the development of the "bulge" of the population – those people with lesser degrees of hearing loss and/or later ages at onset – to become consumer activists. By the late 1970s, individuals who had a hearing loss began to respond to what they perceived as inequity in the allocation of tax dollars for research and an overall lack of sensitivity to their rehabilitation needs, which vary and differ from the needs of persons who have prelingual, profound hearing loss. Individuals who are hard-of-hearing used their own experience with hearing loss, existing literature, and their numbers to empower themselves and to advocate for better services on their own behalf.

With a new voice in public policy amidst an economy that demands sensitivity and accountability, consumers who are hard-of-hearing have been successful in

educating policymakers at the federal, state, and local levels about the rehabilitation and research needs of the entire population. This shift in emphasis has tremendous implications for audiological rehabilitation.

Because SHHH believes that historically most audiologists have focused on both groups – the prelingually profoundly deaf and those with postlingual hearing loss of all degrees, hearing health care professionals are uniquely qualified to join with consumers to develop and implement state of the art strategies that will not only improve hearing in a controlled environment, but improve the overall quality of life for individuals with a hearing loss.

This chapter will begin with the consumer's perspective of how audiological research should be approached. This will include a discussion of the use of terminology relating to rehabilitation and hearing loss. These brief discussions are intended to give readers a sense of how and why the consumer movement evolved and why the population based approach to establishing research priorities for people with a hearing loss became important and effective.

Later discussions about the demography of hearing loss will serve as a springboard to describe some characteristics of a population that requires unique rehabilitation needs. Other factors such as the effect of (or relationship between) hearing, health, and work related issues will also be explored in terms of how they might help identify specific rehabilitation needs in the coming decades. In a broader sense, we hope to underscore the diversity and complexity of the individuals in the United States who have a hearing loss.

Use of Definitions

The term *audiological rehabilitation* implies that efforts should be focused on one narrow area of intervention, that of correcting or improving the sense of hearing with the intended goal of improving function outside of controlled settings. While recognizing the value of audiological rehabilitation and the great strides made over the past few decades in this area, consumers advocate for a broader, less circumscribed approach to helping people with a hearing loss. Many consumers, for example, might shy away from the ominous term, *rehabilitation* because it connotes the presence of a physical disability, medical disease, or dependency.

Still, even the most reluctant person with a hearing loss might benefit from a variety of passive or indirect forms of intervention, such as the establishment of informational counseling and peer support, or appropriate referrals to other sources of education and support. In the absence of available assistance from their community, many consumers who are hard-of-hearing have reached "beyond the hearing aid" and "beyond the medical model" to seek rehabilitation advice and support from others who have successfully coped with their hearing loss (Stone, 1987). Teter (1989) reflects, "the rehabilitation task with this population is to deal more with their minds than with their ears" (p. 12). In this chapter, we therefore interpret the term *audiological rehabilitation* very broadly, so that psychosocial and environmental factors are also considered.

Since the study of hearing loss crosscuts a variety of disciplines – including audiology, education, speech-language pathology, gerontology, psychology, sociology, vocational rehabilitation, and medicine – so does the use of definitions that are used to represent persons with hearing loss. The term, *hearing-impaired* will be abandoned in this chapter, in favor of the single or combined terms, *people (or individuals) who are deaf, hard of hearing, or people with a hearing loss*.

With respect to practicality, the term, *hearing-impairment* is highly ambiguous; it is a generic term used to represent the entire population but rarely is it used in this fashion. Hence, whenever possible, SHHH tries to avoid this term. The word “impaired” is used only in certain contexts, such as when quoting others who have used the term, or when there is a valid reason to be as ambiguous or generic as possible.

There is also an ongoing debate among consumers, advocates, and professionals regarding the proper way to refer to deaf and hard-of-hearing people. Definitional arguments will continue, as it is unrealistic to expect the various groups to agree upon one standard or agreed upon terminology. Still, a standard use of terminology becomes very important in certain situations, such as when establishing policy relating to people who are deaf or hard-of-hearing (Ross & Calvert, 1984). Consumers have learned that unless they are very specific about who they are talking about during advocacy activities, their identity is likely to be subsumed by the status quo – the perception that all “hearing-impaired” people are alike and therefore benefit from the same types of research and rehabilitation. Use of the terms, *deaf* or *hard-of-hearing* describes the specific population(s) that will benefit from the rehabilitation or research.

There is a growing trend, particularly among education and rehabilitation funding agencies, to establish rehabilitation priorities aimed at specific populations of individuals who are deaf or hard-of-hearing. In some cases, subpopulations, such as *late deafened adults*¹ are used to further establish the intended target of research. There are now “Requests for Proposals” that seek applicants to address the rehabilitation needs of specific populations, such as adult-onset hearing loss.

In some circles, it is more in vogue to use the term “deaf” and to work with, and conduct research on, people who are deaf, especially members of the Deaf community. Persons who use the terms “the hearing-impaired” may be perceived by consumers as proponents of the medical model. Many consumers view the medical model of service delivery as a system in which the professional regards a loss of hearing as a pathology to be treated. This perception is especially true in the Deaf community, because deafness is experienced in a cultural sense rather than as a loss or deficiency.

Understandably, some persons who are hard-of-hearing, particularly those

¹In the United States, ALDA (Association of Late Deafened Adults), a consumer organization established in the late 1980s, by people with adult onset deafness. For more information, contact ALDA at 13264 Kerrville Folkway, Austin, TX 78279. Some SHHH members also belong to ALDA.

with related medical conditions and syndromes, have no problem with the medical model, as it gives them hope for a "cure" from painful or debilitating conditions. Notwithstanding this sub-group, most consumers experience the condition of hearing loss in a social context and find research that is solely based on prevention and/or treatment of a pathology to be inadequate or offensive.

DEMOGRAPHIC CHARACTERISTICS OF CONSUMERS

A better grasp of the numbers of individuals who are hard-of-hearing and an understanding of the influence of other demographic variables, such as age, gender, and race, has helped SHHH plan and promote priorities that will reach as many people with a hearing loss and families as possible in the United States.

Prevalence Data

Several relevant studies have provided reliable, national demographic data concerning the number of Americans who are hard-of-hearing or deaf (Armstrong, 1992; Brown, 1991; Gentile, 1975; Hotchkiss, 1989; Ries, 1985). We also know that hearing loss is one of the most prevalent chronic health conditions in the United States (Adams & Hardy, 1989). Current estimates from the National Center for Health Statistics (NCHS) derived from the National Health Interview Survey (1991 NHIS Hearing Supplement) indicate that there are about 23 million persons in the United States with some form of "hearing impairment"¹ (Department of Health and Human Services, 1993). More than 98% of these persons are hard-of-hearing (Armstrong, Brown, Hayward, & Allen, in press). The proportion of individuals who have a hearing problem is comparable to the proportion of individuals who belong to major ethnic groups in the United States, including African Americans and Hispanics (Armstrong, 1992).

A number of data sources are currently available to generate prevalence estimates on hearing loss, including: the 1971-1974 Health and Nutrition Examination Surveys (Department of Health and Human Services, 1981); the 1984 Survey of Income and Program Participation (Frankel, 1985); and, the annual National Health Interview Surveys (for reviews see Adams & Benson, 1991; Moss & Parson, 1986). A particular strength of the National Health Interview Surveys is that the same set of questions have been used over the past two decades to elicit self-assessed hearing ability. Further, published data from the 1971 and 1977 surveys contain estimates pertaining to the different levels of the Gallaudet Hearing Scale (Gentile, 1975; Ries, 1982).

Future Research and Policy Directions

Because of the consistency in the manner in which the questions are worded and the scope of population surveyed, SHHH relies on the published data from

¹This estimate includes both the prevalence of hearing loss and Tinnitus.

the National Health Interview Surveys to support their national policy and development of research priorities. National estimates guide the organization in maintaining a national perspective toward areas of need. For example, while it might be easier to understand and relate to the needs of persons with severe hearing loss, we cannot ignore those with minimal hearing loss, who comprise a majority of the population, many of whom have a progressive hearing loss. Further, NCHS's planned publication of estimates of self-assessed hearing by different levels of the Gallaudet Hearing Scale will provide much needed information on the characteristics of persons with different levels of hearing function.

The availability of data on both general, self-assessed hearing loss (e.g., no hearing loss, bilateral, unilateral) and hearing functioning (e.g., Gallaudet Hearing Scale) – especially as it pertains to different everyday activities – is needed to support future research for persons with a hearing loss and their rehabilitation needs. Because of consumers' interests, we strongly encourage the annual use of hearing functioning scales in the future implementations of the National Health Interview Survey and any other large scale surveys of people who are hard-of-hearing.

The national prevalence estimates described above will continue to support research on hearing loss because the significant size of this population helps to justify the need for a variety of projects. Initiatives in noise abatement and hearing conservation, early identification of hearing loss among children and adults, and the development of technological applications are much needed at both national and community levels.

There is also a need to establish hearing rehabilitation and research centers which focus specifically on the majority population – those with partial, progressive, or late onset hearing loss. Presently, the Department of Education funds 16 rehabilitation training programs in deafness and at least three research and training centers on deafness and "hearing impairment." Unfortunately, the focus of these centers is primarily on early onset deafness. While we can be thankful for the National Institute on Deafness and Other Communication Disorders (NIDCD), established in 1988, the major emphasis at NIDCD is on biomedical research.

SHHH will continue to promote the establishment of hearing rehabilitation centers with research and training agendas that are responsive to the audiological as well as psychosocial needs of persons with partial hearing loss and acquired deafness. We expect to see audiological researchers and allied professionals take a more active role in these new consumer-responsive priorities. Investigators who are interested in involving consumers in the planning, development, and implementation of research and training initiatives may have an edge when competing for the resources that will be available to implement these new priorities. The following section will outline some problem areas, research topics, and other issues that SHHH would like to see incorporated into existing audiological research agendas, including that of the NIDCD.

Age at onset and prevalence. The prevalence of hearing loss increases with age. With respect to most children under the age of 19 years hearing loss is primarily adventitious rather than prelingual or congenital in nature. The 1971 National Census of the Deaf Population showed that 76.8% of the population lost their hearing after 18 years of age (Schein & Delk, 1974, p. 16). In 1971 and 1977, the National Health Interview Survey estimated that between 273,000 and 292,000 individuals 3 years of age or over were deaf in both ears (Gentile, 1975; Ries, 1986). In percentage terms, this is only about one-fifth of one percent of the total population.

FUTURE DIRECTIONS: SPECIAL POPULATIONS

Prevalence and incidence data help SHHH understand growing and declining trends among special populations of persons with a hearing loss in the United States. For example, despite advances in medical technology, which result in the survival of more premature and high-risk infants, the incidence of prelingual hearing loss is declining. This is due primarily to decreasing rates of maternal and infant diseases brought about by public health programs, such as vaccinations (Brown, 1991).

The Elderly Population

The relationship between age and hearing loss becomes very obvious when older Americans are considered. In the future it is expected that the elderly population will consume an increasing proportion of audiological rehabilitation services and research efforts. In the United States, the prevalence of persons who are elderly is projected to increase from approximately 11% to 22% by the year 2050. If current rates continue, by the year 2000, more than 11 million elderly persons will be significantly affected by hearing loss (Brown, 1990, 1991; U.S. Congress, Office of Technology Assessment, 1986).

SHHH is presently encouraging research which examines the extent to which existing audiological service delivery systems reach persons over 65 years of age. These individuals are likely to be living alone and many are found in long term care facilities. The organization is also concerned about the quality of hearing health care services provided to older persons who live on limited or fixed incomes. SHHH encourages researchers to identify specific barriers that prevent older Americans from receiving a full range of appropriate audiological rehabilitation services. Later, plans to eliminate such barriers can be developed.

As the number of older individuals increases, more individuals with a hearing loss will be vulnerable to a system that does little to protect them from possible fraud and price gouging from the hearing aid industry. Furthermore, there is very limited relief available from private insurance companies to help defray the cost of hearing aids and other assistive technology. We urge audiologists and allied professionals to join with consumers, national, state, and local governments to establish policies that better protect all consumers with hearing loss.

Rehabilitation Services in Rural Areas

As the population expands to the suburbs and outlying areas, there is a growing need to expand urban community services to rural communities (Coward & Lee, 1985; Coward & Smith, 1983). These service delivery programs should include the development of pilot and model hearing programs to provide services for elderly individuals who reside in rural areas (Alpiner, 1985; Wilson, 1991). A large proportion of persons who live in rural areas have never had a hearing test and do not know how to access the hearing health care system in spite of the fact that one-third to one-half of persons over 45 years of age might have a hearing loss. Wilson (1991) provides a comprehensive source of information and references concerning the establishment of audiological rehabilitation services to persons who are elderly and living in rural areas. Moreover, she describes the perceptions of elderly rural residents towards services.

Gender, Age, and Hearing Loss

Aging and hearing loss may present more problems for females than males. By the year 2000, there likely will be ten women for every five men over the age of 75 years. Women in the 65 years and older age group are the fastest growing segment of the population in the United States. They are expected to increase to 33.4 million by the year 2035 (Brown, 1991; National Institute on Aging & the National Institute of Mental Health, 1979). This is important because over the last 20 years the labor force participation rates for females has increased steadily. However, it appears that females who are hard-of-hearing leave the work force significantly earlier than hearing females (Armstrong, 1991a, 1991b).

Females who are hard-of-hearing. Since females in general are found in work settings with higher communication requirements than males, these findings have important implications for further research concerning the effect of hearing loss on functioning in the workplace and how audiological rehabilitation might contribute to the removal of communication barriers in work settings. Further, using data provided by the Health and Nutrition Examination Survey, Armstrong (1991b) reported that females who are hard-of-hearing experienced higher levels of depression than women with normal hearing. The implications of these findings is that females who are hard-of-hearing spend a greater proportion of their lives in non-work roles with poorer psychological health than women with normal hearing.

SHHH encourages rehabilitation researchers to develop workshops and focus groups that would identify the concerns of hard-of-hearing females in order to ensure that women are represented adequately in planned clinical research. Such initiatives could stimulate clinicians and investigators to develop a research agenda that would focus on unique approaches to providing appropriate services to women who have a hearing loss and wish to remain active, healthy participants in the work force.

Further, SHHH encourages the development of programs that would investigate the causes of hearing loss that are specific to gender, and conditions that are unique to, or more prevalent among women, or for which there are different vocational retirement effects for women than for men.

Ethnic Minorities

African American males currently experience a lower prevalence of hearing loss than non-black men, despite a lower socioeconomic status which typically is associated with greater prevalence of hearing loss (Brown, 1991; Hotchkiss, 1989). According to the Gallaudet Research Institute's Center for Assessment and Demographic Studies (CADS), between 1988 and 1989, 35% of the 46,000 deaf and hard-of-hearing students who received special education services in the United States were members of minority groups. In 1981, 2% of the students identified by CADS were Hispanic. This figure rose to 13% in 1991.

Research on minorities. Research on hearing loss among minority populations is sorely lacking. There have been several national population-based audiometric surveys on non-Hispanic Whites and African Americans by the National Center for Health Statistics (NCHS), but only recently has a similar survey been conducted on the United States Hispanic population (Lee, Carlson, Lee, Ray, & Markides, 1991). We encourage audiologists and other hearing health scientists to make use of emerging data obtained from individuals who are part of minority groups, including those of Hispanic origin, to identify the unique rehabilitation needs of the diverse population.

THE EFFECT OF SEVERITY OF HEARING LOSS ON RESEARCH AND AUDIOLOGICAL SERVICES

A number of studies have documented the negative relationship between the severity of hearing loss and prevalence of hearing impairment (Armstrong, 1992; Brown, 1991; Hotchkiss, 1989; Ries, 1982, 1985). Relatively few individuals have a hearing loss greater than 90 dB HL in the better ear. For example, recent data published by the Center for Assessment and Demographic Studies at Gallaudet Research Institute revealed that more than 1 million individuals under the age of 18 years had a hearing loss. However, as Ries (1986) reports, using 1982 data, only about 68,000 youths were identified as having a hearing loss sufficiently important for them to receive special education services. Furthermore, only about 23,000 of these youths were classified as deaf. The remaining 45,000 students had lesser levels of hearing loss.

Children and Youth With Hearing Loss

With respect to children and youth, according to the population estimates described above, the majority of children with a hearing loss do not receive comprehensive audiological rehabilitation services. Flexer (1989) noted that all but 1% of children with hearing loss receive the diagnostic and rehabilitative

audiology services they require. Children with mild to moderate or fluctuating hearing losses are either not identified or are not deemed eligible for audiological services by educational personnel. Many educational personnel view hearing loss as an all-or-none phenomenon; a child is either normally hearing or deaf, which rules out the critical need to consider intervention for hard of hearing children (Ross & Calvert, 1984).

Public policy is shifting toward the earlier identification and placement of hard of hearing and deaf students in public school settings, and recent legislation¹ has resulted in a growing awareness of the rights of children and adults with disabilities. Because of this trend, we expect that future directions of audiological rehabilitation will be directed towards developing and implementing measures that provide diagnostic and rehabilitative audiology services to all children and youth, with a hearing loss, not just those identified presently under the Individuals with Disabilities Education Act, or Public Law 94-142.

SHHH continues to rely on the research of audiologists that address the academic difficulties associated with a mild, moderate, and unilateral hearing loss, including ways to accommodate youth who are hard-of-hearing in schools and postsecondary settings (for example, see: Flexer, Wray, Black, & Millin, 1987; Moeller, 1989; Wheeler & Arnold, 1982). This research has guided the organization's efforts to prevent children who are hard-of-hearing children from "falling through the cracks." However, much progress still remains to be accomplished in this area.

Research into innovative ways to identify children who have even a minimal hearing loss is needed. Because existing national studies are based on samples from children who receive special education services, we only have information about the children who fall in the severe end of the hearing loss spectrum. We continue to appeal to demographers and educational researchers to find ways to identify and track children with hearing loss who are not recipients of special education services but who can still benefit from audiological intervention.

Once hard-of-hearing children are identified, educational audiologists, and educational personnel will be faced with increased demands to accommodate a greater number of children in more appropriate ways. School personnel can provide access to more hard-of-hearing children by pooling resources and forming collaborative partnerships which include audiologists and parents. We encourage efforts that recognize the value of parental involvement, not just because it is a parent's right, but because it makes sense to include the family so that there can be some carry-over between the school and the home.

SHHH expects to see a greater demand for educational audiologists, and therefore encourages professional audiology organizations to promote educational au-

¹Title II of the Americans with Disabilities Act applies to all state and local public entities, including school systems. It ensures that all services, programs, and activities of state and local governments can be used by people with disabilities, including individuals with a hearing loss. Regulations can be found in Title 28, Part 35 of the Code of Federal Regulations adopted by the Department of Justice.

diology. More public education and awareness is needed on the value of ongoing audiological services for all children in public schools.

Preservice and inservice training materials are needed to sensitize teachers and other personnel about how to screen or identify a hearing loss. Teachers also need help on how to provide educational access for children who may not be hearing everything being taught in the learning environment.

Top-down approaches to the development of educational access opportunities for hard-of-hearing children are also needed. SHHH has worked with policymakers in deaf education to encourage the establishment of standards for deaf educators and other school personnel that interact with children who are hard-of-hearing. Progress is slow in this area, but we will continue in this direction for as long as necessary. We encourage educational audiologists to participate in the development of policies that might affect children with a hearing loss. Audiologists who are also advocates for children who are hard-of-hearing can promote policies that will not exclude the majority of children with a hearing loss.

Adults With Hearing Loss

The same relationship between severity and prevalence of hearing loss exists for adults. Based on audiometric threshold data and functional hearing scales, several studies have shown that the prevalence of hearing impairment decreases markedly as a function of the severity of hearing loss (Armstrong, 1991a, 1991b; Brown, 1991; Hotchkiss, 1989; Ries, 1986). Specifically, for the entire sample of adults between 25 and 74 years who responded to the Health and Nutrition Examination Survey (1971-1974), approximately 86% of those with a hearing loss had a mild to moderate hearing loss. The remaining 14% reported a better ear hearing level in the moderately-severe to profound range.

Mild to moderate hearing loss in adults. It is obvious that the majority of adult individuals who have a hearing loss do not have audiological severe-to-profound losses. This fact should not lead to the assumption that they have no or fewer audiological rehabilitative needs; rather, their needs are different. As Teter (1989) noted, the population with the most demanding need is that with minimal hearing loss. This is a type of loss for which audiologists may not even have recommended a hearing aid as recently as 5-10 years ago. However, nowadays more professionals recognize that this group of people, many of whom have progressive hearing losses, can often adjust to, and benefit from hearing aids.

Therefore, SHHH maintains that more emphasis should be placed on providing services to this important segment of the population. Audiologists, working with consumers, are best suited to develop effective ways to meet the needs of people with mild to moderate or progressive hearing losses (Teter, 1989).

VOCATIONAL REHABILITATION

Audiological rehabilitation has much to offer allied professionals who are in

the position of making rehabilitation decisions about people who are hard-of-hearing. Unfortunately those decisions are often based solely upon audiological and medical assessments. Recent policies which encourage vocational rehabilitation counselors to improve the quality of services to people with a hearing loss have specific implications for audiologists in clinical settings.

An Underserved Population

The U.S. Department of Education has taken the lead in recognizing the larger population of individuals who are hard-of-hearing as an "unserved, or underserved population" (Corthell, 1992). The Institute on Rehabilitation Issues (IRI), with funding from the Department of Education, developed a timely and meaningful document pertaining to the rehabilitation issues that concern individuals who are hard-of-hearing. RSA defines "unserved" populations as groups of individuals with disabilities who are not served as the result of a variety of policy, practice, and environment barriers. "Underserved" populations, according to RSA, are groups of individuals with disabilities who are "inadequately served" (cited in Corthell, 1992). Lack of outreach and immediate or extended resources, attitudes of service delivery personnel, and communication barriers are some of the factors that combine to result in inadequate service provision to individuals who are hard-of-hearing. Although the IRI report was developed with primary emphasis on vocational rehabilitation services, it has widespread implications for allied professionals, including audiological rehabilitation researchers.

Beyond Diagnostics to Functional Assessment

One of the issues raised by the IRI Prime Study Group was the need for more sensitive and comprehensive ways to measure overall communicative abilities and how they impact on work, family, and overall functioning. SHHH has urged researchers in audiological rehabilitation to promote the use of standardized functional assessment tools. A case history and audiograms are diagnostic tools, not indicators of what type of individualized support is needed, if any. Over the past 14 years SHHH has learned from its membership that in addition to psychosocial reactions to hearing loss, such as increases in loneliness and decline in social interaction, there are a number of environmental factors that have an effect on their ability to communicate effectively. For example, even with the best of hearing aids and audiological rehabilitation services, the person who is hard-of-hearing must overcome such obstacles as social stigma, poor communication between spouses or family members, insensitive co-workers and employers, and inaccessible community settings. The literature supports our findings (Alpiner, 1987; Rosen, 1979; Stone, 1987; Thomas & Gilhome-Herbst, 1980; Vernon, 1984). This means that audiologists in clinical settings must know how to incorporate these obstacles into the assessment process.

Recent efforts by Bess, Lichtenstein, Logan, Burger, and Nelson (1989), as well as Bess, Lichtenstein, and Logan (1991) reflect a growing recognition and interest in this critical area of need. Bess and his colleagues used the Sickness

Impact Profile (SIP), a standardized measure for assessing sickness related dysfunction, to describe the functional and psychosocial impairment levels of hundreds of outpatients over the age of 65 years. Poor hearing was found to be associated with higher SIP scores and increased dysfunction. These findings underscore the need to encourage more research on the relationship between health and hearing loss.

Alpiner (1987) and Alpiner and Schow (1993) described many functional assessment scales, including the McCarthy-Alpiner Scale of Hearing Handicap, designed to obtain information from both the hard-of-hearing person and the significant other. Using this scale, clinicians can identify areas of communication functioning where the hard-of-hearing person and his or her spouse are in agreement as well as disagreement. The Alpiner-Meline Aural Rehabilitation Screening Scale (AMAR) assesses three separate domains of communication functioning: (a) social, emotional, and vocational difficulties associated with hearing loss (hearing handicap); (b) auditory aptitude and discrimination; and (c) visual aptitude for speechreading. The Scale can be administered in 10 to 12 minutes (J.G. Alpiner, personal communication, 1993). Once clinicians learn how to incorporate the results obtained from the administration of this scale into their clinical practice it should be possible to obtain this type of relevant information clinically, even in busy diagnostic settings.

SHHH will continue to support and encourage important advances made by rehabilitation audiologists in the area of functional assessment. We are encouraged by the work that has already been undertaken and hope that previous research will serve as a springboard for other investigators to develop innovative ways that will ensure that clinicians and graduate students in audiology provide more comprehensive hearing health care services to consumers who are hard of hearing.

We will also continue to encourage changes of policy in the Federal-state rehabilitation system with the hope of fostering more collaboration between rehabilitation professionals and audiologists who utilize appropriate measures to determine how individuals with a hearing loss function in the workplace, at home, and in social settings. Ideally, we hope to see the results of functional assessments shared with allied professionals who are in the practice of making decisions about whether or not a given child or adult could benefit from rehabilitation services.

The Effect of Hearing Loss in Work Settings

State-of-the-art hearing aids alone may do little to alleviate the environmental barriers that people with hearing loss face outside of the soundproof booth. In the future audiologists will be expected to evaluate how well existing audiological rehabilitation generalizes in "real world" settings. By working with consumer groups like SHHH, audiologists can develop more effective ways to ensure that their services result in meaningful changes – such as helping with workplace modifications.

SHHH has been aware of job discrimination and stress related to hearing loss for many years. Recent research findings have just begun to confirm our anecdotal observations. According to Armstrong (1992), people who are hard-of-hearing are under-represented in a number of occupations compared to hearing people. In jobs that require communication skills, individuals with a hearing loss experience higher levels of income underemployment. They also tend to be in jobs that have lower education requirements (Armstrong, 1991a, 1992). However, individuals with a hearing loss who have jobs that match their communication abilities tend to stay in the work force as long as their hearing peers (Armstrong, 1991a). For example, a person with a hearing problem who is forced to use a telephone and work in a noisy environment may achieve a better communication match if simple modifications, such as moving to a quieter setting, getting an amplified telephone, and using an assistive device (when needed) are incorporated into the work environment.

Recent data on the use of pension and retirement benefits by males between the ages of 45-61 years of age who are hard-of-hearing indicate that they leave the work force at a higher rate than hearing males. These data suggest that there is a need for a better understanding of the quality of work life for persons who are hard-of-hearing (Armstrong, 1991a).

HEARING AND HEALTH

In the preceding section on the demography of hearing loss, we described a population that, in addition to hearing loss, must often cope with a primary or secondary health problem or disabling condition. This is particularly the case among older persons with a hearing loss and children with a congenital hearing loss.

The Role of NIDCD: Consumer's Perspective

SHHH has representation on the National Institute on Deafness and Other Communication Disorders (NIDCD) Advisory Council. Through their participation on this council, consumers can play an active role in the establishment of research priorities in a setting where historically, they have been excluded.

Our efforts to influence the type of intramural and extramural hearing health research supported by NIH has been slow but nonetheless significant. The NIDCD mission has been "to conduct and support biomedical and behavioral research and research training in the normal and disordered process of hearing, balance, smell, taste, voice, speech and language" (National Institutes of Health, 1989). The NIDCD also supports efforts to create devices which substitute for lost and impaired sensory and communication functions, in addition to research and training related to disease prevention and health promotion. SHHH has attempted to promote more research in the area of behavioral and rehabilitative sciences and we have urged NIDCD to include audiological experts as well as medical experts in their peer review process. We recommend that NIDCD en-

courage young people with a hearing loss to enter the field of science. Hearing loss and its impact on the person goes far beyond the basic medical model that is the foundation of the National Institutes of Health. Until the needs of the whole person are integrated into NIDCD's agenda, the progress of various rehabilitative disciplines will be limited.

COMMUNICATION RESEARCH

Having interacted with thousands of persons with a hearing loss, the authors can make some general observations about their communication skills. If examined under controlled conditions, these observations might produce interesting and descriptive information about the communication performance and rehabilitation needs of adults who are late deafened or hard-of-hearing. Sometimes, clinicians forget to look at how communication is used in a pragmatic sense, such as in social contexts. We have found that some adults who become severely hard-of-hearing or late deafened develop coping strategies to reduce the stress that is associated with communication. These strategies do not always lead to positive outcomes, but rather, can be frustrating for both communication partners. Monopolizing the conversation, "bluffing," and preempting the speaker are just a few examples of coping mechanisms that can lead to communication breakdowns.

Language Use and Hearing Loss

Bates (1976) described three types of pragmatic domains of language use: (a) performatives, which relate to speech acts; (b) presuppositions, which are concerned with listening and use of context in communicating; and, (c) conversational postulates, which relate to the rules of conversation and dialogue. While Bates' work (and other theories and research on this aspect of communication) was initiated with childhood language acquisition in mind, we think it has valuable applications to adults with hearing loss. We are interested in the second and third domains described by Bates – those concerned with listening, context, and following conversational rules. We are interested in whether language samples of hard-of-hearing persons would reveal these coping patterns, some of which are negative. SHHH encourages investigators interested in aspects of communication to consider this type of research initiative. It is important to choose subjects who have had a hearing loss for a sufficiently long period to have developed communication coping strategies that might alter their conversational patterns.

TECHNOLOGY

A discussion of all emerging types of technologies that show promise for hard-of-hearing people is beyond the scope of this chapter, but SHHH will offer some general advice to audiologists who are interested in taking technology out of the laboratory or clinic and into the homes and work settings of as many

consumers as possible.

Although there are many initiatives aimed at providing technology access to people with disabilities, often, little or no emphasis is placed on hearing loss. Part of the problem is that there are relatively few audiologists who are familiar with all of the available assistive devices that work for people with a hearing loss, beyond the hearing aid. This is unfortunate because audiologists should be in the unique position to represent, and advocate for more awareness about the various technologies that can benefit persons who are hard-of-hearing.

The Tech Act

In 1988, the United States Congress passed the Technology-Related Assistance for Individuals with Disabilities Act (P.L. 100-407), referred to more briefly as the "Tech Act." The Tech Act calls for the allocation of funds to states for the development of programs to overcome barriers and make assistive technology more accessible to the public. The Tech Act lends support to two other pieces of legislation, the ADA and the Individuals with Disabilities Education Act (IDEA). For example, if it is determined that a child needs an assistive device in order to acquire an appropriate education, and it is reflected in the child's Individualized Education Plan (IEP), the school district must provide the assistive device(s) for the child while the student is in school.

Individuals in the field of audiological rehabilitation in the United States can make great strides in promoting access to consumers who are hard-of-hearing by learning more about the Tech Act, and other resources that have the potential to fill critical gaps in the service delivery system. Some states have programs supported by the Tech Act but provide little or no emphasis on technology for individuals who are hard-of-hearing. With more and more emphasis on the use of technology in the rehabilitation process, we hope that audiologists who are competent in the area of technology will join with consumers in state-wide or community-based efforts to promote technological access, so that consumers with a hearing loss are not unnecessarily excluded.

Partnerships and Collaborative Relationships

SHHH supports and promotes the establishment of cooperative and collaborative initiatives between educators, state agencies (such as State Commissions or Offices for the Deaf and "Hearing-Impaired"), consumer organizations, and speech and hearing service providers. We have observed some positive outcomes from such programs. Team efforts result in efficient, comprehensive, and otherwise difficult to find technology-related services for children and adults who are hard-of-hearing.

For example, in a recent site visit to Little Rock, Arkansas, we discovered a high degree of professional support and teamwork among rehabilitation providers and consumers. The Arkansas Association for Hearing-Impaired Children (AAHIC), a non-profit parent organization headed by Ms. Lynn Coates, joined with Dr. Hope Keiser, Chair of the University of Arkansas at Little Rock (UALR)

Audiology and Speech Pathology Department in the development of an assistive technology laboratory. Ms. Coates and Dr. Keiser received a grant from the State of Arkansas Office for the Deaf and Hearing-Impaired and the Tech Act to set up and implement the project. This "hands-on" demonstration center is accessible to children and adults of all ages, and includes nine mini-centers around the state. Each mini-center is portable so that elderly persons and rural residents can also benefit from the project. The demonstration center is available as a practicum experience for graduate students, audiologists, and other state agency personnel who provide services to people who are hard-of-hearing. This is just one example of how one state has capitalized on building collaborative relationships to enhance the quality, diversity, overall availability, and efficiency of technology-related services to as many children and adults with hearing loss as possible.

Recently consumers have had a significant influence on policymakers to insure that more recognition is given to all people with hearing loss. Nowadays, consumers are turning more to service providers to seek their assistance in translating policy into action by building bridges between research, clinical practices, and persons in the "real world" who are hard-of-hearing.

SUMMARY

Investigators who apply for funds from federal agencies can enhance their research undertaking and their chances of being funded if they have a clear understanding of who will benefit from their research and/or audiological services. In some cases, it is possible to identify specific subpopulations that would benefit from their efforts.

Audiologists are wise to include consumers and other allied professionals in the planning, development, and implementation of programs intended to benefit people who are hard-of-hearing.

SHHH asks for continued research on the psychosocial, vocational, and health aspects of hearing loss, particularly with regard to subpopulations, such as: elderly people, ethnic minorities, persons living in rural areas, females, and school-aged youth and adults with hearing loss or acquired deafness.

Self-assessment scales, or functional evaluations which include measurements of environmental factors are also of great interest to consumers. Presently, arbitrary criterion are typically used by allied professionals to determine whether or not a given individual who is hard of hearing should receive rehabilitation services.

The present discussion of audiological rehabilitation services and research needs is not comprehensive. Rather, it was intended to give audiological rehabilitators a better understanding of the interests and needs of people who are hard-of-hearing. Hearing loss and the many forms it takes can have a variety of effects on this diverse population – which change across the life span – from infancy to school age; from work to retirement, and beyond.

REFERENCES

- Adams, P.F., & Benson, V. (1991). *Current estimates from the National Health Interview Survey: United States* (Series 10, No. 181). Hyattsville, MD: National Center for Health Statistics.
- Adams, P.F., & Hardy, A.M. (1989). *Current estimates from the National Health Interview Survey: United States, 1988* (Series 10, No. 173). Hyattsville, MD: National Center for Health Statistics.
- Alpiner, J.G. (1985). Diagnostic and rehabilitation aspects of geriatric audiology. *ASHA*, 455-459.
- Alpiner, J.G. (1987). Evaluation of adult communication function. In J. Alpiner & P.A. McCarthy (Eds.), *Rehabilitative audiology: Children and adults* (pp. 44-114). Baltimore, MD: Williams and Wilkins.
- Alpiner, J.G., & Schow, R.L. (1993). Rehabilitative evaluation in hearing-impaired adults. In J.E. Alpiner & P.A. McCarthy (Eds.), *Rehabilitative audiology: Children and adults* (2nd ed.) (pp. 237-283). Baltimore: Williams and Wilkins.
- Armstrong, T.L. (1991a, June). *Determinants of underemployment among older hearing impaired persons: The role of gender and occupation on communication requirements*. Paper presented at the fourth annual convention of the Society of Disability Studies, San Francisco.
- Armstrong, T.L. (1991b). *The relationship between gender and psychological distress in hard of hearing people*. Paper presented to the American Public Health Association, Washington, DC.
- Armstrong, T.L. (1992, April). *Demographic and labor force aspects of hard-of-hearing people*. Paper presented to the American Public Health Association, Washington, DC.
- Armstrong, T.L., Brown, S.C., Hayward, M., & Allan, T. (in press). *Demographic and labor forces aspects of hearing loss* (GRI Monograph). Washington, DC: Gallaudet University, Gallaudet Research Institute.
- Bates, E. (1976). *Language and context: The acquisition of pragmatics*. New York: Academic Press.
- Bess, F.H., Lichtenstein, M.J., & Logan, S.A. (1991). Making hearing impairment functionally relevant: Linkages with hearing disability and handicap. *Acta Otolaryngol* (Stockholm) (Suppl. 476), 226-231.
- Bess, F.H., Lichtenstein, M.J., Logan, S.A., Burger, M.C., & Nelson, E. (1989). Hearing impairment as a determinant of function in the elderly. *The American Geriatrics Society*, 37, 123-128.
- Brown, S.C. (1990). The prevalence of communication disorders in the aging population (ASHA Report No. 19). In E. Cherow (Ed.), *Proceedings of the American Speech-Language-Hearing Association Research Symposium on Communicative Sciences and Disorders and Aging* (pp. 14-25). Washington, DC: ASHA.
- Brown, S.C. (1991). *Aging and the interaction of demography and hearing loss*. Final Report Executive Summary (Contract No. 5R29AG05609). Washington, DC: U.S. Department of Education Division of Innovation and Development.
- Corthell, D.W. (Ed.). (1992). *Serving the underserved – principles, practices and techniques* (pp. 3-73). (Report from the Study Group of the Nineteenth Institute on Rehabilitation Issues). Menomonie, WI: University of Wisconsin-Stout, Stout Vocational Rehabilitation Institute.
- Coward, R.T., & Lee, G. (Eds.). (1985). *The elderly in rural society* (pp. 121-124). New York: Springer Publishing Company.
- Coward, R.T., & Smith, W.M., Jr. (Eds.). (1983). *Family services: Issues and opportunities in contemporary rural America*. Lincoln: The University of Nebraska Press.
- Department of Health and Human Services [DHHS]. (1981). [DHHS public use data tape documentations: Audiometric test, National Health and Nutrition Examination Survey, 1971-1975].
- Department of Health and Human Services [DHHS]. (1993). *Current estimates from the NHIS hearing supplement: United States, 1991* (Series 10). Hyattsville, MD: National Center for Health Statistics.
- Flexer, C. (1989). Neglected issues in educational audiology. *Journal of the Academy of Rehabilitative Audiology*, 22, 61-66.
- Flexer, C., Wray, D., Black, T., & Millin, J. (1987). Amplification devices: Evaluating classroom

- effectiveness for moderately hearing-impaired college students. *The Volta Review*, 89, 347-358.
- Frankel, D.T. (1985). *A summary of the content of the 1984 panel of the Survey of Income and Program Participation* (SIPP Working Paper Series No. 8504). Washington, DC: U.S. Bureau of the Census.
- Gentile, A. (1975). *Persons with impaired hearing, United States: 1971* (VHS Series 10, No. 101) Vital and Health Statistics (DHEW Publication No. HRA 76-1528). Rockville, MD: National Center for Health Statistics.
- Hotchkiss, D. (1989). *Demographic aspects of hearing impairment: Questions and answers*. Washington, DC: Gallaudet University, Gallaudet Research Institute.
- Lee, D.J., Carlson, D.L., Lee, H.M., Ray, L.A., & Markides, K.S. (1991). Hearing loss and hearing aid use in Hispanic adults: Results from the Hispanic Health and Nutrition Examination Survey. *American Journal of Public Health*, 81, 1471-1474.
- Moeller, M.P. (1989). Advice from a master. *ASHA*, 31, 34-35, 39.
- Moss, A.J., & Parson, V.L. (1986). *Current estimates from the National Health Interview Survey: United States, 1985* (DHHS Publication No. PHS 86-1558). Washington, DC: U.S. Government Printing Office.
- National Institute on Aging and the National Institute of Mental Health. (1979). *The older woman: Continuities and discontinuities*. Report of the National Institute on Aging and the National Institute of Mental Health Workshop. Washington, DC: U.S. Government Printing Office.
- National Institutes of Health. (1989, April). *A report of the Task Force on the National Strategic Research Plan, National Institute on Deafness and Other Communication Disorders*. Bethesda, MD: Author.
- Ries, P.W. (1982). *Hearing ability of persons by sociodemographic and health characteristics: United States* (Series 10, No. 140) (DHHS Publication No. PHS 82-1568). Washington, DC: U.S. Government Printing Office.
- Ries, P.W. (1985). Demography of hearing loss. In H. Orlans (Ed.), *Adjustment to adult hearing loss* (pp. 3-20). San Diego: College-Hill.
- Ries, P.W. (1986). Characteristics of hearing impaired youth in the general population and of students in special education programs for the hearing impaired. In A.N. Schildroth & M.A. Karchmer (Eds.), *Deaf children in America* (pp.3-21). San Diego: College Hill Press.
- Rosen, J.K. (1979). Psychological and social aspects of the evaluation of acquired hearing impairment. *Audiology*, 19, 238-252.
- Ross, M. (1991). A future challenge: Educating the educators and the public about hearing loss. *Seminars in Hearing*, 12, 402.
- Ross, M., & Calvert, D.R. (1984). Semantics of deafness revisited: Total communication and the use and misuse of residual hearing. *Audiology*, 9, 127-145.
- Schein, J.D. (1987). The demography of deafness. In P.C. Higgins & J.E. Nash (Eds.), *Understanding deafness socially*. Springfield, IL: Charles C. Thomas.
- Schein, J.D., & Delk, M.T. (1974). *The Deaf population in the United States*. Silver Spring, MD: National Association of the Deaf.
- Stone, H.E. (1987). Adjustment to postlingual hearing loss. In J.G. Kyle (Ed.), *Adjustment to acquired hearing loss* (pp. 113-125). Bristol, United Kingdom: Antony Rowe Ltd.
- Teter, D.L. (1989). Personal reflections in aural rehabilitation: Past, present, and future. *Journal of the Academy of Rehabilitative Audiology*, 22, 11-14.
- Thomas, A.J., & Gilhorne-Herbst, K.G. (1980). Social and psychological implications of acquired deafness for adults of employment age. *British Journal of Audiology*, 14, 76-85.
- U.S. Congress, Office of Technology Assessment. (1986). *Hearing impairment and elderly people: A background paper*. Washington, DC: U.S. Government Printing Office.
- Vernon, M. (1984). Psychological stress and hearing loss. *SHHH*, 5, 3-6.
- Wheeler, J., & Arnold, P. (1982). Teacher's views of their pupils in partially hearing units. *Journal of the British Association of Teachers of the Deaf*, 6, 47-52.

Wilson, G.D. (1991). *A hearing services program for rural elderly individuals based upon their knowledge, preferences, attitudes and needs for these services*. Unpublished doctoral dissertation, Columbia University. (Obtained through UMI Dissertation Information Service, Ann Arbor, MI. Order Number 921219.)