

The Severely to Profoundly Hearing-Impaired Population in the United States: Prevalence Estimates and Demographics

Bonnie B. Blanchfield*
Jacob J. Feldman*
Jennifer L. Dunbar†
Eric N. Gardner*

Abstract

This study informs policy makers and third-party payers of the prevalence and characteristics of the severely to profoundly hearing-impaired population in the United States. Nationally representative data were used for estimations in consultation with an expert advisory panel. The prevalence of severe to profound hearing impairment among the US population ranges from 464,000 to 738,000, with 54 percent of this population over age 65 years. Persons with hearing impairment are more likely to be publicly insured, less likely to have private insurance, have lower family incomes, are less educated, and are more likely to be unemployed than the general population. Approximately half a million Americans are severely to profoundly hearing impaired and appear to be more vulnerable, both financially and educationally, as compared to the US population. As a result, access to medical and technological interventions that may assist their hearing loss may be limited.

Key Words: Deafness, demography, hearing-impaired persons, population characteristics, prevalence

Abbreviations: NHANES = National Health and Nutrition Examination Survey, NHIS = National Health Interview Survey

Hearing impairment is a common chronic condition in the United States, affecting over 22 million Americans (Benson and Marano, 1998). To date, prevalence studies have been limited to gross estimates of the number of people in the US with hearing impairment. There have been no reliable estimates, however, that quantify the hearing-impaired population by severity (Nadol and Eddington, 1988). In part, this may result from the lack of universally accepted definitions of the various levels of hearing impairment. In this article, we consider the range in severity of hearing impairment and estimate the prevalence of persons described as severely to profoundly hearing impaired using nationally representative data. We also characterize this

group demographically and socioeconomically. Our purpose is to familiarize health care providers and third-party payers with the size and characteristics of the potential population for advanced technologies, such as cochlear implants, and to inform policy makers about the population when considering related legislative initiatives.

METHOD

Classifying and Measuring Hearing Impairment Levels

Hearing impairment describes a broad range of hearing deficits and a variety of hearing conditions. Whereas some people are unable to hear a whisper from several feet away, others cannot hear speech shouted directly into their ear. Some individuals experience a progressive loss of hearing as they age, others may experience the sudden onset of deafness, and others are born deaf.

The classification and measurement of hearing loss have been refined over the years. More

*Project HOPE Center for Health Affairs, Bethesda, Maryland; †formerly with Project HOPE Center for Health Affairs, Bethesda, Maryland

Reprint requests: Bonnie B. Blanchfield, Project HOPE Center for Health Affairs, 7500 Old Georgetown Road, Suite 600, Bethesda, MD 20814

accurately than in the past, current audiologic tools can identify patients who might benefit from particular forms of intervention. Common classifications of hearing impairment include slight (16–25 dB), mild (26–40 dB), moderate (41–60 dB), moderate-severe (61–70 dB), severe (71–89 dB), and profound (90+ dB), with each category representing decreasing auditory sensitivity. Although these classifications are commonly accepted, the criteria used to determine the categories differ. For example, decibel levels assigned to the categories may be inconsistent. In addition, some surveys of hearing loss use self-reported evaluation of hearing or functional status rather than audiometric results to define the degree of impairment.

Although hearing impairment classifications based on audiometric test results are largely objective, classification and measurement of hearing impairment based on self-assessment of hearing level can be quite subjective. However, research has shown that self-reported hearing assessment is predictive of the audiometric test result classifications (Nondahl et al, 1998; Reuben et al, 1998). The accuracy of self-reported data has been shown to fall within a few percentage points of actual audiometric results. In addition, the performance of self-reported data in estimating hearing loss has been shown to depend on the number and type of questions asked. Self-reported hearing loss is generally characterized using phrases such as little trouble hearing, a lot of trouble hearing, understands conversation with normal voices, understands whispers, and understands shouting in the ear. These phrases capture a range in severity of hearing impairment by offering alternative descriptions of hearing ability.

Use of functional status indicators to classify hearing impairment is helpful when attempting to quantify the costs to society to maintain the functionality of an individual with hearing impairment. For example, a person who is profoundly deaf may not be able to function independently in the hearing world without significant help from another person (such as an interpreter) or through assistive technology.

This lack of uniformity in defining hearing impairment has made it difficult to assume standard levels of hearing across studies. For this reason, our estimates are based on multiple datasets using self-reports of hearing impairment and functional status and audiometric results. These data are discussed below.

Data

Three nationally representative data sets were used to estimate the prevalence of severe to profound hearing impairment. Each survey addresses hearing loss differently using either self-reported evaluation of hearing loss, self-reported functional status, or audiometric testing. An expert advisory panel consisting of an audiologist, an otorhinolaryngologist, a speech pathologist, and a deafness educator corroborated our assumptions and definitions of hearing impairment. As each survey uses different criteria to identify hearing loss and we obtain similar estimates from each, we are confident in the reliability of our final nationally weighted range of prevalence. Our final estimate of prevalence is based on a synthesis of the results generated from each of the three separate estimates.

The National Health Interview Survey (NHIS) and its hearing supplements from 1990 and 1991 were used to estimate prevalence in the population ages 3 years and older based on the self-reported assessment of hearing loss by respondents (NCHS, 1993, 1995). The NHIS from 1994 and 1995 provided prevalence estimates for the population ages 3 years and older based on self-reported functional status of respondents who indicated that they had a hearing condition (NCHS, 1998, 1999). The National Health and Nutrition Examination Survey (NHANES) III 1988–1994 was used to estimate the prevalence of severe to profound hearing loss in the population of 6 to 19 year olds based on audiometric test results (NCHS, 1997). The Appendix describes the classification procedure for each survey. We assumed that no significant change in the population distribution occurred since these data were collected that distorted or biased our final prevalence estimates.

To minimize the possibility of false-positive responses when identifying the target population, we designed an iterative process to identify severely to profoundly hearing-impaired persons and have calculated two separate population estimates. Initially, we classified only those survey respondents who answered a series of specific questions with no inconsistencies as “very likely” to be severely to profoundly hearing impaired. The limitation to this methodology is the probability of excluding respondents who are severely to profoundly hearing impaired but who provided inconsistent responses to selected survey questions (false negatives). To avoid systematically underestimating the target population, in the second calculation, we relaxed

our inclusion criteria, to allow some response inconsistency and estimate a population that is "likely" to be severely to profoundly hearing impaired.

RESULTS

Approximately 464,000 persons are very likely to have severe to profound hearing impairment in the US; however, an additional 274,000 persons are likely to have this impairment, bringing the total estimate to as many as 738,000 persons. Seniors represent 54 percent of the severely to profoundly hearing-impaired population but only 13 percent of the general US population. Slightly over one-quarter of the severely to profoundly hearing-impaired population is 80 years old or over. Persons of working age represent 38 percent of the severely to profoundly hearing-impaired population (Fig. 1).

Although persons under 18 years of age represent the smallest portion of this group—approximately 8 percent—the prevalence of severe to profound hearing impairment among children is thought to be under-reported. Direct estimates of the prevalence of deafness among children 0 to 2 years of age were not available from the 1990 and 1991 NHIS. Although state-specific studies have estimated the incidence of hearing loss in the population of newborns—2 per 1000 infants in a study of Rhode Island births (Vohr et al, 1998) and 3.14 per 1000 infants in a study of 11 Texas hospitals (Finitzo et al, 1998)—national incidence of hearing loss in newborns is not available. Despite these limitations, we estimated the prevalence in the 0- to 2-years age group in the noninstitutional population on the basis of retrospective age-specific incidence data reported for older indi-

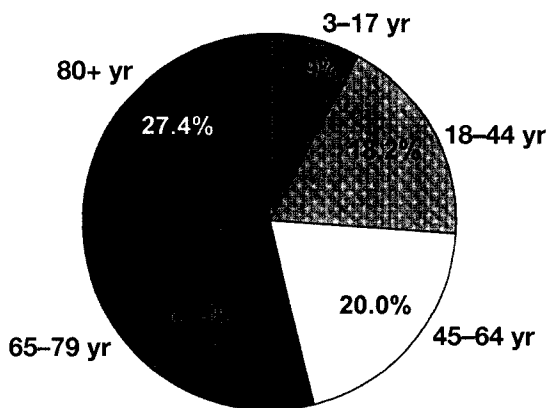


Figure 1 Distribution by age of the severely to profoundly hearing-impaired population.

viduals in the 1990 and 1991 NHIS. For profoundly deaf children ages 3 to 17 years, the question "How old was _____ when he (she) began to have serious trouble hearing or became deaf?" was asked. Based on the response to that question, we estimate that the incidence rate for permanent, severe hearing problems in the 0- to 2-years age group was approximately 5 cases per 10,000 births. The vast majority of these cases were reported to have occurred at birth or within the first year of life. We assumed that the incidence rate for the 0- to 2-years age group has not changed substantially since 1990-1991. We applied this rate to the Bureau of the Census's estimated 11.3 million children under 3 years of age in the noninstitutional population of the US on November 1, 1998. At a minimum, 5600 of these children were profoundly hearing impaired.

Although only 5.9 percent of the severely to profoundly hearing-impaired population is without health insurance coverage, a more important measure is the type of insurance covering this population. An estimated 31 percent of the severely to profoundly hearing impaired have public insurance only, 40 percent have a combination of both public and private health insurance, and only 23 percent of the severely to profoundly hearing impaired have private insurance exclusively (Fig. 2). In contrast, an estimated 13 percent of the general population have only public insurance, 12 percent have public and private insurance, and 61 percent have private insurance exclusively. The percentage of hearing-impaired persons eligible for Medicare coverage who are under 65 years is relatively high compared to the US population generally (Fig. 3).

Our results indicate that most of the severely to profoundly hearing-impaired population are,

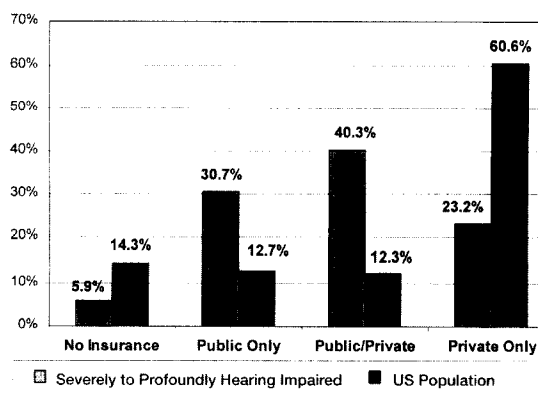


Figure 2 Insurance status of the severely to profoundly hearing-impaired population and the US population.

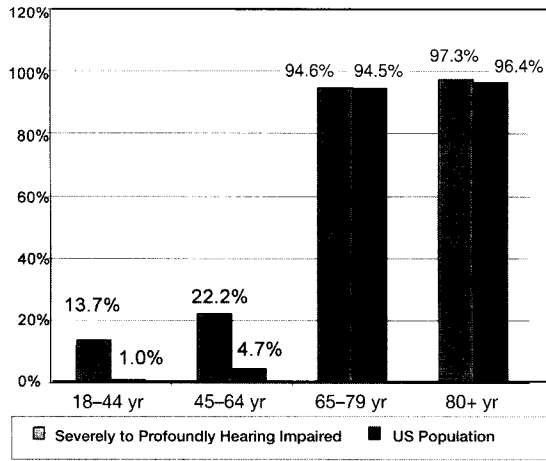
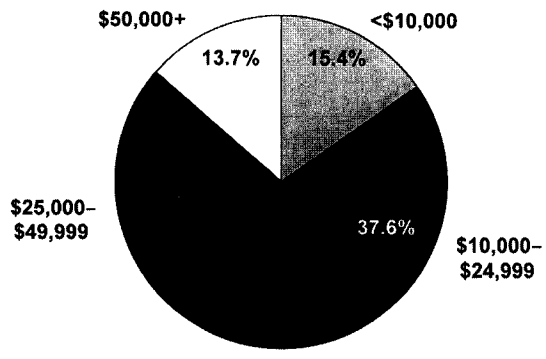


Figure 3 Medicare coverage by age in the severely to profoundly hearing-impaired population and the US population.

on average, poorer than other Americans. Fifty-three percent of the study population have a family income of less than \$25,000 (Fig. 4) compared to 35 percent of the general US population (Fig. 5).

Of the severely to profoundly hearing-impaired population who are over 17 years of age, approximately 44 percent did not graduate from high school compared to only 19 percent in the general population (Fig. 6). Forty-six percent of these hearing-impaired students graduated from high school and reported some college attendance compared to 60 percent of the general population of students. Only 5 percent of the severely to profoundly hearing-impaired students graduated from college compared to 13 percent of the general population.



Note: Total Prevalence of Severe to Profound Hearing Impairment ~ 464,000

Figure 4 Distribution of the severely to profoundly hearing-impaired population by family income.

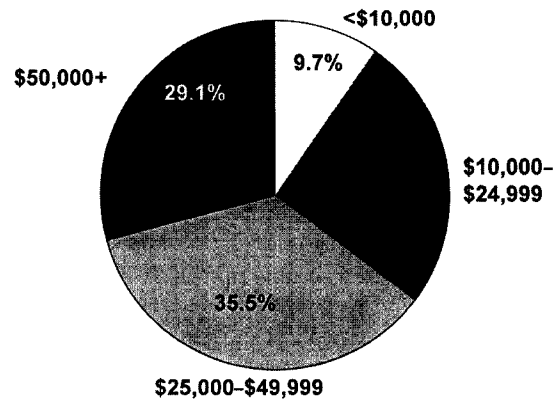
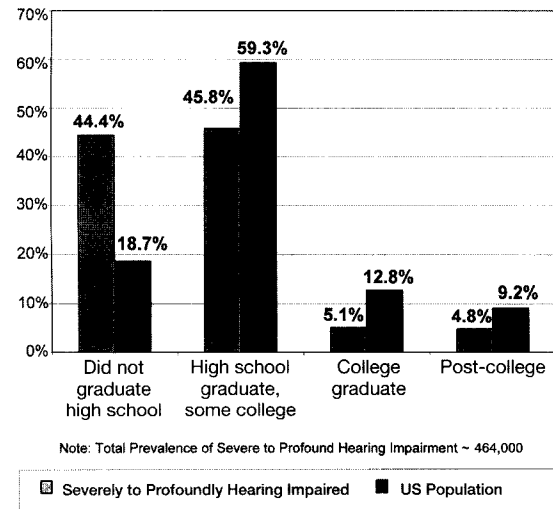


Figure 5 Distribution of the US population by family income.

Although labor force participation of the severely to profoundly hearing-impaired population over age 65 is similar to the general population, many working-age adults with hearing impairment are not in the labor force (Fig. 7). Specifically, 42 percent of those with severe to profound hearing impairment between the ages of 18 and 44 years are not working compared to 18 percent of the general population. Approximately 54 percent of those aged 45 to 64 years are without jobs compared to 27 percent of the general population.

DISCUSSION

Approximately one half to three-quarters of a million Americans are severely to profoundly hearing impaired and require special



Note: Total Prevalence of Severe to Profound Hearing Impairment ~ 464,000

Figure 6 Education level among persons 18 years and over in the severely to profoundly hearing-impaired population and the US population.

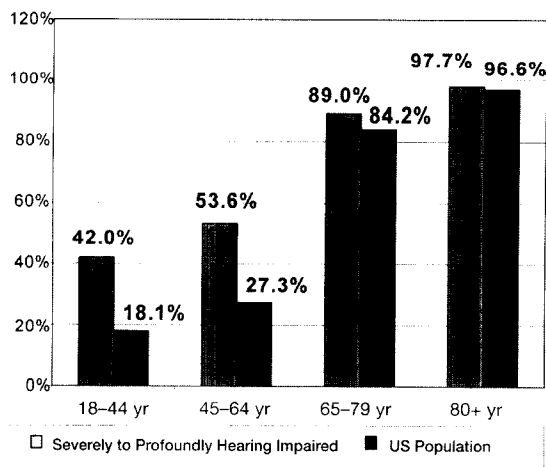


Figure 7 Percentage of population not in the labor force by age in the severely to profoundly hearing-impaired population and US population.

educational assistance, social services, and other resources in order to function in a hearing society. The majority of the hearing-impaired population are over age 65, but a significant portion, nearly 40 percent, are of working age.

Although most of the hearing-impaired population has health insurance coverage, this does not imply that persons with serious hearing impairment have adequate access to the health care they need. Many in this population are covered exclusively under public programs, such as Medicare and Medicaid, and are substantially less likely to have private health insurance. Medicaid benefits are often superior to those of private health insurance, especially in the case of children, but reimbursement rates are dramatically lower than actual costs. Although 43 states cover cochlear implants for children and 37 cover implants for adults, average reimbursement of \$1180 (Perales, 1998) is well below total costs for implantation, which range from \$15,000 to \$25,000 (AAO, 1990). Medicare reimbursement has also been found to be significantly lower than average costs (Kane and Manoukian, 1989). Medical technologies, such as the cochlear implant, may mitigate the disability of deafness by allowing deaf individuals to access and comprehend complex sound stimuli, enabling them to have some functional hearing. Patient use of this intervention has been proven cost effective (Harris et al, 1995; Wyatt et al, 1995; Palmer et al, 1999; O'Neill et al, 2000); however, Medicare and Medicaid may not adequately pay for these procedures, deterring patient access. A significant portion of the population we have identified may benefit from

cochlear implantation; however, financing of this intervention is uncertain.

The fact that the hearing-impaired population is less likely to be privately insured may relate to their lower participation in the labor force and lower income. Nearly half of all working-age adults with hearing impairment do not work compared to one-quarter of working-age adults who can hear. Because of their lower earnings compared to the general population, we speculate that when hearing-impaired persons do work, they work in positions requiring low skills. Resources required for persons with hearing loss to function in work environments may be unavailable or persons with hearing loss may be inadequately prepared for work. Inadequate preparation for work may also be reflected in the population's lower educational attainment.

Severe to profound hearing impairment affects a significant number of Americans. Their demographic characteristics indicate vulnerability in terms of health insurance, income, labor force participation, and educational achievement. To inform health care providers, third-party payers, and policy makers, this study provides an estimate of the prevalence of persons with severe to profound hearing loss and their characteristics, a population with potential need of and use for advanced technologies.

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APPENDIX

Classification of Severity of Hearing Impairment

Self-Reported Hearing Loss Using NHIS Supplements 1990 and 1991

Respondents to these surveys were asked a series of questions regarding their hearing loss. With the assistance of our expert panel, we identified groups of questions that should be answered with a "yes" by someone with severe to profound hearing impairment. We identified those respondents who answered in this way and included them as our target population. We created subsets of data that we used iteratively in our analysis. These subsets are described as follows:

Condition Subset. Includes respondents to the survey who indicated that they or a family member were deaf in both ears. This condition is identified by the code 203 in the NHIS data.

Self-Report Scale. Includes two questions asking respondents to self-assess their hearing problem by answering a series of questions. Respondents indicating that they were deaf in both the right and left ears are targeted.

Gallaudet Hearing Scale. A set of survey questions asking respondents whether they can

hear and understand a whisper, a normal voice, a shout, or a shout in the ear. Responses are scored, and scores are used to indicate hearing level.

A Gallaudet Score of 5. Indicates respondents who answered that they are unable to hear and understand even when a person speaks loudly into their better ear.

A Gallaudet Score of 4. Indicates respondents who answered that they are able to hear and understand when a person speaks loudly into their better ear but unable to hear and understand when a person shouts to them across a quiet room.

Very Likely. The process to estimate the very likely severely to profoundly hearing-impaired population is depicted below. Every survey respondent who indicated using a TDD or a TTY was included in the very likely population. In addition, those respondents reporting that they were deaf in both ears and who scored a 4 or 5 on the Gallaudet scale were also included in the very likely group.

Likely. The process to estimate the likely severely to profoundly hearing-impaired group included those respondents reporting that they were deaf in both ears or who scored a 4 or 5 on the Gallaudet Scale and who also indicated that they had a deafness condition.

Self-Reported Functional Status Using NHIS 1994 and 1995

The 1994 and 1995 NHIS were used to estimate the prevalence of the severely to profoundly hearing-impaired population. Survey questions that asked respondents to assess their functional status relative to a health condition were identified and targeted for analysis.

The 1994 and 1995 NHIS consist of two phases. In Phase I, respondents who indicated trouble hearing normal conversation with a hearing aid were flagged. These persons were then asked a series of questions related to the use of hearing equipment other than hearing aids. Our analysis focused on the use of a TDD or TTY, closed caption TV, assistive signaling devices, and interpreters. Persons who responded positively to any of these questions were considered “very likely” to be severely or profoundly deaf. All other flagged respondents were further evaluated with questions in Phase II.

To meet the criteria of “very likely” in Phase II, respondents had to indicate the following:

- Yes to difficulty using the telephone or doesn't use the telephone for an unspecified reason and
- Yes to someone else regularly uses the telephone for you (for those who don't use the telephone) or
- The respondent indicates that he or she is unable to use the telephone or
- Never uses the telephone without assistance or unable to use the telephone in response to a series of questions asking “when you do not have help, does using the telephone get tiring, does it take a long time, or is it very painful?”

To meet the criteria of “likely” via Phase II, respondents had to indicate the following:

- Yes to difficulty using the telephone or doesn't use the telephone for an unspecified reason and
- The respondent had to indicate that he or she has a lot of difficulty using the telephone or
- using the telephone is very tiring or
- using the telephone takes a long time.

Other Considerations. Some respondents in Phase I indicated that they could not hear loud noises yet reported no difficulty using the phone. Because we felt it was important to include persons who could not hear loud noises, we added several other criteria to mitigate the response inconsistencies. To accomplish this, we examined questions primarily related to the workplace. If an individual reported that he or she could not hear loud noises and needed a hearing-related technical device to work (whether or not he or she was working at the time), he or she was considered to be in the “very likely” classification. Similarly, if someone reported that he or she could not hear loud noises and needed a proxy or an assistant to complete the survey due to a hearing problem, he or she was also placed in the “very likely” classification.

Audiometric Evaluation Using NHANES III

We use audiometric test results from the NHANES III data set to estimate the prevalence of hearing loss in children ages 6 to 19. Based on our review of the literature and consultation with our advisory panel, we present results based on a pure-tone average threshold measured from 500 to 3000 Hz for 70 dB. Because of the very small number of respondents meeting this definition, we used results from the worse ear to characterize hearing levels to increase our likelihood of capturing any child with a severe hearing impairment.