

# How Many Deaf People Are There in the United States? Estimates From the Survey of Income and Program Participation

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The Survey of Income and Program Participation (SIPP) is one of a few national surveys that regularly collects data identifying the American population of persons with hearing loss or deafness. Estimates from the SIPP indicate that fewer than 1 in 20 Americans are currently deaf or hard of hearing. In round numbers, nearly 10,000,000 persons are hard of hearing and close to 1,000,000 are functionally deaf. More than half of all persons with hearing loss or deafness are 65 years or older and less than 4% are under 18 years of age. However, these findings are limited to those who report difficulty hearing “normal conversation” and do not include the larger population of persons with hearing loss for which only hearing outside the range and circumstances of normal conversation is affected. Policy makers, communications technology manufacturers, health and education service providers, researchers, and advocacy organizations have an interest in these results.

The federal government has been the sole source or vehicle for the collection of national data on the demography of deafness in the United States. From 1830 to 1930, the decennial census of the United States included the enumeration of deaf persons. However, because it was clear that the census was not getting reliable counts, questions about deafness were dropped

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(Best, 1943; Schein & Delk, 1974). Not until 1957, when the first national Health Interview Survey was conducted, did the U.S. Bureau of the Census, as the contract agent of the U.S. Public Health Service, resume annual collection of data on hearing loss and deafness in the population (Botman, Moore, Moriarty, & Parsons, 2000; National Center for Health Statistics, 1963; Schein & Delk, 1974).

Since the implementation of the Health Interview Survey, now known as the National Health Interview Survey (NHIS), additional projects that include the regular collection of data on hearing loss and deafness in the United States have been initiated. These include the periodic National Health and Nutrition Examination Survey, initiated by the U.S. Public Health Service in 1959 (e.g., National Center for Health Statistics, 1963, 1964), the one-time-only National Census of the Deaf Population, sponsored by a Social and Rehabilitation Service grant to the National Association of the Deaf in 1969 and which heavily depended on cooperation with the 1971 Health Interview Survey and the 1971 Annual Survey of Hearing Impaired Children and Youth (Schein & Delk, 1974), and the annual Survey of Income and Program Participation (SIPP), implemented by the U.S. Bureau of the Census beginning in 1983 (e.g., U.S. Bureau of the Census, 1986). This article provides estimates of the size and age distribution of the American population of persons with hearing loss or deafness based upon data collected from the most recent SIPP.

### The Problem of Who Counts as Deaf

In the process of identification and enumeration of deaf persons, or any other particular group within the population, at least four constraints are encountered: the context of the inquiry, the indicators used to establish group membership, the methods employed to collect indicator data, and the resources available to execute the project. The SIPP originated as a project of the Social Security Administration in the 1970s (U.S. Bureau of the Census, 1986). The survey is designed to help determine how various personal and social conditions affect the level and stability of personal and household economic well-being in the United States. The rehabilitation model (see, e.g., O'Brien, 2001), where functional impairment is to be overcome in order to mitigate conditions that would be disabling or otherwise cause difficulties, underlies the SIPP inquiries about deafness and hearing loss (Maag & Wittenburg, 2003).

Precisely how questions about hearing loss and deafness are phrased strongly influences who is counted and who is excluded from the count during the enumeration process. This sensitivity to the selection of indicators is a critical issue for researchers, policy makers, businesses, educators, providers of health and social services, and other interested groups or consumers of research findings. The demography of deafness in the United States based upon the SIPP does not provide the same profile as that obtained from, say, the NHIS because hearing loss and deafness are not defined identically across surveys (see, e.g., Lucas, Schiller, & Benson, 2004; note that estimates for the number of persons with hearing loss from the NHIS are appreciably larger than those from the SIPP due, in part, to differences in how questions are phrased). Here, careful attention is given to who is being identified as a person with hearing loss or deafness in the SIPP.

At its most basic level, demographic analysis is about studying changes in the size, growth rate, and composition of a population. It is important to remember that

no matter how a population is defined, there are only two ways of entering it: being born into it; or migrating into it. If the definition of the population includes a social element in addition to the

customary geographic/temporal elements, the "migration" can include a change in the social label, a process often referred to as "social mobility." (Preston, Heuveline, & Guillot, 2001, p. 2)

On the surface, it seems perfectly straightforward to talk about enumerating or estimating the size of the population of persons in the United States with hearing loss or deafness. Ostensibly, one would simply use some agreed-upon measures to identify such attributes as the cause of and age at which individuals first experienced hearing loss or deafness (or when and how their hearing was restored or augmented). At the definitional level, however, the demography of deafness becomes problematic when it is recognized that deafness is not only an audiological condition but also a social label. *Migration* is not simply a matter of moving in or out of the United States (geography) or when a person began to lose or regain hearing (a temporal concern beyond date of birth or migration); there is also social mobility. Here, this does not refer to social class or economic mobility, though such employment, education, and earnings differences certainly do exist (e.g., Barnartt & Christiansen, 1996; McNeil, 2001). *Social mobility* refers to how affiliation and group membership can change, in this case, depending on how individuals and those around them respond to their hearing loss. The most prominent behavioral distinction affecting which social label is applied to persons experiencing deafness is the use of a signed versus a spoken language across a variety of social settings (Mitchell & Karchmer, 2004). Those who identify and organize as a formal or informal association of the Deaf emphasize the centrality of signing, whereas those who take the label Hard of Hearing focus on speech. Differing perspectives on how a person's deafness is defined affect who is labeled deaf, hard of hearing, or as a person with hearing loss and, therefore, who is counted as among their number.

Typical of surveys of hearing loss or deafness, when attempting to distinguish among those who are hearing, hard of hearing, or deaf, the SIPP asks how well a person can hear human speech (see, e.g., Schein, 1989) or, more precisely, "normal conversation." The SIPP asks each individual (age 15 or older) or informant (responding for children aged 6 to 14 years, as

well as some older persons) to respond to the following two questions (U.S. Census Bureau, 2001a, Questions ADQ6 and ADQ7; U.S. Census Bureau, 2001b, Questions CDQ11 and CDQ12):

- “Do you [Does the child] have difficulty hearing what is said in a normal conversation with another person even when wearing your [his/her] hearing aid?” [Note: the respondent is not forced to answer yes or no; the individual may indicate “Person is deaf” in lieu of providing a yes or no response.]

- An affirmative response is followed by “Are you [Is the child] able to hear what is said in normal conversation at all?”

These are fundamentally social questions; they pertain to interactions between a person speaking and the person (who may be experiencing hearing loss or deafness) being spoken to. Given that the idea of normal conversation is commonly shared, it is this manner of social interaction that defines hearing loss or deafness.

It is important to note that the SIPP defines hearing loss and deafness in relation to an individual’s difficulty hearing normal conversation *with* the use of a hearing aid (if worn); from a less conversationally functional and more audiological perspective, some respondents may have a hearing loss that is not going to be apparent using the two questions above. Further consideration needs to be given to whether the person uses a hearing aid (U.S. Census Bureau, 2001a, Question ADQ2c; U.S. Census Bureau, 2001b, Question CDQ7c). A person who reports no difficulty hearing normal conversation when wearing her/his hearing aid, nonetheless, does have a hearing loss. This creates a special subgroup among those with hearing loss or deafness responding to the SIPP: persons who have no difficulty hearing normal conversation *and* use a hearing aid (i.e., “No” response to Questions ADQ6 or CDQ11, but “Yes” response to Questions ADQ2c or CDQ7c).

As noted, the SIPP allows individuals to select the label “deaf” in lieu of indicating the degree of difficulty hearing normal conversation. This alternative response exists because people who are born deaf or who experience hearing loss before acquiring spoken language often do not identify themselves as having difficulty with normal conversation; they identify themselves as deaf (Hale, 2001). These respondents

understand that the standard referent is to normal conversation, which implies that any alternative manner of conversation or social intercourse to which one may have ready access is not normal and does not count; being deaf does count.

Another social basis for defining deafness, introduced above, is the use of speech versus sign language, particularly a preference for the use of one over the other. Largely dependent on both the degree and timing of hearing loss, those who are hard of hearing are distinguished from those who are deaf by their ability and *preference* for the use of spoken language when communicating with others. Clearly, there is more room for social mobility by this definition because language and communication skills and preferences can change over time, affecting how a person with hearing loss or deafness creates a self-presentation and how that presentation is perceived by others. However, the SIPP does not inquire about preferences for the use of speech or sign language, though it does request information about the intelligibility of the individual’s speech (e.g., U.S. Census Bureau, 2001a, Question ADQ8: “Do you have difficulty having your speech understood?”).

As becomes evident in the presentation of findings (see the Findings From the SIPP section), five categories of persons can be derived from the difficulty-hearing-normal-conversation and hearing-aid-use questions, ranging from no difficulty to deaf, but the distinctions are too fine given the limited sample size of the SIPP. Discussions about the demography of deafness from the SIPP need to be limited to three groups of persons: hearing, hard of hearing, and functionally deaf. Persons who are considered *hearing* are those with no difficulty hearing normal conversation and who do not use a hearing aid. Persons who are *hard of hearing* are those who either have no difficulty hearing normal conversation but do wear a hearing aid or have some difficulty hearing normal conversation (regardless of hearing aid use). Persons who are *functionally deaf* are those who indicated they are either deaf or unable to hear normal conversation at all (even when using a hearing aid). The SIPP includes too few respondents in some or all age groups for those identified as deaf or as having no difficulty hearing normal conversation when wearing a hearing aid, which means

that reliable estimates cannot be obtained at this level of detail. Consequently, grouping respondents as hearing, hard of hearing, or functionally deaf is the best that the SIPP has to offer.

It turns out that the SIPP does not collect some data highly relevant to the experience of deafness. In particular, the timing of hearing loss, called the age at onset (see, e.g., Schein, 1989), is not recorded. Instead, and only for adults, hearing loss or deafness has to be considered the “main reason for [the individual’s] difficulties” before the year (and month) of onset is requested. If hearing loss or deafness is not considered the cause of any difficulties with identified activities or diminished sense of personal health, then no onset date is requested. Further, only the main reason is associated with a date, so persons with hearing loss or deafness who perceive some other condition as their main reason for difficulties or fair or poor health would still not have an opportunity to report their age at onset. There are no explicit requests for retrospective accounts of the age at onset of hearing loss or deafness independent of other conditions or perceptions.

### Conduct and Design of the SIPP

The U.S. Census Bureau employs a multistage, stratified, cluster sampling design to annually conduct the multiwave panel, national household survey known as the SIPP (see Westat, 2001, for details). That is, the well-funded and extensively staffed SIPP utilizes a complex sample design to follow a large group of people (*panel*) over a few years, with data collection occurring at regular intervals (*waves*) during that time period. However, for any given panel, questions about disability typically are asked during two waves only, but neither the initial nor the final waves. This means that the SIPP does not collect data on hearing loss and deafness annually but does have two time points separated by about 1 year. It should be noted that the consistency of responses to inquiries about hearing difficulty across the two time points for the 1993 panel was not high (McNeil, 2000), which, at a minimum, raises concern about data reliability for longitudinal studies of hearing loss or deafness using the SIPP. For the panel starting in 2001, the design includes disability questions for two waves: Wave 5 and Wave 8.

For the cross-sectional analysis of available data, here, the SIPP Panel 2001 Wave 5 interviews were conducted from June through September of 2002.

The Panel 2001 Wave 5 interviews sample included 29,532 sample units (households) with a total of 69,413 persons (63,456 over 5 years of age); however, 3.4% of the eligible persons were not interviewed. Thirty percent of the interviews for persons aged 15 years or older were with proxies rather than directly with the individual for whom data was recorded; all data for children under age 15 were obtained through proxy interviews.

Person-level weights are assigned to each respondent. These weights are multipliers that increase or decrease the contribution of each individual’s responses in proportion to their expected prevalence based on the sample design so that nationally representative estimates for the civilian noninstitutionalized resident population can be obtained (i.e., does not include persons who are incarcerated, institutionalized, on military bases, or outside of the United States). Design-effect adjustments for the calculation of standard errors are provided by the U.S. Census Bureau (Tupek, 2004) in a publicly available “Source and Accuracy Statement” on the World Wide Web. The design-effect adjustments are necessary because the complex sample design employed by the SIPP increases the measurement error associated with each estimate when compared to the errors that would be calculated if respondents had been sampled randomly without regard to population clustering or assuring that persons from all significant social strata were included. As conventional for population estimates, 90% confidence intervals are calculated (estimate  $\pm 1.645 \times$  standard error) to highlight just how far away point estimates based upon the SIPP sample may be from the true numbers of persons in the population.

### Findings From the SIPP

According to the estimates in Table 1, about 11,000,000 (10,688,525  $\pm$  491,406) people in the United States over 5 years of age are deaf or hard of hearing (4.1% of the population, or 41 per 1,000). However, if estimates are restricted to those who have at least some difficulty hearing normal conversation,

**Table 1** Number of persons by level of difficulty hearing normal conversation and age group, United States, 2002

Has difficulty hearing normal conversation (with hearing aid, if used)	Age (years)				Total
	6–17	18–44	45–64	65+	
No—does not use hearing aid	50,344,058	108,963,853	65,012,397	28,316,169	252,636,477
No—uses hearing aid	45,424	145,556	397,198	1,911,879	2,500,057
Some, even with hearing aid	242,666	965,050	2,254,920	3,732,333	7,194,969
Unable, even with hearing aid	12,866	114,984	182,559	503,538	813,947
Person is deaf	24,108	102,146	42,515	10,783	179,552
Total	50,669,122	110,291,589	67,889,589	34,474,702	263,325,002

Note. Source: Survey of Income and Program Participation (SIPP), Panel 2001, Wave 5 public-use file.

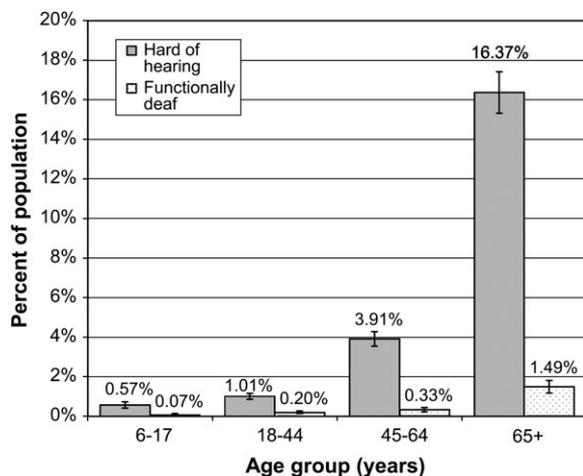
even with a hearing aid, then roughly 8,000,000 (8,188,468  $\pm$  432,052) children and adults would be classified as deaf or hard of hearing (3.7% of the population, or 37 per 1,000). About 1,000,000 (993,499  $\pm$  152,421) are functionally deaf—either deaf or unable to hear normal conversation at all, even when using a hearing aid—(0.38% of the population, or fewer than 4 per 1,000).

Finally, in the neighborhood of 200,000 (179,552  $\pm$  64,889) people in the United States were identified as “deaf” (0.07% of the population, or less than 1 per 1,000). That is, this last category of children and adults did not identify with questions about difficulty hearing normal conversation as an appropriate way to characterize their hearing loss. (Note that these deaf individuals are unlikely to actively identify with classification schemes based upon pure tone threshold audiometry, which often have labels describing hearing loss as ranging from slight to profound and typically make reference to a better-or worse-ear average across several frequencies.) However, there is little reason to have confidence in the estimates from the “deaf” category. A mere 45 out of 63,446 persons over 5 years of age for whom survey responses were obtained (or could be imputed) were identified as deaf. This means that the standard errors on the estimates for this category are very large, particularly when broken down by age group. The 90% confidence interval for deaf children ranges from 325 to 47,891 (0.00% to 0.09% of the ages 6–17 population); from 53,197 to 151,095 (0.05% to 0.14%) for deaf young adults—ages 18 to 44; from 10,932 to 74,098 (0.02% to 0.11%) for deaf middle-age adults—ages 45 to 64; and from –5,123 to 26,689 (–0.01% to 0.08%) for deaf seniors—adults 65 years and older. These estimates are not highly

reliable; the standard errors range in magnitude from 36% of the estimate (all ages) to 148% of the estimate (seniors)! Of particular note is the negative lower bound for seniors, which is due to difficulty estimating standard errors for groups with almost no representation (i.e., three respondents); that is, the estimate is so unreliable that the statistical error at the 90% confidence level is larger than the estimate itself. With respect to the disproportionality across age groups, this is most likely due to wide, but reasonable, sampling variability rather than being representative of the distribution of deaf persons by age in the population.

Given the low reliability of the estimates for persons who were identified as deaf, further discussions about deafness are limited to findings for the number of persons who are *functionally deaf* (i.e., combining deaf with those unable to hear normal conversation at all, even with a hearing aid). The number of respondents identified as functionally deaf is large enough to provide fairly reliable estimates. Similarly, the discussion of lesser degrees of hearing loss is limited to findings for the number of persons who are *hard of hearing* (i.e., some difficulty hearing normal conversation or no difficulty hearing normal conversation, but uses a hearing aid). Among hard-of-hearing persons, there are an estimated 288,090  $\pm$  82,178 children, 1,100,606  $\pm$  161,121 young adults, 2,652,118  $\pm$  248,310 middle-age adults, and 5,644,212  $\pm$  360,335 seniors; among functionally deaf persons, there are an estimated 36,974  $\pm$  29,453 children, 217,130  $\pm$  71,325 young adults, 225,074  $\pm$  72,645 middle-age adults, and 514,321  $\pm$  109,759 seniors.

A bar graph displaying the percentages of persons who are hard of hearing and who are functionally deaf, by age group, is shown in Figure 1 (percentage



**Figure 1** Percentage of persons who are hard of hearing or functionally deaf by age group, United States, 2002. Source: Survey of Income and Program Participation (SIPP), Panel 2001, Wave 5, public-use file.

estimates are printed above each bar). Ninety-percent confidence interval error bars are included in the figure. Except for the group of functionally deaf children, where the size of the standard error is 80% of the estimate itself (only 10 respondents were identified), the standard error of the estimate for each age group of functionally deaf persons is less than one third of the value of the estimate itself. Although the magnitudes of the standard errors are large enough to leave appreciable room for uncertainty about the true population size, they remain small enough to be confident that, with the exception of functionally deaf children, the point estimates are of the right order of magnitude.

For over a century now, various U.S. census and survey efforts have identified substantial age variation in the population of persons with hearing loss or deafness (see, e.g., Best, 1943; Ries, 1994; Schein & Delk, 1974). The findings presented here, based on analysis of the recent SIPP, confirm this pattern of age variation (see Figure 1). The absence of age at onset data, however, does not prevent making inferences about the time-dependent nature of hearing loss or deafness. The dramatic growth in prevalence with increasing age, even with increasing life spans (see, e.g., Arias, 2002) and possible cohort effects (e.g., the maternal rubella “bulge” associated with the 1964–1965, 1958–1959, 1952–1953, 1943–1944, and 1935–1936

birth cohorts; see, e.g., Brown, 1986; Preblud, Hinman, & Herrmann, 1980), could only occur if an increasing number of people are becoming hard of hearing or functionally deaf over their lifetimes. In other words, there is no way that these numbers would occur solely due to people being born into the population with hearing loss. Further, despite relatively high rates of immigration into the United States since the 1970s (see, e.g., Schmidley, 2001), there is no evidence that geographical migration could possibly account for the *more than 20-fold increase* in prevalence of hearing loss and deafness between childhood (ages 6–17) and late adulthood (ages 65 and older).

### The SIPP Answer to “How Many Deaf?”

The SIPP provides fairly tight estimates for the number of *functionally deaf* persons for most age groups except children (ages 6–17) but does not do so for any age group of persons identified as “deaf.” Sampling rare populations is very difficult to do. Obtaining highly reliable estimates for the rarest of persons with deafness, namely children and those who identify as “deaf,” requires a different methodology than that employed by the SIPP, one that raises the probability of sampling the rare population (see, e.g., Kalton & Anderson, 1986; Schein & Delk, 1974). Nonetheless, the estimates obtained from the SIPP are reasonable given previous research (e.g., National Academy on an Aging Society, 1999; Niskar et al., 1998; Ries, 1994; Schein & Delk, 1974), so long as the exact nature of the questions asked is kept in mind.

In sum, as far as it relates to difficulty hearing normal conversation, estimates from the SIPP indicate that fewer than 1 in 20 Americans are currently deaf or hard of hearing. In round numbers, nearly 10,000,000 persons are *hard of hearing* and close to 1,000,000 are *functionally deaf*. More than half of all persons with hearing loss or deafness are 65 years or older and less than 4% are under 18 years of age.

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