

## **Demographics for Deaf Education**

Ross E. Mitchell\*

Graduate Department of Leadership and Counseling

School of Education

University of Redlands

This is a draft of a chapter that has been accepted for publication by Oxford University Press in the forthcoming book *Research in Deaf Education: Contexts, Challenges, Considerations* edited by Stephanie W. Cawthon and Carrie Lou Garberoglio due for publication in 2016.

Draft Prepared: May 11, 2016

\* Author Note: I have to thank my graduate research assistant Yadanara Rodriguez-Britt for assistance with the preparation of this manuscript. I also owe a debt of gratitude to Scott Campbell Brown and Gallaudet University (especially Charles Reilly, Carol Erting, and the Gallaudet Research Institute staff) for the opportunity to lead and participate in conversations about the future of the Annual Survey of Deaf and Hard of Hearing Children and Youth. Nonetheless, I am solely responsible for this text and any errors or omissions therein.

**Abstract**

This chapter addresses the importance of demographic studies for deaf education. It focuses on methods of inquiry that help to answer one of the most basic questions asked by deaf education programs, namely: Who are the children and youth we may expect to be responsible for? Efforts to describe this population who, along with their families, would benefit from specially designed instructional programming and services, have been pursued in various ways. This chapter reviews past and current methods employed to estimate the size and characteristics of the deaf child and youth population in the US and describes the necessary considerations for future work in the field.

*Keywords:* demography, deafness, national surveys, school surveys

### **Demographics for Deaf Education**

This chapter addresses the importance of demographic studies for deaf education. It focuses on methods of inquiry that help to answer one of the most basic concerns for deaf education, namely: Who are the children and youth for whom schools and programs are responsible? Efforts to describe this population who, along with their families, would benefit from specially designed instructional programming and services, have been pursued in various ways. This chapter reviews past and current methods employed to estimate the size and characteristics of the deaf child and youth population in the USA and describes the necessary considerations for future work in the field.

Establishing the size and stability, growth, or decline of the population of deaf young people—from infancy through very early adulthood—is the primary objective of demographic studies addressed in this chapter. However, further information is required to inform the field of deaf education. Not every child with a hearing loss will receive school-based services, specially designed instructional programming, or other accommodations—not as a matter of neglect or resistance but because such children function in the school context as they present themselves. That is, who counts as deaf, the fundamental demographic finding, may not be the same for deaf education as it is for other organized concerns in society (e.g., public health, Social Security benefits, telecommunication services, etc.).

Consistent with the definitions provided by the State of California Commission on Teacher Credentialing (CCTC, 2015), for example, deaf education is to be responsive to the entire range of auditory conditions that “may adversely affect a child’s [school] performance” (p. 5), which includes the condition of being hard of hearing as well as deafness, meaning the demographics of deaf education will include all forms of hearing impairment or loss of a

“unilateral or bilateral [nature], whether fluctuating, conductive, sensorineural, or auditory neuropathy” (p. 5). However, the key issue for deaf education is the determination of possible adverse effect, not simply the auditory epidemiology of infancy, childhood, and youth. The field of deaf education is obliged to be responsive to students’ language abilities, including whether a signed language is used or needs to be taught, familial expectations and circumstances, and whether students present additional conditions or disabilities, among other considerations. So, before addressing the methods of demographic studies for deaf education, the various definitions of and motivations behind who counts as deaf must be distinguished because the child-centered auditory epidemiology central to the CCTC definition, alone, misses the complex interplay among deaf educators, general educators, families, service providers, and the children identified for deaf education.

### **Demography vs. Epidemiology**

*Demography* pertains to who is in the population and how attributes of person such as deafness affect whether such persons flourish in the most basic sense of births, marriage, fertility, and eventually deaths, and can be extended to include a more nuanced sense of access to opportunities in society that enhance one’s chances for survival and reproduction (e.g., maintaining stable employment, being fluent in the dominant language, having greater wealth, attaining higher levels of education, etc.). *Epidemiology* more narrowly focuses on the distribution and causes of disease or other health conditions such as deafness and their consequences for individual longevity, fertility, and cognitive or bodily function. Though understanding the causes (etiology) of deafness can sometimes facilitate better services, instructional supports, and accommodations, equally or more often understanding the familial and community contexts in which deaf and hard of hearing children live is the information

needed by the field of deaf education. Valuably, epidemiology may alert the field to sudden increases in the incidence of childhood deafness, as followed from maternal rubella epidemics prior to widespread vaccination, or changes in how allied health professions intervene, as with proliferation of pediatric cochlear implantation. However, the more general study of life chances and consequent population dynamics, particularly without prejudice as to the status of deafness as a disease or an ill health condition, is the purview of demography.

As necessary, this chapter reviews both the demography and epidemiology of childhood deafness for insights that inform deaf education. However, emphasis is upon understanding what has been learned and how to continue to gain insights about the population of children and youth who present a degree of deafness sufficient to be eligible for special education services or other accommodations in the school setting because their ability to hear and the consequent assumptions about how they interact with others and their environment cannot be taken for granted. Such understanding and insights have been gained and pursued with various concerns in mind, which are addressed below.

### **Perspectives on the Demography of d/Deaf Populations**

Three perspectives have influenced demographic descriptions of d/Deaf populations (more on little “d” deaf vs. big “D” Deaf to follow—in short, sound and status vs. language and cultural identity). These perspectives are known as the medical, social, and cultural perspectives (Kermit, 2009; Mitchell, 2016; Young & Temple, 2014). In one way or another, all perspectives stipulate that auditory function is limited, and this has consequences for how people live, learn, and otherwise participate in social life. At the same time, all three may emphasize the distinctiveness of the views associated with them in order to make a point about different qualities of the deaf experience. Consequently, a full demographic description must explore all

three perspectives to obtain differentiated yet interacting implications for the practice of deaf education.

**Medical.** The medical perspective focuses on how people perceive sound, their degree of little “d” deafness, and the biophysical impairment of their full hearing function (i.e., whether theirs is due to conductive, sensorineural, or neural hearing losses). Included in the medical history of auditory perception is the age at onset of hearing loss, whether the loss is sudden or progressive in nature, and its etiology (e.g., whether functional impairment is due to genetic inheritance, disease, or injury), as well as the severity or degree of deafness. Though emphasis is almost always on how easily speech sounds are perceived without an assistive listening technology, hearing sensitivity is more extensive and varies in its frequency profile. For example, the better ear average (BEA) across a set of pure tone frequency thresholds in the human voice range (e.g., at 500, 1000, and 2000 Hz) is among the most common medical (psycho-audiological) measures of the degree of deafness. Often, technological intervention, particularly hearing aids or cochlear implants (prostheses), follows from treating deafness medically. Further, affiliated services from audiologists and speech and language pathologists frequently are required to fulfil a treatment plan, one that may develop over several years.

Epidemiology is the form of population study typically demanded by the medical perspective. The qualitative differences that go with the labels hard of hearing and deaf in the field of deaf education are, diagnostically, merely differing degrees of deafness (or hearing loss). That is, what counts for deaf education is the child’s degree of deafness and, especially for the day-to-day educational practitioner, both the subsequent treatment and corresponding approach to intervention that must be monitored and accommodated in the school setting.

**Social.** The social perspective focuses on impeded access or barriers to social participation for people with hearing impairment. This is the status, rather than degree, of being little “d” deaf. The social perspective is reacting against any stigma of deafness, not just whether deafness is a hearing deficit (Powell-Williams, 2014; Shakespeare et al., 2006; also see Antia & Kreimeyer, 2015). In this case, attention is drawn to how unexamined or taken-for-granted social arrangements exclude or burden people who experience some degree of deafness, thereby putting them at risk of experiencing disability or discrimination as well.

For those not experiencing deafness, the most basic taken-for-granted social situation is uninhibited access to linguistic communication within the household. Deaf infants and toddlers do not share this norm (except when their families engage in visually accessible and comprehensible linguistic exchanges), which is why the age at onset of deafness is routinely part of demographic and epidemiological studies. Though later hearing loss will still have a significant impact on communication, both at home and elsewhere, typical language development is likely to occur when hearing is unimpaired early in life (but see next subsection on the Cultural perspective). Relevant to deaf education, a whole variety of developmental delays may be experienced by children with early onset deafness in the absence of accessible linguistic communication in their environment—their person-environment fit may be quite poor from their earliest years. And, once in school, “hearing loss has the potential to isolate children and prevent them from the kinds of social interaction in which most children engage” (Antia & Kreimeyer, 2015, p. 2).

Disabling or discriminatory social arrangements or practices may be literally built into the environment, such as office cubicles or other constructions (or partitions) that impede visual access to coworkers. Or, they may be virtually built in, as when uncaptioned videos are posted

on social media sites. That is, the social perspective emphasizes how, in the absence of change, deafness has negative social consequences. Within this perspective, whether individuals identify their deafness/hearing status as hard of hearing or deaf (or Deaf, below), it is less their attribute of person and more whether the person-environment fit makes their deafness a disabling condition. For deaf education, one important example of potential disadvantage is unintentional exclusion from conversations (or other information exchanges) that cannot be seen or heard by the child with a hearing impairment—missed opportunities for incidental, as well as intentional, learning that result in a lack of shared knowledge and background experiences from which to draw, as well as social opportunities—so exactly how someone counts as deaf will depend on how disabling the environment is. By contrast, deaf education can intentionally facilitate an accessible social and physical environment that positively incorporates how life is lived differently with deafness.

**Cultural.** The cultural perspective highlights how the experiences common among those who are deaf, particularly when sign language use is among those experiences, creates a basis for collective identity, solidarity, and community. Big “D” Deaf communities restructure social interaction through signed language and, frequently, redeploy technical means and reconstruct material conditions to enhance visual access and communication—this realignment is part of what creates and sustains a Deaf culture—so that person and environment mutually fit to each other rather than individuals requiring accommodations. But, big “D” Deaf communities are not merely collections of adaptive and affiliated deaf persons. Deaf culture requires and provides for intentional cultivation of its members. Deaf education in the form of schools for the deaf and other sign-language-based instructional and family service programs is one of the central common experiences in Deaf community formation—by their existence, such schools and

programs contribute to who counts as Deaf and, therefore, are among the key indicators for measuring whether deaf children are part of this demographic. Another key indicator is whether the child has Deaf parents because typical language development, and concomitant cognitive and social development, occurs in a household where signed language and other Deaf cultural practices and norms of interaction are part of daily living.

An important addition to the cultural perspective is provided by Powell-Williams (2014), who splits cultural into “subcultural” and “cultural identity,” distinguishing the collective phenomenon of Deaf culture from the individual phenomenon of personal identification as an accepted or marginalized member of either hearing or d/Deaf communities (or both, which would be a bicultural identity; for the Deaf Identity Development Scale, see Fischer & McWhirter, 2001; Glickman, 1993; Glickman & Carey, 1993; Leigh et al., 1998; for the Deaf Acculturation Scale, see Maxwell-McCaw, 2001; Maxwell-McCaw & Zea, 2011). For deaf education, the attention to the cultural identity facet is particularly important for adolescents, and attention to such demographic characteristics as severity of hearing loss, age at onset, language choice (or communication method), and school setting are key personal and interactional factors influencing how these young people personally identify (Leigh, et al., 2009; also see Carter, 2015; Fischer & McWhirter, 2001). However, from the standpoint of demographic research, cultural identity is a potentially unstable phenomenon among children and youth in the process of discovering, confronting, embracing, or rejecting possible selves. Further, like many aspects of political and cultural socialization, who declares and controls the recording of identity labels (e.g., parents, teachers, or the children themselves) affects the meaning to be inferred from them and the educational practices to be employed in response to (or which create) them. As a

consequence, the cultural identity facet of the cultural perspective is unlikely to be a routine component of demographics for deaf education.

**Intersecting perspectives.** These three perspectives on who counts as d/Deaf have to be understood and kept in mind when making sense of demographic reports because, otherwise, there is great risk of misinforming deaf education planning and practice. For example, as Mitchell, Young, Bachleda, and Karchmer (2006) found in their search for an estimate of how many people use ASL in the United States, many people conflated deafness (having hearing impairment) with being Deaf (using ASL), thus, grossly overestimating the size of the population of Americans who regularly sign in ASL while, at the same time, completely ignoring that an important minority share of the ASL signing population has no hearing impairment. (The Mitchell et al. study did not address what has now become a sizeable number of college students enrolled in ASL classes—the third most popular introductory-level language class and the sixth most popular advanced-level course [see Goldberg, Looney, & Lusin, 2015]—because this is a very recent phenomenon for which popularity was growing but had not yet soared at the time of their study.) Having accurate estimates of the ASL signing population might affect, for example, judgment about the demand and prospect for recruiting ASL-English interpreters, Deaf teachers, Deaf mentors, etc. Mitchell and Karchmer (2004a) found that both parents' and their children's statuses as d/Deaf strongly predicted whether children's educational programming was sign-language-based or mainstreamed in classrooms where speaking and listening were the primary, if not sole, means for communication. However, parental hearing status operated through its strong effect on whether sign was regularly used in the home—the language-cultural system—while the child's degree of deafness continued to be independently predictive of the school setting and use of sign language in classroom instruction. In other words, these two examples highlight how

multiple perspectives have to be considered simultaneously in order to identify the demographic influences that have the potential to meaningfully inform deaf education. With a view towards identifying contributions to deaf education research, whether and how well these three perspectives have been combined across demographic studies of deafness is addressed in the following section.

### **The What, When, How, and Why of American Deaf Population Studies**

#### **Reinvestment**

As detailed in the introduction to *Deaf Children in America* (Schildroth & Karchmer, 1986), national interest in demographically describing the deaf population was mobilized through the “Conference on the Collection of Statistics of Severe Hearing Impairments and Deafness in the United States” hosted by the National Institute on Neurological Diseases and Blindness (NINDB) in March of 1964. This conference, which followed over 30 years of neglect since the U.S. Bureau of the Census last included deafness in the 1930 decennial census, came at a time when deafness was beginning to receive renewed attention as a health issue (see National Health Survey, below). At the same time, an Advisory Committee on the Education of the Deaf had been appointed by the then Secretary of Health, Education, and Welfare “to conduct a study of the problems of education of the deaf and of the programs in the nation which are directed at meeting them” (Babbidge et al., 1965, p. v; known to many as the *Babbidge Report*, after its Chairman, Dr. Homer D. Babbidge, Jr.). The “problems of education of the deaf” included poor English literacy, low educational attainment, and subsequent low-level employment and underemployment (limited economic opportunity). The *Babbidge Report* included specific concerns among the broader set that motivated the NINDB conference, namely, “statistics on the prevalence of [early childhood] deafness are not sufficiently reliable or refined

to permit a precise [estimate of the number of children in need of deaf education programs]” (p. 7). Whether inferred from health, rehabilitation services (either school/center- or clinic-based), or education studies, there was widespread recognition that demographics for deaf education were inadequate. Program or policy planning and decision making required better information.

The first major demographic initiative following the NINDB conference, currently known as the Annual Survey of Deaf and Hard of Hearing Children and Youth (hereafter, Annual Survey), was launched in 1968 upon completion of a two-year pilot project funded by the Bureau of Education for the Handicapped in 1965. Both the pilot project and the subsequent Annual Survey program were directed and staffed by faculty, research scientists, and research staff at Gallaudet University (then, Gallaudet College), which was recognized as “an important center for research on deafness and education of the deaf” (Babbidge et al., 1965, p. 55).

The second major initiative was funded in 1969, namely, the National Census of the Deaf Population (NCDP). The NCDP was a one-time study made possible by a grant to the National Association of the Deaf by the Social and Rehabilitation Service of the then U.S. Department of Health, Education, and Welfare, and was launched under the technical guidance of the Deafness Research & Training Center at New York University in 1970 (Schein & Delk, 1974). Consistent with best practices for studying low-incidence (rare) populations (also see Cawthon, 2006; Kalton & Anderson, 1986), snowball sampling was employed following compilation of an extensive directory of membership rosters, as well as hiring and training interviewers familiar with and possessing attributes respected by the nation’s deaf communities. The NCDP was and remains the most comprehensive demographic study of the deaf population of the United States.

Rather than conduct a unique inquiry among children and youth in the deaf population, however, the NCDP depended on the widespread success of the concurrent Annual Survey to

capture the school-age portion of the deaf population. Moreover, its findings pertaining to K–12 deaf education were entirely retrospective (i.e., adults reporting on their prior educational experiences). The NCDP did not attempt to elaborate upon the work of the Annual Survey. Nonetheless, the connection between educational attainment and economic well-being among adults in the deaf population previously lamented in the *Babbidge Report* was clearly established—a connection that remains equally if not more important over four decades later (Walter & Dirmyer, 2013).

### **The Gallaudet Research Institute and the Annual Survey**

Demographic studies in the field of deaf education have been dominated by the Annual Survey, which has a long legacy of broad participation by schools and programs. The Annual Survey has been and remains the most detailed and longest running demographic survey of deaf children and youth. Following its start at the end of the 1960s, the Annual Survey quickly developed substantial institutional and federal funding support, had broad dissemination of findings through technical reports and publications, and established associations with the nation’s leading health statisticians and demographers of deafness. Moreover, the Annual Survey design provides for individual-level data, which allows for a wide range of possible analyses and aggregations. So, it is hardly surprising that the Annual Survey would be the source to which many have looked for the demographics of deaf education.

Calling the Annual Survey a *survey*, however, may be misleading to some readers and research consumers. The Annual Survey was not developed as a large-scale probability-based sample survey even though state-of-the-art survey research had established that both cost and quality control were more easily maintained by employing probability and statistical inference. Instead, the ambitious aim was to produce as extensive a census as possible for the low-incidence

population of deaf students in the United States. (Note: Response rates ranged from around 55,000 during the height of the maternal rubella bulge of the early 1980s to in the neighborhood of 37,000 in the 2000s; e.g., see Gallaudet Research Institute, 2002, 2011; Holden-Pitt & Diaz, 1998; Mitchell, 2004). Pursuit of a census makes sense because the Annual Survey was established prior to and anticipated the necessity of broadly mandated child population counts of students receiving federally funded special education services. Moreover, since there was no prior basis for having a registry of known schools and programs from which to draw a probability-based sample, the Annual Survey had to build its own registry by starting with what was known (e.g., residential and day schools for the deaf, as well as some special classes and centers, were known and their enrollments reported annually in the *American Annals of the Deaf*) and build from there—an outreach effort was undertaken to extend the list of participating schools and programs. Though a large percentage of the intended population was included among participants, and great efforts were made to at least contact all sites serving deaf children and youth, many were missed (more often hard of hearing than deaf children) because the schools in which they were enrolled (often as the only or one of very few deaf children there) were unknown to the Annual Survey staff.

The sample bias associated with the Annual Survey's incomplete census strategy was acknowledged repeatedly (Mitchell, 2004; Ries, 1986; Schildroth & Hotto, 1993). Nonetheless, until the second decade of the twenty-first century, the Annual Survey was regarded as the authoritative source of demographics for deaf education. For example, when the National Research Council's Committee on Disability Determination for Individuals with Hearing Impairments (National Research Council, 2005) reviewed what is known about the determination of hearing loss and its consequences for the purpose of determining eligibility for social security

benefits, the Committee depended almost exclusively on insights derived from the work of the Gallaudet Research Institute, which included findings from the Annual Survey (i.e., the Committee cited Gallaudet Research Institute, 2002; Holden-Pitt & Diaz, 1998; and, especially, Karchmer & Mitchell, 2003). More recently, the U.S. Government Accountability Office (2011), in a response to congressional committee requests for information about how federal programs support deaf and hard of hearing children, depended on the Annual Survey for the most up-to-date statistics pertaining to sign language use for academic instruction (i.e., the GAO cited Gallaudet Research Institute, 2008). In other words, despite its well-known biases, the Annual Survey has been the only source to which practitioners, researchers, and policy makers have been able to turn for detailed and, more importantly, regularly updated demographics that touch upon school-based services, specially designed instructional programming, or other accommodations.

The presently changing status of the Annual Survey is due largely to the fact that the Gallaudet Research Institute is no longer a large unit with multiple research scientists and staff research associates, many of its nationally affiliated statisticians and demographers have long since retired, and its longstanding relationships with a wide array of schools and programs serving deaf students are now, unfortunately, far from sufficient to adequately sample a much more diverse and diffuse population (Mitchell & Karchmer, 2006). Additionally, the Annual Survey has suffered from the same struggle that all large-scale survey research has encountered in the last decade or so, namely, declining response rates and accompanying nonresponse bias (e.g., see Beebe et al., 2012; Lindén-Boström & Persson, 2013; The Pew Research Center for the People & the Press, 2012; Wagner, Cameto, & Newman, 2003). As a consequence of these multiple circumstances, researchers in the field have begun looking to other sources in order to

more fully and representatively characterize the demographics of deaf education (e.g., see Mitchell, 2004; Mitchell & Karchmer, 2011; Shaver, Marschark, Newman, & Marder, 2014).

### **More Recently Established Education Data Sources**

**IDEA Child Count.** In order to obtain schooling-specific information following the passage of the Education for All Handicapped Children Act, Public Law 94-142, in 1975, ongoing production of what is now called the *Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act* (hereafter, the IDEA Child Count; see Data Accountability Center, 2012) has provided essential yet much more limited demographics for deaf education relative to the Annual Survey (see Mitchell, 2004; Mitchell & Karchmer, 2006). In addition to demographic distributions for students with hearing impairment along basic variables such as age (or age grouping) and ethnoracial classification (and mortality for those who had reached the age of 14 or older; also, since 2006, gender and English language proficiency), the IDEA Child Count provides reports on school setting or proportion of time receiving instruction in the regular classroom (i.e., with non-disabled peers) and reason for exiting school (e.g., graduating with a diploma, moving, dropping out, etc.; see Data Accountability Center, 2012). However, the IDEA Child Count is not a census of individuals for the limited number of variables identified. Instead, it is composed of state-level aggregated reports compiled from school- and district-level aggregate tabulations received (and, possibly, supplemented by estimates based upon other information that would indicate there are more deaf children served under IDEA than were reported to the state). The consequence of this design feature is that there is no opportunity for alternative analyses—the data cannot be disaggregated—so there is nothing further to be learned from the data collected to generate the IDEA Child Count because it was never intended to serve such flexible or refined purposes.

Alternative or more extensive demographic cross-classifications with school-based services, specially designed instructional programming, or other accommodations are not a possibility.

(Cross-classification means to tabulate or otherwise reveal contingencies, such as how placement in self-contained deaf education classrooms within regular schools exhibits different ethnoracial enrollment patterns in comparison to regular/mainstream classrooms for deaf students—a two-way contingency—and a more extensive cross-classification might further reveal the imbalance in placements for deaf students who have additional conditions or disabilities between self-contained and regular/mainstream classrooms for each ethnoracial group—a three-way contingency.)

In addition to the design limitations as a consequence of aggregated reporting by states, the IDEA Child Count has been limited to the aggregate category hearing impairment, introduced by the *1990 Amendments to IDEA* (P.L. 101-476), which combined the previously separate deaf and hard-of-hearing categories into one. This aggregate category has been peculiarly persistent given its inconsistency with social and cultural demography, as well as differentiation in both federal statutory language (IDEA [P.L. 108-446, 118 STAT. 2647 et seq., 2004], which frequently distinguishes *hard-of-hearing* from *deaf*, and the Education of the Deaf Act of 1986 [P.L. 99-371, 100 STAT. 781 et seq., 1986], which distinguishes *hearing impaired* from *deaf* students) and regulatory language (34 CFR 300 et seq., 2006; see §§ 308.c.3, 308.c.5, which define *deafness* as meaningfully distinguishable from *hearing impairment*, respectively). This limitation is most apparent when considering whether degree of deafness is an important consideration in school or program placement (which it is; see, e.g., Mitchell & Karchmer, 2011; Shaver et al., 2014) because this meaningful distinction is absent.

**National Longitudinal Transition Studies (NLTS and NLTS-2).** Beyond the Annual Survey and the IDEA Child Count, the only other projects to include demographic studies of deafness that would directly inform deaf education over an extended period of time are the federally mandated National Longitudinal Transition Studies conducted by the contracted research team at SRI International (NLTS, e.g., see Wagner et al., 1991; and NLTS-2, e.g., see Wagner et al., 2003; for comparison across the two studies, e.g., see Wagner, Cameto, & Newman, 2003). These two studies were probability-based sample (two-stage, stratified, random cluster) surveys, the first begun in 1987 and the second in 2001. The first collected data from 15- to 23-year-old students with disabilities (not just students with hearing impairment or deafness), their families, and their education providers (linking all respondents to their respective individual students), while the second started with students ages 13 to 17 years. The more recent NLTS-2 included five data collection waves from 2001 through 2009, providing sufficient time for all sampled participants to reach or far surpass the maximum age for K–12 enrollment under IDEA (i.e., ensure that all students had begun their transition out of compulsory schooling, and many had the opportunity to pursue, if not complete, post-secondary education, work, family, and other possibilities for an independent adulthood).

For both studies, the target sample size was 1,000 students per disability category (except for the very low-incidence category of deaf-blindness), which is sufficient for relatively precise estimates of within-category demographic differences. Though the two statuses of deaf and hard of hearing were collapsed into a single hearing impairment category between the NLTS and the NLTS-2, comparability in the precision of estimates was achieved because the fraction of 15- to 17-year-old students in the NLTS sample across the two categories was nearly identical to that of the same age students in the NLTS-2 sample in the single category. Further, a wide range of

relevant attributes and circumstances were measured for these relatively large samples of deaf youth, which allowed for detailed demographic profiles to be constructed, with the NLTS-2 including several survey items relevant to important changes in deaf education since the NLTS (e.g., distinguishing among signed languages and manual communication systems, classifying hearing ability while using assistive technology, and whether youth had a cochlear implant).

Though the team at SRI International never gave deaf youth their own dedicated report, student and setting attributes (either deaf or hard of hearing in the NLTS, or hearing impaired in the NLTS-2) were cross-classified to reveal some key differences in the distributions of school-based services, specially designed instructional programming, or other accommodations. Unfortunately, the more contemporary NLTS-2 reports did not cross-classify by degree of hearing loss among students with hearing impairment when it comes to deaf education programs and practices; this important level of detail is only given in reference to social demography, namely, “individual and household characteristics” (Wagner et al., 2003).

This unfortunate shortcoming in the reports authored by the SRI International team has only been partially overcome by a recent reanalysis by Shaver et al. (2014). In this recent study, variations in reference to school placement (regular, special, or mixed/transfer between) were examined across both demographic and educational measures, including such demographics of deafness distinctions as whether students were deaf or hard of hearing, whether students’ severity of hearing loss was mild, moderate, or severe to profound, whether their hearing with a hearing device was considered as normal, with a little trouble, with a lot of trouble, or not at all, and whether and how well signed or spoken language was used by the student (and whether sign language was used by members of the student’s household). There were substantial differences in the distributions of deafness, assisted hearing ability, and signed or spoken language use

responses across school placements. Though nationally representative, this complex survey has an insufficiently large sample size to elaborate fully upon the demographic cross-classification questions of importance to deaf education such as, for a particular school placement, whether a student's severity of hearing loss had any relationship to the use of sign language by the student, the school, or the family, to whether the student had an additional condition or disability, or to whether the student had been held back a grade, for example. More educationally relevant questions, such as how demographics vary by school-based services, specially designed instructional programming, or other accommodations either could not be or were not included in the Shaver et al. (2014) reanalysis. Since these absent inquiries require more extensive cross-classification, it will be difficult to make any strong inferences to inform the practice of deaf education.

**Special Education Elementary Longitudinal Study (SEELS).** Additional longitudinal studies that include the deaf education student population have occurred, though they capture much shorter timespans than the NLTS and NLTS-2 programs described above. Most prominent and informative among them is the nationally representative Special Education Elementary Longitudinal Study (e.g., see SRI International, 1999; Wagner, Marder, Blackorby, & Cardoso, 2002), another two-stage, stratified, random cluster sample (first sampling LEAs/special state schools, then students within schools) survey, which collected its first wave of data from over 12,000 children ages 6–13 years of age identified for special education from nearly 300 LEAs and state special schools in the 1999-2000 school year with three subsequent waves, the last in the 2005–2006 school year.

The SEELS has provided one of the few national reports focusing specifically on the relationship between childhood hearing impairment and education separate from the Annual

Survey. Blackorby and Knokey (2006) identified a range of demographic characteristics relevant to deaf education and presented their distributions across school-based services, specially designed instructional programming, or other accommodations. The report does not provide sufficient fine structure to consider the intersection of student and setting attributes that might better distinguish little “d” deaf from big “D” Deaf students, particularly in terms of the three perspectives of medical, social, and cultural deafness. (Given the complex sample design and sample size, such extensive cross-classification would be unwarranted because estimates would have large uncertainties—chance rather than reliable relationships.) Nonetheless, there is enough detail to make clear that deaf children’s circumstances and their education cannot be fully understood without a multi-perspective approach to deaf students’ demographics.

**Early Childhood Longitudinal Study (ECLS).** A final contemporary longitudinal study of education that incidentally rather than intentionally includes students in deaf education is the Early Childhood Longitudinal Study, Kindergarten Class of 2010–2011 (ECLS-K:2011; e.g., see Tourangeau et al., 2015; U.S. Department of Education, 2014), yet another nationally representative, two-stage, stratified, random cluster sample survey, which collected its first wave of data from over 18,000 children enrolled in kindergarten from nearly 1,000 schools (initially, with another 300+ due to students transferring during their kindergarten year) offering half- or full-day kindergarten in the 2010–2011 school year with subsequent waves in grades 1 through 5 in the 2011–2012 through 2015–2016 school years. Two collection waves (fall and spring) occurred in grades K through 2 and one wave (spring) in grades 3 through 5. In addition to establishing whether children were identified as having hearing impairment each year by a survey of the child’s special education teacher, an evaluation of children’s hearing was conducted in the fall 2012 and spring 2014 collection waves.

The value of the ECLS-K:2011 is that it will be the first national, school-based, prospective study of childhood hearing ability. Though the sample size is too small to offer much in the way of demographics for deaf education (a prevalence of roughly 2 per 1,000 means less than 40 deaf students are likely to be identified from among the 18,000 participants), insights about the interrelationship between educational trajectories and lesser degrees of childhood hearing loss may be a possibility. That is, the prevalence of hard of hearing children is much greater than that of deaf children (e.g., Mehra, Eavey, & Keamy, Jr., 2009; Mitchell, 2005, 2006; Niskar et al., 1998), and there is a higher incidence of later onset hearing loss of lesser degree (e.g., Eiserman et al., 2008; Fitzpatrick, Whittingham, & Durieux-Smith, 2013; Watkin & Baldwin, 2011). And, since lesser degrees of hearing are more prevalent among children from low-income households (e.g., Niskar et al., 1998), there is potential for sorting out whether hearing loss, regardless of its degree, is at the heart of childhood school challenges or one of many conditions compounding the barriers to receiving and sustaining an equitable education for children from low-income households (e.g., Wagner et al., 2003). Certainly, as Antia and coworkers have demonstrated (see, e.g., Antia & Kreimeyer, 2015), there is reason to be concerned about the educational and school experiences of children and youth with mild and moderate hearing loss. Recent release of ECLS-K:2011 audiometric data may offer new (or confirm current) insights about this segment of the deaf child population.

### **Other and More Recently Established Non-Education Data Sources**

**National Health Survey (NHS).** Before there was the Annual Survey, information about the prevalence of deafness or hearing impairment in the United States was being systematically collected through the National Health Survey program (see National Center for Health Statistics, 1963). Now under the aegis of the Centers for Disease Control and Prevention (CDC), it

continues to be managed by the National Center for Health Statistics and conducted by the U.S. Bureau of the Census (and its contract agents). The NHS program has provided more or less detailed reports (or the data analyzed for reports by others) on the demographics of deafness since 1959 (U.S. National Health Service, 1959). The primary reason for highlighting the NHS programs is that findings from the National Health Interview Survey (NHIS; e.g., Boyle et al., 2011), a nationally representative, complex, multistage, stratified household (random cluster) survey of the non-institutionalized population (see Parsons et al., 2014), and the National Health and Nutrition Examination Survey (NHANES; e.g., Lin, Niparko, & Ferrucci, 2011; Niskar et al., 1998), a nationally representative, four-stage, stratified household and noninstitutional group quarters (random dwelling unit clusters and then random individuals from within them) survey of the non-institutionalized population (see Johnson, Dohrmann, Burt, & Mohadjer, 2014), have been important to validating or making adjustments for the biases in the Annual Survey (Ries, 1986) and other demographic studies of deafness (Schein & Delk, 1974). And, from a strictly deaf demographics (as opposed to deaf education) standpoint, because multiple years of NHIS data collected within the same decennial sampling frame can be stacked for analysis, demographers are able to obtain less timely but more precise estimates of the size of the deaf child and youth population than might be provided from a single year's data collection (e.g., Boyle et al., 2011; Mitchell, 2005).

The NHS programs have not typically attended to any details about the schooling of deaf children and youth. Presently, the NHANES does inquire about whether children have been identified for special education, but not for which disability categories, services, programming, or accommodations. In the past, it had included an item pertaining to whether parents had been told their child had a learning disability, but this is no longer the case. In its audiometry

component, which is not included in each biennial cycle, the NHANES has a less than comprehensive item pertaining to assistive listening devices—one that does not include any classroom-specific services—and excludes children under 12 years of age as eligible respondents. However, the NHIS does inquire about additional disabilities, such as a learning disability, ADD/ADHD, intellectual disability, and behavioral or emotional problems, as well as inquiring about whether the child has been identified for special education or early intervention services. Further, the NHIS identifies whether children with less than excellent or good hearing (i.e., less than good in at least one ear) have ever used assistive technology to communicate and with response possibilities that include classroom-specific services.

The NHS programs have been the most popular and frequently cited sources for the demographics and epidemiology of childhood (dis)abilities, including deafness (e.g., Boyle et al., 2011; Halfon, Houtrow, Larson, & Newacheck, 2012; Mehra, Eavey, & Keamy, 2009; Niskar et al., 1998; Schein, 1996; Shargorodsky, Curhan, Curhan, & Eavey, 2010; U.S. Government Accountability Office, 2011), but the NHS-based findings in these reports have been almost entirely about little “d” deafness and nothing about deaf education. Many survey items represent both medical and social perspectives, but they typically do so without regard to identifying means by which to remove disabling social barriers or discrimination. The only exception pointing to the cultural perspective, and certainly toward the elimination or reduction of disabling social barriers, is found in the NHIS child questionnaire item pertaining to assistive technology devices or types (see National Center for Health Statistics, 2015, p. 42). This one item includes three response possibilities that include visual communication means, two of which specifically address sign language. (Note: Though the 2011–2012 NHANES Audiometry questionnaire included a sign-language interpreter among possible assistive listening devices

[sic], there was no opportunity for the respondent to identify that they specifically utilized sign-language interpreters.) Clearly, deaf education requires a different data source to meet its precise and detailed needs.

**Survey of Income and Program Participation (SIPP).** The SIPP is intended to provide federal government agencies with information relevant to participants in their various programs, programs that may include transfer payments and other benefits for those with deafness (disability). For the latest SIPP, the sixth wave of data collection for the 2008 panel of this longitudinal, two-stage, stratified household (random cluster) survey of the non-institutionalized population has two disability-specific topical modules (TMs) to include both adults and children with sufficient detail to identify the degree of severity of hearing loss: Adult Functional Limitations TM and Child Functional Limitations TM (Brault, 2012). As documented by Brault (2012) and Mitchell (2006), during the 2000s, roughly 30,000 to 35,000 households participated in the disability-specific topical modules (i.e., 60,000 to 70,000 individuals, or their proxies, were interviewed). Only for adults and children over five years of age did SIPP make inquiries about respondents' deafness/difficulty hearing, hearing aid use, and ability to hear normal conversation (Mitchell, 2006; U.S. Census Bureau, n.d.a).

Unfortunately, outside of the grade level in which the child is enrolled, there are no inquiries about a sample child's schooling, let alone whether that child receives school-based services, specially designed instructional programming, or other accommodations. The SIPP provides the ability to distinguish between children who are hard of hearing and functionally deaf (see Mitchell, 2006), and documents a broad range of family and household circumstances, but its demographic contribution to informing deaf education (as opposed to understanding the deaf population) is inadequate.

**American Community Survey (ACS).** The ACS is the latest federal, two-stage, stratified household (random cluster) survey program to systematically inquire about deafness (U.S. Census Bureau, 2014). (Note that the ACS has two phases, one to address properly identified primary sampling units [PSUs] and one to follow up with unreachable PSUs, each with two stages, and includes group quarters as well as housing units as cluster populations stratified prior to sampling; also, unlike housing units, individuals are sampled from within the total number of group quarters residents.) Annually, the ACS completes well in excess of 2,000,000 housing unit interviews and over 150,000 group quarters interviews. Moreover, its design allows analysts to stack up to five years of data to further increase sample size (i.e., improve precision of estimates both nationally and by region or state) because each year of the five-year data collection sample has a unique sampling frame. At the same time, the ACS is like the SIPP in that it provides almost no information about children's education except for grade level in school (and whether attending a public or private school).

What makes the ACS important is that it is the means by which the more detailed inquiries of the Census are undertaken, now, because it replaced the "long form" beginning with the 2010 census, as well as being conducted annually (beginning in 2005), covering each U.S. county over a five-year cycle, rather than as a nationally comprehensive decennial survey. Of particular importance to deaf population demography, the ACS marks the return of deafness data collection for the Census. It does so with a single question, answered "Yes" or "No": "Is this person deaf or does he/she have serious difficulty hearing?" (U.S. Census Bureau, 2015, p. 9, item 17a). As a consequence of the enormous sample size of the ACS, the one-year estimate for the number of children under 5 years of age "with hearing difficulty" (those recorded as "Yes" for the deafness question) has a margin of error of 9% for girls and less than 7% for boys.

(Estimates for older children are equally or more precise.) No other federal study approaches this level of precision for this age group.

Though the deafness question is quite limited, in conjunction with the ACS non-English home language use item (U.S. Census Bureau, 2015, p. 8, item 14), it would appear to improve demographers' abilities to incorporate the cultural perspective in the demographics of the deaf population (in general, not just for children). That is, in principle, a five-year stacked data file from the ACS would allow analysts to make fairly precise estimates for small segments of the population, namely, deaf (and hearing) signers of ASL. However, despite an explicit directive to collect and preserve reports of non-English language use in the home that specifically included any mention of American Sign Language (ASL) (see U.S. Census Bureau, 2008, p. 4-169), as well as Recommendation 4-3 of the Institute of Medicine of the National Academies pertaining to language data collection by health care entities (Institute of Medicine, 2009, p. 119; also, for ASL-relevant concerns for the Department of Homeland Security's Commercial Mobile Alert Service, see National Research Council, 2011), the data files from the ACS do not include a code for ASL (see U.S. Census Bureau, n.d.b) because "those who use ASL are presumed to know English ... and are coded as being English speakers" (U.S. Census Bureau, 2013; also see Mitchell et al., 2006). So, at present, the lone benefit of the ACS to the demographics of deafness for deaf education will be its ability to provide fairly precise state-level estimates of the child deaf population, particularly very young children, which is something no other federal survey is capable of doing.

### **Future Demographic Studies**

Before looking forward, a brief reprise is needed. Over the last half-century, important changes in the demographics of the deaf student population receiving special education services

have occurred, changes that have had profound consequences for schools, programs, placements, and services. At the same time, the current profile of students in deaf education is much less clear, and construction of that profile is much less timely. If the field of deaf education is to receive continually updated and detailed demographic summaries, there will need to be another infusion of time, talent, and treasure into the collection of statistics pertaining to the deaf child population of the United States.

The preceding review makes apparent that population changes challenge demographers to employ alternative methods to keep up with the increasing diversity and dispersion of deaf children and youth across a range of educational settings and placements (Mitchell & Karchmer, 2006, 2011; Shaver et al., 2014). In particular, though it has been precisely targeted at deaf children and youth receiving special education and related services, and has secured an unequalled number of respondents (i.e., large sample size), the Annual Survey is no longer able to sample well the increasing proportion of mainstreamed deaf students. At the same time, the large-scale, federally-sponsored, probability sample surveys of schools providing special education programs in general (i.e., NLTS, NLTS-2, and SEELS) have taken samples of deaf students too small for the multiple cross-classifications demanded by the field of deaf education. And, like the Annual Survey, these federally-sponsored studies suffer from the same challenges of large-scale survey work in general, namely, low response rates (e.g., Wagner, Cameto, & Newman, 2003), as well as the uncertainty of whether non-response (or under-sampling) bias will compromise generalizability.

The non-education-specific federal survey programs (i.e., NHS, SIPP, and ACS) are truly large-scale efforts, but their general-population-oriented designs necessitate long data collection periods before precise estimates can be provided for small segments of the population (except for

the ACS). In addition to annual (or biennial, or less frequent) cycles not capturing large enough samples of the deaf child population sufficient for timely and meaningful analysis of demographic variation within that sub-group sample, these surveys fail to provide any information relevant to the practice of deaf education. Moreover, unlike the education-specific survey programs, the NHS, SIPP, and ACS are unable to address the cultural perspective on the demographics of the deaf population. This shortcoming is quite serious because it leads to a distortion of the public and policy discourse about deaf people in the United States, in general, as well as under-informing the field of deaf education about important deaf population attributes. Clearly, a special effort informed by this 50-year history of the demographic study of deafness is needed to restore faith and confidence in the statistics of deaf child and youth populations.

### **Getting the Desired Demographics for Deaf Education**

I would contend that a number of elements have to be considered in moving forward. First, the Annual Survey instrument is quite valuable. An advisory group should be formed to make both an initial and ongoing review of the instrument for clarity and effectiveness in obtaining the information sought, which ought to include interviews with prospective respondents. As needed, revisions should be made to ensure that survey both has continuity across time for meaningful longitudinal studies and relevance to current practice. Supplements may need to be employed from time to time as well.

Second, this is not an inexpensive undertaking. Nearly all of the major federal survey programs have moved to designs that extend collection throughout the year and across the regions of the country in order to stabilize and retain high quality field personnel, as well as be able to generate annual (or biennial) nationally representative estimates. If regular data collection and reporting is to occur, some sort of partnering with the Census (or working directly

with its contract agents) should be considered. Of course, the Census (or its agents) would have to be prepared to employ field representatives capable of working effectively with schools and programs educating deaf children and youth, as well as their families (who may be deaf themselves). That is, although the Gallaudet Research Institute was previously able to staff and administer the Annual Survey on its own, I believe a cooperative relationship between Gallaudet University (or a consortium of universities with relevant population and program knowledge and experience) and the Census or its agents, but not a wholesale transfer of this work to a federal agency, would be more successful.

Third, and potentially quite challenging, there needs to be some sort of leverage or incentive for participation. For example, some federal survey programs are coercive; that is, compliance by selected schools is mandated—refusal is not an option—as is the case with the decennial census for the entire U.S. population. Without a mandate, some reasonable and compelling (without being effectively coercive) incentive system will be required. With the move to computerized record management nearly universal in the schools, and analysis and report generation software affordable and readily identified, the promise of school- and program-level reports following data collection does not offer the same incentive it did when the Annual Survey was launched. Neither universities nor the federal government have data management, analysis, and reporting advantages to the degree that was true in the past.

Fourth, success in restoring a survey program at the scale of the Annual Survey would require introducing complex probability-based sampling designs to both improve representativeness and provide a basis for effectively weighting responses. Mitchell (2004) was able to develop a weighting scheme to substantially correct the non-response biases in the Annual Survey at one time, though that strategy is insufficient for the present. Whether from a

full national registry of schools (e.g., the Common Core of Data [CCD] registry kept by the National Center for Education Statistics), or a separate project that somehow produces the first complete registry of schools and programs serving deaf children and youth, there needs to be a firmer basis for weighting whatever responses are obtained in future survey efforts. Regardless of whether a registry is ever developed, at a minimum, sustained and dedicated attention to snowballing toward a registry would be a valuable starting point.

Fifth, federal regulations pertaining to educational and health records make the collection of data for any Annual Survey like project incredibly expensive, especially if the data are to be collected and stored in a manner that allows for longitudinal study. Without having to fund such a project at a very high cost, either revised (or special) rules and regulations will have to be developed or a legal mandate will be necessary to help keep down the costs. As noted in the third point, above, mandates have been and continue to be used to facilitate national survey projects. If the Annual Survey, or a successor survey, is to maintain its scale, extensive detail, and longitudinal analysis features, efficient and effective means will likely require some official regulatory action by the federal government. This is all the more reason to develop a formal partnership (second point, above) with Census.

Finally, I would note that the demographics needed for deaf education are not going to come from minor adjustments to the large and successful non-education-specific federal survey programs. Nor can the IDEA Child Count be readily revised to carry this load. No, the Annual Survey was the right project at the time. And, if it were not for changes in the distribution of deaf children and youth receiving special education and related services across the country, the Annual Survey would continue to be both authoritative and amenable to weighted adjustment for accurate national estimates. There is no ready substitute. The field of deaf education needs to

mobilize in support of a renewed commitment to demographic research that supports its informational needs. A reformed and rejuvenated Annual Survey is the best bet.

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