Demographics of Deaf Education: More Students in More Places
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Recently, we were asked to respond to the perception that the population of deaf and hard of hearing students in special education is the federal Child Count, which has been published in annual reports from the U.S. Department of Education to the Congress since 1979 (U.S. Department of Education, 1979). The Elementary and Secondary Education Act Amendments of 1965 (also known as the State Schools Act) initiated the provision of federal funds to support the education of students with disabilities, but it was not until the Child Count, mandated by the Education for All Handicapped Children’s Act (EAHCA) of 1975 (which in subsequent reauthorizations was renamed the Individuals with Disabilities Education Act [IDEA]), that comprehensive enumeration of children designated to receive special education services was regularly reported. The combined unduplicated counts for students served through the State Schools Act (PL 89–313) and EAHCA/IDEA (PL. 94–142) were consolidated into a single Child Count following the passage of the Improving America’s Schools Act of 1994.

Prior to the first Child Count, only the Gallaudet Research Institute’s (GRI) Annual Survey of Hearing Impaired Children and Youth (now...
called the Annual Survey of Deaf and Hard of Hearing Children and Youth; hereafter, Annual Survey), established in 1968, provided annual national data on students receiving special education primarily in response to their hearing loss or deafness. However, the Annual Survey's response rate was not stable initially, and there are no data to verify that annual increases or decreases in sample size reported to the Annual Survey should be attributed to concurrent changes in the size of the population sampled by the survey. So, despite the much richer and detailed description of the demographic characteristics of deaf and hard of hearing students provided by the Annual Survey, school-based population estimates are best derived from the Child Count.


A graph of the trend in prevalence is shown in Figure 1. From the mid-1970s

Figure 1

through the late-1980s, there was a steady reduction in the prevalence of students identified for special education due primarily to hearing impairment from 1.2 to just less than the 1 per thousand in the school-age population. As indicated, this decline corresponds very closely to the exit of successive maternal rubella birth cohorts (e.g., see Brown, 1986; Preblud, Hinman, & Herrmann, 1980; Schirro, 1986). The contribution from the last epidemic, spanning 1963–65, would have exited the system by all mechanisms, including reaching the maximum age, by 1986-87, which is the lowest prevalence point on the graph (just less that one per thousand). The late 1980s also marked the low point in the total population of deaf and hard of hearing students in special education reported to the Child Count. Since that time, the population has steadily increased (e.g., U.S. Department of Education, 1997, 1998, 2000, 2001, 2002), as is shown separately in Figure 2, while the prevalence has increased and possibly stabilized at about 1.1 per 1000. It is not clear whether the curiously large prevalence jump in 1994–95 (indicated in Figure 1) reflected some trend or simply changes in the way data were reported by states to the U.S. Department of Education.

As shown in Figure 3, for more than a decade now the population of students with hearing impairment in special education has followed the rise and fall of the total school-age population very closely, exhibiting similar age structure. Most noteworthy is the similar decline among 6- to 11-year-olds regardless of hearing status from 2000 forward (solid triangles for those with hearing impairment and open triangles for general population). During this same time period, there has been a fairly steady prevalence rate of approximately 1.1 per 1000 for students with hearing impairment in the schools (see Figure 1). In the absence of any radical changes in public health, this constant prevalence rate means that the size of the

Figure 2
IDEA Child Count of students with hearing impairments, ages 6 to 21 years, U.S. 1987–1988 to 2002–2003 school years

Deaf and hard of hearing population in special education is likely to change in direct correspondence to the size of the total school-age population at any given time.

**Are Students More Widely Dispersed in the Mainstream?**

National data on the distribution of deaf and hard of hearing students among various educational settings has been available for more than three decades, though trend analysis has been limited largely to analyses of the Annual Survey. No matter the choice of comparison years, over any multi-year period, a smaller share of deaf and hard of hearing students received their education in a special school for the deaf than was previously the case (Holden-Pitt & Diaz, 1998; Karchmer, Milone, & Wolk, 1979; Schildroth, 1980, 1986, 1988; Schildroth & Hotto, 1995). Over the past quarter century, the percentage of deaf and hard of hearing students attending special schools has declined by more than half. As is shown in Figure 4, which graphs the 15 most recent years’ data from the annual IDEA Child Count (U.S. Office of Special Education Programs, n.d., Table B4A), the percentage of students in separate and residential facilities has largely been in decline, as has the share of students receiving greater than 60% of their instruction outside of the regular (mainstream) classroom. The percentage of students instructed in regular education settings more than 40% of the school week (i.e., less than 61% outside of the regular classroom) has climbed from 45 to about 65, owing almost entirely to growth in the number in regular education settings for at least 80% of the time.

Under the influence of special education laws meant to increase inclusion, deaf and hard of hearing students are ever more spread out (e.g., Craig,

**Figure 3**


![Graph showing trends in U.S. school-age population vs. IDEA, Part B, students with hearing impairments, by age group, 1990–1991 to 2002–2003 school years.](source)

Source: U.S. Office of Special Education Programs (n.d., Table B2A).
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The Child Count cannot provide information about additional demographic trends for students receiving special education, however, because of the narrowness of the mandate and the manner in which the states' data are reported to it. State officials enter aggregate totals into each of the boxes provided on a standard tabular form summarizing disability, age, and race/ethnicity as follows: totals for each disability category by year of age (3–21 years) and by race/ethnicity for students 6–21 years of age (U.S. Department of Education, n.d.). The Child Count does not collect data on, for example, student gender, language use in the home, degree of hearing loss, age at onset, use of assistive listening technology (including cochlear implants), or co-occurring conditions (sometimes referred to as additional disabilities). This is in contrast to the Annual Survey, which collects and secures confidential, individual student records from thousands of participating schools and programs on a voluntary basis, which, thereby, allows any demographic cross-tabulation that can be constructed from the wider array of available data. (Detailed information about the Annual Survey has been reported by Holden-Pitt & Diaz [1998], Mitchell & Karchmer [2005], and Schildroth & Hutto [1993].)

Based upon reports to the Annual Survey, there are two noteworthy trends to add. First, an increased proportion of the students have secondary or co-occurring conditions in addition to deafness—with the overall percentage likely exceeding 40% (Mitchell, 2004). At the same time, it is now becoming much more common for young students to receive cochlear implants. Again, applying the method described by Mitchell (2004) to Annual Survey data, we estimate that, for students 6–11 years of age with severe to profound hearing loss, the prevalence of students with cochlear implants has increased from less than 15% in 1999–2000 to more than 22% in 2002–2003 (just 3 years' time!).
What Are the Major Challenges for the Collection of Data from Schools Serving Deaf and Hard of Hearing Children?

The issue we now turn to is how the new demographic realities of the education of deaf and hard of hearing students relate to the design of research and the collection of data. The increased dispersion and diversity of deaf and hard of hearing students poses major challenges for researchers trying to do large and generalizable studies. This is not only a concern for university researchers, but also for school administrators and other educational practitioners as well. In a policy environment that demands research-based justifications for programs and interventions to be implemented in the schools, collecting the evidence for “what works” is not a simple task.

With more than 35 years of experience managing the Annual Survey and reporting special population normative performance levels on standardized tests of academic achievement for deaf and hard of hearing students (e.g., Gri, 2005; Holden-Pitt & Diaz, 1998; Karchmer & Mitchell, 2003), the GRI now appears to be encountering more obstacles associated with collecting data from which nationally representative findings may be reported. We draw on our personal and institutional experience to identify concerns for research on deaf and hard of hearing students in the schools today.

First, though the prevalence of students with hearing impairments in the U.S. special education population has been stable lately, it is lower than it was up to the late 1970s when students with deafness caused by maternal rubella were part of the mix. This low-incidence group is about 10% less prevalent than it was 25 years ago, which means that deaf and hard of hearing students are even less likely than they were before to be included in any random sampling of the school-age population. Rare population sampling methods have to be employed to obtain both adequate participation and representation (e.g., Schein & Delk, 1974; for a discussion of these methods, see Kalton & Anderson, 1986; Thompson, 2002), many of which require a registry of individuals or organizations that serve these individuals. However, no complete registry of organizations serving deaf and hard of hearing students exist at this time. Research is required just to establish a registry of schools and programs serving these students, especially if a subgroup of this special population is of interest (e.g., those with cochlear implants, who are born to deaf parents, for whom English is not spoken at home, etc.).

As is clear from the trends identified above, there is an increasing diversity and dispersion underlying the relatively stable prevalence of students with hearing impairments in special education. The ethnic, etiological, and intervention profiles have changed considerably. When it comes to the pursuit of generalizable knowledge, however, the more significant change is the increased dispersion of students among a greater number of schools and programs. Given that students are not randomly distributed among the various educational settings, but are assigned in ways correlated with various demographic characteristics (Karchmer & Mitchell, 2003), research sample selection is not simple. Convenience samples, like those drawn from the school district closest to the university where research is sponsored, are not generally going to build a knowledge base from which generalizable insights can be obtained. It is more difficult to locate the increasing number of students scattered in the mainstream and more expensive to sustain their participation in any given study. But without the students in the mainstream, along with the large numbers of students found in residential and special day programs, there is no way to overcome the systematic biases in assignment.

Third, the current climate of research in schools is less accommodating. Time is at a premium. State-mandated data-reporting requirements already are challenging the capacities of many schools and districts, making the added demands of voluntary data reporting for research purposes a burden too great to bear in some cases. Similarly, for groups at risk for failure on state-mandated assessments of academic achievement, which is true for virtually all students identified for special education (not just those who are deaf or hard of hearing), setting aside time for participation in a research study seems hard to justify in some instances. The data management and collection burdens associated with increasingly demanding school accountability systems have, at least in the short term, put a serious squeeze on the time that school personnel can offer in support of research in the schools.

Finally, the variety of federal regulations governing human subject data confidentiality creates issues for implementation or interpretation. There are the implementation requirements of institutional review boards (IRBs), which interpret regulations governing research with human subjects at all institutions with federal funds. The need for researchers to be responsive to IRB requirements sometimes creates challenges for research designs. Two issues serve as examples, the first being the challenge of obtaining parental permission and informed consent when children are participants in research studies. This is especially
difficult when access to parents is mediated by the schools in which deaf and hard of hearing students are enrolled. Second, difficulty arises when doing longitudinal research in schools. This is because mechanisms for human subject identity protection often inhibit reliable tracking of students over time (e.g., invented identification number lists get lost, making it impossible to link data collection periods). Measuring changes over time, which is often the best way to establish "what works," is not easy if earlier and later records cannot be matched.

The other source of problems from federal regulations is reconciliation varying local interpretations. Two major privacy laws, the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and the Family Educational Rights and Privacy Act (FERPA) of 1974 make the collection of data ever more unwieldy. There is ambiguity, causing some schools officials confusion as to whether HIPAA regulations apply to the release of certain types of data. For example, consider the use of hearing aids. We would assert this is educationally relevant information under IDEA (i.e., appropriate to keep in school records for the purpose of educational programming) and not HIPAA-related data.

FERPA can be a challenge for research because the requirement for written parental permission for release of data is negated only when research is done by organizations conducting studies for, or on behalf of, educational agencies or institutions for the purpose of developing, validating, or administering predictive tests, administering student aid programs, and improving instruction, if such studies are conducted in such a manner as will not permit the personal identification of students and their parents by persons other than representatives of such organizations and such information will be destroyed when no longer needed for the purpose for which it is conducted. (20 U.S.C. § 1232g.b.1.f.)

In other words, much of the information required to understand the diversity of the deaf and hard of hearing student population is shielded by FERPA, except under limited circumstances, without prior written release and informed consent from each student's parent.

Summary

Demographic trends observed in the population of deaf and hard of hearing students in special education clearly, but not unexpectedly, intersect with trends in school accountability and federal regulation of data pertaining to schoolchildren to affect research in deaf education. In important respects, not only do some historical findings lack relevance today, the nature of student participation in curriculum, instruction, and assessment has changed as well. Similarly, the constraints imposed on data collection are more exacting and, in the case of schools, more onerous. If we are to produce "scientifically based research" in order to demonstrate "what works" in deaf education, the burden of, and for, proof is great.

References


