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Chapter 3: Definitions and Demographics

In 1999, Congress passed the Newborn and Infant Hearing Screening and Intervention Act. That law authorized federal agencies, including the Health Resource and Services Administration and the Department of Health and Human Services, to help states voluntarily set up newborn hearing screening and intervention systems. By mid-2001, 35 states and the District of Columbia already had established hearing screening programs for newborns and legislation was pending in 5 more states. Once universally implemented, hearing losses in young children will be identified much earlier than the two to three years that previously was common, and parents will be able to take appropriate steps to optimize their children's environments for developmental and educational success. Screening programs also will provide a clearer picture of the demographics of hearing loss, as many families report "unknown" causes and age of onsets of childhood deafness.

As in other populations, deaf and hard-of-hearing individuals vary widely, and statistics cannot capture the true character of the group. In some ways, deaf individuals would be expected to vary more widely than hearing individuals. Beyond whatever other characteristics one might want to use to describe a group of people, deaf individuals also vary in the degree of their hearing losses, age of hearing loss onset, and the etiologies or causes of the losses. There may be factors related to their hearing losses, regardless of whether they are hereditary or adventitious deafness (e.g., accompanying genetic syndromes, physical injury), and several investigators have obtained results suggesting that hereditary deafness may even carry with it some advantages (Kusche et al., 1983; Zweibel, 1987; c£ Ulissi et al., 1990). Then, of course, there are issues of whether deaf children were born into deaf or hearing families, the extent of their early exposure to language, and the quality of interactions with adults and peers during childhood. These variables make for a more diverse population and, at the very least, will affect the utility of one-size-fits-all approaches to education.

At this point, we should be more specific about what we mean by deaf and hard-of-

hearing learners. Superficially, people are often described as deaf if they use sign language rather than spoken language. But there are many deaf people who use spoken language rather than sign language, hard-of-hearing people who prefer to sign rather than speak, and hearing people who sign exclusively in some settings. Similarly, there are people who are members of the Deaf community even though they are hearing, either by virtue of having deaf family members and growing up in that context or having joined that community and having been accepted. For the purposes of this book, we usually refer to individuals or groups of individuals as being deaf or not in terms of hearing and hearing loss, the latter primarily with regard to whether or not they are able to hear spoken language (with or without amplification).

Because of the physics and biology of speech and hearing, speech perception will be most affected when sounds at the frequencies of 500 Hertz (Hz), 1000 Hz, and 2000 Hz are not heard. In age-related hearing losses, or presbycusis, which will be of lesser interest to us here, perception of the higher frequencies typically is lost before perception of lower frequencies. In congenital and early-onset hearing losses, in contrast, the particular frequencies involved vary widely, and attention must be given to which frequencies are affected as well as how much hearing is lost. Quantitative descriptions of hearing loss are typically given in terms of decibel (dB) loss in the better ear. People with hearing losses up to 25 dB are still considered to have normal hearing. Although definitions sometimes vary slightly, hearing losses from 26 to 40 dB are most often categorized as mild, those from 41 to 55 dB as moderate, from 56 to 70 dB as moderately severe, from 71 to 90 dB as severe, and losses greater than 90 dB in the better ear are categorized as profound.

Hearing losses also are categorized as conductive, involving the middle ear; sensorineural, involving the inner ear and auditory nerve; or central, involving auditory centers of the brain. In all three cases, the measurement of practical interest is the loss of pure tone receptivity, specifying the limit of potential hearing for simple tones. Being able to detect a sound ("I hear something") is very different from being able to identify it ("It's a voice") and far less demanding than the understanding of speech ("It's a man saying 'hello'").

Depending on how broadly one defines hearing loss, the number of people who can be considered deaf or hard-of-hearing will vary widely. Our primary focus will be on individuals of school age, but because hearing loss is so common in older individuals, it might be helpful to get a broad perspective first. For example, the U.S. Bureau of the Census and the National Center for Health Statistics (NCHS) report that there are approximately 23 million people in the United States with chronic, significant hearing losses, or just under 10 percent of the population. Approximately 1.5 million of those individuals are classified as deaf in both ears (NCHS, 1999). However, there is no legal definition of deafness comparable to the federal definition for blindness, so estimates of the number of people who are deaf vary considerably. Thus, whereas the NCHS reports more than 210,000 deaf individuals under 18 years of age (and does not count children under age 3), the Bureau of the Census reports that approximately 61,500 children and youth between the ages of 6 and 21 years have hearing losses and are being served under the Individuals with Disabilities Education Act (IDEA; see chapter 2), and unpublished data from the Center for Assessment and Demographic Studies at Gallaudet University puts the number of deaf youngsters between the ages of 3 and 17

years at just over 50,000.

Overall, the NCHS data indicate that males are about 30 percent more likely to be deaf than females, whites are about twice as likely as African Americans to be deaf, and non-Hispanics are about twice as likely as Hispanics to be deaf. Figures for school-age children are more difficult to come by because the federal data do not meet standards of reliability or precision, but it appears that deaf males outnumber deaf females by about 5:4 during the school years. Approximately 20 percent of individuals who are categorized as having significant hearing loss in the United States experienced the onset of those losses before 18 years of age, and about 5.5 percent of those before age 3.

Etiologies of hearing loss in children vary widely, although accurate numbers are difficult to find. For example, etiology information is available for only about half of the children included in the most inclusive annual survey of children with hearing loss, conducted by Gallaudet University's Center for Assessment and Demographic Studies, and that survey includes only about 60 percent of the deaf and hard-of-hearing children in United States. Generally, though, almost half of the children in the 1999 survey had significant hearing losses at birth, and another 23 percent had onsets after birth (approximately 30 percent are unknown or not reported). Among those children for whom the causes of their hearing losses were reported, 13 percent were linked to hereditary factors. Other frequently reported etiologies include pregnancy or birth complications such as prematurity and Rh incompatibility (8.7 percent), meningitis (8.1 percent), and infections/fevers including measles and mumps (4.0 percent). Maternal rubella was once the leading cause of deafness in younger children, accounting for 24 percent of cases as recently as 1984, but it now accounts for only about 2 percent of the cases.

The variety of causes of congenital or early-onset deafness also may contribute to diversity in the development of those children. Most notably, hearing losses associated with illness or accidents may carry the possibility of damage to other sensory systems or of related neurological effects (Konigsmark, 1972). This relationship means that reports of psychological or behavioral differences between deaf and hearing children need to be considered with care and caution. Differences that might be described as due to deafness may well be the result of other factors. It also is important to note that statistics concerning the academic success of deaf children, literacy rates, intelligence, and so on will include a variety of children and do not only reflect implications of hearing loss.

For most readers, hard of hearing is a broad category that includes people with mild to moderate hearing losses - an interpretation that generally will be appropriate throughout this book. Other authors have described hard-of-hearing people not in terms of the hearing loss, but as people who use spoken language regardless of the amount of hearing they might have. This definition seems to follow from the fact that such individuals might have residual hearing across a fairly wide range (in decibels and frequencies) and be able to process and acquire spoken language. It seems odd, however, to use a term descriptive of hearing loss that is based on spoken language ability, particularly when the difference between deaf and hard-of-hearing learners might end up being one of social orientation or a question of whose parents placed a priority on speech therapy.'

The age at which an acute or progressive hearing loss begins also might have important implications for a child's education. Children who have been exposed to sound, even if they lose their hearing before learning language, appear to have greater success with cochlear implants and may generally be advantaged in linguistic, visuospatial, and other domains (see Marschark, 2001b, for a review). When hearing losses occur after spoken language has been acquired and education begun, we also can take advantage of the fact that children already have an understanding of reference (what words or signs stand for), learning strategies, and social experience. Whether or not they continue to use spoken language into adulthood, it is often easier for such children to communicate with others, even if others cannot communicate easily with them. As we shall see in chapter 4, acquiring a spoken language without auditory access to speech, or acquiring a signed language when parents are not skilled users of it, represents a significant challenge. Hearing aids and cochlear implants can compensate for a considerable amount of hearing loss, allowing those with later-acquired losses make use of learned speech-processing skills and comprehension strategies. Learning language for the first time using either of these technologies may be different matter, and we now turn to their consideration.

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