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# **Introduction**

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Lack of speech is a serious disability. When combined with other disabilities that render a person functionally unable to write or type, it is more serious still. Whatever their age and whether or not they are of normal intelligence, people with such disabilities are very likely to be placed in institutional care. And if they are people who—because of a genetic defect, an accident during gestation or an injury at birth—have never talked, chances are they will be assumed to be profoundly mentally retarded and so will also have been deprived of that education without which no one in this society can aspire to enter the work force or to live as an independent adult.

Children whose speech is limited or are mute because of congenital deafness, but who can use their arms and hands, have long had the opportunity to learn sign language, usually learn to read, write, and spell with some proficiency, and often learn to speak as well. By contrast, children with the kinds of central nervous system damage that preclude both the development of speech and the development of hand and finger motor skills have traditionally not been taught a systematic means—oral, written, or gestural—to communicate either with each other or with the outside world.

People of all levels of intelligence are found in the population with the inability to speak which is one of several neurological or neuromuscular impairments. But, only rarely have distinctions been drawn between those incapable of thinking of comprehending and those who simply cannot

express themselves. Lack of speech has been confused with lack of language and often been automatically equated with lack of intelligence.

As recently as the mid-1970's, there was little or no remedy for either the congenital or the acquired inability to speak when accompanied by severe physical disability. Affected individuals could often communicate with those in their immediate circles by resorting to eye signals, other forms of private language, or the use of primitive language boards. But the emotional and intellectual content of such interactions was limited, consigning these people to social isolation, passivity, and custodial care.

This case study is about the revolution in communication aids that has since changed the outlook for this population, its accomplishments to date, its promise for the future, and its problems. It is also about related public policy and the barriers to fully utilizing the technology now available for the benefit of the individuals in question, their friends and families, and society as a whole.

As no ability is more highly valued in complex modern societies than the ability to exchange and process information, this study deals with a disability that is like no other. But, insofar as people with many handicapping conditions are faced with a poor fit between their potential and the means available to them to fulfill it, this case study is applicable to virtually the entire disabled community.

## TERMINOLOGY

The nonspeaking population is referred to by a variety of terms, including severely speech-impaired, speechless, nonoral, nonverbal, and others. The reason for the multiplicity of terms is that some of the individuals in question can actually produce sounds or a limited amount of speech, but nonetheless qualify as nonspeaking

because what they say is unintelligible, inaudible, or both.

A position paper developed by an ad hoc committee of the American Speech-Language-Hearing Association in January 1980 and revised in 1981 defined a nonspeaking person as one for whom

“speech is temporarily or permanently inadequate to meet all of his or her communications needs and whose inability to speak is not due primarily to a hearing impairment” (35). With the proviso that stuttering and the lack of speech associated with autism will be excluded from consideration—because these disorders are not seriously physically disabling—that definition is the one that will be used here.

The case study will also touch very little on aphasia, language disorder following brain injury,

and the anemia that often accompanies it, which are less the inability to speak than the inability to find the right words to articulate an idea. While this last qualification excludes from consideration many people who have had cerebrovascular accidents (strokes), it does not exclude those—many of them children—who have had the kind of stroke that injures the brain stem and does not result in aphasia.

## DEMOGRAPHY

No precise count is available of nonspeaking persons in the United States who meet the above description. Nor has any census been taken of how many nonspeaking persons owe their difficulties only to developmental problems—inherent difficulty in reading or producing meaningful speech, despite intelligence in the normal range—and how many are also mentally retarded, or mentally retarded alone. It can be said, however, that: 1) more males than females are found in the nonspeaking population, and 2) statistical inferences point to there being at least 750,000 to 1.5 million severely disabled nonspeaking children and adults in this country. Included in this estimate are approximately 90,000 people with congenital impairments (primarily but not entirely a consequence of cerebral palsy); 500,000 with acquired disabilities resulting from severe illness or fever, head trauma, or stroke; and 140,000 persons who have progressive disorders of the central nervous system such as amyotrophic lateral sclerosis (abbreviated as ALS, and known as motor neuron disease in Britain and popularly as Lou Gehrig disease in the United States), multiple sclerosis, dystonia musculorum deformans, some forms of muscular dystrophy, Parkinson’s disease, myasthenia gravis, Huntington’s chorea, Friedreich’s ataxia, and ataxia telangiectasia (9).

It is difficult to estimate the incidence and prevalence of severe speech impairment, because this functional disability affects some, but not all, people in given diagnostic categories, and the num-

bers of people counted in those categories are often themselves *only* estimates.

For example, speech loss is frequently an early sign of the bulbar form of ALS and occurs, as well, in other forms of this lethal disease. But the National ALS Foundation does not know how many people there are in the United States with ALS, nor how many of them are unable to talk (30).

Similarly, the United Cerebral Palsy (CP) Association can only make an educated guess that there are 750,000 individuals with CP in the United States, that 85 to 90 percent of them are speech-impaired, and of that 85 to 90 percent, about 30 percent are without any useful speech (46). The incidence of CP is estimated to be 25 per 10,000 live births. This means that, of those 25, approximately 7 will probably never be able to talk.

Much the same is true of those with chronic degenerative nervous system disorders. Parkinson’s disease (popularly known as shaking palsy) is a case in point. First surgical intervention and then the development of specific drug therapy during the 1960’s have at least temporarily spared many patients the severe motor symptoms of Parkinson’s. But neither mode of treatment has achieved much, if any, improvement in the speech deterioration of these patients. Although no rigorous data are available as proof, the clinical impression of some observers is that, in some cases, the

gain in life expectancy and control of tremors may have been at the expense of accelerating speech deterioration (21).

More than 2,000 Americans each year develop Guillain-Barré Syndrome (popularly known as French polio), which became familiar to the public as a complication of the swine flu vaccine, but can also occur under other circumstances (49). About 75 percent of those with this disease experience loss of speech. Though the loss is usually temporary, it is frightening nonetheless, especially because recovery from this disease is often slow (16).

Current surgery for cancer of the head and neck often includes removal of the larynx, and less frequently, removal of the entire tongue and soft palate. All three procedures obviate the possibility of unaided speech. Again, no precise estimate of the number of persons affected is available.

The absence of reliable data on the size of the physically disabled nonspeaking population and the reasons for their disabilities is a contributing factor to the often inadequate rehabilitation and needlessly high cost of caring for this population.