

Chapter One

History of DeafBlindness

“Labels
Are often misleading
They have negative meanings
That makes one
Feel out of the circle
Called Life”

– Marcia McDermott
(On Being Disabled, 2006)

A Brief History of Services for Deafblind People in the United States

Jerome D. Scheinⁱ

Enid G. Wolf-Scheinⁱⁱ

The history of services for deafblind people in the United States divides sharply between the years before and after the 1964-65 rubella epidemic. Before the epidemic, there were few services; after, many services came into being or existing services were expanded.

This article covers the nineteenth and twentieth centuries, omitting the most recent two or three decades. It does so out of respect for historians' well-supported contention that events' meanings only become clear after the passage of time. Its purview is limited to the United States, even though much information of value to the rehabilitation and education of deafblind people comes from outside this country. These limitations, it is hoped, will sharpen this account's focus.ⁱⁱⁱ

Prevalence

As noted, a major factor in the history of services for the deafblind population is its size. From 1870 through 1930, the U. S. Bureau of the Census estimated the deafblind population per 1,000,000 to range from 10, in 1900, to 160, in 1930 (see Table 1). This extreme variability probably arises, in part, from differences in methods used by census takers rather than reflecting actual population characteristics. However, as the 1964-65 rubella epidemic demonstrated, epidemics can radically alter the prevalence of deafblindness, as can migration and changes in population composition, though less dramatically. At least some of the variation in rates, then, may be accounted for by actual fluctuations in prevalence.

Table 1.
Deaf and Deafblind Persons per Million General Population:
Decennial Years 1870 to 1930

Year	Deaf Persons	Deafblind Persons ^a
1870	4200	30
1880	6750	50
1890	6480	40
1900	4920	60
1910	4860	10
1920	4250	20
1930	4650	160

Source: Adapted from data in Best, 1943.

^a Entries rounded

Even at its highest—with a rate of about 160 per 1,000,000, in 1930—deafblindness in the U. S. was a rare condition. It did not attract much notice until the 1964-65 epidemic added a large number of deafblind children to the population in a brief span of time—an estimated incidence between 1,500 and 2,500. That relatively great increase captured government attention, prompted by parents who demanded assistance for their deafblind children.

The study by Wolf et al. (1982) provided 1980 estimates of the deafblind population. The study divided its estimates into four categories^{iv} (Table 2). Defined in broadest terms, the deafblind population in that year was 346 per 100,000. Although this is much greater than 160 per 1,000,000 for 1930, it still represents a small fraction of the general population.^v For the narrowest definition, the estimate of 20 per 100,000 is 25% larger than the 1930 estimate. However, because of the methodological disparities already noted, direct comparisons of the rates in the two tables should not be over-interpreted.^{vi}

Table 2.
Prevalence and Rate per 100,000 of Deafblindness in the Noninstitutionalized,
Civilian Population, by Four Definitions: 1980

<u>Definition</u>	<u>Prevalence</u>	<u>Rate/100,000</u>
All Definitions Combined	743,275	346
Deaf and Blind	41,859	20
Deaf and Severely Visually Impaired	25,481	12
Blind and Severely Hearing Impaired	357,818	169
Severely Visually and Hearing Impaired	309,117	146

Source: Wolf, Delk, & Schein, 1982.

Definitions

Always problematic, definitions of deafblind persons have fluctuated over the years. In 1972, Congress defined a deafblind child as:

one who has auditory and visual handicaps, the combination of which causes such severe communication and other problems that he cannot properly be accommodated in special education programs for the hearing impaired or for the visually handicapped child (Federal Register, 1972).

Subsequent federal legislation has adopted this definition or a variation of it when addressing education for deafblind children.

The Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) determined eligibility for its services according to the more detailed and, with respect to vision, precise definition:

Central visual acuity of 20/200 or less in the better eye with corrective lenses or central acuity of 20/20 if there is a field defect such that peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, and a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, and the combination of the

two causes such extreme difficulty for the person to attain independence in activities of daily living, psycho-social adjustment or in the pursuit of a vocational objective (cited in Wolf, 1986).

In determining the size of the deafblind population, Wolf, et al. (1982) recognized the diversity in definitions of deafblindness. Rather than choosing amongst them, they developed four categories of deafblindness that attempted to encapsulate those actually followed in the delivery of services:

Deafblind Narrowly Defined - No usable hearing for speech and no usable vision.

Deaf and Severely Visually Impaired - No usable hearing for speech and defective vision in both eyes or blindness in one eye with the other defective.

Blind and Severely Hard of Hearing - No useful vision and severe hearing loss in both ears.

Severely Vision and Hearing Impaired - Vision as defined in the second category above and hearing as defined in the third category (Wolf-Schein, 1989, paraphrased).

The broader definitions recognized the value of identifying persons who, at one time, might not meet the most rigid definition but who were at risk of losing more vision or hearing and, therefore, would then meet the most extreme criteria. For those planning services and providing their funding, those data can be useful.

Rubella epidemic of 1964-65

Until the 1964-65 rubella epidemic, deafblindness received little public attention. At that time, the American Foundation for the Blind's register of deafblind school children listed a total of 564, only 177 of whom were enrolled in educational programs (Wolf, 1987). That epidemic affected about 30,000 neonates, of which an estimated 2,500 were deafblind (Thompson & Freeman, 1995). Salmon & Rusalem (1966, p. 15) wrote, "It has been conservatively estimated ... that there are three thousand deafblind adults in the United States". With a pending influx of nearly three times the in-school population and more than half the total of deafblind adults as a result of the rubella epidemic, it was apparent that heroic measures would be needed to accommodate the sizable increase in the demands for educational and rehabilitation services.

Education^{vii}

The first deafblind student cited in the professional literature appeared in 1849 (Woodruff, 1849). For the remainder of that and the following century, no special educational facilities were established specifically for deafblind children. Those who gained an education were accommodated in schools, many of which had no special arrangements for their loss of both hearing and sight.

From 1800 to 1930, what education was available to deafblind children could usually be found in schools for deaf or blind students—if it could be found at all (Best, 1943). Perkins School for the Blind was one of the first to provide education for a deafblind child, and it was the first to establish a special department for the instruction of deafblind children. Occasionally, states provided some education for deafblind students, but most did not.^{viii} Even as late as the 1960s, few opportunities were provided for deafblind students, and practically none for those with below-average estimates of their intelligence. As Thompson and Freeman (1995) wrote,

School-age children with deaf-blindness who functioned below-average intellectually were most often placed in residential schools or 'asylums' where they were typically provided only custodial and life--sustaining services. During this period [1950-1969], personnel trained to instruct children with deaf-blindness were few in number, and opportunities for personnel inservice training and acquaintance with new methodology and teaching materials were very limited (p. 20).

Preparation for teachers of deafblind students was virtually non-existent until the American Foundation for the Blind sponsored programs in 1949, 1950 and 1951. These early efforts, however, did not stimulate continued interest among established programs preparing teachers of deaf and of blind children (Salmon & Rusalem, 1966).

The federal government became involved in special education when Congress passed the Elementary and Secondary Education Act of 1965. This law, however, did not expressly provide for deafblind students. The Congress initiated its first legislation specifically for deafblind students in 1967, when P. L. 90-247 established the Centers and Services for Deaf-Blind Children Program.

Congress expanded the program to provide research and personnel by passage of P.L. 91-230, in 1970. It established regional centers to identify deafblind students and to create programs, design curriculums, and prepare personnel to educate them.

In 1975, Congress enacted The Education for All Handicapped Children Act (P. L. 94-142). This remarkable law recognized states' primacy in education but required them to

provide it for all children with disabilities. In so doing, it made education a civil right, putting into effect what the courts had been ruling; e.g., that as long as states provided free education for some of their citizens, they must provide it for all. Congress subsequently enacted amendments clarifying and expanding existing legislation, but none so far-reaching as the provisions of 94-142. Congress's subsequent actions have given assurance that its positive attitude toward services for deafblind people will continue, at least in the near future.

Rehabilitation

Federal legislation establishing vocational rehabilitation was first passed in 1916. Called The National Defense Act, it recognized for the first time the nation's obligation to disabled veterans. It was a tentative venture, providing training only for wounded soldiers. This small first step was followed, in 1920, with an expansion of services to include nonmilitary persons. Although successive legislation slowly increased the range of persons covered, the services remained limited to job training and placement. In 1954, the amendments grew to address the need for qualified personnel by offering training grants.

State and local rehabilitation programs, like educational ones, were few and scattered throughout the country before 1964. One of the most outstanding was the Industrial Home for the Blind (IHB), in Brooklyn, New York. In 1917, IHB undertook the rehabilitation of deafblind adults (Salmon & Rusalem, 1966). In the next years, IHB obtained grants from the then-Vocational Rehabilitation Administration (VRA) to serve the increasing numbers of deafblind adults seeking its services.^{ix}

Plans to expand regionally the model exemplified by IHB were put forward in 1958, but even with VRA's encouragement they failed:

"Consequently, when 1962 dawned, the IHB remained the only agency for the blind in the United States with formally organized services for deaf-blind adults" (Salmon & Rusalem, 1966, p. 24).

The 1967 Vocational Rehabilitation Act Amendments authorized establishment of the National Center for Deaf-Blind Youth and Adults (HKNC)—a much-needed rehabilitation facility. This marked the first recognition of deafblindness by the federal government. Previously, deafblind people were considered infeasible for vocational rehabilitation.

This giant step forward was followed, in 1973 and 1978, with further shifts in the federal government's attitude toward persons with disabilities. First, the title of the legislation changed by dropping 'vocational' from its name. The Rehabilitation Services Administration, which replaced VRA, received a mandate from Congress to shift from

economic to social considerations. The legislation provided for independent living services, lifted age restrictions, and broadened to encompass telecommunications and recreation. However, these advances were marred by Congress's failure to appropriate sufficient funds to cover all these services, leading to the observation that "these laws show that congressional attitudes had advanced, even if its fiscal policies had not caught up with its social ambitions" (Schein, 1985, p. 352).

Personages

People make history, so an account that does not highlight at least some of those who were prominent in their days would miss much. For the roles played by deafblind persons, the early days might better be referred to as *herstory* than history. Three young ladies are prominent in the Nineteenth Century accounts of education.

One of the first deafblind students cited in the literature was Julia Brace, a pupil at the American Asylum for the Deaf (subsequently the American School for the Deaf) who enrolled in 1824. Her biographer wrote:

She is the earliest case of any note in our own country, being now 41 years of age; and having resided in the institution for a period of twenty-seven years, is now as she has always been, an object of great interest to those who visit it (Woodruff, 1849, p. 65).

Ms. Brace did not receive the attention that Laura Bridgman did a few years later. Ms. Bridgman's fame is largely due to Charles Dickens, who immortalized her in his account of his tour of the United States (Dickens, 1868). He met her when he visited the Perkins Institute for the Blind and was charmed by her and by the potential that she demonstrated for educating persons who lacked vision and hearing. Perkins' superintendent, Samuel Gridley Howe, had accepted her in order to test his theories about education. He deemed her education a success. Though Howe's assessment was probably valid at the time, Ms. Bridgman, like Ms. Brace, remained at her school her entire life. Neither achieved more than a modicum of independence, so their educations would not be regarded as successful today (Schein, 1983).

By contrast, Helen Keller achieved substantial independence, despite her deafblindness. Born in 1880, she lost her vision and hearing as a result of illnesses suffered in her nineteenth month. Her education by Annie Sullivan has been immortalized in books, movies, and a stage play. Ms. Keller attended Perkins, where she met Laura Bridgman. Ms. Keller attended two other schools, one in New York and the other in Cambridge, to prepare herself for college. She graduated from Radcliffe, in 1904, *cum laude* (Schein 1988).

After college, Ms Keller authored several books, scripted a movie and played herself in it,^x performed in vaudeville, and became a fund-raiser for the American Foundation for the Blind. She was, undoubtedly, the most famous deafblind person in the world, earning awards from a number of countries including her own. Her highly successful education and her magnificent career improved public attitudes toward deafblind persons. They may also have aroused some unjustified expectations for other deafblind children—something for which she cannot be blamed. It should also be noted that hers was not a completely fairy-tale life; she suffered frustrations and occasional loneliness. Nonetheless, "Without exception, those who knew her found most impressive her unflinching enthusiasm for life" (Schein, 1988, p.318).

A history of services to deafblind persons in the United States, no matter how brief, cannot overlook two men: Peter J. Salmon and Robert Smithdas. Both were associated with the IHB. Salmon began his career there in 1917. Not deafblind himself, he took several positions in the agency, eventually becoming its director. His lobbying on behalf of deafblind people is legendary (Hunt, 1966). The founding of HKNC crowned his six-decade efforts.

Dr. Smithdas replaced Helen Keller as the United States' most famous and, certainly, most accomplished deafblind person. He earned a bachelor's and a master's degree, directed educational services—first at IHB and later at HKNC—and wrote several books, while leading an active social life. He is a worthy successor to Ms. Keller.^{xi}

Most of the biographies and autobiographies of deafblind persons emphasize their accomplishments. Implicitly, these accounts mean to counter professional and the public attitudes of hopelessness. Their authors have strongly supported education and rehabilitation of deafblind persons, mostly with pragmatic rationales.

If History Predicts the Future

Historians wisely eschew attempts to characterize the present and never to predict the future. They recognize the need to gain the perspective from elapsed time. So we close this account in full recognition that the education and rehabilitation of deafblind persons will continue to change. Innovations in diagnosis and treatment, devices like cochlear implants, developments like the Internet, and the actions by state and federal legislatures will doubtless positively influence the future for deafblind persons.

However, attitudes toward persons with disabilities, generally, and deafblind persons, in particular, may shift. Discussing dissatisfaction with legislation extending benefits to disabled people, an editorial in the influential New York Times wrote:

The problem is that our resources are finite and therefore limited. But the needs and desires for 'free' social services—that is, Government-financed education, health care, welfare aid to the handicapped and all the rest—are potentially infinite. They cannot all be met and therefore we must work out principles on how to spread our inadequate resources as best we can, to ration them among the many and diverse claimants (Schwartz, 1982, p. A21).

To counter this argument one need not disagree that society's resources are limited. Rather, one can argue that the relatively tiny amount of the federal budget allocated to services for persons with disabilities pales in comparison to expenditures for military hardware. Attacks on services for persons with disabilities obviously reflect a distorted view of priorities. When these attacks arise, some history should aid those who wish to counter them.

In 1864, in the midst of the Civil War and with the opposing forces battling within sight of the Capitol, Congress founded Gallaudet College, an institution of higher education for deaf students. The very idea of educating deaf children had not been completely accepted let alone providing them with higher education. Yet the Congress did just that: it put into place a service for a group with disabilities alongside of provisions for the survival of the republic. That gesture did not imperil the nation; to the contrary, it increased its strength. Gallaudet University today stands as a vibrant symbol of a nation's enduring values.

Summary

The history of services for deafblind persons in the United States prior to 1964-65 was dominated by two facts: deafblind people were rare and providing for their education and rehabilitation strained most service providers' capabilities. The former fact often made them nearly invisible to government and nongovernmental agencies and the latter frustrated well-intentioned efforts to serve them. The deafblind population grew dramatically after 1964--65, but its relative size and the difficulties in serving them have not abated. Service providers and deafblind people can look forward to advances in devices and techniques to ease the service burdens, but they need to remain vigilant to views that disparage attempts to educate and rehabilitate them.

Before 1964-65, state and local governments provided services only sporadically. Two nongovernmental agencies—Perkins Institute for the Blind and IHB—stand out among the handful that did offer services to deafblind persons. Aside from the paucity of services was the lack of qualified service providers.

Following the 1964-65 rubella epidemics, Congress enacted legislation greatly expanding services for deafblind people. Through 1974, when it passed the Education of All Handicapped Children Act, Congress increasingly directed educational services meaningful to deafblind students. It also gave more attention to deafblind adults with programs that sought to improve their economic and social lives. Subsequent actions by the state and federal governments suggest that, in the near future, governments will not abandon its support for the education and rehabilitation of deafblind persons.

Endnotes

ⁱ Dr. Schein is Professor Emeritus of Sensory Rehabilitation, New York University, and Adjunct Professor of Psychology, University of Alberta, Canada.

ⁱⁱ Dr. Wolf-Schein is Adjunct Professor of Education, University of Alberta, Canada. She is also a Fellow of the American Speech-Language Hearing Association.

ⁱⁱⁱ A further narrowing of scope is lack of concentration on specific problems associated with deafblindness: communication, mobility, social relations, recreation, etc. These matters will be covered in other sections of this volume, so their presence here would be redundant.

^{iv} For the detailed explanations of the four categories into which Wolf et al. divided their estimates, see "Definitions" below or refer to the original study.

^v The 1870-1930 data were derived from general-population enumerations, and the instructions given to the census takers in classifying individuals as deaf and deafblind are unavailable. The 1930 estimates derived from general-population censuses, in which identifying deafblind persons was not emphasized, while the 1980 study was a part of a special National Health Survey on hearing loss. As a consequence, more instances of deafblindness were likely missed and population sizes underestimated in 1930 than in 1980.

^{vi} The 1980 estimates are for the noninstitutionalized population. For information about the numbers of deafblind persons in institutions, see Wolf-Schein, 1989.

^{vii} Readers desiring more detail about the education of deafblind children should refer to Farrell (1956) and Wolf (1987).

^{viii} Among those states that enrolled deafblind students were Alabama, California, Massachusetts, Michigan, and Connecticut.

^{ix} Of interest to feminists, not until 1958 did IHB expand services to include deafblind women (Salmon & Rusalem, 1966, p. 24).

^x The movie won critical acclaim, but was not financially successful.

^{xi} For more early biographies, see Rocheleau and Mack (1930) and Tabak (2006). For later accounts, see Salmon and Rusalem (1966).