

## KEYNOTE ADDRESS

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The Planning Committee's choice of the theme for this conference is most appropriate. The recently passed Rehabilitation Act of 1973 expresses the desire of the U.S. Congress for more and better services to severely handicapped persons. This change in legislative emphasis has slowly evolved over the half century since the inception of the vocational rehabilitation program in 1920, and it establishes another important milestone in our history.

### **Terminology**

How does the new law (Rehabilitation Act of 1973) define severely handicapped? Originally, the House proposed that a severely handicapped individual be "(1) under a physical or mental disability so severe that it limits substantially his ability to function in his family and community as one without such serious disability may be expected to function, and (2) who, with the assistance of comprehensive rehabilitation services, can reasonably be expected to improve substantially his ability to live independently and function normally in his family and community." (Conference Report, 1972)

In the compromise bill finally enacted, the definition was altered to "a disability which requires multiple services over an extended period of time resulting from blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, respiratory or pulmonary dysfunction, mental retardation, multiple sclerosis, muscular dystrophy, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia, and other spinal cord conditions, renal failure, and any other disability specified by the Commissioner in regulations he shall prescribe." (Rehabilitation Act of 1972)

This latter wording emphasizes disability categories, but it provides two criteria for the determination of severity: (a) multiple services are required and (b) they are required for a long time. These two concepts could be defined operationally. As of this date, however, no such regulations have been promulgated.

We can appreciate better the complexities underlying the concept of severe handicap by recalling some past terms which may be synonymous with it or, at least, near relatives to it:

- Atypical,
- Illiterate,
- Low-achieving,
- Multiply handicapped,

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Nonfeasible for vocational rehabilitation,  
Seriously disadvantaged,  
Underachieving,  
Undereducated,  
and labels for combinations of disabilities:  
Cerebral palsied and deaf  
Emotionally disturbed and deaf  
Mentally retarded and deaf  
etc.

No wonder that Dr. Larry G. Stewart has indicted "vague nomenclature" as one of the "central obstacles that impede our work with severely handicapped deaf people." (Stewart, 1971) He urges that more attention be given to the sociocultural variables and less to the physical disabilities. The recent report of the Institute on Rehabilitation Services (Zawada, 1973) similarly concludes that physical conditions alone can be overemphasized. Stressing the value of maintaining the distinction between handicap and disability, the report arrives at a definition which implicitly combines the evaluation of the medical, psychological, sociocultural and vocational factors: A person is severely handicapped "who is so specifically limited as to prevent him from engaging in vocational endeavors, without the provision of intensive and extensive rehabilitative services." (Zawada, 1973, page 8)

The common thread running through the definitions is the necessity of services beyond what is usually provided rehabilitation clients, both in nature and extent of services, in order to attain a satisfactory life adjustment. The focus is on what to do, though obviously not specifically. Underlying each of the concepts is a dynamic attitude: an individual is severely handicapped *until* rehabilitation. As a guiding philosophy for those working in the field, it is excellent. Its breadth—encompassing persons with multiple physical and mental disabilities, those who are undereducated, and those who are culturally disadvantaged—satisfies most educators and rehabilitators. Furthermore, two minor pitfalls are avoided.

Some pseudo-sophisticated practitioners state that everybody is handicapped. In support of this contention they point to their own shortness, stoutness or need for glasses, someone else's inability to master German, and another person's chronic indigestion. Whatever they hope to gain by these silly arguments they only succeed in attacking the concept of a handicap, for if everyone is handicapped then the notion of a handicap is meaningless; it conveys no distinction.

Similarly, ethnic group membership alone should not be a sufficient condition for inclusion in the handicapped category. Being Spanish-speaking or black or American Indian puts one at a social disadvantage. But a member of a minority group is not by that fact alone handicapped. To say otherwise would attenuate the usefulness of the term handicapped in rehabilitation.

### Population Estimates

Defining severely handicapped in a nonspecific, dynamic way aids rehabilitation counseling but nearly incapacitates the morbidity statistician! How can you estimate the severely handicapped population when identification of a group member depends upon indefinite and fluctuating criteria? Admittedly, any calculation of the size of the severely handicapped deaf population will yield only a rough approximation. But let us attempt to picture the magnitude of the problem.

An excellent source of data is provided by the Annual Survey of Hearing Impaired Children and Youth. (Rawlings and Gentile, 1970; Rawlings, 1971; Rawlings, 1973) In three previous years the Annual Survey requested the participating schools to indicate which deaf students had an additional *educationally* handicapping

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condition. As Table 1 illustrates, the rates are fairly stable. About 400 of every 1,000 students are reported to have a handicap in addition to deafness. Emotional and behavioral problems account for approximately one-fourth and mental retardation about one-fifth of the total handicaps. Also note that between 68 and 72 per 1,000 students have more than one handicapping condition in addition to deafness. Granting the imprecise nature of the data, the overall effect is sobering. Educators believe that nearly 40 percent of their deaf students are multiply handicapped; i.e., have an additional disability which interferes with the students' education. Recall that these figures apply only to those in educational programs and not those in institutions for the mentally retarded or those too severely disabled to attend school.

**Table 1**  
**Additional Educationally Handicapping Conditions**  
**Per Thousand Deaf Students by Years**  
**and Type of Disability: 1968-71**

Type of Handicap	School Years		
	1968-69 (N-21, 130)	1969-70 (N-29, 131)	1970-71 (N-34, 795)
All Handicaps	419.8	419.6	392.6
Behavioral/Emotional Problems	124.3	129.1	95.9
Brain Damage	*	5.3	4.8
Cerebral Palsy	33.5	33.1	32.3
Cleft Lip/Palate	7.2	6.5	6.2
Epilepsy	*	5.7	6.5
Heart Disorders	8.8	13.9	21.6
Learning Disabilities	*	31.2	26.2
Mental Retardation	80.4	71.5	70.1
Orthopedic Disorders	*	6.6	7.2
Perceptual-Motor Disorders	55.3	54.5	54.2
Severe Visual	41.8	45.0	48.8
Other	68.3	17.2	18.9

\*Included under "Other"

Source: Rawlings and Gentile, 1970; Rawlings, 1971; Rawlings, 1973.

How does the adult data compare? The Metropolitan Washington, D.C. survey in 1962 (Schein, 1968) found 9 percent of the adults in that area had a physical or mental disability in addition to deafness and 1 percent had two or more additional disabilities. Excluded from the survey were those deaf persons residing in institutions, so the overall 10 percent figure likely underestimates multiple disabilities, though it is depressingly large.

The National Census of the Deaf Population (Schein and Delk) obtained a far higher rate in 1972: one-third of all respondents indicated they had one or more disabilities. Nonwhite deaf persons, very sparsely represented in the Washington Survey, had a significantly greater proportion of additional disabilities than the white deaf sample, about 43 percent versus 32 percent. The differences for race were consistent by sex, though generally females indicated a somewhat higher rate for

additional disabilities than males. Again, it must be noted that these figures are for the noninstitutionalized population.

One more insight can be gathered from the National Health Survey. In the 1962-63 special study of hearing impairment, 5.4 percent of persons with binaural hearing impairments stated they also had a severe visual impairment—were unable to read ordinary newsprint even when wearing glasses. (Gentile, Schein, and Haase, 1967) This rate rose to 6.2 percent for those who were deaf; 10.5 percent also specified other difficulties seeing, bringing visual impairments to a total of 16.7 percent among the deaf respondents.

Now these studies deal with multiple disabilities, not handicaps. Furthermore, we have not considered information about literacy rates and other measures of academic attainment which would assist us in identifying the undereducated deaf population. Still, we can see that the probable number of severely handicapped deaf persons is large.

The reasoning underlying that assertion is that a second disability does not add to a deaf person's problems, it multiplies them. Dependent on his eyes for information about the world around him, a deaf person is often handicapped by a visual impairment which may be only mildly disabling to a person who can hear. Even a mild heart attack can create serious difficulties in getting proper medical care and in making a vocational adjustment. Certainly low academic achievement will have more grave consequences for a deaf person than for others. Thus it is reasonable to assume that most multiply disabled deaf individuals are multiply handicapped.

Another important factor is the limited rehabilitation facilities for deaf persons. For example, at present there are only five inpatient psychiatric centers specifically for deaf persons. Recalling that emotional and behavioral problems led the list of additional educational problems among deaf students (see above), one must presume that a large number of deaf persons in need of psychiatric treatment are doing without it. They fall into the handicapped category, because the means for alleviating their disabilities are not available.

With this reasoning, we can now attempt some numerical depiction of the severely handicapped deaf population. The preceding studies lead to the likelihood that from 20 to 40 percent of deaf persons have an additional disability, ranging from asthma to visual impairment.

If we define deafness as the inability to hear and understand speech, then we expect about 873 deaf persons per 100,000. That figure will seem very high, if you are accustomed to calling deaf only those whose hearing loss occurred early in life. The National Census of the Deaf Population coined the term "prevocationally deaf" to refer to persons whose deafness occurred before 19 years of age. The prevalence rate for prevocational deafness is 202 per 100,000. Returning to the larger group of deaf persons, the estimate for severe disability would range from 175 to 350 per 100,000 persons. Applied to the adult population of the United States between 18 and 65 years of age, these rates lead to estimates of from 188 to 377 thousand multiply disabled deaf persons.

You may regard most of these persons as severely handicapped, although at least some of them must have been rehabilitated. It is apparent that whatever assumptions we choose, a very sizable number of deaf persons are severely handicapped. Again, a more precise estimate must await greater precision of definition.

### **Projected Trends**

What about the future? In 1972, at the request of Gallaudet College, I prepared estimates of the future deaf postsecondary population. The details are available in a paper in *Program Master Plan Summary*, July, 1973, from Gallaudet College.

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(Schein, 1973) Table 2 shows the projected number of deaf persons 19 years of age for each year from 1972 to 1990.

Table 2

**Projected Distribution of Nineteen-Year-Old Deaf Population by  
Most Suitable Postsecondary Educational Placement: 1972-1990**

Year	Postsecondary Educational Placement			
	ALL	COLLEGE	TECHNICAL	COMPREHENSIVE
1972	7734	619	4,640	2,475
1973	7938	635	4,763	2,540
1974	8070	646	4,842	2,582
1975	8172	654	4,903	2,615
1976	8494	934	5,521	2,039
1977	8452	930	5,494	2,028
1978	8458	931	5,498	2,029
1979	8358	919	5,433	2,006
1980	8428	927	5,478	2,023
1981	8252	1238	5,694	1,320
1982	8138	1221	5,615	1,302
1983	7982	1197	5,508	1,277
1984	7626	1144	5,262	1,220
1985	7244	1087	4,998	1,159
1986	7034	1477	4,854	703
1987	6858	1440	4,732	686
1988	7189	1512	4,967	719
1989	7022	1475	4,845	702
1990	7582	1592	5,232	758

Under the heading "All" are the total numbers of 19-year-old deaf persons. Under "College" are those who would qualify for entrance to higher education. Those under "Technical" would qualify for admittance to a vocational-technical training program. The last column, labelled "Comprehensive", contains the estimated numbers in need of a comprehensive rehabilitation facility—the severely handicapped group.

These projections are based on optimistic assumptions. These assumptions are discussed at length in the original report, but a listing will give some idea of the basis for the expressed optimism:

- Early detection of loss,
- Early educational intervention,
- Curriculum changes in elementary education,
- Curriculum changes in secondary education,
- Continued programs of personnel development,
- Continuing research to improve education.

Is optimism justified? Here and there, I have seen some indications that a decade of educational innovation and government stimulation have been reflected in improvement in deaf students' academic achievement. However, such evidence is tentative, and many factors could intrude to reverse the trends.

Note, however, that even these sanguine predictions point to more than 2,000 19-year-old students per year who will need intensive and extensive services through 1980. These projections are only for one age group, in order to clarify the trends. Education and Rehabilitation obviously must contend with all ages. But even looking at the one age group, do we presently have facilities for the 2,500 deaf persons who will be 19 years old in 1974? To my knowledge, we do not have adequate facilities for the rehabilitation of half that number of severely handicapped deaf persons regardless of age.

### Politics of Numbers

During this conference you will be discussing personnel and programs, finances, and, I hope, prevention of handicap. Having just provided some figures, I would urge that you add to your discussions consideration of the "politics of numbers."

Perhaps it is our democratic tradition that leads to the heavy weight we place on numbers in making many judgments about providing funds for programs. I would distinguish between numbers needed for planning services and numbers used to assign priorities. I have no quarrel with the former, but grave doubts about the latter.

Let me illustrate with a recent incident. I received a long-distance call from a young man in a major city. He needed to know at once how many deaf persons lived in that city, because he was having difficulty convincing the officials there of the need for an emergency TTY service. When I gave him the estimate of the number of persons in that city who could not use the telephone, he was ecstatic, because deafness without regard to age at onset is 5 to 6 times greater than deafness of early onset.

"Gee, that's wonderful," he said. "I was afraid it wouldn't be big enough to sell!"

My reaction, unexpressed, was somewhat irrational: I was angry. I felt the census data we worked so hard to gather was being misused. Deaf people should have a service because they need it, not because they are numerous.

I think if we try to make a case for educational or rehabilitation services on the basis of numbers alone then severely handicapped people will not receive adequate support. Is it possible to make the case on the basis of necessity? Certainly, it has been at least partially that way through the brief history of rehabilitation in the United States. Compare the number of visually impaired to hearing impaired persons rehabilitated. Table 3 shows the figures for these two impairments in 1969; the prevalence data are from the National Health Survey. Despite the fact that there are almost precisely 50 percent more persons with hearing impairments, the number rehabilitated is exactly reversed: 50 percent more visually than hearing impaired clients rehabilitated.

By this comparison I do not wish to imply that too much money is devoted to services for blind people. Not at all. What I would like to point out is that resources are apparently not allocated solely on the basis of numbers of people. More people suffer from the common cold than any other affliction, yet there is no National Institute of Colds.

We need far more data on severely handicapped deaf people so we can plan properly for their education and rehabilitation. We do not need overinflated estimates to justify providing for them.

This thought was far better expressed by an article in the last issue of the *Journal of Rehabilitation*—an article by one of PRWAD's best friends, Mr. Craig Mills. Expressing a philosophical orientation to rehabilitation, Mr. Mills concludes, ". . . both the rehabilitation movement and the citizens of this country could say together, we believe that the *dignity* of man is his finest possession." (Mills, 1974)

Those are wise words to guide our deliberations here and our practices at home.

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Table 3

**Comparison of VR Closures for Visually and Hearing Impaired Clients to Prevalence of Visual and Hearing Impairments in the Civilian Noninstitutionalized Population.**

Impairment	Cases Closed <sup>a</sup>	Prevalence <sup>b</sup>	Closures Per Million Impaired Persons
Visual	20,516	5,700,000	3,599
Hearing	12,769	8,500,000	1,502

<sup>a</sup>FY1970

<sup>b</sup>FY1965

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