

# THE DEAF-BLIND POPULATION: IMPLICATIONS FOR REHABILITATION

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## I. Extent of the Problem

The number of multiply-impaired deaf-blind children has increased significantly over the last 10 years. A major factor contributing toward this increase has been the rubella epidemic of 1964-65 which has resulted in more than 5000 deaf-blind children and an unknown number of hearing impaired children with concomitant disabilities associated with congenital rubella syndrome such as heart defects, brain damage, mental retardation, eye lesions, bone lesions, anemia and genito-urinary defects.

Other contributing factors toward this increase are infectious diseases such as encephalitis and meningitis, genetic anomalies, congenital debilities and malformations, the improper use of drugs during pregnancy, and irradiation — all of which have increased the number of children with multiple birth defects.

Ironically, the advances of medical science have also contributed to this upsurge of multiple birth defects by reducing the infant mortality rate and extending life by greater control of those infections and diseases which in the past killed many children. As a result, we see a large number of children alive today who now endure an extended lifetime with one or more disabilities. In 1966, the American Foundation for the Blind<sup>1</sup> conducted a survey of 8,887 multiply-impaired blind children. Some 949 of these blind children, or 10.6 percent, reported hearing impairments. The Office of Demographic Studies<sup>2</sup> of Gallaudet College surveyed 41,109 hearing impaired students enrolled in special educational programs across the nation during 1970-71 and reported that nearly 32 percent, or 10,921 students (out of a total of 34,795) had from one to three additional handicaps. Some 1,699 children or 10 percent of the 10,921 students also reported severe visual problems. Maternal rubella accounted for 6,077 cases of hearing loss. The additional disabilities in both these studies included: brain damage, cerebral palsy, cleft lip and/or palate, emotional or behavioral problems, epilepsy, heart disorders, learning disabilities, mental retardation, orthopedic disorders, perceptual-motor disorders, speech, orthodontic defects, and other anomalies.

The National Center for Health Statistics,<sup>3</sup> a unit of the U.S. Public Health Service also conducted a national health survey which reported on characteristics of persons with impaired hearing in the United States from July 1962 to June '63. The information in this report was obtained through a nationwide household interview survey. Following are selected findings which are also relevant to our concerns.

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Approximately 8 million persons were estimated from the interview to have some hearing loss in one or both ears. Some 51 percent, or 4,085,000 persons reported hearing impairment in both ears. Of those 4,085,000 persons, about 222,000 or 5.4 percent, were reported to have severe visual impairments (i.e. unable to see well enough to read ordinary newspaper print even when wearing glasses). The percentages indicate that about one-fourth of the persons 65 years or older who have a hearing impairment also have some degree of visual impairment.

The National Center for Deaf-Blind Youths and Adults has located about 5000 deaf-blind adults and surveys conducted by the Regional Centers for Deaf-Blind Children<sup>4</sup> have located, to date, 5,064 deaf-blind children. These children are to be found in all 50 States, including Puerto Rico, the Virgin Islands, the Trust Territories, and Guam. Some 1,903 of these children are enrolled in full-time educational programs funded in part or totally, by Federal deaf-blind monies (provided under P.L. 91-230, Title VI, Education of the Handicapped Act, Part C, Sect. 622 to establish Centers and Services for Deaf-Blind Children).

An additional 784 deaf-blind children are receiving part-time educational services in residential or day programs which provide more than 30 hours service per year for each child, but less than 3 days per week during the normal school year.

Diagnostic and evaluative services will be provided to some 645 deaf-blind children this school year, for a total of nearly 3000 children receiving such services since 1969. In addition, during this school year, some 3000 parents (or parent surrogates) will benefit from counseling services provided by social workers, parent counselors, or the teachers of the educational programs in which their children are enrolled. Also, some 2000 teachers, aides, and parents will receive inservice training via workshops and institutes funded, planned, and implemented by the Regional Centers.

All of these services and activities are provided through more than 200 programs and projects under subcontract agreements between 11 Regional Centers and their respective state and local education agencies, as well as other State agencies (e.g. Mental Hygiene) and/or private non-profit agencies. Such a wide range of agreements make possible a full continuum of services for deaf-blind children, their parents, teachers and others who work in some way with these children.

The age breakdown provided for 4,096 of these children indicates 2,241 children are between the ages of 6-11. Most of these resulted from the rubella epidemic of 1964-65. It is estimated that 300 additional deaf-blind children are also enrolled in full-time educational programs which are supported entirely by other State, local, or federal funds. This brings the estimated total of deaf-blind children enrolled in full-time educational programs to 2,203, or almost 44 percent. Some 778 of this total are in educational programs located in State hospitals.

## II. Federal Concern for the Deaf-Blind Person

The results of these surveys, especially those which have in fact identified the deaf-blind population, justify the increasing concern two Federal program efforts have for the welfare, education, and rehabilitation needs of deaf-blind persons.

For the Bureau of Education for the Handicapped, these concerns are focused on deaf-blind children from ages 0-21 and are based upon the ability of State, local, and Federal agencies to plan adequately for the short and long term educational and rehabilitation needs of the deaf-blind person. Can we collectively and cooperatively provide in time the total resources required in the way of program alternatives available now and needed in the near future; provide the manpower development and training essential to staff these various programs; and most urgently, provide the

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physical facilities necessary to house these varied programs so essential in meeting the total needs of a rapidly maturing deaf-blind population?

Let us look at some of the reasons contributing to these concerns:

1. Since the inception of the Regional Centers for Deaf-Blind Children in June of 1969, nearly four and one half years later, some 56 percent, or 2,861 deaf-blind children are still in need of full-time educational or training programs.

2. During this time, the intensive efforts of state, local and federal resources have been able to meet the full-time educational needs of only 2,203 children (44%), at an estimated cost of \$20,000,000 for this school year alone. Ten million dollars of this was from Federal deaf-blind funds.

3. To adequately serve the remaining 56% may cost another 20-30 million dollars per year. Or, an estimated total cost of 40-50 million dollars per year for the educational lifetime of these children.

4. These costs do not include the maintenance costs of \$9-10,000 dollars per child/year for the 1000-1200 deaf-blind children now in State Hospitals. Without adequate educational/or training programs for these children, little can be realized in the way of benefits to the child and society for such an investment.

5. If the Bureau's goal of a deaf-blind budget of 25 million dollars is reached in the next 3-5 years, it will fall upon the State Education Agencies and local education agencies to absorb at least 50% of the estimated total cost for the education or training of these children.

### III. Implications for Education and Rehabilitation

The Regional Centers for Deaf-Blind Children are faced with a monumental task in their efforts to assure comprehensive programming and equal educational or training opportunities for deaf-blind children. At their present rate of growth in the planning and implementation of new programs, it will take another 4-5 years to provide adequate services for the remaining 2,861 children not presently enrolled in programs. For too many of these children it will be too late to provide the kind of intervention that might have changed their lives if it had been available sooner. We are now faced with two formidable tasks which must be dealt with simultaneously. The first task is obvious: we must provide urgently needed services for those children who are not presently in any program. To do this, we must expand facilities wherever it is possible to do so; we must provide needed training to supplement the skills and knowledge of teachers who have never before worked with a deaf-blind child; and we must identify new resources that can be adapted to include deaf-blind children in their programs. These children cannot afford to wait for the construction of new facilities which will take 3-4 years to complete before they receive the services they urgently need. However, such building plans may be necessary to meet the long range needs of these children and those already enrolled in day school programs which one day may no longer meet their needs.

The second task is not so obvious but perhaps even more difficult to achieve than the first. We need to examine those programs which now exist (for some 2,203 children) and those new programs we will be planning and developing for those children who are not presently being served; to determine whether they will be appropriate 5-10 years from now, to meet the changing needs of this population. This task is compounded by the new problems we will be faced with by our children who are now ages 6-11 (some 2,241). In the next 3-7 years, many of these children will become young adolescents. Those children at home will present new family crises which will become intolerable to their parents; demanding of us new or alternative program placements which, if we cannot provide them as the needs arise, will result in the institutionalization of a large number of these children. This is an alternative we

want to avoid at all costs. Problems of such magnitude can possibly be resolved by a systems approach which is comprehensive and systematic in dealing with the many complex problems of education and rehabilitation. The National Center for Deaf-Blind Youths and Adults and the Regional Centers for Deaf-Blind Children utilizing this approach can provide a mechanism by which educators, parents, rehabilitation, vocational, medical, social and clinical disciplines can work together to analyze the problems involved in providing a full continuum of comprehensive and ongoing services for the deaf-blind person — from his infancy through full maturity; to establish sound objectives and program priorities; and to develop an organized and rational plan or plans as solutions. Such an approach emphasizes the “whole” person and his individual needs as a person.

We ask for your participation and active involvement in this effort. The role of the vocational rehabilitation counselor and State Divisions of Vocational Rehabilitation as well as State Commissions for the Blind is a vital one in this system. Without your assistance and support we cannot offer any future to parents and the deaf-blind child as he grows up. What will we be educating and training these children for, if we do not prepare now, with your assistance, programs that will be available and ready for them as they leave their educational programs?

In an effort to stimulate State and local concern for the prevocational and vocational needs of deaf-blind children, the Bureau has initiated a one year national planning effort to develop educational services and curriculum which relate to prevocational training needs. We invite you to assist us in this effort — to help us begin to assess, program, and evaluate alternatives for the placement of deaf-blind youths in vocational settings. Joint cooperation between the Regional Centers and the National Center is assured in this critical program area but it can't be done without your help.

We invite you, rehabilitation workers, counselors, psychologists, social workers, teachers, and any one else interested, to visit educational programs for deaf-blind children now, and not wait until they are suddenly forced upon you as clients. Share with us their successes as well as their failures during their educational development. This will make your job much easier and the educator's even more meaningful because then they can tell the parents of these children — that you care, that you are concerned, and that you will help to provide the means by which a future can be assured for as many of these children as it is humanly possible to do so.

### REFERENCES

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4. “The Current Status of Services for Deaf-Blind Persons”, Robert Dantona and Peter J. Salmon, New Outlook for the Blind, published by the American Foundation for the Blind, March 1972.