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Jerome D. Schein
Director, Deafness Research and Training Center, New York University

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REHABILITATING THE DEAF-BLIND CLIENT

JEROME D. SCHEIN
Director, Deafness Research and Training Center, New York University

From the rehabilitation counselor's point of view, the major difficulty in serving deaf-blind clients is communicating with them. Loss of sight and vision may occur at any age and, as will be discussed, the age of onset of the two disabilities affects the ways in which they communicate. Thus, initiating rehabilitation requires that one first determine an effective means of communication with the client. Having resolved that difficulty, there are many more that follow, but these tend to be common to rehabilitation generally, albeit with special aspects that relate to the deaf-blind clients' twin disabilities.

From the deaf-blind client's point of view, accessing services are the high, initial barrier to rehabilitation. Limitations of mobility and communication prevent many deaf-blind persons from receiving services to which they are entitled. Simply put, they either cannot reach the point of service or, having reached it, cannot communicate with the service providers. Add to these problems the fact that deaf-blind clients are cut off from many sources of information – newspapers, radio, television, casual encounters with knowledgeable friends – from which they might learn about social services that would benefit them.

Several states have adopted or are considering adopting the New Jersey Plan for Serving Deaf Blind People (Schein, 1984). This plan recognizes the difficulties faced by deaf-blind people and those who should serve them. Furthermore, the plan is designed to meet the broad, continuing needs of the growing deaf-blind population rather than focusing on only one or two age brackets. This paper outlines the New Jersey plan, most of whose principles can be applied to other states without modification.

Population Size

A careful reading of Needs Assessment of Services to Deaf-Blind Individuals (Wolf, Schein & Delk, 1982) – a nationwide survey jointly sponsored by Rehabilitation Services Administration and Special Education Programs of the Department of Education – reveals the growing magnitude of the deaf-blind population. The study provided five estimates of deaf-blindness in the noninstitutionalized population of the United States. These estimates are shown in Table 1.

TABLE 1
Prevalences of Deaf-Blindness in the Noninstitutionalized Population, by Various Definitions: United States, 1980

Definition	Prevalence Rate/100,00	
All Definitions Combined	743,275	346
Deaf-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, Schein & Delk, 1982

Persons who are legally blind and cannot hear and understand speech even with best amplification number 41,859. Another 383,299 persons are deaf and have severe visual impairments, or are blind and have severe hearing impairments. There are 309,117 persons who are both severely hearing and visually impaired. Add to these 734,275 persons the 13,182 deaf-blind residents of institutions and the magnitude of the problem in sheer numbers becomes evident.

Since deaf-blindness is not evenly distributed geographically, the number of deaf-blind persons in any particular state may be far larger or smaller than what would be estimated by applying these national rates to its population. To illustrate this point, consider three neighboring States. The U.S. Department of Education maintains a register of deaf-blind schoolchildren. For Connecticut, New York, and New Jersey, Table 2 shows the known numbers of deaf-blind students in 1983. Note the great differences in rates. If Connecticut provided educational facilities at the same rate as New York, for example, it would have almost twice as many as actually required. Similarly, if New Jersey provided services based on New York's rates, it would cover only about two thirds of the students in the state. As the data makes evident, using data from one state (or even a group of states) to estimate the size of the population in another state likely will lead to gross errors. While these data refer to schoolchildren, the reasoning extends to any age group. The answer to the problem of determining the number of deaf-blind persons to be served is to conduct a study of its own population.

TABLE 2
Prevalence and Prevalence Rates for Deaf-Blind Students in Three States

State	Prevalence	Rate per 100,000[a]
Connecticut	64	13.25
New Jersey	358	30.84
New York	584	21.90

[a]Ratio of deaf-blind students to all elementary and secondary students.
Source: U.S. Department of Education, 1983

The people most affected by deaf-blindness are elderly persons. Recall that all deaf youths and all blind youths are halfway to becoming deaf-blind. Put in other words, those who are deafened or blinded in early life can expect a decline in their unaffected sense as they grow older. Impairments of vision and audition are very common after age sixty. About 35 percent of all persons 65 years of age and older have auditory impairment (Schein & Miller, 1983). Past 75 years of age, the rate of auditory impairment climbs to almost 50 percent. Similar rates apply to vision. Thus, if a person is already deaf or blind, the probability that that individual will become deaf-blind after 65 years of age is very high. Yet, generally inadequate provisions have been made to care for the needs of elderly deaf-blind persons, either those who became deaf-blind early in life or those who became deaf-blind in senescence. The needs of these people must not be ignored, if for no other reason than that their numbers are increasing rapidly. By the year 2000, 13 percent of the population will be 65 years of age or older. What seems to be poorly understood by social-service planners is that a significant proportion of the anticipated 35 million elderly people are very likely to be both visually and hearing impaired.

Severity of the Condition

The present study estimated three quarters of a million visually and auditorily impaired people need specialized services and personnel not usually available in agencies solely for deaf or blind persons. Either type of agency may, of course, choose to serve persons with multiple sensory disabilities, but the agencies typically do not have personnel who are familiar with the unique concatenation of deaf-blind clients' problems (Anderson, n.d.; English, 1973, Guldager, 1978; Yoken, 1979).

Until recently, most deaf-blind applicants have not been considered feasible for vocational rehabilitation. Competitive employment has been ruled out of the question for the majority of them. Indeed, independent living has been regarded as extremely difficult, if not impossible, for them to achieve (Brewer & Kakalik,

19745; Salmon & Rusalem, 1966). Since passage of the Rehabilitation Act Amendments of 1973 –which revised priorities and removed the requirement of a vocational objective for severely disabled clients — deaf-blind clients have slowly been accepted by State VR and Blind agencies (Morgan, 1973; Schein, 1980; Smithdas, 1982). But with what success?

As the "rubella bulge" has passed through the educational system into rehabilitation, the great transitional difficulties facing deaf-blind students have become apparent. Educators, faced with regulations that force them to abandon their students at ages from 18 to 21 years, realize how ill-prepared the deaf-blind students are to face the world of work (Hanley & Maher, 1980; McInnes & Treffry, 1982; Sontag, 1980). Few deaf-blind 'graduates' have sufficient skills for self-care; many have only the most rudimentary communication skills, and some are not even toilet-trained Rehabilitation, on the other hand, does not have staff prepared to work with these clients (Appell, 1982; Bettica, 1977, Hammer, 1973).

Salmon and Spar (1974) remind us that deaf-blindness does not homogenize its victims; they retain their individuality. They point to some important distinctions in the population:

> *Without in any way minimizing our responsibility to help to meet the needs of the rubella children with whom we are now concerned, we should not lose sight of the fact that there are some children who are deaf-blind as a result of causes other than rubella and that some of these have potentialities that will not be adequately developed through programs designed for low-functioning deaf-blind children. Also, we should bear in mind that for every deaf-blind child in this country, there are probably about nine deaf-blind adults, most of whom have been very seriously neglected (p.60). A major difficulty confronting all social-service agencies has been the lack of personnel specially prepared to work with deaf-blind people.*

Rehabilitation Personnel

The national needs assessment of services to deaf-blind persons reveals the paucity of rehabilitation personnel who are trained and motivated to serve this severely disabled group. Because most deaf-blind clients will require lifelong services, the absence of well-prepared personnel to work with them over extended periods of time becomes even more pressing. Yet only one program in the United States is presently providing the level and quality of education needed to prepare such personnel. Most importantly, adequate personnel are not prepared to assist deaf-blind youth in the transition from school to whatever level of independence they can achieve.

The New Jersey Plan

In response to the growing demands for services for deaf-blind adults, the New Jersey Commission for the Blind and Visually Impaired (CBVI) has adopted a comprehensive plan of services (Schein, 1984). A major departure in planning for deaf-blind individuals is the immediate recognition that most of these persons have lifelong needs; most cannot be considered typical clients for whom cases are opened, worked on for a time, and then closed. Secondly, the plan recognizes the terrible difficulties deaf-blind people have in locating appropriate services and then approaching the agencies offering those services. The deaf-blind person in New Jersey will have one, and only one, agency to contact for all services, CBVI. CBVI will not provide all the services; it will assist the deaf-blind client in locating the agency that should provide the service. CBVI counselors will make contact with and represent the client before whatever agencies do provide the services. The result should be a highly cost-effective means of solving the difficulties of serving a relatively small, but severely disabled population.

Deaf-Blind Specialist. An integral component of the New Jersey plan is the position of deaf-blind specialist (DBS). The DBS' responsibility includes determining the needs of the client and then identifying which agencies can best meet those needs. The DBS does not attempt directly to provide all services that the clients require; indeed, the DBS may provide no other services than counseling, referral, and advocacy.

The DBS strives to establish a lifelong relationship with the client. In principle, the first DBS an agency assigns to a deaf-blind client would be the one who serve the client throughout the client's life. In practice, of course, the DBS for most clients will change occasionally. Benefits to the client and the State are expected to be substantial by reducing the great difficulties that deaf-blind people have in establishing rapport with anyone for the first time, in arranging transportation to reach service providers, and in communicating with them. Relative to the benefits derived, a DBS represents a small added cost to deaf-blind rehabilitation.

The statewide plan for providing coordinated lifelong services to deaf-blind individuals of Kansas (Kansas State Department of Education 1981; Kelley, Eye, Gottula & Freedman, 1982) embodies similar thinking. Kansas should welcome the DBS into their state program for deaf-blind persons. New Jersey has already hired one DBS and plans to hire more in the near future. Other states may soon follow. Recent discussions have been held with the Massachusetts Office of Deafness and the New York Commission for the Blind and Visually Impaired about embodying this position in their programs.

Personnel Preparation. At present, no university is specifically preparing personnel to fill the position of DBS. That situation should change soon. The programs that do emerge should be sure to establish strong rehabilitation backgrounds for their students. If the field does not adopt the concept of the DBS, or if demands for personnel to serve deaf-blind clients fall drastically, the students who have taken the DBS specialization should be completely protected by the fact that they have another string to their bow; they are broadly trained in rehabilitation and are, therefore, employable in a variety of settings where they can work effectively with most disabled clients.

In addition to skills usually associated with preparation to work with deaf and with blind clients, they should have specialized knowledge related to deaf-blind individuals. The combination of disabilities produces a unique syndrome that, while related to the two individual sensory disabilities, is separate from them. Communication will be a particularly specialized area, since deaf-blind persons' preferred modes of communication vary over a wide range (Kates & Schein, 1980). The age at onset will be a major determiner. Those deaf from birth or early in life will usually use manual communication (e.g., clients with Usher's syndrome), those blind persons who later lose hearing will continue to depend upon their oral skills, and those who are born both deaf and blind (e.g. those whose losses are the result of maternal rubella) will most be most limited in communication, depending most upon tactual modes.

Furthermore, the DBS will be called upon to 'broker' services in his state; hence he should be skilled in negotiating with other agency personnel and in understanding their situations, but being firm on behalf of the deaf-blind clients. Clearly, the DBS should develop diverse skills and master a vast amount of material bearing upon his future career.

Summary

The proportion of the population with the twin disabilities of deafness and blindness is growing. Whether the condition is strictly or broadly defined, the number of persons involved is substantial. Yet adequate provisions have not been made in most states to meet the needs arising from their unique disability. Major stumbling blocks to serving deaf-blind clients are lack of (a) an administrative concept that will overcome the severe difficulties they have in accessing the service delivery system and (b) personnel knowledgeable about the syndrome and ability to communicate with most deaf-blind persons.

In response to these two deficiencies found in most states, this paper describes the New Jersey Plan. It calls for a single agency to act as a permanent broker for all deaf –blind clients. In that way, deaf-blind clients are less likely to "fall between the cracks." A second feature of the New Jersey Plan is the Deaf-

Blind specialist (DBS), an individual trained and assigned to work full-time with these clients. This broadly prepared specialist should ease the strain on other facilities. The DBS concentrates on bridging the gaps between his clients and the services they need. The DBS may also fill the role as a service-delivery advocate, since he is acutely aware of whatever unmet needs his clients have. These two features do not dispose of all the problems facing deaf-blind persons, nor covered by the New Jersey Plan. There are many more that will stress even the well-trained DBS to resolve. However, this brief discussion hopes it has added some new perspectives. A decade ago, rehabilitation agencies often ignored the deaf-blind client. A particular agency, now that it is attending to them, will find that these clients require different service tactics and strategies and even better prepared personnel than are presently on its staff. The growing urgency of the problems – made more demanding by increasing numbers and inadequate resources – will not go away.

References

Anderson, H.C. (n.d.). *Reaching the deaf-blind by working together,* St. Augustine, FL: Florida School for the Deaf and the Blind.

Appell, Madeline W, (1980). Family home services and pre-school needs of deaf-blind children; Approaches to meet the service needs of deaf-blind children in both rural and urban areas. In E.G. Wolf (Ed), *The 1980's, Partnership in Planning for Progress*, Bronx, N.Y.: Mid-Atlantic-North and Caribbean Regional Center for Services to Deaf-Blind Children.

Bettica, Louis J. (1977). The deaf-blind maturing youth and active adulthood – needs and services. *In Proceedings of the First Historic Helen Keller World Conference on Services to Deaf-Blind Youths and Adults*. Paris, France: World Council for the Welfare of the Blind.

Brewer, G. D. & Kakalik, J.S. (1974). Serving the deaf-blind population: Planning for 1980. In Carl E. Sherrick (Ed.), 1980 is now, Los Angeles: John Tracy Clinic.

English, J. (Ed.) (1973), Personnel in deaf-blind rehabilitation, Dallas, TX: South Central Regional Center for Services to Deaf-Blind Children.

Guldager, L. (1978), Life-time program for deaf-blind and other multiple handicapped persons. Journal of Visual Impairment and Blindness, 72 (7), 287-289.

Hammer, Edwin K. (1973), Deaf-blind clients: A behavioral model of rehabilitation services. Deafness Annual, 3, 15-29.

Hanley, D. E. & Maher, P.J. (1980). Program planning and development: Identification and coordination of resources for the delivery of life-time services for deaf-blind persons. In E. G. Wolf (Ed.), *The 1980s Partnerships in Planning for Progress.* New York: Mid-Atlantic-North and Caribbean Regional Center for Services to Deaf-Blind Children.

Kansas P. L. A. N. for Deaf-Blind. A model system for providing a coordinated life-long continuum of services to deaf-blind individuals and their families. (1981) Topeka: Kansas State Department of Education.

Kates, L. & Schein, J. D. (1980). *A complete guide to communication with deaf-blind persons.* Silver Spring, MD: National Association of the Deaf.

Kelly, P., Eye, R., Gottula, P. & Freedman, P. (1981), *The Kansas P.L.A.N.: A*

team approach to planning. Topeka, KS: Kansas State Department of Education.

McInnes, J.M. & Treffry, J.A. (1982) *Deaf-blind infants and children.* Toronto: University of Toronto Press.

Morgan, C. (1973), The deaf-blind client can be rehabilitated. In English, J. (Ed.), *Personnel in deaf-blind rehabilitation.* TX: South Central Regional Center for Services to Deaf-Blind Children.

Salmon, P.J. & Rusalem, H. (1966). The deaf-blind person: A review of the literature. *AAWB Annual Blindness*, 15-87.

Schein, J. D. (1980). *Model state plan for rehabilitation of deaf clients: Second revision.* Silver Spring, MD: National Association of the Deaf.

Schein, J. D. (1984). *Serving the deaf-blind population of New Jersey*, Newark: New Jersey Commission for the Blind and Visually Impaired.

Schein, J. & Miller, M. (1982), Auditory disorders: Evaluation and management. In F. J. Kottke, G. K. Stilwell & J. F. Lehmann (Eds.), Krusens Handbook of Physical Medicine and Rehabilitation. Third edition. Baltimore: W.B. Saunders.

Smithdas, Robert J. (1982), Auditory disorders: Evaluation and management. In F. J. Kottke, G.K. Stilwell & J. F. Lehmann (Eds.), *Krusens Handbook of Physical Medicine and Rehabilitation.* Third edition. Baltimore: W.B. Saunders.

Smithdas, Robert J. (1982). Editorial: Of laws and regulations. *Nat-Cent News*, 12 (1), 1-3.

Sontag, Ed. (1980), Future directions in federal programming for deaf-blind individuals. In E. G. Wolfe (Ed.), *The 1980's; Partnerships in Planning for Progress.* New York: Mid-Atlantic-North and Caribbean Regional Center for Services to Deaf-Blind Children.

Wolf, E. G., Delk, M.T. & Schein, J. D. (1982), *Needs assessment of services to deaf-blind individuals.* Silver Spring, MD: REDEX, Inc.

Yoken, C. (1979), *Living with deaf-blindness: Nine profiles.* Washington, D.C.: The National Academy of Gallaudet College