

EDUCATIONAL SERVICES: PRESENTATION

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Abstract: The National Association of State Boards of Education stated in 1992 that children classified as special education students are not achieving what they are capable of; they are not being prepared for life after school; and current mainstreaming practices are not producing their intended outcomes. Many of these problems are due to a rapid shift into decentralized services without a reasonable infrastructure in place to assist the local school systems. We must do the following: Establish a national clearinghouse with a newsletter and resource referral system; set up more meetings and training activities across state lines to ensure a fertile exchange of information; fund development of high quality training materials; fund 8-10 personnel preparation programs within universities that are in strategic geographic locations; conduct research on what methods and services work; develop within each state a network of consultant/itinerant/resource people; utilize more paraprofessionals (similar to Canada's intervener program); develop a "quality indicators" assessment; and finally, set up an advisory committee made up of consumers and professionals in the field.

Introduction

I must admit that it is with considerable trepidation that I follow all the distinguished speakers who have preceded me. How does one follow such an impressive group and have anything left to say? It is worse yet to look at the bright people following me, who have the opportunity to contradict me.

Nonetheless, I am pleased to be here to participate in this symposium, and to assist in the setting of priorities for the future. This was last done by OSERS (Office of Special Education and Rehabilitative Services) in 1978, so it is safe to say that a meeting to revisit federal priorities is somewhat overdue.

As we examine the priorities for OSERS to consider in the next decade, it is perhaps wise to view the educational priorities (a) in the context of the recent history of the education of children who are deaf-blind in our country and (b) in the context of today's approaches to the education of disabled children and youth. So let us first examine our past, and then we will shift our focus to the present.

Recent History

The past two decades have seen some interesting changes in our service delivery to people who are deaf-blind. In the 70s we witnessed the creation and development of a

network of multi-state regional centers for children who are deaf-blind. While they varied in number and composition over time, these centers provided a national network of communication and sharing for those serving children. They tended to be staffed by personnel who had specific training related to people who are deaf-blind, and their staff provided ongoing training and consultation to local programs and produced many publications and training videos which were nationally available.

Most important, the regional centers had the responsibility to develop direct service programs for children who are deaf-blind, prior to the enactment of mandatory education legislation. As a result, in a very short time, from about 1970 to 1975, most states had developed several specialized programs for children who are deaf-blind, within residential schools, state institutions for the retarded (as they were then known), and many public schools (Dantona, 1974). Many "deaf-blind programs" resulted, frequently, as many as four to eight within a given state. Some of our bigger states, like California and Texas, had classrooms for children who are deaf-blind scattered all over the state, within some of their major school systems. A typical state would have a large residential program at the school for the blind, one or two large residential programs within state schools for the retarded, and several small public school classes for six to eight children.

However, it must be noted that, measured against today's standards, virtually all these programs were either in segregated settings or were mostly segregated classes within a public school setting. Another shortcoming was that not all children within the state were served by these specialized programs. In the days prior to P.L. 94-142, these programs could be selective about admissions, and were in fact so. Children not admitted into these classes were either served in other generic programs for children with varied disabilities or were not in an educational program at all. The personnel within regional centers had a responsibility to support, develop and advise the specialized programs for children who are deaf-blind within their region, but they also had a very large consultative caseload of children who were in no specialized service.

It must also be noted that, during this decade, funding was relatively available and adequate. The \$16 million appropriation for Centers and Services to Deaf-Blind Children went a long way toward ensuring that direct services were established and that staff training activities were routinely provided. Federal funding covered over half of the cost of direct service programs in most states, and this healthy federal appropriation was even adequate enough to ensure the continuation of these programs during the recession of the 70s.

Another significant characteristic of this decade was the establishment of several university programs to

prepare personnel. Programs to train teachers were initiated at Boston College, San Francisco State University, Peabody College, Portland State University, Michigan State University, the University of Pittsburgh, Ohio State University, Cal State L.A., Florida State University, the University of Alabama at Birmingham, and others, mostly with federal support (Campbell, 1976). Ponder for a minute the number and geographic dispersion of these programs. We were educating over 100 teachers annually who had specific training. Through the regional centers, the graduates of these programs were readily placed in positions throughout the nation, teaching children who were deaf-blind.

Let us acknowledge that the proliferation of these programs was again directly relative to the healthy funding levels being approved for such training and due to the internal advocacy of Josephine Taylor within the Bureau of Education for the Handicapped. Nonetheless, some regions of the country, notably the Midwest and rural West, had a very inadequate supply of teachers.

During this era, not only was the supply of teachers better than now, but these teachers, when graduated, actually had jobs to go to which were related to their training. A trained teacher could get a job teaching children who were deaf-blind in any state in the nation. In addition, with some experience, they were able to fill the many specialist positions within regional centers, state

departments of education, and universities. We had a pool of people from which to recruit our future leaders. Consequently, many of our states had personnel in leadership positions who had both training and direct teaching experience with the population (Campbell, 1976).

It is also noteworthy that teachers, staff, and parents of children who were deaf-blind were well informed about the purposes of the federal program and the state and multi-state programs under Section 307.11. This was, of course, due in part to the centralization of services, but did result in a level of accountability within these organizations.

What was instruction like during these years? Well, it should first be noted that many children were taught in self-contained classes of children who were deaf-blind, with four to six children being taught by a teacher and several aides. Instruction therefore tended to be carried out in classes with very low staff-student ratios. Frequently the teacher had specific training in either teaching children who were deaf-blind or children with multiple sensory impairments. When such training was lacking, the teacher knew nonetheless that he or she had accepted assignment to a class of children who were deaf-blind, and therefore the teacher participated in all possible training activities, read about the instructional techniques used with the population, and gradually acquired useful teaching skills.

Instruction tended in many programs to be very developmental, with a focus upon academic or "pre-academic" teaching. The teaching of language skills, cognitive skills, reading, writing, math, and sensory development prevailed, and in many schools the teaching of these was very good. Teachers knew how to check the child's hearing aid, knew several possible language modes and how to teach them, could teach braille when needed, could carry out auditory training, utilized appropriate assessment tools, implemented curricula to stimulate the use of residual vision, and had the ability to teach children to use these skills in everyday life situations. The teaching of daily living skills was usually well integrated into the curriculum.

In some places the academic content was over emphasized to the neglect of functional curricula; while some basic daily living skills were taught, too often other practical, applied skills were lacking. Frequently, the activities were not terribly age appropriate, with adolescents required to engage in very juvenile activities. Elements of choice-making and self-determination were frequently lacking from the curricula. Vocational training was either nonexistent in some schools or, in others, was oriented toward preparation for sheltered work. In short, much of what became state-of-the-art instruction in the 80s (Snell, 1987) was typically not addressed.

The Current Status of Educational Services

It has been suggested that we should incorporate into our papers some reference to how educating children who are deaf-blind fits into the context of other regular and special education trends which are prevailing in today's society. It is first essential to note that our entire philosophy of education of children with disabilities has shifted in several ways since the 1970s. We have moved from conducting education solely in segregated facilities to offering more services integrated into the local community. We have moved from centralizing our service offerings to decentralizing them, so as to make them available in every child's community. Functional curriculum which is age appropriate has replaced a lot of academic teaching. Vocational training and placement is now regarded as a key aspect of school curriculum. We have shifted from offering services, which were highly specialized to the child's specific disabilities, to offering a curriculum which is more "generic," being generalized to all children. In this paper, I am not placing a value on these trends; I merely wish for us to acknowledge them as existing and influencing how children currently receive services.

A recent study of the Federal Resource Center at the University of Kentucky analyzed current issues and trends within special education, in an attempt to predict the future. While some of the predictions in this study sound a bit like a summary of

past practices, a few general trends are interesting to note since they have implications for the education of children who are deaf-blind. To quote, "There will be a critical shortage of special education personnel at all levels. In an effort to deal with these personnel shortages, paraprofessionals will have an increasingly important role in service delivery and will provide more direct instruction" (Hales & Carlson, 1992, p. 5). (This prediction raises a question regarding children who are deaf-blind: Who will supervise, monitor and refine the work of these paraprofessionals?) "Also, in an effort to meet the need for services, regular educators will be trained and acquire the skills necessary to serve children with mild disabilities thus blurring the borderline between special and regular education" (p. 5). (What people at the local level have the ability to train these regular educators within most communities? Who can train them?) "States will cut special education funding as more students are served in regular education" (p. 6). (If so, how can we ensure that our students get the resources they need, rather than having special education funding support the football team?)

It has been suggested that perhaps I could tie into this presentation the ways in which America 2000 might have a bearing upon education of children who are deaf-blind. I am not sure this is possible. The America 2000 goals were formulated for the general student population without much regard for how they might apply to special populations

(Mecklenberger, 1992). Therefore, they are largely irrelevant; when one considers the major changes which schools must implement to make education more appropriate for children who are deaf-blind, the America 2000 goals miss the boat. I would suggest that they are an outstanding example of how inclusion might go awry: We have written goals for the general population without regard for how they might need to be individualized to different populations.

These general trends in special education have had some tremendous impact on how children who are deaf-blind are educated. The typical scenario today is that the child is taught in his home community; his classmates are other children with multiple impairments, or with no impairments; his teacher has no specific training in deaf-blindness; if he is fortunate, a trained person may consult with the classroom monthly or annually; his classes focus on many functional skills, but are weak in academic teaching, sensory development and language skills; as he approaches adolescence, he probably has a reasonable program of vocational training, depending upon the community in which he resides; and his parents may not know what to do with him at home, or they may be in need of a knowledgeable person to advise them.

We must acknowledge that we have a fairly strong level of technical assistance being provided through our national program for children

who are deaf-blind. Within each state, the single and multi-state centers for children who are deaf-blind have primarily a technical assistance role. The technical assistance project called TRACES (Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments), operated by Teaching Research in Oregon, has been a fine support to all states as they attempt to upgrade their services to children who are deaf-blind. Likewise, the Helen Keller National Center's Technical Assistance Center fulfills a similar function for transition-aged students. Both of these projects sponsor training nationally, and publish newsletters with good information for the field. Similarly, the American Foundation for the Blind's project to provide training tapes and learning modules in communication and mobility will be a wonderful resource for all of us who have the job of providing basic training on an ongoing basis. We also now have a national information center and clearinghouse (DB-LINK: The National Information Clearinghouse on Children Who Are Deaf-Blind) being developed by Teaching Research and other organizations, including ourselves at Perkins, so that the important literature and resources will be catalogued and easily accessible to all.

Thanks to the enactment of P.L. 94-142, we live now in an era when all children receive educational services. Due to P.L. 94-457, most infants and toddlers will also be receiving the educational headstart which they

require. No longer will we have to see children who are deaf-blind sitting at home uneducated due to distance, funding shortages, or rejection.

The federal legislation has also brought about a philosophical and practical shift toward mainstreaming and toward the full inclusion of all children in their neighborhood schools. Most children and their families now have at least the option of an education in their neighborhood schools. With increasing frequency, this education typically includes at least some partial integration with nondisabled peers.

The integration movement has definitely resulted in a much greater *dispersion* of children who are deaf-blind. While they used to be served in more concentrated pockets, due to the greater abundance of specialized programs, they are now served in a much greater number of schools, spread over a much larger geographic area. You can see a graphic display of this phenomenon on the overheads: the first shows the location of the 215 children who are deaf-blind in New England in 1982, served in a total of 29 school buildings; the second shows our current population of 267 children in 1992, served in 218 different programs or sites. This same phenomenon repeats itself in every state and region in the nation. Infrequently, does one find two children who are deaf-blind served within the same building, let alone the same classroom.

As you might imagine, the population dispersion makes the state coordinator or consultant's job a much more challenging one. How does a consultant/specialist adequately assist and support programs for 185 children who are in 138 different schools in the state? These 138 schools definitely require a greater level of such assistance than in the past, since they do not typically employ specialists for children who are deaf-blind. With only one or two children per building, or often per district, they cannot possibly afford such a low-incidence specialist. Nonetheless, in comparison to past decades, we have a greatly increased number of special educators and general educators who need some basic training in instruction of the children who are deaf-blind.

The forementioned factors result in most states repeating training, again and again, in the very elementary instructional strategies known to be effective with children who are deaf-blind, for an ever-changing body of learners. The result is that very few educators are accumulating the larger body of knowledge which they need in order to conduct sound educational planning for the children.

If we had personnel shortages in the past two decades, they are now increased ten-fold. Only three or four universities nationally now receive federal support for pre-service programs to train teachers of children who are deaf-blind. They are training no more than 20 or so

teachers annually. Many other universities offer programs in severe disabilities, but there is great variation in the extent to which they address sensory losses, and, too frequently, people who are deaf-blind receive only cursory attention via survey courses which provide an overview of a multiplicity of disabilities. Please recall that this is occurring in an era when the need for such trained teachers is at an all-time high, since children are served in such a great *number* of places. Local school systems, which, with increasing frequency, have the mandate to educate the child, must proceed without personnel with the expertise to train and support their teaching staff. For this reason, the Hilton/Perkins National Program has chosen to use much of the funding from the Conrad N. Hilton Foundation to support graduate degree training and/or certification coursework for over 100 teachers annually within six universities.

Another phenomenon worthy of mention is that, with children spread out so far over such a large number of districts, there are very few jobs available for a trained teacher of children who are deaf-blind. School systems are not allocating a specialist position for one or two children in each district, and graduates therefore have to search broadly for jobs in which their specialist background can have broad impact for numbers of children. The expertise of the specialists is broadly needed, but positions which make use of their skills are few and far between.

Given that we have such a severe shortage of adequately trained teachers, we likewise have a greatly reduced pool of people from which to appoint consultants, specialists, and resource people. Where are our future leaders to come from? Even when a school system has the funding for a resource specialist, they have difficulty finding appropriately trained candidates. More than 75% of the positions for state consultants, or coordinators of the state and multi-state programs under Section 307.11 (formerly Title VI-C) are filled by people who have neither training nor direct teaching experience with the population. Yet these are the same folks who are expected to be our resource people, to train the local schools to offer appropriate instructional content to the child who is deaf-blind. Even our national technical assistance projects and programs, such as TRACES, the Helen Keller's Technical Assistance Center, and the American Foundation for the Blind, have increasingly had difficulty recruiting trained personnel when vacancies occur or new projects are begun.

The current era is also one in which funding is less than adequate and definitely harder to access. The federal Section 307.11 program currently allocates \$12.8 million for services nationally. This obviously buys far less service at today's costs than could be purchased for \$16 million in the early 1970s. Due to inadequate appropriations and the ideals of the "new federalism" in which it is affirmed that states should be responsible for most of the

cost of direct services, the Section 307.11 program has evolved into almost exclusively a technical assistance program. The same factors have resulted in fewer federally supported personnel preparation programs. I want to say something loud and clear regarding this recent concept of federal responsibility: When it comes to services to low-incidence populations like people who are deaf-blind, *the new federalism doesn't work!* If we think that states are going to recognize the particular needs of such a small population, and develop appropriate services to meet their expensive needs without federal support, we are kidding ourselves. It has not happened in the past and will not happen in the future. Our population will become lost in the larger masses being served; this phenomenon is already becoming evident.

It has recently become obvious to me that we are having some continuing difficulties in agreeing how to identify the population across the nation. The incidence of deaf-blindness ranges from under 1:1,000 to 3.7:1,000 (deaf-blind:special education children) depending upon which state is doing the counting. This is an especially crucial problem to resolve in that the distribution of funding is directly tied to the child count. Therefore, states which have historically done a poor job of finding their children get less funding, while states who add children to the registry without scrutiny or conscience get more funding. This unfortunate occurrence causes states

to compete jealously against one another and encourages states to inflate their identified populations far past the point of being able to serve them. While many states have greatly underestimated their population on children who are deaf-blind, in the national child count (Baldwin, 1992), others are greatly overstating their population. This seems without purpose unless there can be some considerable financial or programmatic assistance ensuing.

A good summary of our present shortcomings is found in the words of Dr. Robert M. Davila. In addressing the meeting of project directors in October of 1990, he said, "This philosophy, which has at its heart the full participation of individuals with disabilities in every aspect of community life, has, in some ways, outstripped our present ability to make the philosophy a reality for all whom it embraces Although we in OSERS embrace the concept of full inclusion, we also believe that our philosophy outstrips our present capacity to achieve it fully" (p. 2). He goes on to cite the national longitudinal study on transition conducted by Stanford University, which shows about 33% of mainstreamed students failing one or more classes and 10.5% failing six or more classes (Davila, 1990).

Likewise, a recent Policy Guidance issued by OSERS cautions schools that the least restrictive environment (LRE) for a child who is deaf may not be the regular classroom. Because of the "inherently isolating" nature of deafness and the special problems

children who are deaf have in acquiring language skills, "effective methods of instruction that can be implemented in a variety of educational settings are still not available," OSERS says. The notice goes on to say that "this lack of knowledge and skills in our educational system contributes to the already substantial barriers to students who are deaf in receiving appropriate educational services Any setting, including a regular classroom, that prevents a child who is deaf from receiving an appropriate education that meets his or her needs, including communication needs, is not the LRE for that individual child" (Federal Register, 1992, p. 49274-76). If true for children who are deaf, do not these principles apply even more so to the child who has both a hearing and a vision loss?

A recent report, issued on October 23, 1992, by the National Association of State Boards of Education, calls for an inclusive system of education that applies state goals for achievement and outcomes to all students, including those with disabilities. It says that, time and again, the study group was forced to answer "No!" to the following questions:

- Are children currently classified as special education students achieving what they are capable of?
- Are they being prepared for life after school?

- Are current mainstreaming practices producing their intended outcomes? (National Association of State Boards of Education, 1992)

In short, the study is an indictment of both our past practices of segregated education and our present poor attempts at inclusion.

In reflection, I observe that we have bought into a philosophy of integration and service at the local level without any attempt to build an infrastructure and support system to make it work. In stating this, I am not arguing that the philosophy is erroneous or misplaced. Certainly participation in one's family and community are values which we all hold dear for children who are deaf-blind, as for all children. Nonetheless, we must recognize that, at the local level, thousands of children who are deaf-blind are underserved or inappropriately served, for want of any local expertise about the population. Certainly, some local schools employ staff with such knowledge, or staff who have the initiative to find out what they need to know to teach a child. But too often the child's needs are simply not recognized, let alone addressed in the Individualized Education Plan (IEP).

Minimum Educational Requirements

I suggest that children who are deaf-blind typically require certain

educational content within their IEP, if their education is to be appropriate. Obviously, children who are deaf-blind, like all severely disabled children, need functional curricula, age-appropriate activities, vocational training, social interaction with peers (disabled and nondisabled), and so on. However, an educational plan for a child who is deaf-blind must minimally incorporate some other things which must be addressed vis-a-vis the disabling conditions, including the following:

Language goals in the child's most useful modalities, written at the child's current language level.

Sensory development activities. These would typically include auditory training following an established developmental sequence, and, in the case of partially sighted children, low vision stimulation activities, which also follow a developmental sequence.

Teaching strategies which incorporate the child's most likely learning styles, as determined by appropriate assessment strategies.

It is essential to know with what kind of instructional ratio the child learns best; how the child copes with distracting environments; where materials are best placed for the child to attend to them; the size, shape, and color of materials which the child can see; how structured the environment and teaching day must be for the child to make sense of his world; ecologically, what things in the

child's environment promote versus impede learning; and so forth.

Mobility training. This will ensure the person's ability to explore and interact with the environment, to the maximum extent possible for that individual.

Expanding the student's cognitive skills. The curriculum should accommodate the fact that they cannot observe this world very well. To illustrate this point, such adaptations may include (but certainly are not limited to) more tactile explorations opportunities, more use of models and real objects to explain concepts, more reliance upon field trips and actual experiences as opposed to class discussion, more preparation of descriptive information to allow for the student being unable to see instructional materials, and more individual interpreting of the events occurring in the classroom and the environment at large. The young child who is deaf-blind needs specific instruction in the use of objects and their various functions, gradually expanding the child's use of objects through incremental instruction (à la Piaget). These concepts need to be specifically taught, because the child who is deaf-blind often cannot observe how others in the environment make use of objects (Enright, 1977).

Assessing the child's present capabilities for social interaction and creating situations which ensure the opportunity for such interactions to occur. Often the

child who is deaf-blind needs to be specifically taught social behavior, from the earliest acceptances of others into his life space to relating to others through language, playing of games with others, and taking turns. Again, if the child who is deaf-blind does not witness the social interactions of others, he has no model for this kind of behavior to occur spontaneously and therefore often needs specific teaching to acquire such skills. Obviously, for students with a developed language system, it is important for social interactions to be in the child's primary language mode if they are to be "quality" interactions from which the student who is deaf-blind might benefit, and if progress in social development is to be achieved.

Regardless of functioning level, any student who can benefit significantly from currently available educational technology must have access to it and must have appropriate instruction in its use. This is true whether we are talking about a head-switch for a child with severe cerebral palsy or print-to-braille computer software for the mainstreamed student.

Additional Requirements

In addition to the above factors, for students who have the academic capability, there are some other curriculum considerations if an educational program is to be judged appropriate. First, students must have the opportunity to learn to read and write. That is to say, students with the ability to learn it have a

right to be literate, and we have the obligation to teach them. Whether this capability can be achieved through print or whether the child can only learn to read through braille, if they can be literate, they must be. Likewise, if the student is able to follow a reasonably "normal" sequence of courses and earn a high school diploma, he or she must be afforded this opportunity. To "track" students who have the ability to earn a diploma into a "special certificate" track, only because we don't know how to adapt the curriculum for them, is doing them an injustice.

All of the above also presumes an ability on the part of the school district to conduct a reasonably accurate assessment of the child's needs at present and to arrive at some likely educational expectations.

I submit that, all too often, the above specific content needed by the child who is deaf-blind, is altogether lacking. This is frequently true both in full inclusion programs as well as in some of the segregated classes for severely disabled children, in which children who are deaf-blind happen to be served. Sometimes a specialist in one of the senses (teacher of the hearing impaired or visually impaired) or a resource person in moderate or severe special needs will consult to the classroom on a regular basis. However, far too often, this is not a person with real expertise at assessing the child's needs and offering a curriculum which incorporates the above factors. The result is that the child receives a program which is only partially

appropriate. Some of the above needs get addressed in the IEP and others are overlooked, based on the expertise of the people at hand.

Sometimes, not only does the district lack this expertise, but there is also nobody to call upon from the county, the intermediate school system, or the state. Therefore, the consultative input which is provided is also addressing only a part of the child's needs. A comparable lack of expertise on the part of the resource people in the state will produce the same gaps in the appropriateness of the student's plan.

This situation is not acceptable. We cannot continue pretending that a system with such large gaps is a functional system. We will never improve the quality of what children who are deaf-blind receive at the local level unless we all acknowledge that significant improvements are needed. This acknowledgement must be made at every level, from the U.S. Department of Education down to the newly hired teacher aide who has been assigned to a child who is deaf-blind for the first time.

A Brighter Future

Action Steps for OSERS

Many of the problems which we are experiencing in education of children who are deaf-blind today have evolved due to a rapid shift into a decentralization of services without a reasonable infrastructure in place to assist the local school systems in

developing good programs for children. This does not mean that the problems are unresolvable or overwhelming; we simply need to apply some good thinking to develop some likely solutions. What I hope to share is a *vision* of where we might be headed, and some actions which OSERS might consider taking to improve services. Let us first turn our attention to some of the general directions which OSERS might consider to help services nationally, and then look at some specific actions which we as professionals in the field must take to improve matters.

1. We need first to **reestablish a National Network in Deaf-Blindness**, similar to what existed in the 1970s. OSERS has recently awarded a grant for the operation of a national clearinghouse on children who are deaf-blind. We desperately need the national organizations, such as TRACES, the Technical Assistance Center of the Helen Keller National Center, the American Foundation for the Blind, the Hilton/Perkins National Program, and each state's rehabilitation and Section 307.11 projects, to pull together toward common ends to develop the clearinghouse, which helps the field build this national network. A strong national newsletter and resource referral system can become a pivotal point in our relationships across state boundaries. The national clearinghouse must become a vehicle by which professionals, parents, and consumers can be linked together, informed of each other's efforts, updated about literature in the field,

and galvanized to act in mutual support. The clearinghouse will need more Section 307.11 funding to become the national resource which the field needs.

2. We need more frequent **meetings and training activities which cross over state lines**, to ensure a fertile exchange of information in our field, and to avoid costly duplication of efforts. We need continued national conferences, meetings, and symposia, like this event, which bring us together as a community of individuals with common interests. OSERS might sponsor more events like this meeting and reward proposals from states which propose joint activities with neighboring states in order to encourage a more fertile field. No collection of people can consider themselves a professional community unless they are continually visible to each other as a community.

3. We also need more projects funded to develop high quality training videotapes and learning modules. Those who provide training to staff desperately need **a variety of high quality training materials** to enhance the training. I hope the future will see several such training modules developed by a variety of organizations and used in a myriad of ways, but especially to augment "in-person" training. I would especially suggest more requests for proposals for development of training materials which are a little more modest in scope and content than what has been required under the present grant to the American

Foundation for the Blind. As a result, more such products may be developed.

4. To have an adequate supply of specialists, we need at least 8 to 10 **strategically located programs of personnel preparation** within our universities, which are training people to assume positions in both education and rehabilitation. These programs need to be funded for a longer term than a three-year federal grant, and they should be expected to develop into true "Centers of Excellence." I envision such universities not only preparing more personnel, but also conducting inservice training and summer programs, carrying out research, developing training materials, and providing direct technical assistance through evaluating children who are deaf-blind and advocating that their services be improved. Such centers could be firmly rooted in reality via strong, collaborative ties to direct service programs or Section 307.11 programs in their respective regions of the nation. I also envision them strongly linked to one another, to create a national standard of adequate personnel preparation. The training of teachers of children who are deaf-blind has not been a high priority of the federal government for several years. The persons responsible for the Section 307.11 program must convince higher authorities within OSERS to require the Personnel Preparation Division to train more specialists.

5. I suggest that we need some honest, objective **research on what**

methods and services work for people who are deaf-blind. We need no more esoteric or nongeneralizable studies on how to teach four words to a child who is deaf-blind via behavior modification, the benefits of sitting in the same lunchroom as nondisabled peers, or how many people who are deaf-blind one can fit on the head of a pin. The questions we need to answer are easy to identify: What instruction is most essential to ensure growth and development? What services to the child make integrated programs work? What makes them fail? Under what conditions is an integrated setting more limiting than enabling? Under what conditions is a segregated setting necessary or inappropriate? What are the best training systems to ensure that the large numbers of general and special educators know what they are doing with these children? In other words, let's conduct some research which answers the real questions without bias and without the fear that our philosophies and beliefs might be shaken by the answers. In order for the Section 307.11 funds to go further in their impact, I suggest that perhaps a committee of OSEP staff and Section 307.11 personnel could suggest to the National Institute on Disability Research and Rehabilitation (NIDRR) some specific research needs, the topics of which are "field-initiated."

6. To improve services at the local level, we must develop within each state **a new network of consultant/itinerant/resource people**. At the intrastate level we

need such people within each region, employed by the state or by intermediate educational units or collaborative districts. These positions must be filled by specialists, with specific training related to children who are deaf-blind. Their responsibilities should include assistance in program development for individuals and ongoing consultation to all districts within their region. For years, such specialists have been employed in the areas of vision impairment or hearing impairment. Yet, in spite of lack of local expertise, such positions have rarely existed. In short, we need development of a number of jobs and a cadre of personnel who have not existed to this point. I would suggest that this is the only means by which we can pull ourselves out of the continuing downward spiral of having to provide basic training to an ever-changing body of people. A strategy for developing such a group of specialists and creating jobs for them should be a required part of every state's Section 307.11 plan. Some models of what such a plan might look like could be suggested by OSERS to help states understand the concept.

7. If the above cadre of specialists were created, we might benefit from utilizing **more paraprofessionals**, under a model similar to Canada's intervener program. An intervener for each student at the local level could work under the direction of the specialists who periodically consult to the classroom staff. Interveners could have ongoing training from the specialists, very specific to the

individual child's needs. This would increase the likelihood of success in inclusion programs, and allow us to stretch our masters-level specialists further.

8. An inter-agency team of professionals should be funded to **develop a "quality indicators" assessment** which states, school districts and parents can use to determine whether the *content* that is being taught meets a standard of good practice for the teaching of children who are deaf-blind.

To accomplish the systems change that is needed, we obviously need a greatly improved federal program—one which exceeds by far our present capabilities. We need funding beyond our present levels, which means that we must do a lot of work *together* to influence our appropriations committees.

9. Many of the changes I am suggesting require a fresh look at the national program's purposes and activities. In addition, we must find a way for OSERS to receive input on needs from all of you who work at the grass roots level, including teachers, counselors, parents, and consumers. The perspectives on the needs of the population must be shaped by those who work directly with people, and not only those employed in universities or "grant factories." It is beyond my understanding why a national program to benefit a specific population does not have **an advisory committee made up of consumers and professionals in the field**.

Action Steps for Ourselves

In addition to altering the practical means by which services are delivered and personnel are trained, we must also amend our philosophical orientations. There are several issues of a philosophical nature which I believe we must confront within ourselves if the future is to be an improvement upon the present.

1. First, I remind you that current educational philosophy within our field is moving away from specialized services toward more generic services. We must stand firm in our refusal to accept generic vanilla for a population whose needs call for Howard Johnson's 28 flavors. An endorsement of generic services is an endorsement of the current inadequacies in our system, and silence is always an endorsement.

2. We in special education have a "bandwagon" mentality to our prevailing philosophies. Just consider the buzzwords of the past couple of decades: task analysis, behavior modification, patterning, sensory integration therapy, coactive movement, vestibular stimulation, least restrictive environment, age-appropriate, ecological, mainstreamed, non-aversive treatment, integration, assisted (facilitated) communication, and full inclusion. Our tendency is to jump on the bandwagon of the latest buzzwords, and act as though everything we knew previously is obsolete and irrelevant. A scientific body of knowledge does not

accumulate in this manner, and neither does a sound educational philosophy.

3. We must draw upon the strength of our convictions, to advocate for what is right for children and adults who are deaf-blind. In the past, when prevailing educational philosophies or administrative priorities were resulting in harmful results for our populations, we have been less than outspoken about these effects. We must not hesitate to point out inadequacies in services when we see them. We must help when we know what is needed and admit it when we do not know. We must insist upon the level of specialization which this population requires, because nobody else will. We must serve as advocates for the population and be willing to go to hearing or to court to defend what people who are deaf-blind need.

4. We must start to focus more upon the quality of the instructional and programmatic content which people who are deaf-blind are receiving, and we must focus less upon the place in which the person is served. The quality of services is determined by many indicators, of which the number of nondisabled peers in the environment is only one. Permit me to deviate for a moment to quote F. Scott Fitzgerald: "The mark of a truly first-rate intelligence is the ability to hold two opposed ideas in mind at the same time and still maintain the ability to function." We must begin to integrate our ideas about the benefits of integration and the benefits of knowledgeable expertise.

We have acted as though these two ideas are diametrically opposed when, in fact, specialization should be able to happen quite nicely in all settings. We have argued excessively about *where* children should be served; we have not focused enough upon *what* they should be receiving.

These times of change in service delivery have been turbulent times. We are all a bit insecure about our values and priorities for services to the people who are deaf-blind. To borrow the words of Dr. Davila again, "I foresee a time when we will look back to the 1990's, to our frustrations, our growth, our change, our successes and failures, and we will see them as steps in a long, often painful, but ultimately worthwhile process" (Davila, 1990, p. 2). I hope that we will also look back on these days of change and be proud that we insisted upon a consistently high standard of education for children who are deaf-blind throughout and in spite of our own changes and evolutions.

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EDUCATIONAL SERVICES: REACTION

John M. McInnes

Abstract: In the province of Ontario, Canada, a program to provide services to children who are congenitally and early adventitiously deaf-blind had the following goals: to educate and advise parents and siblings how best to deal with the child; to support the classroom teacher so he or she could provide day-to-day support; to work with therapists and other professionals to educate them; and to provide information to members of the medical profession. Specially trained consultants worked with both parents and teachers to develop a program designed to meet the needs of each child, to be delivered in the home, the community, and the school. A fundamental and very successful aspect of the overall program was the use of trained local individuals (interveners) who provided the support necessary to allow the child to function successfully in the least restrictive environment.

I wish to thank the planning committee for this opportunity to share with you some thoughts concerning the points that Mr. Collins has raised in his paper. My initial response after reading his paper, three weeks ago, was that Mr. Collins had done an outstanding job of reviewing the history of services for those who are deafblind. His observation of the present state of affairs of services for those who are deafblind completely parallel those which I have had the opportunity to form during visits to various parts of the United States, and his "blueprint" for future directions leaves little to be desired. In short, my first response to the paper was, "Well done!" I can only echo and reinforce the points he has made.

It is now generally accepted worldwide that deafblindness is a unique disability. In addition, it is gradually being recognized that the label of "deafblindness" covers two different disabling conditions. These

are not blindness and deafness but rather congenital and early adventitious deafblindness, and later adventitious deafblindness.

Moreover, those of us who have had the opportunity to work over the last 25 years with those who are congenitally and early adventitiously deafblind and watch them grow, develop, and exceed our expectations at every step, have reached another milestone in understanding. Those who are congenitally and early adventitiously deafblind do not become later adventitiously deafblind when they leave school. Programs and support services designed to meet the needs of the adult who is later adventitiously deafblind will not meet the needs of those who are congenitally and early adventitiously deafblind when they become adults.

Partly because of a problem caused by compartmentalization into preschool, school-age, and postschool services, and partly

because we in services for those who are deafblind adopted our definition of success from programs designed to support other disabling conditions, we have tended to equate success with independence. We have also adopted a definition of independence to mean "to function without the help of another person." Put another way, we have defined the successful program as one from which the person who is deafblind will graduate, being able to function as though he or she were a nondisabled person or a person who is later adventitiously deafblind.

Defining the Disability

In the most recent world conference held at Orebro, Sweden in July 1990, one of the most elegant and significant ways of encapsulating the whole question of deafblindness was made in a motion, which was unanimously passed by representatives of nearly 50 countries, which changed the spelling of "deaf-blind" to one word: "deafblind." If you think about this you will quickly see that it says in one stroke everything that needs to be said about deafblindness as a unique disability.

Strangely enough, after 25 years, the question I am most asked when working as a consultant in various areas both in United States and in Canada, is, "Who should be treated as deafblind?" We have definitions,

but definitions do not answer the questions of the administrators who are responsible for paying for these services. Meshcheryakov in the excellent book, *Awakening To Life*, addresses the problem. He points out, "Deaf-blindness is [usually] defined as the loss of sight and hearing from birth or early infancy and dumbness resulting from lack of hearing." He states, "The definition is inadequate. The definition of deaf-blindness from the pedagogical point of view should supply an answer to the question. Who needs to be taught as deaf-blind?" (p. 70)

Many administrators in the United States and Canada want a simple measurement by which they can be assured that the costly programs that are being proposed are being proposed for the right population and that this population cannot be served by existing programs designed to serve other disabilities. They are often reluctant to identify infants and children as deafblind either because they do not wish formally to identify another category or because of the cost involved in the specialized services required by this unique population. They often try to rationalize this decision by pointing out that the individual[s] has some usable vision and/or hearing.

In my experience as a consultant, I have refined my presentation concerning the identification as to whom should be served as deafblind to two questions when I am working with professionals and administrators whose expertise lies

primarily outside of the field of deafblindness.

- Does [the individual in question] have sufficient vision to permit him [her] to fully function as a hearing impaired person without any significant problem?
- Does [the individual in question] have sufficient hearing to permit him [her] to function as a visually impaired person without any significant problem?

If they cannot answer yes to both these questions without reservation, the individual should be considered deafblind.

Scandinavian Definition

The Nordic Council of Ministers, on the advice of the Nordic Committee on Disability representing Norway, Sweden, Denmark, Finland, The Faeroes Islands, The Aland Islands, Greenland, and Iceland, have adopted a definition of deafblindness that is forming a focal point for the study of those who are deafblind for various professional groups. The Nordic definition states that a person is deafblind when he or she has a severe degree of combined visual and auditory impairment. Some people who are deafblind are totally deaf and blind, while others have residual hearing and residual vision. The severity of the combined visual and auditory impairment means people who are deafblind cannot automatically use services for people with visual impairments or with hearing disabilities. Thus

deafblindness entails extreme difficulties with regard to education, training, working life, social life, cultural activities, and information. For those who are born deafblind or who become deafblind at an early age, the situation is complicated because they may have additional problems affecting their personality and behavior. Such complications further reduce their chances of exploiting any residual vision or hearing.

Deafblindness must therefore be regarded as a separate disability that requires special methods of communication and special methods for coping with the functions of everyday life. (The Nordic Committee of Disability is an institution for Nordic co-operation subordinated to the Nordic Council of Ministers, [i.e., the Governments of Denmark, Finland, Iceland, Norway and Sweden]. Postal address: The Nordic Committee on Disability, Box 303, S-161 26 Bromma, Sweden.)

A group of leading Scandinavian ophthalmologists and audiologists held a working conference to study the Nordic definition and, as a result of their deliberations, issued the following statement as a guide to other members of the medical profession throughout Scandinavia.

1. Deafblindness is a separate disability. It is characterized by the following criteria:
 - Serious problems in relation to communication with the environment

- Serious problems in relation to orientation in the environment
 - Serious problems in relation to the acquisition of information
2. These problems result from the *combined* [italics added] sensory disability. Deafblindness may occur separately or in combination with other disabilities.
3. Upon suspicion of a person actually suffering from deafblindness, or that it might develop in a person, the following diagnostic procedure should be carried out:
- Examination of the hearing and vision functions by specialists experienced in deafblindness.
 - In addition to the medical examination there is a need for an assessment related to the three functional criteria mentioned (in 1) above. This assessment should be made by staff with special training [in the area of deafblindness] having medical, social and pedagogic background and adequate extensive education.
4. When diagnosing one will find persons that fulfill the three functional criteria of deafblindness, but when using the *current* [italics added] medical methods one cannot register impairments of sight and/or hearing. These persons are also to be considered as being deafblind.

5. As deafblindness is a separate disability, all persons who are deaf-blind, regardless of where they live, regardless of age and eventual [possible] institutionalization, should have access to special habilitation and rehabilitation (special aids, special teaching, special housing conditions etc.). (Statement issued at the conclusion of the Working Conference for Medical Specialists, Dronninglund, August, 86.)

The statement represents the first time a group of internationally distinguished medical professionals have addressed the problem of deafblindness. As such, it represents an important milestone in the development of services for all those who are deafblind.

Deafblindness: A Low-Incidence Disability

Deafblindness is a low-incidence disability. This obvious statement has several implications. This fact has proved to be one of the most potent arguments to help individuals and groups to establish services in both the United States and Canada, because one can reassure administrators that they are not opening the door to a flood of requests for services. In fact, careful presentation of this information has been the most singly important element in assisting in the establishment of services.

Mr. Collins has already identified many of the problems that result from deafblindness being a low-incidence disability in the areas of staff training, program development, the dispersion of clients, particularly of infants and children who are congenitally and early adventitiously deafblind, and often the chronic lack of funding because of the low number of individuals available for advocacy.

Dr. Thomas Clark, of the University of Utah has pointed out another result from this low incidence that is often overlooked or whose importance is not recognized. There is no pool of community knowledge available to those parents or professionals who are involved with those who are congenitally and early adventitiously deafblind.

Programs of Support

Regional and State Networks

The importance of this problem was recognized by the early pioneers in the development of services for infants and children who are congenitally and early adventitiously deafblind in the United States. They developed the network of regional and state centers that was described by Mr. Collins. This network represented perhaps the most carefully thought out solution to this problem of a lack of a pool of basic community knowledge that has been developed to date here or elsewhere. It should not be assumed that there

has been any change in the last 25 years.

This network had the structure necessary to meet the needs of the 70s and the flexibility to successfully enter the 21st century. It represents a solution that is being developed in other countries to provide a variety of support services for infants, children, and adults who are congenitally and early adventitiously deafblind in their home and in the local school system while, at the same time, providing specialized programs and services in central locations where such services are the choice of the parents or the adult who is deafblind.

The comprehensive service program developed by Sense in the United Kingdom under the leadership of Rodney Clarke is gaining worldwide recognition for its broad spectrum of services to those who are deafblind. Its structure is evolving into a parallel of what existed previously in the United States. Based upon my experience, I would predict that any jurisdiction that faces the problems outlined by Mr. Collins will eventually arrive at a delivery structure that will closely parallel this system.

The Ontario Approach

By the late 70s, a well-developed program for infants and children who are congenitally and early adventitiously deafblind existed in the province of Ontario, Canada. Because every child in Ontario is entitled to enter school and because parents of children who are

congenitally and early adventitiously deafblind are free to choose to use either a centralized program such as the deafblind unit at the W. Ross Macdonald School or to have their child who is deafblind attend a local school, it was decided to develop a support system to provide services from the age of identification onward. I was fortunate enough to be given the position to head up a team to make this a reality.

After analyzing the situation, we began our system development using basic assumptions derived from the status quo:

1. Community programs for infants and preschool children would not be likely to have professionals trained to work with infants and children who are deafblind. If these professionals were appropriately supported, they could use their expertise to foster intellectual growth and physical development in infants and children who are deafblind.

2. When the child reached school age, if the parents chose to have the child attend their local school, the classroom teacher would not be a trained teacher of those who are deafblind nor would she or he have access to such a trained teacher on a daily basis.

3. Special classes designed to serve children with other disabilities, while having a low teacher-pupil ratio, would probably not be the best placement for a child who is deafblind.

4. Only one school board in the province had a sufficient number of pupils who are deafblind to warrant development of its own group of professionals and support system.

5. Neither specialist teachers from deafness, blindness, and other disabling conditions, nor generically trained special education teachers were equipped to program for pupils who are deafblind in the regular classroom.

6. Parents and families required as much support as classroom teachers within the educational system if the child was to be successfully integrated into the local community and the school system.

7. An individual program and an accompanying delivery system must detail five-year goals, 12-month objectives and specific success indicators to be observed at each step.

8. Each program should receive the support of a trained professional at least once every two weeks and should have a specific professional to contact should problems arise between visits.

9. The infant or child who is deafblind can be successfully integrated into the local school system and the community if a multilevel support system is built on these assumptions.

10. As more and more children who are deafblind are successfully attending their local school, more and more parents will opt for this

approach for some or all of their child's education.

11. Most important, all children would require the support of trained interveners in the home, classroom, and community setting regardless of the choice of educational setting made by their parents.

The final model we developed integrated a variety of approaches. The model was sufficiently flexible to permit the development, implementation, and evaluation of individual programs for each infant and child who is deafblind in the province as soon as they were identified. The model was based upon a sound philosophical base and implemented by staff with differing levels of training.

It was evident from the first that we could not turn every person who would come into contact with the infant, child, or adult who is congenitally and early adventitiously deafblind into a professional with sufficient background and expertise to deal with all persons who are deafblind. Our mandate was to educate and advise parents and siblings how best to deal with their child; to support the classroom teacher so that she or he could provide day-to-day guidance and support for the individual pupil who is deafblind and the intervener; to work with therapists and other professionals to educate them as to how to apply their expertise to the individual; and to provide information to members of the medical profession that would enable

them to deal more successfully with the patient.

Our mandate also required us to develop a specially trained group of professionals to deliver this service throughout a province that is approximately one sixth the size of the continental United States. We started with teachers, social workers, and care givers who had a minimum of three years hands-on experience. They then received additional training in such areas as program development, implementation and evaluation; school board structure and etiquette, family dynamics, individual training techniques and suggestions for dealing with other professionals. We also encouraged these professionals to maintain a close liaison with the pool of expertise that existed in the deafblind program at the W. Ross Macdonald School.

These professional consultants worked with both the parents and the teachers to develop a program designed to meet the needs of each child, to be delivered in the home, the community, and the school setting. (Any program designed for implementation in an educational setting *only* is sure to fail in the long run.) During their bi-weekly visit, the consultants were also available to accompany the parents and child on visits to medical facilities and to assist the parents in developing a support network to which they could turn for assistance and advice.

To support this system in between the consultant's visits, we developed

a group of locally trained people for each child. These local individuals provided the support necessary to permit the infant or child who is deafblind to function successfully in the least restrictive environment. Because the Ministry of Social Services, community agencies, school boards, and others wanted a job title for these individuals we called them interveners.

Intervention

Intervention has been called a Canadian approach to providing support for persons who are deafblind. In truth, there have been interveners and intervention as far back as one can find written records of successful individuals who are deafblind. What we did was analyze the techniques and methods of working with persons who are deafblind that had been successful with individuals who are deafblind of various ages. We then gave these techniques and methods a name: "intervention."

The idea of codifying the methods and techniques arose out of the international conference held in North Rocks, Australia, in 1976. Dr. Mike Myers presented a paper "Where Are They Now?" in which he showed that over 90% of the graduates from educational programs were institutionalized within five years.

Our first reaction to the paper was that we should change our focus and begin teaching our young people who are deafblind to survive in an

institutional session. However, I also met Dr. Richard Kenney, Superintendent of the Hadley School, at the conference. Dr. Kenney was deafblind.

As I communicated with him using a combination of finger spelling and a teletouch, a young lady was finger spelling into his other hand from time to time. When I asked about this, I was informed that he was receiving the same information from his "young lady" that I was observing and hearing using my eyes and ears.

When I returned to Canada, I began researching the lives of other successful individuals who are deafblind. It quickly became evident that whenever there was a successful person who was deafblind there was one or more nondisabled persons who provided information and support. The question immediately arose, "If the most brilliant and successful persons who are deafblind needed this type of support, how could we expect our infants and children to succeed with less?"

After extensive analysis, long discussions with both individuals and professionals who are deafblind in the field, and numerous attempts, we distilled the role of the intervener to three main actions. The intervener provides the following:

- Sufficient nondistorted information to enable the individual who is deafblind to make age-appropriate decisions

- The motivation to act upon those decisions
- The support necessary for the individual who is deafblind to carry out the actions arising from his or her decisions successfully in a reasonable amount of time

The methods and techniques used to carry out these responsibilities differ according to the age, the needs, and the level of functioning of the infant, child, or adult who is deafblind. Mother will in all probability be the child's first intervener. She will need formal education, training, and support in a far greater degree than that required by parents of children with other disabilities because these parents have alternative sources of information from the community pool of expertise. As the infant grows and develops, other members of the family, and later the extended family, will require the same type of support if they are to provide effective intervention. Because the intention is to supplement and not to replace community resources, preschool workers, physio- and occupational therapists, and other community professionals must receive training and support so that they also can provide intervention and use their expertise effectively. And when the family is ready, individuals will be hired by the family and then trained to provide intervention and deliver the program for this particular child who is deafblind. As new individuals are hired, they also will require training and support to provide intervention and implement the program that has been designed for

the person who is deafblind. Eventually, the individuals who are deafblind will be able to carry out much of this training themselves. At present we have many adults who are congenitally and early adventitiously deafblind who are involved in interviewing, selecting and training their interveners.

In the early 80s, A National Task Force on the Needs of the Deafblind traveled across Canada and received presentations from parents, and professionals, and from youth and adults who are deafblind. The report that the task force produced was called "Intervention is the Key." The main thrust of the document and of the presentations of persons who are later adventitiously deafblind, as well as those who spoke for persons who are congenitally and early adventitiously deafblind, stressed the need for intervention or support which the individual who is deafblind or their advocate could direct, control, and utilize according to his or her own needs.

Conclusion

In conclusion, I can only restate that Mr. Collins has identified the problems, proposed a philosophical approach that is in tune both with society and reality, and laid down a framework that can and should serve as a starting point to develop a nationwide support structure for training, programming, research, and information exchange. The challenge is to turn this paper into reality.

If I can leave you with three thoughts, I would wish them to be the following.

1. Deafblindness is a unique disability that cannot be served by programs designed to meet the needs of other disabling conditions.

2. Infants and children who are congenitally and early adventitiously deafblind will not become adults who are adventitiously deafblind. In other words, programs that meet the needs of adults who are adventitiously deafblind will not meet their needs.

3. The approach taken to develop services for persons who are deafblind must not be fragmented among a number of levels or types of service providers.

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