Improving Outcomes and the Quality of Life for Children, Youth, and Adults who are Deaf-Blind

Judith E. Heumann
Assistant Secretary
Office of Special Education and Rehabilitative Services
U.S. Department of Education

For individuals who are both deaf and blind, having both a visual and auditory impairment represents a unique series of challenges. But we know that with the support of families and friends, the right programs, the right skill development and training, anyone, regardless of the significance of their disability, can achieve their chosen level of independence and dignity. I see my work, and that of my staff in the Department of Education’s Office of Special Education and Rehabilitative Services (OSERS), as helping to create an environment and a society which will foster this independence in new and positive ways.

We in OSERS administer a number of programs designed to increase positive outcomes for individuals who are deaf and blind. I would like to briefly describe these programs, remembering though that programs in and of themselves are not enough. We need the involvement, commitment, and dedication of family members, service providers, and of course, disabled people themselves for these programs to achieve the success for which they were established.

The specific nature of the challenges for meeting the needs of members of this population is reflected in the fact that deaf-blindness is one of the few disability categories with a separate authority under the Individuals with Disabilities Education Act (IDEA) (Part C, Section 622, Services for Children with Deaf-Blindness Program) and an individual budget of more than $12.8 million for Fiscal Year 1994. Historically, it is one of the senior discretionary grant programs administered by Office of Special Education Programs (OSEP). It was first established in 1968 as the Centers and Services for Deaf-Blind Children Program in response to the magnitude of the 1964 and 1965 Rubella epidemic and the resulting number of children who were born deaf-blind (U.S. Department of Health, Education, and Welfare, 1969). This program served as the primary resource for direct services and personnel training for that period. However, with the full implementation of IDEA (formerly the Education for All Handicapped Children Act), which mandated special education and related services
to all children who had a disability, children who were deaf-blind began to receive services under this law. As a result, the focus of the Services for Children with Deaf-Blindness Program was amended to maintain direct services for children who are not served under a state-service mandate, provide technical assistance to improve services, and fund projects of research, innovation, development, and demonstration to improve knowledge and practice.

Significant changes have occurred within the field of deaf-blindness in the last few years. In many ways, the task of addressing the special needs of children who are deaf-blind has grown more difficult. Not only has there been a steady increase in the number of children identified as deaf-blind (9,783 in the latest data count, as of December 1993) (U.S. Department of Education, 1994), but more children have other disabling conditions in addition to impaired hearing and vision. Further, we also face a much different situation than was experienced just a few years ago when more children were in separate schools. According to the December 1993 data count, approximately 78% of children who are deaf-blind are living with parents or extended family. Following this trend, more children who are deaf-blind are attending local schools. At the same time, the supply of qualified teachers needed to provide communication/language skills, orientation and mobility, and the other identified elements of a quality education program for children who are deaf-blind is critically limited.

To make matters more complicated, there is a dramatic disparity in the geographic distribution of where these children attend school and the availability of qualified personnel in the field of deaf-blindness. With such special learning needs, coupled with the critical shortage of trained personnel, the need for expert technical assistance has never been greater.

To assist in addressing these issues, the Services for Children with Deaf-Blindness Program, located in the OSEP, funds projects that build the capacity of states and localities to provide the uniquely individualized supports required for each child who is deaf-blind. The program design incorporates a substantial commitment to technical assistance, with each state and territory served by a state or multistate project. Additionally, a small number of national technical assistance projects contribute expertise in specific content areas. For example, the Teaching Research Division operates the Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments (TRACES), a project funded under OSERS’ Services to Children with Deaf-Blindness Program. TRACES provides technical assistance to state and multistate projects on a wide range of subjects related to services, for children ages birth through age 21. The project is located in Monmouth, Oregon. The Teaching Research Division also operates the National Information Clearinghouse On Children Who Are Deaf-Blind (DB-LINK). Located in New York, DB-LINK responds to individual requests and clearinghouse/informational services. The American Foundation for the Blind, located in New York, is finalizing the publication of much-needed training materials.

The OSEP-funded Technical Assistance Center at the Helen Keller National Center for Deaf-Blind Youth and Adults (HKNC) addresses transition services related to youth and young adults who are deaf-blind. HKNC also receives funds under the Rehabilitation Services Administration (RSA). HKNC provides comprehensive and specialized services to persons who are deaf-blind, their families, and service providers, on a national basis, through three inter-related service delivery components: its model national rehabilitation training center, ten regional offices, and an affiliate network of public and private agencies which are located across America. The objectives of
HKNC are also accomplished by providing training and technical assistance to other agencies interested in providing services for individuals who are deaf-blind.

The mission of HKNC is to facilitate a national coordinated effort to meet the social, rehabilitation, and independent living needs of America’s deaf-blind population through the demonstration of appropriate rehabilitation training techniques, methods, and technologies.

HKNC was established in 1969 at Sands Point, New York; its legislative purpose is three-fold: (a) to provide specialized services, at HKNC or anywhere else in the U.S., which are necessary to encourage the maximum personal development of individuals who are deaf-blind; (b) to train families, professionals and allied personnel at HKNC or anywhere else in the U.S. to provide services to individuals who are deaf-blind; and (c) to conduct research and development programs and demonstrations on communication techniques, teaching methods, aids and devices, and the delivery of services.

As the Assistant Secretary for OSERS, I am optimistic about the future of our programs to assist individuals who are deaf-blind. It must be emphasized that these programs remain as relevant for today’s challenges as the Centers and Services Program was in mobilizing a national response to the Rubella epidemic so many years ago. Through our efforts, these programs are capable of creating significant amounts of advocacy and resources for this population. Increased utilization of technical assistance will help fill gaps in expertise, but we must ensure that new strategies will need to be developed to deal directly with the scarcity of qualified personnel.

Projects under our programs are demonstrating increased efficiency in program management while stressing successful outcomes for individuals who are deaf-blind. Individuals and families from more diverse backgrounds are increasingly empowered and involved with these projects. It is well recognized that no single agency or organization can do everything. Cooperation with others is now an essential part of each project to ensure that resources from the federal, state, local and private levels are coordinated and focused on securing specific outcomes.

As we look toward the future, we must recognize the critical role that families play in the success of our endeavors to assist disabled people in achieving their desired level of independence. Indeed, we are coming to see that a nurturing family life is the single most significant determinant of the child’s ultimate success in making a positive contribution to society. The ways in which families view their children will determine to a great extent how these children will come to view themselves.

For children with disabilities, learning to value themselves is even more critical to their ultimate success. Youngsters with disabilities must learn to really like themselves, because they will spend a lot of time fending off the negative attitudes held about them by others, including well meaning professionals like the ones who educated me. My parents were never ashamed of me, so I was never ashamed of myself. They instilled in me a healthy self-respect, which has helped me through a lot of rough times.

As a final thought, it is useful to remind ourselves that we are part of a larger community striving on behalf of all children, youth, and adults who have a disability or multiple disabilities, and their families. The talents and skills we share are vital to keep this endeavor growing and enriched. I encourage all who read this then to develop new and innovative partnerships, networks, and collaborative efforts. Parents and professionals must work together more to help bring about increased positive outcomes for all disabled children and youth.

REFERENCES


Future Focus Forums

The following articles are the summaries of presentations made by the three authors at a session entitled “Future Focus Forum: The 307.11 Program in the New Millennium.” This session was held at the 1994 U.S. Department of Education, Office of Special Education Programs Annual Project Directors’ Meeting for the Severe Disabilities Branch in November, 1994. The speakers were invited to share their assessments of the program today, their vision of the best possible future, and their realistic assessment of where the program is headed.—ED.

Presentation 1

The 307.11 Program in the New Millennium
Bud Fredericks
Research Professor, Teaching Research

Our task is to do three things:

1. Assess the 307.11 program as it exists today (I include an assessment of deaf-blind education and services today, which I believe to be the result of the quality of the 307.11 program).
2. Provide a vision of an idealized program.
3. Provide a realistic assessment of where the program is headed.

Current Situation

Today’s program has a couple of excellent features as well as many problems. The excellent features include the quality of personnel who are involved. Many are highly skilled, and more are becoming skilled every day. The dedication of hundreds of professionals is noteworthy. Parent advocacy is growing and becoming more organized. An emerging body of literature regarding the education of children who are deaf-blind is far beyond anything that has been present before. Coupled with this literature is the development of some excellent training materials and the trainers to present those materials. Finally, but certainly not least, is the establishment of DB-LINK, a national clearinghouse that focuses on deaf-blind issues.

Now, let us consider the problems. Deaf-blind programs have been flat funded for many years despite the fact that the identified deaf-blind population has almost doubled in the last 10 years and that the cost of living has increased significantly. This lack of funding adversely affects the quality of deaf-blind education.

The quality of educational programs for children and youth who are deaf-blind is very uneven throughout the country. There are pockets of excellence, and there are places where the programs remain quite poor. Despite the proliferation of training materials and extensive technical assistance delivered both within states and through the cooperation of state and federally funded programs, many areas of the country still lack quality services, and many parents still are unaware of how to access such services for their children. The inability of many programs to provide adequate education in communication as well as training in orientation and mobility is a major deficit. The provision of an interpreter-tutor for each child who is deaf-blind is the exception and not the rule.

Although the national parent organization has formally organized and many local chapters of parents are in place, there are too many areas of the country where parents are not organized and therefore are not able to provide a unified advocacy voice. Until such organization and advocacy occur, both state and federal governments will be unresponsive to the needs of children and youth who are deaf-blind.

The deaf-blind population is categorized as low-incidence. Low-incidence populations are not high priorities in many states, and there are even indications at the federal level that the focus on low-incidence populations is waning. There is a danger that the federal government is moving towards decategorization and will once again distribute money on some sort of block grant basis. For low-incidence populations in most states, this will be disastrous. Moreover, there seems to be a movement to consolidate technical assistance efforts into something called noncategorical technical assistance. If so, there is a strong possibility that once again, low-incidence populations will be of low priority.

The lack of trained personnel is an important variable in the delivery of services to children and youth who are deaf-blind. Only a handful of colleges throughout the country prepare teachers of deaf-blind students. Moreover, within programs that prepare teachers of students with severe disabilities, one generally finds little emphasis on communication and mobility training that would be essential to the child who is deaf-blind. Also, at the inservice level, many states have not utilized the training monies available under the Comprehensive System of Personnel Development program (CSPD) to fill these training gaps.

The movement to inclusion has caused division, mistrust, and confusion in the educational arena at
a time when we need a sharper focus and a unified response to governmental initiatives. Some professionals have allowed their advocacy to overshadow their objectivity, and so parents become confused by the highly emotional positions taken by many of our leading professionals. The concept of an individualized program developed for the child’s needs gets lost in the arguments over placement.

Finally, services to adults who have left the educational system are woefully behind those for other populations such as those with mental retardation. Vocational and residential agencies that have the expertise to serve adults who are deaf-blind are rare exceptions.

**Idealized Situation**

To imagine the idealized situation is easy. All the above deficiencies would be fixed. Parent organizations would be established throughout the country and they would drive the national agenda in partnership with professionals. The federal and state governments would respond to the needs of children, youth, and adults who are deaf-blind and provide an array of excellent programs that would satisfy all persons’ needs. Each student would have an interpreter to meet his or her individual needs. Adequate preservice and inservice training programs would provide qualified staff in all situations. Finally, adequate funding would accomplish all of the above.

**Realistic Assessment of the Future**

Predicting the future is a haphazard affair. However, if we attempt to predict the future of the deaf-blind program and deaf-blind services without considering prevailing economic conditions and the attitudinal posture of the majority of our citizens, we may well miss the mark by a wide margin.

Although all the economic indicators reveal that we are in a time of economic recovery and prosperity, this recovery has been achieved by placing significant stress on the American worker. Many have been laid off so companies can streamline operations and show a greater profit margin. Many workers are experiencing the stresses of increased duties from performing tasks previously accomplished by those who were laid off. Increased hours and stress at work translate into increased stress at home. As a result, although our productivity level now leads the world, our workforce is discontented because of either unemployment or overwork.

That situation needs to be considered in conjunction with other trends and attitudes prevalent in our society. Many voters are verbally and actively displaying a distrust of the way in which the government functions. Coupled with this distrust is the ever-present cry against increased taxes and clamor to reduce taxes. If this popular attitude prevails over time, we can foresee little hope of increasing the funding for deaf-blind programs. Without increased funding, we cannot hope to increase the amount and quality of preservice or inservice training programs. The 307.11 programs will remain in their current woefully under-funded condition. Moreover, schools with tightening budgets are not likely to expand services to students who are deaf-blind.

Our national population continues to grow, and its characteristics are being significantly altered. The middle class, the traditional bulwark of advocacy for programs for people with disabilities, is diminishing. The percentage of the population that is below the poverty level is increasing despite the economic growth of the country. More people are being placed on part-time work without benefits. We still have 30% of the population without health care. We hear a constant verbal assault against the welfare system and, consequently, many of those in the poverty class feel threatened by the upper class and the politicians. These trends are problematic for people with disabilities; if many people in the country are hurting, being crowded, and are being threatened, they will not be sympathetic to those who are disabled. People with disabilities take money away from other programs. They cost too much.

Finally, there are other agendas that are more visible than our agenda. When we had a Rubella epidemic, we got the attention of Congress. Medical epidemics usually do, although they may be losing their clout if we observe carefully what has happened to the response to the AIDS epidemic.

Other factors worked for us in the 60s and 70s. That was an era of civil rights concern. We had national leaders who addressed the issue directly and forcefully. People with disabilities became en-
meshed in the civil rights movement and benefited from it. Public Law 94-142 and the Americans for Disabilities Act, both major pieces of legislation, grew out of the civil rights movement. But concern for civil rights may be on the wane. People are upset by the increase in crime that is perceived as prevalent in the city ghettos and thus becomes associated with race. Comparing the national population percentages of Blacks, Latinos, and Whites with the percentage of those incarcerated, we find a disproportionately higher percentage of incarcerated Blacks and Latinos. Therefore, it is perceived that Blacks and Latinos constitute the largest criminal class in the country. There is little thought as to the root causes of this phenomenon, and therefore there is little desire to solve the cancers that plague our cities and also less sympathy for racial civil rights. Add to that the little-publicized fact that 20–40% of those incarcerated in juvenile corrections facilities are categorized as in need of special education. We sit on a potential bombshell when people ask why this is so and why special education has failed.

People with diverse backgrounds are becoming less accepted in our country. More and more national and state figures are speaking out against those who are immigrants. We hear speeches and proposed legislation that will deny illegal immigrants education and health benefits or change immigration quotas so those who are bright will have priority.

All these trends do not bode well for people with disabilities. The one bright spot on our immediate horizon is the Americans for Disabilities Act—a major piece of civil rights legislation that has far-reaching potential for those with disabilities. We still have not realized its full power.

And so, in the short run, we must be vigilant; we must continue to advocate; we must continue to speak out against the tendencies of the current administration to decategorize, for once that happens, low-incidence populations will suffer. We must speak out against the federal government giving the sole responsibility to the states for the education of people with low-incidence populations. Historically, the states have failed to do this well.

In the long run, I do see hope. However, I do not see the easy fruition of that hope. I see the workers of America revolting against the greed of employers and stockholders. I therefore perceive us to be in a time of major transition. How long that transition period will last is unfathomable, but we must move toward a society that is less greedy, more humane, and less oriented toward punishment. I believe that we shall achieve such a society if those who are concerned about the poor, the disabled, and the downtrodden do not become discouraged. They must continue to work for change.

Specifically within the deaf-blind arena, the continued emergence and evolution of the national parent network and the development of strong local chapters of parents will probably be our salvation. PL 94-142, the predecessor to IDEA, was passed primarily through the efforts of parents in partnership with professionals. To preserve and enhance the deaf-blind program, we need to build and nurture the growth of parent organizations.

We must also view ourselves as a microcosm of the national scene. The deaf-blind community is a diverse culture. We must recognize and accept that diversity. We must support those who choose to educate their children in a manner or place different from the one we choose. Most of all, even though we may espouse different philosophies and different ways of educating, we must present a united voice to those in power. If we do not, we shall perish. If we do, we shall most likely flourish.

*The positions expressed in this article are those of the author and do not necessarily reflect the position of the Teaching Research Division or the U.S. Department of Education.*

**Assessment of Today’s 307.11 Program**

Michael T. Collins
Director, Hilton/Perkins Program

As we examine the National Deaf-Blind Program, it is evident that we have fewer financial resources upon which to draw than in the past. Our current funding level has been about the same for over 10 years, and is less than what it was 15 years ago. The federal office funds a smaller number of projects each year and is consistently understaffed. After the basic grants to states are doled out, there is very little left for any type of innovative project. The national technical assistance projects have experienced a gradually diminishing pool of funds with which to provide training. They used to have a specific allocation of funds which could be spent on training activities in each state. Now training has become less oriented to children and methods, and more oriented toward state and agency processes and procedures.

There has been discussion in the past, motivated at least in part by the dwindling funding resources,
about merging the national technical assistance projects. We cannot deceive ourselves. We are not offering an adequate support system on an ever-decreasing budget.

The current context in which the 307.11 program operates is certainly financial, but it is also philosophical. In the current climate, the inclusion movement has definitely resulted in a much greater dispersion of deaf-blind children. While the children used to be served in more concentrated pockets, and in specialized programs, they are now served in a much greater number of schools, spread over a much larger geographic area. This same phenomenon repeats itself in every state and region in the nation. Infrequently does one find two deaf-blind children served within the same building, let alone the same classroom.

As one 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? These 138 schools definitely require a greater level of such assistance than in the past, since they do not typically employ specialists in deaf-blindness. 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 greatly increased the number of special educators and general educators who need basic training in the instruction of children who are deaf-blind.

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

The general trend to serve children locally has had tremendous impact on how children who are deaf-blind are educated. In the typical scenario today, 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 may be in need of a knowledgeable person to advise them.

Another phenomenon is worthy of mention. With children spread out over such a large number of districts, there are very few jobs open to a person trained to teach 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 for jobs in which their specialist background can have broad impact for larger numbers of children. The expertise of the specialists is widely needed, but actual positions that make use of their skills are few.

It has been well established that we have 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?

...we have a greatly increased number of special educators and general educators who need some basic training in instruction of the deaf-blind children.

Even when a school system has the funding for a resource specialist, it has difficulty finding appropriately trained candidates. More than 75% of the positions for state consultants, or coordinators of the programs under section 307.11 are filled by people who have neither training nor direct teaching experience with the population. Yet they are expected to be our resource people, to train the local schools to offer appropriate instructional content to the child who is deaf-blind.

In too many situations the state projects lack personnel with specific knowledge of deaf-blindness. In many cases the coordinators of these projects are assigned to the project on a part-time basis, frequently as one more assignment within the State Department of Education. In every state, dozens, and sometimes hundreds, of school districts are trying to serve children who are deaf-blind, and are not getting adequate help from their state coordinating offices, because these offices are understaffed and employ people who are undertrained.

I observe that we have bought into a philosophy of integration and service at the local level without any attempt to build an infrastructure or 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 we hold dear for all children. Nonetheless, we must recognize that, at the local level, thousands of these children are underserved or inappropriately served. Too often the needs of children who are deaf-blind are simply not recognized, let alone addressed in the IEP.

I would suggest that children who are deaf-blind typically require certain educational content within their IEP, if their education is to be appropriate. I would submit that, all too often, the above specific content needed by the child, by way of his deaf-blindness, is altogether lacking. This is frequently true both in full inclusion programs as well as in some of the segregated classes for severely handicapped 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 trained 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 needs of the child who is deaf-blind, nor is it one who is able to offer a curriculum that incorporates the necessary factors. As a result, the child receives a program that is only partially appropriate. Some of the needs are addressed in the IEP; others are completely overlooked.

Sometimes, not only does the district lack expertise, but there is also nobody to call upon from the county, the intermediate school system, or the state. Therefore, the consultative input addresses 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 student’s plan.

The realities of where children are served today call for a much different support program, or 307.11 program, than we have operated in the past.

This current situation is just not acceptable. We cannot continue pretending that a system with such large gaps is a functional system.

A Best Possible Future for the Program

I offer the following suggestions as specific ways to strengthen the entire system nationally. This is in no way intended to be a complete or comprehensive prescription for all of the aspects which could be improved in a national program.

Strengthen the National Office

This program, within OSERS, has for many years been part of the Severe Disabilities Branch. While this is appropriate, there should be at least two staff working full time on the deaf-blind program. The number of projects to be funded nationally requires at least two staff members if program quality and direction is to be influenced. At least one of these should be a person trained specifically in deaf-blindness, to ensure that the integrity of the program’s focus is maintained. The monitoring and shaping of individual projects can be much more effective if the office personnel include persons with training in deaf-blindness.

Additionally, the national office would benefit greatly from a required advisory committee composed of professionals, parents, and consumers. State projects, multistate projects, university preparation programs, and national organizations should be represented on such a committee.

Improve State and Multistate Projects under 307.11

Each state needs a 307.11 project with adequate funding to offer meaningful support to its children who are deaf-blind. This can only be accomplished through achieving an improved appropriation for the entire program.

Each state and multistate project should be staffed by more than one full-time professional who has training and expertise in deaf-blindness. The number of staff to be employed in each project should be determined by the size of the state and the number of children in need of service. The 307.11 pro-
ject staff should provide very direct training, consultation, and advice, and not simply function as brokers of services. They should personally know each child in need of service, and they should be available to local communities who seek advice and training. They should conduct several formal training sessions annually for district staff, and they should travel to districts throughout the state to offer onsite consultation. They should be required to establish a central body of literature and resources in each state, including assessments, curricula, and audio-visual materials. They should centralize accessible information, share between districts, coordinate with teacher training facilities, provide newsletters, and promote activities that develop a systematic infrastructure within each state. But, to accomplish these goals, they must be funded adequately.

307.11 project applications should be judged in accordance with how well informed the project is about the children they propose to serve: (a) What is their process for identification of children? (b) How in touch is the project with the specific subgroups of children who are deaf-blind? and, (c) How aligned are direct services and technical assistance to the needs of individual children and families?

Funding should be distributed according to the value of the services to be provided and not according to the number of noses each state can claim to count. Adequate systems of child identification should be only one factor within the funding equation. The categories of “unknown” and “not tested” on our census forms should be eliminated.

**Improve Services at the Local Level**

Under each state’s program, we must find a way for teachers with expertise in deaf-blindness to be employed as itinerant and resource teachers to work directly with children and with local building staff. Such positions probably cannot be paid for with federal funding, given the need for hundreds of such positions. Nevertheless, the federal program must find a way of promoting the creation of such positions. We cannot expect teachers-to-be to train in deaf-blindness unless there is a likelihood of employment in the field. Just as a child who is blind is entitled to some minimum amounts of time from a trained vision professional in order to have an appropriate program, so a child who is deaf-blind needs regular input from a professional who is familiar with the concurrent sensory disabilities.

We should be writing into the IEP the amount of time spent with a teacher who is trained in deaf-blindness. Should we require evidence in every state plan that there is a statewide system of adequately trained teachers? Should we define the services of a deaf-blind teacher as a related service within the federal act? They are confusing questions, but perhaps they are the most essential for ensuring the future quality of services for each child.

If a cadre of specialists were created, we might more effectively use paraprofessionals in local schools, under the direction of trained itinerant educators who periodically consult to the classroom staff. This would increase the likelihood of the child’s success in inclusion programs, and allow us to stretch our master’s-level specialists further.

**Expand Preservice Personnel Preparation in Deaf-Blindness**

A mere handful of universities currently prepare personnel in the field of deaf-blind educators. At any point, there are generally not more than three or four teacher training programs nationally with federal funding. In the past four years the Hilton/Perkins program has provided support for about 200 teachers to be enrolled in graduate training. But this is not nearly enough. We need about 10 strategically located centers to train teachers from each region of the country, attached to existing programs that train personnel in deafness and blindness. And we need these centers to be funded for much longer than a three-year grant. There can be no stability in recruitment and training if programs come into and out of existence rapidly. Part D of IDEA should support such centers, and there should be a consensus process to identify all the competencies that such teachers require so that the curriculum in teacher preparation can adhere to standards. With adequate personnel preparation, the 307.11 projects can be expected to hire qualified leaders, and local districts can be expected to employ appropriately trained itinerant and resource teachers. Better federal funding for such programs, combined with continued support from the Hilton/Perkins Program, could put a big dent in the staff shortage in just a few years.

It is imperative that we fund this effort in preservice preparation from the funds earmarked for that purpose. The limited funds set aside for systemic support under 307.11 should be used only for systemic support.
Improve National Technical Assistance

We need more frequent meetings and training activities that 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 the 1992 National Symposium on Children and Youth Who Are Deaf-Blind, that bring us together as a community of individuals with common interests. OSERS and the national projects might sponsor more events like the symposium, on select topics and for different audiences. OSERS might reward proposals from states that propose joint activities with neighboring states, in order to encourage a more fertile field.

Our national technical assistance projects must return to the original mission of providing deaf-blind specific expertise to the local communities who are trying to serve the population. The recent focus on such areas as Personal Futures Planning, Transdisciplinary Team Functioning, Interagency Collaboration, and Systems Change are interesting from a process point of view. But these emphases teach nobody how to work with the child; nor do they plan better content for the young adult. Style without substance is still only style. The needs for training in the basics of assessment, communication, sensory development, and the organization of a meaningful school day are chronic. These require our full attention.

To date, our systems change efforts have been very process oriented. It is time for these efforts to focus on changing the substance and content of how states are organized to serve the population. Each state needs assistance to develop a network of qualified professionals, so the system can truly work. 307.11 projects need help in campaigning for inclusion of deaf-blind training in their local Comprehensive System of Personnel Development projects. To improve services at the local level, we must develop within each state a new network of itinerant specialists in deaf-blindness to function as consultants and resource people. Our national technical assistance projects should be leading the way to help states accomplish this.

Maintain a National Clearinghouse on Deaf-Blindness

For the past two years, a project entitled DB-LINK has been funded to create a national information clearinghouse and easy access to information for all professionals, consumers and families. This clearinghouse has been a collaborative project of American Association of the Deaf-Blind, American Foundation for the Blind, Helen Keller Na-

The positions expressed in this article are those of the author and do not necessarily reflect the position of the Teaching Research Division or the U.S. Department of Education.

Presentation 3

Now is the Time for Action

Dawn Hunter
former Branch Chief, Severe Disabilities Branch,
Office of Special Education

Assessment of the State of the Program

Throughout the history of the program, although the number of children who are deaf-blind has increased dramatically, the resources available have steadily decreased (especially in light of inflation). First of all we are experiencing a critical shortage of professionals who are trained to work with students who are deaf-blind and their families. This personnel shortage is national in scope and includes trained teachers, interpreters, related service personnel (e.g., mobility trainers, audiologists, speech therapists, occupational therapists, physical therapists, personal attendants, intervenors), as well as early intervention staff, rehabilitation counselors, and administrators at the building, district, and state levels. Secondly, because of dwindling federal resources, support to the state and multistate projects (for research, demonstration, training, outreach, and technical assistance programs) has become almost nonexistent.
Despite these personnel and budget cutbacks, we have seen tremendous accomplishments in serving children who are deaf-blind. Innovations in educational and assistive technology have soared. Children who are deaf-blind are successfully being educated in general education classrooms. We are learning more about social relationships and the development of friendships between children who are deaf-blind and their peers. Parents of children who are deaf-blind have organized to form a very active support network for both families and professionals. These parents have also become politically active, and have effected many changes at the local and state levels. In addition, we have seen creative solutions to fiscal limitations with parents, schools, districts, the business community, and community agencies effectively collaborating to better serve students who are deaf-blind. Much has been accomplished in a relatively short period of time.

**Vision of the Future of the Program**

What needs to happen in order to more effectively support children who are deaf-blind? I see at least seven areas that need to be addressed in order to realize our vision:

1. We need a full time state and multistate coordinator in each state. It is virtually impossible for a state, regardless of its size, to coordinate services for children who are deaf-blind without someone serving in this role full time. It is a monumental task to identify children who are deaf-blind, monitor the services being provided to these children, ensure that state-of-the-art technical assistance and training is provided to school districts and families, collaborate with other state and local agencies and organizations, and stay professionally current.

2. For many of the same reasons, we need more than one full-time staff person working with the program at the Office of Special Education Programs. I would like to echo the statements Mike Collins made about increasing the support for the program at this level. One person simply cannot effectively manage and monitor the program. This staff member is also responsible for developing program announcements, setting up and running grant competitions, writing regulations, responding to mail, working on governmental committees, educating others within the department about the needs of students who are deaf-blind and their families, and so on. It should be noted that within the last three years the Services for Children with Deaf-Blindness Program has lost three staff members who spent a portion of their time working with the program.

3. We must proactively continue to establish effective collaborative relationships with other state agencies and programs (e.g., vocational rehabilitation, housing, transportation, mental health) within our respective states. These relationships can assist in (a) better serving students, (b) educating each other as to what resources are currently available or could become available, (c) pooling resources when feasible, and (d) changing negative attitudes and low expectations about people who are deaf-blind. Everyone involved can benefit from establishing these types of collaborative working relationships.

4. Coordinators must determine if they are utilizing all resources available to them (e.g., dollars from Parts B and H of IDEA, Comprehensive System of Personnel Development, statewide system change grants, and other federal discretionary grants) to better meet the needs of students who are deaf-blind and their families. They also need to become familiar with and access other national (e.g., DB-LINK, NICHCY, HEATH, the Professions in Special Education Clearinghouse, ERIC Clearinghouse, National Diffusion Network, NECTAS, the Regional Resource Centers, TRACES, TAC, the Inclusion Institute, the Social Relationships Institute, the Early Childhood Research Institutes, the Transition Institutes), state, and local resources to the greatest extent possible. In addition to accessing resources through these projects, coordinators have the opportunity to inform these projects about the educational, social, vocational, transportation, housing, medical, and recreational needs of people who are deaf-blind and their families.

5. Radical changes are needed, both in the way we recruit and also in the way we train professionals to work with students who are deaf-blind. We can no longer simply hope to see an increase in the number of teachers, related service personnel, and interpreters entering the field, but rather we must be proactive in ensuring that we have a pool of potential professionals. Thus we must better utilize existing systems for recruiting as well as develop new recruiting strategies. We must also take a
careful look at the current preservice and inservice training programs and find a way to stabilize resources for these types of programs. Additional training programs will need to be established. It may be useful to explore a variety of nontraditional training models that encourage potential teachers to work with students early in their programs. Solving the critical shortage of trained personnel will require a great deal of creativity and collaboration at the national, state, and local levels.

6. We need to continue to find effective ways to better support the families of children who are deaf-blind. This will include helping families network more effectively with each other, providing support and training for families, empowering families to be actively involved in the education of their children, and educating “generic” service providers about students who are deaf-blind and their families to help them obtain needed supports and services.

7. We must clearly identify what additional supports are needed to ensure that all children who are deaf-blind are receiving the best education possible. This will include (a) documenting best practices (as well as what isn’t working); (b) identifying “gaps” that require additional program development, materials development, technological development or research; (c) translating research findings into “user friendly,” classroom practices; and (d) developing and using effective strategies to communicate this information. While DB-LINK, TRACES, and TAC have done an outstanding job of beginning this information collecting and sharing process with the very limited federal resources they have had available to them, some of the supports identified above are outside the scope of these projects. Therefore, once these supports are identified resources will be needed for implementation. Another endeavor that would improve services to children who are deaf-blind would be the creation of a professional journal committed to addressing the challenges we are facing as a field.

Radical changes, both in the way we recruit and the way we train professionals to work with students who are deaf-blind, are needed.

Where is the Program Headed?

Never before have we seen general education and special education at the federal level coming together as it currently is. While this is tremendously exciting and holds a great deal of promise for improving educational services to all children, it is also frightening.

On September 22, 1994 the U.S. Department of Education issued a Notice of Request for Comment on the Reauthorization of IDEA (Federal Register, vol. 59, No. 183, p. 48815). Several questions were raised about the discretionary grant programs that are “red flags” for the Services for Children with Deaf-Blindness Program. Three of the questions that were posed are especially relevant to the discussion here:

• How can resources from different programs be consolidated or coordinated to address issues that cut across age ranges, disabling conditions, and types of activities?
• Are there less categorical approaches that would better serve the needs of children with disabilities and their families?
• Should all resources for personnel development be consolidated into a single program to permit greater flexibility in meeting changing personnel training needs?

Given the tremendous needs identified in the first two sections of this article, few can argue that what we currently have cannot be improved. Without a doubt, now is the time for creative approaches, solutions, and doing things differently and more effectively than we have in the past. However, we must address the needed changes in a thoughtful and comprehensive way. Without a sincere commitment from the Department of Education that there is indeed a federal role to support low-incidence populations through research, demonstrations, outreach, training, technical assistance, dissemination and other activities, one cannot be assured that decisions will be made in accordance with the students’ best interests. Will students who are deaf-blind, once again, get lost in the shuffle?

What can be done to ensure that thoughtful and comprehensive decisions will be made by the Department of Education and Congress? Some suggestion may include the following:

1. Be proactive in all IDEA reauthorization activities. Stay abreast of developments and pay particular attention to the discretionary programs (i.e., Parts C - G). Although the public comment period is over for the questions identified above, it is not
too late to call or write to the Department of Education and your legislators voicing your concerns. Provide concrete suggestions. Keep in mind you are dealing with players who are interested in down-sizing and reinventing government. Consequently, suggestions that fit into this framework will more likely be heard.

2. Watch for the proposed budgets that should be out in January. How is the Department of Education proposing to spend special education dollars? Are there any clues in the budget as to what may or may not be happening to specific programs, such as shifts in program budgets? If so, what will this mean for students who are deaf-blind? Also keep an eye on the Program for Children with Severe Disabilities and the Early Childhood Program as these programs have also supported children who are deaf-blind. Ask questions. Obtain specific answers to your questions.

3. Watch the reorganization activities occurring within the Department of Education, particularly in the Office of Special Education Programs. What are the plans for reorganizing? How will these activities affect students, research and development activities, technical assistance, systems change activities, and other needed supports? Again, ask questions.

4. Be vigilant, listen carefully, and act. Things are moving on a fast track. There is no time to stand by and watch. Help others keep informed. Empower parents, family members, and consumers. Involvement is critical.

5. Keep an open mind. We have an opportunity here to do things better than we have in the past. Be pathfinders, seek common ground whenever possible. Look for new and creative ways to ensure effective educational change.

6. Secure commitments from the Department of Education and Congress that each believes there is a unique federal role to support low-incidence populations through research, technical assistance, outreach, training, and dissemination activities for these populations.

Change can be frightening. The challenge for all of us is to remain open to change, always keeping in the forefront, the needs of students’ who are deaf-blind and their families. In order to realize our vision we will have to dust off our grass roots organizing manuals and get busy. We must work together, using our best collaborative and problem solving skills. Creativity and unity will bring about effective and positive change for the students and families we serve. The time is now; if not, it may be never. Before we lose too much, we must get involved.

NOW is the time for action.

The positions expressed in this article are those of the author and do not necessarily reflect the position of the Teaching Research Division or the U.S. Department of Education.

Congressman Randy Cunningham is the chairman of the Subcommittee on Early Childhood, Youth, and Families. One of the tasks for this subcommittee is to review the reauthorization of IDEA. Readers are encouraged to share their comments with Congressman Cunningham.—ED.

Are you an adult who is deaf-blind who is interested in linking up internationally with others on the Internet? Do you know a college student or other adult with dual sensory impairments who has Internet access? Faculty from the University of Utah and Utah State University are currently preparing a list of individuals (“super highway travelers who are deaf-blind”) who share this interest. If you would like more information, send an E-mail message to o’donnell@gse.utah.edu Richard Kiefer-O’Donnell University of Utah
Many students who are deaf-blind engage in behaviors that can be categorized as challenging or interfering. Some, for example, might exhibit vocalizations or motor responses that compete with their attention during instructional activities. Similarly, stereotypic behaviors (commonly termed “self-stimulation”) such as body-rocking, light-gazing, or object-tapping can interfere with learning. Behaviors in the form of a tantrum or property destruction are environmentally disruptive. Finally, very severe forms of behavior such as aggression and self-injury can be physically harmful.

Most educators and parents would agree that, when a student who is deaf-blind displays challenging behaviors, a systematic program of intervention is warranted. When considering how to intervene with a student, it is useful to conceive of the problem behavior as having communication intent (Donnellan, Mirenda, Mesaros & Fassbender, 1984). To illustrate, imagine a deaf-blind child who has a limited range of adaptive skills and who lacks expressive language abilities. The student is not able to request assistance from others through sign language or an augmentative language modality but finds that if he hits himself repetitively, he is approached by adults who, with best intentions, try to manage the situation and calm him down. However, by delivering attention to the student contingent upon his self-injury, that behavior will be learned as a way to elicit a desired reaction. In effect, the behavior communicates the message, “Pay attention to me.” For this student, the challenging behavior serves a purpose and function.

Understanding the functional properties of challenging behaviors should be the first step in the development of an intervention plan. Consider the following example. A girl who is deaf-blind attends a classroom where she participates in a variety of instructional activities each day. Some of the activities are pleasurable for the student and she completes them without difficulty. However, certain other activities seem to be more demanding for her and frequently, she becomes very disruptive when they are presented. In an attempt to reduce the occurrences of disruptions, the girl’s teacher decides to use “time-out” by having her sit away from the group for 1 minute whenever disruptive behavior is displayed. Unfortunately, the time-out consequence in this example is likely to produce an increase in the behavior. This outcome could be expected because the girl finds the instructional activity to be unpleasant, engages in disruption, and then experiences the temporary removal (via time-out) from what she dislikes. By focusing on the typography of the challenging behavior, and not its function, the program of intervention will be ineffective.

This article provides an overview of the important topic of functional assessment as it applies to challenging behaviors of students who are deaf-blind. First, specific categories of functional influences are presented. This information is followed by a review of several assessment methodologies. The article concludes with a brief discussion of treatment implications.

Categories of Functional Influences

Physical-Medical. Challenging behaviors, on many occasions, occur due to acute or enduring physical conditions. A deaf-blind student who presses his or her finger against the eye might do so because of increased intraocular pressure. Or,
repetitive face-rubbing could be the result of an allergy. A situation of extreme fatigue that is the sequelae from periods of poor sleeping or a prescribed medication can lead to agitated behavior. These and similar challenging behaviors represent the student’s attempt to reduce discomfort.

Attention-Eliciting. As noted previously, students sometimes engage in challenging behaviors because the reaction by adults is an increase in social attention. For the student who is deaf-blind, this attention typically occurs as an adult signing tactually by delivering comments such as, “Please don’t scream,” or “No hitting-what’s wrong?” Although the adult’s reaction may, in fact, stop the behavior temporarily, the actual frequency of response might increase because it is eliciting a pleasurable and, therefore, reinforcing consequence.

Object- or Activity-Eliciting. This influence operates similarly to the attention-eliciting function but instead of the social responses from adults being reinforcing, it is the presentation of objects and activities. A common example is the student who exhibits a tantrum and is given a preferred toy, pleasurable materials, or access to a favorite activity contingently because it calms him down. Through repeated pairings of tantrum behavior followed by exposure to desirable objects and activities, the student can learn quickly how to elicit them by tantrumming.

Avoidance- and Escape-Motivated. If a student is confronted with a situation that he or she does not enjoy, performs a challenging behavior, and the situation is either withdrawn briefly or terminated completely, that behavior will be negatively reinforced. Functionally, the student learns to postpone the presentation of particular conditions (avoidance) or to have ongoing conditions discontinued (escape) by engaging in the behavior. Because the avoidance of, or escape from, nonpreferred situations is pleasurable for the student, the preceding behavior will increase. Avoidance- and escape-motivated challenging behaviors are seen primarily under “demand” conditions (e.g., direct instruction, requests for compliance).

Sensory-Pleasurable. Stereotypic behaviors represent fixed, invariant, and repetitive motor responses that, typically, are reinforced by their own sensory consequences. The sensory-pleasurable outcome from eye-pressing, for example, is the photic stimulation produced by the behavior. Body-rocking is associated with pleasant proprioceptive feedback. A deaf-blind student who taps fingers against his or her chin might do so because the tactile contact is enjoyable. The fact that these and similar behaviors are reinforced by “intrinsic” sensory consequences is why they are usually referred to as self-stimulatory.

Methods of Functional Assessment

Indirect Methods. One way to identify the function of challenging behaviors is to pose questions to persons who interact with a student (e.g., teachers, parents, therapists) regarding the conditions under which the behaviors are encountered. Because this approach relies on the subjective reports of significant others, it is considered to be an indirect, or informant-based, assessment method (Iwata, Vollmer & Zarcone, 1990).

Figure 1 is a screening form used by the author during the initial phase of program planning and represents one of several indirect measures. Individuals are asked to complete the form independently, and then the collected information is summarized and reviewed. As depicted in the form, potential functional influences are gleaned by having informants rate the degree of occurrence, for each challenging behavior, within specified conditions. Consistent ratings indicate particular sources of control. For example, if several teachers uniformly indicated that a student’s disruptive behavior was most prevalent during instructional activities as opposed to free-play or alone conditions, these data would suggest an avoidance- or escape-motivated function. It should be emphasized that this form, and similar indirect methods, should be used as preliminary approaches towards functional assessment and should always be incorporated with direct clinical observation, caregiver interviews, and, when possible, empirical data-based procedures.

Several standardized instruments have been developed for the purpose of indirect functional assessment. The Motivation Assessment Scale (MAS) designed by Durand and Crimmins (1988) is a 16-item questionnaire that requires respondents to answer questions such as, “Does the behavior occur following a command to perform a difficult task?” or “Does the behavior occur repeatedly over and over, in the same way?” Each question is answered on a seven-point scale ranging from “never” to “always.” The quantified responses by informants are used to determine an attention-eliciting, object-eliciting, avoidance-motivated, or sensory-pleasurable function for the behavior in question. O’Neill, Horner, Albin, Storey and Sprague (1990) also have described a functional analysis interview form as a structured reporting format for use with practitioners during the initial phase of assessment.
Figure 1

**Functional Assessment Screening Form**

Students: 
Informant: 
Target Behavior: 

**Instructions:** Indicate the level of occurrence of the target behavior by checking off the relevant rating for each designated condition. Ratings are:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>Seldom</td>
<td>Occasionally</td>
<td>Frequently</td>
<td>Very Frequently</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conditions</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>When alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In presence of peers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In presence of adults</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indoors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outdoors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>During transitions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When given a request</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>During training sessions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>During free-time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>During meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morning (7:00a.m.-12:00p.m.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afternoon (12:00p.m.-5:00p.m.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evening (5:00p.m.-11:00p.m.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overnight hours</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Data Collection Sheet

Student: Robert  Setting: Classroom  Date: Today’s Date:  
Target Behavior: “Head-Swaying” (side-to-side movement of the head)  

Instructions:  
One data sheet should be used each day. Write in each scheduled activity and the time (to the nearest minute) each activity begins and ends. When the target behavior begins, start the stopwatch; when the target behavior ceases for at least one full second, terminate the stopwatch. When the activity is over, sum the cumulative seconds on the stopwatch over the total seconds of the activity.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Activity Time</th>
<th>Instructor</th>
<th>% Occurrence of Target Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Begins</td>
<td>Ends</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Descriptive Methods. These techniques rely on data-based assessments whereby the occurrences of challenging behaviors are recorded in "real time" and within specified contexts. The scoring of behaviors in this manner is an advantage over indirect methods because it provides a more empirical basis for identifying purpose and function.

Figure 2 is an example of a data collection sheet prepared for a child who is deaf-blind and engaged in stereotypic head-swaying behavior (moving head in a side-to-side motion). The behavior is recorded during selected classroom activities and the objective of the assessment is to determine whether it is influenced by different conditions (e.g., group activities, 1:1 instruction, lunch, play). As depicted in Figure 2, starting and stopping times of each activity are noted (to the nearest minute). A stopwatch is activated and terminated to time when head-swaying begins and ends, respectively. When each activity is concluded, the total number of seconds of recorded head-swaying is divided by the total duration of the activity to produce a "% Occurrence of Target Behavior" of head-swaying. For example, if it is found that the occurrence of stereotypic responding is considerably higher when he is involved in group activities with less than 1:1 interaction, then the treatment implication is that head-swaying behavior is primarily sensory reinforced and is most likely to occur when the student does not receive direct and frequent instruction.

Data collection forms can be adapted to a variety of challenging behaviors, contexts, and settings. In addition to isolating how the type of activity might affect the display of challenging behavior, other meaningful information regarding function can be obtained. For example, the data sheet shown in Figure 2 allows the classroom staff to determine whether head-swaying behavior is influenced by (a) the duration of the activity (e.g., short- vs. long-duration tasks), (b) the instructor conducting the activity (e.g., the effects of different staff persons), and (c) the time of day the activity is scheduled (e.g., morning or afternoon). To reiterate a point made previously, the ability to correlate empirically the display of challenging behaviors with discernible conditions means that intervention procedures can be matched to functional influences. Other types of descriptive assessment methods include the Inappropriate Behavior Record (Pyles & Bailey, 1990) and the Functional Analysis Observation Form (O’Neill et al., 1990).

Experimental-Analogue Methods. An experimental-analogue approach entails the direct manipulation of purported functional influences to discern whether they affect the frequencies of challenging behaviors differentially. This method, "involves constructing at least one condition (experimental) in which the variable of interest is present . . . and another condition (control) in which the variable is absent" (Iwata et al., 1990, p. 308).

To illustrate an experimental-analogue approach, picture a student who is deaf-blind who participates in three, 10-minute classroom activities each day. The behavior of interest is hitting-out towards the instructor. During one activity, the student is presented with less preferred tasks (demands) and each time the challenging behavior occurs, the instructor ceases the interaction for 30 seconds. This condition includes a time-out strategy and is intended to control for a possible escape-motivated function. That is, if the student’s hitting behavior occurred at high frequencies under this condition, the assumption would be that it was reinforced by escape from, or avoidance of, the demands. During the second activity, the student is given preferred tasks and contingent upon hitting, the instructor states, "No-don’t hit!" This condition is intended to control for an attention-eliciting function because the hitting behavior produces a pleasurable social consequence. Increased responding under this condition would suggest that the student hits to produce an adult reaction. Finally, during the third activity the student is allowed to have free-play while the instructor simply remains in close proximity but without interaction. This condition provides a control for a sensory pleasurable function, that is, tactile or other sensory consequences from hitting which are, themselves, reinforcing. Using this method, it can be seen that the possible function of hitting behavior can be isolated in the most direct way and with maximum control.

Although an experimental-analogue method of functional assessment might seem to be too time-intensive for practical application, it can, in fact, be adapted to most settings. As an illustration, Luiselli (1991) described the functional assessment and treatment of self-injury (striking chin with hands and striking head against surfaces) in a 6-year-old boy who was deaf-blind. Based upon an initial clinical evaluation, it appeared that the self-injurious behaviors were primarily escape-motivated in that they tended to occur when he was presented with instructional demands. An experimental-analogue assessment was instituted by recording the frequency of self-injury during three, 10-minute sessions that occurred regularly within the child’s classroom: (a) direct instruction with manipulative tasks (demand condition), (b) direct instruction with manipulative tasks plus reinforcement for task
completion (reduced-demand condition), and (c) free access to play materials (no-demand condition). During all activities, an instructor physically blocked and redirected attempted self-injury as a protective technique. The results demonstrated that self-injurious behaviors decreased steadily across all three activities and eventually, reached near-zero levels. The outcome from assessment, therefore, revealed that the student’s self-injury was not primarily escape-motivated in function or perhaps, that the behavior was influenced by multiple functions. It was clear, however, that the contingent interruption-redirection procedure proved to be a simple but effective strategy.

Discussion

This brief review addressed the topic of functional assessment of challenging behaviors in students who are deaf-blind. It is beyond the scope of the review to discuss the many treatment implications that must be considered given the outcome from functional assessment, but several areas can be highlighted:

• On some occasions, functional assessment might reveal multiple sources of control over challenging behavior. That is, one behavior of a student, for example, loud screaming, could be attention-eliciting in function in one situation and escape-motivated in function in another. If a behavior appears to be multiply determined, separate intervention programs would have to be formulated for each identified condition.

• In general, it usually is possible to identify behavior-function by utilizing the methods presented in this review. Occasionally, however, the results from assessment might show that the behavior of interest is undifferentiated, that is, it seems to be effected by all variables. An analysis of this type could mean that the behavior is reinforced by conditions that are not readily accessible via the functional assessment. This possibility is most likely to be encountered for challenging behaviors that are influenced by medical factors. It also should be noted that, in some cases, a student’s challenging behavior may occur at a very low frequency, thereby being less sensitive to functional environmental manipulations (Vollmer & Iwata, 1993). Such a situation would require a more prolonged period of assessment before intervention is initiated.

• Practitioners should be keenly aware of ethical considerations when using functional assessment procedures either to record challenging behaviors under naturalistic conditions or during experimental-analogue sessions wherein programmed interactions potentially could increase responding. It is imperative, for example, that the assessment procedures do not put the student or others at risk, particularly when serious challenging behaviors such as self-injury or aggression are targeted. Procedures should be in place to ensure personal safety and protect the physical environment. Finally, if the potential risks from directly manipulating functional variables are significant, or if the actual assessment leads to behavioral difficulties, procedures should be discontinued in favor of more benign strategies.

• Any program of behavioral intervention must focus on the language and communication skills of the student. If functional assessment suggests that the hitting behavior of a student is attention-eliciting, for example, it would be desirable to teach that student how to request adult interactions using a language response. Similarly, escape- or avoidance-motivated behavior should be treated with a language training component that teaches the student how to ask for help or to request a break under demand conditions. This method is termed Functional Communication Training (FCT) and has been demonstrated to be effective as a behavior-deceleration intervention using verbal and nonverbal language modalities (Durand, 1990).

• When the conditions that reinforce a challenging behavior are pinpointed, another component of intervention should be to eliminate them and make the reinforcing consequences contingent upon more adaptive skills and responses. Thus, for sensory-reinforced challenging behaviors, the pleasurable consequences could be made available following alternative responses or new (and more acceptable) ways to produce the consequences could be provided (see Moss, 1994, for useful recommendations in
this regard). If the challenging behavior is reinforced by contingent social attention, adults would be trained to withhold their attention when the behavior occurs and to attend to the student in its absence. Escape- and avoidance-motivated challenging behaviors could be addressed by introducing positive reinforcement into activities that seem to provoke the behavior, using antecedent-control methods to reduce the likelihood the behavior will be encountered (e.g., reducing task demands, allowing student choice-making, using preferred objects), and/or making escape-avoidance contingent upon more acceptable responses (Luiselli, 1994).

In summary, the most effective approach toward behavioral intervention for students who are deaf-blind should be to discover the purpose and function of their responses before a program is implemented. Determining behavior-function enables the practitioner to design an individually tailored intervention plan. In this way, it is more likely that the behavior-change program will be matched to the unique learning characteristics of each student.

References


Author’s Note

Requests for reprints should be addressed to
James K. Luiselli
Psychological and Educational Resource Associates
40 Bronson Way
Concord, MA 01742
(508) 369-0915
You & Me

A Five-Part Video Series About Educating Children Who Are Deaf-Blind

Available now is the first of five videos describing the education of a child who is deaf-blind. This video portrays Riley Ford who is totally blind and has a profound hearing loss, as he attends his neighborhood school.

The video describes Riley’s educational program, portrays methods of communication and mobility, and illustrates the role of the interpreter-tutor. In addition, the impact of Riley’s presence in the school upon other children is shown, together with the social network developed around him.

Each video in the You & Me series, along with its accompanying publications is available at cost. Please make checks payable to Teaching Research Publications in the amount of $15.00 per video (handling and shipping included).

Videos with open captioning are available upon request.

To Order, write to Teaching Research Publications
345 N. Monmouth Ave.
Monmouth, OR 97361

Or call Teaching Research National Coalition on Deaf-Blindness

The National Coalition on Deaf-Blindness evolved as a result of the growing federal trend away from offering specialized services for persons who are deaf-blind. There appeared to be a serious risk that services for individuals with this low-incidence disability would fall under the umbrella of generic services for individuals with severe handicaps. This issue brought to light the need for a national coalition of persons committed to the continuation of services and to advocate for ongoing federal responsibility for individuals who are deaf-blind.

Sponsoring Organizations

Several national organizations recognized for their commitment to deaf-blind services have joined to offer leadership in this coalition. Currently these include American Association of the Deaf-Blind, American Foundation for the Blind, Association for the Education and Rehabilitation of the Blind and Visually Impaired, Council for Exceptional Children - Division for the Visually Impaired, Council on Education of the Deaf, Council of Schools for the Blind, National Association for Parents of the Visually Impaired, Helen Keller National Center, St. Joseph’s School for the Blind, Teaching Research, and Perkins School for the Blind. Leaders of these groups have endorsed the need for such a coalition on behalf of their memberships.

Coalition Activities

Activities of the Coalition have been primarily concerned with advocacy on the federal level. This has included informational letters concerning the needs of individuals who are deaf-blind, individual testimony to Congressional committees dealing with the issues on the handicapped, and direct contact with members of Congress. Two important activities of the Coalition will be to advocate on federal legislative issues, especially the re-authorization of the Individuals with Disabilities Education Act (IDEA), and to organize a national conference.
Membership

The current membership is comprised of consumers who are deaf-blind, family members, professionals in the field of education and rehabilitation, and other concerned citizens. If you would like to maintain an active involvement in the National Coalition on Deaf-Blindness, please fill out and return the attached membership form.

National Coalition on Deaf-Blindness
Application for Membership

Name: __________________________________________________________________________________________
Home Address: __________________________________________________________________________________
Home Phone: __________-________-__________
Affiliated organization: __________________________________________________________________________
Organization Address: ____________________________________________________________________________
Organization Phone: __________-________-__________

Preferred address for Coalition mailing: Home: q Work: q
I would like to request that information about the National Coalition on Deaf-Blindness be sent to the following person/organization who may be interested in joining.
Name: __________________________________________________________________________________________
Address: ________________________________________________________________________________________

NOTE: THERE IS NO FEE REQUIRED TO BECOME A COALITION MEMBER!

National Coalition on Deaf-Blindness
175 North Beacon Street
Watertown, MA 02172
Attn: Steven Davies
Tel: (617) 972-7347
Fax: (617) 923-8076
E-mail: 75674.3101@compuserve.com
Image not available
Clearinghouses in Collaboration

Clearinghouses in Collaboration is a consortium of six clearinghouses funded by the Department of Education, Office of Special Education Programs, that provides information on disability-related issues. We meet regularly to discuss our work, our current projects, and our plans for future projects to ensure coordination, share resources, prevent duplication of effort, and avoid gaps in information.

Clearinghouses in Collaboration focuses on information collection, referral, and dissemination. To learn more about these services and publications, please contact the individual clearinghouses.

ERIC, Educational Resources Information Center Clearinghouse on Disabilities and Gifted Education (ERIC EC)
ERIC is a national information system on education, with a large database of journals and other print materials. ERIC EC, one of 16 ERIC clearinghouses, gathers, abstracts, publishes, and disseminates information on disabilities and gifted education.

ERIC Clearinghouse on Disabilities and Gifted Education
The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091-1589
V: (800) 328-0272; V/TTY: (703) 620-3660;
Fax: (703) 264-9494; Internet: ericec@inet.ed.gov

NICD, National Information Center on Deafness
NICD is a centralized resource on all aspects of hearing loss and deafness. It maintains a database and resource collection on programs and services for people who are deaf and hard of hearing.

NICD
Gallaudet University
800 Florida Avenue NE
Washington, DC 20002-3695
V: (202) 651-5051; TTY: (202) 651-5052; Fax: (202) 651-5054
Internet: nicd@gallau.gallaudet.edu

NICHCY, National Information Center for Children and Youth with Disabilities
Established by Congress, NICHCY is an information and referral center that provides free information on disabilities and disability-related issues. The focus is on education and children and youth, ages birth to 22 years.

NICHCY
P.O. Box 1492
Washington, DC 20013
I enjoyed this issue of *Deaf-Blind Perspectives* but I am not on your mailing list. Please send future issues to the address below.

I've moved! Please send future issues of *Deaf-Blind Perspectives* to my current address.

I'm buried in interesting publications! Please remove my name from your mailing list.

Name: ___________________________________ Agency: ________________________________________________
Street: _____________________________________ City: ______________________ State: ____ Zip: _____________
Comments _______________________________________________________________________________________

Mark appropriate categories (3 max.)

- Person or parent of person who is disabled
- Special education (e.g., teacher, aide)
- Administration (e.g., Dept. of Ed., project director)
- Service provider (e.g., social worker, group home)
- Technical assistance provider
- Higher education teacher/researcher
- Regular education (non Spec.-Ed.)
- Therapist (e.g., OT/PT/speech)
- Teacher trainer
- Government personnel
- Medical professional
- Other ____________________________

Please send my copy in:
- Grade 2 braille
- Large print
- Standard print
- ASCII

Mail to: *Deaf-Blind Perspectives* ! Teaching Research Division ! 345 N. Monmouth Ave. ! Monmouth, OR 97361
or call Randy Klumph (503) 838-8885, TTY (503) 838-8821,
fax: (503) 838-8150, E-mail: klumphr@fstr.wosc.oshe.edu

*Deaf-Blind Perspectives* can be downloaded from Library 5 of the CompuServe Disabilities Forum.

*Deaf-Blind Perspectives* is a free publication, published three times a year by the Teaching Research Division of Western Oregon State College. The positions expressed in this newsletter are those of the author(s) and do not necessarily reflect the position of the Teaching Research Division or the U.S. Department of Education.

---

Non-Profit Organization
U.S. Postage
PAID
Permit No. 344

---

*Deaf-Blind Perspectives*
Teaching Research Division
Western Oregon State College
345 N. Monmouth Ave.
Monmouth, OR 97361

*Forwarding & Return Postage Guaranteed, Address Correction Requested*