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ABSTRACT

This document consists of the three second-year issues of a newsletter concerning people with deaf-blindness. These issues include the following major articles: "A Report on Deaf-Blind Technical Assistance Collaboration" (Paddi Henderson and Rich Mulholland); "Rabbits and Retards" (Joyce Ford), in which a parent describes an encounter between her deaf-blind son and a new friend; "Communication and Language Acquisition: To Teach or Not To Teach" (Kathleen Stremel); "Recreation and Leisure" (Lauren Lieberman); "Sorting Out the Challenges of Fatherhood: Vision and Reality" (Robert W. Moore); "Improving Outcomes and the Quality of Life for Children, Youth, and Adults Who Are Deaf-Blind" (Judith E. Heumann); three presentations on the National Deaf-Blind Program (the 307.11 program) by Bud Fredericks, Michael T. Collins, and Dawn Hunter; "Functional Assessment: Understanding and Identifying the Causes of Challenging Behaviors in Students Who Are Deaf-Blind" (James K. Luiselli); "Heidi's Inclusion in Junior High: Transition and Educational Planning for a Student with Deaf-Blindness" (Susan W. Edelman and others); "Children Who Are Deaf-Blind: A National Interest Requiring National Action'" (John Reiman); and "Let's Have an Institute" (Cheryl R. Kennedy and Bruce A. Dalke). Also included in each issue are news items, conference announcements, and regional reports. (DB)

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Deaf-Blind Perspectives

Volume 2, Issue 1 Fall 1994

A Report on Deaf-Blind Technical Assistance Collaboration

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Restructuring, reorganizing, resizing—all are current buzz words of business and industry. The increasingly competitive environment of our emerging global economy drives many organizations toward organizational change. This momentum behind change in private business and industry is beginning to spread to public entities, as exemplified by movements such as Re-Inventing Government, America 2000, and Health Care Reform.

There are, however, differences that surface when comparing change in the private and public sectors. Business and industry can affect the supply and demand of a product or service by manipulating the micro economies associated with that product or service. Education and other human service organizations, on the other hand, strive to meet the multifaceted needs of their constituents, but have little control over the variables that influence the availability and quality of resources. For example, the number of constituents eligible for services and the responsibilities of many public agencies have steadily increased, but increases in funding have not kept pace.

In This Issue

The Services for Children with Deaf-Blindness Program, which currently funds 46 single state and 3 multistate deaf-blind projects, is not immune to this dilemma. The number of children, birth to age 21, identified as being deaf-blind has grown from less than 2500 at the program's inception in 1975, to over 8400 children reported in the most recent census (Baldwin, 1994). We have also seen more children with complex etiologies and/or severe medical needs being identified, due in part to modern technology's role in the survival of medically fragile newborns.

Because of the implementation of Part H Programs (for children birth through 2) across an increasing number of states, greater numbers of children with disabilities, including those who are deaf-blind, are becoming eligible for state-mandated services. Within states that have implemented a Part H program, Federal Regulations 307.11(a) and (b) clearly state that the state or multistate deaf-blind project is not permitted to provide these direct services. However, according to Federal Regulation 307.11(c), the project must take an active role in coordinating services for these children with other state agencies. This often requires the state or multistate deaf-blind

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project to provide technical assistance services to a large number of agencies so they may provide direct services to these children.

The challenges become even more significant when viewed in light of the funding of the Services for Children with Deaf-Blindness Program. There have been no increases in funding in the past several years, even though all the variables discussed above have greatly affected the quantity and quality of expected services. The projects are being asked to do more for a greater number of children with no additional funding. Combine this with the staggering cost of inflation over the last 20 years, and the result is an urgent need to do things differently.

Clearly, if the expectations for state or multistate projects have changed, then the strategies to meet these expectations must also change. This article will define collaboration as a strategy to meet changed needs and will provide examples of how several state and multistate deaf-blind projects have used collaboration with other agencies for the development, enhancement, and the delivery of services. These efforts have involved multiple agencies within a single state, consortiums consisting of other state or multistate deaf-blind projects, and other combinations of technical assistance providers.

Understanding Collaboration

Successful collaboration requires mutual understanding and respect for each collaborator's work and is driven by the common needs and goals of the collaborators. Agencies within a state who provide services for children who are deaf-blind and their families and service providers (e.g., state and local education agencies, the Services for Children who are Deaf-Blind Project, HeadStart, Department of Health, Coordinated System for Personnel Development) have several inherent commonalities: constituency; state legislation, administrative procedures, and budgets; and participation in a common system (or lack of system) for coordinated service delivery. Such commonalities provide a forum for mutual understanding among intrastate collaborators.

> **"The projects are being asked to do more . . . with no additional funding. . . . the result is an urgent need to do things differently."**

The state or multistate deaf-blind projects also share characteristics that ensure collaborative success. For example, all of the projects are guided by the same federal rules and regulations, providing a common understanding of what must be done. Common needs have been consistently and clearly identified among state or multistate project directors. And, most important, the projects share a common goal: to provide the best possible services to children, families, service providers, and others who have direct contact with children who are deaf-blind.

Collaborative technical assistance activities are as varied as the needs that drive them. Table 1 illustrates five levels of collaboration and the conditions that must be present for success (Western Regional Resource Center, 1991).

Table 1: *Levels of Collaboration*

Level Of Collaboration	In Order To Succeed
Information Sharing ***(agreeing to keep agencies informed)*****:** making sure that collaborating agencies know one another's plans and anything else that might affect their (shared) work.	Those involved must consider the information needs of their collaborators.
Calendar Coordination ***(agreeing to not trip over other agencies)*****:** making sure that the calendars of all collaborators are organized well enough to avoid conflicting schedules.	Collaborators must be willing to constrain calendars and arrange timelines to fit with those of other agencies.
Events Coordination ***(agreeing to do things at the same time, or in logical sequence)*****:** arranging independent events (not necessarily related to the collaborators) at the same time/location, or in logical sequence (immediately following), so that there is some benefit in time, travel, or other event-related savings.	Those involved in the collaboration must set joint calendars; coplan events that are compatible; focus on more or less the same target audience.
Activities Collaboration ***(agreeing on what to do and doing it together)*****:** cosponsoring activities in which collaborators have codependent roles (e.g., sharing parts of a single conference agenda, sending related service personnel to the same location at the same time to facilitate training).	The cosponsored activities must be directed toward reaching compatible goals of the collaborators involved.
Strategy Collaboration ***(agreeing on what to do, how to do it, and what the long-range outcomes should be)*****:** cosponsoring a series of activities in which collaborators agree on a set of outcomes and actions as part of a long-range plan to promote systems change.	Goals and outcomes must be shared and all must agree on the strategy or series of steps to be taken to reach the goal. This employs collaboration for long-range strategic planning for change.

Note. From, Western Regional Resource Center. (1991). Proposal for a grant to operate a regional resource center to serve Region VI. (CFDA No. 84.028). Eugene, OR: Author. *Reprinted with permission.*

Clearly, collaboration can take many forms. Systems as they evolve, may move through all the levels or focus on activities within only one or two of the described levels. Collaboration becomes easier as trust grows and mutual respect deepens. The first few levels of collaboration can help build trust. Relatively small endeavors, such as sharing pertinent information in a timely, consistent manner, create win-win situations for the collaborators. As the complexity of the issues increases, (i.e., moving through the levels of collaboration toward strategy collaboration), a collaborative relationships becomes more complex. Trusting relationships become imperative. The foundation of a trusting relationship is believing that the other person and the agency he or she represents (a) has the integrity to meet commitments and keep promises; (b) will sometimes lead and not always follow; (c) has sensitivity to other people's needs and interests; and (d) will be open and honest while keeping others informed about actions and intentions.

Using Collaboration

As a way of maximizing effectiveness, many state or multistate deaf-blind projects have already participated in one or more levels of collaboration. Table 2 provides examples of recent collaborative activities between states or multistate deaf-blind projects and other organizations. Some efforts are ongoing; others have already taken place or are in the planning stage. By reorganizing, encouraging, and through the mutually reinforcing outcomes of collaboration, future opportunities for collaboration in the Services for Children with Deaf-Blindness Programs are enhanced.

(continued on next page)

Table 2: *Examples of Collaboration*

Collaborative Partners	Need Identified	Collaborative Action	Level Of Collaboration *(from Table 1)*
District of Columbia Maryland Virginia	Ongoing training opportunities for family members and professionals	Maryland sponsoring a parent retreat. Virginia hosting a summer institute; parents and professionals from DC invited to both; DC assisting financially; DC will host future activities for three states	Events Coordination
Indiana Illinois Blumberg Cntr for Studies in Spec Ed Project ENABLER	Information regarding infants and the development of vision	Support for writing of booklet titled "Helping Young Children with Visual Impairments Make Use of Their Vision"	Activity Collaboration
14 states in TRACES Western Region	Literature describing deaf-blind project and common behaviors of children who are deaf-blind	Developed "unified" awareness level brochure to be customized for use by all state projects in the region	Activity Collaboration
Arkansas Texas Five state agencies	Build instate expertise in area of effective practices for individuals who are deaf-blind	Planned and sponsored a conference to train family members and service providers from Texas, Arkansas, Oklahoma, Louisiana	Activity Collaboration
West Virginia North Carolina TRACES	Functional hearing and vision assessment processes and materials	North Carolina shared process and materials for vision assessment; states jointly developed process and materials for hearing assessment	Strategy Collaboration
Illinois Two state agencies American Foundation for the Blind HKNC TRACES	1. Training for professionals on early intervention strategies 2. Statewide parent organization	Sponsored workshop to train professionals and develop goals and action plans for parent organization	Strategy Collaboration
Utah Nine state agencies TRACES	A coordinated system for delivery of all services within the state for persons who are deaf-blind	Regularly scheduled meetings to develop a fully coordinated service delivery system with a single point of entry	Strategy Collaboration
Delaware Five state agencies TRACES	System for delivery of special education services for individuals who live in nursing homes and have complex health care needs	Process developed and implemented with four children for the delivery of special education services in local school district instead of in nursing home setting	Strategy Collaboration
14 states in TRACES Western Region NEC*TAS Western Regional Resource Center California State University-Northridge California Part H coordinator California Part B coordinator	1. Understanding Parts B and H 2. Knowledge of available state, regional, and national resource providers for early childhood services 3. Comprehensive, effective early childhood services delivery system	Two-day meeting held to: (a) discuss resources, (b) identify methods for collaborating with other providers including those not in special education (i.e., other state agencies, medical facilities, preschools), (c) identify components of a comprehensive, effective program for early childhood services	Strategy Collaboration

Benefiting From Collaboration

Numerous benefits result from the collaborative process. First, creativity flourishes when the talents, abilities, and resources of the participants are combined. Creativity not only strengthens the current methods used for providing services, but can lead to the development of new, innovative ideas. Second, as time and money resources become more scarce, collaboration enhances the resources available to any one project. Third, collaborative efforts help build a social support network that has benefits reaching far beyond the workplace and helps maintain personal and professional vitality. And finally, collaboration has been proven to be far more effective than competitive or individual endeavors. In a review of 122 empirical studies conducted by a group of University of Minnesota researchers 60% of the studies found that collaboration promoted higher achievement than competition did. Ninety-five percent of the studies found higher achievement through collaboration than through individual effort (Kouzes & Posner, 1987).

Groups working together and pooling resources can achieve much for children and families. Collaboration provides opportunities for extraordinary results.

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Rabbits and Retards

Joyce Ford
Parent

My 13-year-old daughter, Sarah, is an animal lover. At age two, she adopted her first kitten—a kitten that was destined to wear lacy bonnets and ride in a pink plastic baby buggy. Apparently, neither of them knew that this wasn't typical animal behavior for they both accepted it as a routine part of each day. She was heartbroken at age 4 when roaming neighborhood dogs attacked and killed Tooie early one cold spring morning.

Like many other parents, we immediately began searching for a new pet to help ease her pain. We tried many: two more kittens within the first year, a turquoise parakeet a few years later, a puppy the following Christmas, and a couple of hamsters. Our house was beginning to resemble a zoo, as we didn't seem to have enough sense to eliminate previous pets before adding another one. Sarah loved them all. Still, I did not see the bonding and devotion that had once existed when she was a toddler.

When Sarah was 11 we acquired two adult rabbits from my nephew. It sounded like a good idea. It wasn't. The rabbits were virtually wild and would growl and bite her each time she attempted to care for them. We soon had to find new homes for them. I was convinced that this would be the end of the rabbit business, but it wasn't. Sarah begged for another one. She wanted a little one that she could raise herself.

That Christmas, Santa felt the need to bring Sarah a baby bunny, and for the first time since she was little, I saw the essence of pure love and devotion pour out from within her. She and the bunny shared a special bond.

As time passed, more rabbits were added. We began building cages to house the pedigreed collection and Sarah was spending considerable time with them. Breeding soon took place, and eventually she had her own crop of bunnies to sell for Easter. It was delightful.

In April of 1994, Sarah entered two of her rabbits in a formal competition. This was a new experience for our entire family. It was also one of the few times, other than Christmas mornings, that I could recall Sarah being happy to be up so early. We loaded the whole family into the car along with our thermoses of coffee and hot chocolate and left the house early that Saturday morning for the half-hour drive to a small town west of us. It was a gray drizzly morning, but our spirits were high as we headed off on this new adventure.

I have never seen so many rabbits in one place. Big ones, little ones, wooly ones, and velvet ones. Each of them were accompanied by their loving owners—some adults, some children. There was a great deal of commotion as everyone prepared for the show. Rabbit paraphernalia filled the large room. I decided to escape the confusion by taking Riley for a walk.

We paused outside of the building to put Riley's jacket hood on. It was here that we met Everett, a blonde fifth grader who stared at Riley as he jumped excitedly in the light rain. I said hello and smiled at him. Everett took this friendly gesture as an invitation to talk.

"The kids at my school would call him a retard," he began. "I know they would."

"The kids at my school would call him a retard," he began. "I know they would."

I was surprised by his openness. His words stung me, still I was willing to continue the conversation.

"I think that's sad," I replied, "because Riley really likes school and he especially likes kids. I think that friends are really important to him." I paused as I tied the cord of Riley's hood and tightened the zipper closer to his chin. " Sometimes people are afraid of things they don't know about," I added. "Are you ever like that?"

Everett immediately assured me that, as an 11-year-old, he wasn't afraid of anything.

By now Riley had discovered Everett's presence and was busy trying to identify who this person was. He was feeling his hair, face, shoulders, and arm. I intervened when Everett appeared uncomfortable as Riley reached for his throat. I briefly explained Riley's disabilities and told him that Riley was touching his throat in order to feel him talk. I demonstrated this with Riley's hand on my throat. Everett still appeared nervous.

"Well," I said, "Riley and I were just going to take a little walk. Maybe we'll see you later." It seemed like a graceful way to let Everett off the hook. We turned away and began walking toward a second-hand shop I had spotted on the way into town. I knew it wouldn't be open that early, but I wanted to browse through the windows. Besides, it was pleasant outside in spite of the light rain and Riley was enjoying the walk as well. We stopped at an intersection a block away. I glanced behind me. There, a half-dozen steps behind, stood Everett.

"Would you like to walk with us?" I asked. He eagerly ran to Riley's side. I asked if his parents knew where he was. He told me a short walk would be okay with his dad. And so we continued on our journey, introducing ourselves, discussing our interest in rabbits, and talking with greater ease about being blind and deaf. I taught him sighted guide technique. He showed me what he could remember of the manual alphabet he had learned in Boy Scouts. He asked a lot of questions. I answered each of them. Eventually we decided that it was time to return to the show.

Riley and Everett walked and jumped together on the way back. They discovered a couple of mud puddles to stomp in. They held hands. They felt each other's throats and laughed at the vibrations of their voices. I smiled as I watched them together. It was I who now walked a half-dozen steps behind the two of them–by their choice.

They also chose to spend much of the day together. Everett patiently and carefully showed Riley each of the three hundred or so rabbits on exhibit. They ate donuts together. They checked out the guinea pigs. They shared hot chocolate. Everett taught Riley how to eat "Now-n-Later's," a gooey, chewy candy in a tattered wrapper that had obviously been stuffed into his pocket for some time. They were inseparable.

At the end of the day Everett told me he thought that Riley should be in 4-H. He had decided that Riley could raise rabbits by touch and I agreed with his thinking. He said he wished Riley lived in his town so that they could be in a 4-H Club together. He said he would like that.

Sarah brought home three blue ribbons that night. She was beaming with pride. Her efforts had served her well.

There is something to be said for persistence. I was reminded of that by Sarah, two small boys, and a conversation about rabbits and retards.

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Communication and Language Acquisition: To Teach or Not To Teach*

Kathleen Stremel
University of Southern Mississippi

One of the most important, and often difficult, instruction areas for students who are deaf-blind is communication. Over the years our approach to teaching communication may have changed but our intent remains the same: to teach students the skills necessary for effective interaction with others in their lives. The following article examines some of the history of communication instruction of students with disabilities, including students who are deaf-blind.—Ed.

The Beginning

Once upon a time there was a Training Maiden who was responsible for assessing and teaching language to students who had disabilities. The King decreed that this training should be conducted in a quiet turret room, high in the castle. In this manner, training would be held without other distractions. In those days "functionality' was not yet invented. The Training Maiden carefully selected stimuli that would be consistently presented. She knew the specific response that was being targeted, the conditions under which this response would occur, and the object/activity that would be used to elicit this response. Correct responses, incorrect responses, and approximations were recorded and analyzed so modifications could be made. In this manner, the students could be more successful in learning some aspect of language. This process was called the acquisition phase and, at that time, it was disputed by few persons in the Kingdom.

New Developments

As this type of training continued, there were some new developments in the Kingdom. It was noted that the students were using few of their newly learned responses outside the quiet, turret room. Only the Training Maiden could get the students to talk or use their signs. Only the Court Jester could get the students to play and laugh. Only the Knights could get the students to work. The world outside that turret room was a whole different world, a real world. There were many different objects, activities, and persons involved in the affairs of the castle and kingdom. Many of these persons did not know about the magical techniques that could be used to get the students to state their wants and needs and make choices. Members of the Round Table determined that the acquisition phase was not the only phase of training. Behold, there was generalization and maintenance of training as well. From that day forward, training changed. And that was good. Change was necessary if things were to progress in the Kingdom. Merlin had a vision that these students could be even more successful if *their* perspective was considered. He decreed that all persons should look more closely at the students' worlds and what might be important to them.

The Kingdom Gets Involved

More and more students with severe disabilities, including students who were deaf-blind, were seen in the Kingdom. The educational job became too much for the Training Maiden alone, and rightfully so. No one person in the Kingdom was wise enough to answer all the questions that arose. It was decided that every person who had any kind of a relationship with the students would share the responsibility of increasing their communication skills. Members of the Round Table declared that it was not enough to focus only on "how the students communicated." From that day forward each person also had to look at "why the students communicated." They had to realize that they had to be more sensitive to each student and that there were, in truth, many ways in which a student could communicate. Behold, a facial gesture, a slight movement, a vocalization—without being a word—could communicate something, sometimes, at least to someone who was special in the life of that student. It was determined that all the "natural" happenings in the students' Kingdom held potential for many opportunities to communicate. And this was true. And the Members thought that in this way everyone would live happily ever after. Different procedures were developed and evaluated to show that the natural Kingdom could present many opportunities for development of communication, participation, and relationships (Goetz, Gee, & Sailor, 1985; Halle, 1982; Hart, 1985). And many students flourished under these new rules.

Concerns in the Kingdom

As there was less strife with other Kingdoms, life within and outside the castle became more active. Knights, Knaves, Ladies, Jesters, and Serfs all had a role in keeping the Kingdom safe and productive. But as life went on, it was noted that the Kingdom in its natural state was not always as

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* *For those readers who prefer to digest the author's points in a more traditional format, the author has graciously provided such a draft which Deaf-Blind Perspectives would be pleased to furnish upon request.* —Ed.

good as it could be, especially for students who were deaf-blind. The King and Queen concurred that *all persons*, regardless of rank of nobility or serf, should have a voice in the affairs of the Kingdom. The Queen became especially concerned that this was not the case for many students who did not have the advantage of communicating at a distance. Thus, her findings were posted on the castle wall:

First: Many communication attempts made by the students have not been responded to. And for students with multiple disabilities, very few opportunities for communication have been made available (Houghton, Bronicki & Guess, 1987). Over the years as students with more severe disabilities reached adulthood, their communication attempts diminished, possibly in relation to the diminished opportunities for communication or the noncontingent consequences for their communication efforts (Calculator, 1988). For many of these students, instruction became passive rather than active, with persons acting on, rather than with, the students (Downing, 1988). Persons in many of the environments stimulated the students rather than targeting specific outcomes that would lead to an increase in effective communication and greater participation in the Kingdom.

Second: Many teachers did not understand the progressive nature of communication and language and thus, unknowingly, simply nurtured affective states of behavior (Stillman, 1992).

Third: In fact, many students who were deaf-blind were not acquiring higher forms or more effective communication. It was difficult for anyone in the Kingdom, except Merlin, to learn any new skill when only 5–10 opportunities a day were available to learn the skill. Thus, it was noted that even the Knights who repeatedly practiced hitting a target on a tree were more successful in hunting and in battle than those Knights who only shot their arrows in battle. Often those nonpracticing Knights did not return from battle. However, the practicing Knights who never had an opportunity to hunt or to go into battle soon became bored and lazy.

In summary, the King and Members of the Round Table agreed that the effectiveness of teaching communication and language in highly structured contexts with systematic teaching procedures had been adequately demonstrated (Guess, Keogh, & Sailor, 1978). Whereas the acquisition of communication and language based on direct instruction in 1:1 or small group formats had been effective with many types of students, the corresponding use of the targeted skills in more natural environments had often been disappointing (Halle, 1988; Reichle & Keogh, 1985; Warren & Rogers-Warren, 1980).

Solutions

Thus, in the years that passed, it was determined that generalization was only "real" if some behavior or skill had first been "acquired." The elders determined that possibly some of the new ways were indeed working for some students, but not with others. That somehow, in all the years of "individualization," they had missed looking closely at the individual student. They had not truly looked carefully to see what was working for some students and not for others—and why. A Round Table summit was called to determine the knowns and unknowns so that the Members could report back to the King and Queen.

The Knowns. A Subcommittee of the Round Table reviewed the massive literature and found some interesting findings. The need to utilize *both* direct instruction and the natural environment for those students who infrequently initiated communication and language had been proposed in the past (Keogh & Reichle, 1982; Holvoet, Guess, Mulligan, & Brown, 1980; MacDonald & Horstmeier, 1978) but many teachers of students who were deaf-blind and severely disabled seemed to have forgotten this. Perchance, they thought words such as, *enhancing*, *facilitating*, and *promoting*, would make the student's communication such. Thus, the Members considered the knowns:

1. Engagement: Those students, who were learning to communicate more effectively in their natural environment by using new forms, new uses of communication, and communicating about more things to more people, demonstrated high rates of engagement with their physical and social environment (Halle, 1988; Hart & Rogers-Warren, 1978). Many of these students had vision and hearing abilities so they had the advantage of learning language at a distance. Thus, they could learn incidentally.
2. Motivation: Activities that afford opportunities for communication must also be motivating to the student. That does not mean that activities that are motivating will naturally contain frequent opportunities for communication. For example, work experiences may be very motivating and yet few opportunities for communicating wants and needs may be available. Or, gesturing "finished" may only be reinforcing if it is followed by a cool drink.
3. Repetition: Activities that have frequent cycles of repetitions also present more opportunities to teach communication than those activities in which a skill is not repeated. Activities for younger children are

often more repetitive than age-appropriate activities for older students.

The Unknowns. The Members of the Round Table reviewed the report of the Subcommittee and announced that there remained a number of unanswered questions.

1. Why do there remain so many students who are deaf-blind, with other disabilities, who do not make better progress in communicating?
2. Are the teachers no longer being taught by Merlin to conduct direct instruction or to determine when it is necessary and for which students?
3. Are the magicians the only ones able to use procedures in the natural environments?
4. Do the magicians have to develop new ways of teaching the teachers?
5. Do teachers, who conduct direct instruction, provide more opportunities in the natural environment than teachers who do not conduct direct instruction? Are they then, perchance, more responsive to the students' forms and functions of communication?

Summation

The Members of the Round Table reported to the King: Perchance, we need to look again at direct instruction.

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Deaf-Blind Perspectives
To Be Or Not To Be A Journal

Bud Fredericks
Executive Editor

This is the fourth issue of *Deaf-Blind Perspectives*. When we started this publication we had the goal of creating a forum for parents and professionals to share ideas, opinions, and research. Because of the heterogeneity of people who are deaf-blind, we anticipated we might generate some debate. To some extent we have succeeded. We are receiving some articles of opinion and a few containing research, but to date, we have generated little debate.

We have also established journal-like standards for the publication. Each submission is reviewed by at least three readers who do not know the identity of the author(s). This explains why some of you may have been asked to revise your writing or may have had your article rejected.

We have established these rigid publication standards because we are considering converting this newsletter to a journal. As we consider this, we appreciate any input that you, the readers of *Deaf-Blind Perspectives*, may have.

Some of the concerns that enter into our deliberations for conversion to a journal are the following:

- Are the readers interested in a journal?
- Can we generate a sufficient number of articles to maintain the publication of a journal?
- Are readers willing to pay a nominal fee for a journal? (The journal would be published at cost.)

If we were to convert *Deaf-Blind Perspectives* to a journal, we anticipate that it would

- Maintain rigid standards for publication and continue the practice of having submitted articles reviewed by a jury of peers.
- Have no established philosophical orientation and would entertain articles with differing views.
- Accept for publication an eclectic array of writings—research articles, conceptual pieces, and submissions—that present practices and opinions from parents and providers.

We recognize that this latter characteristic would cause our journal to differ from many existing research journals. We maintain that such a feature is necessary if we are to retain the ability to represent the wide diversity of views that are present.

We are struggling with this decision regarding conversion of this newsletter to a journal. We seek your opinions about such a change.

Please contact us at:
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DB-LINK

Recreation and Leisure*

Lauren Lieberman
Doctoral Student
Oregon State University

People join recreational groups for many reasons—for fun, exercise, and meeting others. They look forward to Tuesday bowling, Saturday hikes, Sunday book discussions. Best of all, when people take time off from everyday responsibilities, they return to them later, refreshed. In a way, recreation re-CREATES us.

People who are deaf-blind and have cognitive disabilities enjoy recreational activities just as you and I do. To combat the isolation and lack of independence that often result from their disabilities, they NEED them even more than we do.

Start with the Individual

What is he or she interested in?

- What types of recreation has he or she participated in previously?
- With whom does he or she prefer to spend leisure time?
- What are this person's favorite activities?
- At what time of day is recreation most enjoyable for this person?

People who are deaf-blind are as diverse in their interests as everyone else. Check the list below for some ideas. Remember, this list is only a start.

Fitness Activities
aerobics
swimming
walking
track and field
wrestling
running
cross-country skiing
weight lifting
gymnastics
bicycling (stationary/tandem)

Outdoor Activities
fishing
hiking
kayaking
sledding
camping
canoeing
horseback riding
rowing

Home Activities
cooking
needlepoint
arts and crafts
gardening
knitting
listening to music

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* *This article is available as a fact sheet from DB-LINK. To request your copy(ies), refer to the contact information at the end of this article.— Ed.*

Table Games
- card games
- dominoes
- bingo
- board games (chess, checkers, etc.)

Community Activities
- bowling
- roller skating
- martial arts
- ice skating
- dances (folk/social)
- diving

Sports Activities[1]
- USABA
- AAAD
- school sports
- Special Olympics
- community leagues
- goal ball (individuals with hearing)

What Activities are Age-Appropriate?

Age-appropriate activities are those activities normally found in the individual's culture and geographic location that are geared to the individual's chronological age.

Observe other people of the same chronological age to determine what activities are appropriate. Some examples of age-appropriate activities enjoyed by teenagers in our culture are bowling, dancing, swimming, and video games. Activities which are not appropriate for this age are duck-duck-goose, riding children's tricycles, or interacting with preschool toys. Many children who are deaf-blind will choose an inappropriate activity. Our goal is to broaden their experience and move them on to choices that are appropriate.

What is Safe?

If the individual is engaging in a new fitness program, the physician should be informed. If there is a heart condition, a potential for retinal detachment, tubes in the ears, or a shunt, the physician will then inform the staff or parents of any cautions that must be taken. But remember, almost any activity can be adapted for individual needs.

What is Available?

Find out what recreational activities are available at the person's home and school. Consult with the following groups to see what is available in the community.

- YMCAs/YWCAs
- church leagues/synagogue leagues
- community leagues
- college- or university-affiliated programs
- local deaf clubs
- local associations for the blind

Research the Communication Patterns

It is important to determine each person's communication patterns and needs. For example, he or she may use augmentative communication devices such as schedule boxes and communication boards that use symbols, pictures, objects, and/or words. Since each person will have developed unique ways of using these, you will benefit from all the information you can gather. This can be as easy as looking in the files or getting the information from previous teachers, residential personnel, parents, siblings, or peers. You'll soon find that each person is unique.

Develop a Plan

Once the above steps have been taken, you can develop a recreation plan. This plan should include short- and long-term objectives that have been developed, if possible, by a team consisting of the individual, the family, and the staff. Remember that the overall goal is to find an activity that will be fun and will provide relaxation. Be sure to set the stage for successful recreation.

Maintain Interest

Establish a Time Period

Establish a period of time that is appropriate for trying out a new activity. At the end of the period, let each person evaluate the pleasure derived from the activity. He or she can then decide whether or not to continue. Use of a time period helps prevent feelings of failure; it also ensures that enough time is given to the activity to provide adequate information for making a good decision. For example: 17-year-old Robert chooses Tae Kwon Do in the community club. The parents suggest a 6-week session to determine if he enjoys the activity. At the end of the 6 weeks, Robert may choose to continue, or he may end the session and choose another activity.

Select the Proper Time of day for the Activity

Try to schedule the recreational activity for the time it is most needed to meet individual needs. For example: Amy is a 14-year-old who is in an educational setting. She is faster than her peers at getting dressed in the morning. As a result, Amy has 20-25 minutes every morning when she has nothing planned, and there are not enough staff to direct her play or an activity. She used to engage in self-abuse and became intensely agitated. When the recreation specialist noted that Amy loves to ride the stationary bike, the bike was made easily

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[1] Work with clubs and organizations for those who are deaf to encourage individuals who are deaf-blind to participate in social activities to reduce isolation.

accessible to her. Now, every morning, Amy gets on the bike and rides for 20-25 minutes. She does not become agitated, and her self-abusive behavior has decreased.

Modify the Activity When Necessary

Most recreational activities were developed with hearing and sighted people in mind. In many cases, an adaptation that is relatively minor can make these activities enjoyable and safe for those who are deaf-blind. For example, the children in Shannon's Girl Scout troop go roller skating every week. Shannon, like many young individuals who are deaf-blind, has difficulty keeping her balance. By using a skate aid device, Shannon can safely participate in roller skating.

Ask each person if he or she prefers the help of a guide or assistance from peers. However, be aware that some persons may prefer activities that promote personal independence.

Discover the Best Ways to Teach

The following teaching strategies will help each individual succeed and make the learning process more effective.

Orient the Individual to the Playing Area

Give each person the opportunity to explore and become familiar with the equipment involved, other persons in the room, and the physical site. The absence of reliable visual and auditory input makes this a time-consuming process, but it is essential.

Explain

Select language (oral, sign, or augmentative systems) appropriate to the pupil's functioning level and communicate the key points of the skill.

Demonstrate

This is a practical teaching strategy only for persons with usable vision.

Use Brailling or Feeling and Imitation

In this method, the individual who is deaf-blind feels the instructor execute the skill or activity being taught. The skill must be carefully analyzed by the demonstrator prior to the instruction in order for the demonstration to be effective.

Use Physical Guidance/Hand Over Hand

Place the student's body and/or limb(s) into the appropriate position and help him or her perform the desired movements at the preferred speed. Physical guidance can range from total physical assistance to a gentle touch that prompts him or her to complete a task.

Enable Choice Making

Many people who are deaf-blind go through their days with someone else making decisions for them. When they get involved in recreational activities, they must use choice-making skills. Begin with simple choices. First, offer two activities and allow him or her to choose the order in which they will be done. Next, give a choice of two or three activities and let him or her choose which one to perform. As each person increases in ability to make choices, remove prompting and allow more independence in decision making.

Use Additional Strategies

Begin with the amount of assistance that will ensure desired performance and success.

Combine teaching techniques to ensure the individual is learning as much as possible. For example, Eddie is 16 and learning the game of T-ball. He is deaf and has some residual vision. When standing at bat in the game, Eddie needs to be reminded of which way to stand and when to bat the ball. The instructor models which way to stand, signs "hit the ball," and taps Eddie on the elbow. Eddie than bats the ball off the "T." In this case, both explanation and physical guidance techniques are used.

Be aware of the individual's responses. Try to minimize assistance as soon as you feel the individual is learning the skill in the appropriate manner.

Provide immediate and accurate feedback so that he or she can make necessary adjustments before the next attempt (McInnes & Treffry, 1993).

Allow each person to practice the skill in an environment that is as normal as possible. This will allow the transfer of skills to occur much more easily.

Be patient. Progress may be slow due to learning the new skill as well as learning a new terminology to go with it.

Decrease physical involvement cues to cues that are natural or typical to initiate desired performance. For example, in a dance unit, start with hand-over-hand assistance (unless he or she has enough ability to start with a less intrusive cue) and work toward a touch cue to initiate desired movement.

Be sure hearing aids and glasses are on and functioning (unless, of course, you are in the pool).

Be sure to select leisure activities that are chronologically age appropriate and also are utilized by the general population (Hamre-Nietupski, Nietupski, Sandvig, Sandvig, & Ayres, 1984).

Consider featuring individuals who are deaf-blind who have special recreational talents on local news shows to raise public awareness.

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NFADB Membership Drive
Join the National Family Association for Deaf-Blind

NFADB has been established to address the needs of families of people who are deaf-blind. If you would like to join this national non-profit organization, please complete and return this coupon.

Regular Memberships: any person who is deaf-blind, the parent, guardian, adult sibling, or other individual having a similarly close interpersonal relationship with a person who is deaf-blind.

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Name ______________________________ Organization ______________________________

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How old is the person who is deaf-blind? __________ Their relationship to you is ____________________

What is the cause of this person's deaf-blindness? ______________________________

Please return with check payable to **NFADB** to:

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NFADB

DB-LINK and **TRACES** announce the availability of their displays for conference poster sessions. These professional looking, lighted displays can be shipped directly to the conference site and returned prepaid. Each display requires a 6-foot table near an electrical outlet (if you want to use the lights). If you would like to reserve one or both of these displays for your next conference, please contact:

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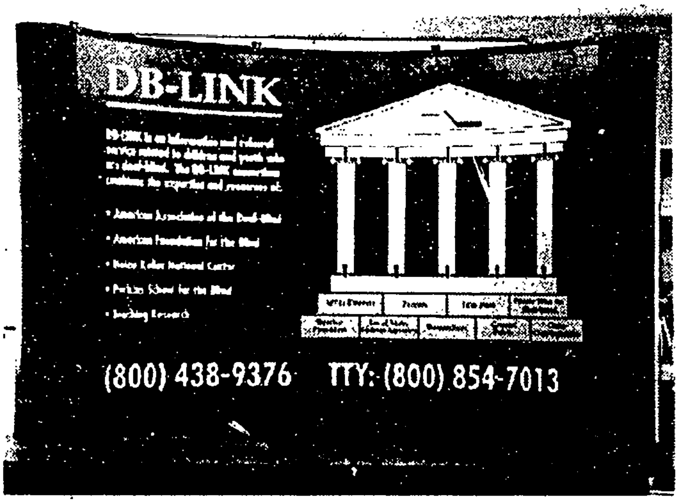

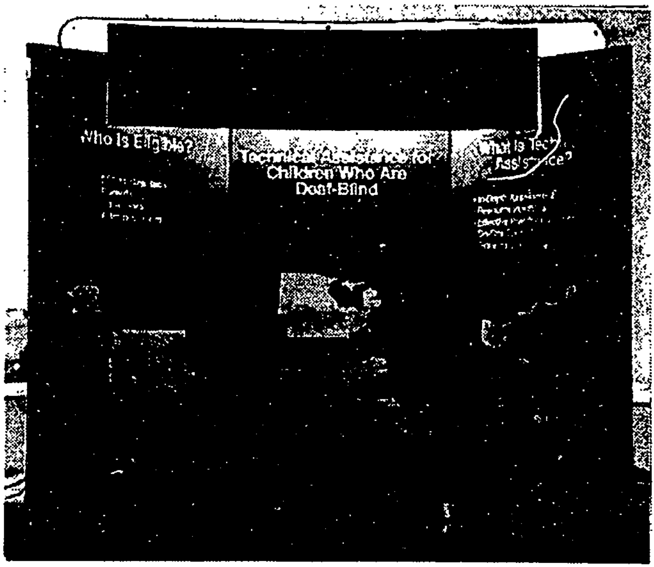

Request for Assistance

The 307.11 Project staff of Arizona, Utah, Colorado, and New Mexico are gathering information on working with families of cultural diversity. The three areas of interest include the following:

- information about sensory impairment that is presented in a language other than English
- information on how to work with families from different cultures
- information about the state of national resources on multicultural education for families with children who are disabled

If you have any information you would like to share, please send it to:

Tanni Anthony
Colorado Dept. of Education
201 E. Colfax Ave
Denver, CO 80203

ph: (303) 866-6681
fax: (303) 866-6811

Thank You!

The editors of *Deaf-Blind Perspectives* would like to extend a special **thank you** to the following individuals who have donated their time to review all of the manuscripts submitted to *Deaf-Blind Perspectives* for possible publication in Volume 1, Issues 1–3.

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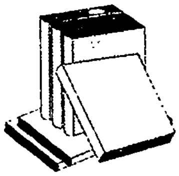
Art Roehrig



For Your Library

Ain't Misbehavin': Strategies for Improving the Lives of Students who are Deaf-Blind and Present Challenging Behavior

by Outreach Department of Texas School for the Blind and Visually Impaired. Austin: 1993

This video tape offers practical strategies for proactively avoiding interactions which challenge relationships. It is valuable to families, educators, educational support staff, in-home and residential support providers, friends and community members, and anyone else who regularly interacts with a child who is deaf-blind. The crucial links between behavior and the issues of communication, control, and quality of life are examined. A copy of the script accompanies the video and is available in braille upon request.

Length: 16 minutes, cost: none send a blank VHS tape (30 minutes minimum) and request this title.

To order contact:
Outreach Department
Texas School for the Blind and Visually Impaired
1100 West 45th Street
Austin, TX 78756
ph: (512) 454-8631

For Your Rolodex

Collaboration Among Parents and Health Professionals (CAPP)

CAPP is a parent-run resource system for children with special health needs and their families. The purpose of the project is to develop a parent organized, nationally coordinated system that will maintain and strengthen parent and family involvement in health care. The project is built upon the recognition that understanding the needs of families is central to achieving this nation's agenda for family-centered, community based, coordinated care. CAPP provides written materials, training packages, workshops, and presentations for families and professionals.

Contact:
CAPP
95 Berkeley Street., Suite 104
Boston, MA 02116
ph: (617) 482-2915
(800) 331-0688

Sibling Support Project

The goal of the Sibling Support Project is to facilitate the creation of statewide systems of peer support and education programs for brothers and sisters of children with special needs. This is accomplished by providing training, providing demonstration and technical assistance to projects and agencies, disseminating written materials and presentations, and developing and refining products related to peer support and education programs.

Contact:
Sibling Support Project
Children's Hospital and Medical Center
4800 Sand Point Way NE
Seattle, WA 98105
ph: (206) 368-4911

National Center on Educational Restructuring and Inclusion (NCERI)

NCERI is concerned with inclusion of students with disabilities in the context of broad educational restructuring. Toward this goal, NCERI addresses issues of national and local policy; disseminates information about programs, practices, evaluation, and funding; provides training and technical assistance to school districts and state departments of education; builds a network of inclusion districts; identifies individuals with expertise in inclusion and conducts research.

Contact:
NCERI
Graduate School and University
Center City University of New York
33 West 42 Street.
New York, NY 10036-8009
ph: (212) 642-2656

Parent Advocacy Coalition for Educational Rights (PACER)

PACER is an educational advocacy organization providing parent education and training to help parents understand the special laws and information on how to obtain special education school programs for their children and young adults. PACER offers workshops and programs on a variety of topics as well as inservice training, interpreter services, computer resource center, transition planning, newsletters, booklets, videos, and other materials

Contact:
PACER
4826 Chicago Avenue South
Minneapolis, MN 55417-1055
ph./fax: (612) 827-2966
(800) 53PACER (Minnesota only)
TTY: (612) 827-3065

Traces

Regional Reports

KANSAS

A series of three staff development training sessions are being sponsored in a collaborative effort by personnel from four projects. Those projects are the Kansas Services for Students with Dual Sensory Impairments Project, HKNC-TAC Project, TRACES Project, and the Kansas Dual Sensory Impairment Pilot Project: Promoting Access for Children with Exceptionalities. Each session is designed to build on the information provided in previous training sessions, but participants may elect to attend one, two, or all three of the sessions. Follow-up technical assistance from the Kansas Deaf-Blind Project is provided for those participants who complete all three sessions.

The first session was July 25–29, 1994, in Topeka, Kansas. The institute activities were facilitated by Terry Rafalowski-Welch and guest speakers included Pam Cress, Program Coordinator of a special project to prepare personnel to provide vision screening and evaluation services to children from birth to three years of age; Joan Houghton, Program Associate from HKNC-TAC; John Mascia, Coordinator of Audiological Services at HKNC; and Sally Roberts, Assistant Professor at Kansas University and Project Director of a project to prepare educational interpreters for the deaf. Topics in this one-week institute include basic anatomy of the auditory and visual systems; as well as interpretation of the results from both medical, functional, hearing, and vision evaluations for the purpose of designing instruction. Additional topics included consideration of sensory impairments in the design of community-based instruction, as well as the impact of dual sensory losses on planning, implementing and evaluating instructional programs.

The second in a series of sessions will occur in the fall with a focus on communication intervention. The third session will occur in the winter with a focus on orientation and mobility intervention for individuals who are deaf blind.

For additional information contact:

Julie Mohesky-Darby
Kansas D/B Project
(913) 296-3953

Cheryl Kennedy
TRACES Project
Northeast Regional Coordinator
(412) 648-7176

ARKANSAS

In 1992 a need was identified for training service providers and families in the area of functional assessment of vision and hearing and subsequent adaptation of materials and activities for children who are deaf-blind. This need was met through group instruction and on-site consultation which focused on two students who are deaf-blind in the Little Rock Public Schools.

In September, 1993, while implementing the consultants' recommendations, it was noted that there was also a need for training service providers and families in effective practices for communication and orientation and mobility for these students. Therefore, during the 1993–1994 school year technical assistance was provided by two consultants with expertise in these areas. As before, there was on-site consultation with child-specific recommendations for three identified students. Large group instruction on these topics was provided at the statewide conference, Special Show, in July, 1994.

Although only three students received hands-on technical assistance, the techniques and strategies suggested will be applicable to many other students with sensory impairments and multiple disabilities.

In addition, the 307.11 coordinator is working to develop these classrooms as implementation sites which can then be used when other local education agencies in Arkansas want to replicate the effective practices demonstrated here.

For additional information contact:

Teresa Coonts
Project Coordinator
(501) 682-4222.

CALIFORNIA

Parents and teachers in California are getting "Just the Facts!" and smiling about it. Specialists with California Deaf-Blind Services (CDBS) have developed over 20 fact sheets for teachers, families, and others who work with individuals who are deaf-blind. The fact sheets are single-topic information pages that are written to be easily understood. They are designed for the beginning professional and others who may not have extensive background or training in this area. In cooperation with TRACES and states in the Western Region, fact sheets have been developed to address medical issues, light sensitivity, basic interaction and communication, ideas for recreation and leisure, and many more topics. New fact sheets are developed based on requests from families and teachers.

The fact sheets have recently been translated into Spanish, allowing many more families to increase their effectiveness and involvement in planning and supporting the educational programs for their children. TRACES is assisting CDBS in translating the fact sheets into several Southeast Asian languages and other Pacific Rim languages. Fact sheets in these languages will be available beginning early in 1995. The fact sheets will also be supported with multimedia. CDBS and TRACES are developing several video tapes that will graphically illustrate and enlarge the information available in the written pages. The fact sheets in English have been made available on SpecialNet on the National Deaf-Blind Bulletin Board and are included in the DB-LINK collection. Additional fact sheets will be disseminated as they become available.

For additional information contact:

Steve Johnson
CDBS
California Department of Education
515 L Street, Room 270
Sacramento, CA 95814
(916) 327-3502
SpecialNet: CA.SE. Johnson

INDIANA

Six teachers of students who are deaf-blind have recently completed their fourth and final summer institute leading to their designation as *mentor teachers*. These mentors support other Indiana teachers in the implementation of educational best practices for students who are deaf-blind.

Summer Institute IV was conducted July 11-15, 1994 at Indiana State University. Topics for the week included housing options and community supports for young adults in Indiana who are deaf-blind, parent perspectives on educational planning for their child, resources available through state agency programs for children and youth who are deaf-blind, assistive technology and augmentative communication strategies, and a session on meeting the visual needs of students who are deaf-blind.

The mentor teachers left the summer institute with technical assistance responsibilities for the upcoming school year. Action plans were developed by each mentor. Follow-up support will be provided by the Indiana 307.11 project coordinator. The mentor teachers will also attend a weekend retreat in September, 1994. The topics for this retreat are the use of creative problem-solving strategies and how to recruit and train the next cohort of mentor teachers.

For additional information contact:

Karen Goehl
Indiana Deaf-Blind
Project
(812) 237-2830

Margie Briley
Regional Coordinator
TRACES
(412) 648-1424

VIRGINIA

The Virginia 307.11 Project has just completed its first Summer Institute for parents, service personnel and teachers of children who are deaf-blind. Presenters and guests from around the United States and Canada were given an overall view of children who are deaf-blind, from the perspectives of community members, the family, and education personnel.

Many of the participants came to the institute as part of an educational team, others made additional contacts with other teachers from their area, and all gathered information on team building. These teams and individual teachers will incorporate the action plans developed in the Summer Institute into the new school year. Participants will also encourage parents to be more involved in the educational decisions as part of the educational team. Better interaction of school, home, and community—with the child at the center—is the goal of this and future summer institutes.

For additional information contact:

Toni Waylor-Bowen
Southeast Regional Coordinator
TRACES Project
(404) 651-4089

TRACES (Teaching Research Assistance to Children Experiencing Sensory Impairments) is funded through Cooperative Agreement No. HO25C30001 by [illegible] U.S. Department of Special Education, OSERS, Special Education Programs. The opinions and policies expressed by TRACES do not necessarily reflect those of the U.S. Department of Education.

Sorting Out the Challenges of Fatherhood: Vision and Reality

Robert W. Moore
Parent

This article shares the perspective of one father of a child who is deaf-blind. The editors of *Deaf-Blind Perspectives* would like to invite other parents to share their views.—ED.

Being a father is one of life's great challenges. This is true regardless of the circumstances in which a man takes on that role. One problem I have faced as the father of a child who is deaf-blind and has other disabilities is sorting out which parts of my experience are regular father-role challenges and which result from an extra increment of challenge due to my son's serious, multiple disabilities. Here is what I have come to think as I sort out my own experience. Other fathers will no doubt have different interpretations of their experiences which are equally legitimate. Perhaps some of what follows is relevant to the experiences of mothers as well, but I'll let women speak for themselves and interpret their own experiences.

> **"From the moment I knew I was going to be a father, I began creating a vision of my child."**

When Cherry told me she was pregnant, it pleased and excited me. We were ending a decade as married students and we were in our early thirties. The time to start our family had arrived. It made me proud when it appeared we had gotten a "hit" on our first try at pregnancy. I embraced my new role as father-to-be with joy and expectation.

From the moment I knew I was going to be a father, I began creating a vision of my child. I built that vision with personal experience, memories, and cultural resources, ideas and images about "childkind." As the pregnancy progressed, we undertook our household preparations, Lamaze training, and social celebrations. I became more committed to my vision. I even learned through ultrasound about 2 months before delivery that I could expect a son.

I believe this vision-making process is a normal part of taking on the role of a father. As with most visions, however, mine was idealized, oversimplified, and unrealistic. That was okay, though. There would be time enough to bring my vision into conformity with reality as my son grew. I expected adolescence would be the time of the greatest challenge as my son created his own adult identity, separate from the one his mother and I had supplied for him. I would have to face the fact that my son would grow into a person with a mixture of strengths and weaknesses, that he would become more complex and more real than the vision I had constructed of him. I was prepared to work through adolescent conflict when it came in a decade or so. I expected to move beyond it into a lifetime of satisfaction as my son's adult friend.

Lew was born in the late summer of 1981 after a seemingly normal pregnancy, labor, and delivery. It wasn't until he was 5 months old that the evidence of problems was too strong to deny. After 2 more months, filled with a multitude of medical tests and consultations, we learned that Lew had suffered a brain injury of unknown origin. He had a seizure disorder and cerebral palsy. In the next few years other diagnoses were added, including functional deaf-blindness and severe mental retardation. Despite his assets (he is a handsome child with a sweet disposition), Lew faced lifelong dependence and ongoing developmental and medical challenges.

Before Lew was 6 months old, I began to grieve for the loss of my vision of him. I believe some of my grief was much like that to which every father is vulnerable as his child moves away from that early parental vision into adulthood. There were some important differences for me, however. Perhaps other fathers of children with disabilities or special health needs have experienced some of these differences as well.

The first difference was that I experienced the loss of my vision for my son much earlier than I expected, earlier than normal, I believe. I imagined that adolescence would be the climax of my confrontation with the fact that my vision was inadequate to explain the reality that my son would become. It was painful for me to take up this developmental challenge in my own life more than a decade before I expected it.

The second difference was that I experienced the whole loss of my vision in a very short span of time. Rather than a gradual, part-by-part giving up of my vision, it quickly became clear that the whole of my vision was inappropriate to the reality that was Lew's life. I couldn't revise my vision gradually with incremental adjustments, or give it up a little bit at a time. It all went at once.

The third difference was the depth to which my vision of my son was shown to be wrong. I was prepared to see Lew grow up to be different from me. For example, I value academic life, but I was willing for him to be an average student. Graduate school, or even college, though desirable from my point of view, would be up to him. I was not prepared to face the reality that he will never read, write, or speak. My vision had what I thought was a generous latitude within which he would make choices that expressed his own gifts and interests. I didn't allow room in my vision, however, for what I now expect will be his total lifelong dependence on others for feeding, dressing, moving, toileting, and deciding.

The fourth difference is in the additional tasks imposed on both Cherry and me by Lew's disabilities. Implementing therapy programs at home, being partners with professionals in planning care and education, dealing with the financing of needed services, advocating for better practices, policies, and laws, and participating in training and support activities are some of the tasks that have made the substance of fathering different for me.

I have found the sadness or grief over the lost vision of my son to be deeply and persistently painful, perhaps an instance of chronic sorrow which has been described by Olshansky (1962) and others. I've worked at revising my vision to consider the impact of my son's disabilities on his life chances. This revisioning has been difficult in part because I started from a poorly informed understanding about the lives of people with disabilities. I had few memories or experiences with which to build that new vision. The culture of segregation and denial which hides people with disabilities from sight gave me few cultural resources to use and even fewer that were hopeful or uplifting. I found myself hungering for stories, for information I could use to construct a hopeful, positive new vision of my son's life.

> **"I have found the sadness or grief over the lost vision of my son to be deeply and persistently painful. . . ."**

Until now, 12 years later, I've not been very successful. Many of the success stories told at conferences and training events don't apply to my son. Some are like miracle stories upon which it seems unrealistic to rely. I've become wary of professional fads upon which some people build their careers which don't have much impact on people like my son. Trust, and trustworthiness, is in short supply. The fragmented vision which persists in my imagination is not particularly positive nor hopeful, at least compared to the espoused values and aspirations that I hear from some professionals who try to help Lew.

I've tried to find generalizations about fatherhood to attain a better understanding of my own experience of fathering. For example, I believe it is common for fathers to eventually see their children grow into people who are different from the oversimplified, idealized, and unrealistic vision that they began constructing before they were born. I think this is a normal, natural part of the life cycle for men who take on the father role. When severe illness or disability challenges their children, however, the way they experience this process may accelerate. It may become more comprehensive and of greater degree than many men are prepared to adapt to with a feeling of success. In addition to grief, I find that I personally also experience a deep sense of failure in my role as a father.

Though many people are ready to discuss grief with me, I find few who will legitimate, affirm, and help me work through my feeling of failure. Some fathers of children with disabilities may not interpret their experience as failure. Others, however, have acknowledged that the idea has the ring of truth for them. Most commonly, when I bring up the topic, people will deny the legitimacy of my feeling with contradictory words meant to be supportive ("Oh, you haven't failed, you're a wonderful father," or some similar denial). Thus a painful, sometimes debilitating aspect of my own emotional life remains mostly private and unshared. I suspect this matter of failure is acute for many fathers of children with disabilities because of the way men are socialized in our society. Perhaps most people find it easier to deal with a man's feelings of grief, or even guilt, than with his feelings of failure. I believe that reticence in facing, legitimizing, and sharing feelings of failure devalues fathers. It is part of a social control system that can reduce their power and feelings of self-worth. This, at least, has been part of the experience that I have had as the father of a child with severe disabilities.

Fathers of children with disabilities face huge challenges in the performance of their roles. I'm sure that not all of them interpret their experience in tha same way. Some of these challenges are faced by all fathers, while extra challenges derive from their children's disabilities. Sorting out the regular from the special challenges has been important to me as I try to be a better a father to Lew.

Bob Moore lives in Lexington, Kentucky. He is married to Cherry Winkle Moore and they have two sons, Jay age 11 years, and Lew, now 12 years, who resides at the Home of the Innocents in Louisville, Kentucky.

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Deaf-Blind Perspectives

Volume 2, Issue 2 Winter 1994–95

This issue of *Deaf-Blind Perspectives* is primarily devoted to considerations that surround the reauthorization of the Individuals with Disabilities Education Act (IDEA). We are very fortunate to have a lead article by Judith Heumann, Assistant Secretary, Office of Special Education and Rehabilitative Services. We are grateful to her for taking the time to prepare and submit the article. However, the reauthorization of IDEA is not without potential problems for the deaf-blind community. These are highlighted by the reprint of the letter from the National Coalition on Deaf-Blindness and by presentations made at the recent Project Director's meeting, which are reproduced in this issue. People interested in the future of deaf-blind education should read all of these articles carefully.—ED.

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.

In this Issue

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 Monmouth, 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

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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.

> **"...the task of addressing the special needs of children who are deaf-blind has grown more difficult."**

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.

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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.

> It is difficult to bring our agenda to the forefront. When we had a Rubella epidemic, we got the attention of Congress.

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 a 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 underfunded 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, are 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 enmeshed 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.

Presentation 2

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.

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

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 [illegible]s. The result is that very few educators are ac[illegible]lating 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? 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.

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

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. We will never improve the quality of services at the local level unless we all acknowledge the need for significant improvements.

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. The purpose of this committee would be to ensure ongoing input into the directions of the program, so services remain strong and focused upon the needs of children. It would also help to ensure a reasonable balance of philosophy and power in the field. In order to set a policy that is responsible and appropriate, OSERS must have a formal, organized means to get advice and input from a variety of sources.

Improve State and Multistate Projects under 307.11

Each state needs a 307.11 project with adequate funding to offer meaningful supports 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

project 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 National Center, Perkins School for the Blind, St. Luke's-Roosevelt Hospital, and Teaching Research. The result is a comprehensive database which contains all of the deaf-blind literature nationally, as well as databases on services, agencies, resources, and individuals who can be of assistance in each state. It is the first time such a comprehensive information source has ever existed. Other clearinghouses typically contain very little information on deaf-blindness and are therefore less useful for people seeking practical information. Through DB-LINK, every person has easy access to the information which exists, even when their state coordinating person is new or less than knowledgeable. The service is too valuable to let go at this point. DB-LINK needs increased funding to keep up with the ever-expanding requests for information and the always increasing sources of new information.

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
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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.

> **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.**

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 Educa-

tion 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.

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Congressman Randy Cunningham is the chairman of the Subcommitte 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.

Write to

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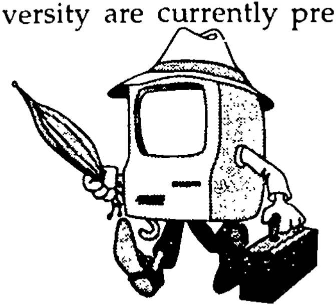
International CHARGE Syndrome Conference

The Second International CHARGE Syndrome Conference for Families and Professionals will be held July 21 – July 23, 1995, at Lewis and Clark College, in Portland, Oregon. For more information contact:

CHARGE Syndrome Foundation Inc.
2004 Parkade Blvd.
Columbia, MO 65202-3121
(800) 442-7604

Members of the CHARGE Medical Advisory Board and other specialists will be available for consultation during the conference.

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



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Functional Assessment: Understanding and Identifying the Causes of Challenging Behaviors in Students who are Deaf-Blind

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Abstract

Many students who are deaf-blind display challenging behaviors that interfere with their learning, disrupt the environment, are socially stigmatizing, and can be physically injurious to themselves and others. Before introducing a behavior-reduction program, it is essential to identify the variables that set the occasion for, and maintain, the challenging behaviors. This review discusses how to achieve this objective through the process of *functional assessment*. Various categories of functional influences are presented, followed by a discussion of assessment methods and their application within educational settings. The review concludes with a summary of treatment implications.

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.

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).

Figure 1

Functional Assessment Screening Form

Student:

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:

0 *Never* 1 *Seldom* 2 *Occasionally* 3 *Frequently* 4 *Very Frequently*

Conditions	0	1	2	3	4
When alone					
In presence of peers					
In presence of adults					
Indoors					
Outdoors					
During transitions					
When given a request					
During training sessions					
During free-time					
During meals					
Morning (7:00a.m.-12:00p.m.)					
Afternoon (12:00p.m.-5:00p.m.)					
Evening (5:00p.m.-11:00p.m.)					
Overnight hours					

Figure 2

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.

Activity	**Activity Time**		**Instructor**	**% Occurrence of Target Behavior**
	Begins	Ends		

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 effect 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 non-verbal 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),

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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.

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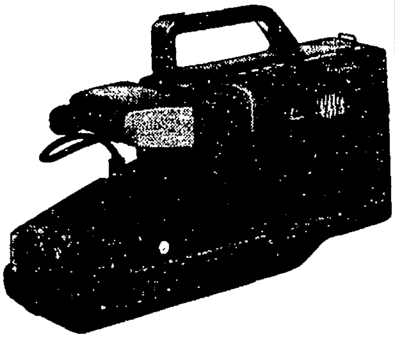

National Coalition on Deaf-Blindness

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: ☐ Work: ☐

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

National Coalition on Deaf-Blindness

Officers:

Michael T. Collins
Chair

Joseph McNulty
Vice-Chair

Scott Marshall
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Sponsoring Organizations:

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Association for the Education and Rehabilitation of the Blind and Visually Impaired

Council for Exceptional Children Division for the Visually Handicapped

Council for Education of the Deaf

Council of Schools for the Blind

Helen Keller National Center

National Association for Parents of the Visually Impired

National Family Association for Deaf-Blind

Perkins School for the Blind

St. Joseph's School for the Blind

Teaching Research

Dear Coalition Member, November 15, 1994

As you know, it is once again time for the reauthorization for the Individuals with Disabilities Education Act. Part of this act, section 307.11, is the part which establishes the Centers and Services for Deaf-Blind Children. We are writing to alert you that this program may again be in jeopardy.

You may recall that five years ago, under the last administration, we had to fight hard to keep a national deaf-blind program. The same threats are presenting themselves today. In November of this year a meeting of all projects funded under this authority was held in Washington, D.C. There, Judy Heumann, Assistant Secretary for the Office of Special Education and Rehabilitation Services, and Tom Hehir, the Director of the Office of Special Education Programs, presented a number of ideas for this reauthorization. One of the trends which they described is the desire on the part of government to combine as many similar things under one program as possible. For example, for all training and technical assistance activity to be combined into one program. Another trend is to eliminate most services which are set up for particular categories of children.

Either of the above trends would be very difficult for deaf-blind children. The major concern is that full implementation of either trend could mean the end of the national deaf-blind program as we know it. No longer would there be such a separate, specialized set of activities to improve services for this population. Whether children who are deaf-blind receive any such special activities would be entirely up to the priorities which individual states establish. The threat is real, because the current conservative Congress may very well agree with these recommendations.

In the past, services under this national program have included the funding of each state's deaf-blind resource center (307.11 program), the support for national technical assistance activities such as TRACES and TAC, DB-LINK (The National Information Clearinghouse On Children Who Are Deaf-Blind), training activities for staff and families, preschool and transitional services for children and young adults, and many unique pilot and demonstration projects. Resource consultation for school districts and development of professional literature and training materials have historically been supported by the program. In fact, without the program, deaf-blind children would not be identified as such, and would have received very little service vis-a-vis their special disabilities. The federal emphasis on low incidence populations such as deaf-blind children is necessary, or their needs will be lost. For example, no categorical funding for deaf-blind children will probably result in all children being taught without the benefit of any specialized knowledge about the handicaps. And, if deaf-blind children are not identified as such, there is no need to train any teachers with specialization in deaf-blindness.

Your help is urgently needed. We desperately need parents, deaf-blind people and teaching personnel to write to Dr. Heumann and Dr. Hehir to tell them how much we need a federal emphasis upon deaf-blind children as a special low-incidence population. It is most helpful if you can summarize what deaf-blind children would not be receiving if such a program did not exist. If you can, say how the program has benefitted you or deaf-blind children whom you know, and indicate the need for our government to keep a national focus on this population whose needs will otherwise be poorly addressed. It is also important to emphasize that, at the local level, deaf-blind children need much assistance and support if their specific learning needs are to be adequately addressed.

Sometime around February or March, we will be conducting a similar letter-writing campaign focused upon the key Congressional committees. We must first await the fallout from the November election, in order to determine who will now be chairing these committees under the new Congress. So we will ask your help with this matter several times during the next few months.

Please take the time to write to these people at the addresses given below. Ask your friends, relatives and professional colleagues to write. We want to convey the clear message that large numbers of people in this country care about what happens to deaf-blind children. Also, please send us a copy of whatever you write, so that we have a sense of the volume of responses.

Thanks for your attention and assistance. We will keep you apprised of the next steps as we go through this year.

Sincerely,
Michael T. Collins, Chairperson
Joseph McNulty, Chairperson

Write to:
Dr. Judith Heumann, Assistant Secretary, Office of Special Education and RehabilitationServices, 400 Maryland Ave., SW Washington, DC 20202
Dr. Tom Hehir, Director, Office of Special Education Programs, United States Department of Education, Office of Special Education and Rehabilitation Services, 400 Maryland Ave., SW Washington, DC 20202

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For Your Rolodex

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
V/TTY: (800) 695-0285; V/TTY: (703) 884-8200;
Fax: (202) 884-8441; Internet: nichcy@capcon.net

DB-LINK, The National Information Clearinghouse On Children Who Are Deaf-Blind
DB-LINK identifies, coordinates, and disseminates information related to children and youth who are deaf-blind. Parents, service providers, administrators, and others interested in services are invited to contact DB-LINK for information. DB-LINK is a collaborative effort including the American Association of the Deaf-Blind, American Foundation for the Blind, Helen Keller National Center, Perkins School for the Blind, St. Luke's-Roosevelt Hospital, and Teaching Research Division.

DB-LINK
345 N. Monmouth Ave
Monmouth, OR 97361
V: (800) 438-9376; TTY: (800) 854-7013; Fax: (503) 838-8150
Internet: leslieg@fsa.wosc.osshe.edu

HEATH Resource Center, the national clearinghouse on postsecondary education for individuals with disabilities
HEATH provides information on educational support services, policies, procedures, adaptations, and opportunities on American campuses, vocational-technical schools, adult education programs, independent living centers, transition, and other training entities after high school for individuals with disabilities.

HEATH Resource Center
One Dupont Circle
Suite 800
Washington, DC 20036
V/TTY: (202) 939-9320; V/TTY (800) 544-3284;
Fax: (202) 833-4760; Internet: heath@ace.nche.edu

NCPSE, National Clearinghouse for Professions in Special Education
This clearinghouse provides information on recruitment and retention and overall supply of professionals in special education and related professional fields, with a particular focus on individuals with disabilities and those from culturally/linguistically diverse communities. It maintains a listing of programs of study in colleges and universities at both undergraduate and graduate levels, and provides resources for financial aid, nontraditional training programs, alternative certification, and job banks, as well as providing specific special education career information.

The National Clearinghouse for Professions in Special Education
The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
V: (703) 264-9476; TTY: (703) 264-9480; Fax: (703) 264-1637

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Deaf-Blind Perspectives

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Heidi's Inclusion in Junior High: Transition and Educational Planning for a Student with Deaf-Blindness

Susan W. Edelman
Jean Knutson
Daniel Osborn
Michael F. Giangreco

University of Vermont
University Affiliated Program of Vermont

What are the markers of a good quality life? How can we contribute to the quality of a student's life through education? These are long-standing questions for parents and professionals alike. Regardless of differences in philosophy or approach, a common denominator among those interested in the public education of children is the desire for students' lives to be better as a result of having attended our schools; beyond that, there is less agreement about what constitutes quality education leading to personally and societally meaningful outcomes. In part, this can be attributed to the fact that what constitutes "quality of life" is individual, subjective, affected by context, and changes over time (Dennis, Williams, Giangreco & Cloninger, 1993).

In reference to students with disabilities, various paths to meaningful outcomes have been suggested; some of these have included functional life skills, traditional academics, community-based training, social skill development and friendships, peer supports, and educational inclusion with peers who do not have disabilities. Regardless of your viewpoint about these or other approaches, individualization or "goodness-of-fit" between how we plan and implement education is crucial to ways in which education will affect perceived quality of life (Schalock, 1990). Although each child shares some characteristics with all other children, and shares other characteristics with some other children, each child also has characteristics that are uniquely his or her own (Speight, Myers, Cox & Highlen, 1991). This highlights the need for individualization as the linchpin that will link planning to meaningful outcomes.

COACH - Choosing Options and Accommodations for Children: A Guide to Planning Inclusive Education[1] (Giangreco, Cloninger, & Iverson, 1993) is an existing tool for planning inclusive education. It uses an individualized approach that explicitly links the selection of educational learning outcomes and supports to family-selected "Valued Life Outcomes." (*See Table 1.*)

In This Issue

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[1] *The version of COACH used by this team was a prepublication version of the one referenced in this article. The version used was substantively the same with several editing differences.*

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Table 1. Valued life outcomes

Valued Life Outcomes	
1.	Having a safe, stable home in which to live now and/or in the future
2.	Having access to a variety of places and engaging in meaningful activities
3.	Having a social network of personally meaningful relationships
4.	Having a level of personal choice and control that matches one's age
5..	Being safe and healthy

COACH is organized into three major parts. **Part 1** (Family Prioritization Interview) is used to identify family-selected priority learning outcomes for the student. **Part 2** (Defining the Educational Program Components) is used to (a) translate the family-selected priority learning outcomes into IEP goals and objectives, (b) assist the full team (including the family) in identifying other important learning outcomes in addition to those selected exclusively by the family, and (c) determine general supports and accommodations to be provided to or for the student to allow access and participation in the educational program. **Part 3** (Addressing the Educational Program Components in Inclusive Settings) is used to determine options for addressing students' educational program components in general education class settings and other settings with people who are not disabled (e.g., community, vocational) through the use of a scheduling matrix and a set of lesson adaptation guidelines. Studies of COACH have included an expert and social validation study which established COACH as congruent with exemplary educational and family-centered practices (Giangreco, Cloninger, Dennis, & Edelman, 1993) and a study of its use and impact with students who are deaf-blind (Giangreco, Edelman, Dennis, & Cloninger, in press).

Case Study of Heidi

While engaged in study of the use and impact of COACH on students who are deaf-blind (Giangreco, Edelman, Dennis, & Cloninger, in press), our attention was drawn to the experiences of a particular junior high team serving a student named Heidi. It seemed apparent that over the course of three years, changes had occurred for Heidi as judged by her family, team members, and, in her own way, by Heidi herself. Initially, this team had used COACH as one part of the process to transition Heidi from a regional special education classroom in a neighboring school district to her local junior high. While our original intention was to understand the use and impact of COACH, we also sought to understand more fully the changes Heidi experienced, what had been done by this team, and how the team's practices and subsequent actions affected Heidi's life.

The purpose of this case study, then, is to relate one student's successful transition into an inclusive educational program in which COACH served as a supportive tool and to describe some of the ways COACH contributed to positive changes in her life. COACH was used in conjunction with exemplary practices such as collaborative teamwork, transition planning, and family-school collaboration. The account of this experience is based on qualitative data from semi-structured interviews with Heidi's mother and the special education teacher who served as her inclusion facilitator, site observations, videotaped school and work activities, a review of her IEP prior to and after completing COACH, and written team meeting records of the use of a problem-solving process to facilitate educational inclusion.

Heidi and Her Team

At the outset of Heidi's transition she was a 14-year-old student with significant vision and hearing impairments, the oldest of three children living with her parents, Jean and Dan Knutson, brother Jamie, sister Beth, cats, and goldfish in a small town in Vermont. For most of Heidi's life she had been a student in a regional, self-contained, special education class of six students, most of whom were labeled "severely and/or multiply disabled." This regional classroom was located over 20 miles from her home. Her mother (co-author) tells us more about Heidi:

> When asked to describe Heidi, I thought it would be easy, but there is no one word that does that... . Professionals say she is mentally retarded, deaf, visually impaired, and non-verbal due to TORCH Syndrome. Her brother and sister lovingly call her 'high tech Heidi,' once she has on her cataract glasses, both hearing aids in and is hitched up to her FM unit. To her Dad and I she is a curly-haired teenager, persistent, happy, challenging, frustrating, difficult (at times), puzzling, and wonderful; full of surprises! All in all, we feel very lucky to have her as she has taught us all that nothing is impossible and to never take the little things in everyday life for granted.

"To her Dad and I she is a curly-haired teenager...full of surprises!"

Heidi's Individual Student Planning Team consisted of a core of people who interacted with her on a regular basis. These included her parents, special education teacher, inclusion facilitator, speech language pathologist, consultant for the deaf and hard of hearing, paraprofessional, and general education teachers (e.g., eighth grade science and art teachers). As Heidi's program developed, a group of her peers participated in team activities. Extended team members, who interacted with Heidi less frequently included an itinerant teacher of the blind and visually impaired, an occupational therapist, a physical therapist, and later, an employment specialist. Heidi's team received intermittent technical assistance from members of the Vermont State I-Team (Rainforth, Giangreco, York & Smith, in press).

Transition Preparation

Heidi's team began the transition process well before the move to her local junior high school. During the winter prior to the move, several meetings were held between the sending team, Heidi's family, and the receiving team at the junior high school. During these meetings information about Heidi's strengths and needs was shared and kept in the forefront of discussions as staff began to develop ideas for her program and schedule for the fall. These meetings gave the junior high personnel a chance to learn about Heidi and gave her parents a chance to get to know people who would serve as Heidi's team in the junior high school. Members of the junior high team also made several visits to observe Heidi in her special education class. At the same time Heidi's mother observed classes at the junior high school. Recognizing the importance of preparation not only for Heidi and her team, but also for the teachers and students in the junior high school, the special educator on the junior high team described these activities:

> In order to create a truly welcoming environment for Heidi, we knew we also needed to involve the eighth grade teachers and the students who would be her classmates the next year. In May, a home economics teacher, special education teacher, and the inclusion facilitator held an informal after-school meeting with the eighth grade teachers. During this meeting, we provided the teachers with information about Heidi and asked for their input into the steps that needed to be taken before September. The teachers indicated that the information needed to be shared with the current seventh grade, that Heidi should have opportunities to visit the school, and that a core group of peer buddies or tutors should be identified. In order to reach the entire seventh grade class, the teachers decided that the information should be presented in English classes. These presentations were to include information about inclusion, about severe disabilities, as well as information about who Heidi was. During the presentations, which took place in May, opportunities were provided for students to volunteer to greet and meet Heidi when she visited, and to serve as buddies or tutors the next year.

Follow-up was provided during the first week of school in the fall with students and teachers with whom Heidi would spend her school day. Information shared at this time was more detailed and specific so that Heidi's classmates could learn about her strengths and needs, her unique sensory characteristics, and her expected learning outcomes. They also learned strategies for communicating with Heidi and discussed ways in which they might help to make Heidi feel welcome as a part of the class. This type of orientation to classmates was to be presented to each new class in which Heidi participated.

Educational Program Planning Pre-COACH Experiences

Though IEP planning was not new for Heidi's team, planning an IEP for an inclusive education program in a junior high was new. When asked about IEP planning *before* using COACH, Heidi's mother described attending meetings where she would be presented with a list of things that the special education teacher thought should be worked on. She would be asked if there was anything that should be added. As the mother said, "They would make up the IEP where I could add to or take from . . . they always welcomed what I had to say or what I really wanted for Heidi." As many parents do, Heidi's parents found themselves deferring to the professionals' selection of goals and went along with the plan presented to them. The resulting IEPs typically contained long lists of annual goals and short-term objectives, including several submitted independently by related service providers for motor and communication skills. This scenario, while typical and well-intentioned, did not provide the family with adequate input into the educational planning process and left the team with a large number of fragmented goals that had an unknown relationship to changes in valued life outcomes for Heidi.

Educational Program Planning Using COACH

Prior to using COACH, each of the core team members familiarized themselves with the COACH manual. They made sure that all team members were in agreement with COACH's basic assumptions and agreed to use it to plan Heidi's IEP with technical assistance and guidance provided by a member of the Vermont I-Team. The team's first use of the COACH was in September of her first year at the junior high school (eighth grade). During the Family Prioritization Interview (Part 1), valued life outcomes and family-selected priority learning outcomes were identified and subsequently restated as IEP goals and objectives. The team used Part 2 of COACH to identify additional learning outcomes and general supports to fill out Heidi's educational program. With Heidi's new IEP in hand, the team turned to the task of implementing the IEP in the context of a regular eighth grade day, including the development of instructional strategies and adaptations.

As the year progressed, the team reached consensus on roles and responsibilities of related service providers and used the scheduling matrix in Part 3 of COACH to identify places and times in the eighth grade schedule where Heidi had opportunities to address her goals. The team used variations on the Osborn-Parnes Creative Problem-Solving process as a strategy for generating ideas for successful inclusion in regular class activities (Giangreco, Cloninger, Dennis & Edelman, 1994). These strategies culminated in a program that capitalized on opportunities in the eighth grade Life Science class and 3D Art class. The rest of Heidi's schedule included physical education, a school job with classmates, community-based instruction with classmates, individual instruction in food preparation, lunch, and a time in which to engage in recreation and leisure activities with classmates.

Heidi's special educator reflected on her progress that first year at the junior high school:

> While the team focused on IEP development and implementation, they also continued to address day-to-day issues related to personal care, behavior management, materials and equipment, staff training, schedule changes, following special education regulations, etc. Although the team had decided to begin each team meeting with a 2-minute success statement, it wasn't until a Transition Planning Meeting in May that we took time to really recognize all the progress that Heidi had made. In the area of communication, Heidi was improving on her ability to focus on people when they communicated with her. She was using more picture symbols and making more requests. She had also greatly improved her ability to maintain appropriate behavior. Through her art class, phys. ed. class, and the time she spent with classmates, she had developed new leisure activities. In the area of vocational skills, Heidi had two school jobs. She had shown dramatic increases in independence on both jobs, and was beginning to self-correct errors. In the area of personal management, Heidi had begun to make her own lunch and was getting around the school with increasing independence.

Heidi's IEP for her freshman year was also generated using COACH. During that Family Prioritization Interview, three of the five valued life outcomes from COACH were identified by her mother as important for Heidi for the coming year. They were (a) having a social network of personally meaningful relationships; (b) having a level of choice and control that matches one's age; and (c) accessing a variety of places and engaging in meaningful activities. As a result of the Family Prioritization Interview, Heidi's mother selected the following overall priority learning outcomes to be addressed for the coming school year:

1. Follows instructions
2. Works independently at a task

3. Shares leisure activities with others
4. Summons others
5. Follows school routine
6. Maintains appropriate behavior
7. Makes requests
8. Participates in individual leisure activities

How is Heidi's Life Better?

Heidi's educational records document the progress and attainment of goals and objectives related to the eight priorities on her IEP. But the real question we want to ask is whether her life has been made any better. Is there an impact on the valued life outcomes selected at the outset of the COACH process? Has she grown in her personal relationships with peers? Does she have any greater independence that would match that of a 15-year-old? Is she able to go places and do meaningful things in her community? Interviews with Heidi's mother and special educator provide some of the answers:

- Previously a paraeducator or other adult went with Heidi into the community (e.g., grocery store, horseback riding); now she goes with friends her own age and the paraeducator is in the background.
- Other kids used to say "Oh, what's wrong with her?" Now kids know her and treat her as they do their other classmates.
- Ownership about finding ways to include Heidi shifted from professionals exclusively, to her classmates and peers who used creative problem-solving to help plan for her ongoing inclusion.
- "She interacts more with her brother and sister at home. She's interested in what's going on!" (mother)
- "In her own way I think she knows she's included and that she's with normal kids. She's doing things they're doing and they're including her." (mother)
- "Other students are real interested in how they can communicate with her better. They genuinely care about what they're doing and want to do what's best. It's not like they're getting extra credit for it. It's just voluntary." (mother)
- In art class, "They put her right in the middle. If she needs something, if she needs help opening paint, for example, she'll tap one of the other kids and hand them the jar. And they've been as excited as I have. 'Hey Heidi wants me to open it. She asked me to do it!'" (mother)
- "You know she's not considered the different one in art class. They just greet her like 'Hello there Heidi. How ya doing?' " (mother)
- Heidi had her first job at MacDonald's and was very proud to bring home a paycheck.
- She dresses herself every morning to get ready for her job independently. She participates in making her own breakfast, clearing the breakfast table, making her own lunch. Her mother remembers, "If she just let me dress her and not throw a fit, I was happy!"
- Bowling used to involve hand-over-hand help. Now she bowls with friends who came up with the idea of using "lane bumpers" so physical assistance isn't needed. She has learned to take turns and knows that you don't just get up and bowl at any time. "It's just like any four kids who are out bowling!" (mother)
- People in the community know her more. Checkers at the grocery store, people at church, kids at school that aren't friends of Beth or Jamie (Heidi's sister and brother) come up and greet her.
- She's learned from imitating her classmates to be quiet when others are quiet. This has enabled her to worship with her family.

The combination of aforementioned events led to Heidi exhibiting a more positive affect and greater self-esteem. "I think she's happier" her mother, Jean, comments, then offers what she supposes might be running through Heidi's mind: "There's a lot of things I can do after all and I'm having a good time doing them!" While an intangible such as happiness is probably impossible to measure, it is not so difficult to recognize, especially by a parent. Jean recalled a day when Heidi brought home her paycheck. When Jean opened her backpack and asked "What's this?" Heidi signed, "want" and took it and put it in her room. In talking with visiting relatives who didn't know about Heidi's job, she suggested to Heidi that she show them her uniform and brought it out. "I got that out, I mean she was all smiles like, 'yeah, this is mine and I wear this when I go to work.' She was really tickled."

Future-Mindedness, Risk-Taking and Expectations

For Heidi's parents, using COACH and having their daughter involved in the local junior high school resulted in changing perspectives. Looking farther into Heidi's future than ever before meant challenging their own current expectations of Heidi's progress and growth and taking risks.

When asked about expectations for Heidi after graduation, Jean reflected on her past and current points of view.

Jean: I wasn't even thinking about a job. What could Heidi do? I felt bad thinking the worst, but I thought if she'd only learn that when she takes her coat off she should hang it up or to act appropriately depending on where she is.

Interviewer: Did you see her in some kind of special ed. day program?

Jean: Yeah. Maybe some peers would come into the classroom but not with her being in the minority like she is here.

Interviewer: How have your expectations changed? What direction are you headed now?

Jean: You know, working, supported work. I can see that.

When asked if she felt there was a relationship between Heidi's gains and successes to the team's use of COACH she replied: "Yeah, I think so because when we made that out it was considering a big part of her life. I mean the future. Not just what do you want her to accomplish by the time eighth grade is over." Confidence in going after what she really wants to see for Heidi meant taking risks. She began saying, "Yeah, I would like her to have a job and live on her own with a support person. I just learned to say those things and then plan for it. You know if you don't start now you can't wait until the day before she graduates and say now I want her to go work somewhere. With Heidi we don't know. I learned it's better to plan big. You don't know until we try things."

"Trying things" paid off for Heidi. For example, pulling back on the paraeducator's one-on-one assistance when Heidi was with peers and letting natural supports take their course paid off for her. No one could have predicted that Heidi would follow the models of her peers for such things as turn-taking in bowling or quieting when her classmates are taking a test or when her family is in worship, but she did! Expectations were raised regarding what Heidi might be capable of attaining because of a willingness to take some well-planned and monitored risks to try new approaches and new activities.

Heidi's story is worth telling. Good things happened for her over these three years, some carefully planned, some unexpected. Her recent experience has improved the quality of her life as judged by her family, and other team members agree. The positive outcomes for Heidi can be attributed to many exemplary practices including a strong home-school partnership with parents as team members, finely tuned collaborative teamwork practices, effective communication strategies among team members, and regular planning and revision of schedules, activities, or instructional approaches based on ongoing assessment. COACH was a tool used to initiate the development of an IEP that had valued life outcomes as the foundation. COACH was a major factor in changing perspective of parents and other team members about Heidi's abilities and about where she would or could go in the future and allowing the parents to consider the "big picture."

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Children Who Are Deaf-Blind: A "National Interest Requiring National Action"

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President Clinton, in his recent State of the Union reference to the role of the federal government in domestic policy, cited "national action in the national interest" as one way of defining federal responsibility. With full awareness of the impending extinction of OSEP's heretofore concerted effort to serve children who are deaf-blind, I realized upon hearing this that we in the deaf-blind community (people who are deaf-blind, their families, and the professionals who serve them) are faced with a herculean task. WE must define and defend for the nation's leaders—and in short order—how the currently mandated (IDEA - Section 622) and structured (Services for Children with Deaf-Blindness Program) federal program to children who are deaf-blind serves national interests. We must vigilantly await the soon-to-be disclosed details of how proposed executive and legislative changes will affect the federal deaf-blind services program. Then, equipped with what we know and feel, we must write and speak out to ensure the program's integrity and vitality.

A raging bipartisan executive and legislative "reduce government" juggernaut threatens to erase 30 years of progress in the evolution of services to children who are deaf-blind and return us to the dark ages of state and local choice. As the plan appears to be unfolding, the choice as to whether and how to serve these children will basically fall to the states; this choice, if the past can instruct us, does no more than to marginalize hope for a bright future. We are assured by Department of Education (DOE) leaders that their basic commitment to children who are deaf-blind is intact and that a "base funding floor" exists in the foundation of the future to make good on this commitment. Assurances lead us to believe that DOE is devoted to these children's (and their families') learning and service needs. Recent rumblings from Washington, however, raise serious questions as to the substance and integrity of such assurances. Will the plank consist of more than "lip-service," simply suggesting to newly homogenized technical assistance centers and broad-scope researchers that they not forget these children? Will the $12.8 million currently dedicated to children and youth (birth–21) who are deaf-blind, fall prey to the de-categorization frenzy that homogenizes cross-disability distinctions and service programming? Will the identity and unique needs of children who are deaf-blind be down played or lost? In fact, to be sure that the "base floor" has substance and winds-up as more than window dressing, we—the deaf-blind community—need to be heard. And, to repeat, what we need to articulate is how and why continuation of the Department's dedicated program for our country's 10,000 children who are deaf-blind is in the national interest.

> "...it is in our national interest to protect and enhance the lives of young citizens, who by virtue of not being able to see and hear, frequently experience isolation and require extraordinary support"

First, although it may not play well in today's political arena (where too many see disadvantage as self-inflicted), it is in our national interest to protect and enhance the lives of young citizens, who by virtue of not being able to see and hear, frequently experience isolation and require extraordinary support. It is in our national interest, as humans and as a people, to recognize and respond to one another's human needs, not as a reflection of some noble altruism or paternalistic patronage, but simply because we care. Yet somehow, this caring threatens to become lost in our zeal to re-invent government. When we hear House Speaker Gingrich speak out against the recent excesses of federally funded "economic and social nannyism," many of us reflexively resolve to rid our lives of government. But for many children who are deaf-blind, to rid their lives of the federal government would be to rid their lives of the only identifiable and accountable resource with adequate means to make a real difference. Specifically, the federal government, through the U.S. Department of Education's Services for Children with Deaf-Blindness Program, cares to the tune of $12.8 million. Remove these dollars or float them into overall programming for children with disabilities, and active caring that is capable of making a difference in the life of a child who is deaf-blind will be replaced by the benign neglect characteristic of approaches of the early 1900s.

Cost-beneficial fiscal allocation constitutes a second national interest. Dollars appropriated by the Department of Education's presently concerted effort serves that interest very well. Deaf-blind-specific research and demonstration projects, technical assistance, teacher training, and information and referral projects, all help advance the quality of services by increasing the knowledge base. To the extent the knowledge base expands, more and better programs can be developed. In turn, better programs mean that more people who are deaf-blind, as they become adults, will be better equipped and require less costly services and interventions to cope both with crises and daily life. These adults, provided with sufficient opportunity to transcend disability by maximizing their abilities, have a greater likelihood of becoming contributing citizens. If the present federal focus on deaf-blindness is eliminated or diluted, any monies saved will likely be paid out many times over to fund costly service and intervention requirements of the future. Deaf-blindness is simply too significant a disability for many who have it to function without assistance. We can smartly choose to empower now, through sound educational programming, young people who are deaf-blind to prepare them for adult life, or, ignorantly, we can believe that an ostrich-approach is viable. Our national interest, and indeed our national coffers, are best served by proactive rather than reactive national action. To dilute, violate the integrity of the Services for Children With Deaf-Blindness Program, would, in addition to boding poorly for the future, severely compromise and undermine expensive gains of the past.

> **"...if states assume responsibility for serving children who are deaf-blind, and if they do it well, the overall cost to American taxpayers may well increase."**

An additional factor related to cost effectiveness is the near certainty that if states assume responsibility for serving children who are deaf-blind, and if they do it well, the overall cost to American taxpayers may well increase. Services duplicated in every state will cost a great deal more than does the current delivery structure in which expert assistance crosses state lines and information is nationally collected, organized, and disseminated. Because of each state's low incidence of children who are deaf-blind, there will be a duplication of services, a duplication that would require the individual taxpayer in each state to pay a larger share of the costs.

Third, amid a national clamor to strengthen the focus on our families and their values, it is clearly in our national interest to address the multitudinous needs of families with children who are deaf-blind. To this end, a significant portion of the Department's deaf-blindness program monies have been targeted toward decreasing the isolation of families by increasing their relationships with each other and with the professional community. Success in this vein inevitably means that children will be more likely to remain with their families instead of becoming institutionalized. And, as if this in itself were not sufficient reason for DOE to continue its focus on the family, imagine the immense cost effectiveness of cultivating committed and ready-to-work parents as knowledgeable advocates, skilled service providers, and resources for professionals! Should DOE trim or abandon its budding partnership with parents of children who are deaf-blind, hope would be lost for the eventual blossoming of this long-nurtured resource. If we define "in as our national interest" increased family cohesion and viability as the primary unit for support, we are compelled to back up this interest with national action.

A fourth national interest is served by honoring, through action the American values of opportunity and quality of life to which every citizen who is deaf-blind has an equal birthright. Action, in this case, means elevating these values beyond empty rhetoric to the level of real programs of assistance—like those programs historically supported by the Services to Children with Deaf-Blindness Program. A global market economy and a world-class educational system will be hollow victories if some Americans become casualties of their lost vision and hearing.

In short, we must make the case that the Services to Children with Deaf-Blindness Program is vital to our national interests. Monies historically designated for this program should be deemed sacrosanct. They should be subject neither to the momentary frenzy toward disability homogenization, nor to illusory thinking about cost ineffectiveness. Planners of the new millennium's promise of a "healthier and more just America" must quickly be brought to the realization that children who are deaf-blind, their families, and the professionals who serve them warrant national action commensurate with their presence as a national interest.

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Traces

Let's Have an Institute

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One of the greatest challenges facing those who provide state and multistate services for children who are deaf-blind (34 CFR 307.11 grantees) is providing information and training to families and service providers about effective education practices. With increasing inclusion of children who are deaf-blind into community schools and other community-based activities, a growing number of individuals need information about the unique educational needs of these children and instructional technology to meet these needs.

With technical assistance to public and private agencies and organizations who serve children who are deaf-blind and their families as a primary mission, 307.11 Project personnel use a variety of methods to provide information to these groups. Since preservice (i.e., college/university course work) touches only a small percentage of the individuals in the service provider workforce, inservice training approaches are prevalent. Among these approaches, inservice training activities, usually identified as "institutes," are a popular choice.

The planning and conducting of an institute can sometimes be a frustrating experience. Substantial amounts of time, effort, and funds are often committed, only to find later that impact has been limited. The purpose of this article is to share various strategies and insights identified by TRACES and 307.11 Project personnel on how they currently plan and conduct institutes. The information included is not intended to be an exhaustive presentation of strategies; rather, it highlights strategies shared by the 307.11 Project personnel.

Identification of Needs

When institutes are viewed simply as isolated activities, when not enough attention is given to how or where the training fits within the overall plan of service, results are limited. Such frustration may be avoided in the planning phase when attention is given to intended outcomes of the training institute as they relate to the vision/mission of the project. Successful institutes result when planners systematically begin their planning by identifying statewide needs, potential participants, and stated outcomes. This task should occur prior to identification of consultants, agenda items, or the selection of format.

Planning Committee

Another successful strategy is to involve appropriate stakeholders in the planning process. This may be accomplished through the formation of an institute committee composed of those who are likely to benefit from an effective institute. Members of the committee are requested to make a year-long commitment for consistent involvement from planning stages to the completion of the institute. Committee members may include members of the advisory committee of the 307.11 Project; representatives from institutions of higher education, who may assist in acquiring graduate level credit for participation; representatives of state departments of education, who may secure continuing education units for participants; parents, who may assist in validation of service needs; and representatives from the state-level CSPD committee for coordination of inservice and preservice training institutes.

Logistics

Attracting participants to a summer institute can be difficult due to summer vacation plans, commitments to work extended school year programs; and the needs of families and service providers to relax and re-energize for the upcoming school year. Reasons such as these have led some project personnel to schedule an institute in fall, winter, or spring. For other projects, an alternative has been to offer a series of shorter (e.g., three-day vs. a week-long) institutes throughout the school year. For example, the following series of institutes titled, "Staff Development Opportunities for Individuals Working with Students with Deaf-Blindness," was offered.

Institute #1 - Summer Institute

Content: Overview of basic anatomy of the auditory and visual system, etiologies of hearing and vision loss, functional hearing and vision evaluations and implications for instruction.

Institute #2 - Winter Institute

Content: Overview of orientation and mobility strategies for individuals with deaf-blindness and implications for instruction.

Institute #3 - Spring Institute

Content: Overview of communication intervention for individuals with deaf-blindness and implications for instruction.

These institutes were offered in three different locations across the state to ensure statewide availability for participants. Several project personnel addressed this same issue of statewide availability through replication of the institute in various locations across a state.

Team Attendance

Some projects have found great success in promoting team attendance (e.g., two or more staff members from the same school building or district). Attendance at an institute typically involves only one person who then returns to attempt to incorporate new knowledge or implement new skills. Working merely from notes and materials, the individual, essentially, is working in isolation. It is no wonder limited implementation results. The teams, on the other hand, appear to have a much greater potential for implementing content information along with process strategies and, therefore, creating positive impact.

Follow-up Activities

Limited implementation of strategies and information by participants following their attendance at an institute may be due in part to "hit and run" style institutes. An example of a hit and run institute is (a) a presentation of strategies related to content without information on how to incorporate those strategies into existing instructional programs and school site structures, and (b) follow-up is not conducted to assist in the implementation of strategies presented during the institute. The expectation that participants can implement strategies upon return to their schools, agencies, or communities without additional support is faulty. Without follow-up results vary from partial implementation to time-limited implementation of strategies to no implementation at all.

Since including follow-up technical assistance activities into the action plan can lead to increased impact and achievement of meaningful outcomes, providing follow-up strategies becomes an essential part of the planning process. Past institute participants found the following follow-up activities beneficial.

- On-site consultation with a mini-inservice training session (i.e., a follow-up site visit by a consultant with feedback on the implementation of the action plan goals combined with a presentation to supplement content information presented during the institute)
- On-site consultation (i.e., a follow-up site visit by a consultant with feedback on the implementation of action plan goals)
- Videotape review consultation (i.e., follow-up technical assistance conducted through consultant review of a videotape provided by the participant. The consultant provides the participant with written feedback on the implementation of the action plan goals)

Application and Practice

The opportunity to learn through application, practice, and immediate feedback is another approach that produces implementation and impact. Conducting an institute that incorporates practice requires careful planning. The institute will need to coincide with the school year so an appropriate practice site will be available. Practice-based institutes often produce an unexpected benefit for the training site in the form of accommodating the needs of additional children and service providers due to the instruction available.

Action Plans

Finally, 307.11 project personnel agreed that the creation of a clearly contracted action plan by participants was an effective approach to ensuring post-institute implementation. An action plan provides information on (a) what knowledge and skills presented at the institute are planned for implementation, (b) the anticipated outcomes, (c) how the implementation is progressing, (d) who is involved in the implementation, and (e) how long it takes to be implemented. It was noted that action plans should be developed as an ongoing process during an institute. Action plans often require refinement and it is better to have this occur during the institute than as the concluding activity of the institute. This ongoing process provides participants the opportunity to plan with other team members, to network with other participants attending the institute, to receive feedback from the presenter and other participants, to embed optimal types and times for follow-up technical assistance, and to plan a process for evaluation of progress. A clearly developed action plan will support the implementation of information presented during the institute.

Summary

In summary, we suggest that effective strategies include early articulation of goals, careful selection of planning committee members, attention to logistics, encouragement of team attendance, inclusion of follow-up activities, inclusion of opportunities for practice, and the formation of action plans. The foregoing is not an exhaustive list, nor have these strategies all been used at the same time. However, we submit that attention to them can result in an institute that is more likely to be successful.

TRACES (Teaching Research Assistance to Children Experiencing Sensory Impairments) is funded through Cooperative Agreement No. HO25C30001 by the U.S. Department of Special Education, OSERS, Special Education Programs. The opinions and policies expressed by TRACES do not necessarily reflect those of the U.S. Department of Education.

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TRACES Regional Reports

NORTHEAST AND NORTH CENTRAL REGIONS

States in the North Central and Northeast TRACES regions are participating in a planning process to address issues related to Usher Syndrome. A meeting scheduled for September, 1995, will address the development of effective screening practices within states. Dr. Sandra Davenport, personnel from deaf-blind projects, and families, and adults with Usher Syndrome will present at the September meeting. TRACES regional coordinators will work with states to develop action plans to strengthen screening processes. Long-term outcomes related to educational planning for students with Usher Syndrome will also be included in the planning process.

Preliminary survey results of 12 state and multistate projects indicate that students with Usher Syndrome are educated in a variety of settings, including regular classrooms, resource rooms, separate classrooms, separate schools, private schools, and public residential schools. Nine of the twelve state and multistate projects reported that there currently is no formal statewide process for identification of Usher Syndrome. However, many states are in the early stages of developing a screening process and have goals related to Usher Syndrome embedded within their grant activities. At least one of the states that responded to the survey has a statewide and systematic screening process.

Additional issues are being identified, including the awareness that many students with Usher Syndrome are often not included in a state's annual deaf-blind census. The group will explore this issue and others to identify strategies which will help ensure that needed services are in place for students with Usher Syndrome.

If you would like more information, please call

Juli Baumgarner
(412) 648-1424 or

Cheryl Kennedy
(412) 648-7176

GREAT PLAINS REGIONAL ALLIANCE

The states of Minnesota, North Dakota, South Dakota, Wyoming, and Montana have formed the **Great Plains Regional Alliance** in a collaborative effort to address the needs of Native American children who are deaf-blind and their families. These states include reservation land of the Lakota/Dakota Indian Nation. Meetings and conference calls of the member states have resulted in a four-year plan that is incorporated within each of the states' grant activities. Immediate goals include establishing linkages with the Native American communities and others who serve the communities. Members are sharing successful strategies that may be adopted across states and will develop public awareness materials to provide information to more rural areas.

If you have suggestions or would like more information, please call

Juli Baumgarner
(412) 648-1424 or

Phyllis Graney
(605) 224-9554

WESTERN REGION

States in the Western Region are collaborating to address transdisciplinary assessment resources. Work initiated through participation in California Deaf-Blind Project's Pilot Project (TEAM) has continued at the individual state level.

In California, materials have been developed and teams have been trained from districts in the Northern, Central, and Southern Regions which have collectively assessed over 50 children who are deaf-blind.

In Arizona, the transdisciplinary team has developed replication materials for districts, assessed two children in their home school, trained one district team, and has four districts waiting for the training.

In Nevada, one school age team was trained, 14 children received functional vision and hearing screening, 2 children received transdisciplinary assessments, and training has begun with a team specializing in infants.

In Idaho, one team was trained, 19 children received functional vision and hearing assessments, and 4 children received transdisciplinary assessments.

In Montana, eight children received functional vision and hearing screening.

Through this collaborative process, a consistent knowledge base was developed across the many individuals representing the states. Individualized models were then developed, based on the states' needs and resources. Inherent to this process has been the ongoing collaborative attitude of all the participating states as they have molded their own transdisciplinary assessment resources.

If you would like more information, please call

Paddi Henderson
(503) 838-8775

PUERTO RICO

Providing consultation and resources to teachers of students who are deaf-blind and who live in remote areas is often difficult. The Puerto Rico Deaf-Blind Project and TRACES have begun a video exchange program to provide teachers on the island with consultation. Video tapes of the teachers and students are taken, with teachers adding information or questions as needed. These tapes are then sent to consultants who view the tapes, make recommendations and comments, and then send the tapes back to the teachers. As teachers review the tapes and implement any recommendations, the tapes are revised with new footage of the class and teacher comments. Through this video exchange, a library of best practices can be developed which can be accessed at any time.

If you would like more information, please call

Toni Waylor Bowen
(404) 651-4089

NORTHEAST REGION

The strategic planning meetings that occurred in the Northeast Region of TRACES identified a need to examine training models. Participants from the New England Center, Rhode Island, and Vermont discussed the use of the INSITE inservice training model for early intervention service providers. The appeal of the INSITE training model is in its focus on family-centered delivery of services.

Recently, personnel from TRACES and these 307.11 projects collaborated in planning a regional training workshop using the INSITE training model. This workshop titled, "A Model of Home Intervention for Infant, Toddler, and Preschool Aged Children with Multiple Disabilities and Sensory Impairment," is scheduled to occur July 10-14, 1995. Tracy Evans-Luiselli, 307.14 Pilot Project Coordinator for the New England Center and one of the certified national trainers of the INSITE model, will provide some of the training. The remainder of the training will be provided by staff from Ski-Hi Institute, Utah State University, Logan, Utah.

Participants who attend the INSITE training workshop will learn about the delivery of effective home programs for children who have dual sensory impairments.

INSITE training objectives for participants include becoming familiar with and gaining basic knowledge about the following:

- The rationale for early home intervention
- The characteristics and needs of children and families
- The role and characteristics of the parent advisor
- How to work with families in the home environment, convey information and teach skills via modeling
- Multiple Insite curricular areas
- An overview of the variety of support services
- An overview of the variety of resource materials

The time commitment for participants will be substantial, but the opportunity to network with colleagues both within and across states, while gaining knowledge and skills related to service delivery, will be significant.

For further information regarding the Northeast regional INSITE activity please contact

Lisa Jacobs
(617) 972-7517

OKLAHOMA

In October, 1993 there were three needs identified by the Oklahoma Deaf-Blind Project Coordinators: (a) to develop model sites demonstrating responsible inclusion of students with deaf-blindness that could be replicated throughout the state, (b) to increase parents' knowledge of effective practices, and (c) to provide service providers and families of children with deaf-blindness with training in personal futures planning (PFP). To meet these needs the Oklahoma Deaf-Blind Project, TRACES, and HKNC-TAC collaborated in providing technical assistance.

Two elementary schools in Oklahoma were selected as implementation sites to receive consultantation for a student transitioning from one school to another. In the new school the student would be in a program that required changing classes several times a day. The Oklahoma Deaf-Blind Project assisted with disability awareness training and facilitated problem-solving by classmates. Project staff followed-up with phone calls and visits. In addition, HKNC-TAC conducted training for staff on the philosophy and process of PFP and will facilitate a PFP meeting for the child at an appropriate future date. This collaborative effort has provided awareness and skill development training to a number of service providers while meeting a specific child's unique educational needs.

If you would like more information, please call

Jan Watts
(405) 325-0441.

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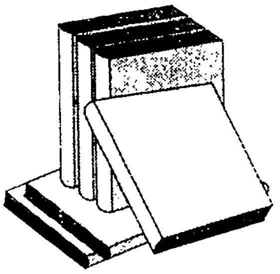
We encourage you to copy and share information from *Deaf-Blind Perspectives*, but please provide appropriate citations.



For Your Library

Developing leisure and recreation opportunities. In Everson, J. (Ed.), Supporting young adults who are deaf-blind in their communities : Transition planning guide for service providers, families, and friends. (1995) Baltimore: Paul H. Brookes.

By K. McNulty, L. Mascia, L. Rocchio, & R. Rothstein

This chapter provides a comprehensive view of recreation and leisure activities. Beginning with a theoretical overview of the value of recreation, the piece then moves to the specifics of guidelines for programming, instructional strategies, profiles and case studies.

Horticulture for the deaf-blind. Horticulture program, Perkins School for the Blind. (1993).

This handbook shares with parents and other professionals, the lessons learned in 14 years of horticultural therapy that has been part of the curriculum at Perkins. Includes descriptions and drawings of adaptations that aid physically disabled people to enjoy gardening.

Leisure options in community settings for deaf-blind people. III European conference of the international association for the education of deafblind people. Potsdam, Germany. (1994).

By T. Gavin

Offers suggestions to service providers on how to ascertain the deaf-blind person's interests, likes/dislikes, fears, etc., so that appropriate leisure activities can be developed. Gavin encourages providers to offer integrated leisure activities that expand upon the deaf-blind person's skills and interests.

Project S.I.M.P.L.E.: activities for individuals with sensory impairments and multihandicaps. In S. Grosse & D. Thompson (Eds.) Play and recreation for individuals with disabilities: practical pointers. (1993), Reston, VA, AAHPERD

By L. Lieberman

This article presents games and activities developed for students who are deaf, blind, deaf/blind, deaf/multihandicapped and blind/multihandicapped. Games and activities are arranged in a developmental sequence, beginning with locomotor skills and ending with fitness and recreation.

DB-LINK Family Resource Directory

Available in late May 1995, the DB-LINK Family Resource Directory lists the services of eleven national organizations that serve as a resource for families of children who are deaf-blind. This directory was produced in cooperation with the National Family Association for Deaf-Blind. Included in the directory are agency summaries, rolodex cards, and postcards to send for additional information.

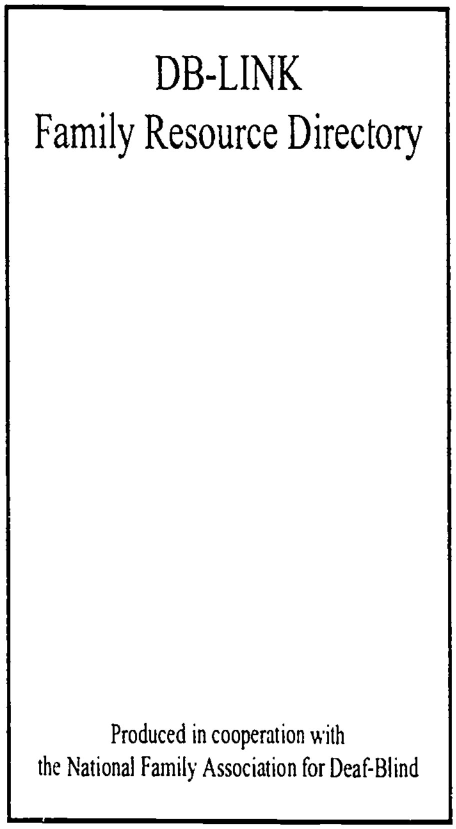
To request your free directory:

Families, please contact

National Family Association for Deaf-Blind
111 Middle Neck Road
Sands Point, NY 11050-1299
(800) 255-0411
(516) 944-8637 TTY

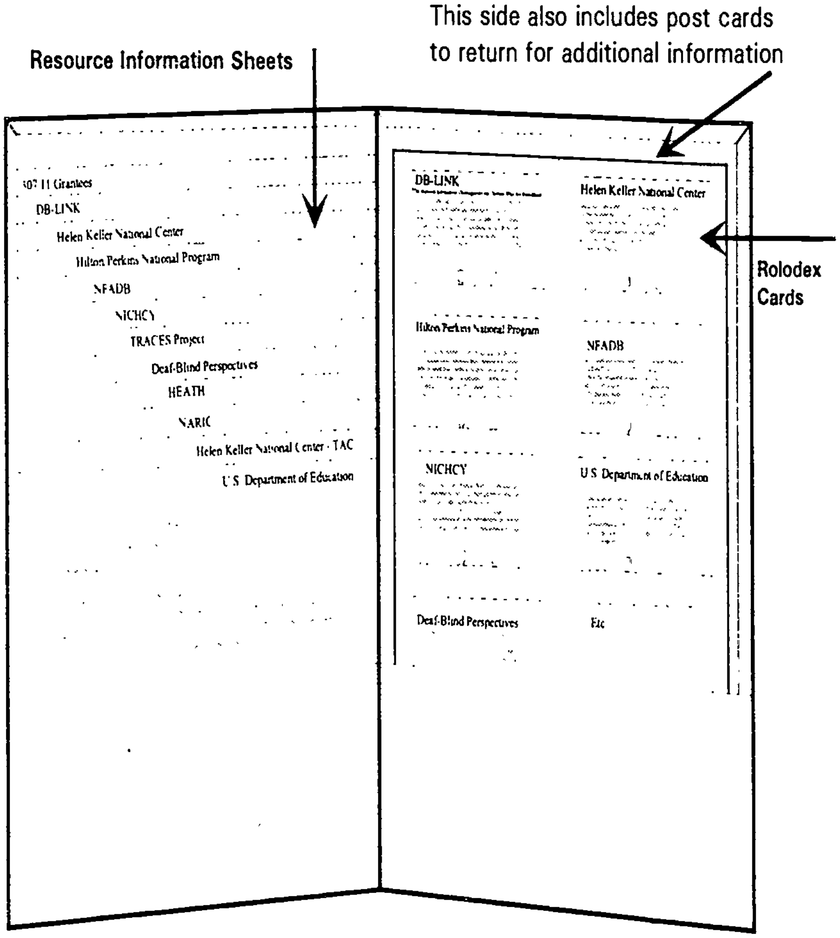
All others, please contact

DB-LINK
345 N Monmouth Ave
Monmouth, OR 97361
(800) 438-9376
(800) 854-7013 TTY



DB-LINK
Family Resource Directory

Produced in cooperation with
the National Family Association for Deaf-Blind



Conferences

2nd International CHARGE Syndrome Conference
Portland, Oregon
July 21–23, 1995

Members of the CHARGE Medical Advisory Board and other specialists will be available for consultation during the conference. Concurrent with the clinic will be an informal welcome session. There will be presentations about the CHARGE Syndrome Foundation. Registration is $75.00 for adults and $30.00 for children (ages 3–18 yrs.).

For more information contact

Marion Norbury
CHARGE Syndrome Foundation
2004 Parkade Blvd.
Columbia, MO 65202
(800) 442-7604

Helen Keller National Center Announces Deaf-Blind Awareness Week, June 24–July 1

When Heather Whitestone was crowned Miss America in 1995, she reminded us that nothing can prevent the realization of a dream. Inspired by Helen Keller, Miss America's message of "Face your obstacles, work hard, and build a support team" inspires all people, but is especially relevant for people who are deaf-blind...one of the most severe disabilities.

Please join the Helen Keller National Center along with other agencies and organizations worldwide, in celebrating the **1995 Helen Keller Deaf-Blind Awareness Campaign.**

Helen Keller speaks through Miss America

The Helen Keller National Center Salutes Heather Whitestone

Like her role model Helen Keller, Heather Whitestone's message inspires all who can see and hear it—and it's even reaching those who can't.

If you know someone who is deaf-blind and who could benefit from programs that build self-reliance through dedicated support teams, call 1-800-255-0411.

Share Helen Keller's Vision

Helen Keller National Center
for Deaf-Blind Youths and Adults*
111 Middle Neck Road, Sands Point, NY 11050

*Operated by Helen Keller Services for the Blind

Design GTFH, 114 Fifth Avenue, New York NY 10011

Conferences

Symposium on Deaf-Blindness: 1995
Austin, Texas
June 23–24, 1995

Open to parents, professionals, and anyone interested in deaf-blindness. Topics include; unique educational and social needs, case study information, using the tactile sense, using low vision, using the auditory system, and deaf-blind services in the 1990's. Together, families and professionals will discuss and show videotaped examples of problems and solutions. Registration is $10.00. The number of participants is limited to 225 with limited out of state availability.

For more information contact

Beth Sanchez
TSBVI Deaf-Blind Outreach
1100 West 45th Street
Austin, TX 78756
(512) 454-8631

Lilli Nielsen National Conference
Novi, Michigan
June 19–23, 1995

The Blind Children's Fund will host a *National Conference For Active Learning: Turning Latent Potential into Dynamic Ability for Infant, Preschool and Multi-Impaired Blind and Visually Impaired Children* with noted Danish educator Dr. Lilli Nielsen. This one week course will present Dr. Nielsen's Active Learning Approach. Original and creative new techniques and materials will be introduced for effectively providing learning environments for blind, visually impaired, and multi-impaired children.

For more information contact

Blind Children's Fund
2875 Northwind Drive Ste 211
East Lansing, MI 48826-5040
(517) 333-1725
(810) 540-4678

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- ☐ Higher education teacher/researcher
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