

Deaf-Blind Perspectives

Volume 1, Issue 1

Fall 1993

Why Deaf-Blind Perspectives?

by
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For more than 20 years the staff at Teaching Research have been involved with matters related to people who are deaf-blind. We provided technical assistance to the Northwest Regional Deaf-Blind Center, directed a number of demonstration projects funded by the federal government, and for the past few years provided technical assistance to the states and regions through TRACES. We conducted, together with the federal government, the National Symposium on Children and Youth Who Are Deaf-Blind. We have most recently formed a consortium with the American Association of the Deaf-Blind, the American Foundation for the Blind, Helen Keller National Center, and Perkins School for the Blind to establish DB-LINK, the National Information Clearinghouse On Children Who Are Deaf-Blind.

During all these activities we published newsletters, reports, made presentations, wrote chapters for books, and in general, tried to promulgate information. The National Deaf-Blind Bulletin Board of SpecialNet was established recently and is being managed by Teaching Research and the California Deaf-Blind Program.

Despite the amount of information being promulgated through these channels, we recognized that there were many issues, problems, concerns and different opinions about matters that affected those who are deaf-blind and their families which were not being adequately discussed in the existing printed periodicals. That such issues existed and needed a medium through which they could be comprehensively aired was amply demonstrated by the papers presented at the Hilton-Perkins National Conference and through the National Symposium on Children and Youth Who Are Deaf-Blind, sponsored by the federal government. We examined existing newsletters to determine whether any met the need that we perceived. We found them all to be quite parochial in their subject matter. For instance, the TRACES newsletter focused only on children and youth who are deaf-blind (birth to 21 years). The Helen Keller TAC newsletter targeted the transition years. We concluded that there was a need for a publication, such as Deaf-Blind Perspectives, that would span the entire age range from birth to senior citizen, and consider the heterogeneity of people who are deaf-blind, to include discussions about those who are deaf-blind and cognitively able and those who are deaf-blind and cognitively disabled.

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We recognized that what we were considering had characteristics that were more journal-like than a newsletter. However, the effort and resources to undertake a journal publication at this time were not available, nor did we wish to ask readers to pay for the publication.

In order to finance Deaf-Blind Perspectives we decided to combine the resources of three entities: (a) Teaching Research currently publishes an eclectic newsletter that focuses on projects that Teaching Research staff are conducting. These range from early childhood special education programs to residential facilities for adults with disabilities who have severe behavior problems. Teaching Research agreed to contribute the resources of that newsletter to Deaf-Blind Perspectives. (b) In addition, TRACES agreed to contribute the resources it had for the publication of its newsletter with the understanding that a section of Deaf-Blind Perspectives would be devoted to TRACES matters. (c) DB-LINK agreed to the same arrangement. Thus the TRACES Newsletter will no longer be published as a separate entity nor will DB-LINK

commence promulgating their own newsletter. In addition, Teaching Research will, during the next couple of years, cease the publication of its newsletter.

What type of articles do we foresee being published in Deaf-Blind Perspectives? We want the newsletter to focus on pertinent issues regarding people who are deaf-blind and those involved with them. An article that discusses the discrepancies between services available for adults who are cognitively able and those who are cognitively disabled might be appropriate. For instance, we know from previous discussions with adults who are deaf-blind that a disturbing issue is the availability of transportation to those who are deaf-blind and cognitively disabled whereas comparable transportation services are not available for those who are deaf-blind and cognitively able.

Other articles might examine inclusion. We certainly have heard many opinions about inclusion and its merits and faults over the past few years. Articles representing the spectrum of opinions would be welcome. The range of subject matter of articles is endless - early intervention, transition, communication techniques, syndrome characteristics, parental concerns, etc. are all appropriate. We encourage controversy and discussion and will at times invite articles that will represent opposing views on topics. We want the newsletter to be perceived as a forum for ideas and discussion.

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We encourage persons who are deaf-blind, parents of persons who are deaf-blind, and professionals to submit articles to Deaf-Blind Perspectives. The articles will be reviewed by a panel of editors and will be either accepted as is, accepted with suggested revisions, or rejected, based on the reviews of the editors. Quality will be the criterion for acceptance. Ideological positions will not be grounds for nonacceptance.

We believe that by presenting the diverse opinions that exist among those who are deaf-blind, their parents, and the professionals who are involved with them we shall begin to accept the differences that exist within the field and perhaps reconcile some of those differences. Thereby, we might help to build a discipline that is united in purpose and yet retains its diversity.

We look forward to publishing this newsletter. We wish it to be of high quality and welcome your suggestions and criticisms. Kudos are appreciated at any time.

Rationale For Editorial Policy On Terminology

by
John W. Reiman
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The promotion of choice, inclusion, and self-determination for people who are disabled requires something from everyone. For those who write on matters related to such persons, the requirement is accuracy and precision.

Imprecise linguistic descriptions of people who are deaf-blind pervade contemporary literature. Do constructs from the vernacular of professionals like "dual sensory-impairment", "with deaf-blindness", and "the deaf-blind" serve the best interest of the people they attempt to describe? To dispute the use of such terminology is not to be pedantic and nitpicky, but to express concern about a real problem. In the paragraphs that follow, I will (a) provide examples of questionable terms and phrases, (b) comment on their possible negative effects, and (c) present an editorial policy for Deaf-Blind Perspectives that will invite greater precision in language used to characterize this population.

Examples of Imprecise Terminology

The terminology in question assumes three primary forms. First, is the medical-model-inspired **pathologizing** variety with its deficit-based watchword, "impairment." "Dual sensory-impaired students", "hearing- and vision-impaired students", "sensory-impaired students", and a host of related descriptions of human beings that champion what is absent about a person and fail to describe what is present—such terms simply alert us to something about a person being wrong. Person-first language (e.g., "students with dual sensory impairments") is purported to address this problem by emphasizing the person first rather than the disability. Placing the person first, however, doesn't erase the negative associations invited by "impairment"—a term out of favor in most other areas of special education and rehabilitation.

A variant on the pathologizing theme is the now popular "with deaf-blindness" (e.g., students with deaf-blindness). The "-ness" is a suffix that forms abstract nouns denoting quality and state (Random House Webster's College Dictionary - 1993). Is an abstract noun adequate for defining the population of people who are deaf-blind? Unfortunately, the abstraction's lack of precision invites creative connotations—the notion of affliction in this case. Combined hearing and vision loss are made to seem like an infirmity or ailment that someone ends up "with." Adversity, distress, hardship, and tribulation are implied. Understandably, some people who are deaf-blind hold contempt for this construct. Escaping disability-related stigma spawned by professionals' use of "with deaf-blindness" terminology, must be an additional and unwelcomed challenge.

A second form of questionable terminology is the **objectifying** variety. "Educators should prepare deaf-blind for..." and "...when the deaf-blind use interpreters" are two examples. Both completely omit the person reference making the human and the disability one and the same. Ironically, there is a twist to this one. On one hand, when hearing/sighted professionals in education and other fields use such language to describe children who are deaf-blind, charges of objectification and paternalism may be leveled. On the other hand, when numerous adults who are deaf-blind (many of whom belong to the American Association of the Deaf-Blind) refer to themselves or to each other, the same terminology deemed as objectifying above, becomes the opposite—validating and affirming. In this context, as a mark of respect and affirmation for community, linguistic, and cultural integrity, usages like "the deaf-blind are...," "some

deaf-blind feel..." and "when Deaf-Blind want..." (note upper-case usage) are the norm.

Terminology of the **overgeneralizing** variety is the third form in question. To say that people who are deaf-blind uniformly think, feel, need, or want almost anything universally, is to discount the heterogeneity and enormous differences that characterize this population. These differences are pronounced in the multiplicity of gifts they contribute to the world, as well as the differences in their needs.. The de facto claim, for example, that "clients who are deaf-blind present with serious communication deficits" (drawn from a counseling context) is fallacious. Can an eighteen year-old Gallaudet University student who is deaf-blind (Ushers Type I) and, using interpreters, maintaining a 3.5 GPA, be viewed as having "serious communication deficits?" Which people who are deaf-blind is the question always begging an answer.

In short, the use of pathologizing, objectifying, and overgeneralizing terminology may compromise accuracy in describing people who are deaf-blind, and may erroneously homogenize such peoples' dissimilar characteristics and needs.

Possible Negative Effects of Such Terminology

Two possible effects come immediately to mind stemming from use of the terminology described above.

First, is it possible that professionals' use of the aforementioned terminology may lend fuel to others' inaccurate portrayals of people who are deaf-blind? A recent telemarketing campaign by a company contracted to raise funds for an agency related to people who are deaf-blind included the following among its categories for sponsorship:

- "Power of Communication" sponsors... who "open up the worlds of hearing and sight for persons who are deaf-blind."
- "Lift the Darkness" sponsors... who "help the curtains of communication be opened and the darkness lifted by the rays of awareness."

Tugging at the heartstrings of potential contributors with misleading images of "worlds being opened" and "curtains lifted" does little to contribute to general understanding of people who are deaf-blind. Isn't it incumbent on us as professionals to forego pathologizing, objectifying, and overgeneralizing terminology in the interest of encouraging realistic and accurate portrayals? Mightn't our inaccurate terminology lend tacit

support to the sale of images as above by modeling imprecision as acceptable?

A second negative effect of the foregoing terminology may be directly experienced by people who are deaf-blind. Amidst deficit-based characterizations across a wide range of print media, what amount of such negativity is directly experienced by the person who is deaf-blind? Imagine one's experience of being labeled in terms limited to what about one was weakened, damaged, injured, or deficient. Whether it be directly through auditorily, visually or tactually received information, or indirectly through the reflected pathos of mass culture, isn't it likely that such terminology does a disservice to the very people it seeks to describe?

As a hearing/sighted person, it would be presumptuous to assume I understood the magnitude of such terminology's negative impact. People who are deaf-blind are presumably affected in untold ways beyond those suggested above.

An Editorial Policy Inviting Greater Precision

Given the above, it shall be the editorial policy of Deaf-Blind Perspectives to require that manuscripts define in no uncertain terms, the population being referenced. The responsibility for defining which subset of people who are deaf-blind each article is referencing, shall remain with the writer (and editors), not the reader. Deaf-Blind Perspectives will edit submissions to reflect person-first language (e.g., "... who are deaf-blind") except in such cases where community, linguistic, or cultural integrity are being cited (e.g., American Association of the Deaf-Blind).

Development of this policy is motivated by the editors' wish to promote respectful relationships between people that honor and embrace individual differences. In the event a writer feels limited by such constraints, we welcome the opportunity for dialogue.

Doors

by
Joyce Ford

Teaching skills to my son who is deaf-blind has often meant dissecting activities into tiny increments. To drink from a cup begins with locating it, grasping it, lifting it...and ten steps later taking a sip. Setting it down right-side up is another skill. Someone appropriately named it backwards chaining; the learning of a skill by chaining the sequence together backwards from the completion to the beginning.

So it was when it came to doors, except that the variety became greater. There are doors with door-knobs, and some with push-bars. There are sliding doors, folding doors, cabinet doors, car doors, and automatic doors in some places. Southwestern Idaho doesn't have many revolving doors...so I put that one aside for later. I focused on the plentiful assortment of doors that Riley encountered daily.

To fully consider the use of doors, I knew that our support services at McKinley Elementary School would be involved as they had been in other activities. Physical therapy would be concerned with Riley's upper body strength. Some doors are quite heavy. The therapist would plan exercises to develop those muscles. Occupational therapy would be troubled with the twisting wrist movement necessary for doorknobs, a motion quite unnatural for Riley. Speech therapy would emphasize signing words such as open, close, inside and outside into Riley's hands. The orientation and mobility instructor would worry about doors that others might dangerously open in Riley's path. Riley would need to be better with his cane. The Special Ed teacher would discuss data: 80% success on 50% of trials with 25% accuracy...a goal would be developed for Riley's Individual Education Plan.

In March of 1992, Riley left the McKinley Special Ed classroom and moved into a regular third grade classroom. Riley is the only deaf-blind student in our school district and one of the first students with severe disabilities to be included full time in a regular education classroom. He was now one of twenty-two third-graders, and the only one who didn't do doors. Fortunately, he was in the company of twenty-one eager 8-year-olds who were more than willing to overlook that. In their eyes, Riley could do lots of other things with them...eat lunch, play at recess, art, P.E., music, and library...all of which they felt were much more important than doors.

The following September the McKinley third-graders moved on to fourth grade, but it was without Riley. As a team, we had decided that Riley needed a full year of regular third grade before moving on. He started this new school year

with twenty-one fresh and eager 8-year-old third-graders who were also willing to overlook the problem with doors.

The children willingly included Riley in their school day activities, but there were no friends when he came home. No one came to play on the weekends. They all lived too far away. Summer would be a long time to spend alone. By December, the decision had been made to move Riley to Valley View, our neighborhood school. Perhaps he would make friends here that would fill the void. The move would occur following Spring Break. Careful planning, attention, and support would be needed for staff and students since Riley would be the first child with severe disabilities to attend this school.

To help with the move, four of Riley's classmates were asked to talk with the third-graders at Valley View. Ellie, a teacher who works with Riley, got them started by asking, "What is one thing that you would want other kids to know about Riley?"

They each answered differently with blatant honesty.

"You need to be gentle with him," one little girl answered. "He won't break, but you need to be gentle."

"Riley can't see and he can't hear...but he's just like us inside," one of the boys added.

The new third-graders began asking their own questions. "What didn't you like about having Riley in your class?"

"I didn't like it that he lived so far away. I can only see him at school and I would like to play with him at his house, but he doesn't live in our neighborhood so I can't go to see him."

"Why did Riley go to your school if he doesn't live in your neighborhood?"

"We don't know," Trisha responded matter-of-factly, "but we feel really lucky that he did."

"How did you feel when Riley first came to your class?"

Darren took this question. "I knew a little bit about Riley before because he was in my sister's class last year. I didn't mind helping him...we all wanted to help him. I just didn't know he would be my friend. Now when I think about my friends, I would have to say that Riley is one of my best friends." Tears came to his eyes. "I'm really going to miss him."

I hadn't planned on this. No one ever mentioned separation and loss. Inclusion was about good things...maybe this was good, but it didn't feel particularly good. Something had to be done to reassure these kids that they would always be an important part of Riley's life.

Riley can't see and he can't hear...but he's just like us inside,

March 31, 1993 was Riley's last day at McKinley. Valley View honored Riley as their V.I.P. with a special bulletin board and a question and answer session. We met at the school at 12:30 and Riley was introduced in person. I brought some pictures and fielded their questions. Some of the questions were similar to the ones the McKinley students had asked a year ago: "Does he like to play Nintendo? What is his favorite color? Does he say words?" They were the questions kids who haven't been exposed to severe disabilities ask.

At 2:30 a farewell party was held at McKinley. I am a familiar face there, and I could tell the third-graders with all honesty and sincerity that they were very special people and that they would not be forgotten. I gave them each a little heart shaped pin with the "I love you" sign on it. Riley and I passed out chocolate cupcakes with mounds of white frosting and blue flowers. We saved the one he had stuck his thumb into several times for himself and carried it back to his desk where he promptly devoured it. I went to get paper towels.

A little girl approached me. "Crystal is crying," she said. "She doesn't want Riley to leave, and neither do I," she added tearfully.

"He is our friend. It won't be the same without him," another voice echoed.

I was surrounded by weeping children and I felt my own tears begin. They had all made cards for Riley...textured with colorful pipe cleaners, yarn, straws, beans, and fuzzy stickers. Each carried their message of friendship and wishes for new friends. Ben wrote Riley's name in braille. Trisha's began with a red velvet heart and contained a message to match it inside.

"You and Riley are going to leave, aren't you?" Crystal asked.

"I promise you we'll come back," I answered.

"But you're going to leave."

"Yes...we're going to leave. But when we leave, you can know in your hearts that you did something remarkable. Part of each of you will go with us, and I hope that part of Riley and I will always stay with you. You taught all of us grown-ups some very important lessons." I kissed her forehead. "This is something we have to do."

There was another group of children on the other side of the room who were not tearful. They were speaking quietly and seriously to their teacher.

There are just so many types of doors. The dishwasher door opens down and the door on the car trunk opens up. The microwave has a button that must be pushed to open its door. When you think about it, there is a lot to teach about doors.

The children across the room were solemn. They spoke their quiet wisdom in turns.

The oven door is hot sometimes and cool at other times. The refrigerator door is cold on the outside and colder on the inside. The back door has a storm door with a pet door. Some doors open to stairs and others don't. There is a lot to consider about doors.

They asked their teacher if another student from the self-contained classroom could come and be part of them. They told her they wanted that. They told her they needed that. She respectfully nodded in agreement.

And while I pondered the complexities of doors and my son's disabilities, Riley it seems, with his tremendous abilities had magically opened the heaviest and most difficult door of all.

Teaching Students Who Are Deaf-Blind and Cognitively Disabled To Effectively Communicate Choices During Mealtime

by

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Individuals who are deaf-blind and have a cognitive disability may not effectively communicate their desires and choices even when provided with the opportunity to do so, in part because of their frequently limited communication skills. The ability of these individuals to make choices may be further constrained by instructional staff and caregivers, who anticipate their wishes and make choices for them. These caregivers and instructional staff may be acting with only the best intentions for these individuals, perhaps in the belief that they are unable to make a meaningful choice. Often, however, these individuals have not been taught how to make a choice. For students who are deaf-blind and cognitively disabled to achieve valued life outcomes, it is essential that they are able to effectively communicate personal choices.

Given the essential nature of the ability to communicate choice and the potential barriers to

choice-making, it is necessary to focus on teaching students who are deaf-blind and cognitively disabled the process of making meaningful choices and to develop a flexible curriculum in which they have opportunities to practice making choices within the context of their daily routines. Mealtime is ideal for this instruction. It naturally occurs on a consistent, daily basis, in school, at home and in community environments. The act of communicating what one wants to eat or drink and receiving what one has chosen results in natural consequences that are highly motivating, thus reinforcing the power of clear communication.

The table that follows offers a set of practical guidelines for teaching students who are deaf-blind and cognitively disabled to make choices during mealtimes. It is offered as an aid to instructional staff and caregivers to illustrate the ways in which a typical daily activity can be

utilized to teach choice-making within the context of a natural routine. In addition, it has implications for how the skill can be increased in complexity as the student progresses. We offer this as an example that can be applied in other settings and activities, which include selecting

something to do, choosing with whom to do it, choosing where to do it, choosing when to do it, or choosing whether to do it at all (Brown & Gothelf, in preparation; Crimmins & Gothelf, in press).

Table 1

Choice-making Instruction		
Guiding Principle	Example	Considerations
<i>People typically make choices in the environments in which the outcomes of their choice are available.</i>	Choosing what to eat should take place where the student normally eats. Teaching choice-making in an artificial environment removes many of the naturally-occurring cues to the event.	Administrative policies and procedures should ensure that the choice-making process can take place. This may involve working with the cafeteria staff or revising lunch-time schedules.
<i>The boundaries in which the choice-making activity takes place should be defined through the use of appropriate aids and cues. Providing boundaries minimizes the visual/motor and cognitive requirements of orienting and reaching.</i>	A dycem placemat can be used to secure a cafeteria tray on a table, or on the lap tray of a student's wheel chair. A second dycem mat can be used to secure the plates and glasses on the tray. (Dycem is a non-slip plastic that is helpful in stabilizing objects on surfaces. It comes in reels or sheets that can be cut to size. It is portable, easily cleaned, inexpensive and available from adaptive aids catalogs).	If cafeteria trays are not available or necessary, the plates of food can be placed on a dycem mat directly on a table. For students with vision, the color of the dycem should be selected to provide contrast with the tray or table and the plates.
<i>Individual preferences play an important role in enhancing motivation for the activity.</i>	The student is presented with two entree samples, one at a time. The items from which a student is choosing should be two things which he or she is likely to want to eat.	Administrators should work with cafeteria staff to ensure that appropriate alternatives are made available. (E.g., if two hot meals are not available, a choice between a hot meal and sandwich, or between two sandwiches should be substituted.) Be aware that food preferences are influenced by a student's cultural and family background.
<i>The student is made aware of the food through tactile/kinesthetic cues (guided or paired movements between the teacher and the student), visual, verbal, gestural and object cues. The teacher must assess the conditions that facilitate comprehension (e.g., with gestures, without gestures, etc.).</i>	For each sample of food, the student is moved through touching the plate, touching the food, smelling the food, and tasting the food. A staff member will say the name of the food, sign it, and shape the student's hands to sign the name of the food.	The student's receptive vocabulary may be limited. Natural routines should be maintained within the normal context of mealtime in order to help the student comprehend the expectancies for his or her behavior.
<i>Choices should be presented consistently in order to reinforce the physical structure within which choosing occurs. Placing the choices in the same locations in relation to the student's body each time they are presented helps the student to anticipate where the sample is likely to be.</i>	The first sample is presented on the student's left, tasted with the left hand, and then removed. The second sample is then presented on the student's right, tasted with the right hand, and then removed. Care must be taken to ensure that the individual is not always choosing the sample on the right or the sample on the left.	The student's ability to reach, grasp, and manipulate utensils or the food itself, may be influenced by poor muscle tone, stability, or coordination, as well as limited visual functioning. Generally, proper postural alignment can be attained through the use of adaptive positioning equipment. Grasping and manipulating utensils can be assisted through the use of adaptive aids such as special spoons, plates with lips, or slant trays. (Campbell, 1987).

Continued

Table 1 continued

Choice-making Instruction		
Guiding Principle	Example	Considerations
Establishing routines within instructional sequences enables the student to anticipate the next step and encourages self-initiated choice-making. A pause or time-delay in a sequence (hands in the lap) may serve as a prompt to the student to initiate an interaction or make a selection (Siegel-Causey & Ernst, 1989).	Both samples are then presented to the student. The student touches the left plate with the left hand, and the right plate with the right hand. As the student touches each sample, he or she is reminded of its name. The student is then directed to place both hands in his or her lap (using verbal and/or physical prompt as needed). The student is then instructed: "It is time to pick what you want for lunch." Language input should be provided at a level and in a mode that the student can comprehend.	If a student does not respond when the question is repeated, the teacher communicates: "That's OK, if you don't want the meat or the rice, I'll ask you again soon." Language input should be provided at a level and in a mode that the student can comprehend. The teacher should always return and provide the student with another opportunity and additional prompting if necessary.
Reliable communication of preference depends upon a foundation of consistent responses to the student's non-verbal behaviors. Non-verbal behaviors need to be acknowledged by the teacher on the assumption that the individual is attempting to communicate meaningful dialog. This provides a basis for communicating shared meanings (Guess, Benson, & Siegel-Causey, 1985; Williams, 1991).	The student chooses the desired food by touching one of the samples, by looking or facial gesture, by starting to eat, by vocal sounds and/or body movements, by signing or in any way indicating his or her preference.	If the student reaches for both, or neither, the teacher must repeat the previous procedure, and reinforce that the student must choose one sample. The teacher must acknowledge any form of communication. If the student repeatedly reaches for both, he should be given some of each for lunch.
Components of everyday routines should be utilized to establish correspondence between words and their meanings. Routines enable students to take an active part in the activity and to communicate with the teacher.	The staff signs "finished" for the undesired plate and moves the student through the sign "finished" and prompts the student to move the plate away.	Initially, the student may require the teacher to move his hands for him. Subsequently, the teacher and the student should cooperatively move their hands together, the student's hands riding on top of the teacher's. The teacher should pause in the pushing action, and allow the student to communicate a desire to continue by moving the teacher's hands.
In addition to establishing correspondence between words and their meanings, the process of systematically using routines in the choice-making process must be established.	The teacher signs "eat" and the name of the desired food, and prompts the student to do the same. This procedure must follow the previous one.	The teacher may choose other ways to communicate the same message, such as signing the student's name followed by the signs for "wants to eat" and the name of the food. Language input should be provided at a level and in a mode that the student can comprehend.
Contingent communicative behavior is reinforced by getting the requested item. The student communicates through an action or a signal to indicate his preference.	The student is served a full portion of the food that was selected.	The student must join the cafeteria line to obtain the full portion of food.

Table adapted from Gothelf, C.R., Crimmins, D.B., Mercer, C.A., & Finocchiaro, P.A., (in press). Teaching choice-making skills to students with dual sensory impairments. **TEACHING Exceptional Children**; reprinted by permission of the editor.

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The National Information Clearinghouse On Children Who Are Deaf-Blind

by
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In the United States today, a heterogeneous group of roughly 7500 children (birth through 21 years) who are deaf-blind, many of whom have additional disabilities, experience considerable unmet needs. For the general public, professionals, and parents to understand and respond intelligently to these needs, they must have access to reliable and well-organized information.

To address the critical need for a systematic approach to information sharing and dissemination, the Department of Education, Office of Special Education Programs, has awarded a cooperative agreement to the Teaching Research Division of Western Oregon State College to establish DB-LINK (The National Information Clearinghouse On Children Who Are Deaf-Blind). Funded in October 1992, DB-LINK collects, organizes, and disseminates information related to children and youth (birth through 21 years) who are deaf-blind.

DB-LINK is a consortium-based project comprised of:

- American Association of the Deaf-Blind (AADB)
- American Foundation for the Blind (AFB)
- Helen Keller National Center (HKNC)
- Perkins School for the Blind (Perkins)
- Teaching Research (TR).

DB-LINK will have a regular column in *Deaf-Blind Perspectives*. DB-LINK staff will write on topics both specific and tangential to DB-LINK. The objective being to provide information useful to the readership of *Deaf-Blind Perspectives*. This article focuses on how DB-LINK works; what parents, professionals, and other interested consumers can expect from DB-LINK; and how DB-LINK can be accessed.

How DB-LINK Works

Figure 1 depicts how information flows within the project. DB-LINK is founded on the information needs of many different consumer groups. Note that information flows both ways—information is collected from multiple sources and shared with a wide variety of consumers. One of DB-LINK's major responsibilities is to provide information through an inquiry-response process. Consumers with questions call DB-LINK toll-free and talk with an Information Specialist. The Information Specialist determines the nature of the question and those that can be answered immediately will be responded to at once. For most inquiries though, the Information Specialist will check multiple sources to answer the question. Depending

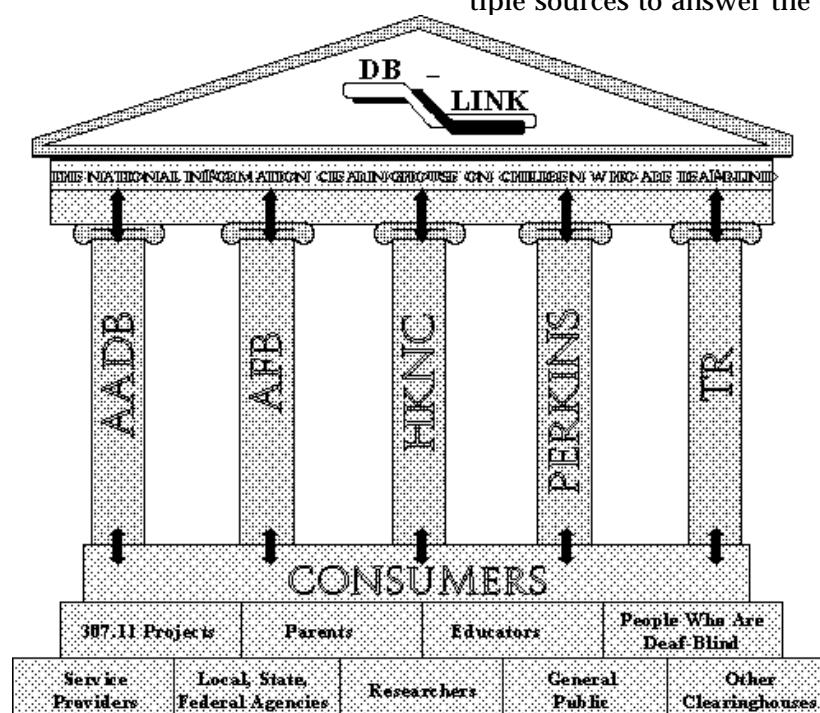


Figure 1 How information moves within DB-LINK

on the nature and complexity of the request, the Information Specialist may consult with other Information Specialists within the DB-LINK consortium. In this way, DB-LINK draws upon the collective expertise of project staff to answer inquiries. For difficult or complex questions, the process of asking a question and getting a response may require up to three or more days, plus the time it takes to get back to the inquirer (e.g., mail, phone). At present, there is no charge for DB-LINK's service.

DB-LINK maintains three databases; Catalog, Resource, and Tracking. Bibliographic information on text sources is contained in the Catalog Database; the Resource Database holds information on services; and the Tracking Database allows DB-LINK to monitor information about the requests.

DB-LINK's first two years (1993 and 1994) will focus on cataloging the vast amount of information located around the country. During this developmental period, inquirers will receive responses that are as complete as possible via the developing databases. However, time will be required for DB-LINK to acquire and organize all available information.

What to Expect from DB-LINK

Though DB-LINK has information about specific materials and resources, DB-LINK does not necessarily own these items. That is, DB-LINK does not act as a library or a supplier. Fact sheets (written summaries on topical areas) will be developed on selected topics throughout the project and these will be available as developed for dissemination. Samples of the types of information DB-LINK can provide are listed below.

Responses to questions regarding:

- early intervention
- general education
- health
- recreational services
- employment
- syndromes
- technology
- inclusion
- orientation and mobility
- special education
- medical issues
- social services
- legal issues
- independent living
- transition
- IFSPs, IEPs, ITPs
- communication
- postsecondary education

Referrals to other organizations such as:

- departments of education
- local disability organizations
- research projects
- regional disability organizations
- advocacy groups
- colleges and universities
- professional consultants
- parent groups
- medical centers

Fact sheets (*beginning in year 2*)

How to Access DB-LINK

Office hours are from 9 A.M. to 5 P.M. Eastern time; after-hours callers will be asked to leave a voice mail message, and an Information Specialist will return their call. Consumers can call DB-LINK toll-free:

**800 438-9376 Voice
800 854-7013 TTY**

Business callers should contact:

Dr. John Reiman
Director
DB-LINK
345 N. Monmouth Ave.
Monmouth, OR 97361

(503) 838-8776
(503) 838-8150 fax.
800-854-7013 TTY

Additionally, DB-LINK can be contacted through:

dblink@tr.wou.edu
<http://www.tr.wou.edu/dblink>

DB-LINK (The National Information Clearinghouse on Children Who Are Deaf-Blind) is funded through Cooperative Agreement No. HO25U20001 by the U.S. Department of Education, OSERS, Special Education Programs. The opinions and policies expressed by DB-LINK do not necessarily reflect those of the U.S. Department of Education.

Traces

Regional News

In each issue of Deaf-Blind Perspectives the TRACES project will examine technical assistance topics. This first issue highlights selected recent technical assistance activities from around the country. Readers interested in more information about these activities are encouraged to contact the person listed or the TRACES Regional Coordinator for that area. Other technical assistance activities, as well as topical reviews, will be featured in subsequent issues.

IDAHO, NEW MEXICO, NEVADA, MONTANA, and WYOMING

Systematic identification of children who are deaf-blind is a primary responsibility of the Section 307.11 Projects. To fulfill this responsibility, an understanding of functional screening processes and the ability to review and interpret the results of a student's audiological and visual assessments are necessary.

Multi-state training provided recently to coordinators of Section 307.11 deaf-blind projects from Nevada, Idaho, New Mexico, Wyoming, and Montana provided the first level of training and information in these areas.

The three days of instruction and practical training resulted in:

1. A basic understanding of the issues related to people who are deaf-blind.
2. The ability to review audiological and visual assessment results and interpret their educational impact on a student.
3. The ability to gain functional information regarding students via observation and interview strategies.
4. The ability to recognize that additional assessment information must be collected on particular students for the purpose of determining sensory loss and the educational strategies.

For more information, contact:

Rich Mulholland, TRACES Western Region (503) 838-8773 or

Earlene Dykes, Arizona State Schools for the Deaf and the Blind, (602) 770-3677.

KENTUCKY

The Deaf-Blind Intervention Program in Kentucky is offering training for parents of young deaf-blind children (ages birth to 3 years) to assist them in the transition from infant/toddler to preschool programs. This two-day training, which is called "Reach for the Stars...Planning for the Future," is a modification of the Personal Futures Planning process used with adolescents and young adults.

Families are encouraged to dream about what they want their child's preschool program to look like. Questions asked include: Will my child go to preschool with children without disabilities? What supports will my child require in preschool? What is the difference between an IFSP and IEP? What rights do I have when my child enters public school? What does a "quality" preschool program look like? Information that a family wants service providers to know about their child is collected in a colorful, illustrated, individual binder which can be taken to the initial IEP meeting.

The training is being offered in all areas of Kentucky where there are young children on the Deaf-Blind census. Anecdotal data indicates that use of this process with this age group has educated families about what services can and should be available as well as having empowered them to request these services for their children. It is hoped that this will enable deaf-blind children in Kentucky to receive appropriate services at an earlier age, and subsequently to better reach their potential.

For more information, contact:

Jennifer Leatherby, Project Coordinator
(606) 257-7909.

LOUISIANA

To provide a single source of information for families, a statewide family resource network called Families Helping Families has been developed. Its mission statement is: "to enable and empower families of individuals with special needs through a coordinated network of resources, support, and information exchange". Based on an initiative developed by the Louisiana Community and Family Support Act; a coalition was formed of existing family programs, a RFP was issued by the Developmental Disabilities Planning Council, grants were awarded, and Families Helping Families Centers were formed around the state.

Current activities include: infant and toddler family outreach, information and advocacy concerning education issues, inclusive education outreach, and serving as an entry point for the community and family support system. Projected future activities are: coordinate existing efforts, market the role of the resource centers, develop collaborative relationships at the local level, and secure ongoing funding.

The Louisiana Section 307.11 Project is using this network to disseminate information about children who are deaf-blind, to assist in its child find efforts, and to distribute a brochure about the project to solicit requests for technical assistance. It is hoped that these "family friendly" resource centers can assist in providing needed support so that appropriate services can be secured with a minimum of effort and frustration.

For more information, contact:
Joyce Russo, Project Director, (504) 342-1525.

MARYLAND

The Maryland Deaf-Blind project recently held its' annual Parent Retreat at a nature retreat outside of Bethesda, Maryland. Rooms for families were located within cabins, which allowed contact time between families outside of the planned meeting times. Some information sessions were held outside, giving an open relaxed feel that led to extended discussions. All the children participated in a "campfire", which lead to siblings discussing what being a part of a family with a child who is disabled was about.

It is important to remember that parents and siblings often bring their own wants, needs and concerns. Coordinators must stay flexible enough to allow for such needs to be met while providing valuable information to all participants. It was

through this flexibility that the Maryland Parent Retreat was such a success!

For more information contact:
Ms. Loretta McGraw, Project Director (301) 333-2498 or
Ms. Diane Kelly, Project Coordinator, Dr. Julie Jones, Project Coordinator, (301) 405-7915

NEW JERSEY

The New Jersey Technical Assistant Project identified as the overall project objective, "to provide a solid project infra-structure that will effectively and efficiently meet the informational, training and technical assistance needs of infants, children, and youth with multiple sensory impairments." A three phase process to address seven outcomes of this objective was developed: (a) Conduct a spring retreat, (b) develop support activities for implementation of recommendations, and (c) conduct a follow-up retreat.

Seven project personnel attended a two day retreat in Philadelphia. There, team members discussed the operations and management plan of the project. Consultants Ms. Gigi DeVault and Ms. Mary Fischer, from the University of Washington in Seattle, facilitated the discussions. Creative Problem-Solving (CPS) strategies were introduced for problem solving and decision making processes. Participants were grouped and provided particular discussion topics by the consultants to facilitate the use of the CPS Model.

After the retreat a comprehensive Consultation Services Summary Report was submitted. This report also included Stream Analysis—a technique for diagnosing, planning, and tracking organizational change. Abstract concepts are operationalized using a graphic mapping process as a system of tracking organizational change. Core team members will participate in continued facilitated training on CPS and Stream Analysis in a retreat planned to occur in September, 1993.

For more information contact:
Jerry Petroff, Director of NJ.TAP,
(609) 292-4462.

WASHINGTON

The Statewide Project for Infants and Toddlers with Hearing and/or Vision Disabilities is a newly proposed project in the state of Washington.

During the 1992-93 period, TRACES provided technical assistance to a statewide task force developed by the Interim Statewide Project for Infants and Toddlers with Hearing and/or Vision Disabilities. Results of this year-long project demonstrated that the following conditions exist for infants and children who are deaf-blind:

1. Approximately 450 children were identified; far below the projected incidence rate for Washington of nearly 1500.
2. Services are fragmented across the state, with families in metropolitan areas far more likely to receive appropriate services than those in rural areas.
3. There is no single point of contact or entry into the system through which families can gain services.

The proposed project's goals generated from recommendations made by the task force are:

1. To improve early identification of infants with sensory disabilities.
2. To ensure statewide educational services and support to families with children aged three and younger with sensory disabilities and the professionals who work with them.

For more information, contact:

Marcia Fankhauser, Project Director, Washington State Services for Children with Deaf-Blindness, (206) 439-6937.

WEST VIRGINIA

The geography of West Virginia often makes finding and identifying children who are deaf-blind difficult. Separated by mountains, small, rural, mining or farming towns are difficult to reach by car, and may have limited resources in health care and education. Dr. Michael Valentine, Section 307.11 Director for West Virginia, is implementing new steps to reach these rural families with children who are deaf-blind.

Dr. Valentine is putting together a video that describes students who are deaf-blind and where to get more information. This video will encompass all levels of the disability, from high functioning students with hearing and vision losses to students who are multiply disabled, and cover all age ranges from preschool to high school.

This video is planned for distribution to local educational agencies, pediatricians, Ear, Nose and Throat Specialists, and local health clinics. It is believed that these places serve as a meeting place for communities, and have the equipment available to show this information. By viewing this tape parents with questions will hopefully ask those questions of available physicians and educators or directly contact the State Office of Special Education.

For more information contact:

Dr. Michael Valentine, Project Director
(304) 558-2696

For Your Library



Out of The Shadows

by Robert and Charlene Petty

Out of the Shadows is about the authors' experiences in raising their son Don, who is deaf-blind. The book also contains poems and personal insights written by Don, a 1980 graduate of the University of Oklahoma.

149 pages, cost: \$7.95.

To order, contact:

Delano Press
P.O. Box 300223
Midwest City, OK 73140
(405) 447-1170
ISBN 0-9632731-0-8

Independence Without Sight or Sound: Suggestions for Practitioners Working with Deaf-Blind Adults

by Donna Sauerburger (1993)

Sauerburger began 20 years ago as an orientation and mobility instructor for adults who are deaf-blind. Her book explores a number of topics including communication, orientation and mobility, and self determination.

194 pages, cost: \$35.00 (specify print or braille).

To order, contact:

American Foundation for the Blind
15 West 16th St.
New York, NY 10011

Technological Resources for Students with Deaf-Blindness and Severe Disabilities

by Nancy Sall, M.S. and Harvey Mar, Ph.D. (1992)

This manual contains a detailed review of 20 computer software programs with vignettes describing how each program was adapted for a particular student; listings of adaptive devices, references, hardware and software companies; and annotated bibliography of 40 articles and papers on special technology

97 pages, cost: \$ 6.00 (for duplication and postage).

To order, contact:

Center for Adaptive Technology
15 W. 65th St.
New York, NY 10023
(212) 873-1409 fax: (212) 875-0733

A Resource Manual for Understanding and Interacting with Infants, Toddlers, and Preschool Age Children with Deaf-Blindness

Linda Alsop, M. Ed., Editor (1993)

This manual provides insights, information, and intervention strategies to those who work with infants, toddlers, and preschool age children who are deaf-blind.

The manual is divided into thirteen sections dealing with intervention, communication, auditory development, tactile stimulation, self-help skills, massage techniques, fine and gross motor skills, orientation and mobility, social and emotional development, health care, and play.

576 pages, cost: \$50.00

To order, contact:

Home Oriented Program Essentials dba Hope Inc.
809 North 800 East
Logan, UT 84321
(801) 752-9533

A Model Service Delivery System for Persons who are Deaf-Blind

Douglas Watson, Ph.D. and Myra Taff-Watson, M.A., Editors (1993)

This monograph offers a comprehensive presentation of guidelines for a community based approach to planning and implementing delivery of services to persons who are deaf-blind.

Updated from the 1983 edition and includes an overview and description of new population characteristics and demographics, communication methods, interagency planning considerations, and transition.

118 pages, cost: \$15.00

To order, contact:

University of Arkansas
Rehabilitation Research & Training Center for
Persons who are Deaf or Hard of Hearing
4601 West Markham Street
Little Rock, AR 72205
(501) 686-9691
fax: (501) 624-3515

Calendar of Events

September 1993

- 18-19 A Transition Weekend for Parents of Children with Visual impairments and Multiple Disabilities, Howard Johnson's Plaza North Hotel, Austin Texas. Guest speakers: Jeff Strully, Shawntell Strully, Cheryl Powledge, and Natalie Green. Sponsor: Texas School for the Blind and Visually Impaired. *Contact:* (512) 454-8631 ext. 103 or 156

October 1993

- 27-29 1993 Project Directors Meeting for the Severe Disabilities Branch, OSEP. Ritz Carlton Hotel, McLean, VA. *Contact:* Connie Jennings (503) 838-8770

November 1993

- 4-6 TASH Conference, Chicago Hilton and Towers, Chicago, IL. Keynote speakers: Eldridge Cleaver, Jonathon Kozol. *Contact:* TASH, 11201 Greenwood Ave. N. Seattle, WA 98133 (206) 361-8870 fax: (206) 361-9208.

- 5-7 "The Challenge Continues" is the theme for a series of workshops in Seattle, Washington. Sponsored by the National Association for Parents of the Visually Impaired. Keynote speakers: Nancy Ford and Steve Perreault. *Contact:* NAPVI 800-562-6265.

- 6-7 "Strategies for Inclusion," Portland, Oregon, Marriott Hotel. Keynote: John Champlin, Ann Lynch, Floyd Hudson, Jeff Champagne. *Contact:* Inez Ambrosek, or Nancy Anderson, (503) 378-3598.

December 1993

- 11-15 International Early Childhood Conference on Children with Special Needs, San Diego Marriott Hotel and Marina, San Diego, CA. *Contact:* DEC Conference (410) 269-6801

July 1995

- 16-20 The 18th International Congress on Education of the Deaf, Jerusalem, Israel. *Contact:* Secretariat, 18th International Congress on Education of the Deaf/1995, P.O. Box 50006, Tel Aviv 61500, Israel.

If you have an event you would like to have considered for our next calendar, let us know.

**Deaf-Blind Perspectives
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| <input type="checkbox"/> Special educator (e.g., teacher, aide) | <input type="checkbox"/> Therapist (e.g., OT/PT/speech) |
| <input type="checkbox"/> Administrator, Dept. of Ed. employee | <input type="checkbox"/> Teacher trainer |
| <input type="checkbox"/> Service provider (e.g., social worker, group home) | <input type="checkbox"/> Government personnel |
| <input type="checkbox"/> Technical assistance provider | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Higher educator teacher/researcher | |

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