

Deaf-Blind Perspectives

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A Dangerous Misrepresentation of the Facts

In

The 15th Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act

Vic Baldwin

Director, Teaching Research

Every year the Office of Special Education Programs is required to produce an Annual Report to Congress (U.S. Department of Education, 1993) that summarizes the national statistics on the numbers of children who received special education and related services under IDEA (Part B) and Chapter 1 of the Elementary and Secondary Education Act (89-313). In order to generate the information needed for this report, each state director of special education must count and compile specific demographic data on all children his or her state has served within the last year under these two funding authorities. The agreed-upon date at which time this count will officially occur is December 1st of each year.

Each state department of education receives its demographic information from the educational service providers within the state. The demographics mainly consist of age, sex, primary and secondary disability, the type of educational setting, and the exiting status of the older students. Once this information has been received by the state department, it is checked for completeness and eventually forwarded to the U.S. Department of Education where it is compiled into the Annual Report to Congress.

The Annual Report is at least an inch and a half thick and contains over 350 pages. It is full of tables that present the information in hundreds of different ways. For the most part, the tables show the numbers of students across all of the states by age groups, funding authority, educational setting, or type of disability.

The Problem

The reported numbers for the disability category of deaf-blind are grossly in error! The first table in the Annual Report (p. 3) shows that the total number of students served in special education programs has been steadily increasing for the past 15 years, with a 2% to 4% jump in each of the last three years. The second table (p. 4) indicates that there are only 1423 students reported nationally under the disability category of deaf-blindness. This is in serious conflict with the nearly 8500 students that are reported by coordinators of programs for those who are deaf-blind in each of the 50 states and territories. Advancing the problem even further, the Annual Report states on page 9 that the number of children under Part B programs categorized as deaf-blind has decreased by 42% in the last 10 years.

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Discussion

My comments will be directed only at those sections of the Annual Report that deal with the disability category of deaf-blindness. I believe the data presented in the Annual Report are in fact dangerously misrepresentative, and I will attempt to discredit the numbers and suggest alternatives.

The Annual Report does not acknowledge that the Secretary of Education is also mandated to conduct an annual count of persons who are deaf-blind, from birth to age 21. Since 1986 the U.S. Department of Education, Office of Special Education Programs has contracted with Teaching Research to conduct this census. This is carried out by requiring the coordinators of programs for those who are deaf-blind in each of the 50 states and territories to report the number of persons who are deaf-blind whom they have identified. This mandated annual deaf-blind census must coincide with the annual state effort to determine the overall count on December 1st. The deaf-blind census requires considerably more information than the state report and therefore is more complete. At a minimum, the An-

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nual Report should include the data that are generated on the federally mandated deaf-blind census and some narrative to explain why the two reports are so different.

Some of the additional information that is gathered on the deaf-blind census provides details on degree of hearing loss, degree of vision loss, etiology, additional disabilities, the funding authority, educational setting, living arrangements, and finally, the label or category that the state department of education used when it counted the student. This last area has shed a great deal of light on why the state department count for the number of students who are deaf-blind is so low.

Of the approximately 8500 persons identified by program coordinators, nearly 50% have been categorized by state departments as "multidisabled" or "mentally retarded." In many of the other cases, the states prefer to use the categories of "vision impairment" or "hearing impairment" as the primary classification. Placement in one of these categories does not mean the student does not have sufficient disabilities in the areas of hearing and vision that would qualify them as being deaf-blind.

Over the years attempts have been made to resolve the large discrepancy, between the way state departments and program coordinators count children, without accusing either group of wrongdoing. It appears that, for a variety of reasons, state departments do not like to use the "deaf-blind" label. Most states will not deny that

“We can not allow our lawmakers to think that there are only 1400 deaf-blind children nationwide.”

these students have losses in both hearing and vision. There is a high probability that these students are in programs for multidisabled students. The teacher is probably certified to teach multidisabled students but such certification does not guarantee they have experience or competency with students who are deaf-blind. If a school district uses the label of "deaf-blind," it runs the risk of noncompliance or having the teacher questioned for appropriate credentials. Identifying the student as deaf-blind would clearly suggest that the instruction must take into account the loss in both hearing and vision. Legally, the safest way for the school district to operate is to use a classification for which it has a qualified teacher.

Each state has a coordinator of programs for those who are deaf-blind who is committed to either full time, or to some significant amount, and this coordinator's job is to locate, assess, and be an advocate for appropriate programming. Therefore, it stands to reason that this person should be the primary source of information about the deaf-blind population in that state. We have advised the coordinators not to get into a confrontation with the state department classification system. In order to justify their classification, which may differ from the state's, they need to supply convincing information about each person's hearing and vision levels and make every effort to document the etiology. The documentation provides a defense for placement of a person on the deaf-blind census. Given all of these precautions and conditions to identify a person as one who is deaf-blind, the likelihood of this count being considerably more accurate than the one from the state department increases significantly.

If none of the arguments so far have convinced you that the data in the 15th Annual Report are in error, then try this: On page 171 (table AA4) there is a breakdown of how many students who are deaf-blind are reported by each state, covering the age ranges from 6 to 21 under both funding authorities (Part B and 89-313). The following is a sample of the numbers of students who are deaf-blind that state departments of education have reported as compared to the deaf-blind Coordinator report.

	15th Annual Report	Program Coordinator Report
Arizona	0	92
Arkansas	2	89
California	132	1219
Michigan	0	225
Nebraska	3	80
New Hampshire	1	57
Pennsylvania	3	406
Virginia	4	243
Wisconsin	5	162

You don't have to know anything about the incidence of deaf-blindness to see that these figures are unreasonable. The highest number for any state is 132 from California. Even if they were right, how could California have 132 and Michigan have none? It just doesn't work that way. There is no reason to believe that the condition of deaf-blindness is not normally distributed across all of the states in the same manner as the other types of disabilities. The figures here are so obviously wrong that printing them without explanation is inviting trouble.

In any state, the number of students receiving special education, is fairly consistent in relation to the total number of students that are enrolled in that state. This number is quite predictable—between 10% and 12%. In some earlier studies that we conducted, we determined that the incidence of deaf-blindness was probably around 2 in every 1000 special education students being served. This number is not precise, so we talk about an expected range based on a standard deviation we found in our sample. If our expected numbers are close, and the deaf-blind coordinators findings are getting very close, then one would expect to find approximately 10 thousand students who are deaf-blind, based on the nearly 5 million special education students served nationally.

We will be the first to tell you that we don't have complete diagnostic information on all 8500 students on the deaf-blind census. We are certainly pushing hard to get the additional information on all students so there will be no question about their eligibility to be classified as deaf-blind. In the meantime, if we are only 50% correct there are still considerably more students than the 1423 reported in the 15th Annual Report.

I want to emphasize that our purpose in identifying and classifying someone as being deaf-blind is for the sole purpose of trying to ensure an appropriate program for them. Such classification has nothing to do with creating separate classrooms or segregated programs or facilities. There is a national movement to do away with disability categories all together. The groupings would be based on educational need rather than labels. This would be wonderful. We could put our energies toward advocating for programs that were capable of offering

instruction that takes into account the need to provide alternative strategies in both the auditory and visual modes. If these decisions are based on sound assessments, then we don't need labels, we simply need programs that have appropriate practices.

In the meantime, if we don't identify persons with these specific needs associated with the disability of deaf-blindness, they will likely go underserved. We can not allow our lawmakers to think that only 1400 children who are deaf-blind exist nationwide. Our system is not perfect but it is light years ahead of the procedures used to gather information for the Annual Report.

Reference:

U.S. Department of Education, Office of Special education programs. (1993). Fifteenth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act. Washington, DC: Author

Family Fun Day

An Experience in Nature

Barbara Cook
Parent

The rain did not stop that Saturday in October. However, the leaves were at their most brilliant color as we gathered in northern Delaware to have fun. The weather did not dampen our spirits; in fact, it added to the day. The fire we built in the large fireplace of the lodge-like building of the Ashland Nature Center made us warm, cozy, and comfortable. Long, low windows allowed the magnificent fall surroundings to invade the room. The outside activities, of course, had to be scrubbed, but there were so many inside activities that the fun continued from 10 in the morning until 5 in the evening. At the end, many were reluctant to say good-bye. Families and extended families (teachers, aides, administrators, interpreters, helpers, etc.) and our children who are deaf-blind talked together, played together, and ate together. We stuffed scarecrows, painted T-shirts, painted faces, painted pumpkins (mostly natural materials were used), saw and touched a Native American Program on the Lenape tribe (excellent tactile material), and played games. Parents and school staff talked together while their children were delightfully engaged in activities with the assistance of others. How relaxing.

The highlight of the day was a presentation of wild animals—the beautiful white dove, the struggling alligator, the languid boa constrictor, the stately red-tailed hawk, the huge snapper turtle, the tree frog, and the toad. The children could see them or feel them or hold

them and were not at all frightened (although some parents and staff seemed less inclined to touch).

At the end, singers from the Philadelphia Folk/Song Society delighted us with stories through song (wonderfully interpreted so all were able to understand). And finally, we were encouraged to sing along with many old favorites. Even the Nature Center Staff, who were fascinated at the obvious enjoyment of our children (who could neither hear or see), had a unique experience. A few modifications and some extra hands made it all possible.

Family Fun Day was made possible through the joint efforts of the Delaware Program for the Deaf-Blind and the Delaware Association of Deaf-Blind, Inc. (Parent Advocacy Group) and partially funded by the Hilton/Perkins National Program, through a grant from the Conrad N. Hilton Foundation of Reno, Nevada.

A Guide for Presenters at Interpreted Conferences

Rhonda Jacobs and Richelle Hammett

(Excerpted and adapted from: And Equal Access For All: Hiring a Qualified Interpreter vs. Ensuring Effective Interpretation by Rhonda Jacobs and Richelle Hammett, 1994).

As you may be aware your presentation will be interpreted for audience members and participants who are users of a different language. In this case, that language will be either spoken English or American Sign Language (ASL), received either visually or tactually. Hiring a qualified interpreter does NOT, in and of itself, ensure that a presenter's remarks will be effectively interpreted to the audience.

Use the following key points as a guide to prepare your presentation for interpretation.

- 1 Have your presentation prepared ahead of time.
- 2 Send a copy of paper/outline of remarks well in advance of presentation to the interpreter coordinator and/or interpreters.
- 3 Set aside time to meet with interpreters before the presentation begins; discuss the presentation, background information, main points, goals/intentions, names and acronyms that will be

1 We are using the convention established by some researchers and some members of the Deaf community of the capitalized "D" Deaf as opposed to deaf. Deaf refers to members of the Deaf or Deaf-blind communities who regard themselves as culturally and linguistically Deaf (i.e., users of American Sign Language). Although in this paper we refer to American Sign Language (ASL), and use the capitalized Deaf and Deaf-blind, the comments herein apply equally to those who use an English-based form of signing and/or do not regard themselves as culturally Deaf (Padden, 1980).

2 Parallel interpretation/transliteration refers to when the presenter is signing, while also having an interpreter on stage signing as well, either in ASL or an English-based sign variety.

used. Discuss various roles as applicable, such as interpreter-guide (with Deaf-blind¹ presenters), parallel platform interpreter/transliterator², and ASL to English ("voice") interpreter, and how these roles affect you.

- 4 If possible, plan to rehearse the presentation with the interpreters. Discuss pacing and pausing with the interpreters.

Working Together with the Interpreters

Remember, the interpreter is representing you, essentially "becoming you" for that period of time. The interpreter must have as much access as possible to what is going on in your thoughts—before going on stage. According to Danica Seleskovitch (1978), an internationally recognized authority on spoken language conference interpreting (Sorbonne, Paris), "Being mistaken about the speaker can. . . seriously impair one's understanding of an entire speech" (p. 26). For interpreters to speak/sign smoothly, they must know what you are going to say before you say it, why you are saying it, and what you want the audience to "bring home." "To understand the message, one must first understand the purpose" (p. 29). Also, interpreters are trying either to understand or to express your message in their second language, while essentially engaging in split-brain activity—expressing one thought while simultaneously listening to the next one.

Consider the following, all too common statements from presenters: "Don't worry, my presentation is only ten minutes," "I'll speak/sign slowly so you'll be able to catch it," or "Just slow me down anytime." These statements represent a central misunderstanding that speed or time is the interpreter's problem, when understanding the message is what is crucial. The point is that each of your thoughts and comments contain a wealth of background, knowledge and shared history. Interpreters are trying to capture that whole and see it from your perspective so that they may, first, understand it and, second, relay it to the intended audience, in order that they may best understand what you are trying to convey.

As Seleskovitch so aptly puts it,

. . . let us imagine that an animal were to pass under our noses so quickly that we could not identify it. If we had not 'understood' what we had seen, would we be capable of describing the animal so that our listeners could recognize it even though we had not recognized it ourselves? . . . the interpreter who has not understood is as incapable of saying anything meaningful as the person who sees something move and, not knowing whether he has seen a snake or a mouse, will refrain from stating definitely whether he has seen one or the other.

Preparation is the key to whether or not the entire undertaking is successful. Even if the entire presentation is not fully prepared and typed out in advance, just telling the interpreter: "I will be talking about a chicken crossing the road, the point being to see if he gets to the other side; whether or not he makes it is dependent on three factors, A..., B... and C..." is immensely helpful to the interpreter. Otherwise, during the interpretation, the precious few moments that she or he should be devoting to picking just the right word, maintaining the proper affect, and doing a myriad of other tasks required of an interpreter, will instead be spent trying to figure out "was that a chicken or a duck? and why is it crossing the road? and what difference does it make anyway?" If you, the presenter, have informed the interpreter of these points prior to the actual presentation, the interpreter is then free to focus on the elements that make for a quality interpretation. He or she will represent you in a manner befitting the occasion while maintaining the integrity of your message.

“...written text read aloud...has only a minimal chance of being ... properly interpreted...”

The authors included the following excerpt for presenters who plan to read their papers at conferences—Ed.

A Note to Presenters Who Plan to Read Their Presentation

(Excerpted from: *Interpreting for International Conferences*, by Danica Seleskovitch, 1978).

Spontaneous speech produces about 9,000 words an hour. However rapid this pace may seem, it represents the speed of mental processes connected with speaking and it is therefore suited to the understanding capabilities of listeners of comparable intelligence and background. An interpreter listening to a speaker speaking off the cuff is therefore in a good position to understand, since he can turn words into ideas at the same speed as the speaker turns ideas into words; he is thus able to keep up with the speaker's delivery. In terms of a written text, the spoken language is more like a rough draft. By definition, a written text is intended to be read, and can be read over and over again, whereas the spoken word is meant to be heard once and once only.

A hybrid form of the two (the written text read aloud or recited from memory) means that the paper being presented has only a minimal chance of being fully understood when delivered and even less of a chance of being properly interpreted. . .

Interpreters are often called on to do "on sight" translations, i.e., to give an on-the-spot oral rendering of a written text as it is being read out at meetings. This amounts to asking them to convey messages which, because of their form and the way in which they are presented, are not amenable to interpretation at all and this

at a speed of 200 words per minute, or 40 times faster than normal written translating work. This absurd state quickly reduces the interpreter to a state of mental and physical exhaustion; usefulness to the listener is practically nil, when compared to the service they are able to render when dealing with free speech. Placed in an impossible situation, he gives up trying to understand: He leaves his sentences unfinished, becomes breathless and frustrated, soothes his troubled conscience when he sees that his colleagues are managing no better than he, is happy to translate a word or two correctly here and there, curses the day he accepted that particular conference, leaves the booth as soon

as the meeting is over and vanishes gratefully into the anonymity of the crowd. The best interpreters, however, those who have proved themselves worthy of the name, refuse to jeopardize their profession's reputation by working under these impossible conditions. They simply switch off their microphones.

The only possible solution to this serious problem is to give the interpreter the opportunity of thoroughly reviewing the documents which are to be delivered at a conference. He should be given a few days before the start of a conference to study and annotate the papers which he will be required to translate orally. In addition, a sufficient number of interpreters would have to be hired to staff the conference so that each one would have enough time, while his colleagues were at work in the booth, to go over the papers which come in at the last minute. This would mean that interpreters would be hired for a longer period of time, the number of days of paid preparation being equal to the number of working days of the conference; it would also mean doubling or tripling the size of the interpretation teams. (p. 134-135).

References:

- Seleskovitch, D. (1978). *Interpreting for international conferences: Problems of language and communication*. S. Dailey & E. N. McMillan (Trans.). Washington, DC: Pen and Booth.
- Padden, Carol (1980). The Deaf Community and the culture of Deaf people." In C. Baker, & R. Battison (Eds), *Sign language and the Deaf Community: Essays in honor of William C. Stokoe*. Silver Spring, MD: National Association of the Deaf.



Cruising the Information Highway

or How Can I Be In Two Places At Once When I'm Not Anywhere At All?

Randy Klumph

Technical/Dissemination Specialist, DB-LINK

At 4:30 on a Friday afternoon, the pediatrician delivered her diagnosis to the parents: The child had CHARGE Association. The parents had thought they would be prepared for this news. After all, their four-year-old had been medically fragile since birth, and it seemed the family was always adjusting to difficult news. However, this was the first time they had been given a name. Up until now their child has been described to them as developmentally delayed or disabled, or showing signs of progressive degenerative hearing/vision loss. Although the doctor was thorough in her answers to the immediate questions, it wasn't until the parents returned home that the majority of the questions began to form. By then it was too late for answers. Offices were closed, the doctor was off shift, and their rural library would be of little help. They would have to wait through what would now be a very long weekend to get the answers they needed.

Most of us, when facing a crisis, want immediate answers to our questions. Information gives us a feeling of control; it allows us to make decisions and move forward in our lives. Information typically comes from our own formal and informal groups (e.g., friends, family members, parent groups, professionals, organizations). Our relationships to people and organizations are fundamental to the successful management of any crisis and they provide the cornerstone of our support structure. Today however, we can add yet another level of support to our list of resources. By taking advantage of technology we can access even more information, electronically, through commercial on-line services and computer bulletin board services (computer BBSs)¹.

Many of us have heard about the information highway, on-line services, and computer BBSs. Many of these avenues are immediately available to anyone who has a computer, a modem, modem software, a telephone, and a subscription to a commercial on-line service (e.g., CompuServe, SpecialNet, Prodigy) or access to a computer BBS (e.g., Disabilities Electronic Network). This ar-

title describes some of the electronic information avenues currently available, what you will need to get started, and whom to contact for more information.

What is the difference between an on-line service and a computer BBS?

On-line services come from "for profit" companies that charge their subscribers to connect to the service. Some charge by the minute, plus extra charges for accessing certain databases or special services. Others charge a flat monthly fee or a variable fee depending on the time of day the call is made (calls during normal business hours are more expensive with some on-line services). On-line services are more comprehensive than a computer BBS in the kinds of services and topics they cover. CompuServe for example, is the most comprehensive of the on-line services with over 600 topical areas or "forums." Some, such as Prodigy, are oriented more toward family interests. All on-line services and most BBSs also have electronic mail service (e-mail), allowing you to send and receive private messages electronically.

Computer BBSs are typically free or they charge a minimal annual fee, and they are usually staffed by volunteers. They are more specific in their subject matter and often have members who are from the same geographic location. The better BBSs however, are able to draw callers from all over the country who are willing to pay long distance charges in order to access timely and useful information in the libraries that are related to the BBS.

What's in it for me?

If you are in the business of gathering or disseminating information (e.g., research, information clearinghouse) or if you are simply a person like those mentioned above, who needs to find answers, you may wish to access the following topics. These are only a very small sample of the many electronic forums and databases that are available electronically, either through an on-line service, computer BBS, or subscription.

- Medicine
- Education
- Health
- Bibliographies
- Adoption Forum
- Financial
- SpecialNet Deafblind Bulletin Board
- Bioscience Documents from the BioSci Network
- Resource Directories
- Nutrition
- Law
- Disabilities Forum
- ABLEDATA
- Internet Deafblind Forum
- Family Medicine Discussion Archives
- Directory of Electronic Journals and Newsletters

Forums are like a combination electronic bulletin board and a meeting hall. In a forum, you will find other people with interests similar to yours—in agreement as well as with opposing views—covering a wide range of topics all related to the particular forum. Messages are posted onto the forum message area and are given a descriptive subject heading. Replies are added to the original message.

¹ For a detailed comparison of the five major commercial on-line services, their costs, and contact information, see PC MAGAZINE, March 15, 1994, Vol. 13, No. 5.

Also in the forums are libraries where participants have placed files of information they have found useful and are making available for others to use (e.g., newsletters, special equipment catalogues, research papers). Most forums have a conference area where "attendees" can ask questions and exchange ideas with invited experts, or get together for group discussions.

Database services differ somewhat from forums since they are for search and retrieval only and do not typically have a forum area. They are usually maintained by a government or other nonprofit agency. As with computer BBSs, some are free, and some are not. There are as many database services as there are disciplines. Some database services maintain only historical information; some maintain current information, and some maintain both. Finding the right one is not as difficult as it might seem unless your topical interest is very obscure.

What equipment do I need?

Hardware/Software:

- Computer
- Modem
- Telephone line
- Modem software

There are many modem software packages available that vary in their level of required skill. Some software packages are specifically designed for a particular on-line service. The CompuServe Information Manager for example, was developed specifically for easy connection and navigation in CompuServe and is for use only on CompuServe. MOSAIC is another navigation software package for use on the Internet. Still other software programs such as Qmodem, Procomm, or Microphone (most manufacturers include modem software with their modems) will allow you to connect to any on-line service or computer BBS. Beyond that, the only other item you will need is a healthy curiosity.

What if I am a technical novice?

If you are a technical novice and need assistance selecting or setting up the correct hardware and software, there is help. Most of us know someone who is "into" computers. Invite this person over for dinner and an evening of technical assistance. Just make sure they know what is in store for them. Most "techies" enjoy helping new users enter the world of electronic communication. They have found it to be an exciting medium and are eager to share their enthusiasm and expertise. If you do not know anyone who fits this description, then consider a class at a community college. In addition, there are many books and magazines available covering all aspects of this topic. Many of the on-line services have voice phone numbers you can call for help with your initial setup questions. Once you have the equipment and are connected to a BBS or on-line service you will find an army of people on-line who are all too happy to assist you. If you want to quickly expand your professional and personal network, then on-line services and computer BBSs provide opportunities to reach into the vast network of parents, professionals, individuals and organizations that are part of this growing technology.

What If This Isn't For Me?

If you choose not to participate in these services, the technology can still be available to you by using the services of organizations who do use it and letting them use their expertise to get the information you need.

For example, at DB-LINK, gathering information (from the obscure to the familiar) and delivering this to the consumer is a daily occurrence. Through the use of computers, modems, and by utilizing the technical expertise of various staff, we have developed access to the global information warehouses that exist electronically. We can search MEDLINE for article citations and abstracts that are indexed from over 4000 medical journals. We can access the NORD database (National Organization for Rare Disorders) for a description of symptoms, treatments, and organizations for a specific syndrome. We can search our own Catalogue and Resource Databases for bibliographic and referral resources. These are just a few of the avenues available that allow us to meet the needs of the people who call.

At 10:30 Friday evening the parents logged onto CompuServe and conducted a search of the NORD Database and PaperChase (the MEDLINE database of references to biomedical literature). After saving the information for later reading, they found forums discussing issues related to people who are blind and people who are deaf. They were able to leave unanswered questions on various bulletin boards. When they "checked their mail" at 7:00 a.m. the next morning, they had four responses. At the 6:00 p.m. mail check they had another seven responses. By 11:00 a.m. on Sunday, "conversations" were occurring regularly as people responded to their need for information. Not all their questions were answered. In fact, they learned they had even more questions, many that would require the resources of a national organization, such as DB-LINK. But they also found that their familiarity with the electronic information networks had given them an advantage in developing their own resources. They were given the names of organizations to contact, books to read, resources in their area, and parent support groups. They also learned about their own coordinator of state and multi-state projects under Section 307.11 and how important this person would become in their lives. They were able to receive answers to their pressing questions. They felt more in control, as their lives moved forward.

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

For more information on the services mentioned in this article contact:

CompuServe
P.O. Box 20212
Columbus, OH 43320
voice: (800) 848-8199
fax: (614) 457-8149

Disabilities Electronic Network (DEN)
Tom Bengaff, SysOp
171 Atlantic Street
Hackensack, NJ 07601
voice: (201) 342-6984
BBS dataline: (201) 342-3273

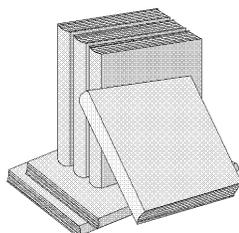
Internet Deaf-Blind Forum
Bob Moore
Stroke Program, Center on Aging - Univ. of Kentucky
Lexington, Ky 40536
voice: (606) 233-5760
fax: (606) 258-2866
str002@ukcc.uky.edu

National Clearing House of Rehabilitation Training Materials (NCHRTM)
voice: (800)-223-5219
voice: (405) 624-7650
fax: (405) 624-0695
BBS and Materials Database
(dataline): (405) 624-3156

Prodigy
Prodigy Services Company
P.O. Box 791
White Plains, NY 10601
(800) 776-0845

SpecialNet
GTE Education Services
5525 Mac Arthur Blvd.
Suite 200
Irving, TX 75038
(800) 927-3000

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For Your Library

Persons Handicapped by Rubella

By Jan Van Dijk (with cooperation of Ruth Carlin and Heather Hewitt) (1992).

This publication discusses relevant studies in the literature relating to children with congenital rubella, and provides parents and professionals with the latest information on appropriate education and management strategies.

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Play and Recreation for Individuals with Disabilities

Susan J. Grosse and Donna Thompson (Eds.)

Practical and detailed suggestions on involving individuals with disabilities in recreational activities. Suggestions for evaluating and adapting equipment and dealing with

specific conditions are given. Many of the chapters contain the names of organizations and bibliographic references.
139 pages, Cost: \$ 23.95 (+ \$2.50 shipping and handling)

To order contact:
Adapted Physical Activity Council of the Association for Research, Administration, Professional Councils and Societies.
1900 Association Drive
Reston, VA 22091
(800) 321-0789

Directory of National Information Sources on Disabilities - 5th Edition (1992)

National Institute on Disability and Rehabilitation Research

This directory identifies and describes organizations that supply disability related information, referral, and direct services on a nationwide bases.

555 pages, Cost: \$ 10.00 (for shipping and handling)

To order contact:
NARIC
8455 Colesville Rd. Ste. 935
Silver Spring, MD 20910-3319
(800) 346-2742 (voice and TTY)

Resource Directory 1993 - 1994

HEATH Resource Center

The HEATH Resource Directory is a biannual selection of resources in the postsecondary education and disability fields. Many of the listed organizations can respond to questions about an individual's own situation. Each section lists additional resources (e.g., books, directories, magazines) and/or organizations.

39 pages, Cost: Free

To order contact:
HEATH Resource Center
One DuPont Circle, Ste. 800
Washington, D.C. 20036
(800) 544-3284 (voice and TTY)

Deaf-Blindness: National Organizations and Resources. Reference circular No. 93-1

Library of Congress; National Library Service for the Blind and Physically Handicapped. Washington, DC: January 1993.

The circular includes information on areas of service: rehabilitation, education, information and referral, recreation, sources for adaptive devices and products, and a bibliography. It is intended for use by people who are deaf-blind, family members, professionals, and the general public.

24 pages, Cost: Free

To order contact:
National Library Service for the Blind and Physically Handicapped
Library of Congress
Washington, D.C. 20542
(202) 707-5100

National Family Association for Deaf-Blind

On June 27, 1994 National Parent Network (NPN) will become National Family Association for Deaf-Blind (NFADB). Tremendous growth in the numbers of families desiring information and connection to each other caused NPN to re-evaluate its advisory role and establish a design team to create a more formal, structured, and operational national organization.

Parents representing individual family members and state organizations around the country have adopted this new title to support and advocate for people who are deaf-blind and the members of their families. The founding members of NFADB have adopted the following philosophy statement: "Individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community." To support this mission, NFADB has targeted a wide range of activities including:

- advocating for all persons who are deaf-blind regardless of age or ability
- supporting national policies that benefit people who are deaf-blind
- helping to facilitate the founding and strengthening of family organizations in each state
- being a resource group, sharing information, and providing referrals
- collecting data, expertise, and resources that are in unity with NFADB's philosophy to assist families
- assisting states with various issues
- collaborating with professionals
- serving as a public information resource

In addition to the organizations' officers, NFADB will have a parent representative in each of the 10 Helen Keller National Center regions of the country. NFADB's officers and regional representatives are:

President	Joyce Ford
Vice-President	Mary O'Donnell
Secretary	Pat McCallum
Treasurer	Mary Lou Guisinger

Region One	Karen Norwell
Region Two	Clara Berg
Region Three	Barbara Caudill
Region Four	Brenda Weaver
Region Five	Peg Pedresen
Region Six	Janet Stevens
Region Seven	To be announced
Region Eight	Alan Wahl
Region Nine	Barbara Ryan
Region Ten	To be announced

Parents of children who are deaf-blind share common issues. A parent of a 24-year-old who has congenital rubella syndrome said, "I have been ignored, pushed aside, or last in line. What a family organization means to me is hope, support, information, and encouragement. I am no longer alone. We are everywhere!"

For more information contact:

NFADB
 111 Middle Neck Rd.
 Sands Point, NY 11050
 (800) 225-0411 ext 275

AADB 1994 National Convention

The American Association of the Deaf-Blind is a national consumer advocacy organization with over 600 members. AADB is organized for the purpose of advancing the economic, educational, and social welfare of persons who are deaf-blind. One of the highlights for this organization is its annual convention.

The convention offers a series of workshops, often held by individuals who are deaf-blind, and daily tours of places of local historical and cultural interest. This year's theme is "Caring for Ourselves: Facing the Changes and Challenges." This is an opportunity for individuals to interact with each other on an educational and social basis.

The convention is open to everyone, including individuals who are deaf-blind, friends, families, and professionals. Interpreters will be provided.

The 1994 convention will be held June 11-17 at the University of North Carolina, Greensboro. The deadline for registration is June 1, 1994.

For more information contact:

AADB 1994 Convention
 814 Thayer Ave Suite 300
 Silver Springs, MD 20910

TTY: (301) 588-6545
 fax: (301) 588-7505

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

Traces

Regional Reports

FLORIDA

During the needs assessment process for Florida last year, it became apparent that the larger community of service providers (e.g., vocational teachers, rehabilitation counselors) needed to be made aware of possibilities in the area of transition for individuals who are deaf-blind. It was decided that a statewide conference of the Council for Exceptional Children Division on Career Development would provide an appropriate audience.

Mike McCarthy, from Missouri, presented a small group session titled, "Is There Life After School for Individuals with Deaf-Blindness?" He provided examples of how individuals who are deaf-blind can live and work in their home communities after graduation if the transition has been planned enough in advance to secure appropriate support services. He presented strategies for collaboration to secure these services and cited the implications for "Individual Transition Planning" and "Personal Futures Planning."

In addition, Mr. McCarthy was asked to give the conference wrap-up luncheon speech. He stressed that it is important to always remain person-centered, and he recounted accomplishments of individuals whom he has known who are deaf-blind. At the end, several participants noted that the entire conference was worth attending because they heard about real people who are deaf-blind who are successfully participating in their communities.

For additional information contact:

Anita Briggs
TRACES South Central Regional Coordinator
(904) 840-7147.

ILLINOIS - Establishing Local, Functional Assessment Teams

On October 18 and 19, 1993, the Illinois Deaf-blind Project, in collaboration with Helen Keller National Center for Deaf-blind Youths and Adults (HKNC), and Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments (TRACES), co-sponsored a conference titled "Training of Trainers: Functional Hearing and Vision Assessment Strategies for Individuals with Deaf-Blindness." The conference was held at the Philip J. Rock Center and School in Glenelg, Illinois. The purpose of the conference was to

provide inservice education to a team of specialists who will then provide support to professionals who serve individuals who are deaf-blind within local communities. Specifically, the professionals will be taught to perform functional vision and auditory assessments. Flo Peck, Low Vision Education Specialist from the Perkins School for the Blind, and John Mascia, Coordinator of Audiological Services from Helen Keller National Center, were the featured presenters.

Ongoing data collection by those who attended the conference will be recorded and analyzed by the Illinois Deaf-Blind Project Coordinator in order to evaluate the effectiveness of local service delivery. Data will include (a) the number of informal vision and/or hearing screenings; (b) the number of inservice training sessions to colleagues; and (c) the number of newly identified children who are deaf-blind. We congratulate all of those who worked so hard to establish this program.

For additional information contact:

Tina Dorsey, Chief Administrator
Philip J. Rock Center
(708) 790-2474
or
Margie Briley
TRACES
University of Pittsburgh
(412) 648-1424

Great Lakes Area Regional Center for Deaf-Blind Education

As a result of a needs assessment survey sent to educators, related services providers, and families of children and youth with dual sensory impairments, the Great Lakes Area Regional Center for Deaf-Blind Education has initiated a goal to focus on the development of assessment guidelines. A set of guidelines is currently being developed to address the following age levels: early childhood, school-age, and transition to adult life. The authors are (respectively) Ellin Siegel-Causey, June Downing, and Jane Everson. While the manuals are in different stages of development, each incorporates input from colleagues, service providers, and families. As part of the development stage of the manuals, a training workshop is utilized to field test the assessment processes outlined in each manual. This activity represents a collaborative effort between the state and multi-state projects under

Section 307.11 in Ohio, Wisconsin, and Pennsylvania; the Helen Keller National Center Technical Assistance Center; and the expertise of the individual authors, reviewers, and workshop participants. As completion of the manuals approaches, a wider dissemination plan is being discussed.

For additional information contact:

Emily Taylor-Snell
Project Coordinator
GLARCDDBE
(614) 785-1163

NEW YORK

The New York State Technical Assistance Project (NYS/TAP) has entered its second year under the leadership of Project Director Mady Appell and Project Co-Director Carole Gothelf. Located in the Developmental Disabilities Center of St. Luke's Roosevelt Hospital Center in New York City, NYS/TAP is committed to supporting parent-professional partnerships, building systems that are responsive to the needs of the people they serve, and delivering the technical assistance needed to ensure appropriate services for children and youth who are deaf-blind.

During the first year of the project, NYS/TAP has been working toward achieving full partnership with the New York Parent Network, Inc. (NYPN), a dedicated group of parents and relatives of persons who are deaf-blind. These people have drawn together to establish a supportive network through which they can share experiences and knowledge, educate others about the needs of their families, and advocate for community services to meet their needs. The NYS/TAP Family Specialist and the President of NYPN presented a poster session at the 1993 TASH Annual Meeting entitled "Parent-Professional Partnerships in New York State." These two projects are fully committed to collaboration and co-operating with families and service providers in order to establish a system in which all children in New York who are deaf-blind and their caregiving families can have their needs appropriately met. The partnership ensures that every group is represented and that opportunities are provided for expression of every viewpoint.

Additionally, NYS/TAP and NYPN have forged reciprocal relationships with the New Jersey Technical Assistance Project and PRISM (New Jersey's statewide parent organization that supports individuals with visual and hearing impairments and multiple special needs and their families). These four projects are now planning their second annual Summer Institute. This collaborative effort grows from the idea that knowledgeable parents and professionals working in unison will ensure appropriate programs for children and youth who are deaf-blind and will be the most effective agents for systems change.

Another important focus for NYS/TAP during the past year has been to obtain an accurate child count. To

achieve this, the NYS/TAP Project Coordinator has developed a computerized system to track each eligible individuals in New York State. This system creates a comprehensive database and, provides the statistical analyses necessary for immediate and long-term planning. The computerized system includes an automated annual follow-up for each individual, and a resource directory of programs serving those who are deaf-blind. As of November 1993, approximately 500 eligible children have been identified and registered; efforts to locate eligible children continue, with the expected total likely to be double the current figure.

For additional information contact:

Douglas Hegley Project Coordinator (212) 523-6230	Clara Berg Family Specialist 212) 523-6230
or	
Cheryl Kennedy TRACES Project Northeastern Regional Coordinator (412) 648-7176	

ALASKA

Usher Syndrome is a genetic disorder involving the loss of both sight and hearing. A sensorineural hearing loss generally is evident at birth or shortly thereafter, while progressive loss of vision due to Retinitis Pigmentosa (RP) begins later in life, usually before adolescence.

It is estimated that 3% to 6% of people who have a hereditary hearing loss have Usher Syndrome. Moreover, Usher Syndrome accounts for more than 50% of all cases of deaf-blindness, with 94 thousand estimated to be affected in the United States.

Several tests are used to determine if a person has RP. The most definitive test is electroretinography (ERG), with an accuracy of about 95%. Screening can determine an individual's disposition toward Usher Syndrome.

The Alaska Services for Children and Youth with Dual Sensory Impairments Project (ADSI) is developing a statewide screening process for early identification of individuals who are at risk. The initial step of this process has been completed with the development of a brochure providing comprehensive information regarding Usher Syndrome, techniques for screening, and available resources. The second phase of the process is to train educational personnel so that they may refer individuals for an ERG. The training is scheduled to occur this spring.

For additional information contact:

Sara Gaar
Program Supervisor
(907) 562-7372

TRACES (Teaching Research Assistance to Children and Youth 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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