

Deaf-Blind Perspectives

Volume 4, Issue 1

Fall 1996

Research-to-Practice: Bridging the Gap Between Research and Demonstration Projects and Practical Needs of Parents and Educators

Harvey Mar
Nancy Sall

DB-LINK expresses appreciation to Charles Freeman, Severe Disabilities Branch, Office of Special Education Programs for providing information about the federal grants program.

Since 1978, the U. S. Department of Education has provided continuous support for research-and-demonstration projects to improve practices and techniques in educating children and youth with deaf-blindness. Beginning with three model projects, the federal program steadily expanded so that by the mid-1980s more than 30 special projects were being funded each year. The overall mission of the Department of Education has been to identify innovative and effective educational approaches. To that end, more than \$54 million has been spent on demonstration, training, research, and systems-change projects since the program's inception.

What have we learned from these special projects? What has been the impact on educational practices? How have the findings, resources, and materials from these projects been put to use? The purpose of this article is twofold. First, it is intended to introduce DB-LINK's new Research-to-Practice Initiative (RPI), which is designed to bridge the gap between research and demonstration projects and the people who stand to benefit most from their findings. Second, it endeavors to inform the reader about a number of recent projects that may be useful to the practitioner; these projects are listed in the second portion of this article.

We know that information generated by research and demonstration projects is *available*, but there are many concerns that it is not readily *accessible* to consumers, family members, and educators. For instance, findings may be reported in research journals that do not go beyond a limited professional audience. Often, materials and resources do not exist in forms that are "user friendly" to parents and teachers. Also, workshops or seminars in which new knowledge is presented may be limited to the schools or geographic regions where these presentations are made. Perhaps the greatest concern is that the mission of the researcher often differs from that of the teacher or parent, who may not perceive a particular project as being directly relevant to a student's day-to-day needs.

The RPI is taking several steps to bridge this gap between researchers and those who need this information. DB-LINK proposes an action plan that involves close collaboration with directors of re-

search-and-demonstration and other special projects on deaf-blindness. Specific objectives and activities of the RPI are to:

Conduct periodic reviews of current and recent federally supported research-and-demonstration projects on deaf-blindness.

DB-LINK has contacted project directors and project coordinators of recently funded projects on deaf-blindness to obtain information about their findings and the availability of their resource mate-

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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.

rials. A brief summary of this information is included in this report. In future issues of *Deaf-Blind Perspectives*, individual projects will be highlighted with emphasis on practical implications to consumers, family members, service providers, and educators.

Identify important project findings and interventions that have practical application in home, classroom, and/or community environments.

Many important interventions, teaching strategies, and observations are buried within project reports. Furthermore, projects may produce information or materials that are not widely circulated. As part of the RPI, DB-LINK will make every effort to access and review technical reports, journal articles, conference proceedings, professional papers, newsletters, handouts, and other resources to identify potentially effective practices and resources. In the process, DB-LINK will work cooperatively with project directors to develop user-friendly forms of this information (e.g., fact sheets, pamphlets).

Share Research-to-Practice findings with the single and multi-state 307.11 projects.

As coordinators of deaf-blind education services, staff on state and multi-state 307.11 projects have the responsibility to ensure that educators in their jurisdictions use state-of-the-art procedures. The Research-to-Practice model will provide 307.11 staff with this information. Each 307.11 coordinator will be able to share this information

with direct service staff through inservice trainings, newsletters, technical assistance, etc.

Share outcomes of the important project findings with NTAC (National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind).

NTAC personnel impact hundreds of professionals across the nation each year who in turn provide direct service to children and young adults who are deaf-blind. Keeping NTAC staff informed of the latest usable research will expedite the transference of these findings to practicing professionals. Armed with knowledge of the latest research, NTAC staff will be able to coordinate the elevation of research to practice by making findings available not only to educators via the state 307.11 projects but also to other professionals through cooperating agencies (e.g., vocational rehabilitation, community colleges, independent living centers) serving young adults who are deaf-blind.

Share pertinent findings with The National Family Association of the Deaf-Blind (NFADB) and local family units.

Many of the research-to-practice findings will also be helpful to parents and family members of children and young adults who are deaf-blind. By sharing the information with NFADB, it will in turn be made available to parents—usually the premier advocates in the lives of young people who are deaf-blind.

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Volume 4, Issue 1

Fall 1996

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www.tr.wosc.osshe.edu/tr/dbp

Communicate with directors and staff of research and demonstration projects about requests for information from family members, consumers, and educators that pertain to their areas of study.

DB-LINK receives many requests for information pertaining to the educational, social, and health issues of people who are deaf-blind. By alerting project directors to these general informational needs, mutual gains can be realized. Future projects may better understand and address the specific needs of individuals who are deaf-blind, their families, and the people who work with them. This, in turn, may serve to promote the development of more useful materials and resources.

Assist projects to identify a wide range of outlets for the dissemination of their findings, products, materials, and resources, including information clearinghouses, parent organizations, consumer groups, and professional organizations.

One concern which led to the formation of RPI is the belief that projects can—and must—promote effective educational practices through implementation of a well-developed dissemination plan. The RPI calls for DB-LINK and project directors to work together to promote the visibility, permanence, accessibility, and replicability of positive outcomes and material resources.

Serve to promote public awareness of current or promising approaches, materials, and results from research and demonstration projects on deaf-blindness.

Findings and resources from special projects often take several years before reaching the targeted audiences. For example, research may be reported in a journal or a final report long after the project has been completed. The RPI aims to reduce the lag time between research findings and their practical applications by publicizing new information as soon as it becomes available.

Current Research and Demonstration Projects

It is interesting to compare recent research and demonstration projects with those funded a decade ago. Certainly, the overall mission of the grants programs in deaf-blindness has been consistent: namely, to “demonstrate innovative and effective approaches” to the education of children and youth who are deaf-blind (Federal Register, July 22, 1985). So, too, have the federal priorities—areas of special concern—remained consistent. Ten years ago, projects focused on such critical areas as communication skills, teacher training, vocational and transitional services, and increasing parental involvement in the educa-

tional process. Obviously, these and other areas are still priorities today.

However, the past ten years have witnessed several substantial differences in how we conceptualize these priority areas. One has been the shift in emphasis from designing innovative educational practices in “least restrictive” or “least segregated” environments to “fully inclusive” or “fully integrated” educational and community settings. The change in terminology is not just semantic. It reflects the *expectation* that children and youth who are deaf-blind be offered and/or provided opportunities and support to participate fully in the schools and programs within their communities. Another change has been the extension of projects on communication skills to emphasize social interactions and relationships. Increasingly, communication training materials and methods, such as the use of symbol systems, tactual signing, and augmentative or assistive devices, are being developed and evaluated in the contexts of natural parent-child interactions and peer relationships. We have recognized that communication skills cannot be separated from social skills, and that they are best taught and studied amidst the complexities of the real social world.

A third change has been in the scope of today’s projects. A long-standing aim of the federal grants program has been to increase local or state “capacity,” which refers to the building up of personnel, material, and informational resources in the regions in which projects on deaf-blindness are conducted. A quick glance below will show that many current projects also have national impact through their creation of task forces, advisory boards, and consortia involving parents, consumers, and professionals from around the country.

Summary

The descriptions of the projects below serve to highlight some of the research-and-demonstration topics of current concern. Each project has tremendous potential to identify effective practices, lessons learned, challenges, interventions, and insights about the education of children and youth who are deaf-blind. DB-LINK’s research-to-practice initiative seeks to help all projects realize their potential to provide information and resources having practical significance, direct and immediate application, and positive outcomes for the students, their families, educators, and service providers.

A Sampling of Current Projects

Current special projects on deaf-blindness are presented here according to their areas of investigation. These include: inclusion, communication and technology, early intervention, professional training and development, lifestyle planning, problem-solving skills, and social relationships. The project directors or coordinators were contacted by telephone to obtain information about useful findings and products available for parents and practitioners.

Inclusion of Students with Deaf-Blindness

Two projects have recently been funded which fall under the umbrella of inclusion. A project called **Full Inclusion Program for Students with Deaf-Blindness** is based at San Francisco State University and is directed by Dr. Lori Goetz. This model and demonstration project has identified and worked with six students who are deaf-blind and who attend full-time inclusive education programs. In addition, a national task force for this project was organized to pursue specific content problem areas and potential solutions, as well as to analyze effective practices. Task force members are also responsible for presenting case studies of inclusive education programs from around the country. The project provides direct support, training, and/or consultation to the students with deaf-blindness, their peers, and educators in fully inclusive programs in California. The project emphasizes the importance of a cohesive team and collaboration among all parties. Dr. Goetz remarked that one of the first questions to ask in developing an inclusive program is, "How do you make a team work in a functional and positive way?" The project is developing a series of products for parents and educators, including an overview of inclusive education practices involving students who are deaf-blind and a narrative of case studies from around the country. This review will be available Fall 1996 through the California Research Institute.

For further information, Dr. Goetz can be contacted at:

San Francisco State University
1640 Holloway Avenue
San Francisco, CA 94132
415-338-1306
e-mail address: lgoetz@sfsu.edu.

The second project within this category is entitled **Related Services Research to Support the Education of Students with Deaf-Blindness** and is based at the University of Vermont. Dr. Michael

Giangreco is the project director. The project seeks to implement and evaluate a set of ten specific guidelines to help educational teams make decisions about how best to deliver related services (e.g., therapies) for students who are deaf-blind in inclusive education programs. The process is called VISTA (Vermont Interdependent Services Team Approach). The project is studying how the application of VISTA affects the provision of related services to students (e.g., location of services, educational relevance, improved knowledge of team members). The VISTA process is described in a manual published by Paul H. Brookes Publishing Co. (Vermont Interdependent Services Team Approach: A Guide to Coordinating Educational Support Services, 1996, 176 pages, \$26.00, 1-800-638-3775.) Additional information about this project, including a series of five "quick guides" for educating students with deaf-blindness and other severe disabilities, can be obtained from Dr. Giangreco at:

University of Vermont
499C Waterman Building
Burlington, VT 05405
802-656-1144.

<http://www.uvm.edu~uapvt/RSRP.html> (*Includes specific research questions, a brief description of VISTA, and numerous listings of products including articles and abstract.*)

Communication and Technology

There is currently one research project on communication and technology. **Use of FM Systems with Children who are Deaf-Blind**, directed by Dr. Barbara Franklin at San Francisco State University, studies the impact of FM systems on the development of communication skills. An FM system consists of a microphone which is worn by the person speaking (e.g., teacher, classmate, parent) and a receiver which is worn by the student with hearing impairment. This project examines how new technologies in FM systems affect social interactions between students who are deaf-blind and their typical peers. Research methods include observations of students using FM systems in integrated settings and interviews of teachers, peers, families, and individuals with deaf-blindness. The project also provides inservice training for teachers and family members on the use of FM systems. Dr. Franklin notes that FM technology has expanded since the development of new, compact, behind-the-ear units. A training manual and videotape on the benefits of this technology are currently being developed. Dr. Franklin can be contacted at:

San Francisco State University
 Department of Special Education
 1600 Holloway Avenue
 San Francisco, CA 94132
 415-338-1249.

Early Intervention

Two projects focus on early intervention. Both are conducted at California State University at Northridge. **Project PLAI: Promoting Learning, Activities, and Interaction in Infants who are Deaf-Blind** is a research validation project on infant-caregiver interactions, co-directed by Drs. Deborah Chen and Michele Haney. Dr. Chen states that the primary goal of the project is to facilitate healthy relationships between family members and infants with deaf-blindness. The project has developed a series of questionnaires for parents and early interventionists to gather information about early communication behaviors of infants with deaf-blindness. Infant-caregiver interactions are videotaped. This information is used to develop interactive games designed to increase positive interactions between infants and caregivers and to promote caregivers' sense of competence when interacting with infants who are deaf-blind. The project also conducts workshops and provides technical assistance to families and early intervention personnel. The questionnaires and curricular games are being field-tested for production in the Fall of 1997. Dr. Chen will present a paper on this project in December 1996 at the Division of Early Childhood Conference (DEC) in Phoenix.

The second project is called **Early Intervention Model Demonstration Network for Infants with Deaf-Blindness and Their Families**. This project, also directed by Dr. Deborah Chen, seeks to improve early intervention programs and services for infants and family members. The project has been working with six early intervention programs in which infants who are deaf-blind are enrolled. Early intervention teams endeavor to identify relevant intervention goals and activities that consider unique issues of deaf-blindness through a systematic Program Self Review. The project has also worked with families to identify useful materials. One outcome of the project has been the development of three videotapes on functional hearing and audiological assessment, functional vision assessment, and early communication behaviors. Discussion guides are currently being developed for the videotapes. The videotapes, discussion guides, and Program Self Review will be available in January of 1997. For ad-

ditional information, contact Dr. Chen or Dr. Haney at:

California State University
 Department of Special Education
 18111 Nordhof Street
 Northridge, CA 91330
 818-885-4604 (Dr. Chen)
 818-885-3874 (Dr. Haney).

Personnel Training and Professional Development

The Perkins National Deafblind Training Project: A Collaborative Model is directed by Marianne Riggio and coordinated by Dr. Barbara McLetchie of Perkins School for the Blind. The project was designed to address the concern that only about 6% of educators working with students who are deaf-blind have had specific training in deaf-blindness. The project has created a national consortium of experts in deaf-blindness on training needs of teachers; conducted a national survey to identify the most critical training needs; conducted eight summer institutes to train teachers of students who are deaf-blind, their parents, administrators, and other service providers; and developed a "standard of competencies"—the skills and knowledge that teachers need to work with students who are deaf-blind. The project is compiling and field-testing the set of teacher competencies, which will help define training standards for teachers. These will be available for dissemination September 1996. Ms. Riggio and Dr. McLetchie can be contacted for additional information at:

Perkins School for the Blind
 125 N. Beacon Street
 Watertown, MA 02172
 617-972-7264 (Ms. Riggio)
 617-972-7226 (Dr. McLetchie).

Lifestyle Planning

A project on **Services for Children with Deaf-Blindness: Lifestyle Planning and Enhancement** is directed by Dr. Norris Haring and coordinated by Dr. Lyle Romer of the University of Washington. The project is designed to develop, implement, and evaluate a set of procedures to improve the lifestyles and quality of educational services for individuals who are deaf-blind. "Lifestyle planning" is a process which identifies students' strengths, builds formal and informal supports and networks, and prepares individuals for successful community living. The project has worked directly with many families by providing technical assistance. Project results suggest that

such person-centered planning can have positive impact on the quality of IEPs (individualized educational programs), as well as on the students' social activities and interactions. The project also has trained nondisabled peers to communicate and interact more effectively with students who are deaf-blind. Subsequent observations indicate that rates of contact and the qualities of interaction improve between students with deaf-blindness and nondisabled peers. A chapter on lifestyle planning is presented in the book Welcoming Students Who Are Deaf-Blind Into Typical Classrooms, edited by Norris Haring and Lyle Romer (Paul H. Brookes Publishing Co., 1995, 480 pages, \$35.00, 1-800-638-3775). An article on peer mediation training also appeared in the December 1995 issue of the professional journal *Education and Training in Mental Retardation and Developmental Disabilities*. For additional information, contact Dr. Norris Haring or Dr. Lyle Romer at:

University of Washington
 Experimental Education Unit WJ-10
 Seattle, WA 98195
 206-543-8565 (Dr. Haring)
 pager 360-786-2525 (Dr. Lyle Romer).

Problem-Solving Skills

One research project is studying how children with deaf-blindness learn to master their physical environments. A project entitled **Overcoming Helplessness: Hands-On Problem Solving Skills for Children with Deaf-Blindness** is collecting information from parents and teachers of children with deaf-blindness. The project is directed by Dr. Charity Rowland and coordinated by Philip Schweigert at Washington State University-Portland Projects in Portland, Oregon. Results will be used to develop a better understanding of how children with vision and hearing impairments come to know about their physical worlds. The project seeks to better describe how children learn to overcome barriers and obstacles, explore objects, use tools, construct objects, match one object to another, and search for and retrieve materials they desire. Results will be summarized for a journal article. In addition, assessment instruments for use in school and at home will be revised so that parents and teachers can monitor how children with deaf-blindness acquire problem-solving skills. A videotape will be made available which illustrates the assessment instrument. For more information, contact Dr. Charity Rowland at

Washington State University-Portland Projects
 1818 S.E. Division

Portland, OR 97202
 503-232-9145
 e-mail address: rowland@vancouver.wsu.edu.

Social Relationships

Three research projects were recently completed on the social relationships and interactions of students who are deaf-blind. One project, Social Relationships of Children and Adolescents with Deaf-Blindness, was directed by Dr. Harvey Mar and coordinated by Nancy Sall at St. Luke's/Roosevelt Hospital in New York City. This project provided support and assistance to help increase social opportunities and interactions for ten students with deaf-blindness. Intervention activities were designed to increase teacher awareness of natural school-based opportunities for social interaction, promote increased parental involvement in creating social opportunities in their communities, increase peer involvement with the students, and support the establishment of socially integrated activities in schools. The project identified specific barriers which impeded social opportunities, as well as useful strategies to promote social interactions and relationships between students with deaf-blindness and their school peers. These are summarized in several products and materials, including the final report (available through DB-LINK or ERIC), a series of handouts entitled Notes for Educators Working with Students who are Deaf-Blind (available from the project coordinator or DB-LINK), an article entitled "Enhancing Social Opportunities and Relationships of Children Who are Deaf-Blind" in the May-June 1995 issue of *Journal of Visual Impairment and Blindness* (vol. 89), and proceedings from a regional workshop on social relationships of children with deaf-blindness (soon to be available from the project coordinator). Parents may be interested in a brief summary of an interview study conducted on parental perceptions of the friendships and social activities of their children (*New York Parent Newsletter*, 1996, vol. VIII, available from New York Parent Network Inc., P.O. Box 423, Yonkers, NY, 10704). For further information about the project, contact Dr. Harvey Mar or Nancy Sall at:

St. Luke's/Roosevelt Hospital Center
 1000 Tenth Avenue, Antenucci-9
 New York, NY 10019
 212-523-6280
 e-mail addresses: hhm1@columbia.edu (Dr. Mar)
 nsall@aol.com (Ms. Sall).

A second project, **Research on Social Relationships for Children and Youth with Deaf-Blindness**, was directed by Dr. Robert Hor-

ner and coordinated by Dr. J. Stephen Newton at the University of Oregon. The project examined stability of social relationships between persons with severe disabilities and members of their communities. Studies also examined ways to reduce barriers to social activities, train peers to become more socially competent during interactions, and enhance social support. Several different studies were published, including: "A Conceptual Model for Improving the Social Life of Individuals with Mental Retardation" in the December 1994 issue of *Mental Retardation*; "Factors Contributing to the Stability of Social Relationships Between Individuals with Mental Retardation and Other Community Members" in the December 1995 issue of *Mental Retardation*; and, "Social Skills and the Stability of Social Relationships Between Individuals with Intellectual Disabilities and Other Community Members" in *Research in Developmental Disabilities* (1996, vol. 17, issue 1). For additional information, Drs. Robert Horner and Steve Newton can be contacted at:

The Specialized Training Program
Center on Human Development
University of Oregon
Eugene, OR 97403
503-346-2462 (Dr. Horner)
503-346-2470 (Dr. Newton)
e-mail address:
steve_newton@ccmail.uoregon.edu (Dr. Newton)

The **Friends for Life** project, directed by Dr. Norris Haring and coordinated by Dr. Lyle Romer at the University of Washington, was concerned with developing strategies and procedures to support meaningful friendships between children with deaf-blindness and their nondisabled peers. Findings from this project suggest that students with deaf-blindness have very low rates of contact with their peers in integrated settings and that relationships that do develop tend to be unstable and fleeting. For the answers to critical questions, such as how to increase the endurance of relationships, the project staff turned to peers for assistance. The project found that empowering peers proved more fruitful in creating meaningful and stable relationships than the use of adult-mediated strategies. Several professional articles were prepared from these studies including an article for the *TASH Newsletter* (February 1993) entitled "Julian's Transition: A Dream Team and Hard Work." A handout on simulation exercises, [Assisting Young People to Meet their Peers Who are Deaf-Blind](#), and information about journal publications are available through Dr. Norris Haring at:

University of Washington
Experimental Education Unit WJ-10
Seattle, WA 98195
206-543-8565.



The National Information Clearinghouse On Children Who Are Deaf-Blind

DB-LINK (The National Information Clearinghouse On Children Who Are Deaf-Blind) is pleased to announce notice of funding for the period 1996-1999. Round II, as we call it, will allow us to build upon our current efforts to expand and provide cost-free information related to children and youth (0-21) who are deaf-blind, their families, and the professionals who serve them. DB-LINK operates under the leadership and central management of the Teaching Research Division of Western Oregon State College.

Over the course of Round II, DB-LINK will:

- Maintain, expand, and disseminate information on deaf-blindness to all groups;
- Oversee the development of selected fact sheets and contribute to *Deaf-Blind Perspectives*;
- Develop and implement the Research-to-Practice Initiative (see article on page 1 of this issue);
- Work towards incorporating technology to complement existing information services including making our databases available via Internet, and online bibliographies;
- Work *with* 307.11 projects to facilitate information sharing; and
- Expand our existing linkages with consumer, family, and professional groups.

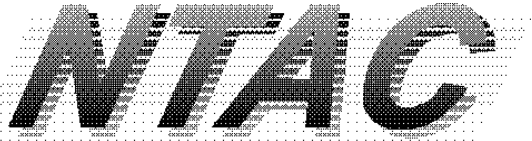
A core group of three agencies has been the backbone of DB-LINK since its inception in October of 1992: Helen Keller National Center, Perkins School for the Blind, and Teaching Research. These three agencies will continue to work in harmony to maintain a national clearinghouse that locates, organizes, manages, and disseminates information about deaf-blindness in areas that include: effective early intervention, special education, and general education practices; related medical, health, social, and recreational services; relevant legal issues; employment and independent living; postsecondary educational services; and information on the nature of deaf-blindness. Other cooperating agencies (American Association of the Deaf-Blind, National

Family Association of the Deaf-Blind, for example) are currently involved with DB-LINK in a variety of contractual and less formal collaborations.

DB-LINK has developed and maintains multiple databases that include bibliographical as well as local, regional, national, and international resources that serve the target population. This information is disseminated to a wide audience including state-level service coordinators, other professionals, parents, employers, and members of the public via DB-LINK Information Specialists housed at the core agencies. An inquiry-response process tailored to the needs of the requestor utilizes a combination of traditional (toll-free voice/tty phones, hard-copy information packets, etc.) and electronic means (Internet, Worldwide Web, electronic bulletin boards, etc.) to disseminate information to consumers throughout the United States.

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National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC)

Teaching Research Division of Western Oregon State College, and Helen Keller National Center are pleased to announce funding of the National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC). The project is funded under the U.S. Department of Education, Office of Special Education and Rehabilitation Services, Office of Special Programs. The primary mission of NTAC is (a) to assist states to improve the quality of existing placements and services for individuals (birth to age 28) who are deaf-blind, and (b) to increase the numbers of children, young adults, their families, and their service providers who will benefit from these services.

NTAC combines the vast resources, expertise and experience of two prominent agencies: Teaching Research and Helen Keller National Center. These two agencies have united in a national cooperative effort to furnish training and technical assistance to families, service providers, state agencies, and organizations responsible for the care and services of infants, young children, school-age children, and young adults who are deaf-blind. By partnering together, the consortium agencies bring years of successful technical assistance experience from the Teaching Research TRACES Project and the Helen Keller National Center - Technical Assistance Center.

NTAC will work with agencies and families within states through the provision of technical assistance to:

- “Facilitate long-range planning and development of collaborative partnerships among families, service providers, and agencies at the local, state, and regional levels;
- “Use “effective practices” and current research findings to enhance training opportunities for families and service providers to increase awareness, knowledge, and skills in meeting the unique needs of children and young adults who are deaf-blind;
- “Assist parents and family members in advocating for and participating in effective service delivery systems for the family member who is deaf-blind;
- “Assist young adults who are deaf-blind to promote self-advocacy and self-determination; and
- “Develop a nationwide database of demographic characteristics of infants through young adults who are deaf-blind.

NTAC is committed to using the most effective resources and approaches to assist states in all technical assistance activities. A focus of NTAC is the utilization of all stakeholders to plan, implement, and evaluate these technical assistance activities.

Contact NTAC staff at:

Teaching Research
Voice: (503) 838-8293
TTY: (503) 838-8821
Fax: (503) 838-8510
Internet: www.tr.wosc.osshe.edu/ntac

and **Helen Keller National Center**
Voice & TTY (516) 944-8900
Fax: (516) 944-8751.

Tomorrow's Deaf-Blind Perspectives

Bruce Bull, Managing Editor

"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."

Bud Fredericks, 1993

This issue marks the beginning our fourth year of *Deaf-Blind Perspectives (DBP)*. With the recent funding of National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC) and refunding of DB-LINK—two of three sources funding this publication—the time seems right to examine how we can best achieve our above-stated purpose. Additionally, I have included findings from the recent *DBP* readership survey that has provided, and will continue to provide, direction to *DBP*.

DBP could not exist without the support of two national deaf-blind projects: NTAC and DB-LINK. Though one function of *DBP* is the dissemination of information pertinent to these projects, we have also make every effort to be more than just another project newsletter. One expected result of combining the national deaf-blind technical assistance efforts of TRACES and HKNC-TAC into NTAC is that *DBP* will reflect the collaboration within this project. Because one of NTAC's charges is to improve services to individuals who are deaf-blind, birth to age 28, *Deaf-Blind Perspectives* will increase its solicitation of manuscripts that focus on young adult issues.

DB-LINK too has an expanded work focus that will affect *DBP*. The DB-LINK Research-to-Practice Initiative (see article on page 1) will work toward dissemination of information related to effective practices—whether developed in research projects, 307.11 projects, or elsewhere—to families and professionals. DB-LINK will facilitate the transfer of helpful information to those who can make a difference in the lives of people who are deaf-blind. *DBP* will be method for disseminating these effective practices.

DB-LINK and NTAC naturally flavor *DBP*. But the readership too shapes the publication through both its contributions and feedback. In the Winter 95/96, (Vol. 3, Issue 2), we included a readership survey to solicit reader feedback. A

non-representative group of respondents, just over 3% (n = 80) of the readership, took the time to provide input. We appreciate it; and we've listened. I've highlighted just a few of the findings here and the direction that this input will provide. (Complete survey results are available upon request.)

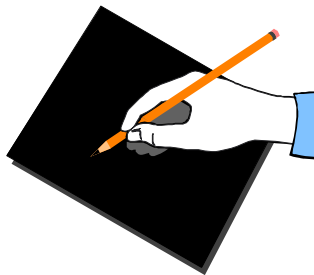
Survey Results

Nearly 78% of respondents felt that *DBP* was "very important" in keeping them informed about the field, and 57% of them read each issue of *DBP* cover-to-cover. This group most frequently listed *DBP* as their main source of information about deaf-blindness. To this small respondent group, *DBP* plays an important information dissemination role. That is why we've listened and responded to their suggestions.

- Two-thirds of those who answered the question about whether we should add a "Letters to the Editor" feature responded positively. We've taken that suggestion beginning this issue. Obviously, this section is dependent on readership participation. We look forward to your opinions.
- Respondents favored "how-to articles" more than any other type. We actively seek out content and how-to articles. One difficulty is that many potential contributors who may have valuable information to share may not have the time to write. I ask you be creative, find someone who would be willing to collaborate with you on the writing task. If you're in a classroom, have a practicum student work on a piece with you; if you're in a parent group, write something with other parents; if you're at a college, collaborate with a graduate student. I know that many of you have information that others can use to improve the lives of people who are deaf-blind. Please share it with us.
- "Advocacy and policy updates" were favored second. *DBP* will continue to keep the field updated, especially during this crucial period while IDEA is up for reauthorization.
- "Research descriptions/quantitative pieces" were favored third. The DB-LINK Research-to-Practice initiative will feed some of the demand for this information, but we will continue to seek out projects in order to utilize *DBP* as a vehicle for dissemination of project findings.
- "Calendar of event" pieces were least favored. We won't include such information unless it specifically targets the field, covers a wide geographical area, or there is substantial lead time before the event. Our publication frequency does not allow us to serve adequately as a provider of more general and/or local information.
- Finally, over one-third of the respondents indicated they would be interested in writing articles for *DBP*! This is encouraging. By "presenting di-

verse opinions,” we can indeed “begin to accept the differences that exist within the field and perhaps reconcile some of those differences.”

DBP has been, and will continue to be, open to everyone—parents, professionals, people who are deaf-blind, and researchers—to contribute to the publication. Amalgamating the best of what the entire field has to offer and sharing it with our ever-expanding readership (currently 2800+) is what *Deaf-Blind Perspectives* is all about. Help us to achieve our purpose.



Letters to the Editor

Dear Editor:

I appreciated Bud Frederick's article, "Reflections, Comments, and Suggestions" (Spring 1996), drawing attention to the role of family services. I hope that 307.11 projects will truly work to develop better partnerships with families.

When I became a Regional Representative for Helen Keller National Center, there were still regional centers for deaf-blind children in many parts of the country. The South Central Regional Center had a family specialist who conducted workshops and maintained contact with families in the region, increasing their knowledge and sense of self-empowerment. The attitude was that families were the critical political/advocacy component of the service delivery system that ensured services would continue and improve.

**Want to share your opinion?
Take a few minutes to write a
Letter to the Editor. Please keep
letters to 250 words or less. The
editorship is developing a pol-
icy for this section.**

In transferring the control of services to a state agency, many educational and advocacy efforts for families were lost. Services to deaf-blind children and to the deaf-blind field as a whole have suffered as a result. This transition has left me with a great sense of loss and uncertainty.

Today, family support seems fragmented. There seems to be less inclination by 307.11 projects to develop real family partnerships. There isn't the same level of commitment to developing friendships with families, to maintaining telephone contact, or to understanding how fundamental the family is to the betterment of programs for deaf-blind children and society as a whole. I don't know how this got lost in the transition from regional centers to state centers, but I wonder if it's not, in part, because the regional centers were more independent and not a part of the bureaucratic state educational system.

C. C. Davis
Regional Representative

Dear Editor:

I concur with Dr. Frederick's recommendation for more parental involvement ("Reflections, Comments, and Suggestions," Spring 1996). However, I also believe we need the involvement of deaf-blind teens and adults of all ages in program development, advisory board membership, and service delivery.

I have been at meetings for parents of deaf-blind children in which no deaf-blind people participated and I have met parents of young Usher adults who have never met a deaf-blind adult!

According to the literature, half of all deaf-blind adults have Usher Syndrome. Parents of Usher kids are not being surveyed about their experiences, which often include early attempts at mainstreaming their children with changes to deaf programs at the request of their children sometime during early adolescence so they can be just like everyone else. In two deaf-blind teens programs, different mothers said to me, "I have never seen my child be so normal before." Both these deaf-blind teen programs had tremendous involvement of deaf-blind adults in planning, counseling, and presenting. This was the first time any of these teens had seen people like themselves in charge.

To omit deaf-blind older teens and adults from planning is to deny that our deaf-blind children can learn anything from people like themselves and; by extension, to imply that our deaf-blind children have nothing to contribute.

Necessary to the success of these programs is the involvement of deaf-blind adults at every opportunity. Parents with newly diagnosed children of all ages can benefit from the wisdom of those who have gone before—other parents and deaf-blind people themselves.

Ilene Miner, CSW, ACSW



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

The deaf-blind community lost a very special person in July with the passing of Mary Margaret O'Donnell. Mary's "career" in deaf-blindness spanned more than thirty years during which she was a driving force in the creation of the New Jersey Association for the Deaf-Blind, served on numerous advisory committees at the state and national level, and helped found the National Family Association for Deaf Blind (NFADB). In 1992, Mary was awarded the prestigious Anne Sullivan Medal at the National Conference on Deaf-Blindness, the first parent to receive this award.

At the time of her death, Mary was serving as president of NFADB. A private, understated person who shunned the spotlight and preferred working behind the scenes, she somehow always seemed to end up in a leadership position. For those of lucky to have known her personally, it was easy to see why. She possessed a wealth of knowledge but never tried to impress others with it—she simply offered them her support and counsel. She had an inner strength and tenacity that enabled her to stay focused, even in times of great confusion. She was a great listener who was open to differing points of view and never failed to recognize the contributions of others.

Mary was a lovely, thoughtful lady who carried herself with class and dignity in all she did. She will be greatly missed.



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All issues of *Deaf-Blind Perspectives* are available on the Internet at www.tr.wosc.osshe.edu/tr/dbp

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

Deaf-Blind Perspectives
Teaching Research Division
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