

Deaf-Blind Perspectives

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Fall 1995

Current Status for Reauthorization of IDEA

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Helen Keller National Center

As this issue of Deaf-Blind Perspectives goes to press, the process of re-authorizing the Individuals with Disabilities Act (IDEA) is far from complete.

Last month the Committee on Economic and Educational Opportunities circulated the House of Representatives' draft for reform of IDEA. Part D of the Draft "IDEA Improvement Act of 1995" would consolidate the current fourteen special purpose (discretionary) programs funded in FY 1995 under IDEA into one new Part D, National Activities to Improve Education of Children with Disabilities.

If one attempts to identify where the existing discretionary programs will be placed within the proposed Act, some are rather apparent. For example, Personnel Training (Part D, Section 631 and Section 632 of the current law) will fall under Section 678—National Activities in Professional Development. The current Parent Training Program is covered by Section 673 in the proposed bill—Technical Assistance for Parent Training and Information Centers. Other discretionary programs such as Instructional Media (Part F, Section 651) and Technology, Educational Media, and Materials (Part G, Section 661) will be included in the new legislation in Section 679—Technology Development and Section 680—Educational Media Services.

This is clearly not the case for the Services for Deaf-Blind Children and Youth! Section 699A of the proposed bill calls for minimum funding requirements for several categories of children, including "\$12,832,000 to address the educational, related services, transitional, and early intervention needs of children with deaf-blindness."

But what portion of the money will be used to fund Parent Training and Information Centers? How much of this funding will be used to support National Activities in Professional Development? If a grant awarded under Technology Development carries out research on the development of technology for children who are disabled that may include children who are deaf-blind, does some of the grant money come from the \$12.8 million set aside in Section 699A?

And who determines how any or all of this money is spent? Who identifies the priorities? Who monitors the programs receiving these funds? The coordinated efforts across program management, research, systems change, technical assistance and information dissemination that have been achieved under the existing Deaf-Blind Children and Youth program will be significantly reduced.

A second concern with the proposed House bill is that Section 699A also includes the statement, "If the total amount appropriated to carry out this part for any fiscal year is less than \$254,034,000, the amounts listed in subsection (a) shall be ratably reduced."

If the recently passed House appropriations bill were to be adopted by the Senate, the amount for the new Part D would drop from the current \$254,034,000 to \$92,491,000, a reduction of approximately 64%. Under the proposed formula, Deaf-Blindness would received less than \$4.7 million. The Senate appropriations mark-up is scheduled for mid-September.

The Senate has not begun its deliberations on IDEA although the Disability Policy Subcommittee of the Labor and Human Resources Committee has announced its in-

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tention to have a first draft by September 18 and a full committee report by October 25.

A number of things must take place before IDEA is enacted. The House is in the process of preparing a second draft of its proposed bill and will present it to the full committee sometime in September. When the Senate's bill is approved, the two bodies will meet to iron out any differences and agree on a final version which will go to the President for his signature.

While we in the field of deaf-blindness are primarily concerned with the Services for Deaf- Blind Children and Youth program, the attention of the legislators, educators and the disability community are on other matters. Major disagreements surrounding issues such as discipline, attorneys fees, the resolutions of disputes on appropriate services and placement, and the funding formula are generating a great deal of debate. There is a good chance that the legislation

may not be finalized until the end of the calendar year.

It is critical that we all monitor the proceedings closely since this bill will determine the educational services to be provided to every child who is deaf-blind in this country.

If you have any questions on concerns, do not hesitate to contact the

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Utah Enhances Services for Children who are Deaf-Blind

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The original manuscript contained language established by the Utah Legislative Task Force that referred to children with "dual sensory impairments." That language has been changed to "children who are deaf-blind" in keeping with the editorial policy of Deaf-Blind Perspectives. —ED

Over the past nine months Utah parents of children who are deaf-blind have lobbied the Utah state legislature for funding for one-on-one intervener services for children who are deaf-blind, birth to five years old. Assistance was provided by the Utah State Office of Education, the SKI*HI Institute, the Utah Project for Children with Dual Sensory Impairments (the Utah 307.11 Deaf-Blind Project), and the Legislative Coalition for People with Disabilities. This lobbying effort resulted in a two-fold piece of state legislation: First, a one-time \$193,500 appropriation was granted for direct intervener services for children who are deaf-blind. Second, a directive was included to develop a legislative task force to design a state plan to address the needs of all individuals, birth through age 21, who are deaf-blind.

The new legislation came about because of the immense dedication of several people. It became clear, during the legislative process, that others concerned about funding for services for individuals who are deaf-blind might benefit from learning about the experience of these parents and professionals. Although many different individuals could provide diverse views on the process and the anticipated impact of this legislation, two primary perspectives were sought for this article: that of a parent of a child who is deaf-blind and that of a representative of the Utah State Office of Education. Both of these individuals were highly instrumental in gaining the interest and support of the Utah State Legislature.

Interview with Stephanie Carlson

Stephanie Carlson is Travis' mom. Travis is a three year-old boy who is deaf-blind.

Q: What was the catalyst for this recent state legislation specific to services for children who are dual sensory impaired?

The SKI*HI Institute informed me that the grant for the Intervener Program for children, birth to three, who are deaf-blind was ending and no other funding had been obtained. Since this program has been such an important part of my son's life, I knew that it could not end. In fact, since it had not been promoted for children aged 5–21, I felt that needed to happen also. I asked the Legislative Coalition for People with Disabilities what needed to be done to obtain state funding for deaf-blind intervention services.

Basic Definition of an Intervener

An intervener is specially trained to provide clear and consistent sensory information to an individual who is deaf-blind, compensating for both vision and hearing loss in such a way as to facilitate and enhance learning and interaction with the physical environment and with society. An intervener acts as the eyes and ears of the individual who is deaf-blind, making him or her aware of what is occurring and attaching language and meaning to all experiences. An intervener intercedes between the individual who is deaf-blind and the environment in such a way as to minimize the effects of multisensory deprivation, and to empower the individual to have control over his or her life.

A group of Utah parents of children who are deaf-blind then met to discuss what services our children need that are not available in the state. With the help of several agencies we put together a plan of action and a financial request.

If I could recommend anything to other groups considering requesting state funding, it would be to plan far enough in advance to begin the legislative process at least six months prior to the beginning of the legislative session. We began this process only two months before the session. We could have saved ourselves many headaches if we had started earlier. I really appreciate our Legislative Coalition. They walked the parents through the process, putting them in contact with the appropriate people to move the process along.

Q: Why was this process initiated?

Again, the primary motivation was the fact that the Deaf-Blind Intervener Program would soon be without funding. My son, Travis, if put in a classroom in a public school or at the Utah Schools for the Deaf and the Blind, would not be able to participate without the help of a person specially trained to provide him with the information which he can't get through his eyes and ears. It is imperative, especially for children more severely impaired, to have a person that understands deaf-blindness and all of the other needs including the specific communication, educational, and medical needs of that one child.

The vast majority of children who are deaf-blind are not at the Utah Schools for the Deaf and the Blind. They are in the public school system where few teachers have been specifically trained in deaf-blindness. That is why the parents pushed for this legislation—to get deaf-blind specific services and training.

Q: What role will parents play in designing the State Plan for all educational services for children who are deaf-blind?

Parent involvement is essential and priceless. There are eight parents out of a total of 32 members on the Legislative Task Force. The parents involved represent all age groups of children from preschool through adulthood. Together we are supplying information about what our children really need at all different ages.

The service providers on the Task Force have different backgrounds and different specialties. Some of them have training in deaf-blindness and some don't. As parents, our specialty is our child. That's why our input is important.

I think all of the Task Force members are very sensitive to the parents' needs and concerns. It has been an exciting, positive experience to see this many people come together for one purpose and have it work so well.

Q: As a parent, what are the most critical long-term issues which need to be addressed through the State Plan?

Communication is the number one priority. We must provide a means for individuals who are deaf-blind to learn to communicate and to communicate appropriately in their natural environ-

ments, especially in school. Some children may need one-on-one interaction with an intervener to communicate. Other children may learn to communicate well using an alternative system such as a communication board. The key is that each child needs an individualized plan in order to receive an appropriate education.

The second issue, which is a major one for our family, is the need to integrate all of a child's services to accomplish the above priority. This is especially important with children who are severely, medically fragile. Travis is a technology dependent child. He has a trach and would be at risk of dying without a medically trained person with him. I believe his medical, educational, deaf-blind, and other related services can be integrated and delivered wherever the educational process is taking place.

The final issue is that of training. There are just not enough people trained in dual sensory impairments to provide the necessary services. The Task Force will design ways for Utah to overcome this problem.

Q: How will the State Plan system of services for children who are deaf-blind differ from the current system?

Although the development of the system is not complete, I can tell you the parents' goals for the State Plan.

All children who are deaf-blind will have access to direct intervention services which are individualized to meet the unique needs of each child and his or her family. The services may be delivered at school, at the local park, in a nursing facility—wherever the child is located.

The entire system of medical, educational, deaf-blind specific and other related services will be smoothly integrated for the benefit of all children and families. Obtaining and coordinating the delivery of all of a child's services will no longer be a nightmare for parents.

And finally, training to provide direct intervention and technical assistance services for children who are deaf-blind will be available to the most appropriate person for the child. Opening the training up to a variety of individuals will help integrate services and decrease the number of service providers in a child's life.

Q: From a parent's perspective, what impact do you hope this legislation will have on your child and family and on other Utah children who are deaf-blind and their families?

I think my hopes can accurately be extended to all of Utah's children. My vision is that when a child is deemed to need intervention services, the most appropriate services for that child will be available and provided by a person trained in dual sensory impairments. I strongly believe that intervener services have had a very positive impact on Travis' life. I hope that through this legislation he will have these services available to him as needed from age 5–21 and even beyond.

I've seen that it is often the parents that are most assertive that are able to get services for their child. I don't want children to do without services because their parents are not assertive enough, or are too tired, or have just met their limit and have no fight left. Getting essential services should not be a battle. I hope we can create an integrated system which provides the services needed in a family-friendly manner.

Finally, the State Plan will establish the framework for families and professionals to assist Travis and other individuals who are deaf-blind to build a life full of the supports and services needed to make their lives meaningful and rich with experience and fun!

Interview with Dr. Stevan J. Kukic

Dr. Stevan Kukic is the Director of At Risk and Special Education Services for the Utah State Office of Education. He is the chair and facilitator of the Legislative Task Force.

Q: Why was this process initiated?

Actually, there were several concurrent events which resulted in the initiation of the legislation. First, the Utah Project for Children with Dual Sensory Impairments (Federal 307.11 Grant) can no longer use federal dollars to fund direct services to children who are deaf-blind. Utah is now mandated to provide direct services to all children with disabilities, birth through 21, through Part H and Part B. Second, the SKI*HI Institute at Utah State University was notified that the federal grants for several technical assistance and direct service projects related to the provision of services for children who are deaf-blind were coming to an end.

The Utah State Department of Health and the Utah State Office of Education had been working with the SKI*HI Institute on securing an alternative mechanism for funding for approximately one year; however, the loss of federal funds resulted in the need for immediate fiscal support to continue the direct services which were being threatened.

Q: The legislative bill clearly defines the membership of the Task Force. Why were these particular agencies selected and how will they contribute to the design of the State Plan?

Services to children who are deaf-blind and their families should not be restricted to the six-hour educational days in which most children are involved. Meeting the intense needs of many infants and students requires substantial collaboration between agencies such as the State Department of Health, Medicaid, Human Services, and others included on the Legislative Task Force. The state of Utah is committed to what we have titled the FACT Initiative. This initiative, "Families, Agencies, and Communities Together," guides multiagency collaborative activities between state agencies, families and other community organizations to enhance services to children at risk, including those who are disabled. Through collaboration we are increasing the effectiveness of what we do.

Other agencies and organizations are included on the Task Force for obvious reasons. Individuals who are deaf-blind, parents, and representatives from many agencies including the Utah Schools for the Deaf and the Blind, local school districts, the Legislative Coalition for People with Disabilities, and the SKI*HI Institute are considered essential and equal partners on the Task Force. Their input, expertise, and efforts are essential in the development of a State Plan, which is our true goal, in contrast to a "state office" or "agency" plan.

Q: The Task Force is on a fairly short time line. What process will be employed to accomplish the sizable task of designing the State Plan?

The Utah State Office of Education has undertaken several major planning initiatives in recent years. In 1991, a strategic planning team of parents, educators, legislators, key decision makers and stakeholders in Utah's special education service system was organized for children and families who are disabled. The document developed by this team, the "Utah Agenda for Meeting the Needs of Students with Disabilities," has become the guiding force for policy development, legislative activities and funding and the restructuring of educational services for Utah's 55,000 students who are disabled.

The strategic planning model used for the development of the Utah Agenda and other strategic planning activities, (Cook, 1989; Gibbs, 1989) is also being used by the Legislative Task Force. This model relies heavily on the concepts of good faith planning and consensus-based decision making. Task Force members have equal opportunities as consumers, parents,

professionals, and advocates to provide input and to feel ownership in the resulting State Plan. The collective desire of the group to design a state plan which will be accepted and funded by the state legislature during the 1996 session also provides the incentive to proceed in a timely manner.

Q: Will the Task Force and the resulting State Plan address all needs affecting individuals who are dual sensory impaired or only educational needs

The intent of the legislation is for the development of a state plan specifically addressing the educational needs of children who are deaf-blind. However, the consensus of the Task Force at the initial meeting was that the educational needs of a child should be considered within the context of his or her whole life. In addition, the group agreed that concern should also be given to the needs that children will encounter as they become adults.

The final State Plan and accompanying budget request which will be proposed to the State Board of Education and the Legislature will outline the educational services to be developed and provided specifically for children, birth through 21, who are deaf-blind. It will also define the means by which all other special education and noneducational services can be accessed and integrated to meet the individual needs of children who are deaf-blind.

Q: How will the State Plan system of services for children who are deaf-blind differ from the current system?

Without having a finalized State Plan, the answer to this question may still be ambiguous. The Task Force has accepted the previously developed objectives and strategies of the state deaf-blind project as the initial concepts to be included in the State Plan. These objectives and strategies focus on the provision of technical assistance for children birth through 21 who are deaf-blind and their families and service providers. To enhance all technical assistance services, three strategies overlie all of the objectives: (a) to institutionalize a centralized statewide system for all deaf-blind technical assistance services; (b) to use a transdisciplinary approach to service development and delivery; and (c) to provide categorical (deaf-blind specific) technical assistance in noncategorical and inclusive settings.

Key components that were not included in the state deaf-blind project are the provision of direct services to children who are deaf-blind, including intervener services, and the identification of a specific funding source for these services. The major work of the Task Force will center on designing the objectives and strategies to include both of these elements in the State Plan.

Q: From the perspective of a State Director of Special Education, what impact will this legislation have on Utah's children who are deaf-blind. Do you foresee any impact on children in the state who have other severe disabilities?

The concept of services for children who are deaf-blind envisioned by the Task Force is consistent with the concept envisioned for services for all students who are disabled in the state of Utah. That is, direct and technical assistance services, support systems, and funding will be provided to allow children to participate in the inclusive home, educational, and community environments which are most appropriate to meet their individual needs.

This legislation has increased the awareness of deaf-blindness, as well as other severe disabilities. It has highlighted the need for a continued emphasis on the provision of categorical services for children who are deaf-blind, regardless of the setting, inclusive or categorical, in which they are served. Although the Task Force will be requesting legislative funding for deaf-blind services, this legislation will assist in developing

the coalitions, partnerships, and support systems needed for a unified advocacy for future funding of all special education services.

Finally, through this legislation, the collaborative efforts of many different individuals and agencies will be focused on the single most important goal: to provide the most appropriate services to meet the unique needs of each child who is deaf-blind. This will happen. In Utah, collaboration is not just a buzz word but a reality.

A great deal has happened since the Utah Legislature approved this legislation specific to individuals who are deaf-blind. The Legislative Task Force began development of the Utah State Plan in May 1995. Since that time five objectives with supporting strategies have been agreed upon. These five objectives are

Objective 1: Consistent intervention services will be developed, implemented and evaluated to meet the unique communication, developmental, academic, social and vocational needs of each individual (birth through 21) who is deaf-blind and his or her family.

Strategies for this objective include the provision of deaf-blind specific services such as interveners, trained interpreters, orientation and mobility specialists and assistive technology devices and services. All families and service providers will have access to a deaf-blind specialist who will facilitate the acquisition and delivery of direct and technical assistance services.

Objective 2: A unified statewide system of coordinated and collaborative technical assistance services will be developed, implemented, and evaluated to enhance the transdisciplinary delivery of the full array of direct services.

Strategies for this objective include the development of a centralized system which can be easily accessed by all families and service providers. This will help eliminate the confusion and frustration encountered when making numerous phone calls while searching for information or services.

Objective 3: Training needs specific to families and service providers of children who are deaf-blind will be incorporated into the state's Comprehensive Interagency System of Personnel Development.

Strategies supporting this objective will focus on expanding pre-service training and ongoing inservice and mentor training programs.

Objective 4: A public awareness system that promotes family-centered services will be developed, implemented and evaluated.

Objective 5: Adequate and equitable funding for implementation of the State Plan will be achieved using a unified advocacy approach in conjunction with the Legislative Coalition for People with Disabilities.

These objectives represent the consensus of the task force and serve as the framework for the development of the State Plan. Detailed action plans to support each of the objectives and strategies are currently being developed. The budget for the legislative funding request is complete and includes the

request for state funds, as well as a matrix showing the collaborative fiscal commitment of many different agencies within the state. It is important to know that many of the specific strategies and action plans developed are or will be implemented and funded through these collaborative commitments. The State Plan and funding request will be submitted to the Utah State Board of Education for inclusion in the Education Budget for 1996-97. Legislative acceptance and funding of the State Plan as the directive for statewide services for all children who are deaf-blind is the desired outcome of this endeavor. How will this outcome help children? All Utah children who are deaf-blind, their families, and service providers will have access to direct and technical assistance services which are designed specifically for individuals who are deaf-blind. An individual's services will be coordinated through a service coordinator with knowledge of deaf-blindness and will be delivered in the most appropriate setting for that individual. This legislative funding will allow for consistency and continued enhancement of services for all children who are deaf-blind within the state of Utah.

References

Gibbs, R. (1989). Action team leader's guide. Austin: Cambridge Management Group, Inc., Texas Association of School Boards.

Cook, B. (1989). Strategic planning for America's schools. Austin: Cambridge Management Group, Inc., Texas Association of School Boards.

Request for Proposals Announced

The U.S. Department of Education, Office of Special Education Programs, Services for Children with Deaf-Blindness Program announced requests for proposals in three priority areas. (See August 10, 1995 Federal Register pp. 40968, 40970-71).

Absolute Priority 1. *Technical Assistance for Children, Adolescents, and Young Adults Who Are Deaf-Blind*

Estimated Size of Award: \$1,600,000

Estimated Number of Awards: 1

Project Period: 60 months

Application Deadline: October 25, 1995

Absolute Priority 2. *Demonstration Projects for Children with Deaf-Blindness*

Invitational Priority: The Secretary is particularly interested in applications that meet the following invitational priority, but an application that meets this invitational priority does not receive competitive or absolute preference over other applications.

- Improve instructional techniques that enhance communication skills, including use of augmentative devices and assistive technology;
- Improve social skills, including social interaction;
- Improve independent living skills, including self determination, mobility, and other community living skills;
- Improve recreation and leisure skills; or
- Improve more traditional skills, including academic achievement and transition and employment skills.

Estimated Range of Awards: \$130,000 to \$135,000

Estimated Average Size of Awards: \$133,000

Estimated Number of Awards: 5

Project Period: 36 months

Application Deadline: October 25, 1995

Absolute Priority 3. *National Clearinghouse for Children Who Are Deaf-Blind*

Estimated Average Size of Award: \$325,000

Estimated Number of Awards: 1

Project Period: 36 months

Application Deadline: November 1, 1995

Application materials will become available on September 11, 1995.

Contact: Robin Buckler, US Dept of Education, 600 Independence Ave SW, Room 4617 Switzer Bldg, Washington, DC 20202-2732; 202/205-9844.

Families and Support Networks

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Introduction

Families of children who are deaf-blind, like people who are deaf-blind themselves, (Mar, 1992) are vulnerable to avoidance, social isolation, and exclusion from social interaction. A recent review of the literature revealed that there is a major need for "more attention in professional writings on the needs and perceptions of parents of individuals who are deaf-blind" (Fredericks, 1992). As support networks for families of children who are deaf-blind become stronger, they can help meet this need by conducting research on their participating families under their own auspices.

The uncommon combination of disabilities associated with deaf-blindness means that there will often be a high level of geographic separation among families of children who are deaf-blind. In Kentucky, for example, with a population of 3.7 million, there are approximately 140 families with children listed in the Kentucky Deaf-Blind Registry maintained by the state's federally funded 307.11 project (Leatherby, 1993). These families are scattered among 120 counties across the state, with several counties having only a single family with a child who is deaf-blind.

Deaf-blindness, that may include other disabilities, presents families with huge caregiving challenges. These challenges often limit a family's mobility, with the result that some families are unable to participate in normal community activities. Some even find it difficult to attend events such as parent-professional conferences which are explicitly designed to address their interests.

Unfortunately, our society continues to stigmatize both individuals who are disabled and their families. This, in combination with the distances and barriers to mobility described above, place families of children who are deaf-blind at higher risk for social isolation. In one survey in which mothers of children who are deaf-blind were asked to name three things that would have helped them to care for their children, the most frequently volunteered response was "more family support" (Vadasy & Fewell, 1986). It is partially in response to such sentiments that family support networks are being encouraged, though what constitutes family support is not universally agreed upon.

One family support effort in Kentucky is the establishment of PCDSI.

PCDSI is a new organization whose mission is to provide information and support to families of children who are deaf-blind.

PCDSI emerged from a series of annual retreats sponsored by the Hilton-Perkins National Project and Kentucky's 307.11 project, known within the state as the Deaf-Blind Intervention Program (DBIP). The support network was informally organized in 1992 and became incorporated with designation by the Internal Revenue Service as a tax-exempt organization in 1993. PCDSI now plans the annual family retreat, distributes a newsletter, represents families in disability coalitions, holds events to raise public awareness, engages in advocacy activities, and has obtained funding to develop a telecommunications network among its participating families. Membership in PCDSI is loosely defined, with families of 69 (49%) of the 140 children on the Kentucky Deaf-Blind Registry having contacted the organization or participated in some of its activities as of late 1993. Information about PCDSI is distributed by the DBIP staff to all families in Kentucky who have a child on the Deaf-Blind Registry. Due to concerns with confidentiality, however, all participants in PCDSI are self-referred to the support network.

The purpose of this report is to describe the results of a survey of Kentucky families of children who are deaf-blind which was conducted under the auspices of Parents Confronting Dual Sensory Impairment (PCDSI).

The survey addressed several topics, including support networks, the state's deaf-blind intervention program, services from other agencies, computers and telecommunication, and family characteristics. This report is limited to a presentation and discussion of the findings regarding family characteristics and family support networks.

Methods

A proposal and draft questionnaire were submitted for approval to the Institutional Review Board for the protection of human research subjects at the University of Kentucky. The procedures and questionnaire were pretested and revised to ensure confidentiality and reduce the duration of the interviews.

A telephone survey was conducted by experienced, trained, supervised interviewers. PCDSI's directory of self-referred families of children with dual sensory impairment provided the list of households to be contacted. Of approximately 140 families in Kentucky with a child on the confidential Deaf-Blind Registry at the time of the survey design, 69 (49.2%) were included in this directory. Of these 69, interviews were not conducted with 16 because 7 were found to have no telephone or a disconnected number, 3 could not be reached after 6 or more attempts, 2 had children who were deceased, 2 refused, 1 parent was hospitalized, and 1 parent said the child was not visually impaired. Of the remaining 56 families who could be reached, 1 completed questionnaire was

lost during data processing. These respondents represented 76.8% of the families listed in the PCDSI directory and approximately 38% of the total number of families on the confidential Kentucky Deaf-Blind Registry. Some questions were not asked of some respondents because predetermined skip patterns in the questionnaire specified that they should not be asked about topics of which they had already expressed no knowledge.

Questionnaire responses were reviewed by supervisors for completeness, accuracy, and clarity. Repeat calls were made where necessary for additional information or clarification. Responses were coded and the data entered and verified for electronic processing. The analysis in this paper uses descriptive statistics only.

Findings

At the beginning of the interview, respondents were assured that their responses would be treated confidentially and reported anonymously, and that the interview would take "about 10 minutes." The actual mean duration of the completed interviews was found to be 17.8 minutes (standard deviation = 6.5), with a median of just under 15 minutes and a range from 10 to 50 minutes.

Interviewers rated the respondents' understanding of the questions as excellent or good for all but 2 respondents (96.3%). The respondents' interest in the survey was very high or above average for 90.5%. Only 1 in 10 (9.4%) revealed any resistance to the questions at any point during the interview. Table 1 shows some characteristics of the participating families.

Respondents were asked to rate the importance of various benefits they might experience as a result of activities of a parent support network. The results of these ratings are shown in Table 2. All of the benefits listed were highly valued by the respondents, with half (47.1%) or more rating each of the items as "very important" to them. Nevertheless, both the mean rating and the percentage rating each benefit as "very important" revealed an ordering. The item "...information on what has been successful helping children with dual sensory impairment" was the most highly valued. Second most important was "...referral to agencies which might be helpful." After these two information-related benefits came friendship, training and participation in advocacy, and emotional support.

Respondents were asked several questions about the quality of their experiences with PCDSI. The responses are shown in Table 3. Although all of the families had been self-referred to the family support

network, 30.2% didn't recognize its name. One-third (32.1%) had heard of PCDSI through "other" professionals, primarily special education teachers. Only small proportions had heard of the organization from other parents or from the state's Deaf-Blind Intervention Project. The newsletter was rated as very useful by 17.0%. PCDSI was perceived to be more helpful in providing information than it was effective in providing support. Half of the respondents (50.1%) were very interested in future involvement in the support network.

Discussion

This survey elicited a high response rate from the families we were able to contact. These respondents, however, are probably not representative of all of the families in Kentucky who have a child who is deaf-blind, even though they make up a substantial part of that population. In particular, it seems that families with young children (less than six years old) may be underrepresented in this set of respondents. Respondent interest in and understanding of the survey was judged by the interviewers to be quite high.

The most important benefit of family support group activities was hearing stories or receiving information on successful interventions that had helped children who are deaf-blind. Such stories not only provide information and direction to families, but also offer hope that good outcomes can be achieved from interventions on behalf of their children. The second ranked benefit, referral to agencies, indicates the instrumental or task orientation of families. Third ranked was friendship, which reveals the need families have for networks to overcome the isolation that can accompany their child's disabilities.

PCDSI was familiar to most, but not all of the respondents. PCDSI was judged to be more successful in supplying information than in providing support. A large majority of these respondents were very or somewhat interested in future involvement with this parent support network. PCDSI is still a new organization, being led for the most part by its original board members and officers. As leadership turns over it is expected that participation will be broadened and the proportion of families who are familiar with the group will increase, as will the benefits to these families. PCDSI should attempt to maximize the opportunities for families to share their stories with one another and to involve professionals in giving accounts of successful interventions for children who are deaf-blind.

Support networks initially are dependent upon professionals to make their existence known to poten-

The most important benefit of family support group activities was hearing stories or receiving information on successful interventions that had helped children who are deaf-blind.

tially interested families. Due to concerns over confidentiality, families with children who are deaf-blind will usually not be known to the volunteer support network until the families initiate contact, usually with the mediation of professionals. The federally funded 307.11 deaf-blind intervention programs have a key role to play in mediating such contacts. To strengthen future research efforts by family support networks, collaborative agreements with 307.11 programs should be made so that a state's entire population of families with children who are deaf-blind can be included in such studies. Arrangements can be made that protect the confidentiality of families who are not participants in the support network, while still giving them an opportunity to respond to the survey.

This survey demonstrates that family support networks can take initiative in gathering useful information from their participating families. Support networks in other states can conduct their own surveys to discover family perceptions of the most desired or useful activities in their states.

Families of children who deaf-blind want information and support from their networks. As one parent commented, "Give me information. With information I can empower myself."

Acknowledgment: This research was supported by Parents Confronting Dual Sensory Impairment, Inc., and by a grant from the Interdisciplinary Human Development Institute at the University of Kentucky.

Table 1. Characteristics of the responding families: Numbers and Percent.

Variables	Values	n	%
Sex of Respondent	Female	43	81.1
	Male	10	18.9
Age of Respondent	<41	18	34.0
	41-50	26	49.0
	51+	9	17.0
Marital Status of Respondent	Single	11	20.8
	Married	42	79.2
Years of Schooling of Respondent	<12	9	17
	12	21	39.6
	13-16	14	26.4
	17+	9	17.0
1993 Total family income, before taxes	000	7	13.2
	10,000-20,000	15	28.3
	20,000-30,000	13	24.5
	30,000-40,000	6	11.3
	40,000+	9	17.0
	refused	3	5.7
Residential stability: "What do you think are the chances you will be living at this address five years from now?"	Very high	35	66.0
	Moderately high	7	13.2
	About even	6	11.3
	Moderately low	2	3.8
	Very low	3	5.7
Sex of child with DSI	Female	25	47.2
	Male	28	52.8

<i>Table 1 continued</i>	Variables	Values	n	%
Age of child with DSI		<6	5	13.2
		6-18	29	54.7
		19+	17	32.1
Interviewer's rating of respondent's understanding of the questions		Excellent	34	64.2
		Good	17	32.1
		Fair	1	1.9
		Poor	1	1.9
Interviewer's rating of respondent's interest in the survey		Very high	35	66.0
		Above average	13	24.5
		Average	5	9.4
		Below average	0	0.0
		Very low	0	0.0
Interviewer's perception of resistance in the respondent at any point in the survey		No	48	90.6
		Yes	5	9.4

Table 2. Relative importance of benefits of support network activities: means, Standard Deviations, and Percents.

Interviewer's Introduction: "You may know that there is a national effort to create support networks for families who have children with dual sensory impairment. I'm going to read several activities that a family support group might conduct. For each, tell me how important it is to you by saying whether it is...[1=] very important; ...[2=] somewhat important; ...[3=] slightly important, or; ...[4] not important at all. For example, how important to you is it for a family support network to provide you with. . ."

Benefit	Mean	Standard Deviation	% Very Important
. . . information on what has been successful helping children with dual sensory impairment	1.09	0.30	90.6
. . . referral to agencies which might be helpful	1.26	0.56	77.4
. . . friendship	1.30	0.54	73.6
. . . advocacy training and participation	1.34	0.48	66.5
. . . emotional support for your family	1.48	0.73	63.5
. . . training and support using computers	1.68	0.98	60.4
. . . social gatherings	1.75	0.85	47.1

Table 3. Perceptions of a statewide family support organization in Kentucky: Numbers and Percent.

Interviewer's Introduction: "You may also know that there is a newly-formed group in Kentucky called Parents Confronting Dual Sensory Impairment, or PCDSI, for short. PCDSI's mission is to provide information and support for families of children with dual sensory impairment."

Questions	Responses	n	%
Have you heard of PCDSI before?	Yes	37	69.8
	No	16	30.2
How did you hear about PCDSI? <i>(How did you hear about PCDSI?)</i>	Newsletter	10	17.8
	Family Forum	5	9.4
	Deaf-Blind intervention project	2	3.8

<i>Table 1 continued</i>	Questions	Responses	n	%
		Another parent/family	3	5.7
		Other	17	32.1
		Not asked	16	30.2
	Do you receive a newsletter from PCDSI?	Yes	7	13.2
		No	29	54.7
		Don't know	17	32.1
	How useful is the Newsletter? Would you say it is . . .	Very useful	10	18.9
	Only people who said they received the newsletter were asked this question. Due to interviewer error, one person who should have been asked was skipped.	Somewhat useful	11	20.8
		Only slightly useful	6	11.3
		Not useful at all	2	3.8
		Not asked	25	47.2
	How effective is PCDSI in providing support for your family? Would you say it is . . .	Very effective	10	18.9
		Somewhat effective	11	20.8
		Only slightly effective	8	15.1
		Not effective at all	7	13.2
		Don't know	1	1.9
		Not asked	16	30.2
	How helpful is PCDSI in supplying information for your family? Would you say it is . . .	Very helpful	12	22.6
		Somewhat helpful	14	26.4
		Only slightly helpful	2	3.8
		Not helpful at all	6	11.3
		Don't know	3	5.7
		Not asked	16	30.2
	How interested are you in future involvement in a support group like PCDSI? Would you say you are . . .	Very interested	27	50.1
		Somewhat interested	17	32.1
		Not very interested	4	7.5
		Not interested at all	3	5.7
		Don't know	1	1.9
		Refused	1	1.9

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An Introduction to the International Organizations and Literature Related to Deafblindness

Betsy L. McGinnity
Perkins DB-LINK

To reflect the international nature of this article, the author uses the language "deafblind" (unhyphenated)—ED.

DB-LINK represents the first attempt in the United States to apply a methodical and organized effort to unify and disseminate the body of information related to deafblindness (see sidebar on terminology). The information specialists at DB-LINK have responded to more than 1800 requests for information since July 1993. To respond to these questions, staff make use of the DB-LINK Catalog database to identify pertinent literature and materials. While most of this literature was generated in the United States, DB-LINK also has access to literature from other countries. In responding to requests, it became apparent that within certain topic areas, the impact of the international literature is significant, (e.g., Usher Syndrome [Sense, United Kingdom], objects of reference [Sint Michelsgestel, Netherlands], or the intervener model [United Kingdom and Canada]).

The perspectives represented in the international literature are sometimes very different from those of the United States. Accessing these materials afford the reader the opportunity to evaluate how cultural values, government, geography, economy, and population demographics can affect theory and practice. As an example, the U.S. literature related to quality of life is often replete with language referring to independence and self-sufficiency, while the Nordic literature related to quality of life discusses combating isolation and developing methods to help people connect with each other. A review of the literature also demonstrates how much we have in common.

The purpose of this article is to serve as an introduction to the international, primarily European, sources of information related to deafblindness that are available in English.

The literature to which DB-LINK has access is frequently developed by one of the many agencies and organizations that are connected to individuals who are deafblind. Many of these organizations publish materials in English. Most countries are now using the term "deafblind." The use of the single word rather than the hyphenated term was adopted at the world conference of International Association for the Education of Deafblind People (IAEDB) in Ordoro, Sweden in 1991. It was felt that the single word more

accurately represented the uniqueness and significance of "deafblindness" rather than the sum of deafness and blindness.

IAEDB was founded over 30 years ago to promote the education of deafblind children and young adults throughout the world. Membership includes representatives from 59 countries. IAEDB holds world conferences every four years and publishes their proceedings from these conferences in English. Recent world conferences were held in Poitiers, France in 1987 and in Orebro, Sweden in 1991. Topics addressed in the proceedings include quality of life, assessment, communication, Usher Syndrome, staff development and adventitious deafblindness. The 11th IAEDB World Conference, "Working and Growing Together," was held in July 1995 in Cordoba, Argentina.

The European Region of IAEDB also holds conferences within Europe. The most recent was held in Potsdam, Germany in 1993. The proceedings from this conference number over 500 pages and cover a wide array of topics, including "Cultural Differences in Early Intervention", "Access to Context—a Basic Need," and "Evaluation of the Social Relationships Between the Deafblind Person and Society."

IAEDB also publishes a newsletter, *Deafblind Education*, twice yearly. The newsletter's focus includes program description, and feature articles on subjects ranging from developing interpreter services in Europe to an examination of the neuropsychological aspects of communication and development. Articles are contributed by authors in both developing and developed countries.

Forty years ago a parent group was initiated in the United Kingdom by two young mothers, Peggy Freeman and Margaret Brock, whose correspondence began with their shared experience of raising babies who were deafblind as a result of maternal rubella. That parent group eventually became Sense, the National Deafblind and Rubella Association. Today, Sense has a staff of almost 1000, a main office in London, six regional centers throughout the U.K., three family centers, a family and respite center, and four special workshops and occupation centers. In addition to providing direct services to children and young adults who are deafblind and their families, Sense conducts staff training activities and sponsors conferences in the U.K. They also publish reports and proceedings from conferences and seminars held in the U.K. Sense publishes a quarterly magazine, *Talking Sense*. The magazine's regular format includes a news section focusing on government and commercial policy issues affecting people who are deafblind, program updates from throughout the U.K., feature articles on a wide array of topics, and membership news. Recent issues have featured articles about how a family adjusted to their son's diagnosis of Usher Syndrome, how to initiate mobility training with a student who is totally deafblind, and a two-part series on intervention.

Sense's Usher Syndrome Services and the British Deaf Association collaboratively sponsor the Usher in the Deaf Community Project. The objective of the project is to promote Usher Syndrome education/awareness among members of the British deaf sign language-using community. The project has created a range of information leaflets that explain Usher Syndrome and were designed specifically for deaf people. The materials include many illustrations and short verbal descriptions. Sense will hold a conference in October 1995 to report on their four-year project and to share materials used in the development of their outreach programs.

The World Blind Union has a Standing Committee on the Activities of Deafblind People. This group includes a large proportion of people who are deafblind and has a particular focus on rehabilitation issues. Proceedings were published from the 5th Helen Keller World Conference held in Osimo, Italy in 1993. The conference theme was "The Quality of Life of Deafblind People, Realities and Opportunities." Among the major topics that were addressed was an overview of organizations of the deafblind, with specific descriptions of the models utilized in France, Denmark, and the United States. Another highlighted issue was the situation in developing countries, with a special focus on India, Africa, and South America.

The Nordic Staff Training Centre (NUD) in Dronninglund, Denmark conducts staff training courses for the Nordic countries (Denmark, Norway, Sweden, and Finland) related to all aspects of deafblindness. They make a variety of their publications available in English. Denmark also has an information center for acquired deafblindness and an information center for congenital deafblindness, each of which provides, similar to DB-LINK, comprehensive information services.

The Canadian Deafblind & Rubella Association also sponsors conferences and publishes proceedings. The next conference, "Living and Learning: A Lifelong Adventure," is scheduled for May 8-11, 1996 at the University of British Columbia in Vancouver, BC, Canada.

ONCE, the Spanish National Organization for the Blind, has translated a number of books related to deafblindness into Spanish. They maintain a database that identifies literature available in Spanish about blindness and deafblindness. They help to make these materials available throughout Latin America.

In this information age, technology is available that allows individuals to have immediate access to information from all over the world. A lot of energy is being expended on the part of information providers to organize and make available information related to deafblindness via the Internet. As DB-LINK continues to organize its resources, it creates even greater opportunities for sharing and exchanging ideas. This profession will be influenced by the ever-expanding influx of ideas from other cultures and other coun-

tries. Ultimately, this may lead to better educational services and outcomes for children who are deafblind.

DB-LINK can assist you in accessing any of the materials mentioned.

DB-LINK voice: (800) 438-9376
 345 N. Monmouth Ave. TTY: (800) 854-7013
 Monmouth, OR 97361
 e-mail:leslieg@fsa.wosc.osshe.edu

Contact information for the organizations mentioned in this article

International Association for the Education of Deafblind People (IAEDB)

Individual membership is open to anyone and is without charge. An annual donation of \$20 is requested. Each country can have a representative on the Executive Committee for every 10 individual members. There is a maximum of three representatives per country.

Corporate membership is open to any school, association, society or any similar organization. There is an annual subscription of \$200. Each corporate member can have one representative on the Executive Committee.

All members will receive *Deafblind Education* and may vote at the World Conference.

IAEDB
 c/o Sense
 11-13 Clifton Terrace
 Finsbury Park
 London N4 3SR United Kingdom

Canadian Deafblind and Rubella Association
 747 Second Ave East, Suite 4 Tel: (519) 372-1333
 Owen Sound, ON N4K 2G9

Conference on Deafblindness
Canadian Deafblind and Rubella Association
 BC Chapter
 Box 140-5055 Joyce Street Tel/TTD: (604) 436-1882
 Vancouver, BC V5R 4G7 Fax: (604) 430-3415

Nordic Staff Training Centre (NUD)
 Slotsgade 8
 DK-9330 Dronninglund

Organizacion Nacional de Ciegos Calle del Prado (ONCE)
 C/ Quevedo, 1 Tel: 589 45 25-26
 28014 Madrid Spain Fax: 589 45 27

Sense
 11-13 Clifton Terrace Tel: 44 171 272 7774
 Finsbury Park Fax: 44 171 272 6012
 London N4 3SR
 United Kingdom

World Blind Union
Committee on the Activities of Deafblind Persons
 c/o Stig Ohlson, Chairperson
 Association of the Swedish Deaf-Blind
 S-122 88 Enskede, Sweden

In 1991, Salvatore Lagati of the Servizio di Consulenza Pedagogica in Trento, Italy began a crusade to get international acceptance of the single word "deafblind" in place of the hyphenated word "deaf-blind." His belief was that "deafblindness is a condition presenting other difficulties than those caused by deafness and blindness" (Lagati, 1993 p. 429). The hyphenated term indicates a condition that "sums up the difficulties of deafness and blindness." The single word would indicate a different, unique condition and that impact of dual losses is multiplicative rather than additive.

Lagati wrote and explained his proposal to 30 agencies throughout the world who work with people who are deafblind. He received very positive feedback from all of the people who responded. In Germany, Poland, Russia and the Nordic countries, the word "deafblind" has always been used without a hyphen. Representatives from other countries including the United States, France, Great Britain, India, Spain and Switzerland agreed that the change was desirable. Lagati presented this information at the IAEDB International Conference in Orebro, Sweden.

By 1993 both IAEDB and Sense had agreed to use the term "deafblind" in their publications. The Canadian Deafblind and Rubella Association also adopted the term. Lagati reported these results at the European Conference of IAEDB in Potsdam, Germany in 1993.

Salvatore Lagati wrote an article that appears in the most recent *Journal of Visual Impairment & Blindness, Special Issue on Deaf-Blindness*. He is now proposing that "the field should come to some agreement on the definition of the term" and then to "use the unhyphenated, one-word term in all publications." (Lagati, 1995, p.306).

This proposal faces an uncertain future in the United States. Terminology has been a hotly debated issue for some time in this country. Political correctness also seems to have greater influence in the US than in many other countries. Recent synonyms have included "dual sensory impaired," "auditorally and visually challenged," person "with deaf-blindness," etc. Editorial policy for *Deaf-Blind Perspectives* (Reiman, 1993) requires the use of the language "person who is deaf-blind." This usage seems to have general acceptance in the U.S. Perhaps, if Salvatore Lagati keeps up his crusade, "person who is deafblind" will have global acceptance in the future.

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38100 Trento, Italy

References

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- Reiman, J. (1993) Rationale for editorial policy on terminology. *Deaf-Blind Perspectives*, 1 (1), 2-4.

Additional Readings

5th Helen Keller World Conference, the Quality of deafblind people: realities and opportunities, Osimo, Italy September 25-30, 1993 / World Blind Union's Standing Committee on the Activities of Deaf-Blind People. 1993.

III. European Conference of the International Association for the Education of Deafblind People Equal and Exceptional. Potsdam (Germany) 31 July - 5 August 1993. Proceedings / International Association of the Education of Deafblind People. Potsdam, Germany: Oberlinhaus, 1993.

Second European conference, report 22-27, October 1988, England / European Commission on Activities for the Deaf-Blind. Peterborough, England: National Deaf-Blind League, 1989.

Summerscale, J. & Boothroyd, E. (1994) Proceedings of the U.K. Conference, Deafblind education: developing and sustaining appropriate provision, Birmingham, England.

Deafblind Education, The Journal of the International association for the education of Deafblind People.

Talking Sense, The Magazine of Sense, the National Deafblind and Rubella Association.

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

Personnel Preparation Past, Present and Future Perspectives

Barbara A. B. McLetchie
Boston College

The author acknowledges the contributions of Stephanie MacFarland and Marianne Riggio. For a complete listing of personnel preparation programs in deaf-blind education, contact DB-LINK.

The 1992 National Symposium on Children and Youth Who Are Deaf-Blind, sponsored by the Office of Special Education and Rehabilitation Services (OSERS) had as "a single goal—a brighter future for children and youth who are deaf-blind" (Reiman, 1993, opening remarks). The National Symposium culminated with several recommendations that would improve services to people who are deaf-blind throughout the country (Reiman & Johnson, 1993).

This article validates the need for continued and increased federal involvement in the preparation of teachers to educate students who are deaf-blind. Further, it discusses the progress made in three of the National Symposium recommendations related to teacher preparation in the field of deaf-blindness: a) the need for additional teachers, b) the need to develop teacher competencies unique to teaching learners who are deaf-blind, and c) the need for collaboration among university personnel, families, service providers and adults who are deaf-blind.

Federal Involvement

The issue of continued federal support in the field of deaf-blindness, including teacher preparation, may seem pale in comparison to the overall radical reductions and eradication of fiscal support the present Congress already has executed or proposes in numerous areas of human services. However, the need for continued federal commitment—with creative collaboration among service providers, families, and adults who are deaf-blind—is more crucial than ever in maintaining and providing basic and adequate educational services in this field.

Historical events over the last three decades clearly demonstrate the impact the federal government has had on teacher preparation in the field of deaf-blindness. In the 1960s, the Rubella epidemic created a national medical emergency that left more than 5000 children with combined vision and hearing losses and unique, complex educational needs. The needs of these children could not be met in traditional special education programs. To assist meeting the needs of this extremely low incidence population the federal government established several high quality university personnel preparation programs in deaf-blindness in the late 1960s and 1970s. Large

numbers of aspiring teachers and others who were uncertain of their future studies were encouraged to choose careers in deaf-blind education because of the availability of federal grants in this field. Additionally, the federal government funded 10 Deaf-Blind Regional Centers across the country. In the 1970s, the vast majority of learners who were deaf-blind were being educated in special schools. These schools developed strong collaborative links with the Deaf-Blind Regional Centers and university personnel preparation programs. This infusion of federal support, along with an increase in trained personnel, fostered new and innovative programs to assist children who were deaf-blind and their families: new assessment tools and curricula were developed, communication modes were adapted for learners who were deaf-blind and had other disabilities, and many parents became actively involved in educational interventions. The activities in the 1960s and 1970s allowed graduates of personnel preparation programs to feel confident about finding a job in the field of deaf-blindness.

In the 1980s, the federal government reorganized the funding structure within the Department of Education. This decreased federal involvement meant that fewer teacher preparation programs continued to receive funding. Consequently the number of personnel preparation programs in the area of deaf-blindness were reduced to a handful despite the fact that there continued to be a steady increase in the numbers of learners who were deaf-blind. The most recent census reports 9,783 infants, children, and youth who are deaf-blind (Baldwin, 1994)—twice the number reported after the Rubella epidemic.

Currently, nearly 80% of learners who are deaf-blind are being educated in local schools (Heumann, 1994-95). Moreover, the population is more widely dispersed than ever before, a trend that is likely to continue with the national move to educate learners who are disabled in their neighborhood schools (Collins, 1992). With this dispersion of the population graduates of personnel preparation programs in deaf-blindness find it increasingly difficult to find positions in the field of deaf-blindness. Typically, school districts with only one learner who is deaf-blind are not willing to pay for a teacher trained in deaf-blindness even though the child has unique educational needs that may not be met by a generic special education teacher.

In 1995, the supply of qualified teachers is "critically limited" (Heumann, 1994-95). As of the summer of 1995 there are only five university programs that are federally funded through the Division of Personnel Preparation, Low Incidence Disabilities. And states have not been able to meet the needs of personnel development in deaf-blindness through their Comprehensive System of Personnel Development (CSPD). Because the number of students who are deaf-blind in each state is extremely small in comparison to the number of students with other disabilities, the concern is that students who are deaf-blind are consid-

ered a low priority when providing appropriate services at state and local levels.

The unique needs of the relatively few students who are deaf-blind, dispersed in classrooms across the country, justify federal support. Without federal involvement the highly specialized services required to educate children who are deaf-blind are at high risk of becoming fragmented or nonexistent. The low priority that states assigned to personnel development in the deaf-blind field may soon become a more critical issue with the impending move by Congress to provide block grants to states that minimize federal involvement. In essence, events of the past and present show that even with federal support there are still too few teachers of students who are deaf-blind. To remove or reduce this support would be unconscionable.

Additional Teachers

Results of a national survey of state and multistate coordinators under Section 307.11 completed for the National Symposium in 1992, and a follow-up survey two years later, support Assistant Secretary Heumann's assertion that a severe shortage of qualified personnel exists in the field of deaf-blindness. In 1992, a national survey from 47 state and multistate coordinators revealed that only 6% or 224 of the 3668 teachers working with 6741 learners who were deaf-blind were trained in deaf-blind education at the university level (McLetchie, 1992). Results of a 1994 follow-up survey of 48 coordinators indicated only an estimated 6% or 347 of the 5445 teachers serving 9046 infants, children, and youth have had specific teacher preparation in deaf-blind education (McLetchie & MacFarland, 1995).

A major recommendation by the National Symposium, relating to personnel preparation, was the need for more teachers. This recommendation included the need for providing federal support to at least 10 university programs specializing in training teachers in deaf-blindness. Though some progress has been made in this area, it remains woefully short of the need. In 1992, four personnel preparation programs in deaf-blind teacher education were funded under OSERS, Division of Personnel Preparation. One other teacher education program was funded through a federal grant to a state. These programs along with three others funded through the Hilton/Perkins Program graduated a total of 18 teachers. Currently, five programs are funded under the Division of Personnel Preparation, Low Incidence Disabilities: one federal grant to a state, one program that receives no external funds, and three other programs partially funded through the Hilton/Perkins Program. Hilton/Perkins contributes to three of the programs that are federally funded and partially funds three other programs. These programs graduated 36 teachers in 1994. This two-fold increase in preparing more qualified personnel over 1992 levels demonstrates significant

progress in preparing more qualified personnel. However, the current picture is uncertain.

Given the present funding trends, it is highly questionable if the federally funded programs will survive beyond their present grant periods. And though The Hilton/Perkins Program has provided start-up support to some of these programs, it cannot support these programs to the extent necessary to meet the current needs. Maybe most disconcerting is that no specific Requests for Proposals to prepare teachers in deaf-blind education have been issued by OSERS, Division of Personnel Preparation since the National Symposium.

Teacher Competencies

Another major National Symposium recommendation related to personnel preparation was the need to establish national competencies in the deaf-blind teaching profession (McLetchie, 1992; Davidson, 1992). Competencies relate to the knowledge and skills teachers require to educate learners who are deaf-blind. For example, teachers need knowledge of the wide variety of communication modes used by learners who are deaf-blind (objects, tactile symbols, pictures, English and other visual/tactile sign systems, fingerspelling, large print or braille, etc.). Teachers need skills in using a variety of communication modes in order to adapt to each learner's preferred mode(s) of communication. Teacher competencies can help assure that students who are deaf-blind not only have access to education but that their education meets a prescribed level of quality. Competencies incorporated into personnel preparation courses and field experiences at the university level can provide a standard for certifying university programs or evaluating grant proposals. National competencies also can elevate teaching in the deaf-blind field to a higher level of professionalism and be a positive force for professional identity. Strong competencies can also serve as self-evaluation tools for teachers so they can be ongoing learners who pursue additional training opportunities to increase their knowledge and skills. In addition, the competencies will assist school administrators in making judgments regarding a teacher's current knowledge and skills and his or her future training needs.

Collaboration

In 1993, The Perkins National Deaf-Blind Training Project was funded by OSERS, Services for Children with Deaf-Blindness Program. The project provides a mechanism for national collaboration with a central focus upon teacher preparation. (The project's goals relate to the National Symposium recommendations discussed in this article: the need to train more teachers and the need to develop teacher competencies unique to deaf-blindness). Collaboration within this project occurs at many levels fostered by

the project steering committee, which includes representation from

- *Parent/family organizations*
National Family Association for Deaf-Blind (NFADB)
- *Adult and transition services*
Helen Keller National Center Technical Assistance Center (HKNC-TAC)
- *Deaf-blind consumer organizations*
American Association of the Deaf-Blind (AADB)
- *state and multistate coordinators of Section 307.11 programs*
Teaching Research Assistance to Children Experiencing Sensory Impairments (TRACES)
- OSERS
- The National Information Clearinghouse On Children Who Are Deaf-Blind (DB-LINK)
- University personnel preparation programs
- National Coalition on Deaf-Blindness.

The project collaborates with universities that have existing programs or faculty with expertise in deaf-blindness. The regions, university sites and faculty are:

- *Northeast Region*, Boston College (Dr. Barbara McLetchie) and Hunter College (Dr. Rosanne Silberman)
- *Southeast Region*, Florida State University (Dr. Pearl Tait)
- *North Central Region*, (Dr. Lou Alonso and Susan Bruce Marks)
- *South Central Region*, Texas Tech University (Dr. Roseanna Davidson)
- *Southwest Region*, San Diego State University (Dr. Kathee Christensen)
- *Northwest Region*, University of Washington (Dr. Norris Haring)

During the 3-year grant period (October 1993 - October 1996) the project provides two consecutive graduate level summer institutes in each of the six regional university sites. The grant provides funds for travel, tuition, room and board for two participants from each state and territory. The two selected topic areas, based upon results of national survey data from 307.11 Coordinators, practitioners, and families are: Strategies to Assist Learners Who are Deaf-Blind in Developing Communication Competence and, Strategies for Including Learners Who are Deaf-Blind in Regular Schools and Communities. Prior to each regional summer training institute, the university site coordinator for the region, 307.11 coordinators, representatives from TRACES, HKNC-TAC, and grant staff participate in regional

planning team meetings. Meetings focus on the selection of course content area (communication or inclusion), presenters, and logistics for the institutes. The 307.11 coordinators select participants to ensure that training meets the needs of each state. The 307.11 program, TRACES, and HKNC-TAC have collaborated with the project and have contributed valuable time and resources. These efforts include attending regional planning team meetings, funding additional participants to attend summer institutes, and contributing the time of their project staff to present at summer institutes.

Eight summer institutes were held in 1994 and 1995 and approximately 200 people enrolled. In 1994, the summer institutes on communication were held in the Northeast Region through Hunter College at the Helen Keller National Center, Sands Point, New York and in the South Central Region through Texas Tech University at its site in Junction, Texas. Approximately 50 people participated. In the summer of 1995, institutes on inclusion and communication were offered through Hunter College and Texas Tech University. Institutes on communication were held at the other four university sites—Michigan State University, San Diego State University, Florida State University, and University of Washington. Next summer, these four universities will provide training on including learners who are deaf-blind in their home schools and communities. The institutes are targeted to train teachers. However, parents, occupational and speech language therapists, vision specialists, interveners, and 307.11 state coordinators have participated.

Progress in developing competencies has occurred over the last two years. The Perkins National Deaf-Blind Training Project has begun to develop competencies in the deaf-blind teaching profession. A competency subcommittee of the National Consortium has developed a draft of the competencies that will be shared with the entire consortium for input in the early fall of 1995. By March of 1996, the competencies will be field tested nationally. The finalized competencies will be disseminated in September 1996, at the close of the grant period.

Progress in collaboration, in training more personnel, and in developing competencies unique to teaching learners who are deaf-blind has occurred since the 1992 National Symposium. Future progress in teacher preparation in the deaf-blind field is tenuous given the present political shift away from federal involvement. Therefore, collaboration among university personnel, service providers, families, and adults who are deaf-blind must continue and expand with creativity and energy—even more so if current federal grants expire. In the larger picture, the deaf-blind field must unite and advocate for quality educational opportunities. Education is a powerful tool that enhances the quality of lives of all people in our society and provides a “brighter future for children and youth who are deaf-blind.” (Reiman, 1992, Opening remarks).

New Local Deaf-blind Association Established

The Pennsylvania Society for the Advancement of the Deaf, Inc., Greater Harrisburg Chapter, is announcing the formation of the Central Pennsylvania Association for the Deaf-Blind (CPDAB)

CPDAB is in the developmental stages and interested parties should contact

Interpreter-Tutor

The **Interpreter-Tutor** is the second in the five-part *You & Me* series illustrating the education of a child who is deaf-blind, in the neighborhood school. This video focuses on the duties of the interpreter-tutor, the job qualifications, and the supports necessary for the success of this position in the educational setting. The video will be available from Teaching Research Publications in December, 1995.

Cost: \$15.00

To order, contact

Teaching Research Publications
345 N. Monmouth Ave.
Monmouth, OR 97361
Phone:(503) 838-8792
Fax:(503) 838-8150



Hand in Hand Materials now Available from American Foundation for the Blind

Huebner, K., Prickett, J., & Rafalowski-Welch, T. (1995). Hand in Hand: Essentials of communication and orientation and mobility for your students who are deaf-blind. New York: AFB Press.

This two-volume self-study text—with contributions from more than 30 nationally recognized experts in issues relating to persons who are deaf-blind—explains how students who are deaf-blind learn, and focuses on essential communication. Cost: \$60.00 + s/h

Huebner, K., Prickett, J., Rafalowski-Welch, T., & Jofee, E., Eds. (1995). Hand in Hand: It can be done. New York: AFB Press.

This one-hour video is an introduction to working with students who are deaf-blind. Accompanied by a discussion guide, the video can be used in its entirety or in sections, and is designed for use with parents, regular educators, and community members. Cost: \$49.95 + s/h

Huebner, K., Prickett, J., Rafalowski-Welch, T., & Jofee, E., Eds. (1995). Hand in Hand: Selected reprints and annotated bibliogra-

phy on working with students who are deaf-blind. New York: AFB Press.

This collection of 27 journal articles on the topics of communication, orientation and mobility, functional skills, implications of various etiologies, and instructional strategies and intervention issues is accompanied by a description of more than 160 important print and audiovisual resources and information on how to obtain them. Cost: \$ 29.95 + s/h

Prickett, J., Jofee, E., J., Rafalowski-Welch, T., & Huebner, K. (1995). Essentials of communication and orientation and mobility for your students who are deaf-blind—A trainer's manual. New York: AFB Press.

This inservice training guide gives structured information and guidelines for using the self-study materials with various audiences. Focusing on the needs of the trainer, it provides sample blueprints for workshops, as well as an overview of training, assessment, and evaluation. Cost: \$29.95 + s/h

For more information, contact

**AFB Press
11 Penn Plaza, Ste 300
New York, NY 10001
(212) 502-7652**

Calendar of Events

April 15, - May 26, 1996, Birmingham, United Kingdom. Professional Development Programme. This professional development program offers participants the opportunity to increase knowledge and skills in a specialist area relating to sensory impairment, visit and observe different specialist services throughout the U.K., discuss work and plans with professionals experienced in similar work, and produce a project related to their work at home with the support of specialists in the U.K.

Contact:
Professional Development Programme
Sense International
The Princess Royal Centre
4 Church Road
Edgbaston
Birmingham B15 3TD United Kingdom

June 19-23, 1996, Toronto, Canada. Reaching Out, the Canadian Conference of Deaf-Blind People. Conference program to be announced.

Contact:
Reaching Out Conference Committee
201-44 Stubbs Dr.
Willowdale, Ontario M2L 2R3 Canada
Ph (416) 225-4482
Fax: (416) 510-8071
E-mail: jascal@hookup.net

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