

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.