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Heidi's Inclusion in Junior High



Deaf-Blind Perspectives

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Table 1. Valued life outcomes

Valued Life Outcomes	
1.	Having a safe, stable home in which to live now and/or in the future
2.	Having access to a variety of places and engaging in meaningful activities
3.	Having a social network of personally meaningful relationships
4.	Having a level of personal choice and control that matches one's age
5.	Being safe and healthy

COACH is organized into three major parts. **Part 1** (Family Prioritization Interview) is used to identify family-selected priority learning outcomes for the student. **Part 2** (Defining the Educational rivaØ 1.0 6er intw ()w ()wJ75 16596 m 3 1

Heidi and Her Team

At the outset of Heidi's transition she was a 14-year-old student with significant vision and hearing impairments, the oldest of three children living with her parents, Jean and Dan Knutson, brother Jamie, sister Beth, cats, and goldfish in a small town in Vermont. For most of Heidi's life she had been a student in a regional, self-contained, special education class of six students, most of whom were labeled "severely and/or multiply disabled." This regional classroom was located over 20 miles from her home. Her mother (co-author) tells us more about Heidi:

When asked to describe Heidi, I thought it would be easy, but there is no one word that does that...
. Professionals say she is mentally retarded, deaf, visually impaired, and non-verbal due to TORCH Syndrome.
Her brother and sister lovingly call her 'high tech Heidi,' once she has on her cataract glasses, both hearing aids in and is hitched up to her FM unit. To her Dad and I she is a curly-haired teenager, persistent, happy, challenging, frustrating,

Educational Program Planning Pre-COACH Experiences

Though IEP planning was not new for Heidi's team, planning an IEP for an inclusive education program in a junior high was new. When asked about IEP planning *before* using COACH, Heidi's mother described attending meetings where she would be presented with a list of things that the special education teacher thought should be worked on. She would be asked if there was anything that should be added. As the mother said, "They would make up the IEP where I could add to or take from . . . they always welcomed what I had to say or what I really wanted for Heidi." As many parents do, Heidi's parents found themselves deferring to the professionals' selection of goals and went along with the plan presented to them. The resulting IEPs typically contained long lists of annual goals and short-term objectives, including several submitted independently by related service providers for motor and communication skills. This scenario, while typical and well-intentioned, did not provide the family with adequate input into the educational planning process and left the team with a large number of fragmented goals that had an unknown relationship to changes in valued life outcomes for Heidi.

Educational Program Planning Using COACH

Prior to using COACH, each of the core team members familiarized themselves with the COACH manual. They made sure that all team members were in agreement with COACH's basic assumptions and agreed to use it to plan Heidi's IEP with technical assistance and guidance provided by a member of the Vermont I-Team. The team's first use of the COACH was in September of her first year at the junior high school (eighth grade). During the Family Prioritization Interview (Part 1), valued life outcomes and family-selected priority learning outcomes were identified and subsequently restated as IEP goals and objectives. The team used Part 2 of COACH to identify additional learning outcomes and general supports to fill out Heidi's educational program. With Heidi's new IEP in hand, the team turned to the task of implementing the IEP in the context of a regular eighth grade day, including the development of instructional strategies and ad

3. Shares leisure activities with others
4. Summons others
5. Follows school routine
6. Maintains appropriate behavior
7. Makes requests
8. Participates in individual leisure activities

How is Heidi's Life Better?

Heidi's educational records document the progress and attainment of goals and objectives related to the eight priorities on her IEP. But the real question we want to ask is whether her life has been made any better. Is there an impact on the valued life outcomes selected at the outset of the COACH process? Has she grown in her personal relationships with peers? Does she have any greater independence that would match that of a 15-year-old? Is she able to go places and do meaningful things in her community? Interviews with Heidi's mother and special educator provide some of the answers:

- Previously a paraeducator or other adult went with Heidi into the community (e.g., grocery store, horseback riding); now she goes with friends her own age and the paraeducator is in the background.
- Other kids used to say "Oh, what's wrong with her?" Now kids know her and treat her as they do their other classmates.
- Ownership about finding ways to include Heidi

When asked about expectations for Heidi after graduation, Jean reflected on her past and current points of view.

Jean: I wasn't even thinking about a job. What could Heidi do? I felt bad thinking the worst, but I thought if she'd only learn that when she takes her coat off she should hang it up or to act appropriately depending on where she is.

Interviewer: Did you see her in some kind of special ed. day program?

Jean: Yeah. Maybe some peers would come into the classroom but not with her being in the minority like she is here.

Interviewer: How have your expectations changed? What direction are you headed now?

Jean: You know, working, supported work. I can see that.

When asked if she felt there was a relationship between Heidi's gains and successes to the team's use of COACH she replied: "Yeah, I think so because when we made that out it was con

Children Who Are Deaf-Blind: A “National Interest Requiring National Action”

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President Clinton, in his recent State of the Union reference to the role of the federal government in domestic policy, cited “national action in the national interest” as one way of defining federal responsibility. With full awareness of the impending extinction of OSEP’s heretofore concerted effort to serve children who are deaf-blind, I realized upon hearing this that we in the deaf-blind community (people who are deaf-blind, their families, and the professionals who serve them) are faced with a herculean task. WE must define and defend for the nation’s leaders—and in short order—how the currently mandated (IDEA - Section 622) and structured (Services for Children with Deaf-Blindness Program) federal program to children who are deaf-blind serves national interests. We must vigilantly await the soon-to-be disclosed details of how proposed executive and legislative changes will affect the federal deaf-blind services program. Then, equipped with what we know and feel, we must write and speak out to ensure the program’s integrity and vitality.

A raging bipartisan executive and legislative “reduce government” juggernaut threatens to erase 30 years of progress in the evolution of services to children who are deaf-blind and return us to the dark ages of state and local choice. As the plan appears to be unfolding, the choice as to whether and how to serve these children will basically fall to the states; this choice, if the past can instruct us, does no more than to marginalize hope for a bright future. We are assured by Department of Education (DOE) leaders that their basic commitment to children who are deaf-blind is intact and that a “base funding floor” exists in the foundation of the future to make good on this commitment. Assurances lead us to believe that DOE is devoted to these children’s (and their families’) learning and service needs. Recent rumblings from Washington, however, raise serious questions as to the

“...it is in our national interest to protect and enhance the lives of young citizens, who by virtue of not being able to see and hear, frequently experience isolation and require extraordinary support”

substance and integrity of such assurances. Will the plank consist of more than “lip-service,” simply suggesting to newly homogenized technical assistance centers and broad-scope researchers that they not forget these children? Will the \$12.8 million currently dedicated to children and youth (birth-21) who are deaf-blind, fall prey to the de-categorization frenzy that homogenizes cross-disability distinctions and service programming? Will the identity and unique needs of children who are deaf-blind be down played or lost? In fact, to be sure that the “base floor” has substance and winds-up as more than window dressing, we—the deaf-blind community—need to be heard. And, to repeat, what we need to articulate is how and why continuation of the Department’s dedicated program for our country’s 10,000 children who are deaf-blind is in the national interest.

First, although it may not play well in today’s political arena (where too many see disadvantage as self-inflicted), it is in our national interest to protect and enhance the lives of young citizens, who by virtue of not being able to see and hear, frequently experience isolation and require extraordinary support. It is in our national interest, as humans and as a people, to recognize and respond to one another’s human needs, not as a reflection of some noble altruism or paternalistic patronage, but simply because we care. Yet somehow, this caring threatens to become lost in our zeal to re-invent government. When we hear House Speaker Gingrich speak out against the recent excesses of federally funded “economic and social nannyism,” many of us reflexively resolve to rid our lives of

government. But for many children who are deaf-blind, to rid their lives of the federal government would be to rid their lives of the only identifiable and accountable resource with adequate means to make a real difference. Specifically, the federal government, through the U.S. Department of Education’s Services for Children with Deaf-Blindness Program, cares to the tune of \$12.8 million. Remove these dollars or float them into overall programming for children with disabilities, and active caring that is capable of making a difference in the life of a child who is deaf-blind will be replaced by the benign neglect characteristic of approaches of the early 1900s.



Cost-beneficial fiscal allocation constitutes a second national interest. Dollars appropriated by the Department of Education's presently concerted ef-



Let's Have an Institute

Cheryl R. Kennedy
University of Pittsburgh

Bruce A. Dalke
Western Oregon State College

One of the greatest challenges facing those who provide state and multistate services for children who are deaf-blind (34 CFR 307.11 grantees) is providing information and training to families and service providers about effective education practices. With increasing inclusion of children who are deaf-blind into community schools and other community-based activities, a growing number of individuals need information about the unique educational needs of these children and instructional technology to meet these needs.

With technical assistance to public and private agencies and organizations who serve children who are deaf-blind and their families as a primary mission, 307.11 Project personnel use a variety of methods to provide information to these groups. Since preservice (i.e., college/university course work) touches only a small percentage of the individuals in the service provider workforce, inservice training approaches are prevalent. Among these approaches, inservice training activities, usually identified as "institutes," are a popular choice.

The planning and conducting of an institute can sometimes be a frustrating experience. Substantial amounts of time, effort, and funds are often committed, only to find later that impact has been limited. The purpose of this article is to share various strategies and insights identified by TRACES and 307.11 Project personnel on how

Institute #1 - Summer Institute

Content: Overview of basic anatomy of the auditory and visual system, etiologies of hearing and vision loss, functional hearing and vision evaluations and implications for instruction.

Institute #2 - Winter Institute

Content: Overview of orientation and mobility strategies for individuals with deaf-blindness and implications for instruction.

Institute #3 - Spring Institute

Content: Overview of communication intervention for individuals with deaf-blindness and implications for instruction.

These institutes were offered in three different locations across the state to ensure statewide availability for participants. Several project personnel addressed this same issue of statewide availability through replication of the institute in various locations across a state.

Team Attendance

Some projects have found great success in promoting team attendance (e.g., two or more staff members from the same school building or district). Attendance at an institute typically involves only one person who then returns to attempt to incorporate new knowledge or implement new skills. Working merely from notes and materials, the individual, essentially, is working in isolation. It is no wonder limited implementation results. The teams, on the other hand, appear to have a much greater potential for implementing content information along with process strategies and, therefore, creating positive impact.

Follow-up Activities

Limited implementation of strategies and information by participants following their attendance at an institute may be due in part to "hit and run" style institutes. An example of a hit and run institute is (a) a presentation of strategies related to content without information on how to incorporate those strategies into existing instructional programs and school site structures, and (b) follow-up is not conducted to assist in the implementation of strategies presented during the institute. The expectation that participants can implement strategies upon return to their schools, agencies, or communities without additional support is faulty.

Without follow-up results vary from partial implementation to no implementation at all. This ongoing process provides participants the opportunity to plan with

- On-site consultation with a mini-inservice training session (i.e., a follow-up site visit by a consultant with feedback on the implementation of the action plan goals combined with a presentation to supplement content information presented during the institute)
- On-site consultation (i.e., a follow-up site visit by a consultant with feedback on the implementation of action plan goals)
- Videotape review consultation (i.e., follow-up technical assistance conducted through consultant review of a videotape provided by the participant. The consultant provides the participant with written feedback on the implementation of the action plan goals)

Application and Practice

The opportunity to learn through application, practice, and immediate feedback is another approach that produces implementation and impact. Conducting an institute that incorporates practice requires careful planning. The institute will need to coincide with the school year so an appropriate practice site will be available. Practice-based institutes often produce an unexpected benefit for the training site in the form of accommodating the needs of additional children and service providers due to the instruction available.

Action Plans

Finally, 307.11 project personnel agreed that the creation of a clearly contracted action plan by participants was an effective approach to ensuring post-institute implementation. An action plan provides information on (a) what knowledge and skills presented at the institute are planned for implementation, (b) the anticipated outcomes, (c) how the implementation is progressing, (d) who is involved in the implementation, and (e) how long it takes to be implemented. It was noted that action plans should be developed as an ongoing process during an institute. Action plans often require refinement and it is better to have this occur during the institute than as the concluding activity of the institute. This ongoing process provides participants the opportunity to plan with

other team members, to network with other participants attending the institute, to receive feedback from the presenter and other participants, to embed optimal types and times for follow-up technical assistance, and to plan a process for evaluation of progress. A clearly developed action plan will support the implementation of information presented during the institute.

Summary

In summary, we suggest that effective strategies include early articulation of goals, careful selection of planning committee members, attention to logistics, encouragement of team attendance, inclusion of follow-up activities, inclusion of opportunities for practice, and the formation of action plans. The foregoing is not an exhaustive list, nor have these strategies all been used at the same time. However, we submit that attention to them can result in an institute that is more likely to be successful.

TRACES (Teaching Research Assistance to Children Experiencing Sensory Impairments) is funded through Cooperative Agreement No. HO25C30001 by the U.S. Department of Special Education, OSERS, Special Education Programs. The opinions and policies expressed by TRACES do not necessarily reflect those of the U.S. Department of Education.

screening process and have goals related to Usher Syndrome embedded within their grant activities. At least one of the states that responded to the survey has a state-wide and systematic screening process.

Additional issues are being identified, including the awareness that many students with Usher Syndrome are often not included in a state's annual deaf-blind census. The group will explore this issue and others to identify strategies which will help ensure that needed services

TRACES Regional Reports

NORTHEAST AND NORTH CENTRAL REGIONS

States in the North Central and Northeast TRACES regions are participating in a planning process to address issues related to Usher Syndrome. A meeting scheduled for September, 1995, will address the development of effective screening practices within states. Dr. Sandra Davenport, personnel from deaf-blind projects, and families, and adults with Usher Syndrome will present at the September meeting. TRACES regional coordinators will work with states to develop action plans to strengthen screening processes. Long-term outcomes related to educational planning for students with Usher Syndrome will also be included in the planning process.

Preliminary survey results of 12 state and multistate projects indicate that students with Usher Syndrome are educated in a variety of settings, including regular classrooms, resource rooms, separate classrooms, separate schools, private schools, and public residential schools. Nine of the twelve state and multistate projects reported that there currently is no formal statewide process for identification of Usher Syndrome. However, many states are in the early stages of developing a



*in their home school, trained one district team, and has
four districts*

student transitioning from one school to another. In the new school the student would be in a program that required changing classes several times a day. The Oklahoma Deaf-Blind Project assisted with disability awareness training and facilitated problem-solving by classmates. Project staff followed-up with phone calls and visits. In addition, HKNC-TAC conducted training for staff on the philosophy and process of PFP and will facilitate a PFP meeting for the child at an appropriate future date. This collaborative effort has provided awareness and skill development training to a number of service providers while meeting a specific child's unique educational needs.

If you would like more information, please call

*Jan Watts
(405) 325-0441.*

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

DB-LINK Family Resource Directory

Available in late May 1995, the DB-LINK Family Resource Directory lists the services of eleven national organizations that serve as a resource for families of children who are deaf-blind. This directory was produced in cooperation with the National Family Association for Deaf-Blind. Included in the directory are agency summaries,

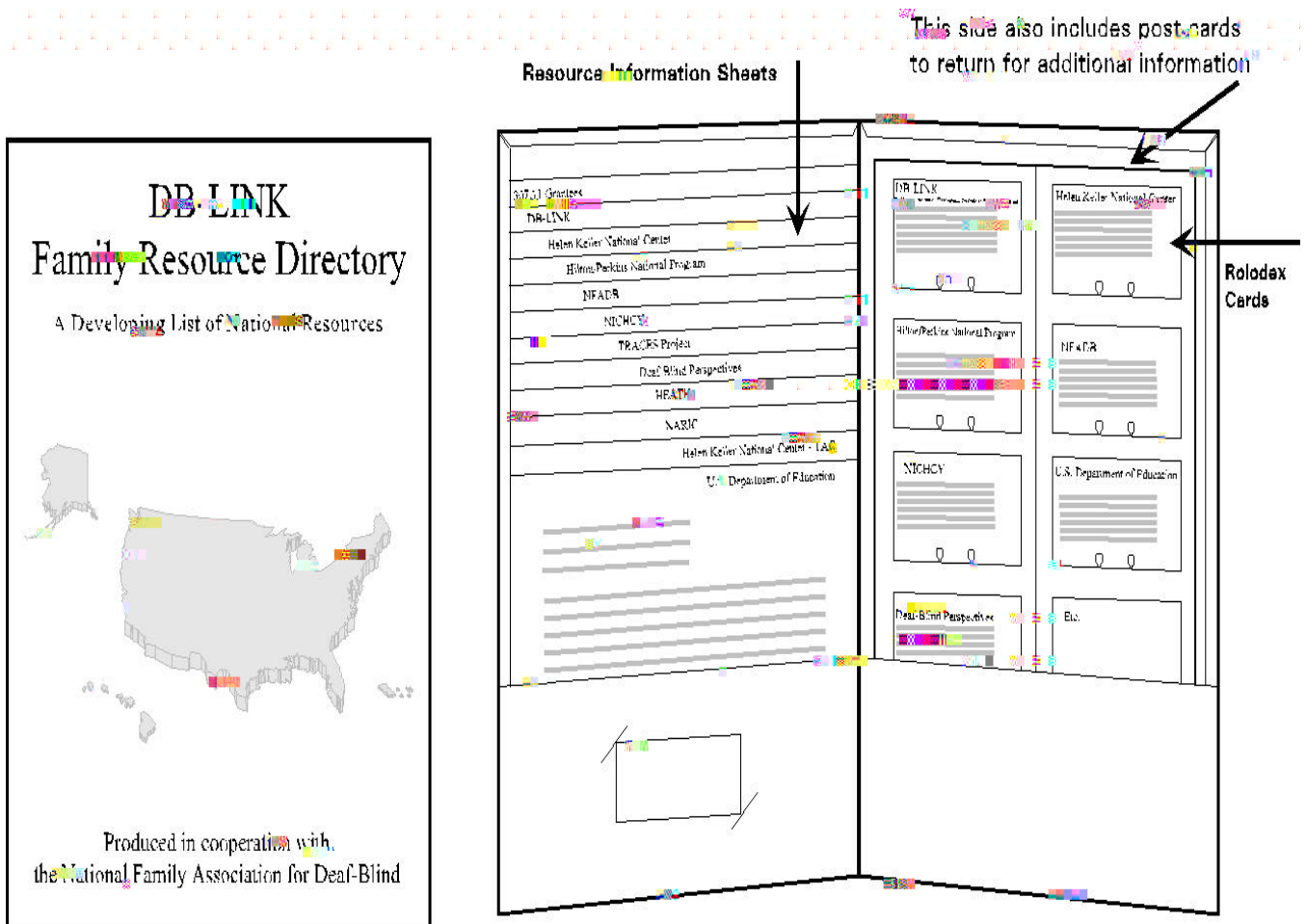
rolodex cards, and postcards to send for additional information.

To request your free directory:

Families, please contact

National Family Association for Deaf-Blind
111 Middle Neck Road
Sands Point, NY 11050-1299
(800) 255-0411
(516) 944-8637 TTY

All others, please contact



Helen Keller National Center Announces Deaf-Blind Awareness Week, June 24–July 1

When Heather Whitestone was crowned Miss America in 1995, she reminded us that nothing can prevent the realization of a dream. Inspired by Helen Keller, Miss America's message of "Face your obstacles, work hard, and build a support team" inspires all people, but is especially relevant for people who are deaf-blind...one of the most severe disabilities.

Please join the Helen Keller National Center along with other agencies and organizations worldwide, in celebrating the **1995 Helen Keller Deaf-Blind Awareness Campaign.**

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Conferences

Symposium on Deaf-Blindness: 1995 Austin, Texas June 23–24, 1995

Open to parents, professionals, and anyone interested in deaf-blindness. Topics include; unique educational and social needs, case study information, using the tactile sense, using low vision, using the auditory system, and deaf-blind services in the 1990's. Together, families and professionals will discuss and show videotaped examples of problems and solutions. Registration is \$10.00. The number of participants is limited to 225 with limited out of state availability.

For more information contact
Beth Sanchez
TSBVI Deaf-Blind Outreach
1100 West 45th Street
Austin, TX 78756
(512) 454-8631

Lilli Nielsen National Conference Novi, Michigan June 19–23, 1995

The Blind Children's Fund will host a National Conference For Active Learning: Turning Latent Potential into Dynamic Ability for Infant, Preschool and Multi-Impaired Blind and Visually Impaired Children with noted Danish educator Dr. Lilli Nielsen. This one week course will present Dr. Nielsen's Active Learning Approach. Original and creative new techniques and materials will be introduced for effectively providing learning environments for blind, visually impaired, and multi-impaired children.

For more information contact
Blind Children's Fund
2875 Northwind Drive Ste 211
East Lansing, MI 48826-5040
(517) 333-1725



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