Issues and Concerns Related to Inclusive Education for Students Who Are Deaf--Blind

Findings Task Force of a Model Demonstration Project

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A national task force of individuals involved in a variety of settings with students who are deaf--blind was created as part of a model demonstration project. Its purpose was to examine inclusive educational practices for students who are deaf--blind. The project, Full Inclusion Programs for Students Who Are Deaf--Blind Model Demonstration Project (OSERS Grant #H025D30013, Lori Goetz, Principal Investigator) combined input from project personnel working at sites in California that serve deaf--blind students in inclusive programs. with that of the Task Force. This article presents the activities, responsibilities, and findings of the Task Force. In particular, it focuses on issues specific t oprograms serving students who are deaf--blind.

Background and Special Features of the Task Force

The Task Force was composed of 13 members, in addition to project staff: Two parents of deaf--blind students, three directors of national research projects, four directors of 307.11 projects (including state projects), two representatives of national technical assistance projects for programs serving individuals who are deaf--blind, one consultant in deaf--blindness, and one representative from an IHE (Institution of Higher Education). The roles of some Task Force members overlapped several of these categories. Its members met twice annually since 1994, gathering each time in San Francisco with key project staff.

Most often, the national components a demonstration project are either programs included in the project's network of sites, or the representation from the project's advisory committee. The work of this Task Force differed from these two entities in that it was broader than that of a particular demonstration site, and it included more direct involvement than an advisory committee. The Full Inclusion Project's proposal delineated the charge of its Task Force as "to address the inclusion of deaf--blind students in fully inclusive programs... to pursue specific content problem areas and potential solutions, as well as to analyze effective practices." (Goetz, 1993, p. 11). The design of the proposal specifically focused the work of the Task Force on addressing, from a national perspective, the barriers to successful inclusive programs for students who are deaf--blind.

From the first meeting it was evident that Task Force members and project personnel were committed to and energized by working together. The group's first order of business was explicitly defining inclusive programs as fully inclusive programs (cf. Sailor, 1991). The Project's proposal specified programs in which students who are deaf--blind "are full--time members of age--appropriate, regular classrooms in their home schools, and receive any supports necessary to accomplish participation in both the learning and social communities of their peers" (p. 2). As case studies unfolded, however, it became evident that not all case study situations reflected full inclusion defined in this way. More implicit, but very strongly held by

Task Force members and project personnel, was the understanding that "successful" inclusive programs for students who are deaf--blind ensured that they are "…not only served, but well--served, in programs which protect their unique service needs while supporting full membership in the life of the school" (Goetz, 1993, p 4). Accomplishments of full inclusion programs would be considered in relation to these **dual** outcomes of academic achievement and social participation for deaf--blind students.

The Task Force was fortunate to include among its members three directors of current research and demonstration projects on the study and support of social relationships of individuals who are deaf--blind. At some of the earliest Task Force meetings, these three directors shared insights and initial findings of their own project work (R. Horner, Research on Social Relationships for Children and Youth with Deaf--Blindness, #HO25R20002; H. Mar, Social Relationships of Children and Adolescents with Deaf--Blindness, HO#25R20004; N. Haring/L. Romer, Lifestyle Planning and Enhancement Project, HO#25D30001). Each emphasized different and essential dimensions of relationships and their development: reciprocity, creating social opportunities, and peer training (including both the training of student peers and the use of adults who are deaf--blind as "peer" instructors). These presentations added depth and breadth for further understanding a target outcome of social participation.

Work of the Task Force

From the start, Task Force members agreed that case study presentations were to be central to their meetings. The studies would form the basis of group discussions of issues and concerns re-

Research to Practice
A Focus on Inclusion

Parents and teachers of children and adolescents who are deaf--blind frequently have questions about inclusive education programs. Several typical questions were presented to Dr. Lori Goetz , Director of the recently completed project, *Full Inclusion Program for Students with Deaf--Blindness*

(Q) As a parent of a school--age child who is deaf--blind, I have fought for years to get the special services and programs my child now receives, like an intervenor, a teacher who can sign, a vision consultant, and special equipment. Would my child lose these services if she attends a regular class in the public school?

The answer is NO. Placement in a regular class does not, and SHOULD not, mean a loss of services. Our experience has shown us that when an effective and collaborative teaming process is in place for all of the specialized service pro-

lated to inclusion, and documentation of the studies would be ultimately the foundation of several of the final products. Together, project staff and Task Force members outlined several key points to guide the development of the case studies. This group also shared tasks of designing and refining questionnaires to collect information about the following topics: (a) the related services available to students (e.g. interpreters, O&M services); (b) the presence of inclusion indicators reflecting best practice; (c) student characteristics; (d) site demographics; and (e) family history related to inclusion. Each of these questionnaires was completed by a team that included the student's parent, inclusion support teacher, and Task Force member. This data was analyzed to provide a data-based "snapshot" of the students, school programs, and families who participated in the case studies. It is discussed in detail in a separate document (Solo, 1996).

Project staff and Task Force members established a schedule for the presentation of individual case studies with each Task Force meeting including two or three reports. As planned, the presentations provided the forum for the Task Force to carry out its charge. Discussions held an important added benefit, serving as a kind of technical assistance consultation for specific students. The exchanges of the group sometimes became informal problem-solving sessions addressing difficulties students and/or their families and/or their instructors were experiencing. The project staff and Task Force members could carry back to students' teams the suggestions and possible solutions generated by this rather uniquely qualified group.

Issues

A number of issues emerged from the evaluation of ase study reports, some common to inclusive programs in general and others specific to those serving students who are deaf-blind. Issues frequently encountered in the development of inclusive programs in general involved the following:

- The need for a primary support teacher (i.e., someone who takes the lead in the inclusion process for an individual student (Stainback & Stainback, 1990a).

- The need for ongoing, broad-based training of program staff and students on strategies to facilitate effective inclusion of the focus student (Stainback, Stainback, & Forest, 1989).

- The need for integrated services (Rainforth, York, & Macdonald, 1992).

- The need for parental involvement (Strully, Buswell, New, Strully, & Schaffner, 1992), and

- The need to develop students' sense of belonging in their school communities (Stainback & Stainback, 1990b).

Several of the above issues appear to be amplified by the complexities of deaf-blindness (cf. Haring & Romer, 1995).

The case studies also identified issues not ordinarily cited as obstacles to inclusive programs. Since these issues may be of special interest to educators in the field of deaf-blindness, details follow.

viders, and when there is an inclusion support teacher to coordinate and integrate specialized services with the regular ed. curriculum, students don't lose any of the services/equipment that they and their families have fought for, and the learning outcomes for students are just as good as (if not better than) learning that happens in more self-contained settings.

(Q) Are some children who are deaf-blind more likely to succeed than others in an inclusive education program?

Our project has had experience with all different ages and ability levels that are represented in the "deaf-blind" population. We've worked with a preschooler who has multiple support needs in terms of motor, cognitive, and communicative functioning, and a junior high school student who

participates at grade level in the core curriculum. I don't think it's a matter of the "type" of student, but instead it's a matter of having the necessary supports and services integrated into the regular ed. program.

(Q) What resources (e.g., videotapes, articles) do you recommend that would help parents and teachers learn more about inclusive schooling?

Harvey -- there are really so many that this becomes impossible. If pressed, I can provide a list of references/resources. I'm sending you hard copies of two checklists from the Univ. of Minnesota UAP that I think are excellent consumer-friendly examples.

(Q) I'm a math teacher in a junior high school. Next semester, I will have a 13 year old student who is deaf-blind and cognitively disabled in one of my classes. I need help, but where do I start? How do I make abstract math concepts meaningful for the student? How

The Need for Additional Instructional Time

The most basic guidelines for the instruction of students who are deaf--blind emphasize the importance of allowing for added time (Gee, 1994; Welch & Cloninger, 1995). An exchange of information involving an individual who is deaf--blind simply takes more time. Several of the case studies underscored this point. This need existed both during school hours and after.

Several studies reported that academically capable students who are deaf--blind faced a variety of obstacles related to school work. As students progressed to middle school and high school levels, in particular, it was increasingly difficult for them to keep abreast of the volume and pace of academic content. When students who are deaf--blind chose to follow the standard general education curriculum and ultimately earn a general education diploma, rather than pursue an altered curriculum and a special education diploma, the options for lessening workloads narrowed.

Reports noted that keeping up academically with peers can place added stress on a deaf--blind student. Students who have dual sensory impairments expend considerable effort in classes to receive and interpret auditory and/or visual information. This is very fatiguing for students (Prickett, 1995). There were also numerous descriptions of conditions which could contribute to sensory overload for students who are deaf--blind, such as the complex sensory demands of routine transitions between high school classes which are simply taken for granted by students without disabilities.

Many of the options available to keep up academically with peers were unappealing to students or conflicted with some of the desired social benefits of inclusion. The options included a) eliminating elective subjects that might be of special interest to a student in order to allow for additional study time; b) increasing "pull out" time for tutoring and concentrated study; and c) extending the school year through the summer months. Such "solutions" essentially risked isolating or segregating a student. Several graduation alternatives included extending high school education through age 21 (although the student would not graduate with peers) and leaving high school without a diploma to complete a GED later. Again, these alternatives presented significant disadvantages and conflicted with general goals.

Several case studies noted homework in relation to the issue of added time. As would be expected, the hours involved in the completion of homework expanded also, due to the complexities deaf--blindness presents for receiving and conveying information. Added to this is the expansion of the volume of homework as a student's grade level increases. Accounts of students who are academically at grade level and who are also deaf--blind detailed the stress the students and their parents experienced with students' homework assignments. The students, already fatigued by their need to focus attention and concentrate during the school day, were finding the extension of such efforts exhausting. Some parents felt compelled to take on a role of teacher or tutor for their children at home; one case reported that parents were essentially re--teaching material at home. In addition, the pace of classes was

can I attend to this one student when I have a class of 24 teenagers?

Curriculum adaptations are essential here. Whether it's a matter of providing the written lesson information in braille, or a matter of deciding that while the deaf--blind student will not master algebra rules, he may participate meaningfully through distributing materials to each class member throughout the lesson, through use of a rotating peer partner who will work with the student to complete modified activities, such as tactile scanning to compare lengths, that have been specifically prepared by an inclusion support teacher who knows the student and his IEP goals and objectives.

(Q) How do you get other kids to communicate and interact with the student who is deaf--blind in an inclusive school? What are some of the more effective strategies to promote social relationships?

There are lots of strategies a team can use. We've done a bunch of research and think at least three things are really helpful:

1. Providing information about the student through class activities like signing clubs, circles of friends, and ability awareness lessons;

2. Providing interactive communication media through computer adaptations, games, and media that support kids in interacting with each other, and

3. Teacher facilitation through jumping into a shared activity when help is needed, and then backing off to let students interact directly with each other to solve a problem or to have fun.

(Q) If I am interested in having my child in a full inclusion program, who should I talk to and what are

such that the student missed important information, even with the advantage of a skilled interpreter.

Technological supports did not seem to eliminate the complications of or overcome the challenges of information exchange for students who are deaf--blind. In fact, Task Force members noted hove instruction in the use of alternate media and devices made further demands on students' class time.

Use of Interpreter--Tutors or Intervenors

Discussions of the use of and/or need for interpreter--tutor or intervener services by students who are deaf--blind were common to many of the case studies. This was not surprising, as this is frequently a key topic in education of individuals who are deaf--blind, regardless of students' placements (Ford & Fredericks, 1995). Studies echoed current concerns of the field, particularly the lack of definitive job descriptions and job qualifications for roles that extended beyond that of a certified interpreter. Reports exemplified the inconsistencies that exist from state to state and even, in some cases, from district to district within the same state. Other concerns included finding individuals to fill such positions, and the types and amount of assistance that these individuals should provide students and rapid turnover of staff which was disrutive to a student's program.

Discussions of the Task Force focused on the balance of appropriate responsibilities for both teachers and interpreter--tutors or interveners. In inclusive settings the position of interpretor--tutor or intervenor held added importance and presented additional challenges when the individual was a student's key communication partner in the school program. The relationship between the interpreter--tutor or intervener and the student, as well as the student's family, in some cases surpassed a working relationship. The roles of teachers, interpreter--tutor or intervenor, and advocates are easily blurred.

Developing Social Supports and Friendships

The case study reports, as well as reports from the research projects, addressed the issues of students who are deaf--blind truly belonging within their school communities, building social relationships and networks through school activities, and fostering friendships through school. Some reports noted the establishment of peer--based social support networks in individual schools. At several sites, regular meetings of "peer buddies" (Alwell & Gee, 1994) were organized to provide opportunities for students who are deaf--blind to meet other students and develop friends. Groups at some sites focused on sensitizing and familiarizing peers with aspects of deaf--blindness. They also presented strategies for bringing about direct interactions with students who are deaf--blind. Group discussions sometimes evolved to address concerns of students in general, but still considered the added impact of deaf--blindness.

Other groups focused on activities that attracted students simply because the activities **themselves** were fun or appealing. Also, the activities selected were purposefully accessible, recurring, and those which the individual with disabilities (deaf--blindness) enjoyed and was good at (cf. R. Horner, 1996). Frequently, personnel

some of the first steps I might take?

I think it's always a good strategy to be networked with other parents who have their children in inclusive programs, especially at the local level. Visiting these programs in your own district is one way to get information about what is possible and working. Other resources include a state TASH (The Association for Persons with Severe Handicaps) chapter, or your state 307.11 (Deaf Blind Services) project in order to put you in touch with a network of successful parents and teachers who are implementing, or trying to implement, inclusive education.

(Q) What other materials or resources will your project have available for teachers and parents?

We have a couple of manuals that I think could be very helpful:

1. Inclusive Instructional Design: Facilitating Informed And Active Learning For Individuals Who Are Deaf--Blind in Inclusive Schools, by Kathy Gee, Morgen Alwell, Nan Graham, and Lori Goetz (1994). This manual reflects six years of project activity focusing on including deaf--blind students. It can be ordered through the California Research Institute at San Francisco State University, 612 Font Blvd., San Francisco, CA 94132. Cost: $15.00.

2. As of June, 1997, we will also have a manual of case studies available that tells the stories of a range of students who are deaf--blind as they've become general class members. It is titled Including Deafblind Students: Report from a National Task Force, L. Goetz, Editor. The cost is to be determined; it will also be available from the California Research Institute at the address listed above.

from special research, demonstration, or system change projects initiated the development of the various peer groups within schools.

Several case study reports noted that specific schools had adopted the general philosophy, "**All** students belong." At such sites, the development of social networks for students who are deaf--blind appeared to be easier, since involvement and participation in school activities were basic expectations.

Fundamental to belonging is mutual respect. Case study reports provided accounts of how the efforts, talents, and needs of students who are deaf--blind were respected by their peers. One report described how a student w ho is deaf--blind, though very social and active in his class activities, would usually eat by himself, seated away from others in the school cafeteria. Initially, his educational team, consultants, and concerned peers wanted to "problem solve" this situation in which the student seemed excluded. Later discussions recognized that the student chose to eat alone; his preference based, perhaps, on a desire or need to take a break from the efforts involved in the exchange of information --— a simple desire not to converse. (Task Force members, in their own discussion, speculated that the environment also may have contained too much ambient noise or other distractions for easy communication.) Most important, whatever the reason, the student's individual choice was respected.

Reports from the social relatinships research projects directed Task Force discussions to the reciprocal nature of true friendships. Several accounts of personal observations of interactions between general education students and those who are deaf--blind, and both formal and informal interviews or discussions with regular education students, affirmed this "dimension" of their relationships. Some regular education students felt they shared a friendship with their peer who is deaf--blind, and received at least as much as they contributed to the relationship.

Communication

As one would expect in almost any project involving students who are deaf--blind, communication issues and concerns were woven throughout the case study reports and research work. Reports indicated that several students primarily utilized interpreters, interpreter--tutors, or interveners for most communication needs. While recognizing that the provision and easy access to such services were vital for students who are deaf--blind, Task Force members expressed concern that, if the support person were a student's only direct communication partner, an inclusive setting could still be very isolating. Task Force members seemed to agree that communication support personnel in school programs had dual key functions: the clear provi-sion of information and the facilitation of direct communication with instructors and peers. Case study reports described a variety of other strategies employed, where appropriate, to support more direct communication, including (a) on--site sign language instruction for staff members and students, (b) use of FM systems and other amplification devices, (c) informal instructions in the use of individual communication systems and devices, and (d) awareness activities related to deaf--blindness and non-symbolic communication modes.

The concerns of the Task Force members for the communication needs of students who are deaf--blind extended beyond the basic necessity of supporting direct communication partners. In the project's Inclusion Indicators Questionnaire, Task Force members were directed to collect information on whether a "student receives planned assistance to facilitate social network building with peers who provide a linguistic community." This item reflected the Task Force's recognition of students' needs for natural language models and access to deaf--blind culture.

Summary

The case study reports by Task Force members have provided a series of "snapshots" of how programs throughout the country have approached and addressed inclusion of students who are deaf--blind from the varying perspectives of the different individuals who authored these case study reports. The salient issues and barriers discussed here, and their potential solutions, are offered in the hope that when all the reports are synthesized and made available through the project manual (Goetz, 1997), readers will feel supported in their own efforts to include students who are deaf--blind in regular education programs. In addition it is hoped that they will glean strategies that will directly benefit their students.

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THE LONGEST DAY OF THE YEAR

Lisa Manfuso

For as long as I can remember my father talked of retiring. He even had the days, hours, and finally minutes timed for the last five years of his "career" on an assembly line at General Motors. He would get up every morning, look himself in the mirror, and tick another day off the old calendar he kept in the bathroom. He was 52 years old when he retired. A very ac-

tive, young, athletic, 52--year old man The jubilation of retiring, with no specific time to get up, no lunch to be made for work, no workmates, eventually got to the better of him. He began to putter with his cars, and with his boat. My dad owns a 22' day sailor that he uses out on the Chesapeake Bay. He learned how to sail recently, in the last ten years, navigating his small boat on the sometimes choppy Chesapeake.

The moving of June 20th dawned early. I awoke to the keening of my deaf/blind son Mark. We started our days early, waking before the sun. The earliness never bothered me and I enjoyed the quiet of the morning with Mark. He was just finished school, and was enjoying some time off between school and the beginning of summer school. I noticed that the calendar indicated that this morning was the first day of summer. Judging by the weather forecast, I would say that summer had arrived just on time. The forecast was to be sunny, hot and humid, as Maryland summers are infamous for. I thought of taking the kids to the pool, so that we be cool when the phone rang. It was my father.

There is something that I must interject before we go any farther with this story. You see, my father was uncomfortable taking the children out on his boat. He was afraid that they would fall overboard, or something like that, and that somehow he would be responsible. Especially for a child like Mark, who had no sense of fear of the water, and when put in unfamiliar surroundings became

quite upset. We spoke about the first day of summer, and Dad reminded me that it was also the longest day of the year. I asked him what he was going to do with his day, and he commented the same answer, "Putter with the boat", as he had all week. I grinned, the mental image of my father at the marina, working on his already meticulous boat. "Want a crew?", I asked, imaging the wind in my face. Expecting him to balk, or say no, surprisingly he said, "Sure, when can you be ready?".

As I got Mark and his younger sister, Kristen ready to go for a day cruise, I became apprehensive. We had never done that before. Kristen did understand the rules of the boat, she had spent a whole week out on this small boat with her grandparents, but Mark? How was I to handle him? Would he even keep a life jacket on? Would he become upset, and overwhelmed at the sensation? As apprehensive as I was, I am most definitely sure that my father was more so. He had seen Mark keening, and overstimulated. At that time, Mark was head--to--head with me, and physically just as strong. I became very nervous as we arrived at the marina. As we approached the boat, Mark tried to walk off the pier, unknowingly of

course, but scary enough to keep my nerves on edge. He was not on familiar ground, and made his body very stiff, an most unmovable. It took my father and I to maneuver him into the boat and down below to the cabin. I put his life vest on, he took it off. I put it back on, he took it back off. Dad was above trying to hoist off from the pier, end needed my help. Kristen clamoring for attention was singing a song, trying to amuse the anxious adults.

Motoring out away from the docks, I saw the worried expression on my fathers face as Mark's keening increased. In the middle of the channel he set sail, and the wind kicked up the sails. Soon after the gentle rocking of the boat seemed to relax Mark, and the soulful keening stopped. He was sitting on the bottom of the boat, between the kitchen table and the sofa in the small cabin. Thefaster that the boat sailed, the more relaxed he became, allowing me to put his life vest on. Soon, we heard giggling from the cabin as the sensation of the water careened us as the wind kicked up, catching the sails moving us as quickly as if we were made of paper.

Alter a half an hour passed, my father and I relaxed. Out in the Bay, we felt the wind kiss our cheeks. The white puffy clouds hanging like cotton in the sapphire sky. The salt water spray splashed at our cheeks softly. The smell of the sun, and the canvas sails, and the bay air all mixed together for a soothing but exhilarating tonic. Mark was giggling so hard down below that he was rolling on the floor. My father and I looked at my children, his grandchildren in wonder. After, a short while, I wanted Mark up in the cockpit with us. So he could also enjoy the air. As I pulled him, up I noticed Dad becoming anxious again, but he said nothing, as he assisted in retrieving the giggling Mark.

Sitting in the cockpit, at first Mark stopped giggling. He had also stopped laughing, looking as apprehensive as I felt. The wind died down, and the boat came to a halt. Mark, began to vocalize his anxiousness. The wind puffed gently at the sails again, and we were off once again. Mark's face split into a big grin The wind picked up whipping into our faces with a frenzy. The sails puffed and strained with the exertion of the tension. The mast groaned as we picked up speed. I was helping to trim the sails, Mark sitting close to me giggling and tightening his body with excitement. He seemed to say with his body 'Faster, Faster', laughing as we went. The day progressed and we sailed for hours. We set sail for a small island where my father set anchor and we started to have lunch. Mark wanted no part of it. He kept moving his body, taking my hand and pulling me, as if he wanted to go. Not communicating with tactile signing or fingerspelling, we determined that he was not yet fin-

ished sailing, and was becoming increasingly frustrated. In a good humor, my father picked him up and threw him into the Bay. He quieted down quickly, laughing as swimming is his favorite activity in the world. Soon, we all joined him, laughing at the marvelousness day, and the treasure that Mask had bestowed upon us. Sailing back to the marina was a quieter sail, for it was late in the afternoon and the wind had died. It was fortunate for us that the gentle breezes and lulling rocking of the boat, the summer warm sun, and a full belly made Mark very sleepy. He relaxed and sighed contently, making my father comment that he also would like to take a nap.

We pulled up to the docks, Mark and Kristen both asleep down below. My father quietly trimming the sails so that we could maneuver in to his slip at the marina. It had been a wonderful day, one that none of us will forget. Mark likes to sail now. Always anxious at first, until he remembers his friends; the wind, water, and of course --—the sails.

(This story was written two years ago. Mark is now 15 years old, has become a great companion on the boat, and still finds his friends the wind, and water. My father still has the boat, and is still retired.)

Usher Syndrome Family Weekend

Madeline W. Appell, Paul M. Molloy, Ilene Miner, and Jerry Petroff

A family weekend conference for children and youth in New York and New Jersey who have Usher Syndrome was held February 14--17 at the Woodcliff Lake Hilton in Woodcliff Lake, New Jersey. Forty children, teenagers and young adults came with their families for a series of lectures, seminars, and discussions about the challenges of progressive dual sensory impairment. Professionals from a variety of disciplines and adults with Usher Syndrome were also invited. A number of young adults with Usher Syndrome who attend college or are employed came to share their experiences with the younger participants and serve as lecturers, role models, and confidants.

Sessions were held on a variety of topics, facilitated by individuals with expertise in each field. Highlights from some of these sessions are listed below.

Communication and Information

Mary Ann O'Neil, and John Reiman, Ph.D.

A major goal of this conference was to help parents establish communication with their children, other parents, and professionals and to give them an opportunity to meet and talk with adults with Usher Syndrome. Formal communication sessions, facilitated by Mary Ann O'Neil, provided a forum for parents and professionals to discuss communication barriers and for parents to begin plans to network with one another. Informal discussions continued long after the formal sessions, and plans for continued networking had been initiated by the end of the weekend. Participants also learned how to find information to learn more about Usher Syndrome and issues related to deaf--blindness.

Medical Issues

Sandra Davenport, M.D. and John Mascia

The complex genetics of Usher Syndrome were explained with the use of remarkable models created by Dr. Sandra Davenport. Families and individuals with Usher Syndrome could visualize inheritance patterns by handling models of chromosomes, genes, and DNA, the building blocks of inheritance. Dr. Davenport also simulated the visual field and hearing loss of each child and youth for family members by using special eyeglasses and plugs to block hearing. John Mascia talked about cochlear implants.

Orientation and Mobility

Joe Cioffi

Participants openly shared their feelings and experiences about using a cane and about their mobility instructors and teachers. Many of the feelings were negative, but some participants shared positive experiences. Two teenagers stated that their self--esteem had increased since they started using canes because they are now able to protect themselves and maintain their independence.

Access to Services

A. Landi, I. Popkin, D. Steele, and P. Lago--Avery

A panel comprised of individuals representing state agencies that provide rehabilitation training for individuals who are deaf--blind described how to access services. In addition, a representative from the National Technical Institute for the Deaf, Patty Lago--Avery, who has Usher syndrome herself, talked about educational options, entry into college, and programs and services available to individuals who are deaf--blind.

Psychosocial Issues

Ilene Miner, CSW

This session allowed parents to share feelings, fears, and aspirations. They had the opportunity to talk openly with two young adults with Usher Syndrome and ask them about their lives, their struggles and how they cope with day--to--day uncertainties about their lives and their vision.

Peer Discussion Groups

P. Molloy, J. Nuccio, J. Boardman, and P. Lago--Avery

Discussion groups, conducted in American Sign Language with voice translation for those whose primary receptive avenue is hearing, were co--led by adults who have Usher Syndrome. This was the first time that many participants saw someone like themselves in a leadership position. Issues that emerged during these groups related to self--esteem, fears about the future, fears about loss of independence, and concerns about parents.

The organizers gained a number of insights as a result of this weekend conference and a previous one held in 1995. These insights are summarized below.

Medical issues are complex. Presentation of these issues should be both formal and informal with time allowed for private discussions. Repetition of information is also important. Most individuals with Usher Syndrome and their families do not grasp all the implications of the disorder the first, or even the second time, they hear it.

A conference or retreat that focuses on self-- empowerment begins with network building among consumers, their families, and professionals. Time should be scheduled for discussion of communication and attitudinal barriers that destroy trust.

It is important to talk openly about concerns related to Usher Syndrome. Many people feel that talking about depressing issues will have a negative effect upon those who have the syndrome and their families, but the opposite is true. Teens and young adults at the conference benefited from the opportunity to talk about their lives and to share fears and concerns that they won't be able to succeed or take care of themselves. Uncertainty about the future and vision loss were discussed openly with older adults who have Usher Syndrome who are coping with this uncertainty and exerting control over their lives. It became clear that individuals with Usher Syndrome need each other.

Equipment Fair

Julie Anderson and Jim Bellanich from The Helen Keller National Center demonstrated new adaptive equipment for people who are deaf--blind.

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Madeline W. Appell, Paul M. Molloy and Ilene D. Miner are associated with the New York State 307.11 Project. Jerry Petroff is with the New Jersey 307.11 Project.
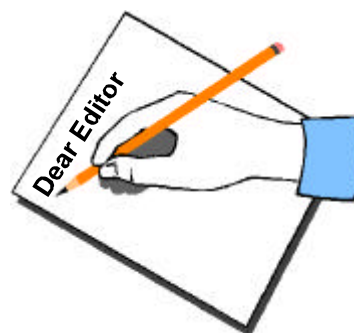
Letters to the Editor

Syndromes, Behavior, … Winter 1996--97

Dear Editor,

I have been receiving this publication for about a year and wanted to let you know how much I enjoy it.

I work at a hospital that provides long--term care for children with multiple handicaps and medical needs. I began my job there as a special education teacher in the summer of 1994 fresh out of colllege with NO experience with "kids like these." Honestly, few people have had experience with kids like mine. I instantly fell in love with the kids and their challenges and am constantly searching for new information. We have kids with very rare genetic disorders as well as kids who have been the victims of accidents and abuse.

Your most recent issue with the article "Syndromes, Behavior, and Educational Intervention" (Van Dijk & Nelson) was very infomative without getting lost in jargon.

Please continue to provide such good articles and I will continue to share your publications with my co oworkers and my kids' parents.

Thank you,
Kimberly Hall

———————————

Deaf--Blind or Deafblind, or, …Winter 1996--97

Dear Editor

I cannot express it better than those experts did. The German association of parents of deafblind children (those with a vision less than 2% as blind is defined by German laws) decided to call it "TAUBBLIND" (http://selbsthilfe.seiten.de/taubblin.htm) without a hyphen. We applied the European Communities Deafblind Secretariat in April 1994 to rename as follows: European Deafblind Network (EDbN). As EDN was already used we decided unanimously for the "small b" to accurately express what we feel.

It's always a pleasure to receive new ideas and recommendations by the Perspectives. To publish via WWW is really a gift for all those outside the centres of the field research of deafblindness.

Thanks and regards,
Wolf--D. Trenner
Vice chair of FG Taubblinde e.V.
-- Bundeselternvertretung Deutschland

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Dear Editor

It seems to me that we are losing our perspective. Instead of focusing on the <u>individual who happens to be dual sensory impaired</u>, is our point of convergence labels and semantics?

It seems to me that we are losing our perspective. Instead of focusing on the individual who happens to be dual sensory impaired, is our point of convergence labels and semantics?

In the great scheme of things, our numbers (persons who are deaf--blind, parents, siblings, professionals, significant others) are few in the movement to further the important and necessary causes of people who are deaf--blind. (You know the drill.) Why are we now challenged to become involved in a divisive exercise such as "to be or not to be"? What is the questions?

I have noticed that some of the folks who are proclaiming the word deafblindness as more appropriate, have yet to adopt `people first language' n their dialogue. Please…let us not get caught up in wordsmithing, but instead, let us place our collective focus on persons and how we can assist them to become and maintain themselves as happy, productive, and satisfied human beings.

Sincerely,
Patricia J. McCallum

Mother of Jon (A person who happens to be deaf--blind)

————————————

Dear Editor,

Yes, I do agree with you about dropping the hyphen from the disability category "deaf--blind" There are good reasons to consider this change. You think that people that are deaf and blind should be called "deafblind" and not deaf--blind, So in your mind the word deaf--blind is not correct. I said that it's good sound to me so I want to put my organization name "Central Pennsylvania Association of the Deafblind." That's nice.

Thank you,
Zenola Tyson
President, CPADB

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For Your Library

Basic Skills for Community Living : A Curriculum for Students with Visual Impairments and Multiple Disabilities

Levack, Nancy (Ed.); Hauser, Susan (Ed.); Newton, Lauren (Ed.); Stephenson, Pat (Ed.) / TSBVI. 1996/1997 edition. Austin, TX: Texas School for the Blind and Visually Impaired, 1996/1997. Length: xviii, 278pp + appendices

Details a curriculum created for students aged 6 to 22 who have visual impairments combined with other disabilities such as hearing impairment and significant developmental delays. Topics include assessment, community--based instruction, functional activities and developmental skills, developing an IEP, transition planning, teaching strategies, domestic activities, career education, recreation, communication, calendars, social skills and behavior management. Appendices include assessment and planning forms. Order from: Texas School for the Blind and Visually Impaired.

The Education of Dual Sensory Impaired Children: Recognizing and Developing Ability

Etheridge, David (Ed.) London: David Fulton Publishers, 1995. Length: xviii, 129

Deals with the education of dual sensory impaired children (impairments were either present at birth or acquired early) from birth to age fourteen. Topics include assessment, curriculum, communication, sensory stimulation, and the importance of the family. Order from: Sense.

Effective Practices in Early Intervention: Infants Whose Multiple Disabilities Include Both Vision & Hearing Loss

Chen, Deborah (Ed.) Northridge: California State University, 1997. Length: 294pp + blank forms

Presents information developed as a result of a project at California State University, Northridge (the Model Demonstration Early Intervention Network serving Infants who are Deaf--Blind and their Families). Topics include program development, early intervention teams and collaboration, identification of infants who are deaf--blind, vision and hearing assessment and intervention, gross motor development in infants with multiple disabilities, medical interventions, beginning communication, and transition to preschool. Four videos were also developed as part of this project: "Vision Tests for Infants," "What Can Baby See?," "What Can Baby Hear?," and "Making the Most of Early Communication." For information about ordering the manual, contact Deborah Chen at the Department of Special Education, California State University, Northridge, 18111 Nordhoff St., Northridge, CA 91330--8265, (818) 677--4604. Three of the videos are available from AFB Press. "What Can Baby Hear?" is available from Paul H. Brookes Pub.

Improving Access for Deaf--blind People

Berg, Robert. Deaf--Blind Service Center. Seattle, WA: Deaf--Blind Service Center, 1995. Length: 17.30 mins.

A video intended for hearing and sighted people who work in recreational facilities, such as zoos and museums. It explains how to provide service and improve access to facilities for deaf--blind consumers. Order from: Deaf--Blind Service Center, WAT Alliance, Seattle, WA, (206) 323--9178.

Including Students with Severe and Multiple Disabilities in Typical Classrooms: Practical Strategies for Teachers

Downing, June E. Baltimore: Paul H. Brookes Publishing Company, 1996. Length: xiii, 196

Presents strategies for educating students with severe sensory and multiple impairments in public schools. The appendices include resources for providing technical assistance for teachers and information about augmentative communication systems.

Low Vision: a Resource Guide with Adaptations for Students with Visual Impairments

Levack, Nancy; Stone, Gretchen; Bishop, Virginia. 2nd ed., 2nd printing. Austin, TX: Texas School for the Blind and Visually Impaired, TSBVI, 1996. Length: xii, 264pp

A comprehensive guide to low vision for teachers, service providers, and parents with up--to--date medical, optical, and technical information. Contains information on functional vision evaluations, media assessments, assess-ments for distinguishing between learning and visual disabilities, and guidelines for planning and implementating programming that will enhance students' visual functioning. Also included is information on computer access and other electronic approaches to solve the challenges of low vision. Order from: Texas School for the Blind and Visually Impaired.

New Language of Toys: Teaching Communication Skills to Children with Special Needs

Schwartz, Sue; Miller, Joan E. Heller. Bethesda: Woodbine House, 1996. Length: v, 290

Shows parents how to use toys and other play activities to aid a child's language development. Includes children through age six. Order from: Woodbine House, Inc., 6510 Bells Mill Road, Bethesda, MD 20817, or by calling (800) 843--7323.

Planning Today--creating Tomorrow: Guide to Transition

Steveley, Janet D.; Houghton, Joan; Goehl, Karen S.; Bailey, Brent R. Bloomington: Blumberg Center for Interdisciplinary Studies in Special Education, 1996. Length: iii, 52

A booklet containing information designed for individuals involved in transition planning for persons with deaf--blindness including those with other disabilities. Discusses components of transition planning, resource information, and transition terms and definitions. Order from: Indiana Deaf--Blind Services Project, Blumberg Center, School of Education 502, Indiana State University, Terre Haute, IN 47809.

Positive Behavioral Support: Including People with Difficult Behavior in the Community

Koegel, Lynn Kern (Ed.); Koegel, Robert L. (Ed.); Dunlap, Glen (Ed.) Baltimore, MD: Paul H. Brookes, 1996. Length: xvi, 510pp

Positive behavioral support is used to help people develop adaptive, socially desirable behaviors and overcome patterns of destructive and stigmatizing responding. It is typically used for people with developmental, cognitive, or emotional/behavioral disabilities, but can have more general applications. This book details case studies, research--based strategies, and discussions by various authors in the field of behavioral intervention. Geared towards behavior analysts, speech--language pathologists, educators, and child development professionals. Recommends strategies for reducing and preventing challenging behavior, encouraging family involvement, enhancing educational experiences, and expanding opportunities for social interaction.

Project Craft: Culturally Responsive and Family Focused Training

Chen, Deborah, Ph.D.; Brekken, Linda, Ph.D.; Chan, Sam, Ph.D. Baltimore, MD: Paul H. Brookes Publishing, 1997. Length: 60 mins.

This instructional video and its accompanying "Facilitator Guide" offer early interventionists an introduction to working with culturally diverse families. Promotes understanding of stereotypes and the media, cultural diversity, family values, relationship building, communication styles, and language acquisition. Families of children with disabilities from various cultural backgrounds and the professionals who work with them share their experiences and advice.

Reach out and Teach: Meeting the Training Needs of Parents of Visually and Multiply Handicapped Young Children

Ferrell, Kay Alicyn. / American Federation for the Blind. 4th Printing. New York: AFB Press, 1996. Length: 257

Designed to give parents guidance in raising and educating their visually and multiply handicapped children from infancy to young adulthood. It is meant to be used in conjunction with the Reach Out and Teach Reachbook. Practical information is supplied on diverse topics, such as: how teachers teach, finding help, family issues, fine and gross motor development, daily living and communication, sensory and cognitive development, school years and beyond. The Reachbook is a workbook that provides tools to assess and record a child's development and to document parenting and teaching strategies and information gathered by parents from various sources.

A Sensory Curriculum for Very Special People: a Practical Approach to Curriculum Planning

Longhorn, Flo. London: Souvenir Press, 1995. Length: 242pp (Human Horizons Series)

Outlines a curriculum for each of the senses, using stimuli which can be varied to suit the age of the student. Designed to help teachers working with children with profound multiple handicaps combined with sensory and physical impairment. Suggests ways to integrate the sensory curriculum into a whole school program. Order from: Sense.

Student Portfolio: a System for Documenting the Strengths, Needs, and Abilities of Students Who Are Deaf Blind

Kansas Services for Children and Youth with Dual Sensory Impairments. Topeka, KS: Kansas State Board of Education, 1996.

A student portfolio is a collection of work, videotapes, interviews and other items documenting a student's abilities. It is used primarily with students with dual sensory losses. The purpose is to share information about an individual who is moving from one setting to another and can be used as an assessment tool within the education or transition planning process. This report includes a variety of forms to be used in the creation of a portfolio. Subjects include demographic data, preferred learning styles, MAPS summaries, student preferences, background maps, communication and educational summaries, and residential and vocational histories.

Tangible Symbol Systems

Rowland, Charity, Ph.D.; Schweigert, Philip D., M. Ed. / Oregon Health Sciences University -- Portland Projects. Rev. ed. Portland: White Horse Studios, 1996.

A new version of the original video, "Tangible Symbol Systems," which was first produced in 1990. It illustrates communication options for a broad range of individuals of all ages who are unable to communicate through speech or manual signs. The instructional process involved in implementation of a tangible symbol communication system is illustrated. Parents and teachers are interviewed and case studies of 5 children over various periods from 4 months to five years are followed. The children shown are variously: deaf--blind, deaf, developmentally delayed, orthopedically impaired, and developmentally delayed with impaired vision. The video is accompanied by a manual. Based on Jan van Dijk's work with deaf--blind children, the techniques are also suitable for individuals of all ages with cognitive and/or severe communication deficits due to other disabilities. Can be ordered from Communication Skill Builders, 555 Academic Ct., San Antonio, TX 78204--2498, (800) 228--0752.

Teaching Students with Visual and Multiple Impairments: A Resource Guide

Smith, Millie; Levack, Nancy. / TSBVI. Austin: Texas School for the Blind and Visually Impaired, 1996. Length: xxii, 524pp

A resource guide for teachers of students with visual and multiple impairments. Topics include: best teaching practices, special needs of students with visual and multiple impairments, biobehavioral state management for students with profound impairments, and screening of infants and toddlers. A section on students with deafblindness and multiple impairments includes information on meeting this population's needs, screening, assessment, and communication strategies. Assessment tools and sample forms for planning an IEP are appended.

Videotape Protocol for Developing a Student Resume: Employment Skills and Work History

Wiley, David. / TSVBI Deafblind Outreach. 1996. Length: 3pp (SEE/HEAR, vol. 1, #3, Summer 1996, pp.14--16)

Students with deafblindness or who have visual impairments and other disabilities can use videotape resumes and profiles to show prospective employers and employment advocates a picture of the students' abilities and

preferences by illustrating activities, routines, strategies for instruction and support, job activities and work--related skills. A device for planning and making a video-tape is included.

When Hearing Loss and Retinitis Pigmentosa Happen Together: Meeting Educational Needs

Pennsylvania Department of Education, Bureau of Special Education, Instructional Support System of Pennsylvania; Distance Learning Center. Gibsonia, PA: Distance Learning Center, 1996. Length: 157 min.

A video aimed at teachers of deaf students. It begins with a good overview of Usher syndrome. Presenters talk about ways to check for Usher in the school environment and what to do if one suspects a student may have Usher. Teaching suggestions are offered. Funding sources, possible service providers, and support groups are discussed. A sign language interpreter signs throughout the video. May be ordered for $12.00 from Allegheny Intermediate Unit, Distance Learning Center, 5347 William Flynn Highway, Route 8, Gibsonia, PA 15044--96044.

Competencies for Teachers of Learners Who Are Deafblind

McLetchie, Barbara, A. B.; Riggio, Marianne. / Perkins National Deaf--Blind Training Project. Watertown, MA: Perkins National Deaf--Blind Training Project, 1997. Length: 17pp

Teachers of deafblind children and youth, must have specialized competencies in order to meet the complex and unique needs of their students. Areas and knowledge delineated here are the outcome of a collaborative process involving university faculty and 307.11 project directors and are intended as a blueprint for personnel preparation programs in deafblindness. Areas of competencies discussed: general knowledge about deafblindness; personal identity, relationships and self esteem; concept development; communication; hearing--vision; orientation and mobility; environment and materials; and professional issues. A copy in large print is available.

I'm Moving on: This Book Will Help Me as I Move on into my Community

Trujillo, Toni (Ed.); Tavarez, Trudy (Ed.); Rubald, Tim (Ed.); Roach, Wanda (Project Coordinator) / New Mexico Deaf--Blind Services Transition Project. Santa Fe, NM: New Mexico Deaf--Blind Services, 1996. Length: 51pp

A manual designed as a personal record book or portfolio for dual sensory impaired individuals who are transitioning into community life. Included are forms to document the individual's mode of communication, favorite persons and places, medical and health issues, and prized possessions by photographs and/or video. With this manual, individuals in transition can inform new acquaintances and staff about his or her life experiences and needs. It is in-tended to be used in conjunction with "Moving On, Helping Individuals with Deaf--Blindness Move Successfully into the Community: A Manual for Transition Planners." Order from: New Mexico Deaf--Blind Services, 1060 Cerrillos Rd., Santa Fe, NM 87503, (505) 827--6707 for $20.00 plus $5.00 shipping. The companion manual for transition planners is available separately.

Ordering sources:

Paul H. Brookes Publishing, Co., P.O. Box 10624, Baltimore, MD 21285--0624

Texas School for the Blind and Visualy Impaired, 1100 W. 45th St., Austin, TX 78756--3494, (800) 638--3775

AFB Press, Eleven Penn Plaza, New York, NY 10001, (800) 232--5463

Sense, 11--13 Clifton Terrace, London N4 3SR, England, (0171) 272--6012

July 10-11, 1997

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Charity Rowland, Ph.D. & Philip Schweigert, M.Ed.

*Oregon Health Sciences University
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This image announced National Helen Keller Week.

1997 National Conference on Deafblindness

The Individual in a Changing Society
June 6-9, 1997
Washington Hilton and Towers
Washington, D.C.

This conference will focus on the needs and rights of people who are deafblind and how these needs and rights will be affected by a changing society. The conference will address a wide array of issues confronting infants, school-age children, and adults who are deafblind, their families and the professionals who serve them.

For more information, contact

The Hilton/Perkins Program
175 North Beacon Street
Watertown, MA 02172
Ph. 617.972.7228
Fax 617.923.8076

No registrations will be accepted after May 31.
No on-site registrations will be permitted.
Late registration fees apply after April 6.

Sponsored by The Hilton/Perkins Program

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