

Deaf-Blind Perspectives

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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 to programs 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.

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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-

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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 case 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 how 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 intervenor 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 disruptive to a student's program.

Discussions of the Task Force focused on the balance of appropriate responsibilities for both teachers and interpreter--tutors or intervenors. In inclusive settings the position of interpreter--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 intervenor 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.



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