

The Nature of the Social Experiences of Students with Deaf-Blindness Who Are Educated in Inclusive Settings

Silvia M. Correa-Torres

Abstract: This qualitative case study investigated the nature of social experiences and opportunities for communication among students who are deaf-blind, their sighted peers with no hearing loss, and adults in inclusive settings. Strategies used by adults to promote interaction were also observed. Implications and suggestions for future research are provided.

The education of individuals who are deaf-blind has gradually changed from medically driven, institution-based services to the most recent models that include “mainstreaming” and inclusion in general education settings. The Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 (P.L. 108-446) serves as a statement of national policy in the United States to guarantee all students with disabilities a free and appropriate public education. Under the least-restrictive-environment (LRE) stipulation of IDEIA 2004, public agencies must ensure that students with disabilities are educated with students without disabilities to the maximum possible extent.

A growing body of empirical data in the field of special education reflects a fervent interest in the social competencies of and opportunities for students with

multiple disabilities, including those with deaf-blindness, to communicate and interact socially with their nondisabled peers and with adults in general education settings (Downing & Peckham-Hardin, 2007; Hunt, Soto, Maier, Liboiron, & Bae, 2004). Although there are benefits and positive outcomes of inclusion, to provide children with multiple disabilities, including those who are deaf-blind, with the same opportunities for communication and socialization as their nondisabled peers, it is necessary to provide “substantive changes in the structure of the classroom, a different conceptualization of professional roles, and a continuous need for collaboration teaming” (Hunt, Soto, Maier, & Doering, 2003, p. 316). Researchers have also found that students with multiple disabilities are more likely to be closer to and to depend more on teachers for communication and are not likely to initiate interactions as often as their nondisabled peers; it seems that inclusion is successful when an intervention or modification model is

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implemented (Mar & Sall, 1995), as well as when members of the educational team are trained and willing to work with these students.

The number of students who are deaf-blind who are included in general education classrooms and attend school in general education settings is constantly increasing. The *24th Annual Report to Congress on the Implementation of IDEA* (U.S. Department of Education, 2002) indicated that in the United States, 1,320 students with deaf-blindness, aged 6–21, had received special education services during the 2000–01 school year. This report on the implementation of IDEA provided information on the number of children with disabilities in the school system for 2000–01 and information about the educational placements of these students from 1991 to 2000. Of all the students with deaf-blindness who received special education services under IDEA during the 1999–2000 school year, 39% received such services in general education settings less than 40% of the time, about 10% were served in general education settings 40%–79% of the time, and 15% were served in general education settings 79% of the time or more. “Overall, students with disabilities continue to be served in less restrictive environments, although variation in placement by age, race [or] ethnicity, and disability continues to occur” (U.S. Department of Education, 2002, p. III-47).

Deaf-blindness and inclusion

As is explained in the 2004 amendment to IDEA, deaf-blindness is a condition in which a combination of a visual impairment and a hearing impairment causes a severe communication need

and other developmental and learning problems for a person. Because of these particular needs, the person with deaf-blindness cannot be educated in specialized educational programs that are intended exclusively for students with visual impairments, hearing impairments, or severe impairments.

Inclusion for students with disabilities means that *all* students in a school, regardless of their strengths or weaknesses in any area, need to become part of the classroom and school community. Turnbull, Turnbull, Shank, and Smith (2004) described the difference between inclusion and mainstreaming by stating that students who are part of a mainstream setting attend special education classes most of the time and are integrated in some nonacademic, general education classes for part of the day, whereas the goal of inclusion is to integrate students with disabilities into the same classes as their nondisabled peers at *all times*. “Full inclusion” for a student with deaf-blindness means that the student attends a general education class with nondisabled peers in the school that he or she would go to if he or she did not have a disability. It should be noted that the adaptations and accommodations for students with deaf-blindness are different from the ones that are generally used for students whose only or primary disability is blindness or deafness.

Although students who are deaf-blind may be fully included in school settings, social interaction or communication opportunities are not guaranteed; one cannot expect that inclusion, by itself, will increase social interaction. Communication is one of the major challenges faced by people who are

deaf-blind, who have limited access to important social cues (such as facial expressions and body language), as well as to the goings-on of family members and friends. Students who are deaf-blind may be excluded from many informal social interactions "in which friendships and social networks are built and maintained" (Mar & Sall, 1995, p. 280); they face many unique challenges in building and keeping relationships with others, but especially with their peers. Therefore, the purpose of this study was to determine the nature of the social experiences of students with deaf-blindness, their sighted peers with no hearing impairments, and adults in inclusive settings. Through the use of interviews, observations, and examination of artifacts, the following questions were addressed:

1. What is the nature of the social experiences of students who are deaf-blind in inclusive settings?
2. What strategies do adults use to increase and facilitate the social experiences of students who are deaf-blind in inclusive settings?

Methodology

PROCEDURES

The procedures used in the study were approved by the Institutional Review Board of the University of Northern Colorado, as well as by all the school districts in which data were collected. The participants in this qualitative study were three students with deaf-blindness, one parent of each student, and the teachers and paraprofessionals or interveners who worked with the students. The partici-

pants were identified by teachers of students with visual impairments and the consultant and coordinator of the deaf-blind projects in Colorado and in Utah. In a letter, the teachers of students with visual impairments were told about the study and were asked to nominate students for possible participation in the study and to inform the students of their nomination. When the teachers nominated a student, a study packet containing a consent form for the parents, a contact information sheet, and a demographic information form were sent to them. Interested families returned all three forms. Once permission was granted by all the participants and school districts in each case-study area, observations and interviews with the parents and the teachers were scheduled.

PARTICIPANTS

Students and their parents

The students for the study presented here were chosen deliberately because they were deemed the most likely candidates to offer valuable information that could not be gathered in as much detail from other possible participants. The criteria for their selection included the presence of a combination of visual and hearing disabilities that were determined by medical or educational authorities to affect learning, a chronological age ranging from 5 to 17 years, and enrollment in an inclusive educational setting with same-age nondisabled peers. Specific information was gathered on each student from the school's records, the demographic information form, and feedback from the parents and teachers.

The students with deaf-blindness who participated in this study, Mark, Emily,

Table 1
Demographic characteristics of the students.

Demographic characteristic	Emily	Mark	Eric
Age	9	7	7
Grade	4	1	K/1
Gender	Female	Male	Male
Condition	Deaf, blind, and cerebral palsy, multiple disabilities	Dual-sensory disabilities and cerebral palsy, multiple disabilities	Wolf Hirschhorne syndrome (4P), multiple disabilities
Hearing loss	Profound	Mild to moderate	Mild to moderate
Visual diagnosis	Retinopathy of prematurity	Cortical visual impairment	Colobomas
Learning modality	Visual learner	Visual learner	Visual learner
Additional disability	Yes	Yes	Yes
Communication mode	Vocal (developing)	Vocal, nonverbal, body language, gestures	Nonverbal, gestures
School placement	Inclusion	Inclusion	Inclusion
Time in this school placement	5 years	2 years	3 years
Previous placement	Inclusion	Inclusion	Inclusion
Daily hours in the inclusive setting	5	3.5	6
Primary language used at school	English	English	English
Primary language used at home	English	English	English
Parent interviewed	Mother	Mother	Mother

and Eric, attended different neighborhood elementary schools with their same-age peers and had been in inclusive settings their entire school lives. None of the three participants was totally blind or profoundly deaf, and all had additional disabilities (please see Table 1). The amount of time the students were in an inclusive setting daily varied from 3 to 6 hours. Table 1 presents the demographic information that was reported by the students' parents on the demographic form.

All three parent participants were the mothers of the students with deaf-blindness. Each mother was asked a series of questions related to her child's disability, previous and current educational setting, communication mode, goals of the Individualized Education Program (IEP), and other demographic information.

Paraprofessionals and the intervener

All three paraprofessionals and the intervener who participated in this study were female and represented a broad range of experience (from 9 months to 5 years), with an average of 4.5 years of educational working experience in various roles. The highest educational degree earned by all the paraprofessionals and the intervener was a high school diploma; however, one was working toward obtaining an associate's degree. Only the intervener had received formal training in working with students who are deaf-blind. McInnes and Treffry (1993, p. 275) defined an intervener for students who are deaf-blind as "a person who mediates between the deaf-blind person and his environment to enable him to communicate effectively with and receive non-distorted

information from the environment.” The three paraprofessionals reported that they had received informal training in working with students who were deaf-blind through the school district, deaf-blind consultants, or vision and hearing specialists.

Teachers

Three general education teachers and one special education teacher (an inclusion facilitator) participated in the study. All were female and represented a broad range of experience, with an average of 15 years of teaching experience, 14 years of teaching in the inclusive model, and 2.5 years of teaching students with deaf-blindness. Two teachers had bachelor’s degrees, and the other two had master’s degrees. All the teachers had some kind of teaching license; three of the four had elementary education certification, and one, the inclusion facilitator, was certified to teach students with significant cognitive needs. One teacher had more than one certification.

DATA COLLECTION METHODS

For this qualitative study, interviews and artifacts were used to obtain information about the social experiences that the students who were deaf-blind had in inclusive settings. Observations were used to corroborate the information provided by the teachers and paraprofessionals in their interviews and to learn about the quality of interactions between the participants and their nondisabled peers.

Interviews

Eleven people were interviewed for this study—3 parents, 4 teachers, 3 paraprofessionals, and 1 intervener. The partici-

pants were asked to provide information about their perceptions of the students’ opportunities for communication in their current educational settings, the strategies and approaches they used to improve the frequency of social interactions, and their insights about inclusion. The interviews consisted of a series of open-ended questions that were tailored to each type of interviewee. I and a research assistant audiotaped and then transcribed the interviews.

Artifacts

In addition to the interviews, the participants were asked to provide certain artifacts to corroborate the study’s conclusions through triangulation (Merriam, 1998). They filled out demographic fact sheets and provided copies of the students’ current IEPs, information from which was compared to their responses during the interviews and my observations in the classrooms to determine similarities and differences in the communication goals.

Naturalistic observations

Merriam (1998, p. 96) suggested that one reason for conducting observations is to “triangulate emerging findings . . . used in conjunction with interviewing and document analysis to substantiate the findings.” Observations were conducted in general education classrooms and in other settings in which instruction took place (such as the lunchroom and the playground) and where students with deaf-blindness were included. Opportunities for communication and socialization that were offered to these students, the strategies used by the teachers and paraprofessionals to facilitate communication, the

interaction between the students and their nondisabled peers, and interactions with adults were observed. In this study, *interaction* was defined as any social contact or behavior between two people: student to student or student to adult.

Two observation periods, each lasting the full school day, were conducted for each of the deaf-blind participants or case studies. For two of the cases, the first observation occurred before the interviews with the teachers, paraprofessionals, and the intervener took place. The second observation was conducted shortly after the interviews were concluded. For all the observations, written accounts of the observations as field notes were made.

DATA ANALYSIS

Different levels of analysis are used for case studies. If more than one case is used in a study, cross-case analysis must occur (Yin, 2003). The first step in analyzing the data in the study presented here was to convert the transcribed interviews into systematic categories. To do so, I systematically transformed raw data (the transcribed interviews) into naturally occurring meaning units through the process of coding. I then coded the data, the main categorizing strategy used in qualitative research (Maxwell, 1996), by examining each incident, phrase, sentence, or paragraph to determine the meaning unit in the development of concepts and eventual categories. These units of data became the basis for the defining categories used in the study presented here.

Meaning units were then placed into provisional categories on the basis of similar content using the constant-

comparison method. During this process, each meaning unit was compared with every other meaning unit, in and between categories, to look for similarities or differences (Lincoln & Guba, 1985). Meaning units that seemed to be alike were clustered into provisional categories. The students' IEPs were coded according to the communication goals that the educational teams were working on with the students at the time of data collection.

Findings

NATURE OF SOCIAL EXPERIENCES

The majority of the interactions of the deaf-blind students that I observed in the classroom were with adults, especially with the paraprofessionals and intervener who worked one to one with the students. The observed interactions included the provision of assistance and direction and of affiliative comments (such as "what a great job you are doing!" and "I love your dress") and the facilitation of play. Because of their unique disability-related needs, the students with deaf-blindness required assistance when performing daily classroom activities. The assistance and direction required to complete work in the class were facilitated mainly by the paraprofessionals and the intervener. However, I observed that nondisabled peers who served as "helpers" in the classroom sometimes provided such assistance. The opposite was observed during free time or play, when all the students' interactions were with their nondisabled peers (for example, students sat next to Emily during story time and played with her hair; students wanted to play with Mark during recess, inside and outside the classroom; and students [all

girls] sat next to Eric during story time and held his hands).

STRATEGIES USED BY ADULTS

The teachers, paraprofessionals, and intervener talked about the strategies they used to promote and facilitate interactions and socialization among the three students and their sighted peers with no hearing loss in the classroom. Although some participants said that there were no “specific strategies,” they all said that they used a variety of approaches and activities to include the three students in classroom activities. One strategy that was commonly mentioned was having “long conversations” with all the students in the classroom about disabilities and different learning styles. Another approach was to “model” or demonstrate to the nondisabled students methods of communicating with the deaf-blind students by talking and interacting with the students who were deaf-blind. The third strategy was to use “helpers” or “buddies” to promote the involvement of the students with deaf-blindness with their nondisabled peers. Although in some situations, the use of “helpers” for students with disabilities could result in their being perceived as helpless by their nondisabled peers, in two of the three cases, the strategy seemed to promote social interactions.

Overall, the participants suggested that the most important methods to promote social interactions and facilitate inclusion were to include the three students who were deaf-blind in all the activities in the classroom and to treat them like “all the other children.” Yet, data gathered from observations and the field notes suggest there was a difference between how the

educator participants perceived their implementation of strategies to facilitate inclusion and interaction and what they actually did. That is, the observations did not confirm the participants’ reports of modeling for nondisabled peers and including the students with deaf-blindness in all the classroom activities.

THE BENEFITS AND CHALLENGES OF INCLUSION

As I mentioned earlier, for inclusion of students with deaf-blindness to be successful, changes in the roles of team members and collaboration among these professionals are essential (Hunt et al., 2003). In general, all the participating teachers, paraprofessionals, and the intervener had positive attitudes toward inclusion and were somewhat involved in the process. They reported the following important and positive outcomes of inclusion: personal satisfaction for them, the development of social relationships among the students who were deaf-blind and their nondisabled peers, the progress exhibited by the students with deaf-blindness, and the positive effect on the sighted peers with no hearing loss. Although the participants viewed inclusion positively, they also talked about the challenges they faced in trying to include the three deaf-blind students in all activities of the classroom. The most frequently mentioned challenges were the lack of training to work with students who are deaf-blind and not knowing what to do with these students in the classroom.

THE REALITY OF INCLUSION IN SCHOOLS

The study presented here found that the “inclusion models” (in terms of providing social interactions and facilitating

inclusion for the students with deaf-blindness) were different in each of the educational settings that were observed. Although *inclusion* is clearly defined as the education of students with disabilities together with their nondisabled peers in general education settings within neighborhood schools (Alper, 2003), such a model was replicated in only one of the schools where the data were collected. All the participant teachers and paraprofessionals in this study perceived their educational settings to be inclusive for students with disabilities, but the observations revealed that the students who were deaf-blind were more mainstreamed than included in the school and classroom activities. Only one of the three students was truly included: Mark. The other two students were only integrated, part of the time, in some classes with their nondisabled peers and spent the remaining time in specialized classes or worked one to one with adults in activities like therapy or eating.

It is important to mention that in Mark's case, an inclusion facilitator at the school provided full-time support. In this case, the inclusion facilitator used strategies that were not used in the other two cases. Some of the strategies that she talked about and that were observed in the classroom were collaboration with other team members, the use of more than one paraprofessional to work with the student, adapted assessments, the use of different work-group members, and the use of peers as partners or "helpers" when working on classroom activities. Table 2 presents the specific strategies that she used and the targeted audience.

LIMITATIONS OF THE STUDY

The purpose of the study was to determine the nature of social experiences among students with deaf-blindness, their sighted peers with no hearing loss, and adults in inclusive settings. Although the study yielded information on the nature of these social interactions, it had five limitations that need to be noted. First, the availability of sites serving this population was limited for the study. Second, the size of the sample was small, limiting the generalizability of the results. Third, the amount of time per observation was limited; more time is essential to gather the necessary data and to grasp what really happens in the classroom. Perhaps, if I had spent more time in the classroom, I could have observed more interactions among the students with deaf-blindness, their nondisabled peers, and adults. Fourth, the participants' level of comfort while I collected data in the classrooms may have affected their responses and behavior. Although I tried not to be intrusive in the classrooms, I do not know if the short time I spent with the students, teachers, paraprofessionals, and interveners before the observations had any influence. Fifth, there was no intra- or interobserver agreement, and it was not possible to videotape the observations.

Critical implications and recommendations

The findings highlight some critical implications for teachers and other school personnel who are involved in the education of students with deaf-blindness in inclusive settings. First, it appears that

Table 2
Strategies used by the inclusion facilitator.

Strategy	Target audience	Goal of the strategy
Collaboration	General education teachers, specialists, paraprofessionals	To provide consistency on the presentation of information and materials to the student who is deaf-blind
Same schedule	Peers	To have the same schedule for <i>all</i> the students in the school
Use of partners or buddies	Peers	To promote communication and collaboration between the student who is deaf-blind and classroom peers
In-service training	General education teachers, paraprofessionals, school principals	To educate school personnel on how to facilitate inclusion
Change work-group members in the classroom and have more than two students in each group	Peers	To promote communication and collaboration between the student who is deaf-blind and classroom peers and to provide the student who is deaf-blind with different opportunities
"Modification day"	General education teachers, paraprofessionals	To help teachers modify their class lessons weekly
Adapted assessments	General education teachers	To create assessments according to the needs of the student who is deaf-blind
Use of more than one paraprofessional	Paraprofessionals	To avoid dependence on adults

general education teachers and paraprofessionals who work with students with deaf-blindness may not always be adequately trained or prepared to meet the students' needs or to provide specialized services to the students in inclusive settings. Specific knowledge and skills are required to work with students who are deaf-blind, to provide them with high-quality services, and to support their unique needs. In-service training for general education teachers and paraprofessionals from state consultants on deaf-blindness would give them the tools for effectively modifying classroom activities and lessons and accommodating the students' needs.

Second, although the participant teachers, paraprofessionals, and intervener said that they used different strategies or ap-

proaches to promote interactions among the students who were deaf-blind and their nondisabled peers, these approaches were not observed in two of the three cases. This finding raises a question about the frequency with which these strategies are used and the perceptions of the professionals about how they use these strategies. Given that most of the participants did not have formal training to work with students who are deaf-blind and that there was an inclusion facilitator in only one school, it is possible that the participants did not know what strategies to use or how to use the strategies with which they were familiar appropriately and effectively. Also, specific training in inclusion as the best practice for providing services for students with disabilities is imperative. For many professionals in the fields

of special education and inclusion, the issue is not the lack of training, but the type of training they receive. The training model used to prepare special education teachers should change from one that prepares teachers to have separate small classrooms where students come to receive special education services to one that prepares teachers to be case managers in the schools and to provide such services through collaboration and support to general education teachers and paraprofessionals.

Third, researchers have found that inclusion is beneficial not only for students with disabilities who are included, but for their nondisabled peers (Downing & Peckham-Hardin, 2007; Mar & Sall, 1995; Romer & Haring, 1994). As I previously mentioned, one strategy that seemed to facilitate interactions in the classroom was the use of student helpers or buddies. It is important for adults who work with students who are deaf-blind—in this case, teachers, paraprofessionals, and interveners—to educate nondisabled peers about strategies that empower and encourage them to interact with students who are deaf-blind. Again, personnel who are not appropriately trained or who do not have the suitable classroom supports may not know what strategies best facilitate these interactions.

An unexpected result of the study was the realization of the diversity of “inclusion models” that were found in the three schools. The educators in all three schools reported that they used an inclusion model. However, it was found that the concept of inclusion and, even more important, how inclusion was implemented in some of the educational settings that

were observed was different from what inclusion is intended to promote and support. In two schools, the students were mainstreamed in some classes, were not academically or socially included, and were isolated most of the time. In only one case was the student fully included. In that school, an inclusion facilitator was hired and provided support to the student and to the educational team whenever it was needed, as well as educated the school personnel about inclusion. Some of the inclusion facilitator’s strategies that seemed to be helpful were the use of multiple paraprofessionals, in-service training about inclusion for the school personnel, no use of “pullout” (when students with disabilities are removed from the general education classroom to receive specialized services away from their nondisabled peers), and using work groups in the classroom with nondisabled peers. Implementing appropriate inclusion models in schools and having an inclusion facilitator who provided support and education seemed to have made a difference in the quality of the educational services that the student received.

Need for further research

The study presented here provided a framework for identifying the nature of the social opportunities that students who are deaf-blind experience in inclusive settings. As the procedures and findings were considered and evaluated, many ideas for future research in this area emerged. Five crucial points on which future research should focus are the following. First, it would be beneficial to conduct action research in classrooms where students who are deaf-blind are

truly included. On the basis of the findings of the study presented here, an action plan that involves support for teachers and other educational staff and for students who are deaf-blind and their non-disabled peers and strategies to promote interactions could be developed.

Second, it is important to involve non-disabled peers in research with students who are deaf-blind. This group is often overlooked, and it is important to ask them how they feel about having a student who is deaf-blind in their classroom. To promote communication between students who are deaf-blind and their non-disabled peers in any educational setting, but especially in inclusive classrooms, it is crucial to offer nondisabled peers enough support and information about deaf-blindness and communication systems. The perspectives of these peers may be vital for increasing the frequency and quality of interactions between them and the student who is deaf-blind in the classroom. Third, the time for observations should be longer than was allowed here to see the students in a greater variety of situations.

Fourth, research should be undertaken with older students who are deaf-blind. My review of the literature found that most of the research in this field has been done with elementary school-age students. Research should also be conducted on older students with deaf-blindness and their experiences in general education classrooms. Fifth, research should also be conducted with students with deaf-blindness who are more academically involved and are being taught the general curriculum like their typically developing peers.

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Silvia M. Correa-Torres, Ed.D., COMS, assistant professor, School of Special Education, University of Northern Colorado, Campus Box 141, Greeley, CO 80639; e-mail: <silvia.correa-torres@unco.edu>.

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