



Chapter 1

Foundations

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Issue I. Educators should be knowledgeable about the diversity of students who are deafblind and their unique educational needs.

Issue II. Educators should have the knowledge and skills to meet the unique educational needs of students who are deafblind, including those with additional disabilities.

Issue III. Educators should have knowledge and skills to develop students' communication abilities.

Issue IV. Educational professionals who provide assessments of students who are deafblind should understand the impact of combined vision and hearing losses and be able to communicate using students' forms of communication.

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Issue VII. Administrators, educators, and other team members should be knowledgeable about the legislation and state and federal resources that support the education of students who are deafblind.

Introduction

For most people, the term *deafblind* brings to mind Helen Keller, someone whose accomplishments and achievements have marked her as one of history's most extraordinary women. Today's population of students who are deafblind continues to require special programs and professional teachers to meet their educational needs. Deafblindness is more than the combined result of vision loss and hearing loss. In reality, this combination of losses creates a unique and complex disability that requires highly specialized teaching approaches unique to deafblindness and support from local special education administrators and state systems of special education. The population of students who are deafblind is very heterogeneous.

Unlike Helen Keller, who had no vision and no hearing, the majority of learners who are deafblind have some residual use of either or both senses of vision and hearing. Many of these students have additional physical and developmental needs, complex medical conditions, and/or challenging behaviors. Some students will attend college and go on to live and work independently, while others who are deafblind will need a significant amount of lifelong support.

Students who are deafblind, like all students, are individuals and have strengths and needs that are very specific to who they are. Each will require an individually tailored educational experience, which should be addressed in the development and implementation of the Individualized Education Program (IEP). There are, however, some challenges common among all people who are deafblind that should be considered by those who provide educational services:

- The effects of combined vision and hearing losses isolate students from people and the environment. The major challenge that educators face in diminishing this isolation is to build their students' abilities in communication, concept development, and social competence. Communication provides access to the curriculum and all learning.
- Students who are deafblind require services that are delivered by a team of skilled professionals and paraprofessionals who can create appropriate communication and learning opportunities and provide the student with access to the regular education curriculum and to learning in natural environments.
- Because of the impact of deafblindness on students ability to access and connect with people and the environment, most students who are deafblind require one-on-one support to facilitate equal access to the same learning as their sighted-hearing peers (Alsop, 2002, p. 59).
- Every educational team should include a professional with specialized knowledge and skills in deafblindness to provide direct services, support, and training to families, education professionals, therapists, paraprofessionals, and other team members.

- A meaningful educational program involves families and professionals working together on an ongoing basis to support the students' educational growth and development.

Issues and Practices

Issue I. Educators should be knowledgeable about the diversity of students who are deafblind and their unique educational needs.

Individuals learn about the world mostly through their senses of vision and hearing. Vision and hearing are the main sensory avenues for accessing and interacting with the world around us and for perceiving events as close or distant. When vision and hearing are reduced, even to a mild level, the losses affect the ability to communicate, develop personal relationships, and acquire concepts. Deafblindness affects human development and well-being.

The population of students who are deafblind is highly diverse. Students who are deafblind are rarely totally deaf and totally blind; most students have some usable hearing and/or vision. Ninety percent of students identified as having deafblindness have additional disabilities. These may include additional motor, health, behavioral, and/or developmental disabilities. Some students may be able to learn academics, while others may require a more functional approach to learning. Students who are deafblind are the most diverse and complex group of students receiving special education services.

Each state has its own definition of deafblindness. The U.S. Government defines deaf-blindness as (Individuals with Disabilities Education Improvement Act of 2004):

“Concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.”

According to the 2005 National Deafblind Census reports, there are 9,658 students, age birth to 21, who are deafblind (National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind [NTAC], 2005) with varying etiologies. The single leading cause of deafblindness is related to complications of prematurity. The Census identifies the following top ten etiologies:

- hereditary (chromosomal syndromes and disorders) (2,107)
- prematurity (1,112)

- pre-natal complications (790)
- post-natal complications (715)
- CHARGE syndrome (572)
- microcephaly (369)
- cytomegalovirus (CMV) (334)
- hydrocephaly (284)
- meningitis (279)
- usher syndrome (246) (Killoran, 2007, p.35)

There are no typical students who are deafblind. The complexity of their vision and hearing losses in addition to other disabilities varies from student to student. They are a heterogeneous group with “a broad continuum of needs and learning styles” (Killoran, 2007, p. 7). Some children who are born deafblind are identified with hearing and vision problems right away, while others may not be identified until later in childhood. For example, children who have complex medical challenges may not be identified as deafblind until their general health status improves. Other students have normal hearing and/or vision at birth but acquire sensory losses during childhood or as young adults.

Whether the deafblindness is congenital or acquired, a student’s use of vision and/or hearing can change over time. His or her vision and/or hearing may improve because of growth, development, and/or intervention, or their vision and hearing may deteriorate from lack of intervention or physical causes.

Students who are deafblind often have a broad and complex constellation of needs and may challenge the skills and resources of the local school system. Meeting their needs requires creative planning and personnel training to provide the student with an appropriate education.

Issue II. Educators should have the knowledge and skills to meet the unique educational needs of students who are deafblind, including those with additional disabilities.

Deafblindness is a low incidence disability. There may be only one student who is deafblind in a district. Most often, educators have not had any previous experience with deafblindness. With guidance from a deafblind specialist, a quality educational program can be developed.

While teachers of students with visual impairment and teachers of the Deaf, can each provide valuable input, together they do not equal a deafblind specialist. Each team supporting a student with deafblindness requires a specialist with skills based on a high level of knowledge of the combined, complex effects of vision and hearing losses (e.g., communication, challenges in accessing information and the environment). This person helps team members acquire the knowledge and skills needed to identify and develop the student’s abilities. (See chapter 2 on personnel.)

Importance of Trust

Building a trusting relationship is the springboard in the education of students who are deafblind (van Dijk, 2001, p. 1). Because of the reliance of a student who is deafblind on others, to safely and meaningfully access the world that surrounds him or her, trust is at the core of all interactions and teaching. A student must ask of an educator:

- “Can I trust you to help me access my world in a way that is clear and complete?”
- “Can I trust you to help me move safely between environments?”
- “Can I trust you to understand my needs and desires and to respond to me?”
- “Can I trust you to teach me the concepts that the other kids know?”

Importance of Active Engagement

It is estimated that 75% of what sighted-hearing people know about the world is not learned in school (Gold & Tait, 2004, p. 87). Children with vision and hearing gain information naturally by watching and listening to what is going on around them. They learn concepts, how to communicate, how to interact with others, how the environment is organized, and how to move about. When academic curricula are developed, it is with the assumption that students have acquired many concepts and language abilities before they enter school. For students who are deafblind to acquire the basic concepts and skills that other students learn by exploring, watching, and overhearing, they should be fully immersed in real-life activities and provided with conversation and language to help them understand the world.

Best Teaching Practices

Although methods of instruction have changed over the years, the core of “how to” questions guiding practices have remained the same:

- How to help students build personal, trusting relationships with family members, peers, and other significant people in their lives?
- How to provide predictable routines that will develop anticipation and stimulate communication?

- How to develop the student’s ability to use a variety of communication forms or methods (e.g., gestures, objects, pictures, signs, speech) that they can understand and that can be understood by others?
- How to create learning environments that foster the desire to communicate and develop and expand the student’s interests?
- How to foster development of concepts that lead toward social, academic, and functional abilities?
- How to help the student to build and sustain social relationships?
- How to help the student to understand the organization of physical environments?
- How to assist the student in moving safely and confidently through different physical environments?
- How to stimulate the student’s curiosity and problem solving abilities?
- How to provide real-life learning experiences?
- How to prepare the student for the transition from school to adult life?
- How to support the student so he or she may live a meaningful and happy life?

Most students who are deafblind need one-on-one communication support to access the learning and social environments. In some states, one-on-one support is provided by an intervener who is a paraprofessional with specific training to meet the needs of students who are deafblind. Interveners, under the guidance of the deafblind specialist and classroom teacher help students access the learning environment. Students may also need the support of a sign language interpreter. (See chapter 2 on personnel.)

Students who are deafblind often require a team of several professionals (e.g., occupational therapist, physical therapist, nurse) to address the full constellation of disabilities that affect learning. This requires collaborative planning to minimize the confusion caused by lack of or limited access to people and the environment; to develop communication and social relationships; and to provide cohesive, consistent, and meaningful learning opportunities.

Issue III. Educators should have knowledge and skills to develop students’ communication abilities.

The unique communication needs of students who are deafblind are the most fundamental priority for teams to recognize and address. Attention to this area not only requires that the student have a communication system. It encompasses developing the concepts and

relationships that form the basis of communication.

Students who are deafblind communicate using many forms or methods. Some use presymbolic communication forms such as body movements, touch, objects, pointing, natural gestures and eye gaze. (See chapter 2 on personnel.) Other students who are deafblind use symbolic communication forms that include signed communication and fingerspelling (both visual and tactile), print, braille, electronic or computer-activated voice-output devices, and speech. (See chapter 2 on personnel.)

Educators who communicate with students who are deafblind should understand and use the communication forms that are most natural for the students they teach; they should also learn to be responsive to communicative attempts that can be highly idiosyncratic and difficult to interpret.

The development of communication abilities is dependent on exposure and repetition; these are at the core of language development. Sighted-hearing infants and toddlers hear words hundreds or thousands of times before their meaning is clear and they begin to use words expressively (Goetz, 1997, p. 12). Students who are deafblind require the same amount of exposure and repetition, regardless of whether the communication input is sign language, objects, touch cues, or other forms of receptive communication. It is critical that students be given all available opportunities to develop their receptive and expressive communication abilities.

Students should receive instruction in their preferred forms, but higher forms should be modeled to encourage the student to progress from presymbolic to symbolic forms of communication.

Communication Systems

A communication system consists of everything the student uses for communication. A student who uses presymbolic communication may rely on a calendar system, an object and/or picture communication book, and the use of gestures. A system for a student who uses symbolic language may include a braille alphabet board or a computer with voice and braille output and tactile signs. Students should be given many opportunities to use their communication system with multiple communication partners in varying environments.

With the increase of cochlear implants for children with deafblindness, it is also critical to ensure that students have comprehensive, integrated, ongoing therapy and support from a collaborative team of specialists and educators to facilitate the development of auditory perception, vocalization, receptive and expressive communication, as well as speech and language intelligibility.

School-Family Partnerships in Developing Communication Systems

Collaboration among families, educators, and speech and language professionals is a key to ensuring that communication systems developed for students will meet their needs outside of the school setting. It is important to learn both what families know about the ways their child

communicates and what they communicate about because family members are the most important people in the child's life and their most consistent communication partners.

Accessing Visual and Auditory Information

Students who are deafblind must have the fullest possible access to the visual and auditory environment in order to maximize opportunities to learn and develop their communication abilities. Every student with any residual vision should have access to a comprehensive low vision exam. There are a variety of low vision aids and devices that may be appropriate. In addition to devices that will assist the student in reading print and in orientation and mobility, there are also tools to assist students with low vision to access the computer such as screen readers and magnifiers.

Likewise, every student with deafblindness should receive comprehensive audiological services. The audiologist may prescribe assistive listening devices, such as hearing aids and an FM system, that will help the student access the auditory environment without amplifying extraneous environmental noise. With appropriate amplification, the student may be able to receive or use speech or sound as part of the communication system.

The field of computer technology is ever-changing, and the advancements are a boon to individuals with disabilities. It is critical, therefore, that each student with deafblindness has a technology evaluation conducted by someone knowledgeable in deafblindness and appropriate devices.

Finally, when any assistive communication device is prescribed for an individual student, it should be accompanied by the professional support necessary for use and maintenance by the student, family, and school personnel. Just as all assessment is ongoing, so too should be the assessment of specific technology devices. Students change in all areas (physical, sensory, and developmental), and as they change and grow, there is a crucial need for adjustment to or change in the assistive communication devices.

Issue IV. Educational professionals who provide assessments of students who are deafblind should understand the impact of combined vision and hearing losses and be able to communicate using students' forms of communication.

Educational assessment is an ongoing process and leads to effective planning. It involves family members working with professionals who understand the impact of deafblindness.

Assessment

Every student should have necessary clinical evaluations (e.g., ophthalmological, audiological, neurological) as a base. There are no standardized tools that have been developed specifically for

students who are deafblind. (See chapter 3 on assessment.) Educational assessment of students with deafblindness is multifaceted and includes sensory abilities; social and communication skills; and developmental, motor, and self care abilities. Family members must be at the core of the process so that educators can fully understand the unique abilities and needs of students and set appropriate educational priorities. Government mandated assessments, by laws such as No Child Left Behind (NCLB) must also be addressed in the assessment process.

Qualifications of Professionals Conducting Assessments

Educational professionals who are directly involved in the many facets of educational assessment should have a strong understanding of how the disability of deafblindness affects opportunities to learn and communicate. At a minimum, each team should have a deafblind specialist to work in tandem with others who are conducting assessments. This person should possess the knowledge and skills necessary to interact with the student in ways that will lead to meaningful and accurate results and effective planning. The assessment process should empower families.

Issue V. Educators should value family members as equal partners in educational planning for students who are deafblind.

As the population of students with deafblindness has changed since the beginning days of the field (Education of All Handicapped Children Act, 1975) to Individuals with Disabilities Education Act of 2004 [IDEA]), so too has the family's role as a member of the educational team.

The most competent professionals will welcome family members into the team and appreciate their information and perspective about the student. For the team serving a student with deafblindness, this partnership is essential if the student is to be given every opportunity to achieve his or her maximum potential as a member of his or her family and community. Information from family members provides the foundation for the team's knowledge about the student. This may include such information as:

- the strengths of the child;
- the child's medical, educational and experiential history;
- important people in the child's life;
- the child's personal preferences and dislikes;
- information about how they communicate with the child and how the child communicates with them;
- the child's daily routine;
- the family's hopes and educational priorities.

Issue VI. Educators should be knowledgeable about appropriate service options and supports needed by students who are deafblind throughout their education and transitions.

Transitions

For students who are deafblind, even the smallest of changes can be significant and confusing. Transition is not just about moving from one service or placement to another. Changes within a program and changes in teacher or environment or routine, can all be considered transitions. They all require thinking, planning, and support for what lies ahead.

The transitions that occur in the early stages of a child's life will mean considerable changes for their families as well. Communication, relationships, and environment are critical to the student's ability to learn, and are essential elements of family life. Those who provide transition supports should consider the effect of change on the family and, at the same time, respect that the family may be the most expert at understanding their child's nature and abilities.

The school years present a number of significant transitions for students who are deafblind. Nothing will be more important than the presence of a coordinated plan that starts early, continues to evolve as the child grows, and furthers the development of communication and social skills. As the student moves from early teen years into adulthood, it is critical to maintain a well defined focus in achieving their individual post-school outcomes. It must be realized that youth who are deafblind are at serious risk for living an isolated life with limited social relationships, and ability to live independently. Unfortunately, research reveals that students who are deafblind have, in general, not been provided an education that leads to a successful adult life (Petroff, 2001, p. 1). It is critical that students with deafblindness be provided with deliberate and well coordinated plans for the transition to successful adult life to include postsecondary education, employment, as well as community and residential living.

Educators and families should work together throughout a student's life to consider individual needs, to provide opportunities to learn and develop skills, and to identify and secure supports that will allow him/her to mature and lead a successful and enjoyable adult life.

It is important to remember that in the 2004 reauthorization of IDEA, it was reaffirmed that students with disabilities should have access to a full array or continuum of educational placement options (IDEA, 2004) to meet their individual educational needs.

Choosing the Best School Program

Choosing the appropriate program for an individual student is one of the most difficult decisions that parents and other team members face. The process most often involves weighing the many pluses and minuses of each potential program.

Placement choices should be based on the student's needs, the values of the family and the quality of services available in each potential setting. A good informed decision depends on the knowledge of the team members. The team should define clearly what setting is truly least restrictive for the student.

While educational and placement decisions are made on an annual basis, it is important to remember how crucial consistency and continuity are in the life of the person who is deafblind. In thinking about what is the least restrictive placement, the team should evaluate the impact each placement might have on the ability of the child to achieve his potential for lifelong independence, community participation, social interaction, and personal happiness. (See chapter 4 on service planning and placement options.)

Issue VII. Administrators, educators, and other team members should be knowledgeable about the legislation and state and federal resources that support the education of students who are deafblind.

The federal government, through the Office of Special Education Programs (OSEP), has supported programs for children who are deafblind since the late 1960s. These programs connect a dispersed network of experts and service providers to ensure that this low incidence population receives services and information appropriate to its complex educational needs. These programs and personnel are crucial for supporting the education of students who are deafblind and in assisting districts and states in meeting the requirements of both IDEA and No Child Left Behind (NCLB).

Although the Code of Federal Regulations contains the current federal definition of deafblindness, addressed in IDEA, that is used to determine eligibility for services, a number of states have implemented their own definition of deafblindness (Killoran, 2007, p. 7).

The provision of quality educational services to low incidence populations depends largely on correctly identifying students. Unfortunately, many local education agencies fail to accurately identify as deafblind students with combined sensory losses. They may report them as only blind or deaf, multiply disabled, or developmentally delayed. As a result, many of these students are denied the expertise required to address their learning needs, and schools and districts miss opportunities to take advantage of available support for training, assessment, and program design. It is important for educators to know their state's definition of deafblindness and to be aware of the resources of their federally funded state deafblind project.

Under NCLB all students are now expected to be educated in the general curriculum and to demonstrate knowledge of the curriculum through testing. (The Education Trust, 2003, p.3). Participation criteria and curriculum alignment varies from state to state. Depending on the

nature of their combined vision and hearing losses and the presence of additional disabilities, students with deafblindness may be candidates for accommodations to standard assessments or alternate assessments. This determination requires input from professionals who are knowledgeable about the education of students who are deafblind.

Currently OSEP funds a national program to support education for personnel serving infants and youth who are deafblind to ensure that the requirements of IDEA and NCLB are met. This program supports the following projects:

- *State/Multi State Deafblind Projects* Each state has a federally funded technical assistance project that provides assistance and training to local education agencies (LEAs), school districts, teachers, and other professionals working with students who are deafblind. These projects also provide support to families and are responsible for identifying students with deafblindness in their states. Personnel in these projects bring content expertise and best practices in deafblindness to the LEA, district, and classroom level. Their collaborative efforts build capacity and enhance local and state resources. A full list of state projects is available on the web at: <http://www.nationaldb.org/ppStateDBProjects.php>
- *National Consortium on Deaf-Blindness (NCDB)* This project combines the resources and expertise of three organizations, Teaching Research Institute at Western Oregon University, Hilton/Perkins Program at Perkins School for the Blind, and the Helen Keller National Center. The Consortium provides technical assistance on a national level; makes information relevant to deafblindness easily available through DB-LINK (www.nationaldb.org); and promotes personnel training to improve the skills and knowledge of those working with children who are deafblind. Activities include workshops, national conferences, webinars, consultation, information dissemination services, and product development. NCDB staff work with families, service providers, state deafblind projects, educational service personnel and federal agencies to ensure that children who are deafblind receive the assistance they need to achieve educational results consistent with the promises of NCLB and IDEA. The web site of NCDB can be accessed at <http://www.nationaldb.org>

Legally, it is the responsibility of the local education agency to provide the direct and consultative services that are required by the IEP. Services from these programs are meant to supplement those services.

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