

Educational Programming for Students Who are Deafblind: Position Statement

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## **Introduction**

### **Field of deafblindness**

Historians have described the characteristics of the field of deafblindness by examining its roots in the fields of blindness, deafness and in multiple disabilities (Collins, 1995; Enerstvedt, 1996; Fish, 1934; Hart, 2006; McInnes, 1999). Deafblindness is a unique field because it relies upon practices from the aforementioned disciplines to meet the complex communication and programming needs of individuals with very diverse conditions. However beyond its formation from multiple bases of knowledge, the deafblindness field has developed some unique characteristics which extend beyond its parent fields and it may be argued that this expansion comes from the needs of students who are deafblind themselves. Helen Keller, who is widely recognized as the most famous person to have deafblindness, represents an example of a gifted individual who happened to be deafblind. Demographic data offers a more accurate picture of the wide ranging span of abilities and needs of children and adults who have combined vision and hearing loss.

### **A Changing Population**

The 1963-64 rubella epidemic within the United States, which served as a catalyst for the creation of a federal approach to educating children who are deafblind, introduced a population of children who were congenitally deafblind that presented unique educational needs both communicatively and behaviorally (Enerstvedt, 1996). Many of the children who were born deafblind as a result of congenital rubella syndrome (CRS) experienced additional physical, cognitive, and health-related challenges (Chess, Fernandez & Korn, 1978). Some researchers also reported the presence of maladaptive behaviors in persons born with CRS (Chess &

Fernandez, 1980). As the field of deafblindness developed concurrently with the indelible influence of this population of children, practitioners and researchers were simultaneously challenged to seek interventions that developed reliable communication systems for children as well teaching strategies to cope with and replace challenging behaviors (Hart, 2006).

During the decade of 1986-1995, CRS was reported to account for about one third of the population of children and adults receiving education and rehabilitation services (Riggio, 1992). In 2007, Killoran authored a ten-year review of the national deafblind child count. He found that the top ten leading causes of deafblindness, accounting for 70% of the children listed, had remained constant over the decade but the rank order had changed. CHARGE Syndrome was identified as the leading single syndrome associated with deafblindness while heredity and prematurity rank as the most common etiologies (Killoran, 2007). Killoran also reported that 90% of the children recorded on the census had additional disabilities (Killoran, 2007).

### **Definition**

Although the term deafblind implies a complete absence of hearing and sight, most children who are considered deafblind actually have some functional vision or hearing (NCDB, 2007). The federal definition used to determine eligibility for funding states:

Deaf-blindness means 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. 34 CFR 300.8 (c) (2)

This definition of deaf-blindness is the only disability definition in the CFR that defines a disability in terms of educational placement. A better, more helpful definition would focus on the student's learning needs and the impact of dual sensory losses. "The key feature of deafblindness is that the combination of losses limits access to auditory and visual information. Children with deafblindness require teaching methods that are different from those for children who have only

hearing or vision loss. “When *both* vision and hearing are affected, especially from birth or early in life, natural opportunities to learn and communicate can be severely limited” (NCDB, 2007, p. 1). Although definitions of deafblindness vary around the world – by degree and severity of vision and hearing loss – there is universal recognition of the deleterious effects that dual sensory impairments have on one’s access to environmental information, as well as acknowledgment that this unique disability requires specific teaching strategies to abet and support learning (Ernsveltdt, 1996).

## **Principles of Educational Programming**

### **Early Identification**

Early identification of hearing and vision loss is essential to identifying children who are deafblind and to providing them with appropriate augmentation (eyeglasses, hearing aids, FM systems, and other technologies) that will maximize their access to environmental information and communication, and to educational programming that meets their needs.

In their 2009 report on the early identification of infants who are deafblind, Malloy, et. al reported findings from the *National Deaf-Blind Child Count* (NCDB, 2008), which includes data on children who are deaf-blind from birth through age 21 in every state. According to the child count, there are almost twice as many children in the age 3- to 6-year-old category than the 0- to 3-year-old category, suggesting that many children who are deafblind are not referred to state deafblind projects until age 3 or older (Malloy, et. al., 2009, p.3) This indicates that children are being identified as they enter school, rather than during the years when early intervention could make a significant impact upon their language and cognitive development (National Child Count, 2008; Muller, 2006; Malloy, et. al. 2009). Identifying children with concomitant hearing and vision loss as early as possible must be a priority.

## **Assessment**

High quality educational assessment is the foundation of high quality educational programming. Assessment of children who are deafblind is especially challenging because of the diversity of the population, including varying degrees of vision loss and hearing loss and the presence of additional disabilities. These disabilities interact with each other and their impact on development cannot be understood by simply adding the effects of each disability. Standardized tests have little relevance to this population because children who are deafblind are not represented in the norming groups (Silberman, Bruce, & Nelson, 2004). Assessments of children who are deafblind must address the complexity of their needs including communication, vision, hearing, cognition, motor abilities, and mobility with respect for the priorities of the child and family. Learning media assessment and assistive technology evaluation are critical to supporting access to the curriculum. Such a holistic assessment can only be conducted by professionals who understand the impact that deafblindness has on the child's development; that are competent in using the child's expressive and receptive forms of communication; and are able to work effectively within a collaborative team approach.

The educational evaluation reports, based on thorough assessment, should include an explanation of how the child's sensory losses affect his/her education needs. (Riggio and McLethchie, 2008)

Impact statements should address how deafblindness may result in isolation, reduced opportunities to learn through observation, the need to invite exploration, the impact on concept development, the need for specialized communication interventions (such as tactile sign language).

## **Communication as a Priority in Educational Programming**

Communication and language instruction is the cornerstone of educational programming for children who are deafblind. Deafblindness severely limits the child's access to models of communication and language and to the general curriculum (Bruce, 2005). Many children who are congenitally deafblind struggle to develop symbolic communication. Children and adults who are congenitally deafblind with additional disabilities often communicate in highly idiosyncratic ways, including communicating through challenging behaviors. Research studies have found that such unconventional (or non-conventional) communication is often unrecognized and unsupported by communication partners (Romer & Schoenberg, 1991; Rowland, 1990; Verveloed, van Dijk, Knoors, & van Dijk, 2003). Thus assessment and support of a child's pre-symbolic forms of communication is essential for understanding what the person is communicating about currently and helping support the child in learning symbolic forms of communication.

The child-guided approach to assessment and instruction is emphasized in the field of deafblindness, growing out of the early work of Jan van Dijk and others. Key elements of this approach include the establishment of trusting and harmonious relationships with the child, coactive movement routines, anticipatory strategies, (including the anticipation shelf or daily schedule), memory strategies (including memory books or journals), and dialogues expressed in a variety of communication forms (Janssen, Riksen-Walraven, & Van Dijk, 2003; MacFarland, 1995; van Dijk, 1967). Supporting the child to develop a rich experiential history is critical to both concept development and meaningful communication. Additionally understanding how the person is using her residual sensory information is critical to interacting in meaningful and supportive ways. Within this process, augmentative and alternative communication (AAC) may

be explored which includes a plethora of strategies for supporting what students may already be communicating about using presymbolic means (Mar & Sall, 1994).

Children who are deafblind who acquire symbolic forms have utilized a variety of modes (McInnes, 1999). The development of linguistic expression is grounded in the use of multiple forms of communication at the prelinguistic level (Rowland, 2004; Rowland & Stremel-Campbell, 1987). For both students who acquire symbolic communication and for those who rely on solely on presymbolic forms, an educational team's recognition of the ways in which a student with deafblindness may utilize more symbolic communication forms is essential.

Tactual sign language, tactual finger spelling, Tadoma methods of speechreading, use of object symbols, print on palm, finger braille, or braille communication cards rely upon the student's tactual sense for receptive communication with partners. Close range sign language, sign language in the student's field of vision, lipreading, picture symbols, large print communication boards, or regular print rely upon the student's residual visual system. Speech relies upon a student's residual hearing and vision. A constellation of variables should be considered when teaching and supporting a student in learning symbolic forms. It is beyond the scope of this paper to address each consideration adequately, but generally, the individual student's use of hearing, vision, and touch along with the ability to maximize the student's residual senses through magnification, amplification must be considered.

It is also important to note that if a student experiences increased vision or hearing loss, the communication system might need augmentation or adaptation to meet the student's new needs. For example, students with Usher Syndrome Type II may find that with additional hearing or vision loss that sign language becomes a means of supporting the use of speech (Ingraham, 2007). Additionally, younger children who have experienced gains in access to

visual or auditory information through assistive devices or medical intervention, may find new communication strategies that include the use of new forms. Regardless of the communication form that the student is utilizing, having access to supportive communication partners, both educational professionals and peers, is vital to the student's development.

### **Staffing and Educational Programming**

Children who are deafblind should have an Individualized Educational Program (IEP) developed and implemented by a team that includes at least one member who has expertise, knowledge and skills in deafblindness. Teachers who have preparation in the educational specialty of deafblindness are necessary to provide optimal programming (Riggio, 1999). Although there is a shortage of such personnel, the student who is deafblind must have access to specially trained individuals who have knowledge of the impact of concomitant sensory losses on the development of communication, cognition, motor skills, and social-emotional well being. An integrated child-centered approach produces a more supportive environment for the student.

While some children who are deafblind will work with sign language interpreters, others will require the services of an intervener. An intervener is a one-to-one staff person with specific knowledge and skills related to deafblindness that are listed in the paraeducators section of the Council for Exceptional Children's international standards for the preparation and certification of special education teachers (Council for Exceptional Children, 2008). Interveners support access to information that is readily accessible to children who are hearing and sighted. In addition they provide the experiential basis for conceptual understandings, and they support others to interact with the child who is deafblind (Silberman, Bruce, & Nelson, 2004).

Most children who are deafblind benefit from the services of a Certified Orientation and Mobility Specialist (COMS). As many have noted in the field, the ability to be oriented in one's

environment and to move successfully is an integral part of developing numerous, interconnected skills (Huebner, Prickett, Welsh & Joffee, 1994). Conceptual development and language acquisition, grounded in the exploration of objects and movement routines, has been studied both in children who are deafblind and in children without disabilities (Bruce, 2005; Werner & Kaplan, 1964; Wetherby, Reichle, & Peirce, 1998). Movement in and exploration of the environment lead to the child's understanding of his own body and conceptual construction of the world, including associations between actions on objects and their names and the categorization of objects with similar functions (Bruce, 2005; Werner & Kaplan, 1964). Sauerburger (1993) articulated the following unique aspects of O&M services for individuals who are deafblind: the use of multiple forms of communication, preparation to communicate with the public and to understand the reactions of the public, and unique street crossing strategies. Huebner and colleagues emphasized the importance of congenitally or adventitiously deafblind children receiving systematic instruction to learn to be oriented and independent across multiple environments (Huebner, et. al, 1994).

Collaborative teams share a framework for team functioning and they provide coordinated and comprehensive educational services grounded in the student's valued life outcomes (Cloninger, 2004). Parents are at the core of collaborative teams, bringing knowledge and expertise of their child's characteristics and experiential history. The critical input that parents bring about instructional priorities and aspirations for their child's future should be the basis for educational planning.

Children who are deafblind may have their needs met in a variety of settings, including full inclusion in the general education classroom with support provided by a special education teacher and intervener, resource rooms, self-contained classrooms within public school, and

special schools. Across these various placement options, children who are deafblind require very low staff to student ratios to ensure their access to information and their active engagement.

There is a well-documented, ongoing critical shortage of personnel with expertise in deafblindness. Increased, consistent financial support from OSEP is essential to universities that provide teacher preparation in deafblindness so that they can provide teachers with the knowledge and skills required to educate children who are deafblind. Because educational team membership changes frequently, there is also a need for a mechanism to provide ongoing training and support to interveners and other team members.

### **Assistive Technology**

Assistive technology rather than being a stand-alone area of instruction is one that may be integrated into teaching with students who are deafblind in the areas of augmentative communication (Schweigert, 1989); orientation and mobility (Parker, 2008); vocational training (Lancioni, Bellini, Oliva, 1993); and numerous other areas of learning. As in each area of instruction, collaborating to create approaches that utilize appropriate types of assistive technology, is highly dependent upon the student's unique access needs as well as her needs to participate in the environment. Some specific types of assistive technology that have been designed for and with people who are deafblind include: vibrotactile devices to detect environmental sounds (such as a vibrating doorbell), personal alert-vibrating systems (such as smoke detectors, phones, alarm clock), deafblind communicators with refreshable braille displays, and the telebraille (Ingraham, 2007). While these devices represent the high-tech end of the assistive technology spectrum, it is important to note that a plethora of strategies and tools that comprise the broad definition of assistive technology may be applicable depending upon the student's and her team's needs. A variety of low tech devices, including vibrating pagers, dual

communication boards, and anticipation shelves may be supportive of students across environments or in specific settings. It is critical to note that the use of assistive technology need not be based upon a person's cognitive abilities as there are several examples of use of AT to empower people who are deafblind with multiple disabilities (Hanson & Hanline, 1985; Parker, 2009; Schweigert, 1989).

### **Technical Assistance**

Since the 1970s the federal government has recognized its significant role in supporting states to build their capacity to serve children who are deafblind. This task has become more challenging as students have increasingly received educational services in their local districts. Essentially there are 10,000 children in nearly 10,000 different school districts which rarely have any experience or local expertise educating a child who is deafblind. These districts must rely on state deafblind projects to provide technical assistance and training that allows states to appropriately address the educational needs of this very low incidence and highly complex group of students (Collins, 1992; Thompson and Freeman, 1995).

### **Support and Leadership Training for Families and Young Adults**

The family of each child who is deafblind should have access to support and training from specialists who are knowledgeable about deafblindness to enable them to acquire the tools they need to support their child's development. There is no more powerful advocate for a child than his/her family (McNulty, 1995). These individuals also have a very unique experience of family life helping to educate and support a child whose experience of the world is so unique. Identifying, training and supporting family members to speak to the needs of children who are deafblind at the state and national level is a significant need.

Similarly, some young adults who are deafblind can also function as advocates and spokespersons for groups of students who are deafblind. The provision of teen retreats, trainings, and leadership opportunities for youth who are deafblind results in the development of a growing national network of advocates and spokespersons (Carr, 1995; Parker, Bruce, Spiers, Ressa & Davidson, 2010). Young adults and teens who are deafblind also may benefit from talking with adult mentors who are deafblind for gaining perspectives on self-advocacy and developing a stronger sense of identity (Miner, 1997; Morgan, Bixler, & McNamara, 2002).

### **Research in Deafblindness**

In Ronnberg and Borg's (2001) international review of the research conducted in the field of deafblindness, they concluded that the lack of research in the field was due to the following factors: the heterogeneity in the low incidence population, methodology required by experimental designs, and scientific obstacles of the studies' undertaken. Despite these obstacles, educational research has been produced over the past 40 years which has included participants who are deafblind at various ages (Parker, Davidson & Banda, 2007). Collectively, this corpus of research, both qualitative and quantitative, offers practitioners and parents guidance for teaching and supporting students with dual sensory impairments; however numerous gaps still exist. Research that identifies effective practices and emerging promising practices is critical for progress. For low-incidence disabilities like deafblindness, specific federal support is necessary to support these research efforts.

### **Position**

The Division on Visual Impairments of the Council for Exceptional Children believes that special consideration must be given to the issues facing those who are deafblind. The circumstances creating concomitant hearing and vision losses produce unique needs for students

who are deafblind. A definition of deafblindness should be adopted that focuses the student's learning needs and the impact of dual sensory losses. Early identification of hearing and vision losses in infants and young children should be a priority. Students who are deafblind should receive comprehensive assessment from qualified professionals. Access to trained teachers and support personnel and to a continuum of placement options should be available to students who are deafblind. Due to the low-incidence nature of deafblindness, federal support is needed for personnel preparation programs in order to train teachers and interveners to address the critical shortage of trained personnel in deafblindness. Federal funding is also needed to support the state and national deafblind projects to provide specific technical assistance and training to help states and local education authorities provide educational services to students who are deafblind. Support and leadership training opportunities should be provided to students who are deafblind and their families in order to develop their capacities to speak for the needs of students who are deafblind. Finally, on-going research is vital to evaluate emerging practices and promote the implementation of effective practices.

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