Educational Programming for Students who are Deafblind

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Historians have described the characteristics of the field of deafblindness by examining its roots in the fields of blindness, deafness, and 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 that 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 offer a more accurate picture of the wide ranging span of abilities and needs of children and adults who have combined vision and hearing loss.

Issues

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 as 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 and found that the top ten leading causes of deafblindness, accounting for the condition in 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 (2007).

Definition

Although the term deafblind implies a complete absence of hearing and sight, most children who are considered deafblind 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 students' 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, there is universal recognition of the deleterious effects that dual sensory impairments have on access to environmental information, as well as acknowledgment that this unique disability requires specific teaching strategies to abet and support learning (Ernsveldt, 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, etc.) that will maximize 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) that include 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). Apparently, 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 (Malloy et al., 2009; Muller, 2006; National Child Count, 2008). 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, 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 evaluations are critical to support access to the curriculum. Such a holistic assessment can only be conducted by professionals who: understand the impact that deafblindness has on children's development; are competent in promoting and using unique, individualized forms of expressive and receptive communication; and can work effectively within a collaborative team approach.

     Educational evaluation reports, based on thorough assessment, should include explanations of the potential impact of specific sensory impairments on educational needs (Riggio & McLethchie, 2008). Impact statements should describe the potential of deafblindness to result in isolation, offer reduced opportunities to learn through observation, impede concept development because of reduced opportunities to explore, and require 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 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. Researchers 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 for the acquisition of pre-symbolic forms of communication are essential for understanding current communication and for supporting the acquisition of symbolic communication.

     The child-guided approach to assessment and instruction is emphasized in the field of deafblindness, based on the 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 anticipation shelves or daily schedules), 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). Developing a rich experiential history is critical to concept development and meaningful communication.

Additionally, understanding how individuals use residual sensory information promotes meaningful and supportive interactions. Within this process, augmentative and alternative communication (AAC) may be explored, including a plethora of strategies for supporting presymbolic communicative attempts (Mar & Sall, 1994).

Children who are deafblind who acquire symbolic forms have used 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, educational teams must recognize the potential for students with deafblindness to acquire more and/or more refined symbolic communication forms.

Tactile sign language, tactile finger spelling, Tadoma methods of speechreading, use of object symbols, print on palm, finger braille, or braille communication cards rely upon the student's tactile 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 on residual vision. Speech relies on residual hearing and vision. A constellation of variables should be considered when teaching and supporting the acquisition of symbolic forms. It is beyond the scope of this paper to address each consideration adequately. However, in general, the individual's use of hearing, vision, and touch, along with the potential to maximize residual senses through magnification and amplification, must be considered.

If students' vision or hearing deteriorates due to a progressive condition, their communication systems might need augmentation or adaptation. For example, students with Usher Syndrome Type II may find that, as hearing or vision deteriorate, sign language may support their use of speech (Ingraham, 2007). Additionally, younger children who gain access to visual or auditory information through assistive devices or medical intervention may benefit from new communication strategies and forms. Regardless of communication forms, access to supportive communication partners, both educational professionals and peers, is vital for optimal development and learning.

Recommended Practices

Staffing and Educational Programming

Children who are deafblind should have an Individualized Educational Program (IEP) or an Individualized Family Service Plan (IFSP) 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, students who are 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 optimal supportive environments for students with deafblindness.

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 students who are deafblind (Silberman, Bruce, & Nelson, 2004).

Most children who are deafblind benefit from the services of a certified orientation and mobility specialist (COMS). The ability to be oriented in one's environment and to move efficiently and independently is important for developing many interconnected skills (Huebner, Prickett, Welsh, & Joffee, 1994). Conceptual development and language acquisition, grounded in the exploration of objects and movement routines, have 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 understanding of one's 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 orientation and mobility 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 provide coordinated and comprehensive educational services grounded in valued life outcomes (Cloninger, 2004). Families are at the core of collaborative teams, bringing knowledge and expertise of their child's characteristics and experiential history. The critical input that families contribute to instructional priorities and aspirations for their children's future should be a prime consideration 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, should 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. Collaboration to identify appropriate types of assistive technology for unique, individualized needs is critical for students with deafblindness to access learning opportunities. 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 clocks), deafblind communicators with refreshable braille displays, and the telebraille (Ingraham, 2007). While these devices represent high-tech assistive technology, a plethora of strategies and tools that comprise the broad definition of assistive technology may be appropriate depending upon the needs of students and teams. A variety of low tech devices, including vibrating pagers, dual communication boards, and anticipation shelves may support students across environments or in specific settings. The use of assistive technology should not be based upon cognitive abilities; there are several examples of using assistive technology to empower people who are deafblind with multiple disabilities (Hanson & Hanline, 1985; Parker, 2009; Schweigert, 1989).

Technical Assistance

Since the 1970s the U. S. Department of Education has supported states in building 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 that rarely have any experience or local expertise in educating children who are deafblind. These districts must rely on state deafblind projects to provide technical assistance and training to appropriately address the educational needs of this very low incidence and highly complex group (Collins, 1992; Thompson & Freeman, 1995).

Support and Leadership Training for Families and Young Adults

Families of children who are deafblind should have access to support and training from specialists who are knowledgeable about deafblindness to acquire the tools they need to support their children's development. Families are their children's most powerful and enduring advocates (McNulty, 1995); therefore, providing support to help these families advocate for the unique needs of their children is important.

Similarly, some young adults who are deafblind can also function as advocates and spokespersons for supports and services for students with deafblindness and their families. Teen retreats, trainings, and leadership opportunities for youth who are deafblind could facilitate 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

Ronnberg and Borg (2001), in an international review of research conducted in the field of deafblindness, concluded that the lack of research in the field was due to: the heterogeneity of individuals with deafblindness, methodology for experimental designs, and scientific obstacles. Despite these challenges, educational research has been published over the past 40 years that included participants with deafblindness 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 children and youth with deafblindness. The circumstances creating concomitant hearing and visual impairments produce unique needs for students who are deafblind. A definition of deafblindness should be adopted that focuses on students' 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 to develop their capacity to advocate 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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Children with visual impairments must be taught compensatory skills and adaptive techniques in order to be able to acquire knowledge from methods other than sight. The presence of a visual impairment can potentially impact the normal sequence of learning in social, motor, language and cognitive developmental areas. American Council of the Blind. Council for Exceptional Children-Division on Visual Impairment. CEC-DVI has interests that encompass curriculum development, parent counseling, development and selection of appropriate materials, research needs, teacher preparation, career education and vocational preparation of infants, children and youths with visual impairments.