Special Education, Related Services, and Supports for Children Who Are Deaf-Blind

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Abstract

The purposes of this article are (a) to create opportunities for meaningful discourse, (b) to promote shared understanding of the situated perspectives of stakeholders, and (c) to stimulate solutions-focused collaborative problem solving among stakeholders for improved design and delivery of special education and related services for children who are deaf-blind. An overview of the history and evolution of service delivery for children who are deaf-blind, as well as a presentation of deaf-blind child count demographic data, serves as a platform from which to ponder both lessons learned and to highlight considerations of future directions for the design and applications of policy, practice and research. This information is timely as education legislation (i.e., the Elementary and Secondary Education Act and the Individuals with Disabilities Education Act of 2004) is under review for reauthorization; these laws will determine the future of education that will impact all of America’s children including children who are deaf-blind.

Keywords: deaf-blind, current services, future needs

We can, whenever and wherever we choose, successfully teach all children whose schooling is of interest to us. (Edmonds, 1979, p. 23)

As we enter the second decade of the 21st century, a post 9–11 America is mired in “The Great Recession” in a world that has become “increasingly hot, flat, and crowded” (Friedman, 2008). Civility, diversity of opinion, and respectful discourse have lost ground as Americans increasingly self-segregate to associate with like-minded groups, and it appears that polarization and intolerance are the result of shielding ourselves from uncomfortable realities (Kristof, 2009). In contrast, our population of 300 million has become increasingly diverse across a number of dimensions and social institutions (e.g., economic, political, social, cultural, linguistic, religious, geographic, dis/ability, gender, age, housing, employment, health, social services, transportation, and education). Education is viewed as a ladder to opportunity and great equalizer, and since the “War on Poverty” began in 1965, education policy has been driven by goals of equity and excellence to overcome disadvantage.

However, consider the complexity, enormous costs, and competing agendas as public education operates with oversight from local, state, and federal governance authorities across 15,000 school districts or local education agencies (LEAs). Multiple stakeholders with diverse perspectives regarding the role

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and purpose of education often compete for resources, recognition, and respect. Consider the concerns of those who are members of minority groups and who experience discrimination, marginalization, and exclusion as a result of the historical legacies of racism and the differential treatment of immigrants and English-language learners (adults as well as children). The disadvantages these groups face intersect with poverty in complex ways that continue to confound public educational policies and practices (Kozleski & Smith, 2009).

Now consider the challenges presented by children who are deaf-blind and who represent one of the lowest incidence and most diverse groups of learners receiving early intervention, special education, and related services (Muller, 2006). Of the nearly 10,000 children identified as having combined hearing and vision loss, 90 percent experience concomitant physical or intellectual disabilities or complex medical and behavioral challenges (Killoran, 2007).

The purposes of this article are (a) to create opportunities for meaningful discourse, (b) to promote shared understanding of the situated perspectives of stakeholders, and (c) to stimulate solutions-focused collaborative problem solving among stakeholders for improved design and delivery of special education and related services for children who are deaf-blind. This is an earnest attempt to grapple with difficult issues and “wicked problems” (Deshler, 2009) in an era of unprecedented knowledge production, societal change, budgetary crises, and concern about the future. An overview of the history and evolution of service delivery for children who are deaf-blind, as well as a presentation of deaf-blind child demographic data, serves as a platform from which to ponder both lessons learned and to highlight considerations of future directions for the design and applications of policy, practice, and research. This special issue of AER Journal is timely and occurs as education legislation (i.e., the Elementary and Secondary Education Act and the Individuals with Disabilities Education Act [IDEA] of 2004) is under review for reauthorization; these laws will determine the future of education that will impact all of America’s children including children who are deaf-blind.

A Review of the Past

The worldwide rubella epidemic of 1963–1965 was followed by the birth of children with multiple disabilities or concomitant vision and hearing loss due to maternal prenatal exposure. The epidemic heightened awareness of the needs of children with severe disabilities, including those with deaf-blindness.

Initiatives to address the needs of these children and their families began during the Kennedy Administration and were followed by the Johnson Administration’s “War on Poverty” and “Great Society” initiatives, including passage of the Elementary and Secondary Education Act in 1965. Public Law 90–247 (1968) included authorization establishing regional centers to meet the needs of children with deaf-blindness, and, in 1969, the Department of Health, Education, and Welfare established eight, increased shortly thereafter to ten, centers under the Centers and Services for Deaf-Blind Children Program, funded by a $1 million appropriation. The regional centers’ charge was to prepare teachers and school personnel to provide educational services for children with deaf-blindness and to develop methods, materials, and intervention models for children and support for their families. The centers served as a foundation for regional and national training and technical assistance (TA) networks.

In 1975, Public Law 94–142, the Education for All Handicapped Children Act (EHA), established requirements for all children with disabilities to be provided a free, appropriate, public education (FAPE) based on an individualized education program (IEP) in the least restrictive environment (LRE). Children who were previously excluded from public schools based on arbitrary determinations of “educability” were now entitled to an education. Notably, this legislation brought heightened attention and focus to making services available in local school programs throughout the country. By 1976, the 10 Centers for Deaf-Blind Children were funded by $16 million in federal appropriations and were providing direct services to children and TA to regional, state, and local agencies. In subsequent years, these 10 centers were decentralized as multistate and single-state deaf-blind projects were established during the 1980s.

Since its inception in 1980, the U.S. Department of Education’s Office of Special Education Programs (OSEP) has funded TA projects and personnel preparation programs to build state and local
capacity to serve children who are deaf-blind and their families. Since 1986, a series of national TA centers have worked with regional, multistate, and state deaf-blind TA projects to increase state and local capacity in the provision of appropriate educational and related services to students identified as deaf-blind. As a result of those projects and programs, professionals, advocates, individuals who are deaf-blind, and parents have collaborated to make progress in identifying evidence-based intervention practices for children who are deaf-blind, developing high-quality training materials and resources, and developing networks across states to share information. OSEP support for these projects continues to this day, with program authorization outlined by the Department of Education in the March 25, 2008 Federal Register, which articulates the ongoing challenges and needs of children who are deaf-blind:

Children who are deaf-blind are often isolated and disconnected from people and activities in their homes, schools, and communities both because they cannot access visual and auditory information and because they are not provided the individualized supports necessary to access this information. Without individualized supports to access visual and auditory information (i.e., environmental information, such as who is present, what is being said, and what activities are occurring), children who are deaf-blind are at greater risk for not attaining age-appropriate milestones in communication and language, movement/orientation and mobility, social skills, and activities of daily living, which in turn affects educational outcomes. Consequently, students who are deaf-blind often exit school at age 22 without viable postsecondary education, employment, or independent living options. (U.S. Department of Education, p. 15744)

Most state educational agencies, Part C state lead agencies, and LEAs lack sufficient numbers of personnel with the specialized training, experience, and skills that are needed to provide appropriate early intervention, special education, and related services to children who are deaf-blind (Collins, 1992; Markowitz, 2001; McLetchie, 1992). The critical shortage of personnel to serve children who are deaf-blind can limit access to a FAPE for these children.

The National Deaf-Blind Child Count Registry data show that although there has been significant growth in the number of children served in local community schools, 85 percent of school-age children who are deaf-blind continue to receive their services in separate settings. More work is needed to ensure that early intervention, special and regular education, and related services personnel have adequate skills to appropriately serve infants and toddlers in natural environments, which may include home and community settings, and school-age children in the LRE (U.S. Department of Education, 2008).

IDEA 2004 Part D legislation allocates $12.8 million to “address the educational, related services, transitional, and early intervention needs of children with deaf-blindness” (IDEA, 2004, [HR1350, Sec. 682 (d)(A)]). With these funds, OSEP supports 52 state TA projects to improve results and services to children who are deaf-blind (i.e., 50 states, Puerto Rico, and the Pacific Basin), and a national center, the National Consortium on Deaf-Blindness (NCDB), as well as professional development grants to improve teacher preparation. The state deaf-blind TA projects and NCDB are part of the OSEP Technical Assistance and Dissemination network and provide TA, resources, data/information, and materials to states, local schools, educational professionals, and families.

A Demographic Snapshot of Children Who Are Deaf-Blind (Birth to Age 21)

NCDB is charged to collect, coordinate, report, and maintain data from an annual National Child Count of Children and Youth Who are Deaf-Blind. NCDB, and its predecessors, have completed the child count since 1986 by collaborating with the state deaf-blind TA projects to gather data on children who are deaf-blind, based on the following IDEA 2004 definition for deaf-blindness: “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” (Child with a Disability, 2007).

The 2008 National Child Count of Children and Youth Who Are Deaf-Blind identifies 9,872 infants,
children, and youth (birth through age 21) that meet the federal eligibility criteria for deaf-blindness (NCDB, 2009). This number has remained relatively stable over the past 10 years. The vast majority (91 percent) of these students who are deaf-blind live at home with parents, extended family members, or foster parents. Table 1 provides numbers of students by age group; Table 2 provides numbers of students by ethnicity.

### Etiology

Given the role the rubella epidemic played in stimulating early federal support for services for children with deaf-blindness in the 1960s, rubella syndrome as an etiology associated with deaf-blindness has declined significantly. Presently, data are collected on over 70 possible etiologies underscoring the challenges in identifying impact and need. Of the most commonly identified etiologies 24 percent of students are identified as experiencing deaf-blindness due to hereditary/chromosomal syndromes and disorders, another 12 percent due to prematurity, 7 percent due to prenatal complications, and 6 percent due to postnatal complications. The single most commonly identified syndrome is CHARGE syndrome, representing 7 percent of all students reported. In fact, the prevalence of students identified with CHARGE syndrome has increased over 130 percent in the last decade.

### Concomitant Disabilities

Over 90 percent of children and students have one or more additional disabilities. Sixty-six percent have a cognitive impairment (the most frequently reported additional impairment), followed by physical impairments (60 percent), and complex health care needs (49 percent). The trends associated with concomitant disabilities have remained relatively consistent over the past 10 years.

### Educational Settings

There have been significant shifts in the location where educational services are provided for children with special education needs. Prior to EHA, children with moderate to severe disabilities were typically denied entry to public schools, although some states did provide services in special schools. Despite gains in early intervention settings, however, the pace of integration and inclusion for school-age children who are deaf-blind lags behind other students identified under other eligibility categories. In 2008, the edue-
tional settings for infants and toddlers, preschool-age children, and school-age children were as follows.

**Early Intervention Settings**
*(Birth through Age 2)*

The data for infants and toddlers are consistent with national data reflective of settings for students with other disabilities. About 82 percent of infants and toddlers who are deaf-blind are served at home and 8 percent are served in community settings.

**Early Childhood Settings**
*(Age 3 to 5)*

Data reflect that 14 percent of children in this age group are served in regular early childhood settings, with approximately 8 percent served in regular early childhood settings between 40 percent and 79 percent of the school day. Approximately 20 percent of preschool students are served in separate classrooms and 17 percent are served in separate schools.

**School-Age Settings**
*(Age 6 to 21)*

Approximately 11 percent of school-age students are served in regular classrooms, with 7 percent served in regular classrooms between 40 percent and 79 percent of the school day. Thirty-eight percent are in regular classrooms less than 40 percent of the day and 29 percent receive services in separate schools or residential facilities.

**Questions, Observations, and a Look Toward the Future**

How does America identify best and promising practices to address the needs of the 10,000 students identified as deaf-blind by NCDB and state deaf-blind TA project child counts? What local, state, and national systems need to be in place to ensure quality implementation of these practices? Contemplating these questions can be daunting, particularly when considering the large number of individuals involved in present efforts to provide quality educational services for students who are deaf-blind (e.g., the students themselves, families, teachers, teaching assistants, principals, school personnel, university personnel, state and local education agency personnel) and how the influence of their respective interests and perspectives can support or hinder implementation efforts. Questions arise about shared understandings and differing perspectives of this wide variety of stakeholders. However, it is imperative that strong partnerships and shared visions among all stakeholders, including parents, researchers, state and local education agencies, service providers, and consumers be established to address standards-based curriculum alignment, instructional coherence, and system and program accountability.

A further complicating scenario is that NCDB deaf-blind child count data differ widely from IDEA Part B and Part C State Child Count data reported annually by state education agencies. Although the reasons for this are beyond the scope of this article, readers are encouraged to read the NASDSE Forum article by Muller (2006) for insights on this discrepancy. IDEA Part D discretionary grants require the state deaf-blind TA projects to work with NCDB on the deaf-blind child count based on the rationale that these data are essential for the design and delivery of effective TA to assist states in providing appropriate services based on descriptive data regarding current demographics needed to inform current and future needs. How can we ensure that no child who is deaf-blind is left behind or denied opportunities for access, participation, and progress in the general education curriculum?

Disability labels are not benign. Some disability labels carry greater stigma than other labels, and the degree or level of involvement of disability is a cofactor in stigmatization and segregation (Smith, 2001). Students who are served under the disability categories of mental retardation, multiple disabilities, autism, and deaf-blindness are less likely than their peers who fall into high-incidence categories to spend their school day in inclusive classrooms (Smith, 2006).

Great strides in medicine and health have led to improved identification of children who have special education and related service needs, and identification of specific etiologies have informed policy, research, and practice for children with complex and specialized health and education needs. Consider how perceptions, public expenditures, and service delivery have changed since “autism” became “autism spectrum disorders.” Smith (2008–2009) argues that our view of “the medical model” would
be informed by the World Health Organization's (2010) International Classification of Functioning, Disability, and Health (ICF):

The ICF puts the notions of “health” and “disability” in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus “mainstreams” the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric—the ruler of health and disability. Furthermore ICF takes into account the social aspects of disability and does not see disability only as a “medical” or “biological” dysfunction. By including Contextual Factors, in which environmental factors are listed, the ICF allows [for] the impact of the environment on the person’s functioning.

For example, in 2010, The American Association of the Deaf-Blind (AADB) suggested the following definition that appears to have been influenced by the ICF:

Deaf-blind or deafblindness is a combination of hearing and vision loss of any varying degrees that affects a person’s ability to communicate, get environmental information, participate in the community, obtain and keep a job, and maintain independence. (AADB, 2010)

In contrast, the IDEA definition of deaf-blindness appears to focus on special education programs rather than IEP provisions:

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)])

Do shared eligibility labels and programmatic concerns trump individual student needs and family preferences? Advocates of inclusive education argue that such policy implementation is inconsistent with policy, research, and practice and incongruent with the promise of FAPE in the LRE. Conversely, other families and professionals contend that children who have intensive or specialized support needs are best served in separate school programs (e.g., Garvue, 2009). Some argue that center-based service delivery configurations are the most efficient, efficacious, and cost-effective and cite IDEA language regarding the continuum of services despite guidance stating:

The process for determining the educational placement for children with low-incidence disabilities (including children who are deaf, hard of hearing, or deaf-blind) is the same process used for determining the educational placement for all children with disabilities. That is, each child’s educational placement must be determined on an individual case-by-case basis depending on each child’s unique educational needs and circumstances, rather than by the child’s category of disability, and must be based on the child’s IEP. We believe the LRE provisions are sufficient to ensure that public agencies provide low-incidence children with disabilities access to appropriate educational programming and services in the educational setting appropriate to meet the needs of the child in the LRE. (Department of Education, 2006, p. 46586)

A review of the IDEA funding related to children who are deaf-blind has fluctuated from $1 million in 1969 to slightly under $15 million under IDEA Part D deaf-blind services program authority in the 1980s. The deaf-blind program authority was augmented by an additional $12.4 million from the mid-1980s until IDEA 97 Part D program authorities were reduced from 14 to 5 and specific authority for both deaf-blind and severe disability was eliminated. However, IDEA 97 and 2004 retained a $12.84 million funding floor dedicated to this population.

Several key special education initiatives are being implemented across the country, including response to intervention, early intervening services, universal design for learning, and positive behavioral interventions and supports. How are the interests of children who are deaf-blind or have other low-incidence disabilities or complex support needs currently included in these efforts? How can they be included in these school improvement efforts? Such complex and important questions require thoughtful discourse
among stakeholders regarding equity, access, participation, and outcomes for the individual as well as a focus on how we configure the design of educational service delivery systems. How do we best ensure that policy-makers and program implementers are informed by stakeholders? How do we efficiently prepare and deploy human resources to meet the needs of children who are deaf-blind? In this era of fiscal concerns and state budget cuts, how will children with complex support needs fare in the context of macro education issues regarding cost–benefit and efficiency as education systems race to the top? Do professionals in deaf-blindness inadvertently identify children who are deaf-blind as “other” in our attempts to describe their needs? Do we convey the message that teachers must be “miracle workers”? How can we increase use of individualized supports by using paraprofessionals and interveners? How can we best foster civil and scholarly exploration of stakeholders’ perspectives when so many have such great needs? Passions are high, and we must promote shared understandings of the “wicked problems” confronting us. Any real and perceived slights and old wounds from the past must be put aside to mobilize resources. We must identify how both the “bottom-up” and “top-down” school improvement efforts converge across federal, state, and local levels to best leverage systemic change to benefit children who are deaf-blind. As we contemplate these important issues and questions it is our fervent hope that we can capitalize on stakeholder passions and commitments to employ solutions-focused problem solving and use of data to improve the design and delivery of needed special education and related services. Our field has learned a great deal since 1965 and our collective knowledge, skills, and abilities can inform and improve education systems in a manner that is “value-added” and increases the capacity of education systems to differentiate instruction and provide individualized supports to learners that will improve outcomes for all children including those who are deaf-blind.

Disclaimer

This paper is intended to promote the exchange of ideas among researchers and policy makers. The views expressed in it are part of ongoing research and analysis and do not necessarily reflect the position of the U.S. Department of Education.

References


Child with a Disability, 34 C.F.R. § 300.8 (2007).


Smith, A. (2006). Access, participation, and progress in the general education curriculum in the least restrictive environment for students with significant cognitive


U.S. Department of Education. (2008). Office of Special Education and Rehabilitative Services; overview information; technical assistance and dissemination to improve services and results for children with disabilities—State technical assistance projects to improve services and results for children who are deaf-blind; notice inviting applications for new awards for fiscal year (FY) 2008. Federal Register, 73(58), 15744–15750.