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Critical Issues in the Lives of Children and Youth Who Are Deafblind

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The coeditors of an *American Annals of the Deaf* special issue on deafblindness introduce readers to critical issues surrounding children and youth who are deafblind. These issues—early identification, communication, social-emotional needs, family and multicultural issues, universal design and assistive technology, transition planning, and personnel preparation—are explored further in the articles that follow. By way of introduction, the present article provides definitions of deafblindness and a discussion of the heterogeneous nature of the population. The history of the field of deafblindness is then explored in terms of three distinct population shifts, from (a) individuals of the 18th and 19th centuries who became deafblind due to illness, to (b) the influx of individuals with congenital rubella syndrome in the 1960s who had disabilities besides deafblindness, and (c) the current population of children and youth with deafblindness, which includes individuals with other complex disabilities.

Keywords: deafblind, critical issues, history of deafblindness

The prototypical image of deafblindness is that of Helen Keller at the water pump signing "water" with her teacher, Anne Sullivan. Depicted in numerous books, plays, and movies, this moment is both poignant and powerful, as we see the young girl connect with the symbolic world of language. Although the story of Helen Keller continues to inspire, the history of deafblindness and deafblind education extends beyond the life of Helen Keller and includes a very heterogeneous population with widely different stories to tell.

At first blush, it would seem easy to define deafblindness, but in reality, its definition has never been as straightforward as the lack of vision and hearing. In fact, most individuals who are deafblind have and make use of at least some vision and/or hearing (Schalock, 2015; R. van Dijk, Nelson, Postma, & J. van Dijk, 2010). Moreover, deafblindness cannot be defined by simply adding deafness to blindness. Salvatore Lagati first advocated dropping the hyphen between *deaf* and *blind* in 1995, arguing that the concurrent losses of vision and hearing constitute a unique disability. In 2004, after much debate and lobbying from the deafblind com-

munity, the European Parliament declared that "deafblindness is a distinct disability that is a combination of both sight and hearing impairments, which results in difficulties having access to information, communication, and mobility."

The principal special education law at the federal level in the United States, the Individuals With Disabilities Education Act, includes the following definition of deafblindness:

> 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))

Regardless of the definition used, the population of persons who are deafblind is highly heterogeneous, and the effects of the deafblindness vary from person to person. For example, there is a wide difference between the effects of congenital deafblindness and late acquisition of deafblindness because individuals with late-acquisition deafblindness will have likely already developed language and have an understanding of a vast array of concepts gained through the senses of vision and hearing. The effect of deafblindness cannot be understood by adding up the effects of the visual impairment and the hearing loss. This is because vision and hearing are the two distance senses people rely on most as they learn. When other disabilities such as motor impairments are added to deafblindness, the effect is multiplicative because vision and hearing interact with all of the body's systems (R. van Dijk et al., 2010). Although their characteristics are varied, individuals who are deafblind also have commonalities, including difficulties with receptive and expressive communication and, because of limited access to sensory information, difficulty gathering and bringing together usable information from which to understand the world (Bruce & Borders, 2015).

Despite the broad range of characteristics of the deafblind population, the number of scholars and practitioners in the field of deafblind education is small, with a rather limited recorded history. However, the historical legacy of deafblindness provides much rich information, as distinct shifts have occurred in the composition of the population of individuals who are deafblind, and in the growth and evolution of knowledge and thinking about critical issues in the lives of children and youth who are deafblind.

Historical Perspectives

Although the Quran contains metaphorical references to deafblindness, for the most part the concept of deafblindness is absent in early historical texts (Enerstvedt, 1996). In the 18th century there began to be discussion of how individuals who were both deaf and blind might be taught to communicate. In 1779, l'Abbé Deschamps, a French cleric, posited a theoretical approach to how children who were blind, deaf, and mute might be educated. He wrote that others must help them understand that when people with vision and hearing want something, they move their lips to get it, and that people who are deafblind can also move their tongues and lips to ask for things. He also suggested that children who were deafblind could position their hands to feel the speech organs when others talked. He also emphasized the importance of patience and repetition (Enerstvedt, 1996; Farrell, 1956). In 1795, Lorenzo Hervas y Panduro, a Spanish Jesuit and philologist, proposed the use of signs that would be accessible to individuals who were deafblind through touch, smell, and taste. He further proposed a book of raised letters that individuals could use to spell out words (Enerstvedt, 1996; Farrell, 1956). In 1789, the first of several case studies of successful education of individuals who were deafblind emerged with the story of Victorine Morriseau in Paris (Collins, 1995). In the same time frame, the philosopher Dugald Stewart told the story of James Mitchell, a resident of Scotland who was reported to have congenital deafblindness. Although Mitchell had developed simple signs to express his needs to his family and rode freely around the family farm on horseback, several British scholars concluded that nothing could be done for him, and went on to state that deafblindness was the most crippling of disabilities (Enerstvedt, 1996).

The first recorded attempt in America to educate and teach language to a child who was deafblind occurred in 1837, when physician and educator Samuel Gridley Howe brought 7-year-old Laura Bridgman, who had become deaf and blind at the age of 2, to the New-England Institution for the Education of the Blind (now known as the Perkins School for the Blind). Laura's education was focused on teaching her the English language by matching raised letters and words to familiar objects. Once she understood that a word in raised letters represented an object, she was taught to read by means of raised letters arranged on a board. Later, she was taught to spell using the manual alphabet. Howe stated that once Laura understood that objects had names, she wanted to know the name for everything (McGinnity, Seymour-Ford, & Andries, 2004). In 1842, Charles Dickens was introduced to Laura and was so taken with her story that he wrote about her in his travelogue *American Notes for General*

Circulation (McLetchie, 1995). Although Laura Bridgman returned home a few times, the trips were not successful and she was reported to feel isolated and depressed. She lived most of the remainder of her life at Perkins (Lane, 1984; McLetchie, 1995).

Born in 1880, Helen Keller became sick at age 19 months with an illness that resulted in the loss of both her vision and hearing. By the time Helen was 6 years old, her behavior was becoming increasingly difficult. When her parents read the Dickens account of Laura Bridgman, they contacted the Perkins School for the Blind for help. In 1887, Perkins dispatched Anne Sullivan to Alabama to be Helen's teacher. Sullivan largely used the same techniques Howe had used with Laura Bridgman 50 years earlier. As Helen experienced objects or activities, Sullivan would fingerspell their names into Helen's hands. Sullivan looked for teachable moments and followed Helen's interests. It was a conversational approach, with language provided throughout the day (Robbins, 1983). John Macy, Sullivan's husband, wrote that she used a natural method for teaching language based on how children with vision and hearing learned language, rather than the repetitive word definitions used by Howe (Enerstvedt, 1996). Helen later used Tadoma (a communication technique that involves placing one's thumb on another person's larynx and other fingers close enough to the mouth so that the movement of the lips can be felt) and mastered oral language. With Sullivan at her side, she completed her college education, graduating cum laude from Radcliffe College in 1904.

In addition to Laura Bridgman and Helen Keller, other individuals who were deafblind were educated in the age of deafblind history that Enerstvedt (1996) characterizes as the "epoch of a few stars" (p. 62). Included in this group are Julia Brace of the United States, Ragnhild Kaata of Norway, and Olga Skorokhodova of Russia. Enerstvedt notes that while certainly remarkable, these women did not have other impairments and were not congenitally deafblind. Based on the case studies that detailed the educational successes of these "stars," between 1900 and 1950 several programs were established in the United States and Europe to teach children who were deafblind. The European schools included Condover Hall in the United Kingdom, Zagorsk School near Moscow, and St. Michieslsgestel in the Netherlands. Programs in the United States were begun at schools for the blind, including Perkins, the Michigan School for the Blind, Overbrook School for the Blind, and the New York Institute for the Blind (Collins, 1995).

Between 1962 and 1964, a worldwide pandemic of rubella resulted in the birth of thousands of individuals who were deafblind due to congenital rubella syndrome (CRS), and a new age of deafblind education was ushered in. The individuals with CRS, unlike those with deafblindness written about previously, were deafblind from birth and for the most part had additional cognitive and physical disabilities. In the United States alone, more than 5,000 persons were identified as having CRS (Collins, 1995). Globally, schools were unprepared for the influx of this new population of children with deafblindness. Existing programs for the deafblind were expanded and new ones were founded; however, the educational strategies that had worked so well with Laura Bridgman and Helen Keller were in need of modification and expansion (J. van Dijk & Nelson, 1998). The Tadoma used at Perkins was not successful with this group of children (McLetchie, 1995), and motor impairments made other traditional strategies ineffective (J. van Dijk & Nelson, 1998). Many of the children, particularly those with rubella-related cataracts, showed patterns of repetitive, stereotypical behaviors, and attempts to eliminate the behaviors often resulted in their replacement with new, equally challenging behaviors (R. van Dijk et al., 2010). In addition, the new population was extremely heterogeneous, and intervention methods had to be individualized for each child.

In response to the pandemic, educators from around the world worked together to meet the new challenges. The child-guided methods and patterns of typical language development Anne Sullivan had used with Helen Keller and the tactile language methods Samuel Gridley Howe had used with Laura Bridgman were incorporated into new methodologies that guided educators as they helped children move toward symbolic language (R. van Dijk et al., 2010). Important methodology that has been adopted worldwide emerged from the work of Jan van Dijk and colleagues in the Netherlands that demonstrated that children who are deafblind can successfully join in favorite movement activities and establish conversations based on those activities. Theories of attachment and methodical play used successfully in Russia were added to what became known as the van Dijk conversational or movement-based approach to education of children who are deafblind. Because of the complexity and heterogeneity of the population, the van Dijk curriculum did not include a rigid developmental sequence, but rather was a structure for daily activities of the children (J. van Dijk & Nelson, 1998). For the most part, the education of children who were deafblind continued to occur in central specialized schools often far from the students' home communities. However, in the 1970s the U.S. government funded a network of mul-

tistate regional centers that served children with deafblindness in the United States. These centers served as clearinghouses for information and gave professionals a mechanism for sharing ideas and expertise. Training and consultation were provided to local schools that could then be used to serve the children closer to home (Collins, 1995).

The first rubella vaccine was licensed in 1969, and gradually, over the next 25 years, the students with CRS aged out of the school system. In most developed countries, rubella infection is now rare, and in 2015 the Americas were declared by the World Health Organization to be free of rubella transmission. However, about 100,000 cases occur each year worldwide (Lambert, Strebel, Orenstein, Icenogle, & Poland, 2015).

As CRS has waned in prevalence, a third shift in the population of children who are deafblind has come to the forefront, as medical technology has enabled more infants with very low birth weights and/or significant health impairments, including deafblindness, to survive and even thrive. The 2014 National Center on Deaf-Blindness Child Count (Schalock, 2015) found that complications of prematurity were the most prevalent single cause of deafblindness. Children with conditions such as CHARGE syndrome that involve multiple organs survive infancy at higher rates because of medical advances including gastrointestinal feeding technology and tracheostomies. According to the Child Count, CHARGE syndrome is the most prevalent syndromic cause of deafblindness, and its incidence is continuing to rise. The children and youth represented by this new third population shift have come to the field with very significant and multiple disabilities in addition to their deafblindness. In 2005, over 20% of the children and youth in the Child Count had no additional disabilities. In 2013, only a little over 10% had no additional disabilities. In 2005, 31% of children and youth in the Child Count had four or more additional disabilities; in 2014, 43% had four or more disabilities (Schalock, 2015). At the same time, there has been a continued trend away from educating these children and youth in centralized schools and institutions. As of 2014, 93% of the students classified as deafblind in the United States were educated in their home communities; 60% received educational services in local schools (Schalock, 2015). In addition, the use of cochlear implants across the age ranges increased dramatically from 2009 to 2014 (Schalock, 2015).

Although many of the teaching strategies developed for children with CRS are effective with this new group of children, a renewed international effort to identify, research, and implement strategies that can best address the complexity of needs faced by this population seems timely. Continuous evolution of methodology, including maximization of the use of technological applications, is needed, as well as renewed advocacy to ensure that services are in place at the local, state, and national levels. At the same time, as educational practitioners and researchers grapple with how best to serve the population with multiple disabilities on top of deafblindness, they must not fail to keep in mind the 10% who do not have additional disabilities.

Finally, as our historical tour concludes, we find that although medical science has been able to prevent many of the causes of deafblindness found in the past, others loom on the horizon. In 2015, a mosquito-borne virus, Zika, began a sweep through Latin America and the Caribbean. In April 2016, scientists at the Centers for Disease Control and Prevention (CDC) concluded that there is a causational relationship between prenatal Zika virus infection and microcephaly and other severe fetal brain defects (Rasmussen, Jamieson, Honein, & Peterson, 2016). Microcephaly is associated with small head size and incomplete brain development, and while it is difficult to predict with any certainty the specific difficulties that might result, there is a strong possibility that the congenital Zika virus could affect children's vision and hearing. Therefore, the CDC has strongly recommended hearing and vision evaluation for infants with congenital Zika virus infection (Staples et al., 2016).

Critical Issues

As we look at critical issues in the lives of children and youth who are deafblind, we see that some of the issues have remained constant across the recorded history of deafblindness. Other issues have increased in importance, and still others have either evolved over the decades or are new. In this *Annals* special issue we have chosen to focus particularly on early identification, communication, social-emotional needs, family and multicultural issues, universal design and assistive technology, transition planning, and personnel preparation.

Across the three eras described in the present article, the primary etiologies of deafblindness have shifted from being attributed to unnamed illnesses in the first, to rubella in the second, to prematurity and syndromes in the third. These etiological shifts, coupled with the heterogeneity of the population and misunderstandings about the definition of deafblindness, have presented challenges to early identification. In the first article of this special issue, Anthony discusses the importance of early identification of deafblindness, etiologies currently associated with deafblindness, and medical screenings and evaluations for

hearing and vision loss. Early identification of deafblindness is essential to referral for appropriate medical and educational interventions.

A need for intensive intervention in communication is seen in every era and across historical population shifts, and we have seen a continuing need for research on the efficacy of various strategies used in teaching communication to individuals who are deafblind. In the absence of other communication modes, the young Helen Keller used challenging behaviors to control her environment. In their article, Bruce, Nelson, Perez, Stutzman, and Barnhill apply the framework of the four aspects of communication (form, function, content, and context) to organize their discussion of research findings on communication. Bruce et al. find that studies on receptive communication and literacy are an area of research need, while a relatively strong body of evidence exists to support increasing the frequency of expressive communication across forms and improving the skills of communication partners.

Social-emotional difficulties have been identified as particularly prevalent in children who are deafblind, including those with CRS and CHARGE syndrome, and there is an ongoing need for evidence-based strategies to help students moderate stress, self-regulate, and develop social relationships and friendships. Hartshorne and Schmittel begin their article with an overview of social-emotional development, focusing on attachment, empathy, and friendship. Next they discuss threats to social-emotional development experienced by children and youth who are deafblind, including etiological risks, sensory systems and sensory needs, individual and familial stress, lack of resources, challenging behaviors (which are often associated with limitations in communication), and struggles with self-regulation and self-monitoring. The authors suggest that inclusion in general education classrooms, supported play, and positive behavior supports that attend to how children who are deafblind experience other people, time, and space hold promise for promoting social-emotional development.

Although Helen Keller received much of her education at home, the importance of the family and the need to provide family support to an increasingly diverse population have come to the forefront because the vast majority of children and youth who are deafblind are now educated in their home communities rather than institutions and residential schools. Due to the lack of research on families of children who are deafblind, Correa-Torres and Bowen draw on literature on other disabilities that require high levels of support in discussing the impact of the diagnosis of deafblindness on parents and siblings. Families require highly individualized services that are considerate of their unique cultural and linguistic characteristics, and they need access to information and resources. Moreover, the shortage of professionals from minority backgrounds presents a barrier to the provision of family supports to diverse families that include a child who is deafblind, and this shortage remains a challenge for personnel preparation.

In contrast to the 18th century, when low-level technologies such as raised and embossed letters were used with individuals with deafblindness, technology options in the 21st century are vast. But knowledge of how to use these technologies effectively in curricular design to improve access and engagement is in the early stages. Hartmann and Weismer present three frameworks for organizing best practices in curriculum development: UDL (universal design for learning), SETT (student, environment, task, and tools), and SAMR (substitution involving technology, augmentation, modifying learning experience, and redefinition). UDL calls on teams to frontload their preparation to meet the needs of all learners, as opposed to making adjustments later. SETT supports team members in the assessment of each learner's needs in the context of the demands of each activity across the environments in which the learner participates. SAMR provides teachers with a framework to support decision making about how to integrate technology in the classroom. Future research is needed to learn more about how professionals make decisions about curricular access and engagement.

Successful transition planning is a relatively new concept. As we have already noted, Laura Bridgman was never able to transition back to her community, and planning for the future might have changed the outcome of her story. Transition planning remains crucial with the "new" population of students with multiple disabilities if they are to have meaningful futures. Zatta and McGinnity discuss the concept of quality of life as the grounding concept of current transition planning. Instruction on the expanded Common Core curriculum, community participation, person-centered planning, collaborative efforts that include the family, and coordinated services are among the essential elements of successful transition efforts.

The need for children and youth who are deafblind to have access to teachers and interveners who have specific knowledge and training in deafblindness has remained unchanged over the centuries. However, the deafblind population is now larger than in the 18th century, and students are dispersed throughout the country rather than clustered in large center-based schools. In addition, as Correa-Torres

and Bowen observe, the population of students is increasingly diverse. Therefore, the need for diverse and qualified teachers of the deafblind and interveners has never been greater. Parker and Nelson apply the framework used in response to PL 99-457 (the Education of the Handicapped Act Amendments of 1986), which mandated early childhood special education, as they call for a comprehensive system of personnel development in deafblind education. They define the components of the framework: standards, preservice training, inservice/professional development, leadership development, research, and, centrally, planning, coordination, and evaluation. They then discuss what is in place and present ideas on how to move forward to develop such a coordinated and comprehensive framework.

As we reflect on the historical and contemporary experiences of learners who are deafblind and their families, we see early identification, communication, access, and engagement in schools and communities as ongoing challenges. Supports for families and transition services have changed remarkably, in part in response to legal mandates as well as increased advocacy by the families of children who are deafblind. The proliferation of technology, including cochlear implants, has created new opportunities for engaging with others and with the curriculum, but also requires that educational teams make very individualized decisions to meet the varied needs of each learner who is deafblind. Across articles in this *Annals* special issue, we are gratified to see the body of research that is available, but we also recognize the need for increased research. Future educational efforts and research will particularly have to address the increasing population of children with multiple disabilities and how best to meet their needs for social relationships, communication, and individualized learning at home and in their communities and schools.

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References

Bruce, S. M., & Borders, C. (2015). Communication and language in learners who are deaf with disabilities: Theories, research, and practice. *American Annals of the Deaf, 160,* 368–384.

Collins, M. T. (1995). History of deaf-blind education. *Journal of Visual Impairment and Blindness. 89,* 210–212.

Enerstvedt, R. T. (1996). The development of education for deaf-blind people. In R. T. Enerstvedt, *Legacy of the past: Those who are gone but have not left: Some aspects of the history of blind education, deaf education, and deafblind education with emphasis on the time before 1900.* Retrieved from http://folk.uio.no/regie/pdfd/Deafblind.pdf

European Parliament. (2004). *Declaration of the European Parliament on the rights of deafblind people*. Retrieved from http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P5-TA-2004-0277+0+DOC+XML+V0//EN&language=SL

Farrell, G. (1956). *Children of the silent night* (Perkins Publication No. 18). Watertown, MA: Perkins School for the Blind.

Individuals With Disabilities Education Improvement Act Amendments of 2004, Pub. L. No. 108-446, 20 U.S.C. §1400 et seq. (2006 & Supp. V. 2011)

Lagati, S. (1995). "Deaf-blind" or deafblind"? International perspectives on terminology. *Journal of Visual Impairment and Blindness, 89,* 306.

Lambert, N., Strebel, P., Orenstein, W., Icenogle, J., & Poland, G. A. (2015). Rubella. *Lancet, 385*, 2297–2307. doi:10.1016/S0140-6736(14)60539-0

Lane, H. (1984). *When the mind hears.* New York, NY: Random House.

McGinnity, B. L., Seymour-Ford, J., & Andries, K. J. (2004). *Laura Bridgman*. Retrieved from Perkins Schools for the Blind website: http://www.perkins.org/history/people/laura-bridgman

McLetchie, B. A. B. (1995). Teacher preparation. In N. G. Haring & L. T. Romer (Eds.), *Welcoming students who are deaf-blind into typical classrooms* (pp. 89–104). Baltimore, MD: Brookes.

Rasmussen, M. D., Jamieson, D. J., Honein, M. A., & Petersen, L. R. (2016). Zika virus and birth defects: Reviewing the evidence for causality. *New England Journal of Medicine, 374*, 1981–1987. doi:10.1056/NEJMsr1604338

Robbins, N. (Ed.). (1983). *Deaf-blind education: Developing individually appropriate communication and language environments.* Watertown, MA: Perkins School for the Blind.

Schalock, M. (2015). *The 2014 National Child Count of Children and Youth Who Are Deaf-Blind*. Monmouth, OR: National Center on Deaf-Blindness. Retrieved from https://91372e5fba0d1fb26b72-13cee80c2bfb23b1a8fcedea15638c1f.ssl.cf1.rackcdn.com/cms/2014_National_Deaf-Blind_Child_Count_Report_v112015_641.pdf

Staples, J. E., Dziuban, E. J., Fischer, M., Cragan, J. D., Rasmussen, S. A., Cannon, M. J., et al. (2016). Interim guidelines for the evaluation and testing of infants with possible congenital Zika virus infection: United States, 2016. *Morbidity and Mortality Weekly Report*, *65*(3), 63–67. Retrieved from http://dx.doi.org/10.15585/mmwr.mm6503e3

Van Dijk, J., & Nelson, C. (1998). History and change in the education of children who are deaf-blind since the rubella epidemic of the 1960s: Influence of methods developed in the Netherlands. *Deaf-Blind Perspectives, 5*(2), 1–5. Retrieved from National Center on Deaf-Blindness website: http://documents.nationaldb.org/dbp/pdf/dec97.pdf

Van Dijk, R., Nelson, C., Postma, A., & van Dijk, J. (2010). Deaf children with severe multiple disabilities: Etiologies, intervention, and assessment. In M. Marschark & P. Spencer (Eds.), *Oxford handbook of deaf studies, language, and education* (Vol. 2, pp. 171–192). New York, NY: Oxford University Press.