Optometry (2008) 79, 378-390

A telephone survey of low vision services in U.S. schools for the blind and visually impaired

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KEYWORDS
Health care quality;
Access and evaluation;
Disabled children;
Low vision

Abstract The scope of clinical low vision services and access to comprehensive eye care through U.S. schools for the blind and visually impaired is not well known. Advances in medicine and educational trends toward inclusion have resulted in higher numbers of visually impaired children with additional cognitive, motor, and developmental impairments enrolled in U.S. schools for the blind and visually impaired. The availability and frequency of eye care and vision education services for individuals with visual and multiple impairments at schools for the blind is explored in this report using data collected in a 24-item telephone survey from 35 of 42 identified U.S. schools for the blind. The results indicate that 54% of the contacted schools (19) offer clinical eye examinations. All of these schools provide eye care to the 6 to 21 age group, yet only 10 schools make this service available to children from birth to 3 years of age. In addition, two thirds of these schools discontinue eye care when the students graduate or transition to adult service agencies. The majority (94.7%) of eye care is provided by optometrists or a combination of optometry and ophthalmology, and 42.1% of these schools have an affiliation with an optometric institution. When there is a collaborative agreement, clinical services for students are available more frequently. The authors find that questions emerge regarding access to care, identification of appropriate models of care, and training of educational/medical/optometric personnel to meet the needs of a very complex patient population.
Optometry 2008;79:378-390

In order to meet the needs of children with vision impairment and blindness, 3 U.S. schools for the blind and visually impaired began operations in the first half of the 19th century. These schools were located in Boston, New York, and Philadelphia, with the Perkins School for the Blind, in Boston, the first school to be incorporated, in 1829.[1]

For more than 20 years, the Perkins School for the Blind and the New England College of Optometry have collaborated to deliver eye care and vision education services to the students enrolled at the school and to individuals with multiple disabilities throughout New England. This article reports on a survey to determine the availability of eye care and models of service used at other schools for the blind throughout the United States.

Epidemiology of blindness and visual impairment in children

Worldwide, vision impairment is a relatively uncommon but significant condition. The causes of vision impairment vary throughout the world by geographic region and by level of economic development. For example, a common

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1529-1839/08/$ -see front matter © 2008 American Optometric Association. All rights reserved.
doi:10.1016/j.optm.2007.11.010

cause of childhood blindness in India historically has been vitamin A deficiency. However, with this issue identified and interventional systems put in place along with developing economic infrastructure, there has been a significant reduction blindness from this cause. As economic development in India has occurred in the last 30 years, there has been an increase in the number of children with vision impairment caused by retinal disorders, perhaps because of improved survival rates of premature babies.[2]

In the United States, childhood vision impairment and blindness is not common and is often found in conjunction with other disabilities. Though firm national statistics are not available, a project sponsored by the Centers for Disease Control and Prevention was implemented to estimate the prevalence of various developmental disabilities. This study, which was done in the greater Atlanta area over the last 25 years, serves as a useful proxy.[3] The Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), which was performed in the greater Atlanta area over the last 25 years, serves as a useful proxy.[3] The prevalence of vision impairment (IV) was studied in this area from 1991 to 1994 for individuals ages 3 to 10 years.[3] In 1996 the prevalence of VI in 8-year-olds was 1.4 per 1,000 and in 2000 it was 1.2 per 1,000.[4] The MADDSP also showed that approximately 66% of children with vision impairment also had another disability, such as mental retardation, cerebral palsy, or epilepsy.[4]

Additional information can be gleaned from data provided by "The Babies Count: The National Registry for Children with Visual Impairments Birth to 3 years." This surveillance project had participation by 14 states and collected data from children who were referred to early intervention programs between January 2000 and March 2004. Some preliminary data from 1,533 children enrolled in this study, sponsored by the American Printing House for the Blind, reveals a relatively equal sex distribution (55% male, 45% female) with 40% being legally blind, 25% visually impaired, and 35% unknown at time of survey. The most prevalent visual conditions were cortical vision impairment (24%), retinopathy of prematurity (17%), optic nerve hypoplasia (9%), and albinism (6%). The most prevalent non–vision-based disabling conditions, including syndromes, were cognitive disabilities (19%), brain trauma or damage associated with cognitive disabilities (16%), and cerebral palsy (15%).[5]

However, the rates of visual impairment in children may be underestimated for a variety of reasons. Prevalence and incidence rates of visual impairment may be under-reported because of the lack of access to care, decreased rates of participation in the community or education system (whether in a school for the blind or a traditional school), or enrollment at another school/institution for another disability. Finally, prevalence rates of children with vision impairment from specialized schools or residential programs may not accurately reflect the actual number of children with significant levels of impairment in the community. Reasons for this inaccuracy, or these levels of impairment, include residence in rural versus urban settings, cultural bias against seeking medical help, and a lack of preschool programs or services for younger children with additional handicaps.[6]

Schools for the blind and visually impaired

The population at U.S. schools for the blind has changed dramatically over the last 20 years for 2 reasons. The educational trend of inclusion and mainstreaming have allowed for increased education of individuals in the local public school for whom vision loss is the sole disability. Secondly, because of the increased survival rate of individuals from complicated pregnancies and births as well as the increased survival rate of low and very low birth weight babies, there are an increased number of visually impaired children who also have many complex intellectual, sensory, and other medical issues for which the local public school system is ill-prepared. Thus, the population at many schools for the blind often consists of many visually impaired children with additional impairments.[7] At Perkins School for the Blind, these additional impairments include intellectual, motor, hearing, behavioral, and sensory (including hearing loss and sensory integration difficulties).

Other publications have described the student populations at schools for the blind and visually impaired in Oklahoma,[8] the Alabama School for the Blind,[9] and Illinois School for the Visually Impaired[10]; as well as reports on the causes of visual impairment among children in Iowa.[11,12] These studies have reported significant differences in the prevalence of various conditions. For example, retinopathy of prematurity is found in 0.8% of students in the Alabama School for the Blind, 10% at the Oklahoma School for the Blind, and 7.2% of children seen in Iowa.[9,11] The reasons for the discrepancy may be partially attributable to the time frame of data collection. For example, the Oklahoma study was published in 1988, and the Illinois study was published in 2001. Between these dates medical advances that reduce the mortality rate for infants with low birth weight or an improved treatment that limits vision loss were developed.

Research by Pal et al.[13] found that children with vision impairment enrolled at a school for the blind in India benefited from refraction and low vision services. Wilkinson's work highlights the need for optical as well as nonoptical approaches to low vision care and the necessity for a team approach to care.[11,12] Miller et al.[14,15] also noted the importance of using a multidisciplinary team when evaluating individuals who are visually or multiply impaired.

Care for people with disabilities

Many children who are enrolled in U.S. schools for the blind and visually impaired can also have other diagnoses

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