

Community Services, Needs, and Resources in Visual Impairment: A 21st Century Public Health Perspective

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Abstract: This article suggests that a 21st century public health perspective on community needs and resource mobilization in vision impairment be grounded in a holistic concept of the community. This perspective should recognize the nature and magnitude of blindness and visual impairment within the significant technological, demographic, political, and sociocultural changes that characterize today's complex community structures. These changing community dynamics are linked with strategies for organizing and mobilizing resources. The article concludes with three propositions and a call for political action to transform our currently fragmented system of providing services into an integrated strategy for the 21st century.

A public health practitioner views a community—that is, people living in a geographically and (usually) governmentally defined area—as an organic, dynamic living system. This system is a complex entity that experiences stresses and strains; manifests signs and symptoms of health and disease; and creates a more or less health-promoting environment. To a public health practitioner, the health of the individual is inevitably influenced by the health of the community. This interdependence requires that service providers understand the changing signs and symptoms of the communities as potential barriers to the optimal health of its residents. Lack of understanding and appreciation of these community dynamics will ultimately limit our ability to

treat, educate, and rehabilitate the people we serve.

A 21st century public health perspective on community needs and the mobilization of resources for individuals with vision loss should, therefore, be anchored in a deep understanding of the changing nature of communities and the essential integrative role that service providers need to play in response to these changes. Unfortunately, health care, education, and rehabilitation providers are too often handicapped by their continuing differences in training, terminology, philosophy, values, and practice—differences that limit their collective and collaborative effectiveness. In attempting to work together, the members of this provider infrastructure seek a common goal; too often, however, they

become part of the fragile, fragmented, and ineffective structures with which blind and visually impaired individuals and their families contend every day. A public health approach can serve as a framework for more fully and effectively integrating services across service providers, especially at the local level.

Approaches to overcoming barriers to the integration of services at the community level should start with recognition of the significant technological, demographic, political, and sociocultural changes that characterize today's complex community structures. These include interactions among social and physical environments, genetics, individual behavioral and biological responses, disease, health care, health and functional well-being (Evans & Stoddart, 1990). Ultimately, the needs of individuals with vision loss and the providers who serve them can best be met by a community "that is continually creating and improving those physical and social environments and expanding those community resources which enable people to mutually support each other in performing all the functions of life and in developing to their maximum potential" (Duhl, 1990, p. 94).

This article presents an overview of the multifarious changes occurring in our communities, and focuses on the roles of aging and technology as two key forces in reshaping daily life. Vignettes illustrating a diverse set of circumstances will highlight the need for each of us to go beyond our disciplinary perspectives (see Boxes 1–4) to help create a new, holistic sense of community that can begin to ameliorate the current fragmented system of service delivery for people who are blind or visually impaired. The article concludes with

three propositions aimed at promoting interdisciplinary collaboration powered by information technology and bolstered by common goals.

Magnitude and nature of the need

One of the most significant challenges for public health planning is the uncertainty of prevalence data on individuals who are blind or visually impaired, particularly at the community level. The following list is not intended to be comprehensive; instead, it is illustrative of the diverse sources of information on selected segments of the population.

- Based on data from the 1996 National Health Interview Survey, less than 1% (0.6%) of those under the age of 18 are visually impaired (defined as blindness in one or both eyes, or any other trouble seeing even when wearing glasses), representing 448,000 children and youth (Adams, Hendershot, & Marano, 1999).
- Only one in three children has received eye care services before age 6. Many childhood eye diseases can be treated and cured if detected early, yet the number of children tested falls short (Prevent Blindness America, 2005).
- The Department of Veterans Affairs has estimated that, in 2003, 157,000 veterans, 44,000 of whom were enrolled in Veterans Administration health care, were legally blind. The majority were elderly and had additional disabilities and other health care issues (VA Healthcare, 2004). In 2006, the executive director of the Blinded Veterans Association testified before

the House Veterans Affairs Committee that the Walter Reed Army Medical Center staff members alone have treated nearly 120 soldiers with either blindness or significant visual injuries, and that at least 78 service members connected with Operation Enduring Freedom or Operation Iraqi Freedom are receiving benefits connected to vision loss. Miller continued in his testimony to state that the number of blinded veterans enrolled in the Veterans Administration, by the year 2010, will grow to almost 55,000, and that the number will continue to rise. Today, there are 1,212 blinded veterans waiting an average of almost 19 weeks to enter one of the 10 Veterans Administration Blind Rehabilitation Centers (Miller, 2006).

- The Vision Council of America estimates that more than one million U.S. baby boomers will double the blind/visually impaired population over the next 30 years (Kuykendall, 2005). Vision impairment ranks as one of the four prominent contributors to lost independence in this older population (Leonard, 2002).

The expansion of the blind and visually impaired population is complicated by its heterogeneity. The population of individuals who are blind or visually impaired in the United States is generally similar to the diversity of the general population but tends to be older, more female, poorer, and somewhat different ethnically. It includes individuals from traditionally underrepresented groups, such as those who have recently immigrated to the United States or who are first-generation citizens, those who reside in rural areas, those who fall below the

Ethnic and linguistic diversity

A young Mexican mother of three children, one of them an infant diagnosed with a visual impairment due to Downs's syndrome, speaks only Spanish. Her early intervention vision support teacher is bilingual in Spanish and English. The family lives with several other male and female relatives and their young children in a two-bedroom house in a mid-size city in Massachusetts. When the service provider works with the mother and baby, they often must do so quietly because the male relatives' work schedule necessitates that they sleep during the day.

Box 1.

poverty line, those who are unemployed or underemployed, and many others who are underserved for a myriad of reasons (Leonard, 2002) (see Boxes 1 and 2).

It is very often difficult to establish clear prevalence trends, given the complexity of

Family structure and poverty

A single teenage mother of a 1½-year-old boy with multiple disabilities, including a seizure disorder and visual impairment, lives in a single room in a large city. In addition to working with the child, the service providers spend a portion of their visits working with the mother to schedule medical appointments and the necessary transportation, which is often unreliable. The vision teacher sometimes accompanies the young mother to her visit with the ophthalmologist. The vision teacher also writes a grant to obtain a bath seat as well as a switch-activated toy for the child.

Box 2.

the data. This difficulty presents real problems for effective health planning. For example, over half of the number of children who are blind or visually impaired in the United States (59%) also have additional or multiple disabilities (Kirchner & Diamant, 1999). These data, as well as reports of higher prevalence rates of multiple impairments among infants, children and youth, have been supported through other research (Ferrell, Shaw, & Dietz, 1998; Ferrell & Suvak, 1993; Johnson-Kuhn, 1995; Mervis, Yeargin-Allsopp, Winter, & Boyle, 2000). Cavanaugh and Pierce (1998) found that, among adults being served in disability-specific and general rehabilitation agencies, roughly 50% had disabilities secondary to blindness or visual impairment. The vast majority of the elderly have additional conditions such as diabetes and cognitive, hearing, or balance disorders.

Adding to this variation in ethnicity, language, geographic location, socioeconomic status, and the presence of additional disabilities and other health impairments is the reality that blindness and visual impairment themselves differ from individual to individual. And these differences manifest themselves along the lines of functional vision, adaptation to vision loss, age of onset, stability or progressive nature of the condition, and stability or fluctuating nature of functional vision (Huebner, 2000; Riley, 2000).

Population changes in the United States, coupled with the magnitude and growing diversity of the blind and visually impaired population, yield a complex and challenging landscape for individuals with vision loss and the professionals who serve them. Knowledge of these forces and the skills to address them on

both a national and local level are essential for effective intervention, whether it be by the individual, family, or service provider.

Changing communities

The last 50 years have brought profound changes in the nature of communities, their health status, and the growing complexities facing their members with visual impairments, as well as those who serve them. The following e-mail, recently received by one of the authors from a former graduate student in blindness and vision impairment, highlights the multiplicity of day-to-day challenges facing individuals within these changing communities:

Do you recall teaching us to look at the whole student; his family, ethnic, medical, cultural, and educational backgrounds? I have a middle-grade student who has so much going on. He has retinitis pigmentosa, which left him with light perception. Both parents are serving time in jail. He lives with his grandparents, a young uncle, his sighted older brother who is very academic and athletic (who makes it his responsibility to assist his brother in studying whenever possible), and a younger female cousin. They are living below the poverty level. My student was also identified as learning disabled two years before he lost most of his vision. His maternal grandfather was murdered, and the list could go on, but I think you get the picture.

I so enjoy and wonder at his sense of humor. With all that is sad and

challenging in his life, he manages to maintain his humor and positive perspective on life. At times, this gets him in trouble with his teachers and paraprofessional, as he misses the non-verbal cues that he is going too far. When he is working for me, he always reins in and gets back on task, but then I let him know he is pushing a bit too far. I want to encourage his enthusiasm and creativity.

This boy and his surrounding life influences represent but a microcosm of the evolving considerations providers must address in the ever-changing community landscape. Changing communities and the factors altering them are essential considerations for service providers striving to adopt a 21st century public health perspective on community needs. Population demographics; ethnic, racial, and linguistic diversity; crime; poverty; economic disparities; family structure; and information technology are just some aspects of the American community that have seen dramatic transformation. Two of the most significant forces changing the public dynamics of our communities are the aging of the U.S. population and the emergence of information technology.

AGING

One of the most significant demographic changes in our communities is the aging of the general population. A number of characteristics of the elderly underscore the interdependence of the factors that are shaping their public health status. From 1950 to 2004, the proportion of the population age 75 years and over rose from 3% to 6%. It is projected that by 2050,

12%, or about one in eight Americans, will be 75 years or older (National Center for Health Statistics, 2005). The relationship between age and visual impairment is dramatic. More than two-thirds of visually impaired adults are over age 65. The leading causes of visual impairment in the U.S. are age-related; these include cataracts, macular degeneration, primary open-angle glaucoma, and diabetic retinopathy (National Institutes of Health, 2000).

The significant increase in visual impairment with age is often accompanied by increases in other chronic conditions, such as senility, lung disease, diabetes, hearing loss, and heart disease, which limit activity (see Figure 1). These limitations of activity have been accompanied by an increase in the proportion of adults 65 years of age and over who report needing help with activities of daily living (ADL; National Center for Health Statistics, 2005). In general, there is a threefold increase in the number of elderly persons reporting ADL limitations in the 64–74 and 75 and older age groups (see Box 3).

Age-related disparities in the ability to perform ADL tasks independently are complicated when the variable of ethnicity is considered. For example, Hispanics are expected to be the nation's largest minority group and to triple in population by mid-century to 98 million, approximating 25% of the total population (Prewitt, 2001). The implications of this demographic change are compounded in light of the finding that, compared to whites, Hispanics have three times the risk of developing Type 2 diabetes and a higher risk of complications (National Institutes of Health, 2000). In addition,

Community resources and linkages

A 68-year-old retired widow, who has been legally blind for the past three years due to diabetic retinopathy, lives in her own home with a male friend in the suburb of a major city. Three years after her first call to her state services for the blind, she was visited by a rehabilitation counselor. While she continues to be on a waiting list to receive counseling, daily living skills training, and orientation and mobility services, she and her partner explain her increasingly more pressing needs to her endocrinologist, internist, ophthalmologist, diabetic nurse, and even emergency room physicians and nurses. Her diabetic nurse teaches the woman how to use adaptive devices for measuring her glucose levels and preparing her daily insulin injections. The diabetic nurse also links her with an independent living center, a countywide private rehabilitation center for the blind, a support group, and a consumer organization.

Box 3.

among older adults, the proportion reporting limitations in activities of daily living was higher among Hispanics and non-Hispanic blacks than non-Hispanic whites (National Center for Health Statistics, 2005).

The dramatic changes in demographics related to aging will put stress on families, caregivers, and their communities. The needs of the frail elderly for care represent a large part of the chronic care system, and will place increasing demands on shrinking families (Wolf, 2001). In addition, elder abuse is emerging as a significant problem in our communities. According to the best available estimates, between one and two million Americans age 65 or

older have been injured, exploited, or otherwise mistreated by someone on whom they depended for care or protection (Bonnie & Wallace, 2003). Estimates of the frequency of elder abuse range from 2% to 10%, based on various samplings, survey methods, and case definitions (Lachs & Pillemer, 2004).

Notwithstanding concerns about today's fragile family structure, the U.S. Administration on Aging's (2006) fact sheet reports that "the degree of caregiver involvement has remained fairly constant for more than a decade, bearing witness to the remarkable resilience of the American family in taking care of its older persons. This is despite increased geographic separation."

TECHNOLOGY

Perhaps one of the most dynamic factors affecting so many day-to-day aspects of our lives, as well our approach to and delivery of services to individuals with visual impairments, is the breakneck pace of change in information technology permeating all aspects of our lives. Over the past 25 years, American communities have been transformed into "cybervillages." The distance of geography has been trumped by the connectedness of technology. Internet cafés, Blackberries, pod-casting, blogging, Wi-Fi friendly cities, wired communities—the new language of the cyber-communities is empowering individuals and groups by affording them greater accessibility and potential responsibility for their own well-being. However, current community disparities limit the potential impact of these technologies.

The trends in technology have built up sufficient momentum to reach the White House, where President Bush launched

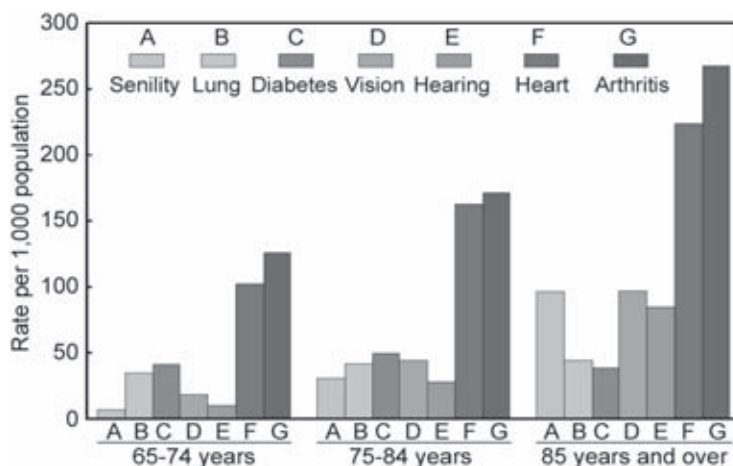


Figure 1. Chronic conditions causing limitation of activity, 2002–03. Source: Centers for Disease Control and Prevention, National Center for Health Statistics, *Health, United States, 2005*, figure 20.

an ambitious agenda for change, entitled *Transforming Health Care: The President's Health Information Technology Plan*. The President's announcement of the plan during his State of the Union address on January 20, 2004, included a strategy to ensure that most Americans have electronic health records within the next 10 years and that information technology is aggressively used to improve the quality of health care in the United States (Office of the U.S. President, 2004).

The march of technology has affected those who are blind and visually impaired in contradictory ways. Advances in medical and clinical technology mean longer life spans for people today, thus an increase in an aging population that is more likely to be diagnosed with age-related visual impairment (Stuen, 2000). On the other end of the life cycle, advances in medicine and clinical technology enable newborns who once might not have been viable to survive and live with disabling health conditions associated with visual impairment (Zambone, Ciner, Appel, & Grayboyes, 2000).

Modern technology has also been responsible for enabling individuals with visual impairment to gain greater access to information (Kapperman & Sticken, 2000) and to participate with nondisabled peers and colleagues on a more level playing field (American Council of the Blind, 2006; National Federation of the Blind, 2006). Technology has also enabled vision professionals, as well as individuals with visual impairments and their families, to access information about disability, education, and law, in turn helping to lessen the potentially negative impact that a disability may have on one's life (see Box 4). Examples include the BVI-Parents electronic mailing list (<http://groups.yahoo.com/groups/BVI-Parents>), which daily brings together more than 550 parents and other concerned individuals from around the world to discuss topics related to raising children who are blind or visually impaired; the web site of the Texas School for the Blind and Visually Impaired (<http://www.tsbvi.edu>), which offers multiple resources and web

Technology

A 9-year-old girl who is visually impaired, in second grade at her local elementary school, was adopted from China by her American parents a year and a half earlier. The student was homeschooled by her mother during the previous school year in order to ease the child's transition into her new family and community. She communicates with her classmates, teachers, and family in English but is showing some delays in concept development. While in the planning stages of the adoption, the child's parents joined an electronic mail list for parents of children who are blind or visually impaired in order to inquire about the child's eye condition, typical educational needs of students who are visually impaired, and ophthalmologists with good reputations in her geographic area. The parents of this child also used the electronic e-mail list to connect with other families across the country that homeschool their children with visual impairments and to begin collecting curricular resources.

Box 4.

connections for "all blind and visually impaired students in Texas"; and the electronic mailing lists of the Association for Education and Rehabilitation of the Blind and Visually Impaired (<<http://mail.lists.aerbvi.org/mailman/listinfo>>).

National and community public health strategies

The changing fabric of communities—and their goals and strategies in serving the needs of members who are blind and visually impaired—reaffirms the importance of community health strategies in mobilizing resources. This is not a new concept. The recognition that "health is

a community affair" was underscored 40 years ago in the report of the National Commission on Community Health Services (1966), which called for a melding of the many separate programs into a community-wide system for greater effectiveness. More recently, then First Lady Hillary Rodham Clinton (1996) echoed the value of community when she called for American society to identify the "places where our 'village' is flourishing—in families, schools, churches, businesses, civic organizations, even cyberspace—[so that] we can begin to create for our children the better tomorrow they deserve."

Healthy People 2010 (U.S. Department of Health and Human Services, 2001) is one example of a national plan to improve the lives of American communities and their citizens, targeting the most significant preventable threats to health and establishing national goals to reduce these threats. Its concluding chapter (Chapter 28) identifies opportunities, issues, and trends related to vision loss, and points to the importance of low vision services as part a comprehensive 10-point plan to improve vision health. The plan outlines specific needs to be addressed, such as increasing eye examinations, reducing refractive errors and preventable blindness, and expanding the use of vision rehabilitation services and visual and adaptive devices by people with visual impairments.

Healthy People 2010 also includes a companion document, *People in Healthy Communities—A Community Planning Guide* (U.S. Department of Health and Human Services, 2001). It calls for building community coalitions to create a vision, establish partnerships dedicated to improving community health, and measure outcomes. More recently, the

Institute of Medicine (2002) identified the vulnerabilities of a “Post-September 11” public health system and called for a “multisectoral engagement in partnership with government and the roles that different actors can play to support a healthy future for the American people.”

These broad national appeals for the establishment of a community partnership constitute an urgent call for change. Some positive action has taken place, for example, in mobilizing community resources for the visually impaired. As a result, locating services is easier than it was in the past. This is, in part, possible through publications and web site searches of the American Foundation for the Blind’s (2005) most current publication of a directory of services for blind and visually impaired people in the United States and Canada. This well established resource lists information on over 1,500 organizations, agencies, and product manufacturers, providing descriptions of services along with full contact information, including web sites and e-mail addresses. Further, a web search by the author for “agencies and organizations of and for the blind in the US” took .46 seconds to identify 23,200,000 results. Yet:

Despite the existence of a number of vision rehabilitation services in the U.S., access to these services has been limited. The reasons for this include inadequate referral rates from optometrists and ophthalmologists, a general unawareness among the visually impaired concerning the availability of services, and financial and physical barriers. Consequently, access to, and the adoption of, vision rehabilitation

services has, to date, been suboptimal. (Agency for Healthcare Research and Quality, 2004, pp. 36–37)

Underlying reasons for this disparity include the diversity of the blind and visually impaired population and the complexity of the delivery of services for this low-incidence disability. Service provision is frequently spread thin and operates independently of related providers, both within and outside its primary functions. Interventions may be conducted by public and private agencies, through provision of direct services or consulting. They may be disability-specific or general, and center-, community-, or home-based. Providers may serve people of all ages, but most focus on specific age ranges (birth to 3; working-age adults, etc.).

Whether or not these organizations consider themselves to be working within the broader community framework, they do serve a national community of interest. Blind and visually impaired individuals throughout the nation (and beyond) receive services in various settings on a variety of levels: in states, districts, counties, or local cooperatives; in remote hamlets; on Native American reservations; in ethnic enclaves within larger, complex communities; in affluent suburbia; in poverty-stricken inner cities, or in a megalopolis made up of many different communities and cultures.

Individuals who are visually impaired, as well as their families, all want the same thing: quality and appropriate services in a timely and consistent manner. In this regard, the role of families and patient support systems can be strengthened and expanded, especially through

the use of information technology. Those closest to the problem are usually the best in catalyzing the mobilization of resources to acquire the services. Too often, the problem is not lack of resources but obstacles to accessing them efficiently and effectively. Overcoming such barriers requires innovative initiatives within and around the community to bring about access and partnership solutions.

Mobilizing to meet the need

It is incumbent upon eye care providers and education and rehabilitation specialists to conceptualize and implement a collaborative national action plan to meet the needs of blind and visually impaired individuals of all ages. All of us working in this field should become engaged in advocating for specific objectives directed at the needs of people with vision loss. The complex dynamics of the 21st century community present a challenge to providers to extend themselves and, in some instances, reinvent their professional paradigms. To do this, a new concept of community, empowering both consumers and providers, is called for. Within the new paradigm, service providers will not only recognize the changing community dynamics, but will see themselves as part of these dynamics and realize that they may be required to change their ways of working.

The overarching reality is that all the stakeholders will benefit from a unifying strategy, a shared understanding, and a catalyst for seizing the opportunities that the 21st century offers. Following are three propositions designed to mobilize the community for collaboration and impact:

1. Establish a model Community Action Commission, bringing community stakeholders together to develop a strategic plan for addressing the needs of individuals with visual impairment. Such a commission would include public health professionals and providers serving blind and visually impaired people, and its efforts would be directed at implementing a political action agenda underpinning the following two initiatives.
2. Establish a national Blindness and Vision Impairment (BVI) eVillage that serves as a portal for all the stakeholders to access resources, share knowledge and experiences, and promote a holistic collaboration. The eVillage would be community centered and problem oriented.
3. Establish, as part of a comprehensive electronic health card profile, a BVI data set that serves as an information matrix containing the relevant data on an individual's vision impairment. It would use a common language that is clear and meaningful to the individual, the family, and the service provider, which would facilitate collaboration. It would offer more than traditional medical data and include educational, rehabilitation, and other pertinent information in a form that is accessible to all parties concerned. Allowing for the fact that confidential information might need to be made more accessible to a greater number of professionals, confidentiality would have to be enforced. The idea of an electronic health card profile may be a controversial proposal, but, as imagined here, the benefits of collaboration would outweigh the negatives.

It is our belief that timely communication and collaboration across the consumer/provider/community spectrum is a prerequisite to meeting the community's needs fully and effectively. It is not sufficient, however, simply to fulfill the responsibility that falls to each team member in executing the plan. At the core of this team are the individual and the family. Effective communication requires centralized resources that are easily accessible, interactive, and problem-oriented. Until every individual in need can access the right services by the right professionals at the right time and in the right place, we will have failed. It is only through creative and collaborative partnerships that this can be achieved.

The eVillage concept is certainly not new. It is being used with increasing impact around the world. Governments, businesses, and consumer groups of all types are converging their interests and strategies in cyberspace. The BVI eVillage would be more than an assemblage of facts and hyperlinks. It would be an objective, inclusive, and interactive source of knowledge to empower individuals, families, service providers, and communities to transfer and apply existing information to the solution of problems. It would be marketed to all stakeholders and involve them in everything from chat groups, on-line education, and e-consultations to decisions about triage and referrals. Certainly, the effectiveness of such an initiative would have to be sensitive to professional and legal issues so that it maintains public credibility. Private and public leadership should be urged to explore ways to bring groups together to address the steps necessary to realize this proposition.

The personal electronic card with a BVI data set is at the heart of the emerging

national health technology plan. The concept is to develop an electronic means of collecting, sharing, and updating all relevant information for a blind or visually impaired individual in a private and secure manner. The card would complement and extend the traditional electronic medical record, inasmuch as it would include the family and community context in which an individual functions. Such a source of information could transform the ways in which services are provided, eliminating discontinuity of information, reducing mounds of paperwork, and cutting costs of record keeping. We are all familiar with the building blocks already out there—electronic medical records, electronic exchange of test results, telehealth and tele-education, etc. The technology exists, and pilot projects should be launched to begin incrementally building such systems for blind and visually impaired individuals. The BVI data set would not be a stand-alone card, but would be designed to be integrated into a comprehensive health card, and would serve as a catalyst for its promotion.

The realization of such initiatives will demand leadership characterized by creativity, resourcefulness, and persistence. This article has proposed a Community Action Commission to move this process along. Such a commission could be an organic part of the “emerging public health focus” that is presented in this special issue of *JVIB*. Without the kind of coordinated follow-up proposed here, we may lose a key ingredient in the public health approach: mobilizing through political action to support a healthy and productive blind and visually impaired segment of every community in achieving its potential.

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