

The Low Visibility of Low Vision: Increasing Awareness through Public Health Education

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Abstract: The importance of an informational outreach program focused on eye health and visual impairment is underscored by surveys showing that the vast majority of Americans have misperceptions about or have never heard of low vision. This article uses the National Eye Institute's Low Vision Education Program as a model for the development, implementation, and evaluation of a public health education initiative. The components of an effective public education program are outlined in the context of what people know, don't know, and want to know about vision loss.

In keeping with the intent and obligation of public health educators to provide the best available information about advances in health and vision care, the National Eye Institute (NEI), part of the National Institutes of Health, U.S. Department of Health and Human Services, has developed a marketing message—*Make vision a health priority*—designed to encourage Americans to work toward the goal of incorporating eye health and vision care into their health maintenance routine. The slogan was developed in consultation with eye health professionals. NEI, working in conjunction with allied agencies and organizations, advocates that individuals adopt sight-saving strategies as an integral part of health care. This public health message is proving effective in focusing the attention of individuals and communities on methods for maintaining and improving vision health and eye care.

Through its National Eye Health Education Program (NEHEP), NEI conducts large-scale public and professional health education efforts focused on glaucoma, diabetic eye disease, and low vision, and additional topics are added as warranted by medical advances. NEHEP, established in 1991, is coordinated by NEI in partnership with national organizations in the public and private sector, with the goal of increasing awareness among health care professionals and the public about scientifically based health information that can be applied to preserving sight and preventing blindness.

NEHEP partners work together to reach identified target audiences, informing them of the importance of early detection and treatment of eye diseases and conditions, particularly glaucoma, diabetic eye disease, and low vision. This outreach effort was developed to enlighten and persuade people in the United States to

make appropriate changes in behavior in the interest of improving their eye health. Its stated aims (NEI, 2004) are to implement large-scale information, education, and applied research programs related to vision health and eye disease; and ensure that the results of eye and vision research are used for the benefit of all people.

Why educate the public about low vision?

Visual impairment is one of the 10 most frequent causes of disability in the United States (Verbrugge & Patrick, 1995). Low vision is a visual impairment that is not correctable by standard glasses, contact lenses, medicine, or surgery, and that interferes with a person's ability to perform daily activities. By elevating vision to a health priority and making this a major goal of the NEHEP partnership, NEI seeks to improve disability outcomes. NEI and Lions Clubs International Foundation (2006) jointly funded a 2005 survey of public knowledge, attitudes, and practices related to eye health and disease. Its findings suggest that the public is amenable to receiving vision health information, given that 71% of Americans rated loss of eyesight as the health condition that would have the most negative impact on their daily lives.

Some 3.3 million people over age 40 are blind or have low vision (Eye Diseases Prevalence Research Group, 2004). For Americans aged 65 years and older, vision loss and blindness are pressing health conditions. As Americans live longer, the individual and public health burdens of vision loss are expected to increase. Based on data from the NEI-Lions Club (2006) survey, only 16% of adults over the age of 18 have ever heard of low vision.

Vision loss and blindness can definitively and adversely affect an individual's independence and quality of life. For purposes of examining public health education efforts, low vision, a condition in demonstrated need of public attention and education, can serve as a salient and practical example of the ways in which effective programs are designed and implemented. In particular, this article will focus on the Low Vision Education Program sponsored by NEI, which has elements of development, implementation, and evaluation that demonstrate how NEI uses a public health education model.

WHAT PEOPLE KNOW, AND NEED TO KNOW, ABOUT LOW VISION

Although the prevalence of low vision is increasing, public understanding about the condition remains limited or, in some cases, misperceived. Blindness or low vision affects approximately 1 in 28 Americans older than 40 years. The specific causes of visual impairment, and especially blindness, vary greatly by race and ethnicity. The prevalence of visual disabilities is expected to increase markedly during the next 20 years, largely because of the aging of the U.S. population (Eye Diseases Prevalence Research Group, 2004).

Some vision loss may be preventable. Through qualitative and quantitative research, NEI has come to understand the importance of communicating the message that vision loss from eye disease often can be slowed, and the effects of vision loss can be mediated by use of low vision rehabilitation services. A second important message to communicate is that some vision loss occurs without symptoms, making regular and routine medical eye examination a health care necessity.

Many people who have low vision may initially perceive their impairment as simply “not seeing very well.” Some believe that loss of visual acuity automatically occurs with advancing age. Although low vision can be a direct result of aging, it may also result from eye diseases such as macular degeneration, glaucoma, and diabetic retinopathy. Individuals at risk for eye disease are often older; glaucoma, for example, is especially prevalent in those aged 60 and over.

Visual impairment due to low vision—and the resulting loss of independence and quality of life—is of particular concern to older Americans. However, some ethnicities do have greater risk for certain eye diseases at younger ages. African Americans, for example, often face an increased risk for developing glaucoma after the age of 40. Vision care delivered by an eye health professional, including an annual dilated eye exam, is the best prevention—and the focus of a critical public health message. Although vision that is lost to disease usually cannot be restored, people who have lost some sight can make the most of their remaining vision.

Building a public health education program

Evidence-based information is key to developing public health messages and communication strategies. National Institutes of Health (NIH) have spent years and significant resources investigating and developing health communications models. NEI used a four-stage model adapted from social marketing efforts to design and implement its low vision and other public education efforts. The four stages (see Box 1) are designed to be cyclical. The last stage feeds into the first,

creating a continuous cycle of planning, implementation, and refinement.

In Stage 1, the foundation of the health education program is formulated. In this

NEI model

- Stage 1. Planning and strategy development
- Stage 2. Developing and presenting concepts, messages, and materials
- Stage 3. Implementing the program.
- Stage 4. Assessing effectiveness and making refinements

Box 1.

initial stage, the organization identifies how to address most effectively the specific health problem under consideration. The organization should also clearly identify its intended audience, discuss and confirm its communication strategy and objectives, and pretest the communication efforts to ensure that they are informed by consumer research. Stage 1 is the time to draft full communication plans—including activities, partnerships, and baseline surveys for outcome evaluation.

NEI began its Low Vision Education Program in 1999. In its development phase and in its current implementation, the program receives direction from a variety of sources, including the NEHEP low vision subcommittee and the NEHEP partnership. Additional expertise has been provided by a panel of experts in the fields of health education, social marketing, and health information technology. The main goals of the Low Vision Education Program (NEI, 2000) are to:

- increase awareness among people aged 65 and older, their families and friends,

and the general public about low vision, and assure them that services, assistive technology, and environmental modifications and techniques are available to help people with low vision and to improve their daily functions;

- increase awareness among those affected by low vision that they are not alone and that help is available;
- increase actions taken by people with low vision, including consulting with eye care professionals and vision rehabilitation specialists, and expand the use of appropriate services, assistive technology, and environmental modifications that might improve their daily functions; and
- increase steps taken by family members, friends, and significant others to support those with low vision.

In sum, the program aims to address the impact of low vision on those who have it and to deliver the message that information and help are available to them, their families, and the health care professionals who serve them (NEI, 1999). As part of this developmental process, focus groups were conducted in selected sites across the country. These groups recruited people who had low vision, people at high risk for developing low vision, and professionals (including ophthalmologists, optometrists, and office staff members) involved in the low vision field.

Key findings from the preliminary research (NEI, 1997) suggests that focus group participants were more interested in seeking a cure for the eye disease than in learning how to cope with vision loss; did not perceive their vision loss to be serious enough to warrant the use and expense of services and devices; did not perceive

themselves to be within the constituency of organizations that offer services for “the blind”; and perceived low vision as part of the natural aging process, assuming that there is nothing to be done except adapt to the loss of independence.

In Stage 2, the concepts of the message are developed and pretested with the intended audience. Qualitative research methods usually are employed for pretesting. Based on outcomes of pretests, modifications to the communication strategy or to the program design can be articulated. For the Low Vision Education Program, focus group research demonstrated that incorporating positive and encouraging messages designed to address the psychosocial issues of independence and the ability to enjoy everyday activities was critical (NEI, 1999). Program messages include: hope and help are available if you are a person with low vision who is making the most of your remaining vision; visual rehabilitation and training can be beneficial and may help restore some measure of independence; minor, low-cost home modifications can make a significant difference in functioning and safety, and may also help restore some independence in daily living; and you are not alone: Help is available for the vision problems that interfere with the activities you used to enjoy.

In response to the focus group research, the program adopted key strategies—a broad-based, consumer media campaign; educational materials; and outreach programs that include a traveling low-vision exhibit—designed to raise awareness about low vision and the availability of rehabilitation services and adaptive devices for all target audiences. These strategies support the core message that hope and help are

available. To accomplish this, NEI provided a central source for low vision information via a toll-free phone number and web site (877-LOW-VISION [569-8474], <www.nei.nih.gov/lowvision>).

Stage 3, implementation, is the “roll-out” phase. With the benefit of careful formulation (Stage 1) and testing of the strategy on the intended audience and content experts (Stage 2), organizations can put procedures to work to accomplish the stated health communication objectives. Organizations should, as part of the implementation process, plan for and execute a periodic review of all program components to make any needed revisions to support program goals.

The Low Vision Education Program is well under way. NEI has developed a consumer-oriented web page that offers large-type options for people with low vision, and has also developed a booklet on the subject that is available in English and Spanish. In partnership with the American Foundation for the Blind (AFB) and Lighthouse International, NEI developed posters to publicize toll-free numbers dedicated to providing low vision resources and information (AFB: 800-232-5463; Lighthouse International: 800-829-0500).

The Eye Site, a traveling exhibit sponsored by NEI, is displayed in shopping malls throughout the country and staffed by volunteers from local organizations (NEI, 2006). It provides information about low vision and eye diseases, and includes an interactive multimedia touch-screen program, a list of local resources, and a display of various low vision assistive devices.

In 2003, NEI launched the Healthy Vision 2010 Community Awards Program, a juried competition that promotes the idea

that vision care is worthy of investment and provides grant money to the most effective community-based eye health education programs. Applicants are judged by a team of ophthalmologists, optometrists, health educators, and community representatives. The 309 awards that have been granted to date have stimulated collaborative community health education initiatives and provided seed money for vision-related health education projects.

Many of the awards have been effective in increasing awareness and use of low vision services. For example, the Greater Boston Guild for the Blind sponsors “Vision Boston,” which has dramatically increased the number of eye exams given at its low vision clinic. The “Living with Low Vision” program by the Badger Association of the Blind and Visually Impaired has educated the public and health care providers about the common causes of vision loss, preventive methods, coping mechanisms for living with low vision, and available visual rehabilitation services through its regional education conference, “Living with Age-Related Macular Degeneration.” In addition to creating a Vision Loss Guide to Services in multiple formats accessible by users with low vision, the Vision Services Education Collaboration project by Area 1 Agency on Aging has reached more than 700 residents and service providers through a series of community outreach events.

NEI has specific goals for these initiatives. Its awards program aims to reach Americans individually and through organizations that influence their communities. The NEI-Lions Club (2006) survey found that a majority of adults accept health care information and doctor visit recommendations from family members,

friends, and community leaders. The effort to reach the 84% of adults who have not heard of low vision (as well as the many adults who could use information about other vision care issues) could logically be addressed by providing funding to community-based organizations. Eye health information, delivered by community members, local leaders, and families, is becoming an established, respected, and reliable channel of communication through the Healthy Vision 2010 Community Awards.

Outcomes of the awards are reported to NEI by the recipient organizations. Increases in dilated eye examinations in a given community, introduction of low vision and other vision impairment information, expansion of vision health screenings and visits to eye care professionals, as well as greater awareness on the part of primary care physicians of the importance of referring appropriate patients for eye health examinations—these are all positive reported outcomes of nationally funded Healthy Vision Community 2010 Awards programs.

A study was conducted by NEI (2002) to assess eye health education programs and needs in federally funded independent living programs for people with visual impairments. For this effort, NEI partnered with the Department of Education Office of Special Education and Rehabilitative Services/Rehabilitation Services Administration Independent Living Services for Older Individuals Who Are Blind (a Title VII-Chapter 2 program) to determine whether there was a need for eye health education or outreach materials and how that need could be addressed. Information was solicited from 83 Chapter 2 program managers. Program

managers from 29 states and the District of Columbia responded via e-mail to discussion items. Program managers in 21 of these states and the District of Columbia reported having some type of eye health education program.

States that reported having more formal programs—formal programs were classified by the researchers as the systematic provision of services, including training, seminars, and eye health fairs—include Connecticut, Illinois, Massachusetts, North Carolina, and West Virginia. In Connecticut, a series of free seminars, entitled “There is Hope When Vision Fails,” are presented in communities around the state. They include information on age-related eye disease, new medical treatments, antioxidant vitamins, and other topics. In Illinois, three vehicles were used for eye health education: support groups, low vision fairs, and a conference. The low vision fairs inform the public about eye health, eye care, and vision rehabilitation services, whereas the conference updates participants about innovative eye treatments, accessible technology, and vision rehabilitation methods and strategies. States that reported having more informal programs—or the sporadic provision of services—include Delaware, Hawaii, Mississippi, and Virginia. Although these programs vary in structure, their main focus is on educating consumers about eye health care, including information on the prevention and treatment of eye diseases and the availability of services.

Another aspect of the Low Vision Education Program undertaken during Stage 3 was the submission and subsequent publication of a letter to “Dear Abby,” the advice column that reaches some 93 million readers through media organizations worldwide. Because

the majority of Americans report not having heard of low vision, finding a way to make the condition known to a broad audience remains a significant goal for the vision health community. The “staged conversation” format of “Dear Abby,” the column’s longevity and wide appeal, and the no-cost nature of the initiative represent an opportunity and a context for visibility that is unparalleled among general outlets for health communication.

In Stage 4, public health education programs often focus on assessment before the cyclical nature of the education project results in it beginning anew. In the best circumstances, outcome evaluation methods have been established in Stage 1 and can easily be put into play at this stage of the process. This is the time to assess the program’s effectiveness and to identify refinements that can enhance it in the future. All public health education programs in this field benefit from a feedback loop that incorporates both information solicited by the program builders and information provided with greater independence by consumers—including eye care professionals.

Evaluation is an active and ongoing component of all NEHEP activities, and the program uses process-evaluation measures to assess various elements of its educational initiatives. During the planning stages, process-evaluation efforts focus on the quality and appropriateness of the materials and approaches being developed. Literature reviews and focus groups are conducted to inform the development of materials and messages. For example, focus groups have been conducted with ophthalmologists, optometrists, and office staff to determine what they know about low vision and vision rehabilitation, what resources they would prefer to use in

their offices, and how they might educate people with low vision, their families, and their friends. NEHEP used the results of these focus groups to refine existing messages and materials and to explore new ways to disseminate information about low vision to eye care professionals.

For example, the traveling exhibit, *The Eye Site* (NEI, 2006), was evaluated for its ability to reach intended audiences, its effectiveness, and its behavior change messages. The survey team provided information to NEI and other interested parties on how to manage, improve, and develop the exhibit. Numerous methodological approaches were employed to assess public opinion and preferences, including an intercept study of exhibit users and nonusers, focus groups, and a suitability assessment of the kiosk panels and interactive multimedia program.

Ongoing evaluation is critical to the success and longevity of NEI programs and enables NEI to determine whether program objectives are being met or if changes are needed to improve effectiveness. The involvement of the NEHEP partnership in the evaluation process allows NEI the opportunity to hear about specific program strengths and weaknesses from practicing eye care professionals and their patients. Members of the partnership often are called upon to assess new materials as they are developed, both for accuracy of content and cultural appropriateness.

By tracking the distribution of materials and monitoring media placements in professional and trade journals, magazines, newspapers, and organizational newsletters, NEI gains insight into the reach of the program. The low vision web site provides readily accessible information

about rehabilitation services and adaptive devices to persons with low vision and their families. NEI is able to track the number and length of visits to this site, as well as the quantity and types of material being downloaded. In addition, NEI conducts random online surveys to assess consumer satisfaction on the ease of navigation, usefulness of information, and user's ability to find the desired information on the site.

The NEI-Lions Club (2006) telephone survey consisted of a base survey conducted nationwide with a random sample of 2,400 adults. The survey also included a supplemental oversample targeting the Asian subpopulation, which was designed to support more precise estimates for the Asian population of the United States. Although the base survey generated valid estimates for the American population overall (including Caucasians, Hispanics, and African Americans), it could not produce valid estimates for the Asian subpopulation. Due to cost constraints, we did not oversample the American Indian/Alaska Native population. Respondents answered questions about their general health, eye health, eye examinations, knowledge about eye disease, information sources, insurance, and demographic information. Between October 2005 and January 2006, 3,180 computer-assisted telephone interviews of the random sample and the Asian oversample were completed in English and Spanish. The results of this study will be used by NEI, the Lions Club Foundation, eye health researchers, and policy makers to guide eye health programs and messages to targeted audiences in order to increase awareness and effect changes in behavior regarding eye health practices.

Because program planning is a recurring process, planning, management, and evaluation should be conducted throughout the life of the program. Health communication helps to promote and improve health status by helping individuals to:

- gain knowledge or awareness of health issues, problems, and solutions;
- obtain accurate information that can influence perceptions and beliefs, and reinforce appropriate knowledge;
- suggest effective actions that can be taken to protect and preserve health status;
- demonstrate healthy skills and show the benefits of behavioral changes;
- refute inaccuracies, myths, and misconceptions;
- increase the demand and support for positive health actions and services; and
- advocate a position and strengthen relationships between relevant organizations.

Effective health communication is based on a social marketing framework—tailoring programs to serve a defined group and implementing a systematic, continuous process driven by decision-based research. Social marketing theories and models can be adapted and assessed to determine which of the specific ideas are likely to work for public health education programs. These can be used to guide the development of messages and materials. These methods also guide program developers as they decide which components of the program to evaluate and how to design evaluation tools. The following steps (from social marketing methodology) should be adopted to make health communication campaigns more effective:

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- Define the communication campaign goal.
 - Define the intended audience clearly and effectively.
 - Create clear and specific messages that stand up to repetition.
 - Pretest and revise messages and materials.
 - Implement the campaign for its defined target audience, and maintain ongoing evaluation.

What works in public health education programs

NEI (2005) conducted interviews with representatives of 10 governmental agencies and nongovernmental organizations to identify barriers to the receipt of health care, in particular, care that may prevent vision loss, and to determine best practices and strategies being used to deal with barriers to such care. According to the study findings, researchers and health care professionals believe that receipt of care is best influenced by establishing partnerships between provider organizations that have differing strengths. Collaborative relationships such as these engage representatives from diverse backgrounds, permit the inclusion of educational institutions that may not be involved directly in providing health care, and enable organizations to pool resources and otherwise achieve efficient procedures. In addition, community organizations that can be involved in partnerships already have working strategies in place to reach the very target populations that are underserved by the health care system, and thus face the greatest barriers to care.

The NEI (2005) study cites as an example an approach used by the Centers

for Medicare and Medicaid Services that addresses public health education as it relates to health literacy. The method (dubbed “4Ls and C”) is used to examine health communication strategies and determine the most appropriate messages based on an evaluation of “Location, Literacy, Language, Low income, and Culture”—five factors that require careful attention and specific focus if health care messages are to be appropriately received and effectively used.

NEI has undertaken extensive qualitative research to test the best ways to communicate prevention and rehabilitation messages to those already living with low vision or eye disease and in groups at high risk for developing eye disease. People with low vision were interviewed in focus groups, one on one, and by telephone. In addition, two existing support groups for people with low vision were interviewed (NEI, 1997). This multi-staged qualitative research has demonstrated that positive messages are key to success in reaching the targeted population. Participants, when asked to identify the most important messages that the program could convey, frequently said they wanted to hear that “information and help are available,” and they wanted to know where they could call to get additional information about their medical problems. Messages with a hopeful tone were most welcome, and participants were interested to learn that low vision is a common problem, not just theirs alone. This research and related findings (NEI, 1999) suggest that addressing the psychosocial issues of independence and the ability to enjoy everyday activities is critical in creating compelling low vision and vision care public health communication strategies. Individuals in

need of preventive vision care information are best served by multiple inputs:

- educated professionals across the health care spectrum, such as primary care physicians who will ask vision health questions and make appropriate referrals;
- outreach programs to increase awareness of vision health issues, such as the traveling low vision exhibit (NEI, 1999);
- outreach programs that help eye health professionals keep partnerships and networks vibrant, and that keep health professionals up to date on the latest vision health information and rehabilitative technologies;
- thoroughly developed educational materials on vision health and the importance of preventive vision care that can serve multiple audiences—from community groups to health care professionals; and
- access to a toll-free number.

Focus groups conducted by NEI have indicated that for people with low vision, in particular, the cost of obtaining visual aids, the need for education in the use of adaptive devices, available transportation (or lack thereof), and access to services from rural areas are all issues that must be considered (NEI, 1999). Ophthalmologists and optometrists agreed that patience and thorough knowledge of available optical aids and devices are necessities when providing low vision care (NEI, 2001). In addition, the patient must be given a treatment plan that includes prescribed visual aids, a list of services performed, lifestyle problems and recommended solutions, and rehabilitative services and training (NEI, 1999). Similar efforts must

be made for individuals facing barriers because of lack of access to health professionals, lack of health insurance, lack of vision care professionals locally, and, possibly, lack of consistency in referrals by health care providers other than vision specialists (NEI, 1997; 1999).

In any public health education campaign or program, media coverage, educational materials, and health communication programs and strategies all need an evaluation component to measure effectiveness. The programs cited here have all been tested, which helps to generate research-based results and guidelines. Continued vigilance in evaluation and program monitoring will go a long way toward ensuring that outcomes are maximized and that the best practices are sufficiently replicated to establish public health education as a national priority in disease prevention, management, and rehabilitation.

Other effective programs

Other effective programs have raised awareness of low vision issues and rehabilitation services. Organizations such as AFB and Lighthouse International have created health education programs that have had an impact, especially for those already living with low vision and vision impairment. AFB (n.d.) has “expanded the possibilities for people with vision loss” by providing information to professionals, employers, older adults, youths, and family and friends through online journals (see, for example, *AFB eNews*, *AccessWorld*, and *JVIB*), online courses (“Using Source Files: An AFB Online Course for Braille Transcribers”; “Bridging the Gap: Best Practices for Instructing Adults Who Are Visually Impaired and Have Low Literacy Skills”), services

(accessibility, advocacy, distance education, parent assistance), and employment opportunities (CareerConnect). Web site visitors can adjust screen colors and text to make it more readable.

The Lighthouse Center for Education (Lighthouse International, 2005c) enhances knowledge and builds awareness about visual impairments and vision rehabilitation services through continuing education programs, professional symposia, international initiatives, special projects, publications, and newsletters. Its continuing education programs are taught by multidisciplinary international faculty. The topics of the accredited courses, seminars, and workshops include comprehensive low vision care, common eye disorders in children, vision rehabilitation therapy, fitting and prescribing telescopes, and diabetes-related eye disease and low vision (Lighthouse International, 2005a). The professional symposia bring together top specialists and researchers to further the understanding of vision loss, and to share new and emerging treatments for people with impaired vision (Lighthouse International, 2005d). The Lighthouse Center for Education's international programs have a "train-the-trainer" approach to strengthening the provision of low vision care in areas of the world where resources are scarce (Lighthouse International, 2005b). Special projects, such as "Vision Loss Is Not a Normal Part of Aging—Open Your Eyes to the Facts!" and "Programs for Partners," help raise public awareness about the benefits of vision rehabilitation for people with impaired vision ("Special Public Awareness Projects," 2005). Lighthouse International (2005a) also has publications and newsletters for audiences with different informational needs.

Conclusion

Public health education works best in a model with multiple components. Health communication initiatives are designed to influence individual and community decisions for positive health action. All government and health policy organizations and agencies should adopt strategies to affect health communication regarding disease prevention and control. In the 10 years since its first publication, and with its 2001 revision, *Making Health Communication Programs Work* (National Cancer Institute, 2001) has become a vital resource for those studying how best to engineer health communication strategies. Defining a group's or individual's stage of readiness—including health status, motivation, and immediate need for intervention—will help tailor messages to affect the process of behavior change.

Influencing behavioral change is a process, not a static outcome. By first defining the change and making contact with the intended audience, organizations can clarify goals and identify the targeted groups. Determining which messages are best communicated and testing the clarity and effectiveness of those messages contributes to unambiguous understanding of the ideas and practices that are the focus of the public health education effort. For example, in light of the ongoing medical advances and substantial health care and prevention research in the United States, responsible public health educators need to offer fact-based and scientific information in a way that the public can access and use. Finally, examining the outcomes of the program and refining the messages, strategies, or program elements enables continued pursuit of the goals and intent of the public health education effort.

