Identification of Variables That Influence Access to Eye Care

Final Report

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EXECUTIVE SUMMARY

Introduction

In November and December 2004, representatives from 10 government agencies and non-government organizations were interviewed by the National Eye Institute (NEI) to gather information about factors that influence the receipt of health care, in particular care that may prevent vision loss. The purpose of this research was to identify barriers to care and to determine best practices and strategies used by other agencies and organizations to deal with those barriers. The National Eye Health Education Program (NEHEP), coordinated by the NEI, would then use these strategies to better design educational materials and programs and collaborate with other government agencies and non-government organizations that specifically address access-to-care issues.

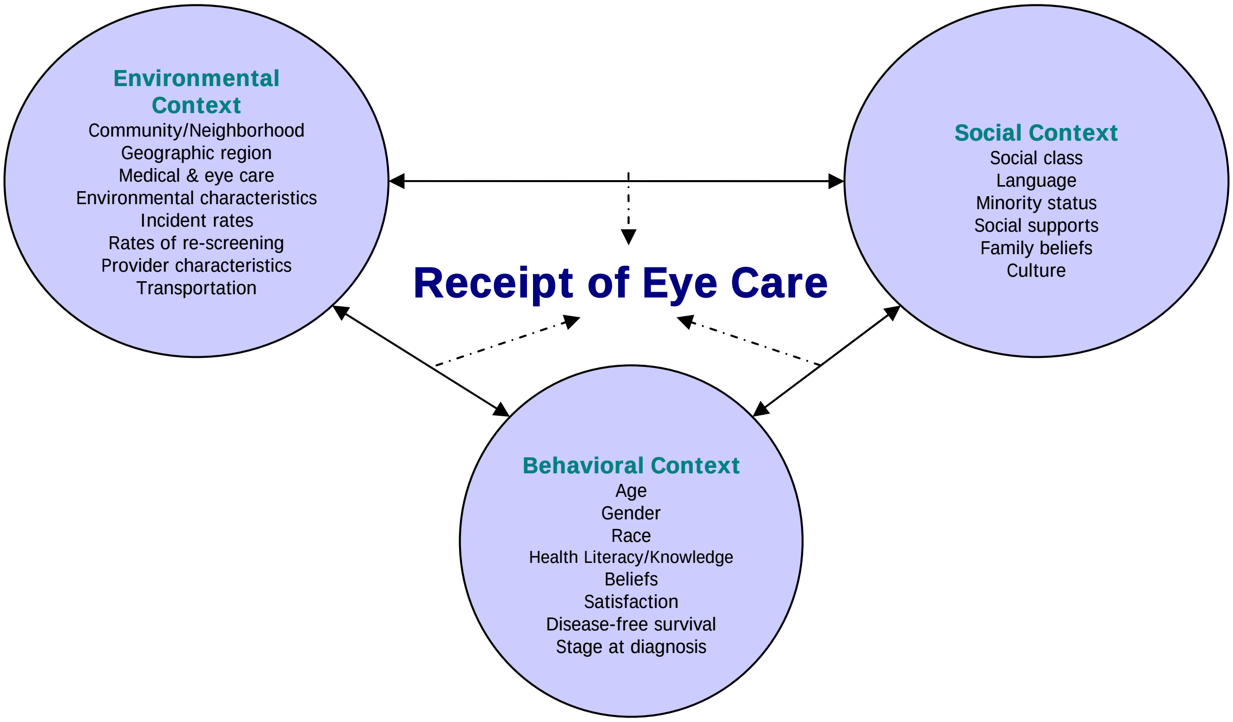
New reports indicate that low vision and blindness are prevalent in the United States population. Furthermore, the number of Americans with eye diseases is growing, making vision loss a major public health problem. Of the Americans who have an eye disease that may impair their vision, many are unaware they have the disease. Research also shows that health disparities in the prevalence of various eye diseases and disorders exist among certain racial and ethnic populations.

Literature Review

A literature review was conducted to provide a framework for this research and guide the development of the discussion protocol. The review of the literature revealed that eye diseases, which include diabetic retinopathy, glaucoma, cataract, and age-related macular degeneration (AMD), cause blindness and impaired vision in millions of Americas across all races and ethnicities (Congdon, O'Colmain, Klaver, Klein, Munoz, Friedman, et al., 2004; Kempen, O'Colmain, Leske, Haffner, Klein, Moss, et al., 2004). Despite the statistics citing increases in visual disorders, vision loss can often be reduced through early detection and timely treatment. Unfortunately, research indicates that many people tend to receive care for vision disorders in an untimely fashion, allowing eye diseases to burgeon into advanced stages, delaying potentially sight-saving treatment (Anderson, Wolf, Musch, Fitzgerald, Johnson, Nwankwo, et al., 2002; Hartnett, Key, Loyacano, Horswell, and DeSalvo, 2005). Findings from research on low vision and blindness in the United States reveal a high prevalence of eye disease and differences in the prevalence, severity, and progression of these disorders by race/ethnicity and other characteristics of these populations (Friedman, West, Munoz, Park, Deremeik, Massof, et al., 2004; Varma, Ying-Lai, Klein, and Azen, 2004; Kempen, O'Colmain, Leske, Haffner, Klein, Moss, et al., 2004; Higginbotham, Gordon, Beiser, Drake, Bennett, Wilson, et al., 2004; Haffner, Fong, Stern, Pugh, Hazuda, Patterson, et al., 1988). Additional research shows that certain racial and ethnic groups not only receive a lesser amount of health care, but also tend to receive a lower quality of health care compared to Whites for various diseases (Smedley, Stith, Nelson, [Eds.], 2002; Mayberry, Mili, and Ofili, 2000).

Differences in access to medical services and differences in prevalence of disease among racial and ethnic groups have become salient issues in health care, especially over the past 25 years. Health disparities result from a complex interaction of many behavioral, social, economic, cultural, biological, and environmental factors.

Hippocrates once said that illness occurs in a social, environmental, and behavioral context. The graphic representation below is one framework for looking at the interaction of factors that serve as barriers to care. Included in the graphic representation are barriers within their respective context to health care services that have been found in the literature.



In 1985, the Secretary's Task Force stated that the interaction of those factors on health status are "poorly understood for the general population and even less so for minorities" (U.S. Department of Health and Human Services, 1985). Thus, a better understanding of variables that influence the receipt of health care and the barriers to the receipt of that care may provide a better understanding as to why health disparities exist. When examining barriers to health care, it is important to understand the full spectrum of health services that may not be received, which includes receipt of eye care. This executive summary highlights research presented in the full report that outlines the variables that influence the receipt of eye and/or health care services.

Methodology

In this assessment, a search was conducted among a number of government agencies and non-government organizations to identify those with mission statements that sought to:

- Improve and expand access to quality health care.
- Protect the health of racial and ethnic minority populations and eliminate health disparities.
- Sponsor and conduct research that provides evidence-based information on health care outcomes, quality, cost, use, and access.

Representatives from five government agencies and five non-government organizations were selected to be interviewed. The list of government agencies and non-government organizations represented included:

Government Agencies

- Agency for Healthcare Research and Quality
- Centers for Medicare and Medicaid Services
- Indian Health Service
- Office of Minority Health
- Health Resources and Services Administration

Non-Government Organizations

- American Academy of Ophthalmology
- American Optometric Association
- Kaiser Family Foundation
- RAND Health
- Robert Wood Johnson Foundation

All interviews used a structured discussion protocol to guide discussions about the receipt of eye and/or health care services, barriers to care, and programs to increase the receipt of health care services. Interviews with agencies and organization representatives were conducted in person or by telephone in November and December 2004.

The interview discussion protocol explained the purpose of the research and included the following discussion items:

- Eye and/or health programs or services provided to the general population.
- Key factors that influence the receipt of eye and/or health care services.
    - Variables that were more likely to influence receipt of eye and/or health care services for high-risk populations.
- Opportunities for individuals and agencies to collaborate and address access to eye and/or health services.
- Strategies and/or approaches the vision community can consider to effectively deal with barriers to the receipt of eye care.

Findings

The majority of the agencies and organizations primarily offer services and programs that are characterized as prevention/screening and education. Those programs and services tend to focus on high-risk target populations by increasing awareness about the importance of early detection and treatment of illness, and by encouraging people to take action based on their increased awareness. However, representatives from a number of agencies and organizations indicated that they did not have any programs or services directly related to the provision, education, or funding of eye care services.

Variables That Influence the Receipt of Care

Representatives who were interviewed outlined the following variables that influence the receipt of eye and/or health care services and barriers that prevent the receipt of such care:

- Insurance status
- Availability of providers
- Health literacy
- Type of insurance
- Language
- Patient perceptions

The majority of agency and non-government organization representatives mentioned insurance status as a key factor in the receipt of health care services. There was also a consensus that barriers to the receipt of general health care may be the same barriers to the receipt of eye care.

The issue of health literacy arose in more than half of the interviews conducted and was cited as being very influential in the receipt of general health care and care for eye disease and vision loss. Agency and organization representatives stated that there is a lack of knowledge across the board about general health conditions, and about the importance of eye screenings.

The issue of patient perceptions was also mentioned in a majority of interviews, in particular perceptions of need. Some populations do not recognize the need for care as readily as others. Even with increased awareness, some people may not act as quickly upon those needs.

Language was another major barrier mentioned in the interviews. Many cultures, Hispanic/Latino and American Indian cultures in particular, were noted as having to deal with language barriers when seeking any type of health care service. Dealing with this barrier can be frustrating for both the provider and the patient.

Agency and organization representatives were further probed about whether barriers to care are the same across racial and ethnic groups, and whether a particular racial or ethnic group experiences more barriers to care than others. For purposes of this research, agency and organization representatives were asked to use as a definition for high-risk those who are predisposed to certain eye health problems due to their family history, race/ethnicity, and/or age. There was a general consensus that the barriers faced by racial and ethnic minorities were different than the barriers faced by Whites, particularly when considering culture and language barriers. The majority of agency and organization representatives believed that racial and ethnic minorities experienced more barriers to health care services. Additional barriers to the receipt of eye and/or health care services that were mentioned included:

- Transportation
- Provider competency
- Usual source of care
- Patient-provider relationship
- Race and ethnicity
- Values and beliefs

Programs, Methods, and Approaches To Increase the Receipt of Care

Given the extensive list of variables that influence the receipt of eye and/or health care services, representatives from government agencies and non-government organizations were asked to offer strategies, methods, or approaches they felt were most effective in dealing with barriers to care. The representatives offered a comprehensive list of approaches to barriers to care. Some of those approaches included:

- Establishing collaborations among partners within the community
- Providing data that can help shape policy and inform policy decisions
- Educating the public about early detection
- Disseminating appropriate health messages
- Providing access to care at low or no cost.

A number of agency and organization representatives indicated that increasing education and awareness to the public is key in dealing with barriers to care. Education about early detection for consumers and standards of care for providers is critical. Also critical to increasing education and awareness is the need to ensure that messages and materials are culturally appropriate, accurate, and disseminated in the right places. The Centers for Medicare and Medicaid Services cited one method as being effective in dealing with barriers to care relating to health literacy: the "4 Ls and C" Method. This method is used to determine the most appropriate messages based on an evaluation of "L"ocation, "L"iteracy, "L"anguage, "L"ow income, and "C"ulture.

Agency and organization representatives were asked to identify characteristics of what they felt were "exemplary" programs or materials that aim to increase the receipt of eye and/or health care services. Some examples of "exemplary" characteristics included:

- Materials and strategies that are culturally appropriate
- Approaches that are community based
- Models that increase cultural competency
- Systems with measurable outcomes.

This research was conducted in part so that the National Eye Health Education Program can better collaborate with other government agencies and non-government organizations to better design eye health education programs that address receipt-of-care issues. Many of the representatives stated that the most successful programs in terms of increasing receipt of health care services involve collaborations between various agencies and organizations. The sharing of experiences and successes of different organizations that are implementing related strategies is a useful method for organizations to collaborate and can maximize the delivery of care to various populations.

Agency and organization representatives reported strategies for establishing collaborations that included:

- Engaging representatives from diverse experiences and backgrounds
- Initiating collaborations with educational institutions
- Establishing partnerships in which all organizations can pool resources.

A collaborative environment that includes partnerships across academic, non-profit think-tanks, and actual service providers will ensure that all aspects of barriers to care can be addressed. Many organizations already have vehicles in place to reach target populations. They also combine efforts to conserve costs and manpower, and to efficiently allocate resources and disseminate messages.

Gaps in Knowldedge and Servces

Despite the efforts underway to increase the receipt of and access to many eye and health care services, there are many areas where programs, materials, and action steps are still needed, particularly for high-risk populations. Agency and organization representatives were asked to identify gaps in knowledge and offer suggestions for improvement, which include the following:

- Getting people to services in a more timely manner.
- Obtaining additional resources to deliver care to target populations.
- Sponsoring more programs that provide screening opportunities for various conditions.

Several agency and organization representatives mentioned the need to provide basic screening, including vision screenings in churches, malls, and senior centers. Many of the agency and organization representatives also touched upon the concept of translational research and its importance in terms of translating messages targeted to specific audiences in a manner that will optimize their chances of comprehending and acting upon information about health care.

Recommendations

This research gathered information about barriers to receiving health and eye care and strategies and approaches to effectively deal with those barriers. Based on the 10 interviews with representatives from the selected agencies and organizations, some key recommendations for dealing with barriers to eye care for consideration by NEHEP are:

- Continue to provide quality outreach, education, and interventions to the American public about eye health and make healthy vision a priority.
- Develop intervention models and methods to reach communities of color, especially if they are considered to be at high risk (i.e., "Take A Loved One to the Doctor Day").
- Create social marketing strategies that account for variables such as location, literacy, language, income, and culture.
- Translate current scientific advances in the diagnosis and treatment of eye diseases and disorders to practitioners and the general public to increase awareness of health care options.
- Identify innovative and creative collaborative opportunities to pool resources, effectively deal with barriers to care, and increase the receipt of eye care. Explore opportunities to create collaborations across service providers, think tanks, and academic institutions.
- Continue to identify methods of assessing the eye health of Americans (i.e., data collected on the eye health of Americans via the National Health Interview Survey) to measure success in meeting Healthy People 2010 targets.

INTRODUCTION

Low vision and blindness are prevalent in the United States population. The 2000 Census estimates that there were 937,000 blind Americans aged 40 and older that year. The number of persons with low vision was estimated to be an additional 2.4 million, bringing the total number of Americans aged 40 and older with visual impairments to 3.3 million, or one in 28 persons (Congdon, O'Colmain, Klaver, Klein, Munoz, Friedman, et al., 2004). Furthermore, the number of Americans with serious eye diseases is growing, making vision loss a major public health issue. It is estimated that by 2020, the number of blind persons aged 40 and older in the United States will increase approximately 70 percent, to 1.6 million people. The number of persons with low vision is expected to increase to 3.9 million, bringing the total number of Americans aged 40 and older with visual impairments to 5.5 million (Congdon et al., 2004).

Of Americans who have an eye disease that is impairing their vision, many are unaware they have the disease. The most comprehensive epidemiological analysis of visual impairment in Latinos conducted in the United States found that 25 percent of study participants, who were newly diagnosed with diabetes during the study, did not know they also had diabetic retinopathy. This finding further contributes to the growing number of Americans with eye disorders (Varma, Torres, Pena, Klein, and Azen, 2004).

Blindness and low vision can lead to a loss of independence and a reduced quality of life. If receipt of eye care was increased, more preventive measures could be taken to avoid costly rehabilitative treatments and prescriptions, as well as the considerable economic and social costs to society. The benefits of preventive treatment in most cases, if not all, are spread to others, and the cost of not using preventive care is borne by others.

Current research reveals disparities in the prevalence of certain eye diseases and disorders. For example, glaucoma is three to four times more likely to occur in African Americans than in Whites, and is about six times more likely to cause blindness in African Americans than in Whites (National Eye Institute, 2004). Unfortunately, differential health status by racial/ethnic group, in general, is common in the United States (Blendon, Aiken, Freeman, and Corey, 1989; Mayberry, Mili, and Ofili, 2000). According to Mayberry et al. (2000), future studies are needed to understand why racial and ethnic disparities in access to various health care services exist.

Healthy People 2010 is a national report that outlines health objectives and goals for the Nation. Included in this report were specific objectives for improving the vision of people in the United States during the 2000–2010 decade via prevention, early detection, treatment, and rehabilitation (U.S. Department of Health and Human Services, 2000). This research, in part, is further prompted by both of the overarching goals of Healthy People 2010, which are to eliminate health disparities among different racial and ethnic groups and to increase the quality and years of healthy life for people of all ages. As stated earlier, visual impairments significantly affect quality of life and disproportionately affect certain racial and ethnic populations more than others.

It is important that Americans receive proper eye care before the onset of a disease so that prevention strategies such as screenings and regular comprehensive dilated eye examinations can be effective. Studies show that early detection and treatment of eye diseases and conditions before the onset of major vision loss, are the best ways to control disorders. Unfortunately, the United States often trails in rankings relating to prevention. Underused preventive therapies could significantly reduce morbidity and increase quality of life.

Aforementioned statistics indicate that certain racial and ethnic populations experience a disproportionately high incidence and prevalence of eye disease, burden of illness, and morbidity. The statistics further show that many members of certain racial and ethnic groups are not even aware that they have visual disorders. Other research extensively documents racial and ethnic disparities in the provision of medical care as a whole (Mayberry et al., 2000). These findings re-affirm the importance of targeting minorities with screening programs and public health messages about their eye health. A targeted measure such as better education about eye disease and their attendant risk factors is likely to decrease the burden of visual impairment among the entire population.

Knowledge of barriers and why different racial and ethnic groups are not receiving eye care at recommended levels is imperative to developing culturally appropriate programs to detect and manage eye diseases. Education programs will help a fragmented public health care system become more accountable for the level of health in different subsections of the American population. It is important to make certain that all patients have access to high-quality health care.

The receipt of proper and timely eye care can affect the quality of life for all Americans and can contribute to the well-being of the Nation as a whole. Public health officials and policymakers cannot afford to let eye disease ravage the increasing elderly population of the United States, especially when many adverse effects of eye disease are preventable. This research will purposefully inform health care professionals and the vision community about:

- Current literature related to access to health and/or eye care services
- Specific programs being conducted by selected organizations and agencies
- Variables that influence the receipt of care and contribute to health disparities
- Approaches and strategies to effectively deal with receipt-of-care issues
- Opportunities in which to collaborate with other organizations and agencies to increase the receipt of eye care and reduce eye health disparities.

LITERATURE REVIEW

General Summary of the Literature

Current literature indicates an increase in the prevalence and severity of eye disease and low vision in the United States. Additional research indicates that the leading causes of blindness and low vision are not being detected early when treatment is available and effective. Eye disease and low vision can lead to a loss of independence and a reduced quality of life, and can increase significantly with age. Moreover, visual disorders also inflict substantial economic and social hardships on society.

Research extensively documents racial and ethnic disparities in the access of health care in general. Barriers to health care services are also well documented. However, there is a notable absence in the literature of studies examining influential factors on the receipt of care for eye disease and vision loss. Moreover, there is a lack of comprehensive research pertaining to whether different racial and ethnic groups disproportionately experience more barriers to the receipt of eye care and whether those barriers differ by race or ethnicity.

Principal Categories of Literature

Literature on Prevalence of Vision Disorders

General

The receipt of eye care is an important concern because the number of vision disorders and cases of blindness is increasing. In 2000, there were a reported 937,000 Americans aged 40 and older who were blind. The number of persons with low vision was estimated to be an additional 2.4 million, bringing the total number of Americans aged

40 and older with visual impairments to 3.3 million, or one in 28 persons (Congdon et al., 2004).

The leading causes of vision impairment and blindness in the United States include diabetic retinopathy, age-related macular degeneration (AMD), cataract, and glaucoma. Diabetic retinopathy is reported to affect 4.1 million Americans aged 40 and older, and vision-threatening retinopathy is reported to affect 899,000 Americans in the same age group (Kempen, O'Colmain, Leske, Haffner, Klein, Moss, et al., 2004). In persons with type I diabetes, retinopathy is found in 86 percent of cases (Klein, Klein, Moss, Davis, and DeMets, 1984; Klein, Klein, Moss, Davis, and DeMets, 1984). Glaucoma is a leading cause of blindness in the Nation. There are 2.22 million people in the country diagnosed with open-angle glaucoma (OAG) and about half of those with glaucoma are unaware that they have the disease (Friedman, Wolfs, O'Colmain, Klein, Taylor, West, et al., 2004). In persons with low vision, cataract was the most frequently reported condition, accounting for approximately 50 percent of low vision cases among African American, White, and Hispanic persons (Congdon et al., 2004). Among White Americans, age-related macular degeneration was the leading cause of blindness, accounting for 54 percent of all blindness in this group. Among African Americans, cataract and open-angle glaucoma (OAG) accounted for more than 60 percent of cases of blindness, while for Hispanic Americans, OAG was the most common cause of blindness (Congdon et al., 2004).

Low vision and blindness have been found to increase significantly with age across all races and ethnicities (Congdon et al., 2004). In fact, diseases of aging, such as AMD, cataract, and glaucoma, are the most common causes of blindness and low vision. It is estimated that the number of blind persons aged 40 and older in the United States will increase approximately 70 percent to 1.6 million people by 2020. The number of persons with low vision is expected to increase to 3.9 million, bringing the total number of Americans aged 40 and older with visual impairments to 5.5 million (Congdon et al., 2004).

Despite the statistics citing increases in visual disorders, vision loss can often be reduced with regular comprehensive dilated eye exams and timely treatment. Unfortunately, research indicates that many people tend to receive care for vision disorders in an untimely fashion, allowing eye diseases to burgeon into advanced stages, delaying potentially sight-saving treatment. In these instances, preventive care such as dilated eye examinations is never obtained. For example, the 1987 National Health Interview Survey revealed that 51 percent of people with diabetes in the United States had not received a dilated eye examination in the prior year (Brechner, Cowie, Howie, Herman, Will, and Harris, 1993). A study of African American and Hispanic patients with diabetes mellitus reported high percentages of patients in both African American (42.9%) and Hispanic (37.3%) groups having either preproliferative or proliferative diabetic retinopathy at the time of initial presentation for an eye examination (Appiah, Ganthier, and Watkins, 1991). In a study of people with type I and II diabetes after the time of baseline examination, 34 percent to 58 percent had untreated diabetic retinopathy four years later (Wang & Javitt, 1996). These reports suggest that suboptimal use of preventive eye care is common.

The literature also shows that even people with health disorders who are likely to have symptoms that involve vision disorders such as diabetes have low rates of eye care receipt, as well (Wang & Javitt, 1996; Anderson, Wolf, Musch, Fitzgerald, Johnson, Nwankwo, et al., 2002). Guidelines provided by the American Academy of Ophthalmology, the American College of Physicians, and the American Diabetes Association attest that patients with type II diabetes should have an initial eye examination shortly after the diagnosis of diabetes is made, and then have eye examinations annually ("Screening guidelines," 1992). According to the literature, many do not follow this recommended eye examination schedule and a gap clearly exists between actual receipt of eye care and recommended levels of eye care receipt. In a study of people with diabetes with Medicare coverage, it was found that only 53 percent visited an eye care professional in one year and 67 percent in a two-year period (Wang & Javitt, 1996). Similar results have been reported elsewhere (Brechner et al., 1993). For African Americans with diabetes, their rates of receipt of recommended eye care were strikingly lower, as only 22 percent of study participants reported seeing an ophthalmologist in the previous year (Anderson et al., 2002).

Research indicates that visual disorders and impairment in the United States increase with age. For example, in a study of Latinos in the Los Angeles area, it was found that those in their 70s and 80s were up to eight times more likely to have visual impairments than their younger counterparts Varma, Ying-Lai, Klein, & Azen, 2004.

Disparities in Prevalence of Vision Disorders

Findings from research on low vision and blindness in the United States reveal differences in the severity and progression of these disorders by race/ethnicity and other characteristics of these populations. For example, diabetic retinopathy has been found to be a leading cause of blindness in the United States. However, there is research indicating that differences in the prevalence, severity, and progression of diabetic retinopathy exist among different ethnic groups, in particular between

Hispanics and Whites (Haffner, Fong, Stern, Pugh, Hazuda, Patterson, et al., 1988; Appiah et al., 1991).

Additional research indicates that Latinos are experiencing high rates of low vision and glaucoma. Rates of low vision among Hispanic persons were higher than that of both White and African American persons (Congdon et al., 2004). The Los Angeles Latino Eye Study (LALES) further documents disparities in the prevalence of eye disorders for Latinos. The LALES found that higher rates of visual disorders in Latinos are increasing among those who are older, unemployed, divorced or widowed, less educated, and those with diabetes (Varma, Ying-Lai, Klein, and Azen, 2004).

African Americans are disproportionately impacted by eye disorders and low vision, as well. Age-specific blindness has been witnessed to be higher for African American persons compared with White or Hispanic persons (Congdon et al., 2004). A high prevalence of OAG is also reported among African Americans compared to Whites (Tielsch, Katz, Singh, Quigley, Gottsch, Javitt, et al., 1991). The Ocular Hypertension Treatment Study (OHTS) further documents disparities in the prevalence of eye disease for African Americans. The OHTS indicates the prevalence of glaucoma is higher in African Americans than in Whites (Higginbotham, Gordon, Beiser, Drake, Bennett, Wilson, et al., 2004). More specifically, in the Baltimore Eye Survey, the age-adjusted prevalence rates of primary open-angle glaucoma was found to be four to five times higher in African Americans than in White Americans (Sommer, Tielsch, Katz, Quigley, Gottsch, Javitt, et al., 1991).

Several factors have been identified that increase the prevalence of certain eye disorders. For glaucoma, associated risk factors were found to be older age, African descent, and higher eye pressure. Chances of developing diabetic retinopathy are higher among African American persons who have diabetes mellitus (Harris, Sherman, and Georgopoulos, 1999). Poorer access to medical care and reduced health literacy compared to Whites have been reasons cited for increased prevalence of diabetic retinopathy among ethnic minorities (Schillinger, Grumbach, Piette, Wang, Osmond, Daher, et al., 2002). Clearly among the major eye diseases, race and ethnicity play a large role in the development of eye disorders.

The Los Angeles Latino Eye Study and the Ocular Hypertension Treatment Study both highlight the importance of targeting minorities to improve their receipt of eye care. Both African Americans and Hispanics/Latinos in the respective studies were witnessed to have experienced high rates of eye disease where study findings reported that many members of both groups were unaware of their eye conditions at the outset of the study.

Literature on Health Disparities

Disparities in Receipt of Medical Care

Racial and ethnic disparity in health care is one of the major focal points of Healthy People 2010, as well as the cynosure of much of the related scientific literature. Racial and ethnic disparities, for the most part, have been well described for African Americans and Hispanics/Latinos, although not as much literature covers other underrepresented minority populations. Existing literature documents disparities in the prevalence of disorders such as heart disease, stroke, cancer, and HIV/AIDS between racial and ethnic groups (Smedley, Stith, Nelson, [Eds.], 2002; Alliance for Health Reform [Reform], 2004). In addition to the literature documenting a rise in the prevalence of blindness and vision disorders as a whole and the growing evidence of disparities that exists between racial and ethnic groups in the prevalence of certain vision disorders, the literature documents disparities in the access and receipt of medical care services and eye care services to treat illness. In a review of the health services literature after the 1985 release of the Department of Health and Human Services Report of the Secretary's Task Force on Black and Minority Health to 1999, Mayberry et al. found that significant differences in access to medical care existed by race and ethnicity within certain disease categories and types of health services delivered (Mayberry et al., 2000).

Relating to medical access for heart disease and stroke, research findings have consistently found that African Americans are less likely to receive life-saving treatments compared to White Americans. In one study, African Americans were 50 to 60 percent less likely to have had angioplasty, 60 to 70 percent less likely to have had bypass surgery, and 50 percent less likely to have had thrombolytic therapy (Weitzman, Cooper, Chambless, Rosamond, Clegg, and Marcucci, 1997). Several factors have been identified that appear to influence the magnitude of differences between Whites and African Americans. These factors include differences in the age and gender distribution of the study population, primary diagnosis of interest, severity of disease, and comorbidities (Mayberry et al., 2000).

In the literature pertaining to medical access for heart disease and stroke are the inconsistent findings that medical access is less likely for other ethnic Americans besides African Americans. Findings from Ramsey et al. found no significant difference for bypass surgery and marginal differences for angioplasty between Mexican Americans and non-Hispanic Whites (Ramsey, Goff, Wear, Labarthe, and Nichaman, 1997). Yet other research indicates that Hispanics were 71 percent less likely to receive thrombolytic therapy (Mickelson, Blum, and Geraci, 1997). A study of differences between Asian/Pacific Islanders and Whites for thrombolytic therapy among acute myocardial infarction patients found marginal differences, yet no significant differences for angiography, angioplasty, or bypass. For Native Americans, the same study found no significant differences in invasive procedures when compared to Whites (Canto, Taylor, Rogers, Sanderson, Hilbe, and Barron, 1998).

Additional research shows that African Americans and Hispanics/Latinos not only receive lesser amounts of care, but tend to receive lower quality health care compared to Whites for diseases including HIV/AIDS, cancer, cardiovascular disease, diabetes, and mental health.

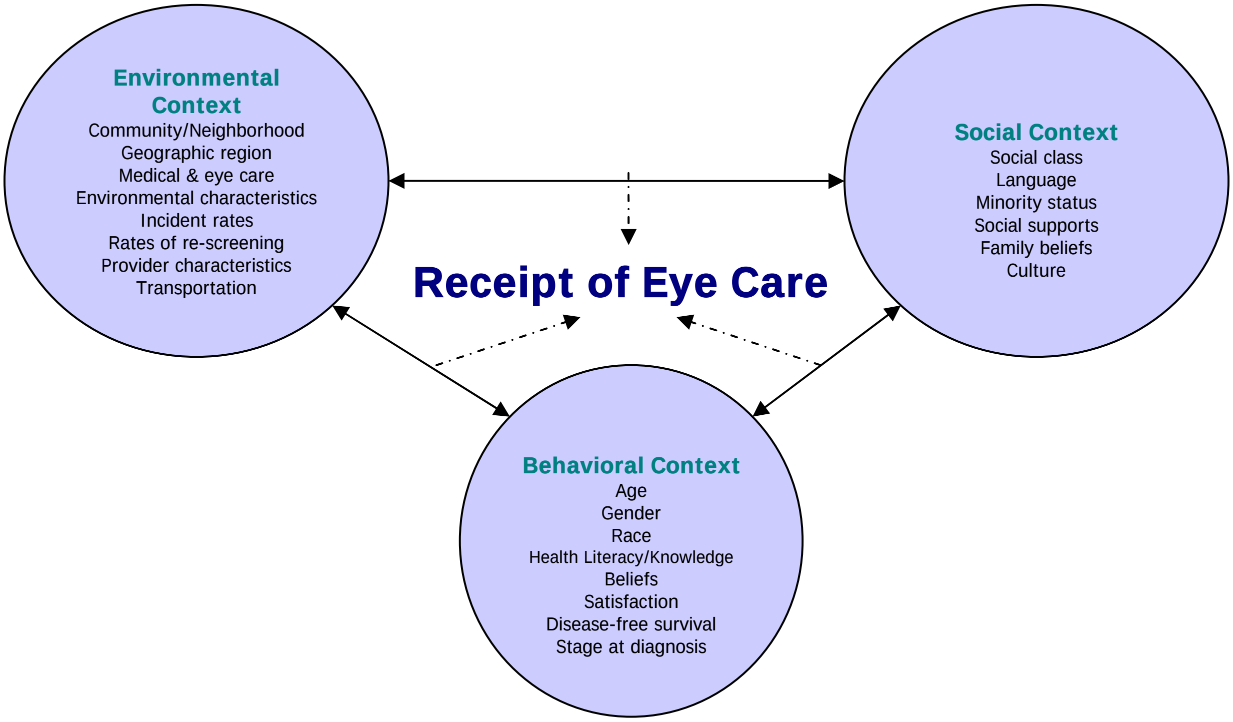
Disparities in Receipt of Eye Care

Additional literature documents disparities between different racial and ethnic groups in the access and receipt of eye care services to treat illness. In the Los Angeles Latino Eye Study, researchers found that Latinos were much more likely to have received general medical care than to have received eye care (Varma et al., 2004). Other literature concluded that minority populations do not receive adequate vision treatment and prevention compared with Whites. Wang et al. report that for people with diabetes, only 59 percent who were African American Medicare beneficiaries underwent an eye examination in the course of a year. For those Medicare beneficiaries aged 65 to 69 years, only 60 percent had seen an eye care professional in the two years prior (Wang & Javitt, 1996). African Americans have been found to have poorer access to and use of eye care services, which has ultimately led to increases in visual disorders ("The advanced glaucoma," 2000) due to cataract and OAG (Devgan, Yu, Kim, and Coleman, 2000).

Literature on Barriers to Health and Eye Care

Differences in access to medical services and differences in prevalence of disease among racial and ethnic groups has become a salient issue in health care, especially over the past 25 years. Health disparities have become the focal point of several seminal documents related to health care in the United States. Much of the research also explores the magnitude of health disparities and why those disparities exist. A consensus appears to exist acknowledging that health disparities are due to a complicated and complex interaction of many behavioral, social, economic, cultural, biological, and environmental factors.

Hippocrates once said that illness occurs in a social, environmental, and behavioral context. The graphic representation below is one framework for looking at the interaction of factors that serve as barriers to care. Included in the graphic representation are barriers within their respective context to health care services that have been found in the literature.



In 1985, the Secretary's Task Force stated that the interaction of those factors on health status are "poorly understood for the general population and even less so for minorities" (U.S. Department of Health and Human Services, 1985). Thus, a better understanding of variables that influence the receipt of care or the barriers to the receipt of care may provide a better understanding as to why health disparities exist. This understanding may have an impact on the elimination of health disparities, as called for in "Healthy People 2010," and on the improvement of the health status of all Americans.

When examining barriers to health care, it is important to understand the full spectrum of health services that may not be received, which includes receipt of eye care. The body of literature speaking specifically to barriers to receipt of eye care is very sparse. This research will specifically attempt to address this gap in the understanding of variables that influence the receipt of eye care.

Behavioral Context

There is mounting testimony that indicates various factors influence how a person behaves and greatly impacts the receipt and quality of health care services and health outcomes. Research documents variations in the receipt of eye care by factors such as gender, race, and age. In the aforementioned study of eye care services among Medicare beneficiaries with physician-diagnosed diabetes, those aged 65 to 69 had the lowest rate (43%) of eye examinations. Those aged 75 to 85 had the highest rates (56–58%). Women were also 20 percent more likely to visit an eye care professional than men. African American beneficiaries were 30 percent less likely to visit an eye care professional compared with White beneficiaries (Wang & Javitt, 1996). Thus, younger age, male gender, and African American descent are characteristics typically associated with lower rates of eye care receipt.

Health Literacy

Several studies have framed literacy, health literacy in particular, as a barrier to the receipt of health care, which has both health and financial implications. Health literacy has been described as "the degree to which people have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Parker, Ratzan, and Lurie, 2003). Patients with inadequate health literacy are more likely to not use preventive health services such as vaccinations and mammograms, and more likely to improperly read medication dosing instructions and referral paperwork (Williams, Parker, Baker, Parikh, Pitkin, Coates, et al., 1995; Scott, Gazmararian, Williams, and Baker, 2002). In a series of focus groups and interviews with patients who have inadequate or marginal health literacy, they reported experiencing problems with navigation, completing forms, following medication instructions, participating in provider-patient interactions, reading appointment slips, and using coping strategies (Baker, Parker, Williams, Pitkin, Parikh, Coates, et al., 1996). As a result of these barriers, the quality of a patient's interaction with the health care system can be considerably compromised. This compromise could lead to "impediments to timely access to care and cause inappropriate use of services, including medical mistakes" (Dubow, 2004).

Several aspects of the health literacy dimension of receipt of care are noteworthy because of their direct relation to the importance of eye care and this research. The ability to comprehend begins with one's eyesight, and then the ability to read information. As Baker and colleagues point out, "Reading requires adequate vision, concentration, work recognition, working memory, and ability to process information" (Baker, Gazmararian, Sudano, and Patterson, 2000). Lack of health insurance and low income (Berkman, DeWalt, Pignone, Sheridan, Lohr, Lux, et al., 2003), as well as failing eyesight, reduced memory, and hearing loss have been found to be variables that confound one's reading ability and impacts health outcomes (Murphy, Davis, Jackson, Decker, and Long, 1993). Studies attest that health literacy is a marked problem among the elderly. One study found that there was considerably higher prevalence of inadequate and marginal health literacy among persons aged 85 and older

(Gazmararian, Baker, Williams, Parker, Scott, Green, et al., 1999). This finding is particularly troubling given that eye disorders and low vision noticeably increase with age, and the aging of the Baby Boom generation is upon us. Current estimates of the cost of low health literacy range from $30 to 73 billon annually (Friedland, 1998).

Health Insurance

In reviewing the literature for barriers to health care, several pieces of research showed that whether a person has health insurance or not is a major factor in the receipt of health care. Possession of health insurance determines the level of one's access to health care services and ultimately, one's health outcomes. Those who are uninsured have a decreased chance of receiving needed care, particularly care for chronic conditions and recommended procedures (National Academy of Sciences, 2003). This decreased chance of receiving care is further documented in the Commonwealth Fund Minority Health Survey, which suggests that health insurance impacts a person's level of satisfaction with health care quality, tendency to postpone receiving necessary care, ability to access preventive services, available options, and perception of discrimination (Hargraves, 2000). Insurance status clearly plays a pivotal role in the perception of the health care system, dictates the rates of receipt of care, and ultimately predicts health outcomes. Those without insurance are more likely to experience poorer health outcomes and increased mortality than those with insurance.

In 1999, 42 million Americans were uninsured and almost 18 percent of the non-elderly population were uninsured (Kaiser Commission on Medicaid and the Uninsured [Kaiser], 2001). Today, there are approximately 45 million Americans, or 15.6 percent of the population, without health insurance coverage (Appleby, 2004; Hadley & Holahan, 2004). Current estimates reveal that nearly two-thirds of nonelderly Americans receive health insurance coverage through their employers and almost all the elderly are covered through Medicare (Kaiser Commission on Medicaid and the Uninsured [Kaiser], 2003).

Typically, the uninsured tend to be low-income Americans with family incomes below 200 percent of the poverty level. However many of the uninsured are also part of the working class. Two-thirds of the uninsured come from low-income families and one-third are low-income parents and children. Four out of five (81%) of the uninsured are in working families where 69 percent of households have a full-time worker, and 12 percent have a part-time worker. Those in low-paying jobs, particularly unskilled laborers, service employees, and those employed in small businesses, are at greater risk of being uninsured (Kaiser, 2003). These work industries typically fail to offer employer-sponsored health insurance and offer salaries that leave them ineligible for public assistance programs. Yet at the same time, those jobs do not provide enough additional income to cover privately obtained health insurance.

People who are uninsured or underinsured are less likely to get timely and routine care, and are more likely to be hospitalized for preventable conditions (Kaiser Family Foundation [Kaiser], 2005). Insurance coverage has been found to determine how soon a person receives health services and the quality of services received. People with insurance are more likely to have preventive services and screenings such as mammograms, prostate exams, and colon and cervical cancer screenings. Gaps in employer health insurance coverage and limits of coverage by public programs such as Medicaid leave millions of Americans uninsured, which creates barriers to obtaining timely and appropriate health care (Kaiser, 2003). Consequently, the health and well-being of the uninsured are severely impacted, as well as the health and well-being of the Nation in the long run.

The issue of insurance coverage as a barrier to health care becomes even more striking when race/ethnicity is considered. Race and ethnicity have been found to be significant factors involved in being uninsured (Fronstin, 2001). Bodies of literature reveal that people from certain ethnic groups are more likely to not have health insurance when compared to Whites, and thus experience poorer health status and receipt of inadequate health care. In 2003, the overall percentage of nonelderly African Americans without health insurance (21%) was greater than the proportion of Whites (13%) without health insurance. The Kaiser Family Foundation cites that Hispanics experience the highest rates of uninsurance among all ethnic groups with a 34 percent uninsurance rate (Kaiser, 2005)

As it specifically relates to eye care, a study to evaluate the efficacy of community-based, culturally specific eye disease screening clinics for urban African Americans with diabetes found that lack of health insurance proved to be the primary barrier to receiving needed treatment (Anderson et al., 2002).

Research further details the negative health outcomes due to a lack of insurance. Literature reveals that a reduction in mortality of 5 to 15 percent could be achieved if the uninsured were to gain health coverage of some type (Kaiser, 2003). Furthermore, the Institute of Medicine cites that an estimated 18,000 Americans die prematurely each year due to lack of health insurance coverage (Smedley et al., 2003).

Health insurance not only affects one's access to health care services, but bears impact on one's financial well being, as well. Without adequate health insurance, high medical bills become almost a certainty. Of those who were uninsured, more than one-third reported having difficulty paying medical bills in the past year, and nearly one-quarter were contacted by a collection agency (Kaiser, 2003). An examination by the Kaiser Commission on Medicaid and the Uninsured reveals that 47 percent of uninsured persons delayed seeking medical care. Of those who were uninsured and needed care, 35 percent never received any (Kaiser, 2003).

Race/ethnicity

Bodies of literature indicate that race and ethnicity account for disparities in health care in the United States. There is considerable evidence that patient socio-demographic characteristics including race and ethnicity have an impact on both physician behavior during medical encounters and on the diagnoses and treatments patients receive. Moreover, these differences continue even when patient income, insurance coverage (payer), and disease severity are controlled for (van Ryn & Burke, 2000). Thus racial and ethnic minority patients, who are insured at the same levels as White patients, receive lesser amounts of care and a lower quality of care.

A plethora of research speaks to how insurance coverage serves as a barrier to the receipt of health and eye care services. However, closely connected to insurance coverage is race and ethnicity. In the majority of literature relevant to this issue, race/ethnicity typically is not cited directly as a barrier to receiving care. More specifically, race and ethnicity are indirectly cited as barriers to receipt of care through their associations with other factors such as insurance coverage, income, and geographic location. The impact of race and ethnicity independently serving as barriers to health care becomes more apparent when discussing provider characteristics such as discrimination and racial bias.

Racial and ethnic differences in access to health services and use of those services among enrollees is not monitored by most private health systems, despite the monitoring being legal. Furthermore, states are not required by the Federal government to report evidence of disparities in care among Medicaid and State Children’s Health Insurance Program (SCHIP) beneficiaries, or promote data collection and monitoring of disparities among other publicly funded health systems (Reform, 2004). Lack of such data clearly leaves an incomplete picture for citizens, policymakers, and consumers of the true state of affairs of disparities in access to care in the United States.

Environmental Context

Several factors that influence the receipt of care occur in an environmental context. The researcher has categorized variables such as medical and eye care environment characteristics, provider characteristics, geographic location, and neighborhood as environmental variables. Environmental variables are factors outside a person that impact the receipt of care. Although insurance status is categorized in the behavioral context, several dimensions of insurance status are deemed to be a part of the environmental context, particularly when examining medical and eye care environment and provider characteristics.

Medical and Eye Care Environmental Characteristics

Much of the literature references insurance type as a barrier to the receipt of health care services. This aspect of insurance as a barrier to health care highlights how characteristics of the medical care environment can influence the receipt of care. Financial and organizational forces within the medical care environment tend to look unfavorably upon insurance provided through Medicaid. This form of insurance coverage is considered by providers to be a less attractive source of coverage when compared to private insurance due to its oftentimes low reimbursement rate. In many cases, providers outright refuse to see Medicaid patients, and in other cases they restrict the number of Medicaid patients seen (Reform, 2004). These restrictions, in many instances, affect the receipt of care and the level of quality in health services rendered.

The literature further indicates that minorities who do have insurance are almost three times as likely as Whites to be covered by publicly funded programs, such as Medicaid, and are less likely to have employment-based coverage (Reform, 2004). This occurrence raises serious concern over the relationship of type of health insurance and health disparities that exist between various racial/ethnic populations in this country.

Characteristics of the medical and eye care environment such as organizational factors and financial forces, weigh in on the receipt of care. Interestingly, being in a managed care plan has been cited as a barrier to health care. According to a report by the Institute of Medicine, the gatekeeper rules of managed care potentially pose greater barriers to care (Smedley et al., 2003). Associated with managed care settings are short encounters between physicians and patients. In efforts to contain costs and as a result of high patient volume that is typically witnessed in managed care environments, the time for physicians to properly diagnose and understand the medical concerns of patients is compromised. Faced with the necessity to cut time spent with patients, even well-intentioned providers may resort to generalizations or stereotypes of racial and ethnic minority groups (Reform, 2004).

Provider Characteristics

Provider characteristics such as discrimination and racial bias, cultural insensitivity, deficient knowledge and training, and biases and beliefs about screening and treatment are all barriers to the receipt of proper and adequate health and eye care. As indicated earlier, the majority of studies discuss racial and ethnic disparities in health care in conjunction with other variables such as insurance status and geographic location. However, the independent effects of race as a barrier to health care are most realized when discrimination and racial bias are present, often on behalf of the medical care provider. In referencing the aforementioned IOM report, which states that the gatekeeper rules of managed care pose great barriers to care for minority patients, a study found that African Americans were nearly one-and-a-half times more likely than Whites to be denied authorization for care after an emergency department visit for the same severity of problems (Reform, 2004). This is a clear example and indication that traits of discrimination and racial bias exist in our health care system. This example further exemplifies the complex web that engulfs several variables: race and ethnicity, insurance type, and provider characteristics. In combination, these variables serve as a barrier to the receipt of appropriate health care.

Geographic Location

In the United States, 25 percent of Americans live in rural communities (U.S. Department of Health and Human Services, 2000). In those communities, a number of Americans do not have access to health care services. The prevalence of diseases such as cancer, diabetes, and heart disease exceed rates found in urban communities. People dwelling in rural areas are less likely to use preventive screening services, have less access to emergency and specialty services, and are more likely to be uninsured when compared with people dwelling in urban areas (Bowyer & Kleinstein, 2000). This difference in health care use is due, in part, to variables such as neighborhood associations and geographic insurance coverage.

Geographic location and neighborhood associations are variables that act as barriers to the receipt of care. In fact, when focusing on racial and ethnic minorities, disparities in the access to medical care becomes more apparent as minority groups are more likely than Whites to live in medically underserved communities and have fewer choices with regard to where they seek care. African Americans and Hispanics mainly live in racially segregated neighborhoods and have poverty rates three times that of Whites. African American and Hispanic ethnic groups are also about twice as likely as Whites to rely on a hospital-based provider as a regular source of care. (Lillie-Blanton, Martinez, Salganicoff, 2001). Geographic location also influences other aspects of the health care system. In a study of the availability of prescription pain killers, it was revealed that only one in four pharmacies with adequate supplies was located in a predominantly non-White neighborhood, compared to 72 percent of pharmacies in predominantly White neighborhoods (Morrison, Wallenstein, Natale, Senzel, & Huang, 2000).

The association of the receipt of eye care with geographic location and neighborhood is noted in a study of eye care services among Medicare beneficiaries with physician-diagnosed diabetes. In that study, lower rates of eye care use are noted among people who reside in counties with higher levels of poverty. In the same study, albeit with a slight association, regional education level was found to impact receipt of eye care. A higher density of eye care professionals in beneficiaries' residence areas was associated with greater likelihood of receiving eye care. Use of eye care was slightly higher among those living in metropolitan areas compared to those living in nonmetropolitan areas (Wang & Javitt, 1996).

The literature also indicates that geographic location influences the receipt of care as it relates to insurance coverage. As mentioned above, having health insurance impacts the timely and appropriate receipt of health care. This relationship is depicted in research by Fronstin, which states that 20 percent or more of the population in eight south central states were uninsured (Fronstin, 2001). Literature reveals that uninsurance rates vary widely across states, largely due to differences in state economies, employer-sponsored coverage, the share of families with low incomes, and the scope of state Medicaid programs. A three-fold difference is noted between the states with the lowest and highest rates of uninsurance. States such as Minnesota, Iowa, and Wisconsin have rates of uninsurance between 9–10 percent. In comparison, Texas has a rate of uninsurance of 27 percent (Kaiser, 2003). This disparity of uninsurance rate by geographic location may easily translate into differences in the receipt of timely and appropriate health care services.

Research exists that confounds the significance of the influence of insurance coverage. Even when health insurance is available, receipt of care (particularly as it relates to preventive care) is not realized at recommended levels. The RAND Health Insurance Experiment, a large randomized control trial, provided empirical evidence about the use of health care services by level of cost sharing in various insurance plans. When examining the RAND Health Insurance Experiment for one of the most important preventive health measures, childhood immunizations, the study found that persons on the free plan used more preventive care than those on the cost-sharing plan. However, overall use was still low. Under the free plan, members did not pay for the vaccines or for physician services. Only 59 percent of children aged 0–6 in those families received any immunization during the three-year experimental period. This low immunization rate indicates that even free access to health care does not lead to receipt of recommended levels of care (Lurie, Manning, Peterson, Goldberg, Phelps, and Lillard, 1987). Thus, other factors or dynamics must be at play in the lack of receipt of care for even insured populations.

The quality of care received may also have an influence on the receipt of future health care services. Research over the past several decades consistently shows that even when minorities are insured at comparable levels to Whites, they are apt to receive lower quality health care for the same health conditions. This tendency occurs across a wide range of health conditions, including cardiovascular disease, diabetes, HIV/AIDS, mental health, and other clinical services. The receipt of a lower quality of care is often realized through less desirable treatments or no treatment at all throughout a variety of clinical settings, ranging from public and private hospitals to outpatient clinics (Reform, 2004).

Social Context

Cultural Beliefs

The literature speaks of several barriers to the receipt of care stemming from a supposed social context. Examples of these barriers include social class, minority status, and cultural and family values. A number of culturally based beliefs and values impact the receipt of care. Certain beliefs such as mistrust of health care providers and shame are key aspects of racial and ethnic minority groups that must be overcome to increase appropriate receipt of health and eye care. Researchers have noted that mistrust of health care providers is often a reason for delay in seeking medical services. Shame or stigma that can be associated with seeking care for certain problems such as HIV/AIDS could also serve as barriers to care. Furthermore, the reliance on "folk" remedies, which is common in many cultures, adds to the delay in seeking care from traditional health care providers (Reform, 2004). The literature does however, appear to give much importance to these barriers in the receipt of care or explaining disparities as others already cited.

The literature states that some ethnic groups, such as Hispanics, tend to have beliefs in fatalism that are a part of their culture. For example, the slow loss of eye sight by a Hispanic grandfather is typically considered to be a part of the inexorable process that will eventually lead to senescence and death.

Language

Communication is another barrier to the receipt of both health and eye care services. According to the 1990 U.S. Census, almost 14 million people living in the United States do not have good English-language skills (Woloshin, Bickell, Schwartz, Gany, and Welch, 1995). The timeliness and quality of care is thus hampered by the inability of patients, who are mostly of racial and ethnic minority groups, and providers to effectively communicate. As a result, lower rates of appropriate followup care, lower patient satisfaction with care, less access to specialty care, and poorer adherence to treatment plans are witnessed (David & Rhee, 1998). In fact, studies show that the language barrier is responsible for Spanish-speaking Hispanics having worse health status than English-speaking Hispanics (Kirkman-Liff & Mondragon, 1991). For populations experiencing language barriers, their providers must rely on one of three suboptimal mechanisms, each of which has its weaknesses: their own language skills, the skills of family or friends, or ad hoc interpreters (David & Rhee, 1998).

METHODOLOGY

Identification of Points of Contact

A search was conducted among a number of government agencies and non-government organizations to identify those with mission statements that sought to 1) improve and expand access to quality health care, 2) protect the health of racial and ethnic minority populations and to eliminate health disparities, and 3) sponsor and conduct research that provides evidence-based information on health care outcomes, quality, cost, use, and access. Five government agencies and five non-government organizations were selected for interview. The final list of agencies and organizations included:

Government Agencies

- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Medicare and Medicaid Services (CMS)
- Health Resources and Services Administration (HRSA)
- Indian Health Service (IHS)
- Office of Minority Health (OMH)

Non-Government Organizations

- American Academy of Ophthalmology (AAO)
- American Optometric Association (AOA)
- Kaiser Family Foundation (KFF)
- RAND Health
- Robert Wood Johnson Foundation (RWJF)

All interviews were conducted in November and December of 2004. The interview with the Health Resources and Services Administration included a representative speaking on behalf of the National Association of Community Health Centers and the East Jordan Family Health Center, as well as a representative from the Massachusetts League of Community Health Centers. Descriptions of government agencies and non-government organizations can be found in Appendix A.

Each of the government agencies and non-government organizations was contacted to identify a person who could 1) speak on behalf of the agency or organization about its programs, services, or research, 2) identify barriers to the receipt of eye and/or health care services, 3) identify opportunities to collaborate, and 4) provide suggestions or approaches to deal with barriers to care for high-risk populations. During initial contact, each agency and organization was informed that the National Eye Institute (NEI) was attempting to gather information about factors that influence the receipt of care, in particular care that may prevent possible eye disease and vision loss. In many cases, repeated contacts were made in order to identify a representative and schedule an interview time.

A study description and an interview discussion guide were sent to agencies and organizations to help select the most appropriate person to interview. Agencies and organization were informed that interviews could be conducted in person or on the telephone. One organization was unable to participate in an interview and submitted responses to discussion questions via e-mail. Two of the selected non-government organization representatives were unable to participate in the interviews. As a result, two additional organizations were selected to interview.

Protocol Development

An interview discussion protocol was developed to guide discussions about the receipt of eye and/or health care services, barriers to care, and programs for high-risk populations. This discussion protocol (see appendix B) was modified slightly so that it could be used in telephone discussions (see appendix C). The interview discussion protocol included introductory paragraphs identifying the researcher and explaining the purpose of the research. The purpose was to identify best practices and strategies used by other agencies and organizations so that the congressionally mandated National Eye Health Education Program can better design educational materials and programs and collaborate with other government agencies and non-government organizations that specifically address access-to-care issues.

The protocol contained discussion items on the following topics:

- Eye and/or health programs or services provided to the general population.
- Agency and organization definition of the term “high-risk population.”
- Key factors that influence receipt of eye and/or health services for high-risk populations.
- Effective approaches to dealing with barriers to care.

- Characteristics of exemplary programs or materials that attempt to increase the receipt of services for high-risk populations.

- The kinds of programs or materials needed to increase the receipt of eye and/or health services for high-risk populations.

- How individuals and agencies can collaborate to address access to eye and/or health services for high-risk populations.

- Strategies and/or approaches the vision community can consider to effectively deal with barriers to the receipt of eye care.

- Additional agencies and organizations suggested to contact to further explore issues surrounding barriers to care, strategies, and programs to increase the receipt of eye and/or health services.

Data Analysis

All in-person and telephone interviews were audiotaped. Permission to audiotape interviews was obtained from each agency and organization representative. All audiotaped interviews were sent to a transcription service, and content analysis was performed on transcribed interviews. Content analysis has been defined as a systematic, replicable technique for compressing many words of text into fewer content categories, based on explicit rules of coding (Krippendorff, 1980). Content analysis enables researchers to sift through large volumes of data with relative ease in a systematic fashion (General Accounting Office, 1996). Content analysis can be a useful technique for allowing us to discover and describe the focus of individual, group, institutional, or social attention (Weber, 1990).

FINDINGS

Agency/Organization Eye and Health Programs and Services

All of the representatives from government agencies and non-government organizations described programs or services that their organization provided to the general public. A number of representatives characterized their programs and services as multidimensional, where programs and services contained aspects of prevention/screening, education, research, treatment, and advocacy. The majority of the organizations interviewed primarily offered services and programs that were characterized as prevention/screening and education. Even fewer characterized themselves as primarily focused on providing research services. Three of the organizations characterized themselves as providing all of the aforementioned services.

The programs and services offered by each government agency and non-government organization were directed at a range of populations. The mission statement of each organization primarily dictates which services and programs will be directed toward which segment of the population. The Robert Wood Johnson Foundation has programs and services geared toward homeless children, seniors, new immigrant communities, Hispanic American communities, and people with mental health and substance abuse conditions. Institutions that primarily conduct research, such as RAND Health, focus more on special populations. RAND Health is conducting research on a range of topics from health disparities in colon cancer and breast cancer, to the provision of pharmacy benefits to elderly and working-age people.

Below are some comments on particular populations served who were mentioned by agency and organization representatives.

- "We speak to Americans as a whole and then in addition to that, we have congressional mandated priority populations that we pay particular attention to. Our specific priority populations as mandated by Congress are women; children; the elderly; racial and ethnic minorities; low income people; and then individuals with special health care needs, which includes people with disabilities, people requiring chronic care, and people at the end of life. And in addition to all that, we've also identified as one of our priority populations, persons that live in rural areas." - Agency for Healthcare Research and Quality (AHRQ)

- "We provide services to all age groups. About 7 percent of Health Center users are over 65 or older, 66 percent are people of color, 89 percent are at 200 percent of poverty level or below. The largest racial ethnic groups we provide services to are Whites and Hispanics or Latinos, followed by Blacks or African Americans." - Health Resources and Services Administration (HRSA)

- American Indians (federally recognized tribes throughout the United States), Alaska Natives - Indian Health Service (IHS)

- Individuals 65 and older, African Americans, Hispanics/Latinos; individuals with glaucoma or a history of glaucoma in their family history; people with diabetes who are age 65+ - American Academy of Ophthalmology (AAO)

- African Americans, Hispanics/Latinos, Asian Americans, and Native Americans – Minority underserved populations – Office of Minority Health (OMH)

As noted above, a number of the organizations provided programs and services to high-risk populations. The interviewed representatives were asked to clarify the meaning of "high-risk" population. There was some overlap in the definition of the term, "high-risk" population, but there were also some marked differences. Agency/organization definition of "high-risk" also seemed to be highly associated with the mission statement of the agency or organization. For most organizations, the term, "high-risk" population, included vulnerable populations that have both financial and social barriers to receiving health and health care services. Some organizations, in particular organizations characterized primarily as providing research, were unable to provide a definition of "high-risk."

Following is a brief collection of eye and/or health programs or services that were mentioned that certain agencies and organizations provide to the general population. These programs and services are of interest because they focus on "high-risk" target populations, attempt to increase awareness among target audiences of the importance of early detection and treatment of illness, and encourage target audiences and health care providers to take action based on their increased awareness. A number of agencies and organizations indicated that they did not have any programs or services directly related to the provision or funding of eye care services.

Agency for Healthcare Research and Quality (AHRQ)

- National Healthcare Disparities Report is an annual report to Congress on the status and trends in disparities in healthcare.
- U.S. Preventative Services Task Force brings together scientists from across the Nation to try and offer guidance to U.S. providers about what kind of preventative care they should be providing to different individuals.
- Evidence-Based Practice Centers summarize scientific information for people in hopes that it will then allow them to make suggestions to provider groups about what they ought to be doing.
- Medical Expenditure Panel Survey is a huge survey of the general population. Its primary goal is to collect information about health care expenditures. More recently, additional information related to quality improvement has been gathered.

American Academy of Ophthalmology (AAO)

- The EyeCare America, Seniors EyeCare, and Diabetes EyeCare Programs provide medical eye exams and care at no out-of-pocket cost for those U.S. citizens or legal residents, aged 65 and older, who have not seen an ophthalmologist in three or more years, and do not belong to an HMO or the VA.
- The Glaucoma EyeCare Program provides a glaucoma eye exam for those deemed to be at increased risk for glaucoma. Those eligible for this program include U.S. citizens or legal residents, those who have not had an eye exam in 12 months or more, are at increased risk for glaucoma (determined by a combination of family history, race, age), and do not belong to an HMO or the VA.

American Optometric Association (AOA)

- “One of our programs is called Vision USA and it specifically matches up optometrists by Zip code for the people who need eye exams who don’t have them. The Vision USA program is a national program, focused on providing comprehensive eye care services, complete exams, glasses, whatever’s needed to the working poor.”
- “Healthy Eyes, Healthy People Program is designed to address the 10 vision objectives and educate the public, as well as our own doctors about these objectives and what we can do to meet the objectives in the next 10 years.”

Robert Wood Johnson Foundation (RWJF)

- “One program that was specifically focused solely on vision was a grant to Johns Hopkins School of Medicine, Wilmer Eye Institute. It was a program that provided eye screening, diagnosis, and treatment for the low-income elderly. The project provided six eye-screening locations in senior centers and churches in the Baltimore area. It was a very innovative program because it really was trying to actually train community outreach workers to do vision screening in any community setting and to pick up glaucoma, cataracts, and macular degeneration.”
- “We have one program that provides dental sealants to 6,000 kids in Cleveland schools through the dental school at Case Western Reserve University.”
- “We have a program that is replicating a Los Angeles program that trains 2,000 kids a year to run the L.A. marathon.”
- “We have a new program that we’re funding, which is a public health radio soap opera targeting the African American community.”

- "We have multiple programs that are working specifically with new immigrant populations and connecting them to health and mental health services."

Factors That Influence the Receipt of Care

As previously discussed, several studies have noted that people at risk for vision loss are not receiving optimal eye care, although these diseases are treatable and preventable (Klein, 1997). This research into barriers to the receipt of care sought to find the reasons for underuse of eye care services. Barriers to the receipt of health care services have been described in the literature as a complex web of interactions of many behavioral, social, economic, cultural, biological, and environmental factors, as mentioned earlier. To help ascertain what variables influenced the receipt of care and the barriers to the receipt of care, representatives of government agencies and non-government organizations were questioned about why they perceived health disparities to exist.

The responses from the representatives seem to mirror the description of a complex web of interactions referenced in the literature, particularly when one looks at the barriers described by each agency and organization as a whole. Depending on the types of services and programs offered by each organization and the recipients of those services and programs, the barriers to care cited by the different organizations varied significantly. In general, barriers to the receipt of eye and/or health care services that were mentioned ranged from insurance status and type of insurance, availability of providers, and language barriers, to transportation, health literacy, and patient perceptions. There also seemed to be a consensus that barriers to receipt of general health care may be the same barriers for eye care.

The majority of all agency and non-government organizations mentioned insurance status as a key factor in the receipt of health care services. One organization representative said, "I think there has been a long history of studies at RAND, most of them federally funded or funded by the Robert Wood Johnson Foundation, that have shown that having good insurance is really important to the provision of preventive services. I think if we sort of looked at the studies over time and asked 'what's one of the big themes,' insurance status would certainly be a theme. Another big theme is that higher levels of cost-sharing seem to decrease service use for preventive services."

Much of the research on barriers to care speaks to fundamental factors such as race and ethnicity, insurance status, and transportation. Other research speaks to socioeconomic determinants such as income, wealth, and education. However, one theme that arose from this research and is increasingly documented in the literature is the theme of patient perceptions. One agency representative said, "People have different perceptions of need. Some populations don't recognize the need for care as readily as others; and as one recognizes, they may not act as quickly upon those needs." There are, however, many dimensions that play into patient perceptions, such as patient-provider communication, patient-provider relationships, trust and distrust of providers, and the health care system itself.

Ultimately, what dictates patient perceptions is health literacy. To be an efficient consumer of health care, one must be knowledgeable of disease processes and the prospects of preventive care to avoid unnecessary morbidity and mortality. One of the variables mentioned in this research as being influential in the receipt of general care and care for eye disease and vision loss was health literacy. Health literacy was mentioned as a barrier in more than half of the interviews conducted. Agency and organization representatives stated that there is a lack of knowledge across the board about general health conditions, and there is lack of knowledge and information about the importance of eye screenings.

As mentioned earlier, health literacy has been defined as the degree to which people have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Thus, also connected to the barrier of health literacy is literacy or education level in general, and the ability to read and write. A number of organizations mentioned lack of literacy as a barrier to the receipt of eye and/or health care services.

Another component of health literacy, which is oftentimes overlooked, but mentioned in an interview with one agency representative, is that our system of health care is constantly changing, particularly as it relates to coverage, billing, and the use of third-party payers. The representative said, "In our system for a patient that's become a big obstacle. I mean for you and for I who are so-called educated people, it's a mounting challenge to figure out open-window enrollment and which program to sign up with, what your co-pay is going to be, and how often you can be seen by a practitioner, and who your primary care manager is, and all these other acronyms that go along with health care." Being literate of changes in our health care system could be considered just as necessary as understanding disease processes. Adequate information about coverage and billing of eye and or health care services is critical to increasing health literacy.

Another representative elaborated on how providers themselves serve as barriers to the receipt of health care services, which is supported in the literature. The literature typically references providers serving as barriers to care based on examples of discrimination, racial bias, cultural insensitivity, and deficient knowledge and training. This organization representative felt that a practitioner's point of view of providing care to the community is often one-dimensional. The representative stated, "I think traditionally doctors go to school and learn that you stay in your clinic and the patients come to you and you provide the care. Well that's not public health… if you want to improve the receipt of eye and vision services, you have to go out in the community."

Another major theme in terms of barriers that surfaced in the interview with government agencies and non-government organizations is language. According to the 2000 Census, among the 262.4 million people aged 5 and over, 47.0 million (18%) spoke a language other than English at home (Shin & Bruno, 2003). In a number of interviews, it was mentioned that many cultures have to deal with language barriers when seeking any type of health care service. This interaction can prove to be frustrating for both the provider and the patient. Often in most cultures, English is understood well enough to go to the store and do casual things. However, when dealing with issues related to health care and the terminology that is associated with various medical conditions, it is very difficult for a patient to understand if they are less familiar with English. In many cases, it is necessary to involve children to translate messages between the provider and patient.

Table IV-1 contains a complete list of key factors that influence the receipt of eye and/or health care services captured in interviews with 10 government agencies and non-government organizations. Although a particular agency or organization did not mention a particular barrier in their responses to this interview, their agency or organization may support the inclusion of other key factors as barriers to the receipt of care.

Table IV-1: Factors That Influence the Receipt of Eye and/or Health Care Services

Barriers to the Receipt of Eye and/or Health Care Services

- Insurance status and type
- Availability of providers
- Usual source of care
- Language barriers
- Transportation
- Health literacy
- Education/Literacy
- Cultural competency
- Provider competency
- Provider mentality
- Race and ethnicity
- Income and wealth
- Culture
- Values and beliefs
- Access to media
- Lack of collaborations
- Patient perceptions
- Trust and distrust
- Patient-Provider relationship
- Health care system (billing)

Barriers for High-Risk Populations

After identifying factors that influence the receipt of eye and/or health care services, agency and organization representatives were asked whether they felt those variables differed for high-risk populations compared to Whites. For purposes of this research, agency and organization representatives were asked to use as a definition for high-risk those who are predisposed to certain eye health problems due to their family history, race/ethnicity, and age. Populations typically considered to be at high-risk for eye disease include minority groups such as African Americans, Hispanics, Latinos, American Indians, and Alaska Natives. There was a general consensus that the barriers outlined in Table IV-1 and mentioned throughout the interviews differed for high-risk populations compared to Whites, particularly when considering culture and language barriers. One representative mentioned that the degree in which the barriers differ really depended on what the barrier was. That representative said, "… when you look at location, say rural versus urban, I think you see some of the same types of things. But then when you look at, for example, language barriers, you may see larger disparities."

Various reasons were offered by agency and organization representatives when questioned about whether different racial and ethnic groups disproportionately experienced more barriers to the receipt of eye and/or health care services. The majority of agencies and organizations believed that racial and ethnic minorities experienced more barriers to health care services. One organization representative said, "Yes, minority groups often experience limitations in obtaining services due to lack of access to education and/or work opportunities." Another representative agreed saying that "…minority groups are disproportionately represented among the uninsured or underinsured and because some minority groups have limited English-language proficiency." Fear of deportation was also stated to be more common among racial and ethnic minorities, thus leading to more barriers to the receipt of care for this population.

There was less consensus when agency and organization representatives were asked whether barriers to care were different for racial and ethnic groups. One representative who agreed that barriers affected racial and ethnic groups differently commented, "You know, I think from what we know about acculturation, about other patient-level factors such as socioeconomic status and language, and what we know about other system-level factors such as insurance status and type of insurance, I would expect that there would be variations among ethnic groups." Other representatives felt that some barriers are the same across racial and ethnic groups, but also that some barriers are unique to certain racial and ethnic groups. One agency representative said, "I think there are some factors that are probably common across most of the racial and ethnic groups, for example, insurance and economic status. You know, minorities across the board tend to have lower socioeconomic status and higher rates of uninsurance. But then there are other barriers that are very specific to certain ethnic groups. Language is predominantly a larger issue for Hispanic and Asian populations than it is for Blacks or African Americans."

Programs, Methods, and Approaches To Increase the Receipt of Care

Given the extensive list of variables that influence the receipt of eye and/or health care services, representatives from government agencies and non-government organizations were asked about what strategies, methods, or approaches are most effective in dealing with barriers to care. The representatives offered a very comprehensive list of approaches to barriers to care, ranging from collaborating with partners within the community, to providing data that can help shape policy and inform policy decisions, to educating the public about early detection, to disseminating appropriate health messages, and to educating providers and providing access to care at low or no cost.

A number of agencies and organizations indicated that increasing education and awareness to the public is key in dealing with barriers to care. Education about early detection and what care of the population should be is critical. One agency representative said, "We've noticed that education is definitely key in spreading the message and creating awareness. It is also important to make sure that those materials are culturally appropriate, accurate, and getting to the right places." Education among providers was also mentioned. Providers need to be educated about culturally relevant material, and need to be knowledgeable about available resources and materials to better inform their patients.

A method that was mentioned as being effective in dealing with barriers to care relating to educating the public with important eye and/or health information is the "4 Ls and C" Method. This method is used by the Centers for Medicare and Medicaid Services (CMS) to determine the most appropriate messages based on an evaluation of "L"ocation, "L"iteracy, "L"anguage, "L"ow income, and "C"ulture. This method assists CMS in letting their beneficiaries know about what benefits they have and what programs are available to them. CMS has also used social market research to help define messages and to reach their populations differently.

An interesting approach that was mentioned by two agency representatives is that in order to effectively deal with barriers to care, representatives of the health care system need to lose the "one size fits all" mentality. Although the two agency representatives were talking about the same concept, they were referencing two vastly different viewpoints:

1) A population perspective, where there is a tendency to lump certain populations together into one group, assuming they have the same characteristics throughout. For example, many aspects in the Native American population are different: their languages, daily life, housing, transportation, culture, outlook, and their perceptions of "western health care." The process of lumping segments of ethnic populations together should be avoided.

2) "One size fits all" mentality, which speaks more from a barrier perspective. This perspective notes that the most effective approach to dealing with barriers to care is to come up with solutions that deal with a particular barrier. There is no one single solution that will solve everyone's problems. Rather, each problem needs to be addressed as a problem. For example, insurance needs to be addressed as a problem, language needs to be addressed as a problem, and cultural competency needs to be addressed as a problem. Solutions need to be tailored for each of the barriers individually, as opposed to fixing one problem and expecting everything to be correct.

Other strategies, methods, and approaches mentioned in the interviews with representatives from government agencies and non-government organizations are noted below.

- Change practitioner's view of providing care to a community
    - Go out into the community and seek those people who are not receiving care.

- Collaborate with partners within the community
    - Collaborate with the health department.

- Provide empirical data
    - Provide data that can help shape policy and inform policy decisions.

- Provide models of care that offer systemic changes and better opportunities for low-income and uninsured families to have full participation in health care.

- Identify groups that have particular vulnerabilities.

- Construct programs that are comprehensive in accounting for the cultural, economic, transportation, and other factors that may influence the availability of care.

- Educate the population about early detection
    - Educate the population about what their care should be; about what the disease is; and how they can manage it, delay it, or prevent it.
- Educate providers
    - Educate practitioners about culturally relevant material.

- Provide access to care at low or no cost.

- Determine the appropriate messages using some type of criteria
    - Use social market research to help define messages and reach populations differently.

- Provide transportation assistance or mobile vans.

- Look at payment policies and things of that nature that would be incentives for providers to work with underserved populations and give them the care that they need.

- Providers' participation is key.

- You need to have providers in rural areas and they need to be accessible and available. Clinic hours should be available, including some after-work hours or weekend hours.

- Stress affordability and accessibility.

- Lose the "one size fits all" mentality
  - Don't focus on one solution to all health care problems.

Exemplary Programs and Materials

Interview representatives were also asked about characteristics of programs or materials that aim to increase the receipt of eye and/or health care services that would be considered "exemplary." Examples of exemplary characteristics ranged from being culturally appropriate, those providing community-based outreach, and those increasing cultural competency, to those implementing some type of performance feedback and loan repayment programs. An interesting characteristic noted by one agency representative was a linkage between issues of quality of care with the receipt of care. This representative felt that programs that "married" issues of quality of care with the receipt of care had a better chance of increasing the receipt of eye and/or health care services.

Materials and programs were noted to be exemplary if they were developed in a "culturally appropriate" fashion for the target population. In many instances, one's culture, religion, and ethnic history need to be examined to ensure messages are culturally sensitive. The term "culturally appropriate" also extends to the way in which materials and programs are disseminated, as well. One agency representative said, "When you're trying to spread a message with Asian-American females about mammography, you would need to understand that they would not take that message or accept that message through a male. The message needs to be sent through a female because in their culture, it is disrespectful for a male to talk to them about their breasts or things of that nature. So when you're educating specific populations, you need to understand some of their cultural, religion, and history so that you can get the message across in a dignified manner."

Additional characteristics of exemplary programs and materials mentioned by government agency and non-government organization representatives are listed in Table IV-2 below.

Table IV-2: Characteristics of “Exemplary” Programs or Materials That Increase the Receipt of Eye and/or Health Care Services

Characteristics of “Exemplary” Programs or Materials That Increase the Receipt of Eye and/or Health Care Services

- Loan repayment programs
- Community-based outreach
- Increased cultural competency
- Rigorous collection and analysis of data
- Buy-in from community members
- Appropriateness of reading level and language
- Health-literate materials
- Cultural appropriateness
- Performance feedback
- Online basic health information
- Community-based input
- Current clinical, diagnostic, and treatment technique use
- Collaborative in nature

In light of the diverse strategies, approaches, and methods offered by agency and organization representatives, a number of programs or materials were noted that addressed factors that impeded the receipt of eye and/or health care services in general, and programs for high-risk populations, in particular. Following are highlights and descriptions of certain programs and services that are of interest because they 1) focus on “high-risk” target populations, 2) attempt to increase awareness among target audiences about the importance of early detection and treatment of illness, and 3) encourage target audiences and health care providers to take action based on their increased awareness. Several of the representatives interviewed indicated that they did not have any programs or services directly related to the provision or funding of eye care services. However, programs that they considered exemplary are noted below.

- “I think that one of the exemplary programs has been the long-standing work that the Robert Wood Johnson Foundation has done in school-based health centers. In each of the school-based health centers, vision screening is an important part of their programming, often for children who would not otherwise have access to it. Another component of it is the support of an infrastructure of community health centers and volunteer models that provide community-based primary care networks throughout the United States in raising awareness through advocacy and through communications, in particular about the cost to our country of having 47 million uninsured.”

- “The REACH program is our way to reach the community through community partners, working with some mobile community partners where we can get the information out that’s accurate and right out into the community. The program is national in scope and it focuses on reaching persons with low-income, literacy, language, and cultural barriers."

- "The Race and Ethnic Health Disparity Initiative conducts outreach, education, intervention. We develop intervention models to reach communities of color. We offer research and technical assistance to minority researchers, as well as institutions which focus on cultural competency."

- "We also sponsor an annual health care outreach project. It's called "Take A Loved One to the Doctor Day," a collaborative [effort] with the Office of Minority Health and the Office of the Secretary and what this revolves around is early detection and prevention. We have a lot of community health centers that are part of this outreach campaign. They offer free services, sliding-scale services in many cases, to persons without health care or persons not eligible for health care with Medicare. And then, as well, we also partner with universities to offer mobile eye exams during this event."

- "We have a grant program that's called "Translating Research Into Practice." In addition to sponsoring really good research, we also want the products of the program to not only be papers that are published in scientific journals, but tools that can be directly used by providers to influence and improve care."

- "We have a new project called "REACHES." With the program, we are trying to develop direct relationships with large purchaser or provider groups to make sure that the products that we've developed, the tools that we developed, are useable and implementable."

- "The Diversity Open Door program is one way that our administrator has opened the doors of the agency to allow advocacy groups and those who are interested in the health of our served populations to address CMS as sort of just [an] open forum."

- "Joslin Vision Network conducts a tele-imaging system for diabetic retinopathy. They take pictures of the retina of diabetic patients, fax them into Phoenix where they have readers who examine those for diabetic retinopathy, and provide a report back to health centers. They access the

> population that is outside the eye clinic. They're trying very hard to go to people who are not getting seen already by eye clinics."

Collaborations

A number of the programs that effectively address barriers to care and increase the receipt of eye and/or health care services are those that involve collaborations between various agencies and organizations. The interviews revealed that sharing the experiences and successes of different organizations that are doing the same thing is a useful way that organizations can collaborate and maximize the delivery of care to various populations. Representatives from agencies and organizations spoke about the importance of collaborations and provided some examples of exciting partnerships that their organizations were involved in that they felt had a lot of potential for addressing the receipt of care. One agency representative said, "We have a memorandum of understanding with the National Association of Community Health Centers that was signed this year, to promote and facilitate programs and special initiatives to ensure that the medically underserved have access to comprehensive vision care. So we are taking the issue of vision care on as an association and the National Association of Community Health Centers is, as well."

Several beneficial strategies were revealed that help establish collaborations. Agency and organization representatives were asked how people and agencies/organizations that address the receipt of eye and health care services for high-risk populations could collaborate. A theme that emerged was to seek collaborations that are diverse in experiences and backgrounds. This "cross culture" environment will ensure that all aspects of barriers to care can be addressed. One organization representative said, "I think probably one of the important things is to facilitate those collaborations and partnerships across academic and non-profit think-tank operations and the actual service providers who might not have the research expertise on how to design studies, but have hands-on experience of population needs."

Another interesting theme that was mentioned in several of the interviews was to initiate collaborations with educational institutions. One organization representative said, "…as you look at those Health Centers that have a cooperative agreement with an educational institution like the New England College of Optometry, I think you see a different level of services that the faculty and the students bring to that environment." Another representative said, "When you meld training and clinical practice, there is a different level of excellence and I think those are the exemplary programs."

An interesting point of pooling resources was mentioned in several agency and organization interviews as it related to collaborations. It was noted that many agencies or organizations have vehicles already in place to reach target populations. Representatives said it was worthwhile to seek those organizations and establish partnerships with them to save on costs and manpower, and to have the most efficient allocation of resources to disseminate messages. "The Social Security Administration, who has an ongoing translation program, and they're translating a lot of their messages into 14 languages and what we're trying to do is partner with them to get as many of our key messages translated in multiple languages. We almost always do Spanish, but what we're trying to do is go down into the multiple languages a little farther[...]They're also going to help us with our drug card enrollment and our prescription drug benefit in trying to reach the lower income, underserved populations a little differently too[...]So SSA has become a key partner with us and within the last year we developed an inter-agency agreement with them to begin this process."

Additional comments by government agency and non-government organization representatives about collaborations that their agencies and organizations have created are listed below.

- "We partner with 10 of the leading health plans in America, along with the Robert Wood Johnson Foundation, to form this learning collaborative. This group meets on a regular basis to examine the collection of disparities information in the health plans, as well as design interventions to try to overcome some of the barriers that they identify. I think the first year we are going to focus on trying to improve quality of care for diabetes."
- "I think looking at who the key leaders in communities are in terms of health care and incorporating programming that's affordable and accessible into it. When focusing on vision-screening collaborations, we should implement models for vision screening and treatment that are very accessible, very affordable, very portable, particularly in low-income communities and new-immigrant communities where there is difficulty in making eye care a priority."
- "Collaborations are important. To collaborate, it takes a strong leader that wants to make things happen and bring in all the players in the community and go for it! I mean it's not easy, it is not easy. And it takes a strong leader that doesn't try to dominate, but facilitates and lets everybody have their say and then comes to a common agreement. And

you know I'm making this very simple, but it's not simple work, but it can be done."

- "We have something called a Health Disparities Collaborative, and it's a program that's been going on about six years now, and we are in partnership with several organizations, including the National Association of Community Health Centers (NACHC). Diabetes was the first collaborative we did, and of course there was a component of vision services where one of the measures we looked at was a dilated eye exam. The idea is that a system of care is set up so that you are ensuring that people are receiving the appropriate services at the appropriate time, and that it's planned out and not just sort of "crisis care," but more planned care. The idea was then that you would get better health outcomes, and indeed we've been able to show some of that. We've gone onto other chronic diseases, as well as onto prevention, cancer screening, and really looking at the entire system of care, the way in which the practice is designed, looking at even some financial management aspects. And so that's one program that is very much an attempt to improve the quality of care, as well as improving access to care."

- "I think the key thing is for the organizations to put into writing what is agreed to, about what action steps they are going to take, and to hold themselves accountable. It's the many fronts, legislative, education, communication exchange and information exchange, and several other areas, that are developed in the collaboration. But too many of the collaborations are weak. They don't share information with each other, they don't give each other enough feedback, especially positive feedback so that the agencies continue to move this agenda forward."

Gaps in Knowledge and Services To Increase the Receipt of Care

Despite the many programs and materials that aim to increase the receipt of eye and/or health care services, many gaps in knowledge and services exist that we as public health officials can address to better reach high-risk populations and to decrease health disparities in this country. Government agency and non-government organization representatives were asked what kinds of programs and/or materials and action steps are still needed to increase the receipt of eye and/or health care services for high-risk populations. One gap identified in the interviews was the need to address getting people to services in a more timely manner, obtaining additional resources to deliver care to target populations, and providing care to meet the demand for care. One agency representative said, "Here in Gallup we have about a 60-day wait for routine eye appointments. We need somehow to address getting people services in a more timely manner, and that translates to just more manpower and abilities."

The representatives also mentioned a need for more programs that provide screening opportunities for various conditions. When a person is screened, it provides an opportunity to detect possible disease and to begin the process of referrals. Several agency and organization representatives mentioned a need to provide basic screening and vision screenings in churches, malls, and senior centers. One organization representative said, "I would love to see more basic vision screening in churches, in malls, in senior centers… I think we have to look at ways that are inexpensive and perhaps not perfect, but that are a significant step ahead of having no screening at all." What is important to note is that the process of receiving care extends through the referral process. Several representatives mentioned that systems need to be in place to take the next step after screenings occur. This process will allow people who test positive to quickly get in and receive the specialized services they need.

Another major gap in programs, materials, or services that could positively impact the receipt of eye and/or health care services for high-risk populations is the proper dissemination of educational materials that are rooted in science and in theory. These materials then need to be translated into messages targeted to specific audiences in a manner that will optimize their chances of adhering to the public health messages. Several interviews touched upon the theme of translational research and its importance in terms of improving information about health care. One agency representative said, "We often collect information and distribute it in ways that don't have the biggest impact on a lot of groups, in particular racial and ethnic minorities. I think we do a particularly bad job of attending to their information needs. We have a lot of information, for instance, that talks about quality of care and how to make sure you're receiving quality of care from a provider and how to pick a good doctor and a good health plan and all that kind of stuff, but a lot of it has not been translated to documents that are specific to different racial and ethnic groups or socioeconomic groups." Another representative added that, "We don't always make products that target specific audiences optimally to maximize their understanding and to maximize the chances to actually implement those findings. Another thing we do a lot of with our dissemination is we mail it to the providers and put it on our Website. That doesn't help patients who don't have access to the Internet or don't go to their provider's offices."

Additional comments by government agency and non-government organization representatives about programs and/or materials and action steps that are needed to increase the receipt of eye and/or health care services for high-risk populations are listed below.

- "There are a lot of things at the system level that we can think about doing that could improve the delivery of preventive eye care services. There's great promise in the electronic medical record, the use of physician reminders, and instructory care, so that patients are more aware of what they need and more activated to go get it."
- "I think reaching out into the community to provide services in an atmosphere that's more comfortable for those who need it and more accessible is important. That doesn't mean the doctor's office you know, that means maybe churches or schools or health centers where they… where they… these folks may feel more comfortable coming for care than to a private doctor's office."
- Produce material at appropriate grade levels for comprehension.
- Distribute your message and materials directed to your audience using a variety of traditional methods: TV, radio, newspapers, and creative venues such as free press periodicals, laundromats, beauty parlors, assisted-living units, HUD housing, local medical clinics, senior meal sites, churches, libraries, schools, billboards, Websites, etc.
- Translate material into multiple languages, as appropriate.
- "I think well-designed representative research studies are critical. I think anything that the vision care community can do to facilitate partnering with service providers, whether it's a health plan or public health departments, and to help us deal with HIPAA-related privacy issues, IRB-related issues, and to somehow streamline access to data in the identified form for conducting research, the more we can learn about the magnitude of this problem and what the best solutions are."
- "My feeling is that eye/vision services and behavioral health don't get the same upfront marketing of their utility, necessity, and value that primary care services and dental services do. And I think it impacts access to care on the patient's side, because they don't necessarily understand when

they need it and when they don't."

- "I think the vision community needs to look firmly into the issue of the uninsured and not being able to pay for services. Certainly providing services free of charge would be of benefit."
- "I think the academic community, the schools of optometry, and ophthalmology resident programs ought to be more involved and tapped for their resources in helping, whether it's a public awareness campaign, helping get their students [into] more of a mindset to deal with these [barriers to eye care] issues throughout their careers, as well as providing care directly in their local communities."

How the Vision Community Can Help

Several comments were also noted on how the vision community can better assist government agencies and non-government organizations to decrease barriers to eye care and increase use of eye health services and programs. One piece of advice was to fund collaborative research. An organization representative said, "I would think that it's very important to fund collaborative research between service providers and academic institutions to better understand the determinants of disparities and the provision of eye care services and rates of blindness among high-risk groups in our country." Other advice included identifying good ways of assessing the eye health of Americans, and sharing our best practices.

Additional comments on how the vision community can assist government agencies and non-government organizations to decrease barriers to the receipt of eye are listed below.

- "Conduct good research and make us aware of it and then lobby us so that we do have visual recommendations or more visual recommendations. This would be extremely helpful for the U.S. Preventative Services Task Force guidelines."
- Provide opportunities for groups to meet each other at conferences/educational seminars.

- Make materials available to be tailored with the logo/message of the participating organizations.

- Identify what you know, what is good, what is high-quality visual care. This is how you measure it, this is how it should be tracked, then that helps us to include visual care in what we do.

- Help spread the word about programs.

- Identify or craft good ways of measuring the visual health of Americans and tell us about it. Say to us, "You ought to really track this as part of your core activities." That would help us in terms of providing more advice about visual care.

- Provide listserves and Web links.

- "I would say by sharing their [Vision Community] best practices and sharing some of the experiences that they've had, perhaps via some of our Open Door Forums, where advocacy groups can share their interests and questions and concerns with us.

DISCUSSION AND RECOMMENDATIONS

Discussion

In the interviews with the various health care experts, many barriers to the receipt of care were identified. It is important to note from the discussions with agency and interview organizations that many barriers are highly related to others and there is a considerable overlap. For example, patient perception has been noted in the literature as a barrier to the receipt of health care services and mentioned within this research. Another barrier that could easily be rolled into patient perception is distrust of the providers or the health care system as a whole. The fact that certain barriers are highly related to others or could be lumped into a category with another variable may be an area where the problems of barriers to care or health disparities exist. Perhaps barriers to care need to be dealt with in their purest form. Many times as found in this research, we as public health officials look for a "one-size fits all" solution to the many problems facing our health care system today. Perhaps this phenomenon occurs and we do not even notice it. Attempts need to be made by organizations responsible for educating the masses, both patients and providers, to address these issues/barriers in their simplest form and not to impose "one-size fits all" approaches and expect immediate and positive results.

Barriers that were more frequently mentioned in the interviews, such as availability of providers, insurance status, and transportation, may fall outside the realm and principle mission of NEHEP. However, as it relates to the mission of NEHEP to increase awareness among health care professionals of the need for regular comprehensive dilated eye examinations, it is important to ensure that providers continue to be sensitive and aware that these barriers exist and that they prevent the receipt of any type of eye care. Perhaps educating and preparing eye care professionals with the knowledge and direction of how to seek high-risk populations at risk for eye disease will heavily influence the receipt of eye care services.

Several barriers do fall within the spectrum of services that the NEHEP program offers, in particular language barriers, health literacy, cultural competency, and patient perceptions. It is important to communicate to the general public culturally sensitive and timely information about the receipt of eye care services. Programs and materials need to be developed and customized to account for Americans who have lower reading and writing levels. This customization could lead to an increase in timely receipt of eye health services and increase the use of needed preventive eye care. Materials and information should also be provided to consumers of health care in their native languages as much as possible to ensure that appropriate health decisions are understood and made. This translation is critical in confronting various perceptions of need mentioned in agency/organization interviews. One of the primary goals of NEHEP is to increase action taken by people with eye conditions. A firm understanding of treatments and treatment options, as well as the need to seek care, is critical for action to be taken. It is also worthwhile to devote attention to identifying those populations that do not recognize the need for eye care as readily as others, and targeting those populations with educational campaigns so that vision care can be sought in a timely fashion to meet their eye health needs.

Health literacy was mentioned as a major barrier to the receipt of eye and/or health care services. Outside of patients being knowledgeable of disease processes is the need to be literate of changes in our health care system, particularly as they relate to coverage and benefits, billing, and the use of third-party payers. In 2003, an estimated 15.6 percent of the population, or 45 million people, were without health insurance coverage, up from

15.2 percent and 43.6 million people in 2002. On the other hand, the number of people with health insurance coverage increased by 1 million in 2003, to 243.3 million (84.4% of the population) (DeNavas-Walt, Proctor, and Mills, 2004). This increase represents a huge segment of the population who may have problems navigating our health care system and obtaining vision care servcies. This increase also speaks volumes that some other factors or dynamics besides insurance coverage must be at play in the lack of receipt of care. The NEHEP program needs to develop ways to assist Americans to navigate our health care system, which will further lead Americans to take appropriate action based on their increased awareness of low vision and eye disorders. Assistance in being literate about our health care sytem is particlarly important as it relates to eye care in light of the fact that vision care services typically fall outside the realm of services offered in most health plans. This type of assistance alone may have a positive impact and increase the receipt of eye care services.

Although a number of the organizations interviewed provided a limited amount of direct services, programs, or research on eye health, the comments and suggestions provided on how to increase the receipt of eye care give valuable insights that NEHEP representatives can learn. These suggestions can allow NEHEP to better design strategies and approaches to meet the goals set forth by the NEHEP program. Attempts were made on behalf of the agency and organization representatives to speak as much as possible about eye health programs that they were knowledgeable of. Nonetheless, much stands to be learned in which the NEI can borrow best practices and lessons learned through the provision of services, programs, and research on other medical conditions and aspects of our health care system. Borrowing from strategies and approaches outlined in this report and highlighted in the recommendations section, the NEHEP can better position itself to confront barriers such as health literacy, language, attitudes, and perceptions that prevent the receipt of eye care services.

The issue of barriers to care is a very difficult subject to deal with. It must be handled with a high level of sensitivity and patience. There are many factors that play into the receipt of any type of health care service, and many of the factors interact and build off one another. This interaction poses difficulty when tackling this issue because when developing interventions, health care professionals may address one aspect of a problem, but may be unaware of another factor that is driving the barrier they are confronting. This situation is particularly true when researching how culture and family dynamics may be hidden behind and drive other barriers.

A particularly useful tool in confronting barriers to the receipt of eye care and general health care services are the practitioners. They provide the first line of care and serve as an entry point to our health care system. They also have a great impact on whether patients are informed of needed subsequent care and whether that care is sought by patients. One suggestion of this research is to educate and encourage providers to improve their quality of care and level of communication with their patients. This improvement will enhance their relationship and have a positive impact on the quality of care that may have beneficial effect on the receipt of care. An improved relationship between providers and patients will also aid in the education of patients in terms of disease processes and patient options, which will also allow providers to delve into personal history about patients and gain an understanding about family history of certain conditions. However, providers need to be reminded that with every patient, they should maximize the time spent and not "rush them out of the door."

Ultimately, this provider–patient interaction begins with Americans having a usual source of care. There are several creative ways in which to get Americans to a usual source of care. One of those ways that NEHEP has continually done is to educate and increase awareness of eye disease among target audiences. However, if partnerships and collaborations with other agencies and organizations can be created, this will assist the NEHEP in accomplishing its goals given the limited amount of resources available to do so. For example, partnering with other organizations that provide physicals to seniors is one way of getting people into the health care system. If messages about eye health were "piggy backed" on physical exams or if eye exams were also included with those physicals, we would have increased the receipt of eye care. We also would have provided education as a part of that physical and eye exam, and the patient would have been informed of preventive care services that they might have needed.

Lastly, as previously mentioned herein, there is a lack of specific empirical data and research on barriers to the receipt of eye care. It is important to employ both quantitative and qualitative research methods to explore how barriers to care and what barriers to care influence the receipt of vision care services. There are social, environmental, and behavioral dimensions as mentioned earlier in the literature review. An understanding of how those dimensions interact needs attention and further exploration. Once a better understanding of those interactions is made, a concerted systematic educational intervention can be employed to better address this issue.

Recommendations

This research has gathered information about barriers to care and strategies and approaches to effectively deal with these barriers for high-risk populations. The goal of effectively dealing with barriers is to decrease levels of health disparity. The National

Eye Health Education Program should consider incorporating the following recommendations into its program objectives and goals:

- Develop materials and recommendations that educate eye care professionals about the importance of going out into the community and providing care.
- Develop materials and educate providers about the significance of providing culturally competent eye care.
- Produce materials for the general population at appropriate reading levels to ensure proper comprehension.
- Translate materials into multiple languages, as appropriate.
- Distribute messages and materials directed to a target audience by using a variety of media and methods.
- Develop intervention models and methods to reach communities of color, especially if they are considered to be of "high-risk" (i.e., "Take A Loved One to the Doctor Day" or the public health radio soap opera targeting the African American community mentioned earlier.)
- Continue to provide quality outreach, education, and interventions to the American public about eye health, and make healthy vision a priority.
- When developing new materials, consider creating social marketing strategies that account for variables such as location, literacy, language, and income (i.e., the "L"ocation, "L"iteracy, "L"anguage, "L"ow income, and "C"ulture framework as described within the report.)
- Consider various social marketing strategies to develop the appeal of eye health.
- Encourage and sponsor well-designed representative research studies.
- Place an emphasis on translating current scientific advances in the diagnosis and treatment of eye diseases and disorders to practitioners and the general public to increase awareness of health care options.

- Explore opportunities to develop partnerships with the academic community (i.e., schools of optometry and ophthalmology resident programs) to address barriers to care.

- Look for innovative and creative collaborative opportunities in which resources can be pooled to effectively deal with barriers to care and increase the receipt of eye care. Look to create collaborations across health plans, think tanks, and academic institutions.
- Continue to identify methods of assessing the eye health of Americans. (i.e., data collected on the eye health of Americans via the National Health Interview Survey to measure success to meeting Healthy People 2010 targets.)

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Appendices

Appendix A

Descriptions of Agencies and Organization

IDENTIFICATION OF VARIABLES THAT INFLUENCE ACCESS TO EYE CARE

List of Relevant Government Agencies and Key Non-Government Organizations

Government:

1. Agency for Healthcare Research and Quality (AHRQ)
2. Centers for Medicare and Medicaid Services (CMS)
3. Health Resources and Services Administration (HRSA)
4. Indian Health Service (IHS)
5. Office of Minority Health (HHS)

Non-Government

1. American Academy of Ophthalmology (AAO)
2. American Optometric Association (AOA)
3. Kaiser Family Foundation (KFF)
4. RAND Health
5. Robert Wood Johnson Foundation (RWJF)

Descriptions of Government Agencies and Key Non-Government Organizations

GOVERNMENT

1. Agency for Healthcare Research and Quality (AHRQ)

The main functions of the Agency for Healthcare Research and Quality include sponsoring and conducting research that provides evidence-based information on health care outcomes; quality; and cost, use, and access. The information helps health care decisionmakers (patients and clinicians, health system leaders, purchasers, and policymakers) make more informed decisions and improve the quality of health care services. The mission of AHRQ is to support research designed to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. The research sponsored, conducted, and disseminated by the Agency for Healthcare Research and Quality provides information that helps people make better decisions about health care.

The strategic goals of AHRQ are to support improvements in health outcomes; strengthen quality measurement and improvement; and to identify strategies that improve access, foster appropriate use, and reduce unnecessary expenditures. Adequate access and appropriate use of health care services continues to be a challenge for many Americans, particularly the poor, the uninsured, members of minority groups, rural and inner city residents, and other priority populations. The Agency will support studies of access, health care utilization, and expenditures to identify whether particular approaches to health care delivery and payment alter behaviors in ways that promote access and/or economize on health care resource use.

Address Information	**Contact Information**
Agency for Healthcare Research and Quality 540 Gaither Road Rockville, MD 20850	Phone: (301) 427-1364 Email: info@ahrq.gov

Organization URL: **www.ahrq.gov**

2. Centers for Medicare and Medicaid Services (CMS)

The mission of the Centers for Medicare and Medicaid Services is to ensure health care security for beneficiaries. In serving beneficiaries, CMS will open their programs to full partnership with the entire health community to improve quality and efficiency in an evolving health care system. The goals of CMS are to protect and improve beneficiary health and satisfaction; foster appropriate and predictable payments and high-quality care; promote understanding of CMS programs among beneficiaries, the health care community, and the public; promote the fiscal integrity of CMS programs and be an accountable steward of public funds; foster excellence in the design and administration of CMS programs; and provide leadership in the broader health care marketplace to improve health.

The objectives of CMS are to 1) expand health care choices and further strengthen programs and services to adapt to beneficiary needs, 2) improve quality of care and health outcomes for the beneficiaries of CMS programs, 3) improve access to services for underserved and vulnerable beneficiary populations, including eliminating health disparities, and 4) protect beneficiaries from substandard or unnecessary care.

Address Information

Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244-1850

Organization URL: **www.cms.hhs.gov/**

Contact Information

Phone: (877) 267-2323
(410) 786-3000

3. Health Resources and Services Administration (HRSA)

The mission of the Health Resources and Services Administration is to improve and expand access to quality health care for all. The goal of HRSA is to move toward 100 percent access to health care and 0 health disparities for all Americans. As *The Access Agency* of the U.S. Department of Health and Human Services, HRSA ensures the availability of quality health care to low-income, uninsured, isolated, vulnerable, and special-needs populations and meets their unique health care needs. The strategies HRSA employs to reach its aims are to eliminate barriers to care, eliminate health disparities, ensure quality of care, and improve public health and health care systems.

HRSA directs programs that improve the health of the Nation by expanding access to comprehensive, quality health care for all Americans. HRSA works to improve and extend life for people living with HIV/AIDS, provide primary health care to medically underserved people, serve women and children through state programs, and train a health workforce that is both diverse and motivated to work in underserved communities.

Address Information

Health Resources and Services Administration
U.S. Department of Health and Human Services
Parklawn Building
5600 Fishers Lane
Rockville, Maryland 20857

Organization URL: **www.hrsa.gov**

Contact Information

4. Indian Health Services (IHS)

The IHS provides a comprehensive health services delivery system for American Indians and Alaska Natives with opportunity for maximum tribal involvement in developing and managing programs to meet their health needs. The mission of the IHS, in partnership with American Indian and Alaska Native people, is to raise their physical, mental, social, and spiritual health to the highest level. The goal of the IHS is to ensure that comprehensive, culturally acceptable personal and public health services are available and accessible to all American Indian and Alaska Native people. The foundation of the IHS is to uphold the Federal government obligation to promote healthy American Indian and Alaska Native people, communities, and cultures, and to honor and protect the inherent sovereign rights of tribes.

In order to carry out its mission, uphold its foundation, and attain its goal, the IHS: 1) Assists Indian tribes in developing their health programs through activities such as health management training, technical assistance, and human resource development, 2) Facilitates and assists Indian tribes in coordinating health planning; in obtaining and using health resources available through Federal, state, and local programs; and in operating comprehensive health care services and health programs, 3) Provides comprehensive health care services, including hospital and ambulatory medical care, preventive and rehabilitative services, and development of community sanitation facilities, and 4) Serves as the principal Federal advocate in the health field for Indians to ensure comprehensive health services for American Indian and Alaska Native people.

Address Information

Indian Health Service (HQ)
The Reyes Building
801 Thompson Avenue, Ste. 400
Rockville, MD 20852-1627

Organization URL: **www.ihs.gov**

Contact Information

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5. Office of Minority Health (HHS)

The mission of the Office of Minority Health (OMH) is to improve and protect the health of racial and ethnic minority populations through the development of health policies and programs that will eliminate health disparities. OMH was established in 1985 by the U.S. Department of Health and Human Services (HHS). It advises the Secretary and the Office of Public Health and Science on public health program activities affecting American Indians and Alaska Natives, Asian Americans, Blacks/African Americans, Hispanics/Latinos, Native Hawaiians, and other Pacific Islanders.

OMH advises the Department on health policy issues affecting health status and access to care among minority populations. It coordinates programs to help HHS implement minority initiatives, including the HHS Disparities Initiative, the White House Initiative on Historically Black Colleges and Universities, the White House Initiative on Educational Excellence for Hispanic Americans, the HHS Hispanic Agenda for Action, the White House Initiative on Tribal Colleges and Universities, the Executive Order on Increasing Participation of Asian Americans and Pacific Islanders in Federal Programs, and the HHS Minority HIV/AIDS Initiative.

OMH works with HHS operating divisions and other Federal departments to improve collection and analysis of data on the health of racial and ethnic minority populations. It monitors efforts to achieve Healthy People 2010 goals for minority health.

Address Information	**Contact Information**
OMH Resource Center P.O. Box 37337 Washington, DC 20013-7337	Phone: (800) 444-6472 Fax: (301) 251-2160 Email: info@omhrc.gov

Organization URL: **www.omhrc.gov/**

NON-GOVERNMENT

6. American Academy of Ophthalmology (AAO)

The mission of the American Academy of Ophthalmology is to advance the lifelong learning and professional interests of ophthalmologists (Eye M.D.s) to ensure that the public can obtain the best possible eye care. The AAO maintains six key activities: education, eye care information, advocacy, ophthalmic practice, quality of care, and Eye Care America. Education is a primary focus of Academy activities and the Academy offers a number of programs to meet the educational needs of Eye M.D.s and other members of the eye care team.

The Academy also develops and produces a wide range of print and electronic educational materials, including reference books, audio and videotapes, CD-ROMs, self-assessment programs, and an online education center. These materials provide ongoing education for practicing Eye M.D.s, residents, and other health professionals.

Through a variety of materials and programs, including patient education publications, public information campaigns to promote eye health and safety, as well as relationships with news media, the Academy provides balanced, credible, and timely information on preserving and protecting vision. The Academy's Government Affairs Division in Washington, D.C. represents Eye M.D.s and their patients before Federal and state policymakers. Academy staff and physician leaders regularly meet with government officials to provide input on legislative and regulatory issues that affect the delivery of quality eye care.

The Academy offers a variety of managed care and practice management programs to assist its members in responding to the increasing socioeconomic demands placed on the physician. In addition to a wide variety of practice-related publications and materials, the Academy offers seminars on practice management, coding assistance, as well as a career search and employee location program. Lastly, Academy members are committed to providing the highest possible quality eye care. To assist them, the Academy produces a number of materials to support them in the clinical decisionmaking process. The cornerstone of this program, the Academy's Preferred Practice Pattern series, provides a series of guidelines to identify the characteristics and components of quality eye care. A number of other publications, designed to supplement the Preferred Practice Pattern series, provide additional information on new technologies and complementary therapies, to help Eye M.D.s sift through an ever-expanding body of clinical knowledge.

Address Information	**Contact Information**
American Academy of Ophthalmology P.O. Box 7424 San Francisco, CA 94120-7424	Phone: (415) 561-5800 Fax: (415) 561-8533

Organization URL: **www.aao.org/**

7. American Optometric Association (AOA)

The mission of the American Optometric Association (AOA) is to "Advance the profession and serve optometrists in meeting the eye care needs of the public." The objectives of the AOA are centered on improving the quality and availability of eye and vision care. The AOA fulfills its missions in accordance with the following goals: Health care and public policy related to eye care will uniformly recognize optometrists as primary care providers and ensure the public has access to the full scope of optometric care; optometrists and other professionals will look to the American Optometric Association for professional standards, research, and education leadership, which serve to enhance and ensure competent, quality patient care; and the public, optometrists, and other professionals will turn to the American Optometric Association for reliable and current information related to optometry, eye care, and health care policy.

Address Information	**Contact Information**
American Optometric Association 243 North Lindbergh Blvd. St. Louis, MO 63141	Phone: (314) 991-4100 Fax: (314) 991-4101

Organization URL: **www.aoanet.org**

8. The Henry J. Kaiser Family Foundation (KFF)

The Henry J. Kaiser Family Foundation is a non-profit, private operating foundation focusing on the major health care issues facing the Nation. The Foundation is an independent voice and source of facts and analysis for policymakers, the media, the health care community, and the general public. KFF develops and runs its own research and communications programs, often in partnership with outside organizations. The Foundation contracts with a wide range of outside individuals and organizations through its programs. Through their policy research and communications programs, KFF works to provide reliable information in a health system in which the issues are increasingly complex and the Nation faces difficult challenges and choices. The Foundation is not associated with Kaiser Permanente or Kaiser Industries.

Kaiser Family Foundation programs include the following: Kaiser Commission on Medicaid and the Uninsured; Media Fellowship and Internship Programs; California Health Policy Project; Entertainment Media Partnerships; Health Care Marketplace Project; HIV Policy Program; Medicare Policy Project; Program for the Study of Entertainment Media and Health; Public Opinion and Media Research Program; Race/Ethnicity and Health Care Program; Program for Health and Development in South Africa; and Women's Health Policy Program.

Address Information	**Contact Information**
Headquarters 2400 Sand Hill Road Menlo Park, CA 94025	Phone: (650) 854-9400 Fax: (650) 854-4800
Washington, DC Office / Public Affairs Center 1330 G Street, NW Washington, DC 20005	Phone: (202) 347-5270 Fax: (202) 347-5274

Organization URL: **www.kff.org/**

9. RAND Health

RAND Health is a research division within RAND, the first organization to be called a "think tank." For more than 50 years, RAND has been working to improve policy and decisionmaking through research and analysis. RAND Health continues that tradition, advancing understanding of health and health behaviors, and examining how the organization and financing of care affect costs, quality, and access. Today, the staff of RAND Health includes more than 170 experts, many of whom are nationally recognized.

RAND also draws on the expertise of the entire RAND staff, who work in areas ranging from international policy and national security to civil justice, public safety, education, child policy, and science and technology.

RAND Health research studies are coordinated through eight centers and three programs such as the RAND Center for Population Health and Health Disparities. Many of their projects address current policy concerns, but they also work extensively on the scientific basis for improving service delivery, system performance, and organizational effectiveness. The RAND Center for Population Health and Health Disparities has five basic objectives: 1) study the effects of neighborhoods on health throughout the life cycle and the pathways by which these effects are felt, 2) develop a rich data resource that can be used to enhance understanding of how neighborhoods influence health, 3) develop robust community-based participatory research partnerships within each of the three cities in which RAND is located (Santa Monica, California; the Washington, DC, area; and Pittsburgh, Pennsylvania), 4) foster a community of interdisciplinary researchers (particularly biological and social scientists) focused on the social determinants of health, specifically the role of neighborhoods, and 5) inform public policies aimed at improving population health.

Address Information

RAND Health Communications
1700 Main Street
P.O. Box 2138
Santa Monica, CA 90407-2138

Contact Information

Phone: (310) 393-0411, ext. 7775
E-mail: RAND_Health@rand.org

Organization URL: **www.rand.org/health**

10. The Robert Wood Johnson Foundation

The Robert Wood Johnson Foundation seeks to improve the health and health care of all Americans. To achieve the most impact with their funds, the Robert Wood Johnson Foundation prioritizes their grants into four goal areas: 1) To assure that all Americans have access to quality health care at reasonable cost. Nearly 44 million Americans, more than 8 million of them children, go without health insurance. The lack of insurance is the single greatest barrier to obtaining timely, appropriate health care services. 2) To improve the quality of care and support for people with chronic health conditions. One hundred million Americans suffer from chronic health conditions, and that number is almost certain to increase as the population ages. 3) To promote healthy communities and lifestyles. One's health behaviors, level of social interaction, and other factors outside medical care are important influences on overall health. 4) To reduce the personal, social, and economic harm caused by substance abuse: tobacco, alcohol, and illicit drugs. Tobacco, alcohol, and illicit drugs inflict an enormous toll on Americans, especially among the youth.

To accomplish these goals, the Robert Wood Johnson Foundation uses a variety of strategies: they support training, education, research (excluding biomedical research), and projects that demonstrate the effective delivery of health care services. Rather than paying for individual care, the Robert Wood Johnson Foundation concentrates on health care systems and the conditions that promote better health.

Address Information	**Contact Information**
The Robert Wood Johnson Foundation P.O. Box 2316 College Road East and Route 1 Princeton, NJ 08543	Phone: (888) 631-9989

Organization URL: **www.rwjf.org**

Appendix B

Interview Discussion Protocol (In-Person Script)

IDENTIFICATION OF VARIABLES THAT INFLUENCE ACCESS TO EYE CARE

Interview Discussion Protocol (In-Person script)

Good morning/afternoon. My name is Robert Alexander. I am working on behalf of the National Eye Institute (NEI) to gather information about factors that influence the receipt of care that may prevent possible eye disease and vision loss. Although I understand your organization may not directly address issues regarding receipt of eye care, we are interested in learning about any programs your organization is sponsoring or conducting to increase the receipt of eye and/or health care services, to reduce barriers to care, and to reach high-risk underserved populations.

New reports indicate that leading causes of blindness and low vision are not being detected early and thus, people may not be benefiting from sight-saving treatments. A key question is, why? These interviews are part of a larger study the NEI is conducting to determine factors that influence the receipt of eye care. Early next year, focus groups will be conducted with the general population to gain additional insight about barriers to receipt of eye care.

With new prevalence data and the information obtained through these interviews and focus groups, the congressionally mandated National Eye Health Education Program can better design educational materials and programs to collaborate with other government agencies and non-government agencies that specifically address receipt-of-care issues.

Discussion Items

Questions about your agency/organization

First, I would like to ask you a few questions about your agency/organization. Please answer from your perspective as a representative of your agency/organization, and not from your personal viewpoint.

1. Please describe any eye and/or health programs or services your agency/organization provides to the general population.

   Probes:

   a. Specifically, how would your agency characterize each of the program(s)/service(s) that your agency/organization offers (check all that apply)?

      prevention/screening
      education
      research

treatment

advocacy

b. What specific population(s) does your agency/organization provide these services or outreach to?

c. Do you have any materials or Web addresses where we can learn more about these programs/services you are referring to?

If yes, please send them to Robert Alexander Jr., ORC Macro; 11785 Beltsville Drive, Suite 300; Calverton, MD 20705 or, if they can be e-mailed, please send them to Robert.Alexander@orcmacro.com.

In the upcoming questions, I will make reference to high-risk populations.

2. Could you explain how your agency/organization defines the term "high-risk population"?

Questions about factors that influence the receipt of care

I would now like to ask you a few questions about factors your agency/organization perceives to influence the receipt of care and how your agency/organization attempts to address them. For the remainder of the interview, please limit the meaning of "high-risk populations" to those at high risk for eye disease, which are minority populations such as African Americans, Hispanics, Latinos, American Indians, and Alaska Natives.

3. What are some of the key factors that your agency/organization feels influences the receipt of eye and/or health care services?

Probes:

a. Do you think that those factors differ for high-risk underserved populations compared to Whites? If so, please identify the key factors that you feel influence the receipt of care for high-risk underserved populations.

b. Do you feel different racial/ethnic groups disproportionately experience more barriers to the receipt of eye and/or health care services? If so, please explain why.

c. Do you feel that factors vary across different racial/ethnic groups that influence the receipt of eye and/or health care services? If so, please explain why.

4. What does your agency/organization feel is the most effective approach to dealing with barriers to care?

Probe:

a. What mechanisms does your agency/organization have in place to address factors that impede the receipt of eye and/or health care services?

Questions about programs to increase the receipt of health care services

I would now like to ask you a few questions about strategies your agency/organization employs to address factors that it has identified that influence the receipt of care.

5. What do you feel are some characteristics of exemplary programs or materials that attempt to increase the receipt of services for high-risk underserved populations?

Probes:

a. Are you aware of exemplary programs and materials that aim to increase the receipt of eye and/or health care services for high-risk underserved populations?

b. What kinds of programs and/or materials are needed to increase the receipt of eye and/or health care services for high-risk underserved populations?

6. How can people and agencies/organizations addressing the receipt of eye and/or health care services for high-risk underserved populations collaborate?

7. What strategies and/or approaches can the vision community consider to effectively deal with barriers to the receipt of eye care? What advice would you offer them?

Probe:

a. How can the vision community better assist you and other agencies to decrease barriers to eye care and increase use of eye health services and programs?

8. Are there any other agencies/organizations or people whom you suggest we contact to further explore issues surrounding barriers to care, strategies, and programs to increase the receipt of eye and/or health services?

9. Can I contact you again to clarify your responses?

Yes If yes, by: Phone E-mail Both
No

Phone: ____
E-mail: ____

If you have any additional comments, please feel free to contact me at (301) 572-0459 or via e-mail at Robert.Alexander@orcmacro.com. Thank you for your time and valuable comments.

Appendix C

Interview Discussion Protocol (Telephone Script)

IDENTIFICATION OF VARIABLES THAT INFLUENCE ACCESS TO EYE CARE

Interview Discussion Protocol (Telephone script)

Good morning/afternoon. My name is Robert Alexander. I am working on behalf of the National Eye Institute (NEI) to gather information about factors that influence the receipt of care that may prevent possible eye disease and vision loss. Although I understand your organization may not directly address issues regarding receipt of eye care, we are interested in learning about any programs your organization is sponsoring or conducting to increase the receipt of eye and/or health care services, to reduce barriers to care, and to reach high-risk underserved populations.

Our conversation will take no more than ½ hour. Is this a convenient time for you to talk to me?

Yes Note date of discussion __________
No If no, set up a time to call back and terminate call. ____________

If yes:

I'd be happy to e-mail or fax you the nine discussion points I would like to cover in our phone call.

New reports indicate that leading causes of blindness and low vision are not being detected early and thus, people may not be benefiting from sight-saving treatments. A key question is, why? These interviews are part of a larger study the NEI is conducting to determine factors that influence the receipt of eye care. Early next year, focus groups will be conducted with the general population to gain additional insight about barriers to receipt of eye care.

With new prevalence data and the information obtained through these interviews and focus groups, the congressionally mandated National Eye Health Education Program can better design educational materials and programs to collaborate with other government agencies and non-government agencies that specifically address receipt-of-care issues.

Discussion Items

Questions about your agency/organization

First, I would like to ask you a few questions about your agency/organization. Please answer from your perspective as a representative of your agency/organization, and not from your personal viewpoint.

1. Please describe any eye and/or health programs or services your agency/organization provides to the general population.

   Probes:

a. Specifically, how would your agency characterize each of the program(s)/service(s) that your agency/organization offers (check all that apply)

prevention/screening

education

research

treatment

advocacy

b. What specific population(s) does your agency/organization provide these services or outreach to?

c. Do you have any materials or Web addresses where we can learn more about these programs/services you are referring to?

If yes, please send them to Robert Alexander Jr., ORC Macro; 11785 Beltsville Drive, Suite 300; Calverton, MD 20705 or, if they can be e-mailed, please send them to Robert.Alexander@orcmacro.com.

In the upcoming questions, I will make reference to high-risk populations.

2. Could you explain how your agency/organization defines the term “high-risk population”?

Questions about factors that influence the receipt of care

I would now like to ask you a few questions about factors your agency/organization perceives to influence the receipt of care and how your agency/organization attempts to address them. For the remainder of the interview, please limit the meaning of “high-risk populations” to those at high risk for eye disease, which are minority populations such as African Americans, Hispanics, Latinos, American Indians, and Alaska Natives.

3. What are some of the key factors that your agency/organization feels influences the receipt of eye and/or health care services?

Probes:

a. Do you think that those factors differ for high-risk underserved populations compared to Whites? If so, please identify the key factors that you feel influence the receipt of care for high-risk underserved populations.

b. Do you feel different racial/ethnic groups disproportionately experience more barriers to the receipt of eye and/or health care services? If so, please explain why.

c. Do you feel that factors vary across different racial/ethnic groups that influence the receipt of eye and/or health care services? If so, please explain why.

4. What does your agency/organization feel is the most effective approach to dealing with barriers to care?

Probe:

a. What mechanisms does your agency/organization have in place to address factors that impede the receipt of eye and/or health care services?

Questions about programs to increase the receipt of health care services

I would now like to ask you a few questions about strategies your agency/organization employs to address factors that it has identified that influence the receipt of care.

5. What do you feel are some characteristics of exemplary programs or materials that attempt to increase the receipt of services for high-risk underserved populations?

Probes:

a. Are you aware of exemplary programs and materials that aim to increase the receipt of eye and/or health care services for high-risk underserved populations?

b. What kinds of programs and/or materials are needed to increase the receipt of eye and/or health care services for high-risk underserved populations?

6. How can people and agencies/organizations addressing the receipt of eye and/or health care services for high-risk underserved populations collaborate?

7. What strategies and/or approaches can the vision community consider to effectively deal with barriers to the receipt of eye care? What advice would you offer them?

Probe:

a. How can the vision community better assist you and other agencies to decrease barriers to eye care and increase use of eye health services and programs?

8. Are there any other agencies/organizations or people whom you suggest we contact to further explore issues surrounding barriers to care, strategies, and programs to increase the receipt of eye and/or health services?

9. Can I contact you again to clarify your responses?

Yes If yes, by: Phone E-mail Both

No

Phone: ____

E-mail: ____

If you have any additional comments, please feel free to contact me at (301) 572-0459 or via e-mail at Robert.Alexander@orcmacro.com. Thank you for your time and valuable comments.