

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED— FINAL REPORT

Submitted to:



Submitted by:

ORC MACROSM

11785 Beltsville Drive
Calverton, MD 20705
Telephone: (301) 572-0200
Facsimile: (301) 572-0999

TABLE OF CONTENTS

	<u>PAGE NUMBER</u>
I. INTRODUCTION	1
II. METHODOLOGY	1
A. Protocol Development	2
B. DATA COLLECTION PROCEDURES	2
C. RESPONSE RATE	3
D. DATA ANALYSIS	4
III. FINDINGS	4
A. INTRODUCTION	4
ITEM 1: GOALS/OBJECTIVES RELATED TO EYE HEALTH EDUCATION PROGRAMS	5
ITEM 2: CHAPTER 2 EYE HEALTH EDUCATION PROGRAMS	6
ITEM 3: PORTION OF CHAPTER 2 PROGRAM DEDICATED TO EYE HEALTH EDUCATION ACTIVITIES	12
ITEM 4. EFFECTIVE APPROACHES IN COMMUNICATING EYE HEALTH INFORMATION TO CONSUMERS AND PROFESSIONALS	14
ITEM 5: FORMAT IN WHICH CONSUMERS AND PROFESSIONALS LIKE TO RECEIVE EYE HEALTH INFORMATION	16
ITEM 6. WHAT CHAPTER 2 PROGRAM MANAGERS NEED TO ENHANCE THEIR UNDERSTANDING OF EYE HEALTH EDUCATION PROGRAMS	17
ITEM 7. RESOURCES/TECHNICAL ASSISTANCE CHAPTER 2 PROGRAMS NEED TO ENHANCE THEIR EYE HEALTH EDUCATION EFFORTS TO FRIENDS, FAMILY, CAREGIVERS, AND OTHER PROFESSIONALS	18
ITEM 8. HOW NEI CAN BETTER ASSIST CHAPTER 2 PROGRAMS	20
ITEM 9. STATE CONTACTS TO RECEIVE OUTLOOK	22
IV. SUMMARY AND RECOMMENDATIONS	22
A. SUMMARY	22
B. RECOMMENDATIONS	23

I. INTRODUCTION

The National Eye Institute (NEI), Office of Communication, Health Education, and Public Liaison awarded ORC Macro a contract in March 2002 to assess eye health education programs and needs in Federally funded independent living programs for the blind and visually impaired. For this effort, NEI partnered with the Department of Education's Office of Special Education and Rehabilitative Services (OSERS)/ Rehabilitation Services Administration (RSA) Independent Living Services for Older Individuals Who are Blind Program (Title VII-Chapter 2 program) to determine the need for public education and outreach strategies on low vision. Since 1999, when the NEI launched a public education program on low vision, it has sought to identify ways to increase the awareness of the benefits of vision rehabilitation.

The goals of this project were threefold—

1. To gather information on the low vision outreach/education activities in Chapter 2 programs, including goals and objectives they may have set.
2. To determine awareness of the NEI's low vision education program.
3. To identify ways in which NEI can assist Chapter 2 programs in their public outreach/education programs.

In order to meet these goals, ORC Macro developed a work plan that contains 7 tasks—

1. Meet with NEI project officer to review work plan and study methods.
2. Meet with OSERS/RSA Program Officer, Chapter 2 Program to learn more about the program and its needs and to obtain a copy of the names and addresses of Title VII-Chapter 2 Program Managers and Coordinators.
3. Review Title VII-Chapter 2 legislation.
4. Develop a discussion protocol that would be e-mailed to the Chapter 2 listserve (as provided by OSERS/RSA).
5. Conduct the discussion by e-mail, telephone, or mail.
6. Analyze the data.
7. Prepare a final written report for NEI.

A description of the methodology is present in Section II of this report. Information that Chapter 2 Program Managers provided about their goals and objectives, eye health education programs, approaches used to communicate eye health information to consumers and professionals, as well as program managers' needs for information and resources about eye health education programs, and ways that the NEI can better assist them are presented in Section III: Findings. The final portion of the report, Section IV: Summary and Recommendations, provides a summary of key findings and recommendations for NEI's consideration.

IV. METHODOLOGY

In May 2002, ORC Macro staff met with NEI to review the proposed work plan, project goals, and to discuss how this effort would be accomplished. At the suggestion of the NEI project officer, ORC Macro staff met with Dr. Edna Johnson, OSERS/RSA Program Officer, Chapter 2 Program at the U.S. Department of Education in Washington, D.C. At this meeting, Dr. Johnson

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

and her assistant provided ORC Macro staff with an overview of the Program and background information about the legislation. She provided us with—

- *Rehabilitation Services Administration, Independent Living Services for Older Individuals Who are Blind—Title VII-Chapter 2 Annual Report for FY 2000.* This report was written by members of the Rehabilitation Research and Training Center on Blindness and Low Vision, Mississippi State University, and submitted in February 2002.
- The name, mailing address, e-mail address, and phone numbers of each state's or territory's Title VII-Chapter 2 Program Manager/Coordinator and consultants affiliated with the Title VII Chapter 2 Program.
- A listserv of e-mail addresses for each of these individuals.

A. PROTOCOL DEVELOPMENT

After carefully reviewing the documentation, ORC Macro staff prepared a discussion protocol suitable to be e-mailed to everyone on the Chapter 2 listserv. The protocol included introductory paragraphs explaining that NEI, in partnership with OSERS/RSA's Title VII-Chapter 2 Program, was seeking information about any eye health programs and outreach efforts they may be conducting in the United States and its territories. The protocol, which was approved by the NEI and OSERS/RSA's Title VII Chapter 2 Program, contained discussion items on the following 9 topics—

1. Goals and/or objectives related to eye health education programs.
2. Description of eye health education programs that the Chapter 2 Program has in place—including information about the programs' focus, audience, and barriers.
3. Portion of Chapter 2 program dedicated to eye health education activities.
4. Effective approaches in communicating eye health information to consumers and professionals.
5. Type(s) of format(s) consumers and professionals prefer to receive information.
6. What Chapter 2 Program Managers need to enhance their understanding of eye health education programs.
7. What resources Chapter 2 Program Managers need to enhance their education efforts targeted to consumers and professionals.
8. Suggestions on how NEI can assist Chapter 2 Programs.
9. Name/address to which NEI publications can be sent.

B. DATA COLLECTION PROCEDURES

ORC Macro designed a tracking form to monitor the delivery and receipt of e-mails, telephone conversations, and/or mail that was sent to us via the U.S. Postal Service. On July 2, 2002, the first wave of e-mails (with return receipt) was sent from ORC Macro to the Chapter 2 listserv. One e-mail was returned undelivered. It turned out that the individual no longer worked for the agency and OSERS/RSA provided a new e-mail address for the new Program Manager. Program Managers/Coordinators were asked to respond by July 19, 2002.

The initial response rate was low. Program Managers from nine states raised some concerns about responding to the e-mail. In response to their concerns, Dr. Johnson sent out an e-mail

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

letter to the entire listserv on July 23, 2002, clarifying the intent and purpose of the initial e-mail. In her e-mail she wrote the following:

“Several program managers have expressed an interest in getting more information about eye health education/outreach. Although eye health education/outreach is not a funded component of most of our Chapter 2 programs, we have the opportunity to partner with the NEI to learn more about your needs regarding eye health education/outreach and to find out whether you need or would like more information and resources related to low vision and vision rehabilitation to share with your clients, at-risk seniors, families, and care givers.”

In addition, Dr. Johnson wrote, “The intent of the survey is to determine whether there is a need for eye health education/outreach materials and how that need can be addressed, and not to highlight what our programs are doing or not doing.”

The original nine discussion items were attached to Dr. Johnson’s introductory letter and sent by her office to the listserv.

A third and final wave of e-mails was sent from Dr. Johnson’s office on August 19, 2002. Dr. Johnson thanked the 18 states that had responded and encouraged those who had not responded to submit their responses no later than August 30, 2002.

A copy of the three e-mails, including the introductory letter and discussion items, which were sent out to the Chapter 2 listserv, are shown in Appendix A.

C. RESPONSE RATE

In total, ORC Macro sent the discussion questions to 83 Chapter 2 Program Managers, Program Coordinators, and consultants.¹ This mailing included one or more individuals for each state and the District of Columbia, four U.S. territories, and nine consultants. ORC Macro received responses from 29 states and the District of Columbia.² As shown in Table 1, the overall response rate from the states was 59 percent; we received 30 responses from 50 states and the District of Columbia.

TABLE 1: NUMBER AND PERCENT OF STATE RESPONDENTS

RESPONSE	NUMBER OF STATES	PERCENT
E-mail or mail response ³	30	59%
No response	21	41%
TOTAL	51	100%

We did not receive responses from any territories or consultants.

Listed below are the 30 states that responded—

¹ The Program Manager position is vacant in Guam and therefore an e-mail was not sent to the territory.

² We received two responses from Georgia. Georgia has five contractors that provide services to consumers throughout the state. Because the state is the unit of analysis for this project, Georgia is counted once. Responses from both respondents are included in the report.

³ ORC Macro received 30 responses via e-mail and 2 responses via the U.S. Postal Service.

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

- Alabama
- Connecticut
- District of Columbia
- Delaware
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Iowa
- Massachusetts
- Mississippi
- Nebraska
- New Jersey
- New York
- North Carolina
- North Dakota
- Ohio
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wyoming

Despite three attempts of contacting respondents by e-mail, the following Chapter 2 Program Managers from the following 21 states did not respond—

- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Indiana
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Michigan
- Minnesota
- Missouri
- Montana
- Nevada
- New Hampshire
- New Mexico
- Oklahoma
- Tennessee
- Wisconsin

D. DATA ANALYSIS

ORC Macro project staff carefully reviewed the responses to each one of the nine discussion items. Responses to each of the discussion items were entered into separate MS Word files by state. The open-ended responses were content analyzed in order to identify patterns and themes and report how frequently they emerged. When appropriate, frequency counts and distribution tables were generated.

V. FINDINGS

A. INTRODUCTION

The major findings of this study are presented in this section of the report. It must be noted that many Program Managers did not respond to every item in the protocol. In fact two Program Managers simply responded that they were not going to respond to the items in the protocol. One of these managers did write that the state she represents “refers its customers to their eye health specialists for these services.” Another state, New Jersey, did not answer the specific items, but rather sent a copy of the “New Jersey Rule” that delineates the agency’s Eye Health Services and Prevention Program.

Presented below, item by item, are the major findings. More detailed information about goals and objectives and eye health programs are presented in Appendix C and Appendix D.

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

As noted in the email that was sent to each of the respondents, the first five items refer to Chapter 2 eye health education programs. The last four items are more specific to the needs of Chapter 2 staff, contractors, and consultants.

ITEM 1: GOALS/OBJECTIVES RELATED TO EYE HEALTH EDUCATION PROGRAMS

Program managers were asked to identify written goals and/or objectives that their program established related to eye health education including, if appropriate, when they were established. Eight states (25%) that responded to this discussion item said they have one or more goals/objectives, although they were often not formalized.

One state, Rhode Island, currently does not have goals and objectives, but have set a goal for the next year. Their goal for January 2003 is to develop a glaucoma/vision-screening program for the elderly.

Ten other states—Alabama, Florida, Georgia, Illinois, Mississippi, Oregon, Pennsylvania, Vermont, Virginia, and Washington—wrote that they do not have or were unaware whether they had any goals/objectives related to eye health education programs. Program Managers from the remaining 13 states did not respond to this item.

Program Managers from the following states wrote about their goals and objectives.

Nebraska	To emphasize services to help consumers deal more effectively with the very real problems of blindness with which they must struggle every day.
New Jersey	The goal of the Eye Health Services program is to save sight and restore vision whenever it is medically possible.
North Carolina	The goal of the program is to use every available resource to provide services to prevent blindness where possible and restore sight for individuals who have suffered vision loss.
Ohio	Provide informational presentations to community organizations and health facilities regarding the Chapter 2 program and the services available to Older Blind individuals under this program.
South Carolina	Goal: To prevent, stabilize, or restore the loss of vision. Objective: Provide appropriate medical services to detect eye diseases in their early stages.
Texas	The goals of the Blindness Education, Screening, and Treatment Program (BEST) include reaching an estimated three million people through a combination of a media campaign, eye screenings, and funds for emergency sight-saving medical services for persons with no other resources. The goals and objectives are incorporated into the agency's annual strategic plan and reported to the legislature.

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

- West Virginia** To provide information on blindness and prevention to the consumer, family members, caregivers, volunteers, senior center staff, home health workers, civic groups, and the general public.
More specifically, to—
- Conduct a minimum of 30 outreach presentations annually, which can include displays and/or exhibits at state and local health fairs, senior expos, etc.
 - Conduct a minimum of 10 in-service training opportunities annually.
- Conduct a minimum of 5 in-service training sessions to a vocational school or educational facility.
- Wyoming** The formal or planned objective for Eye Health Education of Wyoming Independent Living Rehabilitation (WILR) is primarily one of advocacy and individual information and referral.

The full list of complete verbatim responses regarding states' eye health-related goals and objectives, cited by the Program Managers, are presented in Appendix C in alphabetic order by state.

Only North Carolina, Texas, and West Virginia specified when their goals and objectives were established:

- **North Carolina** "The Medical Eye Care Program's goal was established when the agency was founded in 1935."
- **Texas** "The BEST goals were first established in FY 2000."
- **West Virginia** "Our goals were established and approved by RSA in our 1999 West Virginia Older Blind Grant Application."

ITEM 2: CHAPTER 2 EYE HEALTH EDUCATION PROGRAMS

Chapter 2 Program Managers were asked to describe their eye health education programs that they currently have in place. Of the 30 Program Managers that responded to the discussion protocol, Program Managers in 21 states (70%) reported having eye health education programs. Importantly, as will be shown below, some of the eye health education programs are more formalized than others, which we refer to as "informal" programs. States that do have at least minimal programming include Alabama, Connecticut, Delaware, District of Columbia, Hawaii, Idaho, Illinois, Massachusetts, Mississippi, New York, New Jersey, Nebraska, North Carolina, Ohio, Rhode Island, South Carolina, South Dakota, Texas, Virginia, West Virginia, and Wyoming.

Brief descriptions of five states that have more "formal" eye health education programs are presented below (see Appendix D, pages 1-4 for a complete list of verbatim responses).

- | | |
|----------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| ▪ Connecticut | "Connecticut sponsors a series of free seminars, typically 5-6 per year, in various communities throughout the state called 'There is Hope When Vision Fails.' The seminars include, but are not limited to, information typically presented by an ophthalmologist on age-related eye disease, new medical treatments, antioxidant vitamins, etc." |
|----------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

<ul style="list-style-type: none"> ▪ Illinois 	<p>Illinois utilizes three vehicles for eye health education. The first includes support groups that are established by facilities and individual staff. Attendees include family, friends, and associates of the persons who are visually impaired. These groups receive information from optometrists, ophthalmologists, and health educators such as a diabetic educator. The second vehicle includes low vision fairs are conducted to inform the public with regard to eye health, eye care, and visual rehabilitation. [Third,] since 1991, Illinois has co-sponsored an international Discovery Low Vision Conference, attended by customers, rehabilitation professionals, medical personnel and exhibitors. Participants are updated on innovative eye treatments, accessible technology, and vision rehabilitation methods and strategies.”</p>
<ul style="list-style-type: none"> ▪ Massachusetts 	<p>“The BRIDGE Program contracts with an outreach/in-service training consultant for 20 hours per week. The Program also contracts with VISION Community Services (a private non-profit) to conduct approximately 40 low vision support groups around the state. Each new group undergoes an 11-week orientation program, which includes basic information about eye conditions and eye health.”</p>
<ul style="list-style-type: none"> ▪ North Carolina 	<p>“North Carolina’s Division of Services for the Blind has several programs including an Independent Living Rehabilitation (ILR) Program (Part B and Older Blind) and a Medical Eye Care Program. Medical Eye Care Program takes the lead in providing eye health education for consumers and the general public including eye exams, treatment, corrective lens and/or surgery, and the provision of low vision aids. The services are available to individuals who have very limited incomes and meet financial eligibility requirements. Additionally, vision/glaucoma screenings and eye health education are provided to individuals regardless of their income. These services are provided by the Nurse Eye Care Consultants (NECC). ILR counselors also provide eye health information for consumers, families, and the general public...”</p>
<ul style="list-style-type: none"> ▪ West Virginia 	<p>“The staff conduct in-service training sessions and presentations that include information on blindness and prevention. The information that is disseminated is obtained from the NEI Web site, such as the booklets on the different types of eye diseases, the awareness programs and posters on the various types of eye diseases, the use of simulators to depict the eye diseases, updated information on the latest research being done, as well as new drug treatments or vitamin therapy, etc.”</p>

Examples of eye health education programs that are more “informal” include the following—

<ul style="list-style-type: none"> ▪ Delaware 	<p>“In Delaware we do not have a "formal" eye health program. We do have a low vision program that provides a complete exam from a contracted low vision specialist and the recommended devices are ordered for the consumer. We do encourage our consumers to see their eye care professional on a regular basis. We have an employee who is designated for outreach only. She currently participates in local health fairs, provides presentations to civic groups and organizations, and visits the eye care professionals to make sure they are aware of our services.</p>
<ul style="list-style-type: none"> ▪ Hawaii 	<p>“None on a formal basis. The agency does send a representative to about three health fairs a year. At those fairs, there is usually an ophthalmologist present who does glaucoma screening. Our representative present will have several brochures on various eye diseases as well as agency brochures on hand.”</p>

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

▪ Mississippi	“Mississippi Independent Living (IL) program assists in coordinating 12 Peer Groups for blind and visually impaired consumers around the state. We encourage these groups to invite health care professionals to speak at monthly meetings. We provide these groups with brochures and information as requested.”
▪ Virginia	“Again, nothing official. We routinely conduct outreach activities, which include eye health information materials.”

A complete list of states that have more “informal” eye health education programs including verbatim responses, can be found in Appendix D, pages 5-8.

Program Managers from five states—Georgia, Florida, Iowa, Nebraska, and Pennsylvania, wrote that they do not have specific “eye health information” programs. A list of their verbatim responses can be found in Appendix D, pages 9-10.

Program Managers who indicated that they have eye health education programs were asked to provide additional information, including—

- (a) The focus of the program(s)
- (b) Whether they have different programs for consumers and professionals
- (c) Barriers encountered when implementing their program(s)
- (d) Whether they have an eye health education Web site
- (e) Written materials they developed/distributed.

Program Managers’ responses to these items follow.

(A) WHAT IS THE FOCUS OF YOUR EYE HEALTH EDUCATION PROGRAM(S)?

Educating the consumer about eye health care, including information on the prevention and treatment for eye diseases and services available, are the main foci of several states’ eye health education programs. West Virginia’s program is also geared to professionals including home health workers and senior center staff. In Wyoming, staff work closely with eye care professionals to ensure a more complete, holistic care plan for consumers. The verbatim comments that Program Managers wrote are listed below:

▪ District of Columbia	“Consumers are made more knowledgeable about their eye condition, community services, and optical devices that can be helpful to them.”
▪ Idaho	“The Peer Support Group program consists of a Group Coordinator who establishes the date and place for each monthly meeting. The Group then decides what the next meeting topic will be, which is usually an optometrist/ophthalmologist who will discuss eye conditions and treatment.”
▪ Massachusetts	“The [BRIDGE] consultant provides outreach programs to low vision support groups, Councils on Aging, residents of assisted-living facilities, adult day health centers, and health fairs.
	The content of these programs includes definition of legal blindness, causes of blindness among seniors, benefits and services, aids, and applications. The goal is to provide useful information in order to

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

	maximize independence. Similar information is provided during the initial training for low vision support groups.”
▪ New York	“These programs vary, but are aimed at educating people about the importance of regular eye care, the signs of vision loss, and the services available to individuals who are legally blind.”
▪ South Carolina	“The focus of the vision-screenings is to detect vision-related disease such as glaucoma and diabetic retinopathy in their early stages. Ophthalmology residents of the Medical University of South Carolina provide the screenings to us at no cost. The focus of the presentation is to inform other aging professionals and members of the community at large about vision rehabilitation and eye diseases common in older persons.”
▪ Texas	“Diabetes management to avoid additional vision loss.”
▪ West Virginia	“The foci of these in-service training sessions and presentations are to promote awareness of the Older Blind Program, as well as to inform consumers, family members, caregivers, senior center staff, home health workers, and the general public on blindness and prevention. Specific information is provided on the Older Blind Program, as well as the four major eye diseases (glaucoma, diabetic retinopathy, ARMD, and cataracts); how to work with an individual who is experiencing blindness or severe visual impairment; the psychological effects of blindness and low vision, the availability of assistive technology, sighted-guide training, "hands-on" activities with assistive technology, videos on the different types of eye diseases, and simulation activities. During these presentations, we encourage regular eye exams with local optometrists and ophthalmologists. We also attempt to disseminate information on the latest research and new drug or vitamin treatment.”
▪ Wyoming	“Continuous education regarding goals and objectives of WILR’s Vision Rehabilitation Evaluation reports that reflect cited eye pathology by O.D. or M.D. and intervention taken during the rehabilitation process has, in turn, developed a more comprehensive relationship between Visually Impaired Specialists and Eye Care professionals. As a direct result, it lends to a more holistic care plan for the client (consumer)/patient.”

(B) DO YOU HAVE DIFFERENT EYE HEALTH EDUCATION PROGRAMS FOR CONSUMERS (I.E., FRIENDS, FAMILY, AND/OR CAREGIVERS) AND PROFESSIONALS (I.E., NURSING HOME OR SENIOR CENTER STAFF)?

Of the responses received, Program Managers in two states, New York and West Virginia, mentioned different eye health programs for consumers and professionals. The verbatim comments that Program Managers wrote are listed below:

▪ Idaho	“We don't have separate programs or approaches for consumers and professionals. I have given in-service training to various nursing home staff, e.g., nurses, nurses’ aids, and other facility professionals.”
▪ Massachusetts	“The consultant provides in-service training on request to staff at rehabilitation hospitals, assisted-living facilities, adult day health centers, nursing homes, home care workers, and caregiver groups. In-service training covers tips about how best to assist patients with vision loss,

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

	including sighted guide techniques.”
▪ New York	“Consumers are taught about eye care and available services, while professionals are exposed to information about how to recognize and respond to signs of vision loss.”
▪ South Carolina	“The presentations are geared to a specific audience, as required. The eye screenings are targeted toward individuals attending senior centers in rural areas of the lower part of the state.”
▪ Texas	“Targeting persons with diabetes.”
▪ West Virginia	“The presentations and in-service training opportunities are available to all of the above. However, if requested the consumers, family members, and caregivers receive more one-on-one instruction and specific information relative to their eye disease.”
▪ District of Columbia	“No.” [The District of Columbia does not have different programs for consumers and professionals.]

(C) DO YOU HAVE SPECIFIC PROGRAM(S) DIRECTED AT GROUPS SUCH AS UNDERSERVED AND/OR MINORITY POPULATIONS?

Program Managers in the District of Columbia, Massachusetts, New York, and South Carolina reported that they have programs targeted to underserved and/or minority populations. While not specifically an eye health education program, the Rhode Island Program Manager wrote about plans to implement a glaucoma screening program developed with African Americans in mind. Screenings would be geared for high minority population areas. Idaho does not have specific programs that target these populations, but they do distribute brochures and pamphlets in Spanish to individuals who may be underserved and/or minorities. The Program Manager in West Virginia specifically indicated that they do not have any programs targeted toward specific groups. The verbatim comments that Program Managers wrote are listed below:

▪ District of Columbia	“Written information is provided to the underserved population concerning their eye conditions and other community programs.”
▪ Massachusetts	<p>“The Massachusetts Commission for the Blind (MCB) minority outreach worker has worked with the BRIDGE outreach consultant in a number of minority outreach initiatives.</p> <p>Outreach to the Asian community: In-service training for staff of the Chinese Gold Age Center, in-service training for caregivers and professionals from Chinatown at MCB, booth at Chinatown elder health fair.</p> <p>Outreach to the Latino community: low vision support group for Latinos, booth at Multicultural Center in the South End.</p> <p>Outreach to the African American community: Boston elder low vision support group, booths at several health fairs in inner-city Boston, in-service training with the Vivienne S. Thomson Independent Living Center low vision group in Jamaica Plain.</p> <p>Outreach to Russian immigrant community: BRIDGE program sponsored low vision support group that meets monthly in Russian.”</p>

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

▪ New York	“Contractor agencies in areas with large ethnic populations generally provide specialized programs directed to individuals in those groups. Many of the contractors employ staff who are multi-ethnic and multi-lingual.”
▪ South Carolina	“Yes. The eye screenings were targeted for rural areas in the lower portion of the state to screen low income, minority individuals. South Carolina has a minority population of approximately 32 percent with a good portion of this population located in rural counties in Low Country South Carolina.”
▪ Idaho	“We do not have specific programs for the under served/minority populations. We do have agency brochures and pamphlets on eye conditions in Spanish, which we disseminate to these populations.”
▪ West Virginia	“No.”

(D) WHAT BARRIERS, IF ANY, HAVE YOU ENCOUNTERED WHEN IMPLEMENTING YOUR PROGRAM(S)?

The barrier most often identified by respondents was inadequate funding. Cultural differences, accessibility issues, and insufficient number of diabetes educators were also identified as barriers. The South Carolina Program Manager was the only respondent who said they did not encounter any barriers. The verbatim comments that Program Managers wrote are listed below:

▪ District of Columbia	“It may take several visits to resolve a specific consumer problem. Some consumers are reluctant to participate in the program and this can prolong the time spent to meet their needs.”
▪ Idaho	“Lack of adequate funding, compounded by state budget cuts. Cultural differences make it difficult to establish consistent communication.”
▪ Massachusetts	“Funding for materials in other languages.”
▪ New York	“The most difficult barrier is in having the funds to do a comprehensive job in this area, as we are generally forced to use all available funds to meet the increasing demand for rehabilitative services and equipment.”
▪ Texas	“Lack of sufficient number of diabetes educators with special understanding of the needs of older persons with diabetes and vision loss. Limited financial resources to serve a growing population.”
▪ West Virginia	“Accessibility issues at senior centers, home health agencies, etc. The cost involved in providing information in alternative formats.”
▪ South Carolina	“No barriers have been encountered. However, our primary focus is to provide vision rehabilitation services to older blind individuals.”

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

(E) DOES YOUR CHAPTER 2 PROGRAM HAVE ANY EYE HEALTH EDUCATION WEB SITE(S)?

Respondents from six states and the District of Columbia—District of Columbia, Indiana, Massachusetts, Rhode Island, South Carolina, Texas, and West Virginia—said they did not have an eye health education Web site. The remaining 25 respondents did not respond to this item.

(F) HAS YOUR CHAPTER 2 PROGRAM DEVELOPED/DISTRIBUTED ANY WRITTEN MATERIALS (BROCHURES, PAMPHLETS, ETC.)?

Program Managers were asked whether their Chapter 2 Program developed and/or distributed any written materials (brochures, pamphlets, etc.). If they did, we asked them to send a copy to ORC Macro. Six Program Managers responded to this item. Their verbatim comments are listed below:

▪ Georgia	“The Center for Visually Impaired (CVI) has used its own operating money, not VII-2 monies, to create and disseminate brochures for the program. Two of the brochures will be mailed to you. CVI has also created and used a poster to advertise services to the aging population—it is not specific to Project Independence, but for all services/programs that benefit an aging population.”
▪ Mississippi	“We use brochures from the VA, Preserve Sight, MS, and the National Eye Institute. Every consumer applying for services with our program receives a packet of information, not only about our program, but also brochures about the various eye problems and diseases, and eye health.”
▪ South Carolina	“We have not developed our own brochures, but utilize brochures provided by NEI and Prevent Blindness America.”
▪ District of Columbia	“No. Material received from other sources are distributed.”
▪ New York	“No, nothing recent.”
▪ West Virginia	“No.”

Five states—Massachusetts, Georgia, New York, Illinois, and Indiana—mailed copies of brochures and pamphlets they distribute. Copies can be found in Appendix E.

ITEM 3: PORTION OF CHAPTER 2 PROGRAM DEDICATED TO EYE HEALTH EDUCATION ACTIVITIES

Eighteen Program Managers (60%) responded to this item. The portion of their Chapter 2 Program activities dedicated to eye health education ranged from 0 to 20 percent. In Illinois, for example, approximately 20 percent of staff time is spent on eye health education activities. This can be contrasted with four other states—Florida, Pennsylvania, Utah, and Washington, which reported that “no” portion of their program is dedicated to eye health education activities. The verbatim comments that Program Managers wrote are listed below:

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

▪ Illinois	“Approximately 20 percent of staff time goes to interpreting and reviewing eye reports with customers, arranging speakers and planning low vision fairs, and arranging and planning support groups. Illinois also partners with the Illinois College of Optometry, Chicago Lighthouse, and practicing optometrists to develop standards for low vision services, which are disseminated through working agreements with 55 low vision clinics.”
▪ District of Columbia	“ 10 percent. ”
▪ Texas	“Approximately 10 percent. ”
▪ Virginia	“Less than 10 percent. ”
▪ Ohio	“Approximately 2 percent to 5 percent of staff time is devoted to educational activity.”
▪ North Carolina	“Approximately 2 percent of the ILR Counselors’ time is dedicated to eye health education activities.”
▪ Hawaii	“Very nominal, would say less than 1 percent of program time is involved with eye health education.”
▪ West Virginia	“As indicated earlier, our eye health education activities include presentations, displays and/or exhibits, and in-service training opportunities, which are included in the objectives of our grant, as well as in the job description of each staff person. Each staff person is required to complete a minimum of five presentations or displays, two in-service training sessions, and one in-service training to an educational facility.”
▪ South Carolina	“A small portion.”
▪ New York	“None. We rely on our contractors to provide these services in their communities in order to maintain a steady source of referrals.”
▪ North Dakota	“We haven’t identified a specific amount within the budget.”
▪ Idaho	“We have not allocated specific amounts of dollars for eye health education activities. This information is disseminated by the regional teachers during the course of their instruction.”
▪ Vermont	“Funding is not adequate for our current services. Funding to do this [implement eye health programs] would be necessary.”
▪ Rhode Island	“No formal amount of money has been utilized. We would provide any mailings to the clients on macular degeneration as ‘in kind’ with no program costs.”
▪ Massachusetts	“Eye health education is not a formal objective of the program and it is difficult to quantify the portion of the program dedicated to this activity.”
▪ Florida	“None.”
▪ Pennsylvania	“None.”

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

▪ Utah	“None.”
▪ Washington	“None.”

ITEM 4. EFFECTIVE APPROACHES IN COMMUNICATING EYE HEALTH INFORMATION TO CONSUMERS AND PROFESSIONALS

Program Managers in 15 states identified approaches they use to communicate eye health information to consumers and professionals. Approaches include lectures, health fairs, peer support groups, one-on-one discussions, interviews, public service announcements (PSAs), drop-in news articles, and talking books. The verbatim comments that Program Managers wrote are listed below separately for consumers and professionals:

CONSUMERS

▪ District of Columbia	“Guest speakers/lectures.”
▪ Florida	“Traditionally we believe this is provided by the medical community.”
▪ Hawaii	“Health fairs.”
▪ Idaho	“Our Peer Support Group network consists of 32 groups located in various communities in the state.”
▪ Illinois	“Consumers are most effectively reached through the individual teacher and the low vision specialist working in unison to secure maximum visual efficiency.”
▪ Massachusetts	“Speaking at low vision support groups, Council on Aging workshops, assisted living facilities, public libraries, independent living centers, health fairs, community access cable television.”
▪ New York	“Education seminars in senior centers, presentations at health fairs.”
▪ North Carolina	“One-to-one contacts with consumers is considered the most effective approach in communicating eye health information. Consumers are also provided written information in their preferred media, i.e., Braille, LP, and audio tape.”
▪ North Dakota	“Contacts with Aging Services and senior centers in the state.”
▪ Ohio	“We have only used group presentations to either consumers or professionals with a variation in the content based on the audience.”
▪ Rhode Island	“Large-print brochures, articles, and talking books.”
▪ South Carolina	“Interviews with consumers and professionals by our counselors and public presentations.”
▪ Texas	“BEST program Vision Screening and eye medical services diabetes evaluation and training.”
▪ Virginia	“Staff discuss individually based on their circumstances.”

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

<ul style="list-style-type: none"> ▪ Washington 	<p>“A group was formed here in Washington about 3 years ago called the Lions Low Vision Task Force. While it existed, there was some effort made to reach out to medical and rehabilitation professionals in this state but, due to political intrigues within the Lions community, funding was withdrawn from this task force and it has more or less died a slow but quiet death. One of the more beneficial programs it sponsored was a low vision help line, which is now also gone.”</p>
-----------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

PROFESSIONALS

Program Managers in 14 states identified approaches they use to communicate eye health information to professionals. Approaches include lectures, in-service training, one-on-one discussions, interviews, vision screening, e-mail with URLs, and brochures. Their verbatim responses are listed below.

<ul style="list-style-type: none"> ▪ District of Columbia 	<p>“Lectures.”</p>
<ul style="list-style-type: none"> ▪ Florida 	<p>“Traditionally, we believe this is provided by the medical community.”</p>
<ul style="list-style-type: none"> ▪ Illinois 	<p>“Professionals are most effectively reached through the Low Vision Discovery Conference as described in question 2. We do have available a Bureau of Blind Services Link on the Office of Rehabilitation Services Board that acts as a chat room for staff to secure eye health information from other professionals. The concept of technology for broad-based communication is in the beginning stages. For example, Edna Johnson, Ph.D., recently developed the listserv that we are now using for your survey.”</p>
<ul style="list-style-type: none"> ▪ Massachusetts 	<p>“In-service training at nursing homes, assisted living facilities, adult day health centers, rehabilitation hospitals, professional organizations, (e.g., regional group of recreation professionals).”</p>
<ul style="list-style-type: none"> ▪ New York 	<p>“In-service training with home health care aids, caseworkers, etc.</p>
<ul style="list-style-type: none"> ▪ North Dakota 	<p>“Individual contacts between our staff with optometrists.”</p>
<ul style="list-style-type: none"> ▪ Ohio 	<p>“We have only used group presentations to either consumers or professionals with a variation in the content based on the audience.”</p>
<ul style="list-style-type: none"> ▪ South Carolina 	<p>“Interviews with consumers and professionals by our counselors and public presentations.”</p>
<ul style="list-style-type: none"> ▪ Texas 	<p>“Vision screening and eye medical services.”</p>
<ul style="list-style-type: none"> ▪ Virginia 	<p>“I e-mail Web site addresses and send brochures related to preventing eye diseases.”</p>
<ul style="list-style-type: none"> ▪ Washington 	<p>“A group was formed here in Washington about 3 years ago called the Lions Low Vision Task Force. While it existed, there was some effort made to reach out to medical and rehabilitation professionals in this state, but due to political intrigues within the Lions community, funding was withdrawn from this task force and it has more or less died a slow but quiet death. One of the more beneficial programs it sponsored was a low vision help line, which is now also gone.”</p>
<ul style="list-style-type: none"> ▪ West Virginia 	<p>“Providing the information to the professionals in a group setting.”</p>

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

▪ Hawaii	“Not involved in this area.”
▪ Idaho	“We have not had success in this area.”

ITEM 5: FORMAT IN WHICH CONSUMERS AND PROFESSIONALS LIKE TO RECEIVE EYE HEALTH INFORMATION

Program Managers from 17 states identified the format(s) consumers and professionals prefer to receive eye health information. Fourteen Program Managers mentioned print, including five who identified brochures, four who specified large-print material, and one who requested print materials in different languages. Eleven Program Managers preferred video with several indicating videos as the best formats for professionals. Audio tapes were mentioned by five Program Managers. Other formats mentioned include verbal consultation/one-on-one contact (n=3), electronic communication (n=2), Braille (n=2), all accessible formats (n=2), poster (n=1), and PSA (n=1).

The verbatim comments that Program Managers wrote are listed below:

▪ District of Columbia	“Print, video and audio tape.”
▪ Florida	“All accessible formats.”
▪ Georgia	“Large print, standard print for consumers—English and Spanish (Russian and Korean would be nice, only needed occasionally (five times a year). A brief video for professionals in the community would be great to have and disseminate.”
▪ Hawaii	“Print and video.”
▪ Idaho	“Large print and tape for consumers. Professionals prefer tri-fold brochures.”
▪ Illinois	“Consumers prefer to receive information through staff consultation or electronic communication. Verbal information is required for new consumers.”
▪ Massachusetts	“It has been our experience that consumers and professionals prefer to learn from personal contact with a speaker and have an opportunity to ask questions and share experiences. When they pick up materials, they seem to be most interested in concrete information that they can use, e.g., pamphlet on resources in Massachusetts or list of resources for low vision aids. A locally produced 20-minute video tape, ‘Still Independent,’ demonstrates how learning new techniques for activities of daily living can make a big difference. This has been effective in low vision support groups.”
▪ New York	“Mostly print and video. Most of the education seminars and training are presented to people who are not blind or visually impaired.”
▪ North Carolina	“One-to-one contacts with consumers is considered the most effective

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

	approach in communicating eye health information. Consumers are also provided written information in their preferred media, i.e., Braille, LP, and audio tape.”
▪ North Dakota	“Print.”
▪ Ohio	“Again, we have only used the presentation by staff, but I think a well-done video would also be very effective in combination with a verbal presentation by staff.”
▪ Rhode Island	“We have only used the brochures and other written or tape materials, such as a few books on coping with macular degeneration.”
▪ South Carolina	“All formats (especially brochures) have been utilized successfully.”
▪ South Dakota	“A multi-media package approach would be best. For instance, a series of videos, which would be public service announcements, could be designed that would be universal in content but have a specific state number to call would be useful. A companion brochure or poster for doctor or referral agency offices that would provide written literature about the program would be useful. Additionally, give the states ideas as to what to do as a follow up with the "campaign" so the effort is self-sustaining.”
▪ Texas	“Print and video.”
▪ Virginia	“Depends on their vision. When we give material to family members, a video and printed brochures in at least a 14-point font is good. Some like audiotape, others like computer disks or CD.”
▪ West Virginia	“Most consumers request information in large print, audiotape, or Braille. The professionals are more interested in print and videos.”

Another goal of this project was to identify the needs of Chapter 2 staff, contractors, and consultants. Therefore, the remaining items of the protocol asked Program Managers what they needed to enhance their understanding about eye health education programs, what resources/technical assistance they needed, and how NEI could better assist Chapter 2 programs.

ITEM 6. WHAT CHAPTER 2 PROGRAM MANAGERS NEED TO ENHANCE THEIR UNDERSTANDING OF EYE HEALTH EDUCATION PROGRAMS

In all, 12 Program Managers (40%) responded to this item of the protocol asking them what they needed to enhance their understanding about Eye Health Education Programs. The most frequent response was for more information on other organizations and programs providing eye health education (best practice).

The verbatim comments that Program Managers wrote are listed below:

▪ District of Columbia	“More written material in accessible formats. Attendance at workshops and seminars.”
▪ Florida	“Information on which organizations provide eye health education.”

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

▪ Hawaii	“Examples of what other programs are doing.”
▪ Illinois	“Illinois would like to observe a number of eye health programs so that we can determine what will work best for education programs. CNN has provided information on new treatment approaches for eye conditions—these 24-hour news outlets are a great asset in reaching the public as is public radio and television. Program alerts to agencies throughout the country would allow staff to notify customers of upcoming programming.”
▪ Massachusetts	“It would be interesting to see what other programs are doing.”
▪ New York	“Regular updates.”
▪ North Carolina	<p>“Continued provision of training opportunities pertaining to eye health and quality educational materials can enhance our understanding of and ability to provide eye health education programs.</p> <p>Developing more knowledge of available programs and resources in our state can enhance our eye health education efforts as well as continued, expanded use of those resources, of which we are already aware, such as NEI’s.”</p>
▪ Ohio	“How are other states doing it and what materials are available.”
▪ South Carolina	“Accessible and affordable printed, video and audio taped materials. Also information included on Web sites.”
▪ Texas	“We would need to understand how eye health education complements the OIB program, whose focus is on serving those individuals with vision loss resulting in a barrier to independent living. What aspect of eye health education would be appropriate for avoidance of additional vision loss?”
▪ Washington	“Information above all else.”
▪ West Virginia	“Information, suggestions, or samples of the "best-practice" eye health educational programs that other states are using or to receive recommendations from NEI focusing on what should be included in an eye health education program focusing on professionals and the consumer. Additional information on the latest research, drug treatment, vitamin therapy, etc. to provide to consumers and the general public.”

ITEM 7. RESOURCES/TECHNICAL ASSISTANCE CHAPTER 2 PROGRAMS NEED TO ENHANCE THEIR EYE HEALTH EDUCATION EFFORTS TO FRIENDS, FAMILY, CAREGIVERS, AND OTHER PROFESSIONALS

In all, 18 Program Managers (60%) responded to the item of the protocol asking them of the resources/technical assistance they need to enhance their eye health education efforts to friends, family, caregivers, and other professionals. The most common responses were for funding and easily understandable materials in alternative formats, including NEI materials.

The verbatim comments that Program Managers wrote are listed below:

▪ District of Columbia	“More funding to purchase devices used in this area, as well as the
-------------------------------	---------------------------------------------------------------------

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

	<p>technical training in using the devices. Current information in Braille, large print, and on video is also needed.”</p>
<ul style="list-style-type: none"> ▪ Georgia 	<p>“Currently, the Center for Visually Impaired (CVI) will give out NEI information (such as NIH Publication No. 95-3251) through our low vision clinic and/or at health fairs, etc. CVI case managers/social workers use your information and will give out the NEI Web site address to individuals who are computer literate or have family members who are.”</p>
<ul style="list-style-type: none"> ▪ Idaho 	<p>“Presentation materials and a format would be great. I don’t have time to put a program together. I have an M.A. in Blind Rehabilitation, consequently, I have a good working knowledge of eye health.”</p>
<ul style="list-style-type: none"> ▪ Illinois 	<p>“Illinois will refer counselors, instructors, customers, and medical providers to the National Eye Institute Web site so that information may be provided to the public. We were unaware of this Web site prior to this communication. Training materials and program ideas from the Institute would be helpful for Illinois staff development.</p> <p>The National Eye Institute could have a listserv like the Chapter 2 program that advises program managers of any new treatments, trends, or medical developments in the eye care field. Train-the-trainer programs sponsored by the National Eye Institute would benefit the states.”</p>
<ul style="list-style-type: none"> ▪ Massachusetts 	<p>“We distribute hundreds of copies of ‘What You Should Know About Low Vision’ in English and Spanish. We also find the ‘Information for Patients’ and ‘Information for People at Risk’ series of pamphlets very useful at health fairs. It would be helpful to have more materials available in other languages, particularly Chinese, French, and Portuguese.”</p>
<ul style="list-style-type: none"> ▪ Mississippi 	<p>“We appreciate all of the free brochures that we are able to get from NEI, and the cooperation we get from Preserve sight, MS, VA, and the Lions of MS. What we need is more hours in the day, more staff, and always more money.”</p>
<ul style="list-style-type: none"> ▪ New York 	<p>“Fact sheets.”</p>
<ul style="list-style-type: none"> ▪ North Dakota 	<p>“Posters and brochures that can be placed in Eye Doctor offices.”</p>
<ul style="list-style-type: none"> ▪ Ohio 	<p>“Knowing what is available to purchase or copy would be the most helpful.”</p>
<ul style="list-style-type: none"> ▪ Oregon 	<p>“We would need greater fiscal resources if we were to take this on in addition to the services now being provided.”</p>
<ul style="list-style-type: none"> ▪ South Carolina 	<p>“Accessible and affordable printed, video and audio taped materials. Also information included on Web sites.”</p>
<ul style="list-style-type: none"> ▪ Texas 	<p>“We find that self-paced educational videos on CD ROM discs are useful for staff and consumers.”</p>
<ul style="list-style-type: none"> ▪ Utah 	<p>“Information that can be given and easily understood by consumers and that is available in alternative formats.”</p>
<ul style="list-style-type: none"> ▪ Vermont 	<p>“I have not given much thought about what assistance would be helpful to start such a program in our State. Funding is not adequate for our current services. Funding to do this would be necessary.”</p>

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

▪ Virginia	“Information on where to find resources on presenting them to my staff. For example, time, and money, and a facilitator!”
▪ Washington	“Funding, materials, possible staffing assistance at in-services and the like.”
▪ West Virginia	“Information on the resources available to purchase assistive technology for consumers. Specific information on the availability of assistive technology for the blind or visually impaired that are insulin-dependent diabetics. The availability of more information on the latest research, drug treatments, vitamin therapy, etc. would be beneficial.”
▪ Florida	“Do not know what is available.”

ITEM 8. HOW NEI CAN BETTER ASSIST CHAPTER 2 PROGRAMS

In all, 16 Program Managers (53%) responded to the item of the protocol asking them how NEI can better assist Chapter 2 Programs. The most common responses suggested that NEI could assist Chapter 2 Programs with funding (n=4) in order to aid states in implementing programs on the state level and to support their client services such as adaptive skills training and availability of devices. Another common suggestion from Project Managers (n=4) was that NEI could assist Chapter 2 Programs by “publicizing/presenting services offered by chapter 2 programs and its contractors.”

The verbatim comments that Program Managers wrote are listed below:

▪ District of Columbia	“By publicizing the services being offered by the Chapter 2 Program and its contractors. Provide the technical assistance needed in this area.”
▪ Florida	“Identify what is available to the different states.”
▪ Georgia	“Would you present a general overview of the services offered by NEI and how you can work with VII-2 programs in each state? This presentation could take place next March at the Directors meeting (traditionally held in Washington, D.C.)”
▪ Hawaii	“How would you suggest you assist us?”
▪ Idaho	“Very few Project Directors have working knowledge of visual impairment/blindness conditions or services delivery. I feel very strongly about their lack of information in this area and have been concerned for quite some time as to how they may know whether their programs are really addressing these issues. I sent a post to the Chapter 2 list asking how many of them were members of the Association for Education & Rehabilitation of the Blind and Visually Impaired, and only 11 responded indicating they were members of this organization. AER publishes the Journal of Visual Impairment and Blindness, and I presume the Chapter 2 Project Directors who are not members do not subscribe to this journal, either.”
▪ Illinois	“Illinois looks forward to working more closely with the National Eye Institute. Increased communication among the states and the Institute may help in developing common goals and objectives that would

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

	improve the eye health of the people of the United States.”
▪ North Carolina	North Carolina: “Developing more knowledge of available programs and resources in our state can enhance our eye health education efforts as well as continued, expanded use of those resources, of which we are already aware, such as NEI’s.”
▪ North Dakota	“More funding for client services, specifically adaptive skills training and devices. As indicated in numbers 6 and 7 we have other needs but the need for more direct service funding is head and shoulders above the other needs. We can only hope that funding for direct services will not be diverted to "information and referral" types of activities.”
▪ Ohio	“I don’t have any suggestions at this point.”
▪ Rhode Island	“Dissemination of the information on updated macular degeneration treatments would be great at the Project Director’s meeting March 31–April 4. One of our consulting doctors just joined a study of surgical implantation of different substances to control wet macular degeneration. Updated information on not only what is available, but also what is ‘in the works’ would be good.”
▪ South Carolina	Continue to provide information regarding eye health and diseases. Provide funding to assist in implementing programs on the state level.”
▪ Texas	“Participating in advocacy efforts for increased Chapter 2 funds.”
▪ Utah	“Have more contact with them on a state level. Let us know what the NEI does and how we can better work together in this area.”
▪ Virginia	“Have a staff person available to conduct community programs. In Virginia, you would partner with our state agency and conduct six trainings across the commonwealth. We could reach tons of folks, and generate great PR! Information on where to find them and resources on presenting them to my staff. For example, time, and money, and a facilitator!”
▪ Washington	“Outreach at the local level.”
▪ West Virginia	“It would be wonderful to see NEI participate and offer different educational opportunities to attendees at the annual Chapter 2 Older Blind Program Manager’s Meeting. It would also prove beneficial to have the option to order free information on the NEI Web site in alternative formats that include large print, audiotape, Braille and print.”

ITEM 9. STATE CONTACTS TO RECEIVE OUTLOOK

The last item on the discussion protocol asked Program Managers to provide a contact name and mailing address if they were interested in receiving the bi-yearly NEI-published *Outlook*, a bulletin of the National Eye Health Education Program. This publication provides updates and resources on eye health education. Twenty Program Managers responded that they would like to receive *Outlook*. In some cases, respondents provided additional names of individuals who would like to receive this publication. Idaho and Texas reported that they already receive *Outlook*.

A complete list of the names, titles, mailing addresses, and telephone and fax numbers of the Program Managers who would like to receive Outlook can be found in Appendix F.

IV. SUMMARY AND RECOMMENDATIONS

A. SUMMARY

The National Eye Institute joined in partnership with the Department of Education's Office of Special Education and Rehabilitative Services (OSERS)/Rehabilitation Services Administration (RSA) Independent Living Services for Older Individuals Who are Blind Program, (Title VII-Chapter 2), to assess eye health education programs. NEI was interested in determining the current level of outreach activities conducted by Chapter 2 programs throughout the United States and its territories.

In July and August 2002, ORC Macro e-mailed an approved discussion protocol to 83 Program Managers, Coordinators, and consultants. Thirty-one Program Managers representing 30 states responded to one or more of the discussion items. ORC Macro staff carefully reviewed the responses and conducted a content analysis to identify major themes. Then possible frequency counts were generated.

Some of the key findings that emerged from the analysis—

- The majority of Program Managers (75%) said that they do not have goals and/or objectives that are specific to eye health education. Many of the goals and objectives that were identified focused on preventing blindness and restoring vision.
- Most (70%) Chapter 2 Program Managers said they do have an eye health education component in their program. Upon review of the responses, we identified some programs that appeared to be more “formal” and others that were “informal” eye health education programs.

North Carolina's program serves as an example for a “formal” eye health education program. The Program Manager wrote, “Our Medical Eye Care Program takes the lead in providing eye health education for consumers and the general public. The program is completely State funded. These services can include eye exams, treatment, corrective lens and/or surgery, and the provision of low vision aids.

Virginia's response is an example of an “informal” program. The Program Manager wrote, “... nothing official. We routinely conduct outreach activities, which include eye health information materials.”

- Only two program managers mentioned that they provide different eye health education programs for consumers and professionals.
- Of the states that do have eye health education programs, only four Program Managers indicated that their programs directed at underserved and/or minority groups.

ASSESSMENT OF PUBLIC EDUCATION NEEDS IN FEDERALLY FUNDED INDEPENDENT LIVING PROGRAMS FOR THE BLIND AND VISUALLY IMPAIRED—FINAL REPORT

- Program Managers most frequently mentioned funding as a barrier to implementing eye health education programs.
- The portion of Chapter 2 program activities dedicated to eye health education was minimal, ranging from 0 percent to 20 percent.
- Effective approaches in communicating eye health information to consumers includes lectures, health fairs, peer support groups, one-on-one discussions, interviews, PSAs, news articles, and talking books. Professionals appear to prefer lectures, in-service training, one-on-one discussions, interviews, e-mail, and brochures.
- Many Program Managers indicated the format in which consumers and professionals preferred to receive eye health information are printed materials, specifically large-print brochures and materials in different languages. Some Program Managers also mentioned that video serves as the best format for eye care professionals.
- When asked what Program Managers need to enhance their understanding about eye health education, they most frequently mentioned the need for more information on other organizations and programs providing eye health education, (i.e., best practices).
- In order to enhance eye health education efforts targeted to friends, family, caregivers, and other professionals, Program Managers said that funding and easily understandable materials in alternative formats, including NEI materials, would be most helpful.
- As suggested by many Program Managers, NEI could better assist Chapter 2 programs by providing funding to aid states in implementing programs and to support client services in their states. Some recommended NEI could assist Chapter 2 programs by publicizing its services.

B. RECOMMENDATIONS

ORC Macro assessed the responses provided by 30 Chapter 2 Program Managers and offered the following two recommendations for NEI's consideration.

1. CREATE AN NEI/CHAPTER 2 KNOWLEDGE EXCHANGE NETWORK

Several Program Managers were interested in obtaining information about other states' eye health education and outreach initiatives. Some Program Mangers requested a mechanism for exchanging information about best practices and promoting program activities. Another respondent suggested that all Program Mangers need to be informed about new treatments, trends, and developments in eye health.

NEI should consider working with OSERS/RSA and creating a listserv for information exchange.

2. PROMOTION OF NEI MATERIALS AND WEB SITE

Program Mangers often mentioned NEI materials and their Web site. For some, this discussion protocol served as a means for informing them about the NEI Web site and its publications. A review of the findings reveals that, according to Program Managers, consumers like to receive eye health information in print format and professionals in video format.

NEI must work to increase Chapter 2 Program Managers' awareness about NEI's available resources, including its Web site and multitude of materials. They should also encourage Chapter 2 Program Manager' to use and disseminate their materials to consumers and professionals. To facilitate this effort, we suggest that OSERS/RSA encourage its Chapter 2 Program Mangers, staff, consultants, and other providers to carefully explore and obtain information/materials contained on the NEI Web site.

NEI should consider creating a presentation (i.e., PowerPoint) of eye health information that professionals can use with a large audience. Also, NEI may want to create a video library of short, easily understood videos that professionals could use with their clients. A list of available assistive devices/technology would be appreciated.