



## **FINAL**

HCFA MARKET RESEARCH FOR BENEFICIARIES

### **INCREASING MEDICARE BENEFICIARY KNOWLEDGE THROUGH IMPROVED COMMUNICATIONS:**

### **SUMMARY REPORT ON THE MEDICARE POPULATION WITH VISION LOSS**

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The primary author of this report is W. Sherman Edwards, Associate Area Director at Westat, Inc. The report is a synthesis of findings from three other reports prepared under HCFA's Market Research for Beneficiaries contract:

- ◆ *Increasing Medicare Beneficiary Knowledge Through Improved Communications: Inventory Research Findings for Vision-Impaired, Hearing-Impaired, and Low-Literate Beneficiaries*, written by Kenneth R. Cahill, Lisa Green, and Margaret Edder of Barents Group; Jennifer Dunbar of Project HOPE; and Joan E. DaVanzo, formerly of Barents Group [Final Draft, December 1997].
- ◆ *Increasing Medicare Beneficiary Knowledge Through Improved Communications: Focus Group Research Findings for Vision-Impaired, Hearing-Impaired, and Low-Literate Beneficiaries*, written by Barbara H. Forsyth, W. Sherman Edwards, and Martha Stapleton Kudela of Westat, Inc. [Final Draft, October 1998].
- ◆ *Increasing Medicare Beneficiary Knowledge Through Improved Communications: Medicare Current Beneficiary Survey Findings*, written by Kenneth R. Cahill, Mary A. Laschober, Lisa Green, and Margaret Edder of Barents Group; Steve Parente, Laura Hodges, and Jennifer Dunbar of Project HOPE; and Joan E. DaVanzo, formerly of Barents Group [Final Draft, August 1998].

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## CHAPTER 1. SUMMARY

As part of its long-term strategic plan, the Health Care Financing Administration (HCFA) has undertaken an Agency-wide initiative to adapt its operations to improve communications with Medicare beneficiaries and with its provider partners. Helping beneficiaries to understand their choices among health care plans, providers, and treatment options and the implications of those choices on cost, quality, access and outcomes is especially important now that the Balanced Budget Act of 1997 (BBA) has expanded the health plan options available to beneficiaries. The full range of choices envisioned under BBA is not currently available in the market but an increasing number of beneficiaries will face a much more complex set of choices in the coming years. Medicare beneficiaries not only need to understand the various features of these different options to choose the design that best meets their needs, they also need basic knowledge about many aspects of the Medicare program.

### Research Purpose and Methods

The Market Research for Beneficiaries project was designed to provide HCFA with answers to the two fundamental questions that underlie effective communication:

- ◆ **What information do beneficiaries want or need from HCFA?**
- ◆ **What are the best ways to communicate that information to them?**

The Market Research for Beneficiaries project collected data from three sources to answer the questions:

- ◆ An inventory of perceived information needs and effective communication strategies from a variety of organizations and individuals who work directly with Medicare beneficiaries,
- ◆ Focus groups with Medicare beneficiaries, and
- ◆ A national survey of the Medicare population – the Medicare Current Beneficiary Survey (MCBS).

Each of the three data sources has particular strengths. Together, they can provide HCFA with a broad, deep, and representative understanding of communication with beneficiaries. The survey of Medicare beneficiaries helps ensure that the information gathered is representative of Medicare beneficiaries,<sup>1</sup> while the focus groups and inventory of organizations contribute more in-depth information than can be obtained

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<sup>1</sup> The MCBS data used in this report apply only to Medicare beneficiaries age 65 years old or older who were not living in a short-term or long-term care facility during the first two rounds of data collection in 1997.

from a large-scale survey. A description of methodologies for each of the data collection tools is contained in a separate appendix.<sup>2</sup>

As part of HCFA's commitment to adapt its operations and communication strategies to better serve *all* Medicare beneficiaries, the Agency identified a diverse set of beneficiary subgroups that it believes may have special information needs regarding the Medicare program or that may require innovative communication approaches to effectively convey information to the subgroup. This report synthesizes key findings from the three data sources for one of the identified "hard to reach" beneficiary subgroups – **elderly beneficiaries with vision loss (both those with partial vision loss and those who are blind)** who are 65 years old or older and not institutionalized. The report compares the subgroup's information needs and best communication strategies with those of the general elderly Medicare population. Additional summary reports examine the information needs and best communication strategies for African American beneficiaries, Hispanic beneficiaries, beneficiaries dually eligible for Medicaid and Medicare, beneficiaries who live in rural areas, beneficiaries with low education or literacy levels, and beneficiaries with hearing loss.

## **Key Findings and Implications for HCFA**

### Key Findings

Key findings about Medicare beneficiaries with vision loss include the following central points:

- ◆ Elderly beneficiaries with vision loss (those who have some or a lot of trouble seeing or who are blind) **represent almost 40 percent of the total elderly Medicare population**. Because they comprise such a large fraction of the elderly population and are represented in all age groups and socio-demographic categories, beneficiaries with vision loss have **generally the same needs and expectations** about information and communication sources and modes as the general Medicare population.
- ◆ Beneficiaries with vision loss are proportionately older than the general Medicare population, are substantially poorer and less educated, and are in somewhat worse health. They are considerably more likely to have difficulties with activities of daily living and hearing than those in the general Medicare population over 65, and to have difficulties with transportation.
- ◆ Important information needs of beneficiaries with vision loss include prevention of, diagnosis of, and treatment for vision loss, coverage of vision assistive devices, and adaptive and coping strategies.
- ◆ Beneficiaries with vision loss are very similar to general Medicare beneficiaries in the sources they rely on to obtain information about the Medicare program and related topics. For information about the Medicare program nearly two-thirds of those

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<sup>2</sup> See the Appendix to Cahill, et al., *Increasing Medicare Beneficiary Knowledge Through Improved Communications: Summary Report on the General Medicare Population*, Final Draft, October 1988, Health Care Financing Administration.

reporting rely on Medicare. For information about staying healthy a similar proportion relies on providers.

- ◆ Because of their condition, however, beneficiaries with vision loss rely more on family and friends to meet their information needs than do beneficiaries in general.
- ◆ Printed materials are appreciated and used by beneficiaries with some vision loss but appropriate formatting is critical to achieve maximum legibility.
- ◆ Beneficiaries with vision loss view radio as an extremely important medium for receiving information
- ◆ Beneficiary vision losses take a variety of forms and the kinds of limitations on communication materials vary accordingly. For example, printed communications appropriate for beneficiaries with partial vision loss would not meet the needs of the small subset of this population that is blind.

#### Implications for HCFA

- ◆ Recognizing that a large proportion of the Medicare population has some vision loss (40 percent), all communication relying on sight should be designed with this population in mind.
- ◆ Given the lower incomes and more fragile health status of beneficiaries who have lost some or all of their sight, when communicating with this population HCFA should emphasize coverage of those benefits that will prevent further deterioration in vision and health and assist in maintaining independence.
- ◆ Beneficiaries with vision loss appear more likely to actively seek information but less likely to be able to find needed information than the general Medicare population. Therefore, tailoring communication strategies to this group should be a high priority for HCFA. A dedicated Medicare Hotline or a Medicare Hotline option for those identifying themselves as having “poor vision” or “having trouble reading” should be seriously considered. The dedicated hotline would be a conduit through which information specific to their disability and audiocassette versions of the Medicaid Handbook could be obtained by such beneficiaries.
- ◆ As with the general Medicare population, beneficiaries with vision loss rely primarily on HCFA as the source of information about Medicare. HCFA can build on their generally positive feelings about the Medicare program by enhancing its “brand name.”
- ◆ Beneficiaries with vision loss need information about their condition and related health and rehabilitative services for which they frequently turn to community organizations who work with individuals who have some vision loss or who are blind. HCFA should work in partnership with vision-related consumer organizations to provide comprehensive and accurate information; roundtable discussions and seminars were mentioned as a communication method accessible for all levels of vision loss.

- ◆ Because beneficiaries with vision loss differ considerably in their ability to use printed materials, Medicare information should be available not only in appropriately formatted large print, but also in audiocassette and Braille versions.

### **Organization of Report**

This report is organized into four additional chapters:

- ◆ A profile of Medicare beneficiaries who have some vision loss or who are blind compared with a profile of the general Medicare population;
- ◆ A summary of information needs of beneficiaries with vision loss;
- ◆ A discussion of information sources most preferred by beneficiaries with vision loss; and
- ◆ A discussion of communication methods most preferred by this population of beneficiaries.

Each chapter includes a section on implications of the research findings for HCFA's communication strategies for beneficiaries with vision loss.

## CHAPTER 2. PROFILE OF MEDICARE BENEFICIARIES WITH VISION LOSS

The degree of vision loss is commonly categorized as low vision or blindness. A person is considered blind if he or she has no or virtually no remaining sight and visual acuity of 20/1250 or less. Persons classified as low vision have visual acuity between 20/80 and 20/1000. A further breakdown and definition of these classifications is provided in Table 2.1.

<b>Table 2.1 Visual Acuity At Different Levels</b>	
<b>Visual Acuity Measurements</b>	<b>Description of Residual Vision</b>
Normal 20/12 - 20/25	Normal reading distance and performance
Near Normal 20/30 - 20/60	Normal performance, using shorter reading distance
Moderate low vision 20/80 - 20/160	Normal performance with magnifiers or other visual aids
Severe low vision 20/200 - 20/400	Slower than normal, with aids
Profound low vision 20/500 - 20/1000	Limited reading with aids; orientation and mobility problems
Near Blindness 20/1250 - 20/2500	Vision unreliable
Blindness	No Vision

*Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.*

*Data Source: Colenbrander A, and Fletcher D, "Basic Concepts and Terms for Low Vision Rehabilitation," The American Journal of Occupational Therapy, October 1995, vol. 49, no. 9: 865.*

According to self-reports in the MCBS, almost two-fifths of noninstitutionalized Medicare beneficiaries have difficulty seeing, even with corrective lenses. Other estimates of vision loss are that nearly 1 out of 6 Americans 65 or older is blind or severely impaired, with the proportion increasing to 1 out of every 4 persons 85 or older. Only a very small percentage of these individuals – perhaps less than one percent of the Medicare population – are completely blind, but vision loss can represent a significant barrier to communicating with the Medicare population.

Most people begin to lose visual acuity after the age of 40, but the most common kinds of vision loss can usually be compensated for with corrective lenses. Vision loss among the elderly is often associated with structural changes in the eye and diseases of the eye. The most common causes of vision loss among the elderly are (1) macular degeneration, (2) glaucoma, (3) cataracts, and (4) diabetic retinopathy. Some of these causes can be treated with surgery or other means. Depending on the underlying cause, vision loss may take different forms, including general blurring, loss of peripheral vision, loss of forward vision, the presence of spots or lines, difficulties seeing at night, problems with glare, and loss of ability to distinguish colors. If untreated, diabetic retinopathy is associated with a large probability of major vision loss, but effective management of the disease can maintain some visual ability for 90 percent of those affected. Thus, information on the symptoms and effective management of these diseases is an important component of the information needs of the elderly and of those at increased risk for vision loss in particular.

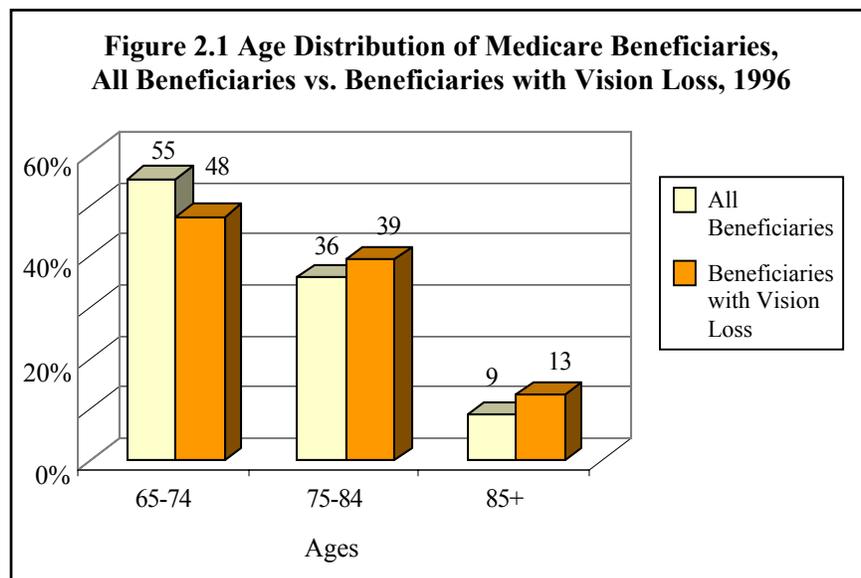
Experts report that people who experience vision loss late in life may not seek diagnosis or treatment because of denial of their condition or for other reasons. People with serious vision loss often have difficulty performing activities of daily living, but may isolate themselves or develop compensating strategies to hide their loss of sight. In focus groups with beneficiaries with vision loss, it was clear that many relied heavily on others for assistance with daily life, particularly transportation, and some were suffering emotional difficulties as they attempted to adapt to vision loss after a long life of seeing well.

### Key Beneficiary Characteristics

- ◆ Beneficiaries with vision loss resemble the general Medicare beneficiary population in most ways but tend to be older, which is not surprising since vision loss is often attributable to or aggravated by aging.
- ◆ Beneficiaries with vision loss are substantially poorer and less educated than the Medicare population in general and, correspondingly, are more likely to be Medicaid recipients (12 percent are dually eligible in contrast to 8 percent of the general Medicare population).
- ◆ Those with poor or no vision also are more likely to report being in fair or poor health and to have problems with hearing and activities of daily living than are beneficiaries in the general Medicare population.

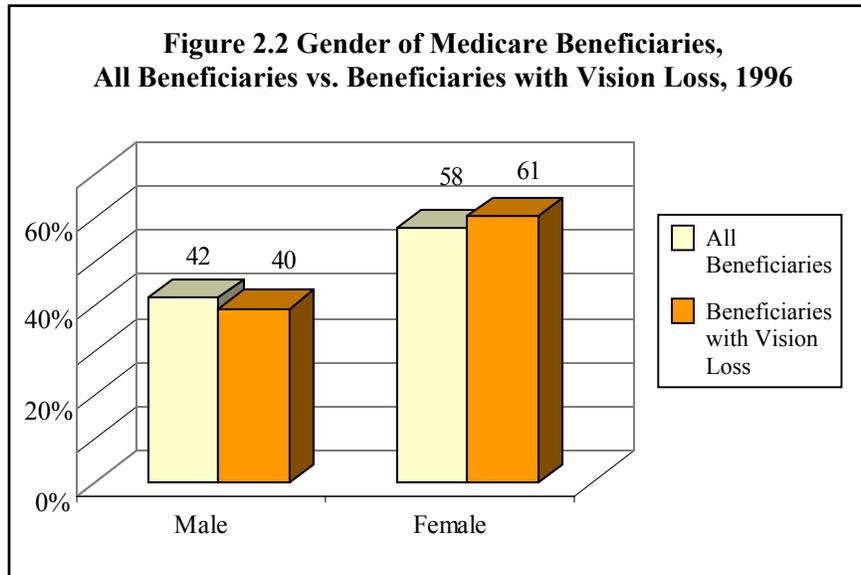
### Demographic Characteristics

About 38 percent of the non-institutionalized Medicare population aged 65 and older report difficulty seeing, even with glasses. Beneficiaries with vision loss in most ways resemble the general Medicare beneficiary population, although there are important differences. Since vision loss is often attributable to or aggravated by aging, it is not surprising that Medicare beneficiaries with vision problems tend to be older than the general Medicare population (Figure 2.1).

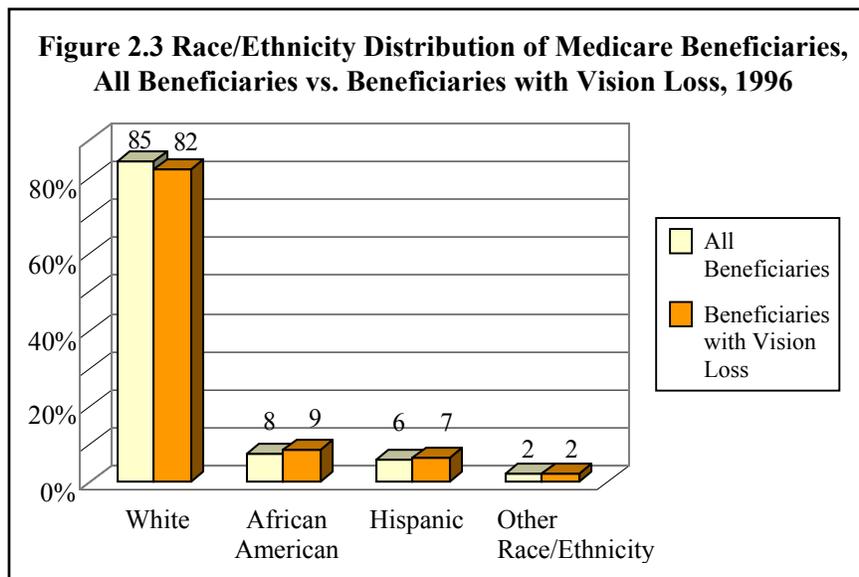


Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.  
Data Source: Medicare Current Beneficiary Survey

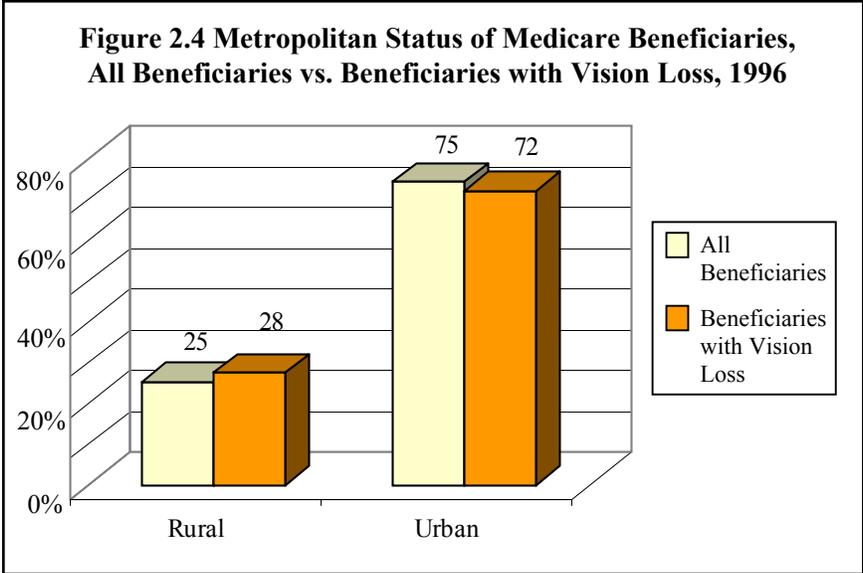
Beneficiaries reporting vision loss are not substantially different from the general Medicare population with regard to gender, race/ethnicity, or residential location (Figures 2.2-2.4).



Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.  
Data Source: Medicare Current Beneficiary Survey

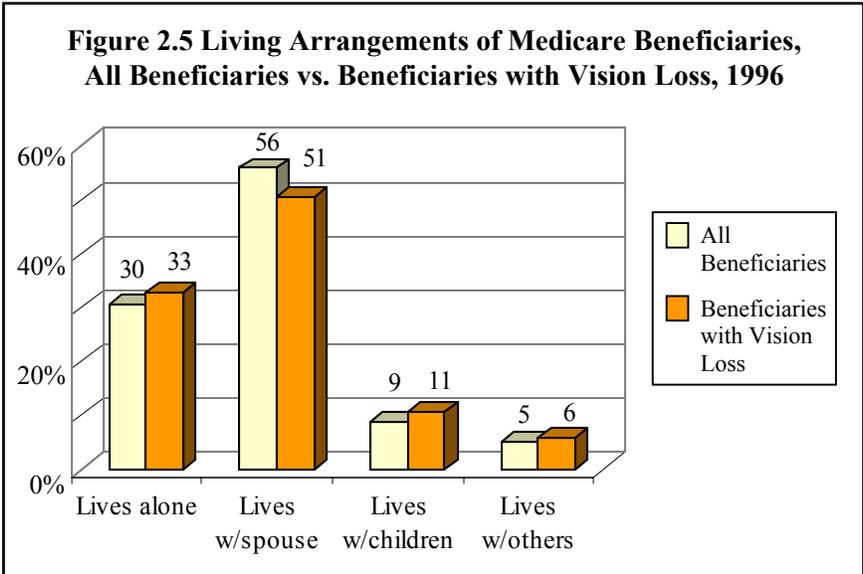


Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.  
Data Source: Medicare Current Beneficiary Survey



Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.  
 Data Source: Medicare Current Beneficiary Survey

Beneficiaries with vision loss are somewhat more likely to live alone or with children or other relatives or non-relatives and less likely to be living with a spouse than the general Medicare population (Figure 2.5).



Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.  
 Data Source: Medicare Current Beneficiary Survey

## Economic Characteristics

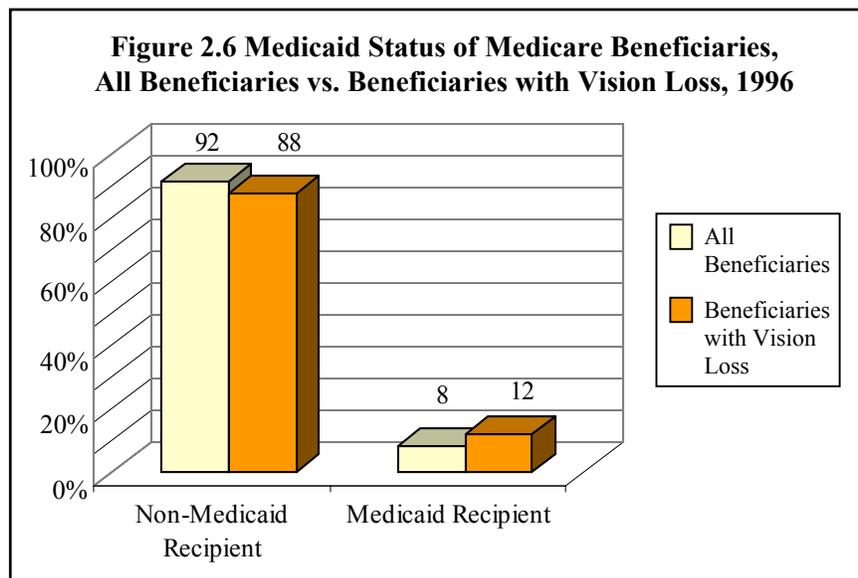
The economic circumstances of beneficiaries with vision loss who are 65 years to 84 years old are substantially different from the general beneficiary population. They are more likely to be in the lowest income group with annual incomes below \$15,000. However, the oldest of those with vision loss are similar to the general population in income distribution, which is a reflection of the observation that older beneficiaries are more likely to experience vision losses (Table 2.2).

Table 2.2 Income Distribution by Age for Beneficiaries with Vision Loss and All Medicare Beneficiaries, 1996								
Income Level	Total Medicare Population		Ages 65 to 74		Ages 75 to 84		Ages 85 and older	
	Vision Loss	All	Vision Loss	All	Vision Loss	All	Vision Loss	All
Less than \$15,000	49.7%	41.7%	43.5%	35.9%	51.8%	44.8%	66.3%	64.4%
Between \$15,000-\$30,000	30.9	34.2	31.9	34.8	32.4	36.0	22.4	24.1
More than \$30,000	19.4	24.1	24.6	29.4	15.8	19.2	11.3	11.6

Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.

Data Source: Medicare Current Beneficiary Survey

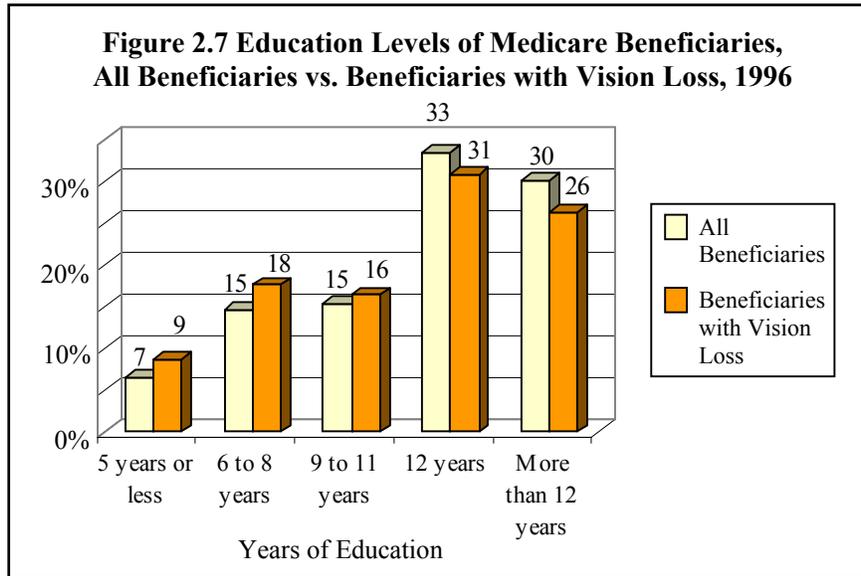
Due to their poorer economic circumstances, beneficiaries with vision loss are also more likely to be Medicaid recipients than beneficiaries in general (Figure 2.6). Again, this difference becomes less pronounced among the oldest beneficiaries as the fraction of all beneficiaries receiving Medicaid increases, commensurate with their diminished incomes and health status.



Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.

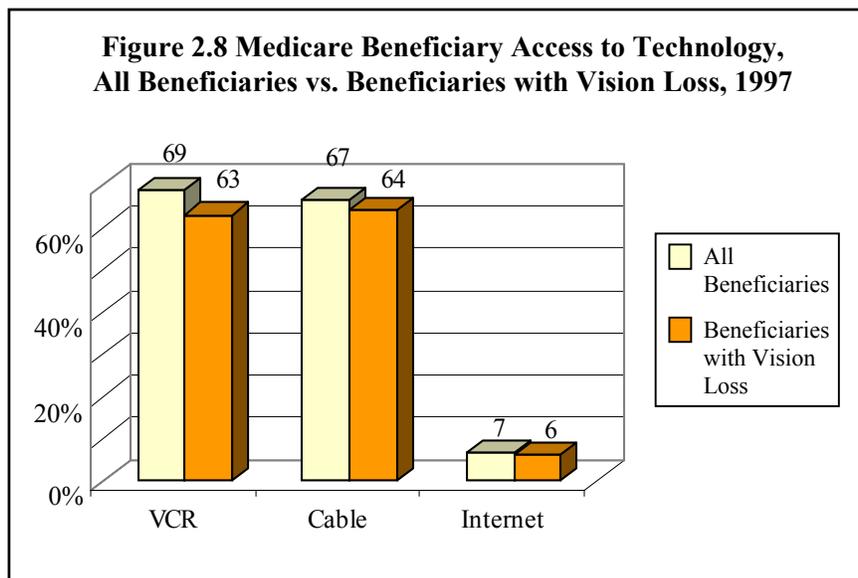
Data Source: Medicare Current Beneficiary Survey

Not surprisingly, since income and education are highly correlated in the Medicare population, beneficiaries with vision problems are less likely than beneficiaries in general to have at least a high school education (Figure 2.7). Both lower educational attainment and vision loss are associated with the older age groups in the elderly Medicare population, which may explain the positive association of lower education levels and beneficiaries who have low vision or are blind.



Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.  
Data Source: Medicare Current Beneficiary Survey

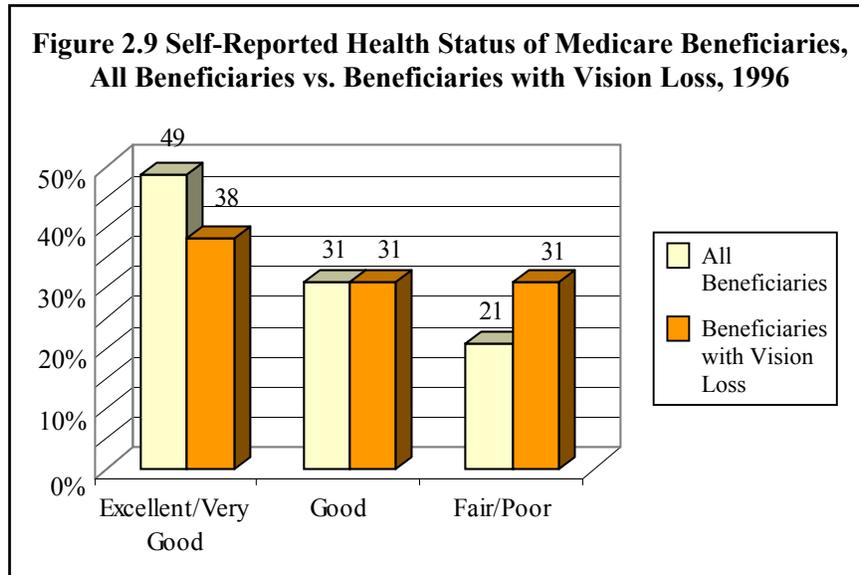
Beneficiaries with vision loss are somewhat less likely than beneficiaries in general to have access to VCRs, cable television, and the Internet. These media not only are highly dependent on vision but also are associated with higher income (Figure 2.8).



Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.  
Data Source: Medicare Current Beneficiary Survey

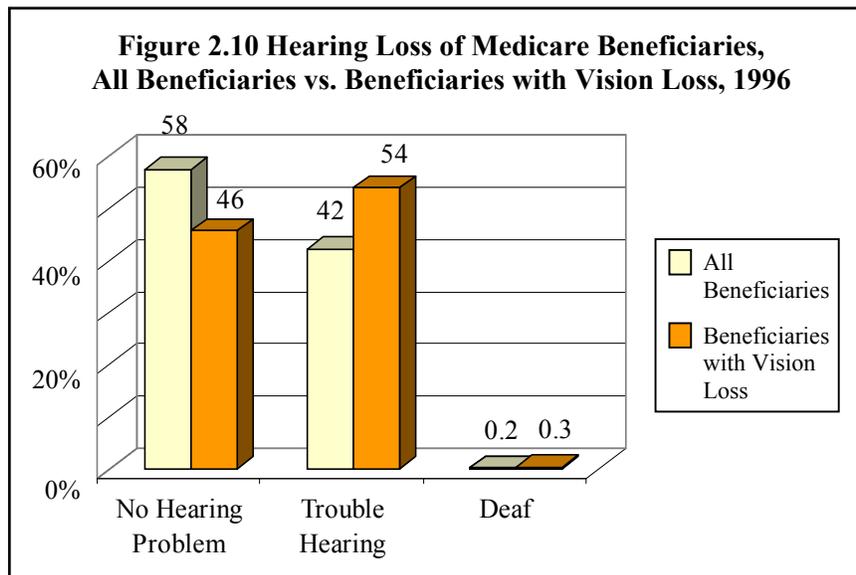
## Health Characteristics

Beneficiaries with vision loss are substantially more likely to report being in fair or poor health, and less likely to report being in excellent or very good health, than are beneficiaries in general (Figure 2.9). In some cases, beneficiaries may view the underlying cause of their condition as reason for considering themselves in less than very good health; in other cases, vision loss may be linked with another chronic health condition, such as diabetes.



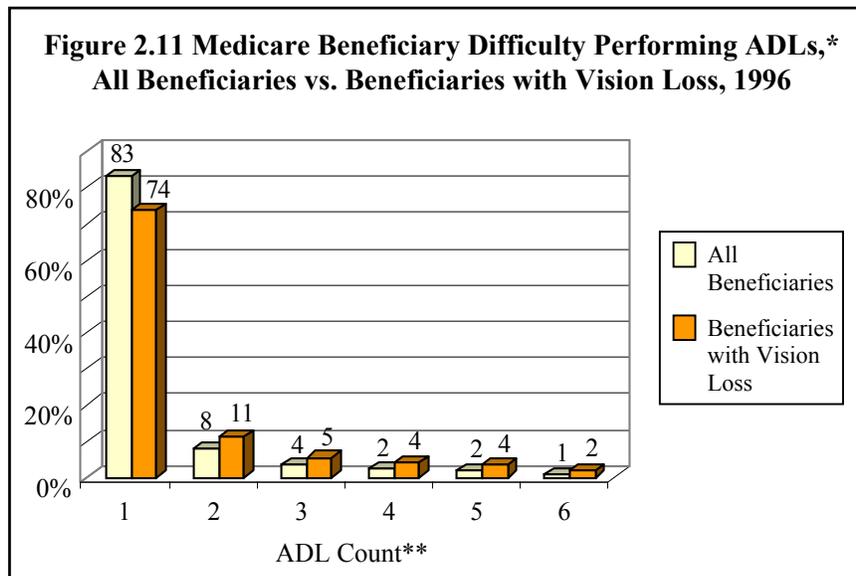
Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.  
Data Source: Medicare Current Beneficiary Survey

Beneficiaries who have experienced a loss of vision are also considerably more likely to report having a hearing loss (i.e., they have some or a lot of difficulty hearing, Figure 2.10).



Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.  
Data Source: Medicare Current Beneficiary Survey

A substantially higher proportion of beneficiaries with vision loss reported difficulty performing one or more activities of daily living (ADLs) without help compared with beneficiaries in general (Figure 2.11). This finding is consistent with other research linking serious vision loss and limitations in ADLs.



Source: Figure prepared by Barents Group LLC, in collaboration with Westat, Inc.

Data Source: Medicare Current Beneficiary Survey

\*ADLs = Activities of Daily Living

\*\*ADL Count = Number of ADLs beneficiary has difficulty performing without help.

Although it is not surprising that beneficiaries with vision loss are more likely to have hearing problems and difficulties with activities of daily living given that they are slightly older on average than the general beneficiary population, communication strategies targeting Medicare beneficiaries who have difficulty seeing must also take into account the generally poorer health and functioning of this population.

### Implications for HCFA

- ◆ HCFA should take into consideration the large proportion of the Medicare population with vision loss in designing any communications relying on sight.
- ◆ Most people affected with vision loss gradually become aware of the problem later in life and may have trouble admitting their difficulties because of perceived social stigma and associated loss of self-esteem. Communication strategies should not rely on beneficiaries identifying themselves as having poor vision but rather should include features that will assist in reaching the target audience (e.g., designing all printed communications so that they are more legible for those with low vision).
- ◆ Because many beneficiaries with vision loss may avoid sight-based communication modes rather than admit their condition or may be unable to see well enough to use them at all, HCFA should continue to make any information primarily communicated through sight also available through alternative modes (e.g., audiocassettes).

- ◆ Given the lower incomes and more fragile health status of beneficiaries with vision loss, when communicating with this population HCFA should emphasize coverage of those benefits which will prevent further deterioration in vision and health and assist in maintaining economic and social independence.

### **CHAPTER 3. WHAT INFORMATION DO BENEFICIARIES WITH VISION LOSS WANT OR NEED FROM HCFA?**

For the most part, beneficiaries with vision loss have information needs that resemble those of the general elderly Medicare population. They ask basically the same questions and demonstrate the same gaps in understanding about the Medicare program. However, beneficiaries with vision loss need additional specific health, insurance, and cost-sharing information related to the condition itself. This chapter summarizes the key findings about the information needs of beneficiaries with vision loss and their Medicare-related knowledge, and highlights differences and similarities between these beneficiaries and those in the general elderly Medicare population.

#### **Key Information Needs and Knowledge of Beneficiaries with Vision Loss**

- ◆ Beneficiaries with vision loss are somewhat more likely than members of the general Medicare population to need basic information about Medicare, since they generally process information more slowly than fully-sighted beneficiaries and are more likely to live alone, lacking someone else in the home to process the information for them.
- ◆ They are also somewhat more likely than the general Medicare population to seek information, but are less likely to find it when they do.
- ◆ Similar to beneficiaries in general, managed care is a subject about which only 28 percent (the smallest fraction for any topic) of beneficiaries with vision loss reported knowing everything they need to know, but it was ranked fourth in importance as a subject about which they want more information. Beneficiaries with vision loss need answers to basic questions about how Medicare managed care works, particularly with regard to care or additional benefits related to their condition.
- ◆ **Additional information needs of beneficiaries with vision loss focus primarily on the condition itself:**
  - ◇ A major concern for beneficiaries with vision loss is being able to afford assistive devices such as glasses, hand-held or face-worn magnifiers, and closed-circuit televisions, most of which are not covered under Medicare.
  - ◇ Beneficiaries with vision loss also need basic information about diagnosis of vision problems, prevention and treatment options, and resources for obtaining more information on these topics.
  - ◇ Especially for those who have lost their vision over time and are not accustomed to having the loss, beneficiaries and their families need advice on alternative ways of dealing with daily life and on coping strategies.
  - ◇ Only a small fraction of potentially eligible beneficiaries are using rehabilitative services so information is also needed on available services that can help individuals maintain or regain their independence.
- ◆ Blind individuals, which constitute a minority of beneficiaries with vision loss, were more likely than the general Medicare population to say they did not want or need additional information about the Medicare program. These groups of beneficiaries

often have assistance from family, friends, or community groups that work with blind individuals, which may be the reason for their responses.

### **Information Needs**

Overall, beneficiaries with vision loss need essentially the same information as the general Medicare population, including information on covered services and finding providers. According to expert informants, managed care is an increasingly confusing and frustrating topic for all beneficiaries, including those with vision problems, especially in terms of its relationship to Medicare. Like many beneficiaries, they do not understand the dual roles of provider and financier of health care.

In the MCBS, beneficiaries with vision loss had somewhat greater needs than the general beneficiary population for information about new Medicare benefits, what services are covered under Medicare, and Medigap insurance (Table 3.1). Their needs for information about finding a doctor, managed care plans, and what they would owe for covered services were about the same as the general Medicare population.<sup>3</sup>

**Common Medicare Questions Asked by Beneficiaries with Vision Loss:**

1. What services are covered under Medicare?  
Are glasses, CCTVs, and other necessary low vision aids covered?
2. Who pays for low vision services?
3. What is the role of managed care in Medicare?  
How does managed care fit into the health care system?

When asked in the MCBS about whether they knew as much as they needed to on these topics, beneficiaries with vision loss were very similar in the distribution of their responses across topics to the general Medicare population, although they were consistently a bit more likely to say they knew little or nothing (third column of Table 3.1). Managed care was the topic with the highest rate of knowing little or nothing (60.6 percent), followed by Medigap insurance (40.1 percent), out-of-pocket costs (34.0 percent), and coverage of services under Medicare (32.7 percent).

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<sup>3</sup> The figures in the first two columns of Table 3.1 are based on very small sample sizes and should not be relied on too heavily.

<b>Table 3.1 Information Needs of Beneficiaries with Vision Loss and All Medicare Beneficiaries, 1997</b>						
<b>Information Topic</b>	<b>Needed information about topic in past year</b>		<b>Of those who needed in past year, did not find information</b>		<b>Knew little or nothing about topic</b>	
	All	Vision Loss	All	Vision Loss	All	Vision Loss
New benefits	4.3%	5.2%	13.8%	16.8%	N/A	N/A
Choosing or finding a provider	2.3	2.5	15.3	20.5	18.4	21.0
Medicare services	5.3	6.4	16.5	21.1	29.2	32.7
Medigap policies	6.8	8.3	17.2	17.7	36.6	40.1
Amount owed for services	3.0	3.2	17.9	20.3	30.8	34.0
Staying healthy	N/A	N/A	N/A	N/A	7.1	9.3
Availability and benefits of HMOs	6.2	5.8	5.7	5.6	57.1	60.6

Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.  
Data Source: Medicare Current Beneficiary Survey

Like the general Medicare population, less than one-third of beneficiaries with vision loss reported knowing everything they needed to know about Medicare HMOs (Table 3.2) and only 42 percent said they know everything they need to know about the Medicare program and supplemental insurance.

<b>Table 3.2 Self-Reported Knowledge of Medicare Topics Beneficiaries with Vision Loss and All Medicare Beneficiaries, 1997</b>		
<b>Medicare Topic</b>	<b>All Beneficiaries Reporting “Everything I need to know about topic”</b>	<b>Beneficiaries with Vision Loss Reporting “Everything I need to know about topic”</b>
Medicare program	46%	42%
Payment for Medicare services	48%	44%
Supplemental Insurance	46%	42%
Medicare HMOs	30%	28%
Choosing or finding a doctor	65%	63%
Staying healthy	77%	75%

Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.  
Data Source: Medicare Current Beneficiary Survey

Finally, when asked what topics were most important to get more information about, MCBS respondents with vision loss gave almost identical responses as the general Medicare population represented in the MCBS (Table 3.3). General information about the Medicare program was rated most important by more than one-third of beneficiaries, and staying healthy by over one-fourth. Notably, although all indicators are that beneficiaries with vision loss (like the general Medicare population) lack information about managed care options, only nine percent of MCBS respondents picked managed care as the most important topic about which to get more information

<b>Table 3.3</b> <b>Information Preferences of Beneficiaries with Vision Loss</b> <b>and All Medicare Beneficiaries, 1997</b>		
<b>Medicare Topic</b>	<b>All Beneficiaries</b> <b>Citing Topic as Most</b> <b>Important to Have More</b> <b>Information On*</b>	<b>Beneficiaries with Vision</b> <b>Loss Citing Topic as Most</b> <b>Important to Have More</b> <b>Information On*</b>
Medicare program	37.5%	37.8%
Staying healthy	25.7%	25.8%
Payment for Medicare services	13.4%	14.3%
Medicare HMOs	9.4%	9.4%
Choosing or finding a doctor	7.5%	6.7%
Supplemental insurance	6.6%	6.2%

Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.

Data Source: Medicare Current Beneficiary Report

\*Percentages are based on the number of beneficiaries who said they needed information about at least one of the topics in the table.

Moving beyond basic information about Medicare and managed care in general, beneficiaries with vision loss often ask about coverage of specific vision services and technologies. One important service that could help many beneficiaries with vision loss is low vision rehabilitation, which consists of training in skills that enable people to perform daily activities in a variety of new ways. Unfortunately it is estimated that only about one-fourth of individuals affected by low vision take advantage of this service; others may be either unaware of the service or unable to afford it. **Information is needed on available services that can help individuals maintain or regain their independence.**

Devices to assist beneficiaries with vision loss such as glasses, hand-held or face-worn magnifiers, and closed circuit TVs are often not covered by health insurance and are beyond the means of many who could benefit from them. Like focus group participants with hearing loss, several low vision focus group participants said they would value information from HCFA to help them make difficult decisions about purchasing equipment to help them deal with their vision loss. Partnerships with organizations working with individuals with vision loss and health care providers would be an effective method for addressing this information need.

*"I would like to know for sure what Medicare would cover when it comes to aids for helping you see better."*

- Low Vision Focus Group Participant

Focus group participants with vision loss showed less variation than other subgroups in terms of their information-seeking preferences. Among the participants with vision loss, there was a general preference to seek focused information when it is needed to address specific questions. As none of the participants drew links between their information-seeking preferences and their vision loss, it is difficult to determine whether the relatively high proportion of reactive information seekers among these participants is related to their vision difficulties.

*“Send me something that is interesting.  
Don’t send me something that is not  
concerned for me....”*

- Low Vision Focus Group Participant

### **Implications for HCFA**

- ◆ Beneficiaries with vision loss have the same basic information needs regarding the Medicare program and other health insurance options as the general Medicare population. The basic information HCFA provides to the general population will be appropriate for beneficiaries with vision loss as well.
- ◆ Beneficiaries with vision loss, however, also have very important information needs related to their condition. HCFA should provide information on coverage of prevention, diagnosis, treatment, rehabilitation and assistive devices related to their condition under original Medicare and other Medicare plan choices. This is especially important because cost is a major barrier to obtaining help for vision loss. The Medicare Hotline should include an option for those identifying themselves as having “poor vision” or “having trouble reading” where information specific to their condition and audiocassette versions of the Medicaid Handbook could be obtained.
- ◆ Beneficiaries with vision loss are likely to seek information reactively but are less likely to be able to find needed information than the general Medicare population, so developing a tailored communication strategy for this group should be a high priority for HCFA.
- ◆ HCFA should disseminate information on vision loss and treatment/assistive options widely because such a large proportion of the Medicare population has experienced some vision loss.
- ◆ HCFA can expect a disproportionate number of contacts from beneficiaries with vision loss because these beneficiaries appear to be somewhat more active information seekers (reactively rather than proactively) compared with beneficiaries in general and because they have very specific condition-related needs for information.

## CHAPTER 4. WHAT INFORMATION SOURCES DO BENEFICIARIES WITH VISION LOSS PREFER?

### Key Findings on Preferred Information Sources for Beneficiaries with Vision Loss

- ◆ Beneficiaries with vision loss are very similar to general Medicare beneficiaries in the sources they rely on to obtain information about the Medicare program and related topics. The preferred source depends on the topic. For information about the Medicare program and out-of-pocket payments the majority of those reporting in the MCBS, and over 40 percent of those inquiring about HMOs in the MCBS, relies on Medicare. For information about staying healthy or locating a health care provider, most rely on providers.
- ◆ In focus groups, beneficiaries with vision loss reported that they rely heavily, and sometimes exclusively, on their family and friends to pass along information that they themselves would miss because they cannot see very well.
- ◆ Beneficiaries with vision loss also rely on medical providers for information, both about Medicare and about their vision loss. Focus group participants also reported former employers and retiree organizations as sources of information about their health coverage.
- ◆ Beneficiaries with vision loss would like more convenient access to information from HCFA, e.g., “one stop shopping” through a multi-purpose telephone hotline for those with low or no vision.

### Information Sources

As shown in Table 4.1 responses to the MCBS, the beneficiary population with vision loss is nearly identical to the general Medicare population in their preferred sources of information for specific topics. The only difference of note is the slightly larger percentage of beneficiaries in general compared with beneficiaries with vision loss who rely on Medicare for information regarding out-of-pocket payments. Beneficiaries with vision loss were somewhat more likely than the general Medicare population to rely on doctors for this information and slightly more likely to rely on family and friends for information about the Medicare program and other insurance related topics.

Focus group participants with vision loss placed greater emphasis on the importance of

*“If there should be an article in the paper and my daughter doesn’t see it, then a friend will call. A good friend who always reads the paper like I used to read it, from cover to cover. She’ll call me and let me know about it.”*

- Low Vision Focus Group Participant

family and friends as sources of information compared with beneficiaries in general. Unlike beneficiaries in the general population focus groups, those with vision loss did not make negative comments about family and friends as

information sources. More often, low-vision participants said they trust family and friends completely.

<b>Table 4.1 Preferred Information Sources for Beneficiaries with Vision Loss* and All Medicare Beneficiaries, 1997**</b>							
<b>Medicare Topic</b>	<b>Medicare/ Carrier/ 1-800</b>	<b>Doctor/ Provider</b>	<b>Community Org.</b>	<b>Family, Friends</b>	<b>Insurance Company</b>	<b>AARP/Sr. Citizens' Group</b>	<b>Other</b>
Medicare program							
<i>Vision Loss</i>	52.7	22.5	8.6	5.5	2.8	7.7	0.3
<i>All Beneficiaries</i>	53.8	22.3	8.3	4.6	2.9	7.7	0.3
Out-of-pocket payments							
<i>Vision Loss</i>	61.7	23.4	4.5	3.5	4.6	2.2	0.3
<i>All Beneficiaries</i>	64.3	20.7	4.4	2.6	5.5	2.1	0.4
Supplemental insurance							
<i>Vision Loss</i>	20.8	11.3	8.3	7.0	41.1	10.1	1.4
<i>All Beneficiaries</i>	19.8	11.6	7.3	6.5	42.5	11.0	1.5
Medicare HMOs							
<i>Vision Loss</i>	41.1	19.2	9.5	8.9	14.0	6.2	1.1
<i>All Beneficiaries</i>	40.4	18.6	9.5	7.7	15.5	7.6	0.7
Finding a doctor							
<i>Vision Loss</i>	13.5	47.8	5.9	25.5	4.2	2.2	0.9
<i>All Beneficiaries</i>	12.6	47.3	6.0	26.5	4.7	2.2	0.8
Staying healthy							
<i>Vision Loss</i>	6.9	65.1	9.5	9.8	2.9	3.8	1.9
<i>All Beneficiaries</i>	6.6	64.7	10.3	9.6	3.1	3.8	2.0

Source: Table prepared by Barents Group LLC, in collaboration with Westat, Inc.

Data Source: Medicare Current Beneficiary Survey

\*Beneficiaries with vision loss include both those with partial vision loss as well as those who are blind.

\*\*Percentages are based on respondents who chose at least one source. Respondents who said they did not need information on the topic are excluded from the figures in the table.

Like those in the general population, beneficiaries with vision loss are receptive to getting more information from HCFA, although they do not often know the name of the agency that runs Medicare. They particularly like the idea of “one-stop shopping” for information.

*“What would be nice, if there was one place you could direct call all your questions without having [to] dial all those numbers. Once you have low vision, it becomes kind of hectic trying to . . . get to know all the lines.”*  
- Low Vision Focus Group Participant

Finally, vision care specialists and consumer organizations like the National Federation of Blind and the National Association of Visually Handicapped are important sources for information about the treatment of and correction for vision loss, but not so much for information about Medicare or health plans.

## **Implications for HCFA**

- ◆ As with the content of basic information about the Medicare program, HCFA can rely on the same sources for imparting information to beneficiaries with vision loss as they do for the general Medicare population. Most importantly, the Medicare program itself is an important source of information for beneficiaries in general and those with vision loss.
- ◆ However, beneficiaries with vision loss also need information about their condition and related services. HCFA should consider assigning a dedicated telephone line for this population where this information would also be available.
- ◆ Beneficiaries with vision loss also depend on vision specialists and vision-related consumer organizations for information related to their condition. Teaming with these individuals and organizations would be an effective way for HCFA to provide comprehensive and accurate information, not only about clinical services but also about the Medicare program.
- ◆ Beneficiaries with vision loss are very likely to be accompanied by a family member or friend on visits to providers. Their reliance on family and friends and providers as sources of information can be used by HCFA. Materials could be made available through providers to educate both the beneficiaries and those that accompany them to physicians' offices.

## CHAPTER 5. WHAT COMMUNICATION MODES DO BENEFICIARIES WITH VISION LOSS PREFER?

### Key Findings on Preferred Communication Modes for Beneficiaries with Vision Loss

- ◆ Communication preferences of beneficiaries with vision loss were similar to the general Medicare population in several ways. In both groups, the Medicare Handbook is used mainly as a reference tool and there is some distrust of information that comes from media such as television and newspapers. Many prefer to receive written information through the mail and focus group participants described frustrating experiences with automated telephone menus. Like other beneficiary groups, beneficiaries with vision loss most prefer in-person communications and brochures (that are designed to account for low vision beneficiaries' needs).
- ◆ Not surprisingly, the group with vision loss differed from the general Medicare population in viewing radio as an extremely important medium for receiving information.
- ◆ Participants with vision loss also had unique needs and experiences:
  - ◇ Seniors with low vision want large print materials and audio-taped information to be more readily accessible.
  - ◇ They are heavily reliant on a variety of assistive devices for receiving information, many of which facilitate their independence, and they want more information about these devices. These include magnifying lenses, telescopic lenses, and closed circuit televisions.
  - ◇ Seminars and roundtable discussions are popular methods for obtaining information for beneficiaries with vision loss because in addition to general information they obtain answers to their individual questions.
  - ◇ However, for all beneficiaries with vision loss, transportation is a major obstacle that can affect their ability to take advantage of some information channels such as meetings or computers in public places.
- ◆ Communication preferences of beneficiaries with vision loss are related to levels of the vision loss and access to support systems:
  - ◇ Participants with relatives or friends who help care for them are more likely to prefer written materials because there is someone available to read to them.
  - ◇ Blind beneficiaries who have learned Braille prefer Braille versions of printed materials.
  - ◇ Low vision beneficiaries, unlike other Medicare groups, have specific preferences regarding the format of informational materials to increase their legibility.

## Communication Modes

The group of beneficiaries with vision loss, like other beneficiary groups, most prefers in-person communications and brochures as sources of information about Medicare. Unlike beneficiaries in general, whose suggestions about the Medicare Handbook usually were confined to content, focus group participants with low vision were concerned about the Handbook's format. About one-half said an audio-taped version of the Handbook would improve their access to the information it contains. Generally, beneficiaries who request the Handbook on audio-cassette can no longer read or are used to relying on recorded information like talking books.

A surprisingly large proportion of beneficiaries with vision loss prefer **printed materials**, either to read themselves or to have others read for or to them. However, the format of printed materials is critical to their accessibility:

*"I think printed information... I graduated, about a month's time, past large print. It's not of much value to me anymore. I can read with my magnifiers. And, of course, as long as I have a good and faithful wife, that simplifies my life a lot... But I think for me the printed would be best."*

– Low Vision Focus Group Participant

- ◆ Large type is important, although experts differ somewhat, suggesting 16 to 18 point type. For beneficiaries with reduced vision fields, too large type may be difficult to read.
- ◆ Ink color is also important – dark black ink is best.
- ◆ Contrast is critical as well – black ink on a flat (not glossy) white background is best. Shading makes printed materials more difficult to read. Black ink on a red background is extremely difficult for persons with vision loss to read and should be avoided.
- ◆ A dividing line should separate text in columns.
- ◆ Paper used in print materials should be of sufficient thickness so that printing does not bleed through the page.

Blind beneficiaries who have learned Braille prefer Braille versions of printed materials. Others want information from printed materials available on audiocassette.

*"I would love a cassette. I have a tape recorder in several rooms. And I'd just slam the cassette in, the tape in, and listen to the tape, books on tape, information on tape."*

– Low Vision Focus Group Participant

**Radio** is an extremely important medium for beneficiaries who are unable to see well enough to watch television. Some rely on radio stations that perform services for people with vision loss such as reading newspaper articles or reciting announcements of grocery store sales.

Beneficiaries with vision loss can often be helped by **assistive devices** that facilitate independent living. In focus group discussions, several participants described the central role that assistive devices play in their lives. They listed activities they are able to participate in because of these tools. Unfortunately, the high cost of assistive technology makes acquiring the equipment prohibitive for many beneficiaries with vision loss. Many

participants criticized Medicare for not covering at least part of the cost of devices that assist vision. Several participants compared their need for low vision assistive devices to the need of individuals who cannot walk for wheelchairs. Only a few participants had devices such as closed-circuit televisions or high-powered telescopic lenses. Most rely on less expensive magnifying glasses, or use talking book, magazine, or newspaper services.

Although only 5.5 percent of beneficiaries with vision loss in the MCBS reported having access to the **Internet** (a slightly lower percentage than in the general Medicare population), low vision need not be a prohibitive barrier to using it. Some of the format rules for printed materials, such as large print and high contrast, apply to World Wide Web sites as well. Users may be offered an option to change type and background colors or font size. Low-vision users can also download information through a voice synthesizer and blind users can print out information in Braille. As with printed materials, beneficiaries with vision loss may have family or friends available to help them obtain information over the Internet and the number with Internet access, while still relatively small, can be expected to grow.

### **Communication Strategies**

The inventory report summarized the main strategies for communicating with the blind and low vision communities. The needs of the two populations should be considered separately as the same materials are not applicable to both (e.g., those with vision loss as a result of the aging process are not likely to know or to learn Braille).

#### **Top Five Communication Strategies for the Blind and Low Vision Communities**

1. Always produce information using a variety of alternative media. This allows for a larger group of beneficiaries to be reached.
2. When producing information in print format, use a larger font to allow individuals with low vision to read with greater ease (16 point font or larger).
3. To create a more readable document, reformat by using a simple style and structure. Avoid using difficult graphics or confusing layouts.
4. Produce text in Braille for the subset of individuals with vision loss who are able to read Braille.
5. Deliver information in an audio format for those individuals who prefer to hear information.

### **Implications for HCFA**

- ◆ HCFA should make all informational materials available in media appropriate for beneficiaries with vision loss because such a large proportion of Medicare beneficiaries has some or severe loss of sight.
- ◆ However, beneficiaries with vision loss differ considerably in their ability to use printed materials so Medicare information should be available not only in large print, but also in audio-cassette and Braille versions.

- ◆ HCFA should produce large print documents in a format that contributes to their legibility by those with low vision, i.e., bold, dark print in a simple layout on a white non-glossy background.
- ◆ Beneficiaries with vision loss often cannot see well enough to watch television and for these beneficiaries the radio is a very important source of information. Therefore, public service announcements about Medicare should run on radio as well as television, particularly on programs designed for people with vision loss.
- ◆ Like Medicare beneficiaries in general and other special groups, beneficiaries with vision loss prefer one-on-one communication. HCFA should consider a dedicated telephone number for beneficiaries with vision loss so they can obtain answers to their questions, including questions related to their condition, without struggling to navigate an automated line.
- ◆ HCFA should consider partnering with community groups serving the low vision and blind to provide roundtable discussions or seminars where participants would have the opportunity to learn about the Medicare program and also ask their own specific questions on a one-on-one basis. These groups would be especially aware of the transportation needs of those with vision loss.
- ◆ As the Internet continues to grow in importance as a communication medium for Medicare, HCFA web pages should follow design principles for users with vision loss or offer format tailoring for such users.