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Evaluation of the Medicare Low Vision Rehabilitation Demonstration

Beneficiary Case Study

Final Report

To
Centers for Medicare and Medicaid Services
Submitted by the
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EXECUTIVE SUMMARY

Introduction

The purpose of this report is to present the results of Brandeis University's evaluation of beneficiaries' experiences of the Low Vision Rehabilitation Demonstration (LVRD). The LVRD was authorized by Section 645 of the 2003 Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (P.L.-173), which directed the Secretary to conduct "a study to determine the feasibility and advisability of providing for payment for vision rehabilitation services furnished by vision rehabilitation professionals ... (including) ... an orientation and mobility specialist, a rehabilitation teacher, or a low vision therapist." Conference report language from the House bill (H.R. 2673) specified a five-year demonstration and authorized first-year funding of \$2 million. The Centers for Medicare and Medicaid Services (CMS) used these authorities to develop a demonstration to begin in 2006 with spending up to \$2 million annually.

Traditional Medicare coverage of vision services

One of the overarching goals of the DHHS *Healthy People 2010* initiative is an "increase in the use of vision rehabilitation services by people with visual impairments," who include more than 3.6 million persons over age 40. The purpose of the LVRD is to see if Medicare can do more to support low vision (LV) rehabilitation services. These services tend to focus on promoting beneficiaries' functioning and independence rather than on medical cures for LV problems. Traditionally, funding for LV rehabilitation services has come from state, local, and charitable sources and has tended to focus on younger persons. These sources are not adequate for the increasing number of older persons with vision impairments.

Since the mid-1990s Medicare has allowed physical therapists, occupational therapists and speech therapists to bill for LV rehabilitation services, but it has limited the ability to bill for the services of three types of traditional vision rehabilitation professionals: low vision therapists (LVTs), who specialize in training patients to use optical devices such as magnifiers; vision rehabilitation therapists (VRTs), who focus on adaptation inside the home; and orientation and mobility specialists (OMSs), whose specialty is training in mobility outside the home. The services of these professionals could only be billed "incident to" a physician's services, i.e., using the physician's Medicare billing number, and only when the services were provided in the physician's office.

Until 2002 reimbursement for LV rehabilitation services was discretionary for Medicare Carriers, based on requests for reimbursement from providers; and such services were being reimbursed in only half of the states. A 2002 CMS memorandum directed Carriers to advise providers of the "incident to" coverage of LV rehabilitation services, including coverage of LVTs, VRTs, and OMSs. However, this order was rescinded in 2005, leaving physical therapists, occupational therapists and speech therapists as the only covered therapy providers.

Demonstration design and timetable

The purpose of the Demonstration is to examine the impact of standardized national coverage for vision rehabilitation services by OTs, certified LVTs, VRTs, and OMSs under “general supervision” of physicians, including services provided in the patient’s home. Six Demonstration regions were selected: the States of NH, WA, NC, and KS, and specific areas in and around the cities of New York and Atlanta. Under the Demonstration, Medicare providers in these regions are allowed to bill for up to nine (9) hours of LV rehabilitation services over the life of a beneficiary (later changed to 12 hours per beneficiary per year). The Demonstration began on April 1, 2006, and is scheduled to continue through March 31, 2011.

CMS developed reimbursement rates for the Demonstration using a Relative Value Units (RVUs) analysis that started with existing RVUs for two OT services and then calculated rates for the LVT, VRT, and OMS based on their salaries compared to OTs. CMS actuaries also estimated that the marginal costs of the Demonstration would not exceed the \$2 million per year Congressional limit, given the assumptions that only 0.4% of beneficiaries would use LV rehabilitation, that only half of their costs would be due to the Demonstration, and that beneficiaries could only receive 9 hours of LV rehabilitation in their lifetimes.

CMS awarded the contract to evaluate the Demonstration to Brandeis University. This report on beneficiary experiences is one of two qualitative studies of the LVRD’s implementation. The other is a study of nine providers who either participated in or considered participating in the Demonstration. The provider case study is contained in a separate report.

The beneficiary case study

The case study collected information from nine beneficiaries in the Atlanta area who had received LV services from the Center for Visual Impairment (CVI), one of the organizations participating in the Demonstration. Four of the beneficiaries were interviewed in their homes, one in a senior center, and the other four by telephone. The open-ended interview questions focused on beneficiary characteristics, the process of referral and care, the LV rehabilitation services they received, their experiences with these services and providers, and the effectiveness of the services.

Beneficiary characteristics

The nine respondents ranged in age from 70 to 95 years and included seven women and two men, six Caucasians and three people of color. The only income for four of them was Social Security and/or SSI. Five had received LV services through the Demonstration and four received them outside the Demonstration. Five lived with adult children, one lived with a spouse and adult children, one lived with a spouse, and two lived alone.

Seven of the nine had macular degeneration, two had glaucoma, and two had a detached retina. Six of the nine reported multiple diagnoses. One of the nine was treated at CVI but ultimately did not turn out to have an eye problem. The effects of the conditions on respondents' lives give meaning to the term "low vision": They were not blind because they could distinguish some objects, but the limits of their vision hampered their performance of many everyday activities.

Services received

Respondents described similar histories of service utilization leading up to their eventual referral to CVI. Typical providers included an ophthalmologist for the medical conditions in their eyes, a sub-specialist for retinal problems, and an optometrist for help with their vision. Some of their eye care physicians seemed to be well connected to LV services, while others did not refer patients to CVI even when patients asked if anything could be done with LV problems.

The respondents' experiences at CVI were uniformly positive. Everyone was offered a range of help that usually included the optometrist's exam, a visual device to help with activities such as reading or sewing (e.g., magnifying eyeglasses, a hand-held magnifier, a telescope, a bright light), home modifications (e.g., adding raised dots to appliances and training in how to use them), other aids from the CVI store (large-format checkbooks, video readers, talking clocks, canes), and home visits to install and train regarding other devices and aids. Other needs were recognized and met through a more consumer-directed approach in the CVI low vision store, e.g., one respondent recognized the need to know time upon seeing talking clocks in the store. Beneficiaries reported that the staff seemed to communicate and work as a team, and they all felt they were treated with respect.

Effectiveness of services

LV rehabilitation services are not designed to reduce the vision deficits of LV patients, but rather to help them function better with their vision limitations. Thus the effectiveness of LV services seemed to be a function of remaining vision. At best, LV services helped respondents function with their problems and address their main goal, e.g., reading or using a computer. At worst, the LV services offered some respondents help at the margin, e.g., ability to read newspaper headlines but not stories. Others found little if any relief.

Additionally, effectiveness was affected by two barriers to using LV rehabilitation services: the need to travel to the CVI offices and the cost of devices. All respondents relied on family members to bring them to CVI, and due to this reliance and to the distance to the offices, only one beneficiary made more than a single visit to CVI. All of the LV patients in the study received at least one device in their visit to CVI, but the costs of devices are not covered in Demonstration benefits. A CVI charitable fund was available to cover up to \$100 in devices, and this allowed beneficiaries to overcome this

barrier for the basic prescribed devices, but not for more expensive devices such as \$400 TV glasses and a \$1,600 desktop video magnifier for reading that some desired.

Summary

The beneficiaries who were interviewed illustrate the fact that diseases of the eye and the diseases' concomitant impacts on vision affect elders across the range of age, gender, and class. Some respondents had been living with the conditions for decades, while for others the conditions were more recent and progressing rapidly. Vision problems affected independence in daily living, particularly the ability to get around outside their homes, but also their ability to perform activities inside their homes that require strong and clear vision, e.g., close-up activities like reading and sewing and managing money, middle-vision activities like cooking, and distance vision to watch TV.

After exhausting their searches for cures from medical providers, at CVI beneficiaries found professionals ready to listen and assist them, devices that could enhance their remaining vision, as well as other aids in a store tailored to their needs. The basic service was paid for by their Medicare and by the agency's charitable funds. None of the respondents had enough remaining vision to fully meet their primary goals, most prominently being able to read without difficulty, but almost all found some help with reading, as well as in some other area of daily living.

Mindful of the limitations of the small and selective study sample, the experience of the respondents pointed to some shortcomings in the way the care system served beneficiaries. First, some medical providers were reported to lack knowledge of and referral relationships with LV providers. Second, the lack of coverage of devices and other adaptive items in the LVRD benefit was a barrier to receiving help for some beneficiaries, and the barrier would have been greater had CVI not covered devices through charitable funds.

I. Background on the Demonstration

A. Introduction

The purpose of this report is to present the results of Brandeis University's evaluation of beneficiaries' experiences of the Low Vision Rehabilitation Demonstration (LVRD). The LVRD was authorized by the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (P.L.108-173). Section 645 of the Act states:

(1) **STUDY.** The Secretary shall conduct a study to determine the feasibility and advisability of providing for payment for vision rehabilitation services furnished by vision rehabilitation professionals.

(2) **REPORT.** Not later than January 1, 2005, the Secretary shall submit to Congress a report on the study conducted under paragraph (1) together with recommendations for such legislation or administrative action as the Secretary determines to be appropriate.

(3) **VISION REHABILITATION PROFESSIONAL DEFINED.** In this subsection, the term "vision rehabilitation professional" means an orientation and mobility specialist, a rehabilitation teacher, or a low vision therapist.

Conference report language from the House bill extended the period for the Demonstration and added funding (U.S. House of Representatives, 2003):

This demonstration project should be conducted over a period of five years beginning July 1, 2004. The Secretary shall expend from available funds appropriated to him in FY 2004, including transfers authorized under existing authorities from the Federal Supplementary Insurance trust Fund, an amount not to exceed \$2 million for FY2004 to carry out this demonstration project.

In 2005 the Centers for Medicare and Medicaid Services (CMS) requested approval from the Office of Management and Budget to implement the Demonstration beginning in 2006 (Centers for Medicare and Medicaid Services, 2005). CMS interpreted the authorization language to mean that the Secretary was authorized to spend up to \$2 million annually to conduct and evaluate the Demonstration.

B. Traditional Medicare coverage of vision services

1. Vision impairment and vision rehabilitation services

Vision impairment is a significant and growing problem in the United States. In 2007, it was estimated that more than 3.6 million Americans age 40 and older had some level of vision impairment (including blindness) at a total cost of \$51.4 billion to the U.S. economy (Prevent Blindness America, 2008). The prevalence of impairment increases quickly after age 75 (Prevent Blindness America, 2008) and is expected to double overall during the next 30-years (Centers for Disease Control and Prevention, 2006). As a part of its *Healthy People 2010* initiative, the U.S. Department of Health and Human Services has set as one of its overarching goals an “increase in the use of vision rehabilitation services by people with visual impairments” (U.S. Department of Health and Human Services, 2000).

The primary purpose of low vision (LV) rehabilitation is to provide services to people with moderate-to-severe visual impairment skills that will help them live independently and improve their quality of life. These services include teaching skills such as meal preparation, shopping, and money management, as well as by providing training in safety procedures. Rehabilitation is also aided by enhancing remaining vision through the use of and training in devices, equipment and supplies, such as magnifiers, lights, prisms, telescopes, and large-font printed material. Vision rehabilitation may help prevent falls, burns and other accidents that may occur for vision-impaired people (Association for Education and Rehabilitation of the Blind and Visually Impaired, 2008). The traditional vision rehabilitation professionals work in three job categories: Vision Rehabilitation Therapists (VRTs - also called Vision Rehabilitation Teachers), Low Vision Therapists (LVTs), and Orientation and Mobility Specialists (OMSs).

In the mid-1990s, policy analysis pointed to shortcomings in the capacity of existing vision rehabilitation services to meet the needs of an increasing population of older people who were experiencing vision impairment. First, many state and private agencies required clients to be legally blind to receive assistance (Mogk, L., Watson, G., & Williams, M., 2008). Second, rehabilitation programs were designed to address the needs of younger clients. Third, most programs operated with small budgets and served only a small number of clients. Given the epidemiology of impaired vision among elders that shows that the number at risk is in the millions and continues to grow (Prevent Blindness America, 2008), there was growing concern that the LV rehabilitation system was not ready to meet the needs of older people with vision impairments.

2. Initial Medicare coverage of vision rehabilitation services

Beginning in the mid-1990s, ophthalmologists and optometrists successfully argued that Medicare regional Carriers should add codes for visual impairment to the list of existing Medicare rehabilitation reimbursement codes. This first occurred in Kansas, Michigan, Florida and Illinois (Mogk, L. et al., 2008). At that point, only three groups of professional therapists were recognized by Medicare and given provider numbers to be

used for independent service provision: physical therapists (PTs), occupational therapists (OTs) and speech therapists. Traditional low-vision rehabilitation therapists (LVTs, VRTs, and OMSs) were not recognized by Medicare. In order for these three groups of professionals to be reimbursed for their services, they were required to work directly with physicians. At the time, their work could be billed to Medicare “incident to” a physician’s services (using the physician’s Medicare billing number), and their rehabilitation services could be provided only at the physician’s practice location (Mogk, L. et al., 2008). By 2002, Medicare was providing reimbursement for low vision rehabilitation services in 26 states under the "incident to" provision.

In May of 2002, CMS formalized Medicare coverage of LV rehabilitation through a Medicare Program Memorandum (Transmittal AB-02-078, issued May 29, 2002), which made reimbursement for LV rehabilitation a local coverage decision for Medicare Carriers (Centers for Medicare and Medicaid Services 2005). The Memorandum directed Carriers to inform physicians and other providers about the availability of medically necessary rehabilitation services for visually impaired beneficiaries. The Memorandum stated that LV rehabilitation could be covered when delivered under the direct supervision of the physician or, “incident to” a physician’s professional service by OTs, PTs, or other LV rehabilitation professionals. Under “incident to” rules the physician must be present “on the premises” during the delivery of LV rehabilitation services.

In June 2005, CMS issued a clarification to Carriers that removed LVTs, VRTs, and OMSs from the list of providers that could be reimbursed under the "incident to" provisions (Mogk, L. et al., 2008). As of July 25, 2005, LV rehabilitation could be provided only by OTs and PTs under direct supervision, or “incident to” a physician’s professional services, but not by certified vision rehabilitation professionals and not in the patient’s home (Centers for Medicare and Medicaid Services, 2005).

C. Legislative authorization to demonstrate expanded coverage

Congressional interest in testing expanded coverage of LV rehabilitation services under Medicare was evident in bills introduced in both the House and the Senate between 1999 and 2003. They included:

- The Medicare Vision Rehabilitation Coverage Act of 1999 (H.R. 2870) was introduced on September 15, 1999 by Representative Capuano of Massachusetts and cosponsored by 120 other House Members. It was meant to “amend title XVIII of the Social Security Act to provide coverage of vision rehabilitation services under the Medicare Program.” No action was taken on this bill.
- The Medicare Vision Rehabilitation Services Act of 2001 (H.R. 2484) was introduced on July 12, 2001 by Representatives Capuano of Massachusetts and 135 other House Members. It was meant to “amend title XVIII of the Social Security Act to improve outpatient vision services under Part B of the Medicare Program.” A similar bill was introduced in the Senate (S. 1967) on February 26,

2002 by Senator John Kerry of Massachusetts along with 13 cosponsors. No action was taken on either bill.

- The Medicare Vision Rehabilitation Services Act of 2003 (H.R. 1902) was introduced on May 1, 2003 by Representative Foley of Florida and had 79 cosponsors. A bill of the same name was introduced in the Senate (S. 1095) on May 21, 2003 by Senator Sununu of New Hampshire along with 18 cosponsors. No action was taken on either bill.
- On December 8, 2003, the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 became Public Law 108-173. Section 645 of the law authorized a demonstration study relating to vision impairments. The Conference Report on the House bill (H.R. 2673) authorized funds for the Demonstration. These two bills were described in Section A Introduction of this report on page 1.

D. Demonstration design and timetable

The bill introduced by Senator Sununu in 2003 (S. 1095) that would have provided low vision rehabilitation services to Medicare beneficiaries was used by CMS as the "blueprint" for the LVRD (Centers for Medicare and Medicaid Services, 2005). CMS entered into a contract with the Cornell University Institute for Policy Research to assist in the detailed design of the Demonstration. In addition, CMS received input from stakeholder groups, such as the National Vision Rehabilitation Association.

According to the final design, the purpose of the Demonstration is to examine the impact of standardized national coverage for vision rehabilitation services provided in the patient's home by physicians, OTs, certified LVTs, VRTs, and OMSs (Centers for Medicare and Medicaid Services, 2006). The Demonstration allows the latter three previously unqualified professionals to be reimbursed by Medicare for rehabilitation services under "general" medical supervision, that is, the services could be provided outside the office setting under a care plan signed by a physician.

To implement the Demonstration, CMS developed reimbursement rates for LV rehabilitation services using a Relative Value Units (RVU) analysis that started with existing RVUs for two OT services (sensory integration and self care/home management). Next, salary data were collected for OTs, VRTs, OMSs, and LVTs. The ratios of the salaries of the latter three groups to the salaries of OTs were used to calculate reimbursement rates for three new LV specialists. The resulting reimbursement rates for 15-minute service units for the four groups in 2005 were as follows:

OT: \$28.04
OMS: \$14.97
LVT: \$14.97
VRT: \$12.81

There were no new reimbursement rates for the Demonstration for optometrists, so participating optometrists used existing billing codes. Also, existing reimbursement

codes for OTs, which paid at higher rates than the Demonstration's OT code, remained available.

The final Demonstration design includes six geographic areas that take into account the diversity of the population in need, cost, and available professional resources. The six areas are the states of New Hampshire, North Carolina, Washington, and Kansas, and the metropolitan areas of New York City and Atlanta, Georgia. In Demonstration areas, CMS waived an existing "incident-to" rule in order to enable LV specialists to provide physician-prescribed LV rehabilitation services in beneficiaries' homes or other appropriate settings under general physician supervision. These specialists must be certified by the Academy for Certification of Vision Rehabilitation Professionals and may only provide services specified in an individualized written plan of care developed by a qualified physician or occupational therapist in private practice (Centers for Medicare and Medicaid Services, 2006).

In order to participate in the LVRD, beneficiaries must:

- Be enrolled in Medicare Part B fee-for-service coverage.
- Not be enrolled in a Medicare Advantage plan.
- Have an established medical diagnosis of moderate to severe and profound visual impairment (20/60 to 20/200 vision).
- Have an established individualized plan of care written by a physician (including ophthalmologist or optometrist) or occupational therapist in private practice (must be reviewed every 30-days).
- Be able to derive benefit from vision rehabilitation therapy.
- Live in one of the Demonstration areas.

CMS actuaries estimated that these Demonstration areas and eligibility criteria would yield approximately 147,000 Medicare beneficiaries who might benefit from LV rehabilitation services (Centers for Medicare and Medicaid Services, 2005). This was based on an estimate that 4.7% of the Medicare population would be eligible for LV rehabilitation services. Actuaries also estimated that only 7.8% of the eligible beneficiaries would use LV rehabilitation services and that only half of the Medicare costs incurred would be due to the Demonstration, primarily due to a small increase in the number of providers and to the provision of services in the home. Given these assumptions, the reimbursement rates for new Demonstration services, and the initial limit on Demonstration services to 9 hours per lifetime, the actuaries estimated that the Demonstration costs would not exceed the set limit of \$2 million per year.

The Demonstration began on April 1, 2006, and is scheduled to continue through March 31, 2011, for a total of five years (Centers for Medicare and Medicaid Services, 2006).

E. Evaluation design and revision

In September 2005 CMS awarded a contract to evaluate the Demonstration to Brandeis University in partnership with the New England Research Institute. The initial LVRD evaluation study included both qualitative and quantitative assessments. The quantitative study included a quasi-experimental study of utilization and costs using claims data. The study also included a beneficiary survey to determine satisfaction and outcomes, and a qualitative component of multiple site visits to understand the implementation process (Bishop, C. E. et al., 2004).

Due to the low uptake of the Demonstration, in early 2008 CMS requested that the initial evaluation design be changed to focus on qualitative studies of the LVRD's implementation. A redesign calling for case studies of nine organizations and nine beneficiaries with LV conditions was finalized in June 2008. The methods and findings from the evaluation of beneficiaries' experiences are described in the next chapter. The findings from the provider case studies are found in a separate report (Leutz et al., 2009).

II. Evaluation of the Experiences of Beneficiaries

A. Methods

This section details the methods for the beneficiary case study, including the study questions, the sample selection methods and the sample, and the data collection and analysis methods.

1. Study questions

The study questions focused on beneficiary characteristics, the processes of referral and care, the LV rehabilitation services beneficiaries received, their experiences with these services and providers, and the effectiveness of the services. The report is organized to address these questions in turn.

a. Beneficiary characteristics. Is there a varying degree of severity or length of impairment among participating patients?

b. Services received. What types of LV rehabilitation services do patients receive? Are there differences in the types of LV rehabilitation services offered across types of providers and types of patients? Where do patients receive their services? Are there differences in perception of services related to in-home care versus “incident to” services? Do beneficiaries use services that are not paid for by Medicare? If yes, who pays for these services?

c. Experiences with providers. How do patients experience their care from LV rehabilitation providers and physicians? Do the types of experiences differ by type of provider? Do the experiences differ by type of patient (e.g. racial/ethnic group, severity and type of vision impairment)? Do these experiences change over the period of the LVRD? Is there a difference in the nature of the interaction between patient and provider across types of providers and patients?

d. Effectiveness of services. Are beneficiaries’ needs for rehabilitation services addressed? What are the barriers and facilitators for patients in using rehabilitation services? How are barriers addressed?

2. Selection of beneficiaries

The study design called for a qualitative study of fewer than 10 beneficiaries with a diagnosis of low vision who had either used or not used LV rehabilitation services under the Demonstration. The design stipulated that interviews would be conducted in a single service area. Given the difficulty of identifying and contacting beneficiaries who need LV rehabilitation but who do not receive it, the study included only beneficiaries who had received LV rehabilitation services. By including only beneficiaries who had

received LV rehabilitation services, the sample increased the number of perspectives on the use of those services. However, by not including beneficiaries who need LV rehabilitation but who do not receive it, the perspectives of those who do not use these services (whether due to lack of knowledge, lack of access, choice not to use the services, or whatever) are not included in the study.

The beneficiary respondents were selected with the assistance of a LV provider participating in the Demonstration in Atlanta, the Center for Vision Impairment (CVI). The evaluators asked CVI to identify Medicare beneficiaries among their patients who had recently used CVI's LV services, including both Demonstration participants and non-participants. The evaluators helped CVI prepare a letter introducing the study. CVI mailed the letter to patients and then followed up with a phone call to determine interest in being interviewed. Through this process, CVI identified 10 patients who accepted the offer to be interviewed, split evenly between participants and non-participants. CVI provided the evaluators with their names, phone numbers, and addresses. Given the small numbers in the sample, the selection of sample members by a provider, and the lack of non-users, there are limits to how much the findings cannot be generalized to the broader population of Medicare beneficiaries with LV problems.

3. Data collection and analysis methods

The evaluators developed a guide for a 30-minute to 60-minute interview. Besides gathering basic demographics about beneficiaries, interview questions were mostly open-ended and designed to address the study questions. Verbal consent procedures assured confidentiality to beneficiaries and also advised them of the purposes of the study, the voluntary nature of the interview, and the fact that refusing to participate would not jeopardize their services under Medicare or from CVI. No material compensation was offered or provided for participation. The procedures were presented to the Brandeis University Institutional Review Board for the protection of human subjects and approved. The approved interview guide, including the opening verbal consent questions, is found in Appendix A.

Interviews with beneficiaries were conducted in October 2008. Nine of the ten beneficiaries contacted agreed to be interviewed. Five beneficiaries were interviewed in their homes or in a community setting during the evaluation team's visit to interview CVI staff. The other beneficiaries were interviewed soon after the site visit by telephone. Beneficiaries' responses, as well as observations, were recorded through detailed notes taken during the interviews, with additional observations recorded soon thereafter. Two staff members were present for most interviews - one conducting the interview and the other taking notes. The notes were transcribed into word processing files for analysis. After all the interviews were conducted, the notes from all interviews were re-organized into matrices according to study questions. Responses were analyzed and synthesized to convey the nature, range, and tendencies of responses. The results of these analyses are presented in this report. Additionally, each of the respondents is presented as a brief case study, which summarizes his or her demographics, eye health and vision problems, service use and experience with providers, and outcomes from LV rehabilitation services.

A few details not relevant to interpretation and findings have been changed in each case to thwart any attempt to identify individuals. The individuals are presented in Appendix B.

B. Findings

1. Beneficiary characteristics

Five of the beneficiaries who were interviewed were participants in the Demonstration, and four were not. In all areas of the interviews there was nothing that distinguished the participants from non-participants, including the respondents' conditions, services received, knowledge of the Demonstration (essentially non-existent among all of them), or how services were paid for (similarly, none knew much if anything about whether Medicare had paid or not). As described below, this may be due to the fact that CVI has funds to pay for both LV services and devices for their patients, and some Medicare beneficiaries were billed to Medicare and others expensed to CVI accounts. The CVI policy was to make services accessible, and these respondent beneficiaries experienced easy access.

a. Demographics. The respondent beneficiaries ranged in age from 70 to 95 (mean age 80) and included seven women and two men (see Appendix B for sketches of each). Six identified themselves as white, two as black and one as mixed race. All nine had income from Social Security. Three had Social Security as their only income. One received SSI as well as Social Security. One had Social Security as well as income from investments, and the other four had Social Security plus pensions (from teaching, the military, the VA, and a deceased husband). All said English was their primary language.

Most respondents lived with others: Five lived with adult children, one lived with a spouse and adult children, and one lived with a spouse. The other two lived alone. Of the five living with adult children, two occupied in-law suites in single-family homes. Of the two living alone, one lived in assisted living and also had a son and daughter-in-law who lived nearby and provided help. The other lived in her own home and had a son and a daughter who lived nearby, who provided some help with transportation to medical appointments. The respondents living with adult children all reported that they received help around the home, with shopping, and transportation to medical appointments.

b. Severity/type of patient impairment. The respondents reported a range of conditions that led to their visual impairments, and six of the nine reported multiple diagnoses. Seven of the nine had macular degeneration, two had glaucoma, and two had a detached retina. Three have had surgeries for cataracts. One of the nine ended up in the sample because she was seen in CVI after a referral for an eye problem, even though she ultimately did not have an eye problem.

The length of time since respondents were diagnosed with their conditions varied from 2 years to 35 years (median of 15 years/mean of 14 years). The effects of the conditions on

respondents' lives illustrate the meaning of the term "low vision." They were not blind because they could distinguish some objects, but the limits of their vision hampered their performance of many everyday activities. Only one could still drive, and she felt unsafe and limited herself to light traffic. All could get around in their homes, but they were in danger of tripping, and most had difficulty cooking, reading buttons on appliances, and watching television. The most common and pressing problem that they reported was difficulty reading.

2. Services received

a. Types of services. The providers interviewed in the service delivery part of the case study described their low vision services as essentially "the end of the line" for beneficiaries with vision problems. That is, after medical interventions no longer hold any hope of improving a patient's vision, the patients are appropriately referred for LV services to see what kind of adaptations can be made to enhance what vision is left and/or to adapt their environment to help them perform activities. All of the eight respondents with eye conditions described a similar history of service utilization leading up to their eventual referral to CVI. All had a regular ophthalmologist for the medical conditions in their eyes, as well as sub-specialists for retinal problems. Most respondents also saw optometrists for help with their vision. Visits with these providers were generally described as regular over the course of their illnesses. Most of the physicians worked in private practices, but at least two respondents received services in medical centers.

Respondent pathways to CVI indicated that some of their eye care physicians were well connected to LV services, while others were not. Four of the respondents indicated that their regular ophthalmologists referred them to CVI on their own or when the respondent asked if anything else could be done for their low vision. However, three described scenarios in which they asked their ophthalmologists repeatedly if there was anything to help them, and they were told, to paraphrase several, "there is nothing more to do." One of the three received the CVI referral from an ophthalmologist who was not her regular physician, another from her regular optometrist who provides glasses, and another by driving by CVI with her daughter, who saw the CVI sign. It was not clear how one of the respondents found CVI. The one patient who had pain in her forehead and eyes, but ultimately was found not to have problems with her eyes (respondent #7 in Appendix B), ended up seeing eye care doctors along a frustrating pathway of referrals.

The respondents' experiences at CVI were uniformly positive in terms of how they were treated, what services were available, and how well services were coordinated. Everyone was offered a range of help that usually included the optometrist's exam, a visual device (e.g. magnifying eyeglasses, a hand-held magnifier, a telescope, a bright light), home modifications (e.g., adding raised dots to appliances and training in how to use them), other aids from the store (large-format checkbooks, video readers, talking clocks, canes), and home visits to install and train regarding other devices and aids.

The respondents all appreciated the help and the ideas, and they all felt very well treated, but most were also disappointed that their low vision needs persisted. At best, LV

services helped them function with their problems and address their main goal, e.g., reading for respondent #5, or using a computer for #8. At worst, the LV services offered help around the edges, e.g., ability to read headlines but not stories (#3), or little if any relief at all (#1).

b. Place of service. The standard sequence of services for these beneficiaries was to begin with the eye exam at CVI, followed usually by orientation to a device by a LV specialist, followed by a visit to the LV store. Follow-up services in the home were offered to three of the respondents, and two accepted. Most of the respondents did not feel they needed in-home services, based on the fact that they still had enough vision to see to get around inside their homes. Most also had family members to help them, and some had already made some environmental adaptations, e.g., raised dots on appliances. Respondents knew about follow-up services at CVI, but no one had come back except one man attending classes on using a computer. Besides coming back to purchase more elaborate and expensive devices, none saw a reason to go back in the immediate future.

c. Payment for services. It was difficult to obtain accurate information from the respondents about how CVI's services and devices were paid for. Some were confused, and others did not handle their own bills. No one remembered paying CVI for the care received by the optometrist or LV professionals, and none remembered being billed for Medicare coinsurance. All either received or were offered some kind of free device, e.g., a monocular or a hand-held lighted magnifier. Most also bought something else in the CVI store, and several saw something else they wanted but could not afford, such as a desktop video magnifier costing about \$1,600.

3. Experiences with providers

a. Patients' experience with care from LV rehabilitation providers and physicians. Respondents had a great deal of experience with medical providers (mainly ophthalmologists), and they have worked closely with them to treat and slow the progression of their illnesses. But medical providers were not described as having helped respondents accommodate to their vision problems, and in this sense their experience with LV providers at CVI was very different. The LV providers focused on the vision respondents had and tried to help them use it through devices, advice, and training. Respondents appreciated the LV providers' patience and willingness to listen and take the time to help. The patients also enjoyed shopping in a large store that caters to people with vision problems, offers a wide range of products, and is staffed by helpful people.

b. Differences by provider type and patient characteristics. In discussing experiences with LV providers, most respondents focused on the exam and the ways the optometrist introduced devices. Some also described working with another staff member after the exam, who helped them more thoroughly to choose a device and learn to use it. However, they did not mention the low vision therapist's title. Two patients did mention home visits by a vision rehabilitation therapist and an orientation and mobility specialist, and another knew she had talked to a social worker. The important thing to the beneficiaries was that the staff seemed to communicate and work as a team, and the

respondents all felt they were treated with respect. This was true whether or not beneficiaries came away feeling that they had received help that relieved their vision problems.

c. Change in experience over time. There was no way to know from the interviews whether beneficiaries' experiences changed over the period of the Demonstration. The respondents were interviewed about half way through the Demonstration, and all but one had only one visit to CVI.

4. Effectiveness of services

a. Rehabilitation needs met and unmet. The respondents described thorough and professional efforts on the parts of the LV providers to assess their vision problems and remaining capabilities, to find devices and use training to maximize the use of the vision they have, and to help them perform tasks and get around safely in their homes. Every respondent expressed a desire to read, and this need was met through devices for most respondents, if only to use a large format checkbook, or a hand-held magnifier to read a label in a store or a newspaper headline. Only a few could still read books or magazines, and then only with difficulty. Some did not have enough remaining vision to read at all. The need to use home appliances was met for several through the application of raised dots, which was done by CVI staff in some cases and family members in other cases. Only one respondent expressed a desire for help to see things clearly in the distance, but he could not afford the special glasses he was shown. Other needs were recognized and met through a more consumer-directed approach in the CVI low vision store, e.g., one respondent recognized the need to know time upon seeing talking clocks in the low vision store.

b. Barriers to services. The two biggest barriers to using LV rehabilitation services were travel to the CVI offices and the cost of devices. CVI serves the entire Atlanta metropolitan area, and some of the respondents had to travel as much as 50 miles to get there. The barrier was overcome through assistance from their families, and even respondents who lived close by needed help traveling to the center. Distance barriers were overcome by these beneficiaries, but the inability to travel independently would be more of a problem for those without friends or family to help, and it was also a barrier to return visits.

The more important barrier was the cost of devices, which are not covered in the Demonstration. Fortunately, CVI has a fund to pay for up to \$100 worth of devices, which was used by all respondents. Without this, several of the lower income respondents would likely have come away from their visits without the monocular and/or the lighted, hand-held magnifier that seemed to be the basic prescription for CVI patients. The cost of additional and more expensive devices was a barrier for most respondents. Some were able to purchase less expensive aids, e.g., \$110 talking clocks, but several had seen items they wanted but could not afford, e.g., \$400 TV glasses and a \$1,600 desktop video magnifier for reading.

III. Summary

The beneficiaries who were interviewed illustrate the fact that diseases of the eye and the diseases' concomitant impacts on vision affect elders across the range of age, gender, and class. Macular degeneration was the most common condition in the sample. Glaucoma, detached retinas, and other diagnoses were also reported. Some respondents had been living with their conditions for decades, while others reported more recent onset of conditions and more rapid progression of effects on their vision.

Vision problems affected the beneficiaries' independence in daily living, particularly their ability to get around outside their homes. Also affected were their abilities to perform activities inside their homes that require strong and clear vision, e.g., close-up activities like reading and sewing, middle-vision activities like cooking, and distance vision to watch TV. In summary, vision problems tended to affect their IADLs (shopping, cooking, cleaning, money management, traveling outside the home, using the telephone, and medication management), much more than their ADLs (bathing, dressing, using the toilet, transferring, and eating). To get the help they needed, five of nine were living with adult children, two lived with spouses, and one had moved to an assisted living facility.

The respondents relied on specialists for treatment of their eye conditions - sometimes two or three different specialists. Because this was a sample of low-vision patients, all were nearing the end of treatments to stop the decline in their vision. Some respondents said their doctors gave them the message that there was nothing more that could be done. Other doctors knew about the CVI, the largest LV provider in the area, and referred their patients there.

At the CVI beneficiaries received the message that something could be done to help them, and they were closely assessed for the nature of their visual impairments and the nature of their remaining vision. They found the professionals ready to listen and to assist them. In addition, they found devices that could enhance their remaining vision, as well as other aids in a store tailored to their needs. The basic service was paid for by Medicare and by CVI's charitable funds.

None of the respondents had enough remaining vision to fully meet their primary goal of being able to read without difficulty. However, almost all of the respondents reported receiving some help with reading and daily living. For most respondents, the single visit to the CVI was sufficient for the time being, and only two accepted the offer of a visit to their home by a LV rehabilitation professional to help adapt their environment. One came back to the center regularly for classes. One-stop shopping was important, because traveling to the center was not easy due to distance and the need to rely on family, and coming away with help from that visit was facilitated by a CVI fund that paid for basic devices.

Finally, given that this study was based on interviews with just nine beneficiaries in one metropolitan area who used the services of a particular LV provider, it is not appropriate to use findings to recommend whether or not Medicare should offer LV rehabilitation services. However, two areas stand out as ways in which the help that these beneficiaries received could have been improved. First, some medical care providers seemed to have little knowledge of and limited referral relationships with LV rehabilitation providers. Had these providers made referrals on their own and earlier, their patients may have experienced less frustration looking for help and received LV rehabilitation services in a more timely manner. Second, the lack of coverage of devices and other adaptive items in the LVRD benefit was a barrier to receiving help for some respondents. This barrier would have been greater had CVI not covered a modest amount of devices through charitable funds.

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Appendix A: Interview Guide

Interview guide for beneficiaries

Introduction

Thank you for agreeing to talk with us. Let me cover just a few things before we start.

We are working for the federal government on an evaluation of a Medicare demonstration program about low vision services. The questions we'll cover in the interview are about the types of low vision impairments you have, the treatments you have received from doctors and other rehabilitation providers, and your views of how well you have been taken care of, and how much the services have cost you - if anything.

When we write up the study, we will not use any names of respondents, so what you tell us is completely confidential. Whatever you say, it will not affect your Medicare benefits. Also, I need to be sure that you understand that this interview is voluntary on your part. You do not need to do this, and if you do agree to start, you can stop at any time if you want.

Given that background, are you willing to go ahead with the interview? (Proceed only if the respondent agrees.)

Thanks again for agreeing to take the time to talk to us. First I have a few questions about your home situation.

Personal

1. Do you live with someone or do you live alone?

(If not determined) - Are you single, married, widowed, divorced?

2. (If not obvious) - What type of place do you live in - a condo? Apartment? Assisted living? Other? (Explain if other)

Medical

Next I have quite a few questions about your vision and the services you use,

3. Can you tell me about your visual impairment?

PROBES:

What is the source or illness?

How is your vision affected?

How severe is the impairment?

4. How does your impairment affect your daily living? (ex: chores, getting around safely, social interactions with others)

5. How long have you been impaired?

Services

6. Over the last two years, what kinds of professionals have you seen for your vision impairment? What did they do for you?

PROBES:

Do you see an optometrist?
optometrist done?

Y N

IF YES: What has the

Do you see an ophthalmologist?
ophthalmologist done?

Y N

IF YES: What has the

Do you see an occupational
therapist or OT for help?
done?

Y N

IF YES: What has the OT

Do you see a LV
rehabilitation specialist for help?
rehabilitation specialist done?

Y N

IF YES: What has the LV

Do you see an OMS for help?
done?

Y N

IF YES: What has the OMS

7. Did any of these providers seem to work together - or not?

PROBES: Who?

How did they or did they not work together?

8. How would you describe your experience and your interactions with these professionals?

LIST PROFESSIONALS SEEN, IF ANY:

PROBES: (Ask for each professional seen from last question)
For example, did they treat you with respect?
Did they listen to your issues?
Did they explain things well?
How were they most helpful?

9. Were your needs for rehabilitation services addressed?

LIST PROFESSIONALS SEEN, IF ANY:

PROBES: (Ask for each professional seen from last question)
How yes and how not?

(If the beneficiary saw an OT, OMS, VRT, or LVT): Did you see the (MOS, OT, LVT, or VRT) in the office or at home?

(IF BOTH): What did you like and not like about seeing a provider in one place versus the other place?

(IF NO HOME VISIT): What do you think about the idea of seeing your providers at home?

10. Over the last two years, have there been any changes in the help you have received with your vision impairments?

PROBES (If yes, specify):
Any new services or providers?
Any changes in place where you get treatment?
Any change in the type of services you've received during the last two years?

Any change in how well the treatments worked for you?

11. Have there been things that have made it difficult to get the services you believe you need?

PROBES:
Like travel problems?
Costs?
Confusion about what you're options are?
Problems getting things arranged? (i.e. scheduling appointments)

Providers not showing up when they are supposed to?
Personal difficulties like illness or fatigue?
Anything else?

12. Are there things that have helped you get around any of these difficulties?

Payment

I have just a few questions about how services get paid for.

13. Do you have insurance that has helped you pay for these services?

PROBES:

How about Medicare? Is there a copay or deductible that you have had to pay?

14. Did a private Medicare supplement like Medigap or an HMO help you pay for treatment?

(IF YES): Do you know how much they helped you pay?

15. How about Medicaid? Do you have Medicaid?

IF YES: Do you know if Medicaid helped pay?

IF YES: Do you know how much Medicaid helped pay?

16. Do you know if any other program helped pay for your low vision services? IF YES: Which one and what did they pay for?

Personal

I just have a few more questions.

17. Can you tell me how old you are?

18. Do you have Social Security?

19. Do you have any income beyond Social Security? IF YES: What?

20. What race or ethnicity would you say you are?

21. Is English your primary language? IF NOT: What is?

22. Thanks again for taking the time to talk to us. Is there anything you would like to add?

Appendix B: Respondent Profiles

1. Female Participant, age 70

She developed uveitis, an inflammation of the middle layer of the eye, after a piece of metal deflected into her eye 15 years ago on her job as a physical therapist. She hasn't worked since. She has developed other problems, including a torn retina, and can barely see the outlines of people. She lives with a daughter in a condo for part of the year and with a son in another state for part of the year. In terms of providers, she has "seen them all" - ophthalmologists, optometrists, and retina specialists, but none of them seem to know the origin of her eye problems, especially the chronic infections. She was referred to CVI by her out-of-state physician. The CVI optometrist said she could buy glasses but the glasses would not help her with the activities she wanted to do. CVI gave her a monocular, and an orientation and mobility specialist came to her house and put dots on appliances. She is unhappy with her situation: that no one can help her see better, that CVI does not have classes, and that they don't offer transportation. Her only income is from Social Security, and she is in a Medicare HMO. She normally pays a \$75 copay for eye exams, but she does not remember paying for the CVI visit.

2. Female Participant, age 89

She has macular degeneration that was diagnosed 18 years ago. A more recent stroke left her with limited movement in her arms. Her vision impairment affects everything. She is afraid of falling. Glasses help some, and she can read large print books. Her son and daughter-in-law live nearby and help her a lot. They take her regularly to her ophthalmologist, but he says there is nothing he can do. She got her glasses from an optometrist who told her about CVI. CVI recommended a few more things, including a lap table and a monocular she uses when she reads, but reading is still difficult. She has Medicare and a Medicare supplement. She has Social Security and income from investments and is currently in the Medicare Part D "donut hole" and paying for eye drops that cost \$100 a bottle. She was not clear who paid for the CVI services.

3. Female Participant, age 95

She was diagnosed in 1993 with glaucoma, which has since advanced, and she now has early macular degeneration. She lives in an apartment in her daughter's house. She can see big things like furniture, but she has trouble with steps and curbs. She cannot use the stove or dishwasher or anything that is very detailed. She has seen her ophthalmologist for 10 years, as well as a retina specialist. The former suggested that she go to CVI, where she received useful suggestions, for instance, how to fold the newspaper and follow lines with the lighted magnifier they gave her. But in the end she still has difficulty reading, because she can only view one word at a time. Another problem is that she needs to hold the magnifier in one hand, which limits her ability to do activities that require both of her hands. She went back to CVI hoping for a device that she did not need to hold. She said the therapist was "most helpful" and let her try a few devices but none worked for her. She liked the reading machine she saw in CVI's store, but it cost \$1,600. Besides Social Security, she has a small pension. She has no Medicare supplement and does not know if she paid a copay for the CVI visit.

4. Male Participant, age 79

He developed macular degeneration three years ago, and two years ago he lost his left eye completely. The problems affect his balance. He lives with his wife in an apartment in his son's basement. He asked several doctors and nurses he saw to help him get a strong magnifier, but no one could tell him where to get it. Finally, a retina specialist sent him to CVI. The CVI eye doctor worked with him to choose a 6X magnifier/light and TV glasses tailored to the distance from his chair. The \$100 cost of the magnifier was paid by a CVI fund, but he could not afford the \$400 TV glasses. The doctor also gave him a portable magnifier that he uses in stores. In the CVI store he bought a talking clock radio that gives the time and weather when you push it (\$110), a large format check register, a shaving mirror (\$8), and some dark felt-tipped pens. He is saving for a \$1,600 projector that he saw. Besides Social Security, he has a military pension and a military supplement to Medicare. He is not clear how the CVI visit was paid for.

5. Female non-Participant, age 92

Eight years ago she was diagnosed with a detached retina in her left eye (the result of a scratch during cataract surgery) and macular degeneration in her right eye. She has no vision on the left and is close to losing center vision on the right. She lives in her house with her daughter. It is difficult for her to read and cook, and she bumps into things and stumbles. Last year she fell down the stairs and broke her ankle. Her regular doctor and her ophthalmologist said nothing could be done about her vision, but her retina specialist recommended CVI. The CVI optometrist recommended better reading glasses and a better hand-held magnifier, and the therapist helped her to use them along with a bright light and a clipboard for up-close reading. The social worker told her about other programs and support groups. CVI staff has been helpful answering questions on the phone after the visit, and she and her daughter wish CVI was closer than 40 miles. She has a small pension beside Social Security, and she has no supplement to Medicare. She does not remember paying a copay for the CVI visit, and the devices she received were paid for by a CVI fund.

6. Female Participant, age 81

She was diagnosed with macular degeneration two years ago, and her vision is declining rapidly. She has no peripheral vision and must move things very close to read. She lives with her son in a townhouse, and her other children also help out. She gets around inside, but her son has to cook or help her cook. Her biggest complaint is no longer being able to read the Bible every day. An ophthalmologist sent her to CVI, where she got an exam, magnifying reading glasses, and a talking clock for free. She has tried the glasses but they give her terrible headaches so she no longer uses them. She regrets that "I had to put my Bible down." CVI offered to have someone come to read to her, but she turned that down. She has the New Testament on tape, and her daughter is going to get her the Old. Despite the problems with the glasses, she felt respected and listened to at CVI, and explanations were good. Most helpful was that the CVI worker was visually impaired. She has Medicare and Medicaid, and she never saw a bill from CVI (although she suspects her daughter might have paid). Her only income is Social Security.

7. Female non-Participant, age 77

She ended up in the sample because she was treated at CVI, even though she has since learned she does not have eye problems. Rather, her problem is severe headaches that started less than a year ago and that cause pain in her forehead, eyes, and nose. The pain does not affect her daily living except that she has to walk around with her hand on her head. She lives in her house with her daughter and grandchildren. To address her problems she has gone from her physician to an optometrist who found no vision problem, to an ophthalmologist who thought the pain was from her neck, back to her primary care physician, and finally to a chiropractor who has not yet resolved her problem but is costing more than she can afford. Her small income comes from Social Security and SSI. She has both Medicare and Medicaid, but she reports that none of the providers will accept them for payment. She has no money to pay for the care, so she did not ask any of the providers for more help.

8. Male non-Participant, age 78

He was diagnosed with macular degeneration 30 years ago and more recently developed temporal arteritis, a painful inflammation of the arteries along the sides of the head. He cannot drive, shop or cook, and it is difficult for him to read. He lives with his wife in their house. Both his ophthalmologist and a hospital eye clinic said there was nothing they could do to help. He found CVI when his daughter saw the CVI sign while driving through Atlanta. The CVI exam did not yield any new diagnoses or devices, but CVI told him about its program to train people to use a magnification software program to prepare people with vision problems to go back to work. CVI allows him to attend the classes for a \$100 contribution toward the usual \$400 fee. He can now use his computer and the internet, but his vision blurs after 30 minutes. He refused CVI's offer for in-home help, but he has followed their suggestions for stick-on bumps so he can feel the on/off buttons on appliances. He bought these and a pair of sunglasses that he is happy about. The only source of income for him and his wife is Social Security, and they do not have any Medicare supplement. He does not remember paying for the CVI visit.

9. Female non-Participant, age 77

She lost central sight in her left eye 12 years ago from a hole in the macula, and now she is losing peripheral vision in the same eye due to glaucoma. She has half of her vision in her right eye due to macular degeneration, which has recently moved from dry to wet. This means that the blood vessels behind the retina are bleeding, which can quickly cause blindness. She has had monthly injections of Lucentis for two years, which has slowed the decline. She lives alone in her house and can see enough to watch her large screen TV and also to drive short distances when traffic is light. Her children take her to medical appointments. She sees an optometrist for glasses, one ophthalmologist for the glaucoma and another for the macular degeneration. The latter referred her to CVI, where she bought some glasses to watch TV (they haven't worked very well), large letters to paste on her keyboard (good), and bumps on her appliances set up by a CVI vision rehabilitation therapist (VRT). She already had a magnifier and a 2-foot by 2-foot white board with lines and large print phone numbers. She has income from Social Security and her deceased husband's pension. Medicare and a supplement pay for medical visits but not the \$1,000 deductible for the \$2,000 Lucentis injections. She was not asked to pay for the CVI services.