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**Evaluation of the Home
Health Independence
Demonstration:**

**Evaluation of the Home
Health Independence
Demonstration: Barriers
to a Successful
Experiment Were
Multifaceted, and
Difficult Policy Issues
Remain**

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EXECUTIVE SUMMARY

Under Section 702 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2002 (P.L. 108-173) Congress mandated that the Secretary of the Department of Health and Human Services undertake a demonstration of a change to the Medicare home health benefit eligibility criteria regarding homebound status. CMS was to study the impact of the change in the following areas: how much the change would cost, how large a population would qualify under revised eligibility criteria, and what proportion would qualify of those who already receive Medicare home health benefits under the present definition of *homebound*. However, only 58 beneficiaries enrolled in the demonstration—far fewer than the Congressionally imposed limit of 15,000. Therefore, to guide future policy, this report seeks to explain why so few beneficiaries enrolled, what the experiences were of those who did enroll, and how the home health agencies currently view the homebound restriction.

THE MEDICARE HOMEBOUND REQUIREMENT

The Medicare home health benefit was originally designed to meet an individual’s post-hospitalization needs. When the legislation was written, a beneficiary could receive home health care only after a hospital stay. The homebound requirement was instituted as a cost-containment measure—once a beneficiary was well enough to travel, the beneficiary would receive care in an ambulatory setting. Over the years, the benefit was changed so it is no longer just a post-hospitalization benefit, but the homebound requirement has remained in place.

Under the current regulations, in order to receive Medicare home health services the Medicare home health recipient must be certified by the physician as confined to the home. While the Medicare Benefit Policy Manual indicates that the home health recipient is not necessarily bedridden, “the condition of these patients should be such that there exists a normal inability to leave home and, consequently, leaving home would require a considerable and taxing effort.” The homebound requirement allows Medicare home health patients to leave their home to obtain health care and attend religious services, and to take “infrequent” trips of “short duration” for other reasons and still maintain the benefit.

For disabled beneficiaries who want to use the Medicare home health benefit to meet their long-term needs, limiting excursions to short and infrequent trips can be a difficult lifestyle burden. Disabled beneficiaries who are able to leave their home more often either have to forgo those outings, or find an alternative way to meet their care needs.

DESCRIPTION OF THE DEMONSTRATION

The Medicare Home Health Independence Demonstration was designed to study the costs and benefits of waiving the Medicare homebound rule for chronically disabled beneficiaries. Enrollment in the demonstration allowed these beneficiaries to leave their home more frequently and for longer periods than the current regulations allow, without risking loss of their Medicare

home health benefits. To qualify for the demonstration, a Medicare beneficiary had to meet all the current Medicare home health eligibility requirements, as well as the following requirements as stipulated in the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (P.L. 108-173, Section 702):

“For purposes of subsection (a), a Medicare beneficiary is eligible to be deemed to be homebound, without regard to the purpose, frequency, or duration of absences from the home, if-

(1) the beneficiary has been certified by one physician as an individual who has a permanent and severe, disabling condition that is not expected to improve;

(2) the beneficiary is dependent upon assistance from another individual with at least 3 out of the 5 activities of daily living for the rest of the beneficiary’s life; (which were defined as eating, toileting, transferring, bathing and dressing.)

(3) the beneficiary requires skilled nursing services for the rest of the beneficiary’s life and the skilled nursing is more than medication management;

(4) an attendant is required to visit the beneficiary on a daily basis to monitor and treat the beneficiary’s medical condition or to assist the beneficiary with activities of daily living;

(5) the beneficiary requires technological assistance or the assistance of another person to leave the home; and

(6) the beneficiary does not regularly work in a paid position full-time or part-time outside the home.

These criteria were developed to identify severely ill, chronically disabled people who had a difficult time accessing health care and hence were not trying to “game” the system to use the Medicare home health benefit merely for convenience. The target group was people who might have been in a nursing home, or at least would have been confined to their home, were it not for technological advances that allowed them to live at home and gain limited mobility.¹

The demonstration was implemented in three states (Colorado, Massachusetts, and Missouri) on a voluntary basis, starting October 4, 2004, and ending October 3, 2006. The states were chosen to represent the Northeast, Midwest, and Western regions of the US (as stipulated in the legislation), have at least one urban area where there was likely to be a large population meeting the target criteria, and contain a moderate number of home health agencies. Agencies, who participated on a voluntary basis, were expected to enroll both new home health beneficiaries, as well as beneficiaries who were currently on their caseload.

¹Conversation with Mark Bayer of Congressional Representative Markey’s staff.

EVALUATION DESIGN

The low enrollment in the demonstration precludes us from being able to evaluate the demonstration as planned. Instead, we conducted interviews with stakeholders, used claims data, and conducted an agency survey to understand why so few beneficiaries enrolled in the demonstration. As part of the agency survey, we pre-selected patients who, based on administrative data, appeared to meet the some of the demonstration criteria, and asked agencies to abstract health record information on those patients.

RESEARCH FINDINGS

Why was the demonstration enrollment so low?

A number of different factors contributed to the low demonstration enrollment, including:

Home health agencies encountered barriers to participation. Estimates from the survey suggest that just 25 percent of the agencies who had at least one eligible beneficiary participated in the demonstration. These barriers include:

- *Agencies feared losing money on costlier patients.* Agencies said they anticipated that the typical demonstration patient would require a great deal of care, and that under Medicare's prospective payment system, the agency would lose money on these patients.
- *Agencies faced difficulties enrolling Medicaid-eligible beneficiaries.* Agencies said incongruence between the Medicare and Medicaid home care benefits and payment systems makes it difficult to switch patients from the Medicaid home care benefit to the Medicare benefit.
- *Agencies estimated that they would be paid less for care under the Medicare benefit.* A few agencies who investigated enrolling dually-eligible patients in the demonstration found that they would be paid less under the Medicare benefit than they were currently being paid under the Medicaid program.
- *Agencies felt many potential enrollees would not benefit from the program.* Some agencies found that many of their patients who met the demonstration criteria were unable to leave their homes more than the current regulation allows. As a result, agencies didn't feel it was worthwhile to enroll the beneficiary in the demonstration.

Medicare beneficiaries encountered enrollment barriers. These include:

- *Some beneficiaries prefer home care programs offered by the Medicaid program to the Medicare home health benefit.* Disability advocates suggested that Medicaid programs, which are specifically designed to meet the long-term needs of disabled persons, are more appealing to disabled beneficiaries.

- *Some beneficiaries didn't want to change their support systems to participate in a demonstration.* A few agencies who tried to enroll beneficiaries found that they didn't want to change their current care arrangements, even if it was financially advantageous to do so.

Stringent demonstration enrollment criteria kept enrollment low. The demonstration criteria were designed to target a very specific group of beneficiaries—beneficiaries who were ill and severely, permanently disabled. As a result, many stakeholders perceived that too few beneficiaries qualified for the demonstration—because it excluded disabled beneficiaries who did not meet the need for permanent skilled nursing services or those who wanted to continue to work in the community. Indeed, many stakeholders who strictly interpreted the criterion “permanent skilled nursing care” indicated that they could only think of two conditions that met this criteria. Many home health agencies interpreted the criteria much more broadly, however, and could have enrolled more patients who met the criteria had they chosen to participate.

Official enrollment process may have missed some demonstration enrollees. Technical difficulties with the official demonstration enrollment process may have missed some demonstration enrollees. In our survey of home health agencies, agencies reported that they enrolled 169 beneficiaries—which, if weighted for agency selection and non-response, translates into an estimated 330 demonstration enrollees. Whether agencies failed to execute the enrollment process successfully, or, for some reason, over-estimated the number of patients they enrolled, is unknown.

How many beneficiaries could be eligible for a permanent program?

In order to gain some information about how many beneficiaries may qualify for the future program benefit, we selected a patient sample of “potentially” eligible beneficiaries from those who received Medicare Home health services, and asked agencies to assess whether the beneficiary would meet the demonstration enrollment criteria. We estimate that among those who met our potentially eligible criteria over a year, 2,149 patients would have been eligible for the demonstration. Of these patients, however, agencies indicated that 78 percent were so ill that they could not leave home for more than the current regulations allow. Thus, we estimate that 473 patients in the three states could have met the demonstration criteria and benefited from the program. We can not tell what proportion of those 473 patients would, without a benefit change have chosen to remain in Medicare home health and limit their excursions. Nor can we estimate how many beneficiaries who didn't meet our sample criteria (including those who only receive home care outside of the Medicare benefit) might meet the eligibility criteria.

We also found that the number of eligible beneficiaries will depend upon how broadly or strictly agencies interpret the enrollment criteria. In particular, agencies had different interpretations of what qualified as permanent skilled nursing need, and when conditions qualify as “permanently disabling.”

Are these beneficiaries costly to serve?

With only 58 official participants in the demonstration, who received care from agencies that were disproportionately rural and non-profit, one can not estimate how much it will cost to serve these beneficiaries. However, agencies anticipated that these types of patients would be expensive to care for; and we found those few participants did use a relatively large amount of home health and other health care services compared to the average Medicare home health user.

IMPLICATIONS OF FINDINGS—CHANGING THE BENEFIT

Despite its limited enrollment, the demonstration provided a number of “lessons learned” regarding the possibility of implementing, in the Medicare home health benefit. These include:

Barriers to be addressed

In order to implement a change that would encourage agencies to serve these beneficiaries, CMS would have to address the barriers agencies face to participation. They would have to develop a payment mechanism, such as a case-mix group, that addresses home health agencies’ financial concerns by compensating them for serving beneficiaries like the individuals officially enrolled in the demonstration, who were quite ill and used a much higher level of care than a typical Medicare patient receiving home health care. Otherwise, some agencies may find ways to avoid serving these patients, and simply eliminating the homebound regulation is unlikely to improve access to care.

Second, CMS will want to increase efforts to communicate official guidance to home health agencies on serving dually eligible beneficiaries who will receive home care under the Medicare and Medicaid benefits concurrently. This could include communicating policy on who is responsible for coordinating the home care if multiple providers are involved and further guidance on how charges should be allocated between the two payers. State Medicaid programs will also need to review their policies regarding beneficiaries who may now qualify for the Medicare home health benefit under the existing homebound rule but who are enrolled in a Medicaid program for home- and community-based services that the beneficiary may prefer over Medicare home health care. CMS could work with state Medicaid agencies and with home health care trade associations to resolve these issues.

Precautions that might be considered

Once the barriers are mitigated, the concern will be that a “woodwork effect” will develop that was not evident in the demonstration: the emergence of large numbers of beneficiaries “from the woodwork,” drawn by the new benefit to seek services. We can not tell from this demonstration how large that effect may be, but it is clear that the eligibility criteria used in the demonstration limited the number of qualified enrollees. To limit the expansion possibilities, CMS will have to provide clear guidance on exactly what constitutes (1) a permanent skilled care need, and (2) a permanent disabling condition.

The demonstration provided other valuable information that will help CMS and Congress understand the challenges of addressing the issues in the homebound requirement. These include:

Changing the homebound requirement will not automatically change how agencies interpret and implement it.

We found that even after CMS clarified the homebound requirement in 2001, agencies continued to interpret it either more strictly or more loosely than the current regulation warrants. This reflects how difficult it is to reach agencies with programmatic changes, and for them then to incorporate those changes into their functions.

Eliminating the homebound requirement for the severely disabled will not eliminate the “homebound” problem.

For many agencies, the homebound problem does not apply solely to the severely disabled. Agencies identified a number of patient groups whose care and lives might be enhanced if the homebound requirement were to be eliminated. CMS may wish to conduct research to provide evidence for these assertions. For example, they might try to determine where patients receive traditional nursing services—such as catheter changes and frequent wound evaluations—to learn whether accessing this care is as difficult as some agencies suggest. Furthermore, CMS may wish to consider a demonstration to determine whether extended home care benefits can improve patient health and decrease the use of expensive acute care services.

Future demonstration enrollment processes should be validated.

The enrollment process appears to have missed recording a large proportion of the enrollees. In this demonstration, where many factors contributed to the lack of enrollment, this did not drastically impede the evaluation. However, had there been substantial enrollment, the failure to capture a large proportion of the enrollees would have harmed the evaluation substantially. Thus, establishing a validation process for future demonstration enrollment is important.

I. BACKGROUND

Under Section 702 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2002 (P.L. 108-173) Congress mandated that the Secretary of the Department of Health and Human Services undertake a demonstration of a change to the Medicare home health benefit eligibility criteria regarding homebound status. CMS was to study the impact of the change in the following areas: how much the change would cost, how large a population would qualify under revised eligibility criteria, and what proportion would qualify of those who already receive Medicare home health benefits under the present definition of *homebound*. However, only 58 beneficiaries enrolled in the demonstration—far fewer than the Congressionally imposed limit of 15,000. Therefore, to guide future policy, this report seeks to explain why so few beneficiaries enrolled, what the experiences were of those who did enroll, and how the home health agencies currently view the homebound restriction.

A. LEGISLATIVE BACKGROUND AND POLICY

When Congress designed the Medicare program in 1965, little was known about the health care needs of the elderly. Congress modeled the Medicare benefit based on what was known about health insurance at the time—which was based on a much younger population (Blumenthal et al. 1988). Congress designed an acute care benefits package that covered therapeutic care but not supportive, palliative, or preventive care. In order to receive home health care, a beneficiary had to have a 3-day prior hospitalization and could receive a maximum of 100 visits. Since home health care was viewed primarily as a post-acute care benefit, the homebound rule was put into effect, with the physician prescribing the home health care and overseeing the patient's homebound status. The benefit was intended to be short term, to help people who could not

travel recover from their illness. Those well enough to travel were expected to go to their primary care provider for health care services.

Research has since demonstrated that the health care needs of the elderly differ from those of younger people. Many elderly people have chronic illnesses that require long-term care to prevent exacerbation or further decline (Eichner and Blumenthal 2003). Furthermore, in 1972, Congress extended the Medicare benefit to disabled beneficiaries—a group that also has chronic, long-term care needs.

The home health care benefit has evolved over time to meet some of those chronic needs. The 1980 Omnibus Budget Reconciliation Act eliminated the requirement of prior hospitalization and the 100-visit limit. In response to the *Duggan v. Bowen* decision in 1998, the Health Care Financing Administration (HCFA, now the Centers for Medicare & Medicaid Services [CMS]) issued reinterpretations of the coverage guidelines to allow skilled nursing and accompanying aide care for chronic conditions, rather than only for acute illnesses.

These changes in the benefit, however, resulted in large increases in service use and costs. Between 1990 and 1997, Medicare home health payments grew at an average annual rate of 25 percent (Government Accountability Office 2002). But while the reinterpretation of the guidelines accounted for some of the increase, other factors contributed as well, including the increased provision of home health care to beneficiaries who were not eligible. To address this issue, HCFA implemented Operation Restore Trust—a two-year project to counter fraud and abuse—and a number of home health claims were found to be erroneous because the beneficiary did not meet the homebound criteria (Government Accountability Office 1998).

Another factor behind the increased expenditure growth was that Medicare paid home health agencies on a cost-reimbursed basis that offered them little incentive to operate efficiently. In an

effort to curb the growth in expenditures and promote agency efficiency, Congress implemented payment reform in the Balanced Budget Act of 1997. It instituted an Interim Payment System (IPS) from 1997 to 2000, which imposed annual limits on per-patient Medicare payments. It also mandated the prospective payment system (PPS), which was implemented in 2000. Under the new PPS, Medicare pays home health agencies a fixed amount, adjusted for a beneficiary's care needs, for a 60-day episode of care. If an agency can deliver care that meets the patient's needs for less than the payment amount, then the agency earns a profit on that episode; however, if the costs of care exceed the episode payment amount, the agency bears the financial loss. There are no limits on the number of episodes a patient can receive. Since the implementation of these payment reforms, expenditures decreased substantially—from \$17 billion in 1996 to \$8.5 billion in 2001—although expenditures have been rising slowly since, and in 2005 totaled over \$12 billion (CMS 2007a and 2007b).

B. DEFINITION OF HOMEBOUND AND HISTORY OF THE SECTION 702 LEGISLATION OF THE MEDICARE MODERNIZATION ACT

Under the current regulations, the Medicare home health recipient must be certified by a physician as confined to the home. While the Medicare Benefit Policy Manual indicates that the home health recipient is not necessarily bedridden, “the condition of these patients should be such that there exists a normal inability to leave home and, consequently, leaving home would require a considerable and taxing effort... Generally speaking, a patient will be considered homebound if they have a condition due to an illness or injury that restricts their ability to leave their place of residence except with the aid of: supportive devices such as crutches, canes, wheelchairs, and walkers; the use of special transportation; or the assistance of another person; or if leaving home is medically contraindicated.”

Home health patients may leave the home, on an unlimited basis, for absences related to the need to obtain health care. Such health-related absences include, but are not limited to, attending medical adult day care centers. Absences to attend religious services are permitted without restrictions. Home health recipients may leave for reasons other than to access health care, but only if these absences are infrequent or for periods of relatively short duration. While no exact definitions for “infrequent” or “relatively short duration” have been provided, agencies are encouraged to view the patient’s condition and home absences over an extended period of time rather than over a short period, such that frequent absences in a short period would not disqualify the patient from continuing to receiving the home health benefit.

The demonstration legislation had its roots in the circumstances of a 39-year-old Medicare beneficiary who suffered from amyotrophic lateral sclerosis (ALS) and whose mobility was limited to moving three fingers. He used a portable ventilator, a computerized speech processor, and received nutrition through a tube in his stomach. He was able to leave his home when accompanied by family or friends, and he had a special van that allowed him to travel. He received Medicare home health services regularly, and an aide would come each morning to help him dress [www.amendhomeboundpolicy.homestead.com].

He was determined that his illness not hamper his participation in the community, so he took part in various activities outside the home, which included traveling to ALS fundraisers, participating in church, and attending the Florida-Georgia State football game (for which he stayed overnight). His home health agency informed him that he was in violation of the homebound requirement, and discharged him from Medicare home health, having declared him ineligible since he was no longer homebound. His benefits were later reinstated, but at the “cost of his freedom” [www.amendhomeboundpolicy.homestead.com].

This individual began a grassroots effort to end the homebound requirement for Medicare beneficiaries. He was supported by the disabled community and by U.S. Representatives Edward J. Markey (Massachusetts) and Christopher Smith (New Jersey), who introduced legislation (H.R. 1490) to change the homebound restriction for disabled beneficiaries.

Legislators were concerned about the potential cost to the Medicare program from changing the homebound requirement. The compromise solution was to implement a demonstration that would allow CMS to estimate how much the benefit change would cost. Indeed, some policymakers were so concerned about the potential costs associated with this benefit change (especially given the history of rapid growth in home health costs following the loosening of eligibility criteria) that they limited the demonstration to 15,000 participants.

C. DESCRIPTION OF THE DEMONSTRATION

The Medicare Home Health Independence demonstration was designed to study the costs and benefits of eliminating the Medicare homebound rule for chronically disabled beneficiaries. Enrollment in the demonstration allowed these beneficiaries to leave their home more frequently and for longer periods than the current regulations allow, without risking loss of their Medicare home health benefits. To qualify for the demonstration, a Medicare beneficiary had to meet all the current Medicare home health eligibility requirements, as well as the requirements in Section 702 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (P.L. 108-173):

1. The beneficiary has been certified by one physician as an individual who has a permanent and severe, disabling condition that is not expected to improve.

2. The beneficiary is dependent upon assistance from another individual with at least 3 out of the 5 activities of daily living for the rest of the beneficiary's life.¹
3. The beneficiary requires skilled nursing services for the rest of the beneficiary's life and the skilled nursing is more than medication management.
4. An attendant is required to visit the beneficiary on a daily basis to monitor and treat the beneficiary's medical condition or to assist the beneficiary with activities of daily living.
5. The beneficiary requires technological assistance or the assistance of another person to leave the home.
6. The beneficiary does not regularly work in a paid position full-time or part-time outside the home.

These criteria were developed to identify severely ill, chronically disabled people who had a difficult time accessing health care and hence were not trying to “game” the system to use the Medicare home health benefit merely for convenience. The target group was people who might have been in a nursing home, or at least would have been confined to their home, were it not for technological advances that allowed them to live at home and gain limited mobility.²

The legislation required that the demonstration be “conducted in three States selected by the Secretary to represent the Northeast, Midwest, and Western regions of the United States.” CMS chose Colorado, Massachusetts and Missouri, since these states met the criteria, had at least one urban area where there was likely to be a large population meeting the target criteria and had a moderate number of home health agencies. The demonstration started on October 4, 2004, and ended October 3, 2006.

Enrollment could be accomplished in two ways: (1) the beneficiary could ask a home health agency whether he or she could enroll, and if the agency and the beneficiary's physician deemed

¹ The activities of daily living are defined as bathing, dressing, eating, toileting, and transferring.

² Conversation with Mark Bayer of Representative Markey's staff.

that the patient met the clinical criteria, the agency could proceed with enrollment; and (2) the agency could identify eligible beneficiaries through its usual process of admission and patient reviews, and if a physician concurred that a beneficiary met the clinical criteria, enrollment could proceed. The agency then informed the beneficiary that he or she was eligible to enroll in a demonstration of limited duration, and that the patient was not subject to the homebound requirements. Thus, demonstration enrollees could have been patients who were already receiving home health care, or new home health patients.

The agency enrolled the patient in the demonstration by entering a special code on the usual Medicare home health bill. Agencies typically submit two bills for a patient for a 60-day episode: the initial and the final bill. Agencies could enroll a patient on either one of these bills, and enrollment started at the beginning of the 60-day period related to the bill. Agencies were instructed to continue to enter the special code on all subsequent bills to retain the patient in the demonstration.

Home health agencies submit their bills to Regional Home Health Intermediaries (RHHIs) for payment, and the RHHIs create a weekly computer file that contains all the claims for demonstration enrollees. That file was sent to Abt Associates, Inc., the demonstration support contractor, which sent a letter informing the patient about the demonstration.

Home health agency participation was voluntary. If an agency did not wish to enroll demonstration patients, it did not have to do so. Agencies could also choose to refer potential demonstration patients to other agencies, or to the toll-free number maintained by Abt Associates to locate agencies that were accepting patients.

D. GOALS OF THIS REPORT

Because the demonstration enrolled so few participants—a total of 58 Medicare beneficiaries—the evaluation cannot fulfill its original mission: to estimate the costs and

benefits of modifying the homebound criteria. In this report, we describe data we collected in an effort to understand the factors that may have contributed to the low enrollment, including the agencies' perceptions of the restrictiveness of the demonstration eligibility criteria, perceived incentives and disincentives to participate, and beneficiary-related barriers. We synthesize the information obtained to understand the likely effects of the policy change that the demonstration was intended to test.

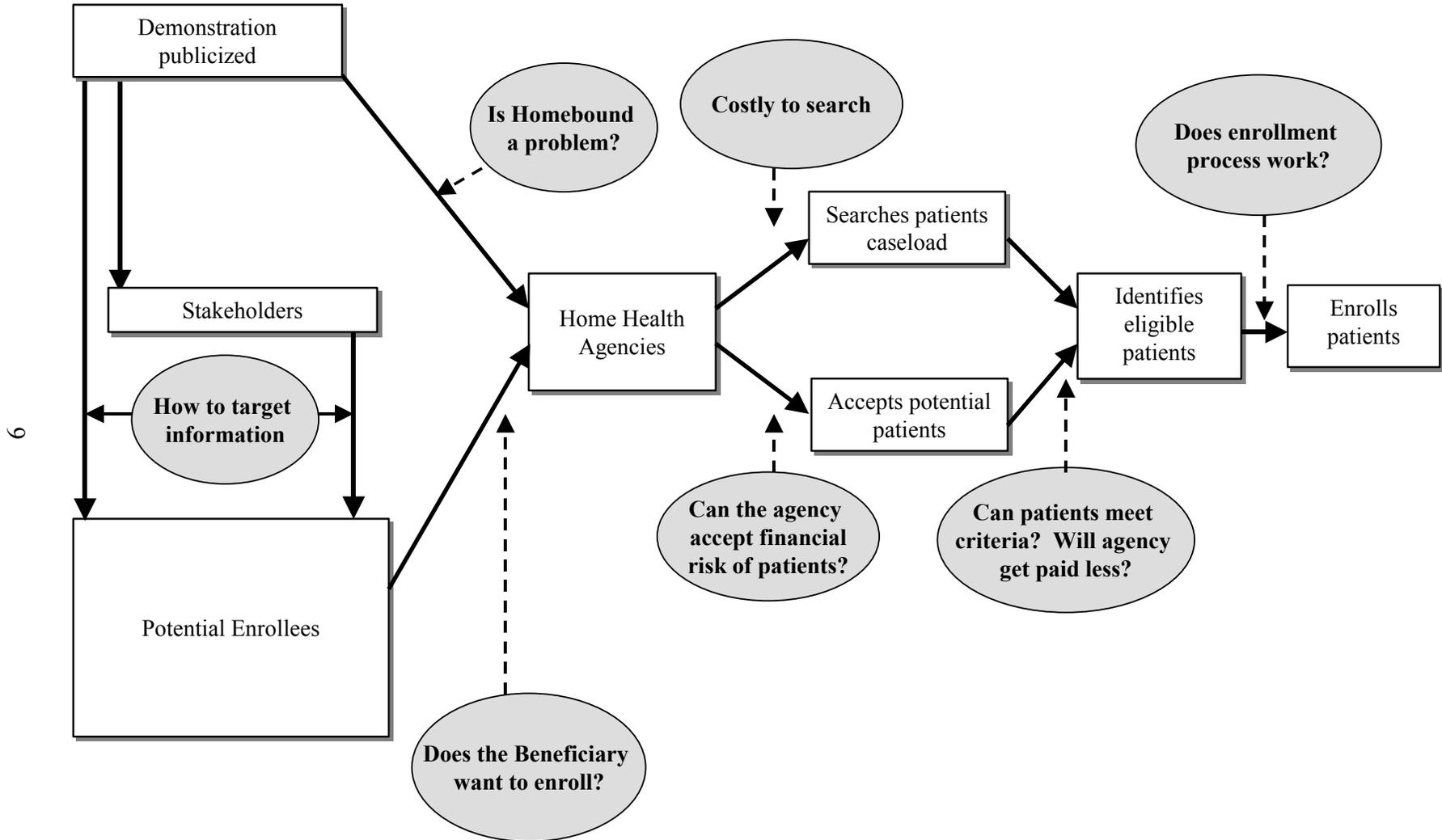
A key issue is understanding why so few participants enrolled. If it was because few beneficiaries neither qualified for the demonstration nor wanted the benefits, then eliminating the homebound requirement for the severely disabled population would have little financial impact on the Medicare program. As shown in Figure I.1, a number of different factors could account for the low enrollment, including:

- Home health agencies and potential enrollees might have been unaware of the demonstration.
- Agencies or potential enrollees might have declined to participate.
- Few enrollees might have qualified for the demonstration.
- The mechanics of the enrollment process might have failed.

Understanding which of these factors played important roles in limiting enrollment will help us understand the implications of permanently changing the benefits.

FIGURE I.1

HOW THE INDEPENDENCE DEMONSTRATION IDENTIFIED AND ENROLLED BENEFICIARIES



Round shaded items are potential barriers or hurdles.

II. DATA COLLECTION METHODS

To assess the Home Health Independence Demonstration and the factors that caused such low enrollment, we used (1) a “mixed-mode” method in which we collected qualitative data from key informants and supplemented with Medicare claims data for beneficiaries who enrolled, and (2) a survey of home health agencies that were identified as having provided care to Medicare beneficiaries who were potentially eligible to enroll.

A. QUALITATIVE DATA COLLECTION

The qualitative data collection was designed to address two issues. First, we wanted to understand how the demonstration was being implemented. Second, after it became evident that there would be few participants, we wanted to understand the factors that may have contributed to the low enrollment, including the agencies’ perceptions of the restrictiveness of the demonstration eligibility criteria, perceived incentives and disincentives to participate, and their attitude towards the homebound requirement.

1. Interviews with Stakeholders

About nine months after the demonstration started, to assess how the demonstration was being implemented, we conducted site visits to interview stakeholders in the three states (Colorado, Massachusetts, and Missouri). Not all participants were available during the site visits, so we conducted telephone interviews with the others. In each state, we interviewed:

- Representatives of the state home health associations
- At least two large home health agencies
- An agency that, at the time, had enrolled beneficiaries in the demonstration
- A representative from a Center for Independent Living

- A representative from the MS Society and at least one other beneficiary advocacy group
- State Medicaid officials

We discussed the following topics with them:

- Their awareness of the demonstration outreach efforts
- Why agencies and beneficiaries did, or did not, participate in the demonstration
- Whether respondents understood the demonstration criteria, and whether they thought the criteria were restrictive
- The availability of other providers (such as nursing homes, assisted-living facilities, or other community-based care services) that could substitute services for home health care to potential demonstration enrollees
- Whether the homebound criteria as implemented in the regular Medicare home health benefit were a problem for home health agencies and beneficiaries
- How Medicare home health benefit could change to improve access for disabled beneficiaries

To understand the goals of the legislation, the barriers to achieving that intent, and the general issues regarding the homebound requirement, we interviewed Congressional staff and lobbyists involved in crafting Section 702, staff at CMS, and representatives of nationally based home care organizations. Topics for each of these interviews varied by respondent, depending on their role in either implementing the legislation or participating in Medicare program operations. These interviews took place in the six months after the demonstration ended. A list of all persons we interviewed, and their affiliations, is in Appendix B. Throughout this report, we refer to these sources as informants.

2. Interviews with Beneficiaries

To understand the perspective of the demonstration's enrollees, we interviewed eight selected enrolled beneficiaries. We developed two versions of the protocol, one tailored to the

beneficiaries who were already receiving Medicare home health at the time of enrollment, and one designed for the beneficiaries who were just starting Medicare home health services when they enrolled. Both protocols asked about their knowledge about the demonstration, the impact of the demonstration on the extent and nature of their use of home health care services and home absences, their attitude toward the demonstration, and the impact of permanently implementing a change to the homebound criteria. The second protocol included additional questions about the enrollment process, as this group, which consisted of beneficiaries who were not in Medicare home health, might undertake extra steps to find an agency to enroll them.

Sample selection was conducted in October 2006. To improve recall, we first excluded beneficiaries whose last episode of home health care was over a year ago. A total of eight beneficiaries were selected from the remaining enrollees. We randomly selected four beneficiaries from Missouri, three from Colorado, and one from Massachusetts, with a range of number of episodes.¹

We conducted the beneficiary interviews between October and November 2006. We also contacted beneficiaries' home health agency to obtain information on their demonstration enrollment date, skilled nursing need, medical condition, and home health care services. In our analysis, we used the information from both the patients and the agencies.

B. MEDICARE ADMINISTRATIVE DATA

To understand the amount of health care services used by enrolled beneficiaries, we matched the demonstration enrollment file to the Standard Analytic Files to obtain Part A data, and to the National Claims History file to obtain Part B data. To do this, we first needed to establish the

¹ Our first interview was with a proxy respondent, as the beneficiary could not hear on the telephone. The proxy did not know anything about the demonstration, so we decided not to use this interview and selected, as a replacement, an interview with another beneficiary from the same state.

date that the beneficiaries enrolled, as the enrollment file did not contain this information. By working with Abt Associates, the demonstration contractor, we were able to contact all the agencies and establish the enrollment date for 57 of the 58 beneficiaries.

We were able to obtain preenrollment claims for all 57 of these enrollees. However, to obtain complete claims to assess postenrollment experiences, we excluded 13 beneficiaries who enrolled after March 31, 2006.² We were able to observe all Medicare health care services used by the enrollees, as none enrolled in a Medicare HMO plan during the analysis period.

C. AGENCY SURVEY

To understand the extent to which various factors were contributing to the lack of enrollment, and to gain a fuller picture of agencies' views of the homebound requirement, we surveyed agencies in the three demonstration states. The survey had two goals: (1) to reveal barriers that impeded enrollment, such as problems with eligibility definitions or other reasons that beneficiaries did not qualify, and to gather any other relevant information that agencies could provide; and (2) to examine the way agencies in the demonstration states applied the demonstration eligibility criteria in practice. The survey was designed in two parts: the first collected information about the home health agency, the second about agency clients who were identified in administrative data as potential enrollees.

We decided to select patients who were potentially eligible for the demonstration, because agency feedback suggested that if we didn't purposely try to select eligible patients, we may not identify any beneficiaries who were eligible for the demonstration.

² To conduct the analysis for this report, we obtained claims in December 2006, after the demonstration ended. We allowed four months for the lag between when services are rendered and the claims become available; thus, we had data available through July 31, 2006. To analyze four months of postenrollment utilization, we had to use only those beneficiaries who had enrolled before March 31, 2006.

We identified “potentially eligible” patients as those who appeared to have met at least some of the demonstration enrollment criteria based on the information submitted in their OASIS Start-of-Care Assessment.³ Home health agencies are required to conduct a comprehensive assessment for every Medicare and Medicaid patient upon admission and every 60 days thereafter, and to submit information from that assessment to CMS. We identified “potentially eligible” patients as those who had been receiving Medicare home health services from these agencies for two or more consecutive 60-day episodes, who used technical or human assistance to move, and who had three or more ADLs for which they needed assistance.

In December 2005, we sent a draft version of the survey to the three state home health associations for comments. The questionnaire was significantly shortened as a result of the comments received from the associations, and the revised draft was pretested in April 2006. The final instrument (four pages long) contained questions about the agencies’ implementation of the homebound requirement in routine operations, their Medicare caseload and referrals, Medicare discharges related to the homebound criteria, participation and barriers to participation in the demonstration, and the current impact of the homebound regulation on Medicare beneficiaries. In addition, agencies were asked to abstract information about five “potentially eligible” clients from their medical records. The information to be extracted specifically addressed the demonstration eligibility requirements. A Paperwork Reduction Act package was submitted to OMB in May 2006 and approved on November 21, 2006. A copy of the survey instrument and the accompanying letters sent to agencies are in Appendix C.

³ We used the start-of-care instrument from the last episode in the series of episodes to capture the patients health status, as not all potential patients had an end-of-episode document.

1. Sample Design

The goal of the sample design was to select a representative sample of home health agencies that have patients who are potentially eligible for the demonstration in each of the three participating states, and to select a representative sample of such patients within each selected agency. The sample for the survey was drawn in two stages: (1) agencies, and (2) patients within agencies.

For both stages of selection, we constructed the sample frames by first obtaining from CMS all patient assessment instruments submitted to the CMS OASIS repository from May 2005 to November 28, 2006. We then aligned all the start-of-care instruments for each person at each agency, and dropped any instrument that had either an invalid patient Medicare ID number or an invalid home health agency number. We then determined whether the individual patient met our criteria for eligibility for record extraction on the survey, and summed for each agency the number of patients who did so. Agencies were eligible for the survey if they had at least five potentially eligible patients.

There were 54 eligible agencies in Colorado, 85 in Massachusetts, and 68 in Missouri. In the first stage of sampling, we selected all 54 agencies in Colorado, 67 of 85 in Massachusetts, and 67 of 68 in Missouri, for a total of 188. Of the sampled agencies, 29 Colorado agencies, 36 Massachusetts agencies, and 41 Missouri agencies responded to the survey. See Appendix D for details.

2. Data Collection

Data were collected through a mail survey during an 11-week period from January through March 2007. Dillman's Tailored Design Method (2000) guided the collection methodology. This multistage approach consisted of up to five contacts with each agency, including a

prenotification telephone call, a letter explaining the purpose of the study, the initial survey mail-out package, a reminder post card, a nonresponse survey mailing, and telephone followup for nonresponders.

The initial 188 survey packets, sent by Federal Express, included a personalized cover letter, the mail questionnaire, and FedEx return materials. The cover letter explained the purpose and importance of the study, emphasized that participation was voluntary, and provided assurance that responses were confidential. The letter provided a toll-free number for agencies to call with questions and offered \$50 for participation. Also in the package was an endorsement letter from U.S. Representative Edward J. Markey of Massachusetts, who encouraged home health agencies to participate because their input would help Congress develop policy in this area. (As noted in Chapter I, Mr. Markey was one of the sponsors of the legislation mandating the demonstration.)

We received a total of 106 responses from the agencies in time to be included in this report, for a response rate of 56 percent. In this report, we refer to these sources as respondents. Table II.1 shows the number of responses, and the response rates by state. Table II.2 shows the response rates for the sample of five beneficiaries per agency for these agencies.

TABLE II.1
RESPONSE TO AGENCY SURVEY, BY STATE

State	Total Eligible Agencies	Sampled Agencies	Participating Agencies	Response Rate (Percent)
Colorado	54	54	29	53.7
Massachusetts	85	67	36	53.7
Missouri	68	67	41	61.2
Total	207	188	106	56.4

TABLE II.2

RESPONSE RATES FOR THE BENEFICIARY SAMPLE

State	Total Eligible Patients in All 207 Eligible Agencies	Total Eligible Patients in 188 Selected Agencies	Total Selected Patients in 188 Selected Agencies	Total Eligible Patients in 106 Participating Agencies	Total Selected Patients in 106 Participating Agencies	Completed Medical Record Abstractions	Completion Rate Among Participating Agencies (Percent)
Colorado	776	776	270	426	145	139	95.9
Massachusetts	3,483	3,324	335	1,788	180	178	98.9
Missouri	1,383	1,378	335	788	205	197	96.1
Total	5,642	5,478	940	3,002	530	514	97.0

3. Sample Weighting

Once data were collected, we constructed two sets of weights—one to be used for analysis at the agency level and the other at the patient level. These weights were assigned to each selected, eligible, and completed case, and make the case represent all the eligible cases in the state’s target population, including those not selected and those that were selected and eligible but did not participate. All the estimates provided in this report are weighted. Details of how we calculated these weights are in Appendix D, as well as Tables with all of the standard errors for estimates reported.

III. DID AGENCIES AND BENEFICIARIES KNOW ABOUT THE DEMONSTRATION?

For any demonstration to enroll participants, the outreach must inform potential participants about the project. For the Home Health Independence demonstration, the outreach effort had to reach two groups: those who would provide the benefit and those who would use it. First, it had to reach home health agencies, who needed to be educated about the demonstration so that, if they chose to participate, they could enroll eligible patients they were currently serving. Second, it had to reach eligible beneficiaries who were not currently using Medicare home health services or were receiving services from agencies who chose not to participate, so that they could find a participating agency and enroll in the demonstration.

Before the demonstration began, CMS made general information available for everyone who might be interested. The Secretary of Health and Human Services, Tommy Thompson, announced the demonstration in a press conference in June 2004. The agency released articles to the press during that summer and implemented the Home Health Independence website in September 2004. It also conducted meetings with regional offices, RHHIs, and state survey agencies and began working with outreach partners.

Early in the demonstration, CMS and its outreach contractor, Abt Associates, focused their efforts on two target groups: (1) home health agencies and state home health associations, and (2) relevant stakeholder groups (or outreach partners) who could inform Medicare beneficiaries about the demonstration. The latter included disease-specific associations (such as the ALS Association) and health care providers who work with eligible beneficiaries, such as physicians and case managers. It was expected that the home health agencies and outreach partners would identify most of the demonstration participants. As it became evident that enrollment in the

demonstration was proceeding very slowly, CMS implemented an outreach strategy that sought to contact individual beneficiaries directly.

A. HOW WAS THE DEMONSTRATION COMMUNICATED TO HOME HEALTH AGENCIES, AND WAS IT SUCCESSFUL?

The key group that had to be educated about the demonstration was Medicare-certified home health agencies. They had to know why they should participate, what they needed to do, and how to enroll patients. Without their cooperation, the demonstration would not enroll anyone.

While a few outreach activities were targeted at agencies early on to make them aware that the demonstration was pending, the outreach began in earnest in the month before the demonstration was to begin. Separate Open Door Conference Call meetings were conducted for home health agencies from each demonstration state in September 2004. Before those meetings, agencies in all three states were informed of the meeting by mail and by telephone; agencies in Missouri and Colorado were notified both by “fax blast” and by email.

These early meetings were well attended. In total, 457 Medicare-certified agencies operated in these three states at the time, and a total of 225 agency participants attended: 74 in Massachusetts, 68 in Colorado, and 83 in Missouri. Assuming that most agencies had only one representative at each meeting, almost half the agencies were in attendance.

After the initial set of meetings, other outreach activities aimed at home health agencies occurred, including mailings to all 457 Medicare-certified home health agencies describing the demonstration, additional Open Door meetings, and information disseminated in conjunction with the state home health associations and the Visiting Nurse Association of America. Most of the outreach activities that were specifically aimed at home health agencies were completed by December 2004.

In our discussions with home health agencies and the state associations, all our respondents indicated that the demonstration was well publicized at the beginning.¹ All the agency representatives we spoke to had heard of the demonstration, most through multiple sources. The state home health associations also thought that in general their member agencies knew of the demonstration and understood it. Abt Associates also conducted follow-up telephone calls with 73 agencies to make sure that they had received the information and knew about the demonstration. The agencies contacted indicated that they knew about the demonstration; thus, the evidence suggests that home health agencies did know about it.

B. HOW WAS THE DEMONSTRATION COMMUNICATED TO BENEFICIARIES, AND WAS IT SUCCESSFUL?

1. Outreach to Beneficiaries Through Key Stakeholders

One of the challenges of this demonstration was being able to identify potential patients who were not in home health care but could be eligible for the demonstration. The eligibility criteria—having a severe, disabling condition; needing daily help with at least 3 ADLs; and needing permanent skilled nursing care—define a unique set of beneficiaries that have no “natural” affiliation with any particular set of organizations or service providers. CMS and Abt Associates recognized that reaching these beneficiaries was going to be challenging, so early on they decided to target a very broad set of outreach partners. They contacted any group that they thought might have members who would qualify for the demonstration, or might be able to refer someone.

¹ A few informants indicated that after the initial outreach efforts, they heard very little about the demonstration, and thought that it would have been beneficial to hear more about which agencies were participating and what their experiences were. But this would have been difficult, given the limited participation.

A wide variety of organizations were contacted in an effort to publicize the demonstration. Table III.1 lists the different types that were approached. The most frequently contacted were disease-specific, such as the Alzheimer's, multiple sclerosis, and Parkinson's societies. But the outreach also included case manager organizations, senior advocacy and social services providers, and advocacy organizations for persons with disabilities. Most of these contacts took place during the first six months of the demonstration (October 2004 to March 2005), and it appears that these activities did generate some interest. As shown in Figure III.1, the number of hits on the CMS Home Health Independence website increased from December 2004 to March 2005, and then fell off.

The extent that the contacted organizations tried to inform beneficiaries about the demonstration varied substantially. Some were not interested in helping with outreach. Others participated passively, by displaying brochures at their sites or placing information on their website or in their newsletter. But a few organizations did play an active role in finding potentially eligible beneficiaries and encouraging enrollment, and at least one home health agency designed and distributed its own brochure.

The Multiple Sclerosis Society of Massachusetts was an early supporter of the demonstration and took an active role in finding participants. The Society used its database to identify 700 people with MS who have Medicare coverage, and sent letters to all of them. They also maintain a database of health care providers (neurologists and clinics) who serve MS patients, and mailed letters to them as well. Finally, the Society published an article about the demonstration in their newsletter, half of whose circulation of 20,000 are known to have MS.

TABLE III.1

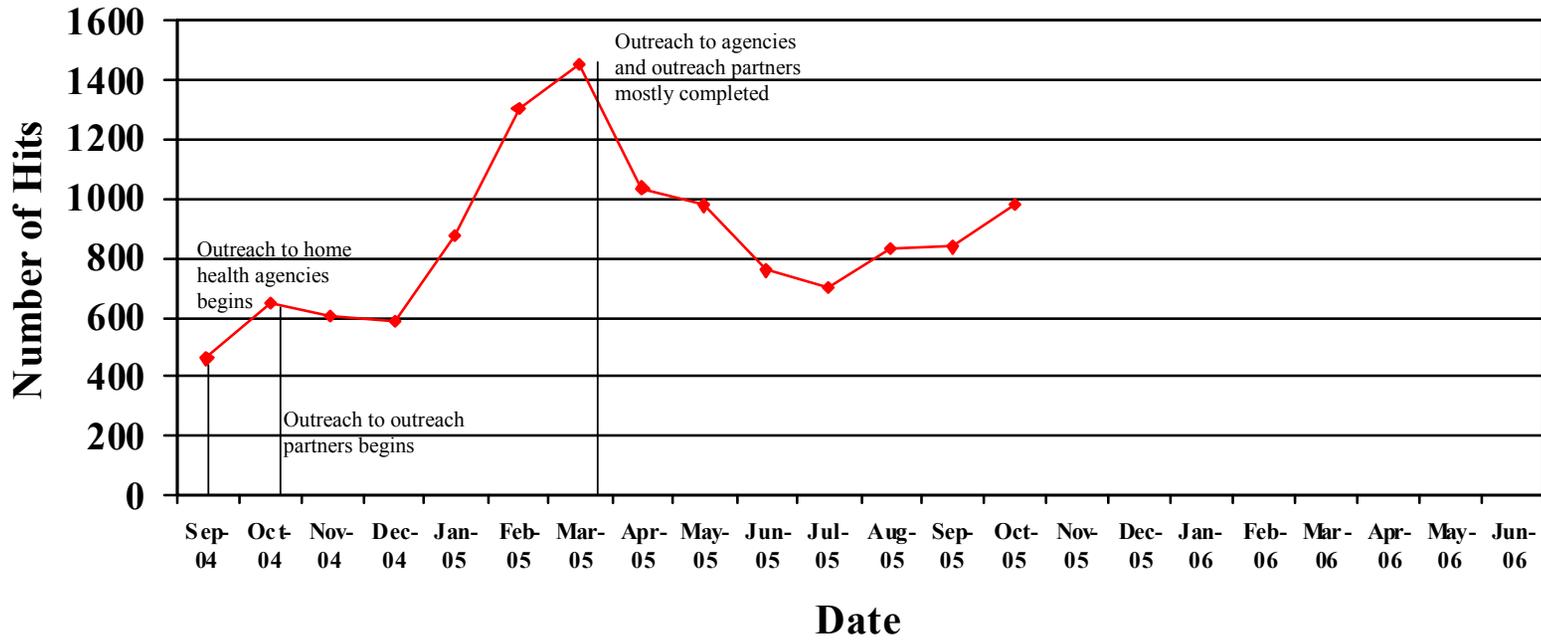
TYPES OF ORGANIZATIONS CONTACTED IN THE OUTREACH EFFORT

Area Agencies on Aging , Senior Services agencies
Case Manager Associations
Congressional Representatives
Dept. of Veterans Affairs
Disability Advocacy organizations
Disease-specific organizations – Alzheimers, Parkinson, Amyotrophic Lateral Sclerosis, Multiple Sclerosis, Heart Disease, End-Stage Renal Disease, Arthritis, Mental Illness, Brain Injury, Diabetes, Cancer, Epilepsy
Family Caregiver Coalitions
Farm Worker/Migrant Health Workers
Geriatrics Society
Health Care Administration Organizations
Hospice Organizations
Hospital Associations
Independent Living Centers
Information and Referral providers
Nurses Associations
Occupational Therapy Associations
Optimist Club
Pharmacy Associations
Physical Therapy Associations
Physicians and physician organizations
Regional Conference of Governments; county governments; local governments
State Insurance Assistance Programs
Senior Advocacy and Medicare Rights Organizations
State Medicaid Agencies

Source: Abt Associates, Inc.

Note: Contacts could include brief presentations, attendance at a function with a distribution of materials, and provision of materials to be posted on websites and in newsletters.

FIGURE III.1
 NUMBER OF HITS ON THE CMS HHI WEBSITE



Source: Abt Associates, Inc.

Note: Data on number of hits was not available after October 2005 due to changes in CMS website.

The response to the 700 letters mailed to Medicare beneficiaries with MS demonstrates how difficult it is to reach eligible beneficiaries. The office received more than 100 calls in response to the letter—more than it had ever received in response to a mailing. However, many of the people who responded misunderstood the intent of the demonstration. The vast majority of the calls came from caregivers who were calling in the hopes that they could get more hours of aide care so they could leave the home. Others wanted themselves or their loved ones to become more physically mobile, and were hoping that the demonstration would provide needed special transportation or home modifications. Of all the calls fielded, only five or six of the patients actually met the demonstration enrollment criteria as understood by the Society, and only two of those beneficiaries had Medicare home health benefits in the past but lost them because of not being homebound. The remaining patients were so disabled that they met the current homebound criteria and were unable to leave their homes more often than the current Medicare rules allow. This suggests that the reason for low participation may have been that too few beneficiaries were eligible rather than ineffective outreach efforts, an issue that Chapter IV will explore further.

The experience of the Colorado chapter of the MS Society also demonstrates the difficulty of reaching the target audience. This chapter operates the Independent Living Empowerment and Advocacy Program, which helps people with the highest physical needs and lowest resources become independent (MS Society, Colorado Chapter, Annual Report 2003). Services are coordinated by a case manager. The program manager thought that this program would be fertile ground for identifying demonstration participants and thus had the case managers review their cases to find potentially eligible clients. From this program, which provided case manager services to 588 people in 2003, the case managers identified just a few clients who they believed met the demonstration criteria. When these patients were presented to the local home health

agency, the agency informed the case managers that these clients left their homes so infrequently that they met the homebound criteria and could receive Medicare home health without enrolling in the demonstration.

2. Direct Outreach to Beneficiaries

Anticipating challenges in targeting the information to eligible beneficiaries, CMS and Abt also conducted outreach directly to beneficiaries. Their original plan was to send an informative brochure to each beneficiary with the Medicare Summary Notice (MSN), which is sent quarterly to beneficiaries.² The brochure was designed to be promotional, and it invited interested beneficiaries to call 1-800-Medicare for further information.

It took awhile for CMS to approve the brochure and varying amounts of time for the RHHIs to start the distribution process. The first brochures were sent in January 2005 to home health users in Massachusetts; and by May 2005, all beneficiaries in all three states were receiving the brochures.³ In July 2005, an alternative approach was implemented. Instead of mailing a brochure with the MSN, the RHHIs printed information about the demonstration directly on the MSN for all beneficiaries who received home health services in the previous months and carriers printed it for those receiving Part B services. Some RHHIs continued to distribute brochures as

² If a payment is due to a beneficiary from Medicare, the MSN is sent at the time that the claim is processed.

³ Because a few home health agencies in the selected states do not bill through the RHHI, not every beneficiary in the state who was receiving Medicare home health or Part B services received a brochure.

well. In total, more than 200,000 brochures were distributed to beneficiaries, and many others received information printed on their MSNs.⁴

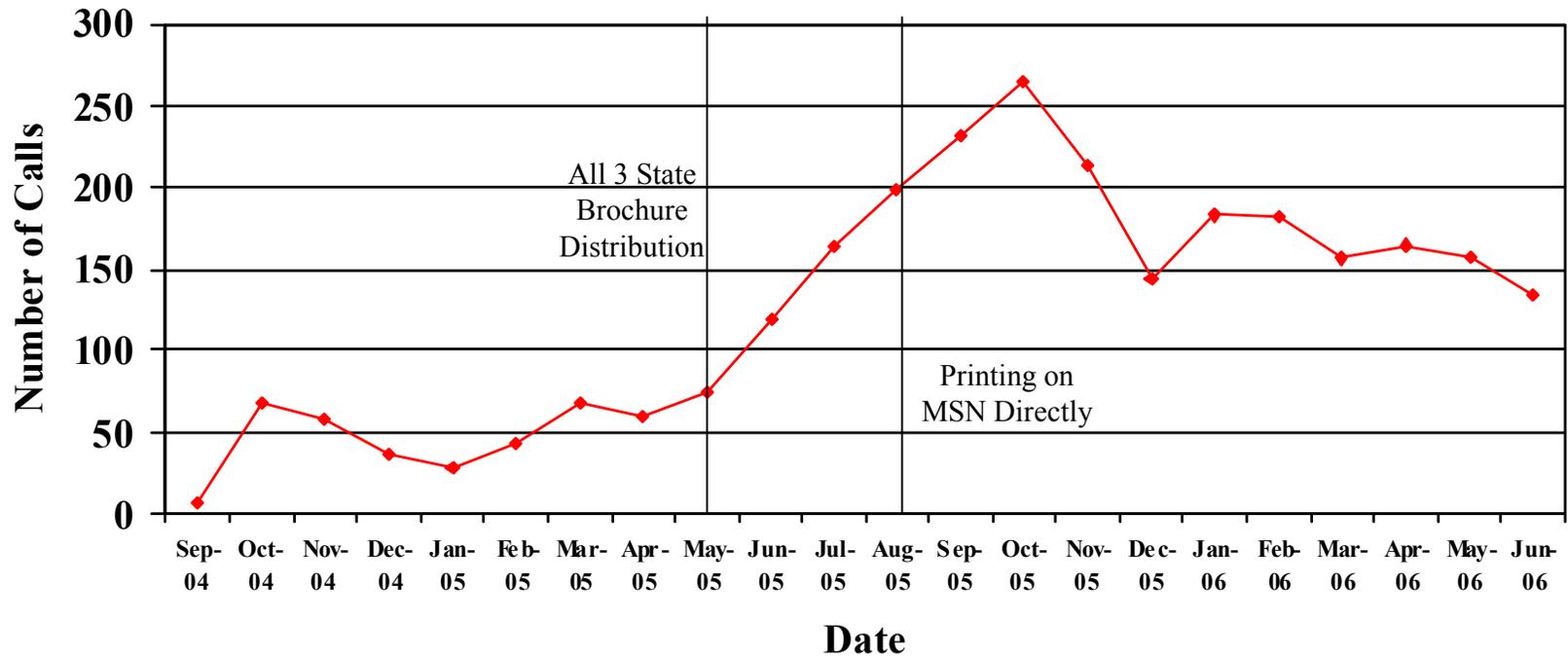
The brochures and MSNs seemed to have generated awareness of the demonstration. The beneficiaries were instructed to call the 1-800-Medicare number for further information, and if the operators could not handle the call, the beneficiary was given a phone number at Abt Associates. The total number of calls per month received by these two sources started to increase after the brochures were first distributed in January, and the number more than tripled as the brochures and MSN notices were distributed in all states (Figure III.2). But while this outreach effort generated interest, it did not result in more demonstration enrollment. Abt Associates staff who handled calls noted that most were from beneficiaries (or their caregivers) ineligible for the demonstration. Most of the callers either did not have a skilled care need or qualified for the regular Medicare home health benefit. They were investigating the demonstration to see whether they could get more help with non-skilled care services.

3. Was the Beneficiary Outreach Successful?

The demonstration efforts to reach out directly to beneficiaries were extensive. But when we asked agencies and beneficiary groups whether information was communicated to potential enrollees, few were willing to offer an assessment. Some informants noted that far more extensive outreach efforts were being conducted simultaneously (for Medicare Part D), and the demonstration information may have been pushed aside by the other activity. Still other informants noted that it is hard to determine how effective a communication is: “With the

⁴ Information on the number of times MSNs were distributed with the Home Health Independence notice is unavailable.

FIGURE III.2
NUMBER OF INQUIRY CALLS ABOUT HHI DEMONSTRATION
 (Includes Calls to 1-800.Medicare and to Abt Associates, Inc.)



Source: Abt Associates, Inc.

Note: Numbers of telephone calls to Abt Associates, Inc. for March 2005 is missing, thus the March 2005 data only shows the number of calls to 1-800-Medicare.

MSN = Medical Summary Notice

amount of information that is being disseminated these days, it's difficult to know what actually reaches the individual." Thus, in contrast with the outreach efforts to home health agencies, where informants felt confident that they knew agencies had heard the information, few felt that they knew whether the eligible beneficiaries had been reached.

IV. WHY WAS PARTICIPATION IN THE DEMONSTRATION SO LOW?

Understanding why participation in the demonstration was so low is important for understanding what Congress may want to do should it decide to implement a national benefit change. Chapter III discussed evidence that outreach activities were successful—most home health agencies and outreach partners were aware of the demonstration, and extensive efforts were made to inform beneficiaries directly. If participation was low because agencies or beneficiaries (or both) faced barriers, then it might increase if the barriers were removed. However, if it was low because few Medicare beneficiaries met the eligibility criteria, then legislators may wish to consider developing different criteria.¹

A. LOW AGENCY PARTICIPATION WAS A KEY FACTOR IN LOW DEMONSTRATION ENROLLMENT

Agency participation in the demonstration was low. Only a minority (27 percent) of the surveyed agencies enrolled patients in the demonstration. Of course, if agencies did not have any patients eligible for the demonstration, they could not have participated. However, examining the patient data gathered in the agency survey, we find that of all the agencies that had eligible patients, only 26 percent reported enrolling patients in the demonstration.

In our discussion with home care providers and their associations, it became evident that agencies had various reasons for not wanting to participate in the demonstration. Because participation was voluntary—agencies did not have to accept demonstration patients—agencies did not have to do anything if they chose not to participate. At the early open-door meetings

¹ Appendix A contains the mandating legislation for the demonstration, including beneficiary eligibility criteria.

where they first heard the details of the demonstration, some agencies voiced their concerns to CMS and Abt Associates, the demonstration contractor, and indicated that they would not participate. The home health associations in the three states all professed neutrality about whether their member agencies should participate, but they made it clear that they thought a number of factors would make participation difficult.

1. Reasons for Agency Nonparticipation

a. Risk of Enrolling Costlier Patients

One of the key reasons agencies and their associations cited in the interviews and survey for the lack of participation was the financial risk. They viewed the potential demonstration patient as being very resource intensive—one who would likely need a large number of home health aide and skilled nursing visits. Under Medicare’s home health prospective payment system, agencies lose money on patients whose care costs more than the preset payment level. Because the patients targeted by the demonstration were *permanently* and severely disabled and required *permanent* skilled nursing care, agencies felt that the typical demonstration patient could cause them to lose money over a long period. Agencies viewed serving these patients without additional payment as an “unfunded government mandate”—and they were glad that the demonstration was voluntary.

During the demonstration outreach, CMS did make it clear to agencies that just because a potential client required assistance with ADLs, the agency did not necessarily have to provide that care for the beneficiary to qualify. For example, a family member who was supplying assistance could continue to do so, and the agency could provide skilled nursing care or some other supplemental coverage. But agencies were concerned that situations change, and while a

patient might start with a number of supportive resources, over time it would be the home health agency providing all of the daily care needs.

We noted in our interviews with agencies that some of the patients who would likely qualify for the demonstration were already in their caseloads, and thus agencies would not bear any additional financial risk by enrolling them. Agencies doubted that this was true. First, they indicated that the types of patients that they envisioned enrolling in the demonstration were likely to be covered by the Medicaid program—not Medicare. (The Medicaid program provides long-term care to disabled recipients, and agencies are more used to serving the disabled under the Medicaid program. Many of these Medicaid recipients, who may be dually eligible, would not have the skilled care needs required by the demonstration.) Second, if agency caseloads contained Medicare patients who were severely disabled, it was unlikely that those patients were able to go out more than the current Medicare regulations allowed. This perception was corroborated by our agency survey: agencies reported that 74 percent of the sample of patients we identified as “potentially eligible” for the demonstration—and 78 percent of the patients the agencies deemed able to meet all the eligibility criteria—would be unable to leave the home if the homebound requirement were eliminated. Further, some of the surveyed agencies reported that they opted not to participate because their patients who met the eligibility criteria were too sick to leave the home more often. Hence, the demonstration was viewed as more paperwork for the agency, but with no benefit for the patient.² In addition, one home health association noted that agencies were concerned that if they enrolled only their current patients, it would be

² Although the demonstration was specifically designed to impose very minimal paperwork burden, some respondents believed that *any* additional paperwork counts as more paperwork. Furthermore, while the actual paperwork of enrolling the patient in the demonstration may have been minimal, agencies still needed to search their caseloads, obtain the approval of the beneficiary’s physician, and track the case through their internal systems.

considered discriminatory if they did not enroll new ones. Because agencies did not want to risk accepting the new patients, it was safer not to participate at all.

b. Difficulties with Joint Billing for Medicare/Medicaid Dual Eligibles

Because agencies thought that Medicare/Medicaid dual eligible clients were more likely to qualify for the demonstration, the question arises: why didn't more duals enroll? Agencies indicated that they faced more barriers to enrollment with Medicaid patients as a result of the interaction between Medicare and Medicaid payment systems. According to two of the state home health associations, the problem arises because under the Medicare episode payment system, agencies are paid a set amount to cover care for a 60-day period, and that amount includes care from a home health aide. Because the home health aide/personal care services provided under the Medicaid benefit are more generous than the home health aide services that Medicare provides, the Medicare payment does not cover the extent of care provided under Medicaid. Thus the associations argued that because the Medicaid program is considered to be the payor of last resort, as long as the episode is in place, the agency cannot bill Medicaid for the additional services. While this is actually not true—CMS has notified agencies that this is not the case and has provided information about how to bill Medicaid for services under these circumstances—the misperception lingered and dissuaded agencies from enrolling dually eligible participants into the Medicare demonstration.

Even for those agencies that understood that they could bill both the Medicaid and the Medicare programs, the system still made it difficult to enroll Medicaid recipients. Neither policymakers nor home health agencies want home health agencies to “double dip”—that is, charge both Medicare and Medicaid for the same service. But the Medicare episode payment

system makes it difficult to clearly delineate what services are paid for by Medicare. This lack of clarity adds to agencies' bookkeeping and care procedures a level of complication that does not exist if all services are covered under one type of insurance.

To complicate things further, agencies anticipated that many of the beneficiaries who would qualify for the demonstration would be those who receive personal care services under Medicaid from independent Personal Care Assistants (PCAs). Although PCAs and home health aides do provide care that can be similar, PCAs do not necessarily meet the same qualifications as home health aides, and home health agencies do not always provide PCA services. (Indeed, some of the PCAs are employed not by any agency but by the individual beneficiary, as in the Massachusetts Personal Care Attendant Program.) When the care being provided is not overseen completely by the home health agency, questions arise as to the nature of the agency's responsibility in the provision of care and what can be billed for and by whom.

One agency offered a hypothetical example: if a Medicaid enrollee has a care plan that allows her to receive 40 hours a week of PCA services, but she enrolls in the Medicare Home Health Independence demonstration, then the Medicaid program would expect the agency to provide 28 hours a week of home health aide services under the Medicare benefit.³ According to the agency, the Medicaid program would no longer allow the beneficiary to receive 40 hours of PCA services under the Medicaid program and hence would reduce the number of hours the PCA could attend to the beneficiary. The agency would then have to try to coordinate the provision of the 28 hours of home health aide services with the 12 hours provided by an

³ Twenty-eight hours is the maximum amount of skilled nursing and aide care that can be provided under the Medicare benefit, as established by the Balanced Budget Amendment of 1997. See Section 206.7 of the Home Health Agency Manual.

independent PCA. The agency was also concerned that the PCA, whose hours would be cut from 40 to 12 per week, would be forced to obtain another job, and the beneficiary would lose her PCA provider.

c. Lower Medicare Reimbursement Rate

The final barrier for agencies in enrolling dually eligible home care recipients, according to one provider who actively tried to enroll beneficiaries (and a few other survey respondents), is the low rate of Medicare reimbursement. One agency had decided for reasons unrelated to the demonstration that it wanted to increase its Medicare caseload. The agency saw the demonstration as a way to do this, and actively searched its Medicaid caseload to identify clients who could qualify. The agency was able to find only four clients that met the criteria, and two of them opted not to enroll. The agency then calculated the payment rates it would receive for the remaining clients and realized that the episode payment of \$2,500 that it would receive from Medicare to cover a 60-day period was much lower than the roughly \$4,000 a month it received from the Medicaid program—and opted not to encourage the participants to enroll.

d. Other Reasons for Agency Nonparticipation

A few respondents to the survey noted a number of other reasons for not participating in the demonstration. A few indicated that they were too busy or had other management priorities that precluded them from learning about the demonstration.

2. Reasons for Agency Participation

Although most of the interviewed agencies indicated that participation was not worth the financial risk, 25 agencies did officially enroll patients in the demonstration, and enrolled anywhere from one to 10 patients. These were primarily rural, nonprofit, or government

agencies: 46 percent were from rural areas (compared with 34 percent nationwide); 62 percent were nonprofit, 23 percent were government affiliated, and 15 percent were for-profit. (Nationwide, 34 percent of home health agencies are nonprofit, 15 percent are government affiliated, and 52 percent are for-profit [Medpac 2004].)

The agencies we spoke with that did participate did so because they thought it was the “right thing to do.” When asked whether they were concerned about the cost of serving these patients, they indicated either that it was their mission to serve them or that they had not considered the cost issues and had not investigated whether the cost of services provided to these patients would exceed their reimbursement rate.

B. DID BENEFICIARIES FACE BARRIERS TO ENROLLING?

Because most agencies were not participating in the demonstration, as the survey data demonstrates, it makes it impossible to identify whether there were other systematic barriers to beneficiary participation. The demonstration enrollment process depended upon agencies to enroll patients, and agencies’ nonparticipation makes it difficult to observe other factors that would hinder enrollment. Further, many of the agencies we spoke with had not tried to enroll participants—and the associations were unaware of agencies that had chosen to participate. Thus, the informants that we interviewed could only hypothesize as to what may have hindered patient enrollment.

1. Barriers for Medicare Beneficiaries

For patients who were already in Medicare home health, informants generally didn’t think there would be patient barriers to enrollment. If a Medicare home health recipient was enrolled, the only thing that would change for the beneficiary is that he or she would be permitted to leave

home more often. Hence, the only concern that informants thought could arise is what would happen to the beneficiary at the end of the demonstration. That is, would the beneficiary lose the Medicare home health benefit if he or she left home more often than currently allowed and then the demonstration ended? This question was raised during CMS's Open-Door meetings, and CMS explained that the beneficiary would not lose home health eligibility as long as the person met the homebound requirements after the demonstration. That is, behavior during the demonstration would not affect post-demonstration eligibility.

2. Barriers for Medicare/Medicaid Dual Eligibles

Informants did identify barriers for patients who were receiving Medicaid services. The first barrier, as articulated by disability advocates we interviewed, is that Medicaid home care benefits are better designed to meet the needs of disabled beneficiaries than the Medicare home health benefit. First, advocates argue that most disabled beneficiaries do not require skilled nursing services but instead need more personal care services. Because the Medicare home health benefit does not cover personal care services but covers home health aide care only when there is also a need for skilled care, many disabled beneficiaries do not qualify for Medicare home health services.⁴ Second, even if the recipient does need skilled care, the dominance of the “medical model” in Medicare home health (which requires that the plan of care be created by a skilled provider and approved by a physician) misses the point that those with disabilities want to control their own care—they do not want to be “taken care of.” Potential enrollees for the Home

⁴ Note, however, that informants involved in the design of the legislation said that this demonstration was specifically not designed to meet the needs of people who needed unskilled care. As one informant noted, “This was not a back-door attempt to get a long-term care benefit into Medicare home health”—the designers were looking to provide care to a much smaller group of beneficiaries.

Health Independence demonstration who were dually eligible also had the options from their state Medicaid programs or home- and community-based waiver programs, such as Missouri's PCA Program, Colorado's Consumer Directed Attendant Support Program, or Massachusetts's Personal Care Attendant Program. According to some disability advocates, these programs were much better at meeting the needs of disabled beneficiaries.

3. Other Barriers

Informants and a couple of survey respondents also identified other factors that kept beneficiaries from enrolling in the demonstration. One issue raised was that beneficiaries were reluctant to change the status quo, even if it would be financially advantageous. For some of these beneficiaries, it takes a great deal of effort to put support services in place. Thus they do not want to change that support system, even if it means that Medicare would now pay for services that they would otherwise pay for themselves.

C. HOW DID THE DEMONSTRATION ELIGIBILITY CRITERIA AFFECT THE DEMONSTRATION?

1. How Did the Stakeholders Perceive the Eligibility Criteria?

One factor that all informants cited as a major barrier to enrollment was the stringent eligibility criteria that had to be met in addition to the regular Medicare requirements.⁵ Informants as well as the survey respondents indicated that they thought these criteria, particularly the permanent skilled nursing need and employment requirements, were too

⁵ As described in Chapter I, these criteria were having a permanent disability, a permanent skilled nursing need other than medication management, a permanent need for daily help with three of five ADLs, requiring a daily attendant to treat and monitor the condition or provide ADL assistance on a permanent basis, and a need for the assistance of a device or person to leave the home. In addition, enrollees could not be working for pay outside the home.

restrictive and were contributing to the low enrollment. When asked about whether eligible beneficiaries knew about the demonstration, one responded: “If you can look at that list of eligibility criteria and tell me who qualifies, maybe I can tell you if they knew about it.”

a. Perceived Restrictiveness of the Permanent Skilled Nursing Criterion

Interviewees generally agreed that the most difficult criterion to meet was the need for permanent skilled nursing care. Designers of the legislation had included this criterion to identify people who were ill and needed health care services, but they did not want to name specific diseases because they were concerned that if they did, they would inevitably leave out a rare condition that should qualify. Many of our informants—as well as staff at CMS—had a difficult time identifying any skilled nursing need that was permanent. The only two permanent skilled nursing needs that informants could identify were (1) changing of a Foley catheter and (2) giving injections for pernicious anemia. A few informants thought that gastrostomy tubes or tracheotomy care might qualify as permanent skilled care needs, but others thought that these skills could be taught to caregivers and hence should not be considered permanent skilled care.

In addition, a few agencies indicated during the Open Door sessions that they interpreted the permanent skilled nursing criteria to be in violation of the Condition of Participation. One of the conditions states that in order to receive Medicare home health services, a patient must be “in need of skilled nursing care on an intermittent basis,” where “intermittent” means skilled nursing care that is either provided or needed on fewer than 7 days each week or less than 8 hours of each day for periods of 21 days or less.” The agencies interpreted the demonstration criteria as needing permanent, daily skilled nursing care that would exceed the 21 day threshold.

While this interpretation is not correct, this misperception was another contributing factor to agencies nonparticipation in the demonstration.

b. Perceived Restrictiveness of Employment Criterion

In Massachusetts, disability advocates and respondents argued that the employment criterion was also a significant barrier to enrollment. Informants noted that one group of beneficiaries who might have qualified for the demonstration were the developmentally disabled, but because they are generally employed in sheltered workshops, they would be ineligible.⁶ Disability advocates suggested that the work requirement would be a large impediment to enrollment, as many disabled people want to receive help precisely so that they can go to work and engage in productive activity. Note, however, that when designing the law, some legislators felt strongly that if a person were able to go to work, Medicare should not be paying for home health aide care and that was why the work criterion was incorporated.

2. Analysis of Effect of Eligibility Criteria

To understand better which of the eligibility criteria limited enrollment, we selected patients who were already part of the surveyed agencies' caseloads and who, based on their administrative records, potentially met the enrollment criteria.⁷ (See Chapter II for details on the data and sample.) In our survey, we asked agencies to indicate which of the demonstration criteria these patients actually met. The responses, presented below, are weighted to compensate

⁶ CMS confirmed that sheltered workshops were considered employment outside the home, and hence these beneficiaries were ineligible.

⁷ These criteria include that the person had two contiguous episodes of home health care, required help with at least three ADLs, and needed human or technological assistance to move.

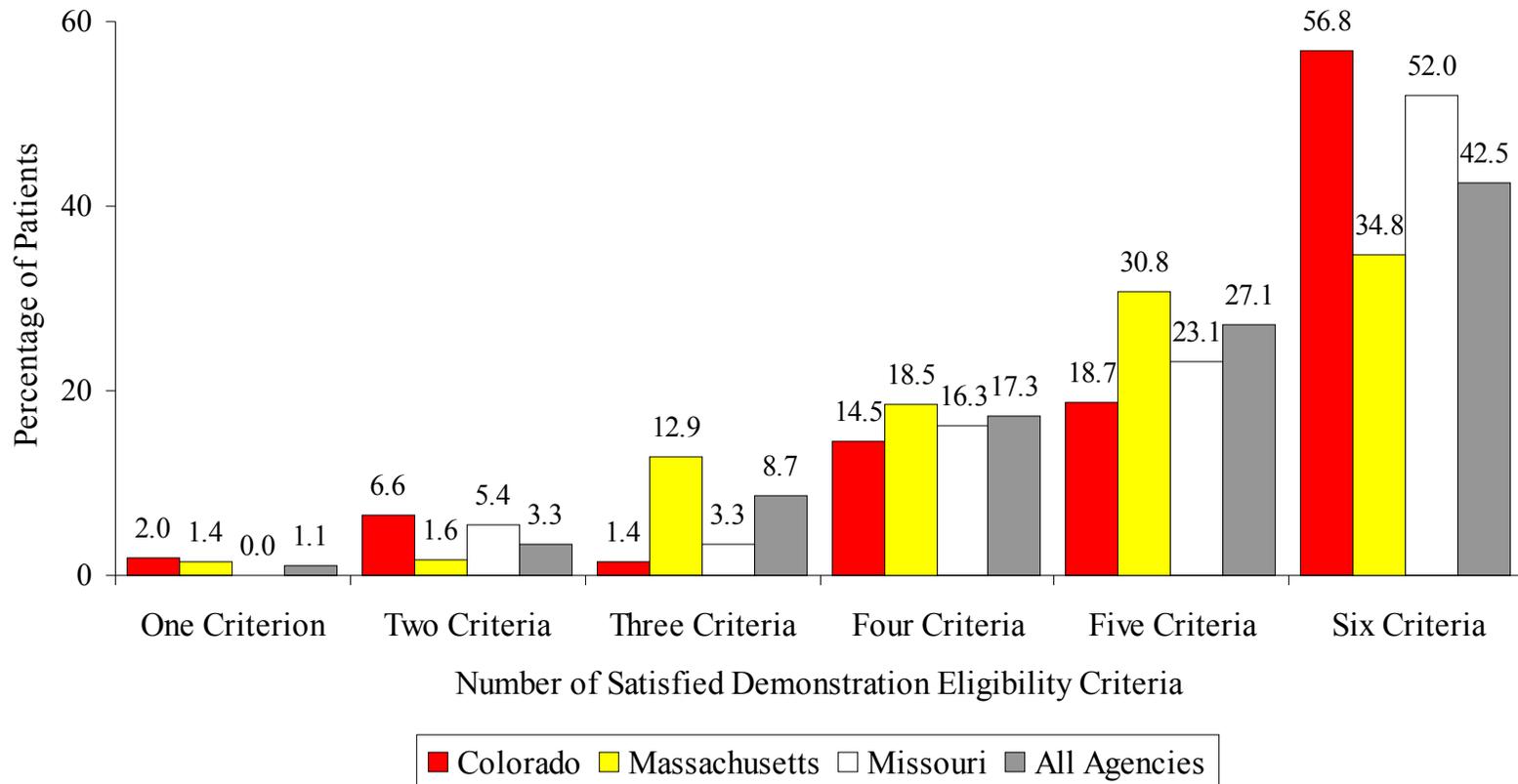
for the differences in the probability of agency selection and nonresponse. We purposely selected patients from OASIS who we thought were good candidates for the demonstration (had two prior episodes of home health care, needed help with at least three ADLs, and used technological or human assistance to leave the home), but because these criteria do not exactly correspond to the demonstration criteria, our estimates of the number of eligible enrollees may be underestimated, as we are implicitly assuming that there are no eligible patients among those that did not meet our “potentially eligible” criteria. However, the number of patients who would meet the demonstration eligibility criteria but not meet our potentially eligible criteria is likely to be small.⁸

Based on the survey data, many more beneficiaries than the official 58 enrollees would have been eligible, but the total eligible beneficiary population would still be much smaller than the 15,000 person cap Congress imposed. The surveyed home health agencies indicated that about 42 percent of the sample of potentially eligible patients identified from the administrative records met all the eligibility criteria, representing a total of 2,015 people with a 95 percent confidence interval ranging from 1,523 to 2,507 in the three states (Figure IV.1). This is an undercount of the total eligible patients, as the sample represents only agencies that had at least five patients who met the potential eligibility criteria. If we assume that the same proportion of patients in the

⁸ For example, it is very unlikely that beneficiaries would have a permanent need for help with 3 or more ADLs yet at the same time not have needed any help with ADLs during their home care stay. As noted in Chapter II, we had opted to select patients based on their potential eligibility because if we used a general random sample, we thought we might not identify any eligible patients.

FIGURE IV.1

DIFFERENCES AMONG POTENTIALLY ELIGIBLE MEDICARE HOME HEALTH PATIENTS
IN THE TOTAL NUMBER OF SATISFIED DEMONSTRATION
ELIGIBILITY CRITERIA, BY STATE



Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007.

non-sampled agencies (those with fewer than five patients) met the criteria, 134 beneficiaries would be added to the eligible population, for a total of 2,149.⁹

Patients in Massachusetts were the least likely (35 percent) to meet the eligibility criteria, in contrast to the proportions of eligible patients in Colorado (57 percent) and Missouri (52 percent). The greater difficulty patients in Massachusetts had in satisfying the criteria may have contributed to the state's enrolling only six patients, the fewest in the demonstration. The low enrollment could also reflect the relative generosity of other kinds of services these types of beneficiaries use (nursing homes, assisted living, and home- and community-based services), which might have led fewer of them to use Medicare home health services. However, other factors may have contributed to the low enrollment—such as differences in how the agencies interpreted the criteria or fewer agencies in Massachusetts willing to participate.

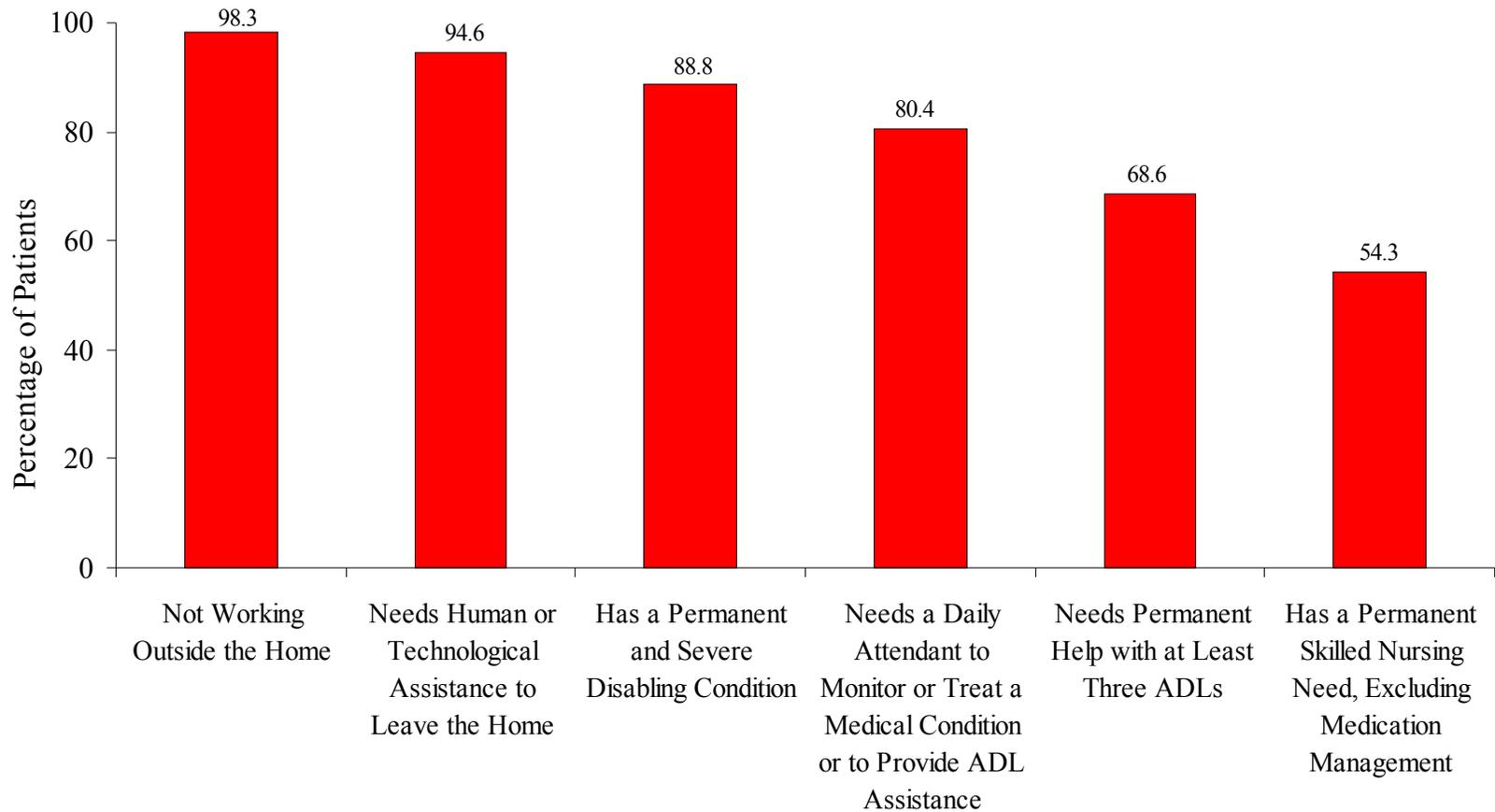
Confirming the expectations of stakeholders, the permanent skilled nursing need was the most difficult requirement for beneficiaries to meet. Slightly over half the potentially eligible beneficiaries (54 percent) had a permanent skilled nursing need as defined by the agency (Figure IV.2). In contrast, a high proportion (95 percent) needed human or technological assistance to leave the home, and about 98 percent of the beneficiaries did not work regularly outside the home.¹⁰ The frequency of meeting the other criteria fell between these two extremes:

⁹ We identified 314 patients in all the non-surveyed agencies who met the “potentially eligible” criteria. Patients served by agencies that did not submit OASIS data or did not submit valid OASIS data would be excluded from this estimate.

¹⁰ To measure employment status, agency respondents were asked to select among various employment statuses that would fulfill the criterion of not working outside of the home regularly. They were not given the option to indicate that the patient was employed outside of the home. Therefore, the missing responses could not be interpreted to mean clearly that the patient was employed or that the agency skipped this item. Excluding these responses from the analysis would have generated a result showing that 100 percent of the patients did not work outside of the home regularly. Therefore, unlike the other analyses, all “don't know” or missing responses were included in the base for computation.

FIGURE IV.2

PERCENTAGE OF POTENTIALLY ELIGIBLE MEDICARE HOME HEALTH PATIENTS MEETING EACH OF THE DEMONSTRATION CRITERIA



Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007.

69 percent met the criterion of requiring permanent help with at least three ADLs, 80 percent required an attendant on a daily basis to monitor or treat a medical condition or to provide assistance with ADLs, and 89 percent had a permanent and severe disabling condition.

3. Effect of Agencies' Varying Interpretations of Key Criteria on Number of Eligible Beneficiaries

One important factor to consider is how the agencies' interpretation of the criteria affected enrollment. Two of the criteria—permanent skilled nursing and permanent and severe disabling conditions—had to be interpreted by the agencies. To understand how the agencies defined these two criteria, the survey asked the agencies to indicate if the selected patient met the criteria, and, if so, to list the specific ICD-9 code(s) or medical conditions and the type of permanent skilled nursing need(s). Some of the surveyed agencies interpreted the skilled nursing criteria more broadly than many of the associations, advocacy groups, and home health agencies with whom we originally discussed the demonstration. While many of the informants we spoke with indicated that the only permanent skilled nursing services they could think of were catheter care and administration of drugs for pernicious anemia, the surveyed agencies cited 11 types of such services. Among the patients in the survey who were identified as having a permanent skilled nursing need, the most common service was assessment, which was provided to 48 percent of the potentially eligible patients.¹¹ Catheter care (38 percent) and injections (16 percent) were the next most common permanent skilled nursing needs, which is consistent with the perception that these services would account for most such services. Other services that the agencies identified as involving permanent skilled nursing included wound care (15 percent of the patients); foot and

¹¹ Excludes patients for whom agencies indicated, but did not identify, a permanent skilled nursing need.

nail care (12 percent); and teaching patients, caregivers, and/or their home health aides (10 percent). The other permanent skilled nursing needs mentioned included blood draws, tracheotomy and ventilator care, gastrointestinal tube care, intravenous line care, ostomy maintenance, and dialysis.

These broad interpretations are likely to generate debate among caregivers and policymakers over whether some of these services are truly permanent in nature, and hence whether the patients are truly eligible. Aside from the catheters and injections, these services may be considered permanent only in certain situations, thus creating gray areas for interpretation. According to the Medicare Benefit Policy Manual, assessment and observation by a nurse are generally deemed reasonable only if changes are expected in the condition and consequently the treatment regimen.¹² Therefore, assessment would not be a permanent skilled nursing need for patients whose conditions are stabilized, even if they are not likely to improve. Teaching cannot be a permanent service, according to the Medicare manual, as it is expected to end when it becomes apparent after a reasonable period that the caregivers who are receiving the training cannot be trained. With respect to wound care, while it is possible that certain wounds would not heal and would thus necessitate permanent care, many wounds tend to resolve over time—and one would need a way to try to distinguish between the two types.

Foot and nail care may generate the most debate as to whether it is a permanent skilled nursing service. Unlike the other nursing services the agencies identified, this service is not explicitly defined as “skilled nursing” in the Medicare Benefit Policy Manual. Furthermore, it

¹² The Medicare manual does not define *permanent skilled nursing care*, as it was a new concept for this demonstration.

can be argued that this is a skill that can be taught to caregivers. However, as foot and nail care involves cutting, some states do not allow home health aides to perform it, which suggests that caregivers may be similarly limited. For example, in the state of New York, nail cutting falls under the category of home health aide services that are “permissible only under special circumstances” (New York State Department of Health 2007).

As with the types of permanent skilled nursing care defined by the agencies, it is also not clear as to whether these conditions are permanent in nature. For example, agencies listed conditions that do not start off as disabling, but inevitably become progressively disabling over time, such as Parkinson’s disease, multiple sclerosis, and Alzheimer’s disease. The surveyed agencies also specified conditions that are not always disabling but can be disabling under certain circumstances for certain individuals. These include wounds, severe depression, obesity, diabetes, and congestive heart failure. These conditions need further clarification to determine the conditions under which they qualify as “disabling” as well as when they become “permanently” disabling.

In summary, in the specific context of the demonstration, a few thousand beneficiaries could have qualified if all agencies had chosen to participate and if there were no other barriers for participation such as the financial disincentives and billing issues faced by the agencies, and the greater appeal of the Medicaid benefit for dual eligibles. In the view of the surveyed agencies, most of those patients would have been unable to leave their homes even if the homebound requirement had been lifted. However, under the demonstration, agencies were allowed to define such criteria as “permanent skilled nursing need” and “permanently disabled,” and we found that some of the surveyed agencies opted for very liberal interpretations when they indicated if potentially eligible patients met the criteria. This suggests that there is potential for growth in

the number of beneficiaries who could qualify if all agencies were to adopt the most liberal definitions that some used.

4. How Would Relaxing the Criteria Affect the Numbers of Eligible Beneficiaries?

If legislators were to loosen the eligibility criteria to allow more beneficiaries to qualify, eliminating the requirement of needing permanent skilled nursing would result in the greatest increase in eligible beneficiaries. Under the restrictions of our sample selection criteria, the total number would grow from 2,015 to 2,864, or 18 percentage points, from 42 percent to 60 percent (Table IV.1). The second largest increase in eligible beneficiaries would result from removing the requirement of needing permanent assistance with at least three ADLs: the total would rise from 2,015 to 2,390, and the proportion of eligible beneficiaries from 42 percent to 50 percent. If legislators opted to remove both requirements, the permanent need for skilled nursing and help with three ADLs, the proportion of eligible beneficiaries would rise to 75 percent, or a total of 3,569.

Another possible way to change the criteria would be to reverse the exclusion in the Section 702 statute of medication management as a permanent skilled nursing service. We asked agencies in the survey which of the potentially eligible patients who did not have a permanent skilled nursing need did have a need for permanent medications management, and agencies indicated that 10 percent of their potentially eligible patients required only medication management. If medication management were allowed to be a permanent skilled care need, the proportion of eligible beneficiaries would increase from 54 percent to 64 percent.

TABLE IV.1

THE FIVE MOST FREQUENT COMBINATIONS OF SATISFIED DEMONSTRATION ELIGIBILITY CRITERIA
AMONG POTENTIALLY ELIGIBLE MEDICARE HOME HEALTH PATIENTS

Type of Patient	N	Percentage of Total Patients	Demonstration Eligibility Criteria Satisfied					Needs Daily Attendant
			Permanent and Severe Disabling Condition	Needs Human or Technological Assistance to Leave Home	Not Working Outside the Home	Needs Permanent Skilled Nursing Care	Needs Permanent Help with at Least Three ADLs	
Meeting the most frequent combination of criteria	2,015	42.5	X	X	X	X	X	X
Meeting the second-most- frequent combination of criteria	849	17.9	X	X	X		X	X
Meeting the third-most- frequent combination of criteria	375	7.9	X	X	X	X		X
Meeting the fourth-most- frequent combination of criteria	328	6.9	X	X	X			X
Meeting the fifth-most- frequent combination of criteria	230	4.9	X	X	X			

Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007.

D. TECHNICAL PROBLEMS WITH ENROLLMENT

Another possible explanation for the observed low enrollment is that the electronic enrollment reporting process failed to work as planned, and thus more beneficiaries were enrolled than the records indicate. The process was designed to minimize the reporting burden for participating home health agencies by incorporating enrollment in the usual billing practices. Generally, home health agencies submit a Request for Anticipated Payment (RAP) at the beginning of an episode and a final claim at the end. Under the demonstration, to enroll a patient, agencies were instructed to enter the code “HHDEMO” in the Remarks field (FL84) of the RAP, the final claim, and any intervening claims for the episode. The RAP and claims would be transmitted to the RHHI, sometimes by using the software or services provided by contracting vendors, which would process it through the Fiscal Intermediary Standard System (FISS). The FISS had been modified so that when Part A claims were processed, any claim with the HHDEMO code would be written into a special file. Each week, this file would be transferred to the CMS Data Center. Abt Associates, the demonstration support contractor, would identify all RAPs or claims with the HHDEMO code for new beneficiaries, add this record to its enrollment database, and send a welcome letter to the beneficiary.

During the demonstration, enrollment problems occurred at the agency level, during transmission to the RHHI, and during the FISS processing. According to the demonstration contractor, there were two types of enrollment problems at the agency level. The first involved agencies that failed to enter the code on the RAPs or claims. When the agency failed to enter the code on the RAP and all the claims for an enrollee, these claims would not be transferred to the CMS Data Center or Abt Associates, and the enrollee would not be added to the enrollment database. When the agency entered the code on only one of the claims but not all of them, CMS and Abt Associates would have a record of the enrollment, but the possibility would arise that

the agency had entered the code by mistake on the one claim and this patient was not really an enrollee—and there was at least one case where this actually occurred. The second problem involved agencies’ entering an incorrect code, such as “HH DEMO” or “HOME HEALTH DEMONSTRATION.” Such variations would not be flagged by the FISS, and these records would not be transmitted to the CMS Data Center or Abt Associates. Problems also occurred during the transmission of RAPs and claims from the agencies to the RHHI. Although the agencies may have entered the code correctly on the RAPs and claims, the code may not have been transmitted to the RHHI. At least one home health agency’s billing vendor systematically failed to transmit data from the remarks field to the RHHI along with the claims.

The fourth type of problem was related to the FISS, which in some cases failed to identify claims with the correct “HHDEMO” code; hence, these claims were not transmitted to the CMS Data Center and Abt Associates. Abt Associates identified this problem in May 2005, but the FISS system change to address it was not implemented until August 2006, near the end of the demonstration. In the interim, the two “main” RHHIs serving the demonstration states undertook monthly runs to identify all claims with the valid code “HHDEMO” and variations, such as “HH,” “DEMO,” “DEMONSTRATION,” and so on. (The other two RHHIs declined to do such runs on a regular basis because they had only a few providers in the demonstration states.) Eventually, about a third of the new, official demonstration enrollees were identified via these special runs.

It is impossible to know how many enrollees were “lost” in the enrollment process because agencies failed to code the claims at all or because they submitted a code variation that was not picked up by the algorithm used for the special runs. However, Abt Associates reported an official demonstration enrollment of 58 patients, while the agencies in the survey reported that they enrolled 330 patients (weighted as indicated above; with a 95 percent confidence interval

from 101 to 559)—and 330 patients will be an undercount, as some enrollees came from small agencies that did not have enough potentially eligible enrollees to be included in the survey.

What could account for the difference between the official enrollment figures and the estimated number of enrollees from the survey? Weighting the estimates for nonresponse could account for some of the difference—we assume that the agencies who did not respond have the same likelihood of enrolling patients as those that did, and this may not be the case. In addition, the technical problems in transmission of claims may have lost patients, but agencies may have reported on the survey that they enrolled patients who they “meant” to enroll. During our evaluation site visits to two agencies, they reported to us that they had enrolled patients, but the demonstration contractor did not have these patients on their records. Upon further investigation, the agencies found that the information had not been recorded on the claim.

V. WHO ENROLLED IN THE DEMONSTRATION, AND WHAT WERE THEIR EXPERIENCES?

In this chapter, we describe the demographic characteristics and medical conditions of 57 official demonstration enrollees using their Medicare claims from before the demonstration.¹ We also present health care expenditure and utilization data for 44 of these demonstration enrollees who enrolled early enough in the demonstration for us to observe their health care utilization.² As discussed in Chapter IV, agencies that officially enrolled their patients in the demonstration were disproportionately small, rural agencies, and thus their experiences cannot be used to project to national estimates. However, the information can be used to understand better the conditions of the beneficiaries who were enrolled in the demonstration; they will represent some part of the overall population that can be expected to qualify for such a benefit.

A. WHO ENROLLED IN THE DEMONSTRATION?

1. Demographic Characteristics

The average enrollee was more likely than the typical Medicare home health beneficiary to be a young Caucasian male (Table V.1). While people under 65 made up 10.4 percent of Medicare beneficiaries receiving home health care in the fee-for-service program nationwide in 2004 (CMS 2006a), 38.6 percent of the enrollees were in this age category. Racial/ethnic minorities accounted for only 5.3 percent of the enrollees, in contrast to 17.8 percent of Medicare

¹ A total of 58 beneficiaries enrolled in the demonstration, but we could not obtain an enrollment date for one participant.

² We could not observe health care utilization for all 57 enrollees due to time lags in Medicare claims data. See Chapter II for more details.

TABLE V.1

DEMOGRAPHIC CHARACTERISTICS AND COMMON DIAGNOSES
FOR ENROLLED BENEFICIARIES

Demographic Variables	
Age (percent)	
Under 65 years	38.6
65 years and older	61.4
Female (percent)	47.4
Medicaid state buy-in for Part B (percent)	21.1
Minority (percent) ^a	05.3
Number of Different Diagnoses in Prior Year (Mean)	10
Most Frequent Diagnoses in Prior Year [ICD-9 Code] (Percent)	
Other disorders of urethra and urinary tract [599]	36.8
Chronic ulcer of skin [707]	31.6
Diabetes mellitus [250]	28.1
General symptoms [780]	28.1
Symptoms involving urinary system [788]	24.6
Other paralytic syndromes [344]	21.1

Source: Medicare claims files for 57 demonstration participants.

^aIncludes all beneficiaries who are not categorized as white.

home health users nationwide. Males represented 52.6 percent of the enrollees (and 35.9 percent of the national home health users group).

Contrary to the anticipation among the agencies we interviewed that dually eligible beneficiaries would be more likely to fit the demonstration criteria, the proportion of enrollees who were dually eligible (21 percent) was just slightly less than the proportion of the dual eligible home health users (23 percent) in 1999 (McCall et al. 2003).^{3,4} The low rate of dual eligibles could reflect the emphasis of the demonstration criteria on enrolling severely ill disabled beneficiaries, which may have excluded more Medicaid recipients than our home health agency interviewees anticipated; it might also reflect a reluctance to enroll Medicaid patients, as discussed in Chapter IV.

2. Health Conditions

Consistent with the targeting of a permanent and severely disabled population, the patients in the demonstration had multiple health problems. Each enrollee received health care services for an average of 10 different primary diagnoses during the year prior to enrollment. Many suffered from chronic illnesses associated with disability and lack of mobility. In the year before the demonstration, urological disorders were the predominant problem for these enrollees, with about 37 percent receiving care for unspecified infections and obstructions of the urethra and the urinary tract and about 25 percent receiving care for symptoms involving the urinary system. Chronic ulcer of the skin was another common problem, for which about a third of the enrollees

³ We are defining *dually eligible* participants as those whose Part B premium was paid for by a state Medicaid buy-in program. This definition does not encompass the entire dually eligible population.

⁴ Includes Medicare beneficiaries in both the fee-for-service and the managed care programs. The buy-in rate was calculated from the Medicare EDB.

received care. Other frequent conditions included diabetes mellitus, general symptoms such as memory loss or fever, and “other paralytic syndromes.” These diagnoses were also reflected among the enrollees who were interviewed. Paraplegia was common among the beneficiaries we interviewed, particularly the younger ones, and these patients were likely to need help with catheter care. Other conditions included Alzheimer’s disease, leg paralysis from stroke, vascular and circulatory problems, Parkinson’s disease, and progressive muscular atrophy.

3. Utilization and Expenditures

We were not surprised that, with their extensive medical issues, demonstration enrollees had mean Medicare expenditures five times higher than for the average Medicare enrollee in the year preceding enrollment.⁵ Part A and Part B expenditures for the enrollees averaged \$18,299 and \$17,474, respectively, with total Medicare expenditures of \$35,773. In comparison, the average Medicare beneficiary generated an annual program payment of \$3,843 for Part A covered services and \$3,177 for Part B covered services, with payments of \$7,021 for total Medicare payments (CMS 2006d).⁶

The enrollees’ higher expenditures were due to their greater use of a number of different services. In the year before enrollment, 72 percent of the enrolled beneficiaries were admitted to the hospital (in contrast to 21 percent of Medicare beneficiaries nationally), 23 percent were admitted to a skilled nursing facility (in contrast to the national average of 4.9 percent), and

⁵ The analysis from this point on includes only the 44 patients who enrolled in the demonstration prior to March 31, 2006, and for whom we had complete data through July 31, 2006.

⁶ Excludes Medicare enrollees of managed care programs. The payment per enrollee rates were calculated based on Medicare data and may include some rounding error. Note that national estimates for home health users were unavailable.

75 percent received home health services (in contrast to 7.8 percent; Table V.2) (CMS 2006d and 2006e).⁷ Home health expenditures for the demonstration participants in the year before their enrollment were \$5,581, compared with \$4,039 for the average Medicare home health recipient (CMS 2006e).⁸

The health problems of these patients continued after they enrolled. Over the first four months after enrollment, 36 percent entered the hospital (compared with 21 percent over a full year for Medicare beneficiaries nationally) and incurred \$4,417 worth of home health payments, again exceeding what the typical Medicare home health user incurs in an entire year.⁹

B. UTILIZATION OF HOME HEALTH SERVICES

Reflecting the severity of medical conditions and health care needs, the demonstration enrollee received, on average, more home health visits than the average Medicare home health patient. In the year prior to enrollment in the demonstration, the average enrollee received 63.3 visits, about double the yearly average of 31 visits for the national home health users' group (Table V.3) (CMS 2006e).¹⁰

There was considerable variation across the three states in both the number of enrollees and the average number of home health visits received in the year prior to enrollment. Massachusetts

^{7,8} Excludes Medicare enrollees of managed care programs.

⁹ In most cases, we would expect the four month average home health expenditures of \$4,417 for these demonstration enrollees to approximate their twelve month average home health expenditures. The premise for this assumption is that for the average Medicare beneficiary, the average number of episodes per year is two episodes, and the episodes are generally contiguous. However, the considerable difference in the home health expenditures in the twelve month period and the four month period preceding enrollment for these demonstration enrollees suggests that their case is very likely to continue after our four month observation period, and that their average yearly home health expenditures following enrollment will exceed the four month total of \$4,417.

¹⁰ Excludes Medicare enrollees of managed care programs.

TABLE V.2

HEALTH UTILIZATION BEFORE AND AFTER DEMONSTRATION ENROLLMENT

	In the Year Before Enrolling in Demonstration	Up to 4 Months Before Enrolling in Demonstration	4 Months After Enrolling in Demonstration
Percentage with a hospital admission	72	36	36
Percentage with a skilled nursing facility admission	23	14	2
Percentage receiving home health care	75	61	100
Mean total home health care expenditures (dollars)	5,581	2,141	4,417
Mean total Part A expenditures (dollars)	18,299	7,971	5,162
Mean total Part B expenditures (dollars)	17,474	7,149	9,830
Mean total Medicare expenditures (dollars)	35,773	15,121	14,991

Source: Medicare claims files for the 44 demonstration participants who enrolled in the demonstration prior to March 31, 2006.

TABLE V.3

MEDICARE HOME HEALTH CARE UTILIZATION BEFORE AND AFTER DEMONSTRATION ENROLLMENT, BY STATE

	8 to 12 Months Before Enrolling in Demonstration	4 to 8 Months Before Enrolling in Demonstration	Up to 4 Months Before Enrolling in Demonstration	4 Months After Enrolling in Demonstration
Mean Number of Total Visits				
Colorado				
All enrollees (n = 15)	11.5	2.4	13.7	56.0
Home health users	34.6 (n = 5)	35.5 (n = 1)	68.5 (n = 3)	
Massachusetts				
All enrollees (n = 5)	76.9	62.5	63.7	69.8
Home health users	96.2 (n = 4)	78.1 (n = 4)	63.7 (n = 5)	
Missouri				
All enrollees (n = 24)	13.6	22.1	20.7	44.2
Home health users	29.8 (n = 11)	31.2 (n = 17)	26.2 (n = 19)	
All Three States				
All enrollees (n = 44)	20.1	20.0	23.2	51.1

Source: Medicare claims for 44 demonstration enrollees who enrolled in the demonstration prior to March 31, 2006.

Note: All enrollees include enrollees who used home health services and enrollees who did not use home health services. Home health users include only the enrollees who used home health services. The number of enrollees who received home health services (19) is provided for each period.

had the fewest enrollees (6), Colorado had 15, and Missouri had the most (24). The average of 203.1 home health visits received by the five Massachusetts enrollees in the year before enrollment was many times greater than the 27.6 visits and 56.4 visits received by the Colorado and Missouri enrollees, respectively (Table V.3).¹¹ This gap reflects the differences in the composition of the groups of patients enrolled within each of these states. Massachusetts had enrolled a very small number of beneficiaries, and they were all high users of home health care. In the four months preceding enrollment, all five were receiving home health care and received an average of 63 visits. In Colorado, only a few of the enrollees were receiving home health care prior to the demonstration, but those that used home health care had a high number of visits: 68 in the four months preceding enrollment. It was the opposite situation in Missouri, where 79 percent of the enrollees were already receiving home health services, but their average number of home health visits (26) was modest compared with the levels for Colorado and Massachusetts.

Across all the enrollees, the average number of visits doubled in the four months after enrollment from the prior four-month period—from 23 to 51 (Table V.4). About 93 percent of the increase was due to increases in skilled nursing and home health aide visits. Skilled nursing visits increased from 11 to 21 and home health aide visits from 9 to 25. Physical therapy visits accounted for 5 percent of the increase, and other services (speech therapy, occupational therapy, and medical social worker visits) accounted for the remaining 2 percent.

¹¹ Six enrollees were from Massachusetts; but as noted in Chapter II, we could not obtain the enrollment date for one beneficiary.

TABLE V.4

MEDICARE HOME HEALTH UTILIZATION BEFORE AND AFTER DEMONSTRATION ENROLLMENT FOR ALL,
NEW, AND CONTINUING MEDICARE HOME HEALTH PATIENTS

	8 to 12 Months Before Enrolling in Demonstration	4 to 8 Months Before Enrolling in Demonstration	Up to 4 Months Before Enrolling in Demonstration	4 Months After Enrolling in Demonstration
Mean Number of Skilled Nursing Visits Overall				
New (N = 17)	2.9	1.3	0	14.8
Continuing (N = 27)	12.5	14.2	18.6	25.2
All	8.8	9.2	11.4	21.2
Mean Number of Home Health Aide Visits				
New (N = 17)	3.4	0	0	30.1
Continuing (N = 27)	12.5	12.7	14.5	21.7
All	9.0	7.8	8.9	24.9
Mean Number of Physical Therapy Visits				
New (N = 17)	1.1	0.5	0	3.8
Continuing (N = 27)	2.2	2.3	3.5	3.5
All	1.8	1.6	2.1	3.6
Mean Number of Other Types of Visits ^a				
Mean number of other types of visits (new) (N = 17)	0.2	0	0	1.0
Mean number of other types of visits (continuing) (N = 27)	0.7	2.2	1.2	1.6
All	0.5	1.4	0.8	1.4
Mean Number of Total Home Health Visits (All) ^b				
Total home health visits (new) (N = 17)	7.7	1.8	0	49.7
Total home health visits (continuing) (N = 27)	28.0	31.4	37.8	52.0
All	20.1	20.0	23.2	51.1

Source: Medicare claims for 44 enrollees—17 new and 27 continuing Medicare home health beneficiaries—who enrolled in the demonstration prior to March 31, 2006.

Note: “New” refers to demonstration enrollees not receiving Medicare home health care at the time of enrollment and “continuing” refers to demonstration enrollees already receiving Medicare home health care at the time of enrollment.

^aIncludes occupational therapy visits, speech therapy visits, and medical social worker visits.

^bMay not add up due to rounding error.

The increase in the average number of visits reflects an increase in use among both demonstration enrollees who were already receiving home care and those who were new to it (who had not received services in the four months prior to their enrollment). Total visits increased for the 17 enrollees who were already receiving home care—about 62 percent of enrollees—from 38 to 52 visits for the four-month period. The 27 new patients, representing 38 percent of all enrollees, received 50 visits, on average, in the four months after enrollment.

Even though the new and continuing patients had similar total visits in the post-enrollment period (50 visits for the continuing patients versus 52 for the new), the composition of those visits was quite different. Service use among the new patients was mostly for home health aide services (61 percent of all visits, with 30 percent of visits for skilled nursing), whereas the use by continuing patients was 49 percent for skilled nursing and 42 percent for home health aide.

In sum, the official demonstration enrollee had multiple health problems and high use of Medicare care services before entering the demonstration. In addition, as many expected, these beneficiaries also used a large amount of home health care relative to the typical Medicare home health recipient, primarily skilled nursing and home health aide services. Their high health care utilization continued into the demonstration, and this is reflected in their use of home health services as well. Home health service utilization increased after enrollment for the new and continuing beneficiaries, and their total number of post-enrollment visits was similar, but new enrollees used more home health aide services.

C. HOW DID THE DEMONSTRATION AFFECT HOME ABSENCES?

An important issue for the demonstration is to understand how the change in regulations will affect home absences. If beneficiaries did not leave their homes more than the current

regulations allow, then changing the current regulation may be less beneficial than anticipated. Through our interviews with eight selected beneficiaries, we found that while the demonstration provided an opportunity to leave the house, the two most important factors that influenced how much these beneficiaries could go out were (1) their physical condition and (2) the willingness and ability of the caregiver or others to help them leave the house. Thus, while these patients are not representative of patients who would likely use the benefit, it does suggest that in some situations, implementation of the benefit may not by itself allow the beneficiary to leave the home more often. The implementation of the program in itself may in some situations not be expected to lead to increases in home absences.

For example, among the eight beneficiaries we interviewed, the patient who used the demonstration's homebound criteria to leave the house the most often suffered from very poor health. However, he was able to go out extensively because of his wife's ability to accompany him and obtain help for him to leave the house. Severely ill with Parkinson's disease and muscle atrophy, he was unable to stand and could not have left the house himself. His wife wanted to take long drives, go shopping, and eat out. Although she was much smaller and unable to help him in and out of the car, she was able to obtain assistance from her son and the local police when they went out. On average, the patient spent about 96 hours a month outside of the home, all of this time in the company of his wife, also his caregiver.

A second beneficiary benefited from the demonstration's homebound criteria because her relatively stable health status allowed her to leave the house independently. She was much more mobile and functional than the other seven. As a result, she did not require assistance and left the home more often. Although she was recovering from a leg wound and had to transport a portable wound vacuum, she could get around with a cane and drive herself. She spent the

second most time outside the home, about 46 hours a month, visiting the senior center, shops, and her daughter.

Of the remaining six beneficiaries, there were two distinct groups. The first group, which consisted of three beneficiaries, made more limited use of the demonstration's homebound criteria because its members were fairly disabled and needed help to leave the home. These people all suffered from paraplegia, which naturally limited their mobility. All noted they were reliant upon others for help transferring in and out of the wheelchair and car or for rides. The beneficiary who engaged in the most diverse range of leisure activities during the demonstration said she relied upon her friends to drive her, help get her in and out of the wheelchair, and stretch her legs every three hours to alleviate muscle spasms. Absences from the home for these three beneficiaries averaged about 20 hours a month.¹² They said they could not leave the house much more than this because they needed help to do so, which suggested that finding help determined the extent to which they could leave the home.

The second group of three beneficiaries had more health problems, which greatly restricted their ability to leave the house even with assistance. They spent the least time outside the home and probably would have satisfied the homebound requirement had they been subject to it. Two were paraplegics, one had partial leg paralysis, and they all had the same limitations in mobility as the first group. However, this group suffered from additional health issues during the demonstration that further restricted their ability to leave the home. For example, one patient was suffering from open pressure sores and could not leave the house at all. His agency even disenrolled him from the demonstration, assuming that since he was physically unable to leave

¹² These home absences exclude leaving the home to obtain medical care or attend religious services.

the house, he was no longer eligible to participate. Yet he hoped that if his condition improved, he could try to get out once a week to visit family and friends, do some shopping, and attend some classes. Another patient had just been discharged from a nursing home and suffered leg paralysis from a stroke in addition to diabetes and vascular disease. During the demonstration, she left the house for only one hour a week with her husband to listen to music. The third beneficiary in this group valued her freedom to leave the house so much that she paid privately for skilled nursing services prior to the demonstration, which she said she did in order not to be subject to the homebound requirement. She was able to get around because she lived with her daughter, who transported her in a van outfitted to accommodate her wheelchair. However, during the demonstration, she developed Alzheimer's disease, which greatly reduced the time she could leave the home. Her activities, which had included going to movies, restaurants, and stores, became limited to visiting another friend with Alzheimer's disease two times a month for about three hours.

D. OTHER BENEFITS OF THE DEMONSTRATION

All the beneficiaries we spoke with thought that the demonstration was a good idea. They felt that being able to interact with the outside world improved their emotional outlook and kept them mentally alert. It helped to distract them from their illness and alleviated their sense of isolation. For example, a 55-year-old woman, paralyzed for 17 years, felt the homebound restriction was a way of segregating people who are disabled. When she was able to go out under the demonstration, she no longer felt as if she were locked up in her bedroom. Even though she was going out for only 24 hours a month, excluding absences to obtain medical care and attend religious services, she said she was heartbroken to see the demonstration end.

Having the option or ability to go out without fear of losing home care services, even if home absences were minimal because of physical limitations, was important. One patient, a 33-year-old man paralyzed for 10 years, said the homebound restriction was a very significant issue for younger people like him. He felt that being cooped up was detrimental to his mental health, and he wanted the opportunity to see his family and friends, even though he went out for only 10 hours a month under the demonstration. However, he noted that just having the choice to go out was the most important factor.

E. SUMMARY

Based upon their medical profile and health utilization patterns, the official demonstration enrollees represent a sicker and costlier home health care patient base than the average Medicare recipient of home health care. During the demonstration, even those who used Medicare home health services before entering the demonstration increased their use of home health services. This is likely to reflect exacerbations in their health conditions unrelated to the demonstration, as we found that they had a high level of use of other services. Most were constrained by the severity of their illness or their dependence upon others for help to leave the home, which limited their home absences. Nevertheless, some of the beneficiaries appreciated having the freedom to go out without fear of loss of home health care benefits, even if they could seldom exercise this choice. We must caution, however, that while the official demonstration enrollees provide some insight into the characteristics, costs, and experiences of a specific group of enrollees, we cannot generalize to the overall group of enrollees or potential benefit users. Given the small sample size and the unrepresentativeness of the agencies of these demonstration enrollees, we are unable to draw any conclusions about the type of beneficiaries that would enroll, and their costs, if the

demonstration were permanently implemented. Nevertheless, these data support the perceptions of the stakeholders, expressed in their interviews, that the demonstration enrollees may pose a financial burden and that some of the enrollees may not be able to leave the home even under the demonstration's homebound criteria.

VI. DO AGENCIES ENCOUNTER DIFFICULTIES WITH THE HOMEBOUND REQUIREMENT IN USUAL MEDICARE?

Based on our stakeholder interviews, agency perceptions about the demonstration most likely contributed to their lack of participation. Chapter V described the agencies' concern over serving potentially costly enrollees and billing for dual eligibles. Agencies were unsure whether dual eligibles would be willing to switch from Medicaid or the other programs. They also questioned whether their Medicare caseloads would be physically able to leave the home or how many could meet the eligibility criteria. In addition to these perceptions about the demonstration, it is also possible that how agencies perceived the purpose of the demonstration—removing the homebound requirement—may have affected their willingness to participate. Perhaps intervening events had made the homebound requirement more acceptable, or perhaps the requirement was not as widespread a problem as originally believed. One consideration is that CMS issued a Program Memorandum in February 2001, just as the legislative language authorizing the Home Health Independence demonstration was being written, that clarified the homebound requirement by detailing certain types of home absences that would *not* jeopardize continued coverage of home health care by Medicare. That memorandum might have eased the concerns of both agencies and beneficiaries about the potential consequences if home health patients left their homes. In addition, it may be that home health agencies rarely have patients who need care that cannot meet the homebound requirement, and thus agencies may not perceive eliminating the requirement as an issue of concern. Understanding these and other possible factors underlying the low enrollment could help inform future policy.

A. PROGRAM MEMORANDUM AND AGENCY INTERPRETATION

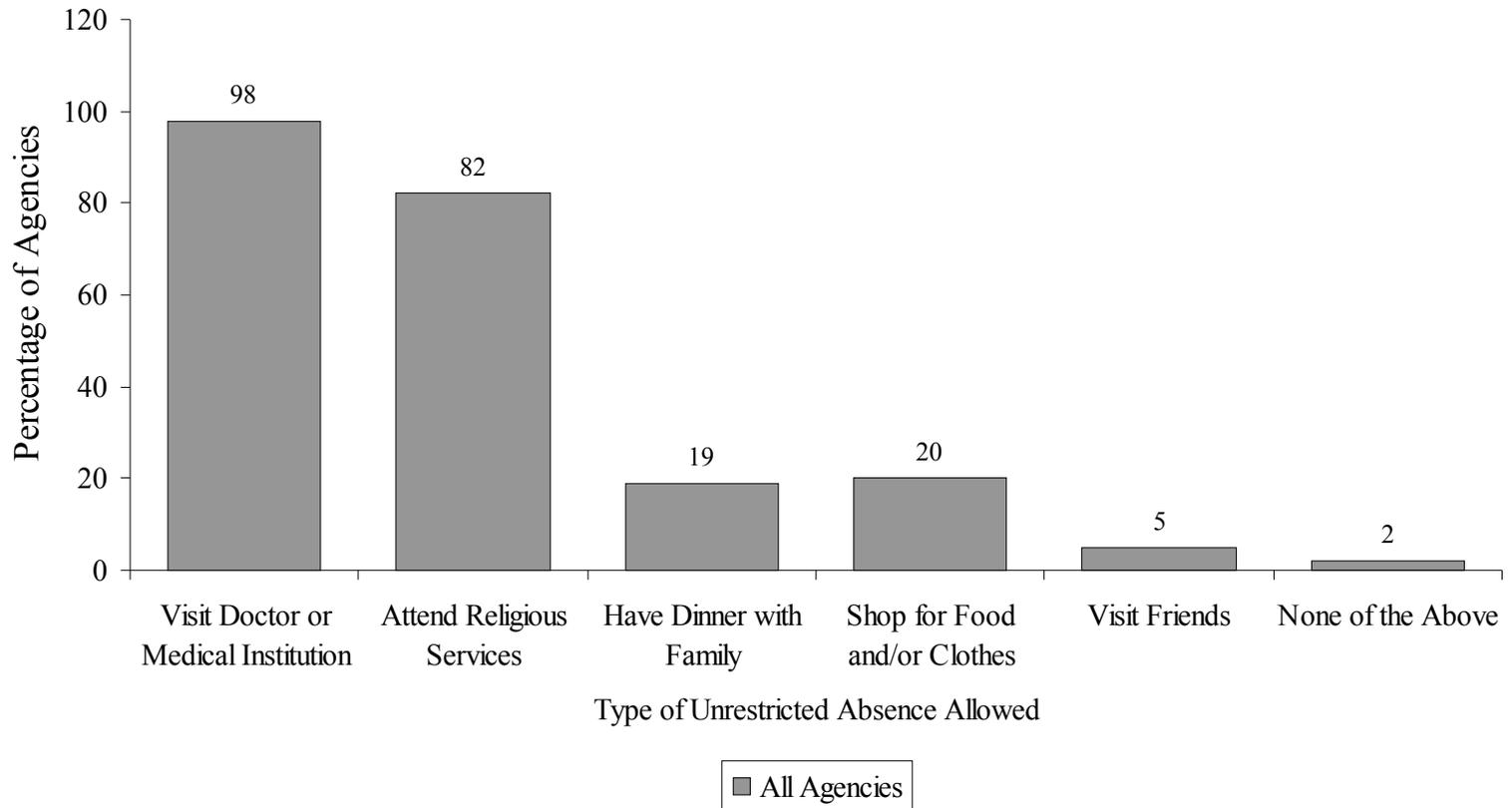
In its February 2001 memorandum, CMS clarified the definition of *homebound* in the Medicare home health program, stipulating that homebound status is not negated by (1) any absence from the home for the “purpose of participating in therapeutic, psychosocial, or medical treatment in an adult day care program” or (2) “any absence for religious service” (Program Memorandum, February 6, 2001). Furthermore, the CMS Home Health Agency Manual was amended to state that “occasional absences from the home for non-medical purposes, e.g., an occasional trip to the barber, a walk around the block, a drive, attendance at a family reunion, funeral, graduation, or other infrequent or unique event would not necessitate a finding that the patient is not homebound if the absences are undertaken on an infrequent basis or are of relatively short duration and do not indicate that the patient has the capacity to obtain the health care provided outside rather than in the home” ([www.cms.hhs.gov/Manuals], accessed April 17, 2007).

How did agencies implement the homebound requirement after this memorandum was issued? Not uniformly.

Although the only *unrestricted* absences allowed under the regulations are absences to obtain medical care (including medical adult day care) or attend religious services, a significant proportion of the agencies reported that they define *homebound* both more liberally and more conservatively than the memorandum states. While nearly all the agencies understood that patients could leave the home at any time to obtain medical care, almost 19 percent of the agencies did not think that patients could attend religious services without limitations (Figure VI.1). In contrast, other agencies seem to apply the regulation more liberally than written. We

FIGURE VI.1

REASONS PATIENTS CAN LEAVE THE HOME WITHOUT RESTRICTIONS AND STILL BE CONSIDERED HOMEBOUND



Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007. Number of agencies reporting is 105.

specifically asked agencies in the survey about whether the patient could have unlimited home absences for four additional reasons: (1) to have dinner with family, (2) to shop for food, (3) to shop for clothing, and (4) to visit with friends. About 19 percent of the agencies believed patients could leave the home as often as they wanted to have dinner with their family. Agencies also indicated that patients could have unlimited leave to shop for food (14 percent), to shop for clothes (6 percent), and to visit with friends (5 percent). Overall, only 57 percent of the agencies appear to have interpreted the regulations correctly: that unrestricted absences applied *solely* to absences to visit a doctor or medical institution or to attend religious services (Table VI.1).

Similarly, agencies differed in how they interpreted “infrequent and relatively short duration” when considering how often a person could go outside the home for restricted reasons and still be considered homebound. Examining how agencies define *infrequent*, we find that 20 percent said that patients could leave the home only for unrestricted reasons in order to be considered still homebound—no other absences were allowed (Figure VI.2). The largest group of agencies (43 percent) thought that patients could leave the home for restricted reasons once a week. However, 19 percent thought that patients could leave more than once a week, with a very small minority (4 percent) indicating they could leave more than five times a week.

Agencies also have varying definitions of “short duration.” Six percent of the agencies reported that patients could leave the house for less than an hour and remain homebound, while 30 percent reported that they could leave for 1 to 2 hours, and 20 percent said for 2 to 3 hours (Figure VI.3). Only a few (9 percent) thought patients could leave for 5 or more hours, which suggests that most agencies would probably concur with home health agency of the primary advocate for this legislation when it interpreted his overnight trip to a football game as a violation of the homebound requirement.

TABLE VI.1

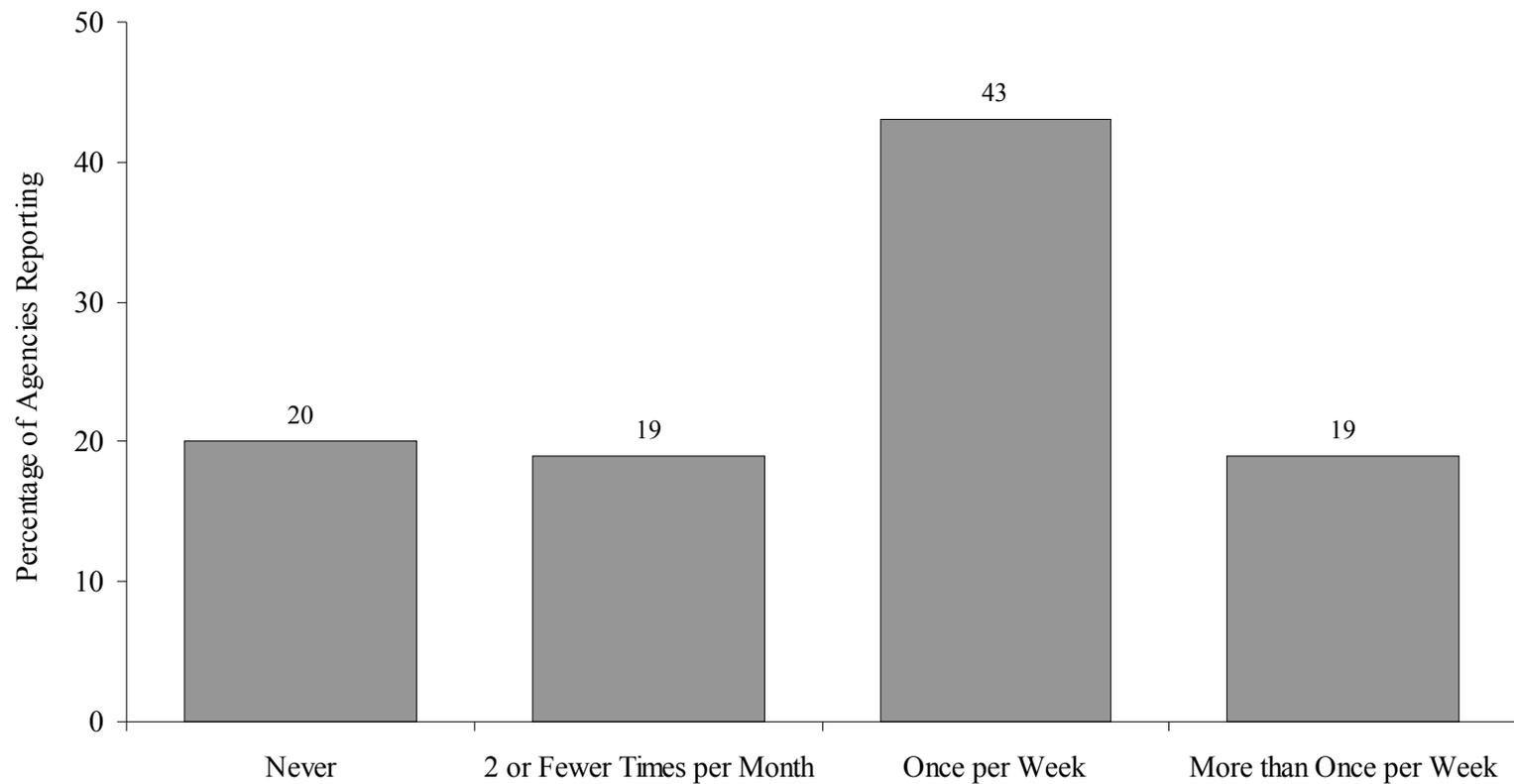
THE FIVE MOST FREQUENT COMBINATIONS OF TYPES OF UNRESTRICTED ABSENCES ALLOWED
UNDER THE MEDICARE HOMEBOUND REQUIREMENT

Type of Agency	N (Weighted)	Percentage of Agencies	Types of Unrestricted Absences Allowed					
			Visit Doctor or Medical Institutions	Attend Religious Services	Have Dinner with Family	Shop for Food	Shop for Clothes	Visit Friends
Allowed most frequent combination of absences	117	57.2	X	X				
Allowed second most frequent combination of absences	32	15.7	X					
Allowed third most frequent combination of absences	23	11.2	X	X	X			
Allowed fourth most frequent combination of absences	11	5.7	X	X		X		
Allowed fifth most frequent combination of absences	9	4.6	X	X	X	X	X	X

Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007. Number of agencies reporting is 105.

FIGURE VI.2

HOW FREQUENTLY CAN A PERSON LEAVE THE HOME FOR RESTRICTED REASONS
AND STILL BE CONSIDERED HOMEBOUND?

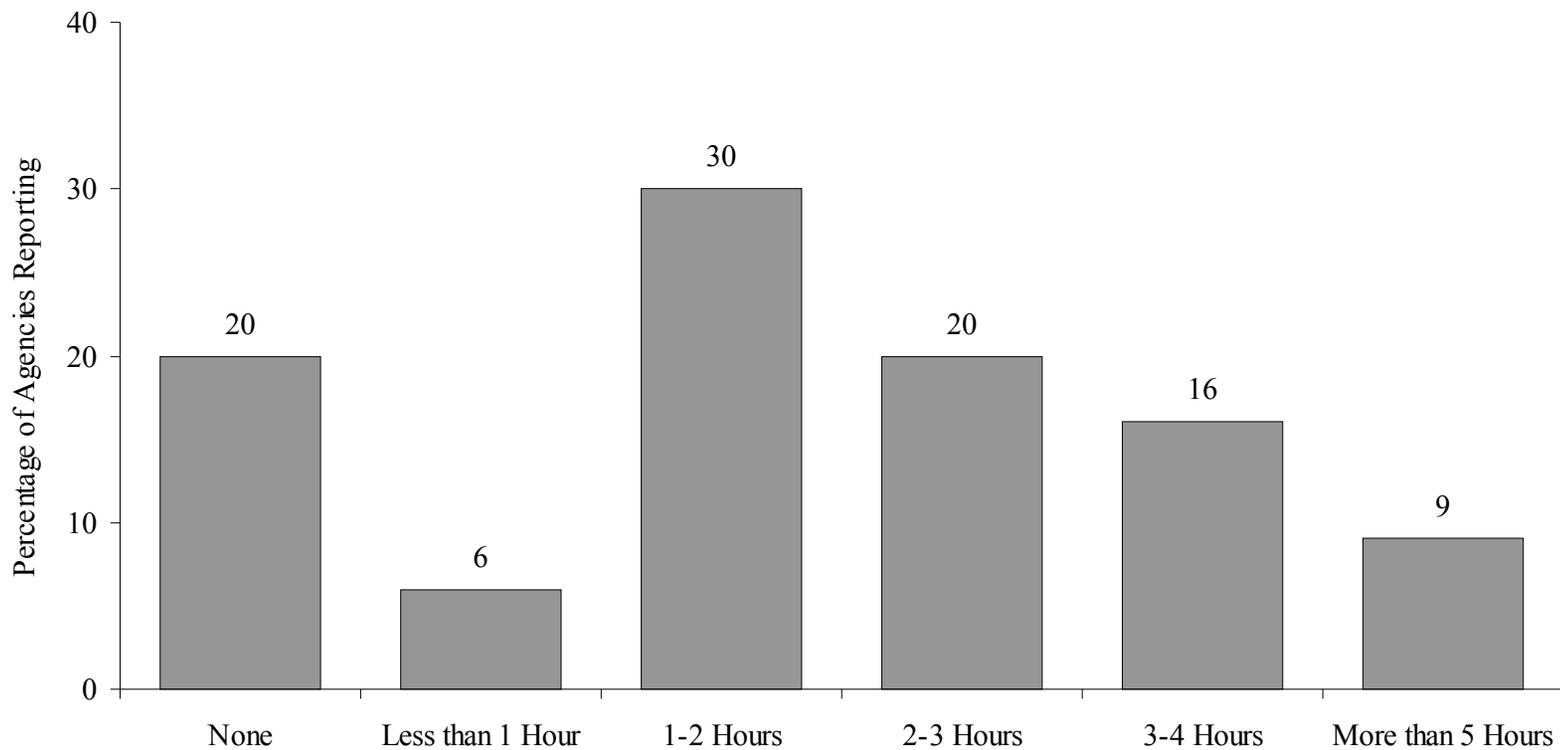


Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007. Number of agencies reporting is 99.

Note: Because of rounding, numbers do not add to 100 percent.

FIGURE VI.3

HOW LONG A PERSON CAN BE AWAY FROM HOME FOR RESTRICTED REASONS
AND STILL BE CONSIDERED HOMEBOUND?



Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007. Number of agencies reporting is 99. Excludes agencies who indicated that none of the activities in Table VI.1 were restricted.

Note: Because of rounding, numbers do not add to 100 percent.

Given the considerable variation among agencies in their interpretation of the homebound requirement, it seems unlikely that the CMS memorandum clarified the requirement enough so that agencies are no longer concerned about “gray” areas. Furthermore, agencies are not applying the criteria so liberally that the kinds of conflicts that David Jayne encountered in his desire to leave the home and still maintain his Medicare benefit would be resolved.

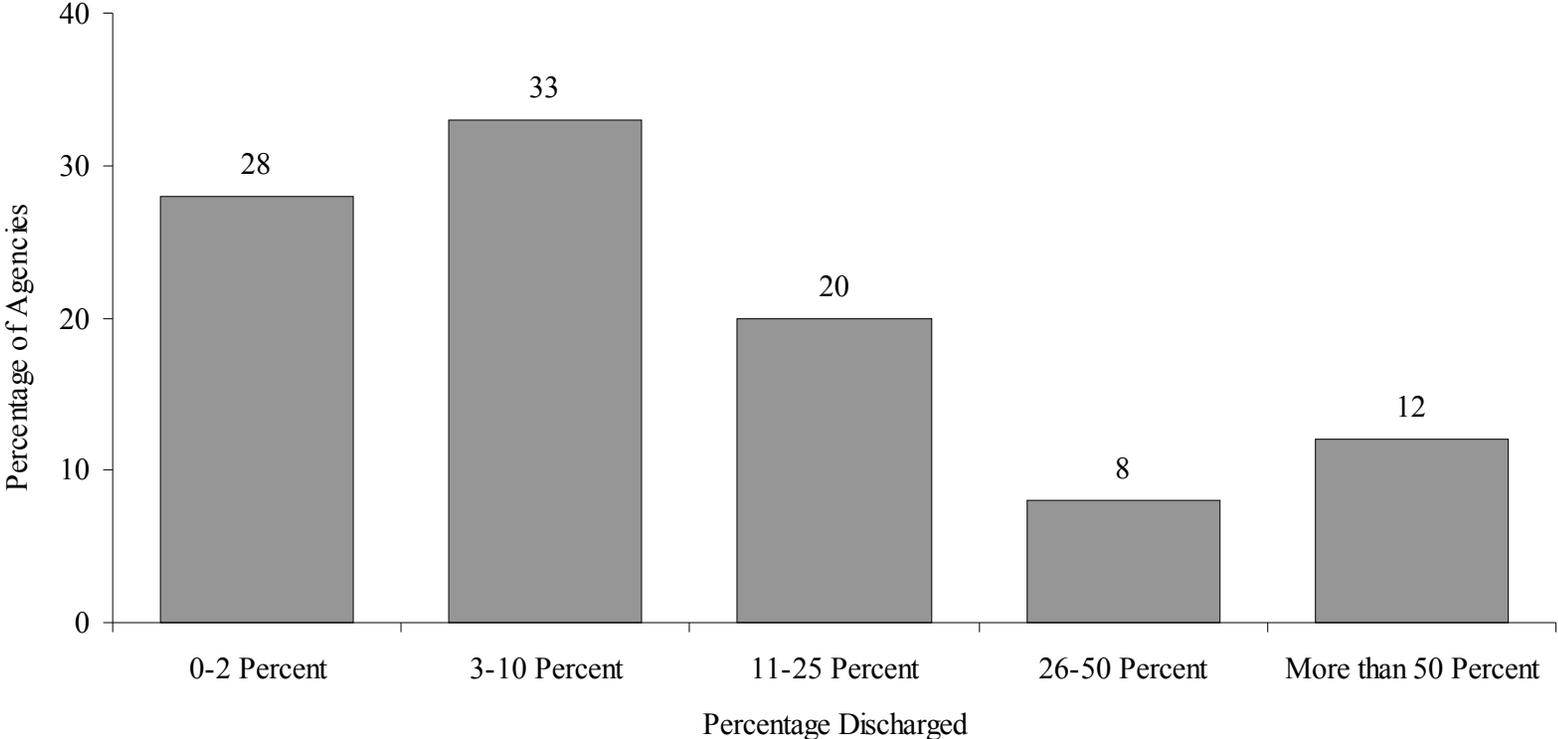
B. IS THE HOMEBOUND REQUIREMENT AN IMPORTANT LIMITATION FOR LARGE NUMBERS OF PATIENTS?

Another possible explanation for the low enrollment is that too few beneficiaries are limited by the homebound requirements, so few could take advantage of the demonstration’s change in eligibility criteria. We asked agencies what proportion of their discharges, and what proportion of their denials of admission, were solely because the patient was no longer homebound. Because agencies generally do not keep data on the homebound status of their patients upon discharge or denial of admission, we could not collect precise estimates of patients that were discharged or denied admission resulting from violation of the homebound requirement. We derived these estimates from the agencies’ reporting of categorical levels of the percentage of patients affected, multiplied by their patient caseload. As the standard errors on these estimates are fairly large, we present them below along with the point estimates.

A majority of the agencies (61 percent) reported that fewer than 10 percent of their Medicare patient discharges were due solely to the patient’s loss of homebound status, with 28 percent of the agencies citing fewer than 2 percent (Figure VI.4). In contrast, 12 percent indicated that more than 50 percent of their discharges were due to loss of homebound status. This distribution across agencies translates to roughly 119 patients (standard error = 34.27) per agency per year who were discharged because they no longer met the homebound status, or 13 percent (standard

FIGURE VI.4

PERCENTAGE OF MEDICARE PATIENTS DISCHARGED BECAUSE THEY WERE NO LONGER HOMEBOUND



79

Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007. Number of agencies reporting is 100.

error = 2.11) of the agencies' overall Medicare patient caseload. Across all the surveyed agencies, this amounts perhaps to 23,249 patients, with a 95 percent confidence interval between 9,943 and 36,555 per year.

Eighty percent of the agencies also reported that less than 25 percent of their referrals were denied admission to Medicare home health because the patient was not homebound, with a large minority (38 percent) estimating the figure to be fewer than 2 percent (data not shown). This translates to roughly 10 patients (S.E. = 2.16) a year, or just 2 percent (S.E. = 0.33) of their overall Medicare patient caseload. Across all the agencies, it added just 2002 patients (with a confidence interval between 1,174 and 2,829) a year. That so few of the referrals are denied admission because of the homebound requirement is partially explained by the fact that all referrals are prescreened by physicians and discharge planners for the patient's ability to meet the requirements to receive Medicare home health services.

Thus the homebound requirement affects a minority of the average surveyed agencies' caseload, and it typically is not an issue when agencies are admitting patients to care. But it is a cause for discharging patients, and substantially more patients are affected by the homebound requirement than would have been eligible for the demonstration.

When we asked agencies whether the homebound requirement poses a problem, the majority (77 percent) responded that it does. When asked who might benefit from the demonstration's revised homebound criteria, the agencies generally identified beneficiaries with a broader set of conditions than the narrowly defined target group that meets the demonstration's eligibility criteria. Thus, the demonstration, which by design focused on a very specific subset of patients, did not address the general problem with the homebound requirement as perceived by most agencies.

So who do agencies think would benefit from a change in the homebound requirement? In our survey, they indicated two underlying reasons to waive the requirement: (1) to help those patients who could benefit from going out more, and (2) to help those who could benefit from more home health services.

Agencies indicating that patients would benefit from going out more held that engaging with the community improved the mental outlook of patients—and this could include both short-stay and long-stay patients. A few agencies suggested that the homebound criteria should be eliminated altogether, as they argued that the outlook of *all* patients can be improved by increased social contact. Others suggested that the homebound requirement should be eliminated for patients who are likely to miss social contact, including those who live alone or those accustomed to attending social programs (such as senior congregate meals). One agency suggested that the requirement should be eliminated for anyone who has a spouse in a nursing home, because in many cases, no matter how taxing an effort it is to leave the home, the at-home spouse will be distressed if he or she cannot visit the confined spouse. And some agencies indicated that the homebound requirement should be eliminated for the types of patients the demonstration was designed to help—the disabled, and in particular, the young disabled—even those that still wanted to work.

Agencies who thought that the requirement should be eliminated for those who could benefit from more home health services generally focused on patients with chronic health care needs. Agencies gave examples of patients who had a difficult time learning self-care and even though patients recover sufficiently to leave the house, they need more teaching and monitoring to remain healthy. Other agencies suggested that skilled monitoring of chronically ill patients

would improve their health, help them avoid future hospitalizations, and, in turn, lower Medicare costs.

Another group of agencies suggested that patients who could benefit from more home health care are those for whom there is simply no ambulatory care setting that provides

EXAMPLE VI.1

One of the demonstration enrollees was a quadriplegic who needed catheter changes on a regular basis, but her physician's office was small and equipped only with an examination table. It was difficult for her to transfer between her wheelchair and the table. At home, she had equipment to help her transfer to her hospital bed, which allowed greater flexibility for changing her catheter.

the same type of care as that given by home health providers. For example, agencies suggested that most physicians do not want to change catheters monthly, so that without home health, patients have few alternatives to get their catheter changed (Example VI.1). Another example cited was that most physicians do not want or need to provide frequent (daily) monitoring for a wound, and it is taxing for the patient to go to the physician's office every day for such care. Other agencies cited cognitively impaired patients who need skilled care monitoring (such as medication management) that is not available in a doctor's office.

In contrast, a substantial minority of the surveyed agencies (23 percent) responded that the homebound requirement was not a problem. There appear to be many different reasons for this view. As one respondent in the qualitative interviews indicated, "In 13 years of home health care, I have never had a patient that needed care but didn't meet the Medicare homebound requirements and that I couldn't get onto Medicaid. And Medicaid allows flexibility in its homebound rules, so it's just not a problem." One large Visiting Nurse Association noted that while it wished the homebound requirement were more flexible (Example VI.2), it understood that costs had to be controlled and noted that it required its charity care patients to be homebound for the same reason. Some agencies also expressed concern about patients who would want to

continue home health care because it was convenient and thought that these patients were dissuaded by the homebound rule. Hence, while there is no one reason underlying the

EXAMPLE VI.2

“There are people who need our service. But then, one day, they have no food in the house, and they go out to the grocery store. It’s hard and taxing, but they do it. And now they are no longer homebound. But we don’t make the rules; we can only apply them. Just a little more flexibility would make the system work much better.”

agencies’ views, many agencies expressed that they were able to work with the homebound requirement as it is.

These varied responses—everything from “the homebound requirement is a problem for everyone” to “homebound is not a problem”—demonstrate why this issue consistently draws attention from policymakers but is not resolved. Agencies that apply the policy every day not only interpret it differently but also see different benefits and drawbacks to the requirement. Thus no one solution meets the needs of the majority of the agencies.

VII. RESEARCH FINDINGS AND LESSONS LEARNED

Congress passed Section 702 of the Medicare Modernization Act to determine how much it would cost to eliminate the homebound requirement for permanently disabled Medicare beneficiaries in need of daily assistance. Although the demonstration enrolled few participants, it provided information about why potential participants didn't enroll, how many could have enrolled, and the costs of providing care for those who did enroll. This information provides valuable lessons learned for future benefit changes.

Why was the demonstration enrollment so low?

A number of different factors contributed to the low demonstration enrollment, including:

Home health agencies encountered barriers to participation. Estimates from the survey suggest that just 25 percent of the agencies who had at least one eligible beneficiary participated in demonstration. These barriers include:

- *Agencies feared losing money on costlier patients.* Agencies anticipated that the typical demonstration patient would require a great deal of care, and that under Medicare's prospective payment system, the agency would lose money on these patients.
- *Agencies faced difficulties enrolling Medicaid-eligible beneficiaries.* Incongruence between the Medicare and Medicaid home care benefits and payment systems makes it difficult to switch patients from the Medicaid home care benefit to the Medicare benefit.
- *Agencies estimated that they would be paid less for care under the Medicare benefit.* A few agencies who investigated enrolling dually-eligible patients in the demonstration found that they would be paid less under the Medicare benefit than they were currently being paid under the Medicaid program.
- *Agencies felt many potential enrollees would not benefit from the program.* Some agencies found that many of their patients who met the demonstration criteria were unable to leave their homes more than the current regulation allows. As a result, agencies didn't feel it was worthwhile to enroll the beneficiary in the demonstration.

Medicare beneficiaries encountered enrollment barriers. These include:

- *Some beneficiaries prefer home care programs offered by the Medicaid program to the Medicare home health benefit.* Disability advocates suggested that Medicaid programs, which are specifically designed to meet the long-term needs of disabled persons, are more appealing to disabled beneficiaries.
- *Some beneficiaries didn't want to change their support systems to participate in a demonstration.* A few agencies who tried to enroll beneficiaries found that they didn't want to change their current care arrangements, even if it was financially advantageous to do so.

Stringent demonstration enrollment criteria kept enrollment low. The demonstration criteria were designed to target a very specific group of beneficiaries—beneficiaries who were ill and severely, permanently disabled. As a result, many stakeholders perceived that too few beneficiaries qualified for the demonstration—because it excluded disabled beneficiaries who did not meet the need for permanent skilled nursing services or those who wanted to continue to work in the community. Indeed, many stakeholders who strictly interpreted the criterion “permanent skilled nursing care” indicated that they could only think of two conditions that met this criteria. Many home health agencies interpreted the criteria much more broadly, however, and could have enrolled more patients who met the criteria had they chosen to participate.

Official enrollment process may have missed some demonstration enrollees. Technical difficulties with the official demonstration enrollment process may have missed some demonstration enrollees. In our survey of home health agencies, agencies reported that they enrolled 169 beneficiaries—which, if weighted for agency selection and non-response, translates into an estimated 330 demonstration enrollees. Whether agencies failed to execute the enrollment process successfully, or, for some reason, over-estimated the number of patients they enrolled, is unknown.

How many beneficiaries could be eligible for a permanent program?

In order to gain some information about how many beneficiaries may qualify for the future program benefit, we selected a patient sample of “potentially” eligible beneficiaries from those who received Medicare Home health services, and asked agencies to assess whether the beneficiary would meet the demonstration enrollment criteria. We estimate that among those who met our potentially eligible criteria over a year, 2149 patients would have been eligible for the demonstration. Of these patients, however, agencies indicated that 78 percent were so ill that they could not leave home for more than the current regulations allow. Thus, we estimate that 473 patients in the three states could have met the demonstration criteria and benefited from the program. We can not tell what proportion of those 473 patients would, without a benefit change have chosen to remain in Medicare home health and limit their excursions. Nor can we estimate how many beneficiaries who didn’t meet our sample criteria (including those who only receive home care outside of the Medicare benefit) might meet the eligibility criteria.

We also found that the number of eligible beneficiaries will depend upon how broadly or strictly agencies interpret the enrollment criteria. In particular, agencies had different interpretations of what qualified as permanent skilled nursing need, and when conditions qualify as “permanently disabling.”

Are these beneficiaries costly to serve?

With only 58 official participants in the demonstration, who received care from agencies that were disproportionately rural and non-profit, one can not estimate how much it will cost to serve these beneficiaries. However, agencies anticipated that these types of patients would be expensive to care for; and we found those few participants did use a relatively large amount of home health and other health care services compared to the average Medicare home health user.

A. LESSONS LEARNED—CHANGING THE BENEFIT

Despite its limited enrollment, the demonstration provided a number of “lessons learned” regarding the possibility of implementing, in the Medicare home health benefit. These include:

Barriers that need to be addressed

In order to implement a change that would encourage agencies to serve these beneficiaries, CMS would have to address the barriers agencies face to participation. They would have to develop a payment mechanism, such as a case-mix group, that addresses home health agencies’ financial concerns by compensating them for serving beneficiaries like the individuals officially enrolled in the demonstration, who were quite ill and used a much higher level of care than a typical Medicare patient receiving home health care. Otherwise, some agencies may find ways to avoid serving these patients, and simply eliminating the homebound regulation is unlikely to improve access to care.

Second, CMS will want to provide clear guidance to home health agencies on serving dually eligible beneficiaries who will receive care under the Medicare and Medicaid benefits concurrently. This would include identifying who is responsible for coordinating the home care if multiple providers are involved, and how charges should be allocated between the two payers. State Medicaid programs will also need guidance as to how to address beneficiaries who may now qualify for the Medicare home health benefit under the more liberal homebound rule but may already be enrolled in a Medicaid program for home- and community-based services that the beneficiary may prefer over Medicare home health care. CMS could work with state Medicaid agencies and with home health care trade associations to resolve these issues.

Precautions that might be considered

Once the barriers are mitigated, the concern will be that a “woodwork effect” will develop that was not evident in the demonstration: the emergence of large numbers of beneficiaries “from the woodwork,” drawn by the new benefit to seek services. We can not tell from this demonstration how large that effect may be, but it is clear that the eligibility criteria used in the demonstration limited the number of qualified enrollees. To limit the expansion possibilities, CMS will have to provide clear guidance on exactly what constitutes (1) a permanent skilled care need, and (2) a permanent disabling condition.

B. LESSONS LEARNED—THE HOMEBOUND REQUIREMENT

The demonstration provided other valuable information that will help CMS and Congress understand the challenges of addressing the issues in the homebound requirement. These include:

Changing the homebound requirement will not automatically change how agencies interpret and implement it.

We found that even after CMS clarified the homebound requirement in 2001, agencies continued to interpret it either more strictly or more loosely than the current regulation warrants. This reflects how difficult it is to reach agencies with programmatic changes, and for them then to incorporate those changes into their functions.

Eliminating the homebound requirement for the severely disabled will not eliminate the “homebound” problem.

For many agencies, the homebound problem does not apply solely to the severely disabled. Agencies identified a number of patient groups whose care and lives might be enhanced if the homebound requirement were to be eliminated. CMS may wish to conduct research to provide

evidence for these assertions. For example, they might try to determine where patients receive traditional nursing services—such as catheter changes and frequent wound evaluations—to learn whether accessing this care is as difficult as some agencies suggest. Furthermore, CMS may wish to consider a demonstration to determine whether extended home care benefits can improve patient health and decrease the use of expensive acute care services.

Future demonstration enrollment processes should be validated.

The enrollment process appears to have missed recording a large proportion of the enrollees. In this demonstration, where many factors contributed to the lack of enrollment, this did not drastically impede the evaluation. However, had there been substantial enrollment, the failure to capture a large proportion of the enrollees would have harmed the evaluation substantially. Thus, establishing a validation process for future demonstration enrollment is important.

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APPENDIX A
APPLICABLE LEGISLATION

SEC. 702. DEMONSTRATION PROJECT TO CLARIFY THE DEFINITION OF HOMEBOUND.

(a) **DEMONSTRATION PROJECT.**—Not later than 180 days after the date of the enactment of this Act, the Secretary shall conduct a 2-year demonstration project under part B of title XVIII of the Social Security Act under which medicare beneficiaries with chronic conditions described in subsection (b) are deemed to be homebound for purposes of receiving home health services under the medicare program.

(b) **MEDICARE BENEFICIARY DESCRIBED.**—For purposes of subsection (a), a medicare beneficiary is eligible to be deemed to be homebound, without regard to the purpose, frequency, or duration of absences from the home, if—

(1) the beneficiary has been certified by one physician as an individual who has a permanent and severe, disabling condition that is not expected to improve;

(2) the beneficiary is dependent upon assistance from another individual with at least 3 out of the 5 activities of daily living for the rest of the beneficiary's life;

(3) the beneficiary requires skilled nursing services for the rest of the beneficiary's life and the skilled nursing is more than medication management;

(4) an attendant is required to visit the beneficiary on a daily basis to monitor and treat the beneficiary's medical condition or to assist the beneficiary with activities of daily living;

(5) the beneficiary requires technological assistance or the assistance of another person to leave the home; and

(6) the beneficiary does not regularly work in a paid position full-time or part-time outside the home.

(c) **DEMONSTRATION PROJECT SITES.**—The demonstration project established under this section shall be conducted in 3 States selected by the Secretary to represent the Northeast, Midwest, and Western regions of the United States.

(d) **LIMITATION ON NUMBER OF PARTICIPANTS.**—The aggregate number of such beneficiaries that may participate in the project may not exceed 15,000.

(e) **DATA.**—The Secretary shall collect such data on the demonstration project with respect to the provision of home health services to medicare beneficiaries that relates to quality of care, patient outcomes, and additional costs, if any, to the medicare program.

(f) **REPORT TO CONGRESS.**—Not later than 1 year after the date of the completion of the demonstration project under this section, the Secretary shall submit to Congress a report on the project using the data collected under subsection (e). The report shall include the following:

(1) An examination of whether the provision of home health services to medicare beneficiaries under the project has had any of the following effects:

(A) Has adversely affected the provision of home health services under the medicare program.

(B) Has directly caused an increase of expenditures under the medicare program for the provision of such services that is directly attributable to such clarification.

Deadline.
Deadline.
42 USC 1395x
note.

117 STAT. 2336 PUBLIC LAW 108–173—DEC. 8, 2003

(2) The specific data evidencing the amount of any increase in expenditures that is directly attributable to the demonstration project (expressed both in absolute dollar terms and as a percentage) above expenditures that would otherwise have been incurred for home health services under the medicare program.

(3) Specific recommendations to exempt permanently and severely disabled homebound beneficiaries from restrictions on the length, frequency, and purpose of their absences from the home to qualify for home health services without incurring additional costs to the medicare program.

(g) WAIVER AUTHORITY.—The Secretary shall waive compliance with the requirements of title XVIII of the Social Security Act (42 U.S.C. 1395 et seq.) to such extent and for such period as the Secretary determines is necessary to conduct demonstration projects.

(h) CONSTRUCTION.—Nothing in this section shall be construed as waiving any applicable civil monetary penalty, criminal penalty, or other remedy available to the Secretary under title XI or title XVIII of the Social Security Act for acts prohibited under such titles, including penalties for false certifications for purposes of receipt of items or services under the medicare program.

(i) AUTHORIZATION OF APPROPRIATIONS.—Payments for the costs of carrying out the demonstration project under this section shall be made from the Federal Supplementary Medical Insurance Trust Fund under section 1841 of such Act (42 U.S.C. 1395t).

(j) DEFINITIONS.—In this section:

(1) MEDICARE BENEFICIARY.—The term “medicare beneficiary” means an individual who is enrolled under part B of title XVIII of the Social Security Act.

(2) HOME HEALTH SERVICES.—The term “home health services” has the meaning given such term in section 1861(m) of the Social Security Act (42 U.S.C. 1395x(m)).

(3) ACTIVITIES OF DAILY LIVING DEFINED.—The term “activities of daily living” means eating, toileting, transferring, bathing, and dressing.

APPENDIX B

PEOPLE INTERVIEWED FOR THIS EVALUATION

Sandra Bastinelli	Centers for Medicare & Medicaid Services
Mark Bayer	Congressman Markey's staff
Carol Blackford	Centers for Medicare & Medicaid Services
Suzanne Carron	MS Society Gateway Chapter
Ellen Caruso	Home Care Association of Colorado
Henry Claypool	Advancing Independence
Lisa Cootz	Missouri Department of Health and Senior Services
Beverly Dahan	Colorado State Medicaid
Michelle Dickson	MS Society, Central New England Chapter
Kirsten Dunham	PARAQUAD
Alrick Edwards	Abt Associates
Laura Gilbert	Personal Assistance Services of Colorado (PASCO)
Henry Goldberg	Abt Associates
Dianne Green	VNA and Hospice of Cooley Dickinson
Ginni Hain	Centers for Medicare & Medicaid Services
Trish Harris	Prospect Home Care
Cheryl Haun	MS Society, Colorado Chapter
Debbi Heifman	MS Society, Colorado Chapter
Joan Hynek	Marion County Health Department
Andrea Levy	MS Society, Colorado Chapter
Sue Major	Marion County Health Department
Viki Manley	Colorado State Medicaid
Kenneth McNaulty	Boston Visiting Nurse Association
Nancy Moore	Centers for Medicare & Medicaid Services
Phillip Otto	Centers for Medicare & Medicaid Services
Diane Paulson	Medicare Advocacy Project
Marie Reed	Centers for Medicare & Medicaid Services
Marie Regan	Massachusetts Medicaid
Julie Reiskin	Colorado Cross Disability Coalition
Carol Reynolds	Disability Center for Independent Living
Levonne Reynolds	MS Society, Colorado Chapter
Barry Rosenberg	Personal Assistance Services of Colorado (PASCO)
Constantance Row	American Academy of Home Care Physicians
Mary Schantz	Missouri Alliance for Home Care
Waunita Schwandtner	Missouri Department of Health and Senior Services
Helen Segal	Massachusetts Home Care Association
JD Sherwood	Centers for Medicare & Medicaid Services
Vicki Shier	Abt Associates
Carrie Smith	Centers for Medicare & Medicaid Services
Mary St. Pierre	National Association for Home Care and Hospice
Mary Stockman	BJC Home Care
Joan Taylor	VNA of Denver
Virginia Tischler	Boston Visiting Nurse Association
Jill Van Dinter	MS Society, Colorado Chapter
Kathleen Walch	Centers for Medicare & Medicaid Services
Robert Wardwell	Visiting Nurse Associations of America
Janet Wittennauer	SSM Home Care

APPENDIX C
SURVEY PACKAGE



DEPARTMENT OF HEALTH & HUMAN SERVICES

Centers for Medicare & Medicaid Services

7500 Security Boulevard
Baltimore, MD 21244-1850

January 2007

«NameNew»
«Address1»
«Address2»
«City», «State» «Zip»

Dear «Salutation»:

I am writing to ask for your help with an important study sponsored by the Centers for Medicare and Medicaid Services (CMS) about the *Home Health Independence Demonstration*. Mandated under Section 702 of the Medicare Modernization Act (MMA) of 2003, the demonstration allowed beneficiaries meeting certain requirements to waive the homebound requirement while receiving home health services. The demonstration was implemented in the states of Massachusetts, Missouri and Colorado on October 4, 2004. You may also know the demonstration under the name of *Homebound Exemption Demonstration*.

The purpose of the survey is to learn about your agency's experiences with the homebound requirement and the home health independence demonstration. The survey includes questions about the agency's knowledge of the demonstration, experiences in identifying eligible participants and implementing the demonstration, homebound characteristics of the agency's patient load and understanding of the homebound requirement. Results from this study are important to the development of policy related to the homebound requirement for home health patients, so we hope you will agree to participate.

CMS has hired Mathematica Policy Research, Inc. a private national research firm to conduct the survey. We assure you that all information collected will be totally confidential and will not be reported in any way that identifies you or your agency personally. ***We are only collecting this information for research purposes and to improve program operations.***

Please help us by completing the enclosed survey, which should take about 30 minutes to complete. In appreciation of your time and effort, we will send a check of \$50 upon receipt of your completed survey. ***If you have any questions please call Mathematica and say you are calling about the Home Health Independence Demonstration Survey. The toll-free number is 800-298-3383.***

Thank you for your assistance.

Sincerely,

Director
Office of Research, Development, and Information

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-1006. The time required to complete this information is 30 minutes per response. If you have any comments concerning the accuracy of the time estimate(s) or suggestions for improving the questionnaire, please write to: CMS, 7500 Security Boulevard, N2-14-266, Baltimore, MD 21244-1850.

FORM APPROVED: 11/21/2006

OMB No. 0938-1006
APPROVAL EXPIRES: 5/31/2007

MATHEMATICA
Policy Research, Inc.

Survey of Home Health Agencies

January 1, 2007

Centers for Medicare & Medicaid Services (CMS)

INSTRUCTIONS

This questionnaire should be completed by the person or persons who know the most about the composition of the home health agency's caseload and activities related to CMS's Home Health Independence Demonstration. Even if your agency did not participate in this demonstration, it is very important that you complete this questionnaire. Please use black or blue ink to complete this questionnaire. Most questions can be answered by simply placing a check mark in the appropriate box. For a few questions you will be asked to write in a response. If you are unsure about how to answer a question, please give the best answer you can rather than leaving it blank.

If you have any questions, please contact Valerie Cheh, the study director, at Mathematica Policy Research, Inc. (609) 275-2385, Monday through Friday, between 9:00 a.m. and 5:00 p.m. (Eastern Time). Valerie Cheh is also available to answer your questions via email at: vczeh@mathematica-mpr.com.

Please return the completed questionnaire in the enclosed pre-paid Federal Express mailer by February 15, 2007. If you need to arrange for Federal Express pick-up, you can call the toll-free 800 number on the mailer.

As a token of our appreciation you will receive \$50 for completing this questionnaire.

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-1006. The time required to complete this information collection is estimated to average 30 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection.

The Home Health Independence Demonstration

The Medicare Home Health Independence Demonstration was a project being conducted by the Centers for Medicare & Medicaid Services (CMS) that allowed qualifying Medicare beneficiaries who received Medicare home health benefits in COLORADO, MASSACHUSETTS, and MISSOURI to leave their home more frequently and for longer periods without risking the loss of those benefits. You may know this demonstration as the **Homebound Exemption Demonstration**.

Who could participate in the Home Health Independence Demonstration?

To be eligible for the demonstration, the individual must have been a Medicare beneficiary who was enrolled in Part B, met all of the eligibility criteria for Medicare home health, and received home health services under the traditional Medicare home health benefit and NOT through an HMO. In addition to these requirements, the individual must have met six additional criteria, which are as follows:

- (a) Beneficiary had a permanent and severe disabling condition that was not expected to improve;
- (b) Beneficiary required skilled nursing services for the rest of beneficiary's life (not necessarily daily or with any fixed frequency) and the skilled nursing was more than medication management;
- (c) Beneficiary required technological assistance or the assistance of another person to leave the home;
- (d) Beneficiary did not regularly work in a paid position full-time or part-time outside the house;
- (e) Beneficiary was dependent upon assistance from another individual with at least 3 out of the 5 activities of daily living (eating, toileting, transferring, bathing and dressing) for the rest of beneficiary's life;
- (f) An attendant was required on a daily basis to monitor and treat the beneficiary's medical condition or to assist the beneficiary with activities of daily living.

This ability to leave home more often, for any purpose, and for longer periods of time was the **ONLY** change under the demonstration. Beneficiaries must have met **ALL** the other usual eligibility and coverage criteria for Medicare home health care (including having limitations that make leaving home require a considerable and taxing effort). The Home Health Independence Demonstration began on October 4, 2004 and ran for two years. A maximum of 15,000 Medicare beneficiaries (across all 3 states) were allowed to participate.

Questions 1-3 are how your agency defines homebound.

1. Please check all the specific activities for which the "homebound" patient may leave the house without any limits on the frequency or length of absences without jeopardizing his or her homebound status and still be eligible for Medicare home health.

CHECK ALL THAT APPLY

- 1 Have dinner with family members
- 2 Visit the doctor or medical institutions
- 3 Go to religious services
- 4 Shopping for food
- 5 Shopping for clothes
- 6 Visiting friends
- 7 None of the above

For the next two questions, please exclude any activities that you marked in question 1.

2. Under normal circumstances, a homebound patient can leave the house no more than:

CHECK ONE BOX ONLY

- 1 Once a month
- 2 Once every other week
- 3 Once a week
- 4 Two or three times a week
- 5 Four or five times a week
- 6 More than five times a week
- 7 Can't leave the house for any other activities

3. Under normal circumstances, the maximum amount of time a homebound patient may be away from home is:

CHECK ONE BOX ONLY

- 1 Less than 30 minutes
- 2 30-59 minutes
- 3 1-2 hours
- 4 2-3 hours
- 5 3-4 hours
- 6 More than 5 hours
- 7 Can't leave the house for any other activities

Please answer questions 4 through 9 based on your agency's last fiscal year. Your state annual report may be helpful in answering these questions.

4. What was the total number of patients your agency served in the last fiscal year?

_____ NUMBER OF PATIENTS

5. Approximately what percent of these patients had Medicare as their primary payer?

_____% MEDICARE

6. In the last fiscal year, approximately what percent of your total Medicare patients were discharged from receipt of home health care services?

CHECK ONE BOX ONLY

- 1 Less than 10 percent
- 2 11-25 percent
- 3 26-50 percent
- 4 51-75 percent
- 5 76-99 percent
- 6 100 percent

7. Of the Medicare patients who were discharged, approximately what percent were discharged because they were no longer homebound?

CHECK ONE BOX ONLY

- 1 0-2 percent
- 2 3-10 percent
- 3 11-25 percent
- 4 26-50 percent
- 5 51-75 percent
- 6 76-100 percent
- 7 100 percent

8. In the last fiscal year, approximately how many Medicare referrals did your agency not admit for home health services?

CHECK ONE BOX ONLY

- 1 0 - 10
- 2 11 - 25
- 3 26 - 50
- 4 51 - 75
- 5 76 - 100
- 6 Over 100 *(Please estimate specific number)*

9. Of the denied Medicare referrals, approximately what percent met all of the requirements for Medicare home health except the patient was not homebound?

CHECK ONE BOX ONLY

- 1 0-2 percent
- 2 3-10 percent
- 3 11-25 percent
- 4 26-50 percent
- 5 51-75 percent
- 6 76-100 percent
- 7 100 percent

10. The last question is about patients who have received Medicare home health services from your agency within the past two years. We have identified 5 patients and have listed their Medicare ID number and name at the top of each column. To answer these questions, it is important to review the patient's medical record. For each patient, please indicate whether or not the patient meets each eligibility criterion.

Eligibility Criterion	HIC # _____ Name _____	HIC # _____ Name _____	HIC # _____ Name _____	HIC # _____ Name _____	HIC # _____ Name _____
	a. Has a permanent and severe disabling condition Specify medical conditions and ICD-9 codes _____ _____ _____	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/> _____ _____ _____	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/> _____ _____ _____	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/> _____ _____ _____	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/> _____ _____ _____
b. Needs permanent skilled nursing care (not including medication management) Specify skilled nursing care _____ _____ _____	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/> _____ _____ _____	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/> _____ _____ _____	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/> _____ _____ _____	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/> _____ _____ _____	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/> _____ _____ _____
c. Needs permanent skilled nursing care for medication management only	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
d. Needs permanent help with ADL:					
1. Bathing	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
2. Dressing	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
3. Eating	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
4. Toileting	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
5. Transferring	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>

Eligibility Criterion

e. Requires an attendant (not necessarily paid) on a daily basis to treat and monitor medical condition or provide ADL assistance for rest of beneficiary's life	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
f. Requires human or technological assistance to leave the home	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
g. Employment status: (CHECK ONE ONLY)	1 <input type="checkbox"/> NOT EMPLOYED 2 <input type="checkbox"/> EMPLOYED, ON SICK LEAVE 3 <input type="checkbox"/> EMPLOYED, WORKS FROM HOME 4 <input type="checkbox"/> DON'T KNOW	1 <input type="checkbox"/> NOT EMPLOYED 2 <input type="checkbox"/> EMPLOYED, ON SICK LEAVE 3 <input type="checkbox"/> EMPLOYED, WORKS FROM HOME 4 <input type="checkbox"/> DON'T KNOW	1 <input type="checkbox"/> NOT EMPLOYED 2 <input type="checkbox"/> EMPLOYED, ON SICK LEAVE 3 <input type="checkbox"/> EMPLOYED, WORKS FROM HOME 4 <input type="checkbox"/> DON'T KNOW	1 <input type="checkbox"/> NOT EMPLOYED 2 <input type="checkbox"/> EMPLOYED, ON SICK LEAVE 3 <input type="checkbox"/> EMPLOYED, WORKS FROM HOME 4 <input type="checkbox"/> DON'T KNOW	1 <input type="checkbox"/> NOT EMPLOYED 2 <input type="checkbox"/> EMPLOYED, ON SICK LEAVE 3 <input type="checkbox"/> EMPLOYED, WORKS FROM HOME 4 <input type="checkbox"/> DON'T KNOW
h. Medicare coverage: (CHECK ALL THAT APPLY)					
1. Part A	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
2. Part B	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
3. Medicare Advantage	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
4. Hospice Benefit	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>
i. Number of 60-day episodes of home health care received in the last 12 months	<input type="text"/>				
j. Able to leave the house if homebound requirement is waived	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>	1 YES <input type="checkbox"/> 0 NO <input type="checkbox"/>

Please remove the labels from the top of each column when you have completed this section.

11. How many patients did your agency enroll in the demonstration?

|_|_|_| NUMBER OF PATIENTS YOUR AGENCY ENROLLED IN THE DEMONSTRATION

12. Please use the space below to describe any problems your agency encountered enrolling patients into the demonstration or reasons why your agency decided not to participate in the demonstration.

13. Do you think the homebound criteria are still a major issue for Medicare patients? YES NO

14. Please describe the type of patients for whom you think the homebound criteria should be waived.

Thank you for completing the survey. Please fill out your name, address and telephone number on the label below. We will use this information to send you the check for \$50 for completing the survey. We will use the telephone number to call you if we have any questions regarding your responses. All of your information is confidential. We will remove the label from this form. Information reported to CMS will not be identified by person or agency.

APPENDIX D

SAMPLING APPROACH AND CALCULATING WEIGHTS

A. AGENCY AND PATIENT SELECTION

The goal of the sample design of the Home Health Independence demonstration was to select a representative sample of home health agencies that have patients who are potentially eligible in each of the three participating states (Colorado, Massachusetts, and Missouri) and to select a representative sample of such patients within each selected agency. The sample for the survey was drawn in two stages: (1) agencies, and (2) patients within agencies.

There were 54 eligible agencies in Colorado, 85 in Massachusetts, and 68 in Missouri. In the first stage of sampling, we selected all 54 agencies in Colorado, 67 of 85 in Massachusetts, and 67 of 68 in Missouri, for a total of 188.

Before sampling the agencies in Massachusetts and Missouri, we sorted them by zip code and used a sequential sampling technique based on a procedure developed by Chromy.¹ We selected agencies with probability proportional to size, where size was defined by the number of potentially eligible patients in the agency. When agencies were so large that their probability of selection was equal to or greater than one, we selected those agencies with certainty and removed them from the random selection process. In fact, 42 of the 67 agencies selected in Massachusetts were selected with certainty, as were 58 of the 67 in Missouri.

Within each of the selected agencies in each of the three states, we needed to select patients. Before sampling, we sorted each agency's set of potentially eligible patients by gender, and then by age within gender, and selected a Chromy sequential sample of five patients per agency with equal probability.

¹ The Chromy procedure offers all the advantages of the systematic sampling approach but eliminates the risk of bias associated with it. It makes independent selections within each of the sampling intervals while controlling the selection opportunities for units crossing interval boundaries. Chromy, J.R. "Sequential Sample Selection

B. AGENCY AND PATIENT WEIGHTS

For the agency weights, the first step was to calculate the probability of selection for each selected agency (which was equal to one for the certainty selections: 154 of the 188 agencies in the sample). The inverse of this probability is the agency base weight. We then classified the final disposition codes for the agencies into two groups: (1) eligible and participating, and (2) eligible and nonparticipating.²

After examining response patterns by variables we thought might be relevant to both response propensity and outcomes of interest (urban/rural, number of potentially eligible patients, geographical location), we created six weighting cells, dividing each of the three states into two cells. For Colorado and Massachusetts, we divided the agencies into those having more or less than the median number of potentially eligible patients. For Missouri, we divided the agencies into those in urban or nonurban areas. The median number of patients for Colorado agencies was 11; for Massachusetts agencies, it was 27. Within each cell, we summed the base weights for all eligible agencies, summed the base weights for all eligible and participating agencies, and created a nonresponse adjustment factor as follows:

$$ADJ_{nr}(agency) = \frac{\sum_{\text{all eligible agencies in state}} \text{agency base weight}}{\sum_{\text{all participating agencies in state}} \text{agency base weight}}$$

We then applied this adjustment to the agency base weight as follows:

$$WT(agency) = (\text{agency base weight}) \cdot ADJ_{nr}(agency) \text{ for participating agencies}$$

(continued)

Methods.” Proceedings of the Survey Research Methods Section of the American Statistical Association, 1979, pp. 401–406.

² No agencies were considered to be ineligible or to have unknown eligibility status.

$WT(agency) = 0$ for ineligible and nonparticipating agencies

We then did a small ratio adjustment for Massachusetts ($85 \div 85.789$) so that the sum of the weights for that state summed up to the right number of agencies. For each state, the sum of the final weight is equal to the total number of eligible agencies in the state. We used SUDAAN software in our analysis to account for sample design complexities in the variance calculations.

For the patient weights, the first step was to calculate the marginal probability of selection for each selected patient within participating agencies. This probability was equal to five (the number of patients selected), divided by the number of potentially eligible patients in the agency. The inverse of this probability was the patient base weight. We then classified the final disposition codes for the patients into two groups: (1) eligible and medical record abstract received (“complete”), and (2) eligible and no abstract received. Six agencies had between 1 and 5 missing beneficiary records, for a total of 16.

The weighting cell was the agency, although we collapsed agencies if needed (for the three agencies with 3 or more missing records out of 5).³ Within each cell, we summed the base weights for all eligible patients, summed the base weights for all eligible and complete patients, and created a nonresponse adjustment factor as follows:

$$ADJ_{nr}(patient) = \frac{\sum_{\text{all eligible patients in agency}} \text{patient base weight}}{\sum_{\text{all complete patients in agency}} \text{patient base weight}}$$

We then applied this adjustment to the base weight as follows:

$$WT_{\text{marginal}}(patient) = (\text{patient base weight}) \cdot ADJ_{nr}(patient) \text{ for complete patients}$$

³ We attempted to pair up each of these three agencies with another agency of a similar size and geographic location. To get a reasonable nonresponse adjustment factor, we had to collapse one of the agencies with three others.

$WT_{\text{marginal}}(\textit{patient}) = 0$ for ineligible and non-complete patients

We then multiplied this marginal patient weight by the final agency weight to get the final patient weight, and did a final ratio adjustment to end up with the correct total number of potentially eligible patients across all agencies in each state. For each state, the sum of the final weight is equal to the total number of potentially eligible patients in all eligible agencies in the state. We used SUDAAN software in our analysis to account for sample design complexities in the variance calculations.

TABLE D.1

ABILITY OF POTENTIALLY ELIGIBLE MEDICARE HOME HEALTH PATIENTS
TO MEET DEMONSTRATION CRITERIA
(Weighted Percentages, Unless Otherwise Noted)

	All 3 States	CO	MA	MO
	Percentage (SE)	Percentage (SE)	Percentage (SE)	Percentage (SE)
Of Potentially Eligible Patients, Percent that Meets the Eligibility Criterion of:				
Has a permanent and severe disabling condition	88.79 (3.56)	90.65 (4.75)	88.85 (5.59)	87.65 (4.43)
Needs permanent skilled nursing care (not including medication management)	54.33 (6.76)	68.45 (6.88)	45.74 (9.40)	68.12 (4.61)
Needs help with three or more ADLs	68.56 (3.97)	76.05 (4.06)	64.57 (5.60)	74.40 (3.92)
Requires an attendant on a daily basis for medical or ADL assistance for rest of life	80.43 (3.33)	77.01 (5.41)	78.87 (4.64)	86.20 (5.07)
Requires human or technological assistance to leave home	94.59 (2.32)	84.02 (5.21)	95.04 (3.51)	98.99 (1.00)
Not employed, on sick leave, or works from home	98.32 (0.97)	98.57 (1.24)	99.05 (0.53)	96.34 (3.46)
Of Potentially Eligible Patients, Percent that Meets the Total Number of Criteria:				
One criterion	1.10 (0.85)	2.03 (1.51)	1.40 (1.39)	0.00 (0.00)
Two criteria	3.32 (1.09)	6.56 (2.89)	1.64 (1.13)	5.36 (2.52)
Three criteria	8.74 (2.19)	1.41 (0.85)	12.90 (3.26)	3.30 (1.74)
Four criteria	17.34 (3.24)	14.48 (4.08)	18.49 (5.05)	16.25 (3.92)
Five criteria	27.05 (4.88)	18.68 (5.25)	30.75 (7.62)	23.09 (4.34)
Six criteria	42.45 (5.47)	56.83 (8.16)	34.81 (8.0)	52.00 (4.56)

TABLE D.1 (continued)

	All 3 States	CO	MA	MO
	Percentage (SE)	Percentage (SE)	Percentage (SE)	Percentage (SE)
Of Potentially Eligible Patients, Percent that Does Not Need Permanent Skilled Nursing Care but Needs Medication Management	10.12 3.84	n/a	n/a	n/a
Of Potentially Eligible Patients, Percent that is Unable to Leave the House if Homebound Requirement Is Waived	74.43 (5.02)	72.92 (8.40)	79.98 (6.20)	61.55 (9.83)
Of Patients Who Meet All Criteria, Percent that is Unable to Leave the House if Homebound Requirement Is Waived	78.28 (4.45)	n/a	n/a	n/a

Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007.

n/a=not applicable.

TABLE D.2

THE FIVE MOST FREQUENT COMBINATIONS OF SATISFIED DEMONSTRATION ELIGIBILITY CRITERIA
AMONG POTENTIALLY ELIGIBLE MEDICARE HOME HEALTH PATIENTS

Type of Patient	Total Patients(S.E.)	Percentage of Total Patients(S.E.)	Demonstration Eligibility Criteria Satisfied					Needs Daily Attendant
			Permanent and Severe Disabling Condition	Needs Human or Technological Assistance to Leave Home	Not Working Outside the Home	Needs Permanent Skilled Nursing Care	Needs Permanent Help with at Least Three ADLs	
Meeting the Most Frequent Combination of Criteria	2,015.70	42.45 (5.47)	X	X	X	X	X	X
Meeting the Second-Most-Frequent Combination of Criteria	849.08	17.88 (4.19)	X	X	X		X	X
Meeting the Third-Most-Frequent Combination of Criteria (248.09)	375.94	7.92 (1.75)	X	X	X	X		X
Meeting the Fourth-Most-Frequent Combination of Criteria (253.33)	328.96	6.93 (2.52)	X	X	X			X
Meeting the Fifth-Most-Frequent Combination of Criteria (105.09)	230.37	4.85 (1.87)	X	X	X			

Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007.

(132.29)

(104.16)

TABLE D.3

AGENCY INTERPRETATIONS ABOUT “UNRESTRICTED” AND “RESTRICTED”
ABSENCES ALLOWED UNDER HOMEBOUND REQUIREMENT
(Weighted Percentages)

	All 3 States
	Percentage (SE)
Activities Homebound Patient May Leave House Without Restrictions:	
Visit doctor or medical institutions	98.05 (1.38)
Go to religious services	81.47 (3.89)
Shopping for food	13.90 (3.47)
Shopping for clothes	6.40 (2.24)
Have dinner with family members	18.56 (3.82)
Visiting friends	5.46 (2.10)
None of the above	1.95 (1.38)
Number of the Unrestricted Activities (Listed Above) for Which Homebound Patients May Leave the House for:	
None	1.95 (1.38)
One activity	15.70 (3.64)
Two activities	57.21 (5.01)
Three activities	17.80 (3.99)
Four activities	0.93 (0.93)
Five activities	1.82 (1.29)
Six activities	4.58 (1.90)

TABLE D.3 (continued)

	All 3 States
	Percentage (SE)
Excluding the Unrestricted Activities, Under Normal Circumstances, Homebound Patient Can Leave House No More Than:	
Once a month	9.90 (2.88)
Once every other week	8.85 (3.18)
Once a week	42.77 (5.23)
Two or three times a week	13.77 (3.50)
Four or five times a week	1.00 (1.00)
More than five times a week	3.86 (1.83)
Cannot leave the house	19.85 (4.45)
Excluding the Unrestricted Activities, Under Normal Circumstances, Maximum Amount of Time Homebound Patient May Be Away from Home Is:	
Less than 30 minutes	0.00 (0.00)
30 to 59 minutes	5.52 (2.09)
1 to 2 hours	29.73 (4.65)
2 to 3 hours	19.77 (4.21)
3 to 4 hours	15.52 (4.02)
More than 5 hours	9.40 (2.87)
Cannot leave the house	20.06 (4.49)
Believe Homebound Criteria are Still a Major Issue for Medicare patients	77.18 (4.38)

Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007.

TABLE D.4

THE FIVE MOST FREQUENT COMBINATIONS OF TYPES OF UNRESTRICTED ABSENCES ALLOWED UNDER THE MEDICARE HOMEBOUND REQUIREMENT

Type of Agency	Total Agencies (S.E.)	Percentage of Agencies (S.E.)	Types of Unrestricted Absences Allowed					
			Visit Doctor or Medical Institutions	Attend Religious Services	Have Dinner with Family	Shop for Food	Shop for Clothes	Visit Friends
Allowed Most Frequent Combination of Absences	117.30	57.21 (5.01)	X	X				
Allowed Second Most Frequent Combination of Absences	32.20	15.70 (3.64)	X					
Allowed Third Most Frequent Combination of Absences	23.04	11.24 (3.17)	X	X	X			
Allowed Fourth Most Frequent Combination of Absences	11.67	5.69 (2.65)	X	X		X		
Allowed Fifth Most Frequent Combination of Absences	9.39	4.58 (1.90)	X	X	X	X	X	X

Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007..

D.12

(11.07)

(7.44)

(6.44)

(5.50)

(3.89)

TABLE D.5

DISCHARGES AND DENIED REFERRALS DUE TO INABILITY TO MEET HOMEBOUND REQUIREMENT
(Weighted Percentages, Unless Otherwise Noted)

	All 3 States
	Mean (SE)
Discharges Because No Longer Homebound	
Mean number of patients per year per agency	119.55 (34.27)
Percent of total Medicare patient caseload per agency	13.36 (2.11)
Total number of patients across all agencies	23,249.48 6,709.23
Approximate Percent of Medicare Patient Discharges Due Solely to Loss of Homebound	
0 to 2 percent	27.96 (4.69)
3 to 10 percent	33.05 (4.96)
11 to 25 percent	19.44 (4.29)
26 to 50 percent	7.53 (2.47)
51 to 75 percent	8.96 (2.79)
76 to 100 percent	3.05 (2.26)
Denied Medicare Referrals for Sole Reason of Not Being Homebound	
Mean number of patients per year per agency	10.47 (2.16)
Percent of total Medicare patients per agency	1.87 (0.33)
Approximate Percent of Denied Medicare Referrals, Due Solely to Not Meeting Homebound Requirement	
0 to 2 percent	38.00 (4.76)
3 to 10 percent	23.91 (4.47)
11 to 25 percent	17.73 (3.88)
26 to 50 percent	9.64 (2.91)
51 to 75 percent	5.38 (2.22)
76 to 100 percent	5.33 1.96

Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007.

TABLE D.6
DEMONSTRATION ENROLLMENT

	All 3 States
	Total (SE)
Total Demonstration Enrollment	330.82 (115.50)
Of All Agencies, Percent That Enrolled Patients	27.30 (4.74)
Total Number of Agencies with at Least One Patient Who Meets Demonstration Criteria	174.21 (9.14)
Of Agencies with at Least One Patient Who Meets Demonstration Criteria, Percent that Enrolled Patients	26.37 (5.05)

Source: Mail survey of home health agencies in Colorado, Massachusetts, and Missouri. Survey was conducted January 2007 through March 2007.