

# COPING WITH MANAGED CARE

*Responding to the Needs  
of the Elderly*

ISSUE BRIEF NO.2

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JUNE 1999

BASED  
ON A  
GRANTMAKERS  
IN HEALTH  
ISSUE  
DIALOGUE

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WASHINGTON, DC

## Foreword

This report is the second in a series of programs made possible by a grant to Grantmakers In Health (GIH) from The Commonwealth Fund to bring grantmakers together with experts in policy, practice, and research to exchange information and ideas about key health issues facing the nation.

On June 17, 1999, GIH convened a small group of grantmakers along with officials from the Health Care Financing Administration and other experts in consumer education, managed care, and health services research for an Issue Dialogue on managed care and the elderly. Intended to both share lessons learned and stimulate new ideas, the Issue Dialogue proved to be a lively and insightful forum on what health funders can do to support development of consumer information, tools, and program models for this vulnerable population. This Issue Brief brings together key points from the day's discussion with factual information on managed care within the Medicare program and grantmaker activities drawn from a background paper prepared for Dialogue participants.

Special thanks are due to those who participated in the Issue Dialogue but especially to presenters and discussants: Bob Berenson, Carol Cronin, Geri Dallek, Richard Della Penna, Jan Eldred, Brian Hofland, Len McNally, Shoshanna Sofaer, Robyn Stone, and Bruce Vladeck. Anne Schwartz of GIH's staff planned the program and worked on the background paper along with Malcolm Williams (also of GIH) and Katie Merrell of the Center for Health Administration Studies at the University of Chicago. Mary Darby skillfully synthesized the background paper with points made at the meeting. GIH also gratefully acknowledges the support and advice of Brian Biles from The Commonwealth Fund in developing the program.

## About

Grantmakers In Health's mission is to help foundations and corporate giving programs improve the nation's health. It works to build knowledge, skills, and effectiveness of individual grantmakers and the field of health philanthropy. It also seeks to foster communication and collaboration among grantmakers and to provide links with experts who can help grantmakers shape their programs.

GIH structures its programs to anticipate changes in the nation's health and health policy and help grantmakers respond to those changes. Its Resource Center on Health Philanthropy monitors the activities of health grantmakers and synthesizes lessons learned from this work. GIH's Resource Center includes a searchable database on the priorities, grants, and initiatives of foundations and corporate giving programs working in the health field.

In addition to its Resource Center, GIH has several special initiatives including its:

- Support Center for Health Foundations — Helping health foundations develop effective programs, organizational structures, and operational styles
- Policy Programs — Building bridges between grantmakers and policymakers
- Partnerships for Maternal, Child and Adolescent Health — Working to foster collaborative efforts between grantmakers and the public sector to improve the health status and well-being of mothers, children, adolescents, and families.

GIH's services are designed for executives, staff, and trustees of foundations and corporate giving programs working in the health field. The organization serves the general health grantmaking community, develops targeted programs and activities for segments of this community, and provides customized services for individual funders. Specific activities include holding meetings (issue-focused forums, workshops, and large annual gatherings of grantmakers), providing education and training, tracking the field and conducting studies of health philanthropy, providing technical assistance on both programmatic and operational issues, making referrals to expert consultants, and brokering professional relationships.

Grantmakers In Health does not give grants or provide assistance in finding grants.

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## Introduction

Perhaps the most dramatic change in the U.S. health care marketplace over the past decade has been the decision of many employers to replace traditional indemnity insurance with managed-care products. Over time, new types of financing and delivery arrangements have evolved in response to employers' needs for predictable growth in premium costs and consumers' demands for high-quality, flexible care arrangements. Indemnity insurance is now a rare form of employee-base coverage and straight fee-for-service payment accounts for a small share of provider payments.

Until the mid-1990s, the elderly (whose primary source of insurance is the federal Medicare program) were relatively unaffected by these changes. In 1985, three years after health maintenance organizations (HMOs) began serving the Medicare population, only 1.2 million beneficiaries were enrolled in HMOs. That has begun to change, however. Although the vast majority of Medicare's 39 million beneficiaries continue to receive health services under fee-for-service arrangements, as of July 1999, more than 6.3 million beneficiaries (about 16 percent) were enrolled in 301 plans (HCFA 1999a).

Growth in Medicare managed-care enrollment was fuelled partly by HMOs' increasing interest in Medicare as a business opportunity. Initially, Medicare's payment rates did not compare favorably with those in the commercial market. In addition, few managed-care plans were prepared to meet the health care needs of the elderly population. By the mid-1990s, however, as most employers pressed for lower premiums, Medicare became a relatively more attractive payer. Increasing numbers of HMOs applied to participate in the Medicare program, with the number nearly tripling between 1991 and 1996.

Growing numbers of Medicare beneficiaries also enrolled in HMOs, drawn by the additional benefits these plans sometimes offered over fee-for-service Medicare. Nevertheless, the elderly still participate in managed care at much lower rates than those covered by employers and Medicaid. Less than 20 percent of the elderly will be in managed care by the end of 1999.

Managed-care participation among the elderly is likely to continue to grow for two reasons. First, as more working-age people are introduced to managed care in the workplace, they are becoming more familiar with it and so may be more likely to choose it when they retire. Second, a greater variety of managed-care options are now available to Medicare beneficiaries. The Balanced Budget Act of 1997 (BBA) made major changes in the Medicare program, restructuring it to incorporate features of the market for employer-based coverage. As the number and types of participating plans in Medicare grows, the use of managed care by the elderly will also likely grow.

The BBA, however, has also introduced some turmoil and instability to Medicare managed care. It made substantial changes in how Medicare managed-care plans are paid, a factor that some plans say has moved them to withdraw from or reduce their participation in Medicare. Thousands of Medicare beneficiaries enrolled in managed care have found themselves having to choose new health plans. Others have had their benefits reduced (particularly for prescription drugs) or seen their premiums rise.

On June 17, 1999, Grantmakers In Health convened an Issue Dialogue on Coping with Managed Care: Responding to the Needs of the Elderly. In response to recent changes to Medicare, considerable attention was given to what types of information and supports the

elderly need to make decisions about their health care coverage. The Issue Dialogue also considered activities affecting the type of care beneficiaries receive once they have chosen among Medicare options. This work focuses on identifying ways to structure health services to most effectively meet the needs of the elderly, particularly the chronically ill and frail.

During the meeting, participants heard presentations from grantmakers who have made major commitments to meeting the health care needs of the elderly and from experts in government, policy, and health services research. Participants engaged in an open exchange of ideas, experiences, and information on the challenges of serving Medicare beneficiaries and those who help them and on what grantmakers can do to support this process.

This report draws on a background paper prepared for the Issue Dialogue and synthesizes the discussion at the meeting. It focuses on the challenges surrounding the future of Medicare managed care and its ability to meet the needs of elderly beneficiaries. This is an evolving area, where, despite several years of research and program experience, a great deal remains to be learned.<sup>1</sup> This paper is divided into five sections, presenting:

- a brief review of recent trends in the elderly's use of managed care and relevant Medicare policies;
- issues related to the elderly as active health care consumers, focusing on strategies for helping Medicare beneficiaries make choices in their best interests and adapt to the operations of a new health plan;

- ongoing efforts to implement new Medicare policies by government and others at the federal, state, and local level, including the response by health plans to the growing numbers of enrolled elderly;
- ways that grantmakers can get involved, including some examples of current activities; and
- lessons from grantmakers' experience with these issues to date.

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<sup>1</sup> Where possible, factual information has been updated to reflect circumstances at press time. Because the program is in flux, readers may wish to consult the Health Care Financing Administration for the most up-to-date numbers on enrollment, plan participation, and program rules.

# Medicare Managed Care: Trends and Policies

Medicare created its risk-contracting program in 1982, allowing traditional HMOs to contract to provide care to Medicare beneficiaries. Through a risk contract, an HMO received a fixed monthly payment per enrolled beneficiary and was responsible for providing all covered benefits to these enrollees. In exchange for agreeing to receive their care through an HMO, enrolled beneficiaries typically had lower out-of-pocket expenses and sometimes received benefits beyond those provided through traditional fee-for-service Medicare (for example, eye examinations and prescription drugs). Over time, these arrangements became more popular, with risk plan enrollment growing from 3.3 percent in 1990 to 11.0 percent in 1996.

Risk-plan contracts specified the geographic area to be served by the HMO. Any beneficiary who lived in the risk-plan service area was eligible to enroll in the plan. HMOs with risk plans were required to provide at least the same benefits as the traditional program, but could also choose to provide additional benefits. They could generally charge beneficiaries additional premiums for these benefits, but in some cases were required to provide them at no cost to the beneficiary. Beneficiaries could enroll in and drop out of plans on a monthly basis.

## Early Years

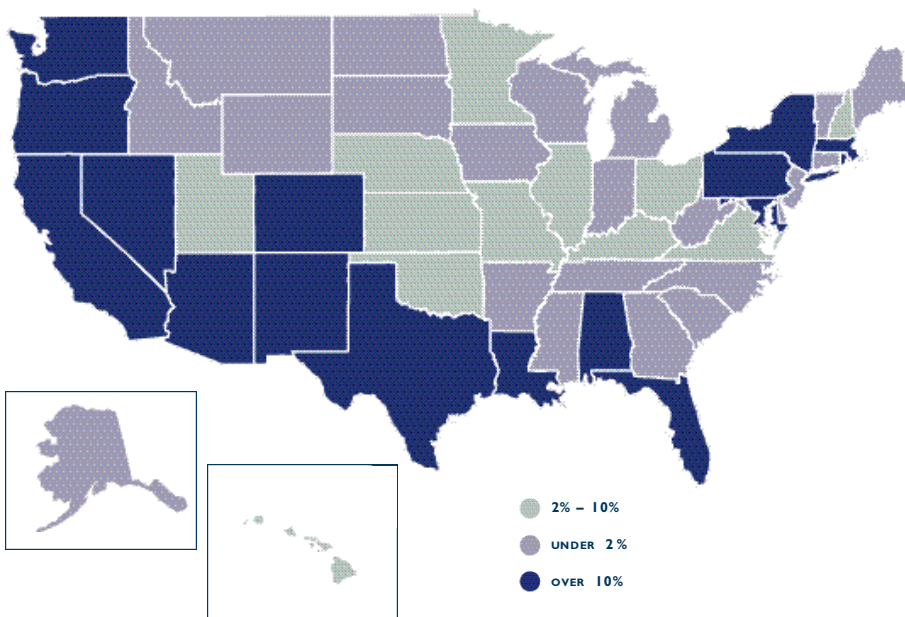
Risk plans were not evenly spread across the country, but were concentrated in the West and Southwest (see Figure 1.) The distribution of enrollees also mirrored the distribution of plans, with higher enrollment rates in the West, Southwest, and Northeast. About two-thirds of enrollees lived in five states (Arizona, California, Florida, New York, and Pennsylvania). Over time, however, the growth in the number of

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***HMO enrollees typically had lower out-of-pocket expenses and sometimes received benefits beyond those provided through traditional fee-for-service Medicare.***

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**Figure 1. Percent of Medicare Beneficiaries Enrolled in Risk Plans, June 1997**



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reductions, and benefit  
changes to beneficiaries***

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plans was associated with some geographic dispersion. In June 1995, 45 percent of beneficiaries lived in areas with no managed-care choices; this number fell to 37 percent a year later. Plan dispersion also led to more choices in certain markets. Between 1995 and 1996, the share of beneficiaries who had five or more risk-plan choices in their communities nearly doubled, from 14 percent to 25 percent. In 1996, well over half of risk-plan offerings included additional benefits at no charge to the enrollee.

### ***1997 Legislation Changes Rules***

The Balanced Budget Act of 1997 dramatically altered Medicare managed care by creating Medicare+Choice, an attempt to integrate the elderly into local health markets, presumably to improve access to care and to slow cost growth. Under Medicare+Choice, the elderly may select coverage from a variety of indemnity and managed-care plans. Individuals will receive and pay for care in different ways, depending on the plan in which they enroll. Despite the new emphasis on choice, however, Medicare+Choice remains, for the most part, an HMO program. Only one provider-sponsored organization and one preferred provider organization are currently participating in Medicare+Choice. No applications for participation have been received from medical saving accounts (Berenson 1999).

With greater choice has come the expectation that beneficiaries will assume new, more aggressive roles as consumers. The idea is that they will take responsibility for making informed decisions about prices, benefits, providers, service quality, and integration with supplementary and retiree health coverage. The success of this policy change will be determined by beneficiaries' ability to understand their new choices, participate effectively in an annual open enrollment season, and then receive and pay for needed care through their chosen plan.

### ***Recent Trends***

Participation in managed-care plans continued to grow after the passage of the BBA. The number of participating plans rose from 307 in 1997 to 346 by June 1998. At that point, more than 5.5 million beneficiaries (about 15 percent) were enrolled. Participation by health plans dropped in calendar year 1999. Some plans left the program, while other plans reduced their service areas. A total of 407,000 beneficiaries were affected by these decisions (of whom 51,000 were left without access to another managed-care plan), but the total number of beneficiaries enrolled in managed-care plans increased to more than 6 million in 1999. Plan participation is expected to decrease further to 275 in 2000.

The increased reliance on private plans rather than individual providers to provide care to Medicare beneficiaries has created some instability in the program. Historically, Medicare's risk program has been quite stable, with just five plan withdrawals during the two years previous to the BBA's passage. By contrast, about 13 percent of plans decided not to renew Medicare risk contracts in both 1998 and 1999. Yet, despite concerns about an industry backlash against new regulations implementing the BBA, new organizations continue to enter the program. As of August 1999, there were 13 pending applications for new plans and nine pending requests for service expansions (HCFA 1999b). While plan withdrawal decisions could leave some beneficiaries without access to Medicare+Choice plans in their service areas, these new applications, if approved, will extend access to nearly 600,000 Medicare beneficiaries.

Many plans participating in Medicare+Choice are restructuring their drug benefits by limiting coverage and increasing out-of-pocket costs for enrollees. In 2000, 86 percent of plans will have annual dollar caps on brand



## THE CENTER FOR MEDICARE EDUCATION: HELPING COMMUNITIES HELP THEIR ELDERLY

*People live in communities – and that, ultimately, is where they go for information and guidance on how to manage their day-to-day lives. That is why the Center for Medicare Education decided to focus its activities on building infrastructures for helping elderly people in the communities where they live.*

*Funded by a four-year grant from The Robert Wood Johnson Foundation, the Center views itself as a resource for a wide range of public agencies, private organizations, and individuals who help elderly people understand and use their Medicare benefits. The idea is to reach people – including physicians, bank tellers, grocery store clerks, even postal workers – who have direct contact with the elderly. Thus, the Center's definition of information intermediaries is quite broad.*

*The goal is to create community-level infrastructures for educating consumers around Medicare and the changes affecting the program, and helping them navigate the health care system and make appropriate choices for themselves. The Center is particularly concerned about improving techniques for educating subpopulations, both in terms of language and cultural sensitivity. Within the next two years, the Center hopes to have a specific emphasis on the chronically disabled elderly, because of the tremendous health needs of this subgroup and their impact on health care resources.*

*The Center's work has five main components:*

*Training. Through a subcontract with the Medicare Rights Center, the Center sponsored train-the-trainer workshops in 10 regional locations. These workshops provided Medicare information agencies with consumer-friendly tools for training professionals, community groups, seniors, and people with disabilities about Medicare rights, options, and benefits. A "Do It Yourself" Medicare Training and Reference Manual is currently in development and will be available in January 2000.*

*Clearinghouse. The Center collects and disseminates information on exemplary products and practices for beneficiary education. Examples of products include pamphlets, brochures, consumer guides, and worksheets that help beneficiaries understand Medicare and their health care choices. The Center also catalogues educational methods and techniques used by professionals to inform Medicare beneficiaries. This information will be available through the Center's web site and by fax and telephone referral.*

*Technical Assistance. The Center produces a series of monthly Issue Briefs that provide technical assistance to professionals in educating Medicare beneficiaries and their families. These Issue Briefs address educational techniques, the development and management of information campaigns, and changes in Medicare and health care policy. For example, one Issue Brief will provide practical information on how to translate materials into different languages; another will discuss ways for dealing with low-literacy populations.*

*Research and Conferences. Through its targeted research agenda, the Center is trying to map the field of beneficiary education, identify and investigate key issues, and come up with solutions. In a project with the National Council on the Aging, the Center is examining beneficiary education at the national and local levels to identify organizations with the resources and commitment to participate in Medicare education efforts. The Center also hopes to build consensus on important issues through small conferences and working meetings. The Center is planning a conference on sociocultural differences and how best to educate subpopulations by bringing together leaders from affected communities, health educators, and experts in decision support.*

*Web Site. The Center is developing a web site ([www.MedicareEd.org](http://www.MedicareEd.org)) that will make the most current information readily available to counselors and health educators throughout the country. The web site will be designed to foster interaction and information exchange between individuals and organizations with shared educational goals.*

name or generic drugs. For the first time, all plans participating in Medicare+Choice will charge copayments for prescription drugs. These changes vary among states, although the total number of Medicare+Choice enrollees with access to prescription drug coverage will remain virtually the same.

Plans are also increasing their monthly premiums. In 2000, the enrollment-weighted average monthly premium to be paid by beneficiaries for basic plans will nearly triple, from \$5.35 in 1999 to \$15.84. The percentage of beneficiaries with access to a Medicare+Choice plan that does not charge a premium will decline from 85 percent in 1999 to 77 percent in 2000 (HCFA 1999b).

The Health Care Financing Administration (HCFA), the federal agency that oversees Medicare, is working with plans and with the beneficiary community to more effectively communicate plan withdrawals, service area reductions, and benefit changes to beneficiaries. In 1998, plans were not obligated to inform beneficiaries until November 2 that they were withdrawing from Medicare+Choice for calendar year 1999, causing a great deal of last-minute concern among beneficiaries about their health care coverage. In 1999, plans were encouraged to notify beneficiaries immediately on notice of withdrawal to HCFA, so that beneficiaries would not learn of the change first through the news media. Plans were also required to send beneficiaries a formal followup letter by September 15 to inform them of their rights and of other plans operating in their area.

From the beneficiary perspective, plan withdrawals, service reductions, benefit cutbacks, and premium increases will force individuals to periodically revisit the process of choosing and learning how to use a new plan. Even those beneficiaries satisfied with their current plan may have to choose a new one if their plan goes

out of business, merges with (or is purchased by) another plan, simply decides to stop participating in Medicare+Choice, or changes its premiums or benefits. Some beneficiaries may have to choose a new plan for two years in a row because of plan withdrawals. The issues that may arise, therefore, in the context of plan open enrollment and orientation are not unique to the initial implementation of Medicare+Choice, but will likely become ongoing concerns.

In addition, the enrollment process and several enrollment policies have changed under the BBA. From now on, Medicare beneficiaries will no longer be able to enroll during any month they choose, but will participate in an annual open enrollment process much like that conducted by large employers. Similarly, they will not be able to disenroll from a plan on a monthly basis. Instead, a one-year lock-in policy is being phased in, combined with an opt-out period during the first three months of enrollment. By 2003, all beneficiaries will be obligated to stay in a chosen Medicare+Choice plan for one year with the option to drop out of a new plan within the first three months of enrollment.

Finally, new policies have been established regarding the definition of emergency care, use of out-of-plan services, and grievance and appeals processes. These affect beneficiaries' ability to compare plan information and to use services effectively within a chosen plan.

### ***Assessing the Impact on Beneficiaries***

Many questions remain about the impact of recent changes in Medicare on beneficiaries. Several groups are tackling those questions. HCFA, for example, is trying to determine the degree to which plans are altering their prescription drug benefits and increasing cost sharing (Cronin 1999). The Henry J. Kaiser Family Foundation, with Westat and the Barents Group, surveyed a sample of those beneficiaries who were affected by plan withdrawals in 1998

to find out when they learned that they would not be covered and where they got their coverage (Neuman 1999). In addition, The Robert Wood Johnson Foundation is funding Project HOPE to use Medicare claims data to study the impact of plan withdrawals on beneficiaries. The Foundation is also funding Mathematica Policy Research to survey beneficiaries about the kinds of information they use to make Medicare choices and how satisfied they are with the choice process (Colby 1999).

## The Elderly as Health Care Consumers

The recent changes to Medicare place new demands on the elderly, asking them to make more complex and more consequential decisions about their health coverage. To choose a plan, consumers need information about what the plan provides, how much they will be expected to pay for services, and how to use plan services. In particular, they may want to compare plans with regard to:

- services covered;
- cost sharing, including deductibles, co-payments, and other fees;
- utilization controls, such as referral requirements for specialty care and pre-authorization for procedures and hospitalization;
- provider network coverage (both geographic and specialty);
- quality or performance measures; and
- grievance or appeals procedures.

In addition, after choosing a plan, beneficiaries must learn how to get health care through their new plan, since the procedures for making appointments, receiving services, authorizing payment, and appealing plan decisions differ from plan to plan.

A growing body of literature explores the challenges of promoting informed decisionmaking by consumers with regard to health care choices. Hibbard, Slovic, and Jewett (1997) reviewed recent decisionmaking and human judgment research with regard to informed consumerism in health care. As they explain, the availability of appropriate information for consumers, such as carefully designed side-by-side plan comparison charts, does not necessarily ensure optimal or informed decisions. Even when relevant information is available, plan comparison data are quite difficult for individuals to process and use to arrive at well-reasoned conclusions. Finally, once information is used to select a plan, different types of information must be acquired and assimilated to make appropriate use of plan benefits.

Despite increasing efforts to produce information that might be useful, important gaps remain. For example, there is little comparative information on how different plans make medical necessity decisions. In addition, much work remains to be done in determining how best to present this information in a manner that is comprehensive and useful to beneficiaries (Sofaer 1999).

Finding ways to educate Medicare beneficiaries about their new choices is proving to be very difficult. Increasingly, many policymakers, consumer advocates, and researchers are reaching the conclusion that it simply is not realistic to expect older adults to become experts on Medicare managed care. Some speak of a need to develop a capacity for triaging information at the local level, so that beneficiaries can access the information they need – whether it is which plan provides coverage for eyeglasses or how to get a referral to a specialist – at the moment that they need it. It is possible that this process could take 5 to 10 years to achieve, requiring numerous modalities of education, ombudsman programs, and grievance and appeals procedures to help consumers make decisions (Stone 1999).

### ***The Role of Information Intermediaries***

Many argue that a strategy is needed for identifying key people to whom older adults can turn for information and help when they need it – and giving those information intermediaries, as they are often called, the training and support required to do the job. A number of questions remain to be answered in this area, including:

- Who is in the best position to provide this assistance to Medicare beneficiaries, keeping

in mind that there is no one-size-fits-all solution?

- What roles are and are not appropriate for information intermediaries?
- Who is willing to play these roles, and at what level of intensity? What incentives and support do intermediaries need to meet beneficiaries' needs?
- Who is able to play these roles? Who is not? What resources and training are needed to

## UNDERSTANDING THE GAP BETWEEN INFORMATION AND CHOICE

*What is the link between education and decisionmaking? Research shows that beneficiaries' knowledge of Medicare is low. That lack of understanding continues with the implementation of Medicare+Choice. Yet other studies suggest that, despite their lack of education, Medicare beneficiaries make relatively rational health care decisions and that they learn from their experiences.*

*In a review of the literature, the Physician Payment Review Commission (1996) found that Medicare beneficiaries knew little about what Medicare covered, the restrictions and limitations on coverage, and cost-sharing policies. They also underestimated the amount of expenses covered by Medicare, did not know whether various types of services were covered, and had limited knowledge about supplemental insurance policies.*

*Other evidence suggests that Medicare beneficiaries may have difficulty obtaining information and understanding the gaps in the benefit package that generate a need for supplemental coverage (Neuman and Langwell 1998). In addition, focus groups of Medicare beneficiaries conducted by the National Academy of Social Insurance (NASI) revealed that beneficiaries were unclear about what health plan they were in or whether it was a supplemental policy or a Medicare HMO.*

*Finally, a survey of Medicare beneficiaries in areas of high managed-care penetration found that they had poor understanding of the difference between managed care and fee for service (Hibbard et al. 1998). Thirty percent of those surveyed knew almost nothing about HMOs, and only 11 percent had enough information to make an informed choice among a variety of plan options. The study also found that HMO enrollees were less able to distinguish between the two systems than those enrolled in traditional Medicare.*

*Patterns of enrollment and disenrollment in Medicare risk plans over the past 15 years or so suggest that beneficiaries learn from their experience with managed care. The data show definite and predictable curves of enrollment and disenrollment among specific communities and among specific plans, depending on market forces in those communities and on individual plan performance. These patterns indicate that individual beneficiaries who enroll in HMOs and like them stay with them; those that who do not like their HMOs leave them and enroll in fee for service. Other beneficiaries switch managed-care plans when they reach the limit on their prescription drug benefit; by enrolling in a new health plan, they can begin a new drug benefit (Vladeck 1999).*

*These data lead some experts to argue that, even without the benefit of education and comparative health plan information, Medicare beneficiaries do in fact make rational decisions about their health care. They suggest that perceptions about the high level and quality of information that beneficiaries need in order to make rational choices are out of synch with how beneficiaries actually go about making those choices (Vladeck 1999).*

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enable different groups and individuals – including professional staff, volunteers, family members, friends, and health care providers — to play these roles?

- If different groups play different roles, how should they be linked?
- What will it cost to engage and support different groups?
- What difference will these efforts make? How long will it take before the difference these efforts make becomes apparent? (Sofaer 1999)

Spouses and children are obvious choices for elderly people to turn to for help in synthesizing health plan information. Although family members and others may act as information intermediaries, helping beneficiaries understand and use plan information, they may also bring their own personal biases to bear. These biases may pertain to the beneficiary's health needs and financial resources or to the relative value of different health plans. For example, a husband and wife may have dramatically different health needs that might be best met by different plans, but one may strongly prefer that both join the same plan. Adult children may not be well informed or realistic about their parents' needs and resources.

Beneficiaries with informal care resources may both value and use plan services and benefits differently from those without such social supports. Studies have estimated that between 70 percent and 90 percent of the care of noninstitutionalized frail older persons is provided by family members, friends, and other informal supports, with or without formal, supplementary service assistance (Stone et al. 1987; Cantor 1989). The needs and constraints of the caregiver, as well as those of the patient, will likely influence when and how care is received.

Other information intermediaries available to Medicare beneficiaries include medical professionals, social service providers, local health officials, volunteers, and faith-based organizations. Early findings from case study research funded by The Robert Wood Johnson Foundation show that there are many information intermediaries for Medicare beneficiaries, but rarely are they coordinated. Within a given community, the nature of these intermediaries and the activities that they conduct vary significantly (Sofaer 1999).

Some experience suggests that a great deal remains to be learned in terms of how to train and prepare intermediaries. The New York Community Trust funded a grant to train family members and spouses to act as health care proxies for elderly people. Program officials initially thought that proxies would seek out training so that they would be prepared in the event of a crisis. Instead, the opposite proved true; the proxies did not want training until a crisis actually occurred (McNally 1999).

### ***Developing Tools to Support Informed Choice***

Underlying current efforts to educate Medicare beneficiaries are tensions between the need for standardization and the need for customization for different groups of beneficiaries. So far, there has been little work to tailor information presentation, either in terms of content or mode of presentation. For example, little use has been made of media, such as video or radio, that may be more effective for less literate groups. Educational efforts still operate in a limited range of languages. This tension between standardization and customization gives rise to a number of questions:

- What needs to be standardized (e.g., terminology, measurement methodologies)?

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- What will be effective only if it is customized (e.g., outreach strategies, communication modes, content)?
- Are there ways to ensure a standard approach for identifying the needs of a particular individuals or groups and then customizing strategies for meeting those needs of these individuals and groups? (Sofaer 1999)

Foundations can play important roles in these evolving efforts to inform Medicare beneficiaries as health care consumers, both at the national and local levels. Experimentation and innovation are sorely needed in this field. The evolving nature of both the Medicare program and the health care market will create new and ongoing information needs – meaning that the need for experimentation in this field will be continuous. In addition, structures and processes need to be developed for sharing experiences and lessons learned from different projects and programs.

## Implementing Medicare + Choice

Carrying out the provisions of the Balanced Budget Act has already involved actors at the federal, state, and community levels, both within and outside government. While government has an obligation to educate beneficiaries about Medicare+Choice and oversee program administration, other tasks cannot (or should not) be performed by government agencies. As a result, implementing Medicare+Choice will present new opportunities and challenges to a wide variety of actors, including private health care plans, health providers, employers (as administrators of retiree benefits), community organizations, family members, and philanthropy. This section summarizes activities by some of these actors, starting with HCFA. Grantmakers' activities are described in the following section.

### ***The Health Care Financing Administration***

The BBA calls for HCFA to develop materials to inform beneficiaries about their plan choices and to undertake a variety of activities to educate beneficiaries, and those who help them, about the changes to Medicare and the effects of these changes. In response to the BBA, HCFA created the National Medicare Education Program (NMEP). Although Congress did not ultimately appropriate all of the funds authorized for HCFA in the BBA, the agency has embarked on all mandated tasks.

Medicare beneficiaries need general, national-level information that can be broadly disseminated, but they also need customized, local information so that they can make decisions in the context of the resources and options that are available to them in their local communities. Accordingly, NMEP comprises a mix of activities, some of which are national and some of which are explicitly local in scope (Cronin 1999). Key components of NMEP include:

- dissemination of materials on changes in Medicare policy to all Medicare beneficiaries;
- a toll-free, computer-assisted call center to answer questions related to plan choices; process requests for plan comparison information and plan disenrollment forms; and make referrals to other information sources when appropriate. The service, which accommodates both English- and Spanish-speaking callers, was implemented nationwide this year;<sup>2</sup>
- a national train-the-trainer effort for information intermediaries;
- a national publicity campaign;
- state and community-based publicity and outreach campaigns including public service announcements, health fairs, and media call-in shows;

<sup>2</sup> The help line (1-800-MEDICARE) operates 24 hours a day, seven days a week, with customer services representatives available from 8 a.m. to 4 p.m., Monday through Friday. The service accommodates both English- and Spanish-speaking callers and offers a TTY line for the deaf and hearing impaired.



- increased funding for the state health insurance assistance programs (SHIPs). These organizations, located either in states' aging or insurance departments, provide personal counseling and assistance to beneficiaries in local communities;
- an Internet site (Medicare Compare) that displays available Medicare+Choice plans by ZIP code, with some information available in Spanish and Chinese. The site, which is located at [www.medicare.gov](http://www.medicare.gov), also provides comparative, state-level nursing home data;
- a strategy for evaluating the effectiveness of different educational tools and testing innovative strategies at the community level; and
- development of partnerships with community-based organizations to aid in the dissemination of information to beneficiaries.

In November 1998, HCFA mailed the *Medicare & You* handbook to 5.1 million Medicare beneficiaries in five pilot states — Arizona, Florida, Ohio, Oregon, and Washington. A condensed *Medicare & You* bulletin was mailed to beneficiaries in the remaining 45 states and territories. These mailings described the rights and protections enjoyed by Medicare beneficiaries, new preventive benefits, and descriptions of the new health plan options.

From the pilot project, HCFA officials learned that beneficiaries use the handbook as a reference source. They also found that they needed to simplify the language used in the book; the first three pages of the handbook, which provide instructions on how to use the rest of the book, are written at a fourth- to sixth-grade reading level.

More recently, in September 1999, HCFA mailed the handbook to all 39 million Medicare beneficiaries. It plans to do such mailing annually. That way, beneficiaries will have the book in hand prior to open enrollment, a process that

will not actually begin until in 2002. HCFA officials want to create an infrastructure now, however, that will prepare beneficiaries for assembling the information they need to make their health plan choices when such decisions are part of an annual open enrollment process (Cronin 1999).

The content and format of HCFA's various communication tools have been informed by research into beneficiaries' knowledge about Medicare and managed care, and their ability to understand information of different types. For example, the research of Sofaer and colleagues (1992) shows that the specific design used to describe cost-sharing responsibilities in a plan comparison chart affects beneficiaries' understanding of these arrangements.

In addition to disseminating information about Medicare+Choice, HCFA is responsible for monitoring the marketing practices and grievance or appeals processes of plans within the program. Plans must submit all marketing materials to HCFA for approval 45 days before distribution. HCFA reviews the marketing materials to ensure that appropriate descriptions of the benefits, fees, and all terms and conditions of membership are included, and that the plans are not engaged in discriminatory marketing practices designed to attract healthier beneficiaries. HCFA also has developed regulations for an appeals process that beneficiaries can access should a claim they make be denied.

HCFA is working with the National Association of Insurance Commissioners (NAIC) to implement a program called Medigap Compare, which would provide Medicare beneficiaries with comparative price information on supplemental Medicare policies, often referred to as Medigap policies. This collaboration of state regulators with a federal agency is critical because Medigap policies are regulated by the states, not the federal government (Cronin 1999).

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***HCFA officials learned that beneficiaries use the Medicare & You handbook as a reference source. They also found that they needed to simplify the language used in the book.***

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## EARLY LESSONS FROM IMPLEMENTATION OF MEDICARE+CHOICE

*Georgetown University's Institute for Health Care Research and Policy, with support from The Commonwealth Fund and the California HealthCare Foundation, is studying early implementation of Medicare+Choice in four communities: Cleveland, Los Angeles, New York, and Tampa/St. Petersburg. Early findings suggest a range of initiatives that foundations can support at the community level to help Medicare beneficiaries, including education and implementation of consumer protections under Medicare+Choice. Following are some early lessons gleaned from the study.*

- 1. Simple messages work best. The Medicare & You handbook that was mailed to 5.1 million Medicare beneficiaries in a five-state pilot test generated little interest or response from beneficiaries. But a Medicare & You brochure that was sent to beneficiaries in the remaining 45 states made a much bigger impact. The reason? The brochure is short, concise, and focuses on five simple messages. Foundations working at the community level have an opportunity to get these types of messages out to Medicare beneficiaries.*
- 2. Communication is personal. Hotlines and mass mailings have a limited appeal. Beneficiaries often need to sit down with an intermediary who can answer their questions in person, provide information, and offer one-on-one counseling. This role is probably best played by the state health insurance assistance programs and area agencies on aging, organizations funded from both public and private sources.*
- 3. Minority elderly people have special information needs. This appears to be particularly true among low-income minority beneficiaries. In New York City, low-income Hispanic beneficiaries told researchers that their initial reaction to receiving the Medicare & You brochure was fear. They were afraid of losing health care and public assistance benefits, and were concerned about the perceived threat to their immigration status. What they needed was reassurance in clear, simple language.*
- 4. The Internet is still uncharted territory to most elderly people. Only 7 percent of the Medicare population currently use the Internet. By contrast, 27 percent of the general population seek health care information from the Internet; by 2005, that figure will increase to an estimated 50 percent. Elderly people need to be encouraged and supported to tap the Internet for health care information.*
- 5. Now is the time to prepare for open enrollment. As open enrollment and lock-in are phased in, beneficiaries will need plan comparison guides. Local foundations have an opportunity to fund good, easy-to-read comparison guides, as well as to translate such guides into languages used in their communities.*
- 6. Education on quality-of-care indicators is lacking. Quality indicators can convey useful information about health plans, but beneficiaries need to understand what they mean and how to use them.*
- 7. Media outreach and education requires support. Community organizations need help in organizing and implementing effective media campaigns, and local reporters need education. This is another opportunity for foundations to make a difference.*
- 8. Basic information on plans is hard to get. Area agencies on aging in the four study states have experienced difficulty in getting plans to send them their marketing materials. In addition, problems with marketing practices by individual insurance agents and managed-care plans persist. As a result, beneficiaries often lack accurate, unbiased information on plans, including which doctors are in plan networks, what prescription drug benefit plans offer, or what types of disease-management program plans operate.*
- 9. Remember the dual eligible population. People who receive both Medicare and Medicaid often get lost in the shuffle. Managed-care plans do not know how to identify these enrollees; as a result, they frequently do not receive all the benefits to which they are entitled. This population needs special education and support that can be provided by local communities working with health plans, Medicare, and Medicaid programs at the state level.*



The regional offices of HCFA are also looking to create partnerships with local organizations to help educate beneficiaries about their new choices. These REACH campaigns (Regional Education About Choices in Health Care) encompass a range of activities, including health fairs, media presentations, and development of educational materials for special populations.

For example, the Kansas City regional office held a one-day, city-wide effort on May 19, 1999, to make Medicare beneficiaries aware of the basics of the program, including their Medicare+Choice options, and the preventive services to which they are entitled as Medicare beneficiaries. More than 1,000 people attended the programs and exhibits at four sites around the city. Participating local partners included Blue Cross and Blue Shield of Kansas, the American Red Cross, Providence Medical Center, Overland Park Regional Medical Center, local health departments and housing authorities, OSCO Drug, the US Administration on Aging, the US Department of Housing and Urban Development, the American Association of Retired Persons, major employers, unions, and others. Beneficiaries appeared to be overwhelmingly positive about the event, and many volunteers and partners have expressed a willingness to repeat it next year. The hope is that the fair will be replicated in other cities.

HCFA's regional office in Boston has held partnership conferences in each of the region's six states. The primary objective of the conferences was to garner support from community-based organizations in conducting informational outreach campaigns. Each state then formed beneficiary working groups to follow up on local outreach activities. The regional office will also hold one regionwide partnership conference to share the ideas generated by individual states' working groups.

In Philadelphia, HCFA has opened "Your Medicare Center," a one-stop customer service walk-in center offering free services to Medicare beneficiaries, their families, and the general public. The Center provides information on Medicare managed-care plans and workshops on benefits, policies, and health promotion topics.

Other activities have focused on special populations of Medicare beneficiaries. For example, in Arizona, HCFA officials are working with Native American tribal elders to disseminate information. Regional workers in Seattle are translating educational materials into Chinese to accommodate the large Asian population in that area.

These regional and local outreach efforts may offer key opportunities for foundations to work strategically with HCFA. Traditionally, outreach at the local level has not been part of HCFA's strategy; local foundations could be important resources and partners for HCFA regional offices. One California grantmaker, the California HealthCare Foundation, already works closely with HCFA's regional office in San Francisco (Cronin 1999).

### ***Health Plans***

Implementation of Medicare+Choice affects both marketing and care processes of health plans. Through their marketing efforts, health plans are an important source of information about insurance options, reaching a large number of elderly through mass media (newspapers and television) and seminars. The information they provide must be approved by HCFA for accuracy. While individuals attending plan seminars can learn a great deal about a particular plan, these seminars are marketing efforts and are not intended to provide objective information on other options. In fact, in focus groups of beneficiaries funded by The Henry J. Kaiser Family Foundation, many participants expressed concern about the objectivity of this

information (Physician Payment Review Commission 1996).

Once elderly consumers are enrolled, plans may offer new enrollee information seminars, brochures, or physical assessments. There is limited information on the scope of services tailored to elderly enrollees by plans, but anecdotal evidence suggests that, for a number of reasons, this is an area to which plans are beginning to pay more attention.

Managed-care plans' experience with Medicare beneficiaries varies considerably. Many plans are

new to Medicare and have only recently begun to provide services for elderly people. Other plans have experienced the so-called aging-in phenomenon that occurs when people who originally enrolled in managed-care plans while they were working decide to continue in managed care when they became eligible for Medicare. Kaiser Permanente of Southern California is such a plan. With a history of more than 50 years, Kaiser serves many beneficiaries now in their 80s and 90s who originally enrolled when they were employed. Southern California Kaiser serves more than 280,000

#### FIVE OBSERVATIONS ABOUT THE DEBATE OVER MEDICARE+CHOICE

*The debate over Medicare+Choice often becomes unintelligible to those not steeped in the arcane details of the Medicare program's inner workings. In fact, the policy issues underlying the jargon are the same as those challenging other sectors of the health system: ambivalence about managed care, the desire to preserve choice and promote quality while somehow reining in costs, and general distrust of the federal government. Following are five key observations made by Bruce Vladeck, former administrator of HCFA, at the June 17 Issue Dialogue.*

1. *Public debate over managed care – and Medicare managed care specifically – is largely anecdotal, misinformed, and emotionally charged. In short, it is prone to a large ratio of hype over substance.*
2. *The demand for choice in the Medicare program did not come from the beneficiaries themselves. Prior to the passage of the Balanced Budget Act in 1997, most Medicare beneficiaries were highly satisfied with their health insurance arrangements and coverage, regardless of whether they were enrolled in HMOs.*
3. *Policymakers decided that choice is good for beneficiaries. This tenet springs from the conviction that markets are morally superior to regulation. It also implies that consumers are somehow responsible for rising health care costs, for the behavior of the health care system in general, and for their own personal health – or lack of it.*
4. *Information is not free: choice has its costs, and acquiring information in order to make choice involves certain costs. For many Medicare beneficiaries, the costs associated with learning more about the program substantially exceed any potential benefit that acquisition of greater knowledge may produce for them.*
5. *Many policymakers and consumer advocates viewed the expansion of choice in Medicare as a safety valve, given the inadequacy of other available mechanisms to ensure high-quality service for beneficiaries. Thus, to ensure that individual beneficiaries don't get stuck in a given plan indefinitely, they are being asked to assimilate sophisticated yet incomplete and imperfect information in order to make more rational choices about how to receive and use their health care services.*

*Taken together, these observations suggest that grantmakers and others involved in serving the elderly should be especially careful about trying to separate the hype from the substance, and not to assume that conventional wisdom about "the government's" objective is correct. The government is actually divided, ambivalent, and experiencing its own internal conflicts. What appears to be the general thrust of policy today may change by tomorrow.*

people over age 65, of whom about 250,000 are covered through Kaiser's risk contract with Medicare. Southern California Kaiser's program for Medicare beneficiaries includes a zero premium, an unlimited drug benefit, and a dental benefit (Della Penna 1999).

Foundations and managed-care plans are well suited for collaboration. Health plans are rich sources of information about beneficiaries, while foundations often have important links and experience at the community level. Some foundations have expressed willingness to work with managed-care plans as conveners to promote better outreach and communication with Medicare beneficiaries and those who work with them.

### **States**

States affect the implementation of Medicare+Choice in several ways. First, with regard to disseminating information, states provide information to the elderly through the state health insurance assistance programs, funded in part by HCFA grants to state offices of aging or insurance, and, in some cases, with additional support from philanthropy. In general, these are small-scale operations, often staffed by volunteers. They offer one-on-one counseling about options for coverage as well as troubleshooting on other issues such as grievances and appeals. These programs are typically well regarded for providing accurate information but reach relatively few people.

In addition, states are responsible for regulating insurance plans. As new types of health plans enter the market, states must decide whether and how they should be regulated. Consideration of their regulatory status by state insurance authorities often arises as these new plans become risk-bearing entities. In some cases, states have applied existing rules governing HMOs to these new plans. In other cases, they have developed separate regulations. Rules governing financial solvency have been a major

consideration, particularly for provider-sponsored organizations. States have chosen to address this and other issues in different ways. As a result, the financial safeguards for Medicare+Choice enrollees differ across states and are still changing as new types of plans enter the market.

Finally, increasing interest by consumers in information about plan performance and quality has led some states to start monitoring and reporting this information. Attention to consumer protection issues is increasing at the state as well as federal level. State actions that affect health plans in general will have an impact on Medicare beneficiaries who enroll in these plans.

## What Grantmakers Can Do

Even with HCFA's strong commitment to educating the elderly about their health plan choices, much work remains to be done. This is not just a question of resources, but of roles. It is important to have realistic expectations about the contributions that different sectors and stakeholders can make. As a government agency, HCFA is required to be neutral and descriptive about a program that is national in scope, even though what many beneficiaries need and want is targeted advice. Similarly, HCFA is not well positioned to respond to the specific needs of individual communities, or of many special populations, such as those with language or cultural barriers, those living with specific chronic diseases, the homebound, and the so-called dual eligible (individuals who receive both Medicare and Medicaid).

The effectiveness of HCFA's efforts to educate beneficiaries and its systems for grievance and

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***Some foundations have expressed willingness to work with managed-care plans as conveners to promote better outreach and communication with Medicare beneficiaries and those who work with them.***

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***Community-based organizations are more in touch with the needs of the community and can tailor information so that it is more readily understood and easier to use by local beneficiaries***

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appeals and for monitoring marketing materials can be enhanced with the help of organizations within local communities. Community-based organizations are more aware of community needs and would be better able to tailor information for use by local beneficiaries. Local communities are also better equipped to provide advocacy services for beneficiaries, including ombudsman programs that offer assistance with understanding plan differences, choosing a plan, and navigating the appeals process. This is especially true for elderly people with language and cultural differences, who lack a social support system, or who are cognitively impaired.

Foundations can get involved by extending HCFA's activities and by addressing issues that go beyond HCFA's role. They can be valuable players in either creating or supporting the infrastructure to assist beneficiaries at the community level.

Following is a description of work by two foundations, the California HealthCare Foundation and the Retirement Research Foundation. Both of these foundations made presentations at the June 17 Issue Dialogue. Medicare-related activities by other grantmakers are highlighted as well, according to their funding strategies. This listing is not exhaustive but is intended to illustrate the diversity of approaches that grantmakers are taking in this area.

### ***California HealthCare Foundation***

The California HealthCare Foundation was established in May 1996, as a result of the conversion of Blue Cross of California from a not-for-profit health plan to a for-profit corporation called WellPoint Health Networks. The Foundation's mission is to expand access to affordable, quality health care for the underserved and to promote improvements in the health status of the people of California.

In 1997, the Foundation launched a five-year, \$15 million grants program designed to improve care for elderly Californians enrolled in managed care. The statewide Program for Elders in Managed Care has three goals:

- to stimulate innovation in service delivery within managed care,
- to provide incentives for managed-care organizations to partner with local health and social services agencies to more effectively integrate acute and long-term care services, and
- to support evaluation of new care models.

Under the Program's first funding cycle in 1998, the Foundation committed \$3.4 million toward development of coordinated systems of care linking community-based service providers with managed-care organizations. Thirteen grants were funded, including three full-scale demonstration projects and ten planning projects.

The demonstration projects will be carried out over three years and will develop new mechanisms for identifying elderly people who need services, coordinate medical care and supportive services for the elderly, and create comprehensive strategies using existing personnel for serving the complex needs of elderly people:

- Sutter Health, Central Area (Sacramento), is collaborating with the University of California at San Francisco's Goldman Institute on Aging to test new ways of identifying and caring for persons with Alzheimer's disease and other dementias. This project involves a number of health plans, providers, and community groups in San Francisco and Sacramento.
- The Brown and Toland Medical Group, a large independent practice association in San Francisco, is contracting with Jewish Family and Children's Services to provide case management and referrals for elderly patients.

- Kaiser Permanente, Tri-Central Region (Los Angeles), is working with the local area agencies on aging and the Visiting Nurse Association Foundation to test the addition of a home and community-based services benefit for elderly enrollees. Beneficiaries identified as frail and at risk for adverse events (such as falls and nursing home placements) will be referred to a geriatric social worker who will assess their needs and arrange for needed services, such as transportation, personal care, nutritional counseling, and home modification.
- The City and County of San Francisco Department of Public Health received \$119,250 for San Francisco's Long-Term Care Integration Project. This project will help the Department and key community-based service providers plan for the integration of all Medi-Cal acute and long-term care services for elders and the disabled in San Francisco.
- The Desert Medical Group in Palm Springs received \$1,194,977 for the IMPACT Study, which will test the cost-effectiveness of a multifaceted disease-management program to improve the care of older adults with major depression or mood disorders.
- The National PACE Association in San Francisco received \$265,122 for development of a consumer satisfaction measurement tool for frail elders enrolled in PACE programs.
- The University of California, Los Angeles, received \$349,933 to develop and staff a coordinating center to support the addition of two Foundation-funded sites to the national IMPACT Study.

The one-year planning grants projects are being led by a diverse group of community-based service agencies, managed-care organizations, and others. Grant recipients are collaborating to develop detailed plans for projects, including:

- the establishment, in ethnic communities of San Diego, of care advisors to advocate for elders enrolled in managed-care plans;
- development of a one-stop-shopping system in Contra Costa County so that elders can be connected to a continuum of services; and
- development of a coordinated delivery system of medical care and services for elderly people in rural Sonoma County.

The Foundation will award a second cycle of grants, primarily for demonstration projects, in December 1999. The Foundation has also awarded five other grants related to elders and managed care:

- The California Association for Adult Services (Sacramento) received \$109,250 to support its "Levels of Care" framework for adult day services. This project will analyze adult day center data on patient function, utilization, and costs. The results will be used to create a new model that will allow centers to offer a broader range of services within one setting through the integration of licensure, funding, and oversight.
- A project of the Families USA Foundation developed a consumer guide on how to use Medicare managed-care data. The guide was

### ***The Retirement Research Foundation***

Based in Chicago, The Retirement Research Foundation is the nation's largest private foundation exclusively devoted to aging and retirement issues. It awards approximately \$10 million each year to not-for-profit and educational organizations to support programs, research, and public policy studies to improve the quality of life for older Americans. The Foundation supports both national and local projects, with about 50 percent of its funding in Illinois. Several of the Foundation's projects focus on serving the needs of elderly people, and particularly Medicare managed-care enrollees, in Medicare, including the following:

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***With support from the  
California Healthcare  
Foundation, Kaiser  
Permanente is working with  
local government agencies  
and the local visiting nurse  
association in Los Angeles to  
test the addition of home and  
community-based services for  
elderly enrollees***

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***A project funded by The Retirement Research Foundation at the University of Massachusetts in Boston has developed a set of surveillance and training tools and techniques for consumer groups***

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designed to help community organizations find, analyze, and interpret federal and state information on Medicare HMOs to compare plan performance, monitor plan quality, and advocate for improved oversight by government agencies. This guide was published in May 1998.

- The Medicare Rights Center developed the Medicare Public Information Campaign, which has facilitated discussions among six key consumer advocates to give Medicare issues a stronger and more unified voice. The group holds monthly conference calls to develop and implement communications strategies to inform policy debate on Medicare and to help Medicare beneficiaries get information they need when they need it.
- The Consumer Monitoring of Medicare HMO Sales and Marketing Practices at the University of Massachusetts in Boston has developed a set of surveillance and training tools and techniques for consumer groups in four states. The project also developed ongoing consumer advocacy capacity for surveillance in each of these states, as well as a monitoring manual produced in collaboration with the Community Catalyst of Boston.
- The Campaign for Better Health, a grassroots coalition of 280 local and state organizations in Illinois, has three objectives. First, it is implementing a comprehensive surveillance campaign of the marketing and sales practices of Medicare managed-care plans in the Chicago area. Second, the Campaign provides leadership training for senior and disabilities organizations on how to implement monitoring tools and for beneficiaries on what to look for in a health plan, what questions to ask, and what rights they have as consumers. Third, it is developing a toll-free Medicare Help Line as a long-term mechanism for effective monitoring.
- The Suburban Area Agency on Aging, which covers suburban Cook County, is developing a

public information campaign for elders and elder education counseling related to Medicare managed care and Medicare+Choice. The Agency is also working with the Coalition for Limited English Speaking Elderly in Chicago to reach out to different ethnic communities.

### ***Funding Strategies***

Grantmakers are involved in a variety of initiatives aimed at helping the elderly. Some of these programs operate at the national level, while others operate at regional or local levels. In addition, they address a broad range of issues, including consumer outreach and education, training and support for information intermediaries, data collection and dissemination to different audiences, and development of tools to measure and report on plan performance. The diversity of funding strategies used by grantmakers in this area reveals a wide scope of opportunity to develop new and innovative programs.

### ***Funding existing organizations that are well positioned to provide information about plan choices.***

A number of New York and national foundations support the Medicare Rights Center to bring expertise, educational materials, and technical assistance to Medicare beneficiaries and to attract and hold the attention of the media on Medicare issues. For example, The New York Community Trust provided a \$55,000 grant in late 1998 to help the Center broaden its media campaign and continue working aggressively with policymakers to develop regulations that protect elders as Medicare managed care expands.

The Consumer Health Foundation provided \$100,000 to the United Seniors Health Cooperative to implement a project on improving senior and disabled consumers' understanding and utilization of Medicare HMOs. The project disseminated information comparing services of HMOs in the Washington, D.C., metropolitan area; trained Medicare counselors



and community leaders to provide guidance to consumers on enrollment and utilization issues; and mounted a public awareness campaign to educate Medicare beneficiaries, their families, and caregivers on how to effectively access and navigate managed-care systems. Similarly, the Arlington Health Foundation is funding its local area agency on aging to act as a Medicare managed-care ombudsman.

***Developing consumer coalitions that can inform individuals about plan choices and track the performance of managed-care plans in their community.***

The Cleveland Foundation and the Mount Sinai Health Care Foundation are both supporting the Coalition to Monitor Medicare Managed Care in Cleveland, Ohio which consists of 22 local organizations including the medical society, the American Association of Retired Persons, the bar association, social service agencies, and faith-based organizations. The coalition conducts a number of activities to help Medicare beneficiaries better understand their choices, including providing clear and concise information about Medicare+Choice. In order to accomplish this, the coalition produces some written information, but relies heavily on a speakers bureau to make presentations to community groups about the choices Medicare beneficiaries have. The coalition helps beneficiaries resolve complaints about their HMOs and assists them in navigating the appeals process for claims denials. The coalition will also identify and help resolve any systemic problems that the appeals process may produce. Finally, the coalition has developed a public policy agenda to lobby for increases in consumer protection, access to care and greater accountability on the part of participating plans.

***Funding organizations that can document emerging problems and act as systematic troubleshooters for the Medicare population.***

The Commonwealth Fund has funded

researchers at Georgetown University to monitor the implementation of Medicare+Choice in three metropolitan areas (Cleveland, Ohio; St. Petersburg, Florida; and New York City), using both case studies and analysis of enrollment patterns. National and state enrollment trends will also be examined. The effort focuses on the extent to which new plans are being established, the characteristics of beneficiaries enrolling in different types of plans, and movement of beneficiaries from fee for service to managed care.

The Henry J. Kaiser Family Foundation has a Medicare Policy Project that produces fact sheets, data books, and reports on different aspects of Medicare policy and its implications for the nation's elderly and disabled. Projects relevant to this topic include a focus group; studies of both Medicare beneficiaries and insurance counselors by Frederick Schneiders Research; an analysis of consumer protections under Medicare+Choice; and case studies of various Medicare managed-care markets including New York, Los Angeles, Tampa, and Portland, Oregon. The Foundation has also supported a major public education effort on Medicare and future options for reform (co-sponsored with the League of Women Voters Education Fund). That work has been more focused on building understanding about future changes in the program than on supporting consumers in their efforts to understand current program rules. Kaiser has also been working on an effort to help adult children educate their parents about their Medicare coverage.

***Advancing the state of the art in the types of information consumers can use to make plan choices***

The Commonwealth Fund has funded researchers at the City University of New York to develop and test new report cards and distribution strategies to communicate information about the quality of HMOs serving Medicare beneficiaries in New York City. Information on plans will be drawn from the Health Employer

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***The Commonwealth Fund is supporting Consumers Union of the United States in producing a comprehensive resource on health insurance and long-term care for use by the elderly and their families***

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Data and Information Set (HEDIS) and the Consumer Assessment of Health Plans Survey (CAHPS). These materials and strategies are being designed for replication in other metropolitan areas.

The Commonwealth Fund is also supporting Consumers Union of the United States to produce a comprehensive resource on health insurance and long-term care for use by the elderly and their families. Supplements to *Consumer Reports* will include specific ratings of Medicare managed-care plans, Medigap insurance policies, nursing homes, and long-term care insurance plans. This project is co-funded by The Robert Wood Johnson Foundation.

***Developing and disseminating tools and training guides for health insurance counselors***

The Robert Wood Johnson Foundation has given a four-year grant to support creation of the Center for Medicare Education, which serves as a resource for information intermediaries who help the elderly and their families to make choices among Medicare options and to navigate the health system. The Center will serve as a clearinghouse to identify and disseminate information on best practices in educational material development and capacity building. It will also provide training for information intermediaries and conduct targeted research on consumer education.

***Sponsoring efforts to determine community needs***

The California HealthCare Foundation funded the National Academy of Social Insurance (NASI) to conduct a series of focus groups to identify what California seniors know about managed care and what types of supports they need to make more informed decisions. That work has produced several videos summarizing the content of the focus groups and a chapter on Medicare managed care in *Medicare+Choice and Managed Care: A Primer*, published by

*Health Affairs*. NASI is also working on a guide for using the videos.

***Developing coordinated systems of care***

Providing access to information and support for making appropriate plan choices and using plan services effectively are important first steps in making managed care work for the elderly. A critical question remains, however, about whether available systems and coverage from which beneficiaries choose are structured to meet the needs of the elderly, particularly those with multiple, chronic, or complex conditions. The activities of the California HealthCare Foundation, described earlier in this report, provide an example of how grantmakers can contribute to exploring and addressing this issue.

## Lessons Learned

During the Issue Dialogue, several participants spoke of the unique opportunities for local foundations to play an important role in serving the elderly. Local foundations know their communities, they have critical ties with community groups in and outside the health care arena, and they are attuned to the needs of their communities. In addition, they often have access to specialized knowledge that local grass roots organizations may not have. Because education and outreach efforts have to be planned and implemented locally, these foundations can act as facilitators, bringing together community partners, specialty health care organizations, and others to address the health care needs of the elderly (Eldred, Dallek 1999). For example, the Quantum Foundation in West Palm Beach, Florida, has teamed up with a local university to create a program in which students preparing for careers in social work are training volunteers to establish a safety network for chronically ill patients (Corbett 1999).



Local foundations should keep in mind that because of their hands-on experience, they are in a position to act as translators for their communities with national grantmakers and other groups. They can open conversations with other foundations, so that funders with different experiences and areas of expertise can come together at the local level. One avenue for reaching out to other grantmakers is the regional associations of grantmakers (RAGs) (Dallek 1999). For example, the Eugene and Agnes E. Meyer Foundation in Washington, D.C., has tapped its RAG to convene area funders and providers on a monthly basis in a forum called the Health Working Group. During these meetings, participants exchange information and experiences to

try to stay on top of local health care issues (Freshley 1999). This approach could be used to convene on strategies to serve vulnerable Medicare beneficiaries.

During the Issue Dialogue, several grantmakers noted that although their programs did not always achieve the desired results, they have learned important lessons from their experiences, including the following:

***Make time for planning.*** Any project that involves collaboration among diverse players who have never worked together benefits from a planning phase. The California HealthCare Foundation was a brand-new foundation launching its first initiative with its Program for

## BENEFICIARY DIFFERENCES MAY CREATE BARRIERS TO EDUCATION

*Choice is confusing, and human decisionmaking is an imperfect process at best. Educating and guiding Medicare beneficiaries is particularly challenging because of their cognitive, physical, financial, and social characteristics. Limitations in these areas can make it more difficult for elderly people to assimilate information and select and use health plan options wisely. Following are some examples:*

- Approximately 20 percent of the elderly have at least one problem related to seeing, hearing, or writing, which could affect their ability to read and understand plan materials and correctly complete enrollment forms.
- Cognitive impairment, including dementia, increases dramatically with age. Estimates vary, but one widely cited study estimated that 18 percent of people between the ages of 75 and 84 and 45 percent of those 85 and older have dementia. Because of cognitive or other limitations, more than 15 percent of the elderly report problems using the telephone or managing their personal finances (Evans et al. 1989).
- Education has long been recognized as a predictor of cognitive function in later life and is likely associated with the ability to process complex information, such as details about health plans (Evans et al. 1993; Kahn et al. 1961; Katzman 1993; O'Connor et al. 1998). Recent survey data indicate that the mean level of education among people aged 65 and older is just over 10 years, with 16 percent having fewer than eight years of formal education.
- Language and cultural differences often create additional barriers to communication. Currently, 9 percent of Medicare beneficiaries are African American, about 2 percent are Hispanic, 1 percent are Asian and Pacific Islanders, and 2 percent describe themselves as belonging to other racial and ethnic groups. About 12 percent of Medicare beneficiaries speak a language other than English (HCFA undated).
- As a group, the elderly are less familiar with new technologies that are rapidly becoming the centerpiece of plan and provider communication. For example, voice mail, automated phone menus, and web pages are now widely used by health plans and providers, but these media may pose barriers even to high-functioning elderly enrollees and patients. As a result, the use of these technologies in the Medicare+Choice marketing and enrollment processes and within plans may create barriers or confusion for older enrollees.

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***Local foundations have critical ties with community groups in and outside the health care arena and they are attuned to the needs of their communities***

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***Any project that involves collaboration among diverse players who have never worked together benefits from a planning phase***

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Elders in Managed Care. For two of its projects, the Foundation built in a four-month planning phase to help the new partners refine their roles, their work plans, and their evaluation methodology (Eldred 1999).

***Get help from the pros.*** An expert advisory committee can be invaluable. Managed care is changing so quickly that it is difficult to distinguish between proposals that are innovative versus those that are becoming the norm. Industry experts can help foundations fund proposals that are truly experimental (Eldred 1999).

***Go there in person.*** Site visits are critical. Grantmakers can learn a lot about the strength of the partnerships they are funding and about the commitment level of the different players through site visits (Eldred 1999).

***Expect stormy weather.*** There is tremendous turmoil and turnover in the managed-care industry, which can affect projects. This is a major challenge for foundations (Eldred 1999).

***Budget sufficient staff time.*** Projects need nurturing and attention. Foundations that lack sufficient in-house staff may want to consider seeking outside technical assistance. The California HealthCare Foundation, with only two staff members on its Program for Elders in Managed Care, is considering farming out the initiative to another institution with sufficient financial support to do the job well (Eldred 1999).

***Think locally.*** Educational strategies need to be adapted to fit local community needs. In addition, levels of knowledge regarding Medicare and health care in general vary considerably among communities and among different types of groups. These differences call for a mix of educational strategies and a need to triage information (Stone 1999).

***Support organizational capacity-building.*** Often what organizations need is money to help improve their management information systems, recruitment and training capacity, and other operations. Think of this as a long-term investment. The Research Retirement Foundation recently made a grant to the Medicare Rights Center, funding a position for a business development director to improve the group's self-sufficiency (Hofland 1999).

***Choose a trusted and competent messenger.*** This is important to the success of any intermediary strategy. Where to look? Daughters, who often wind end up managing the care of their aging parents, can make excellent messengers. Faith-based institutions should also be considered as intermediaries. These are messengers outside the health care arena who are trusted by elderly people (Hofland 1999).

***Simplify, simplify, simply.*** That goes both for the program's take-home message and for its educational and training tools. Simple messages make a greater impact on the public and simple tools are more easily implemented by grass roots organizations (Hofland 1999).

***Unify diverse grass roots groups.*** Work on strengthening coordination and collaboration among advocacy organizations. Too often they are fragmented and working at odds with each other (Hofland 1999).

***Monitoring is best viewed as an adjunct to rather than substitute for regulation.*** In Illinois, the Campaign for Better Health Care, funded by the Retirement Research Foundation, implemented a monitoring and surveillance initiative of Medicare managed-care plans within the state. One of the secondary outcomes of this project was the passage of patient rights legislation by the state legislature (Hofland 1999).

**Give consumers a voice.** Grass roots coalitions have tremendous potential to bring about change by state lawmakers. If the messages come from consumers, legislators listen (Hofland 1999).

**When doing outreach, remember radio.** Older adults are over-represented in radio audiences and radio is a relatively inexpensive medium compared to television (Hofland 1999).

**Where is your audience?** Senior centers are only one of many vehicles for reaching elderly people. Many elderly people are homebound; others simply do not go to senior centers. Find out where your elderly are – and devise strategies for reaching them in those places (Hofland 1999).

**Cast a wide net.** Develop messages about the health care of seniors that resonate with local organizations and groups who are not used to dealing with health care. Infuse the issue with broader community appeal (Sofaer 1999).

**Make elder care a family issue.** Think about ways that local groups can improve health care for elderly people while at the same time helping families solve their health care problems (Dallek 1999). For example, by supporting school-based community wellness centers, the Quantum Foundation is helping to improve resources for the elderly and non-elderly alike (Corbett 1999).

**Focus on navigation – not just choice.** Regardless of whether they are enrolled in traditional Medicare or Medicare managed care, elderly people need help navigating the system (Stone 1999).

**Make education fun.** One community group in the Northeast uses a Jeopardy-style game to help elderly people learn how to make health care choices and navigate the system (Stone 1999).

## Conclusions: Looking Ahead

The future of Medicare and the information needs of elderly beneficiaries represent an evolving area, where, despite a great deal of effort by researchers, policymakers, foundations, community organizations, and others, much more work is needed. During the meeting, several participants voiced questions about what their goals should be and what strategies they could effectively deploy to attain them.

This should not be viewed as a short-term process where success can be measured in two or three years. Instead, it may take five or ten years for programs to produce quantifiable results. This, then, is a time for learning and experimentation. Expectations should be tempered with recognition of the fact that even though the elderly have special information needs, in many ways they behave no differently than the general public. Elderly people cannot be expected to become avid consumers of highly technical information on the inner workings of Medicare. Research has shown that, like most people, the elderly want the information they need at the time that they need it – not before. The same appears to be true for at least some information intermediaries, like family members, who help the elderly.

For foundations and their partners, at least one goal is clear: the need to develop information infrastructures at the national and local levels so that beneficiaries and those who help them can access timely, accurate information when they need it. In other words, build the infrastructure and they will come. This is a goal that foundations can approach collaboratively with a variety of partners, both public and private.

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***Consider the role that faith-based organizations and churches can play in reaching women and their families***

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