



MEDICARE REFORM:

WIDESPREAD CONFUSION, UNCERTAIN BENEFITS

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EXECUTIVE SUMMARY

As the nation's largest public health insurance program, Medicare faces an uncertain future. Funded by the payroll tax, revenues for Medicare have remained fairly constant as a percentage of the gross domestic product (GDP) and are expected to continue at this level. Yet the costs of providing services have escalated dramatically and are projected to grow from a 2000 level of 2.5% of the GDP to 4.0% of the GDP by 2028. This increase is fueled in part by advances in medical technology that improve health and extend lifespan, but also increase health care costs, as well as the profit-driven structure of the U.S. health care system, particularly in the area of prescription drugs, the fastest growing component of health care. Furthermore, the aging of the U.S. population means that as the baby boom generation begins to retire over the next decade, the number of people receiving Medicare benefits will rise dramatically relative to the number of wage earners.

Meanwhile, mounting pressure to provide a Medicare prescription drug benefit led to the passage in late 2003 of the Medicare Prescription Drug, Improvement, and Modernization Act. However, the law was signed amidst great controversy about its complexity, gaps in coverage, involvement of managed care providers, and restrictions on the government's ability to negotiate for lower prescription drug prices. Recent surveys suggest that many Medicare recipients are confused by and opposed to these changes in the program.

With these recent changes in Medicare, and with further modifications likely, it is important to include program participants themselves—their experiences, their opinions, and their needs—in the policy making process. Yet, there is substantial concern that many persons responsible for shaping health care policy are not well informed about health care issues of seniors and people with disabilities and lack a solid understanding of the difficulties they face in securing the health care that they need.

Little attention has been given to assessing the degree to which seniors and people with disabilities are not meeting their health care needs and the degree to which they postpone accessing health care services due to the increased out-of-pocket costs that they would incur. In addition, a lack of information has been collected to understand how Medicare recipients currently obtain information about the many health care options available to them and the ways that this information could be improved to make it more accessible and understandable. With further changes certain to occur as the Medicare program is reshaped and redefined, knowing how to best convey information to current and future Medicare recipients is crucial for their effective use of the program.

In response to this need for information concerning the awareness of senior citizens and persons with disabilities about their health care options, ability to access services, and choices about health care spending in the wake of Medicare reform, the Center for Impact Research (CIR)

conducted a survey of 600 Medicare recipients in the Chicago metropolitan area in 2004, targeting lower-income individuals in homes, senior centers, senior apartment complexes, malls, city colleges, churches, social service agencies, food stores, fast food restaurants, and community centers. In addition to conducting the survey, CIR interviewed Medicare service providers, advocates, and public policy personnel working at public and private agencies. These interviews provided further information about the Medicare program, the needs of Medicare recipients and the resources currently available to them, as well as ways that the various systems serving Medicare recipients might be improved. The findings of this report will assist policy makers and community-based organizations to advocate for programs that will best serve the needs of Medicare recipients.

DEMOGRAPHICS OF THE RESPONDENTS

Age

Nearly one-quarter of the survey respondents were under the age of 65, receiving Medicare benefits due to their disability status. (In Illinois, 12.7% of Medicare recipients are under the age of 65.) There were a greater number of persons age 65 to 69 and fewer respondents within the oldest age brackets as compared to their percentage in the larger populations of Chicago and Illinois.

Race

Almost three-quarters of the respondents were African-Americans, a significant over-sampling when compared to the percentage of African-Americans in the Illinois Medicare population. The remaining respondents were primarily Caucasian, with a small percentage of Hispanic/Latino, Native American and Asian respondents.

Income

Among respondents not part of a couple, 43.8% have monthly incomes under \$750 and an additional 45.1% have incomes less than \$1,501, levels which are below the 100% and 200% federal poverty levels as defined by the U.S. Department of Health and Human Services. As of 2002, 42% of all Medicare recipients in Illinois were "Low Income" residents, with incomes at less than 200% of the federal poverty levels.

RESIDENTIAL ARRANGEMENTS

Most respondents live alone, with the majority of the remainder living either with family or a spouse/partner. This reflects a considerable over-sampling of people living alone as 38.1% of all Chicagoans age 60 or older live alone

FORCED CHOICES

When asked about whether they have to make choices between obtaining medical care and other necessities, 12.5% of the Medicare recipients responded that they currently have to make such a choice due to limited funds. Most frequently, respondents give up food in order to obtain health care.

Female respondents and respondents with disabilities or poor health had to choose between health care and other necessities far more often than male respondents, those without disabilities, or those who are healthier. As respondents' health care expenses increase, the percentage of persons who have had to forgo other necessities to cover these expenses increases dramatically.

EXPENSES

Respondents reported a monthly average of \$621 for non-health care costs, with one-half (50.4%) of these Medicare recipients spending between \$300 and \$600 per month on these expenses. When combined with health care expenses, respondents spent an average of \$787 monthly on all expenses.

ACCESS TO HEALTH CARE

Just over one-fifth (21.9%) of the respondents reported that the cost of health care prevents them from obtaining the care or services that they need, with dental care, home health care, and doctor or clinic visits the services most frequently reported as needed but not received or received at insufficient levels.

Almost 40% of the respondents reported delaying medical care for reasons that included, but went beyond cost. Problems with transportation was the factor that most frequently (18.5%) led respondents to delay care, with problems related to cost (18.4%) and time (17.0%) also significant reasons for delay.

Prior to receiving Medicare, over one-quarter of all respondents had held no health care insurance, while another almost one-sixth had held poor quality health insurance.

While 10% to 15% of the respondents reported that co-payments or deductibles discouraged them from obtaining health care services, the impact was significantly greater for respondents with disabilities or who have low incomes, and even more so for respondents who are the most sick.

Twenty-one percent to 54% of respondents reported that they would be unable to afford co-payments for home health care services, depending on their income level.

PRESCRIPTION DRUGS

The vast majority of the respondents in this study (95%) use prescription drugs.

Given the many types of programs providing prescription drug coverage that are available to Medicare recipients, it was important to ask respondents in which programs were they enrolled. Many respondents had no idea which plan they had or thought that they had one when in fact they were enrolled in another.

At the time of the survey, less than one-fifth (17.0%) of the respondents had applied for a Medicare approved drug discount card, while over one-half (53.1%) had not, and over one-quarter (28.8%) did not know whether or not they had applied for one. Given the large number of choices in discount cards available for Medicare recipients, there is considerable confusion among recipients as well as advocates about the relative merit of the various available options.

The majority of the respondents (93.8%) think that the government should negotiate bulk prices from drug companies on behalf of all Medicare recipients

17.2% of respondents reported using one or more cost-saving measure, including substituting other medicines for the ones prescribed, taking less than the recommended dose, not taking some medications at all, or cutting pills in half. Respondents who are younger or sicker, or those with disabilities tend to use these strategies more frequently than those who are older, healthier, or do not have disabilities. Nearly one-fifth (17.2%) of the respondents reported not taking all of their prescribed medications in order to reduce their expenses.

MANAGED CARE

Over one-third of the respondents have used an HMO for their health care services at some point in their lives, though slightly less than one-half of those ever-users of HMOs are current users.

Almost one-half (49.6%) of those respondents who have used HMOs report being satisfied to very satisfied with the health care that they received, yet only 20.0% of the respondents replied that they would consider getting their health care through an HMO. When examining willingness to obtain health care from an HMO in light of whether they had ever had received care from an HMO, the differences were notable, with 42.1% of those who have ever been in an HMO willing to consider it for their future health care, as compared to only 6.6% of those who had not been previously in an HMO.

When asked what would be important to them if they were enrolled in an HMO, all respondents said that they would value the five following conditions: being able to keep their current doctor; having prescription drug coverage; paying less (or not paying more) than with

private insurance; having a stable program (e.g., same doctors, hospitals, and benefits); and being able to obtain the medical services they need.

HEALTH CARE INFORMATION

Respondents reported high levels of interest in further information about the new Medicare law, drug discount cards, the drug coverage provisions of the new Medicare law, and comparison of Medicare plans.

There is considerable variation in what people would find helpful in improving health care information, even among the respondents to this survey who were primarily low-income, African-American respondents who have high reported levels of literacy. The variation would likely be even greater among a more diverse population.

Most of the Medicare recipients prefer to obtain their information from a variety of sources, with printed materials (71.5%) and face-to-face counselors (69.6%) being the most preferred sources of information. The Internet was preferred by one-sixth (16.5%) of the respondents. Significant differences exist for subgroups concerning a few of the preferred sources of health care information such as printed materials, face-to-face contacts, group presentations, and telephone help lines. Almost one-half of the respondents report that their best information is provided by their doctor, 16.1% from a family member or friend, and 13.6% from a social service agency.

When asked from whom they would prefer to receive health care information, over 80% of the respondents said they are receiving this information from their preferred source. The most significant differences are that more recipients would prefer that their doctors provide them with this information, and fewer recipients would like to rely on family members or friends for this information.

Over one-half (56.7%) of the respondents reported understanding mailed Medicare materials from the government only “sometimes” or “never”; about two-fifths (41.7%) of the respondents reported “usually or always” understanding the materials. This finding is particularly striking, given that over 90% of the respondents reported having strong English reading skills.

Almost two-thirds (65.1%) of those surveyed reported that they would need help in choosing and applying for a health care program if they needed to change plans. Among subgroups, respondents with disabilities, those who are older, or those who receive Medicaid reported that they would need this type of help at significantly higher levels than those without disabilities, those who are younger, or those who do not receive Medicaid.

RECOMMENDATIONS

1. Implement programs and policies to protect Medicare recipients from having to make choices between health care and other basic necessities.
2. Implement programs and policies to protect Medicare recipients from having to use unsafe measures for reducing expenditure on medications.
3. Increase access to health care services for all Medicare recipients.
4. Recognize and reduce the adverse impact of co-payments and deductibles on recipients' access to and use of health care services.
5. Make information about the variety of health care plans and prescription drug insurance options more comprehensible to Medicare recipients. As no single type of information or method of communicating it will serve all of the recipients' needs, a variety of materials distributed through a number of different channels using various methods of sharing information need to be implemented in order to reach the diverse population of recipients.
6. Ensure that HMOs are responsive to the expectations and needs of Medicare recipients who are already enrolled in their plans as well as those who will be enrolling in their programs.
7. Provide support for health care providers serving Medicare recipients who did not have prior health care insurance.
8. Ensure that the government negotiates with drug companies to obtain bulk price discounts for Medicare recipients.
9. Expand research on Medicare recipients to include immigrants, limited English-speaking persons, Caucasians and middle-income individuals.

CONCLUSION

The high level of uncertainty and concern voiced by Medicare recipients who participated in this research requires the attention of everyone engaged in creating Medicare policy, or advocating for and providing services to Medicare recipients. While the most vulnerable Medicare recipients have to make choices between health care and other necessities, most respondents spoke about significant concerns related to being unable to afford or find the health care that they will need in the future.

Most respondents, across most subgroup divisions, reported wanting more information about the health care programs available to them and reported that they would need help if they had to change health plans. However, identifying the ways to improve health care information to

the satisfaction of all consumers is far more difficult than determining topics of information of interest. Even among respondents in this study who are predominantly low-income and African-American, the range in responses to questions about what would make information more accessible and understandable varied widely. Furthermore, although respondents reported high literacy levels, less than one-half usually or always understand the information about Medicare that they receive from the government.

Clearly, the data from this research argue for government and private agencies to use a greater variety of materials to inform Medicare recipients and to those who work with them, advocate for their needs and rights, and provide services to them. This information needs to be provided through a variety of means, including printed materials, individual counseling, group presentations and telephone help-lines. Although the majority of respondents reported preferring to obtain their health care information through their doctors, the enormity of the task that we face over the next ten months in preparing the current Medicare population for all of the changes that are scheduled to begin in January 2006, as well as the millions of people who will become eligible in the next few years, requires that we engage a far greater array of service providers and advocates in educating the Medicare population about their rights, responsibilities, and health care options.

CENTER FOR IMPACT RESEARCH

Founded in 1975, the Center for Impact Research (CIR) focuses its work on issues of economic and social justice. CIR uses community-based research to advocate for and achieve changes in public policy and programs. The Center works collaboratively with diverse partners, who are all striving to eliminate the fundamental causes of poverty and injustice. CIR is focusing its current work in four project areas: Working Families; Children and Adolescents; Seniors; and Alternatives to Incarceration.

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