MEDICARE REFORM:

WIDESPREAD CONFUSION, UNCERTAIN BENEFITS

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TABLE OF CONTENTS

LIST OF TABLES i

EXECUTIVE SUMMARY iv

INTRODUCTION... 1

METHODOLOGY 3

STUDY DESIGN
THE SURVEY
THE DATA
LIMITATIONS

DEMOGRAPHICS 6

AGE AND GENDER
ETHNICITY AND ENGLISH PROFICIENCY
LIVING SITUATION
INCOME
EXPENSES – HEALTH CARE
EXPENSES – NON-HEALTH CARE
HEALTH STATUS

MEDICARE.. 21

ACCESS TO HEALTH CARE
ACCESS TO HEALTH CARE PRIOR TO MEDICARE
PRESCRIPTION DRUGS
2003 MEDICARE REFORM LEGISLATION

DISABILITY ISSUES... 38

HOME HEALTH CARE.. 40

HEALTH CARE INSURANCE.. 45

HMOS

OBTAINING INFORMATION.. 48

DESIRED INFORMATION
INFORMATION SOURCES

RECOMMENDATIONS 56

CONCLUSION 60

APPENDIX 61

List of Tables

Table 1: Age 6
Table 2: Age for Respondents 65+ Years 6
Table 3: Gender 7
Table 4: Gender by Age 7
Table 5: Ethnic Background 7
Table 6: English Proficiency 8
Table 7: Residency 9
Table 8: Live with Whom 9
Table 9: Housing 9
Table 10: Monthly Income - Individuals 10
Table 11: Monthly Income - Couples 10
Table 12: Individual Monthly Income by Disability Status 10
Table 13: Individual Monthly Income by Age 10
Table 14: Individual Monthly Income by Race 11
Table 15: Individual Monthly Income by Location of Residence 11
Table 16: Income Sources 11
Table 17: Monthly Prescription Drug Expense 12
Table 18: Monthly Prescription Drug Expense by Disability Status 12
Table 19: Monthly Non-Prescription Drug Expense 13
Table 20: Monthly Non-Prescription Drug Expense by Disability Status 13
Table 21: Actual Monthly Prescription Drug Expenses 13
Table 22: Actual Monthly Non-Prescription Drug Expenses 13
Table 23: Actual Monthly Medical Supplies Expenses 13
Table 24: Actual Monthly Health Care Premiums Expenses 14
Table 25: Actual Monthly Deductibles and Co-Payments Expenses 14
Table 26: Actual Other Health Care Expenses 14
Table 27: Actual Total Health Care Monthly Expenses 14
Table 28: Actual Total Health Care Monthly Expenses by Disability Status 15
Table 29: Actual Total Health Care Monthly Expenses by Individual Monthly Income 15
Table 30: Actual Monthly Prescription Drug Expenses by Medicaid Status 15
Table 31: Actual Monthly Non-Prescription Drug Expenses by Medicaid Status 15
Table 32: Actual Total Monthly Expenses by Medicaid Status 15
Table 33: Necessities Foregone for Health Care 16
Table 34: Necessities Foregone for Health Care by Gender 16
Table 35: Necessities Foregone for Health Care by Disability Status 16
Table 36: Necessities Foregone for Health Care by Health Status 17
Table 37: Necessities Foregone for Health Care by Live With Whom 17
Table 38: Necessities Foregone for Health Care by Health Care Spending 17
Table 39: Non- Health Care Monthly Expenses 18

Table 40: Other Non- Health Care Monthly Expenses 18
Table 41: Total Non- Health Care Monthly Expenses........ 18
Table 42: Total Monthly Expenses 18
Table 43: Total Monthly Expenses by Income........ 18
Table 44: Level of Health........ 19
Table 45: Level of Health by Age 19
Table 46: Level of Health by Disability 20
Table 47: Level of Health by Monthly Income 20
Table 48: Level of Health by Medicaid Status 20
Table 49: Cost of Health Care Prevents Getting Care by Health Status 21
Table 50: Health Care Services Needed by Not Received Due to Costs 22
Table 51: Reasons for Delaying Care 22
Table 52: Delaying Care by Disability Status 23
Table 53: Delaying Care by Age........ 23
Table 54: Delaying Care by Location of Residence 23
Table 55: Delaying Care by Health Status 23
Table 56: See Same Doctor 24
Table 57: Ease of Getting Appointment 24
Table 58: Wait for Appointment 25
Table 59: Health Insurance Prior to Medicare........ 25
Table 60: Health Insurance Prior to Medicare by Disability Status 26
Table 61: Health Insurance Prior to Medicare by Current Monthly Income 26
Table 62: How Relationship with Doctor Changed 26
Table 63: Where You Get Your Prescription Drugs 27
Table 64: Prescription Drugs through Mail Order by Monthly Income........ 27
Table 65: Prescription Drugs through Mail Order by Where Living........ 27
Table 66: Current Prescription Drug Coverage 28
Table 67: Prescription Drug Discount Cards........ 29
Table 68: Prescription Drug Discount Card by Individual Monthly Income 29
Table 69: Reasons for Not Applying for a Prescription Drug Card........ 30
Table 70: Experiences Applying for a Prescription Drug Card 30
Table 71: Want Additional Prescription Drug Insurance 32
Table 72: Want Additional Prescription Drug Insurance by Health Status........ 32
Table 73: Ways Used to Cut Drug Costs........ 33
Table 74: Use of Drug Cost-Cutting Measures by Age........ 33
Table 75: Use of Drug Cost-Cutting Measures by Health Status 33
Table 76: Use of Drug Cost-Cutting Measures by Disability Status 33
Table 77: Counseled on Drug Side Effects by Age 35
Table 78: Why New Medicare Law Will Benefit Recipients 37
Table 79: Why New Medicare Law Will Not Benefit Recipients........ 37
Table 80: Difficulties in Getting Equipment and Services........ 39
Table 81: Use of Home Health Care by Housing Type........ 41
Table 82: Persons with Disabilities' Use of Home Health Care by Health Status........ 41

Table 83: Effect of Co-Payments on Use of Home Health Care Services 42
Table 84: Co-Payment Effect on Ability to Afford Home Health Care by Income............ 42
Table 85: Use of Personal Assistance Services 42
Table 86: Use of Personal Assistance Services by Disability Status 42
Table 87: Respondents with Disabilities' Use of Personal Assistance Services by Age ... 43
Table 88: Respondents with Disabilities' Use of Personal Assistance Services by Location......... 43
Table 89: Respondents with Disabilities' Use of Personal Assistance Services by Housing Type 43
Table 90: Funding Source for Personal Assistance Services.. 44
Table 91: Method of Accessing Personal Assistance Services.. 44
Table 92: Preferred Hiring Method for Homecare by Age.. 44
Table 93: Preferred Payment Method for Homecare by Age.. 44
Table 94: Sources of Health Care Services and Payment.. 45
Table 95: Sources of Health Care Services and Payment by Disability Status 45
Table 96: Use of Managed Health Care (HMO) System 46
Table 97: Level of Satisfaction with Managed Health Care (HMO) System....................... 46
Table 98: Desired Health Care Information 48
Table 99: Desired Health Care Information by Race.. 48
Table 100: How to Improve Health Care Information.. 49
Table 101: How to Improve Health Care Information by Medicaid Status........................ 49
Table 102: Simpler Explanations Would Help by Health Status 50
Table 103: More Information Would Help By Age 50
Table 104: Seen Medigap Chart Before by Age... 51
Table 105: Preferred Sources of Health Care Information 51
Table 106: Current Provider of Best Information on Health Care....................................... 52
Table 107: Preferred Provider of Best Information on Health Care.................................... 52
Table 108: Understands Mailed Government Medicare Information................................. 53
Table 109: Response to Mailed Government Medicare Information 53
Table 110: Need Help Choosing Health Care Plan by Disability 54
Table 111: Need Help Choosing Health Care Plan by Age 54
Table 112: Need Help Choosing Health Care Plan by Medicaid Status............................. 54
Table 113: Ability to Make Health Care Decisions Independently...................................... 55
Table 114: Ability to Make Health Care Decisions Independently by Age 55
Table 115: Ability to Make Health Care Decisions Independently by With Whom You Live.. 55

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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.

INTRODUCTION

As the nation's largest public health insurance program,[1] 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.[2] This increase is fueled in part by advances in medical technology that improve health and extend lifespan, but increase health costs,[3] 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.[4] Furthermore, the aging of the U.S. population means 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.[5] As a partial response to these concerns, the Medicare Prescription Drug Savings and Choice Act of 2004, which would give Medicare the authority to negotiate with pharmaceutical companies for lower drug prices, was recently introduced in both the U.S. House and the Senate, with Congresswoman Jan Schakowsky and Senator Richard Durbin of Illinois introducing and co-sponsoring the bills.[6]

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[1] There are 35.3 million Medicare recipients age 65 and older and an additional 6.4 million Medicare recipients under age 65 with disabilities. Accessed at http://www.cms.hhs.gov/researchers/pubs/datacompendium/2003/03pg30.pdf, on September 7, 2004.

[2] S. Maxwell, M. Moon, and M. Segal, "Growth in Medicare and Out-of-Pocket Spending: Impact on Vulnerable Beneficiaries," Urban Institute, January 2001.

[3] I. Shapiro and R. Greenstein, "Future Medicaid Growth Is Not Due to Flaws in the Program's Design, but to Demographic Trends and General Increases in Health Care Costs," Center on Budget and Policy Priorities, February 4, 2005. Accessed at http://www.cbpp.org/2-4-05health.htm on February 8, 2005.

[4] "Prescription Drug Expenditures in 2001: Another Year of Escalating Costs," National Institute for Health Care Management, May 6, 2002. Accessed at http://www.nihcm.org/spending2001.pdf on February 4, 2005. For more information about drug profits, see http://www.familiesusa.org/site/DocServer/PPreport.pdf?docID=249 and http://bernie.house.gov/prescriptions/profits.asp.

[5] "Views of the New Medicare Drug Law: A Survey of People On Medicare," Henry J. Kaiser Family Foundation, August 2004. Available at www.kff.org/medicare/pomr081004pkg.cfm; USA Today/CNN/Gallup Poll conducted in March and December 2003. Available at: www.usatoday.com/news/polls/tables/live/2004-03-30-medicare-poll.htm

[6] As reported in Representative Schakowsky's online newsletter at http://www.house.gov/schakowsky/rxdrugs_issues.html and Senator Durbin's online newsletter at http://durbin.senate.gov/sitepages/Issues/healtcare-prescriptiondrugs.htm. Accessed on December 24, 2004.

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.[7]

Furthermore, although studies have analyzed the anticipated costs of medical services for Medicare recipients over the next two decades, 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.[8] This lack of data is troubling because non-adherence to prescribed treatment regimens significantly increases the likelihood that individuals will experience major long-term health problems, compromising quality of life and increasing overall health care costs.[9] Understanding how changes in Medicare influence health care decisions is therefore crucial to developing sound, cost-effective health care policies for these populations.

Finally, 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,[10] targeting lower-income individuals. 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.

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[7] Interview with Cathy Hurwit, Chief of Staff for Congresswoman Schakowsky, June 2, 2003.

[8] M. Moon, "How Beneficiaries Fare under the New Medicare Drug Bill," American Institutes for Research, June 2004, S. Maxwell et al.," Growth in Medicare and Out-of-Pocket Spending," Urban Institute, January 2001.

[9] M. Heisler, K M. Langa, E.L. Eby, A.M. Fendrick, M.U. Kabeto, and J. D. Piette, "The Health Effects of Restricting Prescription Medication Use Because of Cost," *Medical Care* 42(7): 626-634, July 2004.

[10] This included the City of Chicago and suburban Cook County.

METHODOLOGY

STUDY DESIGN

At the outset of the project, the Center for Impact Research (CIR) formed a working group consisting of persons from community service agencies, advocacy organizations, and government agencies.[11] Working group members conferred on research design and survey development. After the data were collected, working group members participated in discussions to interpret the research findings and a subgroup of the working group assisted in crafting the policy recommendations.

The working group had to determine which groups within the Medicare population it wanted to target. Initially, we discussed focusing only on Senior Citizens (age 65+). But this focus would exclude Medicare recipients with disabilities who are under 65 years old and who represent over 15% of the total Medicare population.[12] The group decided that the survey would include both senior Medicare recipients, and those under the age of 65 who receive Medicare benefits due to a disability. Because of the difficulty in accessing institutionalized (nursing home) Medicare recipients, the survey includes only non-institutionalized respondents.

THE SURVEY

When collecting data from marginalized and at-risk populations, the use of peer surveyors increases the likelihood that potential respondents will choose to participate in the research. Furthermore, respondents often feel more comfortable being interviewed by a peer than by a professional researcher, who may seem unfamiliar and whose intentions may seem unclear or threatening. Nine adults were recruited and trained to interview Medicare recipients for the project. These community surveyors were recruited through advocacy organizations, direct service agencies, and community-based centers. There were six female and three male surveyors; six were 65 years of age or older, one of whom had a disability; three were between the ages of 59 and 64, one of whom had a disability.

On three consecutive days, the surveyors attended training sessions that were each two and one-half hours long, during which they learned about survey research methods and the goals of

[11] Working group members include representatives from Access Living, City of Chicago Department on Aging, Council for Jewish Elderly, Health and Disability Advocates, Health and Medicine Policy Research Group, Illinois Alliance for Retired Americans, Illinois Home Care Council, Suburban Area Agency on Aging, and Rebecca Friedman Zuber, Inc.

[12] Centers for Medicare and Medicaid Services. Accessed at http://www.cms.hhs.gov/researchers/pubs/datacompendium/2003/03pg30.pdf on December 24, 2004.

the project. They also practiced administering the survey and made suggestions for its revision. The survey included primarily closed-ended and multiple response questions, with a variety of open-ended questions for obtaining greater detail to enrich the data. The sessions provided in-depth training on appropriate ways to ask questions and query respondents, addressing issues related to ensuring confidentiality and the safety of both surveyors and respondents.

During June and July 2004, surveyors interviewed respondents throughout metropolitan Chicago—in homes, senior centers, senior apartment complexes, malls, city colleges, churches, social service agencies, food stores, fast food restaurants, and community centers. Surveys were completed in approximately 30 to 40 minutes and respondents received a $10 store gift card as an incentive to participate and in appreciation for their time. Surveyors were paid $10 for each completed interview. Six hundred surveys were administered in order to achieve statistically significant data at a 95% confidence interval.

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 DATA

The 600 surveys were administered to Medicare recipients in a non-random manner, with the nine community surveyors traveling throughout the Chicago metropolitan area to interview Medicare recipients wherever they encountered them. We have presented data as available from other sources to provide a larger context for the survey data.

Subgroup differences are presented when they are statistically significant ($p < .05$) and when the strength of the relationships is sufficiently strong to merit attention.

LIMITATIONS

Twelve adults were initially recruited and hired to work as community surveyors for the project. After the training had begun, three dropped out, leaving nine surveyors. Although the original group of twelve surveyors included eight African-Americans, three Caucasians, and one Hispanic, two of the Caucasian surveyors and the Hispanic surveyor dropped out, leaving eight African-American and one Caucasian as project surveyors. The surveyors primarily interviewed respondents in their own communities, which resulted in the respondents being disproportionately African-American.

Furthermore, the survey was not translated into other languages, and the interviewers spoke only English. Thus, far fewer respondents had limited English skills than might have been identified had we been able to translate the survey and train bilingual community surveyors.

Finally, while the initial intention of the research was to target middle income as well as lower income Medicare recipients, almost 90% of the respondents reported income levels below the 200% Federal Poverty Guidelines.[13]

[13] In 2004, the Federal Poverty Guidelines levels were $9,310 for an individual and $12,490 for a couple annually, or $776 and $1,041 monthly. Accessed at http://aspe.hhs.gov/poverty/04poverty.shtml on November 5, 2004. The federal poverty thresholds for annual income for persons age 65 and older in 2003 were $8,825 for an individual and $11,133 for a couple. Accessed at http://www.census.gove/hhs/poverty/histpov/hstpov1.html on November 5, 2004.

DEMOGRAPHICS

AGE AND GENDER

Nearly one-quarter (24.5%) 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.[14] When looking at the age distribution for Medicare recipients age 65 years and older, the study's respondents had a greater number of persons age 65 to 69 (34.9%) as compared to their percentage in the populations of City of Chicago (28.1%) and Illinois (26.5%) and fewer respondents within the oldest age brackets.

Table 1: Age

Age	Frequency	Percent
<65	146	24.5%
65-69	157	26.3%
70-74	115	19.3%
75-79	91	15.3%
80-84	59	9.9%
85-89	21	3.5%
90-94	6	1.0%
95-99	1	0.2%
Total	596	100.0%

Table 2: Age for Respondents 65+ Years[15]

Age	Survey Percent	City of Chicago Percent*	Illinois Percent*
65-69	34.9%	28.1%	26.5%
70-74	25.6%	25.4%	25.0%
75-79	20.2%	20.7%	21.1%
80-84	13.1%	14.0%	14.6%
85-89	4.7%	7.8%	8.4%
90+	1.5%	4.0%	4.4%
	100.0%	100.0%	100.0%
	n=450	n=298,803	n=1,500,025

Within this study, 62.8% of the respondents are women, including 63.3% of the respondents age 65 and older. This is a slightly higher percentage of women than the 60% found within the Illinois Medicare beneficiary population.[16] When looking at the gender distribution by age for respondents over age 65, as these Medicare recipients become older, the percentage of women among them increases.

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[14] Kaiser Family Foundation State Health Facts Online. Accessed at http://www.statehealthfacts.org on October 4, 2004.
[15] City of Chicago and Illinois figures from the 2000 U.S. Census. Accessed at the U.S. Census Bureau website http://factfinder.census.gov on January 29, 2005.
[16] Kaiser Family Foundation State Health Facts Online. Accessed at http://www.statehealthfacts.org on September 8, 2004.

Table 3: Gender

	Frequency	Percent
Male	188	37.2%
Female	318	62.8%
Total	506	100.0%

Table 4: Gender by Age

	<65	65-69	70-74	75-79	80-84	85-99
Male	38.8%	42.0%	39.6%	34.9%	26.3%	28.6%
Female	61.2%	58.0%	60.4%	65.1%	73.7%	71.4%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

n=503

ETHNICITY AND ENGLISH PROFICIENCY

The ethnicity of the respondents reflected a far larger percentage of African-Americans and lower percentage of Hispanics, Caucasians, or Asians than found in the Chicago or Illinois populations. This is due, in large part, to the ethnicity of the surveyors who were predominately African-American and who surveyed respondents in their own communities, which are largely segregated.

Table 5: Ethnic Background[17]

	Survey Frequency	Survey Percent	City of Chicago Total Percent	Illinois Total Percent	Illinois Medicare Population Percent
African-American/Black	434	72.5%	37.4%	15.6%	12%
Hispanic/Latino	21	3.5%	26.0%	12.3%	3%
White/Caucasian	128	21.4%	44.3%	75.1%	83%
Native American	15	2.5%	0.7%	0.6%	--
Asian/Pacific Islander	2	0.4%	5.1%	3.9%	--
Other	11	2.2%	15.6%	6.8%	2%

n=599

In Illinois, 3.8% of persons age 65 and older live in households where all members speak a language other than English and everyone in the household age 14 and older has some difficulty with English. An additional 5.7% of persons age 65 and older live in households where everyone speaks a language other than English, but at least one person age 14 or older is fluent in English. In Chicago, the percentages are over twice the level of the rest of Illinois, with

[17] Cook County and Illinois figures from the 2000 U.S. Census as accessed on the U.S. Census Bureau website http://quickfacts.census.gov/qfd/states/17/17031.html on July 27, 2004. Illinois Medicare population figures are from Kaiser Family Foundation State Health Facts Online. Accessed at http://statehealthfacts.kff.org on September 8, 2004. Census percentages for race do not add up to 100 due to the allowance of Hispanic as well as one other racial identifier in their response categories. Similarly, the total percentage for survey responses exceeds 100% due to 17 respondents reporting more than one ethnic identity.

10.0% of persons age 65 and older living in households where all members speak a language other than English and everyone in the household age 14 and older has some difficulty with English; an additional 11.6% of persons age 65 and older in Chicago live in households where everyone speaks a language other than English, but at least one person age 14 or older is fluent in English.[18]

Given the low number of immigrant respondents, it is not surprising that survey participants reported high levels of English proficiency. English is the primary language of 95.7% of the respondents, the other 4.3% reporting Spanish, Polish, Croatian, Filipino, Greek, Japanese, Lithuanian, Russian, or Vietnamese as their primary language. However, all of the respondents reported being able to speak English with moderate to high levels of skill, while 99.2% reported being able to read English with moderate to high levels of skill and 98.8% report being able to write in English at a moderate to high level of skill. If the survey respondents had included a larger number of immigrants, the level of English proficiency would have been lower.

Table 6: English Proficiency

	English Speaking	English Reading	English Writing
No Skill	0.0%	0.7%	1.2%
Some Skill	2.3%	8.6%	9.9%
Strong Skill	97.7%	90.6%	88.9%
	100.0%	100.0%	100.0%

n=599

LIVING SITUATION

Survey respondents came from across the Chicago metropolitan area, with the majority living in the City itself. Most respondents (71.4%) live alone, with the majority of the remainder (26.5%) living either with family or a spouse/partner. This reflects a considerable over-sampling of people living alone, with only 38.1% of all Chicagoans age 60 or older living alone.[19] Over three-quarters (77.4%) of respondents with disabilities live alone, as contrasted with 63.4% of respondents without disabilities.

[18] 2000 U.S. Census. Accessed at http://quickfacts.census.gov on January 29, 2005.

[19] In Chicago, 112,768 people age 60 and older live alone, out of a total of 295,817 households with one or more persons age 60 and older. Accessed at http://factfinder.census.gov/servlet/ on January 28, 2005.

Table 7: Residency

Location	Frequency	Percent
Chicago - Northside	104	17.4%
Chicago - Southside	272	45.6%
Chicago - Westside	32	5.4%
Chicago - Southwest Side	35	5.9%
Chicago - Loop	1	0.2%
North Suburb	19	3.2%
West Suburb	84	14.1%
South Suburb	50	8.4%
Total	597	100.0%

Table 8: Live with Whom

	Frequency	Percent
By myself	425	71.5%
With a spouse/partner	81	13.6%
With family	77	13.0%
With a friend	11	1.9%
Total	594	100.0%

Most respondents (57.4%) rent their residence; 42.2% own their residence. Significant differences exist in levels of homeownership between respondents with and without disabilities. Respondents without disabilities own their own residence at almost twice the rate (56.8%) as respondents with disabilities (31.6%). However, whether they live in rental or owned residences, most respondents (72.2%) reside in buildings in which there is potential contact with other residents as contrasted with 27.8% of the respondents who live in "isolated" housing (single family homes and townhouses). Just over one-half (52.3%) of the respondents, including both respondents who own and rent their homes, live in subsidized housing arrangements.

Table 9: Housing

	Frequency	Percent
Apartment - Rent	214	35.7%
House - Own	153	25.5%
Senior Housing - Own	63	10.5%
SRO	60	10.0%
Senior Housing - Rent	42	7.0%
Apartment - Own	17	2.8%
Condo - Own	16	2.7%
House - Rent	10	1.7%
Assisted Living Facility	7	1.2%
Other	17	2.8%
Total	599	100.0%

INCOME

As of 2002, 42% of Illinois' Medicare recipients were "Low Income" residents with incomes at less than 200% of the federal poverty levels as defined by the U.S. Department of Health and

Human Services.[20] The income levels reported in this project's survey indicate that survey respondents have lower than average income levels compared with all Medicare recipients,[21] with respondents who are not part of a couple having considerably lower monthly incomes than those who are in a couple.

Table 10: Monthly Income - Individuals

	Survey Frequency	Survey Percent
Up to $750	230	43.8%
$751 - $1,500	237	45.1%
$1,501 - $2,200	35	6.7%
$2,201 - $3,000	14	2.7%
More than $3,000	9	1.7%
Total	525	100.0%

Table 11: Monthly Income - Couples

	Survey Frequency	Survey Percent
$1,001- $2,000	14	37.8%
$2,001 - $3,000	17	45.9%
$3,001 - $4,000	2	5.4%
More than $4,000	4	10.8%
Total	37	100.0%

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, income levels below the 100% and 200% Federal Poverty Guidelines.[22] Among couples, 37.8% are living below the 200% poverty line.

Income varies significantly when looking at disability status, age, race, and location of residence. Respondents with disabilities, who are younger, and non-Caucasian have lower income levels than respondents without disabilities who are older and those who are Caucasian.

Table 12: Individual Monthly Income by Disability Status

	Disabled	Non-Disabled
Less than $751	53.7%	27.6%
$751 - $1,500	38.7%	56.2%
$1501 - $2,200	4.1%	10.3%
More than $2,200	3.5%	5.9%
Total	100.0%	100.0%

n=518

Table 13: Individual Monthly Income by Age

	<65	65-69	70-74	75-84	85+
Less than $751	68.6%	37.1%	35.8%	33.1%	25.0%
$751 - $1,500	31.4%	48.5%	55.8%	46.6%	58.3%
$1501 - $2,200	0.0%	8.3%	7.4%	12.0%	4.1%
More than $2,200	0.0%	6.1%	1.1%	8.3%	12.5%
Total	100.0%	100.0%	100.0%	100.0%	100.0%

n=524

[20] The Kaiser Family Foundation State Health Facts Online. Accessed at http://www.statehealthfacts.org on September 8, 2004.

[21] In 2002, mean personal income among persons age 65+ was estimated at $22,000/year ($1,800/month) and median personal income was estimated at $14,148/year ($1,179/month). Accessed at http://research.aarp.org/econ/dd1-4_income.html on December 15, 2004.

[22] In 2004, the Federal Poverty Guidelines levels were $9,310 for an individual and $12,490 for a couple annually, or $776 and $1,041 monthly. Accessed at http://aspe.hhs.gov/poverty/04poverty.shtml on November 5, 2004. The federal poverty thresholds for annual income for persons age 65 and older in 2003 were $8,825 for an individual and $11,133 for a couple. Accessed at http://www.census.gove/hhs/poverty/histpov/hstpov1.html on November 5, 2004.

Table 14: Individual Monthly Income by Race

	African-American	Caucasian Non-Hispanic	Other
Less than $750	46.0%	33.0%	50.0%
$750 - $1,500	44.2%	49.5%	42.1%
$1501 - $2,200	6.1%	11.7%	2.6%
More than $2,200	3.8%	5.8%	5.3%
	100.1%	100.0%	100.0%

n=537

Income varied considerably depending on the location of residence. Respondents living on Chicago's north side and in the southern suburbs have incomes at the lower end; those in the northern suburbs and on the southwest side of Chicago have incomes at the higher end; those living on the south and west sides of Chicago and in the western suburbs have average incomes between the high and low ends.

Table15: Individual Monthly Income by Location of Residence

	Chicago North Side	Chicago South Side	Chicago West Side	Chicago Southwest Side	North Suburb	West Suburb	South Suburb
Less than $751	64.4%	42.0%	34.5%	8.0%	9.1%	37.7%	51.2%
$751 - $1,500	31.7%	47.3%	55.2%	64.0%	18.2%	53.6%	39.0%
$1501 - $2,200	1.9%	7.4%	6.9%	16.0%	36.4%	1.4%	9.8%
More than $2,200	1.9%	3.3%	3.4%	12.0%	36.4%	7.2%	0.0%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

n=524

Most respondents reported (93.7%) receiving income from Social Security and one-third (33.6%) of respondents reported receiving retirement or pension income.

Table 16: Income Sources

	Survey Frequency	Survey Percent*
Social Security	561	93.7%
Retirement/Pension	201	33.6%
Supplemental Security Income (SSI)	90	15.0%
Investments	28	4.7%
Family/Friends	25	4.2%
Temporary Aid to Needy Families (TANF)	15	2.5%
Employment/Spouse's employment	14	2.3%
Other	4	0.7%

n=599

* Total percentage exceeds 100% due to respondents listing multiple income sources

Of the 128 respondents under age 65 who have a disability, 46.1% reported receiving income from Supplemental Security Income (SSI); 92.2% reported receiving Social Security; and 42% reported receiving both SSI and Social Security.

EXPENSES - HEALTH CARE

Respondents were asked many questions about their health care expenses in order to develop a better understanding of the degree to which Medicare recipients have to make choices between health care and other necessities. Respondents were first asked about their monthly out-of-pocket expenses for medications if they were to take all of the drugs that have been prescribed by their health care practitioners. There was a wide range of responses, from $0 to $3,113, with a mean of $212 and a median of $100 for respondents who use any prescription drugs at all.[23]

Table17: Monthly Prescription Drug Expenses

	Survey Frequency	Survey Percent for All Respondents	Survey Percent for Respondents with Known Rx Expenses
$0	71	13.4%	17.6%
$1-$10	30	5.6%	7.4%
$11-$50	70	13.2%	17.4%
$51-$100	70	13.2%	17.4%
$101-$200	52	9.8%	12.9%
$201-$400	67	12.6%	16.6%
>$400	44	8.3%	10.9%
Don't know	127	23.9%	---
Total	531	100.0%	100.0%

Table 18: Monthly Prescription Drug Expenses by Disability Status

	Disabled	Non-disabled
$0-$10	13.5%	26.9%
$11-$50	12.5%	14.1%
$51-$100	12.1%	15.0%
$101-$200	12.1%	7.0%
$201-$400	16.2%	7.9%
>$400	12.5%	2.2%
Don't know	21.2%	26.9%
n=524	100.0%	100.0%

Out-of-pocket costs for prescription drugs are considerably higher for respondents with disabilities, with these respondents having over three times the level of out-of-pocket expenses as Medicare recipients without disabilities. As would be expected, healthier respondents have lower out-of-pocket expenses than those who are less healthy.

Respondents were also asked about the costs that they would incur were they to purchase all of the non-prescription drugs that they are supposed to take. As with prescription drugs, the most significant subgroup difference is found between Medicare recipients with and without disabilities. Respondents with disabilities spend almost twice as much on non-prescription drugs as respondents without disabilities, averaging $21 monthly for persons with disabilities as compared to $11 for persons without disabilities.

[23] If respondents who reported no prescription drug costs are included, the mean is $175 and the median is $90.

Table 19: Monthly Non-Prescription Drug Expenses

	Survey Frequency	Survey Percent for All Respondents	Survey Percent for Respondents with Known Expenses
$0	116	22.1%	26.9%
$1-$10	134	25.5%	31.1%
$11-$25	112	21.3%	26.0%
$26-$50	39	7.4%	9.0%
$51-$99	8	1.5%	1.9%
$100+	22	4.2%	5.1%
Don't know	94	17.9%	---
Total	525	100.0%	100.0%

Table 20: Monthly Non-Prescription Drug Expenses by Disability Status

	Disabled	Non-Disabled
$0	23.8%	20.5%
$1-$10	21.4%	31.3%
$11-$25	18.0%	26.3%
$26-$50	10.2%	4.0%
$51-$99	2.4%	0.0%
$100+	5.8%	1.3%
Don't know	18.4%	16.5%
n=518	100.0%	99.9%

After being questioned about the costs that would be incurred were they to take all of their medications, respondents were asked about their actual monthly health care expenses, including prescription and non-prescription drugs, medical supplies, and health insurance premiums,[24] deductible, and co-payment requirements.

Table 21: Actual Monthly Prescription Drug Expenses

	Survey Frequency	Survey Percent
$0	147	27.6%
$1-$10	97	18.2%
$11-$50	98	18.4%
$51-$100	57	10.7%
$101-$200	28	5.3%
$201-$400	17	3.2%
$401+	2	0.4%
Don't know	86	16.2%
Total	385	100.0%

Table 22: Actual Monthly Non-Prescription Drug Expenses

	Survey Frequency	Survey Percent
$0	131	24.9%
$1-$10	187	35.6%
$11-$25	100	19.0%
$26-$50	28	5.3%
$51-$99	7	1.3%
$100+	6	1.1%
Don't know	67	12.7%
Total	526	100.0%

Table 23: Actual Monthly Medical Supplies Expenses

	Survey Frequency	Survey Percent
$0	401	76.7%
$1-$10	50	9.6%
$11-$25	13	2.5%
$26-$50	6	1.1%
$51-$99	3	0.6%
$100+	2	0.4%
Don't know	48	9.2%
Total	523	100.0%

[24] Medicare premiums had their largest increase since the program was initiated in 1965, raising the monthly cost by $11.60 to $78.20, *International Herald Tribune,* Monday, September 6, 2004. This increase occurred after the survey had been completed. Accessed at http://www.iht.comarticles/537385.htm on September 7, 2004.

Table 24: Actual Monthly Health Care Premiums Expenses

	Survey Frequency	Survey Percent
$0	89	41.8%
$1-$50	13	6.1%
$51-$100	20	9.4%
$101-$200	38	17.8%
$201-$300	9	4.2%
$301+	5	2.3%
Don't know	39	18.3%
Total	213	100.0%

Table 25: Actual Monthly Deductibles and Co-Payments Expenses

	Survey Frequency	Survey Percent
$0	412	78.6%
$1-$20	27	5.2%
$21-$50	17	3.2%
$51-$100	8	1.5%
$101-$200	5	1.0%
$201+	1	0.2%
Don't know	54	10.3%
Total	524	100.0%

Table 26: Actual Other Health Care Expenses

	Survey Frequency	Survey Percent
$0	462	87.8%
$1-$50	3	0.6%
$51-$100	4	0.8%
$100-$200	1	0.2%
$200+	2	0.4%
Don't know	54	10.3%
Total	526	100.0%

Respondents reported spending between $0 and over $1,200 for their total monthly health care expenses, with an average (mean) of $91, when excluding one-fifth of respondents (20.9%) who said that they have no idea of their health care costs.

Table 27: Actual Total Health Care Monthly Expenses

	Survey Frequency	Survey Percent
$0	43	7.2%
$1-$20	146	24.4%
$21-$50	91	15.2%
$51-$100	62	10.4%
$101-$200	71	11.9%
$201-$400	40	6.7%
$401+	21	3.5%
Don't know	125	20.9%
Total	599	100.0%

Disability status and individual monthly income are the two factors with the strongest relationship to total health care expenditures. Respondents with disabilities were over twice as likely as respondents without disabilities to have no out-of-pocket monthly expenditures on health care, and almost three times as likely to have monthly health expenditures of over $401; respondents without disabilities more often had expenses between $100 and $400. When looking at income, respondents in the upper income group spent considerably more out-of-pocket on their health care costs than those in the two lower income brackets, and those in the lowest income group spent much less than those in the two higher income brackets.

Table 28: Actual Total Health Care Monthly Expenses by Disability Status

	Disabled	Non-Disabled
$0	9.3%	4.0%
$1-$20	25.0%	23.9%
$21-$50	15.1%	15.8%
$51-$100	9.3%	11.3%
$101-$200	8.4%	17.0%
$201-$400	5.8%	8.1%
$401+	4.7%	1.6%
Don't know	22.4%	18.2%
Total	100.0%	100.0%

n=591

Table 29: Actual Total Health Care Monthly Expenses by Individual Monthly Income

	<$750	$751 - $1,500	$1,501+
$0	8.3%	8.4%	1.7%
$1-$20	33.5%	22.4%	10.3%
$21-$50	15.2%	16.0%	10.3%
$51-$100	7.4%	10.5%	10.3%
$101-$200	5.2%	11.4%	31.0%
$201-$400	2.2%	7.2%	17.2%
$401+	1.3%	3.8%	10.3%
Don't know	27.0%	20.3%	8.6%
Total	100.0%	100.0%	100.0%

n=525

The impact of Medicaid receipt on actual monthly health expenses is quite pronounced when looking at costs incurred for medications. Almost one-quarter (24.5%) of respondents receive Medicaid in addition to Medicare. Medicaid is the state administered health insurance program that covers medical expenses for its lowest income residents.[25] The Illinois Medicaid program is a more "generous" program than Medicare, covering a significantly higher percentage of out-of-pocket costs for its recipients, than those covered by the Medicare program. Those respondents who receive Medicaid have considerably lower monthly prescription drug expenses and somewhat lower non-prescription drug expenses than those who do not receive Medicaid, with total health care monthly expenses significantly lower for Medicaid recipients than non-Medicaid recipients.

Table 30: Actual Monthly Prescription Drug Expenses by Medicaid Status

	Receives Medicaid	Does Not Receive Medicaid
$0	30.3%	26.8%
$1-$10	32.6%	13.5%
$11-$50	8.3%	21.8%
$51-$100	3.8%	13.0%
$101-$200	4.5%	5.5%
$201-$400	2.3%	3.5%
>$400	0.8%	0.3%
Don't know	17.4%	15.8%
Total	100.0%	100.0%

n=532

Table 31: Actual Monthly Non-Prescription Drug Expenses by Medicaid Status

	Receives Medicaid	Does Not Receive Medicaid
$0	26.4%	24.4%
$1-$10	42.4%	33.4%
$11-$25	8.0%	22.4%
$26-$50	5.6%	5.2%
$51-$99	4.0%	0.5%
$100+	0.0%	1.5%
Don't know	13.6%	12.5%
Total	100.0%	100.0%

n=526

Table 32: Actual Total Health Care Monthly Expenses by Medicaid Status

	Receives Medicaid	Does Not Receive Medicaid
$0	9.9%	6.3%
$1-$49	53.2%	33.8%
$50-$100	5.7%	13.3%
$101-$150	3.5%	7.6%
$151-$250	2.8%	9.4%
$251+	3.5%	8.7%
Don't know	21.3%	20.7%
Total	100.0%	100.0%

n=599

[25] From the Centers for Medicare and Medicaid Services. Accessed at http://www.cms.hhs.gov/medicaid/consumer.asp on January 28, 2005.

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

Table 33: Necessities Foregone for Health Care

	Survey Frequency	Survey Percent
Food	32	5.4%
Entertainment or travel	24	4.1%
Rent or utilities	17	2.9%
Clothing	10	1.7%
Household items	6	1.0%
Transportation/ gas	3	0.5%
Other	2	0.3%

n=590

* Total percentage exceeds 12.5% due to respondents listing multiple necessities foregone

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.[26]

Table 34: Necessities Forgone for Health Care by Gender

	Male	Female
Has to make choice between health care and other necessities	9.1%	14.4%
Did not have to make choice between health care and other necessities	90.9%	85.6%
Total	100.0%	100.0%

n=498

Table 35: Necessities Forgone for Health Care by Disability Status

	Disabled	Non-Disabled
Has to make choice between health care and other necessities	15.2%	9.3%
Did not have to make choice between health care and other necessities	84.8%	90.7%
Total	100.0%	100.0%

n=582

[26] Other research has indicated a bigger impact of health care costs on persons with disabilities. In a Kaiser Foundation survey published in December 2003, one-third of non-elderly persons with disabilities reported spending less on food and heat to pay for health care. See "Health Care Costs Hurt Disabled Americans," reported on December 12, 2003 and accessed at http://www.cbsnews.com/stories/2003/12/12/health/main588227.shtml.

Table 36: Necessities Forgone for Health Care by Health Status

	Very Sick	Somewhat Sick	So-So	Somewhat or Very Healthy
Has to make choice between health care and other necessities	36.4%	20.0%	15.0%	8.6%
Did not have to make choice between health care and other necessities	63.6%	80.0%	85.0%	91.4%
Total	100.0%	100.0%	100.0%	100.0%

n=589

In addition, respondents who live with family or a friend have been confronted with this dilemma far more often than those who live alone or with a spouse or partner. And, as respondents' health care expenses increase, the percentage of persons who have had to forgo other necessities to cover these expenses increases substantially.

Table 37: Necessities Forgone for Health Care by Live With Whom

	Yourself	With Spouse/ Partner	With Friend	With Family
Has to make choice between health care and other necessities	10.8%	14.8%	18.2%	18.2%
Did not have to make choice between health care and other necessities	89.2%	85.2%	81.8%	81.8%
Total	100.0%	100.0%	100.0%	100.0%

N=585

Table 38: Necessities Forgone for Health Care by Monthly Health Care Spending

	<$50	$50-$250	>$250
Has to make choice between health care and other necessities	11.4%	19.9%	31.1%
Did not have to make choice between health care and other necessities	88.6%	80.1%	68.9%
Total	100.0%	100.0%	100.0%

n=474

The relationship between the need to forego other necessities to cover health care expenses and income was not statistically significant.

EXPENSES – NON-HEALTH CARE

Beyond health care, Medicare recipients reported their other out-of-pocket monthly expenses, with housing and food comprising the majority of respondents' non-health care expenses along with transportation, utilities, and telephone expenses. Over one-fourth (28.8%) of the

respondents reported additional monthly expenses such as entertainment/cable, laundry, and charity.

Table 39: Non-Health Care Monthly Expenses

	Average (Mean)	Median	Range	n
Housing	$326	$250	$0 - $3,000	542
Food	$141	$115	$0 - $700	559
Transportation	$58	$35	$0 - $880	553
Utilities	$83	$40	$0 - $2,400	554
Phone, internet	$43	$40	$0 - $200	560
Other	$26	$0	$0 - $1,855	560

Table 40: Other Non-Health Care Monthly Expenses

	Survey Frequency	Survey Percent
Entertainment/cable	109	74.7%
Cleaning/laundry	18	12.3%
Charge cards/bills	2	1.4%
Insurance	2	1.4%
Charity	10	6.8%
Gifts	1	0.7%
Other	4	2.7%
Total	146	100.0%

Respondents with and without disabilities reported similar non-health care average monthly expenses, with the exception of those for transportation and utilities. For both categories of expenses, respondents without disabilities expended on average approximately one and one-half times the amount expended by respondents with disabilities.

Adding all the expenses together, 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. As income increases, monthly expenditures also increase.

Table 41: Total Non-Health Care Monthly Expenses

	Survey Frequency	Survey Percent
<$300	54	9.5%
$300 - $600	285	50.4%
$601 - $900	115	20.3%
$901 - $1,500	90	15.9%
$1,501+	22	3.9%
Total	566	100.0%

Table 42: Total Monthly Expenses

	Survey Frequency	Survey Percent
<$300	23	5.1%
$300 - $600	190	41.9%
$601 - $900	107	23.6%
$901 - $1,500	99	21.9%
$1,501+	34	7.5%
Total	453	100.0%

Table 43: Total Monthly Expenses by Income

	<$750	$751 - $1,500	>$1,501
<$300	11.6%	0.5%	0.0%
$300 - $600	68.3%	37.7%	7.8%
$601 - $900	14.6%	29.5%	23.5%
$901 - $1,500	2.4%	27.9%	51.0%
$1,501+	3.0%	4.4%	17.6%
Total	100.0%	100.0%	100.0%

n=598

HEALTH STATUS

Over one-half of respondents (51.9%) reported being somewhat or very healthy as contrasted with 12.2% who reported being somewhat or very sick.

Table 44: Level of Health

	Frequency	Percent
Very Healthy	108	18.1%
Somewhat Healthy	202	33.8%
So-so	215	36.0%
Somewhat Sick	62	10.4%
Very Sick	11	1.8%
Total	598	100.0%

Of respondents age 65 and older, 20.9% reported being "very healthy." This reflects a lower level of health among this study's respondents than that reported by AARP, in which 44% of Medicare recipients over 65 years old in 2003 rated their health as very good or excellent.[27] When looking at all of the respondents, self-reported health status improves with age until respondents enter the oldest age category of 85 to 89 years old.

Table 45: Level of Health by Age

	<65	65-69	70-74	75-79	80-84	85-99
Very healthy	8.9%	19.1%	21.7%	24.2%	22.0%	14.3%
Somewhat healthy	29.5%	32.5%	35.7%	37.4%	42.4%	28.6%
So-so	43.8%	33.8%	32.2%	30.8%	30.5%	50.0%
Somewhat sick	11.6%	13.4%	10.4%	7.7%	5.1%	7.1%
Very sick	6.2%	1.3%	0.0%	0.0%	0.0%	0.0%
Total	100.0%	100.1%	100.0%	100.1%	100.0%	100.0%

n=596

Respondents' disability status, monthly income, and Medicaid status had a significant impact on reported health status. Respondents who have a disability are over three times as likely to report being somewhat or very sick as those who do not have a disability. The relationship of health status with income is also strong, with respondents reporting higher levels of health as income levels increase. And respondents who receive Medicaid reported lower levels of health than non-Medicaid recipients.

[27] Accessed at http://research.aarp.org/heatlh/dd101_spending.html on November 4, 2004.

Table 46: Level of Health by Disability

	Disabled	Non-Disabled
Very healthy	9.0%	30.8%
Somewhat healthy	32.7%	36.0%
So-so	41.4%	28.3%
Somewhat sick	14.0%	4.9%
Very sick	2.9%	0.0%
Total	100.0%	100.0%

n=590

Table 47: Level of Health by Monthly Income

	<$750	$750-$1,500	>$1,500
Very healthy	10.0%	19.4%	32.8%
Somewhat healthy	32.3%	35.4%	34.5%
So-so	42.4%	35.4%	25.9%
Somewhat sick	13.5%	8.0%	6.9%
Very sick	1.7%	1.7%	0.0%
Total	100.0%	100.0%	100.0%

n=590

Table 48: Level of Health by Medicaid Status

	Receives Medicaid	Does Not Receive Medicaid
Very healthy	4.3%	1.1%
Somewhat healthy	10.7%	10.3%
So-so	43.6%	33.6%
Somewhat sick	30.0%	34.9%
Very sick	11.4%	20.1%
Total	100.0%	100.0%

n=598

MEDICARE

ACCESS TO HEALTH CARE

One of the concerns voiced by advocates and health care providers is that a significant percentage of Medicare recipients are not receiving the care or services that they need due to the expenses that they would incur if they were to receive it. When asked directly about this issue, 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. Somewhat surprisingly, the only factor that led to a significant difference among the respondents on this issue was the health status of the respondents.

Table 49: Cost of Health Care Prevents Receiving Care by Health Status

	Very/Somewhat Sick	So-So	Very/Somewhat Healthy
Cost prevents care	24.7%	28.4%	16.8%
Cost does not prevent care	75.3%	71.6%	83.2%
Total	100.0%	100.0%	100.0%
n=598			

One-sixth of respondents who reported being very or somewhat healthy said that health care costs prevent them from receiving the care they need as compared to almost one-quarter of those respondents who are very or somewhat sick. Respondents whose health is in the middle range reported problems accessing health care due to cost more often than the healthiest or sickest respondents.

When asked about the specific services that were needed but not received due to the costs, Medicare recipients had a range of responses, with dental care the service most frequently reported as needed but not received or received at insufficient levels.

Table 50: Health Care Services Needed but Not Received/Insufficiently Received Due to Costs

	Survey Frequency	Survey Percent*
Dental care	57	9.5%
Home health care	51	8.5%
Doctor/clinic visits	50	8.3%
Physical therapy	39	6.5%
Podiatry care	35	5.8%
Diagnostics/lab tests	35	5.8%
Hospital visits	31	5.2%
Occupational therapy	31	5.2%
Durable medical equipment	33	5.5%
In-patient mental health care	27	4.5%
Counseling/mental health care	23	3.8%
Supplies	22	3.7%
Speech therapy	11	1.8%

n=599

* Total percentage does not equal 100% due to respondents listing multiple health care services

Medicaid recipients reported not receiving or receiving insufficient levels of dental and podiatry care at two to three times the rate of non-Medicaid recipients. (Medicaid has limited benefits for both dental and podiatry care, while Medicare covers some podiatry care.) However, non-Medicaid recipients were twice as likely to have been unable to see their doctors or go to the clinic as compared to Medicaid recipients.

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.

Table 51: Reasons for Delaying Care

	Survey Frequency	Survey Percent*
Problems with transportation	111	18.5%
The cost	110	18.4%
The time it takes	102	17.0%
Uncertainty if you really need the care	72	12.0%
Fear of what you may be told	58	9.7%
Discomfort or pain with the treatment	52	8.7%
How you are treated by the staff	41	6.8%
Embarrassment	15	2.5%
Other	1	0.2%

n=599

* Total percentage does not equal 100% due to respondents listing multiple reasons for delaying care

The factors most strongly associated with delaying care are having a disability, age, residence, and health status. Respondents who have a disability and who are younger reported delaying care to a greater extent than those who do not have a disability and who are older.

Table 52: Delaying Care by Disability Status

	Has Disability	Does not have Disability
Has delayed care	44.2%	34.0%
Has not delayed care	55.8%	66.0%
Total	100.0%	100.0%
n=591		

Table 53: Delaying Care by Age

	<65 years	65-74 years	75-99 years
Has delayed care	50.7%	40.1%	30.3%
Has not delayed care	49.3%	59.9%	69.7%
Total	100.0%	100.0%	100.0%
n=596			

Respondents who reported being the least healthy and those who live in the south suburban areas reported the highest levels of delaying health care, while those who are the most healthy and those who live on the south and southwest sides of Chicago reported delaying health care services less frequently than other respondents.

Table 54: Delaying Care by Location of Residence

	Chicago - SW side	Chicago - S. Side	South Suburban	All other areas
Has Delayed Care	22.9%	35.7%	58.0%	43.30%
Has not Delayed Care	77.1%	64.3%	42.0%	56.7%
Total	100.0%	100.0%	100.0%	100.0%
n=597				

Table 55: Delaying Care by Health Status

	Very Sick	Mid-range*	Very Healthy
Has Delayed Care	54.5%	41.5%	31.5%
Has not Delayed Care	45.5	58.5%	68.5%
Total	100.0%	100.0%	100.0%
n=597			

*Includes responses "so-so," "somewhat healthy" and "somewhat sick."

The only factors that led lower income respondents to delay health care were problems due to transportation and time.

When asked about the impact of co-payments and deductibles on their willingness to access health care services, most respondents stated that they were not a factor in their decision-making. Required co-payments discouraged 14.9% of respondents from receiving health care,

and 9.9% of respondents were discouraged from obtaining health care due to the cost of deductibles. However, Medicare recipients' disability and health status and their income levels are highly significant factors affecting the impact of co-payments and deductibles on respondents' access to health care. Respondents with disabilities were twice as likely to avoid accessing health care services due to co-payments or deductibles as respondents without disabilities,[28] as were respondents with individual monthly incomes of less than $1,500 as compared to those with monthly incomes over $1,500.[29] This is particularly important, given that the new low-income subsidy will include co-payments at every income level, except for those recipients who are institutionalized. Finally, as respondents' health status decreases, the impact of both co-payments and deductibles increases, with 27.3% of very sick respondents reporting that these costs discouraged them from getting care, as compared to 6% to 7% of the very healthy. Approximately one-half of the respondents for whom co-payments and deductibles affect their access to health care reported that they have to be quite or very sick before they will seek help.

Accessibility of primary care doctors can be examined both in terms of whom people see and the how long one waits for an appointment. Almost three-quarters (74.4%) of respondents see the same primary care doctor each time that they go to an office or clinic for service, and slightly more than that (77.9%) reported that it is very or somewhat easy to have an appointment with their primary care doctor. [30]

Table 56: See Same Doctor

	Frequency	Percent
Yes	442	74.4%
No	57	9.6%
Depends on which clinic I visit	94	15.8%
Don't know	1	0.2%
Total	599	100.0%

Table 57: Ease of Getting Appointment

	Frequency	Percent
Very easy	299	50.0%
Somewhat easy	167	27.9%
So-so	92	15.4%
Somewhat hard	28	4.7%
Very hard	12	2.0%
Total	598	100.0%

Over one-half the respondents are able to have an appointment with their primary care doctor within a few days, with almost one-fifth (18.6%) reporting that it can take a month or longer.

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[28]The co-payment/deductible figures are 18.4%/12.2% for respondents with disabilities as compared to 9.7%/6.1% for respondents without disabilities.

[29] The figures are 16.6% for individuals with monthly incomes under $1,500 as compared to 6.9% for those over $1,500.

[30] In a recent study of 3,200 Medicare recipients, 27% of respondents reported not always getting appointments with their physicians for routine care as soon as they wanted them. T. Lake, M. Gold, A. Ciemnecki, M. Sinclair, N. Diaz-Tena, C. Lamothe-Galette, S. Limpa-Amara, "Results from the 2003 Targeted Beneficiary Survey on Access to Physician Services among Medicare Beneficiaries," Mathematica Policy Research, June 17, 2004, p. xii.

Table 58: Wait for Appointment

	Frequency	Percent
Within a day	167	28.3%
Within a few days	159	26.9%
Within a week	92	15.6%
Within 14 days	63	10.7%
Within 30 days	59	10.0%
Over thirty days	51	8.6%
Total	591	100.0%

A recent study of access to physician services investigating the concern that reduced physician reimbursement rates for Medicare services might result in beneficiaries having greater difficulty receiving timely care similarly found a lack of data to support this concern. However, recipients who had recently moved or changed insurance coverage were at greater risk of having trouble accessing care.[31]

Finally, 4.0% of the respondents in the CIR study reported that their doctor will not provide some health care services for them because they are insured under Medicare. The services most often reported as being denied were prescription and non-prescription medicines (31.8%), dental care (22.7%), specialists (18.2%), and vision care (13.6%).

ACCESS TO HEALTH CARE PRIOR TO MEDICARE

Although the focus of this report is on the health care needs and experiences of persons receiving Medicare, we were also interested in understanding how these experiences and needs had changed from the time prior to their enrollment in Medicare to the current time. 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.

Table 59: Health Insurance Prior to Medicare

	Frequency	Percent
Adequate or good	319	56.9%
Poor quality	83	14.8%
None	159	28.3%
Total	561	100.0%

[31] Accessed at www.mathematica-mpr.com/publications/redirect_pubsdb.asp?strSite=pdfs/targetben.pdf on December 6, 2004.

Among respondents with disabilities, over one-half had held poor quality or no insurance prior to Medicare. The relationship between prior health insurance and monthly income is even stronger, with those persons at lower income levels having far lower rates of pre-Medicare health insurance when compared to those with higher income levels. Close to one-half (44.6%) of respondents with monthly incomes less than $751 had no health insurance prior to Medicare, as compared to one-quarter (24.1%) of respondents with monthly incomes between $751 and $1,500 and 4.5% of those persons with current monthly incomes over $2,201.

Table 60: Health Insurance Prior to Medicare by Disability Status

	Disabled	Non-Disabled
Adequate or good	49.2%	68.2%
Poor quality	19.7%	7.2%
None	31.0%	24.6%
Total	100.0%	100.0%
n=555		

Table 61: Health Insurance Prior to Medicare by Current Monthly Income

	<$751	$751 - $1,500	$1,501 - $2,200	$2,201+
Adequate or good	32.7%	63.6%	82.9%	95.5%
Poor quality	22.8%	12.3%	8.6%	0.0%
None	44.6%	24.1%	8.6%	4.5%
Total	100.0%	100.0%	100.0%	100.0%
n=487				

Slightly less than one-tenth (9.3%) of the respondents noted a change in their relationship with their doctor or physician's group after they had begun to receive their health care coverage through Medicare. Most frequently, respondents reported having to change their doctor.[32] Over one-fifth (21.6%) reported receiving better treatment or resources; 13.7% reported not being treated as well in their new status as Medicare recipients.

Table 62: How Relationship with Doctor Changed for those Respondents who Experience a Change

	Frequency	Percent
Had to change doctor	22	43.1%
Better treatment/resources provided	11	21.6%
Not treated as well	7	13.7%
Can afford health care now	5	9.8%
Other	6	11.8%
Total	51	100.0%

[32] Some respondents may have had to change their health care provider if they lost their Medicaid coverage when they began receiving Medicare services.

PRESCRIPTION DRUGS

The vast majority of respondents (95%) use prescription drugs.[33] When asked where they obtain their prescription drugs, most of the respondents (72.0%) said at a drug store, while one-fifth of the respondents obtain them through their hospital (including the Veteran's Administration).

Table 63: Where You Get Your Prescription Drugs

	Survey Frequency	Survey Percent
Drug stores	409	72.0%
From hospital/county hospital	79	13.9%
From Veteran's Administration	38	6.7%
From doctor's office/clinic	36	6.3%
Discount stores	34	6.0%
Through mail order	32	5.6%
Through the internet	3	0.5%
From Canada	1	0.2%
From another country	1	0.2%
Other	5	0.9%

n=568

* Total percentage exceeds 100% due to respondents listing multiple prescription drug sources.

Most Medicaid recipients (83.3%) obtain their prescription drugs through drug stores; 2.9% from the VA; and 2.2% through mail order. There is considerable discussion about the cost savings of purchasing drugs through the Internet and other countries, yet, less than 1.0% of respondents have used these methods to purchase medications. However, 5.6% of respondents said that they purchase their prescription drugs through "mail order," the location from which the prescriptions are mailed not being specified. These respondents were overwhelmingly in the highest income bracket and residents of northern suburbs.

Table 64: Prescription Drugs through Mail Order by Monthly Income

	<$750	$750-$1,500	>$1,500
Purchases drugs through mail order	1.3%	4.8%	21.8%
Does not purchase drugs through mail order	98.7%	95.2%	78.2%
Total	100.0%	100.0%	100.0%

n=505

Table 65: Prescription Drugs through Mail Order by Where Living

	North Suburbs	Chicago SW Side	All Other Locations
Purchases drugs through mail order	46.7%	14.3%	4.0%
Does not purchase drugs through mail order	53.3%	85.7%	96.0%
Total	100.0%	100.0%	100.0%

n=567

[33] Whether these drugs are used on a regular basis for ongoing health maintenance needs, or only on occasion cannot be determined from the available data.

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. This confusion about plans became clear as surveyors asked respondents to show their prescription drug card in order to verify their responses.[34]

Most respondents (79.6%) currently have some type of prescription drug coverage; over one-fifth (21.2%) of all respondents have two or three types of coverage.

Table 66: Current Prescription Drug Coverage

	Survey Frequency	Survey Percent of Those Covered* (n=476)	Survey Percent of Total Respondents (n=599)
Medicaid	145	30.5%	24.2%
Circuit Breaker/ Pharmaceutical Assistance	85	17.9%	14.2%
County Health Dept.	76	16.0%	12.7%
Medicare HMO	73	15.3%	12.2%
Medigap Plan	68[35]	14.3%	11.4%
Illinois SeniorCare	66	13.9%	11.0%
VA Medical Center	56	11.8%	9.3%
Respondent's former employer	32	6.7%	5.3%
Other	11	2.3%	1.8%
Spouse's former employer	10	2.1%	1.7%
Current employer	3	0.6%	0.5%
Don't Know	1	0.2%	0.2%

* Total percentage exceeds 100% due to respondents listing multiple prescription drug plans.

In addition to insurance-based prescription drug coverage, over one-fourth (25.6%) of the respondents have or have applied for a prescription drug discount card, either through the State, private insurance, Medicare, or a private drug company.

[34] The implications of this lack of understanding or clarity on the part of Medicare recipients regarding their prescription drug coverage are significant for researchers, service providers, and advocates. Self-reported data regarding participation in health plans and programs that serve Medicare recipients need to be verified before implementing policy decisions or service provision based on such data.

[35] This number of respondents reporting coverage by the Medigap prescription plans seems quite high, given the high cost of these plans and their limited coverage. Given that this is self-reported data, the actual incidence may be inflated.

Table 67: Prescription Drug Discount Cards

	Survey Frequency	Survey Percent of Those With Cards* (n=153)	Survey Percent of Total Respondents (n=599)
IL Rx Drug Buying Club/Circuit Breaker	55[36]	35.9%	9.2%
Blue Cross Blue Shield Members First	43	28.1%	7.2%
Medicare approved discount drug card	43	28.1%	7.2%
Other	7	4.6%	1.2%
From a drug manufacturer	4	2.6%	0.7%
Don't know	1	0.7%	0.2%

As income increases, the percentage of respondents with a drug discount card increases significantly, with less than one-fifth (17.5%) of those in the lowest income levels having a card as compared to over one-fourth (25.3%) of those respondents in the middle income level and over one-third (41.4%) of those in the highest income level. [37]

Table 68: Prescription Drug Discount Card by Individual Monthly Income

	<$750	$750-$1,500	>$1,500
Has discount card	17.5%	25.3%	41.4%
Does not have discount card	82.5%	74.7%	56.9%
Total	100.0%	100.0%	100.0%
n=524			

This Medicare survey was carried out in June and July of 2004, six months after the enactment of the Medicare Improvement and Modernization Act of 2003. Starting in the spring of 2004, Medicare recipients became eligible to apply for a Medicare-approved discount card to access discounts on their prescription drugs. The discount drug card program is temporary and will end on January 1, 2006 when the Act's comprehensive prescription drug benefit commences.[38]

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. Five months later, in

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[36] All persons who are enrolled in the Circuit Breaker or Pharmaceutical Assistance Programs are automatically enrolled in the Rx Buying Club (and their pharmacists use it for reimbursement). However, the Medicare recipients may not know that they are a part of this program.

[37] Respondents who receive Medicaid and Illinois SeniorCare (just over one-third of respondents) are not eligible to receive a Medicare approved discount card, thus significantly reducing the number of recipients in the lowest income categories who could have a drug discount card.

[38] "Medicare-approved prescription drug discount card program," Center for Medicare and Medicaid Services. Accessed at http://www.cms.hhs.gov/medicarereform/drugcard/ on September 28, 2004.

December 2004, only 20% of all low-income Medicare beneficiaries nationwide had signed up for the Medicare approved discount cards.[39] In addition, respondents were asked about their use of the $600 transitional assistance credit available to low-income Medicare recipients.[40] None of the survey respondents had applied for or received this benefit at the time of the survey. However, the survey was carried out in June and July of 2004, and the transitional assistance only had become available in June 2004.

Of those respondents who had not applied for a drug card, the majority reported using other options to meet their prescription drug needs, or do not feel that they need a card. For those respondents who have or have applied for a prescription drug card, 43.7% reported a good experience using it.

Table 69: Reasons for Not Applying for a Prescription Drug Card

	Survey Frequency	Survey Percent
Uses other options	96	33.8%
Doesn't need it	67	23.6%
Needs more information or help applying	43	15.1%
Hasn't had a chance to do it yet	15	5.3%
Doesn't think it will help	14	4.9%
Other	49	17.3%
Total	284	100.0%

Table 70: Experiences Applying for a Prescription Drug Card

	Survey Frequency	Survey Percent
Application in process/ Haven't used yet	34	36.2%
Good/okay experience	29	30.9%
Bad experience/ Doesn't help	12	12.8%
Saves money	12	12.8%
Application refused	5	5.3%
Other	2	2.1%
Total	94	100.0%

The large number of choices in discount cards available for Medicare recipients generates considerable confusion among recipients as well as advocates as to the relative merit of the various available options. Formularies vary from program to program and can be switched

[39] Leif Wellington Haase, "Marked Down: The Medicare Discount Card Dilemma," The Century Foundation, December 3 2004. Accessed at http://www.tcf.org/4l/4lmain.asp?subjectid=4&articleid=798. This is particularly problematic, given that these low-income Medicare recipients are entitled to a $600 prescription drug subsidy per year in 2004 and 2005, if they enroll in the discount drug program by December 31 of each of the respective years. The annual subsidy lapses on the last day of each year.

[40] Beginning in June 2004, Medicare began providing a $600 annual credit for prescription drugs, and up to an additional $600 in 2005 to Medicare beneficiaries whose incomes are not more than 135% of the poverty line if they do not have certain types of other drug coverage. These funds are being provided through the Medicare-approved drug discount card in which the beneficiary enrolls. When applying the $600 toward prescription drug purchases, beneficiaries at or below 100% of poverty pay 5% coinsurance and beneficiaries above 100% of poverty pay a 10% coinsurance. Information is from the Centers for Medicare and Medicaid Services. Accessed at http://www.cms.hhs.gov/discountdrugs/overview.asp on February 11, 2005.

every seven days at the discretion of the plans.[41] Plans available in a geographic area may not cover some or all of the medications needed by Medicare recipients, requiring recipients to switch to new drugs whose effects are uncertain.[42] Articles and letters to the editor in Illinois newspapers over the first few months of the program's inception included considerable caution and concern regarding the efficacy of these cards and warning Medicare recipients about their shortcomings.[43]

Survey participants were also asked their attitudes towards purchasing prescription drugs outside of the U.S as well as their thoughts about the government acting as an intermediary to negotiate bulk drug prices on behalf of Medicare recipients. The 2003 Medicare bill prevents the government from negotiating drug prices with manufacturers and restricts the importing of cheaper drugs from Canada and other countries.[44] However, five states—including Illinois—are setting up websites to help their residents purchase pharmaceuticals from outside the U.S., including from Canada, Britain and Ireland, despite the Food and Drug Administration's ruling that such practices are illegal.[45] And on December 31, 2004 Rhode Island became the first state to allow its residents to import prescription drugs from Canada.[46] Although other research reports that a large majority of Medicare recipients want the Medicare law to allow Americans to buy prescription drugs from Canada,[47] less than one-third (30.1%) of the respondents in this survey want to be able to purchase drugs from outside the U.S. However, just over one-half of the respondents (50.3%) believe that such drugs should be included in their prescription drug coverage. Furthermore, a vast majority of the respondents (93.8%) think that the government should negotiate bulk prices from drug companies on behalf of all Medicare recipients.[48]

When asked about whether they would like the option to be able to buy additional insurance to help pay for prescription drugs, slightly less than one-half of the respondents replied that they wanted that option, while almost the same number either wanted it, or would consider it depending on the costs and benefit levels. When respondents' desire for additional prescription drug coverage is examined in light of health status, their desire for additional insurance increases significantly as their health status decreases, with 45.5% of those respondents who are very sick wanting additional insurance as compared to 7.5% of those who are very healthy.

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[41] "Health Care – Drug Cards Dissected," *The Progress Report*, March 26, 2004. Accessed at http://www.americanprogress.org.
[42] FamiliesUSA Special Report, October 20, 2004, p.2.
[43] "Seniors Shortchanged," *Chicago Sun-Times*, May 19, 2004.
[44] "Medicare Law's Costs and Benefits Are Elusive," *New York Times*, December 9, 2003, p. A-1, p. A-18.
[45] "Illinois to Help Residents Buy Drugs from Canada, and Afar," *New York Times*, August 17, 2004, p. A-15. Senate Bill 2128 was introduced in June 2004 and would legalize the safe importation of prescription drugs into the U.S, beginning with Canada. See http://www.aarp.org/states/wi/Articles/a2004-08-19-wi-prescription_imports.html
[46] "Rhode Island to Allow Residents to Import Drugs," *Washington Post*, December 31, 2004. Accessed at www.washingtonpost.com/ac2/wp-dyn/A3986-2004Dec31?language=printer.
[47] From "Views of the New Medicare Drug Law." Accessed at www.kff.org/Medicare/7145.cfm on November 2, 2004
[48] This is a significantly higher percent than that reported by Kaiser/Harvard Survey of Medicare respondents. The Kaiser/Harvard study found that 80% of their respondents favor the government negotiating bulk prescription drug pricing for Medicare recipients. Accessed at www.kff.org/Medicare/7145.cfm on November 2, 2004.

Table 71: Want Additional Prescription Drug Insurance

	Survey Frequency	Survey Percent*
Do not want additional insurance	267	44.8%
Want additional insurance	68	11.4%
Depends on the costs/benefits	178	29.9%
Don't know	83	13.9%
Total	596	100.0%

Table 72: Want Additional Prescription Drug Insurance by Health Status

	Very Sick	Somewhat Sick - Somewhat Healthy	Very Healthy
Do not want additional insurance	18.2%	43.9%	51.9%
Want additional insurance	45.5%	11.5%	7.5%
Depends on the costs/benefits	36.4%	29.5%	31.1%
Don't know	0.0%	15.1%	9.4%
n=595	100.0%	100.0%	100.0%

These questions regarding desire to obtain additional coverage presumed that recipients were able to keep all of the benefits that they have under the current Medicare program. However, this presumption is not accurate. In particular, respondents with dual Medicaid and Medicare eligibility will have significantly different entitlements under the new Medicare program.

Over the past several years, stories regarding the cost-saving measures taken to combat rising drug costs have surfaced. Health care providers and federal and state agencies have implemented programs to force patients to split pills as a cost-saving strategy, as medications often cost nearly the same regardless of their dosage.[49] A 2002 North Carolina study found that when seniors split pills, the actual dose they received differed between 9% and 37% from the prescribed dose, with the upper range of this difference being medically hazardous for some types of medication.[50] Research has documented the fact that seniors who do not adhere to their prescribed drug regimens in order to save money experience "a major decline in health" as compared to other elderly patients who adhere to the prescribed regimen.[51]

Of all the respondents, 82.8% reported usually taking all of their medications as prescribed, regardless of cost. The remaining 17.2% of respondents reported using one or more cost-saving measures, including substituting other medicines for those prescribed, taking less than the recommended dose, not taking some medications at all, or cutting pills in half.

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[49] S. Goldsmith, "Cutting Corners: Critics of Kaiser's Cost-Cutting Efforts Warn of the Dangers of an HMO Policy in which Sick Patients with Shaky Hands Must Split Their Own Pills," *East Bay Express*, April 16, 2003. Accessed at http://www.eastbayexpress.com/issues/2003-04-16/news/feature_print.html on February 22, 2005.

[50] "To Make a Pill More Affordable, Cut It in Half," *New York Times*, April 13, 2004, p. G-10.

[51] "Seniors Not Taking Medications as Directed More Likely to Face Long-Term Health Problems, Study Says," *Kaiser Daily Health Policy Report*, June 25, 2004. Accessed at http://www.kaisernetwork.org/daily_report.cfm?DR_ID=24425&dr_cat=3 on July 6, 2004.

Table 73: Ways Used to Cut Drug Costs

	Survey Frequency	Survey Percent*
Taking substitutes for the prescribed medications[52]	102	17.0%
Taking less than the recommended dose	47	7.8%
Not taking some medications altogether	36	6.0%
Cutting pills in half	25	4.2%
All medications usually taken as prescribed	496	82.8%
n=599		

* Total percentage exceeds 100% due to respondents listing multiple strategies used to cut drug costs

Those 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. However, receiving Medicaid had almost no effect on whether cost-cutting measures were used by respondents.

Table 74: Use of Drug Cost-Cutting Measures by Age

	<65	65-74	75-84	85-89	90-99
Uses drug cost-cutting strategies	23.3%	13.6%	8.0%	4.8%	0.0%
Does not use drug cost-cutting strategies	76.7%	86.4%	92.0%	95.2%	100.0%
Total	100.0%	100.0%	100.0%	100.0%	100.0%
n=596					

Table 75: Use of Drug Cost-Cutting Measures by Health Status

	Very Sick	So-So/ Somewhat Sick	Somewhat/ Very Healthy
Uses drug cost-cutting strategies	36.4%	18.8%	9.0%
Does not use drug cost-cutting strategies	63.6%	81.2%	91.0%
Total	100.0%	100.0%	100.0%
n=598			

Table 76: Use of Drug Cost-Cutting Measures by Disability Status

	Disabled	Not Disabled
Uses drug cost-cutting strategies	18.6%	7.7%
Does not use drug cost-cutting strategies	81.4%	92.3%
Total	100.0%	100.0%
n=591		

[52] This may have included substituting the prescribed medication with a generic one.

Nearly one-fifth (17.2%) of the respondents reported not taking all of their prescribed medications to reduce their expenses. However when comparing the reported costs of taking all medications prescribed or recommended (for non-prescription drugs) to actual monthly expenditures, almost one-fourth (24.2%) of the respondents reported spending less than they were supposed to for prescription drugs; and 10.2% were spending less than they were supposed to spend on non-prescription drugs. There may be multiple reasons for the differences between the responses to the direct question about cost-saving measures being taken by Medicare recipients and this gap in expenses. Medicare recipients may be receiving some of their medications without having to pay for them from their health care providers (free samples) or they may be receiving medications from friends or family without paying for them out-of-pocket. Furthermore, there may have been some confusion by the respondents about the financial questions asking for expenses they would have incurred, had they purchased all of their prescribed or recommended medications.

Counseling for Medicare recipients regarding the potential side effects of medications that they are taking is provided most frequently by physicians and pharmacists. In 1997, the American Pharmaceutical Association adopted a policy that pharmacists should provide counseling to their patients regarding drug usage, safety, and side effects through face-to-face oral consultations and written materials.[53] According to a 2000 survey by the FDA's Center for Drug Evaluation and Research, 74% of patients received written information about proper drug use and potential side effects; 24% received oral counseling from physicians; and 14% received oral counseling from pharmacists.[54] The government's Healthy People 2010 initiative has set a target level of 95% of patients receiving oral counseling from both their physician and their pharmacist on correct drug use and potential risks by 2010.[55] States have considerable discretion in setting counseling rules. For example, in 2003, New York's State Board of Regents adopted rules specifically requiring pharmacists to counsel patients on new prescriptions rather than just offer consultation to all patients picking up prescriptions.[56] In 1997, Illinois added a section to its Pharmacy Practice Act requiring pharmacists to offer patient counseling on every prescription filled.[57]

When asked about whether anyone has counseled them about the possible side effects and risks of the medications that they are taking, 11.9% of the respondents said that no one had spoken to them about these issues. The percentage of older respondents who were counseled on drug side effects was significantly lower than that of younger respondents with those persons age ninety and above one-third less likely than those under eighty to have this issue discussed with them.

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[53] "Objective 17 – Medical Product Safety," Healthy People 2010 Initiative. Accessed at http://www.healthypeople.gov/Document/HTML/Volume2/17Medical.htm on December 16, 2004.

[54] "National Surveys of Prescription Medicine Information Received by Consumers," Center for Drug Evaluation and Research, Food and Drug Administration. Accessed at http://www.fda.gov/cder/Offices/ODS/y2ktitle.htm on December 16, 2004.

[55] "Objective 17 – Medical Product Safety," Healthy People 2010 Initiative.

[56] "Rules on Prescription Counseling Changed," *New York Times*, June 18, 2003, p. B-2.

[57] "Pharmacy Practice Act of 1987," Section 1330.65, Illinois Department of Professional Regulation. Accessed at http://www.dpr.state.il.us/WHO/ar/pharmacr.asp on December 16, 2004.

Table 77: Counseled on Drug Side Effects by Age

	<80 Years	80-89 Years	90-99 Years[58]
Has been counseled	89.2%	83.6%	57.1%
Has not been counseled	10.8%	16.4%	42.9%
Total	100.0%	100.0%	100.0%
n=560			

2003 MEDICARE REFORM LEGISLATION

With the Medicare Prescription Drug, Improvement and Modernization Act of 2003 enacted only six months prior to this study, and provisions of the law being implemented in stages over the next two years, it is not surprising that Medicare recipients' understanding of and attitudes towards this change in their health care coverage reflected a range of perspectives. While the change in the Medicare program is characterized by the federal government as "provid[ing] seniors and people living with disabilities with a prescription drug benefit, more choices and better benefits" and "the most significant improvement to senior health care in nearly 40 years,"[59] advocates for Medicare recipients have characterized it as "inadequate and wasteful…do[ing] more to help drug companies and HMOs than seniors."[60] Reactions by consumer advocacy groups have focused largely on the adverse impact that they believe it will have on costs for Medicare recipients.[61] Focus groups carried out with Medicare recipients across the U.S. found "considerable concerns" with the new law and confusion about its details and how it will be implemented.[62] Many persons who have worked within the Medicare and Medicaid systems for years at policy levels and others with responsibility for the daily management of these systems are reporting high levels of confusion and frustration with the

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[58] There were only seven respondents within this age group.

[59] Centers for Medicare and Medicaid Services, "Medicare Modernization Act." Accessed at http://www.cms.hhs.gov/medicarereform/ December 24, 2004.

[60] "Medicare Reform," American Progress Action Fund. Accessed at http://www.americanprogressaction.org/site/pp.asp?c=klLWJcP7H&b=121807 on December 24, 2004.

[61] "Skimpy Benefits and Unchecked Expenditures: Medicare Prescription Drug Bills Fail to Offer Adequate Protection for Seniors and People with Disabilities," Gail Shearer, *Consumers Union*, June 17, 2003; "Prescription Drugs and the Fight to Save Medicare," Campaign for America's Future. Accessed at http://www.ourfuture.org/issues_and_campaigns/healthcare/6_18_03.cfm on July 21, 2003; "The New Medicare Prescription Drug Benefit: Not So Voluntary," Center for American Progress, Medicare Policy Brief, February 12, 2004; "Medicare Forum Draws Overflow Crowd," Terry Davis, *I'll Be There* (Chicago Jobs With Justice Newsletter), April 2004; "Squeezing Seniors' Pocketbooks," Bill Vaughn. Accessed at http://www.tompaine.com/print/squeezing_seniors_pocketbooks.php on September 20, 2004.

[62] "Reactions to the New Medicare Law," Public Opinion Strategies and Peter Hart Research Associates, June 2004. Accessed at www.kff.org/medicare/7099cfm on August 15, 2004. Analysis by AFL-CIO for its members. Accessed at www.aflcio.org/issuespolitics/medicare/medicarebasics/ns06182003.cfm on November 9, 2004.

new law.[63] Many advocates and service providers have cautioned that the interim drug cards are confusing and potentially more costly for Medicare recipients than current state funded programs and private insurance benefits.[64]

The gap in coverage, known as the "doughnut hole" is an area of great concern to Medicare recipients and health care advocates.[65] In addition to paying annual premiums that are expected to be $420 in the first year[66]—and the $250 deductible—Medicare recipients will be required to pay up to 25% of their drug costs up to $2,250 per year. Beyond this level of prescription drug expenses, program participants will not have drug coverage until annual expenses reach $5,100.[67] There will be a low-income subsidy to fill in the "doughnut hole" for Medicare recipients whose income is less than or equal to 135% of the Federal Poverty Level with limited assets, as well as a co-payment assessed for each of their prescriptions.[68] Low-income recipients between 135% and 150% of the Federal Poverty Level with limited assets also will receive a sliding scale subsidy, a deductible of $50, and a 15% co-payment for covered prescription drugs.

Considerable additional confusion and concern was created when the Department of Agriculture (USDA) Food and Nutrition Service issued a "guidance" on the new prescription drug card benefit, indicating that people who received benefits under the new drug card program would be subject to a reduction in their Food Stamp benefits. Three months later, the USDA revised its guidance eliminating the policy that would penalize low-income Medicare recipients receiving Food Stamps and/or using the interim $600 credit.[69]

Although the law had been passed only six months prior to this survey, respondents were asked their opinions about the new Medicare law and its provisions. Over three-quarters (77.1%) of the respondents have no idea as to whether or not the new law will be of help to them; 7.9% think that it will not help them; and 15.1% think that they will benefit from its

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[63] Vern Smith, Health Management Associates and former Medicaid director, speaking on a conference call sponsored by Kaiser Family Foundation, December 15, 2003.

[64] E-mail letter from Hal Gullett, President of the Illinois Alliance for Retired Americans, May 6, 2004; N. Stanhaus, "Accessing New Prescription Drug Benefits," summary of May 3, 2004 meeting hosted by Retirement Research Foundation and Michael Reese Health Trust.

[65] "Medicare: Money for Nothing but the Drugs Aren't Free," *The Progress Report*, July 27, 2004. Accessed at http://www.americanprogressaction.org.

[66] See http://thomas.loc.gov/home/thomas.html for bill summary and status.

[67] Tommy Thompson, the former Secretary of U.S. Department of Health and Human Services, characterized persons holding such concerns as "pessimists." "Officials: Medicare Plan Aimed at Saving Benefits," Julie Appleby, *USA Today*, July 26, 2004. Accessed at www.usatoday.com/news/health/2004-07-26-medicare-drus_x.htm on December 2, 2004, and quoted in *The Progress Report*, July 27, 2004.

[68] The only exception is Medicare recipients who are institutionalized.

[69] "Food Stamps Should Not Go Down for Seniors and People with Disabilities Who Sign Up for Medicare Drug Cards," Center on Budget and Policy Priorities, July 13, 2004. Accessed at http://www.cbpp.org/6-23-04fa.htm on November 8, 2004. "Revised Policy Guidance – Effective Immediately: Medicare Prescription Drug Card," USDA Food and Nutrition Service, June 18, 2004. Accessed at http://www.fns.usda.gov/fsp/rules/Memo/o4/061804.htm on November 8, 2004. This protection is not in the 2006 benefit, so use of the low-income subsidy may change eligibility for other public benefits such as rent subsidies and subsidized housing.

provisions.[70] Their responses reflected a high degree of speculation, rather than a sense of certainty. When asked why they believe that the new law will or will not benefit Medicare recipients, respondents offered a wide range of responses regarding the impact that they expect it to have on health care costs, the quality and effectiveness of services, and the level of change to which it will lead.

Table 78: Why New Medicare Law Will Benefit Recipients

	Survey Frequency	Survey Percent
Health care will cost less	22	31.0%
It will lead to more services	20	28.2%
It will improve the situation	12	16.9%
It will lead to better services and lower costs	7	9.9%
Other	10	14.1%
Total	71	100.0%

Table 79: Why New Medicare Law Will Not Benefit Recipients

	Survey Frequency	Survey Percent
The changes are confusing	11	34.4%
Health care will cost more/too much	8	25.0%
Doesn't trust government/ prior changes didn't help	6	18.8%
There is no real change from before	5	15.6%
It is an insufficient change/ greater change is needed	2	6.3%
Other	11	34.4%
Total	32	100.0%

[70]The level of confusion or lack of information reported by respondents is much higher in CIR's study than in the Kaiser/Harvard survey of Medicare recipients, which reported that 47% of its respondents had an unfavorable impression of the new law, 26% had a favorable impression, and 26% reported not having sufficient information to have an opinion. See "Views of the New Medicare Drug Law." Accessed at www.kff.org/Medicare/7145.cfm on November 2, 2004. See also "Vulnerabilities of the Medicare Prescription Drugs Bill," *Public Opinion Watch*, March 3, 2004. Accessed at http://www.tcf.org.

DISABILITY ISSUES

People who are under 65 and have a disability become eligible for Medicare after they have received Social Security or Railroad Retirement Benefits for 24 months.[71] Social Security disability payments are converted into retirement benefits when the recipient reaches age 65.[72] Likewise, individuals then become eligible for Medicare through their senior status rather than through their disability status. Seniors with disabilities over age 65 may also qualify for Supplemental Security Income (SSI) payments, which are awarded on the basis of financial need.[73]

The Social Security Administration (SSA), through which persons with disabilities become eligible for Medicare if they are less than 65 years of age, only provides disability benefits for total disabilities, not partial or short-term disabilities. The SSA states: "We consider you disabled under Social Security rules if you cannot do work that you did before and we decide that you cannot adjust to other work because of your medical condition(s). Your disability must also last or be expected to last for at least one year or to result in death."[74] The Centers for Medicare and Medicaid Services projected a total of 6.4 million disabled Medicare enrollees in 2004.[75]

Nearly three-fifths of the respondents (58.3%) have a disability, including 48.3% of the respondents, age 65 or older. Almost one-fourth of the respondents (24.4%) receive Medicare benefits as a result of their disability status. Although they are not classified as disabled by Medicare once they turn 65, three-quarters (75.3%) of the respondents age 65 and older with disabilities reported having what would qualify as a Medicare disability were they under 65 years old. Respondents with disabilities were asked about difficulties that they may have encountered in accessing eight types of durable equipment and supplies and services related to their disability. A total of 43.0% of the respondents had experienced difficulties in at least one area, with eyeglasses reported as the largest source of difficulty.

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[71] "Medicare and You 2005," Center for Medicare and Medicaid Services. Accessed at http://www.medicare.gov/publications/pubs/pdf/10050.pdf on December 17, 2004.
[72] "Disability and SSI," Social Security Administration. Accessed at http://www.ssa.gov/d&s1.htm on December 17, 2004.
[73] See the Social Security Administration's website at www.ssa.gov for further details on Social Security and SSI eligibility.
[74] "What We Mean by Disability," Social Security Administration. Accessed at http://www.ssa.gov/dibplan/dqualify4.htm on December 17, 2004.
[75] Centers for Medicare and Medicaid Services. Accessed at http://www.cms.hhs.gov/researchers/pubs/datacompendium/2003/03pg30.pdf on December 24, 2004.

Table 80: Difficulties in Getting Equipment and Services

	Survey Frequency	Survey Percent of Those Disabled*
Eyeglasses	98	28.5%
Hearing aid	21	6.1%
Walker	21	6.1%
Other durable medical equipment	18	5.2%
Wheelchair	16	4.7%
Medical supplies	15	4.4%
Personal assistant services	15	4.4%
Repairs to equipment	11	3.2%
Dental care	11	3.2%
Podiatry	1	0.3%

n=344

* Respondents could list multiple service/ equipment difficulties

Drug plan formularies did not include the drugs needed by 10.2% of respondents with disabilities, while 7.6% of respondents with disabilities also reported having problems accessing needed specialists.

Finally, respondents with disabilities were asked about problems related to lack of access to services. Problems with inaccessible offices, or with inaccessible medical equipment such as examination tables and mammogram machines were experienced by 5.2% of respondents with disabilities.

HOME HEALTH CARE

Home health care is increasingly being used by patients who prefer to receive services at home; it is also encouraged by health care insurers who incur lower costs in providing health care services in patients' homes rather than in institutional settings.[76] Spending on home health care as a percentage of all long-term health care spending has risen from 4% in 1980 to 27% in 2000, reflecting both an increase in costs for services as well as an increase in the percentage of patients choosing to receive care at home, rather than in an institutional setting.[77] Cost-benefit studies that have analyzed home and community based health services as an alternative to institutionalization have found significant savings for the State of Illinois as well as improvements in quality of life for its participants.[78] Home health care spending grew throughout the 1990s, declining in 1997 when the Balanced Budget Act reduced Medicare payments to home health agencies, but resuming growth after 2000 when the prospective payment system was established. In 2001, the home health agency sector totaled $45 billion.[79]

A Medicare recipient must meet four conditions in order for Medicare to cover home health care expenses. The recipient must be "homebound";[80] need intermittent or part-time skilled nursing care, speech therapy, physical therapy, or occupational therapy; have a doctor prescribe the need for home care and create a plan of care; and select a Medicare-approved home health agency.[81] Home health aides, who do not have nursing licenses but can perform tasks like helping with bathing, using the toilet, and dressing, are only covered by Medicare if the patient also is receiving skilled care. Medicare does not cover 24-hour a day home health care, meal

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[76] See S. Hughes, A. Ulasevich, F. Weaver, W. Henderson, L. Manheim, J. Kubal and F. Bonarigo, "Impact of Home Care on Hospital Days: A Meta Analysis," *Health Services Research*, October 1997, 32:4, p. 415; S. Huges, J. Cummings, F. Weaver, L. Manheim, B. Braun, and K. Conrad, "A Randomized Trial of the Cost-Effectiveness of VA Hospital-Based Home Care for the Terminally Ill," *Health Services Research*, February 1992, 26:6, p. 801. The Medicaid Community Attendant and Services Act (MiCASSA), introduced into the U.S. House of Representatives by Congressman Danny Davis (D-IL), would amend the Social Security Act, allowing individuals eligible for nursing home or intermediate care facilities the choice of applying these funds to community attendant services and supports. Further information is at www.house.gov/davis/micassa.htm and www.tilrc.org/docs/0302wtp05.htm.

[77] Telephone conversation with Tom Wilson, Access Living, February 16, 2005.

[78] Memorandum on "Community Reintegration Cost-Benefit Analysis," from Carl Suter, Associate Director Illinois Department of Human Services to Secretary Linda Renee Baker, June 12, 2000, updated January 15, 2004; L. Alecxih, S. Lutzky, J. Corea, and B. Coleman, "Estimated Cost Savings from the Use of Home and Community-Based Alternatives to Nursing Facility Care in Three States," AARP Public Policy Institute, 1996.

[79] "Healthcare Industry Market Update: Perspectives of Home Healthcare," Center for Medicare and Medicaid Services, September 22, 2003. Accessed at http://www.cms.hhs.gov/reports/hcimu/hcimu_09222003.pdf on December 13, 2004.

[80] The Center for Medicare and Medicaid Services defines homebound as: "To be homebound means that leaving home takes considerable and taxing effort. A person may leave home for medical treatment or short, infrequent absences for non-medical reasons, such as a trip to the barber or to attend religious services. A need for adult day care doesn't keep you from getting home healthcare for other medical conditions." Accessed at http://www.cms.hhs.gov/glossary/search.asp?Term=homebound&Language=English on February 1, 2005.

[81] "Medicare and Home Healthcare," Center for Medicare and Medicaid Services. Accessed at http://www.cms.hhs.gov/quality/hhqi/HHBenefits.pdf on December 13, 2004.

delivery, or homemaker services. Medicare recipients may have to pay 20% of the cost of durable medical equipment such as wheelchairs and walkers provided through home care. Older women are more likely than men to receive care from home health care agencies.[82]

Among the respondents in this study, 26.6% have used skilled home health care services in the past two years. Respondents with disabilities have used skilled home health care services at twice the rate (33.3%) of respondents without disabilities (17.0%); and 34.0% of Medicaid recipients have used skilled home health care services as compared to 24.3% of non-Medicaid recipients. Among all respondents, use of home health care was over 50% greater for Medicare recipients who live in non-isolated housing settings such as apartments, condos, group homes, and single resident occupancy accommodations (SROs), as compared to those who live in isolated settings such as single family houses and townhouses. Finally, among persons with disabilities, use of home health care services varies significantly by health status, with more frequent use by respondents who assess their health status as "so-so" or "somewhat sick" than by respondents on either end of the health spectrum, and least frequent use by respondents who report being healthy.

Table 81: Use of Home Health Care by Housing Type

	Non-Isolated Housing	Isolated Housing
Used home health care	30.6%	17.6%
Has not used home health care	69.4%	82.4%
Total	100.0%	100.0%
n=587		

Table 82: Persons with Disabilities' Use of Home Health Care by Health Status

	Very Sick	So-So/ Somewhat Sick	Somewhat Healthy	Very Healthy
Used home health care	30.0%	42.6%	22.7%	16.1%
Has not used home health care	70.0%	57.4%	77.3%	83.9%
Total	100.0%	100.0%	100.0%	100.0%
n=341				

Under current law, Medicare home health care recipients do not have to make a co-payment for the care received in the home. However, proposed Medicare legislation often considers adopting co-payments on home health care, most recently in October 2004.[83] The co-payment provisions were taken out of that particular bill,[84] but the introduction of co-payments on home health care for Medicare participants remains a possibility.

When asked whether a co-payment requirement would affect their ability to use home health care services, only 10.7% responded that they would use them regardless of the cost. Clearly, for respondents with limited income, use of home health care services would be affected if co-payment levels were sufficiently high, even if the respondents do not anticipate this limitation.

[82] M. Gibson and L. Foley, "Older Women's Access to Healthcare: Potential Impact of Medicare Reform," AARP Public Policy Institute, July 2000. Accessed at www.research.aarp.org/health/2000_08_women_1.html on August 13, 2003.
[83] "House and Senate Weigh Co-Payment for Care at Home," *New York Times*, October 14 , 2003, p. A-1.
[84] "Medicare Bill Won't Include a Co-Payment for Home Care," *New York Times*, October 30, 2003, p. A-22.

Respondents' income was a significant factor in their assessment of the impact of co-payments on their use of services. As income increases, so does Medicare recipients' anticipated ability to afford the co-payment level.

Table 83: Effect of Co-Payments on Use of Home Health Care Services

	Survey Frequency	Survey Percent
Could not afford a co-payment	252	45.2%
It would depend on the co-payment level	242	43.4%
Would use it regardless of the co-payment level	64	11.5%
Total	558	100.0%

Table 84: Co-Payment Effect on Ability to Afford Home Health Care by Individual Monthly Income

	<$750	$750-$1,500	>$1500
Could not afford a co-payment	54.0%	44.1%	21.2%
It would depend on the co-payment level	38.6%	43.7%	59.6%
Would use it regardless of the co-payment level	7.4%	11.4%	19.2%
Total	100.0%	99.2%	100.0%
n=496			

In addition to home health care services, respondents were asked about their use of personal assistance services[85] needed for maintaining independent living situations. Over one-fourth (29.8%) of the respondents had used some type of personal assistance service, primarily for homemaker services, household tasks, and meals. As with use of professional home health care services, disability status was directly related to use of personal assistance services.

Table 85: Use of Personal Assistance Services

	Survey Frequency	Survey Percent
Homemaker services	114	19.0%
Help with chores	109	18.2%
Home delivered meals	90	15.0%
Bathing	33	5.5%
No personal assistance services used	253	42.2%
Total	599	100.0%

Table 86: Use of Personal Assistance Services by Disability Status

	Non-disabled	Disabled
Used personal assistance services	17.8%	37.5%
Did not use personal assistance services	82.2%	62.5%
Total	100.0%	100.0%
n=569		

Like disability status, respondents who receive Medicaid have used personal assistance service at a higher rate (39.1%) than non-Medicaid recipients (26.9%). Among persons without

[85] Among persons with disabilities under 60 years of age, these services are referred to as "personal assistance services" rather than "non-professional" or "homemaker" services.

disabilities, age was the factor most strongly associated with use of personal assistance services, with the use among the oldest age group over ten times the frequency of that among the youngest respondents.

Table 87: Respondents Without Disabilities' Use of Personal Assistance Services by Age

	Age			
	65-69	70-74	75-85	85-95
Used personal assistance services	4.3%	10.9%	24.7%	46.7%
Did not use personal assistance services	95.7%	89.1%	75.3%	53.3%
Total	100.0%	100.0%	100.0%	100.0%
n=220				

Among respondents with disabilities, location and type of housing were the factors most strongly associated with use of personal assistance services, with respondents from Chicago's north side and south suburbs and those in non-isolated housing almost twice as likely to use them as those in isolated living situations.

Table 88: Respondents with Disabilities' Use of Personal Assistance Services by Location

	Chicago North Side	South Suburbs	All Other Locations
Used personal assistance services	49.4%	42.9%	32.4%
Did not use personal assistance services	50.6%	57.1%	67.6%
Total	100.0%	100.0%	100.0%
n=332			

Table 89: Respondents with Disabilities' Use of Personal Assistance Services by Housing Type

	Non-Isolated Housing	Isolated Housing
Used personal assistance services	40.6%	21.6%
Did not use personal assistance services	59.4%	78.4%
Total	100.0%	100.0%
N=330		

Of those respondents who used personal assistance services, over three-fourths (77.9%) of them paid for these services through government programs, while the remaining individuals used a combination of other resources to pay for the services. Respondents accessed these services primarily through their doctor or hospital, or through a family member or acquaintance.

Table 90: Funding Source for Personal Assistance Services

	Survey Frequency	Survey Percent*
Government program	134	77.9%
Out-of-pocket	23	13.4%
Family/friends	21	12.2%
Insurance	17	9.9%
Don't know	2	1.2%
Other	6	3.5%

n=172

* Total percentage exceeds 100% due to respondents listing multiple funding sources

Table 91: Method of Accessing Personal Assistance Services

	Survey Frequency	Survey Percent
Referred by doctor/hospital	70	43.2%
Through family member/ acquaintance	55	34.0%
Called agency	33	20.4%
Other	4	2.5%

n=162

Nearly three-fifths (58.3%) of the respondents reported that they would prefer having an outside agency hire someone if they needed home care services rather than doing the hiring themselves. Over two-thirds (68.6%) of the respondents would want an outside agency to be responsible for handling the payments for home care services if they were needed.[86]

The desire to use an agency to hire and pay for home care services was significantly higher among males, persons with disabilities, non-Medicaid recipients, those with lower income levels, those living in group settings, and those who reported lower health status levels. Respondents' age has a significant impact on their desire to hire and pay for home care services, although the relationship is not linear. More persons age 80 to 84 years indicated interest in hiring and paying for home care themselves than any other age group, yet they still expressed a preference for having an outside agency hire these individuals and pay for these services.

Table 92: Preferred Hiring Method for Home Care by Age

	Hire Someone Myself	Outside Agency Hire	Don't know	Total
Less than 65	21.5%	71.5%	6.9%	100.0%
65-69	26.0%	60.4%	13.6%	100.0%
70-79	18.8%	53.5%	27.7%	100.0%
80-84	33.9%	37.5%	28.6%	100.0%
85-94	19.2%	57.7%	23.1%	100.0%

n=582

Table 93: Preferred Payment Method for Home Care by Age

	Pay Someone Myself	Outside Agency Pay	Don't know	Total
Less than 65	5.6%	88.2%	6.3%	100.0%
65-69	10.4%	73.4%	16.2%	100.0%
70-79	7.4%	64.4%	28.2%	100.0%
80-84	23.2%	41.1%	35.7%	100.0%
85-94	11.5%	65.4%	23.1%	100.0%

n=582

[86] The benefits and challenges of allowing home care service recipients to hire and pay for their home support services in three states is discussed in B. Phillips, K. Mahoney, L. Simon-Rusinowitz, J. Schore, S. Barrett, W. Ditto, T. Reimers, and P. Doty, "Lessons from the Implementation of Cash and Counseling in Arkansas, Florida and New Jersey," Mathematica Policy Research, June 2003.

HEALTH CARE INSURANCE

Although all 599 respondents in this survey receive Medicare, 414 (69.1%) also use either private insurance, Medicaid, or county medical services for their medical needs and expenses. If a larger percentage of immigrants had been surveyed, the percentage of respondents using Cook County's health services would have been significantly higher.

Almost one-quarter of the respondents receive Medicare as well as some type of Medicaid benefit. Whether these respondents are full "dual eligibles," having access to full Medicaid services and drug benefits, or fall within one of the other seven dual eligible categories, and only entitled to partial Medicaid benefits[87] cannot be determined from the collected data. In 2002, 13.3% of Medicare beneficiaries in Illinois were dual eligible (10.3% were full dual eligible).[88] For those who have private insurance, 92.9% pay a premium.

Table 94: Sources of Health Care Services and Payment

	Survey Frequency	Survey Percent*
Medicare	599	100.0%
Private insurance	243	40.6%
Medicaid	145	24.5%
County Health Services	80	13.4%

n=599

* Total percentage exceeds 100% due to respondents listing multiple sources.

Table 95: Sources of Health Care Services and Payment by Disability Status

	Disabled	Non-Disabled
Medicare	100.0%	100.0%
Private insurance	34.3%	49.4%
Medicaid	30.5%	15.0%
County Health Services	14.5%	11.3%

n=591

* Total percentage exceeds 100% due to respondents listing multiple sources.

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[87] For a fuller description of the various types of dual eligible categories, see http://www.cms.hhs.gov/dualeligibles/bbadedef.asp.

[88] From the Kaiser Family Foundation State Health Facts Online. Accessed at http://www.statehealthfacts.org on September 8, 2004.

HMOs

Of a total 40 million Medicare recipients, approximately 4.6 million are enrolled in Medicare managed healthcare companies (HMOs).[89] Medicare recipients have the option of choosing between Original Medicare, available nationwide, and the Medicare Advantage plans (formerly called Medicare + Choice plans) in areas where the Center for Medicare and Medicaid Services (CMS) has contracted with managed care plans, PPOs, private fee-for-service plans, or other specialty plans.[90] Over the past few years, HMOs have closed over 400 of their local plans, citing that the reimbursement rate provided by the government was causing them to lose money.[91] However, the 2003 Medicare Law authorized the CMS to increase contracts with and payments to private companies offering coverage to Medicare beneficiaries. The federal government is poised to allocate $46 billion to managed care over the next ten years, and participation in HMOs is expected to triple to almost 15 million people, including one-third of the elderly, over the next three years.[92] As of December 2004, CMS had approved 37 new contracts and 52 service area expansions, with 42 more applications pending approval.[93]

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

Table 96: Use of Managed Health Care (HMO) System

	Survey Frequency	Survey Percent
Never used HMO	368	61.4%
Ever used an HMO	231	38.6%
Used HMO since enrolling in Medicare	88	14.7%
Used HMO prior to enrolling in Medicare	144	24.0%
Used HMO both prior to and since enrolling in Medicare	10	1.7%
n=599		

* Total percentage exceeds 100% due to respondents listing multiple responses

Table 97: Level of Satisfaction with Managed Health Care (HMO) System

	Survey Frequency	Survey Percent
Not at all satisfied	63	28.1%
Somewhat satisfied	50	22.3%
Satisfied	62	27.7%
Quite satisfied	15	6.7%
Very satisfied	34	15.2%
Total	224	100.0%

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[89] "Managed Care Plan Offered to Medicare Beneficiaries in Chicago and Illinois Suburbs," Medicare News Press Release, November 18, 2004. Accessed at www.cms.hhs.gov/media/press/release.asp?Counter=1264 on December 17, 2004.

[90] Medicare Plan Choices. Accessed at http://www.medicare.gov/Choices/Overview.asp on December 17, 2004.

[91] "Using New Medicare Billions, HMO's Again Court Elderly," *New York Times*, March 9, 2004, p. C-10.

[92] Ibid, p. A-1.

[93] "Managed Care Plan Offered to Medicare Beneficiaries in Salt Lake City and 7 Utah Counties," Medicare News Press Release, December 6, 2004. Accessed at http://www.cms.hhs.gov/media/press/release.asp?Counter=1272 on December 17, 2004.

Almost one-half (49.6%) of respondents who have used HMOs report being satisfied to very satisfied with the health care that they received; however 20.0% replied that they would consider obtaining 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 dramatic, 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 in an HMO previously. Yet 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 for health care expenses (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.

OBTAINING INFORMATION

DESIRED INFORMATION

Federal, state, and local governmental agencies,[94] national[95] and local service providers, advocacy and policy organizations,[96] research and philanthropic organizations[97] provide information on the overall Medicare system, the pertinent legislation affecting recipients' rights and benefits, programs to help recipients pay for their prescription drugs and other health care needs, contact information for specific programs, and general assistance. Yet despite the provision of all of this information, both Medicare recipients and those responsible for addressing recipients' need for information reported a lack of sufficient, user-friendly information that answers the many questions and concerns relating to this program. 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. A higher percentage of African-American respondents wanted to receive each type of health care information, with the exception of information about HMOs.

Table 98: Desired Health Care Information

	Survey Frequency	Survey Percent*
New Medicare law	479	80.0%
Drug discount cards	393	65.6%
2006 Drug coverage	389	64.9%
Medicare plan comparisons	277	46.2%
HMOs	112	18.7%
n=599		

* Total percentage exceeds 100% due to respondents listing multiple responses

Table 99: Desired Health Care Information by Race

	Caucasians	African-Americans
New Medicare law	73.4%	81.1%
Drug discount cards	52.3%	68.2%
2006 Drug coverage	53.9%	68.2%
Medicare plan comparisons	42.2%	47.2%
HMOs	21.1%	18.0%
	n=128	n=434

* Total percentage exceeds 100% due to respondents listing multiple responses

[94] For example, the Centers for Medicare and Medicaid Services at http://www.cms.hhs.gov/; the Administration on Aging at http://www.aoa.gov/about/org/org.asp; Medicare Payment Advisory Commission (MedPAC) at http://www.medpac.gov; Illinois Department on Aging at www.state.il.us/aging; Chicago Department on Aging at http://www.cityofchicago.org/aging/; Chicago Department of Pubic Health at http://www.ci.chi.il.us/Health/.

[95] For example, the Medicare Rights Center at http://www.medicarerights.org; Families USA at http://www.familiesusa.org

[96] For example, the Suburban Area Agency on Aging at http://www.suburban-age.org/; Access Living at http://www.accessliving.org/; Metro Seniors in Action; and Illinois Alliance for Retired Americans.

[97] For example, Center on Budget and Policy Priorities at http://www.cbpp.org; Urban Institute at http://www.urban.org; Henry J. Kaiser Family Foundation at http://www.kff.org; and the Commonwealth Fund at http://www.cmwf.org.

When controlling for subgroups, income and age are the factors showing the strongest differences. Older respondents and those with the highest incomes (over $2,200 per month) reported needing information about health care programs far less frequently than younger respondents and those with individual monthly incomes under $2,200. Medicaid recipients reported wanting information about HMOs at almost twice the level as non-Medicaid recipients, 29.7% as compared to 15.2%.

Identifying the ways to improve health care information to the satisfaction of all its consumers is far more difficult than determining topics of information in which consumers are interested. Over one-half of the respondents wanted more information and over one-third wanted more detailed explanations. At the same time, however, over one-half reported wanting simpler explanations and almost one-fifth reported wanting less information. Furthermore, 35.1% wanted more pictures and 34.3% wanted more charts; yet 30.7% preferred fewer pictures and 32.9% preferred fewer charts. Respondents receiving Medicaid wanted more information and charts, information in large type and on tape at a higher rate than non-Medicaid recipients.

Table 100: How to Improve Health Care Information

	Survey Frequency	Survey Percent*
More information	341	63.3%
Simpler explanations	322	59.7%
Information in large type	268	44.7%
More detailed explanations	216	40.1%
More pictures	210	35.1%
Less charts	197	32.9%
More charts	185	34.3%
Less pictures	184	30.7%
Information in my primary language[98]	154	28.6%
Less information	106	17.7%
Information on tape	96	17.8%
Information in Braille	5	0.8%
n=599		

* Total percentage exceeds 100% due to respondents listing multiple responses.

Table 101: How to Improve Health Care Information by Medicaid Status

	Receives Medicaid*	Does Not Receive Medicaid*
More information	72.2%	60.0%
Simpler explanations	˜	˜
Information in large type	32.7%	48.7%
More detailed explanations	˜	˜
More pictures	˜	˜
Less charts	˜	˜
More charts	45.1%	30.4%
Less pictures	46.9%	31.2%
Information in my primary language	45.8%	22.3%
Less information	˜	˜
Information on tape	12.5%	19.7%
Information in Braille	2.7%	0.2%
n=539		

*Total percentages exceed 100% due to respondents listing multiple responses. ˜ indicates an insignificant relationship.

Respondents with disabilities reported wanting more charts at a higher rate (39.7%) than respondents without disabilities (27.2%). When controlling for disability status, there were only

[98] While 28.6% of the respondents reported that having information in their primary language would improve health care information, over 95.7% of all respondents reported English as their primary language. Among respondents whose primary language is other than English, 44.4% reported that having information in their primary language would be helpful.

a few significant subgroup differences. Younger respondents said that obtaining more information would help them have a better understanding of Medicare. The one exception was for respondents age 90 and older who reported the highest levels of wanting more information to better understand Medicare.

Table 102: More Information Would Help by Age

	Age					
	65-69	70-74	75-79	80-84	85-89	90-94
More information would be helpful	64.4%	66.0%	53.1%	46.2%	42.9%	75.0%
More information would not be helpful	35.6%	34.0%	46.9%	53.8%	57.2%	25.0%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

n=230

A desire for simpler explanations was expressed by over one-half (53.8%) of all respondents, and this increased significantly among respondents without disabilities with worsening health status. This variation in what people would find helpful in improving health care information varies significantly, even among the respondents to this survey who were primarily low-income, African-American respondents who reported high levels of literacy. The variation would likely be even greater among a more diverse population.

Table 103: Simpler Explanations Would Help by Health Status for Respondents Without Disabilities

	Somewhat Sick	So-So	Somewhat Healthy	Very Healthy
More information would be helpful	90.9%	75.8%	55.6%	44.6%
More information would not be helpful	9.1%	24.2%	44.4%	55.4%
Total	100.0%	100.0%	100.0%	100.0%

n=232

Respondents were shown one of the charts frequently used to explain the differences in Medigap insurance plans (see Appendix) to see if they found this type of chart useful for understanding the differences among available and proposed plans. Just over one-fourth (27.1%) of the respondents had seen such a chart before, with the percentage of respondents decreasing significantly with age. Almost one-half (46.4%) of the respondents who had seen this type of chart found it helpful in making decisions about their health care.

Table 104: Seen Medigap Chart Before By Age

	Age						
	<65	65-69	70-74	75-79	80-84	85-89	90+
Seen Medigap or similar chart before	38.0%	32.3%	20.4%	20.9%	19.0%	4.8%	14.3%
Have not seen Medigap or similar chart before	62.0%	67.7%	79.6%	79.1%	81.0%	95.2%	85.7%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

n=587

SOURCES OF INFORMATION

The survey also asked respondents a series of questions about how they prefer to obtain information about Medicare and other health care benefits and programs. 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.

Table 105: Preferred Sources of Health Care Information

	Survey Frequency	Survey Percent*
Printed material	428	71.5%
Face-to-face from a counselor	417	69.6%
Through a group presentation	293	48.9%
Telephone help line	200	33.4%
Through a group in which you participate	122	20.4%
Internet/web	99	16.5%

n=599

* Total percentage exceeds 100% due to respondents listing multiple responses

Significant differences exist for subgroups concerning a few of the preferred sources of health care information. Printed materials are more preferred by men than women, by younger respondents, by non-Medicaid recipients, by African-Americans rather than Caucasian respondents, and by those living in isolated rather than in non-isolated housing. Face-to-face health care counseling was preferred by those with lower incomes, Medicaid recipients,

African-Americans, and those living alone.[99] Group presentations were preferred by those in better health and presumably better able to access venues where such presentations are made; the Internet is favored by respondents with disabilities, who are African-American, who live alone, who do not receive Medicaid, and who live in some type of non-isolated housing arrangement. Both Medicaid recipients and Caucasians reported preferring to receive information through groups, e.g., social and religious groups, in which they participate.

Medicare recipients receive information for making health care decisions from many sources.[100] Almost one-half of the respondents reported 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 this information, over 80% of the respondents said they are receiving health care information from their preferred source. The most significant differences are that more recipients would prefer their doctors to provide them with this information, and fewer recipients would like to rely on family members or friends for this information.

Table 106: Current Provider of Best Information on Health Care

	Survey Frequency	Survey Percent
Doctor	284	49.1%
Family member or friend	93	16.1%
Social services agency	79	13.6%
Government	47	8.1%
TV/radio	21	3.6%
Newspaper	15	2.6%
Pharmacist	14	2.4%
Magazines	6	1.0%
Internet	3	0.5%
Other	17	2.9%
Total	562	100.0%

Table 107: Preferred Provider of Best Information on Health Care

	Survey Frequency	Survey Percent
Doctor	330	57.3%
Social services agency	76	13.2%
Family member or friend	73	12.7%
Government	53	9.2%
TV/radio	12	2.1%
Pharmacist	6	1.0%
Magazines	5	0.9%
Newspaper	5	0.9%
Union	3	0.5%
Internet	1	0.2%
Other	12	2.1%
Total	576	100.0%

Age, disability, and Medicaid status are the three factors that most significantly affect where Medicare recipients currently receive their best health care information and where they would

[99] According to Terri Gendel (Suburban Area Agency on Aging), the people who most benefit from face-to-face counseling are older and female clients, as well as persons in living situations without regular contact from social service staff such as social workers and health advocates.

[100] The questions in this survey specifically asked respondents about the sources of current and preferred information that they use to make decisions about health care benefits or programs (as contrasted with information regarding their particular ailments or conditions). However, participants may have been confused and responded in terms of from whom they currently and would prefer to receive personal health care information.

choose to access this information. Older respondents reported significantly greater reliance on their doctors and family members or friends for health care information, a significantly greater preference to rely on doctors and family members or friends for this help. Respondents with disabilities reported relying less on doctors and more on social service agencies for their health care information needs than respondents without disabilities, although they would like to rely slightly more on their physicians and the government for this information. Respondents who receive Medicaid rely to a much greater degree on social service agencies and family members or friends and far less on their doctors than non-Medicaid respondents. These differences are seen in the preferred provider responses as well, with a significant number also indicating a desire to receive this information from the government.[101]

The mail is used by the government to communicate with Medicare recipients about the program's current benefits, proposed changes, and the many options that recipients need to consider. 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. Respondents who receive this information via the mail overwhelmingly read and save it, with 42.2% reporting asking others for help in understanding it.

Table 108: Understands Mailed Government Medicare Information

	Survey Frequency	Survey Percent
Never	48	8.0%
Sometimes	291	48.7%
Usually or always	249	41.7%
Doesn't receive government Medicare information in mail	9	1.5%
Total	597	100.0%

Table 109: Response to Mailed Government Medicare Information

	Survey Frequency	Survey Percent*
Reads it	517	87.6%
Saves it	416	70.5%
Asks for help understanding it	249	42.2%
Tosses it out	124	21.0%
n=590		

* Total percentage exceeds 100% due to respondents listing multiple responses

Medicare significantly enhanced access to information by providing 3,000 service representatives for their toll-free telephone help line, which can be accessed by service

[101] Although only 2.4% of respondents report currently receiving their best health care information from pharmacists, and only 1.0% would prefer to get their information from this source, the implementation of Medicare Part D on January 1, 2006, with its automatic effect on all Medicare recipients' prescription drug benefit may place pharmacists in a key position to be a far greater source of information for Medicare recipients than they were in the past. The first time that many Medicare recipients find out that there has been a significant change in their plan and benefits may come when they go to their pharmacist to have a prescription filled.

providers and beneficiaries and their families for information about the new benefits and changes associated with the 2003 Medicare legislation. However, the Government Accounting Office documented that over one-third of callers to the government's Medicare help line received inaccurate information or their phone call was never answered.

Using the current information available to them, almost two-thirds (65.1%) of respondents 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, who are older, or receive Medicaid reported that they would need this type of help at significantly higher levels than those without disabilities, who are younger, or do not receive Medicaid.

Table 110: Need Help Choosing Health Care Plan by Disability Status

	Disabled	Not Disabled
Would need help	75.6%	57.7%
Would not need help	24.4%	42.3%
Total	100.0%	100.0%

n=586

Table 111: Need Help Choosing Health Care Plan by Age for Respondents Aged 65+

	Age			
	65-74	75-79	80-84	85+
Would need help	63.0%	64.4%	64.4%	77.8%
Would not need help	37.0%	35.6%	35.6%	22.2%
Total	100.0%	100.0%	100.0%	100.0%

n=446

Table 112: Need Help Choosing Health Care Plan by Medicaid Status

	Receives Medicaid	Does Not Receive Medicaid
Would need help	82.6%	35.7%
Would not need help	17.4%	64.3%
Total	100.0%	100.0%

n=592

Over three-quarters of respondents with disabilities and those age 85 and older would need help in choosing a health care plan, as compared to almost three-fifths of respondents who do not have a disability and two-thirds of those under age 85. The differences are even greater when looking at respondents' Medicaid status, with 82.6% of Medicaid recipients anticipating needing help if they had to choose a new health care plan, as compared to 35.7% of non-Medicaid recipients. With the new Medicare program, changes in benefits to Medicaid recipients are likely to be far more traumatic than non-Medicaid recipients, with their current prescription drug coverage through Medicaid ending December 31, 2005 to be replaced by Medicare's prescription drug coverage on January 1, 2006.

Finally, respondents were asked about their ability to make decisions about their health care needs and the level of support available to them, if it is needed. Most respondents said they feel able to make health care decisions on their own, with no help needed from another family member, friend, or agency staff member. However, this sense of independence varies significantly by age and by residence. Like the questions related to desire for more information, respondents who are more impaired or vulnerable, e.g. those most sick, older, and with disabilities, report a need and desire for more help in making their health care decisions.

Table 113: Ability to Make Health Care Decisions Independently

	Survey Frequency	Survey Percent
Can usually make decisions independently	486	81.5%
Can sometimes make decisions independently	47	7.9%
Usually needs help from another adult	63	10.6%
Total	596	100.0%

Table 114: Ability to Make Health Care Decisions Independently by Age

	<65	65-69	70-79	80-84	85-99
Can usually make decisions independently	82.8%	86.6%	81.1%	77.6%	57.1%
Can sometimes make decisions independently	8.2%	8.3%	6.3%	12.1%	7.1%
Usually needs help from another adult	9.0%	5.1%	12.6%	10.3%	35.7%
Total	100.0%	100.0%	100.0%	100.0%	100.0%

n=594

Table 115: Ability to Make Health Care Decisions Independently by With Whom You Live

	Alone	With Spouse/ Partner	With a Friend	With Family
Can usually make decisions independently	84.4%	81.5%	36.4%	72.4%
Can sometimes make decisions independently	7.8%	6.2%	9.1%	10.5%
Usually needs help from another adult	7.8%	12.3%	54.5%	17.1%
Total	100.0%	100.0%	100.0%	100.0%

n=593

Respondents who are older and living with family or friends are significantly less able to understand and make decisions about their health care needs on their own. This may be due to the availability of social workers, advocates, and other support staff in some settings with whom Medicare recipients can confer regarding their health care decision-making.

RECOMMENDATIONS

1. **Implement programs and policies to protect Medicare recipients from having to make choices between health care and other basic necessities.**

   One-eighth of the respondents in this survey have had to make choices between obtaining health care and other necessities, most often food. Among certain groups (respondents who are most sick, those who are female, those who have a disability, and those who are living with family or friends), the percentage of Medicare recipients being forced to make these choices is significantly higher. As health care expenses increase, the percentage of recipients foregoing basic necessities increases as well. Seniors and persons with disabilities should not be forced into this predicament.

2. **Implement programs and policies to protect Medicare recipients from having to use unsafe measures for reducing expenditure on medications.**

   Over 17% of the respondents in this study resort to practices that are unsafe and unhealthful to reduce expenditure on medications. Those persons who are the sickest and those with disabilities resort to these money-saving strategies far more often than other Medicare recipients. Policies to insure all Medicare recipients can afford their prescribed drug regimens need to be developed and implemented.

3. **Increase access to health care services for all Medicare recipients.**

   Just over one-fifth of the respondents reported that the cost of health care prevents them from obtaining the health care that they need. The services that they did not receive or received at insufficient levels ranged widely, from doctor visits to physical therapy, and from dental care to podiatry. In addition, almost 40% of respondents have delayed accessing health care for reasons including problems with transportation, costs, and time. Delaying care impacts not only individuals' quality of life, but also the long-term costs to the health care system, which later has to address the needs of patients in worse condition because they had to delay care. Ways to increase access of those who are in need of health care services need to be developed and supported.

4. **Recognize and reduce the adverse impact of co-payments and deductibles on recipients' access to and use of health care services.**

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

all Medicare recipients at all income levels will have co-payments for their prescription drugs beginning in 2006. 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. Assuming that deductibles and co-payments continue to be a part of Medicare insurance, greater attention must be given to protect recipients who are most vulnerable to the imposition of these payments leading to a lack of access to 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.**

   There is an extremely high level of confusion among respondents regarding their current health care and prescription drug insurance options. Medicare respondents are making choices, but they are often uninformed or misinformed about the implications of the different plans and do not know which ones would best serve their needs. Almost two-thirds of the respondents reported that they would need help in choosing a health care plan if they were to change plans.

   Over one-half of the respondents reported that they never or only sometimes understand the information provided by government sources, and this was with a sample that reported high levels of English reading proficiency. Information provided by government sources on health care programs needs to be clarified and presented in a way that is useful to Medicare recipients and the people to whom they turn for guidance.

   Respondents reported high levels of interest in the new Medicare law and its drug coverage provisions, drug discount cards, and comparisons of the various available Medicare plans. Approaches to making information about these and other topics more user friendly vary dramatically. Some respondents want more information and charts or more comprehensive explanations; others want less information, fewer charts, and simpler explanations. Some of this variation is a function of individual differences, but significant differences also are related to health status, disability status, and age.

   In addition, respondents reported a variety of ways that they prefer to receive their health care information—through printed documents, face-to-face interviews with counselors, group presentations, and help lines, with significant differences again seen among subgroups. Respondents reported obtaining their best information from a variety of sources including doctors, family members and friends, and social service agencies.

Most people would like to continue to receive information from their current sources, although more respondents would like to continue to receive their health care information from their doctors than would like to continue to receive it from their family and friends.

A large percent of every subgroup within the study reported relying on doctors and doctors' offices for their health care information. Whether respondents meant that they rely on their doctors for information regarding their health care treatment or their health plan options cannot be determined. However, in either case, this has clear implications for those responsible for educating Medicare recipients: doctors need to be educated about the Medicare choices that their patients are facing, and have resources that they can contact or to which they can refer their patients for clear and accurate information.

Furthermore, although few respondents report currently receiving their best health care information from pharmacists, or preferring to get their information from this source, the implementation of Medicare Part D on January 1, 2006, with its automatic effect on all Medicare recipients' prescription drug benefit may place pharmacists in a key position to be a far greater source of information for Medicare recipients than they were in the past. Like doctors, pharmacists need further education and information about Medicare to be able to better serve their clients.

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.**

   All respondents, whether or not they have ever been in an HMO, reported valuing being able to keep their current doctor, having prescription drug coverage, paying less (or not more) than with private insurance, having a stable program, e.g., same doctors, hospital, and benefits, and being able to receive the medical services they need. Given the large numbers of Medicare recipients expected to enroll in HMOs in the next few years, significant consideration should be given to evaluating HMO plans to ensure that participants needs and preferences are met.

7. **Provide support for health care providers serving Medicare recipients who did not have prior health care insurance.**

   Almost one-half of the respondents with monthly incomes less than $750 and an additional one-quarter of the respondents with incomes between $750 and $1,500 had no health insurance prior to Medicare. Their health care needs and the costs for providing services are likely to be far greater than for persons who have had regular health care services prior to receiving Medicare. Health care providers who serve this population should be encouraged and supported. Whether these providers should be given a higher

capitation rate, receive expedited reimbursement for services, or some other type of benefit should be determined based on considerations of fairness and efficacy.

8. **Ensure that the government negotiates with drug companies to obtain bulk price discounts for Medicare recipients.**

   Although few respondents were interested in purchasing drugs from outside the U.S., over 90% of the respondents reported that they wanted the government to negotiate bulk prices from drug companies for Medicare recipients.

9. **Expand research on Medicare recipients to include immigrants, limited English-speaking persons, Caucasians and middle-income individuals.**

   Additional data examining the issues raised in this report need to be gathered regarding populations of Medicare recipients that were underrepresented by this research. In particular, the experiences, needs, and preferences of immigrants, limited English-speaking persons, Caucasians and middle-income individuals should be investigated. There are likely to be significant differences between the data gathered for this report and those that would be obtained for these groups, particularly in regard to accessing health care information. According to a staff member at the City's Department on Aging who works with the elderly, "Our experience is that the needs and concerns of limited English speaking elderly, and the impact of mundane things in their lives is significantly different than [that] among the English-speaking population."[102]

[102] David Mui, City of Chicago Department on Aging, Medicare Working Group meeting minutes, January 19, 2005.

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.

APPENDIX

MEDIGAP INSURANCE PLAN CHART

Chicago Area

INSURANCE COMPANY NAME TELEPHONE NUMBER	AGE	Plan A	Plan B	Plan C	Plan D	Plan E	Plan F	Plan G	Plan H	Plan I	Plan J	PX	PF	XO
# (AARP) UNITED HEALTHCARE INSURANCE COMPANY	65	$792	$1,202	$1,442	$1,358	$1,358	$1,452	$1,366	$2,112	$2,129	$2,669			
	70	$990	$1,503	$1,803	$1,698	$1,698	$1,815	$1,707	$2,640	$2,661	$3,336	3	$0	Y
	75	$990	$1,503	$1,803	$1,698	$1,698	$1,815	$1,707	$2,640	$2,661	$3,336			
800-523-5800 Guaranteed Issue	80	$990	$1,503	$1,803	$1,698	$1,698	$1,815	$1,707	$2,640	$2,661	$3,336			
* AID ASSOCIATION FOR LUTHERANS	65	$1,833		$2,550	$1,950		$2,559		$3,731	$4,197				
	70	$1,917		$2,657	$2,084		$2,690		$3,965	$4,496		0	$0	Y
www.aal.org	75	$1,982		$2,768	$2,187		$2,819		$4,152	$4,736				
800-847-4836	80	$1,982		$2,768	$2,187		$2,819		$4,152	$4,736				
AMERICAN FAMILY MUTUAL INSURANCE COMPANY	65	$643		$1,527			$1,541							
	70	$713		$1,700			$1,715					0	$0	Y
www.amfam.com	75	$823		$1,999			$2,013							
800-333-6886	80	$951		$2,310			$2,331							
AMERICAN REPUBLIC INSURANCE COMPANY	65	$773					$1,492							
	70	$967					$1,830					0	$0	Y
	75	$1,161					$2,163							
800-943-2121	80	$1,341					$2,474							

NOTE: Column PX=Pre-existing Wait, Column PF=Policy Fee, Column XO=CrossOver

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