

# Chronic Care: Making the Case for Ongoing Care

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## Acknowledgments

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## Preface

**C**hronic Conditions: Making the Case for Ongoing Care was created in December 2002 by Partnership for Solutions: Better Lives for People With Chronic Conditions, a Robert Wood Johnson Foundation national program. It was an update of a 1996 publication written by Catherine Hoffman and Dorothy Rice entitled *Chronic Care in America: A 21st Century Challenge*. This revision provides an update of chronic health conditions in the United States. Unfortunately, some of the charts could not be updated and remain as they were in 2002.

The chartbook examines the impact of chronic conditions on individuals and their caregivers, as well as on the U.S. health care system. The updated data is used to highlight the current problems encountered by individuals living with chronic conditions as they attempt to obtain a continuum of services in a health care financing and delivery system primarily oriented to the provision of acute, episodic care. It shows improvement in some areas but a growing prevalence and cost of chronic care.

All of the information is available for use and reproduction without charge; permission from the authors to use the charts is not necessary.

## Introduction



In the early 20th century, infectious diseases such as tuberculosis, pneumonia, and influenza were the leading causes of death, often exacerbated by public health problems such as poor sanitation, overcrowding in cities, dangerous working conditions, and inadequate nutrition and medical care. Appropriately, the health care system in the first half of the 20th century focused on fighting infectious disease and fixing underlying public health problems. As the result of these efforts, the population's health greatly improved and infectious diseases caused by poor public health conditions were greatly diminished by midcentury.

The focus appropriately changed to treating acute, non-infectious illnesses such as heart attacks and strokes. From the mid to end of the 20th century, the system was transformed and research, education, financing, quality metrics and delivery systems all became focused on the delivery of episodic care. As a result many acute episodes were turned into survivable events. Chronic diseases, such as diabetes and hypertension, became much more prevalent as people survived these acute events.

Unfortunately, while our health care needs have evolved, often the health care system has not. It remains an amalgam of past efforts to treat infectious diseases and acute illnesses. It does not focus on today's current and growing problem—increasing numbers of people with chronic conditions, especially those with multiple chronic conditions.

This chartbook is an update of the 2002 chronic care chartbook. In the intervening seven years, the situation has generally gotten worse, although there are some improvements. In 2009, 145 million people—almost half of all Americans—live with a chronic condition. This represents an increase of 10 million people over the estimate that was made in 2002 for the year 2009. The

percentage of health care spending that is associated with people with chronic conditions has increased from 78 percent to 84 percent in just seven years.

The proportion of all Americans with two or more chronic conditions has increased from 24 percent in 2001 to 28 percent in 2006. The percentage of persons with five or more chronic conditions has also increased; now as many as 6 percent of all females and 4 percent of males have five or more chronic conditions. The proportion of Americans with hypertension increased by 7 percentage points and cholesterol disorders have now become one of the most common chronic conditions, rising from 13 percent to 22 percent of all non-institutionalized persons between 2001 and 2006. In addition, average annual out-of-pocket spending has increased by nearly 30 percent since 2001 for those with one or more chronic conditions.

It is important to note that some gains have been made, however. An improvement in the quality of medical care appears to have contributed to a decrease in the number of preventable hospitalizations among Medicare beneficiaries 65 years and older, with a particularly large reduction seen among those with five or more chronic conditions.

Many people with chronic conditions have multiple chronic conditions and this necessitates multiple caregivers. The current system provides few incentives for physicians and other caregivers to coordinate care across providers and service settings. We know that many people with chronic conditions report receiving conflicting advice from different physicians and differing diagnoses for the same set of symptoms. Drug-to-drug interactions are common, sometimes resulting in unnecessary hospitalizations and even death. People with chronic conditions are getting services, but those services are not necessarily coordinated with one another, and they are not always the services needed to maintain health and functioning. Little change is seen in these areas.

People with a wide range of chronic health problems have common difficulties with the current health care financing and delivery system and are looking for fundamental changes. There is also a growing consensus among physicians and the general public that changes are necessary to better serve people with chronic conditions. In addition to improving the coordination of care, the health care system must place a higher priority on primary, secondary, and tertiary prevention to avert disease or slow its progression. For health care providers, slowing disease progression should be as high a priority as

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treating acute episodes of an illness. Likewise, health insurers should cover the services needed by people with chronic conditions and help people maintain their functional status. Many current benefits are based on medical necessity criterion that can be accessed only if medical improvement is expected, something that is unlikely for a person with a chronic disease such as Alzheimer's.

As this chartbook details, the prevalence and costs of chronic health conditions in the United States have wide-reaching effects, both on the health care system and individuals, often with negative outcomes and consequences. As a nation, we spend 85 percent of our health care dollar on people with chronic conditions. The challenge is to use these resources efficiently to provide people with access to high-quality care and appropriate services that maintain health and functioning in the face of disease progression and ensure that this care is coordinated across multiple providers and payers. The health care system has successfully adapted to meet new challenges in the past, and it must do so again.

## SECTION 1

## Demographics and Prevalence

Chronic conditions affect people of all ages and from all walks of life—a child with asthma, a co-worker with hypertension, a neighbor with multiple sclerosis, an elderly relative with arthritis or Alzheimer’ disease. As the numbers grow and grow, it is hard not to know someone whose life is in some way altered by a chronic condition.

In their 1996 book, *Chronic Conditions in America: A 21st Century Challenge*, Catherine Hoffman and Dorothy Rice estimated that by the year 2000, there would be 105 million people with chronic conditions and that by 2020 this number would grow to 134 million people. We will easily exceed these numbers. With new and updated data, we can now estimate that the number of people with chronic conditions has and will exceed that projection by reaching 125 million in 2000, 147 million by 2010 and 157 million by 2020. By 2030 half the population will have one or more chronic conditions. The number and proportion of Americans living with chronic conditions is increasing at rates faster than originally expected.

There are many reasons for this growth. Advances in medical science and technology—new diagnostic testing, new medical procedures, and new pharmaceuticals—are being used to treat acute illness and maintain a level of health and functionality that results in increased numbers of people surviving with chronic conditions. We are also successfully screening and diagnosing chronic conditions with greater frequency. The challenge remains to identify successful treatment programs.

Another cause of the increasing prevalence of chronic conditions is the aging of society. While it is important to note that the majority of people with chronic conditions are under age 65, the likelihood of having a chronic

*Between 2000 and 2030 the number of Americans with chronic conditions will increase by 37 percent, an increase of 46 million people.*



condition increases as one becomes older. For example, hypertension, the most common chronic condition, affects a greater percentage of older than younger people. As the baby boomers age, the number of people living with chronic conditions will grow dramatically. Because women tend to live longer than men, they are more likely to have chronic conditions. Over time, we can expect to see a rise in the number of older women living with chronic conditions, many with multiple health concerns. Often these women are also caregivers to spouses or other relatives or friends with a chronic condition.

Almost half of all people with chronic conditions have multiple chronic conditions, or comorbidities. Not surprisingly, older people are more likely to have more comorbidities. The presence of multiple chronic conditions has specific implications for the reform of health care financing and delivery systems. For example, we need to begin to think beyond specific disease management to the coordination of medical care and assistive services across care settings and among multiple providers. The situation becomes even more serious when the person also has a disability or activity limitation.

More than a quarter of people with chronic conditions also have some type of activity limitation. Activity limitations include having difficulty walking, needing help with personal tasks such as dressing or bathing, or being restricted in the ability to work or attend school. Many people with activity limitations need personal assistance or long-term care, and the continuity of their care would likely be improved by creating links between the acute and long-term care systems.

A significant challenge, both now and for the future, is how to pay for the care—medical treatment and other supportive services—that people with chronic conditions use. Currently, over half the people with chronic conditions are covered by private insurance but many incur substantial out-of-pocket expenses for services not covered by their plans. More than 85 percent of elderly Medicare beneficiaries who have only Medicare coverage have chronic conditions. Particularly troubling, more than 10 million people with chronic conditions are uninsured.

As a society, we need to be aware of the growing prevalence of people with chronic conditions and the problems they face as they interact with a health care system that is currently not well designed to meet their needs.

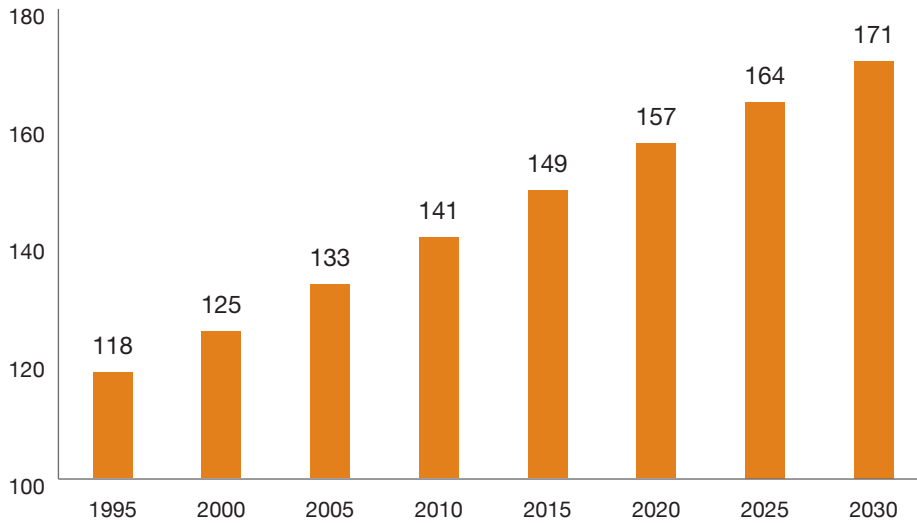
## What Does It Mean to Have a Chronic Condition?

Chronic conditions affect people's physical and mental health, their social life, and employment status in many different ways. Chronic conditions come with varying levels of severity. Some chronic conditions are highly disabling, others less so. Some chronic conditions may not disable a person currently, but may lead to severely disabling effects if not treated early and effectively. Some individuals with chronic conditions live full, productive, and rewarding lives; for others, isolation, depression, and physical pain are the consequences of ongoing chronic illness. Typically the more chronic conditions a person has the greater the likelihood that they will have difficulties navigating the system.



## The Number of People With Chronic Conditions Is Rapidly Increasing

Number of People With Chronic Conditions (in millions)

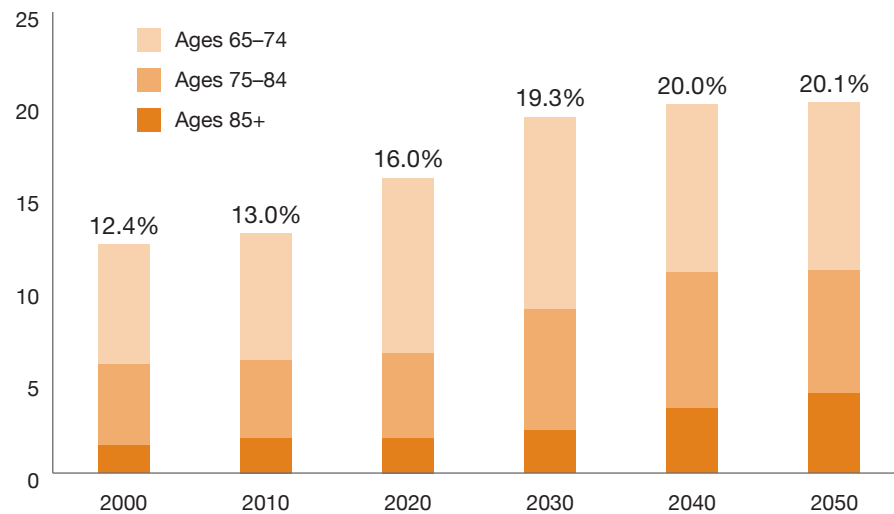


Source: Wu, Shin-Yi and Green, Anthony. *Projection of Chronic Illness Prevalence and Cost Inflation*. RAND Corporation. October 2000.

### Data Highlights

- In 2000, 125 million Americans had one or more chronic conditions.
- This number is projected to increase by more than one percent each year through 2030.
- Between 2000 and 2030 the number of Americans with chronic conditions will increase by 37 percent, an increase of 46 million people.

## Americans Are Living Longer



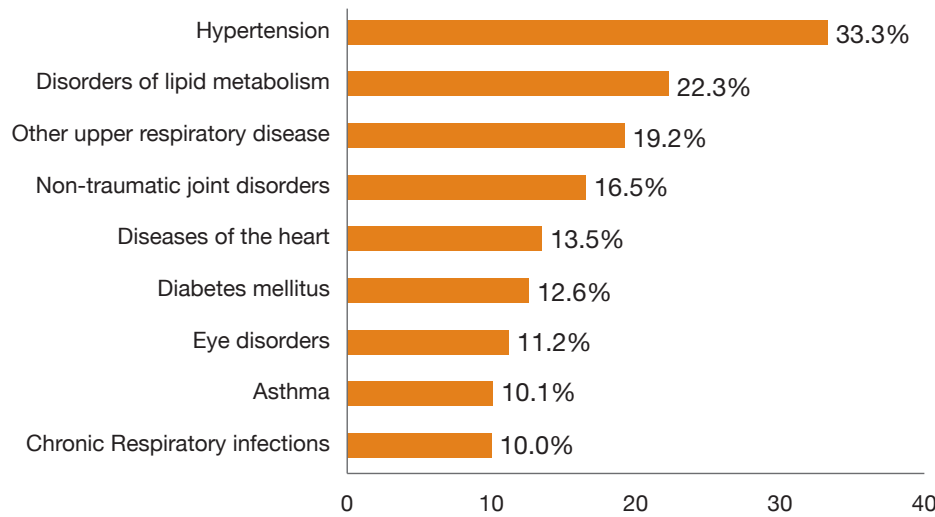
Source: U.S. Bureau of the Census. *Projected Population by Single Year of Age, Sex, Race, and Hispanic Origin for the United States: July 1, 2000 to July 1, 2050*. Washington, August 2008.

### Data Highlights

- By 2040, 20 percent of the population will be comprised of people age 65 and older.
- By 2050 an estimated 88.5 million persons will be 65 and older, essentially more than doubling the number in 2008 (38 million).
- The number of U.S. residents over 85 years is projected to grow by more than 300 percent over the next 40 years.

## Hypertension Is the Most Common Chronic Condition

Percentage of Non-Institutionalized People With Specific Chronic Conditions, All Ages



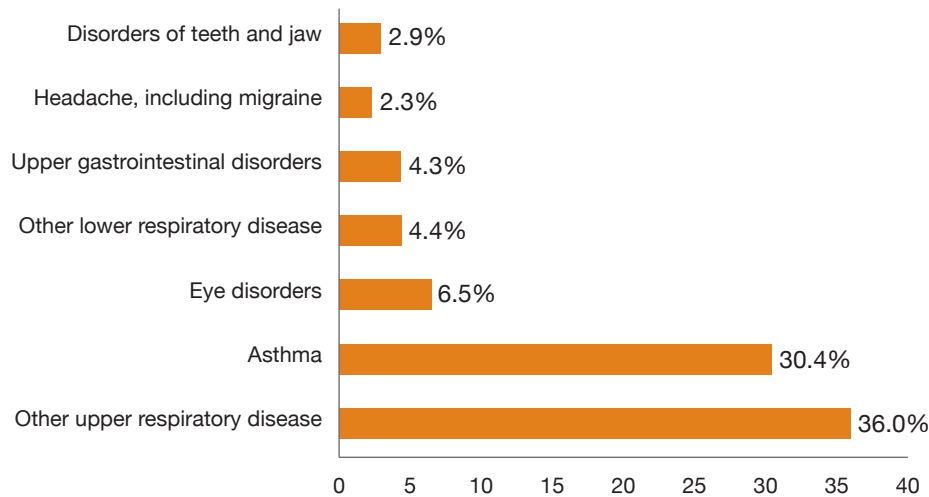
Source: Medical Expenditure Panel Survey, 2006

### Data Highlights

- Leading chronic conditions vary among age groups.
- The leading chronic conditions among people ages 65 and older are: hypertension (60%), cholesterol disorders (41%), arthritis (28%), heart disease (25%), and eye disorders (23%).
- The leading chronic conditions among people ages 18 to 64 are: hypertension (30%), cholesterol disorders (20%), respiratory diseases (19%), and diabetes (12%).

## Respiratory Diseases and Asthma Are the Most Common Chronic Conditions in Children

Percentage of Non-Institutionalized Children (Ages 0 to 17) With a Chronic Condition



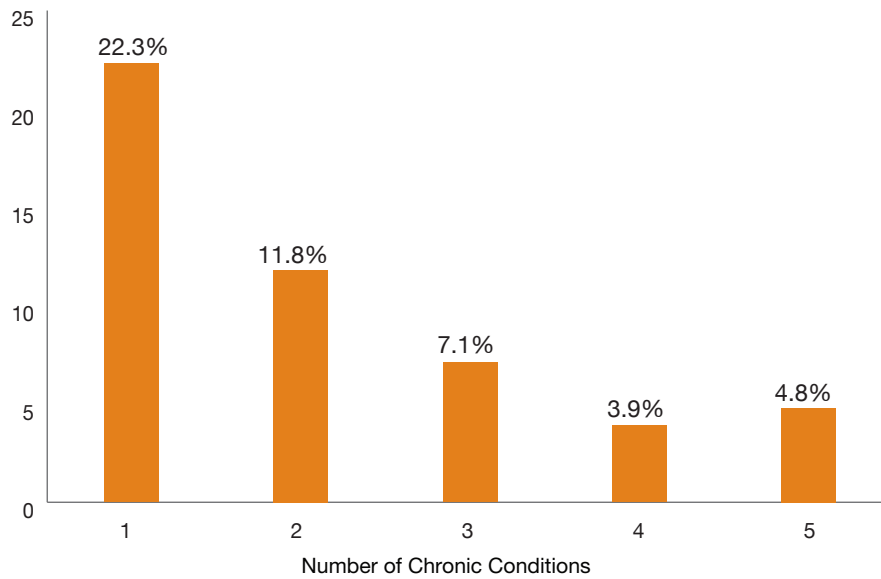
Source: Medical Expenditure Panel Survey, 2006

## Over One in Four Americans Have Multiple Chronic Conditions



- In 2006, 28 percent of all Americans had two or more chronic conditions.

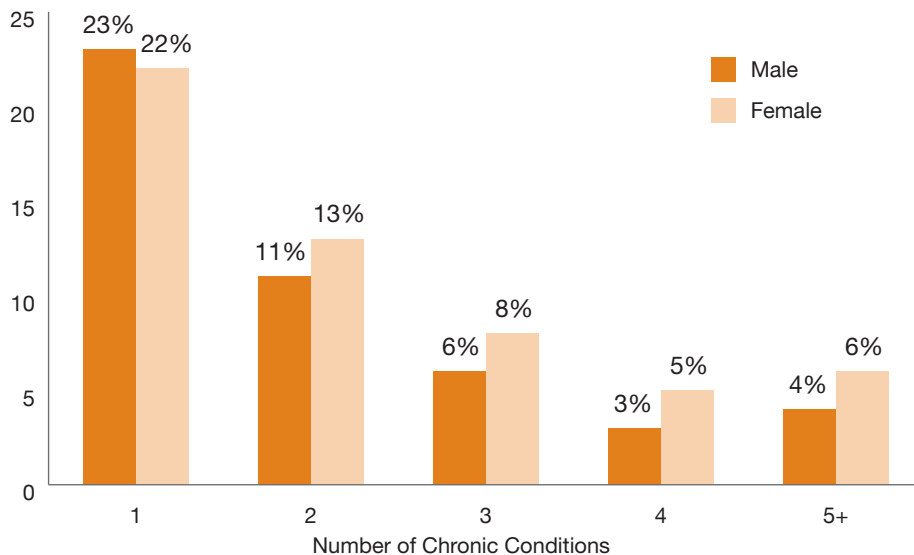
Percentage of All Americans



Source: Medical Expenditure Panel Survey, 2006

## Women Are More Likely Than Men to Have Multiple Chronic Conditions

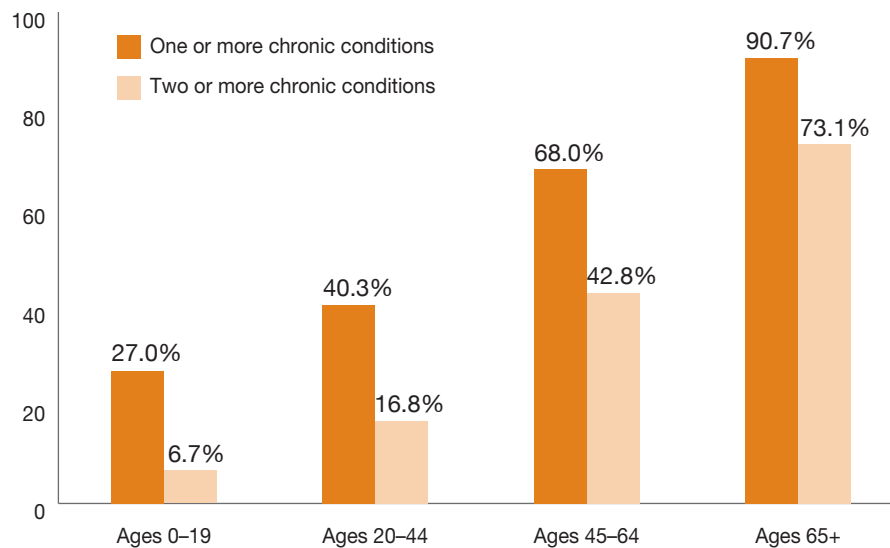
Percentage of People With Chronic Conditions



Source: Medical Expenditure Panel Survey, 2006

## Older Adults Are More Likely to Have Multiple Chronic Conditions

Percentage of Population With Chronic Conditions



Source: Medical Expenditure Panel Survey, 2006

### Data Highlights

- The prevalence of multiple chronic conditions increases with age.
- One in 15 children have multiple chronic conditions.
- Almost three out of four people ages 65 and older have multiple chronic conditions.

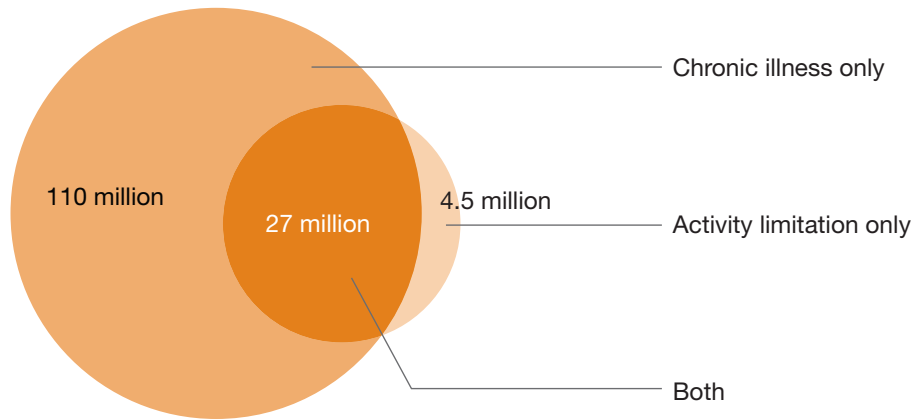
### Consequences of Having Multiple Chronic Conditions

More than half the people with any kind of chronic condition have comorbidities to manage. Having multiple chronic conditions puts people at greater risk for disability and can result in activity limitations (such as difficulty walking and inability to work).

People with multiple chronic conditions have substantially more physician contacts, use more prescription drugs, and are more likely to be hospitalized each year than those with only one chronic condition. They are also far more likely to have difficulty with their personal care, such as eating and bathing.

Although multiple chronic conditions tend to occur with age, more than 6 percent of children have more than one chronic condition and experience higher rates of activity limitations compared to children with one chronic condition. For example, these children experience more days spent in bed and have more school absences.

## One-Fifth of Individuals With Chronic Illness Also Have Activity Limitations



Source: Medical Expenditure Panel Survey, 2006

### What Are Chronic Conditions and Activity Limitations?

**Chronic conditions** is a general term that includes chronic illnesses and impairments. It includes conditions that are expected to last a year or longer, limit what one can do, and/or may require ongoing medical care.

**Serious chronic conditions** are a subset of chronic conditions that require ongoing medical care and limit what a person can do.

**Chronic illnesses** are conditions that are expected to last a year or more and require ongoing medical care.

**Activity limitations** are functional limitations and disabilities that restrict a person from performing normal activities without assistance—such as walking, dressing and bathing—or affect a person's ability to work or attend school.

## SECTION 2

## The Impact of Chronic Conditions on Health Care Financing and Service Delivery

People with chronic conditions, particularly those with multiple chronic conditions, are the heaviest users of health care services. Higher utilization appears in all major service categories: hospitalizations, office visits, home health care, and prescription drugs. As the number of chronic conditions increases so does utilization of medical services. For example, individuals with multiple chronic conditions account for two-thirds of all prescriptions filled. Consequently, the vast majority of health care dollars spent in the United States are for people with chronic conditions and the percentage has been increasing over time. In 1998 the care given to people with chronic conditions accounted for 78 percent of health care spending. It now accounts for 84 percent and that number will undoubtedly continue to increase as society ages and the number of people with chronic conditions grows.

The care received by people with chronic conditions is financed by a variety of payers: private employer-sponsored insurance, government programs such as Medicare and Medicaid, and individuals through their insurance premiums and out-of-pocket spending for services. The largest number of people with chronic conditions are of working age and are privately insured: 78 million people with chronic conditions have private insurance coverage and their care accounts for about 73 percent of private insurance spending. Almost all Medicare dollars and about 80 percent of Medicaid resources are spent on people with chronic conditions.

Health care expenditures and utilization also increase considerably when people have multiple chronic health conditions. There are a number of reasons, including: age, clinical complexity and activity limitations resulting from chronic conditions. In general, health care spending for a person with one chronic condition is almost three times greater than spending for someone

*The vast majority of health care dollars spent in the United States are for people with chronic conditions and the percentage has been increasing over time.*

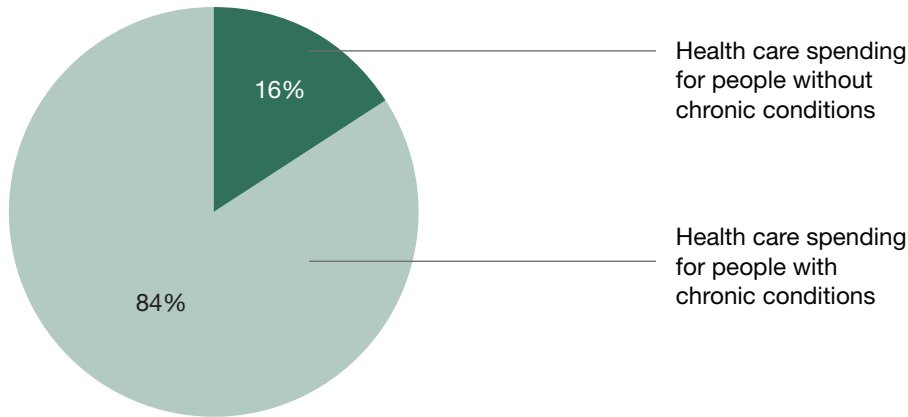
without any chronic condition, while spending is about 17 times greater for someone with five or more chronic conditions.

Adjusting the systems of financing and delivering care to better meet the needs of the chronically ill, will require a renewed focus on preventing disease when possible, identifying it early when it occurs, and implementing secondary and tertiary prevention strategies that slow disease progression and the onset of activity limitations. A survey of physicians commissioned by *Partnership for Solutions* and conducted in 2001 by Mathematica Policy Research, Inc., further illuminates some of the obstacles to providing optimal care to people with chronic conditions. The physicians interviewed agreed that the current health care system is not organized to address the many needs of people with chronic conditions, and that health care services can be hard for patients to access. The physicians also reported that coordinating care for people with chronic conditions is difficult and that they felt their training had not adequately prepared them to care for these types of patients—an alarming finding given the changing face of the American health care consumer. This survey was not updated for this version of the chartbook.

All health care providers and payers—from corporations to individuals—have a stake in seeing that chronic care is more adequately delivered and reimbursed in this country. While managed care service delivery and financing models may have held promise for better treatment of people with chronic conditions, the current market change away from very organized and integrated systems of care only adds to the challenge of better addressing the needs of this growing population. Fortunately, however, there is an increasing interest in these issues. While many of these efforts hold promise, there is much more that needs to be done and the following information points to the need to act sooner rather than later.



## People With Chronic Conditions Account for 84 Percent of All Health Care Spending



Source: Medical Expenditure Panel Survey, 2006

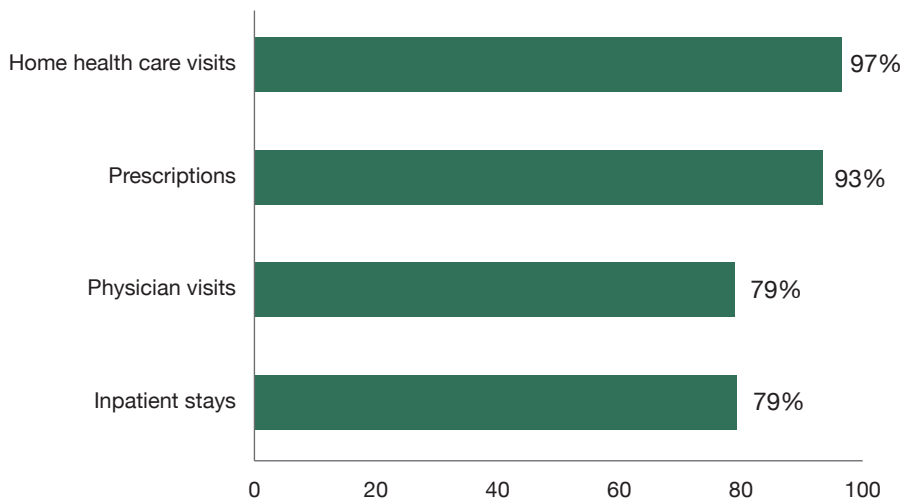
## Health Care Spending for People With Chronic Conditions Is Disproportional to the Percentage of People With Chronic Conditions

- Eighty-four percent of health care spending is attributed to the 50 percent of the non-institutionalized population that has one or more chronic conditions.
- Seventy-eight percent of private health insurance spending is attributed to the 48 percent of privately insured people who have chronic conditions.
- Seventy-three percent of all health care spending for the uninsured is for care received by the 33 percent of uninsured with chronic conditions.
- Seventy-nine percent of Medicaid spending is for the 40 percent of non-institutionalized beneficiaries with chronic conditions.

Source: Medical Expenditure Panel Survey, 2006

## People With Chronic Conditions Are the Heaviest Users of Health Care Services

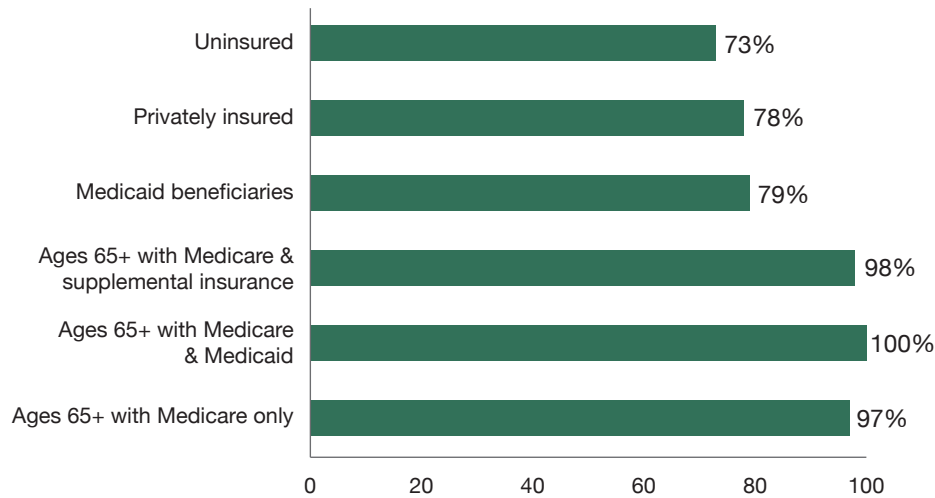
Percentage of Services Used by People With Chronic Conditions



Source: Medical Expenditure Panel Survey, 2006

## Percentage of Health Care Spending for Individuals With Chronic Conditions by Type of Insurance

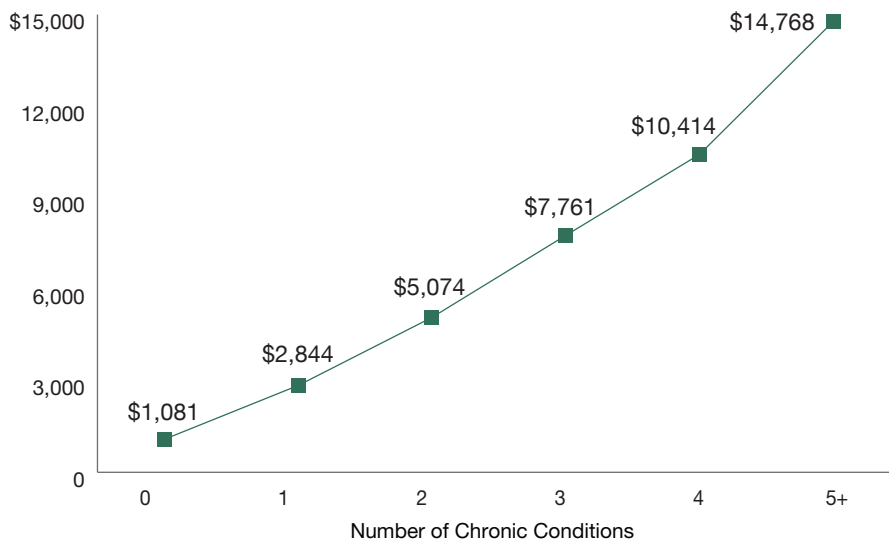
Percentage of Enrollees With a Chronic Condition



Source: Medical Expenditure Panel Survey, 2006

## Health Care Spending Increases With the Number of Chronic Conditions

Average Per Capita Health Care Spending



Source: Medical Expenditure Panel Survey, 2006

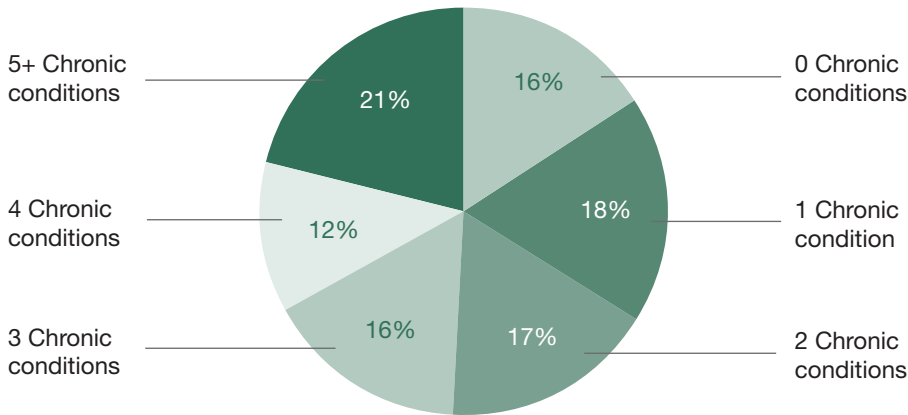
### Data Highlights

Compared to individuals with no chronic conditions:

- Spending is almost three times greater for someone with one chronic condition.
- Spending is over seven times greater for someone with three chronic conditions.
- Spending is almost 15 times greater for someone with five or more chronic conditions.

## More Than Three-Fifths of Health Care Spending Is on Behalf of People With Multiple Chronic Conditions

Percentage of Health Care Total Spending by Number of Chronic Conditions



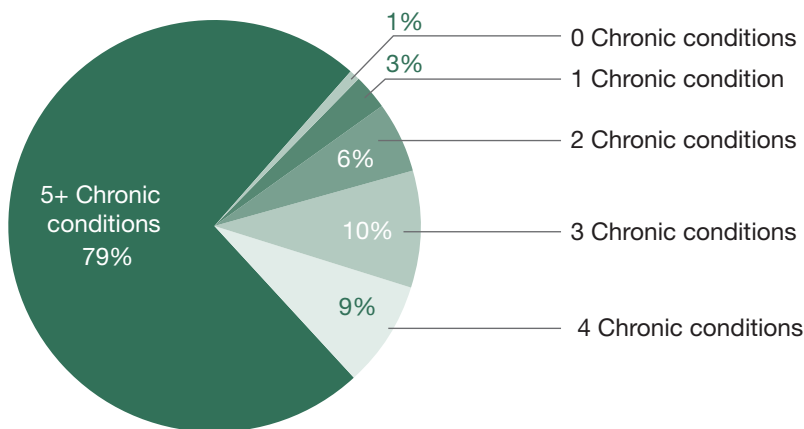
Source: Medical Expenditure Panel Survey, 2006

### Data Highlights

- Sixteen percent of spending is for the 50 percent of the population that has no chronic conditions.
- Eighteen percent of spending is for the 22 percent of the population that has only one chronic condition.
- Seventeen percent of spending is for the 12 percent of the population that has two chronic conditions.
- Sixteen percent of spending is for the 7 percent of the population that has three chronic conditions.
- Twelve percent of spending is for the 4 percent of the population that has four chronic conditions.
- Twenty-one percent of spending is for the 5 percent of the population that has five or more chronic conditions.

## Two-Thirds of Medicare Spending Is for People With Five or More Chronic Conditions

Percentage of Medicare Expenditures



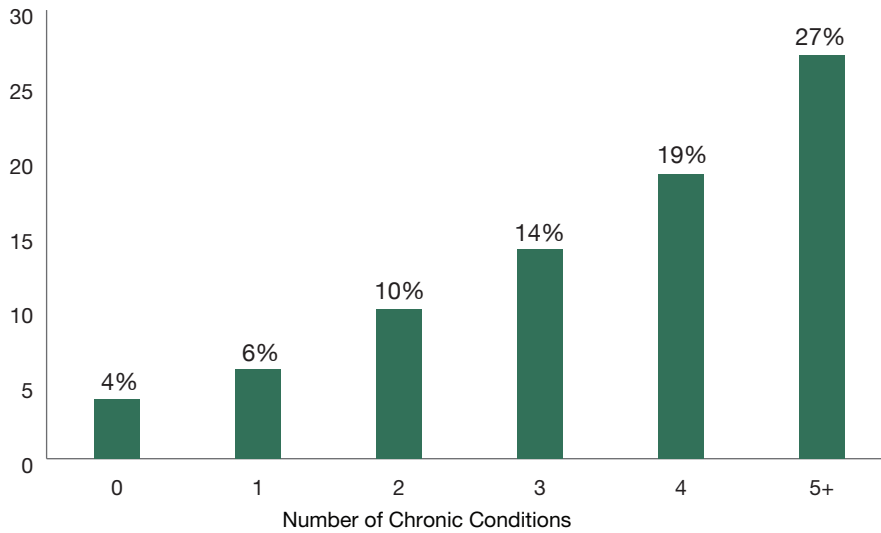
Source: Medicare Standard Analytic File, 2007

### Data Highlights

- Ninety-nine percent of Medicare expenditures are for beneficiaries with at least one chronic condition.
- Ninety-eight percent of Medicare expenditures involve individuals with multiple chronic conditions.

## People With Multiple Chronic Conditions Are Much More Likely to be Hospitalized

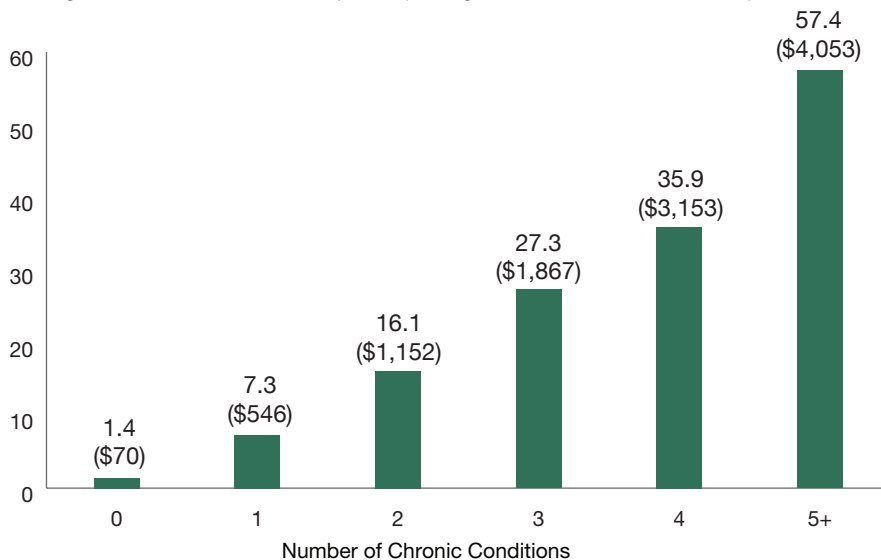
Percentage of People With Inpatient Hospital Stays



Source: Medical Expenditure Panel Survey, 2006

## People With Multiple Chronic Conditions Fill More Prescriptions

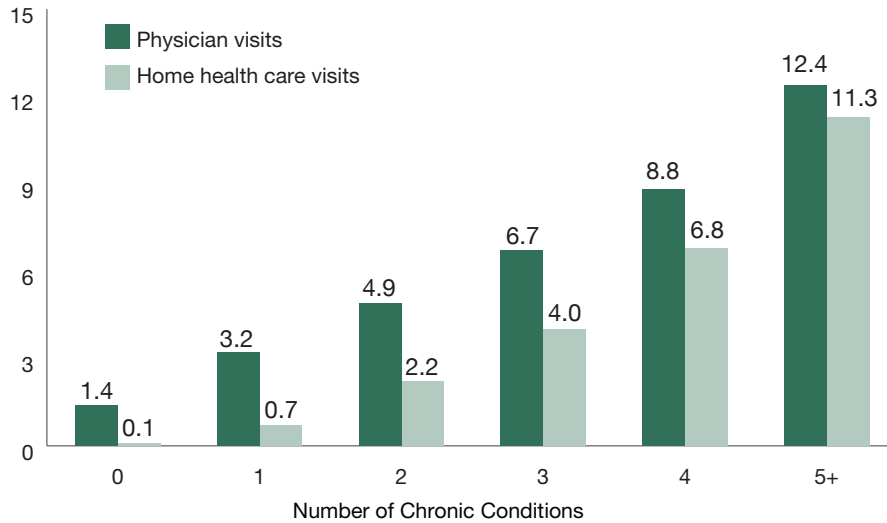
Average Annual Number of Prescriptions/(Average Annual Rx Cost Per Person)



Source: Medical Expenditure Panel Survey, 2006

## Physician and Home Health Care Visits Increase With the Number of Chronic Conditions

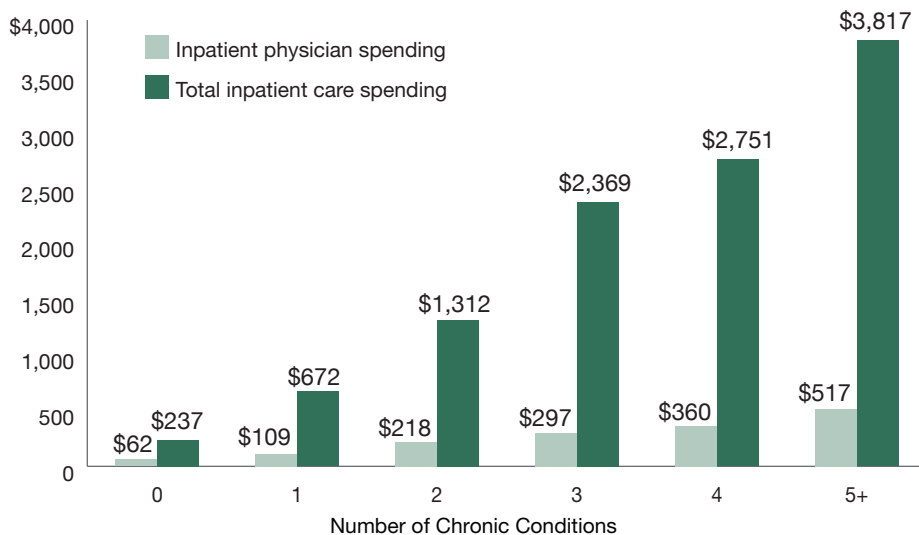
Average Annual Visits Per Person



Source: Medical Expenditure Panel Survey, 2006

## Spending for Inpatient Hospital Care Increases With the Number of Chronic Conditions

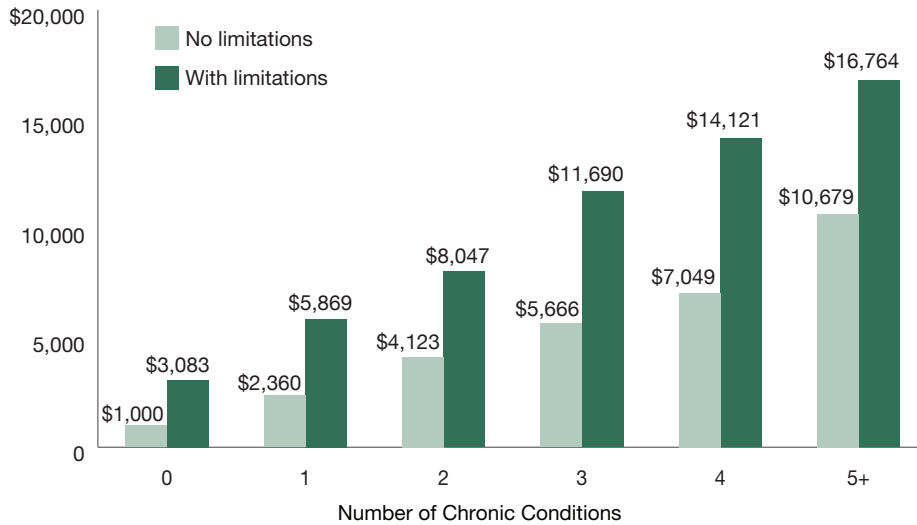
Average Annual Per Person Spending



Source: Medical Expenditure Panel Survey, 2006

## Health Care Spending Often Doubles for People With Chronic Illnesses and Activity Limitations

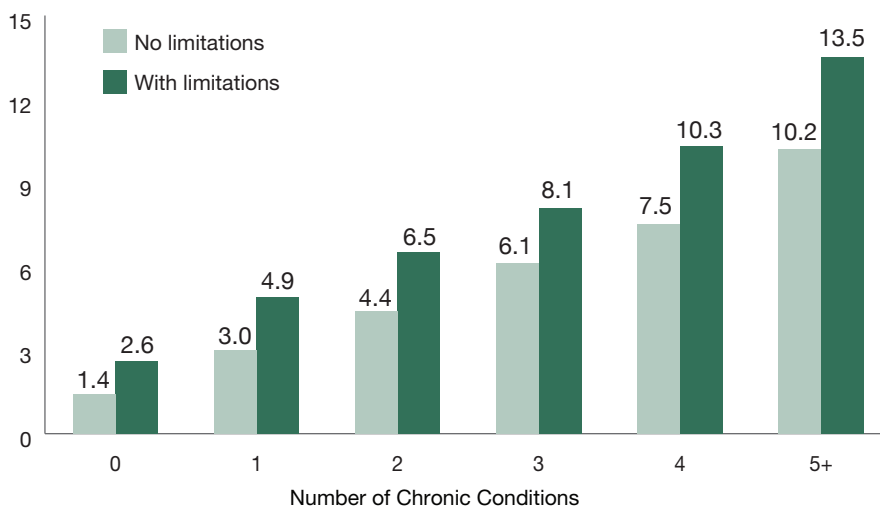
Average Annual Health Care Expense Per Person



Source: Medical Expenditure Panel Survey, 2006

## People With Chronic Illnesses and Activity Limitations Have More Physician Visits

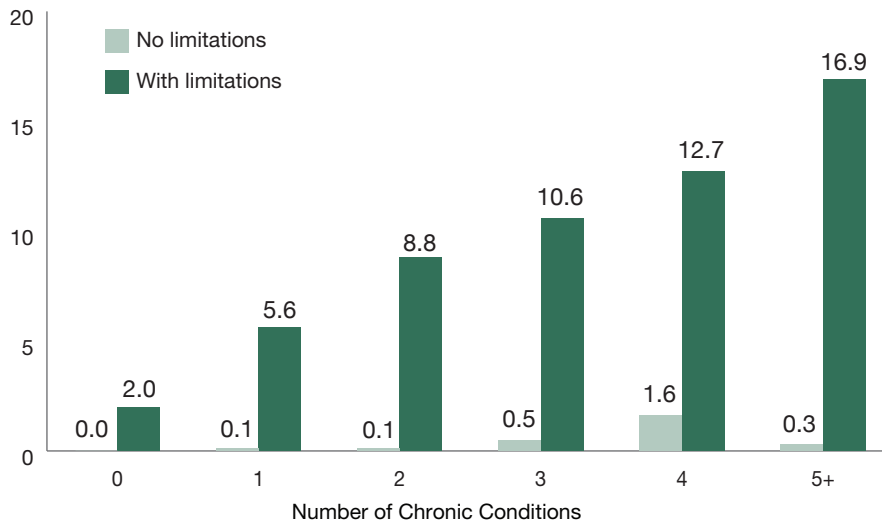
Average Annual Number of Physician Visits Per Person



Source: Medical Expenditure Panel Survey, 2006

## Individuals With Chronic Illnesses and Activity Limitations Have More Home Health Care Visits

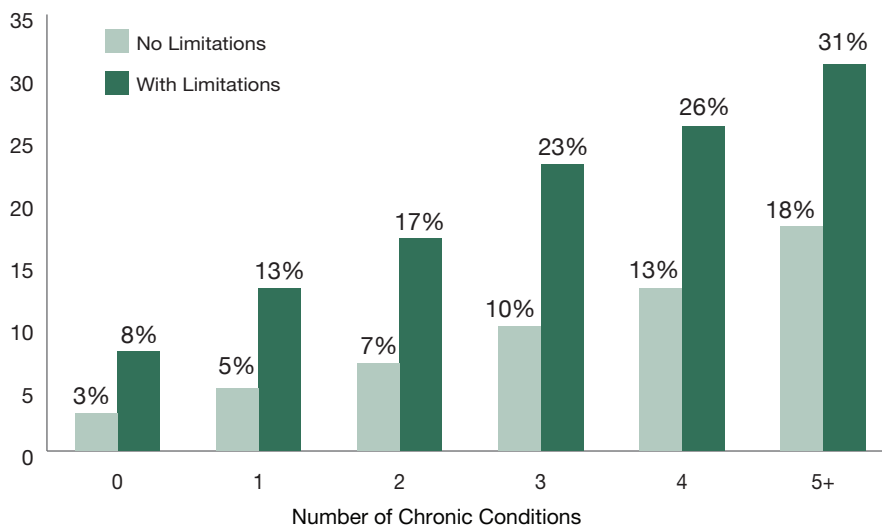
Average Annual Number of Home Health Care Visits Per Person



Source: Medical Expenditure Panel Survey, 2006

## People With Chronic Illnesses and Activity Limitations Are More Likely to Have Inpatient Stays

Percentage of People With Inpatient Stays

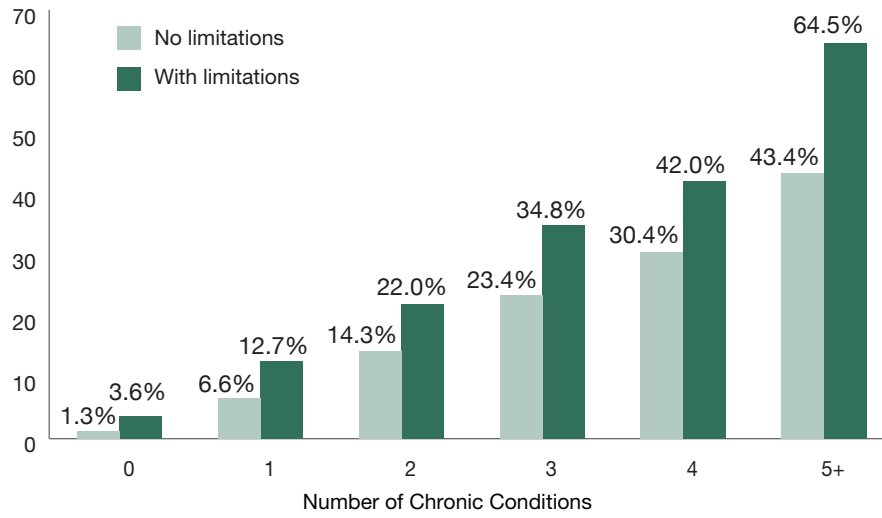


Source: Medical Expenditure Panel Survey, 2006



## People With Chronic Illnesses and Activity Limitations Are More Likely to Fill Prescriptions

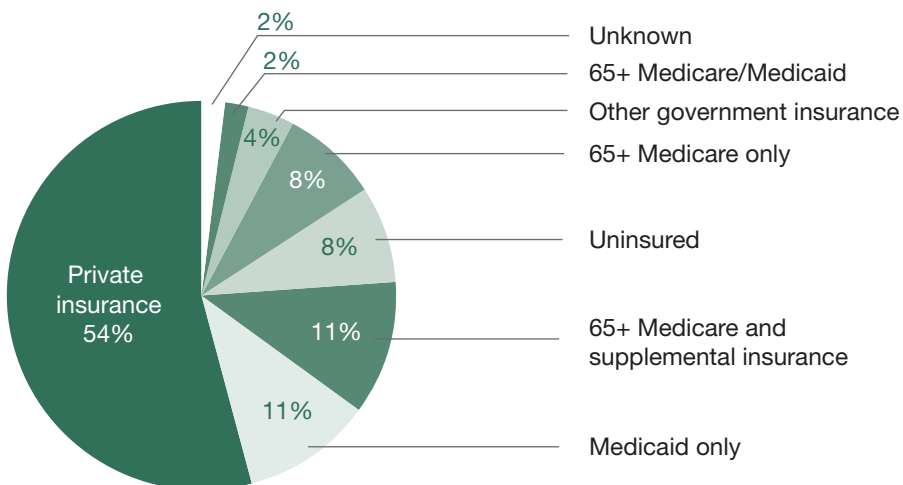
Percentage of People Filling Prescriptions



Source: Medical Expenditure Panel Survey, 2006

## Most People With Chronic Conditions Have Private Coverage

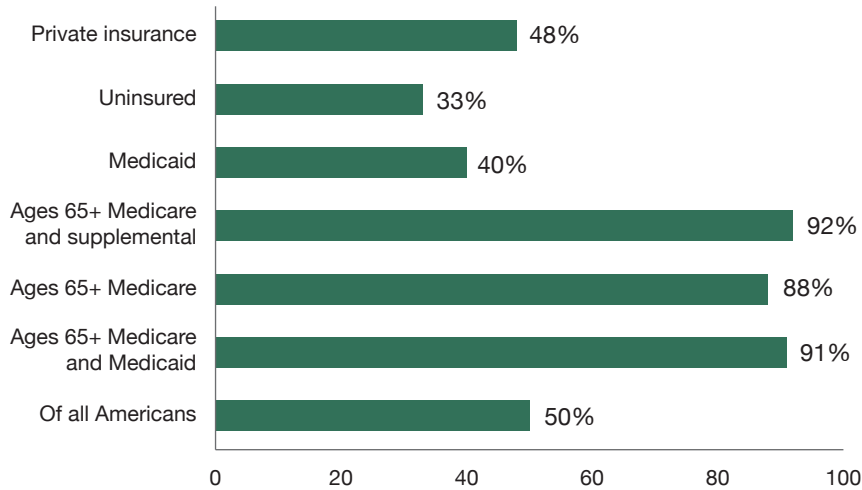
Percentage of Medicare Expenditures



Source: Medical Expenditure Panel Survey, 2006

## People With Medicare Coverage Are Most Likely to Have Chronic Conditions

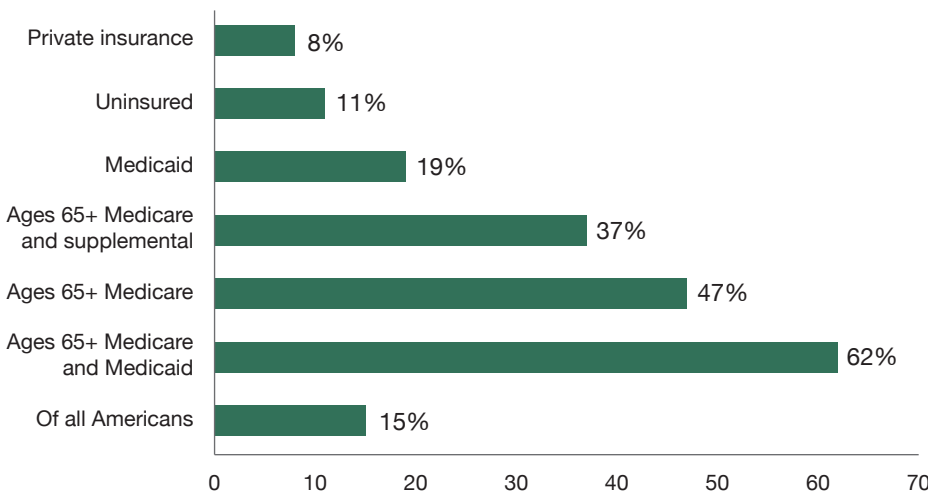
Percentage of Enrollees With a Chronic Condition



Source: Medical Expenditure Panel Survey, 2006

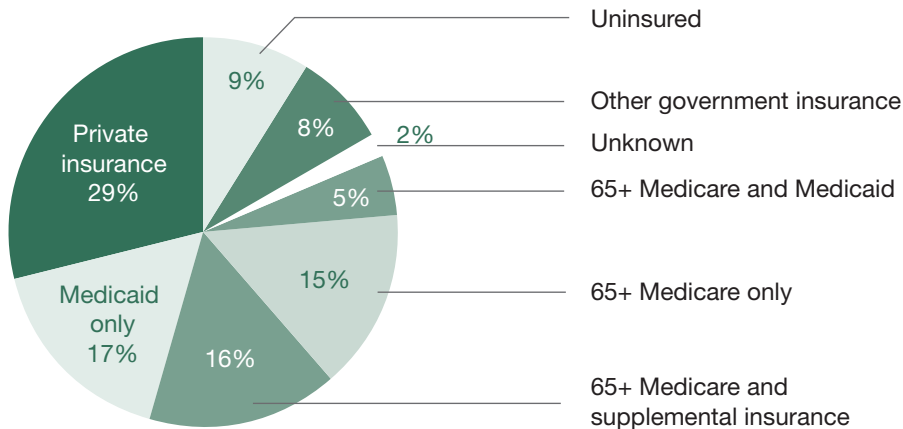
## People With Both Medicare and Medicaid Coverage Have High Rates of Activity Limitations

Percentage With Activity Limitations



Source: Medical Expenditure Panel Survey, 2006

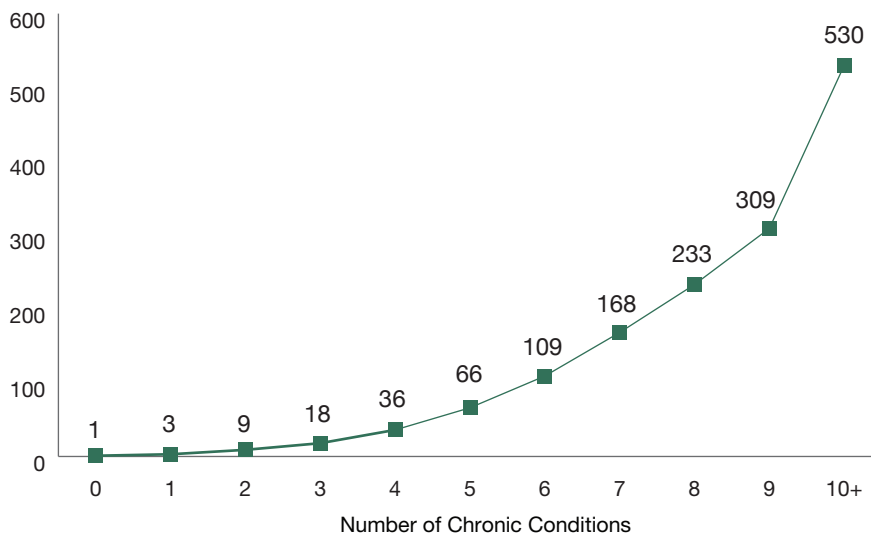
## Most People With Activity Limitations Have Medicare Coverage



Source: Medical Expenditure Panel Survey, 2006

## Higher Number of Chronic Conditions Leads to Unnecessary Hospitalizations

Number of Hospitalizations for Ambulatory Care Sensitive Conditions Per 1,000 Medicare Beneficiaries Ages 65+



Source: Medicare Standard Analytic File, 2007

### Data Highlights

- Ambulatory care sensitive conditions (ACSCs) are conditions for which timely and effective outpatient care may help to reduce the risk of hospitalization.
- Inappropriate hospitalizations increase as the number of chronic conditions increase.
- People with multiple chronic conditions use medical goods and services at higher rates than others and they often receive duplicate testing, conflicting treatment advice and prescriptions that are contra-indicated.
- These factors may play a role in the correlation between increasing numbers of chronic conditions and increasing numbers of inappropriate hospitalizations.

## SECTION 3

## The Impact of Chronic Conditions on Individuals and Their Caregivers

**W**e know that chronic conditions result in higher health care spending and utilization, but what does all this mean for the people who have these conditions and for their families and friends? Unfortunately, the shortcomings of our current financing and service delivery systems have serious implications for these individuals.

First, front-line providers—physicians—believe that poor coordination of care generally leads to unnecessary service utilization: hospitalizations, nursing home placements, and duplicate diagnostic tests. We also know that an increase in the number of chronic conditions correlates with an increase in the number of inappropriate hospitalizations. This is likely related to the greater number of providers treating people with multiple chronic conditions and the higher volume of services they receive. This type of inappropriate utilization inflates expenses in an already stressed health care budget, but more importantly, unnecessary utilization can be costly, frustrating, time-consuming, and even dangerous for patients.

Another consequence of poor coordination is that many individuals often receive conflicting advice from different providers, leaving them with a dilemma—which provider to believe. Without any real ability to discern which is the correct information or most appropriate course of care or treatment, many people are left guessing, further compounding the stress they are already experiencing from their illness or illnesses. In the worst care scenarios, they may even be harmed or receive inappropriate care. People with serious chronic conditions (those with long-term illnesses that require ongoing medical care and that limit their activities) have even greater difficulties with the health care system. They are more likely to receive conflicting advice, have trouble accessing needed services, and receive prescriptions that adversely interact with one another. These findings have not been updated in this chartbook.

*The average annual out-of-pocket spending on health care for people with one or more chronic conditions is \$1,057.*

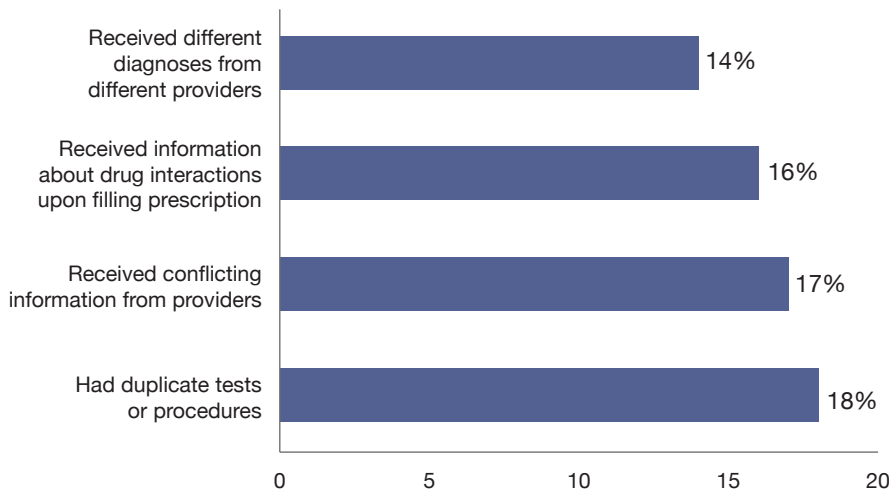
The American public is already aware of the poor state of chronic care in this country. In a survey commissioned by the *Partnership for Solutions* and conducted in 2000 by Harris Interactive, Inc., most Americans reported being fearful of becoming sick and having a chronic condition. They cited the inability to pay for care, the loss of independence, and becoming a burden to family and friends as their biggest concerns. These fears are not unfounded. Personal spending on health care is a significant expense for many people with chronic conditions, and, not surprisingly, as the number of chronic conditions a person has increases, so do the out-of-pocket costs that person incurs.

What is surprising, however, is how much more people with chronic conditions pay out-of-pocket for health care than individuals without chronic conditions regardless of the type of insurance they have. People with chronic conditions spend much more on prescription drugs than people without chronic conditions and, unfortunately, they are sometimes paying for drugs that have adverse drug/drug interactions because care between providers is not coordinated. Among people with insurance coverage, Medicare beneficiaries spend the most out-of-pocket because they have more chronic conditions as a group and Medicare coverage has the “donut hole.” People with serious chronic conditions report numerous difficulties paying for care: some declare bankruptcy, while others borrow from family or friends to pay for care.

People with chronic conditions rely on others not only for financial support but for personal assistance as well. Family and friends devote many hours per week to assisting people with long-term conditions and disabilities. Family caregivers provide personal care, health care, and help accessing services and navigating the often confusing health care system. While these family caregivers may not view their assistance as a burden, people still worry about becoming a hardship to their family and friends. The value of this family caregiving, provided without monetary compensation, dwarfs spending on formal sources of personal assistance.

## People With Chronic Conditions Report Not Receiving Adequate Information

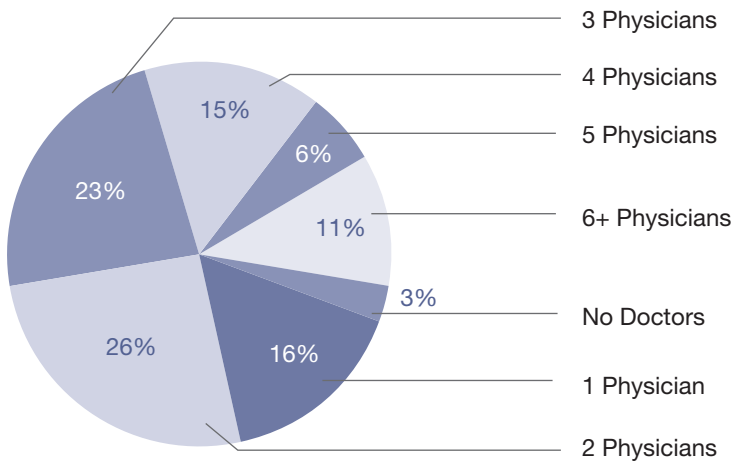
Percentage of Population With Chronic Conditions Reporting Problems



Source: *Chronic Illness and Caregiving*, a survey conducted by Harris Interactive, Inc., 2000.

## More Than Half the People With Serious Chronic Conditions Use Three or More Different Physicians

Number of Different Physicians Seen by People With Serious Chronic Conditions



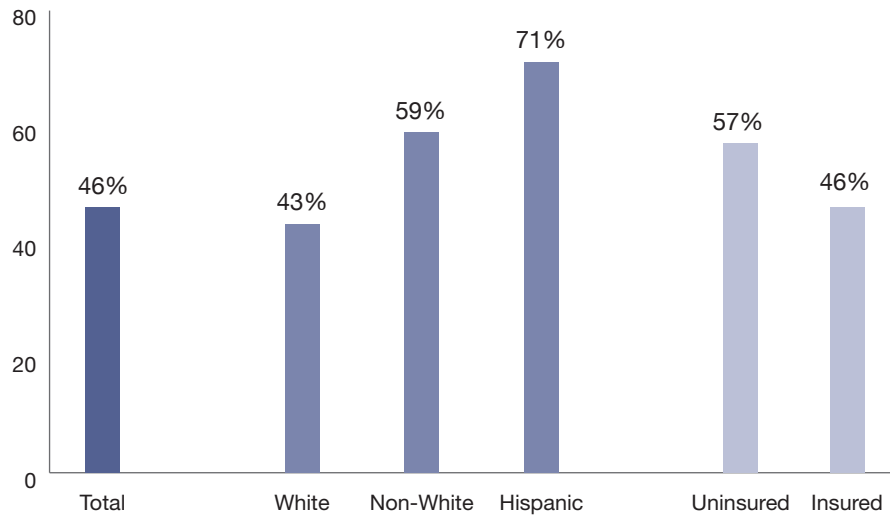
Source: Gallup *Serious Chronic Illness Survey*, 2002.

### Data Highlights

- Eighty-one percent of people with serious chronic conditions see two or more different physicians.

## People With Serious Chronic Conditions Believe They Do Not Receive Needed Treatment

Percentage of People With Serious Chronic Conditions Reporting That They Did Not Receive Needed Care



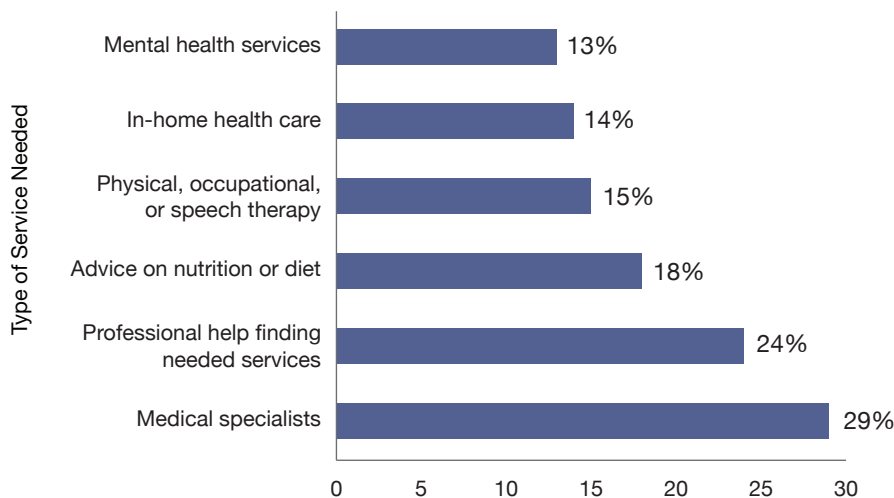
Source: *Serious Chronic Illness Survey* conducted by the Gallup Organization, 2002.

### Data Highlights

- The uninsured are more likely to report that they go without needed medical care, although insured people with serious chronic conditions also report high levels of unmet service needs.
- Hispanic and non-White persons with serious chronic conditions report high levels of unmet service needs.

## People With Serious Chronic Conditions Have Trouble Accessing Specific Services

Percentage of People With Serious Chronic Conditions Reporting That They Did Not Get Needed Service

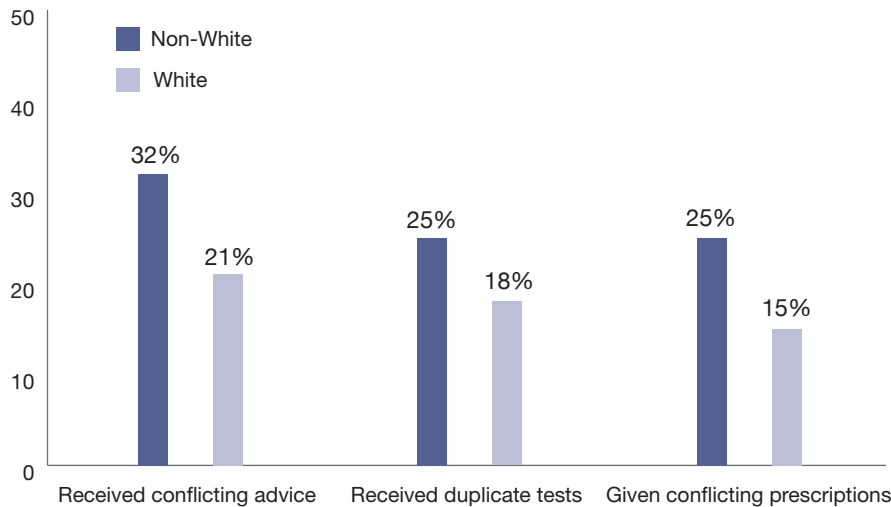


Source: *Serious Chronic Illness Survey* conducted by Gallup Organization, 2002.



## Quality of Care for People With Serious Chronic Conditions Varies by Race

Percentage of People With Serious Chronic Conditions Who Responded 'Sometimes' or 'Often'



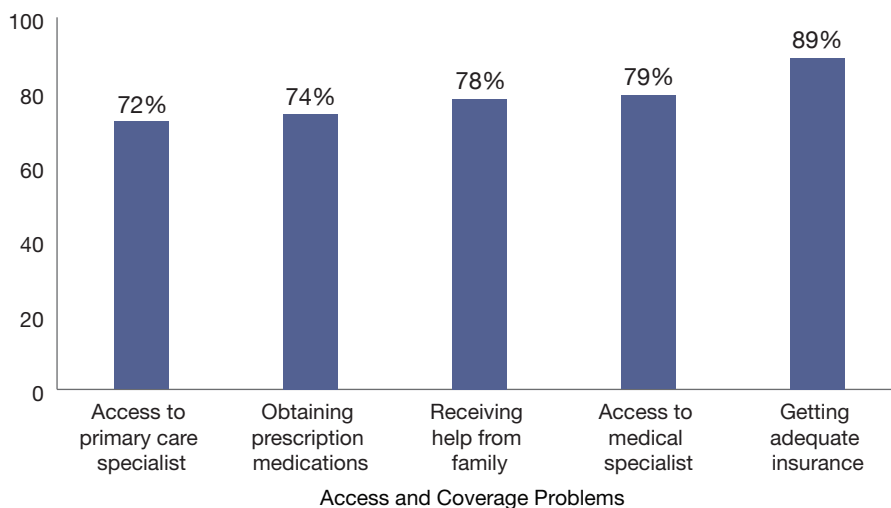
Source: *Serious Chronic Illness Survey* conducted by the Gallup Organization, 2002.

### Data Highlights

- Quality-of-care problems may be exacerbated by lack of insurance, language barriers, and geographic proximity to providers.

## Americans Believe That Access to Care and Coverage Is a Problem for People With Chronic Conditions

Percentage of Population Believing Factor Is a Problem



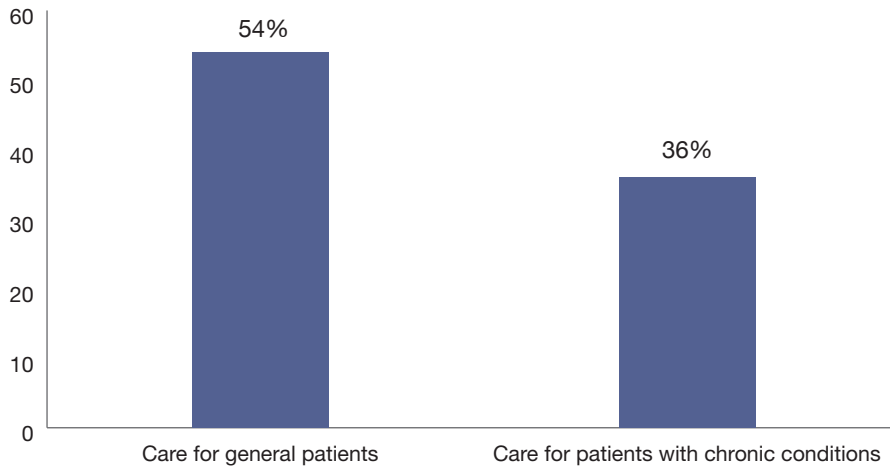
Source: *Chronic Illness and Caregiving*, a survey conducted by Harris Interactive, Inc., 2000.

### Data Highlights

- Approximately three out of four individuals believe that access to medical services is difficult for people who have a chronic condition.

## Physicians Are Less Satisfied Providing Care to People With Chronic Conditions

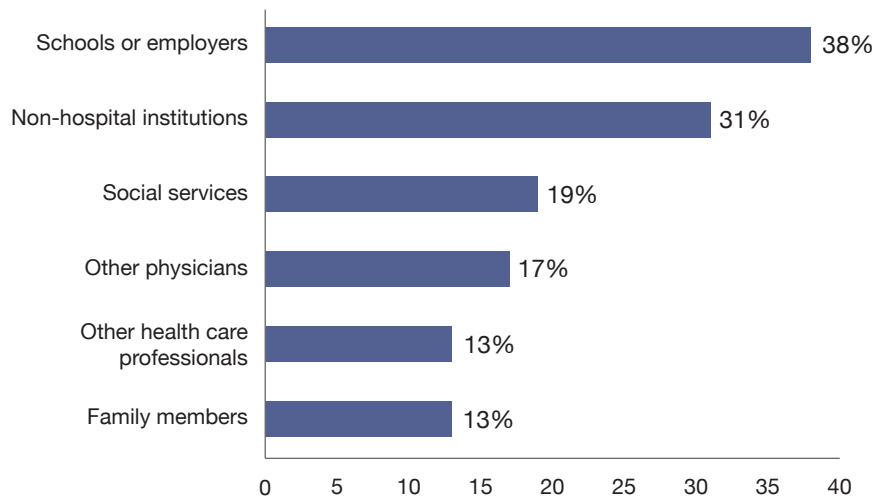
Percentage of Physicians Very Satisfied With Care for Patients



Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

## Physicians Report Difficulty Coordinating Care

Percentage of Physicians Identifying Problems Coordinating Care With Different Providers or Entities



Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc. 2001.

### Data Highlights

- Physicians report that they are less satisfied providing care to people with chronic conditions than to all patients in general.
- Lower physician satisfaction may result from difficulty coordinating with other providers, inadequate health insurance, inadequate clinical training in the area of chronic care, and reimbursement systems that do not adequately recognize the additional time necessary to care for people with complex or multiple chronic conditions.

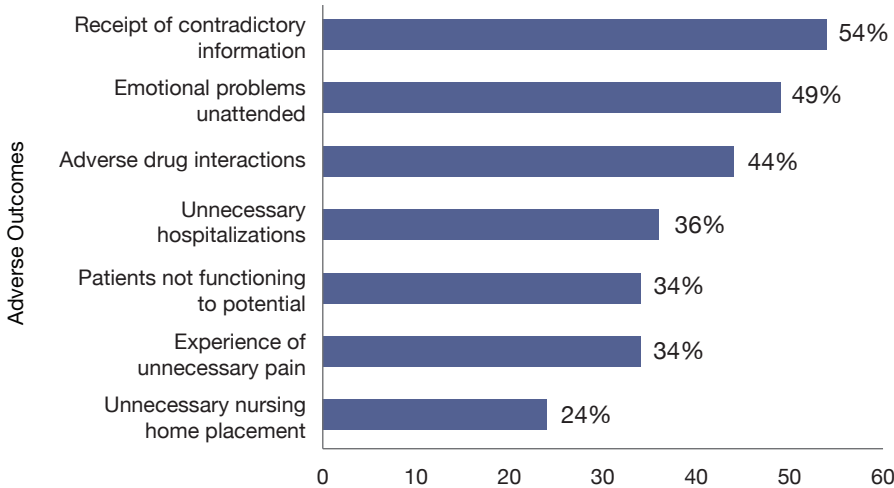
### In Treating Patients With Chronic Conditions, Physicians Believe Their Training Did Not Adequately Prepare Them to:

- Coordinate in-home and community services (66%)
- Educate patients with chronic conditions (66%)
- Manage the psychological and social aspects of chronic care (64%)
- Provide effective nutritional guidance (63%)
- Manage chronic pain (63%)

Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey* conducted by Mathematica Policy Research, Inc., 2001.

## Physicians Believe That Poor Care Coordination Produces Bad Outcomes

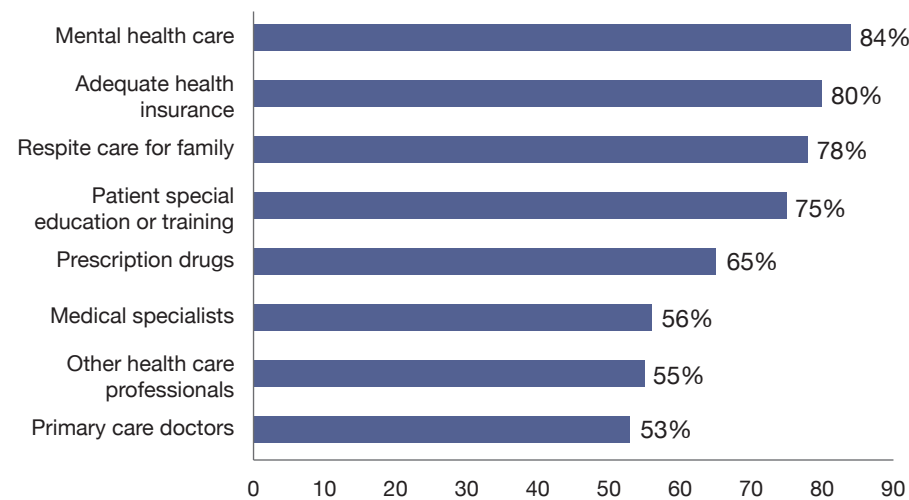
Percentage of Physicians Who Believe That Adverse Outcomes Result From Poor Care Coordination



Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

## Physicians Believe That People With Chronic Conditions Have Unmet Needs

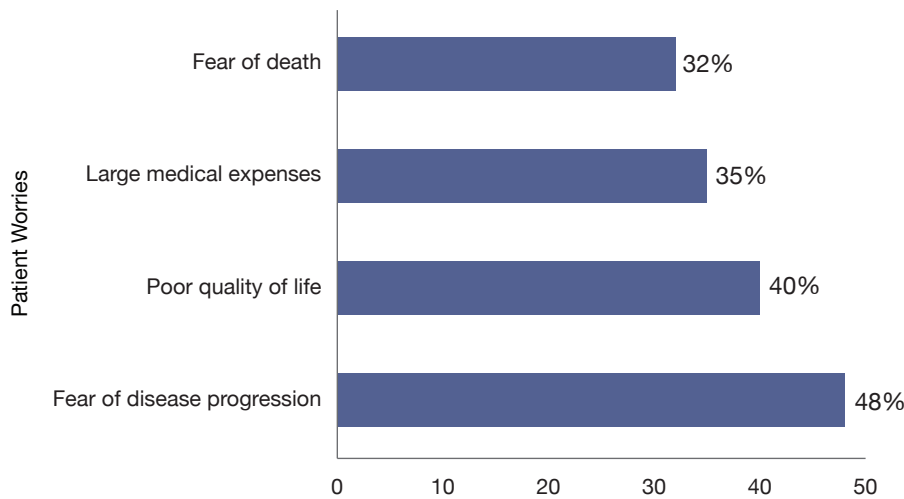
Percentage of Physicians Who Believe Access Is Difficult or Very Difficult



Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

## Doctors Believe That Their Patients Worry About the Impact of Chronic Conditions

Percentage of Doctors Responding Affirmatively



Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

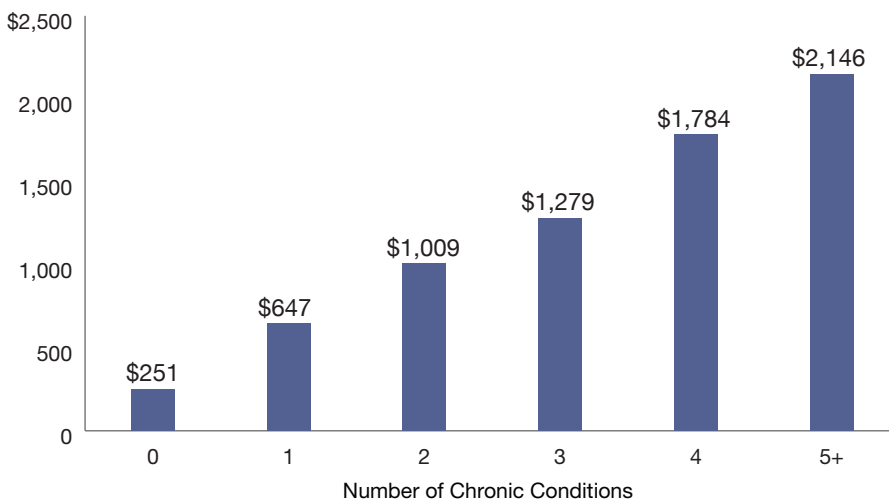
### Data Highlights

- When asked directly, Americans report that their top concerns about having a chronic condition are: inability to pay for care, losing independence, and being a burden to family and friends.<sup>1</sup>

<sup>1</sup> From *Chronic Illness and Caregiving*, a survey conducted by Harris Interactive Inc., 2000

## Out-of-Pocket Health Care Spending Increases With the Number of Chronic Conditions

Average Annual Out-of-Pocket Expenditures Per Person



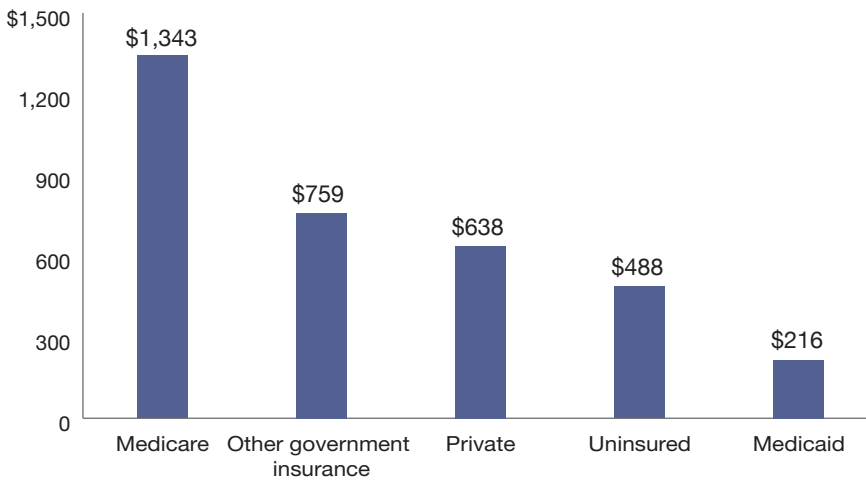
Source: Medical Expenditure Panel Survey, 2006

### Data Highlights

- The average annual out-of-pocket spending on health care for people with one or more chronic conditions is \$1,057.
- The highest average out-of-pocket expense for people with chronic conditions is prescription drugs, while people without chronic conditions spend the most out-of-pocket on dental care.
- One reason out-of-pocket spending is high for people with chronic conditions is that they often pay for items and services that may not be covered by insurance, such as supportive services that people with chronic conditions often need.

## Out-of-Pocket Spending is Highest for People With Medicare

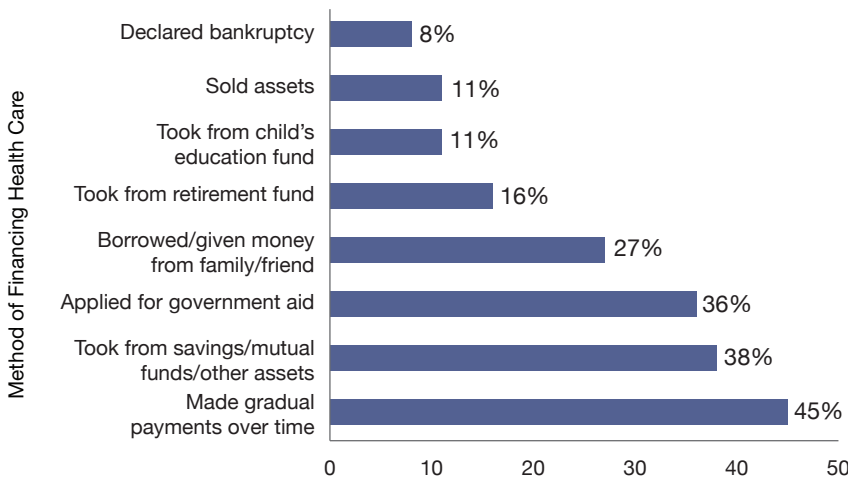
Average Annual Out-of-Pocket Expenditures Per Person by Type of Insurance



Source: Medical Expenditure Panel Survey, 2006

## People With Serious Chronic Conditions Have Difficulty Paying for Their Health Care

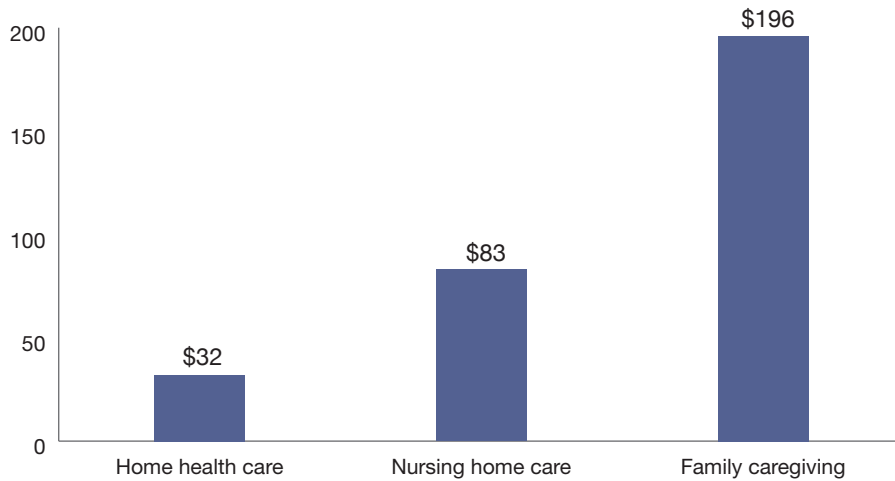
Percentage of People With Serious Chronic Conditions Using This Method to Finance Health Care



Source: *Serious Chronic Illness Survey* conducted by the Gallup Organization, 2002.

## The Estimated Monetary Value of Family Caregiving Greatly Exceeds Spending on Formal Long-Term Care Services

Value of Care, 1997 (in billions)



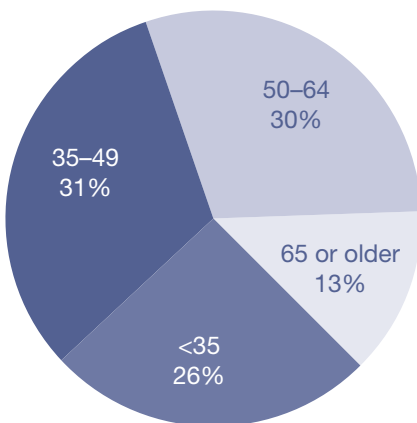
Source: Arno, PS, Levine, C and Memmott, MM, "The Economic Value of Informal Caregiving," *Health Affairs*, 18: 2, March/April 1999.

### Data Highlights

- Family caregiving includes all unpaid services provided by family and friends.
- Because of gaps in the health care system and individual family preferences, much of the care for people with chronic conditions is provided by family and friends.
- One of people's greatest concerns is that they will become a burden to family and friends when they have a chronic condition.

## Informal Caregiving Is a Multigenerational Task

Family Caregivers by Age



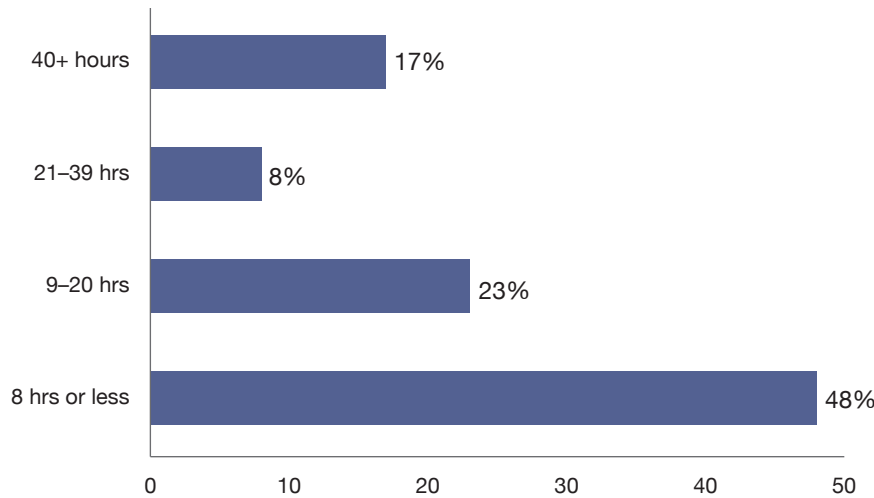
Source: *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, 2004.

### Data Highlights

- Forty-three percent of those providing care are 50 years of age or older.
- Sixty-one percent of family caregivers are women (not shown).

## Hours per Week Dedicated to Caregiving

Percentage of Caregivers



Source: *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, 2004.

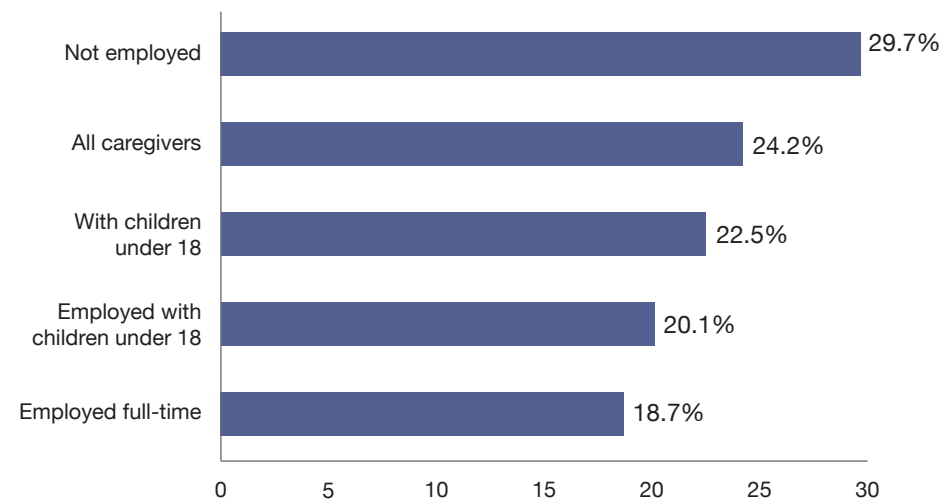
### Data Highlights

Caregivers who provide 40 hours or more per week (17%) tend to be:

- In fair or poor health (29% vs. 16% excellent health, 15% very good health);
- 65 or older (28% vs. 11% 18-34, 15% 35-49);
- Caring for someone with Alzheimer's or dementia (24% vs. 16%);
- Lower income (23% of those earning less than \$30,000 vs. 16% \$30,000-\$49,000, 15% \$50,000-\$99,000, 12% \$100,000); and
- Less well educated (21% of those with a high school education or less vs. 12% college graduate).

## Competing Demands Influence the Weekly Hours of Family Caregiving

Average Weekly Hours of Caregiving



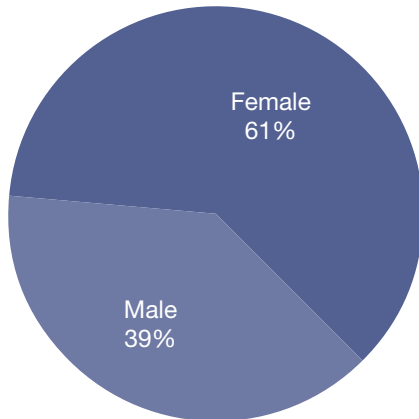
\*Children in the household may include children with long-term illnesses or disabilities.  
 Source: Alecxih, LMB, Zeruld, S, and Olearczyk, B. *Characteristics of Caregivers Based on the Survey of Income and Program Participation. National Family Caregiver Support Program: Selected Issue Briefs.* Prepared for the Administration on Aging by The Lewin Group, July 2001.

### Data Highlights

- Half of family caregivers are employed.
- Forty percent of family caregivers are employed full-time.
- Almost 20 percent of family caregivers work and care for children in addition to caregiving responsibilities.



## Family Caregivers by Gender



Source: *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, 2004.

## A Caregiving Perspective

One person's condition can affect many other people. For the many millions of Americans who require help with everyday activities, family and friends are the first line of support.

Overall, the demand and supply trends in caregiving are pulling in opposite directions. Demand for caregivers is increasing. The chances of becoming a caregiver to someone with a chronic condition are much higher today than ever before—and the likelihood will increase over the coming decades as the elderly population, those most likely to be disabled by a chronic condition, increases.

But the supply is decreasing. Among the factors that are shrinking the pool of possible caregivers are decreasing birth rates; family networks that are getting smaller and more top-heavy; and more older than younger family members. Women have entered the workforce in increasing numbers since the 1960s and are no longer as available as they once were for the traditional female role as unpaid family caregiver. People are marrying and having children at later stages in their lives, which increases the size of the “sandwich generation,” that is, those simultaneously caring for children and for their own parents or elderly relatives. As average family size decreases, fewer children will be available for caregiving, and sibling support networks will also become smaller.

## Conclusion

Since this chartbook's first edition was first published in 2002, the prevalence and costs associated with chronic conditions have worsened. Today, an even greater proportion of the population suffers from one or more chronic conditions and health care spending for persons with chronic conditions has risen steadily.

The proportion of all Americans with two or more chronic conditions has increased, rising from 24 percent in 2001 to 28 percent in 2006. The percentage of persons with five or more chronic conditions has also increased; now as many as 6 percent of all females and 4 percent of males suffer from five or more chronic conditions. The proportion of Americans with hypertension increased by 7 percentage points and cholesterol disorders have now become one of the most common chronic conditions, rising from 13 percent to 22 percent of all non-institutionalized persons between 2001 and 2006. In addition, average annual out-of-pocket spending has increased by nearly 30 percent since 2001 for those with one or more chronic conditions—amounting an average increase of over \$230 per person annually.

It is important to note that some gains have been made, however. An increased emphasis on the quality of medical care over the past few years appears to have contributed to a decrease in the number of preventable hospitalizations among Medicare beneficiaries 65 years and older, with a particularly large reduction seen among those with five or more chronic conditions.

In the coming years, our health care system will devote increasing amounts of resources—both services and dollars—to care for people with chronic conditions. As a society, we need to ensure that these resources are spent as effectively and wisely as possible to maintain the health and enhance the

*The proportion of all Americans with two or more chronic conditions has increased, rising from 24 percent in 2001 to 28 percent in 2006.*

individual functioning of this large segment of our population. There is a general recognition among patients, providers and the public that adjustments within the health care system are needed to improve chronic care in this country.

The health care system can and will continue to adapt. When infectious disease was the leading public and private health care challenge, the health care system was organized to respond. The scourge of infectious disease gave way to problems associated with acute illnesses and events such as heart attacks and strokes. In response, the health care delivery system was modified to provide high-quality, effective treatments that resulted in improved survival rates, and a system of funding such care was organized to share the financial risk among the population.

Today, as chronic conditions have begun to dominate our agenda of health care concerns, another change is in order to address the needs of people with ongoing health care concerns. The data presented in this chartbook suggest that care provided in the current acute, episodic model is not meeting the needs of people with chronic conditions and often leads to poor outcomes for patients with chronic conditions. In clinical practice, chronic conditions require continuous care and coordination across health care settings and providers. People with chronic conditions also often require supportive services such as personal assistance care, home health care or help navigating the health care system. These services need to be more readily available and coordinated as well with clinical treatment in order to make clinical treatment most effective.

The goal of a new, chronic care model of financing and delivering health care services is early diagnosis with interventions that maintain health status and minimize episodes of acute illness. When acute episodes do occur, a chronic care model brings together a coordinated array of appropriate services that restore the individual to the highest possible state of functioning. These reforms are particularly challenging to implement in an environment where service delivery has become less integrated as a result of financial arrangements that pull together various providers into loose networks without incentives that encourage coordination among these groups. Likewise, the growing consumer preference for a less tightly managed health care system exacerbates the problem of coordinating care. While there has been progress in the years since the chartbook was published, the problems remain.

There are many chronic conditions, and many combinations of chronic conditions, that affect individuals in various ways and to differing degrees. While their individual clinical needs may be different, people with chronic conditions share a common set of problems regarding accessing appropriate and coordinated treatments and services, and paying for such care. Because there is a set of clearly defined problems for people with chronic conditions and the providers who treat them, it is incumbent upon us to look for broad-based solutions that can affect the greatest number of people.

We can find these solutions by rethinking how our health care financing system values and pays for the care received by people with chronic conditions. We can find these solutions by re-examining how we train our health care providers to better prepare them for the changing realities of medical practice and patient needs. We can find solutions by developing better connections between supportive and clinical care delivery systems. We can reorient our research infrastructure to address the needs of people with multiple chronic conditions. And finally, we can find solutions by encouraging and supporting patient self-management and family caregiving.

In our search for shared solutions, we need to respond to the issue of improving care for chronic conditions as a whole rather than responding one condition at a time. This model is not unlike the response to the crisis of infectious diseases a century ago, in which public health measures were broadly constructed and applied to address a range of diseases affecting individuals. It is this type of broad-based reform that we need to consider to improve care and quality of life for the growing number of people with chronic conditions.

## Methodology and Data Sources

In this chartbook, we define chronic conditions as health conditions that last a year or more and require ongoing medical attention and/or limit activities of daily living. This definition includes people with chronic illnesses or disabilities, or both. In some places, we refer to serious chronic conditions as health conditions that last a year or more, require ongoing medical care and limit what the person can do. We selected a broad definition similar to the previous definition used by Catherine Hoffman and Dorothy Rice in *Chronic Care in America*, in order to make comparisons between that publication and this one more consistent and meaningful. To determine which conditions met our definition, we convened two physician panels to review all medical conditions represented by the International Classification of Diseases, 9th Revision (ICD-9) codes to identify those that are chronic conditions under our definition. We applied the resulting classification applied to data from the Medical Expenditure Panel Survey (MEPS) and the Medicare Standard Analytic File. (See below for a discussion of these two data sources.) An important caveat is that our data analysis using ICD-9 codes does not always capture information on people whose chronic condition is a disability or functional limitation without an underlying chronic illness.

Data in this chartbook was drawn from a variety of sources, a few of which require some explanation. We relied heavily on the Household Component of the 2006 MEPS, which is a nationally representative sample of the non-institutional U.S. population. This survey is sponsored by the Agency for Healthcare Research and Quality (AHRQ). Two groups of respondents were interviewed three times each during the survey year. The MEPS Household Component provides information on health status, health services utilization, and health care spending. It is a survey of people living in the community and, therefore, does not provide information on people residing in institutions such

as nursing homes. This is an important point. As a result, our data analysis understates the number of people with chronic conditions, as well as health care spending on their behalf. More information about the survey process and instrument can be found at [www.AHRQ.gov](http://www.AHRQ.gov).

The *Partnership for Solutions* commissioned an analysis by researchers at the RAND Corporation using the MEPS data to produce projections of growth in the population with chronic conditions at five-year intervals, 1995 to 2030.

We also used the MEPS data to examine spending on prescription drugs. The data and analysis include spending and utilization information for prescriptions filled—which includes refills and free samples. The Household Component does not capture information about dosage strength and form, and the data is not disaggregated into unique prescriptions.

We have also relied on data from the 2007 Medicare Standard Analytic File. This is a nationally representative sample of 5 percent of Medicare beneficiaries and all their associated service claims for Medicare-covered benefits. Our analysis includes all beneficiaries in the sample, including the aged, disabled, and end-stage renal disease beneficiaries. Our analysis excludes people from the file who died during the survey year in an effort to separate costs associated with end-of-life care. There are some important caveats about this data source as well. First, Medicare+Choice (M+C) spending and the Medicare beneficiaries enrolled in managed care are not included in the sample because these payments are not claims-based. It is not clear how these omissions would affect the analysis, although reports by the General Accounting Office and others have highlighted how M+C enrollees are in better health than the Medicare fee-for-service population. M+C enrollment was about 16 percent of total Medicare enrollment in 2007. Total spending represented by the sample will not total to all Medicare spending in 2007 because some important spending components that are not claims based are absent from the file: graduate medical education, Medicare+Choice, and administrative spending are examples. It is unlikely, however, that this spending would greatly affect the analysis in this chartbook since most of it is not for beneficiary-specific services. We have also not included spending for drug benefits because that information is not available.

We also use data from three opinion surveys commissioned by the *Partnership for Solutions*. All three surveys were designed by researchers at Johns Hopkins. The first was a telephone survey conducted in 2000 by Harris Interactive, Inc.

A total of 1,663 people were interviewed to ascertain their perceptions and knowledge of chronic conditions. Of those surveyed, 983 people either had a chronic condition, cared for someone with a chronic condition, or both. A second telephone survey, conducted by Mathematica Policy Research, Inc. from November 2000 to June 2001, interviewed 1,236 physicians with 20 or more hours per week of patient contact. The survey was designed to learn about physician attitudes and problems treating people with chronic conditions and about the adequacy of physician training relative to caring for this population. The third telephone survey, conducted by the Gallup Organization from November 2001 through January 2002, interviewed 1,200 people with serious chronic conditions, as defined above. The survey was designed to learn more about their experiences and perceptions.

Another data source used in developing our chartbook is The Lewin Group's analysis of the 1996 Survey of Income and Program Participation (SIPP) data for characteristics of family caregivers (those who provide care to family and friends without remuneration). This survey identifies and interviews self-reported caregivers to people in need of assistance with daily activities due to a disability or long-term illness (routine child care was not part of the caregiver identification). This sample results in a lower estimated number of caregivers nationally than other surveys of caregiving in the United States. However, the reported average hours of caregiving provided is slightly higher than that derived from several other surveys. This may, in part, result from interviewing the caregivers directly rather than the recipients of care as is done in those other surveys.