

# Chronic Conditions: Making the Case for Ongoing Care



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**Chronic Conditions: Making The  
Case for Ongoing Care**

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# Preface

In 1996, authors Catherine Hoffman, Sc.D., and Dorothy Rice, Sc.D. (Hon.), published *Chronic Care in America: A 21<sup>st</sup> Century Challenge* with the goal of highlighting a growing issue in the United States: how to provide appropriate health care for people with chronic conditions. The authors encouraged policymakers, providers, and the public to look at health care from a new perspective: the chronic care perspective, with a special emphasis on community caregiving models.

*Chronic Conditions: Making The Case for Ongoing Care*, prepared by Partnership for Solutions in 2002, continues the work of Hoffman and Rice by reexamining the issue of chronic care in America. This chartbook provides an updated overview of chronic health conditions in the United States and the implications of these conditions on individuals, their caregivers, and the health care system.

In particular, the chartbook provides updated prevalence rates and projections for people with chronic conditions; details spending and utilization for people with multiple chronic conditions and chronic illness and activity limitations; and illuminates, from the physician and patient perspectives, the obstacles to providing and obtaining optimal care for people with chronic conditions.

Partnership for Solutions is a national program funded by The Robert Wood Johnson Foundation and based at Johns Hopkins University. The goal of the initiative is to improve care and quality of life for the more than 125 million Americans with chronic health conditions. The Partnership is engaged in three major activities: conducting original research and identifying existing research that clarifies the nature of the problem; communicating these research findings to policymakers, business leaders, health professionals, and advocates for people with chronic conditions; and working with these constituencies to identify promising solutions to the problems faced by people with chronic conditions. This chartbook represents the work of the Partnership's research and communications efforts. Visit [www.partnershipforsolutions.org](http://www.partnershipforsolutions.org) for further information about chronic conditions and policy implications.

*Chronic Conditions: Making The Case for Ongoing Care* was created by Gerard Anderson and Jane Horvath, with the assistance of Robert Herbert, Katie Ridgway, Wendy Pavlovich, Gautum Harjai, Gregory Stevens, Diane Justice, and GYMR Public Relations. Gerard Anderson is the national program director and Jane Horvath is deputy director of Partnership for Solutions.

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and review. The Partnership also thanks Cynthia Anderson for her editorial assistance.

Partnership for Solutions intends that the widest possible audience uses this chartbook. Therefore, all of the information contained here and on the Partnership's Web site is available for use and reproduction free of charge. The source should be listed as: Partnership for Solutions.

Partnership for Solutions, funded by The Robert Wood Johnson Foundation, is made up of a variety of leading organizations that all have a stake in improving the lives of people with chronic conditions. These groups include:

- Alzheimer's Association
- American Academy of Pediatrics
- American Diabetes Association
- American Geriatrics Society
- Family Voices
- National Alliance for the Mentally Ill
- National Chronic Care Consortium

# The Need for Coordinated Chronic Care

During the 20th century, advances in modern medicine and public health contributed to steady increases in life expectancy in the United States. In the 21st century, Americans can expect to live longer than any previous generation. Along with the aging of the population, however, has come an increase in the number of Americans living with one, *and often more than one*, chronic condition. These conditions are unlike most infectious diseases or sudden acute illnesses. By the Partnership's definition, chronic conditions last a year or longer, limit what one can do, and/or may require ongoing medical care. In this new century, we have to confront a new reality: growing numbers of people with chronic conditions seeking care in a system that is not structured to respond to their needs.

While the technology of medicine has improved rapidly, the system of financing and delivering care has been slower to reorient itself to this changing nature of disease. In the past, the health care system has made adjustments to address pressing health care concerns—from combating infectious diseases and eliminating underlying public health problems in the early 1900s to treating acute, non-infectious illness in the latter part of the 20th century. But, while our health care needs have again evolved, the health care system has not. Although we have recently seen a greater movement toward disease management programs that address a specific condition,

the system continues to remain an amalgam of past efforts and does not focus on providing care for people with multiple chronic conditions across the service continuum.

In 1996, authors Catherine Hoffman, Sc.D., and Dorothy Rice, Sc.D. (Hon.), published *Chronic Care in America: A 21<sup>st</sup> Century Challenge* to illustrate a growing issue facing America: how to provide appropriate health care and related social services to people with chronic conditions. At that time, an estimated 99 million people in the United States had chronic conditions. Today, those numbers have increased to more than 125 million people, or almost half of all Americans, living with a chronic condition. By 2020, as the population ages, the number will increase to an estimated 157 million.

These people represent all segments of our society—they are of every age, race, and economic status. Many have multiple chronic conditions, including functional limitations and disabilities. In the general population, people with five or more chronic conditions have an average of almost 15 physician visits and fill almost 50 prescriptions per year. In the Medicare population, the average beneficiary sees seven different physicians and fills upwards of 20 prescriptions per year. With many people using multiple providers and taking a variety of medications, there should be concern about whether care is coordinated, but in the current system

there are few incentives to coordinate care across providers and service settings. There is, however, a growing consensus among physicians and the general public that changes are necessary to better serve people with chronic conditions. In addition to a lack of coordinated care, the health care system currently does not place a high priority on primary, secondary, and tertiary prevention efforts to avert disease or slow its progression.

Despite their different health concerns, people with chronic conditions face many of the same challenges and obstacles to accessing appropriate and necessary care. Many of these obstacles have not changed since *Chronic Care in America: A 21<sup>st</sup> Century Challenge* was published, although the number of people who encounter these problems has increased. People with multiple 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, and out-of-pocket spending is high. People with chronic conditions are getting services, but those services are not necessarily in coordination with one another, and they are not always the services needed to maintain health and functional status.

Many people with chronic conditions rely on caregivers—friends and family—to provide personal assistance and financial support in order to maintain their health

and functional status. Some nine million Americans provide caregiving services, and approximately 40 percent of these caregivers are also employed full-time in other jobs. On average, caregivers spend approximately 24 hours a week providing supportive services. This type of time commitment causes many people with multiple chronic conditions to worry that they will become a burden to the people they love.

This chartbook is designed to broaden the reader's understanding of the current system of care for people with chronic conditions by providing: updated demographic information and prevalence rates for people with chronic and *multiple* chronic conditions (Section I), an examination of how and why the current health care system strains to treat these individuals (Section II), and an overview of the implications of chronic conditions on individuals and their caregivers (Section III).

As a nation, we spend a considerable amount of our health care dollars on people with chronic conditions. This chartbook outlines the challenges the health care system continues to face in using its resources efficiently and effectively to provide access to high-quality, coordinated care and appropriate services that maintain health and functioning for people with chronic conditions.

# Who Are People with Chronic Conditions?

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

In *Chronic Care in America: A 21<sup>st</sup> Century Challenge*, authors Catherine Hoffman, Sc.D., and Dorothy Rice, Sc.D. (Hon.), estimated that by the year 2000, there would be 105 million people with chronic conditions, and that by 2020, this number would grow to an estimated 134 million people. With updated data, we now estimate that the number of people with chronic conditions exceeds that projection, having reached 125 million in 2000 and growing to an estimated 157 million by 2020.

There are many reasons for this growth. Advances in medical science and technology—new diagnostic testing, medical procedures and pharmaceuticals—are being used to treat acute illnesses and maintain a level of health and functioning that results in increased numbers of people living with chronic conditions. We are also screening and diagnosing chronic conditions with greater frequency and success. Earlier detection means people can live with chronic conditions that used to grow to acute care stages before diagnosis.

It is important to note that while the majority of people with chronic conditions are under age 65, the likelihood of having a chronic condition increases as one becomes older. Hypertension, the most common chronic condition, affects a greater percentage of older rather than younger people. Respiratory diseases such as asthma, on the other hand, are the most common chronic conditions for children. Regardless of the types of chronic conditions they have, adults and children confront similar obstacles in the health care system.

Another cause of the increasing prevalence of chronic conditions is the aging of society. As the baby boomers age, the number of people living with chronic conditions will grow dramatically. In 2011, the first baby boomers will become eligible for Medicare, and more than 13 percent of the population will be age 65 or older. In 2030, 20 percent of Americans will be in this age bracket. Even though there has been recent research showing a decline in disability rates among older adults,<sup>1</sup> the prevalence of chronic conditions among this population is not expected to decline.

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<sup>1</sup>Manton, K., and Gu, X. *Proceedings of the National Academy of Science of the United States of America*. May 22, 2001.

**Some other facts include:**

- **Women are more likely than men to have chronic conditions.** In part, this is because women have longer life expectancies than men and so, 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 chronically ill or disabled spouses, other relatives, or friends.
- **Almost half of all people with chronic conditions have multiple chronic conditions.** By 2020, 81 million people will have two or more chronic conditions. In 1996, Hoffman and Rice found that 44 percent of people with chronic conditions had more than one chronic condition. Today, we find that 48 percent of people with chronic conditions have more than one.
- **Twenty-five percent of people with chronic conditions 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 their care would likely be improved by coordination between the acute and long-term care systems.

**The Number of Americans with Chronic Conditions and the Problems They Face Continue to Grow**

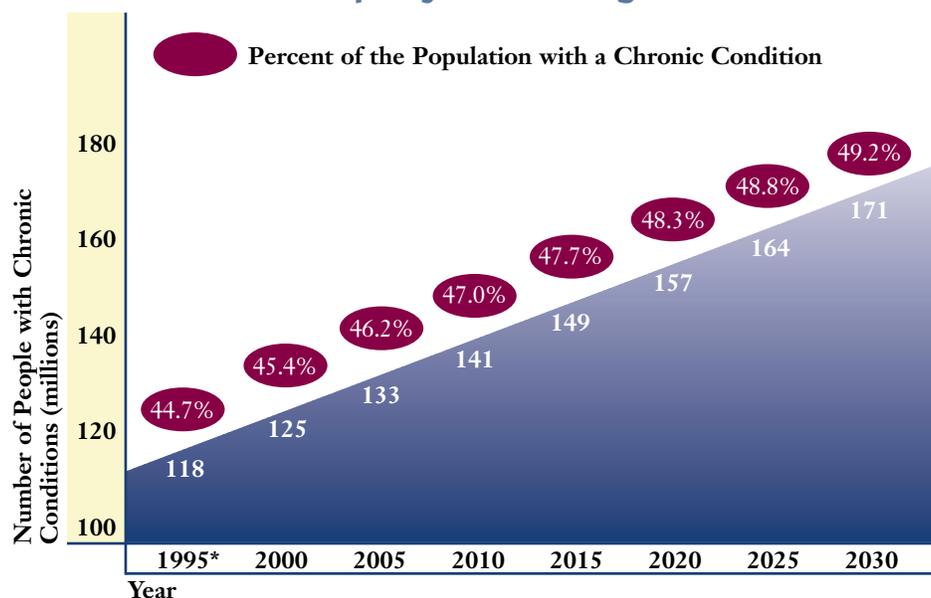
As a society, we need to be aware of the growing prevalence of people with chronic conditions, including multiple conditions, and the common problems they face as they seek care to maintain their health and the quality of their lives. As the number of people with chronic conditions continues to grow, the frequency of problems faced by this entire population will increase. Unless the current health care system changes, an increasing number of Americans with chronic conditions will have unmet health care needs. By working together, providers, patients, and policy-makers can change the way health care is delivered so that the needs of these Americans are addressed.

## 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 radically different ways. Some chronic conditions are highly disabling, others less so. Some chronic conditions, especially diabetes, may not disable a person currently, but may lead to severely disabling effects if not treated early and effectively. Some people return to former levels of daily activity after recovering from a heart attack, stroke, trauma, or other acute episode; others don't. Some individuals with chronic conditions live full, productive, and rewarding lives; for others, isolation, depression, and physical pain are the consequences of severe chronic illness.

Source: Hoffman, Catherine, and Rice, Dorothy P. *Chronic Care in America: A 21<sup>st</sup> Century Challenge*, 1996.

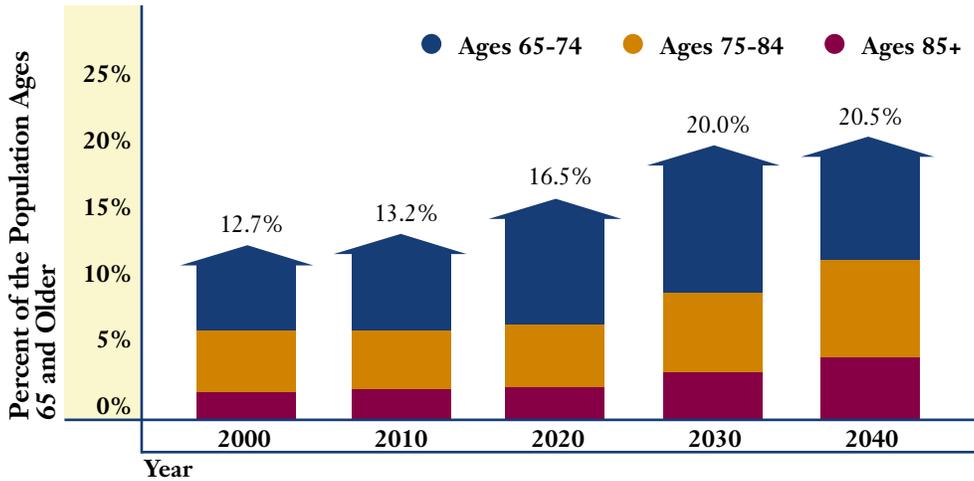
## The Number of People with Chronic Conditions Is Rapidly Increasing



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

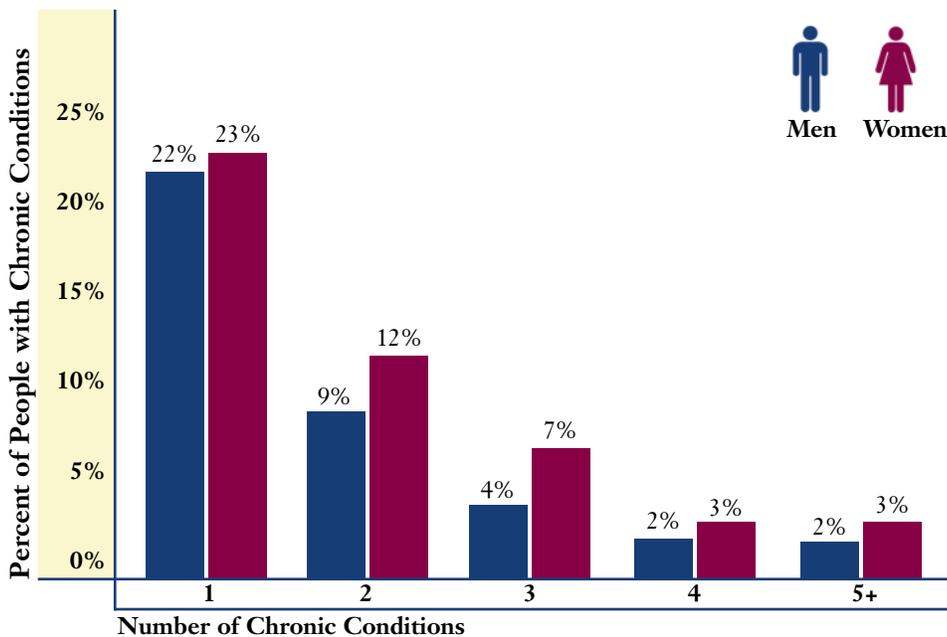
\*The 1995 estimate of prevalence differs from the estimate found in *Chronic Care in America: A 21<sup>st</sup> Century Challenge* by Hoffman and Rice (99 million people) due to different data sources. Hoffman and Rice used the 1987 National Medical Expenditure Survey as the basis for their estimate. This data source is the precursor to the Medical Expenditure Panel Survey, the 1997 version of which was used for the estimate in this chartbook.

## Americans Are Living Longer



Source: U.S. Bureau of the Census. *Projections of the Total Resident Population by 5-Year Age Groups and Sex with Special Age Categories: Middle Series, 1999 to 2100*. (NP-T3). Washington, D.C., January 2000.

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



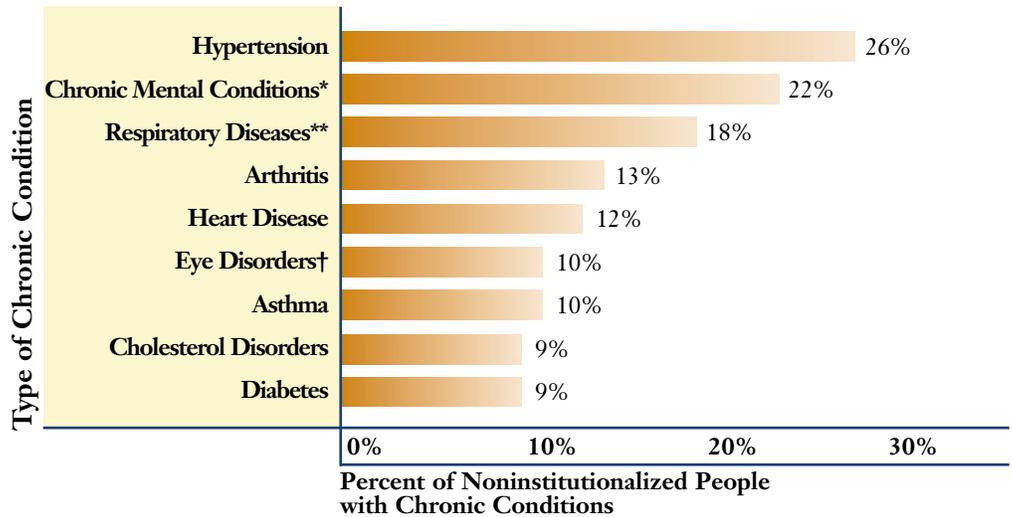
Source: Medical Expenditure Panel Survey, 1998.

“Our population is aging. People are living longer and longer lives with multiple chronic conditions. We believe our health system doesn’t provide them with the comprehensive, coordinated, and consistent care necessary for the best possible quality of life. It’s time to reorder our public policy priorities and redirect our research and clinical care efforts to focus on chronic disease in all its aspects—from prevention to maintaining quality of life.”

—The American Geriatrics Society and the AGS Foundation for Health in Aging

“No one is immune. Mental illnesses involve many of the same challenges as diabetes, multiple sclerosis, Alzheimer’s, and other chronic conditions. As a nation, we need to invest in comprehensive solutions—for treatment, care, and recovery.”  
 —National Alliance for the Mentally Ill

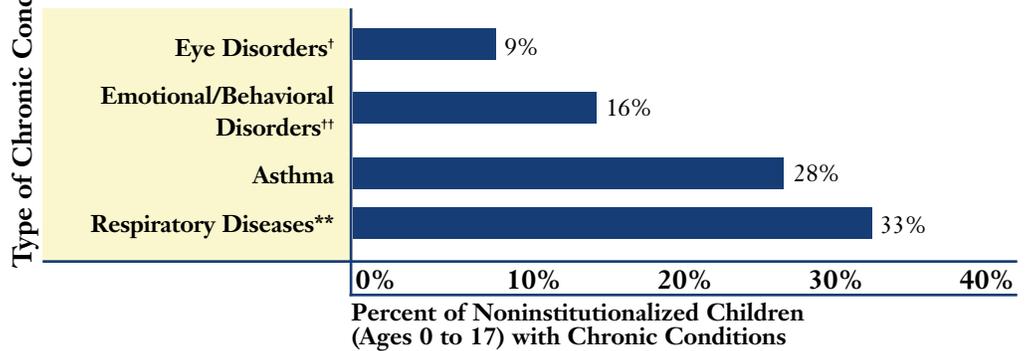
### Hypertension is the Most Common Chronic Condition



Source: Medical Expenditure Panel Survey, 1998.

“Millions of U.S. children with chronic illnesses have health care needs that may be unrecognized, unreimbursed, and unmet. These children and their families require a high level of coordination of care to achieve optimum health outcomes. Failure to meet these needs through provision of quality, coordinated health care may put these children at risk for lifelong disability and dependence.”  
 —American Academy of Pediatrics

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



Source: Medical Expenditure Panel Survey, 1998.

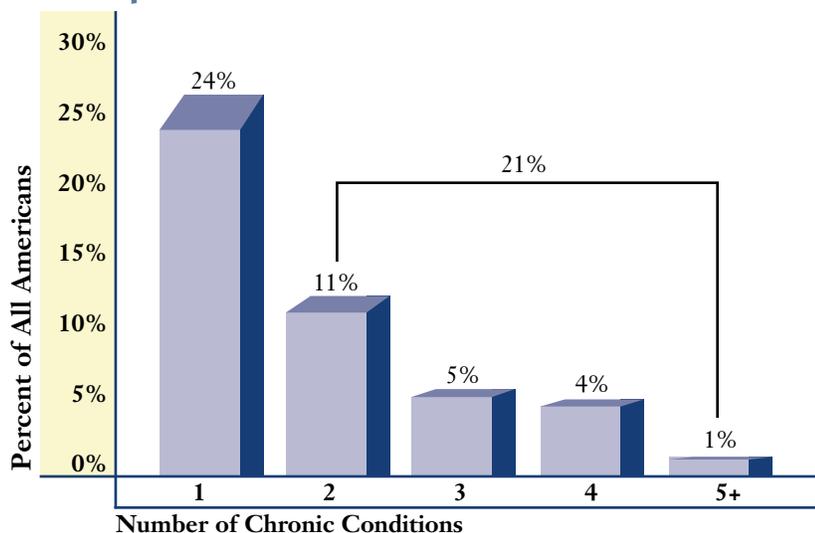
\* Chronic mental conditions include diagnoses such as personality disorders, anxiety, schizophrenia and related disorders, psychoses, and otherwise unclassified depressive disorder and neurotic disorders. Not included are preadult disorders, senility and organic mental disorders, and alcohol and substance abuse.

\*\* Respiratory diseases are upper and lower respiratory diseases, examples of which are allergic rhinitis, pulmonary congestion, and hypostasis. Not included are asthmas and chronic respiratory infections.

† Examples of eye disorders are cataracts, glaucoma, disorders of the globe, and visual disturbances.

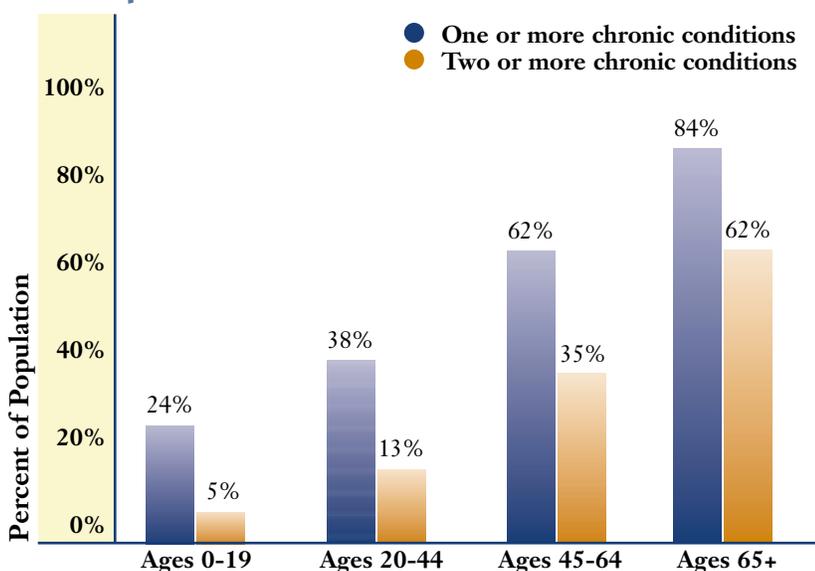
\*\* Emotional/behavioral disorders are preadult disorders that include hyperkinetic syndrome, otherwise unclassified disturbance of conduct, and emotional disturbance specific to childhood and adolescence.

## One in Five Americans Have Multiple Chronic Conditions



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

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



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

## Consequences of Having Multiple Chronic Conditions

Almost half of people with any kind of chronic condition have more than one condition to manage. Having multiple chronic conditions puts people at greater risk of 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 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.

As the elderly age, they face an increased risk of having multiple chronic conditions.

Although multiple chronic conditions tend to occur with age, five 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.

## 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.

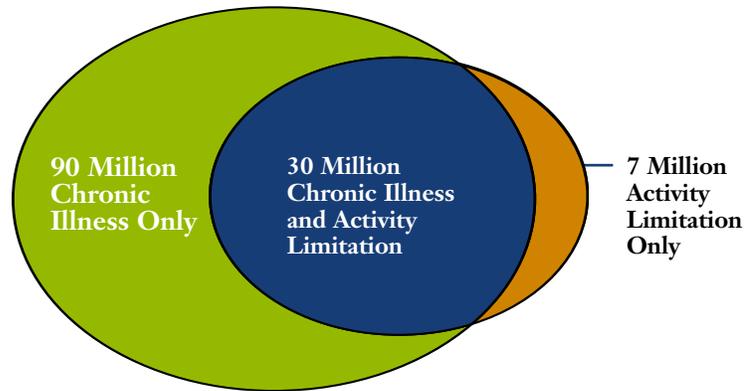
**Serious chronic conditions** are a subset of chronic conditions that require ongoing medical care and limit what a person can do.

**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.<sup>†</sup>

<sup>†</sup>People with activity limitations are identified through the 1998 Medical Expenditure Panel Survey Household Component. People are included if they received help or assistance with Activities of Daily Living (personal care such as bathing, dressing, or getting around the house), or if they received help or supervision with Instrumental Activities of Daily Living (using the telephone, paying bills, taking medications, preparing light meals, doing laundry, or going shopping). People are also counted as having an activity limitation if they reported: having difficulty walking, climbing stairs, grasping objects, reaching overhead, lifting, bending or stooping, or standing for long periods of time; using assistive technology; being restricted in work, household activities, or schooling; having social or recreational limitations; suffering cognitive limitations (having confusion or memory loss, difficulty making decisions, or requiring supervision for their safety); having serious vision problems, deafness, or difficulty hearing; having play-related limitations (for children four years old and younger); or having a mental or physical health problem that limits school attendance or requires a special school program (for children ages five to 17).

## Many People with Chronic Illnesses Also Have Activity Limitations

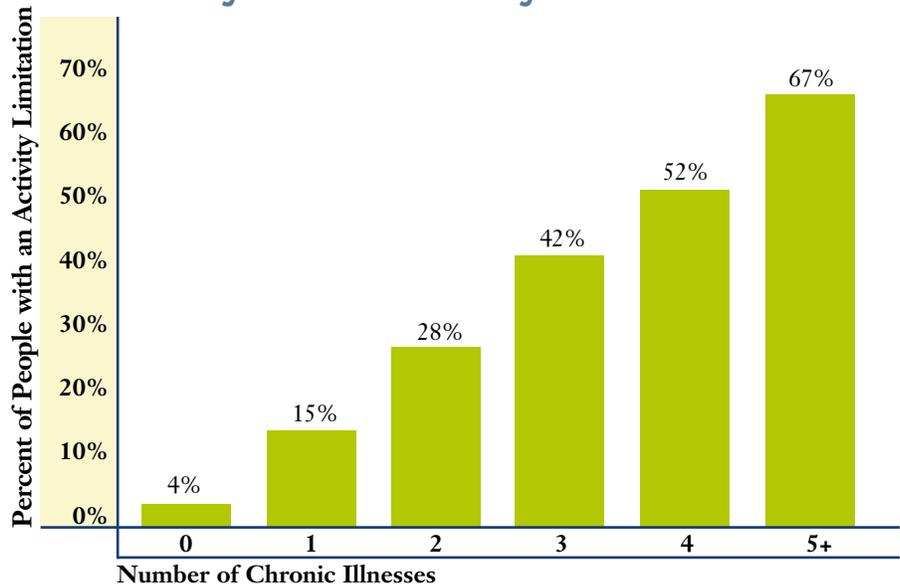


n = 127 Million\*

Source: Medical Expenditure Panel Survey, 1998.

\*In 1998, about 120 million people had one or more chronic conditions (and this number grew to 125 million in the year 2000). As discussed in more detail in the Methodology section, the number of people with chronic conditions is derived from looking at medical diagnoses. There are people who have a chronic condition in the form of an activity limitation that is not based on an illness. This chart reflects the number of people from the 1998 Medical Expenditure Panel Survey who had a chronic condition either in the form of a chronic illness, an activity limitation, or both—127 million people.

## People with Multiple Chronic Illnesses Are More Likely to Have Activity Limitations



Source: Medical Expenditure Panel Survey, 1998.





# How Do Chronic Conditions Affect Health Care Financing and Utilization?

People with chronic conditions are the heaviest users of health care services in all major service categories. The proportion of services used by people with chronic conditions has increased. For example, in 1996, Hoffman and Rice found that 69 percent of all hospital admissions were attributable to people with chronic conditions. Today, that percentage has increased to 76 percent. People with chronic conditions account for 88 percent of all prescriptions filled and 72 percent of all physician visits. Consequently, the vast majority of health care dollars spent in the United States are being spent on behalf of people with chronic conditions. In 1998, the care provided to people with chronic conditions accounted for 78 percent of all health care spending.<sup>1</sup>

Health care spending also increases considerably when people have multiple chronic conditions, as do approximately half of all people with chronic conditions. There are a number of reasons why this is so; age, clinical complexity, and activity limitations resulting from chronic conditions are a few. The more chronic conditions a person has, the more he or she needs and uses health care services.

In general, health care spending for a person with one chronic condition is two times greater than spending for someone without any chronic conditions, while spending is about 14 times greater for someone with five or more chronic conditions. Likewise, individuals with multiple chronic conditions account for two-thirds of all prescriptions filled.

Currently, care for people with chronic conditions is financed by a variety of payors: 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 majority of people with chronic conditions are of working age and are privately insured.

An estimated 66 million people with chronic conditions have private insurance coverage, and their care accounts for about 70 percent of private insurance spending. But many incur substantial out-of-pocket expenses as well for services not covered by their plans. (This information is further highlighted in Section III.)

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<sup>1</sup>For the purposes of this chartbook, health care spending has been defined as direct payments (including private insurance, out-of-pocket, and government program spending) for health care. Indirect spending, such as research, is not included. Direct payment categories in the 1998 Medical Expenditure Panel Survey include: physician visits; hospital inpatient, outpatient, and emergency room visits; prescription drugs; non-physician visits such as midwives, chiropractors, and therapists; dental and vision services; and medical equipment and services. Payments for services under capitated arrangements were imputed by the survey sponsor, the Agency for Healthcare Research and Quality.

Almost all Medicare dollars and about 80 percent of Medicaid resources are spent on people with chronic conditions.

Two-thirds of Medicare spending is for people with five or more chronic conditions. In fact, 85 percent of Medicare enrollees and 39 percent of Medicaid enrollees have one or more chronic conditions.

Adjusting the systems of financing and delivering care to better meet the needs of people with chronic conditions requires a focus on preventing diseases when possible, identifying diseases early when they occur, implementing secondary and tertiary prevention strategies that slow disease progression and the onset of activity limitations, and coordinating chronic care across the service continuum. The lack of such efforts may lead to inappropriate or unnecessary service utilization by people with multiple chronic conditions, further increasing health care spending. The more chronic conditions a person has, the more likely the person will be hospitalized unnecessarily for chronic conditions that could have been effectively treated on an outpatient basis if managed better before becoming acute.<sup>2</sup>

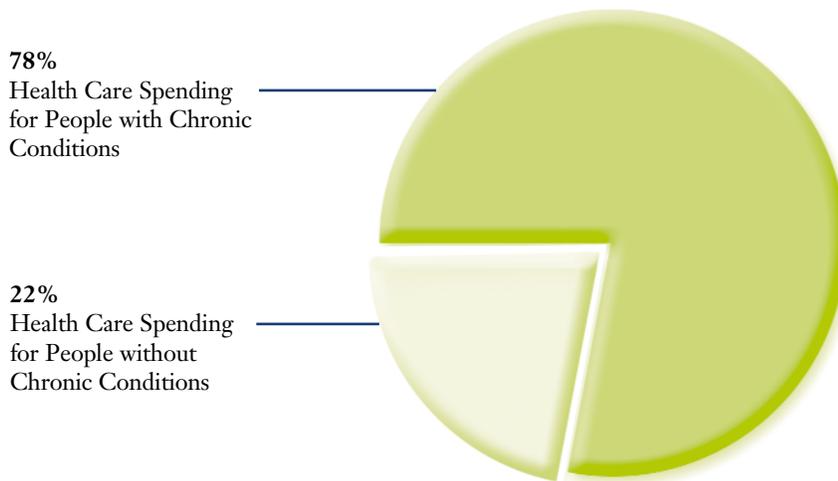
### **Different Diseases, Common Problems, Shared Solutions**

Everyone has a stake in seeing that better chronic care is more appropriately delivered and adequately reimbursed in this country. From health care payors, who currently pay for services that result from duplication or inappropriate utilization, to providers who are not trained to address the needs of people with chronic conditions, to patients who face poor outcomes, all aspects of the system need to be better designed to address chronic care. By better understanding the common problems people with different chronic conditions face along the continuum of care, payors, providers, and patients can become better equipped to work toward identifying and implementing integrated solutions.

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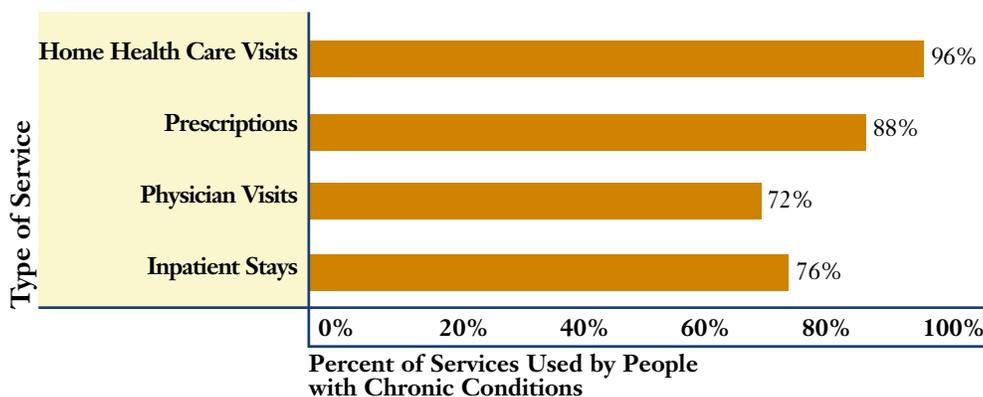
<sup>2</sup>These conditions, for which timely and effective outpatient primary care may help to reduce the risks of hospitalizations, are known as ambulatory care sensitive conditions (ACSCs). Appropriate outpatient care can prevent the onset of an acute illness, control an acute episodic illness, or help manage a chronic condition.

## People with Chronic Conditions Account for 78 Percent of All Health Care Spending



Source: Medical Expenditure Panel Survey, 1998.

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



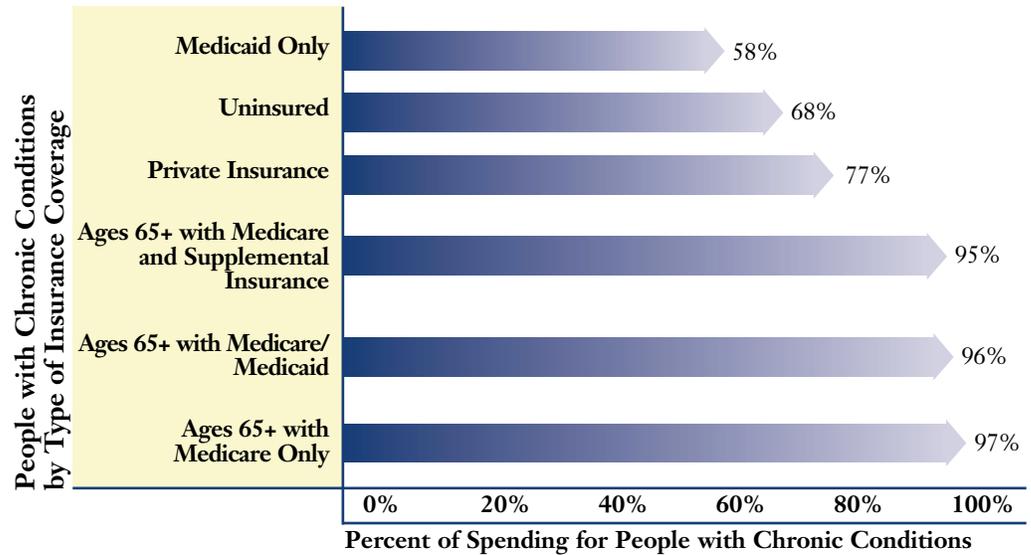
Source: Medical Expenditure Panel Survey, 1998.

## Health Care Spending for People with Chronic Conditions is Disproportional to the Percent of People with Chronic Conditions.

- **Seventy-eight percent** of health care spending is attributed to the 44 percent of the noninstitutionalized population that has one or more chronic conditions.
- **Sixty-eight percent** of private health insurance spending is attributed to the 40 percent of privately insured people who have chronic conditions.
- **Three-fifths** of all health care spending for the uninsured is for care received by the 27 percent of uninsured people with chronic conditions.
- **Seventy-seven percent** of Medicaid spending is for the almost 40 percent of noninstitutionalized Medicaid beneficiaries with chronic conditions.

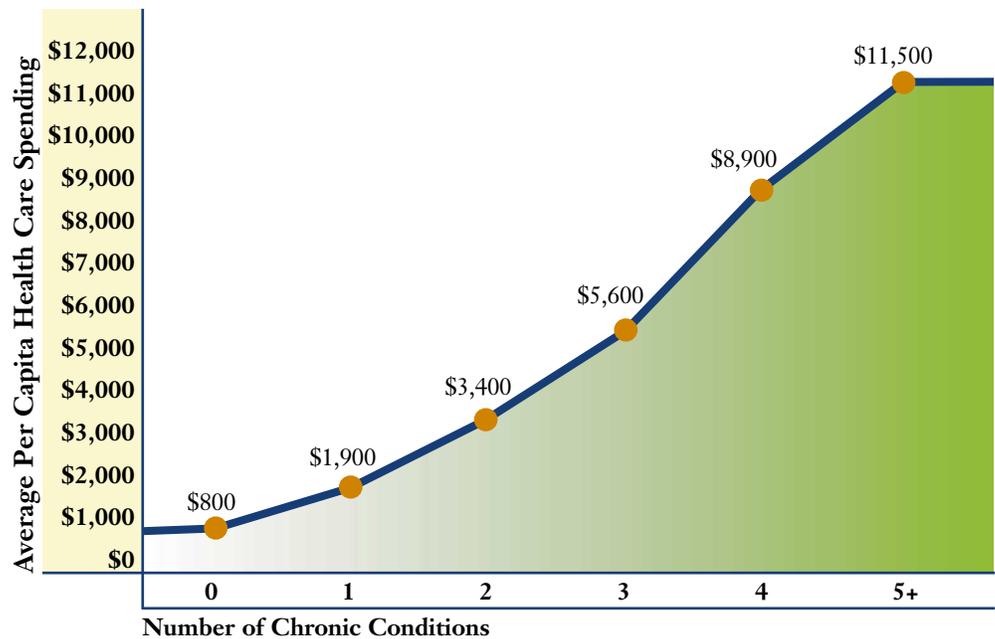
Source: Medical Expenditure Panel Survey, 1998.

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



Source: Medical Expenditure Panel Survey, 1998.

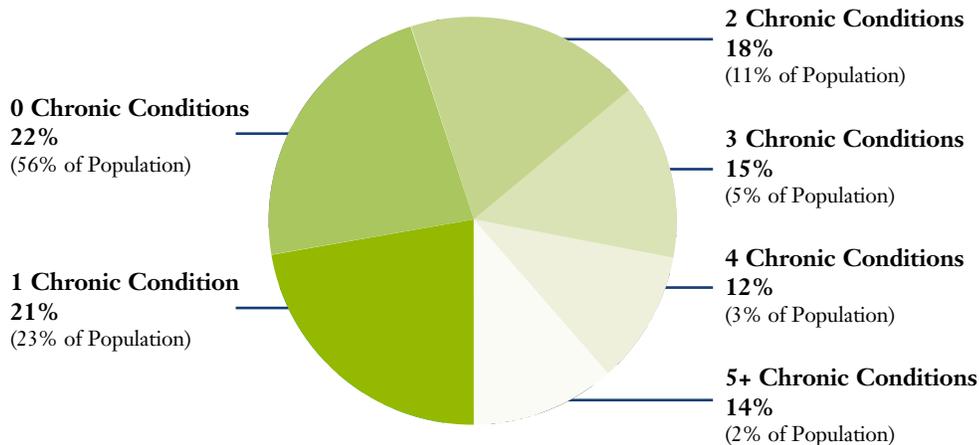
### Health Care Spending Increases with the Number of Chronic Conditions



Source: Medical Expenditure Panel Survey, 1998.

## More than Half of Health Care Spending Is on Behalf of People with Multiple Chronic Conditions

**Percent of Total Health Care Spending by Number of Chronic Conditions\***  
(Percent of Population)



Source: Medical Expenditure Panel Survey, 1998.

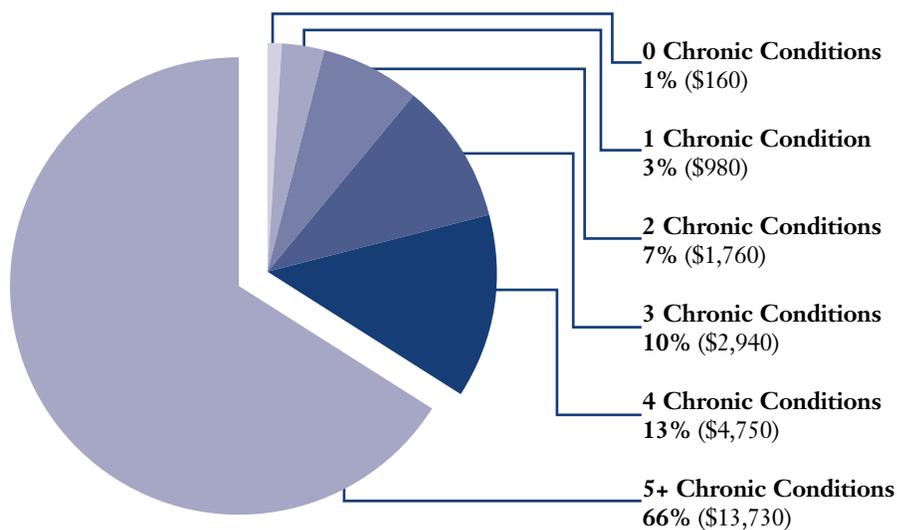
\*Equal to more than 100% due to rounding.

“Research shows that many people with Alzheimer’s disease and dementia have serious co-existing medical conditions. One study showed, for example, that of 5,300 people with Alzheimer’s disease and dementia, 20 percent also had cancer, 28 percent had congestive heart failure, 22 percent had diabetes and 27 percent had chronic obstructive pulmonary disease. Dementia complicates the treatment and increases the cost of care for these co-existing conditions.”

—Alzheimer’s Association

## Two-thirds of Medicare Spending Is for People with Five or More Chronic Conditions

**Percent of Medicare Spending per Person by Number of Chronic Conditions**  
(Average Annual Expenditure)

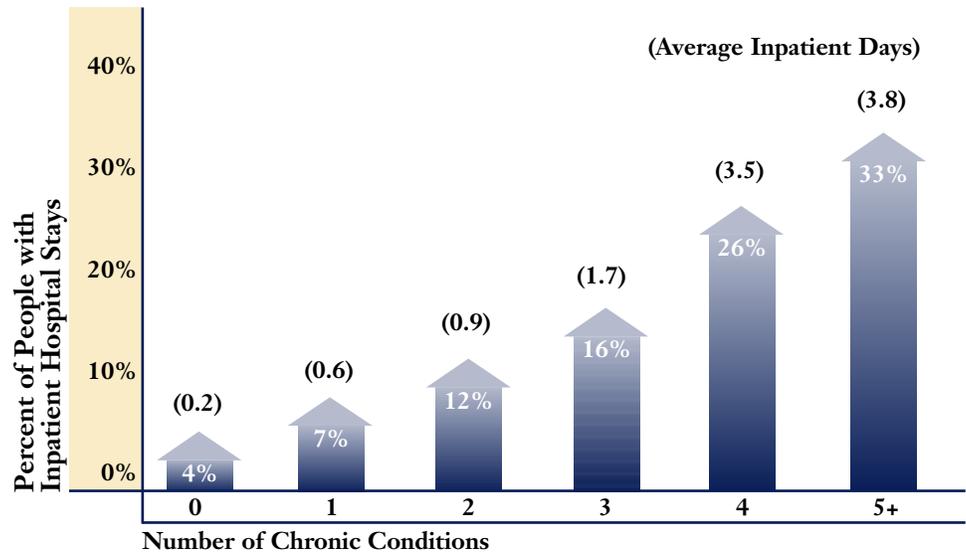


Source: Medicare Standard Analytic File, 1999.

“People with chronic conditions are health care’s largest, highest-cost, and fastest-growing service group. To provide better care, we need reforms structured from the patient’s perspective: assessing quality across treating providers and settings; calculating patient care costs across settings and over time; providing incentives to prevent, delay, or minimize disease and disability progression; and ensuring continuity of care among the multiple providers who are involved in a patient’s care.”

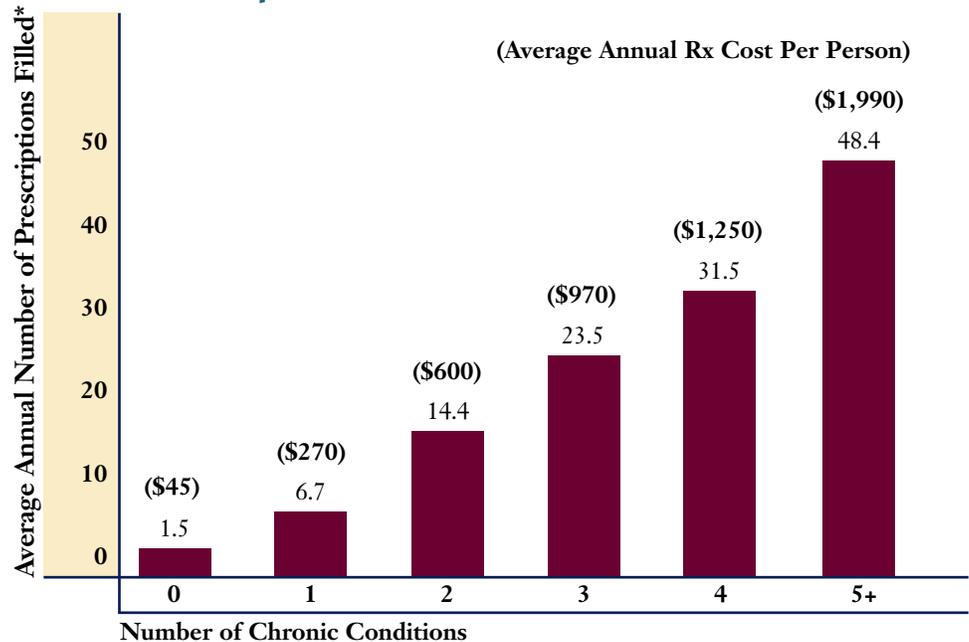
—National Chronic Care Consortium

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



Source: Medical Expenditure Panel Survey, 1998.

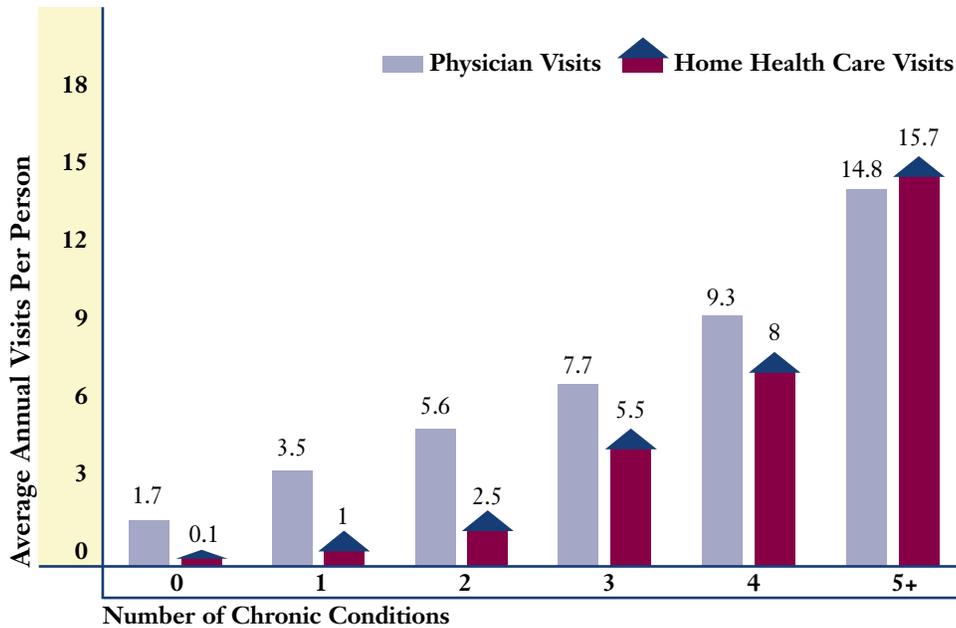
### People with Multiple Chronic Conditions Fill More Prescriptions



Source: Medical Expenditure Panel Survey, 1998.

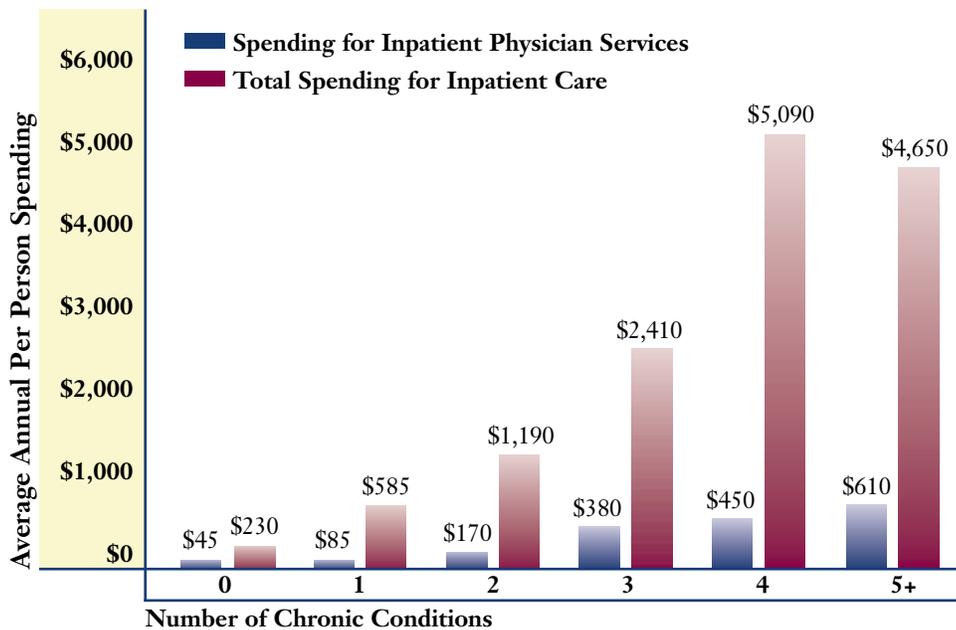
\*The average number of prescriptions filled includes refills and free samples in addition to original prescriptions.

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



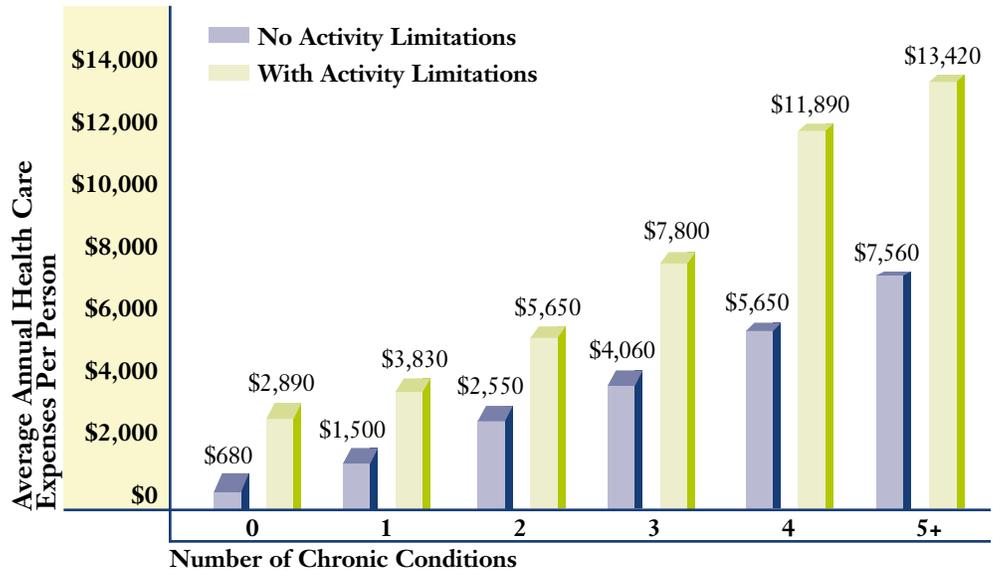
Source: Medical Expenditure Panel Survey, 1998.

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



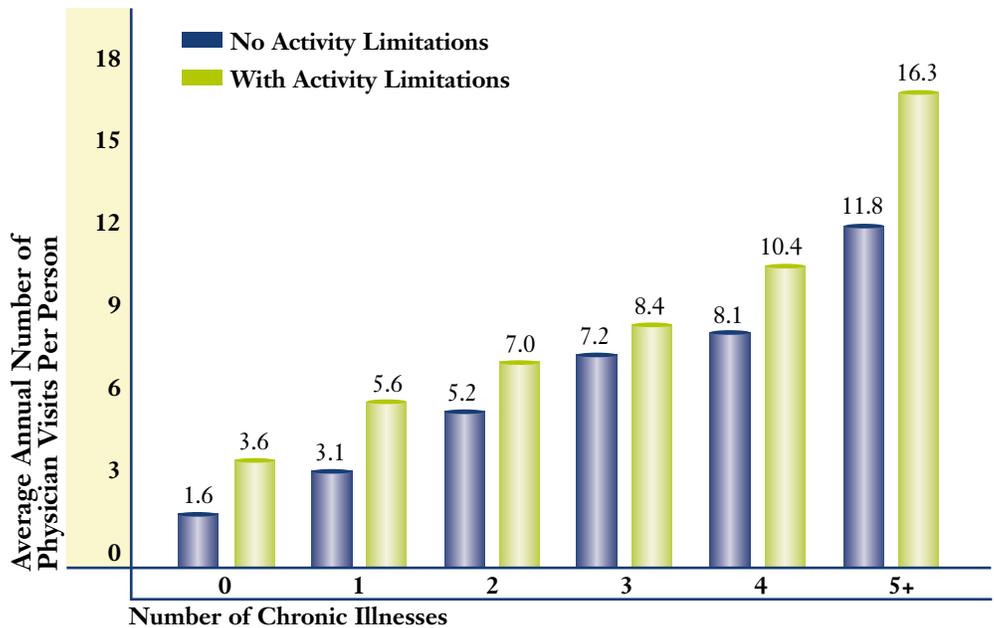
Source: Medical Expenditure Panel Survey, 1998.

### Health Care Spending More Than Doubles for People with Chronic Illnesses and Activity Limitations



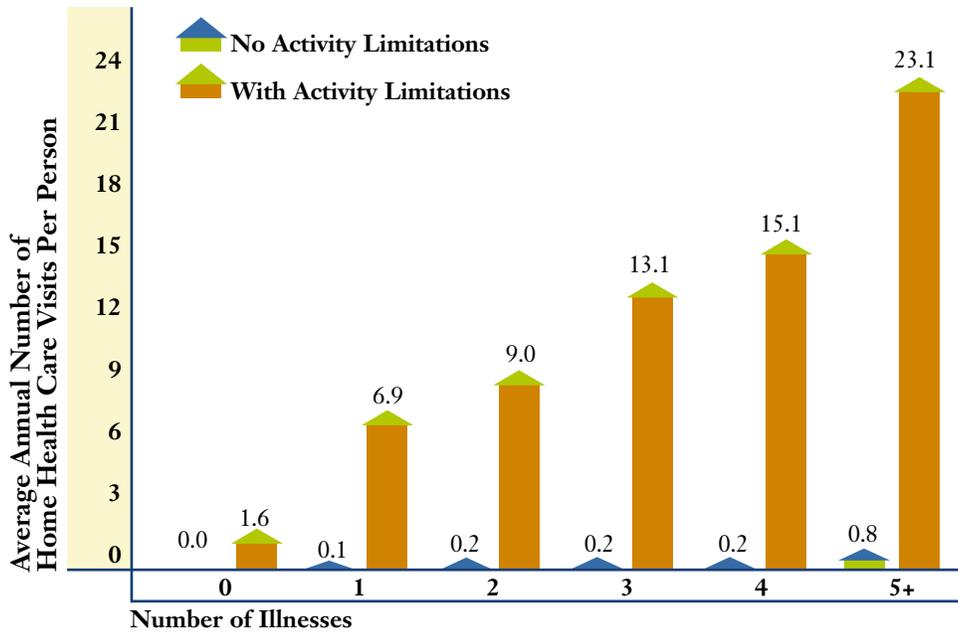
Source: Medical Expenditure Panel Survey, 1998.

### Individuals with Chronic Illnesses and Activity Limitations Have More Physician Visits



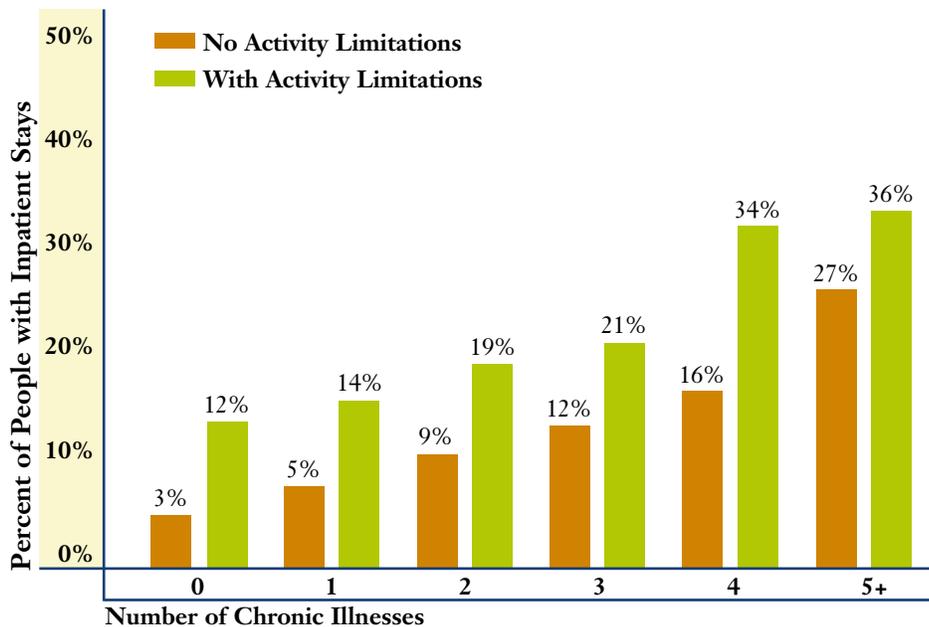
Source: Medical Expenditure Panel Survey, 1998.

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



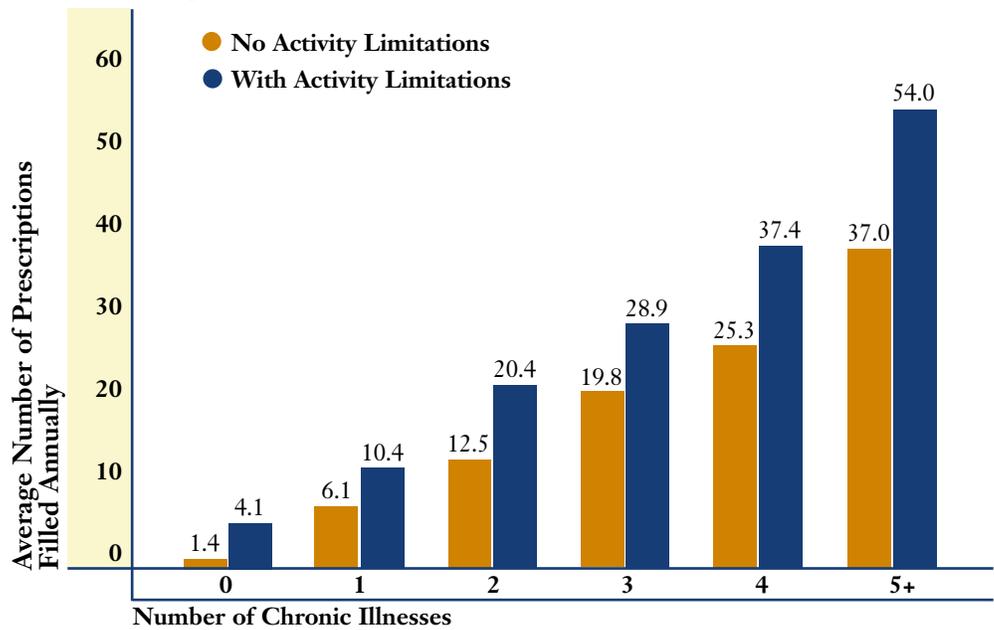
Source: Medical Expenditure Panel Survey, 1998.

## People with Chronic Illnesses and Activity Limitations Have More Inpatient Stays



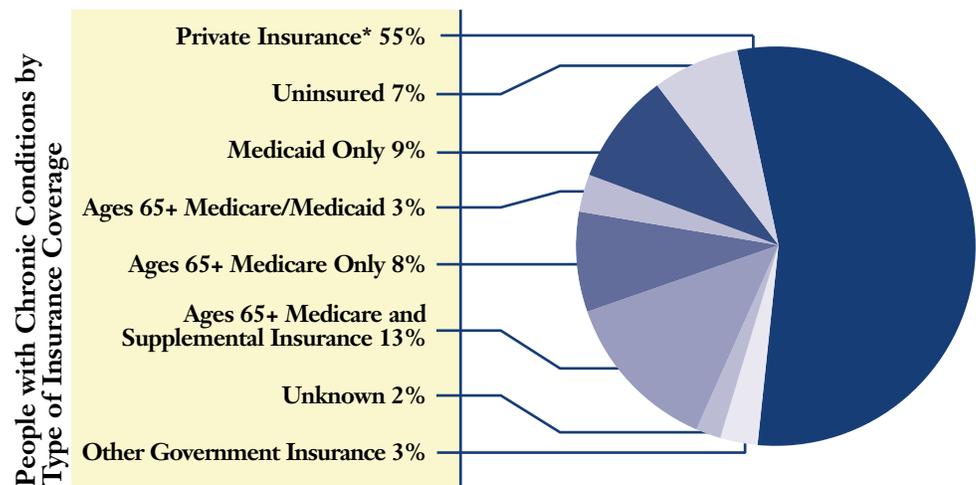
Source: Medical Expenditure Panel Survey, 1998.

## People With Multiple Chronic Illnesses and Activity Limitations Fill More Prescriptions



Source: Medical Expenditure Panel Survey, 1998.

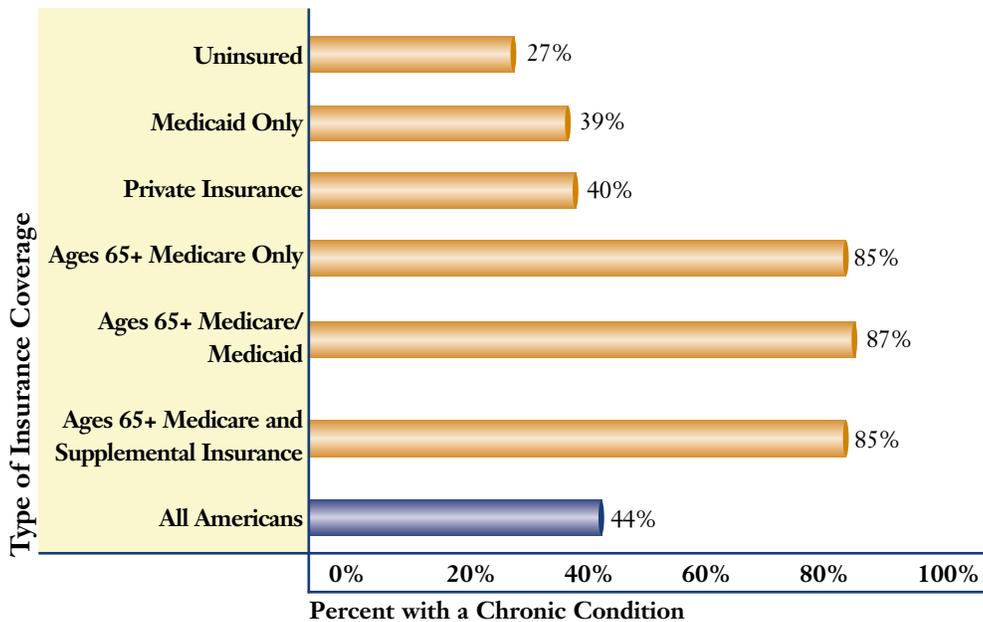
## Most People with Chronic Conditions Have Private Health Insurance\*



Source: Medical Expenditure Panel Survey, 1998.

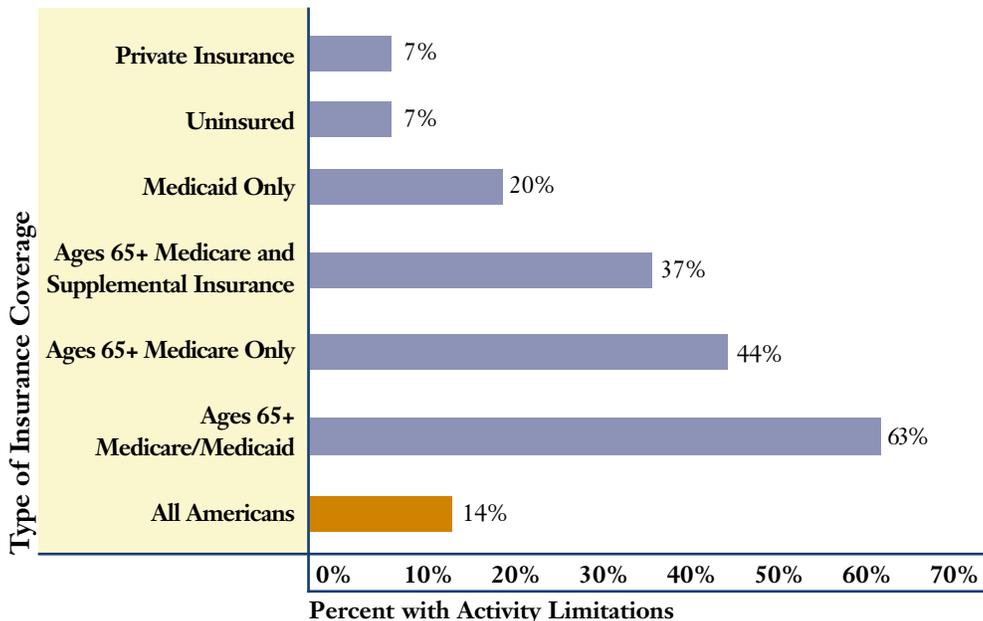
\*Private health insurance includes non-retiree coverage obtained through employer-related groups or commercial insurance purchased through what is commonly referred to as the individual market.

## People with Medicare Are Most Likely to Have Chronic Conditions



Source: Medical Expenditure Panel Survey, 1998.

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



Source: Medical Expenditure Panel Survey, 1998.

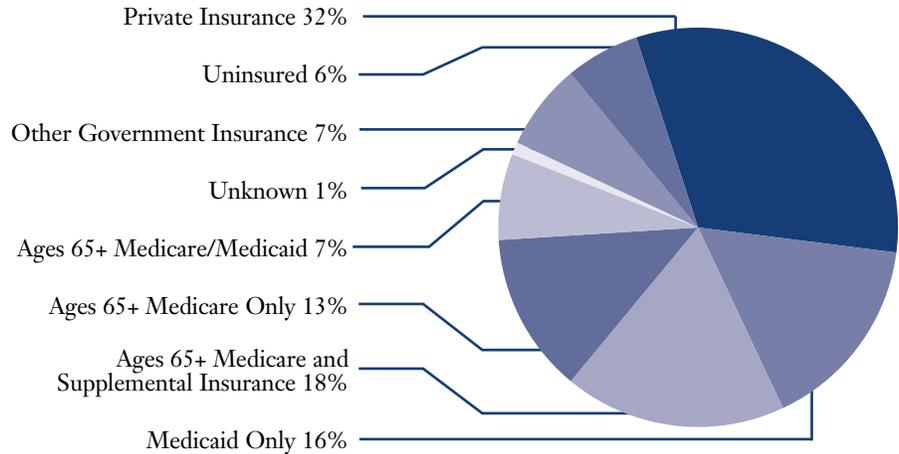
## Health Coverage Distribution Among People with Chronic Conditions

- **Almost 66 million** Americans with a chronic condition have private health insurance.
- **Fifteen million** people over age 65 with a chronic condition have Medicare coverage and supplemental insurance (either Medigap or employer-sponsored retiree coverage).
- **Eleven million** non-institutionalized Americans with chronic conditions have only Medicaid coverage.
- **Eight and a half million** Americans with one or more chronic conditions are uninsured.

Source: Medical Expenditure Panel Survey, 1998.

## Most People with Activity Limitations Have Medicare Coverage

People with Activity Limitations



n=37 million\*

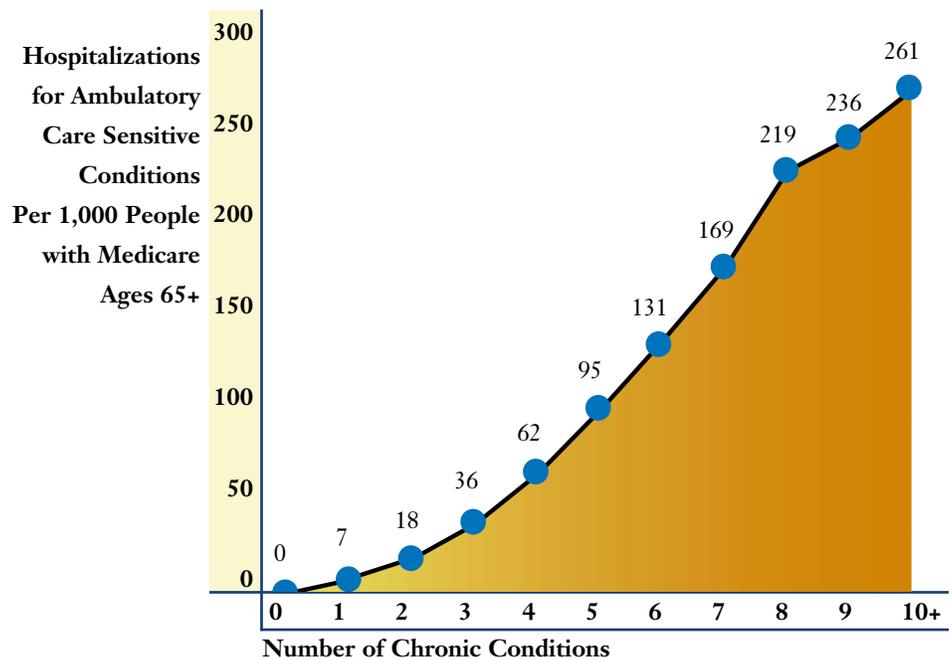
Source: Medical Expenditure Panel Survey, 1998.

\*It is estimated that 37 million Americans have at least one activity limitation, with 30 million of this population having both an activity limitation and at least one chronic illness.

### What Are Ambulatory Care Sensitive Conditions?

Ambulatory care sensitive conditions (ACSCs) are conditions for which timely and effective outpatient primary care may help to reduce the risks of hospitalizations. Appropriate outpatient care can prevent the onset of an acute illness, control an acute episodic illness, or help manage a chronic condition.

## Multiple Chronic Conditions Lead to Unnecessary Hospitalizations



Source: Medicare Standard Analytic File, 1999.





# How Are Individuals and Caregivers Affected by Chronic Conditions?

People with chronic conditions, especially individuals who have more than one condition, have trouble obtaining quality care from the current health care system. They often receive conflicting advice from different providers, leaving them to wonder which provider to believe. Without any real ability to discern what is the correct information or the most appropriate course of care or treatment, many people are left guessing, further compounding the stress they may already be experiencing from their illness or illnesses. In the worst situations, they may even be harmed by inappropriate care that facilitates the progression of their disease. People with serious chronic conditions (those with long-term illnesses that require ongoing medical care and limit their activities) have even greater difficulties with the health care system. They are more likely to have three or more physicians at a given time *and* to receive conflicting medical advice. Many have trouble accessing needed services (e.g., medical specialists, mental health services, in-home health care, etc.), and some even receive prescriptions that adversely interact with one another.

Individuals with chronic conditions have known about problems the current health care system has providing coordi-

nated, quality care. Physicians also understand the effect these obstacles have on their patients' treatment. According to a survey commissioned by Partnership for Solutions and conducted in 2001 by Mathematica Policy Research, Inc., physicians agreed that the current health care system is not organized to address the many different needs of people with chronic conditions, and that health care services can be hard for patients to access. Even when care is received, the physicians recognized that it is often not well coordinated, which can lead to unnecessary service utilization, including inappropriate hospitalizations and nursing home placements, as well as duplicate diagnostic tests. The physicians reported that coordinating care for people with chronic conditions is difficult, and they felt their training had not adequately prepared them to care for this type of patient.

The American public is already aware of the state of chronic care in this country. In a survey commissioned by Partnership for Solutions and conducted in 2000 by Harris Interactive, Inc., Americans reported that they believe adequate insurance coverage and access to care are problems for people with chronic conditions.

## The Public's Three Biggest Fears About Having Chronic Conditions Are:

- Not being able to pay for care
- Loss of independence
- Becoming a burden to family and friends

Source: *Chronic Illness and Caregiving*, Harris Interactive, Inc., 2000.

They cited the lack of assistance from family and friends, difficulty in accessing services, inability to obtain insurance, and inability to pay for care as the major challenges.

For people with chronic conditions, personal spending on health care is a significant expense. As the number of chronic conditions a person has increases, so do the out-of-pocket costs. People with chronic conditions pay more out-of-pocket for health care than individuals without chronic conditions—up to five times more—regardless of the type of insurance they have. People with chronic conditions also spend much more on prescription drugs than people without such conditions. For individuals with one chronic condition, annual out-of-pocket spending for prescription drugs is \$130. This number jumps to \$930 for people with five or more chronic conditions. Among people with insurance coverage, Medicare beneficiaries spend the most out of pocket because their insurance typically does not cover all services, particularly prescription drugs, and because, as a group, they have more chronic conditions. 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.

Many people with multiple chronic conditions rely on others not only for financial support but for personal assistance as well. Almost nine and a half million Americans devote an average of 24 hours per week to assisting family and friends with long-term health conditions and disabilities. Family caregivers provide personal care, health care, and help accessing services and navigating the health care system. Today, more men are family caregivers than in previous years—roughly 35 percent compared with 28 percent as reported by Hoffman and Rice in 1996—however, caregivers continue to be predominately women (65 percent). Of all caregivers, half are employed, 40 percent of those full-time, and nearly 40 percent are 55 years of age or older.

While these family caregivers may not view their assistance as an encumbrance, people with chronic conditions still worry about becoming a burden to their family and friends. The value of this caregiving, provided without monetary compensation, greatly exceeds spending on formal sources of personal assistance.

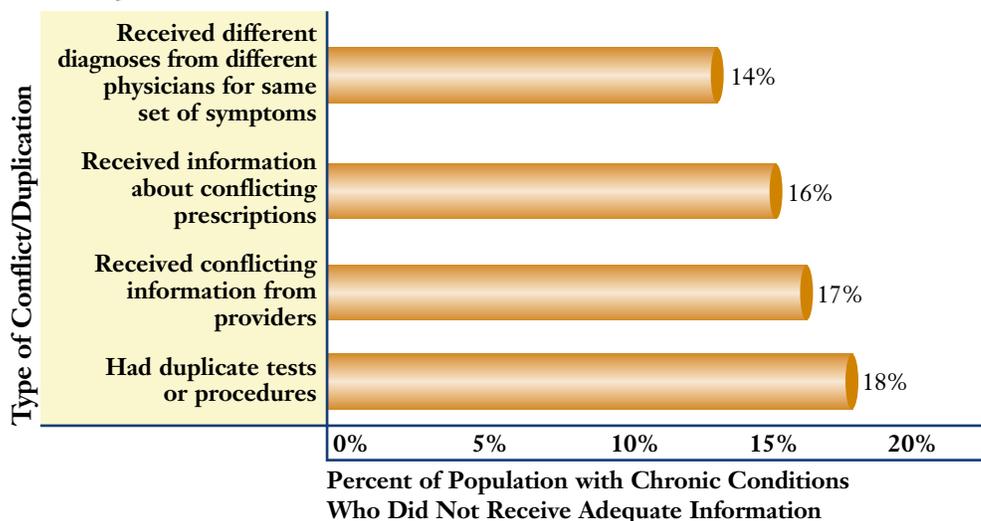
### **Good Health Care Means Coordinated Chronic Care**

For those who live with chronic conditions, their illnesses and disabilities present physical, emotional, and financial challenges. Often the services they need extend beyond the clinical setting to include supportive services such as home health care and personal assistance.

These supportive services help people with chronic conditions maintain their day-to-day activities and improve the quality of their lives. Many people with chronic conditions often need better health care coverage.

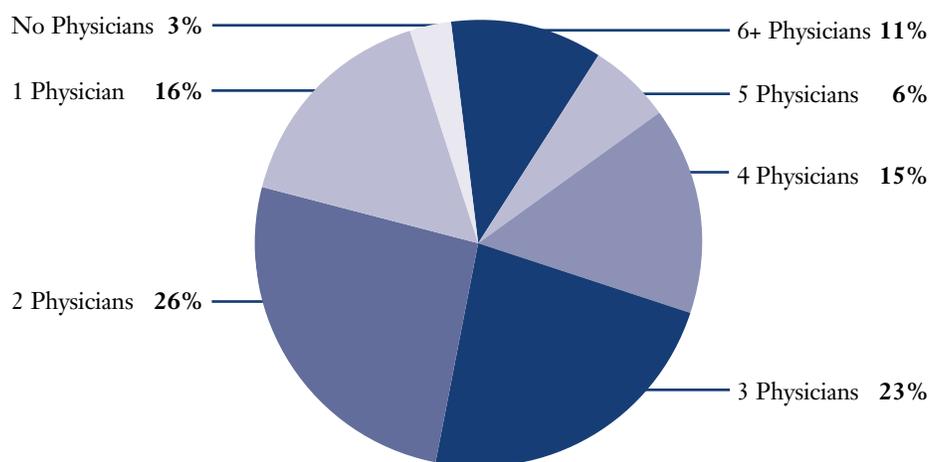
Living well with chronic conditions requires ongoing, coordinated care across health care settings and among various service providers. A chronic care model is organized around individuals' needs and preferences to coordinate services with the goal of maintaining health status and slowing disease progression. Supportive services are leveraged to enhance the effectiveness of medical care and to improve the quality of life for people with chronic conditions. Without an appropriate chronic care model in place that values coordinated care, people with chronic conditions will continue to experience difficulty accessing appropriate services.

### People with Chronic Conditions Report Not Receiving Adequate Information



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

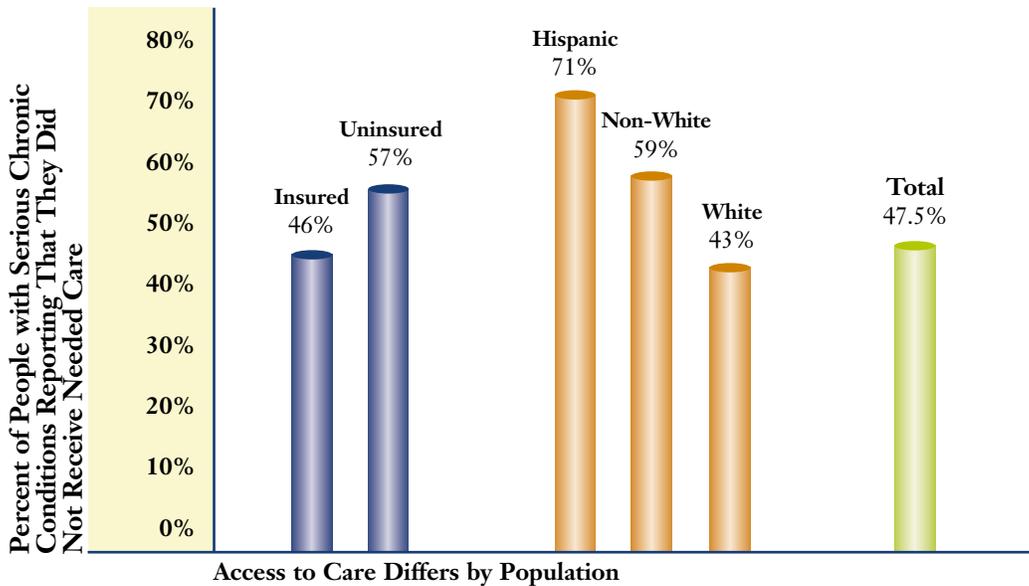
### More than Half of People with Serious Chronic Conditions\* Have Three or More Different Physicians



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

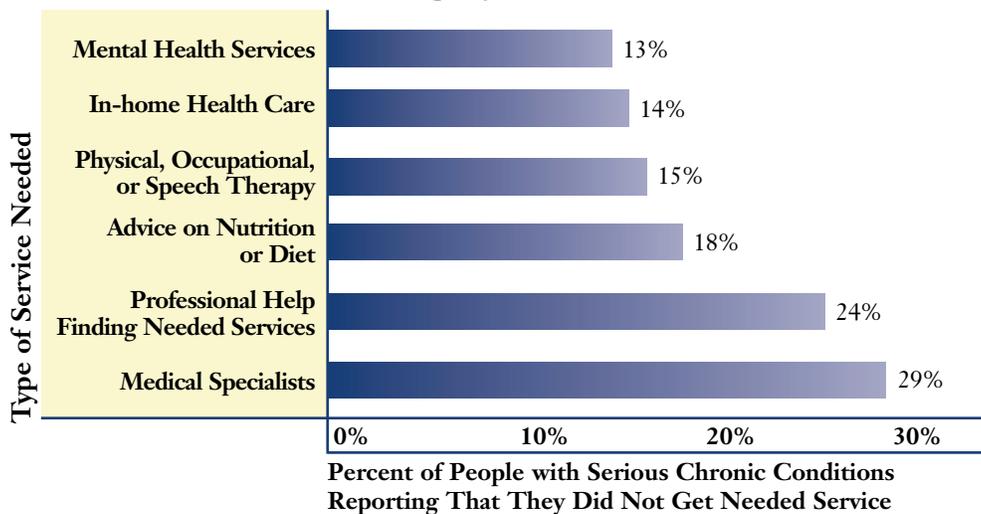
\*People with serious chronic conditions have a condition that is expected to last a year or more, requires ongoing medical attention, and limits what one can do. Serious chronic conditions are a subset of chronic conditions, which are also expected to last a year or more but limit what one can do, *and/or* may require ongoing medical care.

## People with Serious Chronic Conditions\* Report Problems with Access to Care



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

## People with Serious Chronic Conditions\* Have Trouble Accessing Specific Services



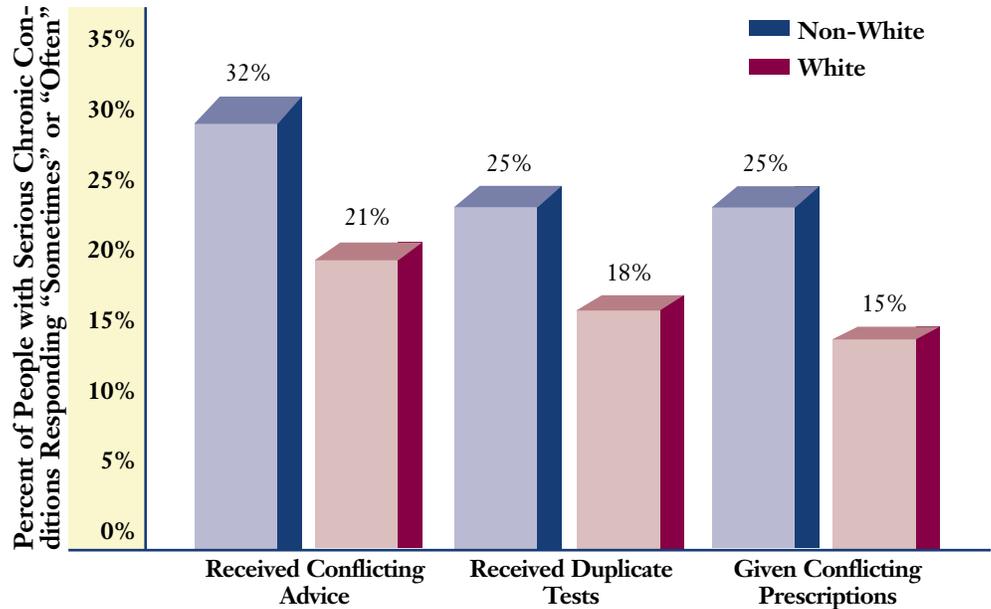
Source: *Serious Chronic Illness Survey*, conducted by the Gallup Organization, 2002.

\*People with serious chronic conditions have a condition that is expected to last a year or more, requires ongoing medical attention, and limits what one can do. Serious chronic conditions are a subset of chronic conditions, which are also expected to last a year or more but limit what one can do, *and/or* may require ongoing medical care.

“Chronic diseases, such as diabetes, require a continuum of care that the current health system does not provide.”

—American Diabetes Association

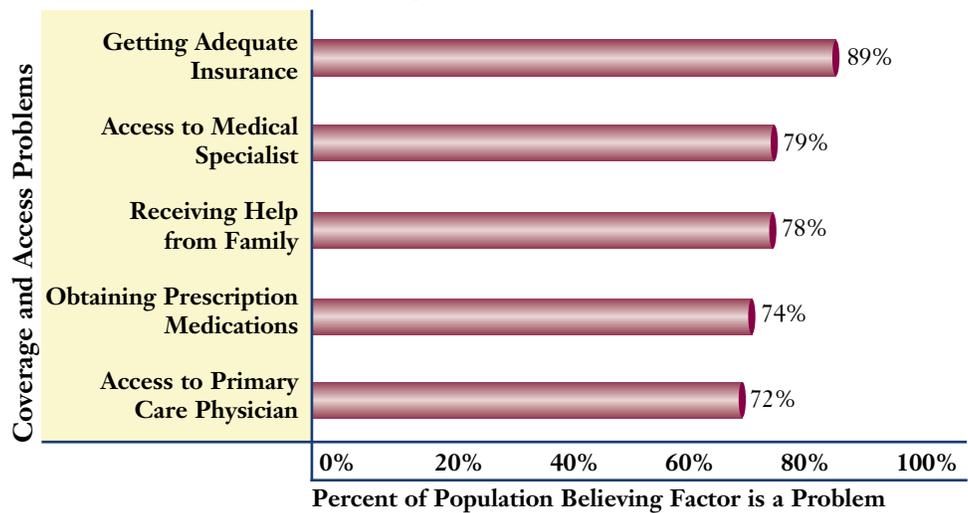
### Quality of Care for People with Serious Chronic Conditions\* Varies by Race



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

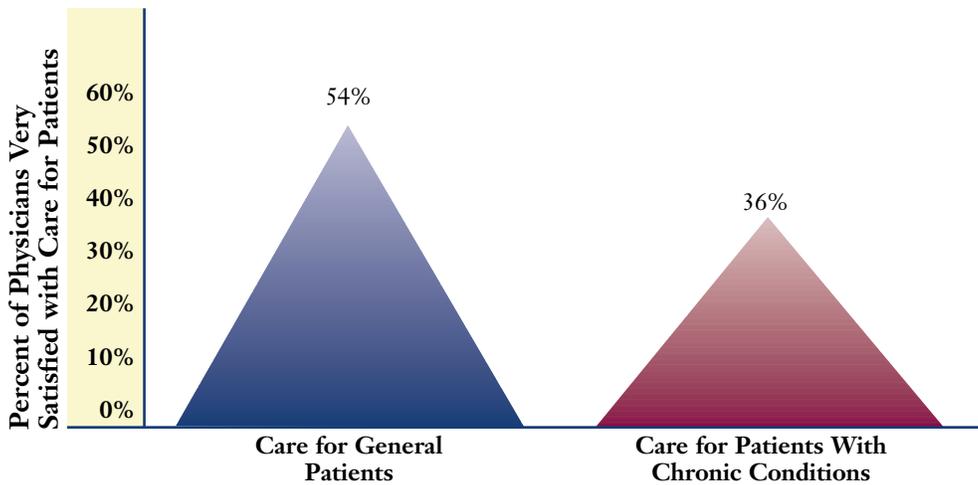
\*People with serious chronic conditions have a condition that is expected to last a year or more, requires ongoing medical attention, and limits what one can do. Serious chronic conditions are a subset of chronic conditions, which are also expected to last a year or more but limit what one can do, *and/or* may require ongoing medical care.

### Americans Believe that Coverage and Access to Care Are Problems for People with Chronic Conditions



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

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



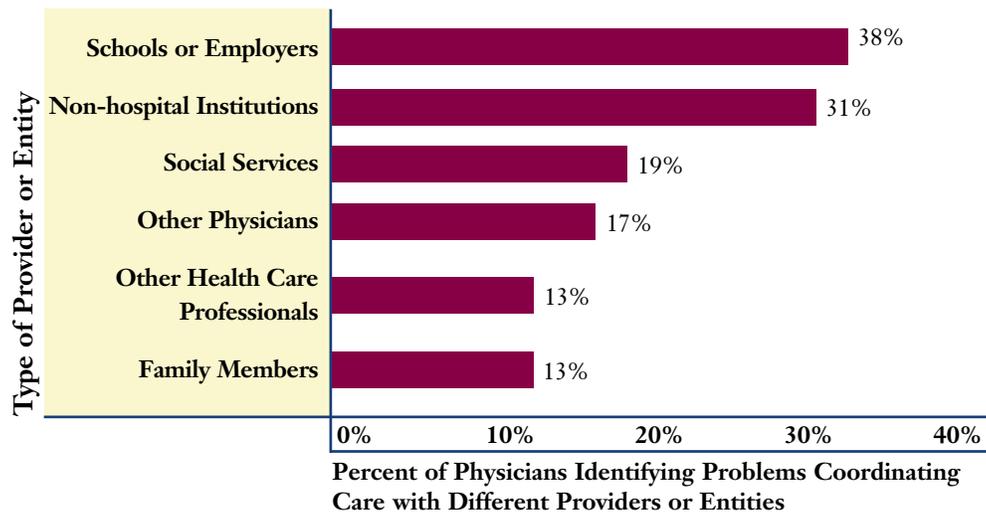
Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

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

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

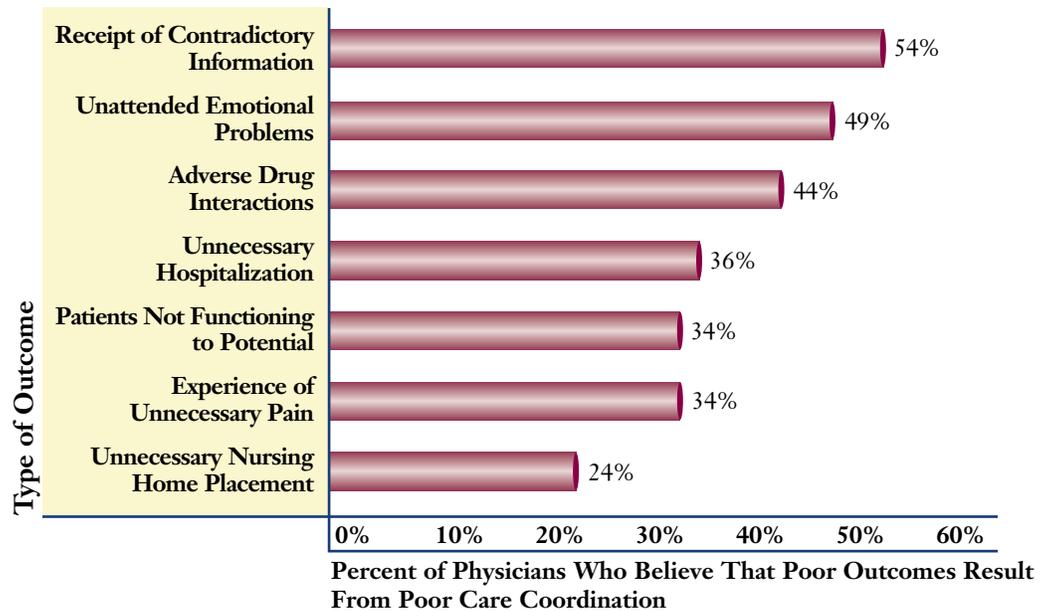
Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

## Physicians Report Difficulty Coordinating Care



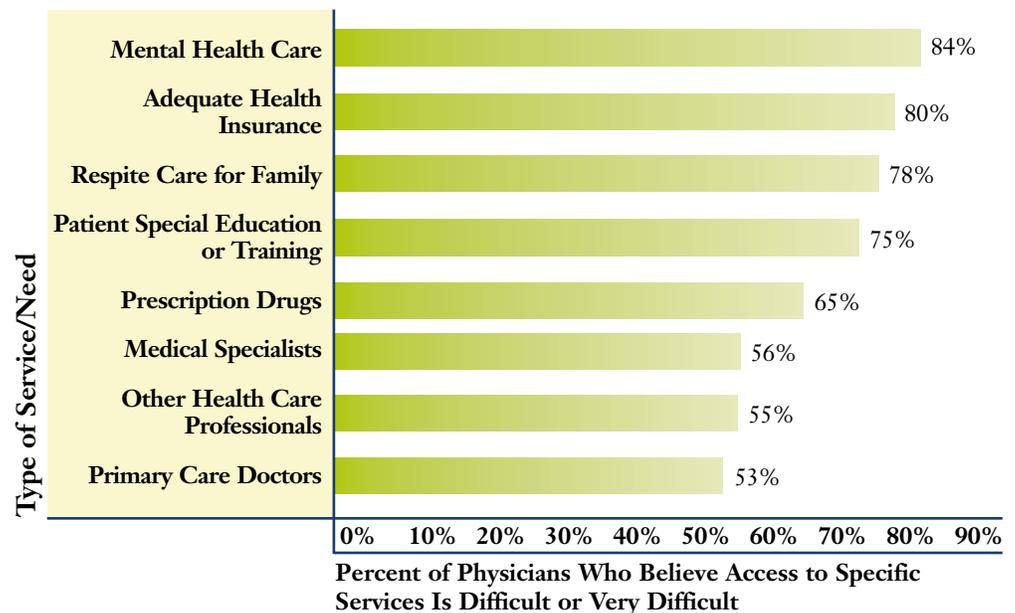
Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

## Physicians Believe that Poor Care Coordination Produces Poor Outcomes



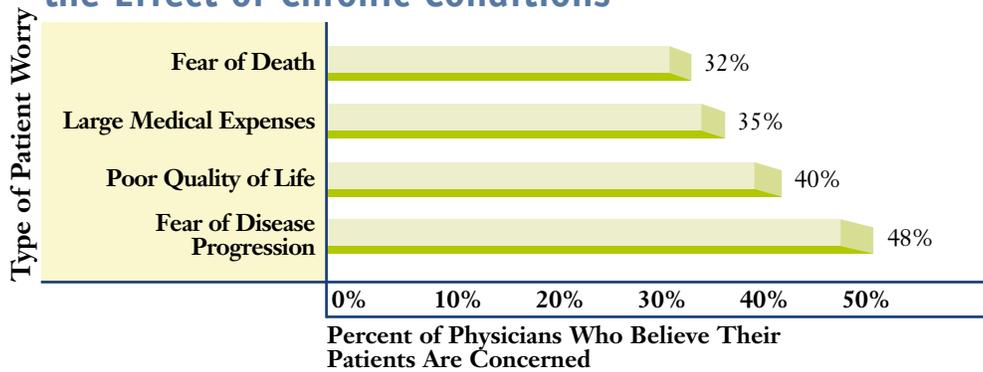
Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

## Physicians Believe that People with Chronic Conditions Have Unmet Needs



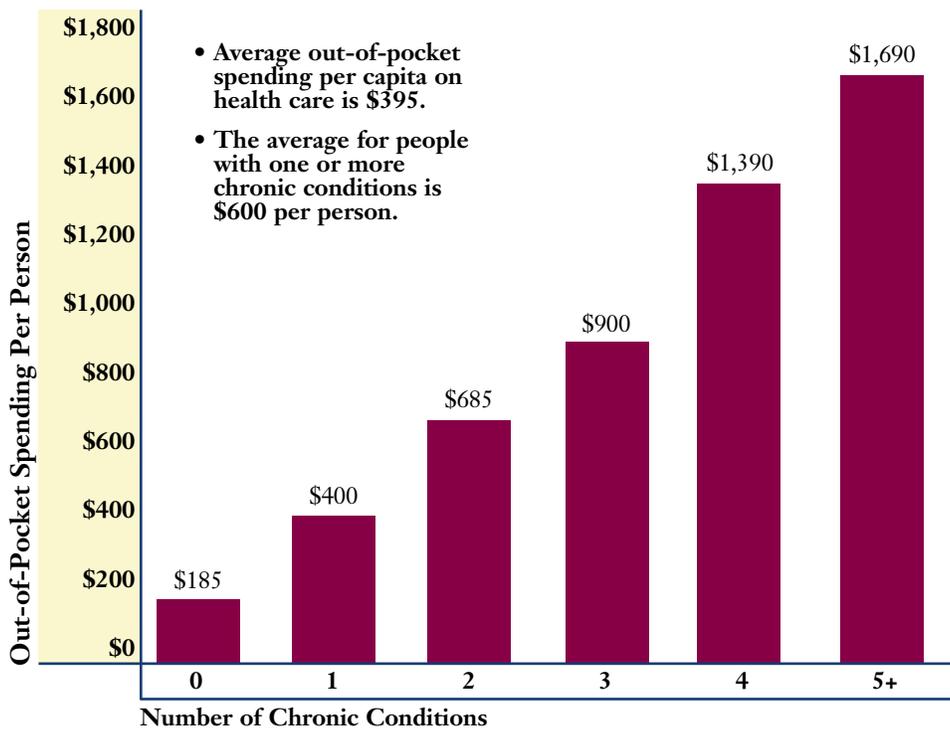
Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

## Physicians Recognize that Patients Worry About the Effect of Chronic Conditions



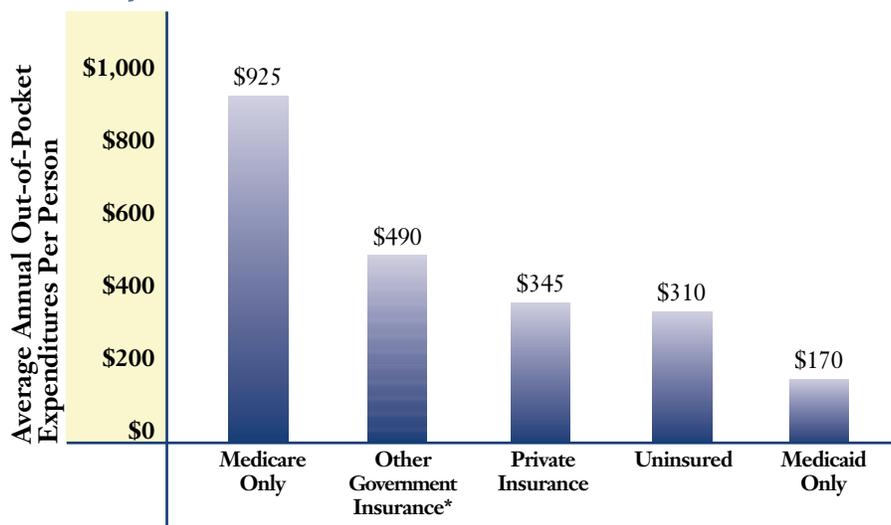
Source: *National Public Engagement Campaign on Chronic Illness—Physician Survey*, conducted by Mathematica Policy Research, Inc., 2001.

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



Source: Medical Expenditure Panel Survey, 1998.

## Out-of-Pocket Spending Is Highest for People with Medicare

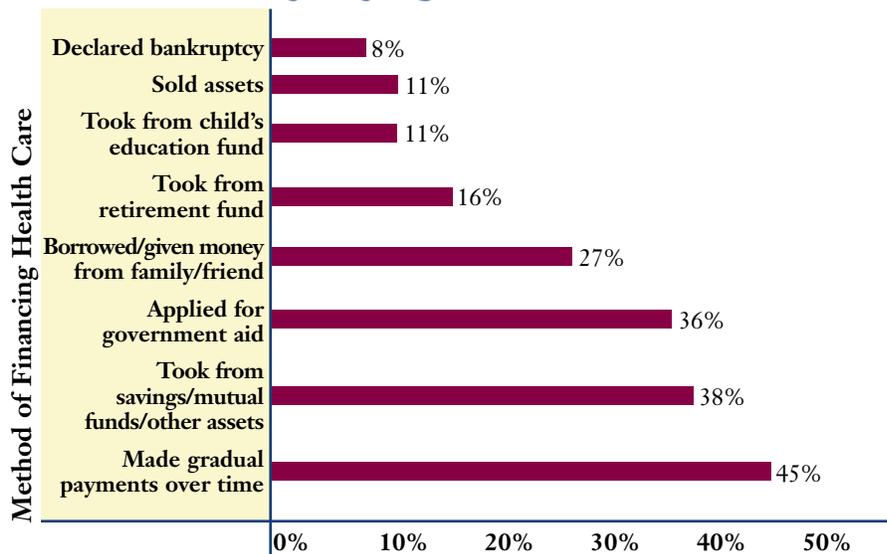


People with Chronic Conditions by Type of Insurance

Source: Medical Expenditure Panel Survey, 1998.

\*Other government insurance coverage includes insurance through the Department of Veterans Affairs, Champus, ChampVA, and the Indian Health Service.

## People with Serious Chronic Conditions\* Have Difficulty Paying for Their Health Care



Percent of People with Serious Chronic Conditions Using This Method to Finance Their Health Care

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

\*People with serious chronic conditions have a condition that is expected to last a year or more, requires ongoing medical attention, and limits what one can do. Serious chronic conditions are a subset of chronic conditions, which are also expected to last a year or more but limit what one can do, *and/or* may require ongoing medical care.

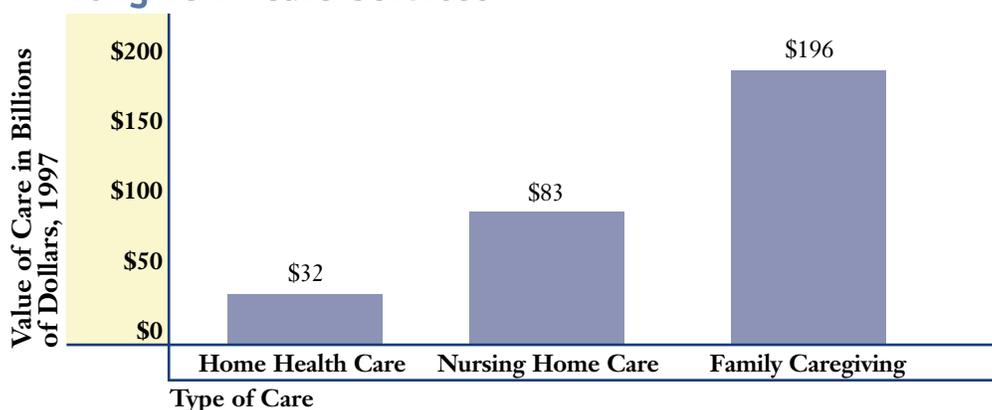
## A Caregiving Perspective

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. In 1998, almost nine and a half million Americans provided some kind of care for people who had chronic conditions.

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 decade 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 and family networks that are getting smaller and more top-heavy, with 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.

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



Source: Arno, P.S., Levine, C., and Memmott, M.M., “The Economic Value of Informal Caregiving,” *Health Affairs* 18:2, March/April 1999.

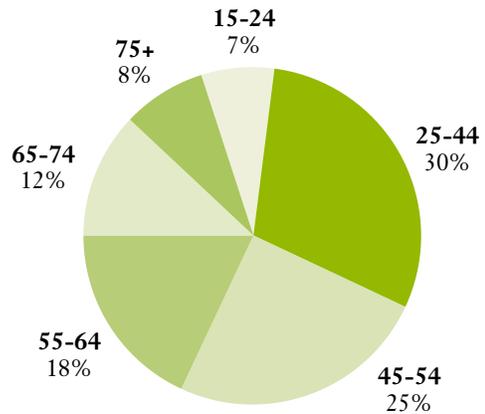
\*The value of informal caregiving is difficult to quantify, and there are other estimates. The numbers cited here are the middle range estimate from Arno, P.S., Levine, C., and Memmott, M.M., “The Economic Value of Informal Caregiving,” *Health Affairs* 18:2, March/April 1999. The estimate includes the value of care provided to people with and without chronic conditions.

“Although advances in medicine, technology, and understanding are helping children and youth with special needs, disabilities, and chronic conditions live longer, more productive lives, the health care system has yet to meet the needs of families as they navigate a complicated mix of services. We must continue to work towards a comprehensive, culturally appropriate, community-based, coordinated, quality, and affordable system of care for all people with chronic health conditions.”

—Family Voices

## Family Caregiving Is a Multigenerational Task

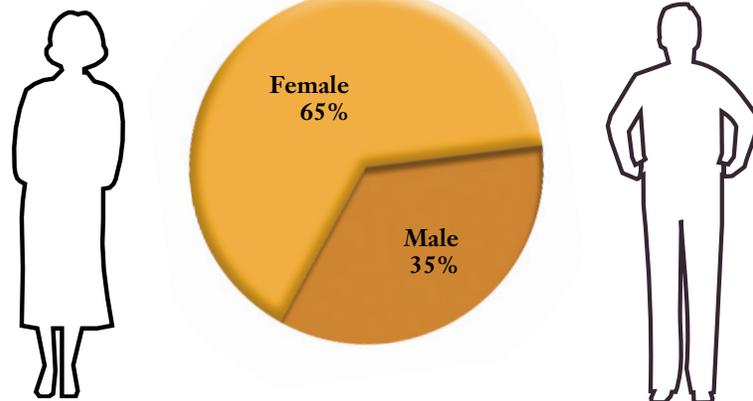
- Today, 9.4 million Americans of all ages provide care to relatives and friends.
- Thirty-eight percent of family caregivers are 55 years old or older.



Family Caregivers by Age

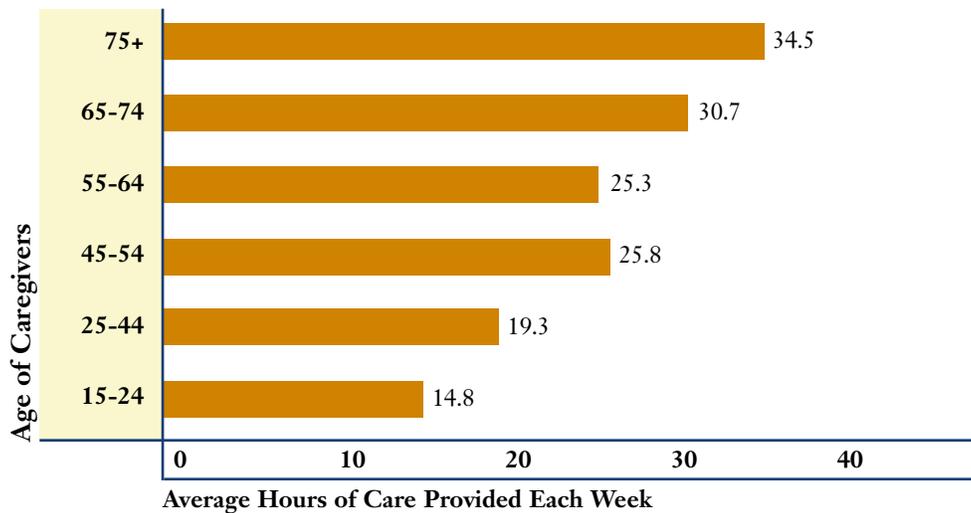
Source: Alecxih, L.M.B., Zeruld, S., and Olearczyk, B. *Characteristics of Caregivers Based on the Survey of Income and Program Participation*. National Family Caregiver Support Program: Selected Issue Briefs. Prepared for the Administration on Aging by The Lewin Group, July 2001.

## Family Caregivers by Gender



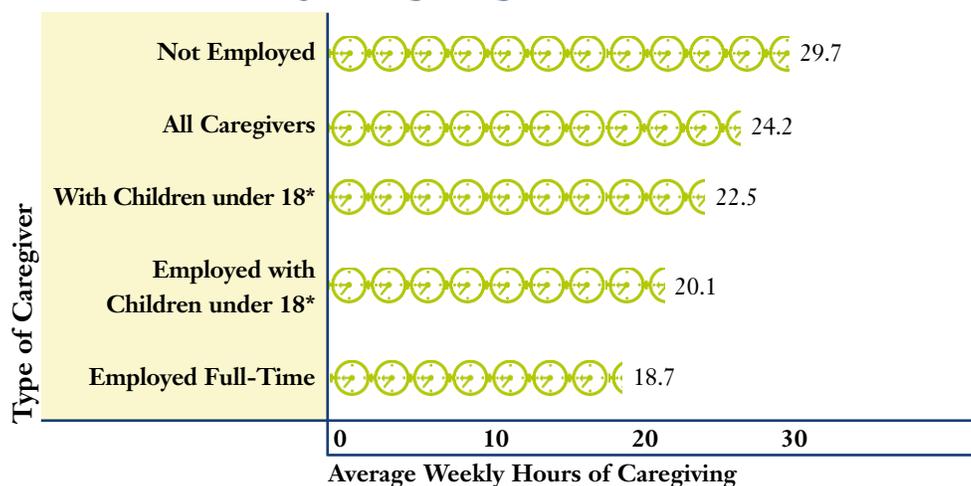
Source: Alecxih, L.M.B., Zeruld, S., and Olearczyk, B. *Characteristics of Caregivers Based on the Survey of Income and Program Participation*. National Family Caregiver Support Program: Selected Issue Briefs. Prepared for the Administration on Aging by The Lewin Group, July 2001.

## The Number of Hours Dedicated to Caregiving Increases with the Age of the Family Caregiver



Source: Alecxih, L.M.B., 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.

## Competing Demands Influence the Weekly Hours of Family Caregiving



Source: Alecxih, L.M.B., 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.

\*Children in the household may include children with long-term illnesses or disabilities.

## A New Model of Care

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 individual functioning of this large segment of our population.

Today, as the issues around more effective treatment and financing of chronic conditions are moving onto the national health care agenda, a change is in order. Care provided in the current system is not cost-effective and often leads to poor outcomes for patients with chronic conditions. This chartbook demonstrates the need for a new model of care that provides coordination and quality care for individuals living with chronic conditions.

Providers, policymakers, payors, and patients can work together to change the current health care system. These stakeholders have helped modify the system before in the face of similar challenges, from treating infectious diseases to acute illnesses and events such as heart attacks and strokes. When infectious disease was the leading public and private health care challenge, the health care system was reorganized to respond accordingly. When problems associated with acute illnesses and events such as heart attacks and strokes became leading health problems, the system was modified to provide high-quality, effective

treatments, and a system of funding was organized to address the financial risk of such illnesses. Changing the present system to better treat chronic health conditions is our nation's current health challenge.

In order to improve the health care systems and outcomes for people with chronic conditions, important issues need to be addressed. These include:

- **Rethinking financial reimbursement and incentives.**

The goal of a new, chronic care model of financing and delivering health care services is early diagnosis of illness with interventions that maintain health status, minimize acute episodes, and limit disability. 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 functional status.

This model is 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.

In order to move toward a chronic care model within the context of the current system, financial incentives that encourage the coordination of care need to be considered. For example, payments for complex care management could be available to physicians willing to take on a clinical coordination role on behalf of people with multiple chronic conditions.

- **Developing better connections between supportive and clinical care delivery systems.**

In clinical practice, chronic conditions require continuous care and coordination across various health care settings and providers. People with chronic conditions also often require supportive services to help them with daily activities or personal care or to assist them in navigating the health care system. An improved system for caring for people with chronic conditions will ensure that a connection is made between clinical and supportive services, with an individual's specific needs in mind, and that these services are readily available and affordable.

- **Examining the training of health care providers to better prepare them for the changing realities of medical practice and patients' needs.**

There are many different chronic conditions, and 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. Physicians and other health care providers should consider these issues when treating people with chronic conditions. And physician training programs could lead the way by including in their curricula courses that will help better prepare physicians to treat and coordinate care for patients with chronic conditions.

Providers, patients, and the public recognize that adjustments within the health care system are needed to improve chronic care in this country. In order to make these adjustments, health policymakers will need to reexamine how our current health care financing system values and pays for care received by people with chronic conditions, how we train health care providers to treat chronic conditions, and how the needs of people with chronic conditions are met.

To develop an effective chronic care system, all sectors of society will need to respond to the issue of improving care for chronic conditions as a whole, rather than responding to one condition at a time. This response 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

For the purpose of this publication, we defined chronic conditions as conditions that are expected to last a year or longer, limit normal activities, and/or may require ongoing medical care. This definition includes people with chronic illnesses or disabilities, or both. In some places, we refer to *serious* chronic conditions, which is a subset of the larger group consisting of those people with health conditions that are expected to last a year or more, require ongoing medical care, and limit what they can do. We selected a broad definition, similar to the previous definition used by Catherine Hoffman, Sc.D., and Dorothy Rice, Sc.D. (Hon.), in *Chronic Care in America: A 21<sup>st</sup> Century Challenge* in order to make comparisons between that publication and this one more consistent and meaningful. We have outlined below the methodology used to determine which conditions met our broad definition and the data sources used herein.

## Methodology for Determining Chronic Conditions

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 to data from the Medical Expenditure Panel

Survey 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 Sources

Data in this publication was drawn from a variety of sources that are detailed below.

### *Medical Expenditure Panel Survey*

For much of the analysis, we relied on the Household Component of the 1998 Medical Expenditure Panel Survey (MEPS), which is a nationally representative sample of the noninstitutional United States 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 on AHRQ’s Web site at [www.ahrq.gov](http://www.ahrq.gov).

We also used the 1998 MEPS data to examine spending on prescription drugs. The data and analysis include spending and utilization information for prescriptions—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.

Partnership for Solutions commissioned an analysis by researchers at the RAND Corporation using the 1996 MEPS data to produce projections of growth in the population with chronic conditions at five-year intervals, 1995 to 2030.

*Medicare Standard Analytic File*

We have also relied on data from the 1999 Medicare Standard Analytic File. This is a nationally representative sample of five 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 plans 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 1999. Total spending represented by the sample will not total all Medicare spending in 1999 because some important spending components that are not claims-based (in addition to M+C) are absent from the file; graduate medical education and administrative spending are examples. It is unlikely, however, that this spending would greatly affect the data presented here since most of it is not for beneficiary-specific services.

*Partnership for Solutions Surveys*

We also used data from three opinion surveys commissioned by Partnership for Solutions. Researchers at Johns Hopkins University designed all three surveys. 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. The 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.

### *Family Caregiver Information*

Another data source used in developing this chartbook was 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 other surveys.