

# Chronic Care in Utah A 21st Century Challenge

Prepared by the





# **Chronic Care in Utah A 21<sup>st</sup> Century Challenge**

**Prepared by the Utah Department of Health**

**March 1998**

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## **Introduction**

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The intent of this report is to draw attention to the problem of chronic conditions in Utah, and to point out possible directions to meet the challenge of caring for a growing population with disabling chronic conditions.

## **The Chronic Care Perspective**

Chronic conditions are the major cause of illness, disability and death in Utah today. Despite broad public awareness of specific life-threatening diseases such as cancer and heart disease, most people are not aware that, collectively, chronic conditions account for three out of every four deaths in Utah.

In Utah, as well as elsewhere, advancing medical knowledge, including early detection of diseases and medical and surgical interventions, has extended the lives of people with disabling chronic conditions, and increased the number of survivors of traumatic injury and birth defects. At the same time, improvements in diet, sanitation, and medical care have significantly extended life expectancy. In addition, the “baby boom” generation, now entering its fifties, will soon swell the over 65 population to record levels, with a corresponding increase in the prevalence of chronic conditions.

Unfortunately, our health care and social service systems are not well organized to meet the needs of the growing numbers of have people who are elderly, have chronic conditions, or both. As a result, increasing numbers of people are at risk for deteriorating health; others find that the services they need do not exist; and, still others find that services they need are not accessible.

## **What is Chronic Care?**

Chronic care is:

- an array of integrated medical and non-medical services and supports taking place in a variety of settings to assist people with chronic conditions to live independent, full lives;
- a continuum of care required over a period of time for people who either never acquired, or have lost functional abilities;
- responsive to each individual’s capabilities and needs as personal health status related to chronic conditions improves, remains stable, or deteriorates;
- an integrated care network of professionals, para-professionals, and informal care givers including family, friends, and community-level organizations.

Chronic care is different from acute care. Typically, acute care is delivered in high technology, intensive, institutional type settings such as hospitals. Acute care uses primarily medical care to fix or cure acute disease or injury. On the other hand, by definition, chronic conditions and impairments cannot be cured. Therefore, rather than cure, the main focus of chronic care is assistance and care delivered in a variety of settings.

Chronic care seeks to help individuals with chronic conditions to maintain independence and a high level of functioning. Chronic care includes medical care, both in response to an acute phase or complication of a chronic condition, and as part of medical management of a long-term condition. In addition, chronic care also includes an often complex array of rehabilitative and supportive services such as inpatient and outpatient medical and nursing care, home health care, homemaker services, adult day care, nursing home care, help with activities of daily living such as dressing, bathing, and eating, rehabilitative therapies, residential and assisted living housing with supportive services, and respite care. Table 1 compares some typical characteristics of acute care and chronic care:

**Table 1: Characteristics of Acute Care and Chronic Care**

Characteristics of Care Type	Acute	Chronic
Goals of care*	Cure: Restore to previous level of functioning	Assistance and care: Maintain independent living, facilitate successful personal and social adjustment, minimize further deterioration of physical and mental health, and prevent acute exacerbations of chronic conditions
Providers of care	Specially trained health care and human services professionals in institutions set up for acute care purposes	Multiple caregiver sources and settings, often includes a network of relatives, friends, and community of services along with hospital, home health care, and social service professionals
Scope of care	Primarily medical care	Broad scope of social, community, and personal services, as well as medical and rehabilitative care
Quality of care	Significant government investment in outcome measures and quality of care standards for most hospital-based acute conditions	Relatively few measures to assess quality of care provided by home health agencies, community-based agencies, ambulatory clinics
Organizations involved in care	Typically occurs within one institution	Multiple organizations, requires organizational collaboration, may integrate primary care, acute care, and long-term care needs
Financing of direct medical costs for non-institutional care**	Private insurance finances about 45% of direct medical costs of acute conditions. Public sources finance about 20% of direct medical costs of acute conditions	Private insurance finances about 33% of direct medical costs of chronic conditions. Public sources finance more than 40% of direct medical costs of chronic conditions

\* Goals of care for individuals where possible

\*\* This analysis doesn't consider expenditures for institutional services, primarily nursing homes

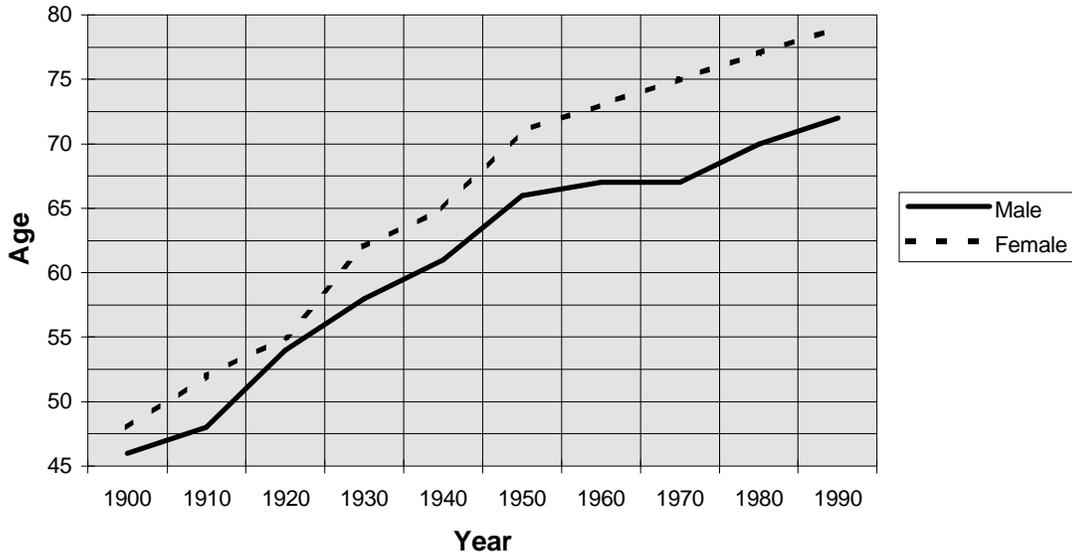
Source: "Chronic Care in America: A 21st Century Challenge," The Robert Wood Johnson Foundation, August 1996

## Section I: The Burden of Chronic Conditions

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### Life Expectancy

**Figure 1. Life Expectancy at Birth by Birth Year, and Sex. U.S., 1900-1990.**

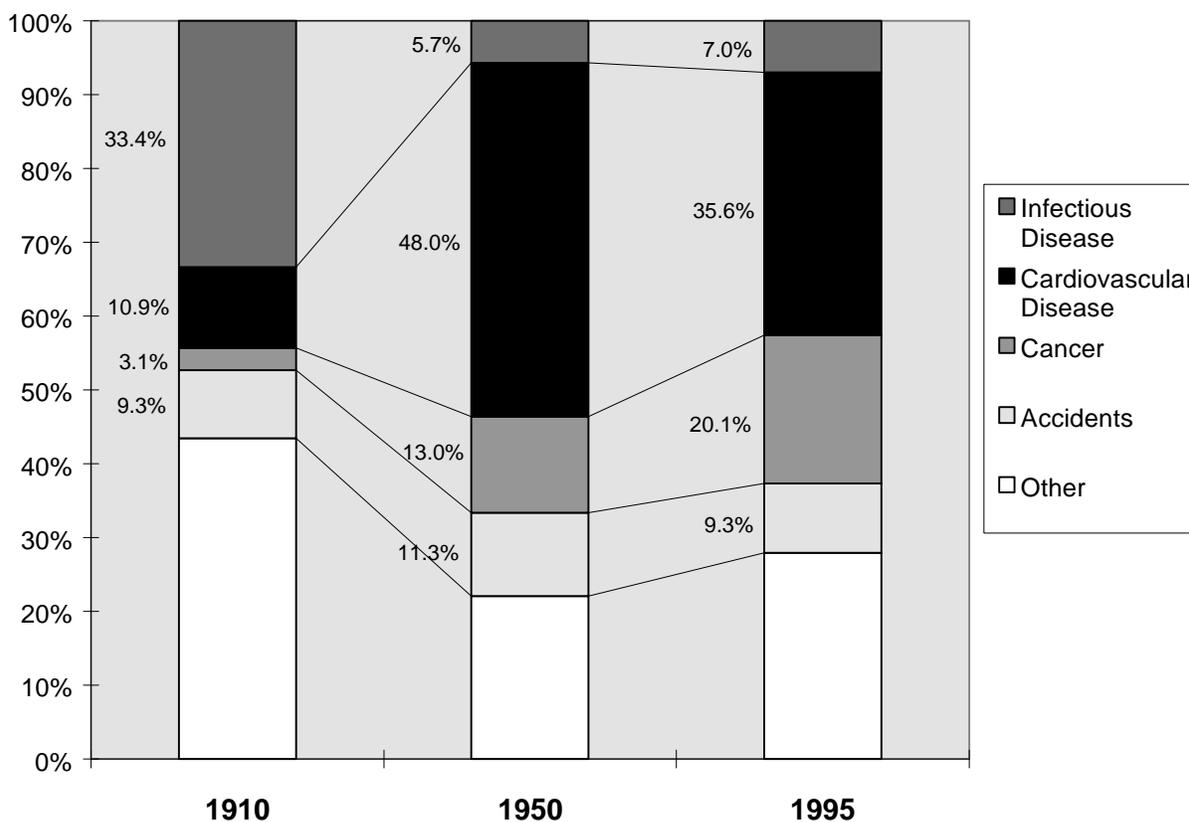


Source: Chronic Care in America: A 21<sup>st</sup> Century Challenge

Increases in life expectancy have resulted from advances in the medical field, against infectious diseases among young adults and children, and in reducing mortality rates from several chronic diseases. Although those gains certainly are applauded by society, they have also increased the number of individuals living with chronic medical conditions or limitations in activity.

## Changes in Leading Causes of Death During the Twentieth Century

**Figure 2. Proportion of Deaths from Selected Causes, Utah: 1910, 1950, and 1995.**



Source: Utah Death Certificate Database

Infectious Diseases - ICD9 codes 001-139, 460-487, 680-709

Cardiovascular Disease - 340-459

Cancer and Other Neoplasms - 140-239

Accidents - E800-E999

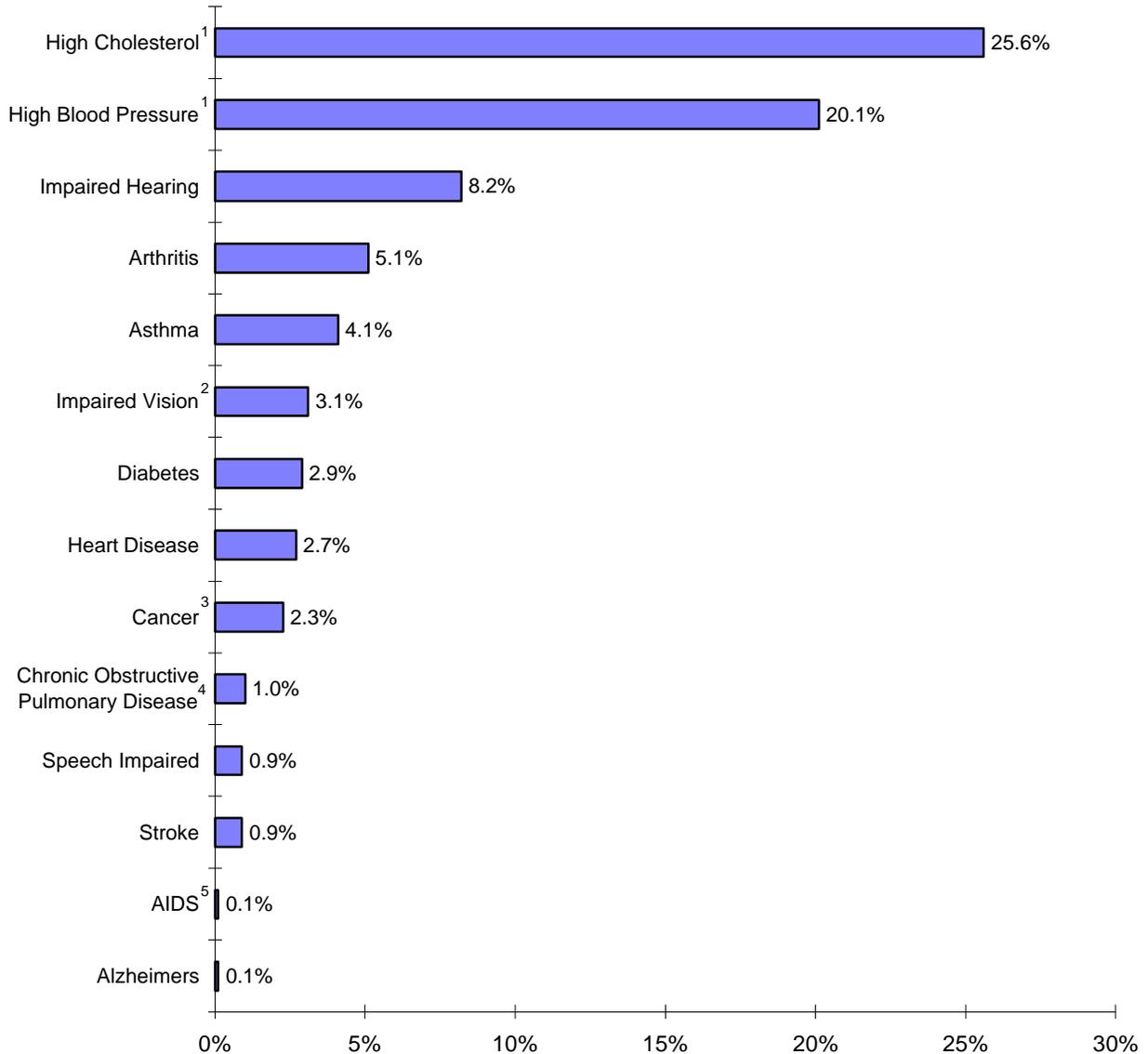
Other - 240-389, 490-676, 710-799

Infectious diseases have been replaced as the leading causes of death for Utahns by chronic diseases, especially cardiovascular disease.

## Prevalence of Selected Chronic Medical Conditions

If one includes high blood cholesterol and high blood pressure, about one quarter of Utahns have one or more chronic medical conditions.

**Figure 3. Reported Prevalence Rates of Selected Chronic Conditions. Utah, 1996.**



1 Analyses included only adults age  $\geq 18$  who reported having been tested.

2 Vision impaired was defined as "serious difficulty seeing, even while wearing glasses or contact lenses.

3 Cancer prevalence estimated by the Utah Cancer Registry

4 Chronic bronchitis or emphysema

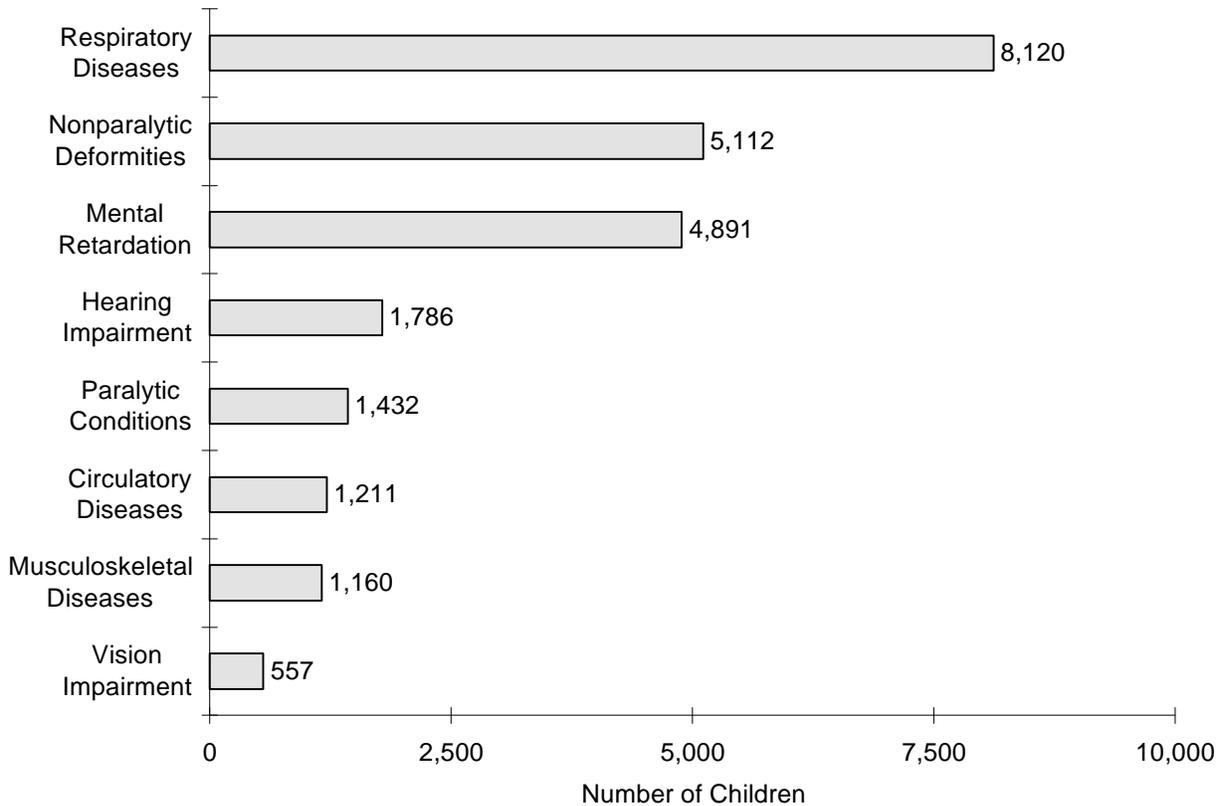
5 AIDS prevalence estimate, Bureau of Surveillance and Analysis, 1996.

Source: 1996 Utah Health Status Survey, Utah Department of Health

## Disabling Chronic Conditions in Children

In 1991, over 24,000 Utah children suffered from disabling chronic conditions. Nonparalytic deformities, paralytic conditions and musculoskeletal diseases accounted for one third of the chronic conditions in infants and children.

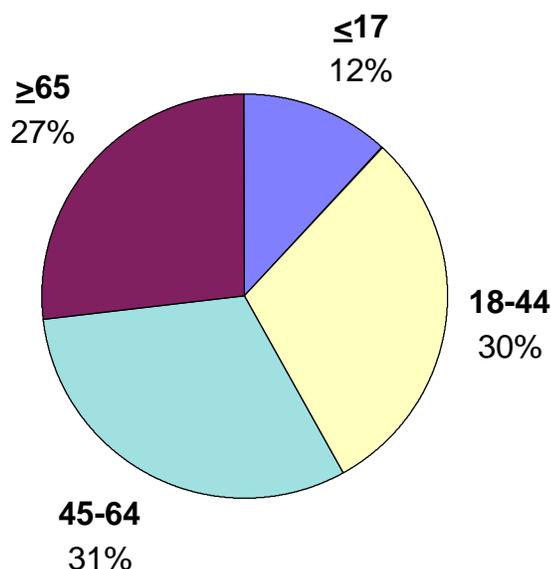
**Figure 4. Estimated Numbers of Children (Age ≤ 21 Years) With a Chronic Condition. Utah, 1991.**



Source: "State Estimates of the Prevalence of Chronic Conditions Among Children and Youth." Paul W. Newacheck, DrPH, Maternal and Child Health Policy Research Center, June/91.

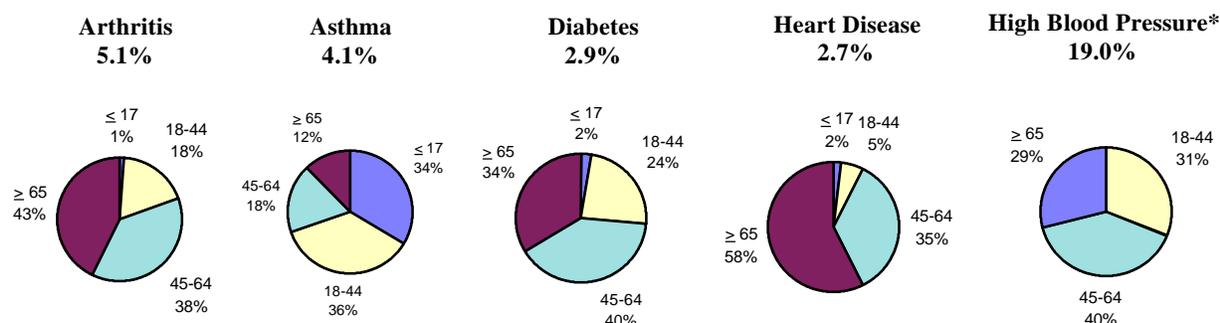
**Only 1 in 4 Living in the Community with a Chronic Condition is Elderly**

**Figure 5. Percentage Distribution of Noninstitutionalized Persons with Chronic Conditions\*, by Age Group. Utah, 1996.**



\*Conditions examined in this figure include Alzheimer's disease, asthma, arthritis, diabetes, chronic obstructive pulmonary disease, stroke, heart disease, and hearing, vision, or speech impairment.

**Figure 6. Overall Prevalence Rates and Percentage Distributions by Age Group of People With Selected Chronic Conditions. Utah, 1996.**

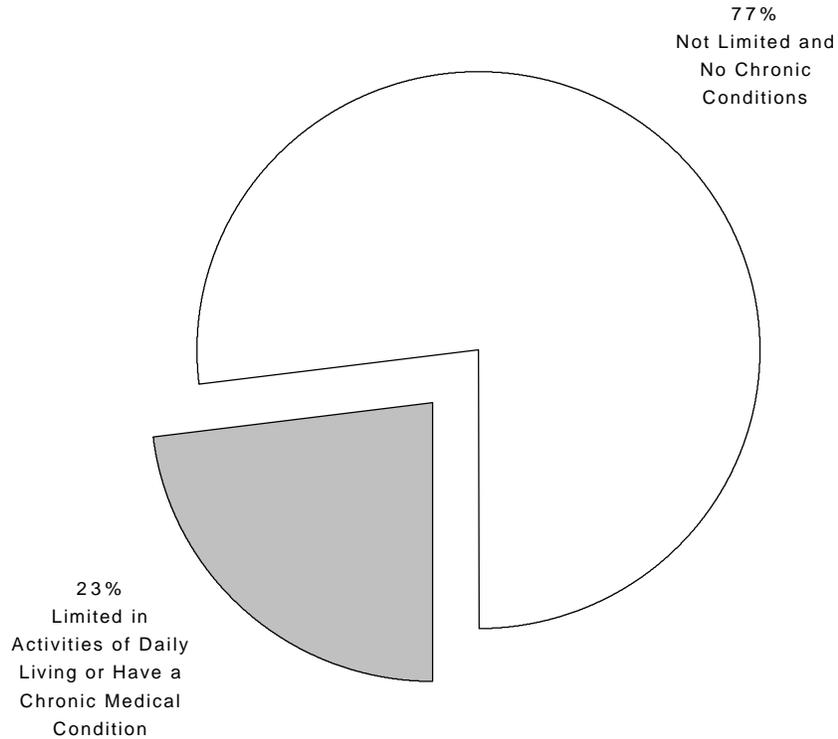


\* Graph of high blood pressure includes only adults age ≥ 18 who reported having been tested.

Source: 1996 Utah Health Status Survey, Utah Department of Health

Some chronic conditions, such as arthritis, affect the elderly predominantly. Others, such as asthma, affect persons of all ages.

**Figure 7. Percentage of Utahns Limited in Activities of Daily Living or Living with a Chronic Condition\*. Utah, 1996**

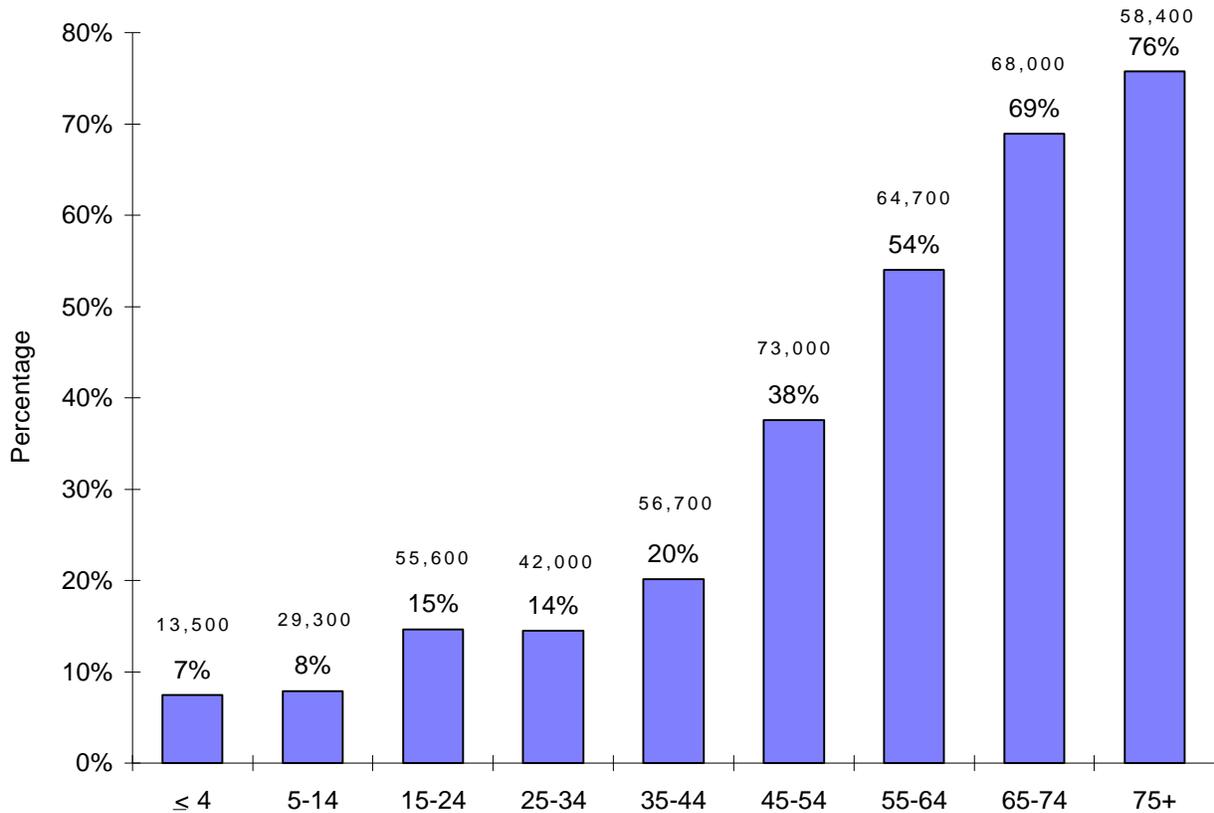


\*Conditions examined in this figure include Alzheimer’s disease, asthma, arthritis, diabetes, chronic obstructive pulmonary disease, stroke, heart disease, and hearing, vision, or speech impairment.

Source: 1996 Utah Health Status Survey, Utah Department of Health

In 1996, about 460,000 Utahns (23%) reported a limitation in performing usual activities because of an impairment or health problem, or had one of ten chronic medical conditions, or both.

**Figure 8. Percentages and Numbers of Utahns Who Are Limited in Activities of Daily Living or Living with a Chronic Medical Condition\*by Age Group. Utah, 1996**



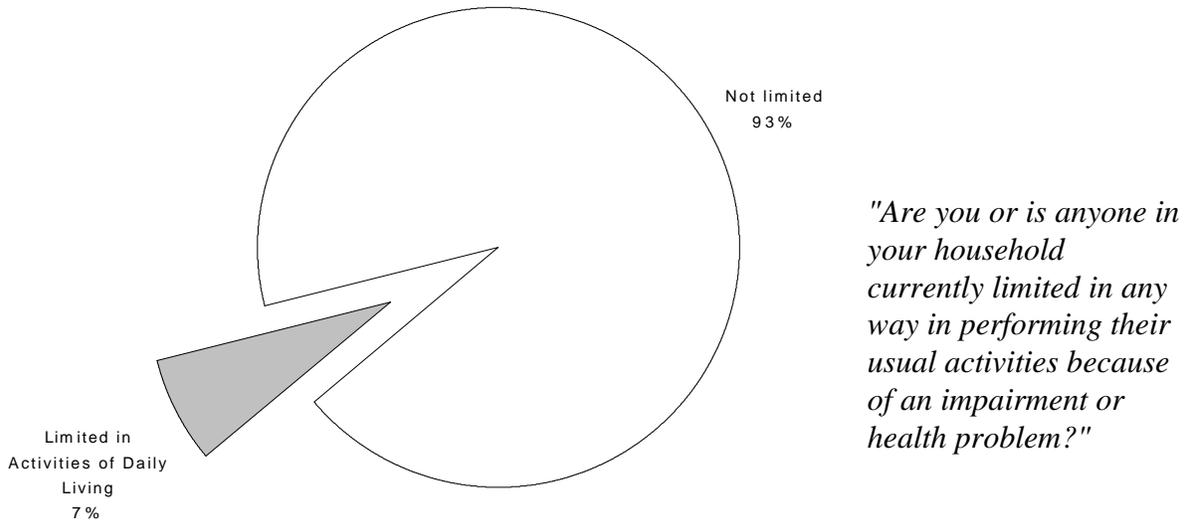
\*Conditions included Alzheimer's disease, asthma, arthritis, diabetes, chronic obstructive pulmonary disease, stroke, heart disease, and hearing, vision, or speech impairment.

Source: 1996 Utah Health Status Survey, Utah Department of Health.

It has often been said that Americans are living longer and healthier lives. However, chronic conditions that limit activities seem likely to be more of a problem in the future. Chronic conditions increase both in number and severity with aging. The higher prevalence of chronic conditions among the elderly, combined with a growing population of elderly people, will lead to a substantial increase in the absolute number of people in Utah with chronic care needs in the 21<sup>st</sup> century.

## Who Has Limitations in Activities?

**Figure 9. Percentage of Utahns Limited in Activities of Daily Living. Utah, 1996.**



Source: 1996 Utah Health Status Survey, Utah Department of Health.

One in fourteen Utahns (7.2%, or about 140,000 people) reported that they were limited in performing usual activities (such as working at a job, doing housework, walking, preparing meals, or other personal care activities) because of an impairment or health problem. That percentage does not include Utahns living in institutions such as nursing homes and may underestimate the actual number of Utahns who are limited by as much as half because of the wording of the survey question.

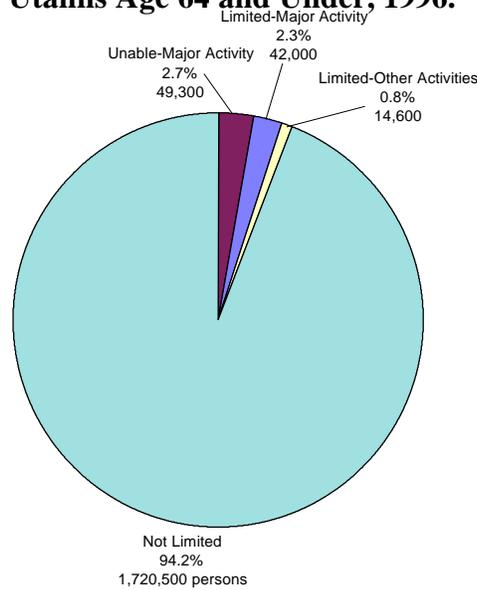
Limitation of activity refers to a long-term reduction in a person's ability to perform the average kind or amount of activities associated with their age group. People are classified based on ability to perform the major activity usually associated with their age group: ordinary play for children under 5 years of age, attending school for those 5-17 years of age, working or keeping house for persons 18-64 years of age, and capacity for independent living (e.g., the ability to bathe, shop, dress, eat, and so forth, without needing the help of another person) for those 65 years of age and over.

## Extent of Activity Limitation - Persons Age 64 and Under

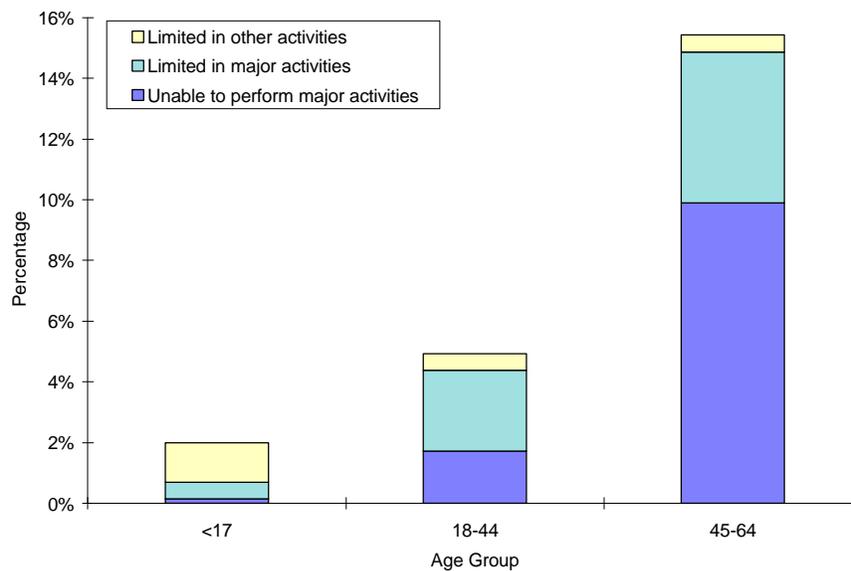
Each person under age 65 was classified into one of four categories according to their ability to perform activities of daily living:

- unable to perform the major activity;
- able to perform the major activity but limited in the kind or amount of that activity;
- not limited in the major activity but limited in the kind or amount of other activities; and
- not limited in any way.

**Figure 10. Percentage of Utahns With Limited Activity According to Extent of Limitation. Utahns Age 64 and Under, 1996.**



**Figure 11. Percentage of Utahns with Limited Activity According to Extent of Limitation, by Age Group. Utahns Age 64 and Under, 1996.**

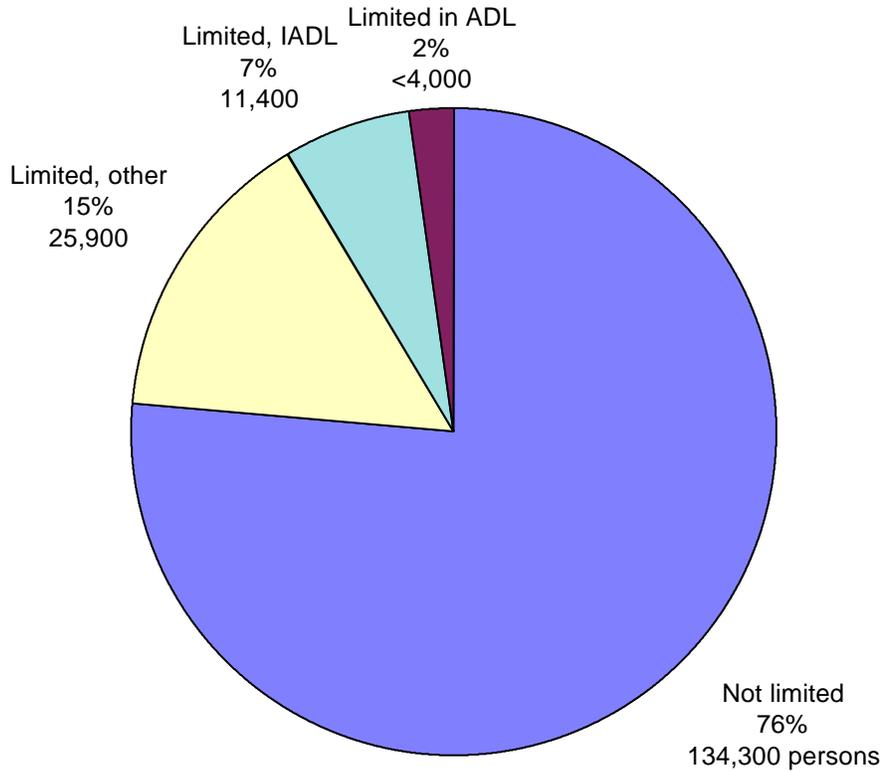


Source: 1996 Utah Health Status Survey, Utah Department of Health

## Extent of Activity Limitation - Persons Age 65 and Over

Persons age 65 or older were classified as either having no limitations, having limitations in Instrumental Activities of Daily Living (IADL) such as shopping and household chores, having limitations in Activities of Daily Living (ADL) such as eating, bathing, and dressing, or being limited in some other way.

**Figure 12. Percentage of Utahns With Limited Activity According to the Extent of Limitation. Utahns Age 65 and Over, 1996.**



Source: 1996 Utah Health Status Survey, Utah Department of Health.

Certain segments of society are more likely to have and be disabled by a chronic condition than others, notably the elderly, the poor, and those who have more than one chronic condition.

However, the elderly are not the only ones with disabling chronic conditions. Chronic conditions affect people of all ages, from newborns to the elderly, and all strata of society, from the poor to the very wealthy.

## **Utahns with Limitations in Activities of Daily Living**

### **Infants and Children (under 18)**

In 1996, over 13,000 Utah children (2 percent of all children) were reported to have a limitation performing usual activities because of an impairment or health problem.

It is commonly believed that most children with severe impairments die early in life or depend on major medical technologies to live at home. However, that belief is incorrect; the impact of a chronic condition on a child and that child's family varies by the type of impairment or illness. Nevertheless, families of children with chronic conditions share a common set of challenges: high health care costs, greater care taking responsibilities, obstacles to an adequate education for the child, and the additional stress those issues create for the entire family.

### **Working-Age Adults (18-64)**

One in twelve working-age Utahns - nearly 100,000 men and women reported a limitation performing usual activities because of an impairment or health problem in 1996.

In Utah, one in twenty (41,000) young adults (18-44) had an activity-limiting chronic condition. Degenerative chronic illnesses begin to surface in young adulthood: high blood pressure and arthritis are common chronic conditions in this age group.

One in six middle-aged adults (45-64) were limited by a chronic condition in 1996, and more than 30,000 (64 percent) of those who were limited were unable to carry on their major activity, such as retaining a paying job or performing housework. These middle-aged Utahns are more than three times as likely to be limited by their chronic impairment or health problem than young adults.

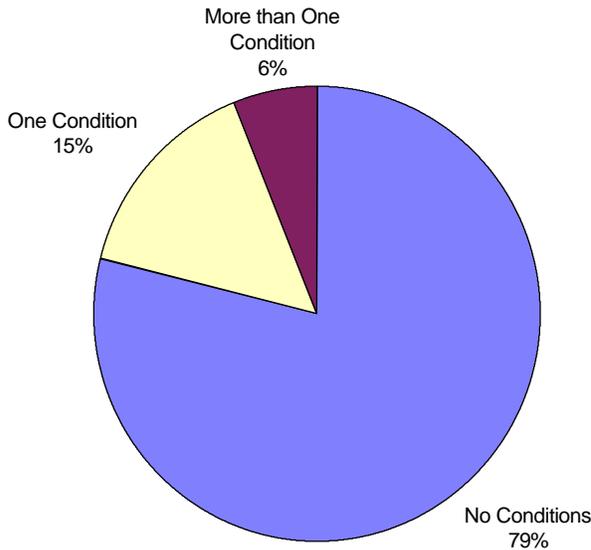
### **Senior Citizens (65 and over)**

In 1996, one-fourth of Utahns age 65 or over not living in institutions (nearly 44,000) reported a limitation performing usual activities because of an impairment or health problem. While the elderly are more likely to have a chronic condition, they account for only about a quarter of all persons who live with chronic conditions. However, several of the conditions most prevalent among the elderly tend to be disabling, which accounts for the high rate of disability in this age group. Conditions such as arthritis, high blood pressure, and heart disease may begin in middle age, but often progress in terms of severity of symptoms and the degree to which they limit a person, as the person ages.

Some chronic conditions are disabling only some of the time and only require episodic care. Chronic conditions do not always get worse; the health status of a person with a chronic condition can improve or deteriorate.

## People with More than One Chronic Condition

**Figure 13. Percentage of Utahns with One or More Than One Chronic Conditions, 1996.**



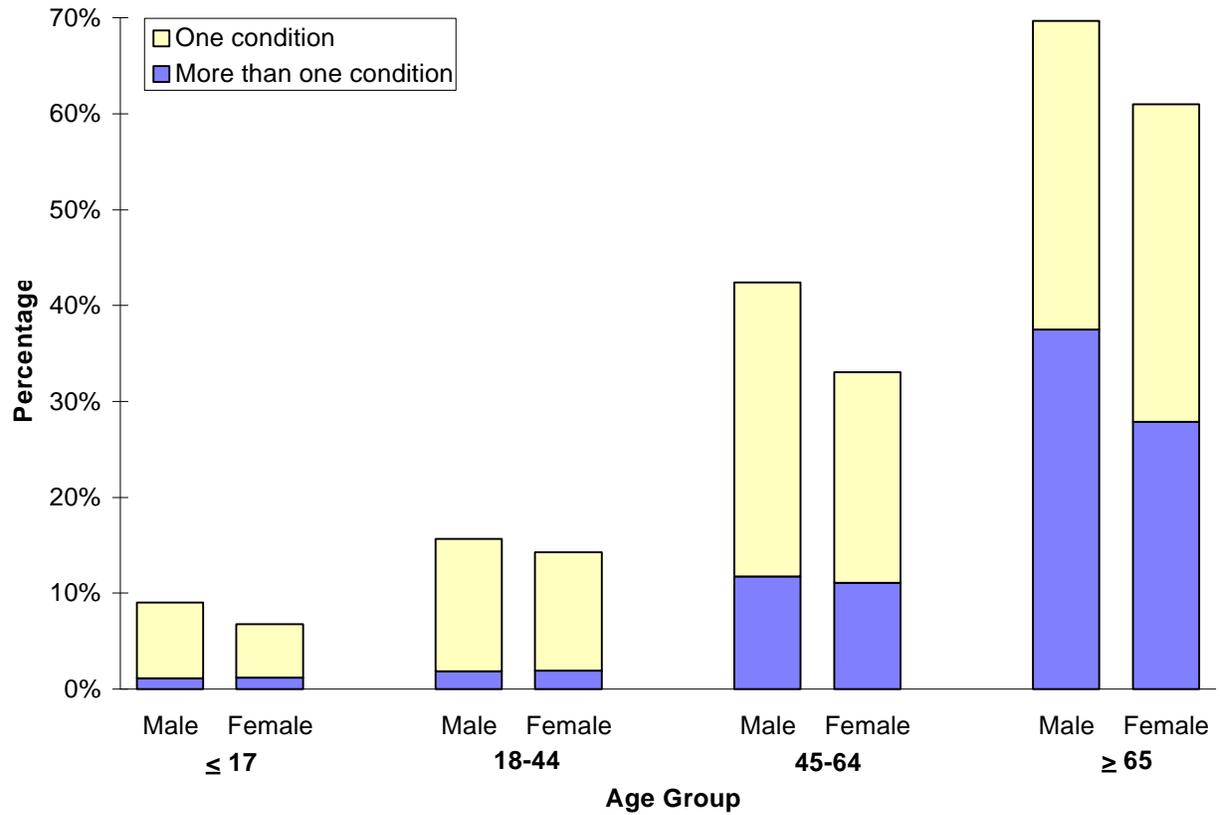
A comorbidity, the technical term for having more than one condition at a time, adds to a person's health burden. Nearly twenty percent of people with chronic conditions have more than one condition to manage. When the conditions are serious, comorbidity puts people at greater risk of disability, and can result in physical limitation (such as the inability to walk) and role limitation (such as not being able to work).

Source: 1996 Utah Health Status Survey, Utah Department of Health

People with comorbidities 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. As a person's chronic conditions increase in number, so do their chances of being limited in the basic activities of daily living (such as eating and bathing).

The risk of comorbidity is greatest among the elderly. As people age, they face an increasing risk of having multiple chronic conditions. Although comorbidities tend to accumulate with age, over 7,000 Utah children have more than one chronic condition. Compared to those with only one chronic condition, these children are more likely to be limited in their activity, spend more days in bed, and have more school absences.

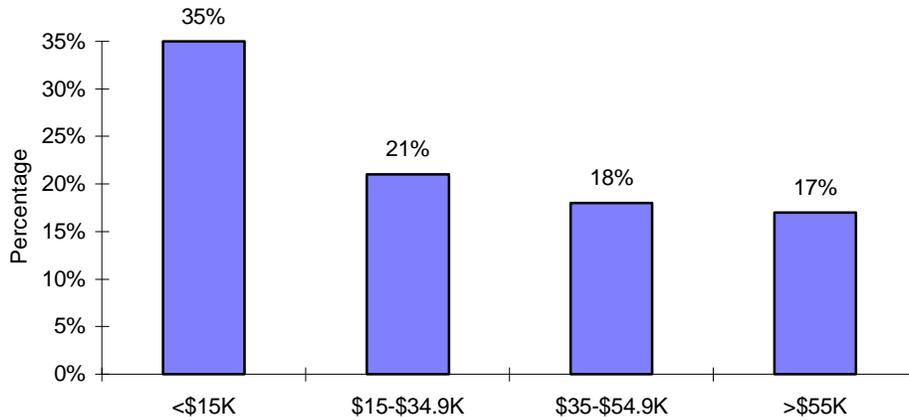
**Figure 14. Percentage of Utahns with One and More Than One Chronic Condition, by Age and Sex, 1996.**



Source: 1996 Utah Health Status Survey. Utah Department of Health.

## Poverty and Chronic Medical Conditions

**Figure 15. Percentage of Utahns with a Chronic Medical Condition by Annual Income, 1996.**



Source: 1996 Utah Health Status Survey, Utah Department of Health

### People in Poverty

People living in poverty are more vulnerable than others are to the risks, situations, and illnesses that can result in permanent activity-limiting conditions.

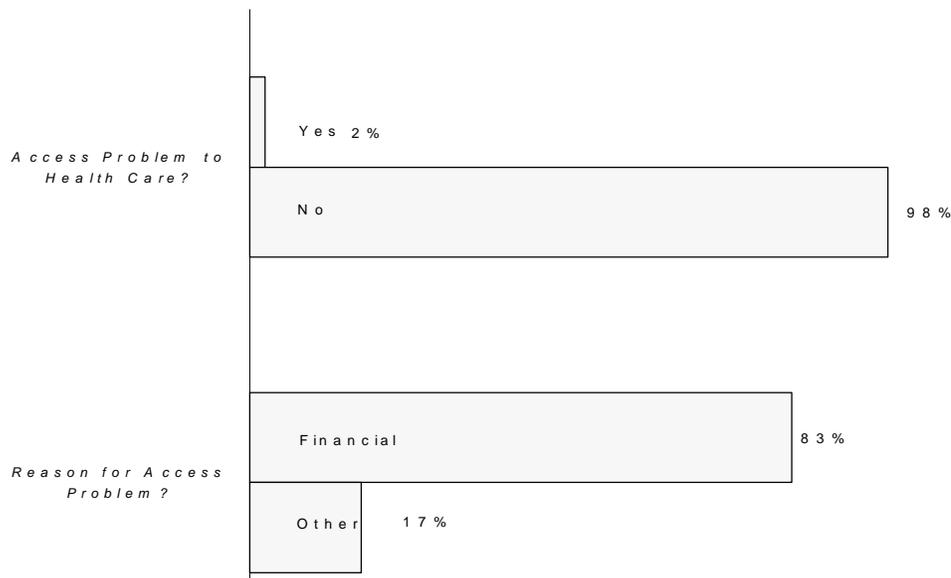
In 1996, over one-third of Utahns with household incomes of less than \$15,000 per year had one or more chronic medical conditions. One in three Utahns with a chronic medical condition had incomes of less than \$35,000.

Several conditions, such as asthma, arthritis, diabetes, high blood pressure, and heart disease, are more prevalent among poor Americans.<sup>1</sup>

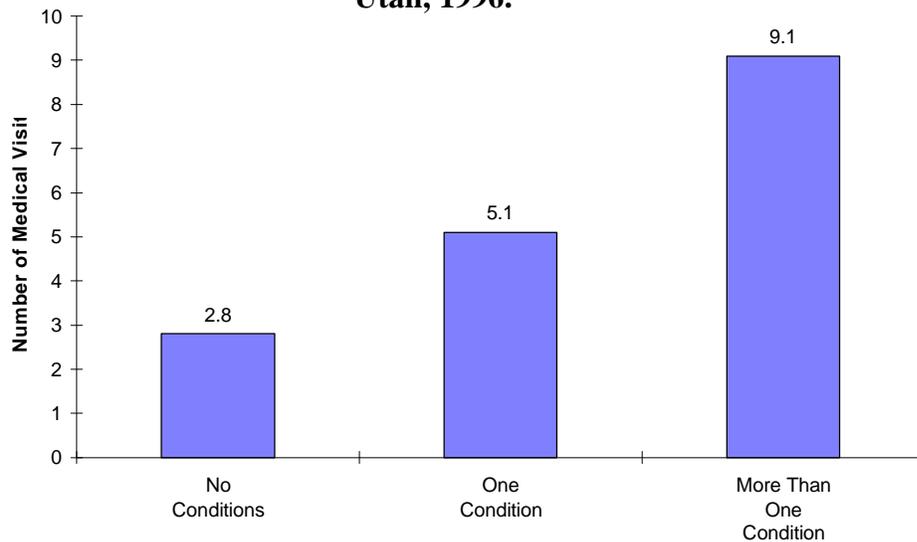
## Access to and Utilization of Health Care Services

In 1996, two percent of all Utahns (or about 50,000 persons) reported that they had a problem with access to health care services. Among those who reported an access problem, 83% reported that the reason for the problem was financial. Utahns with chronic medical conditions were more likely to have been hospitalized in the last year, and had more doctor visits than those without a chronic medical condition.

**Figure 16. Percentage of Utahns Who Had a Problem with Access to Health Care Services, 1996.**

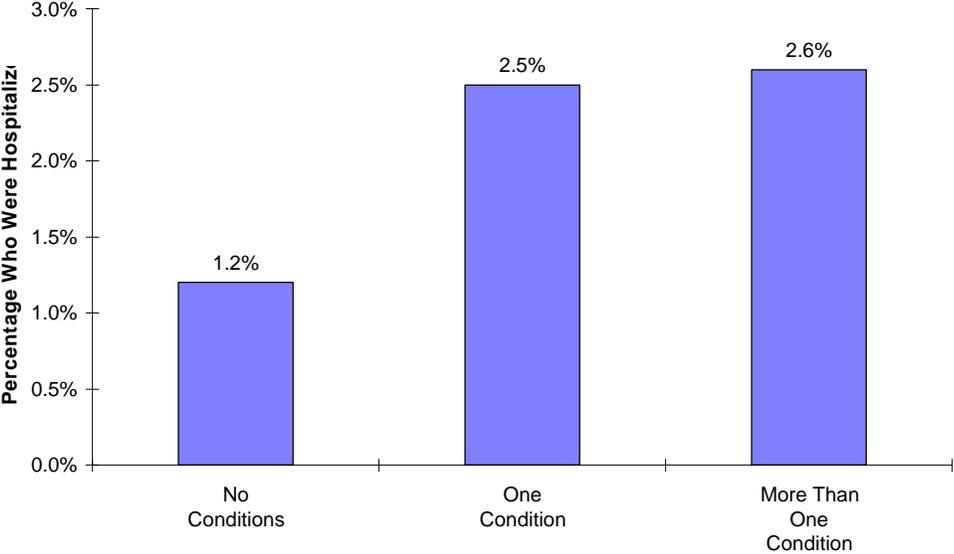


**Figure 17. Average Annual Number of Medical Visits by Number of Chronic Conditions. Utah, 1996.**



Source: 1996 Utah Health Status Survey, Utah Department of Health

**Figure 18. Percentage of Persons Who Were Hospitalized in the Last 12 Months for Reasons Other Than Giving Birth. Utah, 1996.**



Source: 1996 Utah Health Status Survey, Utah Department of Health

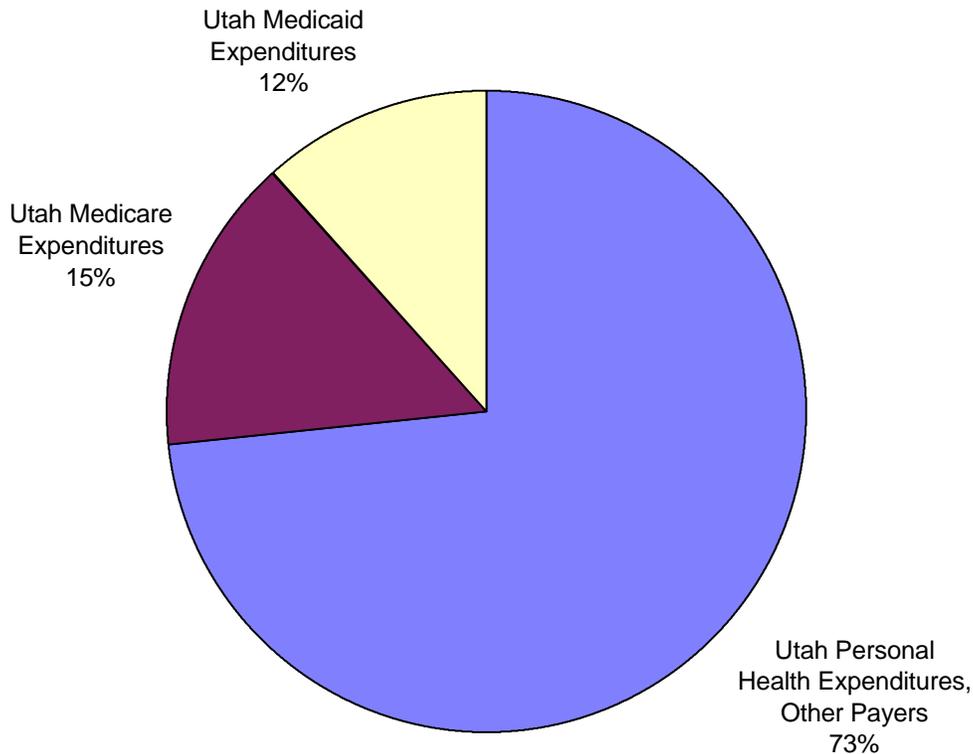
## Section II: The Financing of Chronic Care

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### How is Chronic Care Financed?

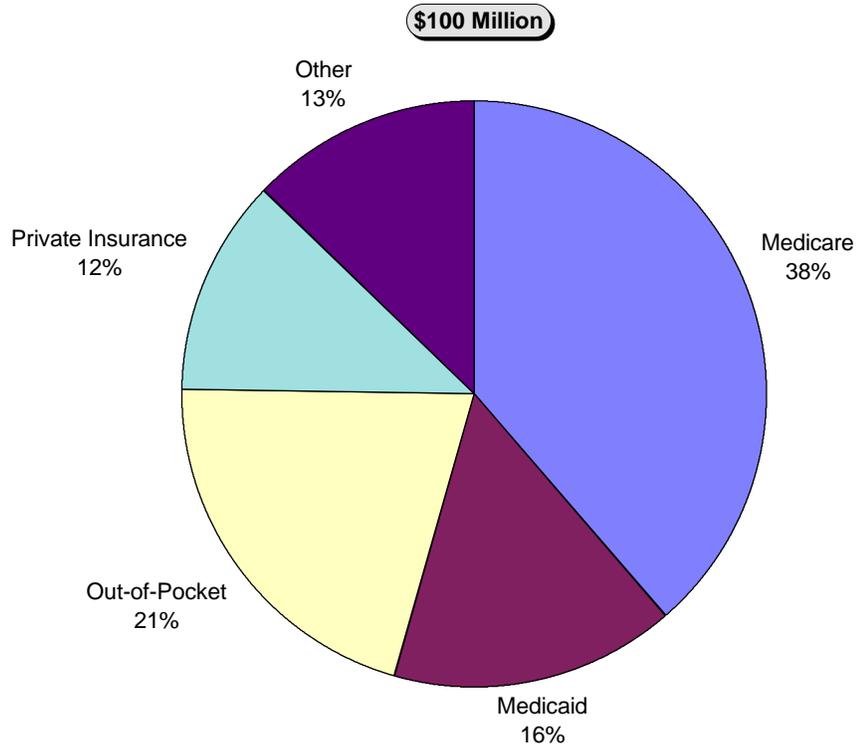
Data were not available on financing of chronic care in Utah. This is an important barrier to understanding and improving the chronic care system in Utah. However, it was possible to examine the payment sources for all personal health care in Utah. This section presents those data and provides some estimates of the amounts spent on chronic care based on national data. In 1993, Medicare expenditures accounted for 15 percent of all personal health care expenditures. The Medicaid portion was 12 percent. The remaining 73 percent was from other payment sources, including private insurance, out-of-pocket payments, and other various payment sources. See Figure 19.

**Figure 19. Portion of Utah Personal Health Expenditures Paid by Medicare and Medicaid, 1993.**

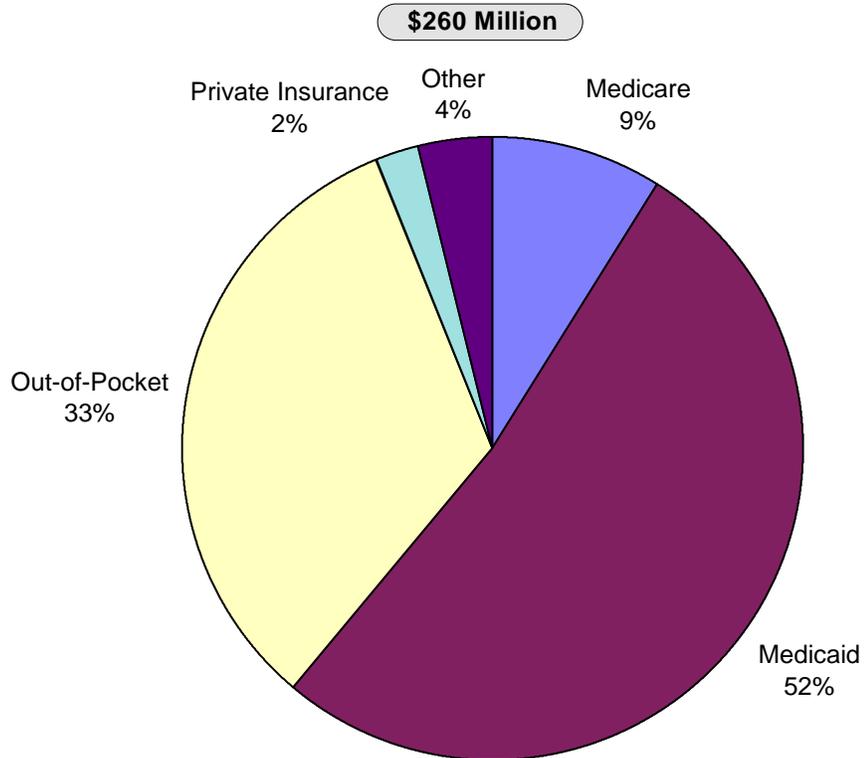


The distributions of payment sources were dramatically different for home health care and nursing home care. Medicare and Medicaid constituted 54 percent of home health care expenditures and over 60 percent of nursing home care expenditures in Utah. Sources of payment for these types of services are shown in Figures 20 and 21.

**Figure 20. Utah Home Health Care Expenditures by Payer Type, 1993.**



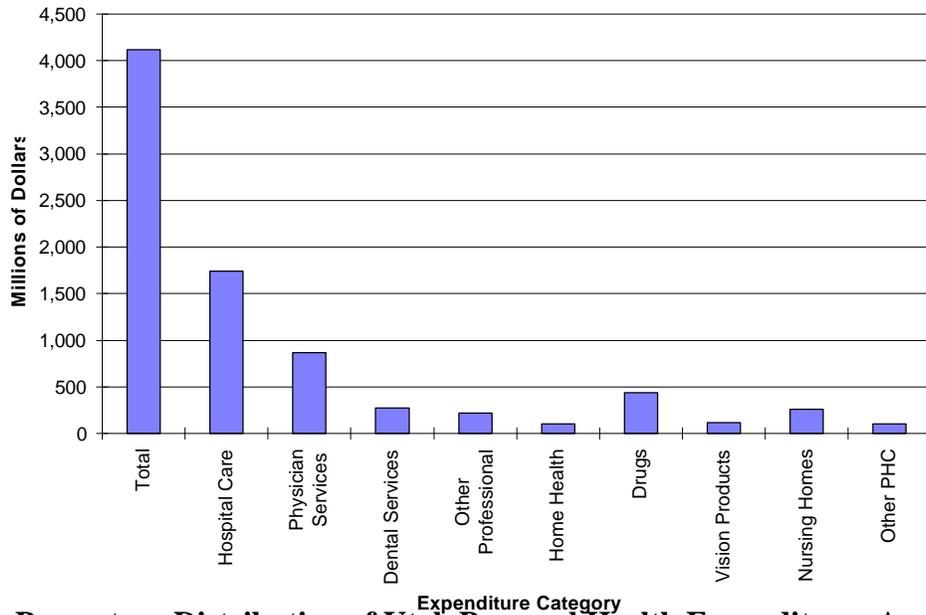
**Figure 21. Utah Expenditures for Nursing Home Care by Payer Type, 1993.**



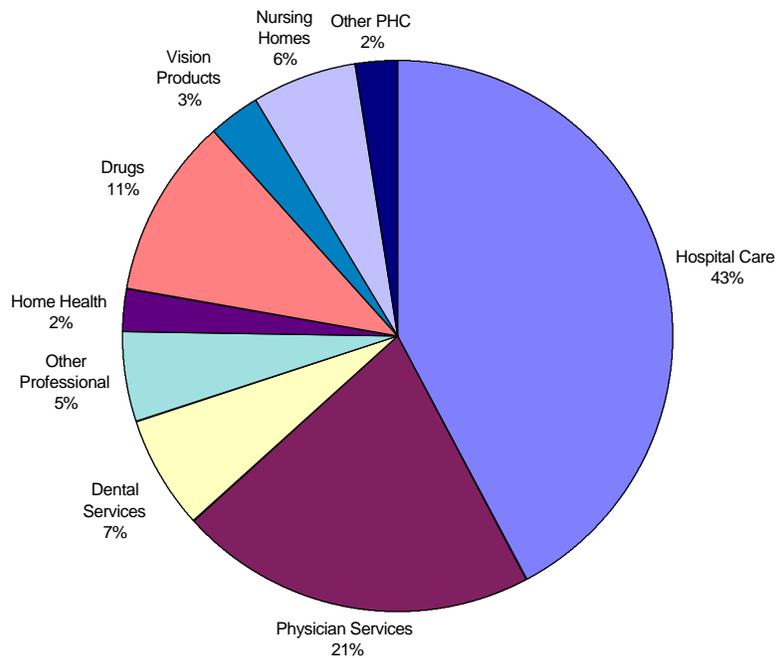
## How Much Does Chronic Care Cost in Utah?

To understand the impact of chronic care costs, it is necessary to put these costs into the context of total health care expenditures. Total Utah personal health care expenditures amounted to \$4.1 billion in 1993. Figures 22 and 23 show how these expenditures were allocated across expenditure categories.

**Figure 22. Utah Personal Health Expenditures According to Expenditure Category, 1993.**

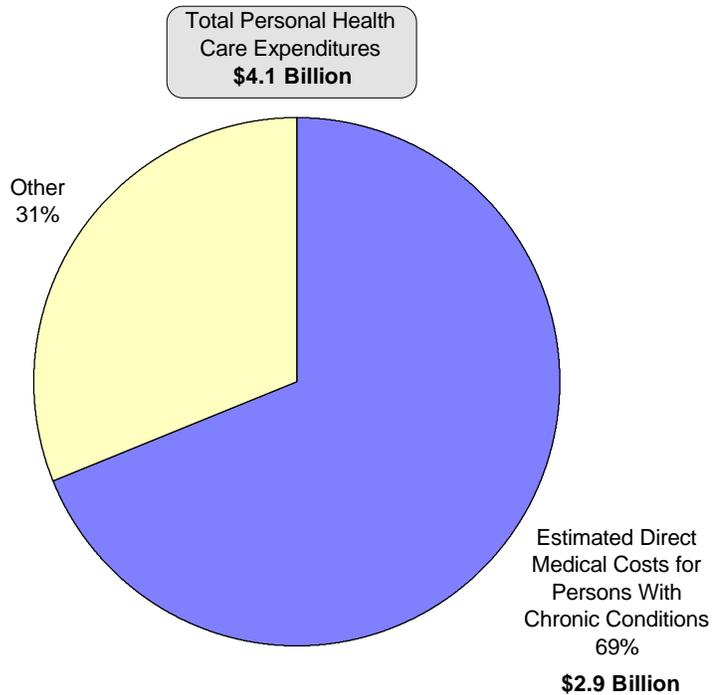


**Figure 23. Percentage Distribution of Utah Personal Health Expenditures According to Expenditure Category, 1993.**



The economic costs of chronic conditions are staggering. Based on the 1987 National Expenditure Survey, it has been estimated that nearly 70 percent of personal health care expenditures are for direct medical costs for persons with chronic conditions. Assuming the national statistics hold true for Utah, approximately \$2.9 billion is spent in Utah for chronic conditions. See Figure 24.

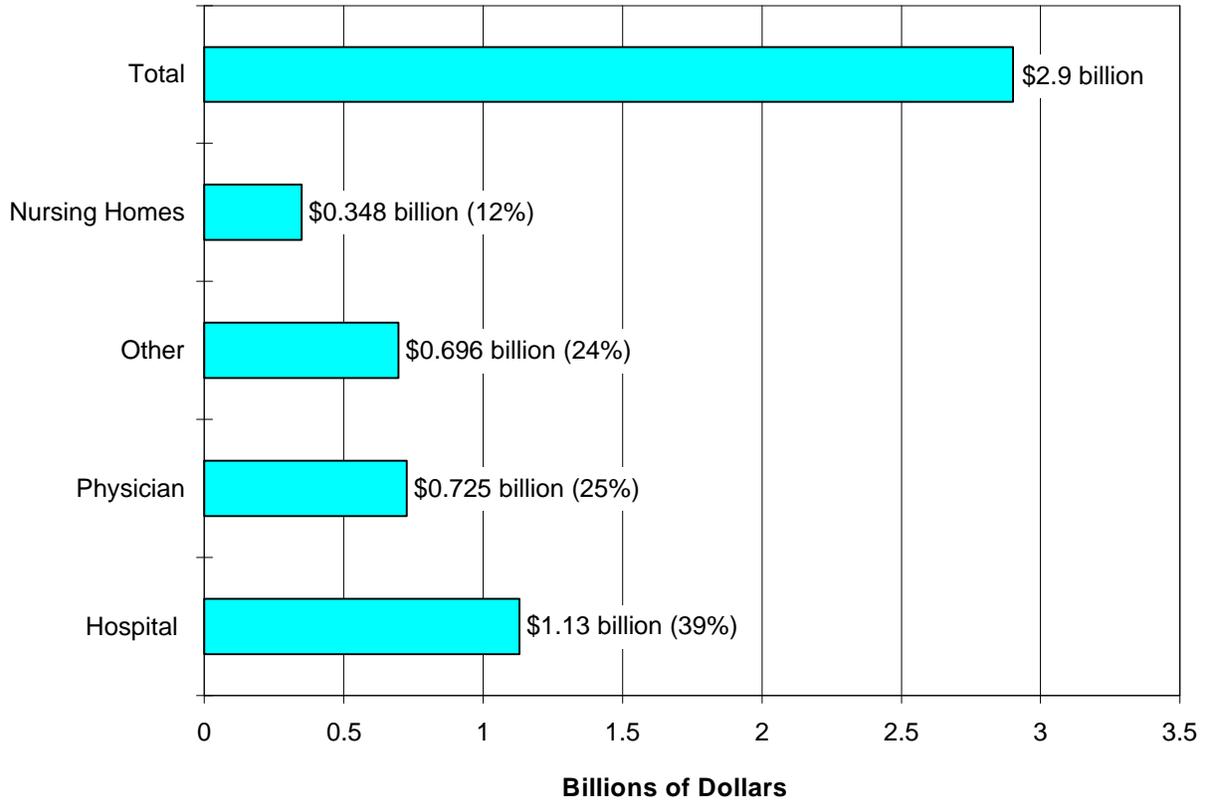
**Figure 24. Estimated Percentage of Utah Personal Health Care Expenditures Used for Direct Medical Costs for Persons with Chronic Conditions, 1993.**



Based on national data, it is estimated that the indirect costs for persons with chronic conditions-- in terms of lost productivity-- add \$1.6 billion to the costs of chronic conditions. That estimate includes \$1.1 billion in indirect costs due to premature death and \$500 million attributed to lost productivity of people who are unable to work (paid or unpaid), or to perform their usual activities. (When a person is unable to work or dies prematurely, the value of his or her productivity to society is lost.) These indirect costs do not include the lost productivity of people who were unable to perform other work or be employed because of caregiving responsibilities.

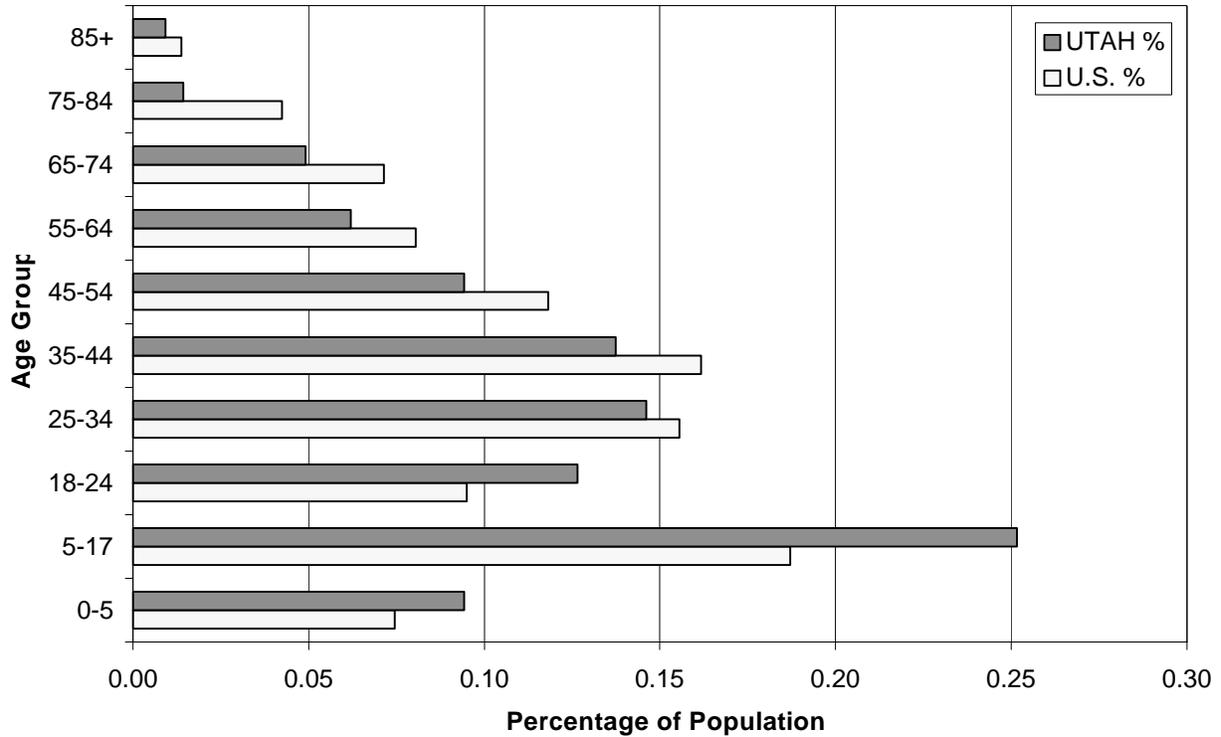
Almost two-thirds of estimated chronic health care dollars are spent on hospital care and physician services. (See Figure 25).

**Figure 25. Estimated Direct Medical Care Costs for Persons with Chronic Conditions According to Type of Expenditure, Utah 1993.**



As mentioned earlier, the Utah population is demographically different from the rest of the nation. These differences include the age distribution of the population which likely have a significant effect on chronic care needs. Figure 26 compares the population distribution by age group in Utah with that of the U.S. Because of the difference in the population distribution, the estimates in this section which were based on applying national percentages to Utah need to be interpreted with caution.

**Figure 26. Population Distribution by Age Group, Utah & U.S., 1995**

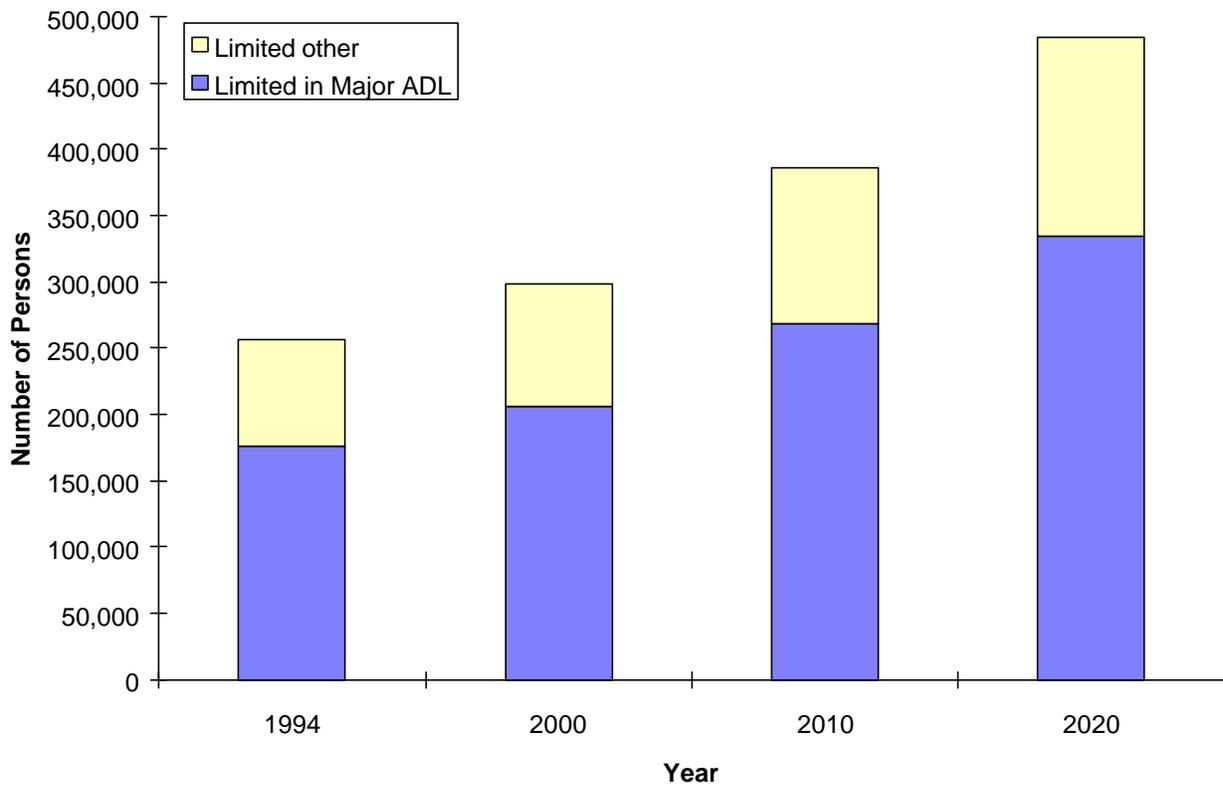


### Section III: Stresses on the System

An effective chronic care system must adequately respond to the needs-- both health care and other needs-- of people with chronic conditions. Stresses on the system can come from currently unmet need or from events in the future that increase or change the need for care and services. This section attempts to identify areas where such stresses exist today or might be anticipated in the future.

#### Current Unmet Need

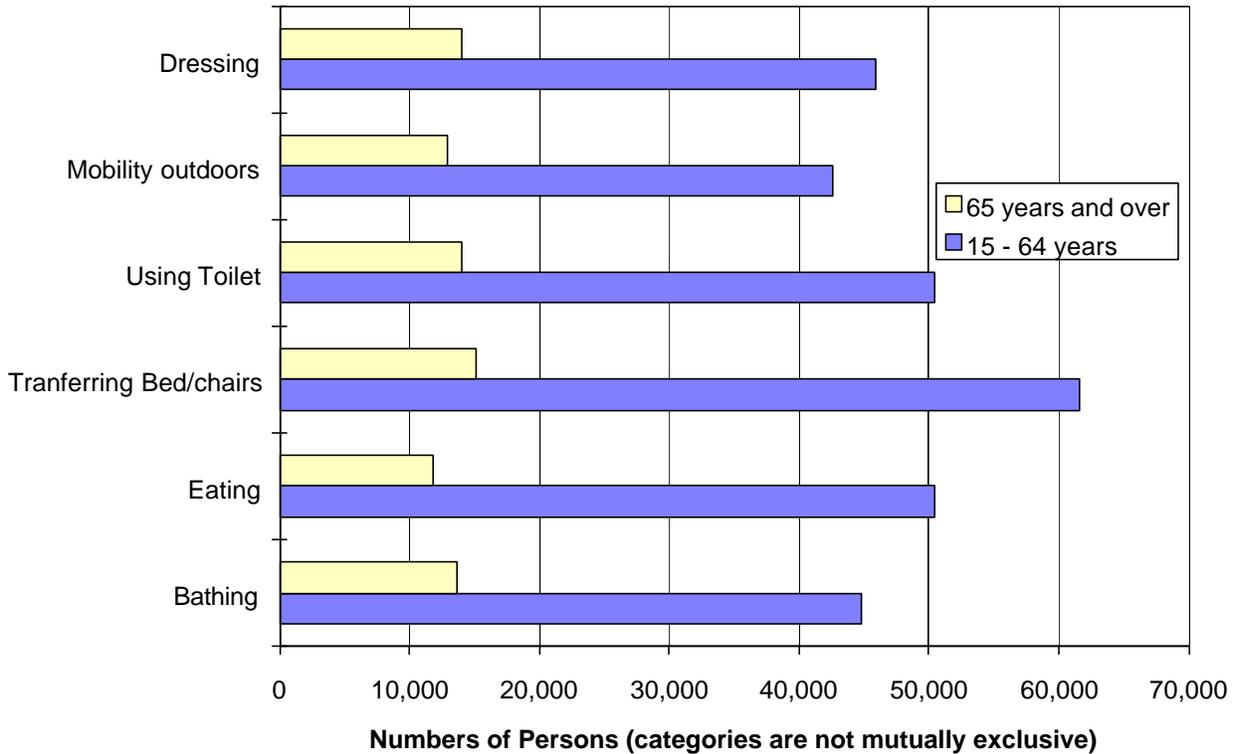
**Figure 27. Estimated Numbers of Utahns with Limitations in Activities of Daily Living: 1994 and Projected to 2020.**



Source: Projections are based on National Health Interview Survey data and Utah's population projections.

An estimated 140,000 Utahns (7%) have limitations in activities of daily living (1996 Utah Health Status Survey). The method used to estimate that number in Utah probably substantially underestimated the number of such people. Estimates from the National Health Interview Survey (NHIS), would suggest that about 270,000 (13.4%) Utahns had such limitations in 1996. If the percentages of Utahns with ADL limitations at various ages remain the same as in the NHIS, the number of such Utahns will increase to 484,000 by the year 2020 (Figure 27).

**Figure 28. Estimated Number of Persons with Unmet Need for Assistance with Activities of Daily Living. Utahns aged 15 and Over, 1994.**



Source: RWJ. Chronic Care in America: A 21st Century Challenge (data from Springfield Massachusetts Study of Populations with Disabilities, National Health Interview Survey, Utah Population Projections).

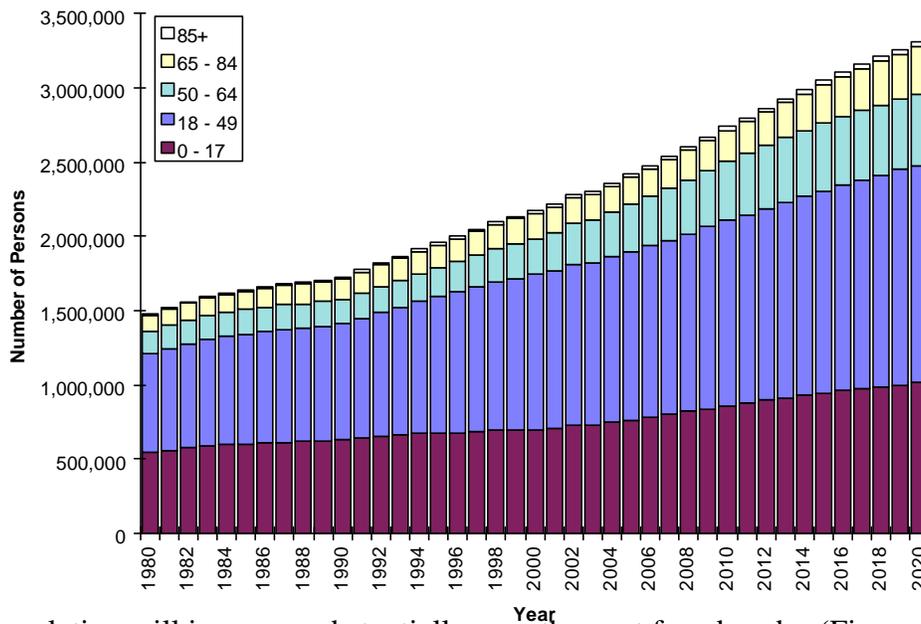
No studies in Utah have examined how well the needs for assistance of people with activity limitations are being met. A study conducted in Springfield, Massachusetts suggested that substantial proportions of such individuals have unmet needs for assistance. If the unmet need for Utahns is similar to what was found in that study, a substantial number of Utahns have unmet needs for assistance (Figure 28). People over the age of 65 are more likely to have activity limitations than are younger people, but there are substantially more people in the younger age group and younger persons with activity limitations are often more likely to have unmet needs.

The data from that 1994 Massachusetts study may not be applicable to the Utah population. Additionally, they cannot be used to measure improvement or the effects of demographic or system change on the extent of unmet need. **If the performance of the chronic care system in Utah is to be meaningfully assessed, information on how well needs for assistance are being met in Utah will be needed.**

Presently available data do not allow us to identify accurately the medical or other conditions that cause loss of independence and need for long term care. If we had that information, we might be able to provide improved care that would prevent or delay that need.

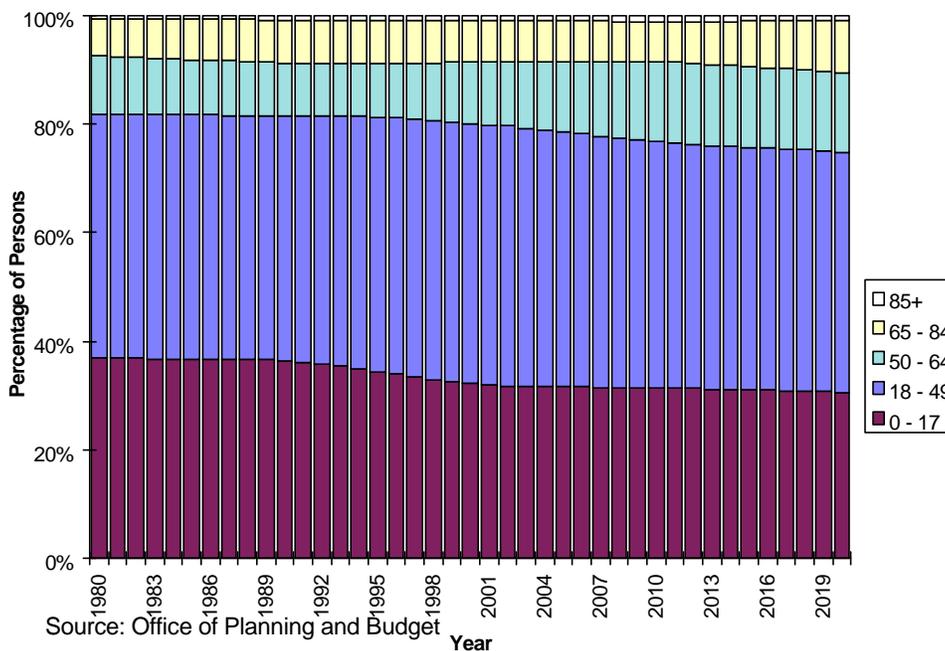
## Projected Change in Need

**Figure 29. Utah Population by Age Group Projected Through 2020.**



The Utah population will increase substantially over the next few decades (Figure 29)-- it is projected to reach 3.3 million by 2020. At that time, 352,000 Utahns will be aged 65 or over, and 33,000 aged 85 or over. The increased number of people in those age groups will substantially increase the number of persons in need of chronic care. The population in those age groups will also increase somewhat relative to the overall Utah population (Figure 30). In 1990, 9% of Utahns were aged 65 or older; that percentage will increase to 11% by 2020.

**Figure 30. Percentage Distribution of Utah Population by Age Group, Projected Through 2020.**



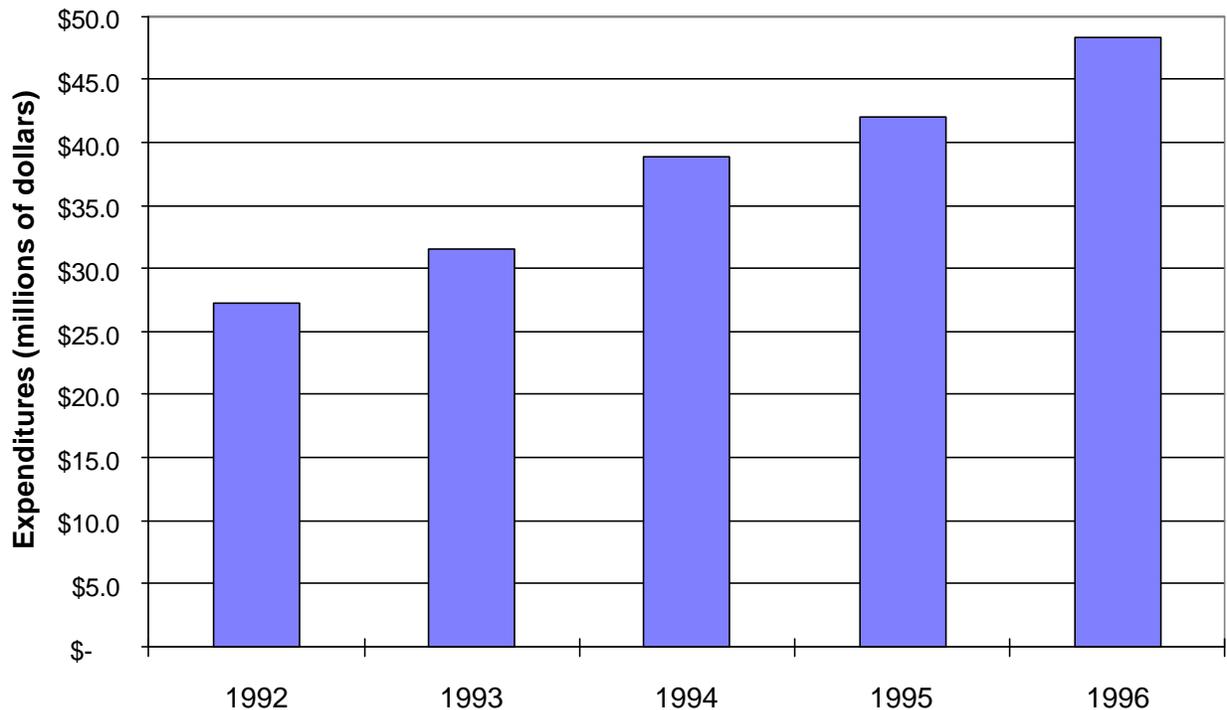
Source: Office of Planning and Budget

## Financing of Chronic Care

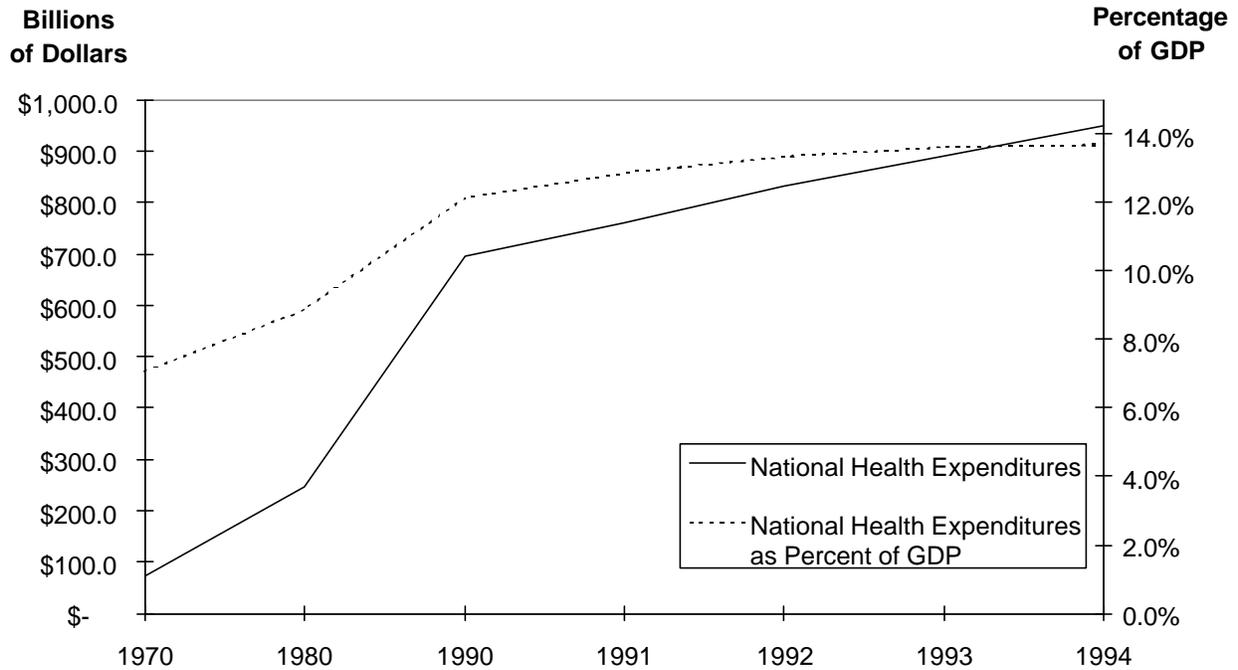
Medicare, the principal health care insurance source for most persons over age 65, does not cover costs of outpatient medications. For many chronic conditions, medications are an important part of disease management. An example is asthma, where appropriate use of medications can improve quality of life and reduce overall medical expenditures by preventing hospitalizations and emergency room visits. This is also true for patients with other important chronic conditions, such as diabetes and heart disease.

In addition to impeding appropriate management of patients with chronic conditions, the failure of medicare to cover medication costs can shift the costs of care from medicare to medicaid (medicaid does cover costs of medicines for eligible patients). The budget for drugs in the Utah Medicaid program has increased substantially in recent years (Figure 31).

**Figure 31. Outpatient Prescription Drug Expenditures, Utah Medicaid Program, Fiscal Years 1992 - 1996.**



**Figure 32. National Health Expenditures, United States, Selected Years 1970-1994.**

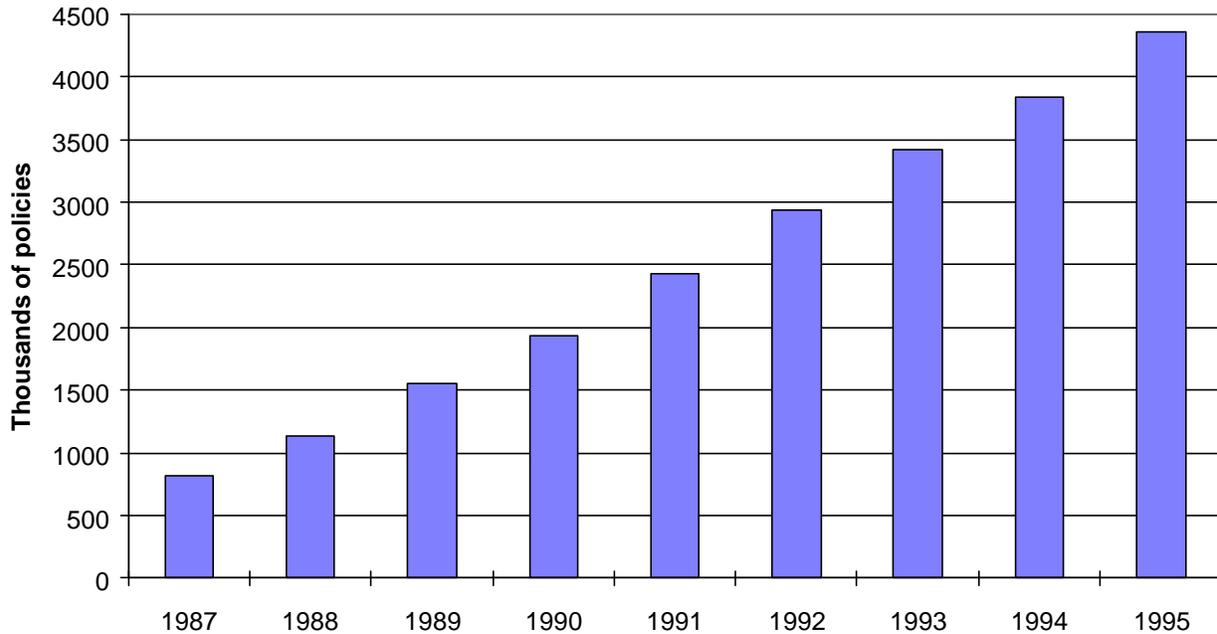


Source: Levit KR, Lazenby HC, Sivarajan L. Health care spending in 1994: slowest in decades. Health Affairs 1996;15:130-144.

Health care expenditures have increased substantially during the past 2 decades<sup>2</sup> (Figure 32). That increase has led to attempts to control costs, including various methods to limit health care utilization. Those methods often suppress appropriate as well as inappropriate utilization<sup>3</sup>. To the extent that health care expenditures approach the maximum that society is willing to pay, resources to meet the increasing demands for long term care will be limited. Also, methods to limit utilization may adversely affect the care provided to persons with chronic conditions.

In order to track expenditures for long term care, standards will need to be developed that specify the conditions, diagnoses, encounter types, and other services that are part of long term care. Those standards must allow the assembly of expenditure data from different data sources covering different parts of the long-term care system, including medicaid, medicare, hospital discharge, and private insurer claims.

**Figure 33. Cumulative Number of Long-Term Care Insurance Policies Sold, United States, 1987 to 1995.**



Source: Coronel S, Kitchman M. Long Term Care Insurance in 1995. Health Insurance Association of America. Washington, D.C.. May 1997.

Increasing numbers of individuals are purchasing insurance policies to help pay for the costs of long-term care (Figure 33), but the percentage of persons who have purchased such insurance coverage remains low. In Utah, as in more than half of all states, the cumulative number of such policies sold equals 6% or less of persons aged 65 or over<sup>4</sup>.

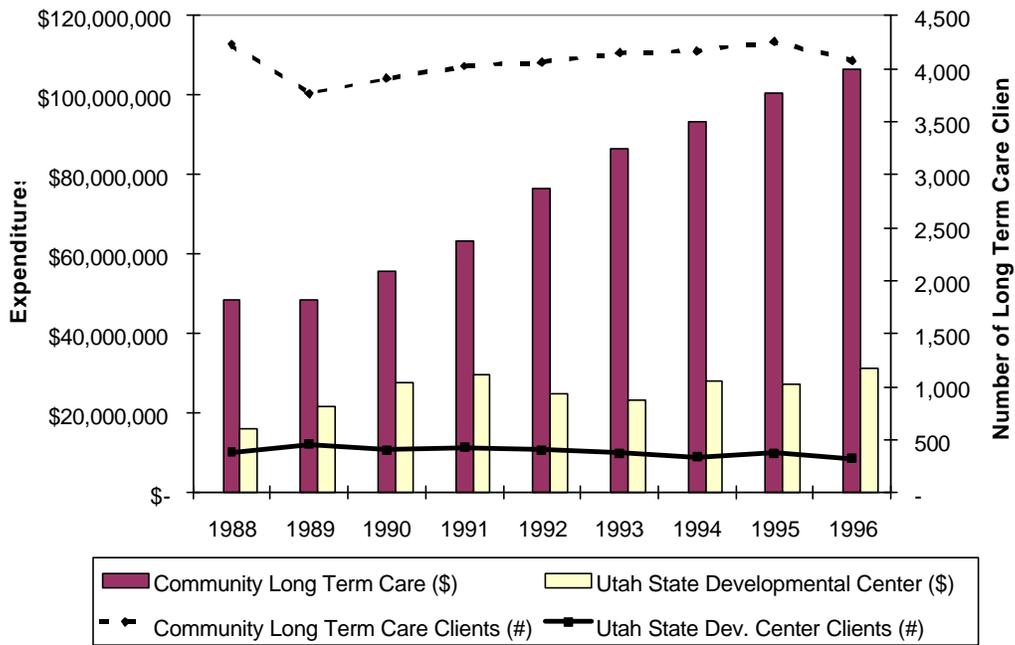
Long-term care insurance has evolved from limited to fairly comprehensive plans; all plans offer nursing home, home health care, adult day care, respite care, and alternate care services; some offer hospice care as well.

The 1996 *Health Insurance Portability and Accountability Act* (HIPAA) included consumer protection standards for long-term care insurance and clarified federal tax treatment of such insurance. This law may result in increased awareness of long-term care insurance and make it more financially attractive, leading to continuing market expansion.

Growth of private long-term care insurance may lessen reliance on publicly funded programs.

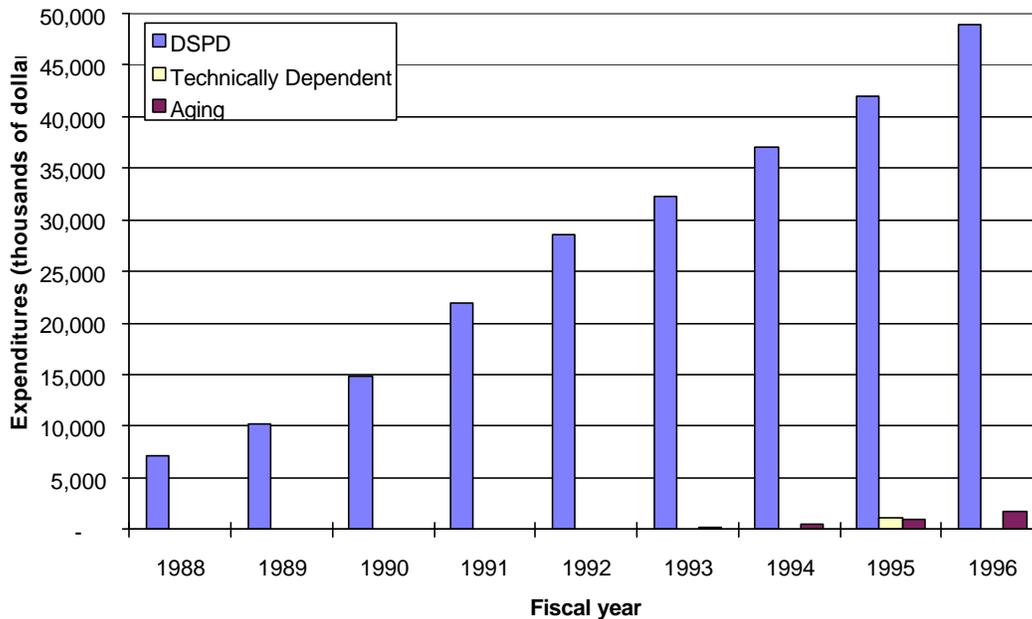
Medicaid expenditures for long term care have increased substantially, particularly in the area of community long term care services. This increase has occurred without a substantial increase in the number of clients served (Figure 34).

**Figure 34. Medicaid Expenditures for Long-Term Care, Utah, FY1988 - FY1996.**



The Utah Medicaid Program has obtained waivers that allow provision of home and community based care for persons who would formerly only have been able to obtain Medicaid reimbursement for nursing home care. Substantial growth has occurred in the Division of Services for People with Disabilities (DSPD) waiver (Figure 35). The Administration on Aging recently rated Utah as “average” regarding its progress toward a home and community-based service system for aging populations.

**Figure 35. Medicaid Expenditures Under Three Home and Community-based Care Waiver Programs. Utah 1988 - 1996.**



An important challenge for the system will be to provide support for family and other unpaid care givers, rather than substituting a paid or public system of care giving.

## **Managed Care System and System Capacity**

The most important challenge in this area is to build an effective and efficient “chronic care system”. The U.S. medical care system is oriented more toward acute and episodic care than toward provision of care for chronic conditions. Such care requires greater coordination among providers, and a different approach to storing and using information.

Managed care is an increasingly important component of medical care financing and delivery in the United States. Managed care has potential to both benefit and harm the care provided to persons with chronic conditions. Managed care can allow more systematic development of care delivery systems, including improved referral and consultative mechanisms, and information systems that track patients’ outcomes and care over time and across providers. On the other hand, managed care can impose barriers to utilization that do not effectively discriminate between appropriate and inappropriate utilization.

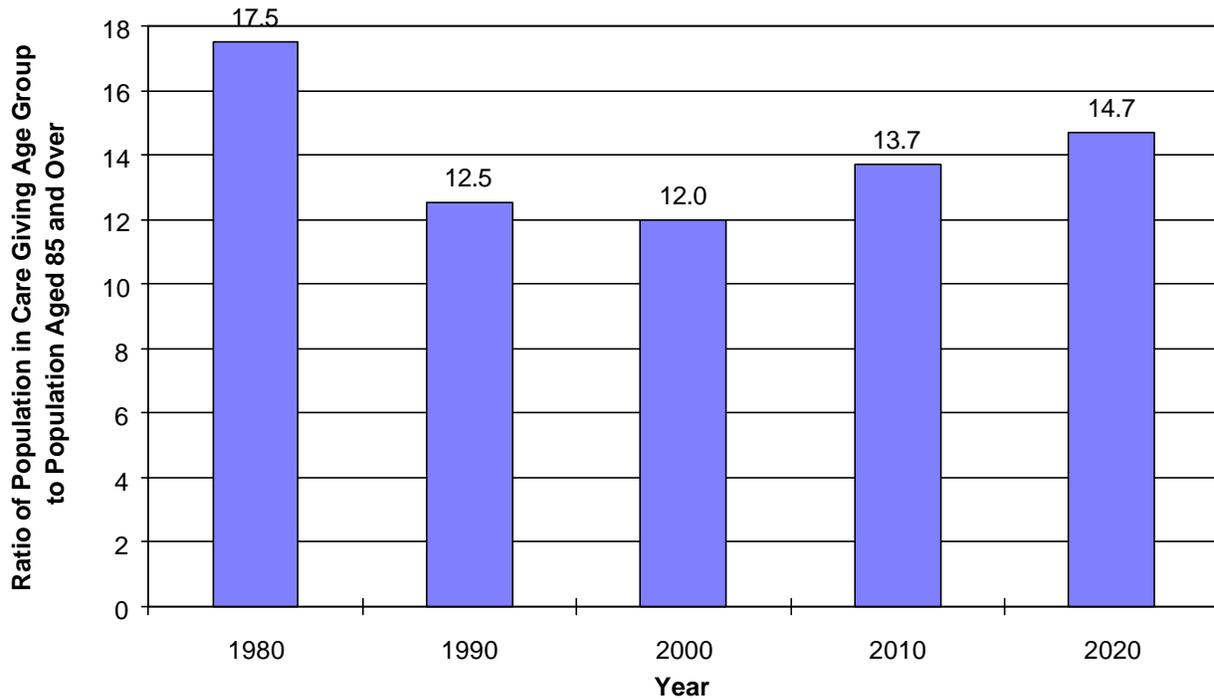
Capacity to provide long term care has increased substantially in Utah -- both nursing home beds and home and community services.

In 1983, 39 home health care agencies were licensed by the Utah Department of Health. In 1997, that number had grown to 103 agencies. An additional 107 branch or satellite offices were operating under the licenses of those entities. We have limited information on the actual service capacity of those entities, however.

The number and occupancy of nursing home beds that are certified for Medicare/Medicaid reimbursement is tracked by UDOH. That number decreased relative to the number of Utahns age 65 and over during the 1990s, due to a moratorium on certifying additional beds for Medicaid/Medicare reimbursement. Numbers of nursing home beds not certified for Medicaid/Medicare are not tracked by UDOH; the number of such beds is believed to have increased substantially.

While long-term care capacity has increased in Utah, the range of options (such as assisted living) and financing for those options have not kept pace with the needs and preferences of the elderly and others who need such care.

**Figure 36. Ratio of Persons in Care Giving Age Group to Persons Aged 85 and Over. Utah 1980 - 2020**



Source: Utah Office of Planning and Budget; Care Giving Age Group is Aged 50-64 years

Much care for persons with chronic conditions who require assistance with activities of daily living is provided by family or other unpaid care givers. Changes in the economics, social characteristics, and demographics of the Utah population are substantially changing the availability of such care givers.

The traditional care giving age group is age 50 to 64 years. Demographic pressures on this care giving group will be less for Utah than for the United States. In the United States as a whole, the ratio between that care giving age group and the age group most often requiring care (age 85 and over) is projected to decrease from 11 to 1 in 1990 to 6 to 1 in 2030 and 4 to 1 by 2050. In contrast, that ratio is projected to increase somewhat in Utah, from 12 to 1 in 1990 to 15 to one in 2020 (Figure 36).

A 1996 national survey<sup>5</sup> found that 23% of US homes contained a “care giver”, someone who had provided care, such as dressing, bathing, toilet needs, or feeding, to a relative or friend age 50 or older within the past year. Three quarters of those were “currently” providing such care. Three quarters of those care givers were women, 41% also had a child under 18 in the household, and 64% were employed (52% full-time).

Care givers frequently experience conflicts between work and their care giving responsibilities, requiring switches from full-time to part time, changes in work schedule, or a leave of absence. A positive finding of that survey was that most care givers found their employer sympathetic to their needs.

The increasing participation of Utah women in the paid labor force has made it more difficult for women to assume that traditional care giving role. In 1950, only 24% of Utah women participated in the paid labor force, compared to 30% for the United States. In 1994, 66% of Utah women participated in the paid labor force, compared to 59% for the United States.

Certain types of providers will be particularly important for an effective chronic care system, such as physicians trained in internal medicine and geriatrics, and geriatric nurse practitioners. The effect of managed care and capitated payment systems on the numbers of such providers is not known. We do not have a mechanism to track numbers of such providers according to specialty in Utah.

Obtaining information on the health status of persons receiving long term and chronic care will be important for evaluating the impact of changes in the care system. Such data should be collected as part of service delivery.

## References

1. Robert Wood Johnson Foundation. *Chronic Care in America: A 21<sup>st</sup> Century Challenge*. Princeton, NJ: The Robert Wood Johnson Foundation, August 1996.
2. Levit KR, Lazenby HC, Sivarajan L. Health care spending in 1994: slowest in decades. *Health Affairs* 1996;15:130-144.
3. Siu AL, et al. Inappropriate use of hospitals in a randomized trial of health insurance plans. *N Engl J Med* 1986;315:1259-66.
4. Coronel S, Kitchman M. *Long-term care insurance in 1995*. Health Insurance Association of America, Washington, D.C., May 1997.
5. National Alliance for Caregiving. *Family Caregiving in the U.S.: Findings from a National Survey*. Bethesda, Maryland, June 1997.



**For Additional Information:**

**On occurrences of chronic conditions in Utah**

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