Medicaid's Role for People with Disabilities

Diane Rowland, Sc.D.
Executive Vice President, Henry J. Kaiser Family Foundation
And
Executive Director, Kaiser Commission on Medicaid and the Uninsured

Testimony before the
U.S. House of Representatives
Committee on Energy and Commerce
Subcommittee on Health

"Helping Families with Needed Care:
Medicaid's Critical Role for Americans with Disabilities"

January 16, 2008

Summary of Testimony by Diane Rowland, Sc.D

- The Medicaid program is our nation's major public health coverage program covering over 58 million Americans, including 8 million persons with disabilities and 6 million low-income frail elderly and disabled Medicare beneficiaries who rely on Medicaid to fill Medicare's gaps.
- Since its enactment in 1965, the major changes in Medicaid involved broadening coverage to people with disabilities through the federal SSI program, making assistance in the community and at home an alternative to institutional nursing home care, promoting improvements in the quality of care in nursing homes, and assisting people with disabilities to return to work while retaining their Medicaid coverage.
- The population with disabilities is diverse, with a wide range of conditions and limitations. To be covered by Medicaid, individuals must meet both income and asset requirements and have a condition determined to be permanently disabling.
- The needs of people with disabilities are extensive and complex, requiring many types of health services and supports that are not traditionally covered by other sources of insurance, but needed to maintain function and, in some cases, independence.
- Historically, differences in functional and financial eligibility criteria between nursing home and community-based care steered people with disabilities into institutional settings. Consumer demand and the *Olmstead* decision have helped to promote expanded access to home and community-based services.
- Although Medicaid is principally recognized as a source of health insurance coverage for millions of low-income children and parents, the program has become the largest single source of health insurance and long-term care and the largest source of public financial support for people with disabilities. Seniors and people with disabilities comprise only 24% of enrollees, yet they account for 70% of program spending. The average per-person cost of caring for persons with disabilities in 2004 was $12,364 compared to $1,474 for non-disabled children and $1,942 for non-disabled adults.
- Medicaid plays a critical role in providing health care services to people with disabilities - both filling in the gaps in Medicare and private health insurance and going beyond the medical model to offer the broad array of services needed by people with severe disabling conditions. Doctor visits and prescription drugs alone are insufficient to enable an individual with severe paralysis to get to a job—personal care assistance, transportation, and assistive devices, all covered by Medicaid—are essential adjuncts to medical care.
- The Medicaid experience clearly demonstrates the importance of providing health and long-term care coverage for the population and the lack of alternative forms of assistance. Reformers should build on the progress that has been made in providing coverage and access to care to those with disabilities and exercise caution when making changes that could affect the health and well-being of many of the poorest and most disabled among us.

Introduction

Mr. Chairman and members of the Health Subcommittee, thank you for the opportunity to testify today on Medicaid's role for people with disabilities. I am Diane Rowland, Executive Vice President of the Henry J. Kaiser Family Foundation and Executive Director of the Kaiser Commission on Medicaid and the Uninsured. I also serve as an adjunct professor at the Johns Hopkins Bloomberg School of Public Health. My testimony today will briefly review the history of Medicaid's development as a vital source of coverage for people with disabilities and provide an overview of its current role providing coverage and access to health services and supports for this population.

The Medicaid program is our nation's major public health coverage program designed to address the acute and long-term service needs of low-income Americans of all ages. It provides health coverage today to over 58 million Americans, including 8 million persons with disabilities and 6 million low-income frail elderly and disabled Medicare beneficiaries who rely on Medicaid to fill Medicare's gaps. Medicaid covers a broad spectrum of services, ranging from basic medical care to behavioral health and long-term services and supports to enable individuals with disabilities to live independently.

Medicaid is an integral part of our nation's health financing system, paying for 16% of overall health spending but nearly half (43%) of all nursing home spending and over half of all public spending on mental health services (Figure 1). It provides coverage for those in the low-income population who are unable to access private health insurance, have chronic conditions that require extensive medical care, and need assistance in the community or in a nursing facility for cognitive and physical disabilities.

Medicaid's History for People with Disabilities

Medicaid was first established in 1965 to fill distinct gaps in the private health insurance system – gaps that left those with the least income and the most extensive health needs without access to coverage and services. Over the years, legislative and policy changes to Medicaid have expanded its reach as needs for safety-net coverage have grown, due to economic and labor force dynamics, rising health care costs, and aging and disability trends. Medicaid has broadened from primarily providing medical care to the welfare population to the main source of health insurance for millions of low-income Americans and the primary program for providing access to acute and long-term care for aged and non-aged people with disabilities.

The most far-reaching change in eligibility and coverage of people with disabilities and the elderly came in 1972 with the enactment of two new federal programs—the Supplemental Security Income (SSI) program providing cash assistance for low-income people with disabilities and the Social Security Disability Insurance (SSDI) program. The implementation of SSI and SSDI brought a uniform national definition of "disability," and the link between Medicaid eligibility and SSI coverage brought a national income floor for Medicaid eligibility (roughly 74% of poverty) for the elderly and people with disabilities in Medicaid—substantially raising levels in many states.

Since its enactment in 1965, the major changes in Medicaid involved making assistance in the community and at home an alternative to institutional nursing home care, promoting improvements in the quality of care in nursing homes, and assisting people with disabilities to return to work while retaining their Medicaid coverage. In 1999, the landmark Supreme Court ruling in Olmstead v. L.C. required states to provide

community-based services to individuals for whom institutional care is inappropriate to comply with the American's with Disabilities Act (ADA) of 1990. Providing services in the community and giving people who need long-term services and supports more control over their care continue to be a central focus of Medicaid reform for both the elderly and people with disabilities.

In addition, in the face of the unfolding AIDS epidemic, Medicaid responded to the emerging health challenge by extending coverage to those with HIV/AIDS who met income criteria as part of coverage for people with disabilities. All of these changes have combined to make Medicaid the primary source of coverage for people with disabilities and the low-income elderly, especially those needing long-term services and supports.

Medicaid's Role Today

The population with disabilities is diverse, with a wide range of conditions and limitations and great variation in severity, symptoms, and overall impact on health and quality of life. These individuals include children with intellectual disabilities such as mental retardation or developmental disabilities such as autism; young adults with spinal cord and traumatic brain injuries or serious mental illness; and older people with Alzheimer's disease or severely disabling chronic diseases such as diabetes and pulmonary disease.

Individuals with these conditions have a range of needs for acute care as well as long-term services and supports. For example, people with intellectual disabilities have specialized needs that would not be met in a long-term services system developed to meet the needs of people with physical disabilities. The need for services ranges considerably and can change quickly.

Who Does Medicaid Cover?

To qualify for Medicaid, individuals must meet both income and asset (generally $2,000 for an individual) requirements and fall into one of the categories of eligible populations. To qualify on the basis of disability, an individual must have a condition determined to be permanently disabling. Most people with disabilities covered by Medicaid come into the program by being eligible for the federal SSI cash assistance program or another mandatory pathway.

States have flexibility to expand Medicaid eligibility beyond federal minimum standards to cover additional "optional" groups, including the elderly and people with disabilities with incomes up to 100% of the federal poverty level and the medically needy. And, because few people can afford the high cost of nursing home care, 38 states allow individuals needing nursing home care to qualify with income up to 300% of the SSI eligibility level. By raising the income standard for people with disabilities, states have allowed children and adults to receive services and remain at home or in the community as an alternative to institutional care. These policies, however, vary widely across the states.

In an effort to promote participation in the workforce, many states provide a means for higher income individuals to buy into Medicaid through the Ticket-to-Work option, enabling individuals with disabilities to work and retain their health coverage. More recently, the new Family Opportunity Act was designed for disabled children with family income up to 300% of poverty to provide community-based long-term services, recognizing that impoverishment to obtain coverage would not be in the best interests of disabled children and their families. Despite efforts to make Medicaid coverage more

available to people with disabilities, millions continue to fall outside its reach because coverage is often restricted to the poorest and most severely disabled.

What Services Are Covered?

People with disabilities experience problems with vision, hearing, communication, mobility, physical actions such as standing or stair-climbing, performing simple activities like bathing, dressing, getting out of bed, and eating, and managing money or a home. Consequently, the needs of people with disabilities are extensive and complex, requiring many types of health services and supports to maintain function and, in some cases, independence. Of the $103 billion in Medicaid spending for people with disabilities, 62 percent was for medically related care and 38 percent was for long-term services and supports (Figure 2).

Medicaid was designed as a program to provide health coverage to people with diverse health needs that includes adults and children with disabilities and, therefore, provides a comprehensive set of acute and long-term care benefits that include and extend beyond standard medical care. This includes supportive services that complement medical care and help people with disabilities maintain their independence—services which are not traditionally covered by other sources of insurance.

State Medicaid programs are required to cover certain “mandatory services” including physician and hospital services, laboratory and diagnostic testing and nursing facility services. States can also choose to cover certain “optional” services such as prescription drugs, personal care services and home and community-based long-term care services. Significant variations in eligibility standards and the scope of covered services across states make the program exceptionally complicated in ways that create gaps in coverage,

but many of the benefits offered at state option are particularly important for Medicaid enrollees with disabilities. For example, access to prescription drugs is essential to the management of acute and chronic physical and mental illnesses. Access to personal care services is important for people with disabilities who work, especially since these services are not provided in most private plans.

Historically, differences in functional and financial eligibility criteria between nursing home and community-based care steered people with disabilities into institutional settings. Many states have expanded access to home and community-based services driven in part by consumer demand and by the *Olmstead* decision that stated the unjustified institutionalization of people with disabilities is a violation of the 1990 Americans with Disabilities Act.

While the majority (59%) of Medicaid spending on long-term services and supports is concentrated on institutional care, reflecting the high costs of providing these services, an increasing share is attributable to home and community-based long-term services. The national percentage of Medicaid spending on home and community-based services has more than doubled from 15% in 1992 to 37% in 2005 (Figure 3). Today more than 2.7 million individuals receive Medicaid home and community-based services.

To address the institutional bias in Medicaid, there are three main ways a state can provide Medicaid home and community-based services (HCBS): through the optional HCBS waivers, the mandatory home health benefit, and the optional state plan personal care services benefit. In 2004, all states operated the Medicaid home health benefit and multiple HCBS waivers, and 30 states offered the optional state plan personal care benefit. HCBS waivers give states considerable flexibility to determine which services

and populations to cover. Consumer direction of personal assistance services has been an important component within home and community-based services for some Medicaid beneficiaries who desire greater control over hiring, scheduling, and paying personal care attendants.

Though HCBS waivers have increased access to services at home and in the community for people with disabilities, states may also set cost controls such as coverage limits, expenditure caps and apply waiting lists for services, regardless of need. The number of people on waiting lists for services continues to grow. In 2006, 280,176 individuals were on a waiting list for HCBS services, up from 206,427 individuals in 2004. Cost controls can prevent access to community services for many Medicaid enrollees with disabilities. In 2006, 34 states utilized some form of cost controls above and beyond the federally mandated cost neutrality formula for the waivers.

More recent efforts to expand access to community-based services include the Money Follows the Person demonstration that allows states to receive enhanced federal funding to transition people from an institution to the community, and the new state plan option for states to provide home and community-based waiver services without needing to get a waiver for seniors and people with disabilities up to 150% of poverty. While these programs are designed to promote greater access to community services, their scope is narrow and may not be sufficient to target all those whose desire is to live in the community. Few states have taken up this new HCBS option to date.

Quality of care is also an ongoing concern in Medicaid because the vulnerable population served has such complex health needs. Greater flexibility in benefit design, and over optional populations, will inevitably increase variability within and across states

in terms of who is covered and the services being received. This increases the importance of assessing and systematically monitoring person-level outcomes including unmet needs and satisfaction with care. Most attention to quality of care has been on nursing homes and not consistently or comprehensively evaluated in community-based settings. Identifying and remedying poor quality care requires mechanisms to monitor quality and incentives for implementing improvement. A recent poll shows the public is very concerned about the quality of long-term care in both nursing homes (51%) and community-based settings (59%, Figure 4).

Impact on Overall Medicaid Spending for People with Disabilities

Although Medicaid is principally recognized as a source of health insurance coverage for millions of low-income children and parents, the program has become the largest single source of health insurance and long-term care and the largest source of public financial support for people with disabilities. While low-income children and families represent the majority of Medicaid beneficiaries, people with disabilities and seniors (who are often people with disabilities over age 65) are responsible for most of the program's spending. Seniors and people with disabilities comprise only 24% of enrollees, yet they account for 70% of program spending (Figure 5).

They account for a greater share of spending because they are more likely to have chronic medical conditions that lead to more physician visits, higher rates of hospitalization, greater use of prescription drugs, and increased need for long-term services and supports, resulting in higher per capita costs compared to low-income families. The average per-person cost of caring for persons with disabilities in 2004 was $12,364. This compares to $1,474 for non-disabled children and $1,942 for non-disabled

adults (Figure 6). People with disabilities had higher per capita acute care spending as well as higher spending on long-term care services than low-income families.

Within the Medicaid program, spending is highly concentrated on a small percentage of beneficiaries. Four percent of the Medicaid population was responsible for 48% of program spending in 2001 reflecting their intensive health care needs, half of which are devoted to services for the disabled (Figure 7). Looking just at people with disabilities, the 11% of this group with costs over $25,000 accounted for 61% of all expenditures on people with disabilities (Figure 8).

Another way to identify high cost and high need Medicaid beneficiaries is to consider their use of long-term services and supports. Medicaid enrollees who use either institutional or home and community-based long-term care services account for the bulk of Medicaid costs. Fifteen percent of disabled Medicaid enrollees who use long-term services and supports account for 58% of all Medicaid spending on the disabled. Three quarters of these 1.2 million enrollees relied on community-based services, and have average total spending of $35,930; per enrollee spending for the disabled using institutional care averaged $76,331. This compares to an average of $6,277 for those with little or no long-term services spending.

Medicaid: Critical Assistance for People with Disabilities

Medicaid plays a critical role in providing health care services to people with disabilities - both filling in the gaps in Medicare and private health insurance and going beyond the medical model to offer the broad array of services needed by people with severe disabling conditions. Doctor visits and prescription drugs alone are insufficient to enable an individual with severe paralysis to get to his or her job—personal care

assistance, transportation, and assistive devices, all covered by Medicaid—are essential adjuncts to medical care. And, for those with chronic conditions that require long-term supports and services, Medicaid is the only source of financial assistance with long-term care within the community and in institutional settings.

Medicaid has come to be a critical complement to coverage from Medicare for low-income people with disabilities and the frail elderly. Dual-eligibles—the 7 million low-income Medicare beneficiaries who are also covered by Medicaid—are among Medicare's sickest, frailest, and poorest beneficiaries. Many suffer from cognitive impairments and chronic illnesses that require on-going help with the activities of daily living—bathing, toileting, dressing, eating, and transferring from bed to chairs.

Medicaid provides the services to fill Medicare's benefit gaps, enabling many to stay in their homes and communities and helping to offset the cost of nursing home care for those requiring greater assistance. Moreover, by offering coverage to low-income people with disabilities during the 29 month waiting period before Medicare coverage commences for those meeting the disability determination, Medicaid provides basic medical care coverage in addition to the broader long-term care services and supports.

Medicaid also helps fill the gaps in coverage available through the private health insurance system. Private health insurance in the individual market is inaccessible to those with severe disabilities due to prohibitions on pre-existing conditions and the very high cost of experience-related policies for people with chronic illnesses. People with disabilities are more likely to be enrolled in Medicaid than the general population. Individuals with disabilities covered by Medicaid are substantially more impaired than those covered by private insurance—almost 50% of Medicaid beneficiaries with any

disability are limited in major life activities compared with 26% of privately-insured persons with disabilities.

When individuals with disabilities have access to employer-sponsored group coverage, such policies are often limited in the scope of benefits to medical services as opposed to long-term supports. Covered benefits are often subject to substantial cost-sharing and strict utilization limits. Medicaid's comprehensive benefits enable people with disabilities who qualify for Medicaid assistance to obtain the fuller range of services they require to help maximize their independence, and, in some cases, support participation in the workforce.

By continuing Medicaid coverage when people with disabilities return to work, Medicaid both provides the personal care and supportive services necessary to engage in work, but also serves to keep the employer-based insurance more affordable by removing the high-risk, high-cost individuals from the insurance pool. Thus, rather than compete with private insurance for the disability population, Medicaid helps make employment and health coverage for people with disabilities possible.

Future Directions and Challenges

Medicaid plays an important role in the health care system, filling in gaps and providing coverage to millions of Americans who would be uninsured if not for Medicaid. Medicaid's role has grown substantially over the past 40 years with the federalization of cash assistance for the aged, blind, disabled; the shift to Medicaid from state-only coverage for the mentally ill and mentally retarded; the emergency of the AIDS epidemic; and greater reliance on home and community-based services as an alternative to nursing home care. As Medicaid's role has evolved, the program has been

under pressure to increase the availability of coverage, especially for the working disabled, and improve access to home- and community-based alternatives to institutional care.

Medicaid is a vital safety net for millions of Americans but a lifeline for people with disabilities. In the absence of universal coverage for health care and other forms of assistance with the cost of long-term care, Medicaid's costs and responsibilities will continue to grow. The challenge for the future is how to balance the substantial needs and costs for care of people with disabilities with fiscal realities.

The Medicaid experience clearly demonstrates the importance of providing health and long-term care coverage for the population and the lack of alternative forms of assistance. Reformers should build on the progress that has been made in providing coverage and access to care to those with disabilities and exercise caution when making changes that could affect the health and well-being of many of the poorest and most disabled among us.

Thank you for the opportunity to testify today and your continued attention to the vital role Medicaid plays in providing coverage to people with disabilities. I welcome your questions.

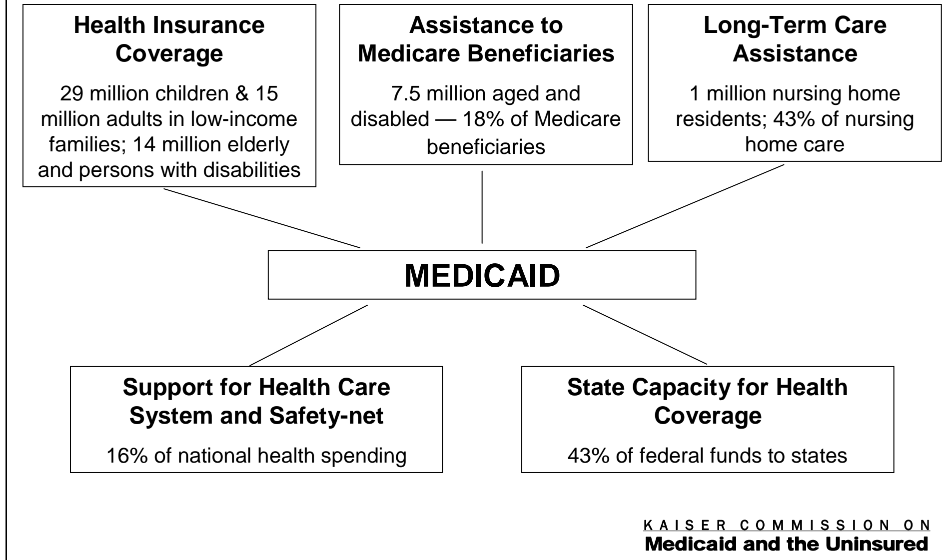


Figure 1
Medicaid Today
Health Insurance Coverage
29 million children & 15 million adults in low-income families; 14 million elderly and persons with disabilities
Assistance to Medicare Beneficiaries
7.5 million aged and disabled — 18% of Medicare beneficiaries
Long-Term Care Assistance
1 million nursing home residents; 43% of nursing home care
MEDICAID
Support for Health Care System and Safety-net
16% of national health spending
State Capacity for Health Coverage
43% of federal funds to states
KAISER COMMISSION ON
Medicaid and the Uninsured

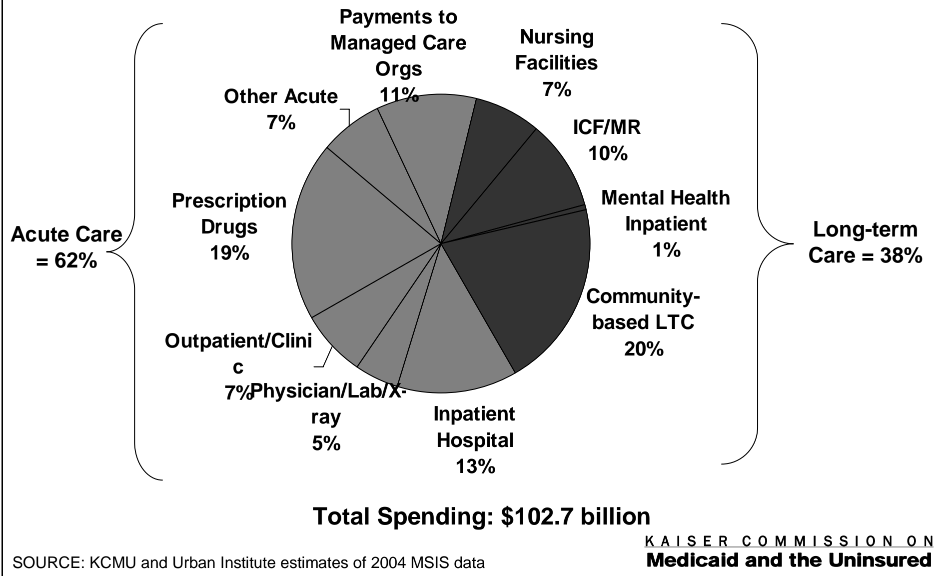


Figure 2
Medicaid Spending by Service for People with Disabilities, 2004
Payments to Managed Care Orgs 11%
Nursing Facilities 7%
Other Acute 7%
ICF/MR 10%
Mental Health Inpatient 1%
Prescription Drugs 19%
Acute Care = 62%
Long-term Care = 38%
Community-based LTC 20%
Outpatient/Clinic 7%
Physician/Lab/X-ray 5%
Inpatient Hospital 13%
Total Spending: $102.7 billion
KAISER COMMISSION ON
Medicaid and the Uninsured
SOURCE: KCMU and Urban Institute estimates of 2004 MSIS data

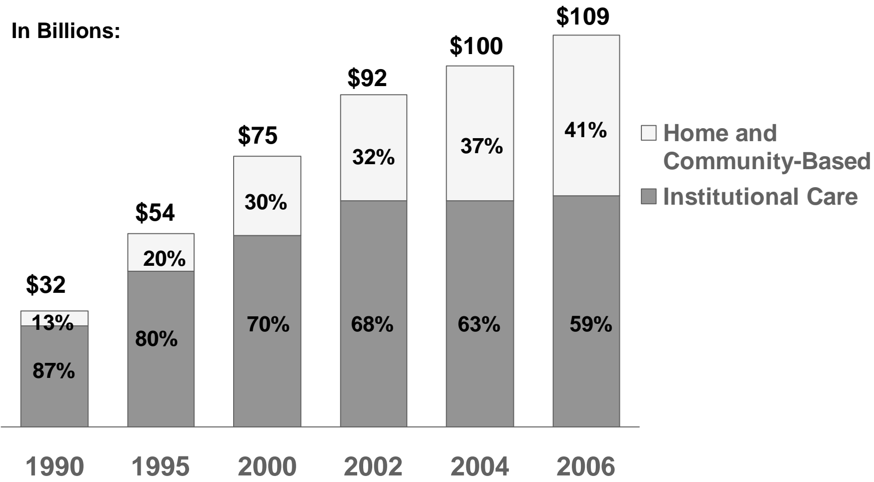


Figure 3
Growth in Medicaid Long-Term Care Services Expenditures, 1990-2006
In Billions:
$32
13%
87%
$54
20%
80%
$75
30%
70%
$92
32%
68%
$100
37%
63%
$109
41%
59%
Home and Community-Based
Institutional Care
1990
1995
2000
2002
2004
2006
Note: Home and community-based care includes home health, personal care services and home and community-based service waivers.
SOURCE: KCMU and Urban Institute analysis of HCFA/CMS-64 data.
KAISER COMMISSION ON
Medicaid and the Uninsured

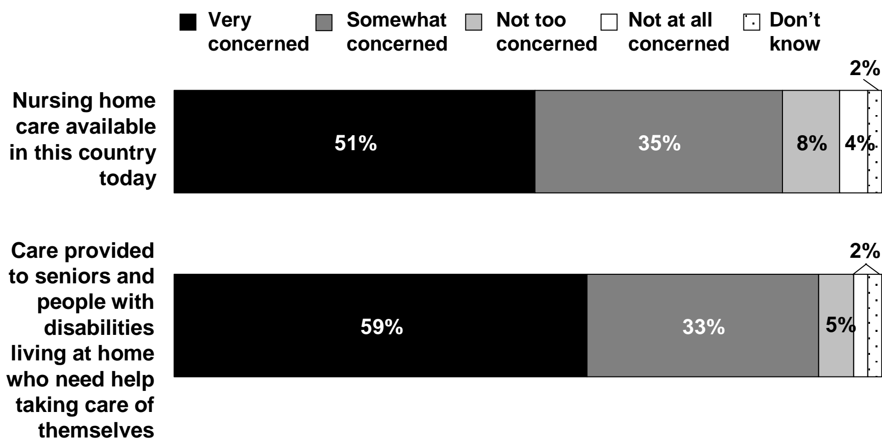
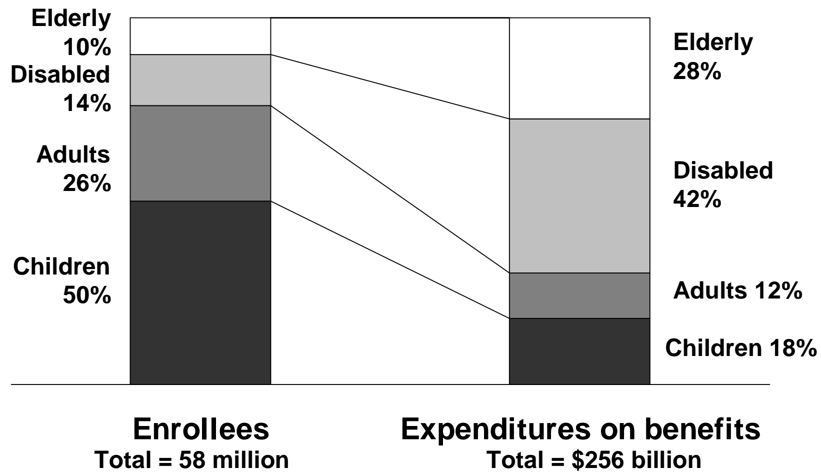


Figure 4
Concerns About the Quality of Long Term Care
How concerned are you if at all, about the quality of …
Very concerned
Somewhat concerned
Not too concerned
Not at all concerned
Don't know
Nursing home care available in this country today
51%
35%
8%
4%
2%
Care provided to seniors and people with disabilities living at home who need help taking care of themselves
59%
33%
5%
2%
Source: KFF Update on the Public's Views of Nursing Homes and Long-Term Care Services (conducted October 1 – October 10, 2007)
KAISER COMMISSION ON
Medicaid and the Uninsured

Figure 5

Medicaid Enrollees and Expenditures by Enrollment Group, 2004

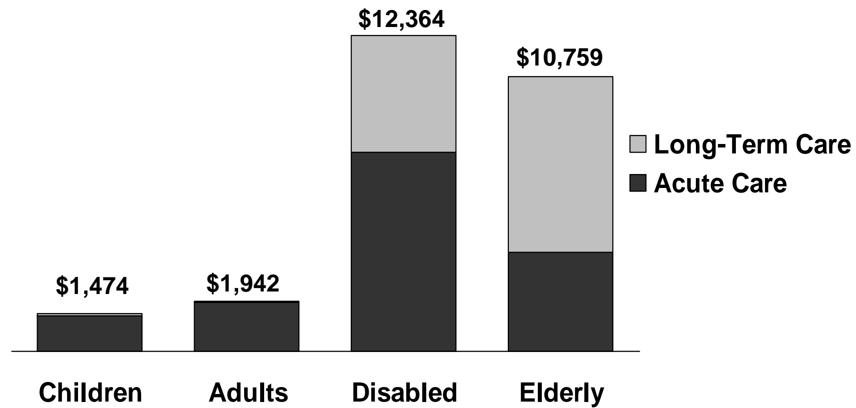


SOURCE: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on FY 2004 MSIS data.

KAISER COMMISSION ON Medicaid and the Uninsured

Figure 6

Medicaid Payments Per Enrollee by Acute and Long-Term Care, 2004

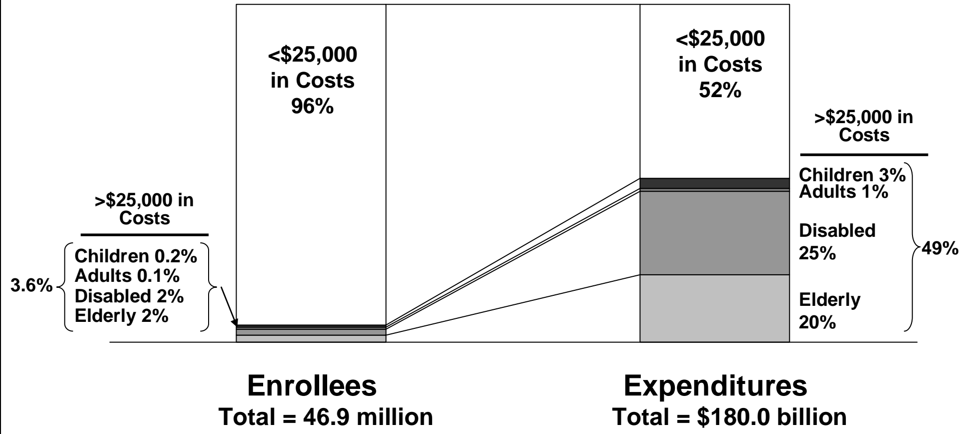


SOURCE: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on FY 2004 MSIS data.

KAISER COMMISSION ON Medicaid and the Uninsured

Figure 7

Role of High-Cost Enrollees in Total Medicaid Expenditures, 2001

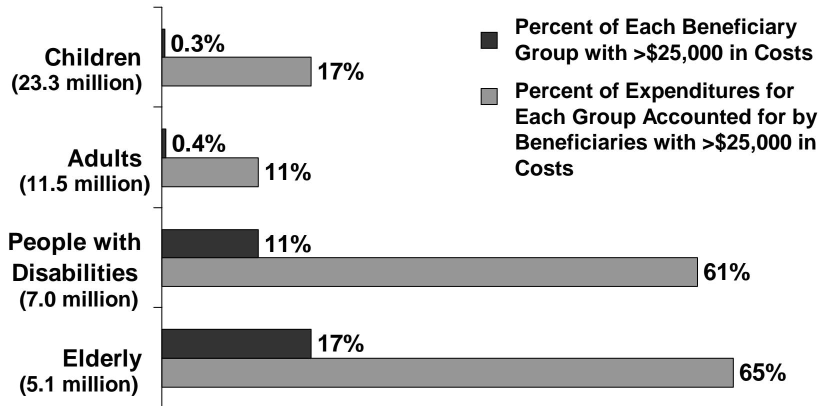


SOURCE: Sommers and Cohen, *Medicaid's High Cost Enrollees: How Much Do They Drive Program Spending?* Kaiser Commission on Medicaid and the Uninsured, March 2006.

KAISER COMMISSION ON
Medicaid and the Uninsured

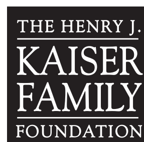
Figure 8

High Cost Beneficiaries Account for Large Share of Expenditures Among Groups



SOURCE: Sommers and Cohen, *Medicaid's High Cost Enrollees: How Much Do They Drive Program Spending?* Kaiser Commission on Medicaid and the Uninsured, March 2006. Data from 2001 MSIS.

KAISER COMMISSION ON
Medicaid and the Uninsured



The Henry J. Kaiser Family Foundation

Headquarters
2400 Sand Hill Road
Menlo Park, CA 94025
(650) 854-9400 Fax: (650) 854-4800

Washington Offices and
Barbara Jordan Conference Center
1330 G Street, NW
Washington, DC 20005
(202) 347-5270 Fax: (202) 347-5274

www.kff.org

Additional copies of this publication (#7732) are available on the
Kaiser Family Foundation's website at www.kff.org.

The Kaiser Family Foundation is a non-profit, private operating foundation dedicated to providing information and analysis on health care issues to policymakers, the media, the health care community, and the general public. The Foundation is not associated with Kaiser Permanente or Kaiser Industries.