

# Long-Term Services and Supports: The Future Role and Challenges for Medicaid

The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bipartisan group of national leaders and experts in health care and public policy.

# **Long-Term Services and Supports: The Future Role and Challenges for Medicaid**

*Prepared by*

Judith Kasper  
The Johns Hopkins University

*and*

Barbara Lyons and Molly O'Malley  
The Kaiser Commission on Medicaid and the Uninsured



THE KAISER COMMISSION ON  
**Medicaid and the Uninsured**

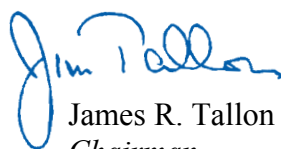
## Foreword

The Medicaid program is our nation's major public health coverage program designed to address the acute and long-term care needs of millions of low-income Americans of all ages. Medicaid plays a particularly important role by covering a range of services and supports including those needed by people to live independently in the community such as home health care and personal care, as well as services provided in institutions such as nursing homes. Overtime, Medicaid has evolved to become the primary payer for long-term services and supports to low-income and disabled individuals, financing nearly half (42%) of the nation's spending on long-term care services. Because Medicaid is often the only source of coverage for these services, it plays a unique role in our health care system, helping to fill in the gaps in private coverage and Medicare.

Much of the policy discussion concerning Medicaid's role as a provider of long-term care is driven by cost concerns – one-third of total Medicaid spending was for long-term care services in 2005. However, sustaining Medicaid's ability to meet the needs of low-income elderly and disabled individuals needs to go beyond consideration of financing to address the effectiveness, equity, responsiveness to individual needs and quality of Medicaid long-term services and supports. Assessing needed improvements is important since in the absence of broader changes to our existing health care system, Medicaid is the major financing system for long-term care in our nation, and the only one addressing the needs of low-income Americans.

To look at future issues in the structure and impact of Medicaid's role in long-term care, the Kaiser Commission on Medicaid and the Uninsured gathered a group of policy makers and experts for a roundtable discussion, "*Charting a Course for Medicaid: Future Directions in Long-term Care Coverage*," in July 2006. The goal of the roundtable was to facilitate an open exchange of information and ideas on Medicaid's role in long-term care and on strategies to improve the financing and delivery of services for people with long-term care needs under Medicaid. Building off the key themes from the roundtable discussion, the Commission prepared this report: *Long-Term Services and Supports: The Future Role and Challenges for Medicaid*. This report draws from a body of health services research to lay out seven major policy challenges facing the Medicaid program today and identifies issues facing long-term care going forward.

By gathering evidence to address key policy issues, such as integrating services, benefit design, quality monitoring and financing, we hope this report will help to lay the foundation for the current and ongoing policy debate regarding Medicaid's future role as a provider of long-term care services and supports for low-income elderly and disabled Americans. The Commission would like to extend its appreciation to Judith Kasper, Barbara Lyons, and Molly O'Malley as well as to Risa Elias for their contributions to the analysis and development of this report.

  
James R. Tallon  
Chairman

  
Diane Rowland  
Executive Director

## EXECUTIVE SUMMARY

Medicaid's role from its inception has been to ensure access to health care for low-income Americans. In fulfilling this role, Medicaid has become the major payer for long-term services and supports to low-income individuals, and a safety-net for those who become impoverished as a result of long-term care needs. In addition to long-standing concerns about the high costs of long-term care, recent developments such as the shift of prescription drug coverage for dual eligibles from Medicaid to Medicare, and initiatives allowing more flexibility in eligibility and benefit design, have drawn attention to the challenges facing Medicaid as a provider of long-term care. This issue paper describes these challenges and lays out issues facing the Medicaid program going forward.

## MEDICAID'S ROLE TODAY

- ***Who Uses Medicaid's Long-Term Care Services and Supports?*** Medicaid plays a critical role for low-income people of all ages with long-term care needs. Over half of those who use Medicaid long-term care services and supports are individuals age 65 and older, but 45 percent are disabled children and adults. Nearly 3.4 million individuals, or 7 percent of the total Medicaid population, rely on Medicaid long-term care services for a range of physical and mental health care needs. Many types of disability, and diverse needs for services and supports, are represented among covered individuals. These individuals include children with intellectual disabilities such as mental retardation, and developmental disabilities such as autism; young adults with spinal cord and traumatic brain injuries, and serious mental illness; and older people with Alzheimer's disease, and severely disabling chronic diseases such as diabetes and pulmonary disease.
- ***What Long-Term Care Services and Supports Are Covered by Medicaid?*** Medicaid currently covers a wide range of long-term care services, in addition to such core services as personal care, that address a beneficiary's limitations in performing routine activities of daily living (ADLs) such as bathing, dressing, getting around one's home, and preparing meals. Medicaid pays for services to meet these needs for low-income people, ranging from a few hours a week in home and community settings, to 24-hour care in institutional settings such as nursing homes. Because of the diverse needs among disabled low-income beneficiaries, personal care alone, while often necessary, may not be sufficient to ensure community residence and integration. Medicaid has evolved to cover a broad spectrum of long-term services and supports in both community and institutional settings that are often essential for low-income disabled Americans.

## POLICY CHALLENGES

The financial challenges posed by Medicaid long-term care spending are the primary focus of many proposals for changes to the program. Sustaining Medicaid's ability to meet the needs of low-income elderly and disabled people goes beyond consideration of financing, however. The effectiveness, equity, responsiveness to individual needs, and quality of Medicaid long-term

services and supports also are central. Seven major policy challenges facing Medicaid long-term care are reviewed below:

- ***Integrating Services for People with Long-Term Care Needs.*** People with long-term care needs also have substantial acute care needs, and often have needs beyond the traditional health care arena such as housing, social services, employment, and assistance in independent living skills. Over time, Medicaid has evolved as the primary safety net payer for long-term care services and now meets a continuum of needs, especially for low-income disabled beneficiaries. The need for Medicaid programs to coordinate with other service sectors has grown, especially with efforts to increase use of community versus institutional services, including transitioning individuals from institutional to community care. Among the consequences of poor care coordination is lack of access to needed services. Medicaid's ability to effectively and efficiently meet the needs of low-income elderly and disabled Americans can be hampered by lack of coordination across providers of acute and long-term care services, as well as inability to address housing limitations or availability.
- ***Impact of Varying Disability Criteria.*** Disability criteria for Medicaid coverage of long-term services and supports limit access to the most severely disabled and are not uniform, creating potential inequities across beneficiary groups and states. Most states set functional eligibility criteria for home and community-based services at the same level that is used for care in a nursing facility which limits access to services at earlier stages in the disabling process when it might be possible to shore up community supports. Each state interprets "need for institutional care" differently using state-administered assessment and eligibility systems. The rationale for variations in eligibility criteria should continue to be scrutinized for its impact on equitable access to long-term services and supports among low-income elderly and disabled people.
- ***Means-Testing the Benefit.*** Individuals must meet financial qualifications for Medicaid coverage of long-term services and supports, in addition to meeting need criteria. Studies show that the covered population consists of the very poor (many with incomes below the poverty line). Additionally, elderly and disabled individuals who qualify for Medicaid must have very few assets (\$2,000 for an individual and \$3,000 for a couple, in most states). Medicaid is also the safety net for long-term care for individuals who become impoverished as a consequence of disabling illness or injury. Programs that provide a means for higher income individuals to buy-into Medicaid, such as the Ticket-to-Work Option for individuals with disabilities and the new Family Opportunity Act for disabled children in families up to 300 percent of poverty, acknowledge that achieving the goals of community integration and residence for disabled individuals may mean reconsidering financial criteria for long-term services and supports that require impoverishment.
- ***Balancing Institutional and Community-Based Care.*** Medicaid covers a continuum of long-term care service settings from nursing homes to the community. Although growth in community-based care alternatives is reducing institutional bias, and allowing more elderly and disabled individuals to live and receive services in community settings, waiting lists are a sign that access to home and community-based programs is limited. States are employing a wide range of approaches to rebalance long-term care in favor of community settings such as

nursing home diversion programs and nursing home transition programs, but restrictions on income and assets for persons in the community may inhibit goals to reduce institutional bias. Allowable resources for persons in the community are very low, and insufficient to maintain community residence without considerable support from family and friends.

- ***Flexible Benefit Design.*** Trends toward more flexible benefit design hold promise and peril. Flexibility provides the opportunity to individualize services and respond to consumer preferences, but poses challenges in maintaining equity and assuring that needs are being met. 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. Whether services and supports are adequate under an increasingly diverse set of programs aimed at different populations will require a focus on outcomes, and not solely on costs, as measures of system and program performance.
- ***Maintaining and Monitoring Quality of Care.*** Quality of care is an ongoing concern in providing services to vulnerable populations, such as low-income elderly and disabled individuals. 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. In a first step toward more comprehensive, standardized assessment of quality of care in Medicaid home and community-based settings, the Deficit Reduction Act (DRA) of 2005 directed the Agency for Health Care Research and Quality to develop quality of care measures that can be used to assess Medicaid home and community-based services (HCBS) programs with regard to program performance, client functioning, and client satisfaction. Many issues remain, such as how to ensure state adoption of quality of care assessment tools that will provide a basis for program evaluation.
- ***Financing Long-Term Services and Supports.*** The number of persons with long-term care needs is projected to grow and the high costs of services mean a substantial proportion will turn to Medicaid. Today, Medicaid pays for 42 percent of all long-term care expenditures and almost half of all nursing home care costs. The most commonly recommended alternatives to Medicaid financing of long-term services and supports, such as greater coverage by private long-term care insurance and use of home equity programs, such as reverse mortgages, are not applicable to many low-income elderly and disabled people served by the program. Purchase of long-term care insurance is closely tied to income and unaffordable for low-income elderly people. Younger disabled people are precluded from purchasing private long-term care insurance by pre-existing conditions, regardless of its affordability. Other efforts to increase the purchase of private long-term care insurance include tax subsidies and state programs such as the Long-term Care Partnership Program – neither of which can be expected to address the long-term care financing needs of lower income Americans.

## SUMMARY

For the foreseeable future, Medicaid will remain the major financing system for long-term services and supports in our nation, and the only one addressing the needs of low-income Americans. Cost concerns drive much of the policy discussion concerning Medicaid's role as a provider of long-term care, but as in other areas of health care, there is increasing focus on quality and indicators that can be used to evaluate quality of care across providers and settings. Innovations in program design that allow coverage of a broad continuum of services and supports, more consumer involvement, and expansions in access (e.g. buy-in provision for higher income families of disabled children) are currently counterbalanced by a confusing array of eligibility criteria, inequities in access to services across and within states, and financial standards that require impoverishment to qualify. The needs for long-term services and supports that Medicaid addresses will not lessen in coming years; they will likely grow. The challenges for those who finance, design and provide long-term care under the Medicaid program are to align incentives to ensure access, meet needs, and provide cost-effective high quality services and supports to low-income elderly and disabled Americans.



## INTRODUCTION

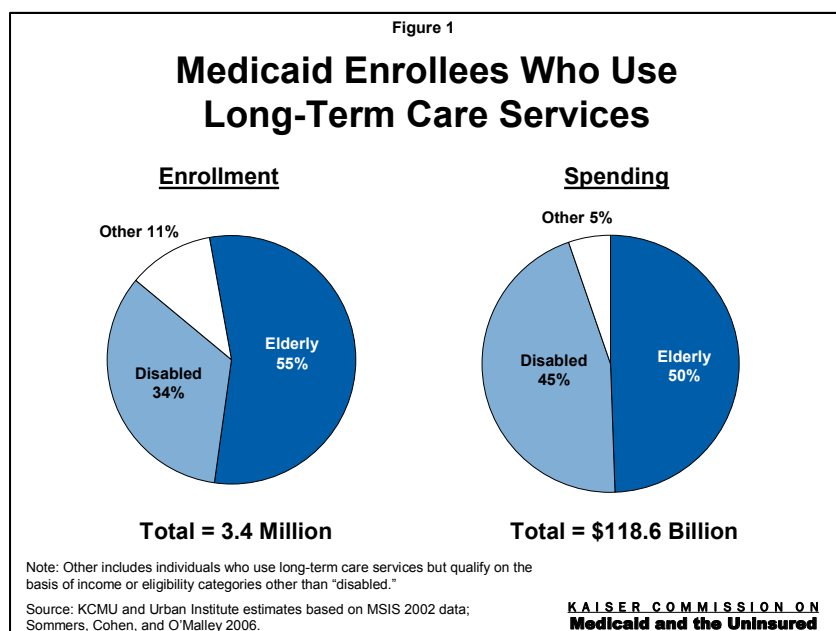
Medicaid's role from its inception has been to ensure access to health care for low-income Americans.<sup>1</sup> In fulfilling this role, Medicaid has become the major payer for long-term services and supports to low-income individuals, and a safety-net for those who become impoverished as a result of long-term care needs. Absent broad systemic changes, Medicaid will remain the major financing system for long-term care in our nation, and the only one addressing the needs of low-income Americans. In addition to long-standing concerns about the high costs of long-term care, recent developments such as the shift of prescription drug coverage for dual eligibles from Medicaid to Medicare, and initiatives allowing more flexibility in eligibility and benefit design, have drawn attention to the challenges facing Medicaid as a provider of long-term services and supports. This issue paper describes these challenges and lays out issues facing the program going forward.

## MEDICAID'S ROLE TODAY

### *Who Uses Medicaid's Long-Term Care Services and Supports?*

**Medicaid plays a critical role for low-income people of all ages with long-term care needs. Over half of those who use Medicaid long-term services and supports are individuals age 65 and older, but 45 percent are disabled children and adults. Many types of disability, and diverse needs for services and supports, are represented among covered individuals.**

Disability and need for long-term services and supports are highest among older people – nearly sixty percent of people with long term care needs are 65 or older.<sup>2</sup> In addition, half of Medicaid long-term care expenditures are for nursing home care and 90 percent of residents are elderly.<sup>3</sup> As a result, it is often assumed that the Medicaid long-term care population consists primarily of older persons in nursing homes. Persons 65 and older do constitute over half (55%) of those who use Medicaid long-term care services, but roughly one-third (34%) are individuals under age 65 with a disability (Figure 1). Another 11 percent are adults and children who rely on Medicaid's long-term services and supports, but became eligible for Medicaid through pathways other than disability.<sup>4</sup>

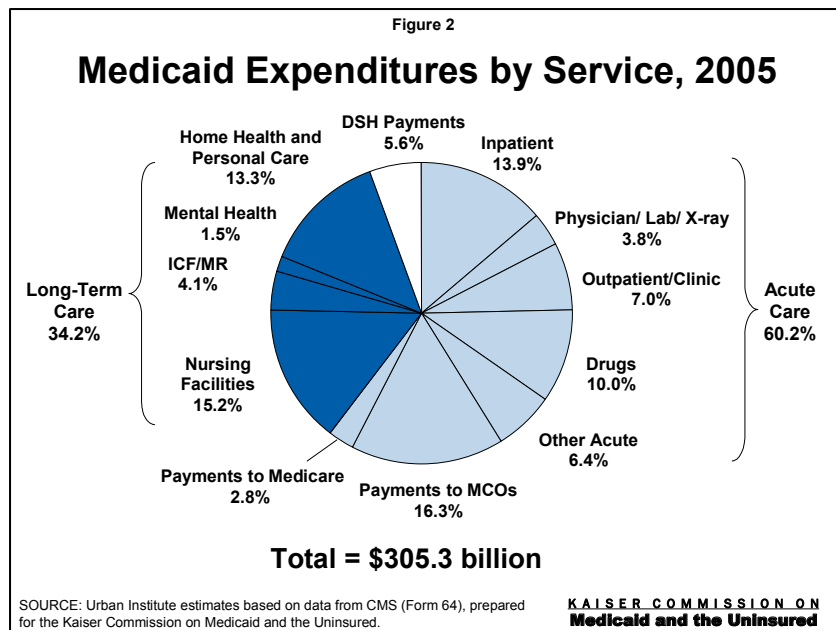


There is considerable diversity in the services used and the settings where these services are provided among those who rely on Medicaid to meet long-term care needs. Nursing home services are used predominantly by older people, while home and community-based services serve a broad age spectrum but are especially important for younger disabled people. The diversity of service and support needs also reflects varying causes of disability among Medicaid beneficiaries who receive long-term care services. These individuals include children with intellectual disabilities such as mental retardation, and developmental disabilities such as autism; young adults with spinal cord and traumatic brain injuries, and serious mental illness; and older people with Alzheimer’s disease, and severely disabling chronic diseases such as diabetes and pulmonary disease.<sup>5</sup>

***What Long-term Care Services and Supports Are Covered by Medicaid?***

**Medicaid currently covers a broad spectrum of long-term services and supports, in addition to such core services as personal care.**

Disability is usually defined in terms of limitations in performing routine daily activities. Core services for people with disabilities are those that address these limitations by providing personal care and assistance in daily activities such as bathing, dressing, getting around one’s home, and preparing meals. Medicaid pays for services to meet these needs for low-income people, ranging from a few hours a week in home and community-based settings, to 24-hour care in institutional settings such as nursing homes. In 2005, spending on long-term care services accounted for roughly one-third of total Medicaid spending (Figure 2).



Because of the diverse needs among disabled low-income beneficiaries, personal care alone, while often necessary, may not be sufficient to ensure community residence and integration. Medicaid has evolved to cover a wide range of other services that are often essential. Persons with mental retardation and developmental disabilities, for example, may need supervision and

cuing to prepare meals or manage finances. Those with mental illness may need supervised housing with onsite psychiatric care and medication management. Persons with spinal cord injuries and traumatic brain injuries may require modification of home environments to accommodate wheelchairs and assistive devices for bathing. Medical transportation is also a critical service for many individuals with severe disabilities.

Medicaid covers personal care services in two ways -- through the personal care benefit (optional and currently offered by 33 states), and through home and community-based waiver programs (every state now operates at least one).<sup>6</sup> Waiver programs are the primary mechanism for coverage of services other than personal care, however. Among the services and supports that can be covered under home and community-based waiver programs are adult day care, homemaker/chore services, respite care, personal emergency response systems, case management, medical transportation, minor home repairs, social services, caregiver training, nutrition counseling, care in special residential facilities (for persons with mental illness for example) and services to persons in assisted living facilities. The standard 1915c waiver application which states submit to the Centers for Medicare and Medicaid Services for approval of waiver programs<sup>7</sup>, lists these and many other services that might be included in designing a specific program. States also are permitted to propose additional services that are “cost-effective and necessary to prevent institutionalization.” This flexibility allows states considerable leeway in structuring their waiver programs. As a result there is variability from program to program in terms of eligibility for and receipt of services, and concerns have been raised about equity of access<sup>8,9,10</sup> Nonetheless, Medicaid provides the only means for low-income disabled Americans to obtain a broad spectrum of long-term supports and services in both community and institutional settings.

## **POLICY CHALLENGES**

The financial challenges posed by Medicaid long-term care spending are the primary focus of many proposals for changes to Medicaid. Sustaining Medicaid’s ability to meet the needs of low-income elderly and disabled people goes beyond consideration of financing, however. The effectiveness, equity, responsiveness to individual needs, and quality of Medicaid long-term services and supports also are central. Seven major policy challenges facing Medicaid long-term services and supports are reviewed below.

### **Integrating Services for People with Long-Term Care Needs**

**People with long-term care needs also have substantial acute care needs, and often have needs related to appropriate housing. Medicaid’s ability to effectively and efficiently meet the needs of low-income elderly and disabled Americans can be hampered by lack of coordination across providers of acute and long-term care services, as well as inability to address housing limitations or availability.**

Long-term services and supports cut across housing, social services, employment, assistance in independent living skills, and health care. Medicaid, which was established to ensure health care for low-income Americans has, over time, evolved as the primary safety net payer for long-term care.<sup>1,11</sup> The important role that Medicaid now fills in providing long-term care means

engagement with many services and supports that are beyond the traditional health care arena. As others have noted,<sup>12</sup> Medicaid now meets a continuum of needs, and this is particularly the case with regard to low-income disabled beneficiaries. With efforts to increase use of community versus institutional services, including transitioning individuals from institutional to community care, the need for Medicaid programs to coordinate with other service sectors, such as housing, has grown. Difficulties in coordinating services for people with disabilities occur at many levels – among health and long-term care providers, and between health-related and other service sectors – potentially hampering the effectiveness of Medicaid in meeting needs and enabling community residence and integration.

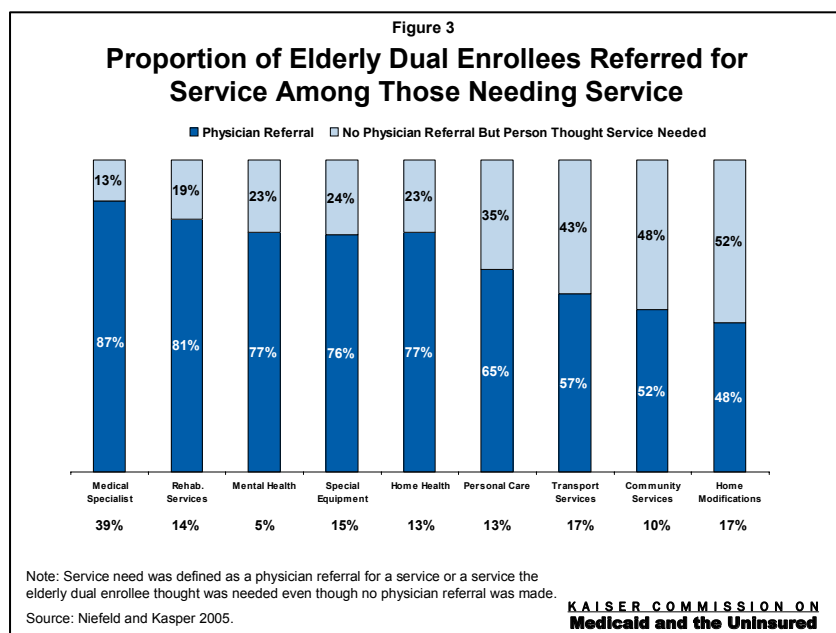
Concerns about care coordination stemming from multiple providers and payers are not new. In the 1930's the Chair of the Committee on the Costs of Medical Care expressed concern about conflicting advice from specialists, duplicate tests, and lack of communication with patients.<sup>13</sup> Recent articles on difficulties in coordinating care have focused on the consequences for persons with multiple chronic conditions.<sup>14,15,16,17</sup> Many individuals with long-term care needs also require care for multiple or complex medical conditions. Heart or pulmonary diseases are major causes of disability among older people<sup>18</sup>; increased prevalence of diabetes, lung disease and other co-morbid medical illnesses have been documented among adults with serious mental illness.<sup>19,20</sup> Management of chronic medical conditions in people with disabilities has implications not only for patient well-being but for appropriate use of services and costs of care, given the high utilization rates of disabled individuals.<sup>21</sup>

Although discussions of Medicaid's role for persons with disabilities usually emphasize long-term services and supports, Medicaid also provides coverage for physician care, skilled therapy (speech and physical therapy), and nursing services for these individuals. Coverage does not always ensure access however. Among the consequences of poor care coordination is lack of access to needed services. Problems in coordinating medical and mental health services for persons with severe mental illness have been repeatedly documented. Berren et al. found Medicaid enrollees with severe mental illness had 18 percent fewer claims for physical health care than Medicaid enrollees with similar physical health diagnoses but no mental illness.<sup>22</sup> In a group of Medicaid patients with severe and persistent mental illness, despite high levels of use of outpatient services, use of primary and preventive services was quite low.<sup>23</sup>

Studies also indicate that people with disabilities are less likely to receive some preventive services (e.g. mammography).<sup>24,25</sup> The importance of a regular physician in access to medical care and routine preventive services is well-established, as is the role of access to primary care in avoiding preventable hospitalizations.<sup>26</sup> Data from a study of elderly dual enrollees in 6 states, indicated a quarter of hospitalizations over a one year period were ambulatory care sensitive (potentially preventable with appropriate primary care), and 8 percent of enrollees experienced such a hospitalization.<sup>27</sup>

Coordination of acute and long-term services remains an ongoing concern, as well. In one study of elderly dual enrollees,<sup>28</sup> physicians were much less likely to refer individuals for long-term care services than for acute care. Among those needing a medical specialist, 87 percent received a physician referral; among those needing community services, home modifications or transport services around half received a referral (Figure 3). In addition, organizational barriers to care –

inability to make appointments or arrangements for services, waiting lists, language or communication difficulties, conflicting treatment options – were experienced much more often than financial barriers.



Enrollment of elderly and disabled Medicaid beneficiaries into managed care is increasing, as is enrollment into HMOs that predominantly serve Medicaid beneficiaries.<sup>29</sup> One recent study suggests that as the market penetration rate of Medicaid-dominant HMOs grows, access to care decreases and total healthcare expenses increase.<sup>30</sup> The DRA encourages a new type of managed care plan called Special Needs Plans (SNP) as one means of integrating acute and long-term care services for disabled Medicaid beneficiaries.<sup>31</sup> Three types of beneficiaries are eligible: institutional (residing or in the community but needing institutional level of care), dual eligibles, and those with severe or disabling chronic conditions (particularly cardiovascular disease, diabetes, CHF, osteoarthritis, mental disorders, ESRD, HIV/AIDS). As of March 2007, there were 321 dual eligible plans, 84 institutional plans, and 71 chronic/disabling plans nationally and in Puerto Rico with 843,000 enrollees (622,000 dual eligibles).<sup>32</sup> An evaluation of the impact of SNPs on costs and quality of care is to be completed by December 2007.

Issues facing SNPs include difficulties in setting appropriate capitation rates, limited plan experience in providing specialized long-term care services, and lack of systems to coordinate Medicare and Medicaid benefits for those covered by both programs. CMS currently provides guides clarifying existing rules and suggested processes for meeting both Medicare and Medicaid requirements and plans to contract with NCQA to identify new performance measures for SNPs.<sup>32</sup> Earlier experience with combining acute and long-term care in HMOs for older people (Social HMOs) showed that integration of acute and long-term care services did not improve simply as a function of providing both types of services in a managed care plan.<sup>33</sup> A later generation of Social HMOs used more innovative approaches to integrating services (e.g. geriatric team care) but did not markedly improve health and functioning or satisfaction with care compared with regular Medicare HMOs.<sup>34</sup>

A final challenge for Medicaid lies in coordinating with service sectors, like housing, that are outside the purview of the Medicaid program but are critical to goals such as transitioning individuals from institutional to community settings. Treatment of assisted living under Medicaid varies. Some states have assisted living waiver programs which allow Medicaid to cover residential as well as care expenses if persons are transitioning from nursing homes. In other states, Medicaid covers services but not the residential component of assisted living, severely restricting this option for most beneficiaries.

The inability to secure affordable community housing, or to modify homes to accommodate the needs of persons with particular types of disabilities, can be major impediments to community residence. Some home and community-based waiver programs cover home modifications, such as ramps, or minor home repairs, although available funds are often capped. Recognition that expenses related to re-establishing a community residence were a barrier to leaving a nursing home, led CMS in 2002 to allow payment for certain one-time expenses, such as security deposits and essential household furnishings, for individuals making a transition. Nonetheless, lack of stable affordable housing options for low-income elderly and disabled people can disrupt efforts to provide needed acute and long-term services and supports in the least restrictive settings. Section 8 housing and housing for persons with special needs (e.g. housing with supervision for individuals with serious mental illness) is often limited with substantial waiting lists, and Medicaid care planners are not typically able to assist in the housing application process.<sup>35</sup>

### **Impact of Varying Disability Criteria**

**Disability criteria for Medicaid coverage of long-term services and supports limit access to the most severely disabled and are not uniform, creating potential inequities across beneficiary groups and states.**

The use of “need for institutional care” as eligibility criteria for home and community-based care limits access to services at earlier stages in the disabling process when it might be possible to shore up community supports. A new state option under the DRA of 2005 allows states to use less stringent criteria for HCBS eligibility but also requires that eligibility criteria for institutional services be more restrictive. Many aspects of this new option (allowances to cap enrollment and maintain waiting lists) make it uncertain whether its implementation by states will actually expand access to community services,<sup>31</sup> but the ability to serve persons who do not require an institutional level of care potentially expands the population of disabled Medicaid beneficiaries eligible for community services.

Approaches to screening and “need” criteria for long-term services and supports vary across states and are driven by many factors including a desire to control costs. Most states set functional eligibility criteria for home and community-based services at the same level that is used for care in a nursing facility. A recent survey found only 6 waivers that used more restrictive functional eligibility criteria than for institutional care.<sup>36</sup> That said, “need for institutional care” is interpreted by each state, using state-administered assessment and eligibility systems to determine whether institutional level-of-care criteria are met. A study from the early

1990's and one more recently, note that "the usual model" is to have multiple, separate screening and assessment tools that are applied to different programs and eligibility groups.<sup>37,38</sup> Pendleton et al. in a survey of states found that few had integrated their systems of assessment for community care on a statewide basis.<sup>39</sup> In 2001, only 3 states coordinated screening and assessment across long-term care programs by "operating a single state administrative agency, using uniform need criteria and standard tools, and having automated databases."<sup>38</sup> Variability in "need" criteria allows states to tailor programs to their specific needs but creates the potential for barriers to access related to difficulties in obtaining information and negotiating the eligibility process across multiple programs.

Variation in who receives home and community-based services (and whether this signals inequitable treatment of individuals with similar care needs) is an ongoing concern.<sup>9,40</sup> In many instances, existing variations appear arbitrary. One example is the implementation by states of a recommendation from the Advisory Panel on Alzheimer's Disease that cueing and supervision in activities of daily living, and supervision for safety reasons (to protect against the consequences of impaired judgment), both be interpreted as meeting criteria for need for institutional care.<sup>41</sup> Some states followed the recommendation, allowing individuals who met either criteria to be considered eligible for nursing home care and home and community-based waiver services. Other states, however, chose to base eligibility on only one of the two suggested criteria (making those who met the cueing/supervision criteria eligible in some states, and those meeting the safety criteria eligible in others), or to require that both criteria be met in order to qualify. Some states did not implement the recommendation, using other criteria altogether. The rationale for variations in eligibility criteria should continue to be scrutinized for its impact on equitable access to long-term services and supports among low-income elderly and disabled people.

### **Means-testing the Benefit**

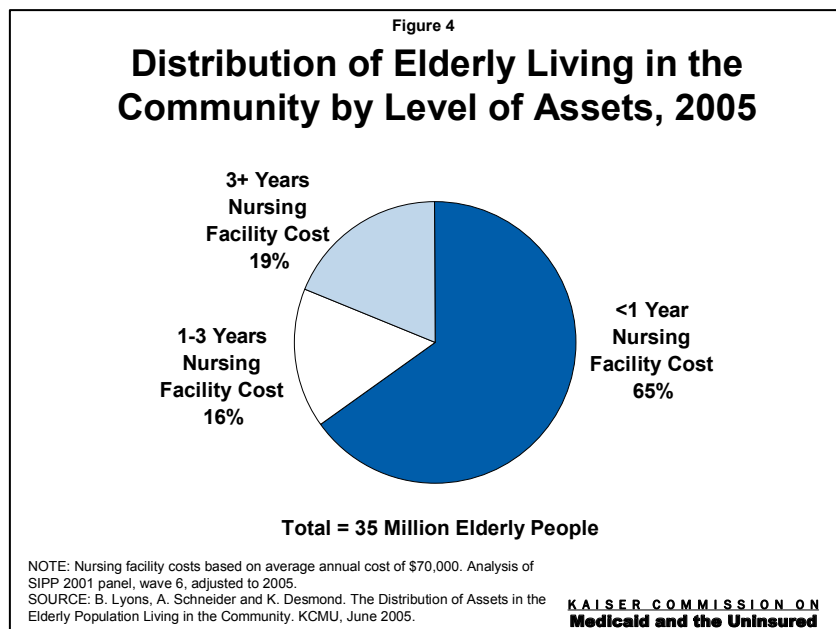
**Individuals must meet financial qualifications for Medicaid coverage of long-term services and supports, in addition to meeting need criteria. Studies show that the covered population consists of the very poor (many with incomes below the poverty line). Medicaid is also the safety net for long-term care services for individuals who become impoverished as a consequence of disabling illness or injury.**

Access to Medicaid long-term services and supports is restricted by financial eligibility criteria. Both income and asset standards (\$2,000 for an individual and \$3,000 for a couple) apply, and are set at very low levels, but these also vary across groups.<sup>42,43</sup> For example, disabled adults of working age generally must have low incomes to qualify (eligibility for the personal care benefit is based on SSI eligibility – 74 percent of the poverty level; individuals who are in nursing homes may qualify at 300 percent of SSI).<sup>42,43</sup> More recently the new Family Opportunity Act will allow families of disabled children with incomes up to 300 percent of poverty to "buy-in" to Medicaid.

A substantial proportion of users of Medicaid long-term services and supports have been poor for long periods. People with disabilities are a large share of the working-age poverty population. In one study, among those who were poor over several years, about half were disabled individuals.<sup>44</sup> Persons with significant disabilities and long-term care needs are often limited in

work force participation and have difficulty accumulating assets. Onset of major health events (such as serious chronic disabling diseases) has been shown to reduce household income and result in substantial lost wealth and savings.<sup>45</sup>

Medicaid’s safety net function also is vital, since most Americans do not have the economic resources to cope with permanently disabling illness or injury. Nonetheless, there has been particular concern that elderly individuals who enter nursing homes and qualify for Medicaid could have paid for their own care. An examination of assets among older people in the community, indicates that two-thirds would be unable to pay for even 1 year of nursing home care (Figure 4).<sup>46</sup>



Congress allowed states to restrict asset transfers beginning in 1981 (Boren-Long Amendment), as a means of limiting spend-down among nursing home patients. Over time additional restrictions have been introduced (e.g. liens on property of living recipients, estate recovery of deceased recipients), most recently in the DRA of 2005 which further tightens rules against asset transfer, includes penalties for asset transfers prior to Medicaid eligibility, denies eligibility for persons whose home equity exceeds certain amounts, and adds new rules for considering income which may reduce the amount available to the community spouse.<sup>31</sup> Several studies find that asset transfer is less common than assumed, and involves modest amounts that would cover very little of the cost of a nursing home stay. Early studies provided a range of estimates for the percentage of persons who spend-down to Medicaid coverage among nursing home patients (27% of elderly in Michigan<sup>47</sup>; 10% from national data<sup>48</sup>). A later study suggested that 44 percent of persons over age 65 who use nursing homes start and end as private payers, 27 percent start and end as recipients of Medicaid benefits, and only 14 percent spend down assets to become eligible for Medicaid.<sup>49</sup>

Lee et al. found 9-15 percent of new Medicaid-eligible nursing home residents had transferred assets, and the mean amount transferred was \$4,000 (asset transfers were in fact more common



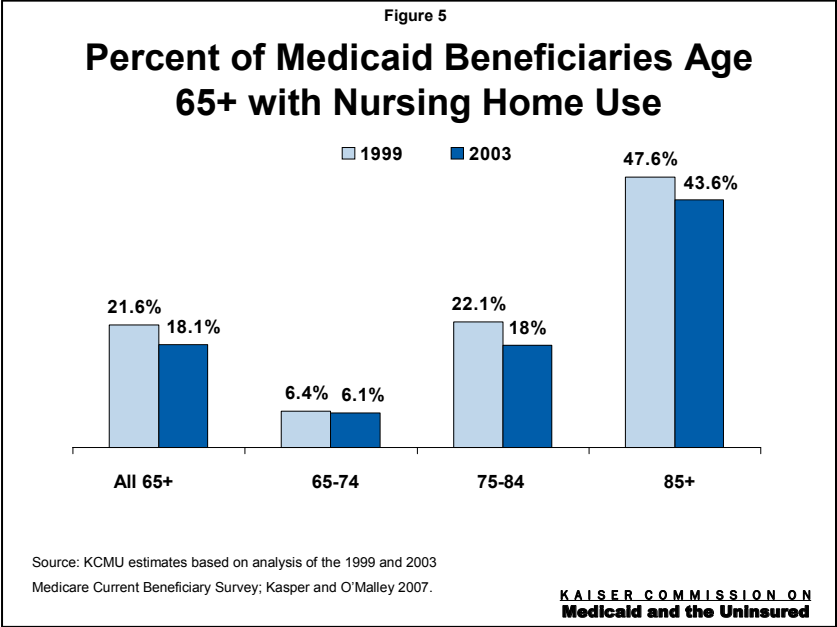
among elderly people who did not enter a nursing home, than among those who did).<sup>50</sup> Another study) found 18.5 percent of persons who eventually became Medicaid nursing home patients transferred assets in the 2 years prior to admission, in amounts averaging \$8,202; 13.1 percent transferred assets in the 4 years prior to admission, transferring on average \$5,380.<sup>51</sup> A recent GAO study questioned whether DRA provisions would have much effect on Medicaid eligibility among nursing home entrants because few applicants transferred assets or had home equity that exceeded DRA limits.<sup>52</sup>

The consequences of requiring impoverishment to qualify for Medicaid long-term care services are rarely addressed. The Family Opportunity Act (DRA of 2005) represents a departure in creating a new state option that offers Medicaid buy-in coverage to disabled children with family incomes up to 300 percent of the federal poverty level (states can cover eligible children at higher income levels with state-only funds). By providing a means for higher income families to buy-in to Medicaid, this option recognizes that requiring impoverishment to obtain coverage would not be in the interests of a disabled child, her parents, or her siblings. The extent to which this option will be adopted by states remains to be seen. Legislation in the late 1990's (Balanced Budget Amendment of 1997; The Ticket to Work and Work Incentives Act 1999) permitted state Medicaid "buy-in" programs for individuals with disabilities who would be able to work if they retained their health coverage. This program also appears to acknowledge that achieving the goals of community integration and residence for disabled individuals may mean reconsidering financial criteria for long-term services and supports that require impoverishment. As of 2006, 26 states had implemented such a program.<sup>11</sup>

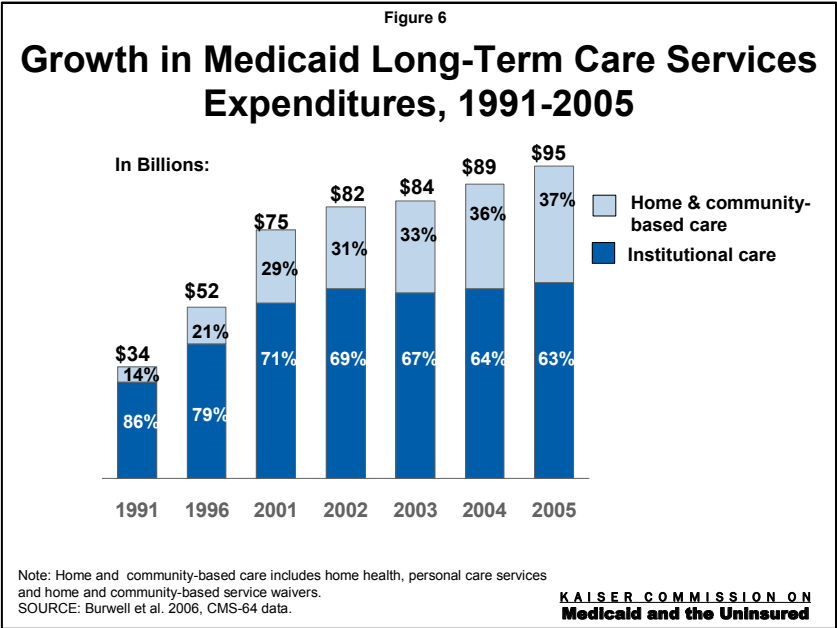
### **Balancing Institutional and Community-Based Care**

**Medicaid covers a continuum of long-term care service settings from nursing homes to the community. Although growth in community-based care alternatives is reducing institutional bias, and allowing more elderly and disabled individuals to live and receive services in community settings, waiting lists are a sign that access to home and community-based programs is limited.**

Historically, differences in functional and financial eligibility criteria between nursing home and community-based care steered low-income people with long-term care needs into institutional care settings. Over the past 20 years, greater parity in eligibility criteria, increased spending on community-based alternatives, and declines in nursing home beds have helped shift Medicaid long-term care spending away from nursing home care. Over the past 2 decades, the absolute number of nursing home residents ages 65 and older has declined.<sup>53</sup> Medicaid beneficiaries have followed this trend. Between 1999 and 2003 the percentage of Medicaid beneficiaries ages 65 or older in nursing homes declined from 21.6 percent to 18.1 percent; for beneficiaries age 85 or older 43.6 percent were nursing home residents in 2003 compared to 47.6 percent 4 years earlier (Figure 5).<sup>54</sup>



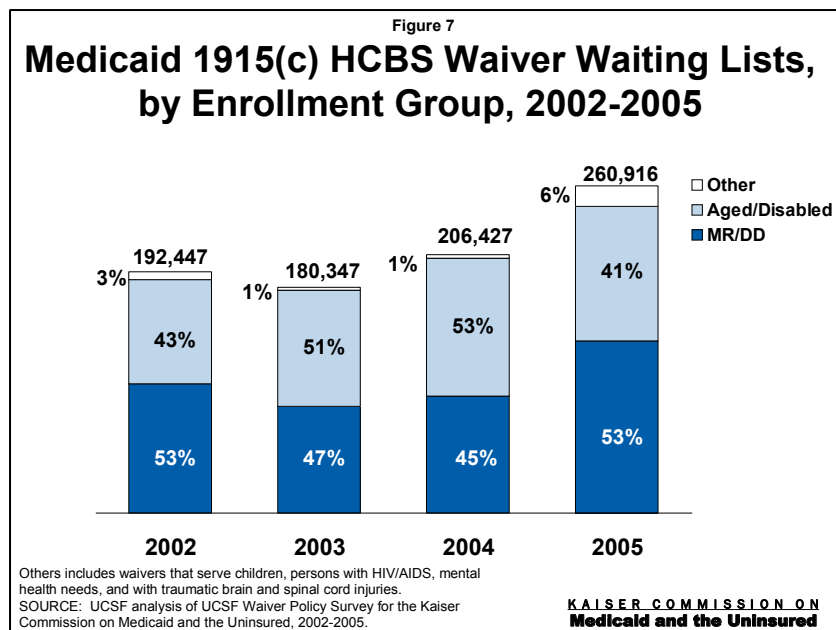
Many states now tie financial eligibility criteria for HCBS waiver programs to the nursing-home standard (although in 2005, 26% of waiver programs still used stricter financial eligibility for HCBS waiver programs than for nursing facilities).<sup>36</sup> The national percentage of Medicaid spending on home and community-based services doubled from 14 percent to 33 percent between 1991 and 2003 (Figure 6).<sup>55</sup> Numbers of nursing home beds also declined between 1990 and 2002 (from 66.7 to 61.4 per 10,000 population), although increases in assisted living beds resulted in a modest increase in all types of long-term care beds over the same period (2.3 to 2.9 million).<sup>56</sup>



States are employing a wide range of approaches to rebalance long-term care in favor of community settings. A review of nursing home diversion programs in 8 states documented procedures that speed up the eligibility determination process, provide immediate payment to community providers (presumptive eligibility), and inform individuals about community options both prior to nursing home entry and, for those admitted, in the early part of a stay.<sup>57</sup> Nursing home transition programs targeted to returning Medicaid-eligible nursing home residents to community settings, although serving relatively small numbers of individuals, represent another initiative to shift resources from institutional to community settings. Less reliance on institutional care is widely endorsed (and legally mandated under *Olmstead v L.C.*) by disabled individuals, their families, and policymakers, but concerns also have been raised about wide variations in the availability of beds across states,<sup>56</sup> and possible future shortages given the growth in persons at the oldest ages.<sup>58</sup>

Despite major shifts toward community care settings, the majority of Medicaid long-term care dollars still go toward nursing home care. Access to Medicaid coverage for community-based services, as opposed to nursing home care, remains more restricted even when functional and financial criteria are the same. Individuals in nursing homes with incomes above the Medicaid qualifying limit can qualify based on spend-down criteria in many states, but community-resident individuals seeking services through waiver programs usually can not.

Restrictions on income and assets for eligibility may inhibit goals to reduce institutional bias. Allowable resources for persons in the community (about \$2000) are very low, and insufficient to maintain community residence without considerable support from family. Family and friends provide high levels of assistance to disabled Medicaid beneficiaries, but caregivers who work or are elderly may have difficulty filling in the gap. In addition, individuals in the community face waiting lists for waiver services. Institutional care may prove the only alternative (waiting lists can also block transitions from nursing homes; to avoid this some states give preference for community services to such individuals). The number of waivers with waiting lists continues to grow. In 2005, 260,000 people were on waiting lists for 102 waivers in 30 states, up from 206,000 in 2004 (Figure 7).<sup>36</sup>



## **Flexible Benefit Design**

**Trends toward more flexible benefit design hold promise and peril. Flexibility provides the opportunity to individualize services and respond to consumer preferences, but poses challenges in maintaining equity and assuring that needs are being met.**

Providing services and supports tailored to individual needs, rather than in a one-size-fits-all fashion, has been a long-standing goal in long-term care program design. Efforts to make Medicaid benefits more flexible and allow consumer involvement in determining and managing services could further expand service options, perhaps even allowing housing to be incorporated into benefit packages. The Cash and Counseling option under the DRA of 2005 will permit states to allow beneficiaries to manage an individual budget to purchase personal care assistance services (hiring caregivers and purchasing items that increase independence) that are part of a plan of care. While many consumers and their families desire more flexibility and control over services and providers, there is concern that states will be forced by restricted federal financing or constrained budgets to exercise flexibility over optional populations and services primarily to reduce access and coverage. The growing waiting lists for HCBS waiver services indicate many states already feel unable to meet long-term care needs.

Other concerns relate to consumer protections and accountability. Benjamin et al. in a study of Medicaid beneficiaries in California receiving services under agency-directed versus consumer-directed care models, found beneficiaries in consumer-directed models reported more positive or similar outcomes for safety, unmet need and satisfaction with services.<sup>59</sup> Nonetheless, concerns remain. As Spillman et al. note, key issues are the level and adequacy of budgets, differing levels of support across states in developing plans of care, managing budgets and handling payroll functions, and how to best monitor the adequacy of care provided.<sup>60</sup> Experience with consumer-directed care models is still limited, and careful attention to implementation at the state level is warranted.

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. Studies of the relationship of state long-term care policies and programs to unmet needs are few, but Komisar et al. found that among elderly dual eligibles, receipt of paid in-home care substantially reduced levels of unmet need.<sup>61</sup> Whether services and supports are adequate under an increasingly diverse set of programs aimed at different populations will require a focus on outcomes, and not solely on costs, as measures of system and program performance.

## **Maintaining and Monitoring Quality of Care**

**Quality of care is an ongoing concern in providing services to vulnerable populations, such as low-income elderly and disabled individuals. 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.**

Quality of care is an ongoing concern in providing long-term services and supports to low-income elderly and disabled individuals. Nursing homes have been a major focus since the early 1980's when the Institute of Medicine report *Improving the Quality of Care in Nursing Homes* led to the Nursing Home Reform Act (OBRA 1987). A key element was the requirement that nursing homes conduct standardized patient-level assessments on all residents. Initially used as a care planning tool, these data now form the basis for evaluating quality of care. A well-developed literature on quality of care in nursing homes has examined the relationship to quality care of ownership,<sup>62</sup> socioeconomic status and race<sup>63</sup> and a host of other facility and patient characteristics.<sup>64</sup> Although serious concerns about the quality of care in nursing homes remain,<sup>65</sup> evidence suggests that the use of a comprehensive uniform assessment tool in nursing homes resulted in significant improvements in quality of care.<sup>66</sup>

Unlike nursing homes, quality of care is not consistently or comprehensively evaluated in other residential long-term care settings (including assisted living facilities) or in home and community-based care. As the IOM report of 2003 noted, there is no core set of quality measures that applies across long-term care settings. The report also questioned the reliance on measures of satisfaction with care as an indicator of quality in home and community-based services.<sup>65</sup> The DRA of 2005 directed the Agency for Health Care Research and Quality to develop quality of care measures that can be used to assess Medicaid HCBS programs with regard to program performance, client functioning, and client satisfaction. These measures are intended for use in assessing the quality of home and community-based services and their outcomes. This effort represents a first step toward more comprehensive, standardized assessment of quality of care in Medicaid home and community based services. CMS also is developing a uniform patient assessment instrument to be used across nursing home and home care settings, which may begin to address the IOM goal of measures that apply across care settings. How these efforts will be coordinated is unclear, but they represent steps toward more rigorous and comprehensive standards for assessing quality in long-term care.

Many issues remain, however, among them how to ensure state adoption of quality of care assessment tools that will provide a basis for program evaluation. (The DRA calls for a comparative analysis of the system features of each state, and dissemination of best practices information.) If the decision to adopt quality of care measures, and procedures for implementing quality of care assessment is left entirely to states, there will be widely varying information available, making it difficult to assess whether needs for long-term services and supports are being met, and whether variations in quality of care exist.

### **Financing Long-Term Services and Supports**

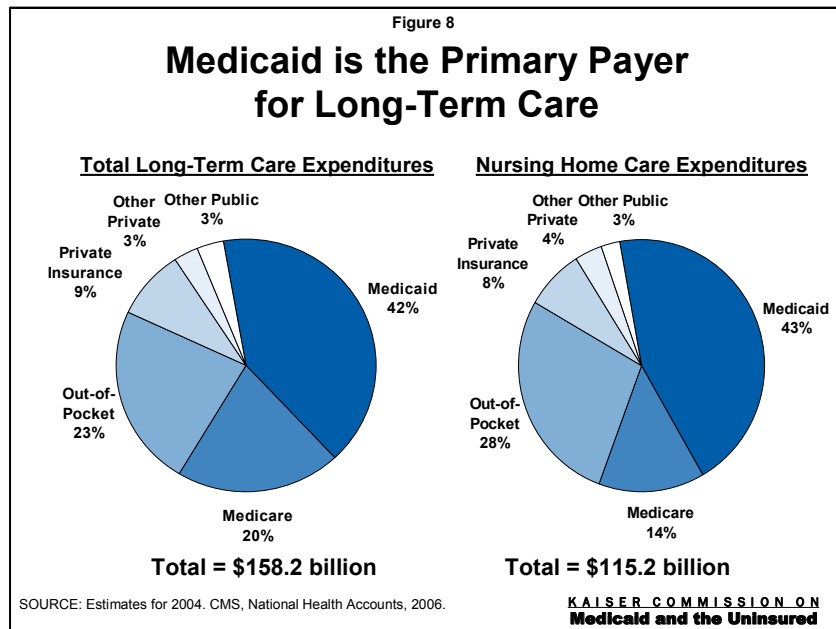
**The number of persons with long-term care needs is projected to grow and the high costs of services mean a substantial proportion will turn to Medicaid. The most commonly recommended alternatives to Medicaid financing of long-term care are not applicable to many low-income elderly and disabled people served by the program.**

A recent report on the long-term care needs of the baby boomers, indicates the increasing size of the older population will result in a growing disabled older population.<sup>67</sup> Furthermore, use of

paid long-term care services will rise, more than doubling between 2000 and 2040. While boomers with long-term care needs will be better educated and have more income than current older disabled individuals, barring major changes in long-term care financing, Medicaid will play an essential role for those who are poor and of moderate incomes.

Disabled individuals under age 65 increasingly enjoy longer life expectancies. Medicaid is the largest single payer of direct medical services for adults and children with HIV/AIDs, who with modern drug regimens survive for substantially longer periods.<sup>68</sup> Studies of persons with Downs syndrome show average life expectancy has increased by about 30 years and average life expectancy is now about 60 years of age.<sup>69</sup> Advances in treatments for people with chronic disabling conditions means that Medicaid long-term services and supports for younger disabled people may be needed for increasingly longer periods.

Medicaid pays for 42 percent of all long-term care expenditures and almost half of all nursing home care costs (Figure 8). Among the most common recommendations for reducing reliance on Medicaid financing of long-term care, are greater coverage by private long-term care insurance plans and use of home equity programs, such as reverse mortgages. (The intended target for these is elderly individuals; younger disabled people are generally ineligible.) A considerable body of research evidence shows that these options would have only a limited impact in reducing reliance on Medicaid among elderly low-income people with long-term care needs.



Purchase of long-term care insurance is closely tied to income and unaffordable for low-income elderly people. In 2002, national data on people ages 55 and older indicated that only 3 percent of older adults with incomes below \$20,000 had long-term care insurance; over half of those who purchased this coverage had incomes exceeding \$50,000 or assets exceeding \$100,000.<sup>70</sup> A GAO report in 2000 stated that while ability to afford these policies is a subjective judgment, estimates are that “long-term care insurance is affordable for only 10 to 20 percent of elderly

individuals.”<sup>71</sup> Younger disabled people are precluded from purchasing private long-term care insurance by pre-existing conditions, regardless of its affordability.

Other efforts to increase purchases of private long-term care insurance include tax subsidies (federal subsidies to employers who provide long-term care insurance and state subsidies to encourage individuals to purchase coverage)<sup>72</sup> and state programs such as Long-Term Care Partnership Programs that allow individuals who purchase approved policies to protect assets and still qualify for Medicaid long-term care benefits. Neither can be expected to address the long-term care financing needs of lower income Americans. The value of tax deductions for long-term care insurance increases with income, and will most benefit those with higher incomes who currently are the primary purchasers of these policies. The expansion of LTC Partnership programs under the DRA of 2005, is aimed at increasing coverage among people with modest economic resources who are at risk of spending down to become Medicaid-eligible. Evidence from the experience of the four early “partnership” states is limited and it remains unclear whether these policies will primarily attract higher income people not truly at risk of spend-down, as opposed to those of moderate income who are the intended purchasers.<sup>73,74,75</sup>

Reverse mortgages are also suggested as a mechanism for paying for long-term care expenses directly or for premiums for private long-term care insurance (reverse mortgages are available only to homeowners at age 62). Three-quarters of older households (single or couples 62 years of age or older) have some net home equity, but the number of individuals who could qualify for reverse mortgages, and the amounts that could be freed up, are estimated to be relatively small, and would “merely postpone, rather than obviate, the need for Medicaid assistance.”<sup>76</sup>

## SUMMARY

For the foreseeable future, Medicaid will remain the major financing system for long-term services and supports in our nation, and the only one addressing the needs of low-income Americans. Cost concerns drive much of the policy discussion concerning Medicaid’s role as a provider of long-term care, but as in other areas of health care, there is increasing focus on quality and indicators that can be used to evaluate quality of care across providers and settings. Innovations in program design that allow coverage of a broad continuum of services and supports, more consumer involvement, and expansions in access (e.g. buy-in provision for higher income families of disabled children) are currently counterbalanced by a confusing array of eligibility criteria, inequities in access to services across and within states, and financial standards that require impoverishment to qualify. The needs for long-term services and supports that Medicaid addresses will not lessen in coming years; they will likely grow. The challenges for those who finance, design and provide long-term care under the Medicaid program are to align incentives to ensure access, meet needs, and provide cost-effective high quality services and supports to low-income elderly and disabled Americans.

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THE KAISER COMMISSION ON  
**Medicaid and the Uninsured**

**The Henry J. Kaiser Family Foundation**

**Headquarters**

2400 Sand Hill Road  
Menlo Park, CA 94025

Phone 650-854-9400 Fax 650-854-4800

**Washington Offices and**

**Barbara Jordan Conference Center**

1330 G Street, NW

Washington, DC 20005

Phone 202-347-5270 Fax 202-347-5274

[www.kff.org](http://www.kff.org)

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